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Centre for Maternal and Child Health

School of Health Sciences

PhD Health Psychology

British Muslims' experiences of pregnancy and birth

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Thesis submitted in fulfilment for the degree of Doctor of Philosophy.

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Abstract

A decolonial and trauma aware approach centring Islamic epistemology in understanding British Muslims' experiences of the perinatal period. This thesis provided a review of the literature, an explorative decolonising methodological approach and empirical qualitative study and analysis in understanding what are British Muslims' experiences of pregnancy and birth.

A systematic review and meta ethnography were conducted of international papers qualitatively looking at Muslims' experiences of pregnancy and birth. The sample were 223 Muslims; 190 Muslim women and, 33 Muslim men. A conceptual framework arising from the systematic review was produced based on the six emerging themes which were: the role of religion as a supportive factor, experiences of health care systems (including language barriers, communication and discrimination), influences of culture and patriarchy, the role of relationships and family (including level of support available), and transition to parenthood. This review laid out the paucity of research on the topic of British Muslims' experiences of pregnancy and birth.

The decolonising methodologies approach highlighted issues of epistemicide and ongoing health and social injustices and inequities and set the context for a decolonial approach in carrying out empirical research and understanding, interpretation and analysis of data in relation to Muslims experiences of the perinatal period. Through the decolonising approach and centring of an Islamic ontology a 11-point model was created demonstrating the Islamic reflective ontological paradigm adopted for the research process.

A Reflexive Thematic Analysis was applied to qualitative online surveys and Narrative inquiry composite case study method to interviews. The process of the RTA developed six key themes: the significant role of Islam during pregnancy and birth, experiences as impacting mental health and emotional states, the importance of social circumstances, NHS experiences: the good, the bad and the ugly, empowerment and recommendations. Consideration included health inequalities and the role of healthcare providers, medicalisation, power and control over women's, bodies, choice, birth trauma terminology. The need for faith sensitive (Islamically rooted) healthcare provision and research for Muslims during the perinatal period was posited.

Acknowledgments

I begin with Alhamdulillah, all praise and thanks to The Almighty Creator, Ar Rahman (The Compassionate) who brought me into this world and put me on this very specific often painful journey and provided for me, giving me insight and experiences in ways I could not imagine, sprinkling my life with miracles and divine wisdom which I am still trying to understand.

My gratitude and Duas (prayers) to all those who have invested in me and been a crucial part of this incredible journey, for your understanding and compassion, nurturance and guidance, understanding and seeing value in my work, believing in me and your encouraging feedback which gave me hope and relief that the importance this held for me and the depths of where I was going with it and how, were deeply understood. You know who you are, and I can never thank you enough for seeing me through the challenging times so poignantly.

To all the people in this world who have experienced trauma, oppression and injustices especially at the tender stage of birth, of coming into this world through trials and in fear, may our collective voices affect the change needed for healing to occur, for better systems and compassionate relational experiences, for better equal healthcare and social justice, for a reconnection to the deeply sacred process of creation and birth and systems and health care that reflect and centre this.

I hope that some of the insights in this piece of work which was done so whole-heartedly are of benefit to others.

Thank you and Jazak Allah Khayr.

List of Abbreviations

NICU	Neonatal Intensive Care Unit
PBUH	Peace Be Upon Him/Her
RTA	Reflexive Thematic Analysis
SR	Systematic Review

Key Islamic Terms

Allah	One God
Ahadith	Plural of Hadith
Alhamdulillah	All praise and thanks to God
Aqiqah	Islamic tradition of the sacrifice of an animal and sharing the meat for food with family, the community and poor, on the occasion of a child's birth in gratitude.
Aql	Intellect/mind
Ayn	'The eye'
Bismillah	With the name of God
Dhikr	Remembrance of God and the signs of God in Creation
Fitrah	Innate intuitive pure innocent nature one is born with
Fikr	Contemplation, concern, reflection, deliberation, thoughtfulness
Jinn	Unseen being
Hadith	Tacit saying, approvals and actions of the Prophet Muhammad pbuh
Ihsan	Excellence - often referred to excellence in character. There are three levels of faith in Islam: Islam, Iman and Ihsan, those who embody it are correspondingly referred to as Muslims, Mumin and Muhsin.
I'tibaar	Consideration of consequences/implications
Islam	Surrender/submission to One true God
Mizan	Balance
Muslim	One who submits/surrenders to God/Allah / lives a God centred life
Nazr	'The eye' (another term used more frequently in Asian languages)
Qur'an	Divine Revelation
Rahm	Womb

Rahmah	Compassionate, loving kindness, deeply merciful, nurturing
Sihr	Black magic/evil
Sunnah	Tradition / way – more commonly used to refer to way of the Prophet Muhammad pbuh
Qalb	Heart
Ruh	Soul
Tadabbur	To ponder, reflect
Tafakkur	Reflect, to contemplate, to be concerned with

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Chapter One: Introduction

1.1 Introduction

This thesis is rooted in a decolonial and trauma aware approach, mindful of centring Islamic ontology and epistemology in order to offer an understanding of British Muslims' experiences of the perinatal period in Health Psychology. A useful starting point would be to consider the vulnerability such an undertaking, that moves away from the traditional Western academic health scientific approach to writing, inherently entails:

> "Thinking with decoloniality inevitably entangles with vulnerable writing…those who claim to theorise with decoloniality disturb Eurocentric epistemologies claiming universal validity and call for a move from universality to pluriversality, from "study about" to "thinking with"". (Zocchi, 2021).

I am adopting a reflective explorative approach to my thesis that is conscious of the multifaceted trauma my community both historically and currently experience. Page (2017) refers to *"vulnerable writing"* as a position occupied by the writer *"who recognises the mechanism of silencing and oppression embedded in the research process…".* She further highlights how researchers and writers in this vulnerable position *"account for the asymmetries, clashes and struggles they live through in interacting with their research objects and subjects… and value encounters and emotions as fundamental elements of knowledge production and propose new modes of data collection, analysis, and expression".* I too experienced some of these struggles and trying to maintain a balance. In balancing these needs, Zocchi (2021) proposes the idea of: *'be brave but be smart'*. She discusses the dilemmas PhD students face between being exposed to creative and intellectual freedom, which she refers to as 'epistemic freedom', whilst simultaneously being restricted by the rules of the academy and notions of success. Western culture in its attempts to elevate notions of objectivity has ended up making "objects of things and people" and in creating this distance lost connection (Zocchi, 2021) Zocchi (2021) refers to this dichotomy as "the root of all violence", which puts the fundamental need for safety into the spotlight. The notion of violence she refers to also connects to the capacity of individuals, society and culture to both perpetuate, and be on the receiving end of, trauma:

> "We humans are the most complex and puzzling of living creatures. We can create, nurture, protect, educate and enrich. Yet we also degrade, humiliate, enslave, hate, destroy and kill. A man can tenderly hold his new-born and moments later beat the baby's mother. Violence permeates our history. In all societies and in each culture, past and present, violence has played a role in shaping our sociocultural evolution" (Perry, 2001, p.2).

The above quote captures both the human capacity to harm and heal. This paradox then manifests not only on the level of individual human beings but also in the communal level in many different ways. In the context of this thesis, I am referring to systems and structures of healthcare inequality based on the intersection of gender, race, ethnicity, religious sects, disability, and socio-economic status and their interplay with medicalisation of women's bodies, obstetric violence, issues of power, control and bodily autonomy and the specific ways in which the harm caused during the perinatal period and the early development impact on a child is perpetuated. Harm of course is also perpetuated though epistemic injustice, including epistemicide which affects our knowledge repertoire. If the fundamental position we occupy is of not feeling safe then we enter a cycle of fear which has an extraordinary impact on our bodies, minds and soul shaping our lived experiences.

Contrastingly the quote above by Perry (2001) addresses the potential for education, nurture, healing, and enrichment, which provides an element of hope. Thinking about how human lives can be influenced and shaped from birth, is an important consideration in attempting to understanding our earliest origins beginning with the time in the womb and the perinatal circumstances we are born in. This thesis is an attempt to understand perinatal experiences of Muslims with an exploration of the role of potential early violence through the medicalisation of birth, the influence of obstetric violence and the particular experience of a marginalised community that may be experiencing institutional, systemic, racial and Islamophobic discrimination. Islamophobia can be overt or subtle and acts as a *"mechanism for excluding or restricting Muslims' participation in political, economic, social, cultural, and public life on an equal footing with their non-Muslim counterparts"* (Amin and Ingham-Barrow, 2021). It has been noted that Islamophobia undermines health equity (Samari et al., 2018). While the impact of racism on mental health and health equity is beginning to be explored, the impacts of Islamophobia remain largely unexplored within research (Amin and Ingham-Barrow, 2021), which in and of itself highlights the very structural issues of Islamophobia.

There is a distinct lack of research on the diverse health needs of faith-based communities, particularly the Muslim community. More particularly there is little in the way of research looking at Muslims experiences around birth and the early developmental period that considers an understanding of the intersection of intergenerational traumas and the effects of colonialism. Little is known about British Muslims experiences of pregnancy and childbirth and the circumstances thereof, particularly those that may be traumatic and adversely affect the mental

and physical health and wellbeing of the parents, and subsequently the developing child. This lack of research is indicative of the wider lack of inclusion and participation of diverse communities in health research (Rai, et al., 2022).

This thesis explores British Muslims' experiences of pregnancy and birth; the overall question being asked was: *'What are British Muslims' experiences of pregnancy and birth?'* This chapter provides the rationale for the study and outlines the methodological approach to be used in answering it. The question itself emerges from a multifaceted, often unrecognised, traumatic context for this population (socio-cultural, political, religious, and psychological), on both an individual and collective level. In order to address the aforementioned context, I took the theoretical perspective of decolonising research methodologies (see chapter three) with the intention of contributing to the research process in a way that is healing and centred in Muslim ways of knowing. I conducted a systematic review of existing literature in the area followed by data collection utilising Reflexive Thematic Analysis (RTA) and narrative (case study) inquiry methods to draw these experiences to the fore, touching on elements of Critical Medical Humanities in support of the philosophical underpinnings of the decolonising methodology. As Beavis et al. (2015) stated: "*clinicians and educators must understand health and healthcare as situated in social, political and historical contexts rooted in colonialism*". Critically reflecting on these contexts and the role they play is necessary in both understanding and responding to the role of colonialism in creating and sustaining health inequity (Beavis et al., 2015).

There have been many attempts to define colonialism over different time periods and contexts. It has often been interchangeably used with imperialism. Some definitions are void of any reference to conquest, domination or the traumatic effects of displacement and control of the indigenous people. The International Encyclopedia of Human Geography (2020), refers to Colonialism as *"the combination of territorial, juridical, cultural, linguistic, political, mental/epistemic, and/or economic domination of one group of people or groups of people by another"* and Loomba, A. (2015) states: *"colonialism can be defined as the conquest and control of other people's land and goods"*. The former definition in the International Encyclopedia of Human Geography, (2020) is broader and more specific, and crucially includes mental and epistemic injustice which is specifically important context for this thesis as I later discuss the colonised mind in section 3.6.2 and refer to the injustices and ongoing

consequences of epistemicide and how they influence healthcare and connect to health inequalities throughout the thesis.

Being aware of these influences provides a rich and situated historical context to understand the intersectional experiences of British Muslims, which may include systems of inequality based on gender, race, ethnicity, religious sects, disability, and socio-economic status and their interplay with medicalisation of women's bodies, obstetric violence, issues of power, control and bodily autonomy

Being mindful of the impact of colonialism on health inequalities is further supported by the work of Dimou (2021) who proposes an approach of the "decolonial option" recognising that: *"all our contemporary ways of being, interacting, knowing, perceiving, sensing, and understanding are fundamentally shaped by coloniality—long-standing patterns of power that emerged because of colonialism and that are still at play (cited in Maldonado-Torres 2007; Quijano 1992)".* It is through the decolonial approach or option as Dimou (2021) states that there is possibility of engaging with ways of knowing and being that are able to not only heal, but also resist and transform embedded harmful patterns of power (Dimou, 2021).

This study aims to contribute to engaging with the reclaiming and restoration of narratives through providing a platform for the sharing of stories. In doing so, the overall question will ask how British Muslims experience pregnancy and birth, and some of the sub questions underlying this will explore how Islam, plays a role in how pregnancy, birth and healthcare are experienced, and any potential influences on mental health and wellbeing for the participants. The empirical phase of this thesis will elucidate the insights gained from capturing extensive, data as well as highlight any commonalities, patterns, contradictions, new or unexpected findings, and what we can learn from these and future implications.

1.2 Origins, history and context of this thesis

This section is divided into three parts: experiences that have influenced my choice of topic as the researcher of this study, followed by a discussion around British Muslims as the study population of this thesis, and finally an overview of the literature around pregnancy and birth as affecting women from non-majority backgrounds. Below I set out what has influenced my knowledge base and choices around this study, my work as a Muslim female Chaplain,

counselling and psychotherapeutic work within the Muslim community particular Muslim women, and my personal journey. Some of these experiences touched on problematic areas that highlighted for me a lack of research and awareness on complex, multifactorial issues impacting British Muslims' health and wellbeing. I then contextualise my own position as the researcher of this study in the section on 'positionality' and how it influenced the trajectory of this thesis. Following this, I discuss the 'population of study' - British Muslims (in section 1.4) - and the importance of understanding early development and health outcomes in the context of fear, health inequalities and potentially discriminatory healthcare provision and research. This is followed by referring to introductory background literature which contextualises the need for a study of this kind. Finally, I discuss contextualising literature that explores birth and mental health, specifically Islam and perinatal mental health, birth trauma, racial and systemic traumas, obstetric violence issues of control, coercion, medicalisation and autonomy and why that is important to consider in my thesis. Chapter two follows with a systematic literature review of the evidence on Muslims' experiences of pregnancy and birth, forming the basis for this study's empirical research.

1.2.1 Influences and interests

I trained in psychotherapeutic counselling both integrative, and psychodynamic (including some psychoanalytic studies, and child observation studies), and as a trauma therapist. As such my leanings towards understanding human behaviour are influenced by various psychological and psychotherapeutic theories particularly trauma work (including birth trauma and adverse childhood experiences), critical psychology. I also consider Islamic spiritual and psychological approaches to my understanding of human behaviour and the human condition.

Other than psychotherapy and spirituality I am interested in gut-brain health and how psychosocial stressors affect an individuals' neurobiology (physical manifestations of illness and ideas of 'dis'-order/ 'dis'-ease), in turn affecting feelings and behaviours and impacting social relations and structures and the ongoing cyclical process this entails. I am also intrigued by how people make sense of their physical and mental health struggles in the context of spirituality and faith and how this becomes a source of hope, strength, and healing. I am interested in how Muslim women experience stress and trauma - especially the stresses that manifest in the perinatal period - and how this may result in an intergenerational impact.

This background knowledge has influenced and shaped the approach to my thesis, and ultimately how I interpret the results of the data gathered. I experienced the PhD process as a period of significant growth in critical thinking and gaining new knowledge, especially the introduction of decolonial research ideas that shaped my writing and personally profoundly impacted me.

1.2.2 Chaplaincy work

Having studied a Masters in Muslim Community Studies alongside my psychodynamic counselling training and Islamic counselling studies, I then worked as a Muslim Chaplain for an NHS trust for a period of six years. The exposure I had to labour and neonatal wards in times of crisis and critical situations of life and death was at times profound and a valuable learning experience. I began to notice the premature babies in Neonatal Intensive Care Unit (NICU) who survived and those who did not, and what factors were at play. I would speak to and support the families and hear their tragic, and at times shocking stories that involved complex psychosocial stressors. Some of the Muslim women would tell me how they prematurely went into labour due to stressors at home - arguments within their families or in-laws or partners who would pressurise them in some way or other. Others would say they cannot bear to see their baby for fear of forming an attachment and would sometimes leave the hospital because of the trauma and psychological impact of what they had experienced, and it would be left to the chaplaincy to make funeral arrangements.

I noticed women who were unable to have closure or had experienced dissociation often suffered the most and continued to have ongoing effects. Sometimes - as some of the women cited – due to cultural factors, they were not permitted to visit their baby in the hospital as they were forced to stay at home and not allowed out (either due to patriarchal family structures or misunderstandings of Islamic teachings). Others described feelings of fear and shame about their pelvic area and how mentioned how they could not talk about this to anyone. Sometimes this meant women with vaginismus were not able to get the appropriate birth plan/support due to fear of discussing something considered taboo and shameful. Some women were not diagnosed with this condition until after they gave birth and were traumatised by severe tearing, describing feelings of violation, using words like “it felt like assault”, and “it felt like rape” but saying it with feeling ashamed and invalidated. Looking this up at the time I came cross expressions such as ‘diagnostic rape’ and ‘obstetric violence’. Many described that their first

sexual experience itself was traumatic as they had not known their partners well due to arranged marriages or had no emotional connection beforehand. These negative associations with the pelvic area led to subsequent difficult feelings during pregnancy and especially birth including the feeling of losing control over bodily autonomy. This would be exacerbated if attended to by a male physician or having to fight for a female doctor, which was not always possible. Having to fight for what makes one feel safe in a life-threatening situation can lead to a traumatic response, including the 'fear - fight - flight - freeze – faint' responses which are regularly evolving to include new insights such as that of collapse, submit and attach (which I learned about on my traumatic studies course). These states often went unnoticed by the healthcare professionals around these women, who cited feeling discriminated against and being treated as if 'stupid'.

There were a plethora of complex factors affecting these Muslim families and especially the women at the critical juncture of birth, life and death. I saw babies the size of my hand with transparent skin, various infections, more tubes than I could count, and who had already experienced what would be considered as severe psychological traumatic experience at such a tender age. I noticed that those parents who had some opportunity to make some skin contact and begin to develop a relationship and were more consciously engaged and talking to their children, were more likely to survive, improved and began to heal. There were countless stories from my time in Chaplaincy which left me wondering about the distinctly Muslim experiences and stories of these Muslim women and men and how these early experiences would leave a lasting impact on these families and the developing child.

1.2.3 Counselling work with Muslim women

I completed my Psychotherapeutic Counselling education with some overlap whilst working as a Chaplain and decided to change field. I wanted to be able to work with women unpacking and processing their traumas for healing, which was not possible in a high turnover short stay environment such as a hospital. I then set up Rahmah Wellbeing – a private practice counselling service which, although open to all, mostly attracted Muslim women. The choice of the name *Rahmah* came from the word for womb (where the essence of life is created) in Arabic. The word for womb in Arabic is *Rahm*, which is derived from the same root as Rahmah, also linked to one of the most profound names of Allah (God) in Islam – Ar Rahman. The word *Rahmah* encompasses meanings of grace, empathy, taking care of, extremely loving, compassion,

mercy, affection, loving tenderness and attentiveness. It is the natural inclination of loving tenderness, which a mother displays towards her child. I also felt strongly that the mind, brain, body, soul and so many other aspects of the human condition have received much attention but not the place and space of the womb where creation happens. This creates a significant gap and social and intellectual injustice on so many levels, another epistemicide of sorts. I felt the work I was doing had the potential to start interesting discussions and act as a springboard for engaging with my community. I was asked to give lectures and talks at various community events where women would come up to me and tell me their stories. I found increasingly from all these anecdotal stories that there were patterns and severe traumas and a hidden-ness – something secret - about this; the complex trails of trauma that would leave a legacy – an imprint on the bodies and minds of these women, and impact their relationships, and their children. I felt that these were stories and voices that needed to be heard.

Many Muslims ended up coming to me after terrible experiences within the NHS or in non-faith sensitive services where they felt they first had to spend a lot of time educating staff, and explaining their worldview, both fearing and being misunderstood and often were. They would describe it as too draining at a time when they really needed to be attended to and feel supported. Additionally, they faced discrimination, inequalities in access to, quality and appropriateness of care. One key observation in my work has been that many of the women, when they were new mothers themselves, felt a lot of their childhood issues evoked in a way they could no longer ignore them, and we ended up working with them parenting their inner child whilst simultaneously parenting their baby – quite the extraordinary journey. This was another reason why I was keen to see a wider evidence base through this study and to see how it played a role, and if similar themes emerged.

1.3 Positionality and reflexivity: My personal experiences

I am aware my choice of topic is inspired by some personal experience of my own (being born through a traumatic birth), and of the many fields I have studied and researched, and people I have spoken to over the years. I reflect on this where necessary through the reflections I engage in throughout the writing of this thesis. When I received a scholarship and offer of a PhD, I felt a huge sense of responsibility to use this opportunity - my position as an academic researcher - to give voice to those experiences that are lesser heard, in recognition of the massive unheard and unsaid trauma internalised and experienced by Muslims' particularly women giving birth.

Academic and health research continue to be dominated by Western epistemologies (ways of knowing) and methods often with little critique, reflection and relevance of the cultural context of these approaches. I feel that as a Muslim academic and researcher I am in a lesser occupied but privileged position in this context and for me it becomes an unsaid dutybound rule to be extremely mindful and critical of the research process. Therefore, in this work I have occupied the position of a critical researcher. It was important to me for this thesis that I bring in research and quote some of the lesser heard of theories and ideas where possible, which at time required more in depth searching and looking for alternatives and critical voices

1.3.1 Interdisciplinary influences and enmeshment of knowledge.

My influences come from my interests in psychotherapy, neuroscience, early attachment theories and adverse childhood experiences, women's health, Islamic psychology, Muslim mental health, critical psychiatry, critical medical humanities, critical research methodologies, and health psychology. My stance is one of blending elements of various approaches to allow me to engage meaningfully with the study of British Muslims' experiences. This idea of blending together is discussed by El Shakry (2017), who draws on the blending of traditions: *"the impulse to blend traditions went as far back as Abu Nasr al-Farabi's neoclassical contemplation of Plato's Republic, one in which Greek ideas were poured into the mold of Islamic philosophy and Arabic thought and the intermarriage of literatures, epistemologies, and ontologies transpired."* (El Shakry, 2017, p.2). This demonstrates the enmeshment of knowledge and ideologies, epistemologies, ontologies and literatures - the cross over learning that occurred between the rich Greek, Latin, Arabic, Indian and Chinese traditions and the importance of recognising that (as will be discussed in the methodology chapter) no knowledge exists in a vacuum For me seeking knowledge and study is a sacred quest and one that needs to be embodied – a teaching I draw on from Islam. Some practices for seeking knowledge in Islam in an embodied way include setting an intention (mind/mental) and performing ablution - to refresh and ground oneself (body/physical) in creating an intentional state. In Islam consciousness of tawhid (oneness) is considered the source of scientific spirit in all domains of knowledge (Bakar, 2012, p.11).

I intended to draw on inter disciplinary thinking as a framework to help me explain the process of how I conducted my research. I thought it necessary to contextualise the history and tradition of other non-Western ontologies that provide a more appropriate 'fit' for this study. I felt

acutely conscious of the process of knowledge production and how to do things in a more meaningful way that centres and respects non-Global North Eurocentric ontologies and for this study to centre Islamic ontology and Muslim epistemologies, which are discussed in detail in chapter three. It was important for me to ensure the philosophical underpinnings of this thesis were in alignment and in recognition and acknowledgement of the historical backdrop - the potential intergenerational traumas of the participants in the empirical research phase and centring their ways of knowing and being. Lokugamage et al., (2020) discuss the idea of *"'recentring' displaced indigenous healing systems, medical pluralism and highlight the concept of cultural humility in medical training, which can benefit patients"*. They further state decolonial approaches' implications for clinical practice, and the powerful impact this approach can have in grappling with the healthcare inequalities, intersectionality and the role of inter-generational trauma experienced by "BAME (Black, Asian and minority ethnic)", (Lokugamage et al., 2020). This is very much an objective of this thesis: scaffolding the study in a decolonial approach as acknowledging health inequalities in minority communities, intergenerational trauma and the multiple intersections that face Muslims during the perinatal period.

1.3.2 Researcher embodiment

> *"The body has a direct role in knowing"* (McGuire 1990, p.286 in Gilliat-Ray, 2010).

Reflection upon the ethnographer's embodied presence in the field is critical for data collection and interpretation processes Gilliat-Ray (2010). She gives examples of research studies that have touched upon the role of embodiment and the body, with the foci being on the participants but missing when it comes to the researcher. She further states that one must go beyond the biographical and identity positionality of the researcher, and reflect upon the ways the researcher and researched mutually construct and produce 'the field' (Gilliat-Ray, 2010). This will be something I will be mindful of and consider in my data gathering process, as well as through my own reflective process and writing.

Furthermore Gilliat-Ray (2010) talks about the silence of researchers surrounding their own embodied engagement in research where there is engagement with alternative spiritualities, where participants themselves often stress the importance of the body and bodily practice. In elucidating this 'silence' she gives an example: *"within the study of Islam in particular, several*

scholars have considered how the categories 'feminine', 'masculine', 'private', 'public', 'pure' and 'impure' are constructed, the way in which the body is conceptualised in the Qur'an, and what the implications of these constructions might be in practice" (Gilliat-Ray, 2010). Understanding how language is constructed and meanings associated, and how words and concepts are being used, is an important part of my study.

What is observed will depend very much on the uniqueness of the researcher and it is important to note our conditioning – who the researcher is and how they shape their research. Borrowing from her idea of ethnographers who are *"equally well trained and well versed in theory and method but of different gender, race, or age – might well stimulate a very different set of interactions, and hence a different set of observations leading to a different set of conclusions"*. (Angrosino and Mays de Perez 2000, 689, cited in Gilliat-Ray, 2010, p.416), I think this idea can be equally applied to researchers. I will utilise her tip for "*ideally including some reflection on physical as well as biographical positionality, and the ways in which participants in our research appear to be responding to us, as embodied, gendered, researchers"* (Gilliat-Ray, 2010, p.416). Particularly she posits embodiment of the research process as playing an important role in the outcomes of discourses – both inherited and ongoing (Butler 1999 cited in Gilliat-Ray, 2010). I set out on this research journey mindful of the Muslim communities individual and collective traumas, experiences and our shared history bearing in mind that the body is a 'vehicle for collective social memory' there is 'potential for creative action and cultural transformation' (Gilliat- Ray, 2010, p.419).

In Islamic psychology, the heart is at the centre of human psychology (Rothman, 2019) and it is given central attention more so than the mind in Western constructions of mental health which tend to prioritise the mind/brain/biology. Linda Tuhiwai Smith (1999), who can be considered the founding mother of Decolonising methodologies asks of the researcher, "Is her spirit clear? Does he have a good heart?" (Cited in Stonebanks, 2008, p.13) Being in tune with ones' spirit and heart are different ways of expressing the need to engage in conscious, reflective and embodied awareness of the research process and practice. This becomes ever more important in research that involves stories of a people and religion who have been dehumanised:

> "To develop counternarratives that are going to bring humanity to a people and religion that have been dehumanized, the researchers have to make a paramount step and ask themselves if they can account for their spirit and heart, ask themselves if their research is ethical, ask themselves if it pays its due respect to the beliefs relating to

> Islam, ask themselves whether it accounts for the context of the Muslim experience, and, finally, ask themselves if it is beneficial to the Ummah [community]". (Stonebanks, 2008, p14).

For many non-Western communities, the centrality of the heart and spirit in guiding ones' feelings, behaviours, actions and ethics are significant, hence asking questions of a nature that refer to the heart and spirit rather than the mind or intellect alone are equated with a deeper sense of sincerity and consciousness. With the words of Stonebanks (2008, p.14) in mind, the next section will briefly discuss the chosen population for the study, moving from the researcher to the researched.

1.4 Why British Muslims?

This thesis aimed to explore and document British Muslims' experiences of pregnancy and birth. Islam is the fastest growing religion in the world (Hackett and Lipka, 2017 Pew Research Center) and the second highest in the UK according to the Census 2011 and 2021. The Pew Research Center also estimated an increase by 70% in the number of Muslims worldwide from 1.8 billion in 2015 to around 3 billion by 2060, further stating that 24.1% (nearly a quarter) of the global population is Muslim (Pew Research Center, 2017). Understanding the health needs of such a large proportion of the population is significant, particular in healthcare. In particular, the aspect of their research that is of interest in the context of my thesis is their finding that Muslims have more children than seven of the other major religious groups they analysed (Pew Research Center, 2017). This makes it pertinent to understand the experiences and needs of Muslims during pregnancy and birth as a significant proportion of the population, and invest in solutions required to improve healthcare, eradicate health inequalities, and address the ongoing impact of early traumas and implications for health.

British Muslims face a multitude of complex factors that can predispose them to unfavourable outcomes. Muslims are constantly under media scrutiny and subject to securitisation, profiling, discrimination, Islamophobia, and the orientalised gaze, and are often dehumanised (Stonebanks, 2008, p.25) It is crucial to reflect upon the context people are finding themselves in and how this impacts their experiences of healthcare, and for this study during the particular phases of pregnancy and birth.

Though Muslims have been part of the fabric of British society from as far back possibly as 1562 according to research by the BBC on 'The first Muslims in England', where many were

brought over as slaves, servants or 'guest helpers'. There have been periods of influx of immigration at varying points throughout history and more so over the last 100 years. A larger wave of migration occurred between the 1950's and 1980's to the UK, particularly large South Asian communities' post partition and post-colonisation, with many migrants carrying with them war-related, forced or economic migration challenges as well as generations of subsequently experiencing racism and ongoing traumas. Post 9/11, Islamophobia and discrimination in general have increased alarmingly, and, as a result, it is interesting and helpful to see how experiences of British Muslims born in the UK differ in context and relation to this, if at all. The events of 9/11 and 7/7 put Muslims in an impossible position of being both stigmatised, feared and receiving hate and feeling the fear and distress that was felt globally but where Muslims were dehumanised, and false and misappropriated connections were made to Islam (i.e. submission and devotion to God) based on the abhorrent acts of some people who claimed to be Muslims. Billions of people were stigmatised due to the actions of a very small minority of people. I wonder if anyone outside of the Muslim community recognises or has thought about how Muslims fear such acts too both as humans like anyone would and as Muslims because of the backlash and attacks that occur post such events.

Muslims make up the second largest faith group of the UK with the figure at around 3 million in 2011(Muslim Council of Britain, 2019). Thirty three percent of Muslims are aged 15 years or under. In over 40 local authorities, forty percent of Muslim women were in poor health. Forty eight percent of Muslims reside in the 10% most deprived local authority districts in England (Muslim Council of Britain, 2019). Given the lack of research on British Muslims' experiences of pregnancy and birth it is important to examine the experiences of British Muslim women and men during pregnancy, birth and the transition to parenthood being mindful of the historical backdrop of colonialisation, migration and complex trauma.

While conducting preliminary research and exploration of the field for this thesis, it was evident that no comprehensive studies existed specifically on the topic of birth trauma for this group of people in a British context. Initially my question was what are British Muslims experiences of birth trauma? For example, searching British Muslims experiences of birth trauma produced 0 results at the time when I conducted a preliminary search just to see what was available on the topic. My specific interest, overall, for this thesis, was in studies that investigate or examine an understanding of being Muslim and giving birth in Britain and what it is about the religion of Islam or the embodied Islamic identity that specifically shapes that experience and the

meanings given to pregnancy and birth and what experiences people have about being specifically Muslim that potentially shapes healthcare provided.

The first stage of my research focused on the conduct of a formal review through a systematic review following the PRISMA guidelines (see chapter two) to determine what peer reviewed journal article were available on Muslims' experiences of pregnancy and birth internationally. I thought it would be novel but necessary to invert the cultural or 'ethnic minority' focus that may touch on peoples experience of making sense in light of their religious identity as Muslims and make the focus of the question an exploration of Muslims' experiences contextualised in their religious and faith (Islam based) perspective (which is my attempt in this study) rather than cultural or experiences of 'minorities' which have and continue to be researched. Given that there is a strong British Muslim identity in Britain and for the reasons mentioned already this is a population group whose experiences need to be documented in the current climate of deeply rooted health inequalities. I am keen not to conflate ethnicity with Islam and Muslims in this study as has frustratingly and clumsily been done countless times. As Laird et al., (2006, p.2425) emphasise it is important and a challenge for clinicians to understand this (Muslim) populations perspectives and experiences in relation to health and biomedicine given the growing population of Muslims in the Western world. This study has contributed somewhat to that understanding by providing a rich data source of first-hand narrative accounts of experiences and perspectives of British Muslims of the perinatal period.

1.4.1 What the Qur'an says about pregnancy, birth, and parenthood

There are a plenitude of verses in the Qur'an and *ahadith* that talk about pregnancy, birth, breastfeeding, and parenthood. It would be a thesis in itself to look at them all meaningfully. For the purposes of this thesis, and in the foregrounding of an Islamic ontology (discussed in chapter three) it is of significance to refer to some that were key in informing my reflections and thinking that resonated for this study. I will refer only to a handful of contextualising verses. I anticipated that experiences which emerge from the systematic review and empirical data may have references to Qur'anic verses.

First and foremost, the first words divinely revealed to the Prophet Muhammad (pbuh) are from Surah Al Alaq (the clot: referring to the congealed like clot which a human being is formed through). These verses formed the very first part of Qur'anic revelation and are incidentally

extremely powerful for this thesis, referring to knowledge and human creation. I am sharing the first five ayah (verses) for context here: *"Read, ˹O Prophet,˺ in the Name of your Lord Who created, created humans from a clinging clot. Read! And your Lord is the Most Generous, Who taught by the pen taught humanity what they knew not."* (The Holy Qur'an, Surah Al Alaq, 96:1-5).

I understand these verses to point to the critical importance of knowledge and the origins of our creation as humans from such humble beginnings and not to forget that as we tread the path of knowledge it is important to keep our ego in check and recognise our interdependence. I have always been quite struck that these were the first divinely revealed words that have formed the final scripture that is the Qur'an: a commandment and metaphor to seek knowledge, to learn and a reminder of our earliest origins and the vulnerability of being a 'clinging clot'; something that requires support, nurturance, help to stay alive, is interconnected and dependent on a wider system. These verses continued to echo throughout my PhD journey and provided the grounding that was often necessary.

Though the above acted as a foundation for my personal ontological position, there are other references which I share below, describing the process and stages of creation and human development as relevant to my thesis:

> *"O people, if you should be in doubt about the Resurrection, then [consider that] indeed, We created you from dust, then from a sperm-drop, then from a clinging clot, and then from a lump of flesh, formed and unformed - that We may show you. And We settle in the wombs whom We will for a specified term, then We bring you out as a child, and then [We develop you] that you may reach your [time of] maturity. And among you is he who is taken in [early] death, and among you is he who is returned to the most decrepit [old] age so that he knows, after [once having] knowledge, nothing. And you see the earth barren, but when We send down upon it rain, it quivers and swells and grows [something] of every beautiful kind."* (The Holy Qur'an, Surah Al Hajj, 22:5).

Further descriptions on the process of creation can be found in The Holy Qur'an, Surah Al Mu'minoon (23:12-14).

The below verses (19:23-26), are often referred to in addressing 'mental health' and suicidal feelings in the Muslim community, i.e., wishing one did not exist. Many women refer to the difficulties and trauma Maryam (Mary, pbuh) went through in giving birth, and the comfort she received through her faith and connection to God. The brief context of the verses are

Maryam (pbuh) giving birth alone, having gone away from her community to give birth so people do not gossip and talk about her as she was not married and was a chaste woman who valued her honour greatly. She was divinely honoured with a miraculous conception, often compared to how Adam (pbuh) was created out of nothing and Gods power in being able to*: "when He wills something 'to be',* is simply to say to it: *"Be!" And it is",* as stated in the Qur'an (The Holy Qur'an 36:82). The following verses relay Maryam's (pbuh) story during labour:

> *"Then the pains of labour drove her to the trunk of a palm tree. She cried, "Alas! I wish I had died before this, and was a thing long forgotten!" So a voice reassured her from below her, "Do not grieve! Your Lord has provided a stream at your feet. And shake the trunk of this palm tree towards you, it will drop fresh, ripe dates upon you. So eat and drink, and put your heart at ease. But if you see any of the people, say, 'I have vowed silence to the Most Compassionate, so I am not talking to anyone today.'"* (The Holy Qur'an, 19:23-26)

The story is full of teachings and metaphors, it highlights anxiety, fear, worry and distress, feeling pushed to the limits. It highlights reassurance and companionship in the form of angel Jibreel (Gabriel) being sent to her to let her know that God is with her too. Further, there is nourishment (spiritual, physical and mental) and her needs being provided for. Dates are mentioned as a source of nourishment giving energy which are now understood to be a 'superfood' full of nutrients (which is starkly different to current hospitalised birth systems in the UK where people are often told they cannot eat or drink anything in a time where one is expending the most energy a human may ever). Maryam (pbuh) is reassured again to put her heart at ease. The heart (qalb) is seen as central in Islamic psychology often more so than the mind (aql). She is also offered advice and guidance in how to deal with people who may taunt her. She is told to take a vow of silence, which according to the traditions and customs of the time was an understood practice. This offers her protection. The rest of the story in the Qur'an goes on to tell us how people mocked her and turns to the story of her baby Isa (Jesus, pbuh). For Muslims, and in particular Muslim women, the meanings and lessons derived from this are held dear and applied to an array of psychological and emotional experiences. I had expected mentions of this story or Maryam (pbuh) to feature significantly in the empirical data which they did.

In the interests of the limitations and restrictions of this thesis, I will share only one further key ayah (verse) which relates to the honour of parents and acknowledges mothers' hardships in carrying a baby and refers to the time period of weaning. It follows with a verse on developing

into an adult that reaches wisdom (which is understood to be around 40), gratitude for one's blessings and forethought for future children (intergenerational impact) and their wellbeing (here referred to righteousness) and a reminder of our immortality (to remain humble through reflecting on and seeking forgiveness for our errors and wrong doings), and of ultimately surrendering to Gods will (literally Muslim):

> *"We have commanded people to honour their parents. Their mothers bore them in hardship and delivered them in hardship. Their ˹period of˺ bearing and weaning is thirty months. In time, when the child reaches their prime at the age of forty, they pray, "My Lord! Inspire me to ˹always˺ be thankful for Your favours which You blessed me and my parents with, and to do good deeds that please You. And instil righteousness in my offspring. I truly repent to You, and I truly submit ˹to Your Will˺."* (The Holy Qur'an, 46:15)

Pregnancy, birth and parenthood are perceived as sacred and spiritual in the Islamic tradition and not reduced to a series of biological and or legal only functions that can be controlled by male physicians or a pathological crisis in need of male intervention (Cahill, 2001) as can seem to be the case in the Western healthcare system's perspectives and priorities. The honour given to mothers and parents in Qur'anic scripture as well as the guidance and teaching in these areas impact the mindset, choices and behaviour of Muslim women, men and families during pregnancy, birth and parenting. It is recognised as a literal process of connecting to the Creator (Ar Rahman – an oft repeated name of Allah as mentioned earlier, also connected to the root word for womb Rahm) and being honoured to carry a child through which one is deeply close to God. A process which is robbed of many, where it is unnecessarily filled with mechanical unnatural interventions and procedures disconnecting women from their autonomy and inner knowingness in a system that treats natural events like pregnancy and birth like they are pathologies and illness - services provided in a hospital for the sick.

1.5 Muslim mental health: early development and health outcomes, discriminatory healthcare and research with a backdrop of colonialism

Ample research has been carried out on how the earliest experiences prenatally and even as early as conception can impact later life development (House and Ridgway, 2006). The physical, emotional, psychological, and spiritual states of mothers and fathers have also been explored and found to impact their mental health and wellbeing, and consequently, the

emotional availability and quality of attachment they have with their children (House and Ridgway, 2006). According to the Harvard Child Study Center on the Developing Child (2019), adverse foetal and early childhood experiences "*can lead to physical and chemical disruptions in the brain that can last a lifetime"*. They further state that the biological changes associated with early stressful experiences can affect brain architecture and physiology of a developing child, resulting in poor physical and mental health outcomes. Moreover, they emphasis the role of brain architecture development being directly impacted by what they term 'serve and return interaction' (Harvard Child Study Center on the Developing Child, 2019) between child and responsive attuned caregivers. Maternal stress during pregnancy increases risk for a range of negative infant outcomes but it is not a given and risk interacts with genetic factors, resilience, and environmental factors, such as early childhood experiences (Ayers, 2017).

The above research demonstrates the importance of parents' relationships with their developing child and how stressful environments and circumstances including the way in which birth happens, can impinge and shape development and outcomes. It is important in light of the research emphasising adverse childhood experiences, that we look at what experiences British Muslim men and women are exposed to during the time of pregnancy, birth, and the potential impact on their children. Many adults who have been born and given birth in the UK are likely to be children of migrant parents who were carrying a multitude of their own traumas of migrating, (possibly leaving war torn homes, loss and grief, leaving behind significant relationships and homes) it becomes ever more important to understand in what ways these adverse experiences may impact the physical and mental health outcomes in any population. - It is well documented that psychosocial stressors have a neurobiological affect (Perry 2001, Schore 2003, Siegal 2003, Van der Kolk 2014, Ogden 2006). Likewise, there is increasing evidence that perinatal experiences may impact on foetal development. Gaining knowledge of the context people are born into by understanding experiences of pregnancy and birth is one steppingstone in understanding this area better. Another particular issue affecting the perception of Muslims in general and potentially care they may receive is the constant bombardment of stories and images that present Muslims in a negative (and to be feared) light, and, or as victims of Islamophobia. This fear of the other, projected on to Muslims as "invaders", and various other terms used in a derogatory way based on persecutory anxiety evoking projections, creates a melting pot of fear and terror in all directions. I am interested in understanding the various experiences and ways in which people - in particular for this thesis

- Muslims are affected – and how this may be 'acted' out in positions of health care where power and control play major roles. This is where employing the concept of 'Cultural Safety' (CS) would be useful and welcome. CS was proposed by Lokugamage et al., (2020) and is an antiracist, decolonising and educational innovation originating in New Zealand. The concept of *"Cultural Safety is one that aims to dismantle barriers faced by colonised Indigenous peoples in mainstream healthcare by addressing systemic racism."* (Lokugamage et al., 2020). They examined healthcare inequities in the UK potentially related to racial discrimination and in doing so state the importance of dismantling the origins of discrimination which leads to structural racism in the first place for there to be any genuine attempt to decolonising healthcare (Lokugamage et al., 2020). Part of this process of action includes employing "'Reverse Innovation' which is about learning from others who have been traditionally subordinate and less powerful" (Lokugamage et al., 2020). Essential elements of CS include: "*undertaking self-reflexivity, a process of understanding one's own culture and the inherent power in relationships…replacing and demystifying colonial history… appreciation of the impact of colonisation on health and well-being".* A critical element of CS is that the recipient of care/education defines and decides whether 'care' or the experience is safe for them.

1.5.1 Securitisation of British Muslims and the affect of PREVENT – fear and why it re traumatises.

Prevent is a UK-wide programme within the government's anti-terrorism strategy aimed at stopping individuals from supporting or taking part in terrorist activities. NHS England's Prevent training requires health professionals to be able to identify early signs of an individual being drawn into radicalisation. It has controversially and disproportionately targeted Muslims. Younis and Jhadav (2019) carried out a study on the governments controversial 'fear based' PREVENT agenda and how this impacts critical NHS staff. They state how the government designates the NHS a *'pre-criminal space'* in its healthcare guidance (HM Government 2015) (Younis and Jadhav, 2019). They highlight PREVENT for being widely recognised as controversial citing Lewis (2018) and the growing body of literature critical towards the policy (Kundnani 2014; O'Donnell 2016; Ragazzi 2017). There is also 'widespread academic criticism (Ross 2016) of the "Extremism Risk Guidance framework" which requires NHS staff to be trained to detect vulnerability to radicalisation. It appears the absence of a robust evidence-base of PREVENT's construction of pre-criminality is connected more to political developments(Younis and Jadhav, 2019). Taylor (2020) state the PREVENT strategy, with its

core tenets of the 'risky' and 'trusted' suspect categories, can be regarded as potentially fostering alienation. Furthermore, it is enacting epistemic and testimonial injustice through the silencing of the Muslim community which can also act as counter-productive for PREVENT (Taylor, 2020).

The role of the PREVENT agenda in the healthcare system in particular targeting Muslims (even if through unconscious bias) creates a fear-based anxiety on both sides – staff and patients. Given this study is looking at birth and pregnancy experiences of British Muslims, I wondered in what ways this fear-based controversial agenda could impact the vulnerable and tender time of pregnancy and birth. Is there added fear around in the culture of the environment of healthcare in general for Muslims? Has trust between Muslims and the NHS been eroded and if so how does this feature during the perinatal period if at all? How might this be interacting in the dynamic of how hospital staff may be engaging with British Muslims? It is also important to think about the fear Muslims may have of being profiled, and in what ways this may play a role in healthcare during a life changing period such as pregnancy and birth. Would it trigger earlier or previous (intergenerational)traumas from the colonialisation period? What might it create in terms of feelings of anxiety, how might it affect mental health of the parents and foetus under stress? This is crucial, bearing in mind long term health implications resulting from early adverse experiences, which can also include the effects of parental trauma and or difficult experiences that take place during pregnancy and or a traumatic birth. Adverse Childhood Experiences (ACE's) are described as traumatic experiences that leave a lasting impact into adulthood; an imprint on the mind and body (Van Der Kolk, 2014). ACE's can begin as early as prenatally if the foetus is exposed to a stressful environment or the mother experienced birth as violent.

1.5.2 Prejudice in healthcare research: political gaze and objectification of Muslim bodies in healthcare.

An example of the prejudice that can be found in health care research is brought to our attention through the work of Laird, de Marrais, and Barnes (2007) (who conducted an ethnographic content analysis of 2342 OVID MEDLINE-indexed abstracts from 1966 through August 2005, derived from a Boolean search for ''Islam or Muslim or Muslims.''). They gave multiple examples of how Muslims are perceived as problematic and in a negative light citing how literature often addresses health issues Muslims present with as*: ''problems''* such as

management of diabetes Ramadan, where healthcare providers are seen " and by implication healthcare providers are perceived as holding *"normal attitudes."* (Laird et al., 2007). This links to the discussion around the importance of decolonising research and the dangers of reductionist, orientalist, othering paradigms that interpret data and attribute meaning from their perspective. Laird et al., (2007) further highlight how the notion of Islam as a subversive anomaly arises most prominently in portrayals of women. They give the example of Muslim women who have opted out of breast cancer screening, the interpretation of which becomes *"because the programs were not structured in a manner that was consistent with the beliefs and customs of Islam''* (Underwood, Shaikha, and Bakr, 1999, taken from Laird et al., 2007). It is quite possible there are multiple different reasons any Muslim woman may choose to opt for, or opt out, of a particular treatment, and always attributing this to her religion does little to advance understanding or respond to real problems and barriers, further feeding the injustice of health inequalities.

Laird et al., (2007) also usefully highlight how *"abstracts often focus on family and gender roles, characterizing Muslim families as patriarchal, hierarchical, and tight-knit, with rigidly defined gender roles obstructing exchanges with clinicians…and further described as deeply concerned with modesty, women appear as passive figures, unwilling to communicate openly (Matin and LeBaron, 2004; Rajaram and Rashidi, 1999). This dominant chord is frequently repeated in the corpus of abstracts under examination"* (Larid et al., 2007, p.343). The same unhelpful narratives, assumptions and deeply concerning limiting interpretations and focus remain. This stumps the research process and potential knowledge or new information that could arise and be helpful for both the community and for service providers. There must be more conscious attempts made to counter these narratives through encouraging more involvement of Muslim academics and the Muslim community in research and healthcare education.

Stonebanks (2008, p.25) highlighted exactly why there has been a failing in research when it comes to representing Muslims citing that:

> "Muslim communities continue to be dehumanized (both in the West and in the East) given the current tragedies relating to the Muslims…through the continued consequences of colonialism and imperialism, Muslim voices have been marginalized, twisted, and ignored, creating a perception of the Muslim as less than human in the Western consciousness. For Muslim narratives to begin to enter the collective consciousness of the West, we must develop methodologies that value the knowledge

> of Muslims, the history, perspectives, and experiences, and be respectful of the relationship to Islam for the research to be truthful, ethical…".

The empirical research that forms this thesis values and centres the knowledge of Muslims. Furthermore, to discover, to grow, to gain some insight, to facilitate that process will be more meaningful in providing new and representative narratives for and with British Muslims which could also potentially lead to establishing more positive relationships and building trust with healthcare services and the research community. Coburn et al, (2013, p.4) talk about the importance of *"operating against the historically nightmarish relations between Indigenous peoples and the colonizer/settler"*, through the power of collaboration between indigenous and non-indigenous researchers working together. However, they remain conscious that despite this they are unable to escape the effects of colonial relations which continue to shape the way in which their article is written and received (Coburn et al, 2013, p.4) They also highlight the anticipation of greater scrutiny of their Indigenous-based arguments and ways of expressing which are perceived as 'unconventional' whereas articles that conform to dominant, colonial ways of knowing and doing research are less open to the same type of scrutiny and attack (Coburn et al, 2013, p.4). These arguments about the colonised and coloniser power imbalances are situated within a wider discourse on decolonising global mental health. Mills (2014) discusses the multiple ways in which colonial violence continues to be perpetuated through different means such as: ideas of benevolently rescuing the 'other' through their notions of 'development'. (Chakrabarti and Dhar, 2009 cited in Mills, 2014), of the epistemological violence of biological reductionism (Shiva, 1990 cited in Mills, 2014) and the 'identity violence' of colonial and psychiatric discourse (Hook, 2005a :480, cited in Mills, 2014). These forms of violence are situated in a wider backdrop of inter/national power (Mills, 2014).

I have spoken further about the historical backdrop of epistemic injustices (in chapter three), physical violence and resultant ongoing trauma experienced by Muslims in section 3.4.6. Mills (2014) illuminates the dangerous and reductionist *"re-configuration of distress by psychiatry as an 'illness' located within the brain – for which there is a 'treatment' (and one that is often chemical)."* It is worrying that many people including some Muslims are adopting the reductionist globalised language of mental health which loses context of the wider picture, of the holistic self that includes the environment, the soul, and other metaphysical, psycho-social and geo-political realities. This has been my observation and I have yet to see any research studies on the causes of the adoption of this globalised language of mental health in the Muslim

community. These reductionist limiting ways of perceiving distress can have serious implications not just for dealing with the suffering that results but also can lead to ignoring the wider backdrop of injustices if we can conveniently blame the individual and their biochemistry which can apparently be fixed by a synthetic chemical. Further negative outcomes include losing depth and breadth of meaning through change of language and not using words from one's mother tongue, a limiting of scope of what the experience means, a reductionist limited focus on diagnostic criteria which is ever changing. What happens for example, if a Muslim woman presents with trauma following birth, perhaps she is coming from an already stressed socio-economic situation, and carrying intergenerational trauma, now she experiences discrimination and obstetric violence during birth – how is her distress to be remedied and or dealt with by the healthcare system that has already discriminated against her, where she felt harmed, where does she go for support, help and healing - to the same system that does not acknowledge or value her? These are the kinds of dilemmas explored in the empirical study and final discussion. Add to this, the current climate in real world contexts of British Muslims, expressions of feelings like anger and injustice can become politicised and scrutinised through misappropriation, and false application of the PREVENT agenda unhelpfully preventing Muslims from expressing what are likely legitimate humane feelings that all people have, and ironically potentially exacerbating mental distress. This enforced political agenda into the healthcare arena is likely to lead to fear and withholding important feelings that could lead to worsening mental health and even suicide. Younis (2019) explored the impact of statutory counter-terrorism policy in health settings and its impact on British Muslim mental health access. An example of the absurdity of using common everyday emotions to screen for extremism is highlighted in his paper on 'Counter-Radicalization: A Critical Look into a Racist New Industry' (2019), where he illustrated how the *"The UK government's CR (counter radicalisation) training relies on an 'Extreme Risk Guidance (ERG22+) framework', listing the first five vulnerabilities:*

- *Lack of emotional resilience*
- *Problems with relationships*
- *Need to feel important, valued, or special*
- *Need for identity, meaning, and belonging*
- *Feelings of threat and insecurity"*

As Younis (2019) stated, *"each of these vulnerabilities are remarkably commonplace, if not all too human. How have they been included in the ERG? Unfortunately, the science behind the ERG is highly suspect and has been critiqued by over 100 academics and various organizations"*. If we think about trauma of any kind, early adverse childhood experiences, such as being born through a traumatic birth, or attachment difficulties these can consequently impact the child or now adult feeling not loved, important or special as mentioned in the above list. It is critical to provide a safe space for people to be able to express their emotions and feelings, their experiences, their 'wounds'. Ironically many of these mentioned vulnerabilities in the framework above are considered basic human needs under Maslow's hierarchy of needs model. It is important to reflect upon the context such as whether the healthcare system feels unsafe due to the above kinds of programmes, whether the misappropriation of these five human traits creates prejudice in health care services and health care research, and how Muslims are navigating this during pregnancy and birth. The very politicisation of Muslims has eroded trust in many areas with some of the most potentially dangerous consequences being in healthcare, if people do not feel safe to reach out, they do not trust the services or service providers they may not access critical health care.

1.5.3 Reflections

I am trying to do something that both gives a historical context to the study and to honour and reclaim a narrative by doing justice to balancing as accurately as possible the needs of those I am representing. This means being mindful of a disempowering and violent past through literal genocide, burning of libraries and texts; epistemicide (will be discussed in chapter three under methodology and philosophical underpinnings). This study was shaped as I worked with it, rather than having had a concrete idea of the details at the outset that would define this.

A brief note on words / phrases used: I have been careful to reduce the number of times using words like mental illness and disorders and have chosen instead to refer where possible to mental distress. I prefer to use terms like mental strain / pressure or mental health, though I still feel these words are too simplified and reductionist, and not taking the whole person approach. They can still be symptomatic of perpetuating western medicalised globalised language of mental health. Using the word 'mental' immediately excludes and thus dismisses the body and soul. I am cautious of pathologising cultures and more inclined to reflect and understand what the meaning and causes behind distress and experiences being shared are. I would rather think about why people feel the way they do. Similarly, with words like 'ethnic minorities' and

BAME which I strongly dislike and experience as clumsy, dismissive, disregarding, and lazy clumping large groups of diverse people with diverse cultures, needs and epistemologies together. However, this one was harder to avoid as it is so commonly understood so I have used it reluctantly where necessary. Furthermore, phrases like Global north and Western do feel like oversimplifications and generalising where in reality there are mixed and complex realities that intersect with a diversity of factors and hierarchies within those that include different communities with different epistemologies and various power structures social, economic, political, cultural, religious and so on. I have used it though to refer broadly speaking to dominant majority ideas where necessary.

1.6 Background contextualising literature

"Historically, nearly all women gave birth at home, with the assistance of other women. It was only through the medicalization of women's bodies that the credibility and knowledge of midwives and traditional healers was forcibly lost",
(Harper, 2005; Weitz, 2003 in Shaw, 2013)

This section presents the seminal issues in literature that are relevant for understanding the context in which women give birth, particularly how this may relate to Women considered to be 'minorities' and who are Muslim. The literature referred to here is that which was not captured in the systematic review process due to the limitations of such a restrictive method (discussed in 7.7.1), though is important to understand context and the issues arising. Some of the issues covered through the literature include a discussion on birth and mental health, Islam and perinatal mental health, trauma and birth trauma, and 'medicalisation' of women's bodies.

1.6.1 Birth and mental health

According to Ayers et al., (2015) between 10 and 20% of women suffer from mental health problems during pregnancy and birth. Zaidi (2017) in her paper on 'perinatal mental health and Islam' places this figure at an estimation of close to 20% of women in the UK as experiencing perinatal mental health issues*.".* Ayers et al., (2015) state that: *"mental health problems can arise in pregnancy or after birth and most commonly* consist *of anxiety, depression, posttraumatic stress disorder (PTSD) following a difficult birth and stress-related conditions…".* They also highlight a finding from Knight, et al., (2014) that, though less common, puerperal psychosis, is one of the leading indirect causes of maternal death. This may

be greater in non-majority groups where constructions of ‘mental illness’ can be conceptualised differently, ignored or hidden. Expressions or non-expressions may vary and may not even have ever been picked up and connected to perinatal mental distress or ‘illness’. They may be unknown, never acknowledged in history and continue to be missing from the picture. This is very serious given that: “perinatal mental disorders are among the commonest morbidities of pregnancy, and make an important contribution to maternal mortality, as well as to adverse neonatal, infant and child outcomes” (Howard and Khalifeh., 2020). Furthermore, Jankovic et al., (2020) found that there were differences in access and utilisation of mental health services in the perinatal period for women from ethnic minorities. In particular, that Black African, Asian and White Other women had significantly lower access to community mental health services and higher percentages of involuntary admissions than White British women (Jankovic et al., (2020). There are a number of factors affecting access to perinatal mental health support for women from ethnic minority backgrounds in the UK from lack of awareness of mental health, different narratives and constructions of problems, lack of service provision appropriate to meet culturally and faith sensitive needs and as Watson et al., (2019) suggest interactions with culturally incompetent and dismissive health providers impacts on ethnic minority women's ability to receive adequate perinatal mental health support in the UK. All of these factors can have a profound negative impact on processing birth trauma and impact the bonding relationship with the baby and thus have long term consequences. Birth trauma experiences for women from ethnic minority backgrounds can be further complicated when those experiences are connected to racism and or Islamophobia, making it exceptionally difficult to seek support from the very system that may also have a part that caused trauma.

It is important to be cognisant of the impact of birth trauma on the development of the child and their early social, emotional and psychological needs. I argue that we do not have a detailed understanding or data of the perinatal period for Muslims to help us think about what specific experiences are going on that may be areas of risk or give us insights into what facilitates recovery and the impact on the developing child before we can think about doing further research.

1.6.2 Islam and perinatal mental health

Zaidi (2017) states that despite Islam being the second largest religion worldwide there is little discussion surrounding Islam and perinatal mental health. She also highlights the gap in

knowledge in respect to perinatal mental health and Islam, with there being limited studies on perinatal mental health in British Muslims. (Zaidi, 2017). This thesis aims to contribute to that gap. She further states that: *"religion may be a source for advice and a large part of a Muslim woman's life during the childbirth continuum."* Understanding this can be crucial for shaping healthcare provision for Muslim women and thus *"health professionals need to be sensitive towards religious beliefs and provide individualised care."* (Zaidi, 2017). Her paper discusses the following areas in the context of an Islamic perspective of perinatal health: '*The importance of motherhood in Islam', 'Breastfeeding in Islam', 'Preference of gender and Islam'* and how Islam condemns this, '*The role of the family'* and *'biological causes'*. Perinatal health and mental health are areas seldom spoken about in the Muslim community. Until very recently Mental Health was stigmatised, though change is taking place. We need to acknowledge that there are people who do not know what perinatal mental health is, do not in believe 'mental health' and may displace any manifestations of 'differing' behaviour, psychological disturbance, or socially 'unacceptable' feelings onto concepts of possession and evil eye effects. This thesis is an attempt to contribute to the conversation using the insights gained from the systematic review and especially the empirical data gathered.

The Qur'an describes intra-uterine life in developmental stages (birth and the honour of parenthood particularly motherhood are also referred to). The descriptions of intrauterine life are quite incredible if thinking the context and era being 7th Century Arabia. Revelation to the Prophet Muhammad (pbuh) who was unlettered i.e., was unable to read is considered one of many arguments for and signs of revelation (Saadat, 2009). This knowledge and the fact that it is 'missing' from the Western history and medical books is an example of epistemicide (discussed in chapter three) and can be illustrative as part of the discussion I mentioned earlier on the control of knowledge production. Just for context when revelation occurred this was a time prior to the development of the microscope around the 17th century (almost 1,000 years later). Furthermore, Saadat (2009) highlights that the *"Qur'an and Hadith provided a detailed description of the significant events in human development from the stages of gametes and conception until the full-term pregnancy and delivery or even post-partum"* and further still that this information corrected many superstitious and vague ideas about human development Saadat (2009). The purpose of mentioning that discourse around pregnancy and birth exists in Islam, is threefold. Firstly, to highlight it exists and did so as far back as the 7th century. time wise this was significantly before it appears in western literature. Secondly, this Qur'anic

reference has largely been wiped from Western literature and thirdly the significance of the teachings around pregnancy and birth for Muslims.

Muslim women and their worldview which is shaped by Islam cannot be separated out. It is crucial that faith sensitive support is provided, and healthcare professionals are trained in understanding the nuances of Muslim women's experiences both in terms of the meaning they attribute to life events such as pregnancy, birth and motherhood and some education on Islamic practices that can be helpful in healthcare.

Hassan (2022) states that Islamic beliefs and practices were at the core of Muslim women's maternity experiences in her research paper, however that Muslim women were lacking in confidence when needing to express their religious needs when engaging with maternity healthcare services. Religious practices mentioned by participants included Recitation of The Qur'an and supplications, maintaining modesty, absences of male health professionals amongst other factors. It would be helpful if healthcare practitioners attending to pregnant and birth Muslim women could be versed in the practices and support that Muslim women draw from their faith. Similarly, Hasnain et al., (2011) in her study of USA Muslim women patients and providers found significant barriers for both patients and providers in the provision of culturally appropriate care for Muslim women. They suggested a flexible collaborative model of care that both caters for the needs of Muslim women and also offers training for providers which could lead to the creation of necessary adjustments in the healthcare system (Hasnain et al., 2011). Recurring themes were reported around lack of understanding of cultural and religious needs, differences around modesty, language related communication barriers, lack of trust and suspicion of the healthcare system (Hasnain et al., (2011). Firdous et al., (2020) conducted a systematic review and thematic synthesis of Muslim women's experiences of maternity services in the UK which found that again there was major significance of Islam in shaping Muslim women's decision making in relation to their care be it antenatal screening or medication. They also state the limited awareness of healthcare professional on the important role Islam plays for these women. Ultimately these women experienced poor maternity care which at times indicated stereotypical and discriminatory behaviour (Firdous et al., 2020).

1.6.3 What is trauma, birth trauma or a traumatic birth?

The origin of the word trauma in the Greek is usually translated as wound. There are a plethora of definitions of the word trauma but mostly they refer to an unpleasant, distressing, shocking, upsetting experience or psychological and emotional wounding. Post-Traumatic Stress Disorder (PTSD) as a diagnosis has changed with each edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) as well as in the International Classification of Diseases (ICD). Given the differences in criteria not just across times but across different diagnostic manuals there is debate over the parameters and definitions that constitute this diagnosis and remain ever evolving and controversial thus it is worth bearing this in mind regarding the definition (Stein et al., 2014, Pai et al., 2019). The latest version of the DSM-5 includes a new category: Trauma- and Stressor-Related Disorders. Initially DSM-IV defined the traumatic event as one that causes threat to the integrity of the person or others characterized by intense fear, helplessness, or horror and the ICD-10 Diagnostic Criteria refer to the importance of events that precipitate distress in almost anyone. Two important changes to the definition of PTSD have been made in DSM-5: One is the requirement of a subjective response of fear, helplessness, or horror to the event has been eliminated and two PTSD has been expanded from exclusively a fear-based anxiety disorder to a disorder that also includes anhedonic/dysphoric and externalizing phenotypes (Stein et al., 204) These definitions have been widely criticised in mainstream literature (Pai et al., 2019). It is important to recognise that there are multiple ways of conceptualising and defining trauma beyond the narrow, clinical, ever-changing definitions. Trauma is understood more widely and broadly than as described in the DSM-5 or ICD. Below a few different definitions and conceptualisations of trauma and birth trauma are considered.

Music (2011, p202) defines trauma as "*a piercing of the skin in its original medical meaning"* and further applies this to psychological trauma as *"a piercing of the psychic skin or membrane".* For many women, processes and experiences around birth can feel overwhelming and trigger feelings of being "unable to take action in the face of trauma" (Dryland 2020) which causes traumatic stress. Turning more specifically to birth trauma Beck (2009) defines 'Birth Trauma' as: *An event occurring during the labor and delivery process that involves actual or threatened serious injury or death to the mother or her infant".* In my reflections on what constitutes how birth trauma is defined, I wondered about the continuing effects and for what time period could the feelings and experiences associated with it be classified as birth trauma,

or does it need a broader term. I know from my work with women that decades later they felt the effects of their trauma that occurred around the time of birth.

Ayers et al., (2020) highlight that although birth trauma as a term *lacks universal acceptance or a standard definition,* it is widely used and understood to relate to ongoing emotional distress as a result of a traumatic birth. The added difficulty around establishing the parameters of the term are due to the interchangeable use of words such as PTSD (Post traumatic stress disorder) to describe trauma around birth (Ayers et al., 2020). The foundation of some of these findings are based on a "meta-analysis of 50 studies" which found that key vulnerability factors included: *"depression in pregnancy, fear of childbirth, poor health or complications in pregnancy, a history of PTSD, or counselling for pregnancy or birth-related factors"* (Ayers, 2017). This paper which was exploring risk and resilience factors of birth trauma and PTSD found that: *"the strongest risk factors during birth were a negative subjective birth experience, having an operative birth (i.e., assisted vaginal or caesarean section), lack of support during birth, and dissociation"* (Ayers, 2017). These kinds of negative experiences including operative birth, lack of support and dissociation can be linked to obstetric violence which is discussed below in section 1.6.6 Trauma experienced around birth could also affect the bonding and attachment relationship between mother and baby. The impact of a non-secure (insecure, anxious, ambivalent or disorganised) attachment relationship would likely have implications for the child's development.

There is minimal research in the areas of resilience and post-traumatic growth in perinatal women, further research is required to understand women's capacity to adapt and grow, and how these insights could inform changes to maternity care provision (Ayers, 2017).

Although *"NICE recommend that practitioners offer advice and support to women who report birth as traumatic and consider that their partner may also be affected and require help (NICE, 2020)",* there are communities that won't report their feelings related to birth, or even know that it is possible to seek help an support and or may not have the language or know the word trauma and what it means and that perhaps it can be used as a word to describe feelings and experiences that we understand in the West as traumatic.

1.6.4 Racial and systemic traumas

This section will touch on institutional racism, including longstanding beliefs about the racialisation of pain. The concerning disparity in maternal mortality rates between white women, and women from Black and other ethnic groups has been highlighted previously in research carried out by Knight et al. (2018, 2019, and 2020b), which highlighted a link between the number of women who died from infections and English not being a first language. A very serious recognition in the report is regarding how communication can be misinterpreted by healthcare workers of different cultural expressions of illness and of the difficulty of some women in expressing themselves the more unwell they became. There are long standing beliefs emanating from slavery about black and Asian women being able to bear more pain, or not feeling as much pain, there are contradictory beliefs that suggest some women of colour are 'weaker' (and therefore presumably cannot bear more, or they complain more (Ali, 2020).

Another misunderstanding or miscommunication could be due to some women coming from cultures of silence and shame at expression of pain and suffering, it can be considered more noble and polite to remain quiet and especially maintain decorum in front of white authority. These subtleties in reasons for not being able to communicate or share difficulties could be missed but also can be worked with in collaboration with and centring the needs of women of colour or 'minorities' and asking them, talking to them, getting to simply know each other so that cultural nuances can be picked up on more. There are deeply concerning issues of institutional racism, (and institutional Islamophobia) and racialisation of pain which connect to the overall colonialisation perception of the other as less than. I discuss an example of this enacted by medical professionals in section 3.4.7. On a more structural level strategies are required to address cultural awareness and develop respect in healthcare providers and within systems (Turienzo et al., 2020). In a study Turienzo et al., (2020) highlight health inequalities and the crucial importance of going beyond addressing biomedical factors alone which are insufficient in dealing with the deeper-rooted disadvantages in society. They suggest a solution to include integrated holistic long term public health strategies that tackle societal and structural racism and disadvantages. They further highlight an area of risk and danger in accessing healthcare which focuses on areas of trust or lack thereof in services. It is this fear and lack of trust that could lead to not accessing services when required which could lead to serious health implications. The lack of culturally sensitive support is also another area that needs to be included in public health strategies to ensure care is appropriate and trust is built with various

communities. Strategies around health care must include cultural and faith awareness and address issues of respect by health care providers and systems. Culturally and faith sensitive healthcare and awareness by healthcare staff of long-standing issues of disadvantage and discrimination are critically important during perinatal care.

According to the MBRRACE report (2020) between *"2016-18, 217 women died during or up to six weeks after pregnancy, from causes associated with their pregnancy",* and that *"9.7 women per 100,000 died during pregnancy or up to six weeks after childbirth or the end of pregnancy"*. In total *"566 women died during or up to a year after pregnancy… 90% of these women had multiple problems"*. Further evidence suggests *"systemic biases due to pregnancy, health and other issues prevent women with complex and multiple problems receiving the care they need*". The report highlights that there is a more than fourfold difference in "maternal mortality rates among women from Black ethnic backgrounds and an almost two-fold difference among women from Asian ethnic backgrounds compared to white women. These disparities emphasise the need for continued focus on addressing the causes of these disadvantages and providing solutions, which necessitates action being by policy makers, service planners/commissioners, service managers, and all health professionals.

The disparity represented through the results in the MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential enquiries |across the UK) report as well as those cited by Knight et al., (2019, who also co-authored the report) have led to a number of initiatives being taken from within black and minority communities in raising awareness as well as through organisations such as The Royal College of Midwives 'Race Matters' initiative which has set out a plan to support research and champion change in outcomes for pregnant women from minority backgrounds. They have a taskforce which aims to 'highlight where health disparities exist and improve understanding of the causes behind inequalities as well as create meaningful solutions. This study aims to contribute to highlighting where health disparities exist and improve understanding as well as provide recommendations from Muslims that could contribute solutions and provide more appropriate healthcare.

Higginbottom et al., (2019) cited that one in four births in the UK is to foreign-born women and that in 2016, the figure was at 28.2%. They noted that this was the highest figure on record, with disproportionately higher rates of maternal and perinatal mortality for some immigrant women. If we add to this, figures of women from ethnic minorities, and of different religious

groups the figures will no doubt be higher. They were examining the factors affecting women's perception of choice and control during pregnancy and birth. A very key area which also came up in my findings – the nuances of which can be read about in detail in the themes in chapter five. Higginbottom et al., (2019) suggested that '*language proficiency, lack of awareness of availability of the services, lack of understanding of the purpose of antenatal appointments, immigration status and income barriers'* were factors affecting choice and control. Similar factors were apparent in varying degrees in the Systematic Review and within my empirical study.

Bharj et al., (2016) cited the authors of the Lancet series on midwifery (Homer et al., 2014; Renfrewetal., 2014; Hoope-Benderetal., 2014; Van Lerberghe et al., 2014) who had illuminated the considerable body of evidence portraying that midwives play a powerful role in the lives of women and new-borns, suggesting the critically placed position of power they may hold in determining and shaping the quality of experiences. This position of power is complicated in the hierarchy of medicine where it is suggested the male doctor physician holds more power than a midwife. Though there are discussions around whether medical patriarchy in perinatal care has been replaced by matriarchy, despite that, many midwives report being treated as inferior and the idea that midwives were untrained and incompetent and required a skilled male medical professional to intervene in the 'dangerous' area of birth still prevails in practice (Cahill, 2011). Whilst a very interesting area to explore, is beyond the focus and scope of this theses, which if there was unending space I would have very much like to have written an entire section on the history of the medicalisation of women's bodies and especially issues pertaining to the womb and how ideas of 'hysteria' continue to shape medicine in relation to women and particularly how they play out in racist structures that perpetuate systemic trauma.

The data collected as seen in chapter five and six, illuminates how powerful the role of midwives is in shaping the quality of experience both negative and positive. The interpersonal relational aspect of the companions at the time of birth is critical in the experience women and their partners go through, having allies at this time is crucial. It has been highlighted that the most damaging form of trauma could be interpersonal trauma (Van der Kolk, 1989 in Music 2011, 206). This is worth noting in relation to the concept of obstetric violence (discussed in section 1.6.5) and abuse some women may experience during birth as carried out by healthcare professionals. Experiencing this level of trauma can have a physical effect including changing the structure and connection of the brain Music (2011, p80). Music (2011, p80) states how the

impact of trauma can be shaped by culture. This is important to reflect upon when looking at the experiences of British Muslims in relation to pregnancy and birth - how might the very unique epistemic experience be felt and internalised, what meanings arise, what connections are made and what consequences manifest.

1.6.5 Context of birthing experiences: issues of control, coercion, medicalisation and autonomy

A number of issues are connected here: the history of women's health in particular the history and medicalisation of birth, women's mental health, menstruation, pregnancy, birth, fertility and everything related to the space of the womb, the 'hysteria' oppression (dismissal, displacement and denial of the expression of women's distress or feelings), and women's sexuality have historically and continue to be problematised, pathologised and under the control of a Eurocentric patriarchal Western medicalised and increasingly corporatised system. These form a backdrop of control and illusion of choice, and can be precursors to disrespect, abuse and obstetric violence in the power dynamic between 'system' and pregnant and birthing women.

According to Leahy-Warren et al., (2021) though *"women across the world value choice and control throughout their maternity care… most women reported not having choice in the model or location of their maternity care but most reported being involved enough in decision-making, especially during birth".* The issue of control and choice was explored in the data interpretation for this study. There appears an illusion of choice especially in relation to childbirth. Choice has been taken away from women and framed in a way that presents false choices to women in a controlled setting (Long, 2002). Shaw (2013) *"rather than being able to exercise informed consent about things that matter, birth choices often are presented in a way that falsely suggest to women that they have control over their births".* An illusion is created of women having control over their births facilitates where in reality it is medical professionals who are in control. As women are distracted with small decisions, medical staff are able to make important decisions with less questioning and resistance. For women their recollections of birth experiences both positive and negative are related more to feelings and "*exertion of choice and control than to specific details of the birth experience."* (Cook and Loomis, 2012).

Stoll et al., (2013) claimed that through their examination of constructions of labour and birth, the women in their study *"with high fear of birth described childbirth as a frightening and painful ordeal and viewed obstetric interventions as a means to make labor and birth more manageable"* and the women *"with low fear constructed birth as a natural event and regarded interventions more critically".* It is possible for the inverse to be equally true as women who fear the medicalisation model of birth may well have higher levels of anxiety about obstetric interventions and may not perceive those as making birth more manageable and may even perceive it as harmful and more frightening.

Holten and de Miranda (2016) examined women's motivations for having unassisted childbirth or high-risk homebirth, exploring literature on 'birthing outside the system'. They focus on studies from Sweden, USA, Australia, Canada and Finland. There is no mention of whether any of the people in these studies were from minority backgrounds. In their findings Holten and de Miranda (2016) evidenced five main themes arising from women's motivations to 'birth outside the system': "resisting the biomedical model of birth by trusting intuition, challenging the dominant discourse on risk by considering the hospital as a dangerous place, feeling that true autonomous choice is only possible at home, perceiving birth as an intimate or religious experience, and taking responsibility as a reflection of true control over decision-making." (Holten and de Miranda, 2016).

These themes reflect women who are empowered and likely educated around birth and the medicalisation of women's bodies. Holten and de Miranda (2016) highlight this is likely because *"women who homebirth outside the system are often well educated and fully informed about their options and have often prepared themselves by reading obstetric textbooks and taking midwifery course".* For some to birth 'outside a system' may be perceived as a viewpoint to hide, especially for people who are from minority groups – resistance and challenging systems and dominant discourse, being autonomous and taking control may not be possible and only accessible to those in privileged positions of a safe majority. Resistance and challenging systems can be seeped in fear, risky and lack safety for minorities. Women from 'minority' groups may feel on one level empowered and educated to make their own choices but may also be torn by whether they can be open about their intuition and their knowledge based informed choices. What is interesting is one of Holten and de Miranda (2016) findings is the theme of *'Positive first choice: birth as an intimate or religious experience'.* A poignant finding regarding the reason for home birthing for some women may not be based on previous

negative experiences or negative perceptions of birthing 'in the system' as it were. Reasons for birthing outside the system can be based on positive reasons, perceiving birth as an intimate and or religious spiritual experience. However not all women despite feeling empowered and being informed and desiring a home birth can necessarily openly share those motivations and the degree to which they can be highly dependent on multifactorial issues. Perceiving birth as an intimate and religious experience is reflected significantly in the empirical data (see chapter five theme on Islam).

Western patriarchal medical philosophy appears to be one of pregnancy and birth as pathology. There appears a need for control and precision in micromanaging birth as a system or organisational process. Birth traditionally a women only exclusive process – the domain of women was perceived as something mysterious and thus to be feared, controlled and brought under the management of the more scientific superior male mind and gaze. What a woman knows intuitively is controlled and dismissed through 'scientific ways of knowing' which override women's ways of knowing. Birth a female collective process with its varying rituals depending on culture and religious beliefs and customs has become side-lined, dismissed as unscientific. Medically influenced and or induced births form a mechanical process of a patriarchal Western Victorian system which has become the norm.

1.6.6 Obstetric violence, disrespect and abuse

There is increasing evidence that obstetric violence is a very real concept experienced by women. What constitutes 'obstetric violence' is discussed in this section. Venezuela was the first country in the world in 2007 to use the term "obstetric violence" - it was considered as a punishable form of violence against women [VAW] (República Bolivariana de Venezuela, 2007). "Obstetric violence" was defined as:

> "the appropriation of women's bodies and reproductive processes by health professionals, expressed as dehumanizing treatment and/or abusive medicalization and pantheonization of natural processes, resulting in loss of autonomy and the capacity to decide freely about their own bodies and sexuality, negatively impacting women´s quality of the life." (República Bolivariana de Venezuela, 2007).

They highlight invisible forms of violence such as potentially, *"gynaecological examinations, external fundal pressure during birth, episiotomy, caesarean section and other medical interventions"*. They are a *"violation of human rights"* and according to Sadler et al. (2016) *"may even be experienced as a form of sexual acts and gender discrimination".* In support of

this, Annborn and Finnbogadóttir (2022) also state how women who have previous exposure to sexual violence have an added vulnerability in regards to violence during birth.

Amroussia et al., (2017) state *that "disrespectful and abusive treatment during childbirth is a violation of women's right to dignified, respectful healthcare throughout pregnancy and childbirth"* and that "*marginalized groups in society such as single mothers are particularly vulnerable to abusive and disrespectful care".* The empirical research for this study draws on the connection between Muslims being a marginalised group and how the intersection of vulnerabilities may connect to abusive or disrespectful care and where this differs and how in what context. How 'mental' and physical healthcare are experienced during the time of pregnancy and birth have been explored in the empirical part of this research.

Miller and Lalonde (2015) discuss *"the global epidemic of abuse and disrespect during childbirth, its history, evidence, interventions"* and reviewed the evidence for disrespectful/abusive care during childbirth (DACF) stating that evidence indicates that *"disrespectful/abusive/coercive service delivery by skilled providers in facilities, which results in actual or perceived poor quality of care, is directly and indirectly associated with adverse maternal and new-born outcomes".* Miller and Lalonde (2015) further highlight that just improving the quality of facilities does *"not guarantee improved maternal outcomes".* Respect, dignity and compassionate care are significant markers in outcomes (Miller and Lalonde, 2015).

Further to this, Annborn and Finnbogadóttir (2022) investigated the meaning of the concept of 'obstetric violence' to women in Sweden. Of their key findings were that the women who experienced psychological and physical abuse during childbirth may interpret this as 'obstetric violence'. They highlight four categories based on their analyses that led to or contributed to obstetric violence these were included: lack of information, issues around consent and not being able to participate in decision making around their labour, lack of sufficient pain relief, lack of trust with staff, experience of abuse including threats of violence where the birth experience was compared to rape, and the need for quality programs in order to secure the rights of birthing women (Annborn and Finnbogadóttir, 2022).

1.7 Research question and objectives

Having laid out the background and context to this study the aim of this thesis is to explore and document what British Muslims' experiences of pregnancy and birth are. The objectives of which include:

- Scaffolding the study in a decolonial approach, centring Islamic ontology and epistemology
- Acknowledging health inequalities in the Muslim community during the perinatal period, and awareness of intergenerational trauma and the multiple intersections that impact Muslims during the perinatal period.
- Present and platform voices and nuanced experiences of Muslims experiences of pregnancy and birth in their complexity and context to gain some insight of what is going on.

This will be studied through the following steps:

1. Conducting an international Systematic Review and meta ethnography of Muslims' experiences of pregnancy and birth.
2. A foregrounding decolonising methodological approach that is explorative in nature that contextualises the need to specifically understand Muslims experiences in a historical and psychosocial context and centre their epistemology.
3. An empirical study of British Muslims experiences of pregnancy and birth comprising of an online qualitative survey (Part I) and interviews (Part II).

1.8 Next stages and thesis structure

The next chapter (two) presents the meta ethnography and systematic review on Muslims' experiences of pregnancy and birth. Chapter three, the methodology, is presented subsequently, followed by chapter four which describes the methods, chapter five and six which present the empirical research as Part I (qualitative survey) and Part II (interviews), closing with chapter seven which concludes with a discussion bringing the thesis to a close. I would like to emphasise that the Systematic Review was conducted first in my PhD journey before I discovered the decolonising approach and thus elements of it or perhaps the use of this method in whole may seem at odds with a decolonising approach. This dilemma is a real reflection of an ongoing personal very visceral lived journey of navigating a PhD journey that involved learning a new way of approaching knowing, unravelling historical impacts of colonialism,

racism and Islamophobia on myself as well as more broadly, learning more about my own ancestral history and the pains and trauma of generations in communities I connect to, whilst also managing the expected conventions of academia in order to fulfil various criteria. It was a heavy process.

Chapter Two: A Meta Ethnographic Systematic Literature Review on Muslims' experiences of pregnancy and birth

2.1 Introduction

Chapter one clearly laid out the paucity of research on the topic of British Muslims' experiences of pregnancy and birth. There is a lack of data regarding the prevalence of perinatal mental health concerns and disorders in Muslims in Britain. Moreover, it foregrounded some of the critical historical backdrop, and contextualised current thinking around perinatal experiences including birth trauma, racial and systemic traumas in a healthcare environment including issues around obstetric violence, control and choices. It was felt that synthesising as many voices as possible through a meta ethnography would be an important path to pave for this thesis. A meta-ethnographic systematic review is an approach which synthesises data from multiple studies enabling new insights into experiences (Sattar et al., 2021). Meta-ethnographies can provide a foundation for theoretical and conceptual ideas through the evidence they generate which can be useful in healthcare practice and policy (Sattar et al., 2021). The idea of a meta ethnography is to add a new layer of knowledge and understanding not just to synthesise.

The meta ethnographic Systematic Review was conducted before I embarked on a decolonising approach which then shaped the rest of the thesis and should be noted as such. This is where I began to grapple somewhat in my journey through academia and question hierarchies of evidence and the process of knowledge 'production'. While the method has its limitations it also provides a thorough, comprehensive process with a review summary as it were of all the available data in answering a specific question using a specific criteria.

Saherwala et al, (2021 highlight the importance of mental health providers becoming culturally competent in recognising and understanding the unique cultural aspects and religious beliefs that Muslim women practice, in order to provide appropriate mental health care for this patient population. They also state that Muslim women experiencing infertility are at a greater risk of developing mental health conditions and that prevalence of postpartum depression (PPD) in Muslim women, particularly Muslim immigrants with poor social support can be increased (Saherwala et al, 2021). They highlight particularities around modesty and being aware that Muslim women may feel uncomfortable asked to dress in a revealing gown or having to expose

herself to a male physician. Furthermore, their research touches upon issues of how Muslims may connect mental distress to ideas of jinn possession, and due to the collective nature of Muslim communities', issues affecting the individual may be seen as impacting the wider family. Breastfeeding is another area of particular importance and high significance for Muslim women and the view that it is more than just a beneficial act for the child's health and for bonding and attachment but also considered a deeply spiritual act through where the mother is fulfilling an obligation ordained by God. Many Muslims believe they are rewarded for breastfeeding and if there are any barriers or difficulties this can have a significant impact on mood, mental health and sense of self-worth (Hassan, 2022). There are various religious practices that healthcare practitioners should be aware of and some that require involvement and support (Hassan, 2022).

Due to the paucity of research on British Muslims' experiences of the perinatal period, it was decided to broaden out the initial literature search to look at international papers on Muslims' experiences in this area hence the systematic review did not place limitations on region. It was thought that this approach would provide a broader context and help highlight and navigate the multiplexities Muslims' experience at the crux of the natural process of birth and an overly medicalised healthcare system both rooted in their own concurrent sociocultural and medico-political contexts. The rationale for this review was that there were limited studies available specifically on British Muslims' experiences of pregnancy and birth at the time of conducting the review and hence I decided to conduct a broader international review of papers to get an idea of what Muslims' experiences are and what kinds of themes may be appearing.

A study by Sutan and Miskam (2012) looking at perinatal loss in a sub section of the Muslim community found that Muslim mothers experiencing perinatal loss showed some level of adverse psychosocial impact which affected their feelings and that their husbands and family members were the main decision makers for Muslim women amongst this particular subgroup of Malay ethnicity. This is an important finding for healthcare providers to be aware of and involve husbands and family in the process however also being mindful of possible different needs of the mothers and perhaps not being able to prioritise those of over family and husband. Their study showed that engagement in religious practice improved mothers' perception of perinatal loss, a strong religious faith made them feel better (Sutan and Miskam, 2012).

This meta ethnography process facilitated the bringing together of stories from existing literature. It also assisted the wider process of this thesis by foregrounding and laying the foundations for the empirical research stage. In doing this meta ethnography some of the lines of enquiry mentioned in chapter one are to be explored in this thesis. Insights and responses around these, were teased out of the emerging narratives and themes in the systematic review of Muslims experiences. A reminder some of the exploratory questions under the main question which was *what are British Muslims experiences of pregnancy and birth?,* included thinking about how British Muslims specifically encounter the medicalised healthcare services of the NHS in the context of a discriminatory political climate, how participants feel their experiences might shape those of their children and their future health and wellbeing, how participants feel their experiences have impacted their mental health and their sense of being a body in the world or how their experiences have shaped their parenting. Whether these featured or not were explored through the SR.

An understanding of factors impacting the earliest experiences a baby is born into are crucial for ensuring lifelong wellbeing as well as ensuring awareness of the impact on parents' wellbeing and ongoing health. This provided a strong rationale for the basis of the systematic review and meta-ethnography that I conducted. The meta ethnography was a helpful process in synthesising and integrating perspectives from different research articles to add to understanding and insights to the topic. Please refer to the author checklist points [1,2,3] in appendix (5)

The main aim of this meta-ethnographic systematic review was to synthesise and add a new layer of understanding of the evidence and literature on Muslims' experiences of pregnancy and birth. A secondary aim was to explore and examine how Muslims in different countries and contexts experience pregnancy and birth. One of the reasons for looking at papers internationally was due to the limited literature available in the UK context on Muslims experiences of pregnancy and birth. The reporting of this meta-ethnography uses the EMERGe guidelines.

Meta-ethnography was considered the most appropriate qualitative synthesis methodology because it provides a useful framework for the synthesising of existing qualitative literature within a structured process and is concerned with experience, guided by Noblit and Hare's (1998) seven stages:

1. “Getting started;
2. Deciding what is relevant to the initial interest;
3. Reading the studies;
4. Determining how the studies are related;
5. Translating the studies into one another;
6. Synthesising translations;
7. Expressing the synthesis.” (Noblit and Hare, 1998).

The seven-step process was used as a scaffold in conducting this meta-ethnography. As a methodology, it was thought to be particularly apt for the collating of various narratives and voices. Further, it provided an opportunity to explore links, and potential divergence or refutational points between existing data. This created a platform that led to the discovery of integrated ‘meta’ concepts, determining how they relate and eventually synthesise. The idea is not just to aggregate studies but produce new interpretations connecting existing studies (France et al., 2015) and to embed the new theoretical insight within the evidence. The process allows for the inclusion of voices that are often unheard as well as space for bringing new insight in. Given that Muslims’ views tend to be underrepresented, underreported, distorted, absent and or *“negatively framed”* (Ahmed & Matthes, 2016), a meta ethnography offers a worthwhile approach in exploring and understanding a marginalised community. One of the aims of this overall thesis is to create a space for stories to be heard, and one of the key aims for this review - as can be seen by the number one inclusion criteria (table 4) - is to include first person narratives. The requirements of Muslim women with regards to health service, in the Western world, remain poorly understood Rodrigues (2011). state Furthermore, they highlight that the publications they reviewed unanimously referred to the lack of knowledge of the Islamic culture and the implications this has for treating Muslim women (Rodrigues, 2011). This review attempts to add something worthwhile in authentically understanding Muslims’ experiences and needs particularly at the time of pregnancy and birth. It is hoped that this information through the focus on first-hand accounts will consequently help improve services and decision-making processes in health care.,. The synthesis process allows for the emergence of new theoretical insights and meaning going beyond individual papers.

Lachal et al., (2017) recognise the value in utilising qualitative synthesis as a meaningful tool for examining participants experiences *“deeply and broadly”*. They state that the process

allows for the integration of studies from different healthcare contexts and participants, which is very important for this synthesis - to bring together all existing data accessible internationally (different contexts and participants) on this subject matter. Furthermore, they describe the usefulness of qualitative synthesise in multiple ways; particularly in *"identifying research gaps, in informing the development of primary studies, and to provide evidence for the development, implementation, and evaluation of health interventions".* (Lachal et al., 2017). Please refer to the author checklist point [4] in appendix (5).

It is important to note that there have been several criticisms of the gaps and lack of clarity with regards to critical appraisal of qualitative research in the original theory of Noblit and Hare (1995). The original theorists did not provide guidance on how to sample or appraise studies for inclusion, however subsequently thorough methods have been developed in assisting the identification and selection of studies (France et al., 2015). They further reported concerns that as much as two thirds of reviewed health related meta ethnographies were not clear in describing their analysis and synthesis processes (France et al., 2015).

This point was taken into consideration and the CASP (Critical Appraisal Skills Programme) checklist for qualitative research was used to guide this appraisal, along with cross referencing with my supervisors in order to reduce 'reviewer bias', as was the expected convention for a Systematic Review. Despite having to adhere to these conventions, I do note the tension this presented and how it differs from my centring of positionality and decoloniality in the rest of my thesis (as mentioned the SR came before my discovery of decolonial ideas but at a time where I was in the process of questioning these very ideas of 'objectivity' which seemed to be part of a positivist construct that aims for scientific 'validity' and this of course is problematic to a degree in my view if taken too literally, while there is no problem in my view of reflecting with another about our thoughts, decision making and choices but when it becomes a strict measuring tool and hierarchises evidence I think that then becomes problematic and misses out important information potentially and gives the message that one researchers view is inherently flawed or less valuable if not kept in check by another and possibly denies that two or more people may have the same 'biases' and therefore it is still not a neutral process.

It is important however, to note that the theory was originally formulated within anthropology and the weighing of 'evidence' is different to the application within healthcare. Inevitably there has been and will continue to be an evolution of the process, and how best it meets the needs

of the research being undertaken. The eMERGe reporting guidelines developed by France et al. (2019), offer a helpful criterion list, and have been referred to as a checklist in the writing of this review. A separate 'author checklist' (see appendix (5)) is available for reference that addresses each point of the eMERGe reporting guidelines.

2.2 Search strategy

The literature search was carried out by AS (myself) as the main author of this study with advice from supervisors: SA and GL. In the process of getting started and formulating a searchable question the PEO (Population, Exposure, Outcome) criteria model was utilised to construct the research question; *What are Muslims experiences of pregnancy and birth?* Please refer to the author checklist points [5,6] in appendix (5).

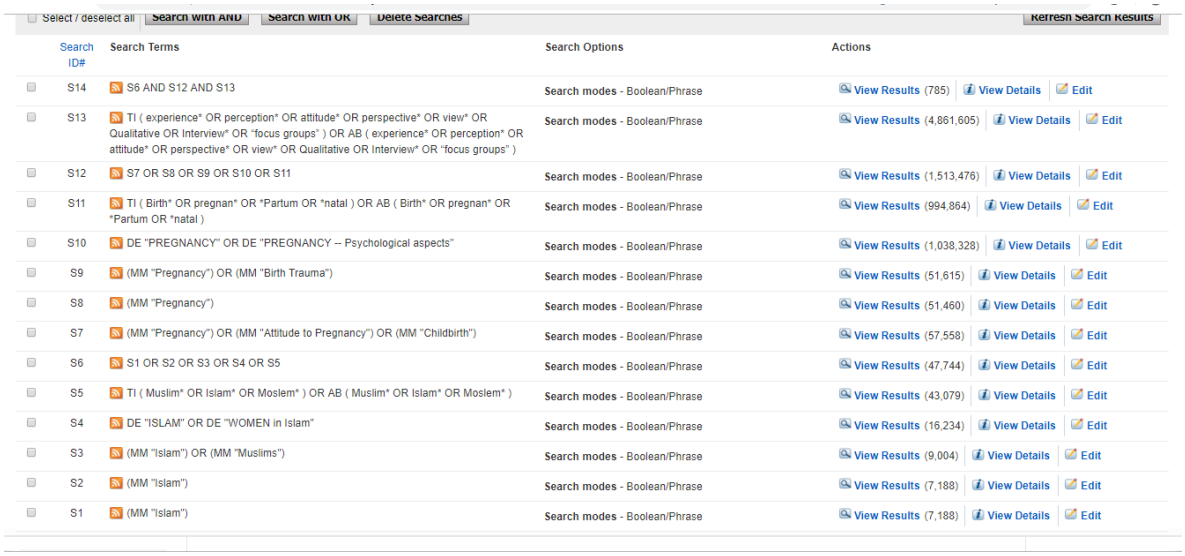
Population	Exposure	Outcome
Muslim and Islam	Birth, pregnancy, perinatal, postpartum	Experiences
TI Muslim* OR AB Muslim* TI Islam* OR AB Islam* TI Moslem* OR AB "Moslem*	TI Birth* OR AB Birth* TI pregnan* OR AB pregnan* TI *Partum OR AB *Partum TI *natal OR AB *natal	TI experience* OR AB experience* TI perception* OR AB perception* TI attitude* OR AB attitude* TI perspective* OR AB perspective* TI views OR AB views TI Qualitative OR AB Qualitative TI Interviews OR AB Interviews TI "focus groups" OR AB "focus groups"

Table 1: Population, Exposure, Outcome Model

The search words were refined using a trial of word searches including words like trauma (Exposure) and British (Population), which were too limiting and ultimately removed from the final search strategy. It was decided with SA and GL that the 'Population' needed to simply include the words 'Muslim' and 'Islam'. Further consideration led to include an alternative spelling hence 'Moslem' was also used to capture more papers potentially. For the 'Exposure' search field birth*, pregnan*, *natal and *partum were used as key words and for 'Outcome' - in discussion with SA and GL and with advice from the library - it was decided that the words experience*, perception*, attitude*, perspective*, view*, qualitative, interviews* and "focus groups" would be used to most widely capture qualitative related experiences– refer to table 1 above. Please also refer to the author checklist points [5] in appendix (5).

Key words searches were combined with Medical Subject Headings (MeSH) and using truncation (*). A systematic search was performed following the PRISMA guidelines. Through two main database platforms; EBSCOHost and OvidOnline, a total of nine specific health related databases (CINHAL, Medline, Psychinfo, Socio index, AMED (Allied and Complementary Medicine), Embase, Global Health, Maternity & Infant Care Database (MIDIRS), Ovid MEDLINE) were searched. These were discussed and decided upon with my supervisors SA and GL as being the most relevant and appropriate to the study field. The search was carried out by myself (AS). The search strategy sought all available studies. There was no limitation on dates or countries, the rationale for this was to ensure the widest capture of data available within the criteria given that the initial informal searches carried out for this thesis produced minimal or zero results of relevance.

The full breakdown of syntax, search combinations and results can be seen in the appendix (1). In EBSCOHost, each MesSH was used in 'advanced search' selecting 'map to tree'. This was followed by key word searches using the PEO and a final combination using AND as an operator. An example of the search syntax used on EBSCOHost can be seen below. Please refer to the author checklist point [6] in appendix (5):



Select / deselect all | Search with AND | Search with OR | Delete Searches | Refresh Search Results

Search ID#	Search Terms	Search Options	Actions
S14	S6 AND S12 AND S13	Search modes - Boolean/Phrase	View Results (785) | View Details | Edit
S13	TI (experience* OR perception* OR attitude* OR perspective* OR view* OR Qualitative OR Interview* OR "focus groups") OR AB (experience* OR perception* OR attitude* OR perspective* OR view* OR Qualitative OR Interview* OR "focus groups")	Search modes - Boolean/Phrase	View Results (4,861,605) | View Details | Edit
S12	S7 OR S8 OR S9 OR S10 OR S11	Search modes - Boolean/Phrase	View Results (1,513,476) | View Details | Edit
S11	TI (Birth* OR pregnan* OR *Partum OR *natal) OR AB (Birth* OR pregnan* OR *Partum OR *natal)	Search modes - Boolean/Phrase	View Results (994,864) | View Details | Edit
S10	DE "PREGNANCY" OR DE "PREGNANCY -- Psychological aspects"	Search modes - Boolean/Phrase	View Results (1,038,328) | View Details | Edit
S9	(MM "Pregnancy") OR (MM "Birth Trauma")	Search modes - Boolean/Phrase	View Results (51,615) | View Details | Edit
S8	(MM "Pregnancy")	Search modes - Boolean/Phrase	View Results (51,460) | View Details | Edit
S7	(MM "Pregnancy") OR (MM "Attitude to Pregnancy") OR (MM "Childbirth")	Search modes - Boolean/Phrase	View Results (57,558) | View Details | Edit
S6	S1 OR S2 OR S3 OR S4 OR S5	Search modes - Boolean/Phrase	View Results (47,744) | View Details | Edit
S5	TI (Muslim* OR Islam* OR Moslem*) OR AB (Muslim* OR Islam* OR Moslem*)	Search modes - Boolean/Phrase	View Results (43,079) | View Details | Edit
S4	DE "ISLAM" OR DE "WOMEN in Islam"	Search modes - Boolean/Phrase	View Results (16,234) | View Details | Edit
S3	(MM "Islam") OR (MM "Muslims")	Search modes - Boolean/Phrase	View Results (9,004) | View Details | Edit
S2	(MM "Islam")	Search modes - Boolean/Phrase	View Results (7,188) | View Details | Edit
S1	(MM "Islam")	Search modes - Boolean/Phrase	View Results (7,188) | View Details | Edit

Table 2: Example of the search syntax used on EBSCOHost.

Below is the breakdown of results produced by each database and how it led to the final screening:

Database	Results	Results- Deduplicate	Final result
CINHAL complete (Results)	193	(193- 109)	84
MEDLINE complete (Results)	358	(358- 245)	113
PsycINFO	133	(133- 97)	36
SocioINDEX with Full Text	101	(101- 64)	37
AMED (Allied and Complementary Medicine)	2	(2-1)	1
Embase	432	(432- 392)	40
Global Health	189	(189- 76)	113
Maternity & Infant Care Database (MIDIRS)	109	(109- 101)	8
Ovid MEDLINE(R)	52	(52- 46)	6
	1569 Records	**1131 Deduplication**	**438 Screening**

Table 3: Results by database

2.3 Screening

All results were imported into EndNote and were processed for deduplicating (AS). A final search of exact duplicates across all references combining EBSCOHOST and OVID searches reduced this final count to 438 records to screen. A second reviewer (GL) reviewed 10% of the de-duplicated library (44) to cross-check and confirm inclusion/exclusion decisions and there was full agreement on the titles/abstracts that were reviewed. Screening based on title and abstract reduced to 19 final articles of potential relevancy. All relevant articles were included. From these 19 full text reviews, eleven were excluded based on the inclusion/ exclusion criteria with eight remaining. Hand searching through forward and backward searches produced a further thirteen articles, which were considered at abstract and full text level adding a further three articles for inclusion relevant to this review. This review is therefore based on 11 articles. The screening process can be seen visually in the below PRSIMA diagram. Please refer to the author checklist point [7] in appendix (5).

2.4 Eligibility: Inclusion and exclusion criteria

The inclusion and exclusion criteria with rationale for each are outlined in the tables below.

	Inclusion Criteria	Rationale
1	First person accounts	To collate raw and first-person experiences
2	Qualitative research (interviews, focus groups) focused on Muslims' experiences of birth (men or women)	To synthesise emic perspectives.
3	Any country	To maximise the scope of findings given the limited literature.
4	Men's voices.	It was felt important to include Men's voices too in an area that can be more female centric.
5	Peer reviewed articles	To ensure quality and comparability of findings.
6	Any date	To maximise scope of findings given the limited literature.
7	English language/ translated into the English language	For consistency and synthesising.

	Exclusion Criteria	Rationale
1	No direct quotes from participants	Not focused on emic perspectives necessary for meta ethnography.
2	Quantitative or mixed methods studies	Not focused on emic perspectives
3	Where there is conflation of culture with religion	Not clearly focused on Muslims lived experiences differentiated from cultural or regional and country contexts
4	Narrow focus on one area only	Will not fit in with comparability purposes and wider context of experiences.
5	Second hand accounts	Not the aim of this review
6	Voices of professionals and not first-person accounts.	Not the aim of this review
7	Does not explicitly contextualise or focus on Muslims experiences in the context of their Islamic faith or the role that it plays in meanings derived from pregnancy and birth related experiences.	This criteria would be needed to fulfil the aim of this review and the absence of it would be out of this remit and not meet the objectives and purpose.

Tables 4 and 5: Inclusion and exclusion criteria

For a detailed account of papers included and excluded with reasons and the criteria they correspond with see appendix (2)**.**

2.5 Quality assessment

Study characteristics and the methodological quality of studies were appraised using the Critical Appraisal Skills Programme (CASP) qualitative checklist. For the checklist of all the studies included in this systematic review, see appendix (3). Although some papers appeared weak in some areas of the checklist, there was an overriding decision to include them based on the essential criteria that they narrated first person accounts of experiences, therefore papers were not excluded based on quality. In some papers, the scientific rigour appeared weaker than others. The most prominent weakness was a general lack of documenting clearly the impact of researchers' role in the recruitment process and or the relationship dynamics with participants. There was little mention of positionality and impact of shared characteristics such as of religion, ethnic background, gender, race of the authors on the participants. Please refer to the author checklist point [10] in appendix (5).

2.6 PRISMA diagram

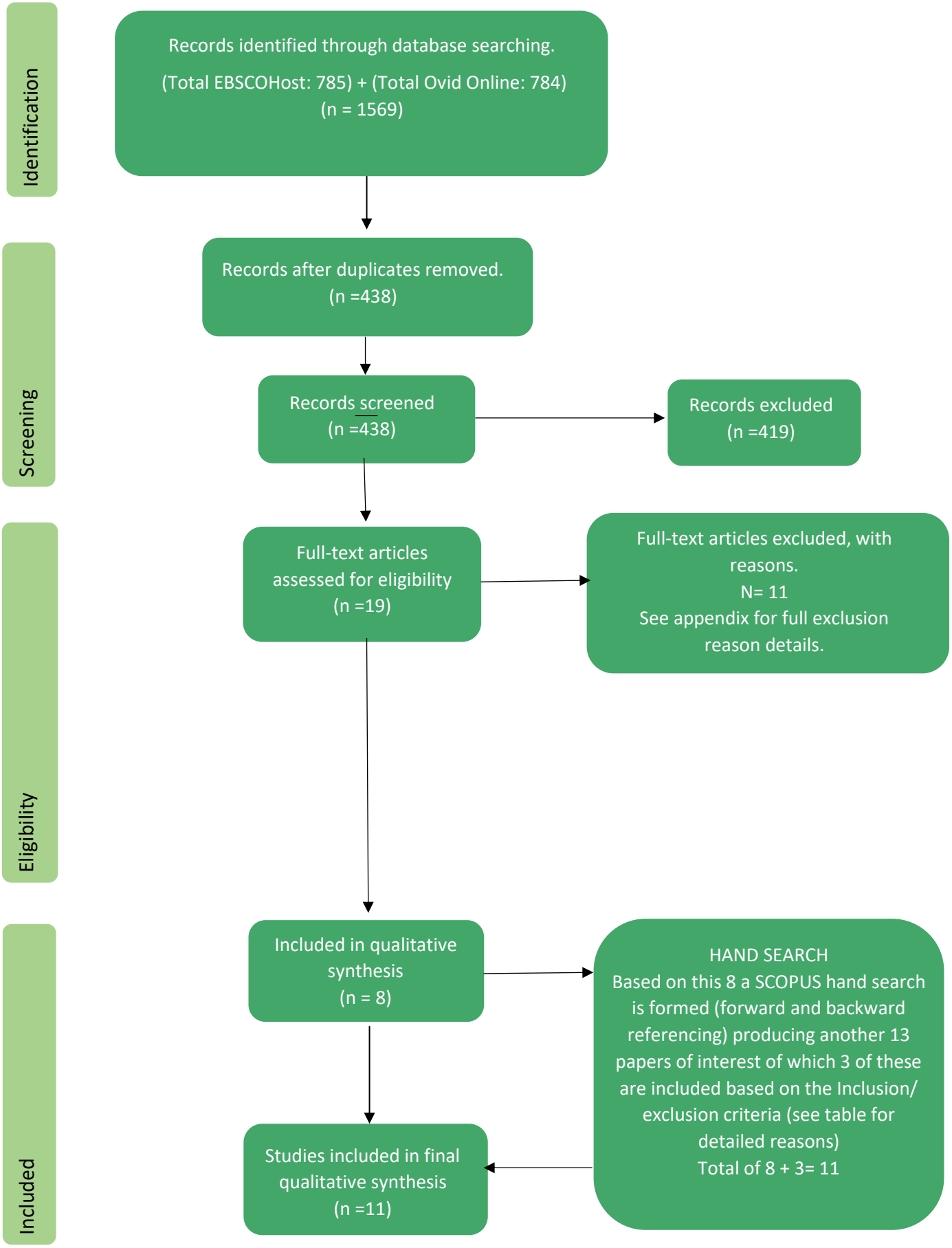


Figure 1: PRISMA Diagram. Please refer to the author checklist point [8] in appendix (5).

2.7 Translating the studies

In determining how the studies are related in this ethnography, the meta-synthesis process initially involved extraction of primary data (first order constructs) and authors interpretations (second order constructs). A table was created for each paper and colour coded. Tables were created that held the first and second order constructs as well as the author given themes for each paper. In the process of establishing commonalities and noticing differences the recurring themes were tallied by paper. This was followed by a second document - a synthesis matrix- where the first and second order constructs were arranged by these emerging themes of which there were eleven initially. This synthesis matrix created a visual (colour coded) picture allowing me to determine where studies synthesised, and which studies had comparable themes. For example, each paper that had elements of 'language barriers' were noted under the one theme retaining the colour coding of each of the original papers. Language barriers was one of the original themes that was eventually merged under healthcare experiences. This was part of the process for understanding how the studies may relate to each other. With all the data now being in the synthesis matrix it was possible to move between the studies to determine some initial thoughts and concepts about how the studies might relate. The aim being to bring together existing findings, exploring connections and combining concepts from the existing data to create a synthesised understanding and interpretation across studies (Noblit and Hare, 1998 in Britten et al., 2002). Please refer to the author checklist point [11] in appendix (5).

Translation is achieved through systematic and constant comparing across the studies. As all the data was within the single document it was possible to move back and forward between the studies to determine some initial ideas about how the studies might relate. With any qualitative synthesis process, it is imperative to remain cognizant of the fact that the synthesis will be *"one interpretation"* of that data (Lachal et al. (2017). Sandelowski and Leeman (2012) highlight the interpretation and translation process as one that *"depends on the authors' judgment and insights and is not a result of a simple coding process, but rather from the researchers' configuration of segments of coded data assembled into a novel whole".* This is an apt analogy of the weaving together of multiple narratives into a 'new' coherent meta theme based 'story'. Lachal et al. (2017) in discussing the extracting, presenting and analysis of data use the analogy of the bricoleur that "*combines techniques, methods, and materials to work on any number of projects and creations".* Moreover, they usefully describe the process and work of a bricoleur

as being able to work outside the limitations of history, "*reorganizing pieces to construct new meaning"* allowing for a nonlinear more diverse and adaptable approach.

As mentioned, all quotes in every study were identified and extrapolated from each paper into a data extraction table formulated for this purpose. A colour coded matrix was formed with all quotes from the eleven papers, with first order (the participants' quotes) and second order evidence (the authors' commentary). The figure below illustrates the headings, under which all of the data were extracted, the first-person accounts (1st order constructs) and the authors interpretation of those accounts (2nd order constructs).

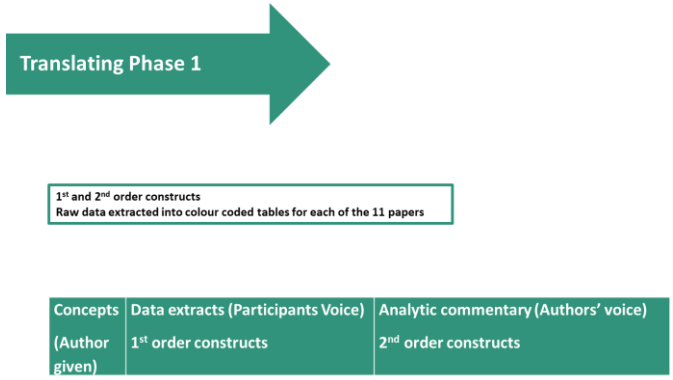


Figure 2: illustration of the headings, under which all of the data were extracted

Each full text paper was read, reread and reviewed by AS and discussed for inclusion in consensus with supervisors (SA and GL). Recurring concepts were noted, following which broad themes were identified as can be seen in the left of the figure below listing 1-11 of the recurring concepts. AS was responsible for the data extraction and GL and SA reviewed the tables. The common themes were cross tabulated. The papers were organised in tabular form, each paper was colour coded which allowed for ease of integration of the concepts into the second stage. Please refer to the author checklist point [9] in appendix (5).

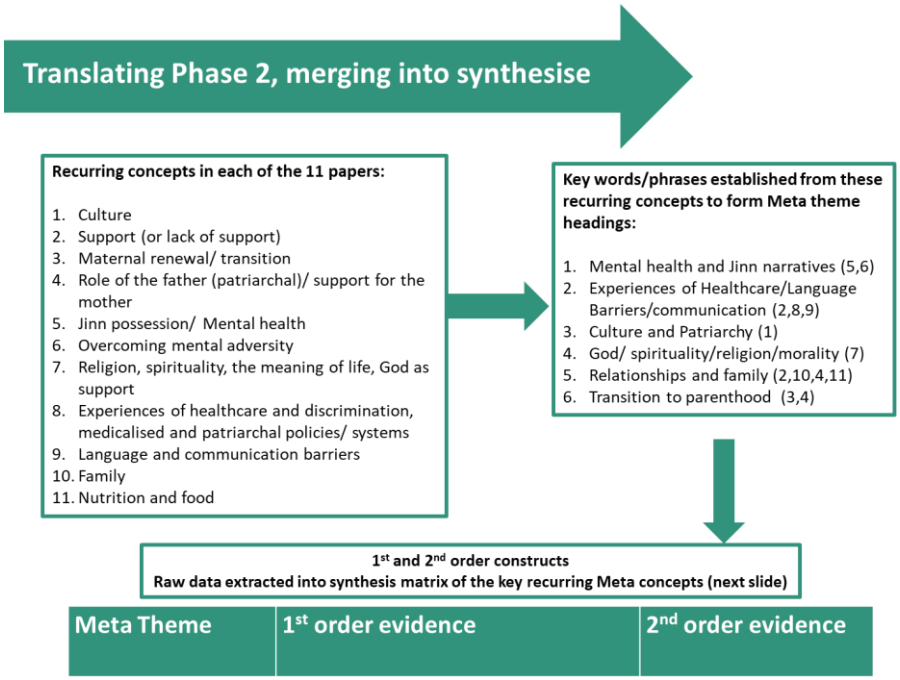


Figure 3: Translating phase, merging into synthesise.

All quotes were compared, and recurring themes were given a name and discussed with SA and GL. The original first and second order constructs were then organised and integrated into the second stage synthesis matrix and after further consideration of overlaps - there were originally eleven themes, however five of these had overlapping elements and were easily merged – as was advised by SA and GL, six final key meta themes emerged. Each of the translated concepts were given an initial word or phrase that described the recurring concepts, this allowed for the development of 'third order' constructs which formed the final meta themes that emerged. These were then developed into a new conceptual framework which led to the relationship between studies being described. Utilising Noblit and Hare's (1998) three different methods of synthesis, assisted in the development of the themes and analysis of the data. Please refer to the author checklist point [12] in appendix (5).

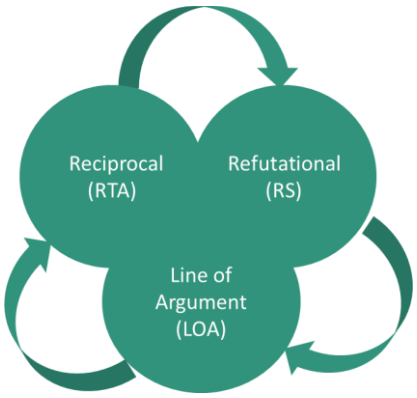


Figure 4: Visualising methods of synthesis taken from Noblit and Hare (1998)

Noblit and Hare (1998) referred to three modes of synthesis as 'Reciprocal Translational Analysis', which involves a translating of concepts from individual studies into one another, resulting in overarching concepts whereby similar ideas can be presented in a theme. (RTA – not be confused with the RTA mentioned later which specifically refers to Reflexive Thematic Analysis). They also proposed 'Refutational synthesis'; exploring and explaining contradictions between individual studies and 'Lines-of-argument' (LOA) which involves building up a picture of the whole from the parts. (Barnett-Page & Thomas, 2009). The diversity of the data required that all three modes be applied to this synthesis. Some commonalities between the papers were identified leading to a reciprocal translation of the studies. However, it was also identified that there were some refutational aspects and 'lines of argument' (LOA) apparent in the process of reading and results write up, especially related to differing experiences in socioeconomic and migration factors. For example, there were both positive and negative experiences of healthcare, support from family and partners and lack of support. This allowed for a new narrative to be developed through the reciprocity of the synthesis and as a line of argument. These are explored in detail in the findings section 2.9.

In the process of synthesising the data and in order to establish the trustworthiness of findings, I discussed the third order constructs and meta themes with my supervisors (SA and GL). The third order constructs (the themes and my interpretations) were discussed with my supervisors and by consensus the original eleven were narrowed down to eight in an earlier draft and can now be seen as the final six meta themes in figure5. Going through the themes, I discussed different drafts on my analysis with my supervisors and we did think about alternative possibilities and in the process of translating, reflected on different way that themes could be framed and adjusted accordingly. For example, in an earlier draft 'nutrition' featured as a theme however it was a strong focus of a couple of papers rather than being more broadly touched upon across all papers, and we felt that elements of it seemed to be in relation to family or healthcare so the first-person narratives could be synthesised with existing themes they most closely aligned with. Another example is the difficulty in finding one word or phrase to represent what was initially referred to as 'God /spirituality/religion/morality' as a theme. This was, after some reflection, and consideration of different possibilities, rephrased as 'the role of

Islam as a faith, way of life and religious identity', to represent the experiences emerging from the first-person accounts. Please refer to the author checklist point [13,15] in appendix (5).

Each themes sub theme was represented using a quote from the participants that most accurately or strikingly captured the overall sub theme. For example, in the first theme 'mental wellbeing and jinn possession narratives', the quote: *"My mother and my sister had Jinn, so it wasn't surprising that I had the same Jinn"* was used to represent the sub theme: 'intergenerational transmission of trauma - a different kind of language'. Here, women spoke of experiences such as not being able to sleep, their baby not sleeping, feeling tired all the time, their siblings or mothers (intergenerational) having experienced the same. They were making sense of this in their context through explaining how they felt being possessed or affected by 'Jinn'. Similar symptoms of not sleeping well, being tired, experiencing anxiety, an unsettled baby, crying all the time for example in a Western context could be considered a normal experience as well as depending on the severity and intensity as postnatal depression or be described using words like insomnia, anxiety, tearfulness (which was also drawn upon in the authors analysis in the second order constructs). All of the sub themes followed this pattern of using a direct quote to illustrate each sub theme in order to stay close to the emic perspectives of the participants while constructing a meta narrative. Please refer to the author checklist point [13,15] in appendix (5).

2.8 Systematic Review Results

Eleven studies were eligible for inclusion. They were all qualitative; with methods of the studies all including interviews or focus groups. The sample across all studies which included interviews and focus groups were 223 Muslims; 190 Muslim women and, 33 Muslim men (across two papers, one explicitly devoted to Muslim men's' experiences). The age range was not always mentioned but was across a wide spectrum, some mothers were first time pregnant, and some had multiple children already. Experiences of birth and pregnancy amongst Muslim's were narrated from Jordan, Syria, Iran, Malaysia, UAE; (Oman and Saudi Arabia), and Bangladeshi women who had migrated to the UK and USA. While sharing a religion, they varied significantly in cultural contexts, socio economic backgrounds and experiences of pregnancy, birth and motherhood. Please refer to the author checklist point [10] in appendix (5).

The positionalities of the authors were not made clear. Through Google searches of the names, I was able to discover that of the authors there were nice Muslim women, three Muslim men, four non-Muslim women, three Non-Muslim men and two 'ethnic minority' women. It was not possible to know much about the personal commitment to Islam and values of authors just through Google searching names. The authors were academics attached to educational institutes. Some authors may be closer to the context of the participants such as the Muslim women authors or the Muslim male authors who co-authored on the role and experiences of father's during pregnancy.

The results of the meta-synthesis' six key themes, can be seen below in the table by each corresponding paper:

	Theme	Authors/ date
1	Mental wellbeing and Jinn possession narratives	Abushaikha & Massah (2013) Miller (1995) Missal (2013) Mustafa & Kittleson (2016) Parvin (2004) Tsianakas & Liamputtong (2002)
2	Experiences of health care: discrimination and diverse needs	Abushaikha & Massah, (2013) Miller (1995) Missal (2013) Mustafa & Kittleson (2016) Parvin (2004) Tsianakas & Liamputtong (2002)
3	Cultural dynamics and Patriarchy	Abushaikha & Massah (2013) H. A. Bawadi & Al-Hamdan (2017) Hala A. Bawadi et al. (2016) Miller (1995) Missal (2013) Mustafa & Kittleson (2016)
4	Relationships and family	Abushaikha and Massah (2013) H. A. Bawadi and Al-Hamdan (2017) Hala A. Bawadi et al. (2016) Hanely and Brown (2014) Missal (2013) Parvin (2004)
5	God/ spirituality/religion/morality	Abushaikha & Massah (2013) H. A. Bawadi & Al-Hamdan, (2017) Hala A. Bawadi et al. (2016) Heidari et al. (2015a) Khalaf & Callister (1997) Miller (1995) Parvin (2004)
6	Transition to parenthood	H. A. Bawadi and Al-Hamdan (2017) Hala A. Bawadi et al. (2016) Khalaf and Callister (1997) Missal (2013) Mustafa and Kittleson (2016) Parvin (2004)

Table 6: Meta themes corresponding papers.

2.9 Findings

Across the eleven papers, 223 people in total were interviewed (or part of focus groups) (33 fathers and 190 mothers). The context and study characteristics can be seen in appendix (4). Please also refer to the author checklist point [10] in appendix (5). The outcome of the synthesis process produced six meta themes which have 3-5 subthemes. Many of the themes had intricately interweaved elements to the story across themes but for the sake of the review had to be sectioned into the most appropriate category - the reader should bear this in mind. For example, 'mental health', 'transition to parenthood' and 'the role of Islam were, at times, difficult to separate out completely. The most prominent theme from my interpretation and analysis was 'mental health and jinn possession narratives'. Therefore, it has been placed in the centre of figure five below, which shows themes overlapping and the circular nature of them. Each theme begins with a brief paragraph describing what the theme is about before using the descriptive phrase and quote that illustrates that sub theme. In these quotes from the studies there was a strong collective nature of the experiences, involving family members, negotiating gender dynamics in the home, around support and the medical healthcare systems, experience of mental health, relationships, transition to parenthood and enmeshment with broader familial, cultural and social roles and expectations. There was a rootedness of the meaning of experiences within a religious way of life that was not viewed as a separate identity or factor but was so deeply embedded in the way people experience and understand life.

Figure 5: Conceptual framework arising from SR analysis.
Please refer to the author checklist point [16] in appendix (5).

2.9.1 Mental wellbeing and Jinn possession narratives

In this theme women spoke of their experiences such as not being able to sleep, their baby not sleeping, feeling tired all the time, their siblings or mothers (intergenerational experiences) having experienced the same. They were making sense of this in their context through explaining how they felt being possessed or affected by 'Jinn'. The symptoms - not sleeping well, being tired, having severe anxiety, an unsettled baby, crying all the time for example in a Western context could be understood as postnatal depression for example or be described using words like insomnia, anxiety, tearfulness (which was also drawn upon in the authors analysis in the second order constructs). For others in different contexts motherhood was equated with a sense of wellbeing and feeling 'fantastic'. Other aspects of the theme drew on difficulties in communicating the need for help and the parameters of who and where to seek help from with a feeling of helplessness and frustration with lack of time with doctors and different manifestations of feeling a lack of control such as perceiving the lack of control and containment as externalised using language of 'possession' so commonly associated with 'jinn' possession narratives.

Key illustrative quotes (theme and sub theme titles)
Mental wellbeing and jinn possession narratives

- Intergenerational transmission of trauma - a different kind of language: *"My mother and my sister had Jinn, so it wasn't surprising that I had the same Jinn".*
- Motherhood feelings: *"Motherhood is fantastic feeling".*
- Helplessness in getting help: *"The doctor doesn't have time to help you. Then how are you supposed to (bring up matters)?"*
- Losing control: *"no control over becoming 'possessed'".*

Intergenerational transmission of trauma - a different kind of language: "My mother and my sister had Jinn, so it wasn't surprising that I had the same Jinn".

Mental health was a prominent and recurring narrative throughout and was explicitly mentioned in six papers (H. A. Bawadi & Al-Hamdan, 2017; Hanely & Brown, 2014; Heidari, Ziaei, Ahmadi, Mohammadi, & Hall, 2015a; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas and Liamputtong, 2002). The meaning of mental health was articulated in a particularly nuanced manner using a variety of narratives, language and semantic constructions depending on culture and interpretation of what mental health means to the individual both through the voice of participants and the authors' interpretations of those experiences. Factors

affecting the experience of mental health and the interpretation of it by Muslim women varied depending on issues of migration, or being in their country of birth, by culture, medicalisation and religious narratives, creating both reciprocal and refutational translations across the studies.

Motherhood feelings: "Motherhood is fantastic feeling".

Two of the studies under this sub theme reported positive mood and feelings around motherhood (H. A. Bawadi & Al-Hamdan, 2017; Khalaf & Callister, 1997). Jordanian Muslim women in H. A. Bawadi and Al-Hamdan (2017) study had contrasting narratives and foci of concern to those of Bangladeshi Muslim women who had migrated to the US or UK- Parvin (2004) study. Jordanian Muslim women described motherhood as a positive impact on their mental health: *"Motherhood is fantastic feeling. The woman's status increases in our society when she becomes a mother, she will prove that she is fertile and could continue the family line of her husband. I have to preserve this advantage that God bestows on me. I have to finish my puerperium with a strong body, so I can take care of my new baby and my other children..."* (H. A. Bawadi & Al-Hamdan, 2017). This suggests the importance of a strong sense of self internalised by the messages of value attributed to the role of motherhood by the society in which they live provided by a supportive network, purpose and meaning. This rooted their experience in a positive context promoting mental health and wellbeing. Similar sentiments were reported in Khalaf and Callister (1997) study, one woman reports her feeling on motherhood: *"I felt that the baby and I were joined together and we were sharing the same dimensions, the same space. So as I was taking care of myself, I was caring for my child. I marveled about how this miracle could happen. The whole process of creation…"*. The positive experiences and feelings around motherhood provided supportive frameworks for some women.

Contrastingly the Bangladeshi Muslim women who had migrated to the UK voiced mental health as restlessness and the worry around being alone to deal with everything (as opposed to the supportive factors felt by women in the H. A. Bawadi and Al-Hamdan (2017) study): *"When people have difficulty that's when it (sadness/restlessness) impinges on their mind, before then it won't impinge"* (Parvin, 2004). Another woman reiterated: "*If there is restlessness in the mind then nothing can be done, you can't care for your children or look after yourself, or anyone. It's like your head/mind becomes crazy, because I worry all the time, because in this country I don't have anyone. I am alone in this country."* (Parvin et al., 2004)

There was a feeling that one had to 'just get on with it', 'put up' with difficult feelings sadness and problems (Parvin, 2004). There was no choice, a sense of helplessness of circumstance, lack of support and a deep sense of being alone with worries that create an almost paralysing state being unable to do anything as supported in a statement by a participant in Hanely and Brown (2014) study*: "I too became ill with the Jinn. My son would not sleep nor settle very well".* Another participant in this study discussed how the feeling of possession which she referred to as a 'she' made her feel: *"She makes me feel very tired all the time, I have no energy and I cannot look after my baby I have to ask my mother and she told me she felt the same way as I do."* (Hanely & Brown, 2014). A sense of helplessness is suggested, feeling oppressed by this (Jinn) external force. Exhibiting symptoms of stress and breakdown or some kind of trauma or postnatal depression may be attributed to being possessed and thus externalised. In the same study another woman stated her experience of being possessed by Jinn: *"Her face is dog like and fire discharges from her mouth. She has an overriding power and none are safe from her clutches. She is a curse to babies in the womb"* (Hanely & Brown, 2014).

The difference between Jordanian women's feeling of positive wellbeing and mental health during the time of pregnancy may be contrasted with the socio-cultural context of the migrant Bangladeshi women in the UK and USA as not having traditional family support structures or their mother's presence that they may have ordinarily relied on. Furthermore, for some not being able to fulfil the same cultural practices of celebration and being faced with the economic and other struggles of migration and not feeling as grounded or supported in their historical and familial context caused this sadness (Hanely & Brown, 2014; Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004).

Helplessness in getting help: "The doctor doesn't have time to help you. Then how are you supposed to (bring up matters)?"

In the study by Parvin (2004) women expressed a sense of uprootedness and stress, not quite knowing who one could turn to or the 'care' being inappropriate or failing. This was also touched upon in the studies by Miller (1995); Mustafa and Kittleson (2016); Tsianakas and Liamputtong (2002) but quite contrastingly Tsianakas et al., (2002) reported both positive and negative experiences and the focus in H. A. Bawadi and Al-Hamdan (2017) study was also on the positive. It is important to note that throughout all the narratives there are differing refutational experiences dependant on a variety of factors predominantly seemingly whether

the population is indigenous or migrant and the level of support available. It is worth noting that the experiences of care being inappropriate and not meeting the needs of the women were all based on studies carried out in Western contexts, mostly women who had migrated or were ethnic minorities.

Although Parvin (2004) does not specifically ask the question using the words 'mental health' there is an inference about states of minds, emotional and psychological stressors. When a researcher asked: *"Why don't you tell the GP about this matter?"* (Parvin, 2004). The following were a variety of responses received: "*Well we think, I have this (emotional) pain because of my own situation. What can the doctor do about it? That's what comes to mind."* (Parvin, 2004). In this paper, the doctor's role is not seen as related to providing emotional or psychological support. It illuminates a question around the role of a doctor and what that means to the women and whether it is okay to talk about mental health and emotions and what that might mean. In another example, one woman replied: *"What type of medicine can you get to have peace in your mind?"* There is a subtle acknowledgment of something psychological and emotional that needs addressing rather than medicating. Furthermore, another woman states that despite communicating her feeling in physical terms; *"Your feet and arms ache, after that, you are young, but you look old, because of the illness (restlessness). But the illness has not been detected"* (Parvin, 2004) the 'illness' is not being acknowledged or recognised. Furthermore, another woman states: *"Well you won't tell (the GP) your innermost problems. You might say, 'I couldn't sleep at night, because of pain, because of this and this'."* (Parvin, 2004). For these women, it still goes 'undetected'. The range of responses in this study significantly pointed to differing understanding of causes of physical illness and the meaning attributed by patients. The authors' of this study quite usefully posit an interesting point around language around psychiatric illness and highlighting the difference between the indigenous population narratives and how Bangladeshi women in their study communicated distress using words such as 'trembling heart', 'restlessness', 'pressure in the heart' (Parvin, 2004). In this paper, women also expressed a frustration with the medical system and lack of time at the doctors; two significant factors at play here, G.P time constrictions and constructions around what illness means and how it is to be communicated, with expressions of emotional dysregulation and what may be understood as mental health concerns not being taken seriously: *"The doctor doesn't have time to help you. Then how are you supposed to (bring up matters)?"* (Parvin et al., 2004). There is a communication here that time at the doctors is limited and only to what constitutes 'proper illness' i.e., that which is not located in emotional distress but has

an apparent physical location. Some of the negative experiences related in Tsianakas and Liamputtong (2002) also spoke of not feeling supported by doctors or the treatment they received as being unfavourable and assuming: *"when I went to the hospital in the first pregnancy it was really upsetting and frustrating because they don't think that you speak English."* This experience clearly led to some distress for the woman narrating her account. For others the distress they felt was less attributed to other people such as medical care availability and familial support but more so the focus of expression of its meaning was in terms of feeling 'possessed'.

Helplessness in getting help: "no control over becoming 'possessed'".

Hanely and Brown (2014) and Heidari et al. (2015a) in both the studies explore ideas that behaviour and moods that go against the norm can often be attributed to spiritual or heart matters such as the described effects of being 'possessed' by an unseen force (Hanely & Brown, 2014) or the consciousness of the mother's feeling that any negative thought or action could be transmitted to the unborn child with the focus being on needing to keep one's spiritual self-positive. Both somatising- communicating physical pain such as headaches and using religiously cultured and familiar language of being 'possessed' or locating the distress and angst in the heart are both different ways of communicating the same here – emotional and psychological distress (Hanely & Brown, 2014; Heidari et al., 2015a; Parvin, 2004). An illustration of this can be seen from a participant who spoke about how she mentally prepared herself prior to her pregnancy to ensure she felt calm and had a 'strong spirit': *"Almost 2 years ago, my mind was calm, our problems got less, and I made my mind that if I want to have a baby, I myself must have strong spirit and soul first; therefore I choose to wear hijab, because it affects myself, and my mind is busy with this, so it has effect on my child as well."* (Heidari et al., 2015a). For this participant wearing a hijab (commonly known as a head covering) was a signifying part of becoming more conscious and mindful of her faith and morality and the impact this would have on her own wellbeing and that of the next generation. Other women (and men) spoke of how they protected themselves (or their wife) against 'evil' and harm or during labour and to in order to stay in a good frame of mind they prayed and or recited Qur'an (Abushaikha & Massah, 2013; Heidari et al., 2015a; Khalaf & Callister, 1997) and became extra conscious of imbibing morally upright behaviours and interactions, including refraining from use of explicit language, or being around those who may be considered morally wavering, not watching anything 'harmful to the eyes', not eating anything 'haram' (Heidari et al.,

2015a). There was a holistic element to what may contribute to or cause distress and mental disturbance and therefore need protecting from. One woman in Heidari et al. (2015a) study illustrated the strength and support she found in reading the Holy Qur'an: *"I read from the Holy Qur'an to the child. When I was in labor I was reading a special paragraph from the Holy Qur'an about protection."* This act helped her feel protected. The recognition of mental states and moral behaviour as affecting the child were at the forefront of some women's minds and had a motivating impact on them to be mindful of their thoughts and behaviours and could be perceived as coping strategies for ensuring their and their unborn child's wellbeing. One woman in this study explained: *"from these first weeks, I'm sure that whatever I do or what I have in my mind will affect my child."* (Heidari et al., 2015a) Another woman in this study stated that: *"this is human after all; sometimes, he/she is angry with someone, feels jealousy, hates someone, I say to myself that all of these are characters that the devil creates in human's soul. I have to avoid these. The more you have these inside, the closer the devil can be to you. So it can be closer to your child too."* (Heidari et al., 2015a).

In the Hanely and Brown (2014) study the author's described the relationship between how some women articulated their experiences drawing parallels with postnatal illness and how it is articulated in Western culture: *"women also held a conviction that once a Jinn had decided to possess a woman she had no control over it entering her body. Jinn would find a woman when she was vulnerable and take over her being. This echoes findings that women with postnatal illness in Western culture often feel powerless and helpless to control their emotions and recovery (Beck 1999)"* (Hanely & Brown, 2014).

Statements made by some of the women, such as: *"When the baby was born I did not want to see her…I cried and cried."* (Hanely & Brown, 2014) and "*I had been feeling sad and lonely but I did not think anything about it"* (Hanely & Brown, 2014) highlight the multifaceted range of emotions that are reported. Women in this study expressed feelings of self-blame and helplessness related to their distress and difficulties in particular the loss of control and of feeling possessed.

The recognition of mental states and moral behaviour as affecting the child were at the forefront of some women's minds and had a motivating impact on them to be mindful of their thoughts and behaviours and could be perceived as coping strategies for ensuring their and their unborn child's wellbeing: *"from these first weeks, I'm sure that whatever I do or what I have in my*

mind will affect my child." (Heidari et al., 2015a) Another woman in this study stated that: *"this is human after all; sometimes, he/she is angry with someone, feels jealousy, hates someone, I say to myself that all of these are characters that the devil creates in human's soul. I have to avoid these. The more you have these inside, the closer the devil can be to you. So it can be closer to your child too."* (Heidari et al., 2015a).

The expression and language used to describe feelings of distress is notably different to what may be apparent in Western frameworks such as in the phrase: "*I too became ill with the Jinn. My son would not sleep nor settle very well."* (Hanely & Brown, 2014). Another woman expressed self-blame in the same study: *"Perhaps it was your fault that you have the Jinn",* (Hanely & Brown, 2014). In this study there were issues of loneliness and lack of support from the husband as well as financial worries, familial pressures and societal expectations that contributed to the distress that was discussed in terms of Jinn possession/mental disturbance. The women who acknowledged their distress in the form of jinn possession found that they received support; there was an understanding of the communication- a collective language that their community is familiar with and understands: *"The people of the village they all feel sorry for you and come and see if they can help. They know you have a tiny baby and they feel that perhaps the Jinn could have left you alone… they try to help you as best they can"* (Hanely & Brown, 2014). This highlighted the role and need for a community wide response and recognition to be helped at a vulnerable transitory time. Notably in this paper (Hanely & Brown, 2014) the authors (through their analysis of the participants comments and in their discussion) married the concepts of Western descriptions of illness around emotions and understanding physiological responses to stress in their discussion, and the Muslim women's descriptions of an external force taking over. Despite the 'language' and attribution to Jinn there were parallel similarities in terms of universal feelings such as that of sadness, loneliness, crying. In this study there was not a clear and single location of mental health or what it meant, whether that be in the mind, the body, the heart, possession by Jinn, social difficulties, the different uses of language, and also the impact of GPs and healthcare professional operating from within their own cultural framework.

2.9.2 The role of Islam as a faith, a way of life and religious identity

This theme is about the role of religion, and the Islamic belief systems and religious identity that influence how meaning is made, around understanding the purpose and gift of life,

managing pain through hope and faith, conceptualising moral choices and practicing of the Islamic way of life in different contexts.

Key illustrative quotes (theme and sub theme titles)

The role of Islam as a faith, a way of life and religious identity

- A gift from Allah; tests, trust and being in a sacred state: *"The pregnancy reminded me of God's ability to create my baby. My faith increased."*
- Pain and Faith: "As the pain increased I was praying to God more and more to release me".
- Breastfeeding and the high status of the mother in Islam: *"Breast milk is blessing from God and He distinguishes women by it".*
- Consciousness, morality and actions: *"I have to control myself".*
- Cross cultural context and variations of practicing Islamic teachings: *"Actually when we are living in England we can't keep everything like we would in Bangladesh…"*

A gift from Allah; tests, trust and being in a sacred state: "The pregnancy reminded me of God's ability to create my baby. My faith increased."

Seven of the studies drew on aspects of religion, spirituality, morality and the role of Allah (God) for the Muslim mothers and fathers (Abushaikha & Massah, 2013; H. A. Bawadi & Al-Hamdan, 2017; Hala A. Bawadi et al., 2016; Heidari et al., 2015a; Khalaf & Callister, 1997; Miller, 1995; Parvin, 2004). Pregnancy and birth are perceived as a deeply spiritual time where the mother is closely connected to her Creator and in a sacred space and presence (Abushaikha & Massah, 2013; H. A. Bawadi & Al-Hamdan, 2017; Hala A. Bawadi et al., 2016; Heidari et al., 2015a). The mother would be viewed by others as being in an honourable state, hence people may ask her to pray for them as one woman in the study by articulates: "*During childbirth the woman is in the hands of God. Every night during my pregnancy I read from the Holy Qur'an to the child. When I was in labor I was reading a special paragraph from the Holy Qur'an about protection. The nurses were crying when they heard what I was reading. I felt like a miracle might happen—that there was something holy around me, protecting me, something beyond the ordinary, a feeling, a spirit, about being part of God's creation of a child."*(Hala A. Bawadi et al., 2016). The high-ranking position of motherhood perceived in Islam as a most honourable status was met with a positive sense of self along with it feeling like a gift from God. One mother in Missal (2013) study reported: *"It is a very nice feeling to be a mother. I feel this baby... I have to take care of her. I have to prove myself. It is like a test from God. I don't know whether I deserve to be a mother or not. Being a mother, not everyone can have this gift from God. We can see some are dreaming to be a mother. So very nice."* (Missal, 2013).

Pain and Faith: "As the pain increased I was praying to God more and more to release me".
Some women in H. A. Bawadi and Al-Hamdan (2017), study felt that whatever happened – whether there would be loss or a disability or an unplanned pregnancy – they had to trust Allah and there was no question of aborting a baby as it was not up to them to decide and would instead see it as a test from God: *"In my last pregnancy I was 38 years and one of my friends delivered Down syndrome. I was scared that I could deliver baby like that. As a Muslim I knew I could not abort that baby . . .Thanks God I delivered a normal baby, but if Allah wants to examine me in this situation, I am ready for that (Participant 1)."* (H. A. Bawadi & Al-Hamdan, 2017). In the studies by H. A. Bawadi and Al-Hamdan (2017), Hala A. Bawadi et al. (2016); Khalaf and Callister (1997), and Missal (2103) men and women reported an immense trust in Allah perceiving pregnancy as a 'gift' and that whatever happens is for the best and an understanding that it could be a test of one's faith.

The trusting and turning to God were also a significant supportive factor during pain. As reported in one woman's statement in H. A. Bawadi and Al-Hamdan (2017) study: *"As the pain increased I was praying to God more and more to release me. I was asking God to be compassionate and bless me. I prayed for my husband, children, parents and whole family goodness in worldly existence and afterlife. I remembered all the people that requested me to pray for them, before the delivery of the head I prayed in high voice to have a healthy baby and be righteous servant of God. I delivered an angelical baby, he is pure and I became pure after all this suffering of labor pain. I knew Allah will reward me for that (Participant 8).* (Bawadi, H.A. & Al-Hamdan Z. 2017).

Breastfeeding and the high status of the mother in Islam: "Breast milk is blessing from God and He distinguishes women by it".
In the study by H. A. Bawadi and Al-Hamdan (2017) and (Missal, 2013) some women who were able to breastfeed felt a huge sense of achievement and honour. One woman spoke of her sense of achievement: *"I breastfed all my children, this was my main aim I have to achieve it after my delivery (Participant 3)."* (H. A. Bawadi & Al-Hamdan, 2017). For some being able to breastfeed was perceived as a divine ordination. Another mother in this study stated: *"Breast milk is blessing from God and He distinguishes women by it, so we have to use it. Our religion Encourages breastfeeding for two years if possible; absolutely there is wisdom of that. In*

Jordan the society also encourages breastfeeding. The first question after delivery and make assure about the health of you and your baby is if you breastfeed your baby successfully (Participant 9). (Bawadi, H.A. & Al-Hamdan Z. 2017).

Consciousness, morality and actions: "I have to control myself".

Women in Heidari et al. (2015a) study were quite focused on protecting their unborn child through abstinence of perceived harmful behaviours, thoughts, words, actions and deeds. One participant expressed her diligence: *"When I am pregnant, I have this vision not to commit sins, not to put myself under sin, not to be in a place where people commit sins; all in all, I have to control myself a little bit. . . Not to put oneself under sin will help to improve spiritual aspect of human and be successful in doing religiously recommended actions and obligations. Because of myself and my child, I do all these. (Participant 14, 40 years old, fourth pregnancy, 36 weeks).* (Heidari et al., 2015a). Other women in this study explained how they avoided music or movies that may be considered immoral: *"I did not even listen to, for example, sexually explicit music, because I thought they will make my child be interested to these things in future. (Participant 14, 40 years old, fourth pregnancy, 36 weeks).* (Heidari et al., 2015a). Some women were more acutely mindful of the use of explicit language whether it be in movies or music or expressed by people around them. One woman in this study gave an example of her husbands' use of language around her and how she felt conscious of not just her own actions but others and her awareness of the potential impact on her unborn child internalising this negativity or immorality: *"... I have an unborn child in my womb, he/she can understand everything I say" (Participant 15, 28 years old, first pregnancy, 6 weeks)* (Heidari et al., 2015a).

Cross cultural context and variations of practicing Islamic teachings: "Actually when we are living in England we can't keep everything like we would in Bangladesh…"

Some of the women in the studies by Miller (1995) and Mustafa and Kittleson (2016) noted that being in a different country impacted their actions and how closely they could observe Islamic teachings/ way of life or the recognition of the importance of this for them in the healthcare system (Tsianakas & Liamputtong, 2002) . These women acknowledged that if they were in their home country, or in a familiar setting with family support, they would do things differently. This can be seen in the study by Miller (1995) with Bangladeshi women living in England: *"Actually when we are living in England we can't keep everything like we would in*

Bangladesh . . . when you step out from your home everything is different. It depends on the family actually . . . my friends their parents were not so strict and they did a lot of things the western way . . . all sorts of things I couldn't do." (Miller, 1995). For some women in Miller (1995) study there was a distinction between learned interpretations of Islamic teachings and advice from cultural and patriarchally dominating teachings especially regarding pregnancy and birth and how much they allowed it to impact their way of life and decisions. One woman in this study expressed her opinion on this: *"they just learn it (the Koran) by heart with... Without having much idea of the meaning. They only get an idea of these meanings from the Imam... that's why a lot of people fast when they are pregnant... the Koran does say that you needn't if it is going to make your baby ill. . . but they were sure they had to."* (Miller, 1995). For her there was a distinction around the flexibility in the actual teachings of Islam such as the dispensation not to fast when pregnant as she spoke of other women who fasted despite this. Some of the women challenged this and along with a healthcare system that struggled to understand the nuances of the culture interwoven with Islam (Tsianakas & Liamputtong, 2002).

2.9.3 Experiences of health care: discrimination and diverse needs.

This theme addresses issues of healthcare both feelings of discrimination and where support was received, worries around feeling judged by healthcare professionals because of the way one is dressed, their ethnicity, desire for different foods and the lack of acceptance or active engagement with patients' diverse needs. There was an expression for a wish to be understood and respected for who they are, worry over momentous and joyous moments being overtaken by lack of communication and fear.

Key illustrative quotes (theme and sub theme titles)

Experiences of health care: discrimination and diverse needs.

- Judgements: *"Making all sorts of wild assumptions... She was alright once she got to know me, but she was being patronising at first."*
- Need for understanding: *"Hey, I am not an American, I am a Bangladeshi. Try to understand me. Ask me what I want to eat. Ask me how I feel."*
- Wish for respect: *"They still must respect our thought... and they must look after us the same as they look after the others, they must treat us with respect, but not differently because of our religion or race or whatever no discrimination or anything"*
- Momentous moments: *"The most beautiful moments of my life turn to exhaustion that is sometimes sickening. You don't know why, you don't know what is going on inside … is the baby dead or alive … just come get your wife when she is discharged. That's the only role for husbands and nothing else here in this hospital.*

Judgements: "Making all sorts of wild assumptions... She was alright once she got to know me, but she was being patronising at first."

Six papers referred to experiences in healthcare (Abushaikha & Massah, 2013; Miller, 1995 Missal, 2013; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002). There were stark disparities of experiences across all the studies and a number of refutational narratives emerged in the synthesis; some positive but overwhelmingly mostly negative experiences dominated. There were also reciprocal synthesis; in the studies by Miller (1995, UK), Mustafa and Kittleson (2016, USA), Parvin (2004, UK) and Tsianakas and Liamputtong (2002, Australia), some of the women across these studies in non-Muslim majority countries were conscious of their colour, ethnicity and physical visibility such as wearing a headscarf, as impacting the treatment they received- feeling and acknowledging discrimination. One woman in Miller (1995) study stated the nuanced layers involved in interacting with a healthcare professional that she experienced: *"Well, I think I give the image of being an Asian woman and people have their barriers... It's difficult to be assertive even when you have the language, I feel I was bossed around, and I feel quite resentful about that . . . and then the health visitor who came to see me before my child was born was making all sorts of wild assumptions too. She was alright once she got to know me, but she was being patronising at first"* (Miller, 1995). The importance of staff getting to know the women beyond stereotypes and assumptions, beyond preconceived judgements was significant in determining whether the experience was positive and felt supportive or negative and anxiety inducing (Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002). Tsianakas and Liamputtong (2002) received negative and positive comments from the participants in their study, the determining factor being very much how the staff treated the women. Those who experienced caring attentive healthcare professionals and felt accepted were very happy with the process. One woman narrated her experience: *"they were worried [concerned] too. The doctors, they are very supportive in Australia because I told them my husband is not around so they are concerned about me. They had a counsellor and she would come and ask me how I am. (Farida)".* Those who felt judged or discriminated against clearly had negative experiences.

The study by Parvin (2004) has a similar participant group to Miller (1995) as well as Mustafa and Kittleson (2016); they all studied the experiences of Bangladeshi Muslim women who had migrated. Some women in Parvin (2004) study described their experiences, frustrations, and feeling a lack of support: *"You need rest at that time, and they just send you home."* (Parvin, 2004). This response was in regards to limited time and services in a hospital setting where

some women felt the need for time for recovery and care that was not available. These women did not have a community and wider family network to go home to where they would be supported, instead they'd have immediate responsibilities of attending to their working husbands and children. The hospital and midwives would have been their only 'refuge' and place of rest and recovery. Some of the women didn't feel confident to be left alone so early in the process and couldn't make sense of feeling left alone, creating feelings of abandonment and uncertainty, not being able to make sense of why they would be sent home or told to do things themselves so early on. *"The nurse is there to help but they say 'you do it yourself'."* (Parvin, 2004). Whether it was feeling discriminated against or not being understood there was a message about basic needs and expectations not being met some of this was rooted in cultural sensitivities.

Need for understanding: "Hey, I am not an American, I am a Bangladeshi. Try to understand me. Ask me what I want to eat. Ask me how I feel."

In the study on Bangladeshi Muslim women by Mustafa and Kittleson (2016), women spoke of not being understood and their feelings not considered, that their 'difference' was not recognised and acknowledged, they were invisible: "*American physicians and nurses expected me to behave as any other American woman. Hey, I am not an American, I am a Bangladeshi. Try to understand me. Ask me what I want to eat. Ask me how I feel."* (Mustafa & Kittleson, 2016). For other women this lack of understanding from health care professionals manifested in other ways; communication, antenatal classes, and food guides: *"I could not understand anything nor could I relate the guide to the food we are used to. I threw the food guide into the trash can. It was written in English with hard-to-understand Bengali subtitles."* It was apparent from this study that there was a need for releventising and making information accessible.

Overlapping with the section on mental health, the experiences of health care and perception of the roles of health care professionals determined how the women felt and shaped their experience. This was highlighted in Parvin (2004) study by a female participant: *"The health visitor didn't ask us these things (about emotional problems) when they came to visit"* (Parvin, 2004). On talking about a 'restless mind', the researcher asked the group of women: *"This is your own private matter (restlessness in mind); does anyone talk about that? Did you tell your health visitor?"* (Parvin, 2004). The respondent then replied that: "*If I tell them, they can't distance (remedy) it"* (Parvin, 2004). There was a general feeling that medical professionals

couldn't quite help with emotional problems, that they did not enquire or understand the women's ways of communicating these issues perhaps subtly or as mentioned in the Mental health theme on using the language of physical location of distress. In the same study it was noted that feelings of frustration and being let down continued with regards to the quality of healthcare services: *"You say what your illness is; they're not bothered to hear you out.". "We don't think the doctor checks patients properly, you say 'I have headache', then he writes you tablets. Normally if there is a pain there, they should check it."* (Parvin, 2004). The level of care experienced was low and lack of communication was a definitive barrier as well as cultural and religious needs and way of life not being understood. This was also noted in Tsianakas and Liamputtong (2002), where one participant stated what she felt would make her feel more comfortable in the process: *"if the doctors are more aware of the Muslim woman's needs in areas of privacy and respecting religious beliefs and ensuring that there are female doctors, then you can go about it comfortably."* Other studies that noted the importance of cultural and religious needs being understood included Miller (1995); Mustafa and Kittleson (2016); and Parvin (2004). Incidentally all four of these studies involved migrant Muslim women suggesting that cross cultural and religious education was lacking, and discrimination was felt by these women in most part.

Wish for respect: "They still must respect our thought... and they must look after us the same as they look after the others, they must treat us with respect, but not differently because of our religion or race or whatever no discrimination or anything."

Unequal healthcare treatment was a recurring thread through the studies. The importance of recognising diversity and difference was crucial in environments where there was a lack of sensitivity and awareness, and the impact was apparent of the quality of services. (Mustafa & Kittleson, 2016). These issues were expressed and captured in a quote from a woman who said: *"I was not treated with respect and care. Their faces changed as soon as they saw me in long dress and "hijab." I did not fully understand their conversation but I could figure it out what they were talking about. They used to ask me why I wear such a dress. They made fun of it"* (Mustafa & Kittleson, 2016). Women in Tsianakas and Liamputtong (2002) study also reported discrimination and being judged, one in particular stated how this manifested for her: "*it is a lot of shock for them when I speak English maybe that is because the way we look or because we come from specific religion, I'm not sure"* . There is active discrimination and a

sense of unequal treatment experienced by women in the studies by Miller (1995); Mustafa and Kittleson (2016); Parvin (2004) and Tsianakas and Liamputtong (2002).

Some women although found their physician caring, struggled with communication issues and language barriers: *"My physician was very caring, but I did not understand her words, because she spoke too fast."* (Mustafa & Kittleson, 2016). There was a notable wish for thoughtfulness, compassion, care and connection across all of the aforementioned four papers. Despite in some instances there being a caring response or interaction of some sort, language barriers often meant that non-verbal communication or a felt sense was relied upon instead to convey compassion however it felt inadequate for communicating more complex feelings at the juncture of such a life changing process. It was as though something significant was lost.

Contrastingly the few experiences of positive health care were also notably rooted in the conveyance of compassion and feeling humanised. One Muslim women spoke of how important feeling human was to her: *"what I like about it is that they make you feel that somebody care about you and your kids, your baby, you know, somebody care…that makes you feel like you are a human, that is the important thing, you are a human, you know…I like it very much."* (Tsianakas & Liamputtong, 2002). This is clearly a different experience that is refutational to the multiple negative experiences stated both in this study by Tsianakas and Liamputtong (2002) and Miller (1995); Mustafa and Kittleson (2016); Parvin (2004).

Language barriers and communication issues affected the experience and quality of healthcare service delivery and outcomes particularly in countries where women were migrants (Miller, 1995, Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002). Incidentally communication or language barriers did not come up in any of the papers where women were natives. With the issues around language and discrimination some women found that even if they spoke the language there was assumption by staff that they could not speak English because they looked different, their colour or dress as mentioned previously. Women spoke of their difficulty in understanding what was being said to them. One woman in Parvin (2004) study stated how foreign it all felt for her: *"Sometimes when you have a baby, a woman comes from the hospital. Bengali girls don't come with the midwife, we don't understand what they say, we just sit there staring at their faces."* (Parvin, 2004). Some women managed the situation by taking someone with them to hospital appointments, though this was not always possible and sometimes even caused great difficulty where the only person they could approach was

their husband. In a traditionally perceived female arena, this was met with uncomfortable feelings. In Miller (1995) study one woman expressed: "*The husband goes because they (the women) feel scared to death, they don't speak the language and everything is so strange. For a woman from the village they feel really strange."* This new and unfamiliar dynamic to negotiate, played out in interactions with healthcare professionals and accessing services, illustrated by a woman in this study: *". . . the GP has complained to us (the language organisers) that husbands and wives never seem to have discussed anything before they come to the clinic"* (Miller, 1995). Difficulties with language barriers and communication created an additionally stressed environment.

Momentous moments: "You don't know why, you don't know what is going on inside … is the baby dead or alive… just come get your wife when she is discharged".

Discriminatory policies that prevented men from attending births had a profound impact on the couples' experience of a significant moment in their lives as a family. The were two studies including the Muslim male voice of experience with regards to birth process and barriers in healthcare. One was by Abushaikha and Massah (2013) in Syria which highlighted how fathers played a role in the pregnancy stages in supporting the mother and focusing on her nutrition, wellbeing and mental health. Abushaikha and Massah (2013) discussed both male and female experiences (23 mothers and 14 fathers). The second was study was by Hala A. Bawadi et al. (2016) based in Jordan, which solely focused on the role of 19 Arabic fathers and their experiences. One Muslim male spoke of the barrier he faced which echoed that of other participants in this study: *"The attending or in-charge doctor ordered preventing any man from entering the labor room, even if he was the husband. Maybe, it would have been a natural thing to go in without any commotion or anything. (First-time father, age 31 yr)."* (Abushaikha & Massah, 2013). Another father in this study relayed how his wife wanted him beside her but hospital policy prevented him: *"She [his wife] asked them to let me enter and be beside her but they prevented me. It is the policy of the hospital; we have to accept it. (Father, age 26 yr)"*. (Abushaikha & Massah, 2013). These barriers created a sense of helplessness and uncertainty of the role of fathers during the childbirth process sometimes reducing the role to mere distant observers of a process. One father expressed how worried he felt not knowing what was going on in crucial moments of his and his family's' lives: *"Unfortunately, I was in the hospital garden. The most beautiful moments of my life turn to exhaustion that is sometimes sickening. You don't know why, you don't know what is going on inside … is the baby dead or alive …*

just come get your wife when she is discharged. That's the only role for husbands and nothing else here in this hospital. (Father, age 33 yr). (Abushaikha & Massah, 2013). Some of the mothers in this study shared similar sentiments, frustrations and helplessness, however in some case both mothers and fathers felt it was unacceptable in their culture for a man to be a witness to the birth. Some expressed this in a passive way as illustrated by a mother: "*It is nice that a husband can feel his wife's suffering, but as Easterners we do not accept the idea. I do not know why … it may be related to our traditions or something. I don't know."* (Mother of 2 children, age 29 yr in (Abushaikha & Massah, 2013)) and some vociferously as noted in the words of a father in the study: *"I am against the idea to be inside with her! As long as there is a health team, whether nurses or doctors … it is comforting. I don't like to see such a scene. Also I am not a doctor or a nurse to be beside her. I can do nothing for her. I cannot offer anything to her in this situation. (First-time father, age 24 yr)"* (Abushaikha & Massah, 2013).

2.9.4 Cultural dynamics and Patriarchy

This theme considers cultural dynamics including the role and influence of patriarchal ideas that led to feeling helpless, that a man was unable to play an active role or even be present for the birth for many. Another aspect was the idea of females protecting the male from having to witness something difficult. There were concerns around gender preference around the new-born and how that cultural ideal made the mother feel, ideas around shame and wanting a female healthcare practitioner and feeling uncomfortable in the presence of males in what is considered to be a private and female area and finally the idea of a collective community and culture that offers support and celebration of the rite of passage of birth.

Key illustrative quotes (theme and sub theme titles)

Cultural dynamics and Patriarchy

- Disempowerment and Helplessness: *"He can't do anything at all".*
- Protecting the male: *"I don't expect that he [her husband] can bear the noises and scenes and seeing me suffer… he can't bear it".*
- Gender values: *"if your child is a girl, then leave her in the hospital and bring a boy instead".*
- Shame and location of power: *"I do not even feel comfortable talking to a man about what I am going through".*
- Cultural rituals of birth and a sense of community: *"If someone gets sick or otherwise busy some of us take her place and do the job. During my pregnancy it was really helpful."*

Disempowerment and Helplessness: "He can't do anything at all".

Six papers (Abushaikha & Massah, 2013; H. A. Bawadi & Al-Hamdan, 2017; Hala A. Bawadi et al., 2016; Miller, 1995; Missal, 2013; Mustafa & Kittleson, 2016) touched on cultural dynamics and patriarchal structures. Culture and patriarchy were weaved throughout many aspects of the primary research studies, and informed experiences of pregnancy, birth, parenthood, mental health, policies and healthcare services. Across the papers there were different views on the role of men, cultural expectations of men and women and the emotional needs of mothers' and fathers' depending on migration, context and cultural milieu. Perspectives and experiences varied depending on whether people were from Arab or Asian cultures, in their country of birth or as migrants and how these various factors interplayed.

In the study by Abushaikha and Massah (2013) there were conflicting socio-cultural attitudes and dynamics at play regarding male attendance at births depending on individuals, couples, their lifestyle and world view. Some women liked to have their partner with them, and the father would want to be there too, some mothers wished for it but the father did not feel comfortable, for some the father would have been happy to be at the birth but the mother felt uncomfortable. One mother explained her understanding of it as cultural dynamic: *"Some people have their husbands go in with them such as foreigners [Westerners]; with us, our people in the Arab world, he is not present. He can't do anything at all. (Multipara mother, age 26 yr)* (Abushaikha, & Massah, 2013). There seemed to be a strong emergence of the male 'can't do anything' attitude. Several men and women across the studies (Abushaikha & Massah, 2013; Hala A. Bawadi et al., 2016) expressed statements of the nature that the man cannot do anything in the time of giving birth. Some men strongly opposed the idea of being present in the delivery room. One father to be in Abushaikha and Massah (2013) study shared his feelings: *"I am against the idea to be inside with her! As long as there is a health team, whether nurses or doctors … it is comforting. I don't like to see such a scene. Also I am not a doctor or a nurse to be beside her. I can do nothing for her. I cannot offer anything to her in this situation. (First-time father, age 24 yr).* Again, reinforcing the notion that the male cannot do anything or offer anything. In a culture that is male dominated and society that is patriarchally driven, in a constantly evolving wider society not having a clearly defined role during this process makes it unclear for the male what is expected of him and what he can offer, possibly leading to feeling helpless (Abushaikha & Massah, 2013; Hala A. Bawadi et al., 2016). However, there were a minority of individual statements by men and women expressing a wish to be together at this important juncture in their lives. One father explained how his wife wanted him there, but

hospital policy prevented him: "*She [his wife] asked them to let me enter and be beside her but they prevented me. It is the policy of the hospital; we have to accept it. (Father, age 26 yr)* (Abushaikha & Massah, 2013). The context of this study and the experiences are of Syrian parents in a Syrian Hospital where hospital policy is influenced by the culture of the country. Individual wishes could not be accommodated.

Protecting the male: "I don't expect that he [her husband] can bear the noises and scenes and seeing me suffer… he can't bear it".

In Abushaikha and Massah (2013) study where the focus was on barriers of paternal presence at childbirth one women expressed it would be nice for the husband to feel his wife's suffering and be able to truly empathise but further contextualised that the idea is unacceptable, often not having an answer for why it was deemed so. She stated that: *"It is nice that a husband can feel his wife's suffering, but as Easterners we do not accept the idea. I do not know why …it may be related to our traditions or something. I don't know. (Mother of 2 children, age 29 yr)"* (Abushaikha, & Massah, 2013). However, in the same study women also offered contrasting views and felt it was inappropriate: In the words of one mother *"I don't find it appropriate. If I am suffering then he will also be suffering, then if he sees me suffering he will suffer more. I don't think it is a good idea. (Mother, age 21 yr)"* (Abushaikha & Massah, 2013). This was not discussed more broadly in the other studies.

In the same study various narratives captured the dynamics between Arab-Muslim couples during childbirth, in particular that being in the delivery room was not considered the 'job' of a man *as one father explained: "I wouldn't go in because it is not my place—that's the point and nothing else. It is not my job. I can't help in anything. I can't do anything it is not my job to go inside … it is not my job. (Father of 3 children, age 30 yr)"* (Abushaikha & Massah, 2013). Another father expressed similar sentiments: *"I'm against the idea of the husband being in the labor room because we are not specialized in this area …. We can't do anything to relieve women from this thing … we as husbands can't do anything except to pray for them … pray to God that she delivers safely and that things will be fine (Father of 3 children, age 39 yr)"* (Abushaikha & Massah, 2013). A female participant in this study further reinforced the notion of protecting the male: *"I don't expect that he [her husband] can bear the noises and scenes and seeing me suffer … he can't bear it. (Mother, age 24 yr)"* (Abushaikha & Massah, 2013).

Alternatively, some men in Hala A. Bawadi et al. (2016) study of Jordanian fathers felt a strong sense of wanting to be there throughout the pregnancy and be supportive in other ways: *"Sometimes I would arrive at home during the afternoon after work to eat and sleep to find her sad and tired so I would ignore my tiredness and talk with her until she feels relieved"* (Hala A. Bawadi et al., 2016). They found different roles they could play to be part of the process as one father stated: *"During the entire period you have to be closer than ever as the wife will be extremely sensitive. The way you communicate with her will affect her psychological status"* (Hala A. Bawadi et al., 2016). For some men there was a heightened awareness of the mothers' physical and psychological wellbeing and trying to 'relieve' any sadness she may feel: *"I tried to be as sympathetic listener especially when she was feeling down. I didn't make her feel like she is alone and encouraged her to discuss her fears and anxieties"* (Hala A. Bawadi et al., 2016). Feelings and perspectives across the two studies (Abushaikha & Massah, 2013; Hala A. Bawadi et al., 2016) varied depending on cultural and familial context, education and understanding of Islam and the role of the male; father and husband. Those who contextualised their roles within Islam as opposed to the patriarchal cultural context were more compassionate and supportive. One father talked of his support for his wife: *"When I got home and saw my wife tired I would start encouraging her and telling her that Allah is with her and He will help her through this and I would always make sure to hold her hand and tell her that 'Heaven lays beneath our mothers feet' like our Prophet PBUH told us, and that all of the pain that you're going through you'll get good deeds for it."* (Hala A. Bawadi et al., 2016). Both studies were based in the Middle East (Abushaikha & Massah, 2013; Hala A. Bawadi et al., 2016) but have significant differences in political and cultural history and the impact this may have had on its citizens and viewpoints. However, it seemed that the difference was more on individual preferences which may be rooted in complex cultural, religious and societal ideas and roles of men and women.

Gender values: "if your child is a girl, then leave her in the hospital and bring a boy instead". Preference for the male child evoked anxiety and anger in some women (Heidari et al., 2015a; Khalaf & Callister, 1997) as well as concerns and acute consciousness for the impact on the wellbeing of the child if it were a female and she were to experience the discrimination from the extended family's preference for a male child (Abushaikha & Massah, 2013; Heidari et al., 2015a; Khalaf & Callister, 1997). In these studies some mothers' felt conscious that their

unborn child should not feel or internalise their own upset at hearing such words so took steps to avoid family members who expressed this preference during their pregnancy with one woman stating that*: "Because my family-in-law are very interested in boys; though nothing has happened, they say if your child is a girl, then leave her in the hospital and bring a boy instead [laughing]…This made me tell my husband that I will try not to go to his mother's house; because I do not want them make me upset; this way my child also will hate them for sure. I do not want my child be like this; why must disgust be formed in his heart or mind. (Participant 15, 28 years old, first pregnancy, 6 weeks)* (Abushaikha & Massah, 2013). For some women there was a lingering anxiety during pregnancy and childbirth regarding the gender of the child and the worry that if it was a girl she would be unwanted in society and suffer. 'This was similarly explored in Khalaf and Callister (1997) study with one women stating: "*During childbirth, the only thing I wanted was to know the sex of the baby. I felt sad when I saw this child because she was a girl and she would suffer during her life."* (Khalaf & Callister, 1997). Another woman in the same study though was happy herself having given birth (not knowing the gender) reiterated the cultural preference for a female and how this dynamic played out with her mother-in-law: *"When I heard the voice of the child, I was happy. I did not know if it was a boy or a girl, but when I looked at my mother-in-law's face I felt she was not happy... They didn't congratulate me. They told me, "God gave you a bride [girl]" and "Next time, God will give you a boy"* (Khalaf & Callister, 1997).

Shame and location of power: "I do not even feel comfortable talking to a man about what I am going through".

In the studies by Abushaikha and Massah (2013); Hala A. Bawadi et al. (2016); Miller (1995); Mustafa and Kittleson (2016); Tsianakas and Liamputtong (2002) shame played a significant role around male attendance during the process of pregnancy and birth, be it a husband or medical processional. Some attributed this to religion with one woman in Miller (1995) study of Bangledshi Muslim women in England stating: *"totally against our religion you see and that's why we do prefer a lady doctor . . . I feel shame actually."* Others also expressed strong feelings on being checked by a male doctor and attributed this to religion. In the study by Mustafa and Kittleson (2016) of Bangladeshi Muslim women in the U.S one woman expressed her discomfort at having a male doctor: *"I do not even feel comfortable talking to a man about what I am going through. Being checked by a male doctor is out of the question. That's how I grew up as a Muslim girl"* (Mustafa & Kittleson, 2016). The gender of the doctor was an

important factor in feeling safe and comfortable. However, contrastingly, shame was also for some a personal feeling to do with their personal shyness rather than attributing it to religion as one Muslim woman in Australia stated: *"my main concern was I couldn't see a male doctor or gynaecologist, I couldn't see that just because I'm sensitive and shy personally"* (Tsianakas & Liamputtong, 2002). The three studies (Miller, 1995; Mustafa & Kittleson, 2016; Tsianakas & Liamputtong, 2002) involving migrant women in a new culture where it is the norm to have male attendance at birth and male medical professionals faced anxiety and challenges in needing to explain this to the healthcare professionals and hoping their needs would be met. Incidentally the studies that were in Muslim countries, the policies prevented a husband attending. The dynamic that women had to face was different. It was a given in the culture in Muslim countries where studies were carried out that there was a sociocultural understanding that the role of a male at birth was generally unacceptable (Abushaikha & Massah, 2013; Hala A. Bawadi et al., 2016). Despite the majority expressions of discomfort with male presence there was, however, a participant in in Miller (1995) study which suggested that there were generational differences: *"No, nowadays it isn't to be honest. It was (in) my Mums day when everything was so different, nowadays I think they don't feel that shame . . . It's nothing harmful or shameful to talk to one's husband, it's not, and this is what we are learning"* (Miller, 1995). There was a distinction made around changing times and views.

Cultural rituals of birth and a sense of community: "If someone gets sick or otherwise busy some of us take her place and do the job. During my pregnancy it was really helpful."

Women described traditional rituals and spoke of how they did not always adhere to them for a new-born. As one woman in the study by Missal (2013) explained her decisions were about empowerment, reclaiming choice and narrative, changing their experiences and not re-enacting the same for the next generation if their opinion differed. She stated her defiance of some of the traditions: *"They say to the new mother you are responsible to do this, but I do not do it. People put kohl (a cosmetic powder used to darken the area around the eyes) on the baby's eyes, so they are big, but I didn't do this. My sister-in-law pinched his nose in the delivery room. My father said verses from the Qur'an on the second day in the hospital. A Qur'an was kept in the baby's crib with the baby. I took haba alhamara [red seed of local plant] for three days to clean the stomach from the bleeding. I did not take halba [traditional herb, fenugreek] for the breast milk because it does not have a good smell."* (Missal, 2013). Being in her native country this process of exploration and challenging traditions was possible for this new mother

where she did not have the challenges of renegotiating a new identity in a new country, where people may want to hold on to culture and tradition when everything around them is unfamiliar.

In contrast, some of the women who were away from their family had created a sense of belongingness in their local communities with other Bangladeshi Muslim migrants which was a significant supportive construct emulating that which they would have found had they been in their country of origin organically in their own cultural context: *"After I had a baby, my extended family members, friends, and neighbors visited me both in the hospital and home, brought me foods and clothes for the baby. Some of them became part of my family."* (Mustafa, & Kittleson 2016). Another woman in this study reiterated the significance of a sense of community: *"We share a three-bedroom apartment, the kitchen and household chores, and spend our leisure time together. If someone gets sick or otherwise busy some of us take her place and do the job. During my pregnancy it was really helpful."* (Mustafa, & Kittleson 2016).

2.9.5 Relationships and family

This theme explores the complex dynamics of family relationships, ideas of fear and protection from both the mother and fathers' perspectives, the role of female support within the family for the mother giving birth, the way in which support may be offered through nutrition and consideration of food as an act of care and support for wellbeing and the struggles where there was a distinct lack of support.

Key illustrative quotes (theme and sub theme titles)

Relationships and family

- Fear and Protection: *"she will see fear on my face and she will get more afraid".*
- Female support and motherly honour: *"*'Heaven lays beneath our mothers' feet'*".*
- Supporting sustenance: *"The most important thing is to be conscious about my food".*
- Lack of support: *"how can you get rest? Is there time?"*

Fear and Protection: "she will see fear on my face and she will get more afraid".

Six studies included elements that touched upon or focused on 'relationships and family'; Abushaikha and Massah (2013); H. A. Bawadi and Al-Hamdan (2017); Hala A. Bawadi et al. (2016), Hanely and Brown (2014), Missal (2013) and Parvin (2004). This theme was most closely interwoven with the theme of 'culture and patriarchy'. Issues related to family were weaved across cultural contexts and were not so clearly divided by migration as were the studies on experiences of healthcare.

Although the concept of father's attending birth or pregnancy related appointments were considered through the lens of cultural norms and patriarchal constructs (Abushaikha & Massah, 2013; Hala A. Bawadi et al., 2016; Miller, 1995) there is also the need for consideration of the psychosocial impact of relationships on women and the feeling of lack of support in a crucial time. In Abushaikha and Massah (2013) study on '*Syrian parents' perceptions of barriers to paternal presence and contribution during childbirth'*, a father expressed how he would not go in the delivery room and feared that his wife would sense his fear, weakening her or causing her to worry. There was a sense of wanting to protect her from witnessing this: *"No. I won't go in because the woman may become more confused… maybe she will see fear on my face and she will get more afraid. (Father, age 39 yr)"* (Abushaikha & Massah, 2013). This puts a different angle on the narrative around male attendance at birth mentioned in the culture section where the emphasis was more around the female protecting the male from experiencing discomfort, here there is a fear from the male that his fear may create fear in the mother hence he sees his act of not wanting to be present as a way of protecting her. For other fathers across the studies, circumstances (such as being away at work, economic pressures, attitudes and belief) prevented them from attending births or being present during appointments, rather than culture, policies or ideologies. Although 'fear' was still part of the narrative, in the sense of worry and being afraid for the mother and baby. One mother in Abushaikha and Massah (2013) study explained how her husband felt: *"He was very worried and afraid for me and the baby. He was away at work … and he kept calling to make sure we were all right. (Mother, age 26 yr)"* (Abushaikha & Massah, 2013). There were also some men who strongly felt against the idea of being present for the birth for cultural or personal discomfort reasons as mentioned in the section on healthcare and in the study by Abushaikha and Massah (2013). One father in the study by Hala A. Bawadi et al. (2016) felt that both the mother, father and family had different roles to play and could all offer support in different ways; there was an understanding that the time around pregnancy, birth and postpartum was a collective responsibility: *"Pregnancy, birth, and postpartum is the responsibility of the entire family. There are somethings that you can do that your wife can't do, and there are somethings that neither you nor your wife can do, so your family should do it."* (Hala A. Bawadi et al., 2016).

Female support and motherly honour: "'Heaven lays beneath our mothers' feet'".

In the primary studies it was apparent that support for the women was manifest in different ways and to differing degrees but tended to be tied with female relations and family members. For some women it was through the advice they received to eat and sleep well, for others physical presence of mothers and sisters to assist with attendance at appointments, household chores, and help with the baby (Hala A. Bawadi et al., 2016; Hanely & Brown, 2014; Missal, 2013). One woman in the study by H. A. Bawadi and Al-Hamdan (2017) explained this for her: "*Once my pregnancy was confirmed I informed my family and my Husband's family, the first advice was that I have to sleep well, take naps during the day, my mother and sister were coming three times a week to my home to clean the house and cook especially first few months (Participant 7)"* (H. A. Bawadi & Al-Hamdan, 2017). Some of the women were supported, valued and cared for particularly in the studies where they were native residents (H. A. Bawadi & Al-Hamdan, 2017; Missal, 2013; Hala A. Bawadi et al., 2016; Hanely & Brown, 2014; Missal, 2013) and rooted within their familial and familiar environment and context not having to battle a completely new system and the challenges of migration, language barriers and discrimination (Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002).

The support of family and relationships were interwoven with the spiritual context and honour of motherhood. For some women support was available, but very much emphasised as female centric support. One mother spoke of how her mother and sister played a role: *"My family, they all have been and still are very helpful. My mother is always there to help me. She kept sleeping with me in my room for the entire first week. She used to wake me up to nurse my baby every 2-3 hours. My older sister kept telling me about her experience with her four daughters and showed me how to nurse my child. My other sister helps me too. They hold him and care for him when l feel tired"* (Missal, 2013). The role of female supporters in the form of mothers, sisters or other women in the community was crucial in allying concerns, fears and anxieties as well as for offering practical support (H. A. Bawadi & Al-Hamdan, 2017; Hala A. Bawadi et al., 2016; Hanely & Brown, 2014; Mustafa & Kittleson, 2016). Some of those who had migrated to the U.S and were of Bangledeshi origin in the study by Mustafa and Kittleson (2016), were able to create communities around them. One woman in this study spoke of how for her support came through extended family, neighbours and the community: *"After I had a baby, my extended family members, friends, and neighbors visited me both in the hospital and home, brought me foods and clothes for the baby. Some of them became part of my*

family."(Mustafa & Kittleson, 2016). It was not the case for all the women, and some felt lonely. One in particular woman in the study by Parvin (2004) on Muslim Bangladeshi women who had migrated to East London, UK, expressed how terribly alone she felt and how this was impacting her mental health: *"It's like your head/mind becomes crazy, because I worry all the time, because in this country I don't have anyone. I am alone in this country."* (Parvin, 2004).

Individual social and family structures and relationships played a significant role in whether women felt supported or not. One woman in her native country of Jordan (Hanely & Brown, 2014) felt alone and that her family were too preoccupied for her: *"I am lonely because I love my husband very much but he is always away at sea and I don't see him very often. I cannot rely on my family to help me as they are wrapped up in themselves".* (Hanely & Brown, 2014). Contrastingly in Missal (2013) study carried out in the Gulf States a mother spoke of how the support around her led to a marked change in status, respect and role change that she felt: *"I feel more respected from everyone around me. My family and friends give me more respect. It adds for me wisdom. I am a wise woman. Now they can trust my speech. I became an adult. There is responsibility."* (Missal, 2013). Furthermore in Hala A. Bawadi et al. (2016) study of fathers, one father expressed how he would encourage his wife emotionally and spiritually stating that: *"When I got home and saw my wife tired I would start encouraging her and telling her that Allah is with her and He will help her through this and I would always make sure to hold her hand and tell her that 'Heaven lays beneath our mothers feet' like our Prophet PBUH told us".* (Hala A. Bawadi et al., 2016). In these two studies there were no factors of migration but difference in individual familial levels of support and family structures.

While migration factors undeniably play a crucial role in determining availability of support, it can be seen that some women despite being migrants were able to find alternative support networks through neighbours and the new community they found themselves in, though sticking to their cultural group (Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004). For others even being in their native country they still had difficult family dynamics to deal with that left them feeling unsupported and or alone (Abushaikha & Massah, 2013; Hanely & Brown, 2014).

Supporting sustenance: "The most important thing is to be conscious about my food".
Both men and women described the role of food, nutrition and nourishment during pregnancy and postpartum as affecting wellbeing (including the preparation of food and by whom) in a layered and nuanced way (H. A. Bawadi & Al-Hamdan, 2017; Hala A. Bawadi et al., 2016; Heidari et al., 2015a; Mustafa & Kittleson, 2016), including associating food consumed as affecting the mental and emotional states of the unborn baby. One woman in Heidari et al. (2015a) study of 22 Iranian women in Tehran was concerned about how the food she consumed would be linked to her unborn child's morality: *"I want (my child) not to be jealous; therefore, I do not eat the meals made by jealous people . . . If my child defies a religious obligation later, it is because of the effect of the foods made by these people. (Participant 6, 24 years old, first pregnancy, 32 weeks).* There was a feeling by women in the study that the moral character of the person preparing the food was of utmost importance and a fear that negative energy could be transferred to the child. There was an overall increased consciousness around food sources, that one woman highlighted: *"I was very much aware of more Halaal sustenance coming to our table. For example, any time we went out, I did not eat foods I did not know about. I was we are not allowed to give him/her these things. (Participant 8, 32 years old, one history of pregnancy)"* (Heidari, Ziaei, Ahmadi, Mohammadi, & Hall, 2015b).

Distinction was made between avoiding 'bad' or unhealthy foods and the importance of 'special' and healing foods during pregnancy in Misaal (2013) and H. A. Bawadi and Al-Hamdan (2017). One Omani Muslim mother in Missal (2013) study spoke about the foods she felt would give her strength: *"Honey gives energy and you will be healthy and strong."* (Missal 2013). For some the advice around food came from mothers and partners. One woman in H. A. Bawadi and Al-Hamdan (2017) study of Jordanian Muslim women stated the advice of her mother and what she was told to eat during her pregnancy: *"My mother was always telling me you have to eat for two (yourself and the baby). I concentrated on drinking milk and consuming diary product. I also took food rich in animal such as meat, chicken and fish. Also, I ate fresh fruits and vegetables, and I avoided starchy food as pasta, bread, and potato (Participant 6).* (H. A. Bawadi & Al-Hamdan, 2017). However, this was contrasted with the women who were migrants in an unfamiliar context (Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002) where they felt misunderstood, unsupported and unable to relate to the advice around food as described in the experiences of healthcare section.

Lack of support: "how can you get rest? Is there time?"

Women talked about emotional problems experienced in interaction with the medical system (Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002); though not so much about emotional difficulties at home except for in a practical manner. Some women spoke of the demands of home and family and not being able to rest and recuperate and being launched right into ordinary busy overwhelming routines having just given birth (Parvin, 2004). One woman in this study described this process for her: *"You bring the baby home. You need to eat, the family need to eat, have to clean the house, have to wash the children, take them to school, take them to Arabic reading (classes). You have to do all this work in one day, how can you get rest? Is there time?"* (Parvin, 2004). The extraordinariness of the time was subsumed by practicalities. There was no time to process or enjoy the experience (Parvin, 2004).

Specifically, in relation to support from husbands, women required prompting and further enquiring questions from the researchers before they shared their experience which reinforced ideas of reluctancy in sharing personal and home matters (Miller, 1995; Parvin, 2004). There was a sense of loneliness and sadness, a loss, for some not being able to rely on family members. This contrasted very much with the women who felt a strong sense of support particularly from female family members and from the status and honour they received as mothers (H. A. Bawadi & Al-Hamdan, 2017; Hala A. Bawadi et al., 2016; Hanely & Brown, 2014; Missal, 2013). The variation was very much dictated by social and economic contexts.

2.9.6 Transition to parenthood

This final theme addresses issues around anxiety and wellbeing, adjusting to parenthood, new roles and responsibilities, difficulties, and the honour and change of status for some, for others a balancing and renegotiation of identity, the father's role and perspective.

Key illustrative quotes (theme and sub theme titles)

Transition to parenthood

- Sleep and anxiety: *"I can't stay, can't sleep, just worry."*
- Pride and honour: *"Women come to congratulate me while I am lying in bed".*
- Renegotiating Identity: *"Where do I fit in?"*
- The father; protector and guardian: *"Pregnancy is a blessing from God, so we take care of this bestowal".*

Sleep and anxiety: "I can't stay, can't sleep, just worry."

Six papers explored the transition to parenthood; H. A. Bawadi and Al-Hamdan (2017); Hala A. Bawadi et al. (2016); Khalaf and Callister (1997); Missal (2013); Mustafa and Kittleson (2016); Parvin (2004). The transition to motherhood and the feelings and processes involved varied for mothers and fathers; there was no *one* process across the studies. There was however some distinction again between the experiences of migrant women and natives, in terms of the support available in assisting the transition and the struggles felt by those without support as stated in the theme on 'relationships and family'. Various anxieties were more prevalent in the women who were migrants and lacked support. Some mothers who already had children worried about leaving them to go give birth and felt rushed and hurried to go home to them, not having support and assurance that they would be well looked after. One mother in Parvin (2004) study of Bangladeshi Muslim women having migrated to the UK stated her worries: *"…Because of them, when I go to hospital I can't stay, can't sleep, just worry."* (Parvin, 2004).

Contrastingly, others spoke of the support they received and how important it was for them to have their mother or female relative with them at every step, teaching and guiding them (Hala A. Bawadi et al., 2016; Hanely & Brown, 2014; Missal, 2013). This was highlighted by a woman in Missal (2013) study: *"I stayed with my mother the first month. My mother slept with me to wake me up to nurse her and bathe her. She taught me how to arrange the cradle for the head and how to cover her so she doesn't suffocate. She told me to hold her carefully and how to clean my breast when feeding her."* (Missal, 2013). Again, the studies are from different contexts, hence the contrasting experiences seem to be drawn along the lines of migration or being in one's native homeland. The support available and the circumstances, challenges and barriers are clearly different if one is a migrant experiencing the process of pregnancy and birth in a completely different context with added stressors of a new country, language, systems and practices that seem unfamiliar (Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002).

Pride and honour: "Women come to congratulate me while I am lying in bed".

For some expectant mothers there was a feeling of pride and a sense of wanting to look and feel good, buying new clothes, dressing up as one may when meeting someone new. This was illustrated in H. A. Bawadi and Al-Hamdan (2017) study of Jordanian Muslim mothers, by a number of women who echoed these feelings: *"Once I knew that I am pregnant I started saving*

a sum of money every month. . . I bought myself new things like pajamas, night gowns in bright colours, perfume, and gold jewellery. All of these things I wear when will-wishers visit me (Participant 1)". (H. A. Bawadi & Al-Hamdan, 2017). Another mother in this study reciprocated similar feelings of pride in appearance and self-care: *"Every morning after the delivery I wake up, take a shower, put make up and blow-dry my hair. Then I wear a new satin night gown. Women come to congratulate me while I am lying in bed (Participant 3)."* (H. A. Bawadi & Al-Hamdan, 2017). For others there was a feeling of achievement and the validation of status. One woman in this study stated how it made her feel triumphant: *"Frankly, I feel of distinction after delivery, this lets me forget all what I suffered during pregnancy and labor. All the people around me take care of my health, comfort, and feelings (Participant 5)."* (H. A. Bawadi & Al-Hamdan, 2017). Contrasting statements represent the different realities of women, even within one study there were a different range of feelings, for some women it felt as though they lost their freedom in the transition (Missal, 2013) and had a responsibility to take care of, for others the joy and awe of new life overtook: *"It is wonderful. There is new life. God gave this baby to me. You feel something in your heart. You will hold this new baby. Before I felt my life was empty, but when 'l knew I will have a baby', my life was full."* (Missal, 2013). For some this shift in responsibility, a move away from 'freedom' required a renegotiating of their sense of self, time, and roles as one new mother stated: *"Before I was free. I am now responsible for the baby."* and *"Before I became a mother I was free. I had time for anything, and I could go any place. But now I feel I have no time for anything."* (Missal, 2013).

The women who had family support and were in their native country were immersed in learning from female family members and taking advice on how to provide care for their new babies (H. A. Bawadi & Al-Hamdan, 2017; Missal, 2013). Some fathers in the study by Hala A. Bawadi et al. (2016) spoke of their role in supporting their wives encouraging them to eat well, going on walks together, talking to relieve any anxiety, ordering food in so they wouldn't have to cook and so on. This was captured in a fathers' statement in this study: *"I tried to surround her with a positive aroma so if she was bored we would sit down and watch TV together, go out for lunch or take her shopping. And if she was pissed off I would tell her to tell me what's on her mind and try to take her mind off things"*. (Hala A. Bawadi et al., 2016). These were ways some fathers in this study supported their wives in trying to remove any anxieties, burdens and pressures and trying to keep them in good spirits. In Missal (2013) study some new mothers' self-confidence gradually increased after the childbirth experience and they felt

positive about themselves as reflected in a statement by a mother who expressed that she felt like a: *"complete woman"* and *"like diamonds."* (Missal, 2013). However, despite the confidence there was also anxiety about the future or return to work: *"I feel confident all of the time but at night when I think: what will you do my son when I return to the university?"* Ordinary questions arose such as *"Will I be a good mother? Can I take care of the baby in a good way?"* (Missal, 2013). Forty days is a recommended rest and recuperation period for women in Islam post-partum, so it is generally considered a significant marker. Confidence grew through this time as one woman in Missal (2013) study stated: *"I feel confident caring for my baby. I did not know much before."* (Missal, 2013). New connections were made within the family as roles and status shifted: *They treat me like a mother instead of like before. They don't call me by my first name but Um Ahmed (mother of Ahmed). I stay with my mother-in-law, but I see my mother daily."* (Missal, 2013). For some women the transition to parenthood positively impacted the relationship with their husband and feeling more loved and valued: *"My husband is very happy. He loves me more since I am a mother. If I want something, he comes quickly."* (Missal, 2013). The positive transitions to parenthood for Muslim women depended significantly on familial support.

Renegotiating Identity: "Where do I fit in?"

Contrastingly, the Muslim women who were away from family or in a new environment found the transition to be strained, stressful and impacting their health and wellbeing and inevitably that of their child (Miller, 1995; Mustafa & Kittleson, 2016; Parvin, 2004; Tsianakas & Liamputtong, 2002). There were issues around identity and belonging in the new contexts, highlighted by the striking statement of a woman in Mustafa and Kittleson (2016) study of Muslim Bangladeshi women who had migrated to the U.S: *"Who am I? A Bangladeshi or an American? Where do I fit in?"* (Mustafa & Kittleson, 2016). For some women in this newfound context there was a change in emotions from hope and excitement to the reality of being a migrant and facing the challenges, barriers, hardships and discrimination that came with that and the new role and responsibility of a parent who had not negotiated parts of their identity: *"I was no less excited when I got the news of our possibility of immigration to the U.S. But, believe me, I never ever think of calling America my home. So I really don't know where I belong."* (Mustafa & Kittleson, 2016). This illustrated the confusion and sadness going from excitement and hope of moving to a new country to the reality of challenges faced, including

discrimination and unfamiliar cultural milieu's that led to a sense of rejection and questioning belonging.

The father; protector and guardian: "Pregnancy is a blessing from God, so we take care of this bestowal".

For the Arab Muslim fathers in Abushaikha and Massah (2013) and Hala A. Bawadi et al. (2016) there was a strong alliance and positioning of the increased role as protector and guardian in their transition to parenthood. The men would pray and feel a stronger sense of responsibility and the need to provide and take care, also recognising the spiritual dimension of the blessing of new life as one father stated how he felt: *"Pregnancy is a blessing from God, so we take care of this bestowal until this gift comes into our hands safely. Allah gave women the power to be mothers, we treasure this uniqueness in her, and we show our gratitude by praying that she stays in good health in order to deliver safely and cherish what she has procreated"* (Hala A. Bawadi et al., 2016). Some men spoke of the responsibility they felt in terms of supporting the mother as part of their role transitioning into a father, a protector and care giver. Another father in this study spoke of his sense of responsibility for the welfare of his wife: *"Pregnancy is a huge responsibility for the husband because he knows the most about his wife's physical and psychological state. Her family might not know as much as you [the father] because you're the one living with her and you should be considerate with her and be her righthand."* (Hala A. Bawadi et al., 2016). The fathers referred to in this theme were in their home countries. There was no comparable study of Muslim fathers who were in non-Muslim majority countries. (Please refer to the author checklist point [14] in appendix (5) the findings section described the interpretive findings of the translation).

2.10 Discussion

Findings of this systematic review showed that for some Muslim men and women their experiences of pregnancy and birth were shaped by and interweaved with their mental health (both positive and negative experiences), the role of religion as a supportive factor and one to draw strength from, experiences of health care systems (including language barriers, communication and discrimination), influences of culture and patriarchy, the role of relationships and family (including level of support available), and transition to parenthood as summarised in figure six:

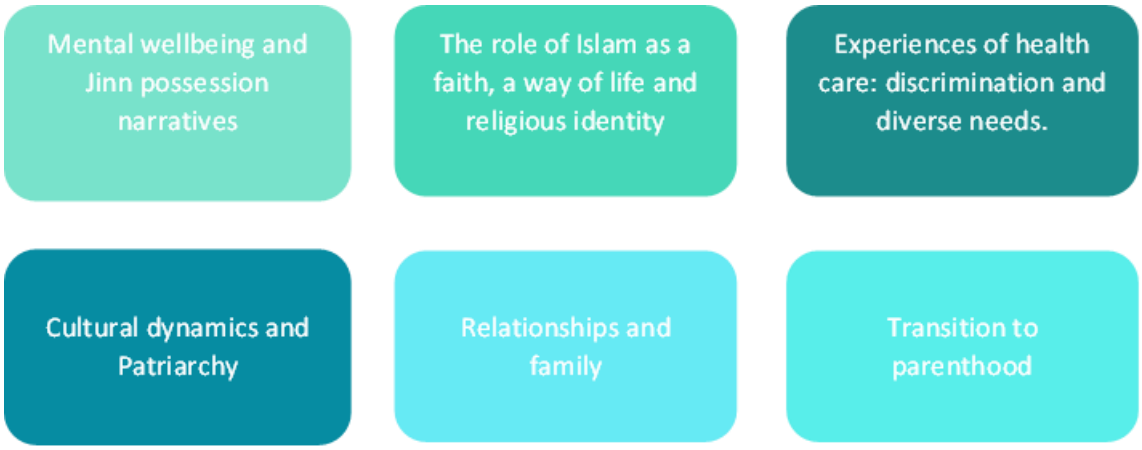


Figure 6: Visual depiction of systematic review findings: summary of the themes.

Some of the studies revealed the differences in experience in all six themes were marked by migration or being a native in one's home country. The negative experiences, discrimination, challenges, struggles and lack of support tended to be experienced by those who were out of familiar context and facing challenges of being in a new country and new cultural dynamics and nuances, sometimes without the English language for communication and without immediate relatives for support. Those who had positive experiences and felt well supported had access to family support, a familiar healthcare system, and fluency in language of where they were accessing healthcare. Despite difficult experiences such as jinn possession or mental health distress, the reliance on family for support and making meaning of their feelings and experiences within the context of their cultural and religious narratives in their native home provided an element of support that some of those who were migrants did not have access to in the same way. However, those who were migrants were more likely to express loneliness and not being understood or feeling cared for. It is useful to think about how experiencing

discrimination and lack of support and the cocktail of feelings this creates may impact on the woman's sense of self as well as the potential impact of this on the foetus. For example, being born into an environment where the mother is experiencing discrimination in the health care system, her needs are not being met, or she is unable to express what she needs, she feels misunderstood or not understood at all, could lead to significant stress which could also be experienced by the new-born.

Fathers found alternative ways to be supportive where culture (attitudes or belief systems) or policies prevented them from attending birth, such as through expressing concern over the mother's wellbeing, being mindful of her nutrition and mental health and being more understanding. There were only two papers that looked at father experiences, so this was a very limited sample. Nonetheless, the variety of experiences even within the two studies gave some glimpses into the different roles played and challenges faced by some Muslim men, which is a useful starting point for investigating further. Please refer to the author checklist point [17,18] in appendix (5).

Findings suggest that experiences of pregnancy and birth amongst Muslim men and women are somewhat demarcated by environment; migration or being in one's native country. Many of the experiences are determined by availability (or lack thereof) of supportive factors such as extended family and relatives being accessible, language, the role of God, religion and spirituality as supportive particularly though pain and or hardships and providing meaning and context to experiences. Understanding why experiences are negative and the potentially longer-term intergenerational impact these can have on the health outcomes of British Muslim parents and children is crucial going forward.

There were notable experiences related in the themes that are likely different from the majority (White British/Western) population and how healthcare professionals might respond. This was apparent in the theme on mental health and different notions and constructions including language around mental health such as attributing distress to being possessed by an unseen force or being. Though this may be increasingly known of as a phenomenon in hospitals that serve multi-cultural populations in the UK it may also be dangerously misdiagnosed or missed. The role of Islam and seeing trials, tests, pain and suffering as a gift from God, the elevated status of breast feeding and the kinds of feelings of loss and grief that Muslim women can face

when they are unable to fulfil this, as well as issues around morality were areas where meaning of experiences and thus responses and intervention could differ from white British secular interpretations. Muslim women faced issues around modesty and needing respect for their boundaries which differ from what is understood as dignity and respect in mainstream healthcare in the UK. This also came up in relation to shame and location of power in the medical hierarchy.

Given that there were no studies available specifically on British Muslims experiences of pregnancy and birth this formed the rationale for my empirical research, where I could focus on this group and what their experiences are in the current climate, including exploring supportive factors that can improve and enhance health outcomes for British Muslim, women and men with potential policy implications. Please also refer to the author checklist point [17] in appendix (5) summarising the main interpretive findings.

Studies varied across several countries with different systems of healthcare available. One of the strengths was the availability of multiple first-person narratives of experiences across all eleven studies which meant this systematic review was able to stay close to the voice of the Muslim women and men's original experiences. Please also refer to the author checklist point [17,18] in appendix (5) summarising the main interpretive findings.

There are some notable limitations including some methodological aspects where studies come from a wide range of countries and thus cultural and political contexts and different time periods. Due to the overriding decision and main criteria to include studies that included first person accounts and not to exclude further on this limited pool, issues around the quality of studies can be questioned as noted in the section 2.1.6. The synthesis of the findings were influenced by the nature of the included studies that were global and across any time span, this inevitably influenced how the meta-ethnography was conducted as it was narrowed to the papers in the limited restrictive search strategy and may affect how comparable the studies are. Had there been multiple studies available for one country, for example, it may have been possible to contextualise further and understand the specific experiences in that country for comparative purposes. However, this broader review offers some interesting insights such as the need for support being universal and dependant on family circumstance rather than country of residence. In terms of how I conducted the meta ethnography, whilst I intended to keep it narrow, there could be papers I missed where Muslims experiences are reported, I acknowledge

that my specific search criteria and strategy may have not gathered everything that has been written.

Limitations included that only one study discussed the reflective role of the researcher, and some studies did not provide enough information in the methods to judge how robustly they were conducted. Of the authors there were nine Muslim women, three Muslim men, four non-Muslim women, three Non-Muslim men and two ethnic minority women. How each paper was written would be influenced by the worldview and knowledge base of the positionality of authors. Further limitations, perhaps partly due to the lack of reflexivity and statement of positionality of the authors, included lack of discussion on structural and institutional racism and Islamophobia and possible trauma. The studies did not explicitly reflect on how some first-hand accounts could be seen implicitly or explicitly as racism or Islamophobia. These kind of implicit, underlying, structural factors raise issues for how themes are constructed and what is emphasised by the authors where they are not spoken about explicitly by participants. I worked with this through creating my own analysis of the first-hand accounts and not relying on the interpretations of authors. There were also notably few examples in the theme discussing the impact of male doctors in a medical system that is underpinned by patriarchy, the few examples mentioned focus on how uncomfortable it was for the Muslim woman and her husband for her to be attended to by a male doctor. The focus was mainly on husbands and family in terms of patriarchy and culture.

Another area that may have impacted comparability was the inclusion of older studies (Miller, 1995) as no limit was placed on publication dates in the review search strategy. It may be that parental perinatal experiences are different across times and with an increase in immigration to Western countries the difference maybe more apparent in healthcare settings influenced by various political climates.

One of the strengths of this synthesis is that it is the first meta ethnography of its kind on a limited pool of literature looking specifically at Muslims emic experiences of pregnancy and birth. It demonstrates a lack of literature in this area and provides some really interesting insights into the diverse range of experiences women and men have from their conception of mental health in the perinatal period to the kinds of particular experiences of discrimination and judgement Muslim women experience in healthcare. This in itself is a significant area and provided context and rationale for my own qualitative study.

I also understand and am aware that I have a particular knowledge base, particular perspectives and psychological construct and arguably if someone else had a different knowledge base it is possible they may come up with different themes. This can be both an advantage and disadvantage. There was constant reflection throughout the process and discussion with my supervisors at all stages. My particular knowledge base and perspective is equally likely to produce an interpretation that is as valid as someone else's and may offer different insights. Please refer to the author checklist point [18] in appendix (5).

This synthesis demonstrates a lack of research interest in Muslims experiences and how their distinct views and beliefs shape their experiences of pregnancy and birth. It further highlights the need for in-depth exploration of each of the issues raised in the findings of this review itself which provides the basis for future research study. Especially in the UK there is so little literature on British Muslims experiences and particularly given the context that I have described in the introduction to this review it lends weight to the empirical research This review is a steppingstone for my empirical qualitative study. Please refer to the author checklist point [18,19] in appendix (5).

2.11 Conclusion

This is the first review of Muslims experiences of pregnancy and birth using a meta-ethnographic approach and following eMERGe reporting guidelines at the time of writing. The synthesis and conceptual framework provides integrated and new insights into the range of difficulties and challenges Muslims face. The review revealed the significance and importance of Islamic beliefs and practices - and the meaning of these - in the lives of Muslims during pregnancy and birth and how awareness of these can have implications for clinical practice. It further illustrated the supportive factors that Muslims draw upon, such as their faith as a way of life, and the nuanced ways in which they interpret and utilise their religious perspectives in the difficulties they face. The synthesis identified a broad range of factors that are important in the Muslim experience. These included the way in which Muslims encounter and are perceived in the healthcare system, how they experience and negotiate the cultural, religious, and patriarchal dynamics around pregnancy and birth. It was notable that those in Muslim majority countries concerns were different to immigrants or ethnic minorities in non-Muslim majority countries. The former did not discuss experiences of discrimination based on racism or rooted

in Islamophobia but perhaps were impacted by socioeconomic or culturally influenced policies such as not allowing the husband into the labour room. The latter seemed to be fire fighting for basic needs to be met, struggling with language and communication, discrimination and understanding a foreign system that did not take into account their whole being. Thus, it seems that discussion of those in Muslim majority countries centred around culture and ordinary experiences with families and were overall more positively framed than those who were in non-Muslim majority countries where the focus was on the challenge of healthcare needs not being met. Furthermore, the roles each person in the family and community plays, to the way meaning is given to mental health and psychological experiences, and how they are interweaved into religious and or cultural conceptions depending on the geographical and familial context. These findings identify the need for a more diverse and inclusive need to engage with Muslims' healthcare needs - of giving birth - beyond stereotypes and the need to question how discrimination and unhelpful policies can play a potentially stressful role during this period. Moreover, it identifies the need to engage with diverse and multiple narratives and expressions people use to describe mental health distress and symptoms without fear or pathologising. Muslim women and men's experiences of pregnancy and birth need to be critically reflected upon and thought about in research and healthcare professions. These reflections include the need to challenge assumptions, preconceived ideas and judgements, and socio-political and cultural dynamics in the wider environment that can impinge and negatively influence researchers and practitioners and thus effect the quality of care received, in this case by Muslims. Healthcare professionals need to understand and support the particular needs of Muslims during the pregnancy and birth stages in order to enhance the quality of the care and experience. The Muslim community also needs to become more aware widely informed about the critical nature of early experiences in particular the perinatal period and its impact on later life development and physical and mental health outcomes. The Muslim community and health services working collaboratively can help to ensure a more supportive compassionate environment that facilitates a less stressful period and better experience.

The review revealed the stress bearing consequences of not feeling supported, mental health expressions not necessarily being understood, complex collective enmeshments in familial, cultural and community structures, discrimination or feared discrimination, as well as the limitations of the studies used, thus suggesting a much needed in depth engagement with Muslims in the current socio-political climate. This must be done with an open, non-judgemental, thoughtful, critically reflective approach that offers a genuine space for helpful

enquiry into how Muslims experience pregnancy and birth, what their stories are and how can they be better supported in a way that means something to them, as well as consideration of what factors they find supportive from their faith, and way of life that can be utilised within their healthcare, to improve outcomes and experiences. Having unpacked the systematic review, which provided the steppingstone and rationale for the empirical phase of my research, I will now move to the methodology and philosophical considerations of my overall thesis, in particular that which will be the frame for the empirical study which comes next. Please refer to the author checklist point [19] in appendix (5).

Chapter Three: Methodology and Philosophical Paradigms

3.1 Introduction

This chapter will outline and detail the philosophical and methodological research paradigms of this thesis and provide a structure for the methods section which in turn forms the foundation for carrying out the empirical study. As mentioned at the outset, this thesis is rooted in a decolonial and trauma aware approach, mindful of centring Islamic ontology and epistemology, in order to offer an understanding of British Muslims' experiences of the perinatal period. This decolonial approach provides the scaffold for the empirical research. There will be a discussion of its' context, both the challenges and contradictions that arise thereof, as well as synthesis with other philosophies considered. Furthermore, there will be an elaboration on, and critical engagement with, the journey that led to framing this study within a decolonising methodologies framework, drawing on Islamic ontology and ideas from critical medical humanities. The thesis can be best visualised as a patchwork quilt: different, colourful patches held together coherently with a thread, which I provide through my writing and connections that I make. There will be exploration of ideas around Western domination of science, objectivism and the importance of 'connectivism', crisis of values or denial of enmeshment of knowledge, and research models alien to the socio-religious realities of the Muslim world. These discussions are illuminated using a historical example of the legacy of colonialisation on Muslim women's bodies and how trauma affects the neurobiology of colonised minds.

In an attempt to understand the nature and construction of assumptions and knowledge there will be a weaving into the narrative, by way of conscious reflection, of the researcher's role and influence on the research (Ponterotto, 2005). In alignment with this, some sections will be written in the first person to reflect the process as a meta discourse; this means referring to 'I' where required rather than referring to oneself as a third person disembodied from the research process.

3.2. Research Question

Before delving into the philosophy of the methodology, a reminder of the Research Question:

What are British Muslims' experiences of pregnancy and birth?

With the research question firmly in mind, the research philosophy will now be discussed.

3.3 Philosophy

It is imperative to state the philosophical position I took for this thesis in order to formulate and define the research design most appropriate and relevant to the study in question. The execution of the empirical research was based upon the ontological and ultimately epistemological paradigms adopted. Epistemology (from the Greek, episteme) is an enquiry into the nature of knowledge. Knowledge in Islam is often expressed in the word 'ilm' however the English translation of the word falls short. 'Ilm' is an all-embracing term covering theory, action, education and wisdom (Azram 2011). The important questions for this thesis related to knowing: how do we know? What is the nature of reality? Who decides what knowledge is valid or acceptable? While the aforementioned questions are all significant, the one of critical importance to this thesis was the latter question of who decides what knowledge is, and what is its' relevance (or not) for the 'who' to be studied? This lead naturally to the question: how is that knowledge to be used? I found myself critiquing the idea of how knowledge is constructed and used within the current context and the reality that I find myself in, and subsequently what my role would be as the researcher of this study with its particular challenges and dilemmas.

All paradigms and philosophy ultimately have their own underpinnings contested by other theorists who may offer critiques or alternative ideas. Arguably, the most important issue is relevance and appropriateness and that the fit should be right for the group or phenomena being studied. Part of this chapter will deconstruct some of these ideas in relation to constructing a meaningful and appropriate argument for the ontology, epistemology and methodology that take the context into account, and that explore and acknowledge 'other' ways of knowing. I will make the critical argument for the ontological position that is the most appropriate for this thesis. The psychological and historical contexts and roots of these theories or philosophies must be thought about and recognised and reflected upon in reaching an understanding of the chosen approach for this study. Researchers have argued that in order to study Muslims, it is crucial to do so within an Islamic ontological framework (Azram, 2011, Davutoglu cited in Morrison, 2014, Elmisseri, 2013, Malik, 2019, Grosfoguel, 2013). Understanding Muslims' experiences of pregnancy and birth is the mainstay of this thesis. To gain some insight into this area and being mindful of ensuring the most appropriate guiding philosophy, I am utilising a decolonising methodology that holds Islamic ontology at its centre and will utilise reflexive

thematic analysis and narrative inquiry case study methods of analysis to facilitate the documenting of experiences. To take this path required thinking creatively and reflectively.

3.3.1 Creativity – an unexpected patchwork

Creativity was the starting point for the 'patchwork quilt' mentioned at the outset of this section. With Grégoire's (2018) statement in mind:

> "Creativity is a crucial issue in science. Scientific research should not be restricted to the logical development and application of known ideas but should promote new ideas to expand knowledge beyond the existing frontiers. Stimulating scientific creativity means not only giving a boost to creative thinking, but also taking into account the factors that put a brake on creativity" (Grégoire, 2018, p.229).

The ideas that Grégoire (2018) presents are in alignment with Islamic understandings of what constitutes knowledge, a process that facilitates the promotion of new ideas and expansion of knowledge and also knowing when to put on the brakes (Grégoire, 2018). In Islam it is understood that God has endowed humans with potentials of creative and conceptual knowledge (Azram, 2011, p. 179). It is important for me that I use these faculties consciously to enhance and further my knowledge base and understanding through various methods of enquiry. This links to the ideas mentioned in the introduction chapter about embodiment and the creative nature of the research process and conversations, whereby such research conversations can lead to a positive creative transformation of some change (Gilliat-Ray, 2010).

A parallel objective of this thesis research process was to delve into different frontiers, lesser trodden paths, to parched fields, to create a 'nourishing' environment that produces something of value ultimately. I kept pondering on the idea that a PhD needs to be something 'different', something that has not been done in the same way before; it needs to offer something unique, be original. I felt a strong personal need for this to be something meaningful, to be a ship for ideas that needed a strong sailor. This strength would have to come from skill and learning along the way; from the heart as well as the mind. This was beyond a purely academic pursuit.

3.3.2 The role of Critical Medical Humanities in my study

Though I was using notions of creativity as a starting point to think about where and how my study should proceed, I required foundational principles to draw on. One of these that provided

helpful direction and a strong discipline, along with the decolonising methodologies umbrella, was Critical Medical Humanities (CMH). CMH is a critical interdisciplinary exploration and examination of health and medicine beyond the clinical encounter only. Looking into CMH laid the first layer in terms of building a theoretical foundation in my mind for this thesis, it supported, and was a complimentary critique to, the decolonising methodology approach for thinking about Muslims' experiences in healthcare, the medicalisation of birth, and the impact on mental health considering intersectionality. The diversity and plurality expected of critical medical humanities have been considered a strength for encouraging creativity and epistemological innovation (Viney, Callard, & Woods, 2015). This was useful to draw upon for my study where it was necessary to be creative (Grégoire, 2018) and work with innovative epistemological and ontological ideas in a critical way. It provided a basis for my thinking and a route into thinking critically around matters of medicalisation of birth and narratives of perinatal mental health, outside of a clinical diagnostic biomedical model. Viney et al. (2015, p.2) discuss a collection of papers and responses in the critical medical humanities field which they express are:

> *"intended as an invitation to keep the field of medical humanities open to new voices, challenges, events, and disciplinary (and anti- or post-disciplinary) articulations of the realities of medicine and health; to be adventurous in its intellectual pursuits, practical activities, and articulation with the domain of the political."*

They argue for a critical medical humanities characterised by a number of areas. For my study in particularly I found three of them to be helpful in my thinking throughout my research process, analysing and writing. These were firstly: *"a widening of the sites and scales of 'the medical' beyond the primal scene of the clinical encounter"*, this helped me to think about the meaning of shared experiences and the story beyond the medical and diagnosis particularly when it came to analysing the empirical research around experiences of mental health. Secondly: *"greater attention not simply to the context and experience of health and illness, but to their constitution at multiple levels"*, I applied this through my analysis and discussion bearing in mind the wider social, historical, political, colonial, psychological and emotional layers and influences to the experiences. Finally: *"robust commitment to new forms of interdisciplinary and cross-sector collaboration"*, this was a strong personal commitment and objective of mine, to be seeking new connections and the possibility of new ideas and knowledge production through interdisciplinary enmeshment. These ideas they share align well with the decolonising methods approach that I have taken and lends themselves to multiple narratives, ideas and possibilities. Critical medical humanities allows for resistance to positivist

biomedical 'reductionism' and is sensitive to narrative-based interventions and their limitations. Being able to draw on ideas of critical discourse from the field of critical medical humanities was an initial stepping-stone in my PhD journey which connected to my discovery of decolonial research through ideas of critical thinking and critiquing existing ways of knowing. This study drew on these ideas along with decolonising methodology literature.

3.4 Historical context

3.4.1 Decolonising methodologies: the impact of colonialism and epistemicide

Epistemicide refers to the intellectual genocide that occurred as a result of colonialism (Grosofoguel, 2013 and Malik, 2019) and is critical in understanding the root of the dismantling of knowledge structures and destabilising the Muslim world and heritage, and its subsequent and ongoing (to date) impact on knowledge, education, science and research. Important historical context is provided by the below:

> "In the late 15th century, Al-Andalus/Muslim Spain was in the final stages of conquest by the Catholic Monarchy and accompanying the physical genocide of the population of Al-Andalus was intellectual genocide, or what Grosfoguel has referred to as epistemicide. Along with murdering and suppressing an entire population of Muslims and Jews, mass burning of libraries was undertaken. The mass burnings of libraries in Al-Andalus signalled the early stages of intellectual colonization that ran parallel to the political conquests of the colonial era." (Grosfoguel, in Malik 2019, p.12).

It is crucial to be mindful of the multi-layered impact this has had on society and particularly the communities on the receiving end of these aggressive and violent acts. This epistemicide has also be an attack on the psychology of Muslims. This is why it is crucial to frame a study with Muslims being mindful of Islamic ontology and epistemology as part of the process of giving power back, restoration and healing. Many immigrant parents faced complex traumas which shifted their focus on survival and then establishing a secure base. In fact, *"immigrants who are not classified as refugees, especially those with low socioeconomic status and those who migrate to a country without authorization, can experience some of the same traumas experienced by refugees"* (Perreira, and Ornelas, 2013). With so much to contend with, fighting to preserve knowledge and literature was not and could not be a priority. There is little to no knowledge, in some later generations of British Muslims, especially the younger ages of the historical context of the extent of the damage caused and felt intergenerationally. Literature, poetry, ideas, philosophies and (especially tragic) stories have been wiped (Malik, 2019).

Much of the dialogue around decolonising the academy and research in academic institutes is centred around north and south epistemologies demarcated by regions and parts of the world, less so around epistemologies rooted in plural groups who are bound by the culture of a religion, for example which is what I am attempting to bring attention to. Islam brings with it a complete holistic ontology and epistemology with diversity within it, depending on where in the world people are from, the synergies of different cultures.

There is increasing consciousness of how our histories have been influenced, distorted and narratives falsely shaped. Some academics and researchers are increasingly wary of importing the intellectual dependency of Western social theories (Hussein, 2013 in Elmessiri). Grosfoguls' (2013) article *'The Structure of Knowledge in Westernized Universities: Epistemic Racism/Sexism and the Four Genocides/ Epistemicides of the Long 16th Century',* is inspired by Enrique Dussel's historical and philosophical work on Cartesian philosophy. In it he discusses the epistemic racism/sexism that is foundational to the knowledge structures of the Westernized University. Grosfugul (2013) proposes that the epistemic privilege of 'Western Man in Westernised Universities' structures of knowledge, is the result of four genocides/epistemicides in the 16th century against Jewish and Muslim populations during the conquest of Al-Andalus (Grosfugul, 2013, p. 73). Grosofoguel (2013) explains that these epistemicides are as a result of the conquest of the Americas in relation to three other world-historical processes such as the Conquest of Al-Andalus, the enslavement of Africans in the Americas and *"the killing of millions of women burned alive in Europe accused of being witches in relation to knowledge structures."* (Boaventura de Sousa Santos, 2010 cited in Grosfugul, 2013, p. 74.)

During the course of my PhD journey, I felt a sense of loss from the noticeable gap in the missing legacy of female knowledge transmission from an Islamic perspective. I had an idea of being able to draw on Muslim female philosophers much like Ibn Khaldun and Al Balkhi for my thesis. I had hoped perhaps I may even find some theories, and or a methodology and methods model to use to anchor my thesis in, much like IPA or feminist theories so easily accessible in western academia and regularly applied. None of this materialised as I was unable to find the works of any Muslim female philosophers, psychologist or social sciences historically or that were providing a theory or model my thesis could easily draw on and apply. There may be reasons for these missing knowledge structures much like Santos (2101) and Grosfugul (2013) discuss. There may also be additional reasons, such as oral transmission

being more common, lack of translation and accessibility in the English language of written works, negative aspects of patriarchal control (of what enters the public domain and opportunities lacking for women), intellectual genocide, colonialisation, politics, and so on.

The canon of knowledge remains largely Eurocentric white and male. Grosfugul (2013) poses an important question in his paper: *"How is it possible that the canon of thought in all the disciplines of the Social Sciences and Humanities in the Westernized university (Grosfoguel 2012) is based on the knowledge produced by a few men from five countries in Western Europe (Italy, France, England, Germany and the USA)?"* He goes on to ask rhetorical questions of the nature of how was it possible for these few men to have achieved epistemic privilege to such a degree that this knowledge is seen as superior to the rest of the world? How did they monopolise the authority of knowledge? And why is it that what we know today of social, historical, philosophical, or Critical Theory is based on the socio-historical experience and world views of men from these five countries? (Grosfugul, 2013, p.74). These questions raised thoughts around power and control, oppression and injustices in knowledge production and consumption for me.

I started to think what does it mean for students, researchers and academics, if the canon of thought that is consumed in the social sciences and humanities is based on these 'few men', in five Western countries that he refers to? Are we (re)producing dangerous systems, systems that are epistemically oppressive? I think we have and continue to. Again, the questions that kept recurring for me were of how do we know what we know? What voices are missing? What do I not know? How do university structures keep revalidating and re-upholding white, male middle/upper class privilege? Knowing some of those answers and the not knowing other aspects was beyond uncomfortable leading to stress for me for long periods of my research. As mentioned elsewhere it felt restrictive that 'scientific' research processes were not accounting for a holistic or wider picture, there seemed to be no space for anyone else's way of knowing and if there was, it was tokenistic and did not feel meaningfully engaged with. The knowledge is degraded and related to social sciences and humanities not the superior 'sciences'.

Despite the end of the colonial period officially, this is where I realised our minds are still colonised. There were definitely points of tension in my engagement with the research process especially when I was considering which methodology to use initially and the thought of having

to anchor my work into authors, theories and structures that felt completely alien and removed from my worldview or that I found problematic and did not resonate. The main question for me was always why would I centre the theories written by white European men or women in another era to analyse the experiences of Muslims? It made no sense to me, it felt wrong, unjust and irrelevant. I was grateful to find the decolonising approach to anchor my work in and to be able to persevere in the unknown territory of trying to do research for the first time in this way to be true to my identity as a Muslim academic centring a God centred way of life and analysing Muslims' experiences in ways that are meaningful to their worldview. We have had plenty of research that is oblivious to the importance of this, which highlights the urgency for critical engagement at all levels of research, science, knowledge, theory formation and policies.

Interestingly Grosfugul, (2013, p.74) discussed how research is guised under the notion of "universality", the postulation that the ideas of these few men in their own social and historical context are applicable to the rest of the world, imposing ideas and ideals on to different geographical locations and sociocultural contexts as if they were *the* standard. This superiority inevitably creates inferiority; other worldviews are considered inferior, that of women and 'other' people leading to sexism and racism.

3.4.2 Western domination of science

Eurocentric, secular, atheist informed application of research ontology, epistemology and thus methodology have been taken for granted as a standard way of knowing that is systemically entrenched within academia, unless questioned. In a globalised world, these methods have been assumed to be superior and 'civilised' and have been internalised as the ideal model in many parts of the world. It is potentially problematic taking knowledge and customs from one environment and trying to impose that on to another environment where there are different sets of values and systems, nuance and context may be missed. Communities subject to the gaze of and bias interpretation in the form of being researched by the White often, male, Eurocentric academic, can feel unfairly scrutinised leading to a feeling of a sense of discrimination and oppression. The issue is one of domination of one group over others, to the point of entrenchment where certain ideas, ontologies, and customs, become the normative culture and anything outside of that is perceived as foreign, or simply wrong or inferior:

> "When any group within a large, complex civilisation significantly dominates other groups for hundreds of years, the ways of the dominant group (its epistemologies, ontologies and axiologies), not only become the

> dominant ways of that civilisation, but also these ways become so deeply embedded that they typically are seen as 'natural' or appropriate norms rather than as historically evolved social constructions." (Scheurich & Young, 1997, p.7 cited in Chilisa, 2011, p.45).

Decolonising theories provide an approach to methodologies that attempt to speak out against normative or mainstream ideologies and create a space of their own, aware of the dominant discourses as well as critical, reflexive and sensitive in prioritising the needs of the communities which they serve and represent. However, they are arguably still not seen with equal value in many academic circles and considered 'soft' approaches.

Similarly devalued are indigenous research methods and theories, which are often not considered valid or worthy, as is evident from the lack of wide availability of examples in academic texts or published articles (Martin & Mirraboopa, 2003). The otherisation and subjugation of people and the power dynamics that have historically occurred and may continue to occur in research, need to be critically challenged at every step of the research process and within academic institutions. Who decides what is valid to research and study and why or why not, in one situation may be very different in another? The hierarchical systems that miss the voices of women and people of other worldviews (and a consideration of divine knowledge and reality beyond rationality) would not as such be an appropriate model for this thesis.

3.4.3 They myth of objectivism and the importance of 'connectivism'

A longstanding issue of debate within academia and elsewhere has been regarding the superiority of knowledge, of methods and or theory, *"whether knowledge is perceived as objective and measurable or subjective and experiential"* (Alvesson and Sköldberg, 2009, p.1). The disciplines and structures of academic research taught in academic institutes have been loaded with undercurrents of supremacy, male dominance and arrogance as will be seen below in discussing the significance of decolonisation. The narrative often pushed in many parts of academia, particularly the 'hard sciences', is that objective, measurable methods are superior under the guise and myth of supposed human rationality and objectivity of observable phenomena, as is highlighted in the quote below:

> "After 370 years, Westernized universities still carry the Cartesian legacy as a criterion of validity for science and knowledge production. Even those who are critical of Cartesian philosophy, still use it as criteria for what differentiates science from non-science. The "subject- object" split, "objectivity" understood as "neutrality," the myth of an EGO that produces

> "unbiased" knowledge unconditioned by its body or space location, the idea of knowledge as produced through an internal monologue without links with other human beings and universality understood as beyond any particularity are still the criteria for valid knowledge and science used in the disciplines of the Westernized university. Any knowledge that claims to be situated in body-politics of knowledge (Anzaldúa 1987; Frantz Fanon 2010) or geo-politics of knowledge (Dussel 1977) as opposed to the myth of the unsituated knowledge of the Cartesian ego-politics of knowledge is discarded as biased, invalid, irrelevant, unserious, that is, inferior knowledge." Grosfugul (2013, p.76, 77)

This is completely antithetical to the arguments for embodiment as a researcher touched upon in chapter one and to the ideas that will be discussed later in this chapter on indigenous and non-Western ways of knowing.

Objectivity is arguably a misnomer. Ample evidence exists regarding how the human mind is affected unconsciously by emotion, physiology, epigenetics and culture as well as our learning and development. The conscious and unconscious messages we receive define perception and how we see the world. The interpretation of information and data will have a significant impact even when variables are accounted for. Recognising the value and validity in the diversity of interpretation can open doors to new insights and discoveries that could lead to all sorts of innovative advancements. At times, this may require a turning away from that which is familiar and understood within the constraints of an existing common framework. That is not to say there should not be an overarching philosophy, however as I discovered in my journey for this thesis, there were several areas I needed to think about - such as enquiring into sources, histories and context of theories and their authors (mostly 'founding fathers').

A theory may seem appropriate on the surface, but I felt exploring the roots was an important area of critical engagement which would help lead me to theories that were most likely to be relevant for this thesis. The ultimate conclusion may be similar, for example by utilising particular data analysis methods which may be rooted in a Eurocentric philosophical theories, however understanding and contextualising the origins of any methodology and philosophy are critical to this study.

3.4.4 The crisis of values or denial of enmeshment of knowledge

In developing my ontological position, I drew on some ideas argued in Davutoğlu's discussion of Husserl's *'Crisis of European Sciences'* (Morrison, 2013). Initially when I set out on this

path of researching a methodology for my thesis, I did so within what I would now refer to as a taken for granted paradigm which included commonly drawn upon methodologies within health and social sciences. These methodologies and philosophies were not something I previously questioned. I started by looking at phenomenology as it seemed to be a well-trodden path in my field and one I was considering using for my study.

In my quest for looking at sources of knowledge, which has come from my Islamic education (looking at chains of narration and context and the authors and their influences is an inherent part of traditional Islamic education), I looked up the three) main 'founding fathers' of phenomenology in the Western world: Heidegger, Husserl, Merleau-Ponty. Reading about their logic, theory and conclusions raised multiple questions for me from my 'Islamic worldview' or personal Islamic ontology. It seemed that some of these ideas were not and could not be perfectly aligned, such as the 'bracketing' out of the self. I believed that it is not possible for the researcher to do so in a study like mine, which is immersive in interpreting qualitative data. It may work in some contexts, but it did not seem like the best fit for my study. This was my first major hurdle.

I now had to look critically at what was available and questioned how I would and should go about this as a Muslim academic wanting to carefully and accurately represent my community, which have often been maligned in a negative and stereotypical light. As I began to understand and learn more about the historical context of Muslim experiences, the knowledge production process became increasingly important. By taking a more critical look at how knowledge is constructed, used and deconstructed through trying to understand the application of the phenomenological ideas of the aforementioned founding fathers. I was able to learn some important history and reasonings for certain positions from this paper. I developed an understanding that there was an argument for me to use an Islamic ontology in my study. Using the incorrect ontology and trying to apply it where it does not fit leads to epistemic injustice.

The main issue that arose for me came with Husserl's key concept of 'bracketing out'. This could not work in a study that is about embodiment of experience, cognisant of Islamic ontology which at its roots is the concept of oneness and unity (tawhid). This was my first major realisation of intellectual dissonance in the formation of this thesis and an awakening. I recognised that using theories that bracket out the researcher would create a split and be the

opposite of connection, embodiment and oneness. The further I read, the more dissonance the ideas created.

Philosophical and ontological roots are not areas I have had to question in any significant, meaningful, intellectually rigorous way before this study. It became particularly critical to question my own narrow information and ideas based on my Western colonialised education, which taught me that these were the most superior (and in some cases only) ideas, until I started questioning and reading more widely. Davutoğlu (cited in Morrison, 2013, p.74) addresses the need to recognise *"the actual or attempted imposition of the Western worldview onto Muslim peoples, whether at the insistence of Western people engaged in (neo-)imperialist enterprises, or Muslims themselves in misguided modernisation efforts"*. There is a distinction being made by Davutoğlu (1994a) regarding the origin of the differences being from the *"philosophical, methodological, and theoretical background rather than institutional and historical differences"* (Davutoğlu 1994a: 2, cited in Morrison, 2013, p.74), that distinguish Islam from the West.

In practice, I found, that when I was looking at Muslim majority countries for methodologies or methods that I could perhaps utilise in my study, I could not find anything relevant, as they were using western ideas in research methods having had a history of being colonised and or having given more importance to Western ideas. The vast majority of current taught research methods and methodologies globally have adopted western ideas of science and research.

The common factor between Husserl's and Davutoglu's ideas was that they both *"perceive a crisis in humanity and identify its causes in scientism and logical positivism, against which they develop their respective phenomenological alternatives",* (cited in Morrison 2013, p.71). Morrison (2013) provides an insight through a parallel history of Husserl's Western thought and worldview with that of Davutoğlu's Muslim worldview. He illuminates for the reader Davutoğlu's *"putatively comprehensive interpretation of Islam, diagnosis of the ills of secularism, modernisation, and crisis of values he finds in Muslim societies; and his prescribed treatment for those ills: the privileging of ontology over epistemology, and the full unfolding of core theological concepts of revelation, monotheism, and prophecy."* (Morrison, 2013, p.71). This is very useful and comprehensive as it considers both the 'ills' of secularism and the 'crisis of values' in Muslim societies, further it seeks to provide some solutions for these 'ills'. This exploration of the 'ills' of secularism and the 'crisis of values' in Muslim societies

made me wonder where I would find my middle ground. It could be appropriate and apt to apply phenomenology and the ideas of Heidegger, Husserl and Merleau-Ponty if I were not studying Muslims' experiences and not Muslim myself within a particular historical context of colonisation.

3.4.5 Research models alien to socio-religious realities of the Muslim world

The dogma of imperial and Western hegemony has, for almost a century (since the widespread domination through colonial powers), considered anything 'Eastern' or non-Western as inferior and uncivilised:

> "Throughout the last two centuries the standard thesis has been that classical science is originally European, emanating directly from Greek philosophy and science. Economic discourse justifies a superior power over the world, which then becomes economically dependent on an international division of labor. All forms of social organization and political management outside the West are considered inferior and incapable of renewal and development. This resulting dogma justifies imperialism and Western hegemony in its worst forms." (Hussein, 2013, p.6).

This has led to a dangerous erasure of history and other people's realities and experiences, not to mention ignoring of the interweavement of Greek and Arabic philosophers and the input of Arabic-Islamic thought as a civilisation that ruled for centuries. Elmessiri (2013, p.1) describes the widespread neglected academic issue of the adoption and acceptance of paradigms, terminologies and research models. Some of these ideas are even alien to the realities and context of the Muslim world yet have become superimposed. Elmessiri (2013) highlights the particular problem in what he refers to as 'third world' countries where, despite the cultural paradigms being different, academics in these countries encounter a foreign Western paradigm in the form of research and science methodologies as permeating their thought processes. Ultimately, reality becomes distorted through the lens of the other.

The paradigms, ontologies, epistemologies, methodologies and theories may have advantages in their own context in the West and be most appropriate but trying to transpose them on to a different cultural context can be problematic and have a distorting effect. Further still, Elmessiri (2013) highlights the process where any community that adopts an imported alien paradigm and – often without awareness of the epistemological implications of such paradigms – end up becoming threatened. It is crucial to think about the long term psychological and practical implications of this on research, on scholars, on practice and how this translates to application

in the real world such as policy implications or clinical practice. Elmisseri, (2013) suggests a remedy by 'establishing a new science with its own mechanisms, methodologies, and points of reference to address epistemological biases and invite 'ijtihad' (interpretation).

It is possible that other possibilities are overlooked, missed or not even conceptualised due to the bias of the prevalent and dominant western models of research. New methodologies will help express new paradigms. It is not necessary that these new paradigms replace existing ones but may function as more relevant and useful and be wider in their parameters and provide a function as a more complex means to study Muslims societies (Elmisseri 2013, p.2).

It is critical to redefine ideas about what constitutes "progress" so that other paradigms can be given the same adulate as 'mainstream', Eurocentric Western ideas. The movement of history is metaphorically compared to a straight line leading to a definite point, versus cyclicality (Elmisseri 2013, p.2). Many cultures and worldviews perceive life as circular and cyclical. This connects to Islamic ideas which are centred around the cyclical nature of creation. There are several passages in The Holy Qur'an that detail the cycles of day and night, even the Arabic alphabet is divided into sun and moon letters embodying the feminine and masculine balance, light and dark as metaphors. There is also connection to the circular and cyclical through female biology in particular the menstrual cycle and the metaphysical, yet what continues to dominate is the linear framework in virtually every aspect of life in the Western world and adopted now globally. In expressing new paradigms, working with a cyclical understanding may offer new insights which may be being missed on a linear plain.

According to Elmisseri, (2013) some people abandoned their heritage without realising the implications of this. This distancing from heritage could also be due to other factors including a healthy adaptation and adoption of ideas. He discusses the idea of abandoning heritage as being linked to the importation of Western thoughts and theories and paradigms into Muslim societies; ideas which were targeted by the West as needing reform in the renaissance period. The propagation of these imported, non-contextual paradigms is dangerous and reshapes value systems and can lend themselves to power structures that attempt to erase history.

As an example, let us take a prominent social scientist in Muslim history such as Ibn Khaldun (c.1332, cited in Hozein, 2010). It is unlikely that he is known or referenced in mainstream Western social science despite having been a major philosopher in the Arabic-Islamic world

and his ideas being translated across the world. The question is what power structures have been at play that led to this erasure of the name from the ideas. He is an important figure in the field of History and Sociology and wrote extensively on education. Writing centuries before European colonialism he observed that it is *"in the nature of conquest that the conquered imitate those who conquer them. This occurs because the conquered are either impressed by the conqueror or erroneously attribute their own subservience to the perfection of the conqueror, failing to analyze the nature of their defeat",* (cited in Malik, 2019). It has created some insecurities; and a want to imitate that which is considered superior. This is an example of where psychological and ego factors not kept in check with spirituality, as is encouraged in Islam, supersede the higher realms of functionality and wisdom.

3.4.6 A historical example of the legacy of colonialisation on Muslim women's bodies

I am going to present an example that illustrates the ongoing legacy left through the process of colonisation that has left imprints on the minds and bodies of Muslims. Many Muslim women are the direct descendants of victims of historical events associated with war and colonialisation. This is important as it connects to my work later in the thesis around intergenerational trauma and keeping that in mind as historical context and bearing in mind the ongoing effects on physical and mental health. The example is of the violence that took place against Muslim women due to the forced Punjab migration of 1947 that was a consequence of the literally bloody mess left by Britain's' colonial movement. These are stories of Muslim women that are generally unheard of in Western history. The months from August 1947 to December 1947 were a dark period of history during which most of the massacre, ethnic cleansing, rape and kidnapping of Muslim women took place (Kiran, 2017, p.161,162).

These atrocities were about power and domination where women, as always, were considered an easy target in the war; a tragedy where the weapon of mass destruction (during this colonialisation period and its consequences) was rape, which literally leaves a legacy of trauma on the body and in particular the pelvic area and what the womb space means for women. This relates to the experiences I mentioned in chapter one of working with Muslim women who were carrying intergenerational experiences of trauma that included a history of sexual abuse. There are of course many such experiences that are not spoken of or documented enough, another example of the legacy of historical trauma that has a particular connection to British

Muslims is that of the Amritsar massacre in 1919 as many of the Muslim population in Britain migrated from Punjab. There are countless examples and stories which would be impossible to cover in this thesis.

Some of these troubling stories, are loaded for some with dishonour, shame and humiliation, as well as not having the language to talk about such horrors and traumas which remain unspeakable. These incidents, poorly documented by historians, rely on oral narration and the efforts of individuals like Kiran (2017) who talked to women and sought out archives to bring to light their stories. In many languages there are no equivalent words for trauma or depression – how could they even begin to relay their horrific experiences in a way that would be understood? There were many Muslim women abducted who did not feel ready or able to go back and join their families in Pakistan due to shame (Zamindar: 2008, 7 in Kiran, 2017, p.172); the loss was unimaginable. The reason why these stories are significant are because these women who were carrying these grave traumas imprinted on their bodies and minds went on to have other children whilst retaining this trauma within. Some were pregnant as a result of rape at the time and went on to give birth to and raise those children without the child ever being told that painful legacy. Some of these women were 'recovered', as Kiran (2017) states, and brought back to their families in Pakistan. Some of these women – or the next generation –eventually migrated to Britain. Papers such as Kiran (2017) are critical as the minority (women) within minority (South Asian Muslim) voice bringing light to such events using primary source material. Kiran (2017, p.163) highlights the epic tragedy (referring to the Punjab violence in 1947 and how it *"changed the destiny of thousands rather millions of women who had not been given centric position in the historical analysis".* She further expounds that a reason being an *"unwillingness of female victims to share their traumatic experiences with the strangers"* (p.163).

Traumas such as these are significant because they provide a historical backdrop to Muslim women in Britain's context. The divide, rule and conquer that came with the colonial agenda in Asia, created a religious ideology-based divide amongst communities that were living in harmony. This period of rule by the British in India became a war about philosophical ideologies about Islam and the West. Pakistan was created for Muslims; the human dimension of the historical discourse that gave 'birth' to Pakistan has brought to light the fact that Muslim women's sacrifice to achieve independence was far greater than has ever been credited.

3.4.7 The neurobiology of trauma - a colonialised people.

It is perhaps useful to think about the above section and the stories in terms of the neurobiology of trauma and how that violence and fear shapes an individual and potentially effects their experiences and health. For that I would like to draw on Bruce Perry seminal work 'Incubated in Terror: Neurodevelopmental Factors in the 'Cycle of Violence' (1997). It is crucial to understand the impact of violence and '*the origins and impact of interpersonal violence'* how it affects development and health, as Perry (1997) states the importance of appreciating how that violence alters development. Experiencing terror and violence on the body whether adult or child locates someone in a position of vulnerability. According to Perry (1997) humans develop what he calls a 'use-dependant' function - growing, organizing and functioning in response to developmental experience. .This was another reason why I felt documenting experiences was so critical a part of the overall story of my thesis. Experiences of violence could also include such as those mentioned in section on 1.6.4 and 1.6.5 on racial and systemic induced trauma and obstetric violence which could be impacting the baby as well as the mother. We need to think about how the experiences during pregnancy and birth can be felt by the baby also and keep in mind the potential ongoing impacts this could have developmentally on physical and mental health.

Yehuda and Lehrner (2018) review the research evidence of the intergenerational transmission of trauma effects and the possible role of epigenetic mechanisms in the transmission. They suggest that epigenetic changes associated with a preconception trauma in parents may affect the germline, and impact fetoplacental interactions (Yehuda and Lehrner, 2018). Furthermore, they suggest that intergenerational trauma may result from developmentally programmed effects which can result from the influence of early environmental exposures, including postnatal maternal care as well as in utero exposure reflecting maternal stress during pregnancy (Yehuda and Lehrner, 2018).

How do we make sense of and keep in mind the multiple layers of violence, from the broader epistemic violence to the individual and personal violence experienced? For example, in thinking about the intergenerational consequences of trauma, an event such as the 1947 massacre, violence, ethnic cleansing and rape of Muslim women is less than 100 years old in history. There are people still alive today who witnessed or directly were victims. So how do

we make sense of all of the violence that surrounds us especially that enacted on the body of women - Muslim women in this case for the purpose of this study.

Perry (2001) states, there is institutionalized violence, violence in behaviours, violence in ideas, violence in words. Here we can see how the application of neurobiological science meets the impact of intellectual genocide – epistemicide; the destroying of stories and knowledge and not giving voice to them as well as the terror imprinted on the physical and mental lives of individuals and the collective consciousness of particular communities. Malik (2019, p.13).

What is of deep concern is how Muslim women's expression of pain and suffering are being responded to using derogatory terms such as what has come to be known as the 'begum syndrome' or 'bibi-it is'. As Ali (2020) states: *"the term (bibi-itis) serves as an example of casual clinical stereotyping that can cause unrecognised bias leading to missed diagnoses, delayed treatment, and preventable unwanted outcomes".* Kmietowicz et al., (2019) highlighted a similar term being used to stereotype south Asian woman presenting with 'non-specific' pains, the 'begum syndrome': *"there are well known stereotypes such as Bibi syndrome or Begum syndrome which are often colloquially used to describe South Asian patients with non-specific complaints. These only serve to undermine patients and as this article points out contribute to health inequality".* Instead of disregarding and dismissing the health concerns Muslim women may be presenting with, in a way that may not be familiar to the medical system currently, it is crucial to understand what is going on. What is the communication of and behind the pain? How has their neurobiology been affected and how does this connect with expressions of ill health?

If there can be more curiosity about the manifestation of pain, there may be more opportunity to engage with providing genuine helpful support, possibly meaningful solutions and healing. One possible line of enquiry could be to think in terms of unconscious trauma that can be held in the body, and which can feel hard to name. Labelling suffering with derogatory devaluing phrases perpetuates original wounds that may be located in colonial and post-colonial trauma, discrimination and their multifaceted fall outs psychosocially. The response to trauma and expressions of 'medically unexplained symptoms' need to be re-evaluated, keeping a whole picture in mind that does not include just the physical or neuro-biological but understands the psychological, social, cultural, colonial and historical factors that contribute to making people unwell. How are these experiences potentially rooted in or associated with violence shaping

Muslims and importantly how are these experiences modified and made sense of within a faith-based context? How does the faith act as resource for overcoming trauma and in healing? These ideas have been explored in the empirical study.

3.5 Islamic ontology

Arriving at the possibility of applying an Islamic ontology to my PhD thesis in Health psychology was an unexpected discovery for me but one I realised had all sorts of potential for something unique and meaningful. Before I started my PhD journey it never occurred to me that it would be possible until I began looking into decolonising research. All I knew was that I needed to be looking at Muslims experiences from a particular non-Western secular education only lens. As a Muslim it is incumbent upon me to be seeking knowledge and to use the most appropriate research methods and methodologies in the process of discovery and knowledge seeking. This would be the case even when I am not pursuing formal academic studies. Thus, I drew on my ideas of knowledge seeking rooted within an Islamic paradigm that helped me arrive to the methods I eventually used. As Dhaouadi (2013, p.15) states, *"A Muslim researcher would logically consult the Qur'an… to further explore the transcendental nature of human intelligence".* It is therefore part of the natural process that a conscious Muslim academic rooted in their tradition would seek to contextualise their research paradigm.

The process of trying to make sense of phenomena and experiences can be an anxiety inducing one of not knowing, especially in the context of a lost or robbed intellectual heritage. It is useful and necessary to have an understanding of one's positioning in ontology to provide a container for the messy art of thinking, all the while remaining open to constructive and thoughtful reflections about that knowledge and what it means relationally. Martin and Mirraboopa (2003) discuss the importance of this awareness in terms of ontology:

> "It is through ontology that we develop an awareness and sense of self, of belonging and for coming to know our responsibilities and ways to relate to self and others". Barbara Thayer-Bacon refers to this as relational ontology and writes: A relational (e)pistemology, which is supported by a relational ontology, helps us focus our attention on our interrelatedness, and our interdependence with each other and our greater surroundings" (Martin & Mirraboopa, 2003, p.206).

This interrelatedness through the recognition of our interconnectedness is apt for a study with British Muslims; a community that at its very essence and ideology is based on one of 'ummah', meaning one body/family/community in the Arabic. An interrelated word is the word for

mother - ‘Umm’, as defined in the Arabic. This is relevant given the broader aim of the overall thesis looking at birth and inevitably motherhood, family and connections.

There was no existing methodological framework with a neatly drawn-out map or guide for bringing these ideas together - from ontology through to methods. It was not as simple as using one ideology for example, phenomenology or narrative theory. This thesis needed a piecing together approach which required some creativity in drawing different parts together to create a whole. Another core idea in the construction of knowledge in Islam is to utilise the embodied experience of wisdom. In order to understand Islamic ontology, it is important to state here that there are two forms of knowledge.

The Islamic understanding of knowledge (ilm in the Arabic) is understood as; revealed and derived knowledge. Azram (2011) elaborates on these two forms in his paper on ‘Epistemology- An Islamic perspective’. The first is ‘Revealed knowledge’ also known as Al-Wahy in the Arabic. The two main attributes of this type of knowledge are *‘instinctive’* (‘fitra’- the innate pure disposition that one is born with i.e., what one innately knows – similar in nature as ‘gut-sense’ or ‘feeling the heart’) and *‘revelation’*; that which was revealed through divine revelation, immortalised in the Qur’an, and Hadith. Part of this divine knowledge are two important concepts known as ‘fikr’ (reflection) and ‘dhikr’ (contemplation and remembrance of God and the signs of God in Creation). In dhikr we remember and contemplate on God and the miraculous signs of nature, which cause us to naturally be in a state of ‘fikr’- reflection-thinking, pondering, wondering about the nature of things, which may lead to searching or ‘research’. This is embodied in the Qur’anic verse:

> *“Verily, in the creation of the heavens and the earth, and in the succession of night and day, there are indeed messages for all who are endowed with insight;…[and] who remember God when they stand, and when they sit, and when they lie down to sleep, and [thus] reflect on the creation of the heavens and the earth: “O our Sustainer! Thou hast not created [aught of] this without meaning and purpose. Limitless art Thou in Thy glory! Keep us safe, then, from suffering…” (Qur’an, chapter 3: verse 190-191).*

Human beings are implored to reflect, to think; to continuously be seeking knowledge. The process of creation, the womb and knowledge are deeply intertwined:

> *“ And God has brought you forth from your mothers’ wombs knowing nothing – but He has endowed you with hearing, and sight, and minds, so that you might have cause to be grateful.” (Qur’an, chapter 16: verse 78).*

This verse teaches that though a baby is born in a pure form (fitrah) without 'knowledge', it is by the grace (Rahmah- also related to the root word for womb- rahm) of God that humans are given faculties to engage with, to understand the signs of creation, and to be in a state of gratitude for what has been provided. Humans are encouraged to 'seek knowledge from the cradle to the grave' and to go as far as China. The reference to China is metaphorical, it means we should travel to the ends of the globe, be limitless, geographically and metaphorically in mind, in pursuit of knowledge. These are well established and known, infamous hadith of the Prophet Muhammed (pbuh).

Moving on to 'derived' knowledge, which can also be understood as acquired. It is understood that this knowledge as all knowledge is from Allah as the human mind and faculties are God given. However, humans use Islamic 'methodologies', ethics, and their faculties through their senses, research and deep thinking to acquire 'worldly' knowledge (Azram, 2011, p.181). Hence all knowledge is connected to the sacred. Ogunnaike (2019) elaborates on this connection:

> "In traditional systems of education knowledge was always connected to the sacred, was connected to piety, to know more was to be more and to be better and so piety and the development of virtue and ethics was always a part of education. Teaching someone without training them in virtue is like selling a soul to the thief" … "knowledge is powerful and connected to virtue and teaching someone without it is dangerous". (Oludamini Ogunnaike, 2019)

Education and all forms of learning and knowledge seeking are processes of developing and cultivating virtue. It is after all a divinely connected and driven endeavour. Azram (2011) expounds on the oft repeated notion that Humans are placed as vicegerents of God on earth. With this comes a great sense of responsibility and duty of care to all of creation and a duty to make use of knowledge to achieve a greater understanding of the physical and spiritual realms. He further extrapolates that, *""Khalil has…rightly observed that: "Muslims cannot carry out their functions as vicegerents or obtain sufficient guarantees and assistance to enable them to achieve their objectives of perpetual progress unless they use scientific research methods and methodologies to discover the laws of the world, nature, and the cosmic system."* (Azram,2011, p.185). Azram (2011) continues by stating that talking on this matter would be futile without referring to and comprehending Faruqi's (a scholar of Islam) integrated view on (hu)man's, knowledge and purpose of life:

> "Allah (SWT) has appointed him (referring to the human) to achieve two objectives. First, humans should transform creation into Divine patterns, i.e., to rearrange its materials so as to make them fully and beneficially serve human needs, which are materials (food, shelter, comfort, procreation) as well as moral intellectual, and esthetic. Second, in the very act of transforming creation, humans need to give substance to ethical values by choosing to enter into those acts of transformation in an ethical way, i.e., in a way that fulfills the requirements of devotion to Allah (SWT) and justice to mankind". (Azram, 2011, p.185).

3.5.1 Conception of Methodology

On methodology, Bakra (2012, p.13) calls for our special attention to the question of methodology stating that there are fundamental differences between the conception of methodology of science in Islam, (or for that matter in every other traditional civilisation such as Chinese or Indian) and that of the conception of methodology in modern science. He states that even the way we look at Islamic sciences in the modern world is through the lens of the modern 'scientific method' as if a universally applicable 'yardstick' of the scholarly community (Bakra 2012). Islamic sciences have always been pluralistic and not exclusive in the adoption and application of different methods in *'accordance with the nature of the subject in question and modes of understanding that subject'* (Bakra 2012).

I found it restrictive and disempowering how ideas of science, research, and knowing seemed so limited and tightly bound with particular conventions yet presented as the ultimate and superior way of knowing. I know from Islamic education that there is a lot more diversity and pluralism in knowledge but the Western mirror to me tells me Islam is backward and has no place in society creating this internal discomfort where one knows what feels right and true but having lost much of our own traditions, ways of knowing and conducting research through epistemicide. This process creates some self-doubt and uncertainty and perhaps even insecurity that is instilled through the education system that only certain ways of knowing are superior and best. It is no wonder that countries that have been colonised have internalised the message that the West is best and to be of significance and accepted they must follow. However, in the process everyone loses out on a diversity of knowledge and experience. Ultimately there is a limiting of knowledge restricted to this 'yardstick' Bakra (2012) highlights.

Bakra (2012) also discusses the idea about the history of the single methodology of science having been demolished 'over the last decade' and the idea of a pluralistic methodology gaining

currency amongst contemporary historians and philosophers of science. Interestingly, to the extent where some have begun *'accepting scared scriptures as an integral component of this pluralistic methodology'.* One attempt to decolonise disciplines has been some 'Islamisation' processes in an attempt to reclaim, redefine and re-own concepts and sources that may have been distorted through history, colonialisation movements, 'ethnic' cleansing and or lost concepts, such as of the recent resurge in Islamic finance and Islamic Psychology where Muslims are looking for answers to questions and problems within the context of their worldviews. The idea is to look at the disciplines from within an Islamic ontology, to apply or reapply or go back to the roots of the founding principles and ethics for example of Islamic finance or understanding of the human psyche through an Islam based ontological view. For my study this means looking at what is meaningful for British Muslims and part of that may be Islamicisation and part may be creating new ways rooted in Islamic tradition. I have taken it as an overall philosophical approach to the topic rather than application of a specific methodology.

3.6 Reflexivity and soul searching

> *"To be reflexive is to have an ongoing conversation about experience while simultaneously living in the moment…."* (Etherington, 2010).

In my search for methodologies, I came across work on indigenous communities decolonising and reclaiming their spaces through reflexivity which helped me to understand that my work had a place and that I could do some of this through reflexivity too:

> "Reflexivity in research design affords the 'space' to decolonise western research methodologies, then harmonise and articulate Indigenist research. Reflexivity is a process that allows us to work … with relatedness of self and Entities. Reflexivity challenges us to claim our shortcomings, misunderstandings, oversights and mistakes, to re-claim our lives and make strong changes to our current realities. Being reflexive ensures we do not compromise our identity whilst undertaking research" (Martin & Mirraboopa, 2003, p. 212).

Papers like Martin and Mirraboopa (2003) lent much needed guidance in framing this thesis. I was able to find support and much needed validation in the struggle of these fellow researchers trying to work authentically to reclaim narratives within a frame, that was representative of their worldview, and that of the communities they would work with. This was a crucial and necessary element of my research process.

I often felt constrained by the reductionist elements, limitations and expectations of health sciences and writing in this context. I recognised that my writing changed as my ideas developed and my confidence grew through gaining more knowledge. At the outset, for example in writing the systematic review, I was unable to centre decolonial and Islamic ontology from as I had not yet come across these ideas hence my writings may at times seem contradictory, though it was part of my development as a researcher discovering a decolonial approach. Whilst I was able to take some ideas from balance some 'reactiveness' with really owning your methods and approach. This is incredibly difficult and a real point of tension, which you do well given constrained circumstances. But we'd really welcome you reflecting on this process more deeply. Without this reflection, the thesis reads a little contradictory at times – whereas as part of your reflection we imagine you might talk about these seeming contradictions and how hard this has been to navigate.

I did go through considerable soul searching and exploration to discover what would be the best, accurately representative, and authentic fit currently available to work with. This required creatively thinking, looking for jigsaw pieces that I was not sure existed in the first place or even where to find them. I could not see myself, my community, our worldviews and ontology represented in the field of research I sought to study. Thus, the enquiry into the nature of knowledge became a pivotal one in an attempt to re-search and re-present our world views and realities as the basis for authentic indigenous academic endeavour. I was able to draw on others work to create guiding principles for my study which are discussed below.

3.6.1 Creating and establishing guiding principles for the study

Martin (2003) puts forth a position for her research, arguing that she will actively use the strength of her aboriginal heritage and will not position herself in a 'reactive stance' of resisting or opposing western research frameworks She further adds that she will view anything western as 'other'. Furthermore, she argues that Indigenist research must centralise the core structures of its own ontology if it is to serve well, arguing that without this what is happening is 'western research done by Indigenous people', and not honouring the ontology that we relate to. I think in my own journey I sometimes may well have worked in a way where there was some 'reactiveness', initially at least. It took some navigating to balance this with also towards the end of my PhD journey owning my methods and approach. However, I did not perceive

everything 'Western' as 'other'. My identity includes a hybrid of 'Western'. I recall a comment about how my research could be seen as resisting. I thought about this many times since, especially as I did not feel this way at all. I did not perceive it so. I came to the conclusion that it was as if my existence was resistance – to others. For me, I was just being, just existing as I am, as do others. It is because I 'bring difference' and embody the pluralistic knowledge that I share, that I may come across as resisting. It is not a narrative I own or connect to. I believe it is possible to bring multiple ways of knowing to the table and they do not necessarily have to be contradictory or resisting even.

Martin (2003) purports four guiding principles for her work which are in in part drawn from the work of Lester. These principles are:

> *"• Recognition of our worldviews, our knowledges and our realities as distinctive and vital to our existence and survival;*
>
> *• Honouring our social mores as essential processes through which we live, learn and situate ourselves as Aboriginal people in our own lands and when in the lands of other Aboriginal people;*
>
> *• Emphasis of social, historical and political contexts which shape our experiences, lives, positions and futures;*
>
> *• Privileging the voices, experiences and lives of Aboriginal people and Aboriginal lands." (Martin, 2003, p.205).*

I have in turn drawn upon and adapted these and formulated the guiding principles for my work within my British Muslimness and in line with Islamic ontology and teachings as the researcher of this study:

> • Recognition of our worldviews, our knowledges and our realities as distinctive and vital to our existence and survival;
>
> • Honouring and contributing of our social mores and values as essential processes through which we live, learn and situate ourselves as British Muslim people.
>
> • Emphasis of social, historical and political contexts which shape our experiences, lives, positions and futures;
>
> • Acknowledgement and awareness of subtle and obvious psychological impact and trauma as a post-colonial people and an internationally persecuted faith community.
>
> • Privileging the voices, experiences and lives of British Muslim people.

In terms of reflecting on how we are 'seen' and who we are, I wondered are we always seen through the eyes of the other reflecting back, how does this shape our reality? does it change our reality? how do we separate out from that? or are we always embroiled with each other? It would remind me of a strongly emphasised oft repeated verse from the Qur'an- 'A believer is a mirror onto their fellow'. This teaching is often used to help people think about what they are internalising and or projecting, and as a concept in Islamic psychology. I feel this metaphor is helpful to think about what we internalise including the negativity and projections around us and to root out that which does not accurately reflect our true experience – this includes secularised methodologies that do not reflect or represent all world views. The idea of this verse is to offer a genuine reflection to help growth. I would like to apply that method in this study particularly in terms of the philosophy underpinning this work. I would ask myself constantly, how do I bring the unique or different ideas in my mind into reality, how do I express them in a way that fits the current paradigms - they did not always. Hence, I had to stretch myself out of my comfort zone of what I thought I knew, both from an academic perspective and my own 'hybrid' evolving self as a British Muslim and woman in a fast paced constantly changing globalised world. To do that, as Grégoire (2018) highlights, it is important to take into account the factors that may 'put brakes on creativity'. Some of these brakes will be considered throughout this process and continued through self-reflection in the meta discourses. Some have already been mentioned above in terms of structural ideas about superiority of research ideologies and dilemmas about going against the beaten path.

3.6.2 The colonialised mind

It is all too easy for researchers to ignore the underlying impacts of the legacy of colonisation and its discourse on indigenous communities as 'deficit' within their research contexts, thus inadvertently perpetuating these effects. As I looked for models to help me, I found gaps and during my search I found the paper by Malik (2019) that was useful and meaningful for me as the researcher of my study, as it was difficult to find research to draw on from Muslim academics that are social scientists and also well versed in Islamic traditions and history, and the papers are of a 'rigorous academic quality' which was the expected convention of a PhD in a Health Sciences school Did not sit well with me. This dilemma led to me grappling in this journey between what felt authentic and accurately more appropriate, and conventions of scientific approaches to academia within the school I was in. These dilemmas would not have been presented in the same way in another discipline.

However, it was these very dilemmas and the uncomfortable sense they created that shaped the evolution and development of my own writing as I became more confident with understanding and applying the decolonising approach more. I found it personally challenging not being able to find the kind of literature and philosophies that I was looking for especially given that previous generations of Muslims were at the forefront of contributing to medicine, philosophy, psychology, architecture, and governance among other areas. It was further frustrating that the bits of information I did find were not in a medium (peer reviewed journal articles) that was expected of my PhD. I did end up excluding potential material because of this and my worry that I would not pass my PhD.

However, I did find it helpful in forming my thinking to look at indigenous ideas around research (such as those of Martin and Mirraboopa 2003, Zavala 2013, Ogunnaike, 2019, Simmons and Christopher, 2003) and draw some guidance and hope from the similar challenges some of these scholars share. I recognise the differences and that though some of the thoughts seem to hold synchronicity this may not translate in real life contexts and practices. Once such example that drew me in particular was the idea that 'we belong to the land' and not that the land belongs to us. This is very much in keeping with Islamic thought in multiple areas, one being the concept of tawhid (unity and oneness not just of God but an integration and connection to the wider ecology) as well as how in the Islamic tradition even a tree is not to be cut without reason and consultation. Indigenous scholars' thoughts and ideas were closest and resonated most in my research process. This process also led me to include the section on what the Qur'an relays about pregnancy and birth as it was an important inclusion of Islamic ontology and epistemology.

Without the process of unravelling my own colonialised mind shaped by the particular expected conventions of academia I would not have been able to take the courage to do this. I very much recognise what may appear is a dissonance in parts of this thesis though I have tried to mitigate it where possible, it reflects that initial journey and conducting a systematic review before coming across decolonial ideas. I found myself writing and justifying in a 'reactive stance' (Martin, 2003) at some points on my journey, using the language I used from academia to justify my choices of using what may be considered 'alternative approaches'.

This was creating discomfort within, and I was struggling deeply about how to navigate this. As I continued to seek knowledge and learn on this journey and became better informed, I was able to be bolder and firmer with my choices and adapt my language accordingly. In fact it was learning from scholars such as Martin (2003) that gave me courage to re position myself and thinking away from a reactive stance. During this process I also came to reflect on ideas of resistance that came up in a conversation regarding my thesis. I realised from this comment that my very existence and just 'being', may be considered by some as resistance, for me it is simply existence. It is only resistance if more than one way of knowing and doing is perceived as being split off, not part of a whole way of knowing and understanding, not accepting the pluriversity of experience and knowledge.

Malik (2019, p.12) discusses this and how *"the secular epistemology that lay at the heart of the Enlightenment era became a driving force for the destruction of knowledge systems of other cultures and societies…occurring parallel to political imperialism was a process of intellectual colonization".* He also highlights the universalising of science, as it was being secularized and developed in the Western world during the Enlightenment era, along with naturalist philosophy, which were *"projected as universal and the only valid way of analyzing the world"* Malik (2019, p12) states that Western scientists became as integral to the colonial project as the military official, leading to intellectual genocide. This has left a lasting imprint in the individual and collective bodies and minds of Muslims for 'generations. Decolonisation is now understood to be more than the handing over from government, it recognises the *"long-term process involving the bureaucratic, cultural, linguistic and psychological divesting of colonial power".* (Pihama, 1993, p.98, cited in Riche, J., 2014).

While knowledge production and science from other cultures and societies were being mythologise' into stories and folklore, science coming from the West was being claimed as universal; hence, science became a means of intellectual colonization. The minds of the non-Western world were being colonised beyond physical borders. The loss for the Muslim world includes how this intellectual colonisation process gradually led to the replacement of the integrative and holistic approach to knowledge that was traditionally inherent within the Islamic ontology, being replaced with a secularized knowledge system that was 'fragmented, reductionist, and materialistic' (Malik, 2019). This has led to multiple problems but particularly - as I can see in the context of my study - the relevance of this point to research methodologies

for example and how it is difficult to find an exact Islamic methodology because the investment has been lacking to develop these fields as was once the case. The:

> "blind imitation of the Western world has prevented the Muslim world from continuing to develop its own models of science and knowledge systems that reflect Muslim cultural identity the re-Islamization of knowledge is not simply the process of glorifying the heritage of great Muslim thinkers that lived many centuries ago; rather, it is the development of an Islamic epistemology that creates a unity of knowledge, where all branches of learning connect back to the fundamental reality of the Oneness of God (tawhid)" (Malik, 2019, p.21).

This is an important contribution that Malik (2019) makes in highlighting the psychological dynamic that has occurred in the Muslim world with a resurgence of Islamicisation. For example, in the fields of Islamic finance and Islamic psychology attempts are being made to reclaim and understand how Islam offers models of knowing for these areas not just for Muslims but for humanity. Despite these attempts there is still significant work to be done and the fields and many other disciplines need developing. The period of grief and loss is not over; the romanticisation of a past gone by is still held on to which prevents us from moving forward to develop new approaches for our current context, though individuals are now critically engaging with these concepts. To date, part of the dynamics that have held us back have included reactionary literature focusing on polemics. However, what may be part of the healing process, could include more works such as offering conceptual frameworks through Islamic ideas which can be tangibly implemented within knowledge production and education (Malik 2019, p.21, 22).

Following Malik's (2019), I hope to contribute towards integrating an Islamic ethos within my field of knowledge. As the researcher of this study, I hope my attempt to at least highlight the importance of integrating an awareness of and being mindful in application of the backdrop of colonialisation and the context of Muslims has allowed some tiny dent to be made in that attempt to integrate, and I would say, reclaim and honour the lost heritage of an Islamic ethos for its relevancy and appropriateness in research.

For Zavala (2013, p.1) decolonizing research strategies are "*less about the struggle for method and more about the spaces that make decolonizing research possible".* This is very important point to think about in how and where I do my research and what space that occupies and what it means for the participants of the study. Ritchie (2014, p.3) states the benefit of' "localised, context-specific Indigenous ontoepistemologies" that have emerged over many centuries as

"each particular group of people learned to live closely in relationship within their specific ecologies. At the heart of this relationality is a sense of spiritual interdependence with the more-than-human world" (p.3). For many Indigenous peoples, knowledge is also seen as spiritual, to be exercised in service of survival of both human and more than - human co-habitors, the purpose of gaining knowledge being "to nurture and regenerate the world" (Kincheloe & Steinberg, 2008, p. 151, cited in Ritchie, 2014, p.3,4). These ideas are in alignment with Islamic ontology and the Muslim psyche which at its essence is a model of unity (tawhid in the Arabic as mentioned above) one that recognises the place of humans in connection with the wider creation where everything including for example ants have rights (An entire 'chapter' of the Qur'an known as Surah Naml – the ant is dedicated to their story) and there is a critical focus on justice and equity as Muslims are taught in the Qur'anic teachings to continually be striving for balance despite the battle of the mind, egos, desires, one is encouraged to seek justice 'even if it be against the self' which means to take oneself to account in the wider ecosystem.

Indigenous onto-epistemologies are a potential source for restoring our damaged relationship with the more-than-human world as Ritchie (2014) states. *'Their knowledge about respecting and healing the Earth can be used to counter the destructive effects of Western science on the Earth (Denzin & Lincoln, 2008b, p. 26) (see also Kincheloe & Steinberg, 2008)"* (Ritchie, 2014, p.4). The centrality of spiritual interconnectedness at the heart reinstates focus or direction in our relationality with as Ritchie (2014) phrases it – "the more-than-human world". I believe as Ritchie (2014) does, that scholars, researchers, academics have an ethical obligation to share responsibility for bringing back and helping to restore indigenous knowledges that can benefit all of humanity. This is a process of decolonisation that:

> "transcends interrelated individual and collective, personal, professional and political realms. It is also intensely emotional, since extending one's paradigmatic interface to embrace a(n) Indigenous onto-epistemology/ies require(s) the intimacy of an emotional connectedness that allows empathic passion" to enter one's relationships" (Kincheloe & Steinberg, 2008, p. 139, cited in Ritchie, 2014, p.4).

This may be difficult for some people, as we are required to shift our worldviews in seriously challenging ways: away from individualistic, linear, hierarchical, authoritarian, patriarchal, compartmentalised, white-privileged complacency, to an unsettled, contingent, relational, spiritual and emotional space, to work within a "cultural interface" (Martin Nakata, 2007, in McGloin, 2009, cited in Ritchie, 2014, p.4). If we are to be agents of social, cultural and

ecological justice, we need to understand the dynamics of local/global Indigenous movements (Kincheloe & Steinberg, 2008, cited in Ritchie, 2014). It is crucial to position ourselves as being in service (*Khidmah* in the Arabic) repairing the world, and that recognising and utilising local and Indigenous knowledges as integral to this process. (Kincheloe & Steinberg, 2008, cited in Ritchie, 2014).

Indigenous research is part of much broader struggles for decolonization; a decolonization that has only been partially and precariously achieved and is therefore still ongoing. Indigenous peoples are no longer simply the objects of other peoples' research and gaze and are acting as self-determining subjects, in all spheres including in research, in universities and other institutions of higher education. Chief Dan George (2001, cited in Coburn et al., 2013) stated that importance of Indigenous scholarship why it matters so much because it is *'one way of proclaiming our cultural worth – both to a colonial society that has sought our deaths as peoples and to ourselves as we reclaim and renew specifically Indigenous ways of being, knowing and doing'.*

3.7 Conclusion

This chapter has explored the underpinning philosophy for this study through the need for employing a creative approach, Moreover, it has considered in depth the historical context, decolonising methodologies and the impact of colonialism and epistemicide. I also explored western domination of science and the idea of objectivism and pitched this against the importance of 'connectivism', particularly in an Islamic ontology frame where connection and unity are central tenets. Furthermore, I explored the 'crisis of values' and enmeshment of knowledge in Western science and in the Muslim world, research models alien to socio-religious realities of the Muslim world with a historical example of the legacy of colonialisation on Muslim women's bodies, the neurobiology of trauma of a colonialised people and a look at the colonialised mind. Islamic ontology was discussed, closing with reflexivity, and creating and establishing guiding principles for the study. Scientific ideas around methodology were discussed in order to engage critically with the research process and how it is conducted, helping us to reflect on choices we make regarding methodology and being considerate of how relevant these are to the context of understanding Muslims' experiences.

The next chapter (four) details the methods that will be used for the empirical research mindful of the historical backdrop for the need to decolonise methodologies. All of the ideas discussed in this chapter informed my work and came under the umbrella of a decolonising lens, which gave me the platform necessary to state and argue the need for the position I took. The decolonising lens helped me to choose the most appropriate methods available to me as a researcher in health psychology.

Chapter Four: Mixed Methods Study and Ethics - moving from theory into practical considerations and applications.

"Qualitative research is about meaning and meaning-making, and viewing these as always context-bound, positioned and situated, and qualitative data analysis is about telling 'stories', about interpreting, and creating, not discovering and finding the 'truth' that is either 'out there' and findable from, or buried deep within, the data."
(Virginia Braun and Victoria Clarke, 2019, p 591)

The methods section is embedded within the conceptual framework of the decolonising approach as discussed in chapter three. This section outlines the specific *context-bound* methods used and the research design, how it is positioned and situated in relation to the original research question which as a reminder is: *What are British Muslims experiences of pregnancy and birth?* Further to laying out the design, this chapter presents the ethical considerations, sampling and participant recruitment processes, the setting within which the research took place, materials used, the processes of conducting the surveys and interviews and discussion of the method of analysis. The analysis tells the *'stories'* through interpreting and creatively engaging with the data [4]. The word data is used instead of 'findings' to refer to the information gathered through data collection.

The aim of the empirical mixed method study was to gather, document and understand what the experiences are of British Muslims' during the perinatal period. Questions were asked which were developed following the insights from the themes in the systematic review.

The objectives of this empirical research were to:

- Acknowledge and understand the health inequalities (including the impact of racism and Islamophobia) Muslims' experience during the perinatal period specifically.
- Raise awareness of intergenerational trauma and the multiple intersections that impact Muslims during the perinatal period.
- Present and platform voices and nuanced experiences of Muslims experiences of pregnancy and birth in their complexity and context to gain some insight of what is happening for Muslims' during pregnancy and birth.
- Highlight the needs and wishes of British Muslims' during the perinatal period to healthcare professionals and for the Muslim community.

The objective of utilising the qualitative online survey method was to gain a wider reach of participants thus capturing a broad range of experiences. The objective of the interviews were to provide an in depth insight into individuals stories and context.

4.1 Research design

The overall study has employed a data driven qualitative mixed methods design with online surveys (Part I) and in-depth interviews (Part II) with British Muslims to explore their experiences around pregnancy and birth. The survey responses were analysed using Reflexive Thematic Analysis (Braun and Clarke, 2019a, 2019c, 2020) and are presented in chapter five. The interview responses were analysed utilising Narrative Inquiry composite case studies (Polkinghorne, 1998, Orbach, 2000, Wertz et al., 2011 and Willis 2019), presented in chapter six[1]. 42 survey responses were received, and four interviews conducted.

Braun and Clarke (2019c) produced a guideline for reviewers and editors for evaluating thematic analysis manuscripts. They state that they *"regularly encounter published TA studies where there are mismatches between various elements of the report and practice"* and therefore they have developed the guide for editors and reviewers, *"to facilitate the publication of coherent and quality thematic analysis – of all forms. The checklist is split between conceptual and methodological discussion/practice and analytic output"* (Braun and Clarke, 2019c). I used this guide for my empirical study as a 'checklist' to ensure I was reflective of the choices I made and how. The questions asked in this guide are worded open and reflectively making it thought provoking and requiring significant interaction before and throughout the process of data analysis. I add a column for notes to explain how and where I have adhered to or diverted from the guide and my reasons and what page this can be found in this thesis for ease of reference. This evaluative guideline table can be seen in appendix (8) along with my responses with references to the page numbers on which the information can be found. The discussion of the processes of the six phases: Familiarisation and Coding (Phases 1–2), Theme Development (Phase 3), Reviewing and Defining Themes (Phases 4–5), Producing the Report (Phase 6) and how I adopt them form the last section of this chapter 4.3. This follows after the practical descriptions below explaining the processes of ethical considerations, sampling strategy and

[1] I chose to present the interview analysis in a separate chapter due to the sheer volume of data across the two (surveys and interviews) which needed to be divided into two sections for readability and as analysis in their own right.

recruitment, participants, setting, materials, data handling and storage, data collection and data analysis.

4.2 Sampling and participant recruitment

Participants for both studies were recruited through the methods of professional contacts, through WhatsApp networks and groups in the Muslim community (there are many thousands of groups and I did not place a limit on where contacts shared further and in what groups, it was up to individuals to decide if they thought it was something they wanted to share further) The recruitment notice was also shared through various social media platforms; Twitter, and LinkedIn targeting the British Muslim community. Part of the recruitment message included permission to share forwarded where deemed appropriate. The snowball effect intended to reach a wider participant base. Using several different avenues for recruitment allowed for a wider dissemination of the study information, for more people in the British Muslim community to access and know that such a study was being conducted and therefore allowed for a wider range of people to be recruited into the study. The recruitment advert was agreed as part of the ethical review (see appendix (6) and (7) which include samples of the notice and posters). The first phase was sending the advert out for the surveys. After all the data was collected and the survey closed, a second phase was initiated, calling for people to take part in interviews following the same approach as described above. The only difference being that for the interviews people emailed me and were therefore in touch with me to enquire and arrange an interview, whereas with the first phase of survey participants who wished to take part did so by clicking on the link to the survey directly.

Information about the study and the invitation to take part was also disseminated through key British Muslim organisations – the Aziz Foundation (who are a British Muslim organisation supporting disadvantaged people and communities around Britain and have provided a scholarship for this PhD), the Lantern Initiative, Inspirited Minds, Muslim Youth Helpline, Muslim council of Britain, British Islamic Medical Association and others via social media were approached. Other key contacts were also identified in the British Muslim community such as contacts through mosques. For the interviews (Part II) once people made contact directly with me through the contact email provided (my City University email) they were then sent the study pack with recruitment information and consent sheets. For all the

communications, contact details for the researcher (myself) were provided, for those interested in the study, to find out more. The following details were provided on all communication:

Please contact: Aaliyah Shaikh, Centre for Maternal and Child Health Research, School of Health Sciences, City, University of London. Email: [removed].

A recruitment pack was emailed to those who contacted me to express interest in the study. This included the Participant Information Sheet (PIS) about the study which outlines the objective of the interviews and overall study, the interview procedure, as well as explained and assured confidentiality and anonymity. There was also an informed consent form emailed to each participant asking if they consent to being interviewed and for the interview to be recorded. A demographics sheet was also enclosed. The recruitment packs for both studies were similar and can be seen in the appendix (6) and (7).

After the recruitment pack had been emailed out to those who got in touch expressing interest to take part via email regarding the Interview, I followed up to answer any questions, provide more information, or to organise a suitable date and time and provide the online link for the interview where participation was agreed. For some who were unsure or felt they did not have time, I offered a link to the survey, so people had an option. Participants taking part in interviews were asked to email back the consent and demographics sheet in advance of the interview taking place. They were also asked for consent verbally at the start of the interview. For the surveys (Part I) 35 females completed the survey and seven males (a total of 42). In the Interviews (Part II) two male and two females took part. The total of participants across the different methods was 46 (37 females and 9 males).

Inclusion and exclusion criteria:

The inclusion criteria for both surveys and interviews were the following,

- I identify as Muslim.
- I was born / raised in Britain (or have experience of pregnancy or birth in the British context)
- I am male or female (mothers or fathers, including if you lost a child).
- I am over 18 years of age.
- I or my partner have been pregnant or had a baby in the last seven years.

Interviews were conducted with the study population who were British Muslims (born and raised in Britain or who had experience of pregnancy and or birth in the British context); men and women 18+. The age range was intentionally left open for the widest group to include every adult. Experiences of pregnancy and birth of both women and men were sought giving the widest possibility of engagement for the population of study to share their stories. This allowed for rich nuanced data gathering that would not be possible if implementing more restrictions. These broad criteria allowed for a diverse range of stories and experiences to be shared giving opportunity to multiple voices and experiences to be documented. In one of the eligibility criteria, in brackets, I added: 'including if you lost a child,' so that people would feel included even if they experienced loss at any of the stages. There was a seven-year limit imposed on the sample of how many years had passed since they gave birth or were pregnant. With regards to the time frame since having given birth, initially with my supervisors, we had discussed five years as being the norm for recall purposes in study's similar to mine. However, initially I had wanted to leave it open so anyone could share their story on the topic. We decided to settle on seven years to give as many people as possible the chance to participate whilst at the same time making the results relevant to current clinical policy and practice, as well as being a significant number in Islamic stages of child development (which are understood as seven-year increments). I also felt this was a subtle but powerful connector and was a small but important practical application of the methodology's decolonising approach.

4.3 Setting

Survey: The setting for the anonymous online survey (Part I) was online. I shared the link in the first week it was live and then a second time as a reminder before it was closing while it was still live. The survey began on 1st April 2020 at 12:00 AM and closed on 30th June at 12:00 AM. The link to the form was shared through the methods mentioned above in section on *Sampling and Recruitment.*

Interviews: The open ended semi-structured interviews (Part II) were conducted via online video (with the option of audio chat – so people had an option and could feel comfortable if they were uncomfortable with face to face), though none of the participants who took part opted for this. The portal used was Zoom – a link for which was sent to participants when arranging a time. The time arranged was mutually convenient for both myself as the researcher, and the participant. I was working from home at the time and conducted these at my desk on my laptop.

The participants were also at home given the pandemic and lockdown. The interviews lasted between 40 and 70 minutes. An audio recording was made of the interviews using the record option on Zoom and at the end of the interview choosing the option to save as audio only on my laptop only and not on the server. I chose to save audio only to further protect the identity of participants and because I only really needed the audio for my analysis though having a video interview allowed for better communication and rapport though it was not necessary to save the video for the purposes of my study. Before pressing record, I asked participants for verbal consent again and to inform them that I would begin recording.

4.4 Materials

Prior to the interview, consent was collected by email (via the consent form) and verbally (recorded at the start of the interview), a demographic sheet was also completed (demographic sheet form see appendix (7)) and collected by email, and a semi-structured interview schedule with open-ended questions was used in the interview. In awareness of a trauma informed approach, I was careful in how the questions were framed so that they would be as open as possible, and the language used sensitive along with ensuring people were signposted to support organisations if required. I would manage the process in terms of how I asked the questions and my awareness of the possibility of memory recall being affected by traumatic events and the need for sensitivity with the content being shared and any emotional distress arising. As a trained psychotherapist I was experienced and skilled in supporting conversations and people, mindful of the different ways trauma can manifest.

The questions were developed having analysed the findings of the systematic review and the themes that arose around areas of significance such as the role of mental health, culture and religion. Questions were then created based on these areas. The purpose being to elucidate if these findings could be expanded on further and understood in greater detail and if new insights could be drawn upon through the empirical research.

I began the interviews by inviting participants to share whatever they were comfortable of their story of pregnancy and birth. Most people covered a wider range of topics that addressed some of my sub questions in my interview schedule so at times I did not need to ask and where there was no mention or if things went quiet and there was a natural opening, if it seemed appropriate, I asked the questions as a prompt for further discussion.

The interview schedule can be seen in appendix (11) and was the same as the survey schedule. However, the main difference was as the interviewer I would first ask the main question and then at appropriate moments the remaining were asked, where further elaboration could be sought, or there was space for naturally connecting further questions. Respondents spoke for 40 -70 minutes.

With the survey questions schedule respondents had the option to answer what they wish and leave what they wish so that there was a sense of option and empowerment and control which is an important part of a trauma informed approach that recognises issues of power and control.

Both the survey and interviews consisted of:

- Participant information sheet (with a tick box option to say they have understood and agreed)
- Eligibility criteria (with tick boxes to indicate agreement)
- Consent form (with a tick box to say they have understood and agreed)
- Semi structured open questions
- Demographics questions

All of the above, can be referred to in appendices (8) and (9).

4.5 Data handling and storage

Interview recordings and transcripts were kept on my laptop and City University Microsoft One Drive account back up for the duration of the study and are to be destroyed upon graduation. All data was handled in line with City University policies of retention and destruction of data conforming to the University's' standards. In assuring confidentiality of data, access to computer files were available by password only and stored for back up on an encrypted device (laptop, hard drive, USB). There were no hard copy written files stored. Everything was electronically kept. The data was available for access by my supervisors (SA and GL) on request and through email. The account used for any communication was my City University email.

The online survey method (Part I) allowed for the complete anonymity of participants. I did not meet or know the identity of participants and they were part of a random sample. The survey had no personal identification nor collected any identifiable information. The only possibility was if a participant revealed some personal information in the free text form, but they were made aware of this in the participant information sheet before taking the survey and how this would be handled, if such identifying information was revealed the identifying information would be removed during analysis. Names of hospitals and sometimes names of children were mentioned which I deleted during data analysis and write up.

4.6 Data collection

The online survey (Part I) data was collected through a form using Qualtrics and was accessible via a URL link. It began with the participant information sheet and included how the data would be used. Following this the next page consisted of the eligibility criteria (all items needed to be selected in order to proceed), this was followed by the consent form which again required all boxes to be ticked before proceeding to the questions. There were 17 questions (see appendix (10) with mostly open-text boxes for participants to type their responses at the end of which there was a signposting link for a resource sheet for support organisations. The final page consisted of ten demographic style questions, again a link to the signposting resource sheet and thanking participants for taking part.

In-depth interviews (Part II) were conducted on Zoom and recorded on the Zoom app and immediately saved to my laptop with a coded title so that only I would know whose interview the recording referred to. The interviews consisted of the main open-ended question asking *What were your experiences of pregnancy and birth* and inviting participants to tell their story followed by the remaining semi structured questions that were also asked of in the survey.

The data was collected during a period in the first lockdown of the COVID-19 pandemic, which coincided with Ramadan (a sacred month for Muslims where fasting and extra mindful worship takes place). Despite it being a month of spiritual significance, for the first-time in modern history, people were unable to attend Mosques and the general global mood was sombre, in a state of fear and with the spotlight on social and health inequalities having magnified.

Despite the global pandemic, the survey garnered 42 complete responses. It may have been that people had more time being at home or with a shift in commitments and travel or equally for some it may have been difficult to make the time or have the space without interruptions. It was also a time the nation was more inclined than ever to be online and to be sharing experiences. The recorded interview data from participants was transcribed with all identifying information removed. The transcripts were saved on my laptop using initials for me to identify. Those taking part in the online survey were not asked for their name or any identifying information, it was entirely anonymous.

4.7 Ethical considerations

4.7.1 Academic ethical procedures and safety

This study gained formal ethical approval from the School of Health Sciences Research Ethics Committee (Ref: ETH1819-1208, see appendix (7)). Ethical considerations included privacy and confidentiality, consent and anonymity. It is important that participants are aware about the aims and objectives of the research and what their involvement entails. Hence, they were provided with a participant information sheet with information about the study and process. This included information about how the data would be handled and stored. Participants were informed that it is a voluntary study, and they can choose not to participate or withdraw at any time up to the point of data analysis. Each participant was asked to complete the consent form prior to taking part. As mentioned in the section on *data handling and storage* all research related documents are stored confidentially and securely in line with the City University's guidelines. Confidentiality is taken very seriously. All documents with any identifying information are de-identified using a code and stored securely and destroyed upon graduation. Other ethical considerations included participant and researcher safety which are discussed below.

Participant safety: Participants were advised that the interviews would require a quiet space away from other people and to ensure one has a good internet connection and no distractions. They were also informed that any direct quotations to be used in the research and publications would be de-identified, so that participants cannot be identified. It was not anticipated that any adverse effects may occur, however, in case someone felt distress recounting their story they were provided with the option to terminate the interview or withdraw which they were informed about at the outset of the interview. On one occasion in an interview the participant

was sad and tearful and along with checking in with them about how they felt and if they wanted to stop, I did remind the person of the support organisations signposting document in case that would be of help, the participant seemed reassured by this. As part of the ethics form, I included that should any participant require further information or support following the interview, they would also be reminded of / referred to the list of support organisations for signposting. This was sent in advance with the email that also contained the participant information sheet, informed consent form and other information regarding the interview and study. With the survey each page contained a link to signposting organisations for support for participants to access if required.

Safety of the researcher: As the researcher I collected data independently online. I had no contact with participants for the survey data collection (Part I). As I was not travelling alone to meet people there were no implications regarding physical safety. For the interviews (Part II), I used my laptop at home in a quiet space to conduct and record the interviews. However, as a member of the same community, I did consider some situations that may arise. These potential scenarios included participants wanting to talk to me beyond the remit of the research or go over the interview time frame, or for the conversation to detract from the task at hand. To ensure this did not happen, I explained the purpose of the interview to ensure participants understood the nature of the meeting, and the boundaries and purpose of the research work being conducted. I was also mindful of gender issues specific to my community; that there may be men who feel uncomfortable talking to me as a female researcher, and women with young children and multiple commitments who may struggle to make time for an uninterrupted interview. These are some of the reasons I ensured the variety of options for an audio only through Zoom (in case someone is uncomfortable with speaking to a female 'face to face' despite it being online – though no one took up the option) and for the survey option to be available for people to be in full control of when they took part to ensure a wide range of accessibility.

4.7.2 Reflecting on decolonial, trauma informed and Islamic approaches to ethics

Beyond thinking about the ethics of the design and execution of this study in terms of university procedures, I also thought about the deeper meaning of ethical research and practice and the considerations I needed to make in terms of being mindful of a trauma informed and decolonial approach that also would reflect on Islamic approaches to ethics. I began by wondering and

asking the question who decides what ethics is and what it includes or excludes when I first worked with the Ethics form procedures for the university. What does ethics mean when using decolonial and Islamic approaches? How is your research navigating the extractivism so often enacted by Eurocentric research?

On a practical level I informally consulted a scholarly group in my community, seeking their advice and expertise on data collection methods, and ethical considerations from a practical perspective and what might work best. The group is formed of members who were on the same scholarship scheme as myself and made up of all different age groups, and disciplines. The responses suggested I needed to offer a range of different options for data collection to meet the differing needs of the various members of our communities and along with the considerations mentioned above around gender, accessibility needs and travel (at the time pre COVID-19), these informed what I then went onto offer as two different options (the survey and interviews). I carefully considered these in the design of this study. Moreover, I was made aware by other Muslim academics of ethical challenges they faced in the community such as being asked to write letters (for legal or medical matters) on behalf of the participants, to act as an advocate and people asking personal information about their marital status which could be considered a common social norm in sub sections of the Muslim community but might be considered inappropriate in 'professional' research settings. This was a useful exercise to engage in asking other Muslim researchers and academics about their experiences so I could be prepared myself for any challenges that arise. Some of these scenarios discussed, I had also experienced in other settings where boundaries can become loose or difficult to conceptualise, so though I had some experience in negotiating these spaces, it was still nonetheless important to be mindful of these potential situations when conducting this research. However, the opportunity for such situations to arise were minimal and limited given the methods I utilised and thankfully nothing of the sort occurred.

4.8 Methods and data analysis: survey

4.8.1 Preliminary considerations and decision-making process

Before arriving at the decision to use Reflexive Thematic Analysis (RTA), I thought extensively over what the most appropriate form of data analysis would be, in the context of the philosophical underpinnings of this study – the decolonising methodologies theoretical framework and overarching Islamic ontology and epistemology. I considered some options

including researching if there were any existing Islamic social or health science methods (historical or contemporary), or methods used by Muslim researchers with the Muslim community specifically. However, I did not discover anything appropriate or relevant to use that was distinct, or even as examples that I could adapt and utilise for my study specifically. I consulted several Muslim academics, scholars and professionals internationally in my search for appropriate methods though was unable to find a specific existing model that I could use. I also explored using Grounded theory, Interpretative Phenomenological Analysis, Narrative Inquiry and Thematic Analysis as possible methods for the analysis of findings. After considerable reflection and reading I concluded that I would use Reflective Thematic Analysis (Braun and Clarke, 2019a, b, 2020), which I adapted and layered with ideas from Islam (discussed below), as the method of analysis for the survey responses and narrative inquiry case study analysis for the interviews.

The RTA approach provided a broader insight into the data and inquiry. RTA though may seem decontextualised, as it is about broader themes rather than individual stories, provides a bigger picture narrative that allows for the discovery of meaning through patterns and themes. These patterns and themes facilitate an inclusion of the wider social and cultural structures, within which meanings are created. The use of the method itself and the specification of the type of Thematic Analysis (TA) - its justification, advantages, alternative types of TA and limitations are discussed below after briefly delving into the explanation of how I arrived at the decision to use RTA.

I have detailed below the conceptual framework of RTA and the rationale for opting for this method. Furthermore, I discuss how I blend in ideas of Islamic epistemology with RTA using the concept of *'Tadabbur'* (an Arabic word meaning "to reflect and think about something carefully, and to analyse its consequences) and its relevance to my method. *Al-i'tibaar* means consideration, contemplation and discernment and *"is considered the condition and psychological framework with which the knowledge of something observed leads to the knowledge of something unobserved"* (Muftisays.com, 2015). In essence *"At-tadabbur is a term meaning the consideration (Al-i'tibaar) of the consequences of things, and it is similar in meaning to the term at-tafakkur"*, (thinking, reflecting, pondering through looking at the evidence of something), *"although thinking is the behaviour of the heart when considering…and tadabbur is the behaviour of the heart with the consideration".* The latter applied to the analysis and how my interpretive considerations are presented. Drawing on these

Islamic ideas added different layers of thought in my analysis process that went beyond the conventional focus on intellectual reasoning alone. Being mindful of the heart's role in processing meaning-making connected to the embodied experience of a researcher who is responsible for capturing the analysis. Utilising the Islamic concepts of *At-tadabbur* (reflection) and *Al-i'tibaar* (contemplation) were important for me to draw on as a Muslim researcher of this study where I am analysing data from Muslim participants and where faith played a significant role in meaning-making and interpretation.

4.8.2 Reflexive Thematic Analysis and its roots in Thematic Analysis: what are the differences?

It is important to be clear that there are different branches of TA as identified by Braun and Clarke (2019, 2020) and that though there are positivist versions that depend on coding reliability, the RTA version of Braun and Clarke (2017, 2020) emphasises *"an organic approach to coding and theme development and the active role of the researcher in these processes".* This approach allows for critical engagement with the data which aligns well with the decolonising framework of this study as according to Clarke and Braun, (2017), *"TA can also be used within a 'critical' framework, to interrogate patterns within personal or social meaning around a topic, and to ask questions about the implications of these. This approach to TA is aligned with critical psychology perspectives (Clarke and Braun, 2014),"* (Clarke and Braun, 2017) Please refer to the author checklist point [1,2,4,9] in appendix (6).

In their 2019 and 2020 papers Braun and Clarke have addressed the developments of TA since their seminal paper in 2006 which became widely used, is cited 89,651 times (at the time of writing this on 26th December 2020) by Google scholar and viewed 291,337 times on Taylor and Francis online gaining massive traction across disciplines. They discuss the mis-conceptualisations and misapplications of TA, which led to them distinguishing their version of TA and coining the phrase *Reflexive Thematic Analysis* and what this method encapsulates.

There are several different approaches of TA which *"reflect divergent paradigmatic and epistemological positions and associated procedural differences"* (Terry, Hayfield, Clarke and Braun, 2017) and are 'clustered' (to borrow Braun and Clarkes' term) into three approaches defined as:

1. Coding reliability: deductive and echoes the scientific method. The steps are theory (deduction) to hypothesis/prediction (identifying themes), to evidence gathering/testing hypotheses (coding). At the core of this neopositivist approach are concerns about 'objective' and 'unbiased' coding. This would not work with my methodology which has already critiqued the problems with objectivism (chapter three), reflects ideas of embodiment and values what subjectivity has to offer. This is also one reason why I made the decision not to use Interpretative Phenomenological Analysis with its concept of 'bracketing' the self as researcher out. Furthermore, this study is seeking to extrapolate meaning from people's experiences rather than be theory driven. Please refer to the author checklist point [4] in appendix (6).

2. Codebook: Often deductive in orientation, themes are developed early in the process, or prior to, analysis using a structured coding framework. The key to this analytic process are multiple coders, for ensuring 'accurate' and 'reliable' coding. In terms of measuring quality of results this approach centres on the use of inter-rater reliability (coding agreement) as a key component. However, as Braun and Clarke (2017) highlight consensus between coders and inter-rater reliability are not usually measures of quality. The coding is not anymore "accurate" as they state, *"at best, inter-rater reliability can only show that two coders have been trained to code the data in the same way, not that the coding is somehow 'accurate' (Braun and Clarke, 2013)."* (Terry et al., 2017, p6).

3. Reflexive: This branch of TA follows a six-phase process (Terry et al., 2017):

- Familiarisation and Coding (Phases 1–2),
- Theme Development (Phase 3),
- Reviewing and Defining Themes (Phases 4–5),
- Producing the Report (Phase 6)

It is an approach that attempts to fully embrace qualitative research values and the subjective skills the researcher brings to the process – a research team is not required or even desirable for quality. This is ideal for a lone researcher such as in a PhD context where one can still consult with supervisors as part of the process, though a research team is not required. RTA is situated as a creative interpretative reflexive, flexible analytical process whereby it can be inductive or deductive. A defining feature of RTA is that researcher subjectivity is inherently valued and understood to be a crucial resource (Gough and Madill 2012), rather than a potential

threat to knowledge production, as conceptualised in Boyatzis' (1998) and other approaches to TA (Braun and Clarke, 2019, p591). This type of TA acknowledges the impact of researcher subjectivity and encourages the researcher to reflect on their influence on data collection, interpretation, and analysis throughout all phases of the study. Furthermore, it provides a method i.e., the six phases to support that process. Please refer to the author checklist point [3,5] in appendix (6).

In an interview with Hayfield (2017), Clarke describes using TA as a journey rather than a fixed map. The coding is open and organic, with no use of any coding framework. Themes should be the final 'outcome' of data coding. Iterative theme development is thought of as an 'analytic output'. The flexibility of this design allows for creative engagement with the data and for delving deeply into the potential meanings as a non-linear method. Please refer to the author checklist point [3] in appendix (6).

A key distinguishing feature is that themes *do not emerge* as if they were already there waiting to be found but they are an active process of pattern formation and identification, they are *generated* (other terms Braun and Clarke suggest are constructed or developed):

> "An account of themes 'emerging' or being 'discovered' is a passive account of the process of analysis, and it denies the active role the researcher always plays in identifying patterns/themes, selecting which are of interest, and reporting them to the readers. (Taylor and Ussher, 2001).4" (Virginia Braun and Victoria Clarke, 2006, p80).

Braun and Clarke (2020) do not believe that *"themes are 'in' the data, waiting to be identified and retrieved by the researcher".* Instead for them themes are creative and interpretive stories about the data, produced at the intersection of the researcher's theoretical assumptions, their analytic resources and skill, and the data. Another advantage of this non-linear and organic process is that it imbibes a dynamic and deeply engaging process of data exploration which allows for the emergence and richness of ideas that a researcher may not have otherwise considered. In RTA the term 'phase' highlights that the analysis, is not a linear process – it is iterative and recursive with the researcher moving between the different phases (Terry et al., 2017) Please refer to the author checklist point [1,2,4] in appendix (6).

Braun and Clarke, 2019 advise that *"quality reflexive TA is not about following procedures 'correctly' (or about 'accurate' and 'reliable' coding, or achieving consensus between coders),*

but about the researcher's reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process" (Braun and Clarke, 2019). They place a strong emphasis on there are being "no 'right' or 'wrong' codes" and that *"codes generated need to be meaningful to the researcher, capturing their interpretations of the data, in relation to their research question"* (Terry et al., 2017). They also state that coding consistency is helped by the researcher working in the circular way of going back and forth through the data to clarify and modify data items. Themes come after considerable analytic work. The points that they detail were adhered to as closely as was possible and monitored using their guidelines/checklist as I proceeded through each phase.

RTA in its current form and the method I followed was coined in 2019 making it a fairly new approach (although it is an evolution or off shoot of TA) and inevitably it may evolve further in future and there may be critiques of it as more people apply it. There is a strong emphasis by the authors that researchers using RTA should not justify or make claims of lack of generalisability as it would give the impression that the study is employing a positivist stance (Braun and Clarke, 2019). Please refer to the author checklist point [20] in appendix (6). Further, RTA does not advocate for inter-rater reliability i.e., multiple coders to justify accuracy stating that this is a positivist reductionist assumption and that it does not result in more accurate or reliable coding. Braun and Clarke (2019), propose a robust reflexive quality guideline to ensure quality within the method.

4.8.3 The methods theory: Reflexive Thematic Analysis (RTA)

"TA is unusual in the canon of qualitative analytic approaches, because it offers a method – a tool or technique, unbounded by theoretical commitments".
(Braun and Clarke,2017).

Reflexive Thematic Analysis (RTA) as a method offers many advantages for a qualitative study interested in exploring experiences. It is an approach that works conceptually well for this study given one of its central tenets is of not being attached to any particular methodology, though that does not make it atheoretical (Braun and Clarke, 2017). Not being attached to a methodology provides flexibility in applying the method to multiple methodologies (Braun and Clarke, 2017,2019) [4,9]. This means that RTA can be conducted within various ontological frameworks, with the recognition that this positioning will relate to the epistemological approaches to the data (Braun and Clarke, 2017,2019). It is crucial for the researcher to be clear

about their underpinning methodology and make it explicit which I have done in chapter three and throughout this thesis. Despite using an inductive approach (data driven as opposed to theory driven) which does not require a philosophical theory to be rooted in, the analysis does not take place in a theoretical vacuum. In my analysis I am mindful of the psychological, social, cultural, religious, and political affects on the Muslim community (and myself as the researcher of this study), underpinned by the guiding theoretical framework of the decolonising approach as a context within which the data is understood, analysed, and presented. Please refer to the author checklist point [3,9] in appendix (6).

4.8.4 Analysing the data

As the author of this study, I was responsible for the data analysis. As stated in detail above the methods chosen for data analysis for the empirical study were the Reflexive Thematic Analysis and Narrative Inquiry case study. The programme NVivo was used in the initial phases of data analysis for assistance to manage data. I drew on Braun and Clarke (2019c) guidelines for reviewers and editors in evaluating thematic analysis manuscripts, which provides the reflexive explanations for my decision making and processes that occurred through the various phases. This guide also served the purpose as a reflexive quality guide/check for myself. The reader can refer to this table of evaluating the methods and methodology, along with my notes and corresponding references for where the responses to the questions have been addressed, in the thesis by page number and [x] in Appendix (6). In addition to this I referred to the COREQ loosely; I read it a few times to note in my mind general areas that could be thought about and referred to within my writing to ensure I covered as many of the topics as possible/relevant. However, I did not then use the COREQ criteria as a dogmatic checklist or table to refer to. I did however incorporate the ‘mental notes’/references I had taken from reading it and assimilated the contents that were relevant into the RTA guideline I used from Braun and Clarke (2019c). Part of the survey included 10 questions on demographics, these were illustrated using pie charts and some descriptive analysis from myself which can be referred to in section 5.1.1.

4.8.5 Development of themes

The analytical processes of the research design were worked through the six phases below.

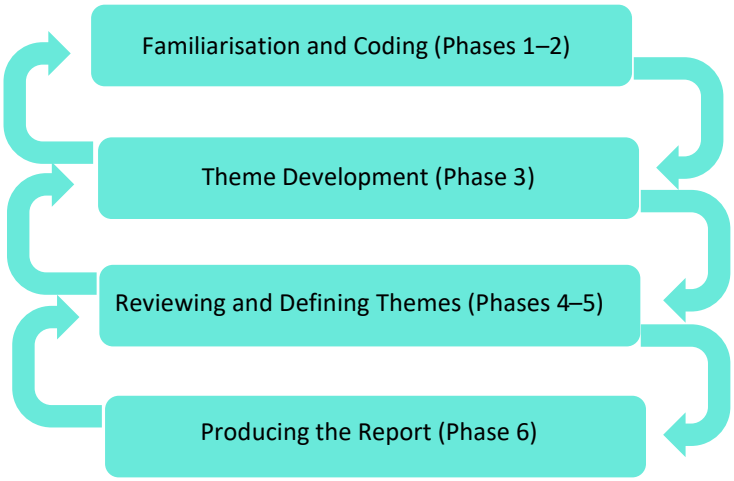


Figure 8: six phases of Reflexive Thematic Analysis (RTA) (Braun and Clarke, 2020)

Below, I detail reflexively how I navigated, interacted with, and developed through each phase. Please refer to the author checklist point [11] in appendix (6):

4.2.1.1 Familiarisation and Coding (Phases 1–2)

This phase required interacting with and thinking about data (Savage, 2000), and moving through unstructured data to the development of ideas (Morse and Richards, 2002). After the closing of the survey, I converted the raw data into an Excel sheet of all the results from Qualtrics. For ease of managing the data I removed the cells which contained the eligibility criteria and all other information that was not related to the survey questions in terms of content I would be drawing on for the analysis. I worked with the 27 questions (17 from the survey and 10 the demographics). Within this Excel sheet, I created pie charts to visually depict the demographic questions. With 42 respondents this was an Excel sheet of (42 x 27 =) 1,134 parts of qualitative data to work with for the analysis. As Braun and Clarke (2006) suggest working through each data set systematically, I went through each question and separated them out in to separate Word documents – in doing so I was familiarising myself with the data, reading and re-reading engaging in the iterative and recursive process. At this stage I did not actively search for patterns or specifically look for anything in relation to the study question, though I began noticing them. I was just taking in what was there. All of the question one responses were inputted one by one into one document and all of question two in another and so on for all of the questions. I was able to upload these files one by one into NVivo. I used the term 'nodes' (from the NVivo programme I used) to refer to the gathering and categorising of data where I looked for emerging patterns and ideas and organised the first layer. It felt like building blocks;

some went with others, some required a new place, for which I created a new node using a word that struck out for me from or about the first data point that needed to go into a new node. By NVivo's own definition [2] *"A node is a collection of references about a specific theme, case or relationship. You gather the references by 'coding' sources to a node."* In order to avoid confusion, I do not refer to codes, to avoid overlap with other approaches of TA that refer to coding frames and codebooks. For me these nodes were about relationships and meaning, a place to gather together emerging patterns from my readings. In this familiarisation and initial categorising phase, I went through each file of the questions responses and once every response had been placed into a node, and this first phase was complete, I was left with 30 initial nodes. The initial node titles were descriptive phrases or words I created taken from the raw data itself such as a concept being referred to for example 'injury during birth', 'negative experiences of care', 'positive experiences', 'husbands' role'.

This method allowed the inclusion of every single unit of data. This was crucial to my method which was data-driven rather than theory driven hence the categorising of the entire data set at least in this phase: *"The process of coding is part of analysis (Miles and Huberman, 1994), as you are organising your data into meaningful groups (Tuckett, 2005). However, your coded data differs from the units of analysis (your themes) which are (often) broader."* The next section describes this process in application from the nodes to thematic categories.

4.2.1.2 Theme Development (Phase 3)

Theme development is concerned with sorting through and collating all the potentially relevant data extracts into themes as well as noting whether the extracts capture important information in relation to the overall research question (Braun and Clarke, 2006). Themes are identified by bringing together components or fragments of ideas or experiences (Aronson, 1994). These components eventually turn into meaningful categories that answer the research question. Given the inductive nature the themes identified must be strongly linked to the data (Braun and Clarke, 2006). Organising the data (a unit of analysis) for me felt like a process of careful observation about where to lay each block of data (i.e., which theme it contributed to developing, or fell under – for those that came later in the process) including make decisions about which data would not make it to the final analysis in terms of being quoted directly. It is in this phase that decision making, and percolating occur. The overall meaning of the data is

[2] http://help-nv11.qsrinternational.com/desktop/concepts/about_nodes.htm

encaptured within the writing of the theme having been a part of the development and shaping my thinking and thus analysis. I did not know what the end would or ought to look like. I was not an architect with final plans. I felt more like an artist or indeed therapist (as I am) going with my intuition and trusting that the process would emerge in meaningful connections through the analysis. Each new node and theme felt like a brush stroke in the development of a picture that was not yet formed in my mind. There were multiple iterative considerations; a going back and forth between reading each participant response for each question and reflecting on *what the message was in that response, what did it capture, what was it relayin*g. Critical engagement with the reading of the texts was necessary as was the importance of thinking about the implicit and explicit meanings in the context of British Muslims' experiences. The process required constant re-reading, reflecting, and reorganising. I began a second layer in order to develop themes. This required going through each of the nodes – and going with the metaphor of building blocks – a second layer was created. Similar in process to the first layer, I went through each node and created a parent title which would act as the theme. As each piece of data emerged with new meaning, new theme titles were created, and other data that were related were collected under this new theme and so on the process repeated until all nodes were homed under a parent theme.

As I progressed through the data some nodes merged under the parent themes, others were new and began a new parent node i.e., theme which came from a phrase or word that I took from the data which represented those nodes. I continued through organising and categorising all the data until all the original 30 nodes were under the umbrella of a parent node which represented the theme. Sometimes with re-reading and revaluating the place of data within nodes I would move it under a different theme where it seemed better connected or I would merge themes. It was not always explicit where they ought to be categorised as the data often were multi layered, nuanced and could fall under more than one theme. I had to make an executive decision on where it either closely fit or would work well within the analysis. It was a bottom-up approach, building from the ground up. The next phase of development required a further re-reading and reorganising of nodes into themes. For example, an original theme '*empowerment, disempowerment and decision making',* became the theme representing nodes: alternative self-care, breastfeeding, change in plans, disempowering, information seeking, and power (all of these nodes contained the responses i.e., raw data). There were many that overlapped so this phase required a further in-depth consideration of the most appropriate theme to house the node and or individual data in that node. This is the stage, *"where the interpretative analysis of the*

data occurs, and in relation to which arguments about the phenomenon being examined are made (Boyatzis, 1998)." Following phase one of establishing 30 initial nodes, a copy was made for traceability under the nodes folder titled: 'Initial nodes' with another copy as a new folder titled: 'thematic categories. This allowed ease of reference as I engaged in the iterative process between the two phases without losing any information. I worked with this latter folder: 'thematic categories', where I collapsed the nodes into organised themes. I then created a further folder where I aggregated the coding from the 'children' tab to the 'parent' tab on NVivo.

In various stages of analysis and especially when using a quote, I would go back to the whole survey response form of the participants' quote in order to help me contextualise the analysis and get an overall sense or picture as I wrote. I was concerned the cutting across the data may lose the essence of or miss important analytical information. This vertical and horizontal cross-check over the data helped me feel a bit more assured that I was not leaving anything important out at least in terms of analytic process. The reader is reminded to bear in mind that many of the themes and experiences overlapped. For the sake of presenting the data, a considered judgement in consultation with my supervisors was made where the data was deemed most appropriately categorised. This was an immersive process requiring repeated reading, searching for relationships and meanings. The process was in alignment with the decolonising approach where research requires constant reflective attention and action. This immersive process of theme development also allowed integration of the Islamic ideas of *tadabbur* and *i'tibaar*, through my interpretation, as the researcher contemplating and reflecting on the process. As Simmons and Christopher, (2003) highlight, there is an absence of published guidance for this process and there is a need for continued exploration in implementing Indigenous methods alone or in conjunction with appropriate Western methods when conducting research in Indigenous communities. I was able to bring in Islamic ideas and layer them within the 'Western' created method of RTA.

Blending or bringing in different ideas was a difficult process especially with few examples to follow. There is acknowledgment that *"currently, examples of Indigenous methods and theories are not widely available in academic texts or published articles and are often not perceived as valid"* (Simmons and Christopher, 2003). I drew on Braun and Clarkes (2006, 2013, 2019) method for thematic analysis in order to facilitate this process as a starting point. As RTA is a new form of the very-well used TA, researchers are only recently beginning to

use it particularly in PhD theses. I did find it challenging finding worked examples of RTA initially when I was first at the methods stage. However, as time progressed and during my writing up phase I did find more recent papers and PhD thesis that had applied RTA and were helpful for me to see. The greater challenge for me was what became taking the 'be brave be smart' approach (Zocchi, 2019) and applying a layer from Islamic knowledge to the method and thus creating a tentative new conceptual working model.

4.2.1.3 Reviewing and Defining Themes (Phases 4–5)

The reviewing and defining theses phases were an iterative process of refining, defining, reviewing and again refining, defining and reviewing continuously. I created a summary of the initial descriptors of the generated 'themes' of which there were nine which were then collapsed further in the writing process. To illustrate the titles of these themes in this phase included: social impact, psychological impacts, NHS experiences, empowerment, disempowerment and decision making, recommendations, religion, awareness of own birth story. These were mostly descriptive initial theme titles at this stage which had helped me to organise the data, with a summary paragraph of what they captured. I then went through a process of reviewing, reorganising some node contents and re-titling the themes. At this stage, I moved from NVivo to Word. I did this using tables I created in Word for each theme and transporting every single quote under it from the original in NVivo. This was a personal preference and method I found helpful for me. I was able to colour code the tables and it helped me visually represent the data in this way. The tables became large and difficult to manage hence for presentation purposes and word limitations for a thesis, I eventually chose illustrative examples of quotes that could go in the final analysis as can be seen in chapter five.

In these phases, I went through yet another reading, and shifted some quotes to different themes or sub themes where appropriate. The descriptor titles also changed at this stage into more analytical interpretations through my readings. The sub themes became direct quotes or words from the data that I felt represented and captured an essence of that sub theme. This process was where the pinnacle of the analytic work emerged into the final themes. For example, the broad theme 'religion' became refined as 'Islam' and then further defined more specifically as 'the significant role of Islam during pregnancy and birth'. I realised myself I may have been unconsciously impacted by acceptable language/words used in a 'mainstream' settings and 'religion' seemed more palatable to present in my initial phases, but Islam as a term was more

accurate and though it has come to be understood under the umbrella of religion in modern Western discourse, it is in the Muslim mind understood as a holistic way of life and there are different ways of thinking about this and its meaning that are beyond the limitations of framing it under the term religion. This experience made me become more acutely aware and re-examine the words I was using more so, to ensure this unconscious process was not occurring elsewhere and where it was to correct it. I realised that my automatic use of religion was rooted in deep unconscious anxiety and fear of how Islam is and may be interpreted and negatively perceived outside the Muslim community, and also in the minds of potential examiners, readers. I wanted to make it easy by using the word religion; these anxieties are perhaps always there underlying but affecting in ways we may not even recognise. I had written significant parts of my thesis at this point, read widely and focused significantly on decolonising and the importance for me as a researcher researching certain experiences in relation to Muslims, yet still at this point, I found myself unconsciously filtering, making it easier to the outsider world so that I would not have to deal with the stress of having to explain, justify, and debate the existence of Islam or being a Muslim. This was a sad realisation and a disappointing one of just how deeply entrenched these experiences are of being (the word I dislike using) a 'minority' of this faith constantly under attack. However, I felt it was important to highlight the intricate subtle ways colonisation of the mind, racism and fear of it, Islamophobia and fear of it all played a part unconsciously on seemingly a small point of the use of one word for me as the researcher. If I were not to have reflected on this the meaning of the data, potential implications and resultant analysis would be affected. I wondered how often this happens in research and in the data, what words people might use that may act as filters or act as safe words e.g., religion instead of Islam. This was an unexpected discovery for me and writing about it helped me reflexively see the process and power of it.

4.2.1.4 Producing the Report (Phase 6)

The 'report' produced is presented in chapter five, next. In the writing of the report, each theme was summarised, then presented in detail with the direct quotes taken from the survey responses, and finally, weaved with interpretive analytic reflections that generated meaning adding to the wider narrative. Because of the volume of the data collected – 42 participant responses over 27 questions (10 of which were demographic) as mentioned at least 1000+ bits of qualitative data were involved in this phase. For this reason, it was not possible to present a

table with all quotes that formed each node that eventually fed into a theme and showing the map of how they became themes from the original nodes.

4.9 Methods and data analysis: interviews

4.9.1 Narrative Inquiry: the composite case study method

Moving on to the method being used for the interviews this section discusses the composite narrative case study method which provided a deep-dive focus following on from the surveys' reflexive thematic analysis. This method gave an opportunity to reflect on nuanced experiences in whole – to access 'emotional truths' (Orbach 2000) – to zoom in to the contexts surrounding experiences of pregnancy and birth of Muslim participants who took part in the interviews. Orbach (2000, p 196) posits the idea of presenting 'emotional truths', which she defined as *"an authentic representation of feeling states rather than a strict adherence to narrative truth"* (2000, p197). The main benefit of the composite approach and my reason for using it was an increased anonymity of stories. Composite narrative interviews *"blend a number of accounts to convey an appreciation of individual experience whilst maintaining the anonymity of participants"* (McElhinney and Catherine Kennedy, 2021). Blundy and Orbach (2000) also state that they use composite accounts to prevent breaches of patient confidentiality. Orbach (2000) also alludes to a further advantage of composites whereby one *"can use a single story to tell a more generally representative account of the experience".* This concept is applied by Willis (2019) who uses the metaphor of braiding stories which aligns with my original analogy in this thesis to weave together narratives. I carefully braided the stories together which were reflective also of the many shorter stories told in the qualitative survey that were presented through the Reflexive Thematic Analysis. Wertz et al., (2011) posit the composite narrative as a "novel method" utilised to:

> "re-present narrative data and findings from research through first person accounts that blend the voices of the participants with those of the researcher, emphasizing the connectedness, the ''we'' among all participants, researchers, and listeners. These re-presentations allow readers to develop more embodied understandings of both the texture and structure".

Wertz et al., (2011) suggest one of the goals of utilising composite first person narrative is to *"increase empathy in health and social care providers",* through the sharing of knowledge and insights captured through qualitative research. It is hoped empathy is evoked and understanding is increased in the readers of the composite stories in my thesis, and that these insights could lead to implementation of change and improvement.

4.9.2 Process and my approach / model for writing the case studies

I share the approach I took in writing the case studies. I drew on a number of writings around narrative methods and loosely followed Polkinghorne's (1998, in Kim, 2016) mode of narrative analysis. These methods focus on the events, actions, happenings, and other data elements. There is a process of recursive movement from parts to whole or from whole to parts, filling in the gaps between events and actions using a narrative smoothing process (Polkinghorne's, 1998, in Kim, 2016). This mode of analysis bears in mind that narrative analysis is not simply a transcription of the data. Itis a method of highlighting the significance of the lived experience, making the range of disconnected data elements coherent and readable, in this sense it is complimentary to the RTA method also. For Polkinghorne (1998, in Kim, 2016) research into meaning is "the most basic of all inquiry". This notion is apt to apply in my study given the focus and inquiry has (from the outset of this thesis) been on experiences and meanings. Further it emphasises connotations and sustains the metaphoric richness of a story. This can be summarised as three broad points: focus on the events as they are narrated, how the story is structured, and the meanings ascribed by the narrator. I used these broad points in my formation of the case studies and how I presented them. Some of this is also relayed through very brief reflections that I have inserted into the case studies, as well as discussed in the final commentary after the case studies are presented.

I have also drawn on Connelly and Clandinin (1990) who suggest three analytical tools for narrative inquiry: *broadening, burrowing,* and *storying and restorying.*

1. *Broadening,* is looking for a (broader) context of the story, including a description of the participant, implied in a told story. It involves a general description of the participant's character or values, or of the social, historical, or cultural milieus in which the research takes place. This is similar to Mishler's (1982a) concept of *expansion,* which essentially involves asking, "what else we know about the storytellers and their local and general circumstances" (Mishler, 1986a, p. 244).
2. *Burrowing* focuses on specific details of data. For example, paying attention to the participants' feelings, understandings, or dilemmas, or a certain event's impacts on the participants or the surroundings. Bearing in mind questions about why and how the happenings have influenced the lived experiences of our participants.

3. *Storying and restorying*, after applying the above-mentioned tools this part involves finding ways to story and restory what has been told so that the significance of the lived experience of the participant comes to the fore.

I drew on these three analytic tools as well as the composite methods described above to illustrate Muslims experiences of pregnancy and birth in their context. I transformed the interview transcripts and my notes into research texts that summarise the key message / focus of the story / reflections by creating narrative case studies. For each case study, I wrote notes for each paragraph of the interview content. I wrote the narrative as a retelling of the original story told to me in the interview. I followed this up with braiding the stories into composite narratives. The language I used closely mirrored the actual wording used originally in the interviews. The narrative retelling is illustrated with original quotes where relevant and is essentially a summarised composite account for the purposes of readability, meeting criteria for word count of the thesis, and presentation. With broadening, I highlighted the particular experiences in relation to the social, (religious) Islamic, cultural and environmental experiences Muslims find themselves in the context of pregnancy and birth in the discussion. With burrowing, I concentrated on each persons' particular focus of experience in the story, such as a partner's own illness at the time or the losses, each case had a particular prominent focus that shaped the experience and thus the elements of the story told. In storying, restorying then braiding into composites, I attempted to capture the stories of the participants in their current context mindful of the broader context.

To illustrate participants experiences of pregnancy and birth in their 'whole' context, four individual case study narratives were written up of the four interviews conducted. Given that the stories were so specific I was concerned about how to maintain and preserve anonymity particularly as the stories were written in whole to keep intact the whole experience. There needed to be another layered rewriting of these. I discussed my dilemma with my supervisors, and it was decided that I would employ the composite narrative method. These four cases are presented as two composite narratives instead as detailed accounts of the stories told during the narrative inquiry interviews. This 'deep-dive' process in some ways can be considered opposite to the 'meta' analysis of the literature review and the meta discussions around philosophy, ontology, epistemology and methodology that occurred at the outset of this thesis providing the broader context. The case studies are presented in chapter six.

I decided not to change the order to chronological telling as I think that 'neatening' the process takes away from the complexity of feelings, emotions, experiences and what matters to someone when telling their story. Though, most respondents started at what was the beginning for them. My narrative accounts followed the stories as they were told. There was some editing required for the composites to make sense and flow. It is tempting to both tell stories in chronology and to have a happy ending, but real-life stories often do not have an ending let alone a 'happy' one. Though, I noticed that the participants offered a natural conclusion of some sort, but this may be my sense as someone engaged in the process who also heard the story and had a conversation in the form of the interview before it was written down and then formed into a case study. I attempted to 'tell it as is', gaps and all. I offered brief reflections of points that struck or impacted me in some way through the narrative.

4.10 Researcher positionality and reflections

This section is a reflection of my position and the process I went through in determining the most fitting method/approach for the analytical framework for my studies. The researcher is not neutral. Braun and Clarke (2019b) emphasise the importance of the researcher to 'own their perspectives' [10] and stress *"the problematic idea of the researcher as a neutral conduit for true meaning, where researchers disassociate themselves – maybe almost unethically – from the knowledge production process".* I have tried very much to be mindful, through every phase of my empirical research and in the writing of the overall thesis, of not dissociating and instead being immersed within the knowledge production process. Braun and Clarke (2019b) also ask for people to reflect on why they began to use the phrase 'themes do not emerge', and what that means. Clarke (2020) encourages researchers to come up with their own terms, stating the critical importance of thinking about the philosophy that underlies the research which will help to think of what other words to use instead of 'emerged'. If a researcher critically reflects, engages, and immerses themselves in the process owning their process and interpretations they will be able to come up with their own terms. I have chosen to use 'developing' as it suggests a dynamic process of taking steps, going through stages and potential growth in a process. Furthermore, it is not static, and it can continue to be *developed* or continue *developing,* perhaps even as it is read or engaged with after it serves its purpose as a structured and formed thesis.

This encouragement to owning the process of interpretations and terms tied in with Şentürk's (2020) ideas of encouraging the researcher, student or seeker of knowledge in developing

'*intellectual independence'* which he roots in the Islamic knowledge tradition. Şentürk (2020) produced a book on comparative theories and methods which aims *"to teach the student to become "intellectually independent" thought the Art of theory building rather than passively applying conventional theories and methods in social sciences that are colored with Eurocentrism".* I drew on this information to help me in my knowledge production process. The steps to becoming intellectually independent include:

- Critically and comparatively analysing existing theories and methods.
- Identifying the origins of existing theories, methods, and ideas.
- Produce own ideas. (Şentürk, 2020)

Coming across these steps provided some much-needed reassurance for me as a researcher, attempting to blend Islamic and critical ideas of knowledge with Western academia, without a clearly defined map. I had been critically exploring theories and methods throughout, I also highlighted how important it was for me to identify the origins of theories and ideas and I attempted to produce my own ideas through the way in which I interpreted the data and through bringing in concepts from Islamic knowledge Taking the context of a decolonised approach has been at the core of shaping my thesis. I have constantly critically analysed and questioned the appropriateness of theories, methods, checklists, and tools and who decides what is valid and or acceptable knowledge. I delved deeply into deconstructing and critically understanding knowledge systems and began reading widely beyond the scope of my thesis (to name a few: from epistemologies of the south, to race and trauma, globalisation of mental health, Islamic research methods, gender, philosophy and much more). As a result, I inevitably spent some time lost in the sea of various disciplines and ideas about knowledge and how to proceed with my own thesis. I later realised this time was invaluable in shaping my thinking and enriching my thesis. I eventually homed in through finding the RTA and narrative inquiry case study methods to analyse my data.

In developing the intellectual independence of a researcher, Şentürk (2020) makes an important distinction *"to acknowledge that although we may stand on the shoulders of giants (as quoted by Isaac Newton) not only should we be aware that those we draw on can and have committed (sometimes grave) errors but we should also be self-critical about our own approach".* Both these points are crucial in order not to idolise ideologies (of others or self) through idealising or demonising them but finding a balance and being aware of the complex, nuanced, layered

process of research and the subjectivities of knowing and making sense. I am aware as an individual I can get carried away with ideas (as I did many times throughout different stages of this thesis), there are ideas and writings I deleted completely. Drawing on the idea of balance – (*mizan:* a central teaching in the Islamic knowledge tradition) is something I have internalised and is a principle I root myself in and brings me back to a grounding. For there to be balance, a holistic and critical perspective is crucial particularly when evaluating theories and methods. Şentürk (2020) introduces the concept of "multiplexity" as a holistic approach in the world of comparative methods and theories. Multiplexity recognizes that *"reality has multiple layers and cannot be reduced to a single layer. As such, it is a comprehensive approach that recognizes each layer of reality, including physical and metaphysical, material and ideal."* His use of the term "multiplexity" was helpful for me as a researcher where I was thinking about, what he calls the *"multiple levels of existence (physical, metaphysical and divine), knowledge (acquired via reason, sense perception, intuition, and divine revelation) and truth (relative and ultimate)".* In his holistic perspective of social research, multiplexity encapsulates the concept of human ontology as consisting of multiple levels: body, mind, and soul, and includes social action of that which is observable and unobservable. This relates back to a section of my methodology which discusses divine/revealed knowledge and human perception and knowingness and how we know what we know and the importance of this for my study. An application of my understanding of multiplexity is in the analytical writings of the findings.

I took courage from the ideas of "intellectual independence" and "intellectual entrepreneurship" (Cutcliffe, 2003). Intellectual Entrepreneurship, "*implies a conscious and deliberate attempt on the part of academics to explore the world of ideas boldly; to take more risks in theory development and to move away from being timid researchers*" (Cutcliffe, 2003, p136). He suggests *"that excessive emphasis on reflexive activity might inhibit intellectual entrepreneurship"* (Cutcliffe, 2003). There is a fine line between reflexivity and intellectual independence or entrepreneurship and as the researcher of this study it was my role to ensure a balance in embodying the processes of reflexive research and actualising the analytic output as an intellectually independent and original outcome. There were times I became overly reflexive to the point I became paralysed in thought and unable to progress. The balance for me was then drawing on intellectual entrepreneurship to help me achieve the required equilibrium to continue. I do not perceive that the two concepts need to be mutually exclusive, but both can be applied.

I recognised that even within reflexivity there were limitations to the approach I took, particularly what my unconscious mind brought in. We can only reflect on that which we can recognise, note, or observe through the filters we apply. As a psychotherapist this is something I think about a lot, but the nature of the unconscious is such that it is not apparent (at least verbally or intellectually) without being curious, observing, probing, noticing and reflection. Being able to see in the mirror or have a mirror reflected at one and or through engaging with the senses and intuition are important tools for bringing into the conscious unconscious choices and thoughts. I saw one of these 'mirrors' reflected back to me as my supervisors who helped me to see my blind spots, assumptions, questioned my choices and decisions. I saw merit in the RTA approach and also recognised the value of Cutcliffes' "Intellectual entrepreneurship" and Şentürks' "Intellectual Independence". One of my responsibilities as the researcher of this study was to find a balance between these two concepts in the way I embodied the research process and particularly in the application of analysis to the data.

I was able to think about how important reflexive thematic analysis was in the approach taken for this study through recognising and establishing the value of the diversity of approaches needed to research indigenous communities' and understanding that each researcher or scholar may need to take a unique approach. Particularly, useful was the notion in RTA that there is no expectation or pressure for generalisability (in fact the complete opposite). Furthermore, in RTA significance is given to the uniqueness of individual stories as being valuable in and of themselves without need for validity vis a vis large quantification. There are no requirements to make claims when utilising the RTA method [20]. Porsanger (2004, p.107) discusses the value and significance of decolonisation of research particularly for the indigenous research, recognising the diversity even within and amongst indigenous scholars:

> "The quest for the decolonization of research and, indeed, of the human mind has recently become one of the hottest and most discussed issues in indigenous research... The process of decolonization requires new, critically evaluated methodologies and new, ethically and culturally acceptable approaches to the study of indigenous issues. These approaches may differ in various ways for indigenous and non-indigenous scholars". (Porsanger, 2004, p.107)

Being mindful of the psychological, spiritual, historical social, collective and political dynamics and utilising a decolonising theoretical framework allows for transformation and development for both the researched and research processes. This mindfulness of the wider ecological context of research and the researched can contribute to creating spaces for hearing,

witnessing and or documenting people's stories in a way they choose which in turn can contribute to processes for healing and recovery, one of which includes being able to share experiences.

From the outset of this thesis, I have been aware of my positionality and influence in creating this research having addressed it in detail in chapter one (and chapter three) of my background and what I bring to this research including my 'personal and social standpoint and positioning' [10]. Braun and Clarke (2019c) highlight the importance of the awareness of researcher positionality where researchers are *"engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong"* (point 10 of their checklist, Braun and Clarke 2019). I am aware that there are various layers to groups that can be demarcated by age, gender, experiences, religion, culture to name a few. I consider myself as an 'insider' researcher in terms of the identity as a Muslim researching Muslims experiences and having been one half of the dynamic of mother and child where birth was a deeply traumatic and near-death experience. As stated in chapter one, I am conscious that my desire to create a space for Muslims voices to be heard is influenced through having witnessed and lived with the first-hand consequences of being born of a silenced traumatic pregnancy and birth experience, in an era where these topics were not acknowledged. I have attempted to be as clear as possible about my positionality and my intention for this research to be a platform that documents lesser heard voices/experiences in particular of British Muslims'. The way in which the data are analysed and written also demonstrate where I own my perspective [10].

I resonated with how Braun and Clarke (2019a) described the process of how their training, values and commitments informed their conceptualisation of TA and those who they learnt from *"modelled the value of being a scholar who cared about the doing of qualitative research and encouraged a critical reflexivity about method"* (Braun and Clarke, 2019a, p590). I was able to embody the position of a critical thinker throughout my thesis having been exposed to different concepts and the opportunity to learn from and consult those who deeply care about how quality qualitative research is done and ensuring its rigorousness. For example, one of my own supervisors gave me a perspective on critical thinking that I had not thought of, and that one sentence was the seed that eventually led to everything that followed and how this thesis was eventually designed in its ups and downs, trips and turns without a map. I pieced together a 'map' at each step using my internal sense compass. It has been a challenging journey but

one full of expansive learning and filled with challenges intellectually, spiritually, and personally. Another researcher asking the same question as I ask of this thesis is unlikely to take the same journey and will have different points on their map though we may potentially arrive at similar 'analytic outputs'. Critical thinking, reading, engagement and reflecting is what shaped my thesis from the methodological framework to the methods and the analytic output / interpretation of the data and overall direction. It was helpful to have a paper like Braun and Clarke's (2019a) *'Reflecting on reflexive thematic analysis',* to draw on as it helped in my reflective process to check that I am not making some of the mistakes they draw attention to (though I am sure I made others) and what I could do to make the analytic process better and reflexive.

4.11 Conclusion

This chapter has detailed the theory and conceptual framework of the methods and distinguished between the differences of Thematic Analysis and its branches, explained the reasoning behind choosing the method of RTA, carefully considered research design and quality implications for the empirical study phase, and shared reflections on researcher positionality. Furthermore, practical descriptions have been set out regarding ethical considerations, sampling strategy and recruitment, participants, setting, materials, data handling and storage, data collection and data analysis including how I navigated and applied the six phase RTA process with the integration of the Islamic ideas of *tadabbur* and *i'tibaar*. The next chapter will provide a detailed analysis of the data where the developing themes are reported.

Chapter Five: Analysis of Data Part I

5.1 Introduction

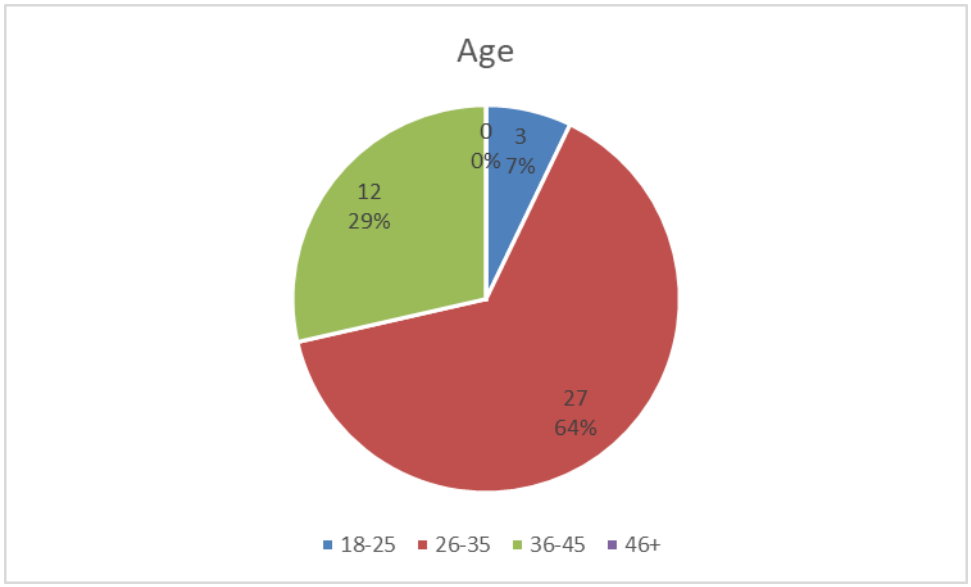
This chapter presents the themes and sub themes that were developed through my analysis and interpretations of Part I (Survey's), this is followed by chapter six which presents Part II (Interviews). The data-driven, inductive, Reflexive Thematic Analysis resulted in the development and creation of six themes after multiple iterations. The use of the RTA method provided a guide map to help me organise and make sense of the data. Though presented as separate themes, the reader is asked to bear in mind the interrelatedness of all the themes, using the metaphor illustrated at the outset of the thesis, of weaving a patchwork quilt.

Before delving into the themes in section 5.2, below is a snapshot of the demographics (not all respondents answered all the questions but there was at least 80% coverage of the survey for the response to be included).

5.1.1 Part I (Survey) demographics

42 participants; 35 women and seven men completed the survey. In the Interviews (Part II) two men and two women took part. The total of participants across the different methods was 46 (37 women and 9 men).

Age



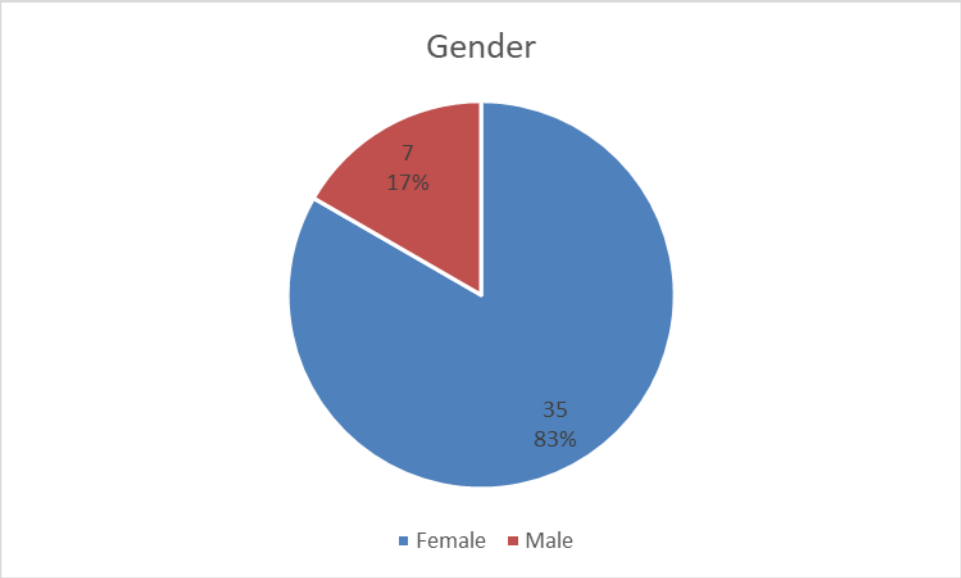
18-25	3

26-35	27
36-45	12
46+	0

As can be seen the vast majority of respondents fell between the 26-45 age groups, 39 in total: 27 respondents (64%) were in the age bracket 26-35, 12 respondents (29%) made up the 36-45 age group, with three respondents (7%) in the 18-25 and no one over the age of 46 responded.

Gender

35 female (83%) and seven male (17%) respondents took part in the survey.



Female	35
Male	7

Heritage (Ethnicity)

In the framing of questions around heritage, I intentionally did not use pre set categories and asked people to state in their own words the 'ethnic' group or heritage that they felt most described them. As discussed in chapter one, I was cautious of using terms like 'ethnic' and minority', hence in my study chose to let people self identify using their own terminology. As the researcher of this study, framed within a decolonising approach, I was in a position to make choices and chose not to perpetuate these reductionist terms and categories beyond necessary.

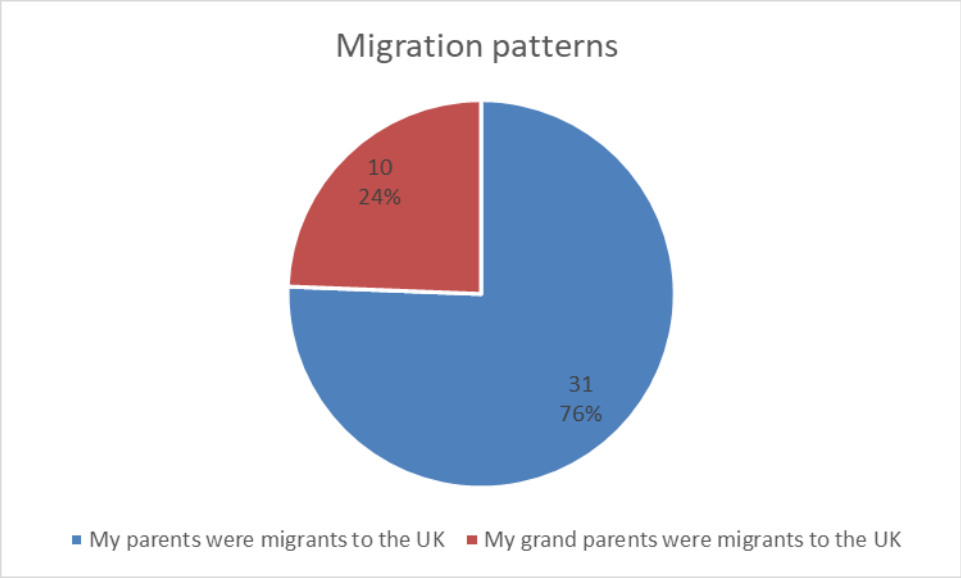
I recognise that it is a collectively understood term when requesting information regarding origin so I loosely used it as a term of reference but added ‘heritage’ and gave people a choice to decribe themselves as they see best. I was conscious I should address this in my analysis here. I noticed that this method brought forth dual connections where some wrote British next to their identity or after a /. This allowed people to identify as it means to them. As can be seen in the below table there were a variety of respondents from Asian, Arab, Mixed and White heritages. There was a glaring absence of British Black African Muslims voices, which is discussed in chapter seven under section 7.6.1 Limitations.

Self described heritage	Number of people
Arab	3
Arab mixed	1
Algerian	1
Asian	2
British Asian Indian	1
British/Irish	1
Bangladeshi British	1
Bangali	1
Bangladeshi	6
British Pakistani	5
Pakistani British	1
Pakistani	10
Mixed race. Jamaican and Scottish	1
Mixed. English/Libyan	1
Indian	5
Indian/Pakistani	1
White	1
TOTAL	42

33 out of 42 participants described themselves as of an Asian heritage (Bangladeshi, Indian, Pakistani) and form the largest ‘group’ of respondents. Six out of 16 of those of Pakistani

heritage wrote British Pakistani, of the eight relaying Bangladeshi origins one wrote Bangladeshi British, three were of Arab origin, four indicated mix origins, five Indian with one stating British Asian Indian, one as White, one as British/Irish, one Algerian.

Migration patterns

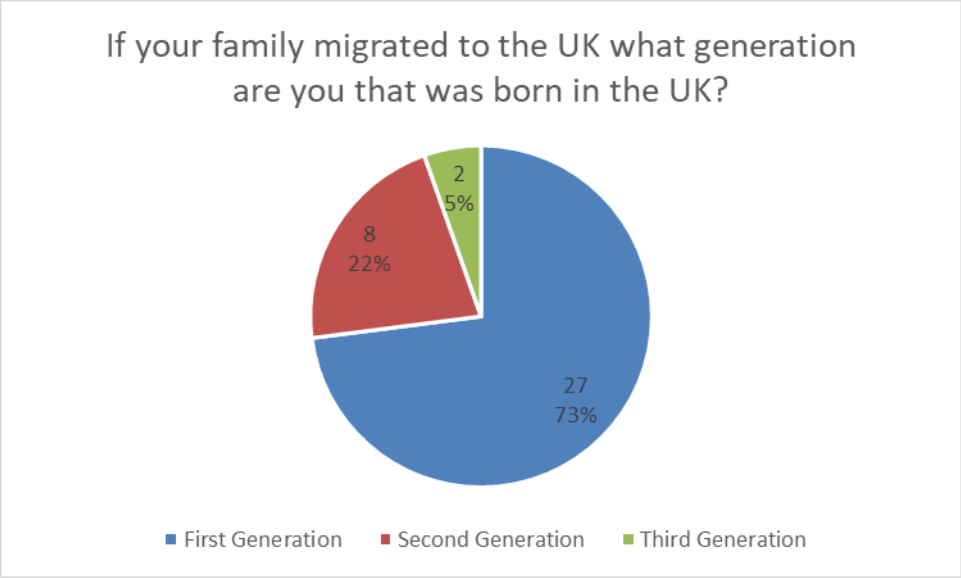


My parents were migrants to the UK	31
My grandparents were migrants to the UK	10

100% of the respondents' parents or grandparents were migrants to the UK.

Generation born in the UK

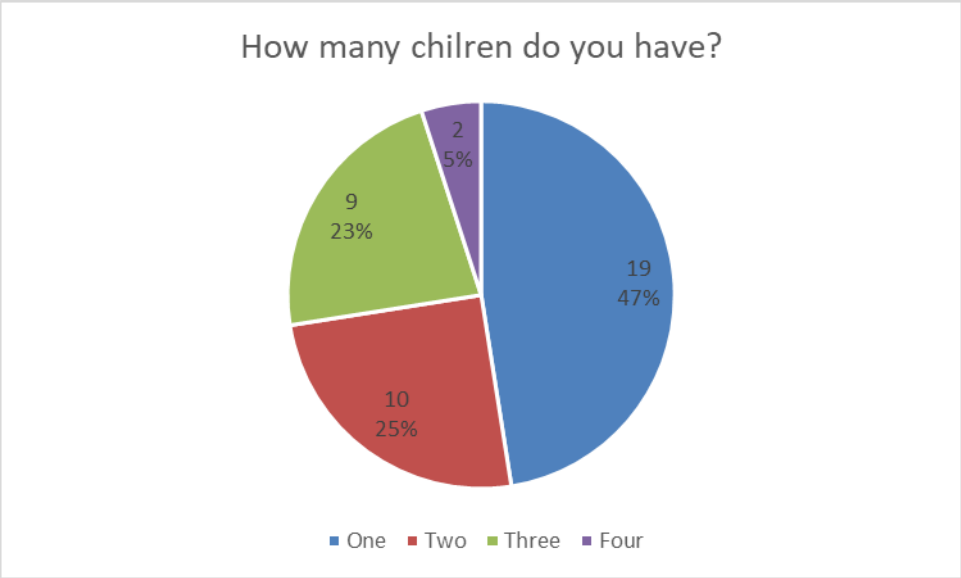
If your family migrated to the UK what generation are you that was born in the UK?



First Generation	27
Second Generation	8
Third Generation	2

The vast majority (73%) of respondents were first generation, followed by almost a quarter (22%) second generation and 5% third generation. I had expected to see more second generation so that was an interesting discovery for me.

Number of children

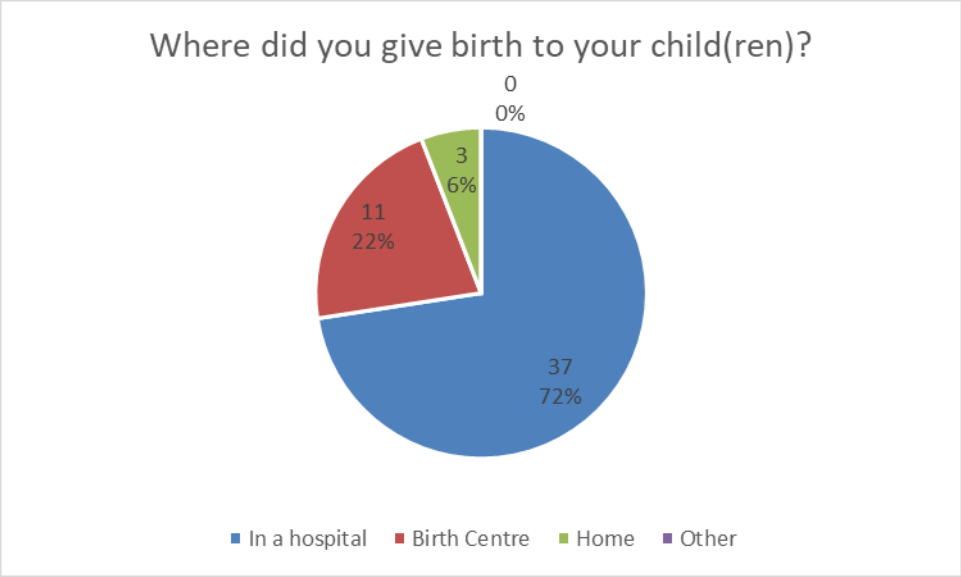


One	19
Two	10
Three	9
Four	2

Ages of children

Ranged from not yet born to 18 with the youngest of the respondent who mentioned 18 having a 7-year-old (which fit the eligibility criteria).

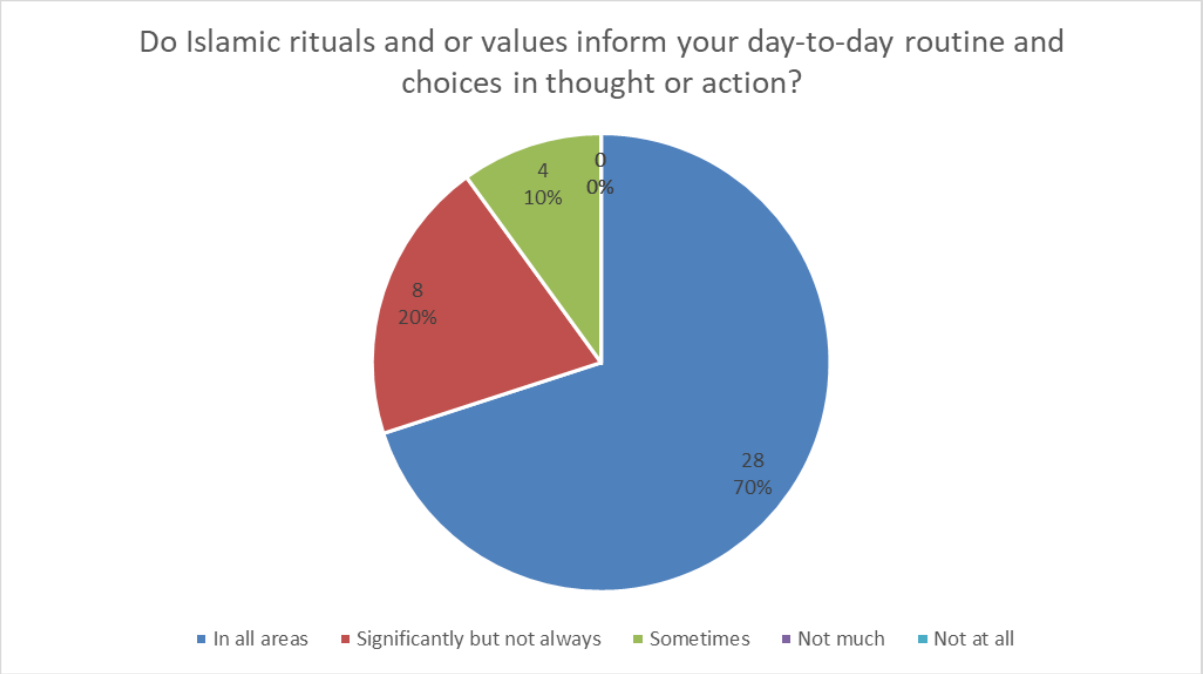
Place(s) of birth



In a hospital	37
Birth Centre	11
Home	3
Other	0

Some shared the variety of places they gave birth if they had more than one experience in a different place. Some spoke of the difference in experience in their responses which are elucidated in the themes.

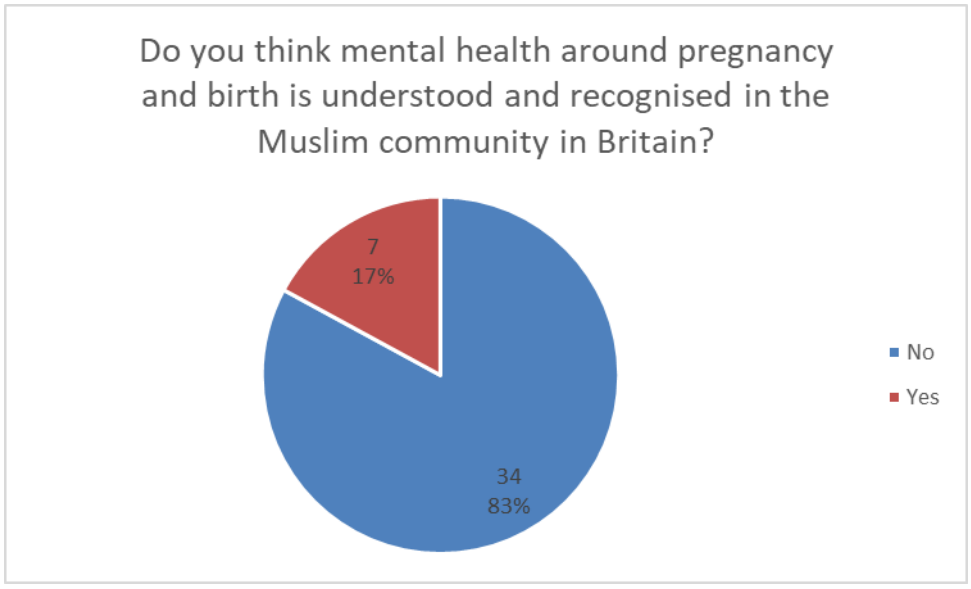
The role of Islam in daily lives and as informing value systems



In all areas	28
Significantly but not always	8
Sometimes	4
Not much	0
Not at all	0

For the vast majority of respondent's, Islamic rituals and or values informed their day-to-day routine and choices in thought or action, with 28 responding *In all areas*, 8 *Significantly but not always* and 4 *Sometimes*. No one respondent *not much* or *not at all*. This is one of the most significant and central findings to reflect on in understanding that Islam played a role 100% for of all respondents in varying degrees, be it sometimes (10%), significantly but not always (20%) and in all areas (70%).

When asked: *Do you think mental health around pregnancy and birth is understood and recognised in the Muslim community in Britain?* 34 respondents answered No, 7 answered Yes and one was left blank.



No	34
Yes	7

5.2 Reflexive Thematic Analysis

"Writing is the process through which the analysis develops into its final form".

(Braun and Clarke, 2013, p. 249)

So begins the process of weaving the threads of the short stories (extracts), of the experiences shared, into a coherent narrative about the data and what it means in relation to the original question of this thesis. The data analysed thematically here was drawn from the 42 qualitative survey free text responses. The average length of responses varied significantly ranging between around 45 and 785 words per question, averaging approximately 415. I wondered about and pondered on every quote I read and re-read in the analytic process about the underlying meanings and what was not being said as well as what was, and the meaning of both and how best to do it justice. I felt acutely cautious of interpreting the information from my perspective, as ultimately the author of any work inherently influences and shapes the writing. I attempted to report the results as closely as I could in this chapter and leave my interpretations and reflections to the discussion chapter. Though in some sections it was necessary to explain or detail something for context in mind of readers who may not be familiar with some concepts – mainly in the sections around the role of Islam and Islamic concepts / meanings of Arabic words / significance. Original participant quotes were not corrected for grammar and spelling and are presented in their raw form. The data analysed thematically in this sectioned is formed of the free text survey questions Six main themes were developed through the data in the reflexive thematic analysis process. These were:

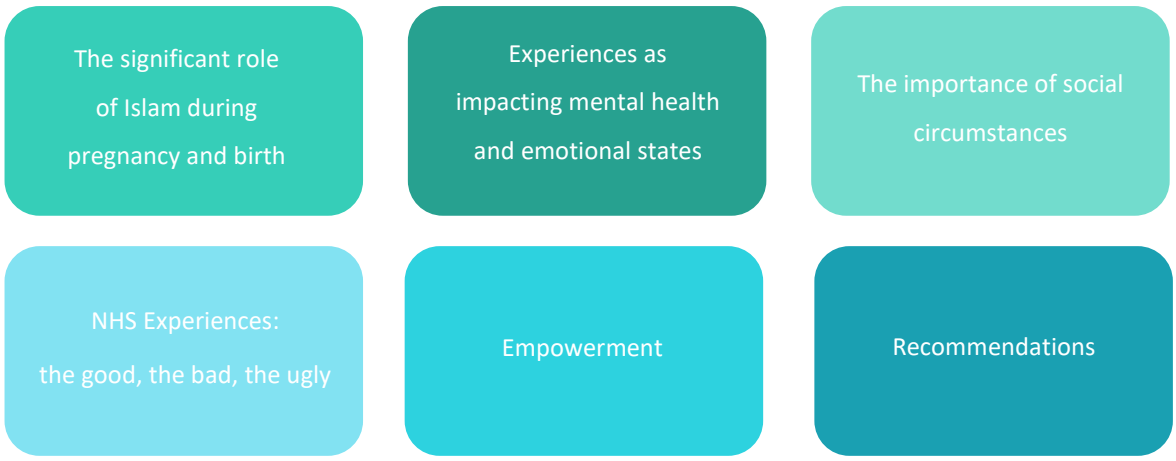


Figure 9: Visual depiction of empirical study Part I (Surveys): Reflexive Thematic Analysis summary of themes.

5.2.1 Theme One: The significant role of Islam during pregnancy and birth

Many of the responses in this theme captured how faith, specifically Islam, played a role in how pregnancy and birth and healthcare were experienced. The first sub theme reflects how gratitude, through the explicit understanding of it from Islamic scriptures, played a role in

participants giving meaning to their experiences. The second sub theme discusses the significance of Surah Maryam (the chapter in The Holy Qur'an that details the story and context in which Maryam (Mary pbuh) gave birth to Isa (Jesus, pbuh). The third subtheme considers the dynamic of differing notions of modesty and need for privacy. The fourth sub theme explores participants relationship with Allah (God) and how they sought refuge through this connection which helped them find peace. The final sub theme considers the role of Islam in participants mental health and wellbeing and how their faith helped them feel mentally resilient.

5.2.1.1 Gratitude: Most beautiful and heart wrenching

The central organising concepts of this theme capture participants experiences of gratitude often indicated using the Islamic word 'Alhamdulillah' (praise and thanks to the Creator, Allah). This is an oft repeated word by many Muslims in relation to anything that one feels grateful for and is attributed to God as providing and gracing us with blessings. Gratitude was expressed significantly, indiscriminately and held power in the expression of the narrative of the experience. Although a sub theme, it was weaved through all areas. This recognition of gratitude to Allah in this theme was woven around being thankful for a healthy baby, children being born safely, wanting children to also be grateful for all the blessings they receive, as articulated by a participant:

> *"I am much more grateful for my children. I recognised that they are only here by Gods will and how I desperately wanted them. I want my children to grow up as faithful servants of God as I feel like it was only by his will that they are here. I want my children to be grateful for all the blessings that they have. And to recognise that it has come from Gods mercy."*

Statements like this when looked at closer carry deep meaning. For example, wanting children to grow up 'faithful' - in the Arabic *Amanah* – which means to be in trust of something i.e., the message of Islam, of living this through embodying a character that upholds high moral values and strives for *Ihsan* (excellence) in character. There are three levels of faith in Islam (Islam, Iman and Ihsan, those who embody it are referred to as Muslims, Mumin and Muhsin). Being grateful for blessings and recognising God's mercy (referred to in the Arabic as Rahmah and encompasses meaning of compassion, grace, loving kindness, attentiveness) have a significant impact on how children are raised in a positive, healthy environment with strong values and conscious awareness. The above sentiments were reiterated in multiple participants quotes who shared similar feelings of deep gratitude, illustrative examples of which can be seen here:

"Being thankful, understanding that this is a privilege and honour and that we are not promised anything. As Allah gives he can take, and we must be grateful for everything"

"We prayed and supplicated a lot for a healthy baby, which we received and were very grateful, giving alms out of thanks".

"The birth was uncomplicated, which I am so thankful for."

"My pregnancy was pretty straightforward Alhamdulilah."

There was a sense of gratitude for things being straightforward, and or for coming through hardship. Furthermore, birth itself evoked a sense of immense feelings of gratitude and deep impact on the heart. Important aspects of gratitude included: the witnessing and sensing of the miracle of life and the blessings tied to this, feeling privileged and honoured, conscious not to take anything for granted, and seeing everything as a gift from God; a blessing. Some of these experiences around appreciation and gratitude are represented in the words of two men, who described their felt sense of being present and witnessing the 'miracle of birth', and how this experience connected to a strengthening of faith, through what for them was a profound and most beautiful experience:

"The second I heard my baby's cry, tears kept rolling down my face. My wife, who at this point wasn't with it, didn't even know why I was crying until they wrapped up baby and placed him in her arms for a moment. It was the most beautiful and heart wrenching experience of my life."

"Islam tells us the significance of birth in the Qur'an. But when you practically see the birth you realise that this truly is a miracle. My wife giving birth made my faith stronger."

Linked to gratitude was a sense of wanting to give and spread further joy and blessings through charity, which is also a part of the Islamic rituals of birth: to give alms, (as well as being one of the five foundational principles of Islam). This included a reciprocal act of giving back out into the community through the giving of charity. Traditionally this would also include the practice of cutting or shaving of the baby's hair on day seven post birth (also for hygiene reasons, not compulsory but part of the tradition) this is weighed, and its' value is paid in silver or Gold.

Gratitude was also connected to a strengthening of faith, witnessing the miracle that is life. Connected to this was also an intellectual comprehension of the potential of higher goodness (*khayr*) that the human mind cannot conceptualise, that even in difficult times there will be

blessings that may not be immediately realised or may be reserved for the next phase of existence (known as *Akhirah*, after life). As can be seen in the sub theme on *Surah Maryam* the use and impact of the Qur'an as a source of comfort, as divinely revealed healing words, is drawn on for wisdom in hardship and acts as deeply significant anchor for meaning making of experiences. These can be thought of in the same arena of say 'affirmations' (as one participant mentioned) on one level – which is a collectively understood term in the wellbeing arena. Words used may be different or unfamiliar in the mainstream healthcare services but in essence may serve a similar purpose. Muslims may use prayer (*salah*, *dua*) and *dhikr* and or meditation and affirmations but the essence of what one is seeking is a state of support, connecting to a higher power and source, comfort, a calming of stressful states through engaging in a meditative, reflective practice. However, what is important here is that for Muslims this is rooted in specifically Islamic practices

5.2.1.2 The power of Qur'anic stories in particular Surah Maryam: Instead of doing positive affirmations I had done dhikr instead.

Respondents spoke of how they used *Surahs* (the nearest meaning in the English would be chapter) from the Qur'an with specific emphasis on Surah Maryam. The story holds deep significance for women in Islam especially as it tells the story of Maryam (Mary, pbuh) giving birth (alone) to Isa (Jesus, pbuh) and her story of strength and having to go against the norm of the society she lived in. Connecting with this Qur'anic narrative about the miracle of birth and the story of Maryam (peace be upon her) who is considered by some as the only female prophet in Islam was prominent for Muslim women. Many of the respondents used the teachings, including the strength that God gives in this story for coping through hardship. This also highlights the strength and critical nature of Islam in people's lives in such life changing stages such as birth and how Islamic teachings are applied as useful cognitive framing tools, helping people feel connected to a wider human narrative. The spiritual aspect and expression of such experiences are core in the Muslim persons' experience. Its validation is significant. Muslim women shared their experiences of Surah Maryam during labour and birth:

> *"I remember playing Surah Maryam when in labour. I prayed in labour and made dua..."*

> *"Islam made me settle my nerves, I used the story of Maryam AS to get me through the whole experience. Instead of doing positive affirmations I had done dhikr instead. I also used labour as an opportunity to ask for forgiveness. In terms of practical ways, I made sure that I was covered modestly, asked for no routine checks (which are not necessary), and asked that anyone who enters the room to knock so I can cover."*

"I think I just had a heightened aware of the amanah (trust) that was being placed with me, so I had to look after my body. I read surat Maryam before the birth to help me prepare. I also tried to make dua (prayers) during labour itself, though that was limited, thinking that the pain of labour would be an expiation for my own sins."

Women shared how Islam and Qur'anic Stories such as that of (but not only) Maryam (pbuh) offered consolation, patience and strength. It was also used as a form of mental preparation and where recitation of prayers and *dhikr* (remembrance of God usually done through supplications and reciting some or all of the 99 names (attributes) of Allah) were utilised over affirmations. The awareness of the *amanah* (trust) of being given the blessing of a child also created a heightened sense of self care. Drawing on Islamic stories such as that of Maryam's (pbuh) ordeal provided a source of strength, connection and endurance through pain:

"I read a lot of Qur'an up until my deliveries, Islam gave me patience and strength to bear the pain, seeking the rewards as described in Hadiths and surah maryams ordeal when giving birth to her son."

There were references to other *surahs* and general prayers that helped distract from pain, anxiety, worry, and gave hope. People recited prayers for a healthy baby and delivery and used Qur'anic recitation or listening to the audio of it as a coping mechanism:

"I would always make dua that my baby be healthy and was making dua during the birth. I played Surah qiyamah (as there was a recitation I really like) and that helped distract me from pain."

"I prayed whenever I had labour pains and it helped a lot."

"In a ritual sense - the adhan, shahadah, date etc, but also in a self-technology sense, as coping mechanism, and story."

"I was making dua throughout my labour. Pregnancy - praying 5 times a day and making dua was consolation when I didn't feel so good."

One mother highlighted an example of how special it felt being able to pray in labour and what this meant for her:

"Being able to pray in labour was something special. I wasn't in active labour and so I was still able to pray."

Others spoke about prayers in relation to the rituals and role of the husband:

"Reading Allah's names during the births, my husband read yaseen throughout, he fed me dates during the birth and afterwards he read the azan in the babies ears and chewed up some dates, my father did this too."

Some mothers linked prayer to impact on their baby and developing child:

"Throughout my pregnancy I read some duas. During the birth I tried my best to make lots of dua and ask for forgiveness. During the birth of my son, we listened to the Qur'an while I was giving birth. The ikama and azaan were read to the children when they were born."

"He is a happy and healthy baby. I think playing Qur'an whilst he was in the womb and then during his birth was important. He seems to enjoy hearing the Qur'an recited now."

5.2.1.3 Modesty: The struggle between shyness and accepting lack of choice in antenatal and maternity services.

There were nuanced experiences relating to the struggles between personal preferences regarding modesty and what that means. These differing notions of modesty which are intertwined with religious obligations were in contradiction with that of hospital culture and availability of requested gender of staff, usually female. This theme linked to the theme which encapsulated respondents' experiences of the NHS especially as occurring in the hospital context and affected by NHS culture. Women explained how they understood that in situations of necessity having a male healthcare practitioner was acceptable. However, this often led to personal feelings of discomfort and unease having to expose certain parts of the body that one does not feel comfortable with exposing. Some of the following quotes are illustrative of the nuanced details of such scenarios:

"I was not happy about the male midwife but had to quickly accept as i had no choice and I know Islamically its ok if I have no choice. Throughout my pregnancy in my scans i had asked for a female sonographer and managed to get one (despite a sign at [name of hospital] saying we can't choose) I just politely insisted I'd appreciate and wait around for female. So when i was in labour i just accepted my luck. i had always tried but knew when to step back if unavailable so i was content. I didn't have to time to delve into it as i was ready to give birth. I had previously written in my notes that i would be taking my placenta home for burial for religious reasons and i remember that was respected. (my mum later came in and made a fuss to dispose of it but the staff were polite and respectful of my decision)."

"We wanted a female only doctor due to our religious needs but sometimes this was not available or the wait was too long, so we had to make do but they did try to accommodate…"

"I couldn't have my full hijab on my head in the operating theatre, it would be good if they can somehow try and find a way where women are least exposed. I know about infection control etc...but I feel areas of my body like my legs didn't need to be exposed to perform the procedure. They could have covered me with a disposable cloth and just expose the area of where they made the cut."

> *"I was too shy to express it. It is difficult to shower and stuff as the visitors of other patients are there. I used to come out with a towel then hijab on top of the towel on my head."*

It was not just women who were uncomfortable, the husband would also experience discomfort and shyness in these unfamiliar situations that required bodily exposure and some level of intimacy with strangers. This was the case especially for those who observe strict segregation rules between genders and then are suddenly faced with a situation where there is no, or little alternative offered. These experiences were challenging and demonstrated a lack of awareness on the part of staff who did not realise (or were even unkind) regarding the sensitivity around modesty in some cultures:

> *"He also felt uncomfortable getting into the pool with me as there were three women in the room."*

Contrastingly, some participants shared positive experiences of being respected and where staff communicated well and positively:

> *"They were very considerate. When me or my husband needed to pray. They also told us they'd let us know in plenty of time of a male colleague needed to check me or baby over."*

> *"I kept my hair covered and my abayah on and nobody said a word...i was respected."*

5.2.1.4 Closeness to God: Peace and seeking refuge

Some elements of this sub theme held ideas of faith, strength of faith, seeking refuge and comfort, which drew out experiences in relation to the question on how significant of a role Islam played in respondents' lives. Having a narrative through a way of life and a belief system helped make sense of loss and grief, of pain and suffering rooted in a grander narrative of the purpose of life and existence. Participants used *Surah* (chapters) from the Qur'an to draw comfort and strength from which helped them feel close to Allah. One example is that of seeking refuge and comfort in *Surah Duha,* which is translated into the English to mean "The Morning Hours" or after the break of dawn, when the sun light appears symbolically and literally. For many Muslims, these verses also speak to us metaphorically and are to be taken as teachings.

Respondents shared the multiple areas of positive influence through Islam on their life choices in relation to pregnancy and birth from nutrition to reciting certain prayers and Qur'anic passages, to helping make sense of loss. All of these positive impacts through their

understanding of Islam and practising rituals and teachings connected to feeling close to Allah. Participants drew on the Prophet Muhammad (pbuh) story of losing his children, they chose names of children that created a connection and nearness to God and to those with virtuous qualities either prophetic names or names taken from the *Surahs* such as *Rahman*. Personal and familial wellbeing was rooted in this connection to and through Islam to the divine and creation. The ability to overcome intense personal struggle and trials were rooted in the comfort that came from seeking refuge in God:

> *"Trying to eat certain foods during pregnancy and after birth. Also certain duas / surahs during pregnancy / birth. The loss of my first baby made me grow close to Allah as i believed He truly loved me and wanted me close to him. This made me accept what had happened easily and connect to experiences of our Prophet pbuh who had lost his sons. Surah Duha helped me after tis experience. Surah Rahman is one of my favourite surahs so that is why i called my son* [removed for confidentiality]. *My eldest son was named after our prophet and also his grandad. My youngest son is named after our prophets closest companion, i have done this so they have qualities of them by their name."*

Another participant stated how she was able to overcome fear instilled in her about potential consequences medically through seeking refuge and closeness to God, through her strong connection:

> *"felt very spiritual and connected to God the second birth because of how much the doctors had scared me about the possibility of having a stillbirth due to cholestasis etc and I really didn't want to be induced and I had so much tawakkul that the day of my induction appointment I ended up having the baby a whole hour before that appointment time."*

Drawing on the power of faith and *tawakkul* (trust in Allah) created a mindset that empowered and led to a sense of control that did not depend solely on a system outside of oneself, thus potentially impacted outcome and the experience. One respondent spoke of the contentment that came from reliance on Allah no matter the outcome:

> *"I felt my faith played a pivotal role in both my pregnancy and birth. I felt content that I could rely on God no matter the outcome, made lots of duaa for a healthy pregnancy and delivery and for my baby, I completed reading the Qur'an out loud during my pregnancy so my foetus may gain some comfort from listening to it too, and used dhikr to time my breathing during contractions (breathe in and say bismillah, breathe out and say alhamdulillah etc.). Alhamdulillah I feel this helped me to have little anxiety in both my pregnancy and labour."*

Again, an interesting link is described with the use of breathing and *dhikr* rhythmically here for managing contraction pain and seeking comfort for the mother and baby. The meaning of the words used are powerful and represent the consciousness and recognition that relief comes

'with' the name of Allah i.e. bi-sm-illah literally meaning *with the name of Allah*. Despite being in intense pain and constricted through contractions, the word Al-hamdulilah (all praise and all thanks to Allah) is being used particularly for the out breath, which creates an expansion and release and there is an expression of gratitude in it. It is important to acknowledge, the mention of the impact of recitation of the Qur'an as providing comfort for both the foetus and mother. For some women it helped through their panic and anxiety or self-doubts and worries:

> *"I was also thinking about the huge responsibility of being a mother when I was pregnant. I found it and still find it at times very overwhelming. Wondering if you'll be good enough…".*

> *"My second pregnancy I had anxiety and panic attacks. I turned to my faith a lot to help deal with such episodes and to get me through."*

> *"Believe and trust in Allah kept calm and made to look forward for best."*

Faith and Islam played a clearly significant, helpful role for many Muslim women during pregnancy and birth. For some this was facilitated through a feeling of safety that came with seeking refuge in Allah and the feelings of closeness and connection that resulted. If respect and value is given to the resource that comes from faith and strength in Islam that many participants experience, this could be a useful and helpful tool in the pregnancy and birth process in healthcare for Muslims in the UK.

When there were challenging or painful circumstances around birth words like, "my faith made me stronger" and "my faith kept me going" were stated. Belief and trust led to a state of calmness and looking forward to better times. Using faith to get through anxiety and panic attacks was also another significant aspect to overcoming difficulty and stress.

Dhikr and *salawat* (salutations on the prophet) helped to get through labour (some used affirmations or hypnobirthing techniques alongside or adapted) as mentioned earlier using techniques such as *Bismillah* breathing in, and *Alhamdulillah* out was a helpful and powerful tool between contractions and during pain and labour. These techniques and practices created the connection that helped women feel closer to Allah.

> *"For me, making constant dhikr, salawat on the prophet really helps me with the pain. And I remember shouting Alhumdulillah when my second child was born. It's a very humbling experience and i personally feel only Allah gets you through it.*

Reading the complete Qur'an during pregnancy was perceived as very important. It provided a source of comfort for the mother and was considered important for the wellbeing and development of the foetus. It is thought that the foetus is sacredly connected to Allah and hearing the words of revelation of its Creator maintains a closeness to the state of *fitra* (natural disposition) we are born with and there is hope the child will be righteous and pious, of good character. The power of belief and spiritual connection during pregnancy and birth impacted the mindset and outcome despite feelings of anxiety and or worry:

> *"…I think the way I'm able to cope is that being a mother is such an important role in Islam which so valued by Allah and so I try to remember this when things might seem difficult and it is comforting to me."*

Some of the women used their knowledge of the value of motherhood in Islam, which helped them feel close to and connected to Allah, to help themselves through various challenges.

5.2.1.5 Islam played a vital role: My faith kept me going mentally

This sub theme had elements of facing challenges that impacted on mental health. These challenges included the physical space - the environment of the birth, the space available, lack of privacy, calmness of environment which allowed for prayer openly without feeling restrictions and feelings that were expressed in the absence of that as well as a 'need to hide away'. Choices were made on consideration of what was available or acceptable for example, a wish to play the Qur'an during birth where practical restrictions did not allow for it or not having choice over hijab/privacy, consciousness of prayer times. Despite these and many other challenges it was faith that kept participants feeling strong mentally. The availability and or restrictions of both accessibility and attitudes of staff affected future decisions of where to birth to allow for a better experience and autonomy which drew out people's experiences in relation to the NHS and healthcare. The difference in experience between being in a busy high turnover ward and a birthing centre or home or other place of calm had a significant impact on the experience (this is also explored in the context of theme four), on mental health and wellbeing, and on how people drew on their faith. Participants shared the centrality of prayer and being conscious of prayer times and access to prayer spaces or lack thereof during birthing. Having this facility available helped them feel calmer and grounded. One participant hared how she and her husband were both able to pray more openly due to the space they were in:

> *"Well as we had our own space due to me not being high risk. We were able to pray openly...my husband was able to make dua for me and baby. Etc*"

Having this kind of spiritual space facilitated also helped in offering a feeling of being accepted wholly. Another participant shared her consciousness around prayer times and the major role of Islam in life for her which again provided a sense of grounding:

> *"I was conscious of prayer times and wudu so did try my best in keeping this up. Islam plays a major role as its a way of life. Maybe if i had more time I could have played the Qur'an in the theatre or something which would have been nice. I would try and see if i can have a home birth if i have any future children."*

The focus on prayer provided a strong sense of grounding and anchoring, bringing a sense of calmness in difficult times. This relates to how important the holistic model of understanding mental health is and including an understanding of spirituality in that for people. The endurance many participants experienced, and the impact mentally was mitigated through focus on prayer as a meditative healing source of support. Part of being able to pray was also a feeling of being accepted and respected through being provided with a space or opportunity to pray or have the Qur'an playing or be able to recite Qur'an / make supplications during labour.

There was a deep consciousness of Islamic practices and teachings, with the view of Islam playing a major role, using words like 'vital' and 'major' to indicate the role of Islam in mental health. Participants understanding of Islam also played a central role in how losses were psychologically and emotionally processed. In all aspects Islamic teachings were important whether in relation to death and burial and following Islamic guidelines (practicalities) or drawing on hope though Islamic understandings of the meaning of life and existence and death and our purpose, to gratitude and fulfilling rights of the baby through the *aqiqah* rituals:

> *"Islam played a vital role particularly in our pregnancy losses. We tried adhere to Islamic teachings in relation to death, burial and post mortem. It was also a central part in giving us hope to continue. During the following pregnancies we tried to follow the Islamic teachings closely and prayed for a good outcome. During and after birth we tried to strictly follow the birth rituals which Islam teaches us. We were particularly conscious of this to demonstrate our gratitude to God. We also ensured that we fulfilled the rights of Aqiqah and enjoyed the celebration with family."*

In this example, Islam played a powerful and central role giving hope to continue following losses which led to increased consciousness in adhering to Islamic teachings in the hope for better outcomes in the future. This was also weaved with immense gratitude and celebration of the gift from God.

One father spoke of how Islam played a transformative role in his becoming a father. He went from being in a bad place mentally and emotionally and having habits that were destructive to recognising a blessing from God, being gifted and given another chance:

> *"As a Muslim male before my son was born I was in a very bad place mentally and emotionally and had bad habits that were destroying my life but when my wife said she was pregnant it changed everything I felt Allah has given me another chance and he still my heritage is Pakistani and family members would say things believed in me because he had blessed me with the child from that point on I dropped all my bad habits and prepared to become a father."*

Another respondent on how vital Islam was for them during the pregnancy and birth process shares how it helped:

> **"***It helped me 100% in keeping me going. My faith kept me going mentally. During this experience it's very easy to give up and lose faith but my religion kept me praying throughout this experience Alhamdulillah's."*

Islam is providing strength, there is an incredible recognition of the power of faith and religion keeping one going in difficult experiences where it would be easy to give up and lose faith. One person who experienced PTSD during the first birth felt Islam had strengthened her in subsequent birth experiences:

> *"My first my mental health was impacted severely, I have ptsd from my experience. My second, third and fourth I feel Islam has strengthened me alhamdulillah."*

Faith keeping one mentally strong came up more than once, directly and indirectly. It acted as a most meaningful and fortifying experience contextualised in the understanding of the bigger picture and context of existence as transient beings whose life does not stop with physical death:

> *"Islam always brings positivity in ones life. My babies were all premature but I never felt worried as I knew Allah is the one who provides."*

Having a trust that things will be okay to the point of modifying what could have been a worrying narrative into one of trust that Allah provides and that things will be okay is again another strong cognitive tool for mental fortification resulting in a better sense of wellbeing. Another respondent who felt terrified also had a strong trust and knowingness in Allah that helped her confidence:

> *"I knew it was natural as Allah had made it so and therefore I could do this. So even though I was terrified I left it in Allah's hands."*

Other comments about the role of Islam on mental strength included:

> *"It helped keep me calm and grounded."*

> *"It kept me determined and hopeful. This is what helped me during my pregnancy and during the birth also. The hope of something better coming out of it kept me going. Knowing that ease will come after this comforted me."*

These experiences tell us how Muslims feel their experiences have impacted their mental health and their sense of being in the world. They were able to benefit from focus on faith during trying times particularly pregnancy and birth.

There were strong links between the sub theme of '*Islam played a vital role: My faith kept me going mentally'* and the sub theme of *'Gratitude: Most beautiful and heart wrenching experience'.*

> *"I had to remind myself that this child is the creation of Allah and a gift from Allah and any pain and difficulty will be rewarded. I also took care of myself as I had to be extra careful with this amanah that Allah bestowed upon me. I was able to pray and continue my days as usual during pregnancy. At the time of birth Mum husband did the Adhaan in my son's ear and then the nurses took him away to clean and clothe him. Everything else was just standard for every child."*

Understanding that a child is a gift and creation of Allah that has been entrusted upon one is a powerful motivator encompassing both gratitude and a recognition to - as one participant stated - *"be extra careful with this amanah that Allah bestowed upon me." Amanah* in the Arabic is understood to be something one is entrusted with and a feeling of responsibility that comes with honouring that gift and trust is held in high regard. Some spoke of how they were able to continue as normal and prayed the usual prayers as well as right through labour even as a source of comfort, pain relief, turning to a higher power in need and as a strong bond - a nearness to God like at no other time, being part of the process of creation, a vehicle through which life is created and emerges. There was recognition that God gives and takes life and that hope lays on the foundation of trust in that relationship with The Creator. Contextualizing challenges within the meaning of life as understood in Islam offered participants a sense of grounding mentally that helped them carry on and persevere through the difficulties they faced:

> *"Islam always plays a very big role especially in tough situations and circumstances. Making dua throughout pregnancy and birth i believe helps emotionally, physically, mentally. Following special guidance from the prophet PBUH such as recommended foods i.e dates. Also the call to prayer being said in baby's ear when born."*

There was a strong belief that *Dua* (supplication or sometimes referred to as prayer) helps emotionally, physically, and mentally plays a significant role in challenging situations. For

some these challenging struggles included an understanding that problems were related to the effects of the 'eye', (known as *'ayn or nazr'*) or black magic (*sihr*):

> *"My mum felt I got nazar because she felt I should have covered my bump more, wore lososer clothing and kept my mouth shut (avoided some family disagreements) this made me feel like I was to blame a little bit. I but it helped me to go be silent, less angry in life."*

> *"I also had marital problems and strongly feel it was due to the effects of nazar. whilst extremely challenging This had a positive impact on my faith."*

For many Muslims this is a strong belief and a 'language' that communicates something that is not often understood in the psychological or mental health world of the Western narrative of distress.

5.2.2 Theme Two: Experiences as impacting mental health and emotional states.

This theme captures experiences of pregnancy and birth as impacting on mental health specifically, in relation to stress and pressure from family, for example in laws or emotionally or mentally unavailable mothers. Though mental health experiences were weaved into the previous theme, as well as experiences of healthcare, it was a significant area in and of itself. Descriptions of experiences that impacted mental health contained expressions of feeling vulnerability and fragility, stress and anxiety were mentioned multiple times, not being understood and lack of support, which are illustrated below through the quotes. Strong descriptor words were used by participants relaying their experiences and the impact these had on their psychological and emotional states of being. Some of these words which will be shared in the context of the quote below included: 'shell shocked', 'mortifying', 'humiliating', loopy', 'disconnected', and 'exhausted'. These particular experiences were in relation to experiences in hospital and within the NHS healthcare system where women felt they had lost control and things were happening 'to them' and not in consultation 'with them'. Participants reported a variety of very challenging experiences of trauma, loss and miscarriage, and the consequences and difficulties involved in getting back to life after these significant events. Other participants shared experiences of paranoia and for some participants their belief in God helped as a coping mechanism.

Lack of social support or pressure led to post birth stress where decisions were not supported, or others decided or pushed their ideas of how to care for a baby. There was a sense that older generations are ignorant of mental health and things are changing with the new generation.

There were a few experiences that were good and had a positive impact on mental health. Some had found it a struggle to talk about the trauma or the mental health aspect and found it challenging.

5.2.2.1 Intense experience of life

It is well known and expected that pregnancy and birth can involve an intense mixture of feelings and be both joyful and painful. It is important to share these expressions by Muslim participants in the context of providing a rich description of the entire data set rather than just what may be considered a 'Muslim centric' only experience. A plethora of emotions and experiences were described by participants as intense and challenging, coupled with an emphasis on the joy of the reward of meeting their baby. Some illustrative quotes on both the

intensity of the experience of birth and the joy felt from seeing the baby are shared:

> *"Labour was intense, probably the most intense experience of my life, and definitely the most rewarding when we finally got to set our eyes on the little one."*

> *"In terms of the birth itself, it was challenging but most definitely a beautiful experience."*

One participant discussed how woven her feelings were with guilt and feeling ungrateful because she was unable to enjoy part of her experience due to the physiological impact of nausea and fatigue. She further illustrated how this changed soon as the nausea and fatigue stopped, into a positive emotional state, full of excitement and getting organised for the new arrival including how it impacted her sense of self as she described:

> *"I didn't enjoy my first trimester because of the constant nausea and fatigue. I felt quite guilty and ungrateful for feeling that way as we had been trying to conceive for nearly a year and were quite desperate to become pregnant in the first place! Once the nausea went away, I loved my second and third trimester alhamdulillah. I felt big and beautiful! I had my appetite and energy back, I spent my maternity leave getting organised and seeing friends and family, as well as swimming and long walks in the summer. It was lovely and I was so excited to become a mother."*

Physical factors such as having energy and appetite as well as the social aspect of being able to visit friends and family, having a supportive partner and being able to enjoy things like swimming and walks, and a having a positive sense of self and body, were important supportive frameworks that lessened the intensity of feelings.

5.2.2.2 She wasn't emotionally available / conflict in views and mega stress.

A number of respondents felt their own emotional wellbeing and mental health were impacted by the emotional states and mental health of family members and significant others, particularly mothers and mothers in law. The presence of a mother at such a life changing time in a woman's life holds significant meaning for many:

> *"My mum has mental health issues, so she wasn't emotionally available. (she's been diagnosed with paranoid schizophrenia so can be unpredictable at times and misunderstanding people)".*

The emotional availability of a mother seemed to hold significance at a time one is about to become a mother themself. The significance of the feelings of mothering and motherhood and one's relationship with their mother can be magnified during pregnancy and birth and should not be discounted. The impact of the feelings being evoked during this period in relation to the

mother-daughter relationship and emotional (un)availability could be explored in further research that may benefit from a psycho-analytic understanding.

There was a notable issue around women being expected to work and do chores as normal in certain family set ups, causing exhaustion, stress and strain and not being allowed to 'complain', having to hide their feelings and carry on. The stress induced through living with in-laws who put pressure on women even during pregnancy and expected them to keep up with chores was illustrated in the following example:

> *"My pregnancy was quite stressful as I was living with my in-laws and didn't really feel very comfortable there, so if i was not feeling well i would only tell my husband and wouldn't share it with anyone else. Alongside helping in the house as is expected I was also studying at university doing a postgrad."*

Multiple factors were apparent as causing stress, to be expected to help around the house as usual, for some to be studying or working and not feeling able to share discomfort and feelings were all significant factors each on their own and together can cause a compounded effect of intense stress. Participants also suggested how education around the importance of this period and the impact it has on the mother as well as addressing cultural issues through mosques would be helpful and this is discussed further in theme six.

Other participants shared feelings about their particular context that had an impact on their mental and emotional health.

> *"Mental health was affected by my mother in laws differing views to my husbands and mine. It would cause conflict at times and as my mother-in-law suffers from mental health issues my husband and I felt we had to compromise a lot more in favour of her. It felt like we were walking on egg shells. Post birth was really tough physically and mentally. If my husband and I weren't around my own parents and sisters and had not received the immense support that we did, I believe we both would have been on the road to depression."*

> *"My emotional health was affected due to family stress. I felt low at points. Days before my son was born, I had a breakdown. I'm not sure what caused it but felt better after giving birth."*

When participants were facing other stressors in their life they felt acutely impacted. This compounded the challenges already faced:

> *"I was mega stress during pregnancy due to pgce and issues with mil and house renovations. Hardest year of my life."*

Some participants faced difficulty in navigating needs and being heard. This sometimes led to having to compromise or forgo their needs and wants due to the mental health needs of others. Contrastingly some participants shared that having family members that provided protective and supportive roles prevented potential depression.

5.2.2.3 'Mental health': the ongoing impact, and resiliency factors.

The timing and onset of mental health problems varied circumstantially and widely. For some it was during pregnancy and or birth for some after, sometimes both, for others triggered by lack of support or the exhaustion that came from lack of sleep or from stressful relationships. For some the first pregnancy and or birth was harder, for others it was later pregnancies and birthing experiences. One thing that was evident was that experiences and existing protective and resiliency factors played a role and the responses were contextual and circumstantial based on these factors.

Those who has a strong sense of self confidence and were able to seek help were able to self-direct through the pain and get the support needed:

> *"Mentally I had mentored myself constantly to keep reminding myself that I can do anything and I have a very high pain threshold. It is for this reason that I refused to take any gas and air or medication throughout the whole birth."*

> *"At one point after returning home I started having thoughts of my husband wanting to harm the baby, and I just remember thinking "oh I've got to get myself and her out of here or he's going to kill her". I found the courage to tell my husband of these thoughts, and although taken aback, he was really understanding and conscious of the weakness I had in my mind. I felt more spiritually uplifted after the first labour and less after the second."*

Supportive factors included having a supportive partner who despite having their own challenging feelings were understanding, and the courage to be able to share distressing thoughts. Further protective and supportive factors in mental health resilience included trust in God (which came out in its own right significantly as can be seen in theme one) and feeling well supported by immediate family and wider circles:

> *"I generally felt in good physical and mental health throughout my pregnancy and birth. I felt like I had put my trust in God and was very well supported by my husband and wider family as well as my friends, which made all the difference."*

For some the transition through pregnancy and or birth triggered anxiety and mental health

challenges and even worsened in some cases, some comments included:

> *"I feel like the pregnancy kick started anxiety for me and it has got worse and I struggle with my mental health a lot more than I ever have."*

> *"I suffered anxiety and panic attacks."*

> *"My mental health took a real knock because I felt and still do completely alone".*

> *"My first my mental health was impacted severely, I have ptsd from my experience. My second, third and fourth I feel Islam has strengthened me alhamdulillah."*

For others there was identification of specific causes (not the pregnancy and or birth itself) as triggering the onset of depression such as the taxing physical impact from medical intervention as one respondent expressed:

> *"Personally, physical and mental health was good during the pregnancy and labour. However use of gas and air exhausted the lungs and had negative impact on physical health e.g. reduced the ability to talk and walk for longer time. This led to postnatal depression due to struggling physically, not be able to meet the demands of postnatal responsibilities and duties*.

The transition to motherhood and the impact on sleep deprivation and social pressures and expectations of motherhood were also expressed as being cause for affecting mental health:

> "*My mental health was not affected during birth or pregnancy, but afterwards at the daily grind of attending the baby 24hrs getting by with little sleep and the pressures to be at ur best at all times, I cried a lot and cried for strength."*

For another mother also, it was not the pregnancy and birth itself but relationship issues that were felt to have potentially impacted emotionally, leading to anxiety and depression:

> *"My second pregnancy was the hardest emotionally, I think it stemmed from having marital issues during the pregnancy and after the birth of my child, I think this could have been the result of my anxiety and depression."*

A partner spoke of the impact on his relationship of his wife developing postnatal depression in relation to the care she received:

> *"My wife developed PND as a result of the care she received. This affected my relationship as my wife became withdrawn and unengaged. She is now fine nonetheless Alhamdulilah."*

For one mother her experience was related to concerns around *'sihr'* (black magic) and its effects. She was conscious of the *sihr* effecting her pregnancy and affected the timing of her sharing the news to family and friends. Despite feeling the effects of *sihr* during pregnancy,

she felt empowered from her previous experience and know-how of how to combat it, so it did not worry her. She also expressed feeling depressed after having difficulties breastfeeding. It was interesting there was a clear distinction made between what were the effects of sihr and what was depression:

> *"I did not share my pregnancy news to close friends for 4 months, and my extended family did not know. until 6 months. I was worried about sihr as it was something that effected my husband and I before pregnancy. I did feel those same effects during the pregnancy, however it did not worry me as I did the usual things I would do to combat it. I also had trouble with breastfeeding as my daughter suffered with reflux, so I was depressed for this reason."*

Another also shared her worries around fear of *'nazar'* (the evil eye) and criticism, which meant she needed to stay away from extended family. However, a strong sense of self care awareness emerged:

> *"Due to all my births being difficult I had to focus a lot on myself in order to recover. So had support from husband and was willing to put my needs first when I needed to. I kept away from extended family as was afraid of nazar and criticism from them."*

Views around the role of mental health and its impact varied. Generally, there was a sense that mental health is not understood and less so perinatal mental health within the Muslim community. Lack of social and community awareness seemed to play a significant role in exacerbating mental health distress. Some emphasised the lack of awareness of perinatal mental health was an issue specifically within the Muslim community and for others there was a recognition that this is a wider issue beyond the Muslim community and that in general as a society this is something we do not address well:

> *"I don't think this is specific to Muslims. I think it is a general problem of too many cases of post natal and anti natal depression. I believe this has a lot to do with lack of family or friend support and the new mother Getting lost in the world of the new baby and forgetting her own wants and desires."*

> *"I know that mental health in general is not a well understood topic in the broader Muslim community, and I would expect this would hold for more specific instances such as mental health around pregnancy."*

Some participants highlighted the lack of appreciation in society for the significance of the life changing experiences of pregnancy and birth. This lack of appreciation and awareness of the changes occurring also played a role in the mental strain put on women and men:

> *"I think in general the stress and distress that can be associated with child birth (or any other life-changing experiences) is not well appreciated. Women and men are expected to simply 'handle it', and this is especially true for women."*

For some participants there was a distinction that mental health is not a 'Muslim' problem but

cultural in terms of being ignored or blamed/ displaced on to *jinn*:

> *"I don't think it's a Muslim problem it's the culture as I'm Pakistani if there is a mental issue it will be brushed under the carpet or they would say it's a jinn and pay a random guy with beard to get rid of it which is a complete joke."*

Further to this, the way in which mental health can be conceived negatively and how some members of the community conflate or connect mental health issues to lack of faith was shared:

> *"general understanding of mental health issues can sometimes be put down to not being faithful enough."*

> *"Mental health in and of itself is poorly understand in the wider and in the Muslim community."*

The varying degrees of the acceptance of the existence of 'mental health' also connected to different generations understandings and their contexts:

> *"I think the younger generations are more in tune with mental health than the older ones".*

> *"I think a lot of the older generation are ignorant of certain mental health issues. And just say thinks like make dua. Which cannot solve serious mental issues."*

The significance of the life changing events of pregnancy and birth and the impact on psychological and emotional states was not recognised, not accepted or fully understood enough in society according to participants. Mothers and fathers needed accommodations that were different to pre pregnancy that were not available. These accommodations were mostly emotional support and understanding of the complexities of mental pressure.

Contrastingly, there were a few respondents who felt that their mental health was good, and pregnancy and birth were overall a positive experience for them:

> *"It was largely a positive experience".*

> *"My mental health I felt has been quite good alhamdulilah".*

> *"I felt amazing at the hospital. In fact I wanted to get a job there working with them as they were so friendly, so I would say my mental health was very well!"*

These experiences were in the context of supportive factors and showed how important the role of a friendly environment and staff were in creating a positive experience and determining

outcome (this is discussed in extensive detail in theme four below). These contrasting experiences reflect the emotional highs and lows individuals felt.

5.2.2.4 Psychological "assault on the body"

In this subtheme women described their embodied experiences of ways in which they felt during pregnancy, labour and birth. They described how the physical changes experienced during pregnancy or what was being done to them in terms of interventions during labour and birth: medications, anaesthesia, pain killers were altering 'psychological' states leading to feeling helpless and feelings of assault which placed them in vulnerable and fragile positions

Some participants shared feeling 'vulnerable' and 'fragile'. These feelings were related to experiences that had made them feel 'overcome', and or 'disconnected' which were on some occasions a result of the birth itself and or pain medication and interventions. Some participants did not state the reason of feeling vulnerable or fragile but shared that was how they felt. One respondent shared a powerful metaphor of the impact on her body and how the process of pregnancy created feelings of vulnerability and fragility:

> *"Pregnancy was an interesting process. I thought I'd really enjoy the feeling of growing a life, another human, inside me, but I actually felt so vulnerable and fragile in a way I had never before. It really felt like an assault on the body."*

Another participant, shared how medication during birth had impacted her, creating feelings of disconnect:

> *"Strong painkillers that knocked me out and made me feel loopy and disconnected".*

Other instances that evoked states of vulnerability included the reliance on and need for others (medical and healthcare staff) at a time of feeling exhausted and requiring relief of pain. One respondent relayed her need for help at a time of exhaustion:

> *"I was exhausted and I yelled and screamed for help, they gave me an epidural, they said my cervix was so elastic it was hard to tell what stage I was at and how much longer I would have to go on for."*

What women were emphasising was a sense of being particularly vulnerable during pregnancy, labour and birth and being affected by things out of their control. What we learn from this is the need to be much more sensitive to individual states and how we can help women to feel empowered and in control rather than exposed or helpless in their vulnerability.

5.2.3 Theme Three: The importance of social circumstances'

This theme encapsulated the impact of the social context and environment on participants at the time of pregnancy, birth and postnatally. Social context here refers to family, friends, partners and the wider social environment participants were in whether that was supportive or stressful. Although the terms social and environment can be broadly defined, in this theme I am understanding the social context to refer to social support and relationships and the broader environment to include housing and living arrangements.

The general sense when it came to support from family was that it was good, some citing "excellent", and that they did not experience any problems, for some there were concerns and the nature of these are elucidated below through extracts. There was a combination of social circumstances that impacted the experiences. It seemed broadly apparent that - as is to be expected - those with good social support, and stable environment, housing and family generally had a positive experience and those that experienced the pressures that come with the lack of social stability and support felt strain and stress.

5.2.3.1 Family support and pressure

For the participants in this study, having family support around them and on their terms during pregnancy and birth was essential, sometimes where this was not available or there were added pressures, this was detrimental to their experience and wellbeing.

The type of housing situation was important. For participants especially those who had experienced living in joint or extended family homes there was a relief at being able to move into their own home which provided a sense of autonomy and focus on the immediate family units needs rather than becoming subsumed by the wider family dynamics and of being told what to do. One participant highlighted how moving to her own home helped her, providing comfort and autonomy which allowed the focus to be on her and her and her baby's needs:

> *"This was my first. We moved into our own home and now I feel so much more comfortable. I feel like i can prioritise my baby 100% without being pressured to do other things if i was with my in laws."*

Family was important but the quality of the interpersonal relationships were a key factor in determining whether participants felt supported or pressured. A partner shared his perspective on how he felt his wife coped really well and the significance of the support they received from family in the early days:

> *"My wife was brilliant, she was so prepared throughout the process and did really well with labour, and then transitioned seamlessly into being a new Mum. Family were extremely supportive, they got there as soon as baby was born, stacked with food supplies, and helped us out a lot in the first few days."*

Contrastingly, where partners and family were unable to or were prevented from being with the birthing mother this created stress. There were various reasons partners or family were unable to be with the mother such as missing fathers, lack of provision for the father, and mothers who found it emotionally and psychologically difficult seeing their own daughters in pain were some factors that led to feeling abandoned and or left alone by social structures and or relationships. For example, one respondent shared how difficult it was for her mother to see her in pain and what it evoked for her thus she had to leave for that reason rather than not being supportive:

> *"My mum and brother were sat outside but my mum couldn't take seeing me in pain so she left."*

One respondent shared how being denied support affected her experience and the contrast between when her partner was with her providing her the support she needed, with suddenly being denied due to Covid 19 restrictions.

> *"I had my partner with me throughout all appointments however due to covid 19 he isn't allowed in any appointments with me so it has caused some stress for me as I do not have the moral support of my partner."*

Most respondents' experiences relate to pre covid (there were only two who shared experiences of pregnancy and birth that occurred during the pandemic as this survey was carried out in the first months of the pandemic) so the differences in experience and context is important to keep in mind.

The environment of the birth was considered supportive, valued and appreciated when it included respect for privacy, and space to birth on one's own terms with one's partner present and included as was highlighted by a participant:

> *"Very good, I felt my husband was allowed to be present at all times. My first labour was us for the majority of time alone and only when I was ready give birth we the midwives called in. our first child was born in a birthing pool. We were given privacy and I was allowed to labour in my own time. Second labour we didn't have much time before the birth"*

Contrastingly, for others the lack of support from the environment they gave birth in - usually a hospital - to facilitate the basic needs of a birthing partner made it difficult for family to offer

the support that the women needed. Sometimes this would mean a woman in the stages of labour and process of giving birth being additionally worried about her partner or mother. The lack of facilitating of a partner meant that the husband or other family members were less nearby, available or able to support the woman because the environment did not allow it:

> *"Baby was born at 2 am. My mum who was with me didn't get a bed to sleep on. She slept in a chair. The following night were able to get a bed.*

While for others family were allowed to stay with them and or visit thus, they were able to experience the support needed as a result:

> *"Very good. Family were allowed to be with me and were very supportive throughout."*

> *"Everyone was amazingly supportive, from parents, siblings, nieces and nephews."*

> *"They all came brothers and in-laws… after the baby was born as it was such a relief to have it finally out and she was as big as a 3 month old, the 0-3 month clothing fit her tightly."*

For some, family members were supportive, and some were not so helpful, mostly the husband followed by immediate family – usually the mother of the woman giving birth were most supportive. However, for some these relations were the least supportive. Extended family or in – laws were lacking in support and understanding of the independent needs and wishes of some of the women and their husbands which created pressure.

5.2.3.2 Husband's Role

Broadly speaking most respondents felt supported by their husband who played a significant role in the birthing process and for some they also mentioned throughout pregnancy. There were some divergent perspectives that highlighted the abandonment and lack of support that resulted from partners who were absent physically and/or emotionally or due to restrictions from healthcare environments which seemed to vary vastly.

The calming presence of a supportive partner alleviated or at least contained anxieties. A partner being able to have a bed / share the room and be present played a supportive role, and where this was facilitated by staff, it made the experience all round more supportive and contained. A number of people shared the importance of this and below are a handful of these responses:

> *"From taking time off work, attending appointment and just being there throughout the pregnancy /birth my husband was the calming presence/ birthing partner. His calming*

presence was what i needed as i was quiet anxious about giving birth being my 1st time. It was nice to share."

"My husband stayed with me the whole time and was allowed to share the room."

"My partner was incredibly supportive and was able to be by my side the whole time (aided by the double bed!). The midwife offered him toast when she offered it to me during labour, which was good since he needed the energy to get through it too. It was emotional for him too. He said it was incredible watching me through the pain and knowing that his role was to help me through."

"Excellent, my husband was allowed to stay with me at all times, and he was given a bed to sleep on. This support was essential, most hospitals do not allow partners to stay, so I was lucky".

The importance of taking care of the fathers' needs is highlighted in both the basics of having a bed to sleep in and being offered food for energy. The support system for a father also feeling he has a role, is respected, valued and his needs are also 'seen' by staff facilitated a better overall experience. The partners' experience was highlighted:

"*My husband attended all the births and was very supportive, but they did mostly ignore him - he was standing during all the births and only got to sit down after the babies were born."*

"Partner was really helpful. Stayed with me all the way even though I kept telling him to go home and have a rest."

Fathers spoke about the way in which they felt they needed to be present whether overcoming their own feelings or needing to provide moral support to their wife. One partner shared how despite not wanting to be in the operating room he overrode his feelings to support his wife:

"I was in the operating room even though I did not want to be there but she needed me. I sat next to her, holding her hand and it was over within minutes."

Another father spoke of the recognition of his role as needing to provide moral and physical support during a traumatic birth:

"[I] was needed more and more in a supportive role. When the birth began, I provided moral, physical support - it was a long birth with a traumatic but eventually happy conclusion."

Multiple women felt that the role of the husband was crucial in preventing longer term psychological distress and provided overall sense of wellbeing, many citing the presence of the partner as 'calming':

"I was ok Alhumdulillah, but felt very mentally and physically weak because of the birth. Looking back I do think i would have gone into postnatal depression with my first birth had I not received the love and support I did from my husband."

"Having husband there was really useful and calming".

"My partner has been great and helped me loads during this pregnancy".

"My husband was with me each time and was the best birth partner ever, I cannot imagine doing it without his support and even his presence helped me."

The husbands support was clearly a key supportive factor for most of the women who shared their experiences. When a partner was unable to stay and support her due to circumstances beyond the couples' control, mainly due to not being allowed, this led to stress and worry for the woman. In some circumstances not being able to be together (or separated by the system which did not seem to value a father's presence), led to each being left alone to cope with the various challenges, whether that be pain and fear for the woman or feeling loss and missing out for the father.

One key feature of this sub theme was how fathers who wanted to be part of the process and be present were not facilitated by the system or were even prevented. Another area highlighted was the impact of absent fathers. The wider impact of the 'absence' of fathers around pregnancy and birth, and the resultant lack of support was significant. The absences were due to a variety of reasons whether being physically absent/ having left the relationship, away due to work, lack of paternity leave:

"Husband didn't have paternity leave so I was new first-time mum by myself coping with baby. It was very long nights and husband didn't help with baby when he was home."

Some women had to cope without even an offer of help from the father and having to deal with his absence:

"Father of first 2 babies was absent, he was irresponsible and immature offered no help."

This was not a universal experience, one woman who did not have a partner present expressed her confidence in her ability to birth alone:

"Partner was absent in both. So I had baby alone but I was confident".

This was a different experience in the context of the rest of the data.

The importance of a husband witnessing the experience of what a woman goes through was highlighted as significant, particularly in terms of how the insight he would gain would affect his levels of respect and increased kindness in treatment. One participant shared what this meant for her:

> *"Relationship wise, my husband was my birth partner as well as my mum. This meant he had a first account of what a woman goes through at this delicate time; I think this was essential as it was a real eye opener for him."*

The father being a witness to and present in the birth process was perceived as crucial not just for support, but it also led to an increased investment in the relationship, mindfulness of the needs of the mother, and being hands on with the child, shaping the subsequent relationship of the family unit in a positive way.

5.2.4 Theme Four: NHS Experiences: the good, the bad, the ugly

This theme tells the story of how British Muslims' specifically, encountered the medical system and healthcare services in relation to the NHS during their pregnancy and or birth journeys. It captured some uncomfortable, distressing and even horrifying experiences, as well as wonderful incidences of compassion and support, and the reality that nothing is black and white. There are nuanced layers to each element of the 'short stories' that make up the whole. Many shared mixed experiences within the same incident where there were both *good, bad and ugly* elements to the encounter acknowledging the complexity of each situation.

5.2.4.1 Discrimination and or disadvantage

This sub theme captured participants experiences of discrimination and instances that created feelings of being at a disadvantage. Disadvantage as a term here included factors such as race/not being white, being treated differently due to dress code, the lack of availability of female nurses that was specifically crucial to Muslim women.

Some participants' experienced discrimination in the NHS setting and described how they were treated and made to feel, which included not wanting to go to hospitals again, losing trust, being judged over visible appearance (dress or skin colour) and being on the receiving end of racist comments. A father described his and his wife's' experience of hostility:

> *"The doctors and administrative staff was really professional and polite. However, the nurses and midwives were very difficult to deal with. They were very inconsiderate narrow minded, and uncooperative. Once I had to leave my wife in the hospital alone to be with my daughter and look after her, the midwife annoyed my wife so much; she had to call me at 12 am to come back to hospital and be with her all the time. We were not treated well by the staff. This included the midwives, healthcare workers and the doctors. Their general demeanour was hostile and uncivil."*

Some participants shared the trauma they experienced as a result of how they were treated and discriminated against. This is illuminated by the quote below:

> *"NHS hospital was traumatic, none of my wishes were respected, I was treated as if I had come off a boat looking for a passport and didn't speak English, I've never experienced that before and feel for any woman not originally British who has to experience that!"*

Another participant relayed how she was judged by a midwife who assumed she: "*couldn't speak English and I told her to not judge me because I wear a head scarf.".*

What specifically emerged in this sub theme was how these experiences of discrimination and or disadvantage were leading to lack of trust between the women and the hospital care and professionals:

> *"With the first I suffered extreme trauma and until now avoid hospitals and midwives need to prove trust with me. My first experience impacted my breastfeeding experience and I struggled tremendously, health visitors were also discriminating towards me."*

A distinction was made by some, who felt their experiences may not necessarily be discriminatory but were either due to the incompetence or unprofessionalism or individual abrasive attitudes of staff members. There seemed to be a particular distinction where participants were giving healthcare staff the benefit of the doubt in some incidences and or being particularly discerning between discrimination and disadvantage or pure bad behaviour on the part of an individual. Two contrasting extracts are shared to highlight different approaches by staff to the same request (for a female staff member):

> *"The only time I felt awkward was when I had my scan. I asked if was possible to be seen by a female. The Male nurse got very angry with me to the point of shouting. It turned into an argument which was very unprofessional of him. I was on my own at the time as my husband was at work"*

> *"I did not feel discriminated against but at a slight disadvantage that due to lack of staff i had a male midwife. (He was very professional and even did my stitches and tried very hard to make me feel comfortable) also the fact that there was a sign saying we can't choose who does our scan."*

For others, they felt their experience was indicative more of lack of care and disadvantage such as staff ill-treating people, not being able to choose a female staff member for deeply personal processes like requiring stitches or as one explicitly stated 'not being White middle class':

> *"I felt the first midwife really couldn't be bothered with my birth. It was my first child and she made me feel like I was annoying her. When I think about it I believe that she was more incompetent rather than displaying any sort of discrimination towards me."*

> *"The experiences in Q3 and Q4 were indicative of staff members who did seem to 'not care' about our needs. Presumably, if we were a white, upper-class family, we wouldn't have been treated in such a way, but it's also difficult to tell if it was discrimination because of who were, or if those staff were just ill-treating everyone that day."*

5.2.4.2 Injury during birth: tears, tears and more tears

There were over 20 experiences shared describing or referring to injury and traumatic births, tearing being the most common, infections resulting from poorly carried out stitching and lack of advice for proper wound care, and the longer-term effects physically and mentally.

Experiences were described as traumatic and even near death, most tears seem to occur in relation to poor or generally discriminatory attitudes that led to being dismissive.

Some women spoke of the injuries in relation to how staff carried out the procedures causing harm and heavy blood loss and risk. Below are just a handful of these experiences that illustrate some context of these experiences:

> *"It was a long labour and she broke my waters too early and I tore to a 3rd degree tear so I had to go into surgery the next morning however they did take good care of me."*

> *"I have second degree tears with the first labour and had to have stitches. In the second labour I did not need stitches. When receiving my stitches I was given injections to numb me...at one point the nurse went through some 'live' flesh which was extremely painful. I was later told by my sister that I should've been offered gas and air for the stitches and shouldn't have had to go through that."*

> *"Due to a mistake of the doctor who cut my wife too much, my wife experienced heavy blood loss."*

> *"I had to have an episiotomy and suffered a lot of blood loss. The stitches became infected and I was in a lot of pain and only completely recovered after 2 months."*

These sorts of events significantly shaped women's experiences and memories of birth.

5.2.4.3 Mistreatment and neglect, shaming and humiliation by healthcare staff

Concerning descriptions were shared of bullying, forceful interventions, using tactics of scare mongering and coercion, shame and humiliation.

A respondent shared how a midwife made shaming comments and went against her wishes disregarding consent, anaesthetising her and thus removing autonomy and choice:

> *"A midwife made a comment about my pubic hair saying it was 'disgusting' she also gave me an anaesthetic even though I declined it twice."*

Other illustrative examples of being subject to shaming, caused to feel embarrassed and humiliated are shared below to give a sense of the types of experiences people are subject to:

> *"My second birth was a bit weird as when my waters broke the midwife said oh have you wet yourself?! I was confused and then she said oh yes I think you've wet yourself. I felt embarrassed because my husband was present. It's only later when I thought of the incident that I realised that it was my waters that had actually broken and I said to my husband I felt as though she was trying to humiliate me :("*

> *"My experience with health Care providers during my pregnancy, at the hospital was not so good. I felt that there was no empathy or care really given. I was just another patient, and they needed the chair space or bed space. I didn't feel cared or looked after there. I was left for hours on a wheelchair, not with it and feeling very sick or being sick in the middle of a waiting area with other people starting at me. It was a very embarrassing and humiliating feeling. They even put the iv fluid on in the waiting area which made me very delirious and confused. The overall experience was not a very good or pleasant one."*

Another experience involved a 'menacing and racist' midwife who attempted to create fear in the expectant mother through use of tactics that involve getting a person in authority i.e., a doctor to perform a violent act (i.e. 'cut you open') in order to exert control, while having the mother in a vulnerable position helplessly strapped to a bed.

> *"In the first I was dismissed and belittled throughout pregnancy, in birth I was strapped to a bed and told if you don't get that baby out now I'll get the doctor to cut you! The midwives in birth were menacing and racist. I was told I came here to get a passport and British baby."*

There were further descriptions by the participants of being 'mistreated', 'neglected', 'belittled', treated with contempt and 'dismissed'. The following highlighted the experience of being dismissed and lack of understanding on the part of staff:

> *"Whenever I brought up the issue of preferring female staff, especially during delivery, I felt dismissed, rather than reassured. I completely understand that they can't accommodate for this, which is why I also made sure to tell them that I understood, however, they seemed to be bothered by my question."*

Furthermore, complaints were being dismissed, a woman described how the whole experience for her was: *"atrocious…put in 3 formal complaints during each pregnancy/child birth."*

A husband shared how he felt about how his wife was treated,

> *"My wife did not deserve to be mistreated and have the experience that she did."*

Mothers relayed the neglect and trauma they experienced from the NHS and from midwives: "*was traumatic, I was treated like an immigrant wanting British nationality by having a baby in hospital (I am British in origin)."* One participant described how her traumatic experiences directly led to a wish to never have a baby in hospital again after the way she was treated:

> *"I feel i have been neglected and left trauma by the NHS with how the midwives treat me and took away my dignity and then lied about it once I complained it was not taken seriously at all and it still scars me to this day. For this reason I do not ever wish to have a baby in hospital again."*

Some of the neglectful experiences seemed to be due to individual healthcare practitioner's personal attitudes; be it racism, Islamophobia or classism and it seemed some may be more

entrenched within and hiding behind an organisational culture, hierarchy and power dynamics. In other circumstances, there seemed to be a void in regularity of care, having to suddenly be dealing with a new midwife that one has not established a relationship with, and a good rapport has not been created. Further descriptions were shared of experiences involving different midwives and lack of continuity of care during each pregnancy, this highlighted how each midwife was different and there seemed to be no sense of standardised care. The care that was received, as well as the approach and attitude of a midwife, was more dependent on individual midwives:

> *"First, every midwife was dismissive, rude, patronising and discriminating. Second, I noted some discriminating behaviour from a couple of midwives, but leading midwife was fantastic. Third, initial midwife was awful but nothing to do with religion, following midwives were lovely. Fourth, leading midwife uses coercive language and is dismissive of my wishes, however this is to do with my age not religion. Every other midwife and a consultant I have spoken to has been fantastic and accommodating."*

5.2.4.4 The 'good'

Woven through the survey responses were examples of positive experiences, illustrated here in the comments of a participant who stated that: *"Alhamdulillah I had a very positive birth experience."*. The factors that facilitated the 'good' included feeling 'reassured', 'having good relationships with kind staff', feeling 'empowered', and 'informed'; as one participant highlighted: *"I felt very informed about my decision."*. One respondent spoke of how her needs were met in the centring of her experience in her Muslim identity - her experience as a Muslim mother and how getting an all women team for her birth was meaningful for her and the feeling that it was like a home birth:

> *"My experience as a Muslim mother was very good...I was able to get all women for my birth. I had no* complications, *so the birth was more like a Homebirth but in the hospital."*

Furthermore, some of these positive experiences depended on individual hospitals, and birth units. The physical environment of where one is giving birth made a clear difference with respondents sharing examples of spacious, calm birthing centres in contrast with hectic stressful hospital wards. There was a clear distinction amongst responses that birth centres and home births, or those in hospitals that had created a 'homey atmosphere' were better experiences:

> *"1st birth experience was amazing, in [name of hospital]Midwife led unit which is located in the hospital and provides a very homey atmosphere with low lighting and comfortable spacious rooms I had a water birth and it was honestly a great experience*

because I quickly forgot most of the details I felt like I was taken care of very well and that before the baby was born they did extra scans etc to check baby's head shape as all my babies are over 8 pounds at birth The only thing was afterwards the midwife made a comment about how in Afghanistan a large percentage of women die in childbirth because they can't get proper access to care. It seemed like such an odd comment later."

As can be seen in this example the complexity and nuances mentioned at the outset of this theme are relayed. While described as a comfortable and great experience, there was what could potentially be understood as at best ignorance or most a micro-aggressive comment made by a midwife.

The availability, accessibility and provision of high-quality facilities such as private rooms, ensuites, and birthing centres in general created a better quality and led to what respondents described as phenomenal and amazing experiences:

"I gave birth at my local NHS maternity unit, initially labouring on the antenatal ward then delivering on the labour ward. Overall, I felt I received good care and the facilities available were excellent, e.g. private rooms with large ensuites, bathtub to labour in and my own side room on the postnatal ward so my husband could stay with us. All the appropriate postnatal advice, baby checks and take-home packages were provided, and we were discharged within 14hrs, with a community midwife follow-up appointment arranged for the next day."

"The care I received was phenomenal. From the moment I was checked in to the moment I left I felt supported with every step of the journey from trying things to help my labour progress to breastfeeding once the baby was born. I'd go as far to say I felt I was in a private hospital."

5.5.4.5 Staff were so loving and caring

There was a clear correlation between loving, caring and attentive staff treatment of women and their using highly positive words like 'amazing', 'wonderful' and 'beautiful' to describe their experience of giving birth:

"The nurses and consultants were absolutely amazing in supporting me and thoroughly explained everything I was experiencing and possible outcomes."

"The hospital was fabulous, no complaints at all, wonderful staff attentive and helpful."

For some participants the experiences of feeling cared about, and their needs being met were tied in with being offered information and support in the form of counselling: "*I was offered*

counselling which really helped", and or access to services and explaining interventions and outcomes.

5.2.5 Theme Five: Empowerment

This theme featured elements of empowerment and factors that led to feeling a sense of agency, including through taking ownership of self-care, education, and decision making, particularly where it involved breastfeeding and the dynamics, which facilitated an important and much needed sense of power in a potentially vulnerable process.

5.2.5.1 Alternative self-care and mental preparation

The form of self-care was different for different people and included going for massages, learning about hypnobirthing, using prayers, music and various mental preparation as well as being organised before the birth, as shared by a number of respondents:

> *"I personally contacted a masseuse for a praises massage every couple of weeks for that for year. She was the one who informed me of my injury."*

> *"I read a hypnobirthing book and found the advice very helpful."*

> *"Was in triage for a while, listening to some calming music and wearing a tens machine as I did in the first pregnancy."*

> *"I was really looking forward to the birth as I knew we would soon have our little one in the world. I prepared mentally beforehand, practised breathing techniques, had my maternity bag ready and used my yoga ball/ was swimming right up until the end of pregnancy."*

One respondent described using dhikr and breathing which helped her feel in control throughout labour:

> *"Throughout my labour I felt mostly in control, made dhikr and focused on my breathing".*

Respondents discussed the choices made around what felt comfortable to share with healthcare practitioners. This sometimes included needing to filter out information and not share their choices and decisions for fear of judgement over those choices and what felt right for baby. This highlighted the need for practitioners to be more patient centred and to provide 'cultural safety' as discussed earlier in the thesis:

> *"I was not willing to share with midwives/ health visitors about sleeping next to baby as felt this would be frowned upon but this was the best way for bond, feeding and for me to get sleep."*

5.2.5.2 Breastfeeding successes and struggles

Issues that arose around breastfeeding were always in relation to lack of support and encouragement, which led to a sense of disempowerment. Examples of empowerment in the process included staff being helpful, providing time and space, words of encouragement, techniques and facilitating rest for parents:

> *"When my daughter was born, I struggled to breastfeed her. She was latching on well but would feed for 4-5 hours at a time and then cry when I took her off. The midwives did their utmost best to support me and also asked the infant feeding team to provide extra support. They also took her and cared for her so my husband I could get some rest as she was continuously crying. My daughter lost too much weight due to the feeding problems which meant we had to stay in hospital longer. The hospital provided us (myself, my husband and I) a private room free of charge. There is usually an extra cost for this."*

> *"Another midwife helped me a lot with breastfeeding the following night. explaining how to latch and different feeding positions."*

Contrastingly, to the success in breastfeeding, where support was provided here is an illustrative example of concerns not being heard, feeling dismissed or pressurised by midwives to give a bottle despite mothers wanting to try or persevere. For those experiencing this, it led to emotional pain and a feeling of loss and sometimes failure. Ultimately it was faith that helped to provide a narrative and way to process the pain through trust in the greater good/purpose/ what was meant to be:

> *"I had not fed my baby until almost 12 hours after he was born. The midwife of the time did not really help us and when I would express concern that my baby hadn't latched yet they would say he's ok, he doesn't need to feed yet."*

> *"As i had gone to hospital day 10 post partum for my acute kidney injury and on drip i was pressured by midwife to give bottle. My other midwife also pressed as his weight wasn't going up as fast as they'd like (it wasn't dropping but my son regained birth weight on day 24). I didn't get breastfeeding support when in hospital. my son rejected the breast and developed a preference for fast flow milk over time. I had an infection too soon after i left hospital and was expressing. Eventually my milk supply went low and i couldn't rebuild with moving cities. That's the most painful part for me that i couldn't breastfeed for a longer period. But my faith in Allah gets me through the fact that every situation has a hidden khair that's beyond my intellect/ ability to comprehend.*

5.2.5.3 Power, astonishment and awe

For many the process of pregnancy and birth taught them a lot about their own bodies, their capacities, what works for them and what does not, fighting for their rights, wishes and beliefs,

bringing with it a sense of power, astonishment at what the body and they could do, and awe in the process:

> *"it was the most painful thing ever, but I was astounded and so proud at the end that I did it. I still look back with awe at the whole process."*

For one woman it was her confidence and previous positive experiences that helped her fight for her rights despite facing opposition and negativity:

> *"My second I was older and home birthed, my midwife was respectful of my religion and preferences, I experienced a couple of prejudiced midwives but on the whole a positive experience. My third I only experienced negatives due to being nearly 40, I fought my case and home birthed with a good midwife (after first initial complaint to change midwives). My fourth I have experienced a lot of negativity due to my age, but due to my experience and confidence I have changed that to a positive experience and am due to homebirth very soon Insha'Allah."*

For many, experience was also a key building block for a strong sense of knowingness about the self, body and the process which led to better experiences in successive pregnancies and births. Support from all, healthcare practitioners, midwives, partners, and family were the driving force in better experiences and an overall sense of empowerment, autonomy and agency; not having to fight and be at odds and engage with tension and resistance:

> *"My first delivery taught me a lot about my body, my dilation slows down after."*

> *"My pregnancy and birth was very lovely, alhumdulillah. It was my first experience at both. I had no complications during or after the pregnancy. I took part in hypnotherapy during pregnancy and this made me feel confident enough to ask for what I want, was equipped with knowledge, and to not give into doctor or midwife pressure. I had a water birth."*

> *"My second and third were homebirths and far better experiences as within my own home I set my own rules."*

One participant described an emotional journey of the impact of not being informed about a condition she had earlier, choice being removed from her and being told when she would be induced – give birth, with little notice:

> *"they didn't tell me I had pre-eclampsia for sure until the end, I was clueless and emotional and just wanted to go home, so every day i was expecting to go home and manage symptoms like that but every day was disappointed. Up until even the day i was due to be induced, I was told we would choose a date at 37weeks, they came to me on that morning exactly and were planning to do it. That was an emotional time for me as I never expected to have to make this choice, I gave in and that afternoon was induced. I had my baby the following day Alhamdulillah.*

The above quote highlighted a power dynamic which centred the healthcare professionals over the woman's' needs. This kind of dynamic could lead to a disempowering experience and raises issues of who controls a woman's body and the timing a baby is born.

A couple highlighted that despite mostly feeling heard, there were still times they felt pressured:

> *"We always felt understood as we could communicate clearly however sometimes we did feel like we were pressed into a corner. Either to make decisions quickly or that the medical professionals knew best."*

There were distinct lines between issues of power and control (by healthcare staff, usually midwives and doctors were mentioned or by the system of the hospital) which led to pressure and anxiety and feeling disempowered. Those who had staff who went at the pace of mother, and baby and or the couple, who informed, supported, facilitated and were mother centred and mother led, had better experiences. These were also the people who expressed feelings of awe and a strong sense of self and empowerment which led to being more prepared for subsequent pregnancies and births.

5.2.6 Theme Six: Recommendations

One of the questions in the survey asked respondents to share any recommendations they had for improvement in care and better outcomes based on their experiences. Below are an aggregation of the recommendations from 32 responses as illustrative extracts under each sub theme. The intent for asking this question was to include direct views of Muslims who have experience of pregnancy and birth and can offer suggestions for what works and what does not. This is perhaps the most valuable data in terms of actionable pointers for community organisations and healthcare providers that could work towards providing equitable care and 'Cultural Safety'. The responses were grouped under sub themes which addressed participants concerns around lack of accessible information and the recommendation of the types of information they would like to see both from mainstream services and within the Muslim community. There were calls for mosques / the Muslim community to provide context specific educational materials around perinatal mental health and wellbeing and education for fathers and wider family rooted in Islamic paradigms. There were recommendations suggested around improving the lack of understanding around mental health and perinatal mental health and the need to recognise and know what birth trauma is.

5.2.6.1 'There isn't any information around this that is accessible'

It was apparent that information – lack of, quality of, and delivery of, was a key issue in participants experiences. A request for more information, included around exercise and for first time mothers, information around particular conditions during pregnancy, information that is more holistic that includes an Islamic perspective:

> *"There isn't any information around this that is accessible for people. My condition (hyperemesis) was a taboo within our community that no one, whether young or old knew about this and put it down to tolerating morning sickness. People could not empathise nor comfort as they didn't know what it was or how it affected me."*

> *"If more advice was provided for first time mothers, this would have been helpful. Overall, I'm ok with the experience but just felt I was missed off quite a few times along my journey."*

> *"Felt more advice would have been useful on how to take care of my wound after a c section. The advice given at the birthing unit and the ward need to be consistent".*

A number of participants state the lack of information or how helpful it would have been to have certain information such as exercise post birth and wound care. Some of the participants shared how the made up for the gaps in information through self-directed searches. This

disconnect can impact the relationship with healthcare providers and create a feeling of not being cared about or acknowledged, as one person shared: "…*I was missed off quite a few times along my journey".*

The importance of the way in which information is communicated was pertinently highlighted by a respondent:

> "*Maybe have adverts explaining mental health with Asian actors as they tend to think it's just a English thing."*

This shows the need to be mindful in the process of creating education materials including the advertising and 'outreach' aspect. If it is to have an effect, it needs to be relevant and applicable to those it is calling to / needs to call to. It needs to appeal and resonate; people need to see representation.

5.2.6.2 A call for mosques to produce materials and be sources of support

There was a message for the Muslim community, mosques, community centres and healthcare providers, to collaborate holistically providing materials around pregnancy and birth that are tailored for Muslim families, bringing together Islamic tradition and modern science:

> *"I think a good starting point would be producing some materials which tackle the issue in a holistic way, taking into account insights from both the Islamic tradition and from modern science. These could be disseminated to mosques and community centres, perhaps used to help Imams and faith leaders develop literacy on these issues."*

This sentiment was further echoed by another respondent who stated the:

> *"Need to teach about it in mosque curriculum."*

There was a further response stating the need for mental health to be normalised and for there to be education from an Islamic paradigm about the experiences of pregnancy and birth:

> *"Normalised mental health, support people to understand what Islam says about the difficult experience they go through during pregnancy/ birth."*

Connecting perinatal health education to Islamic paradigms would be a method that resonates with and connects to people who may not otherwise be open to practices or concepts unfamiliar to their worldview. Contextualising it in an Islamic paradigm can facilitate better education and outcomes in terms of experiences for women and teaching men.

Another account included an example of how a mosque centred social network for mothers aided spiritual and mental struggles related to motherhood. These networks can offer encouragement and support that could be used as a model or concept idea and set up across the country potentially:

> *"The mosque I go to, have a strong social network of mothers who support each other, they've had a really important role in my motherhood experiences here in the UK. We meet on a weekly basis and support each other through spiritual and mental struggles related to motherhood. I imagine not all local Muslim communities have such an offer, but in my experience, this has been really important to provide support and encouragement in my experiences of motherhood."*

Another respondent highlighted a contrasting view on the support available in non-Muslim communities and the disparity with the Muslim community where there is lack of support, information and provisions particularly around pregnancy, birth and perinatal mental health. Again, this demonstrates the potential for collaboration between the Muslim community and other organisations and healthcare service providers to work together to improve experiences:

> *"I feel there is a lot of support in the non Muslim community for mothers, new mothers, breast feeding, antenatal classes etc. But our masajids are not providing the same or even giving a platform for non Muslims to come in a teach Muslims about these things."*

There was a call for Muslims to be involved in and part of the process of education and healthcare around pregnancy and birth and related topics. There is a lot of potential here for people to collaborate, connect, train, teach, support, peer support, and create groups:

> *"More education and material need to be passed on. Plus this needs to be talked about and covered as it is seen as a stigma. We need more professionals from Muslim backgrounds to get more involved too Insha'Allah."*

There were requests for better education around mental health to be available including in other languages. More discussion is required to address issues around the narratives of distress that can be attributed by some to external unseen forces such as jinn/sihr/ayn:

> *"The Muslim community doesn't know much about mental health in general, they always affiliate any type of mental health issue with jinn and sihr. I think there needs to be more information out there for mental health, especially in Urdu, Bengali, Hindi and Arabic."*

Again the above points to a potential of collaboration between mosques and local health services which could include perinatal, mental health, midwifery support.

5.2.6.3 Education, empowerment and the power of social support

The focus on information and education as power and empowerment was a noticeable area:

> "*Muslim women need advice on how to empower themselves to make their own choices about their pregnancy and birth plan. I think social support network is also really important and being able to be open with friends and family about your experiences."*

There was a call for men to be provided with more information and education around what women experience, including referring to and embedding the teaching through the Qur'an and Sunnah sources creating a point of holistic education and connection:

> *"Mental health during pregnancy and after birth is not discussed or given importance. Information for men about what a women goes through and how to support would be great. This should include information about baby blues, postnatal depression and how to support the physical and emotional needs of mother."*

Education around the sex of the baby and addressing cultural preferences for the male were highlighted, as one participant stated: "*I think there is still huge pressure for women concerning sex of the baby. Men need to be better educated about this and be encouraged to look to Qur'an and sunnah about this".*

Having exposure to the healthcare system such as through working in the NHS and knowing where and how to access information can be advantageous and empowering. One participant shared how her experience of working within a health visiting team and witnessing how helpful the process had been for some families encouraged her to attend antenatal classes:

> *"I also think generally Muslims are very dismissive of things like antenatal classes and support. The reason I chose to go to one was because I had worked in a health visiting team years ago and I knew how helpful they had been to some Families. I also was interested in getting as much info as possible."*

This is a critical point about accessibility and knowing where to get information and how it empowers as well as raising questions around who takes ownership of that: individuals, healthcare providers, families and or communities. Perhaps a collective collaborative effort is required with strong leadership to ensure more attention is given to this area.

5.2.6.4 'I don't think mental health is considered at all in the Muslim community'

Recommendations around mental health awareness during the perinatal period were highlighted by several participants. For context - referring to the data in the first section of this chapter when the question: Do you think mental health around pregnancy and birth is

understood and recognised in the Muslim community in Britain? was responded to with a resounding no (83% /34 respondents). Further elaboration was asked for, following this question, the extracts below illustrate some of the core feelings and experiences of participants:

> *"I think mental health focus should be there throughout in the midwife appts and post birth and some classes even online or something to raise awareness so people don't feel alone or weak for saying they are struggling - we waited so long for a baby and people probably think I should not dare to talk about having mental health issues and should just be happy all the time."*

> *"Mindset needs to change. There is more than one way to raise a child. And just because u do something different doesn't mean it's wrong. Ppl questing you makes you feel like a failure.*

> *"I don't think mental health is considered at all in the Muslim community, even learning difficulties are dismissed. I think specific courses offered to the community and attendance encouraged regarding mental health would be helpful, especially Muslim men supporting their wives."*

> *"I don't think people understand the 'emotional' side of being pregnant, how lonely it can feel and also post partum depression. I think people should ask how you're feeling more."*

As can be noted from these few illustrative quotes, there is need for nuanced holistic mental health education and support throughout the entire process of pregnancy, birth and postnatally for mothers, fathers, the wider family support system (including grandparents as one participant highlighted: "…*'signs' of postnatal depression should be given to grandparents."*) and within the community more generally. There is a role to play for everyone involved from midwives: "*For midwives to have more training to recognise the signs, for partners to be given more info on how to support their wives"* regarding perinatal mental health and healthcare providers to partners, families, local Muslim community networks/ mosques. More widely there was a call for improved relevant education and access around perinatal mental health and related topics of general mental health, parenting, emotions, and shame. This kind of education has the potential for affecting the outcome of an experience. For example, support being more available to the mother and father through the wider network being more informed about perinatal related issues, pregnancy, birth, perinatal mental health, traumatic injuries, losses and emotional states. If the community is better informed it could make the difference between someone feeling alone, isolated and potentially depressed or supported and uplifted. Participants shared how important support could be and how it was for them:

> *"The best support is to talk to others in a similar situation, so new mums or those who are expecting , and sharing ideas and thoughts".*

"If fathers and families understood how hard pregnancy and birth can be. It's like it's something shameful that can't be talked about. But everyone does it so I don't get why it has to be so hidden."

"In my experience I've seen women give birth and still be required to cook clean. No rest or help towards looking after baby."

The need for support and for women not to feel abandoned, ignored, and not acknowledged in the process is crucial. Muslim women being required to continue as if nothing has happened and who have no one to share their thoughts and feelings with needs to be addressed as an issue in the community. Perhaps being required to carry on as if nothing has happened is emanating from the wider systems shame that is projected on to the woman as highlighted by a few participants. These nuanced and complex issues need to be sensitively given space to and encouraged to be discussed in the community for any meaningful change to start taking effect.

5.2.6.5 'Birth trauma is not something that is spoken about or recognised'

Staying with the call for more support for women, one participant highlighted another couple of areas not spoken about enough – miscarriage and birth trauma:

"Miscarriage is not spoken about or recognised. More support is need for women - prenatal and post-natal depression isn't really recognised or spoken about. - birth trauma is not something that is spoken about or recognised. - having Muslims involved or Muslim lead projects to support women with the above areas. A space to talk, meet other and counselling to support."

Again, there is a recommendation for a space to talk, meet others for counselling and crucially for Muslims to be involved in and or lead on these projects.

A mother shared her emotional journey of how breast feeding and lack of advice and support from the hospital impacted her mental health, she provided recommendations of proactive support, advice and connection, checking in with the mother for at least a month and for staff to be especially mindful of how individual births may impact each mother-infants' breastfeeding journey:

"I didn't get any advice on breastfeeding from hospital after I gave birth and I think a huge opportunity was missed here. I'm aware of staff shortages in the NHS but breastfeeding is so encouraged and benefits so important that I really think there should be breastfeeding support education in the hospital and this should check in with mother's until at least a month as sometimes it can be difficult for mother's to go out and get support themselves. Also breastfeeding can be affected by what happens in the

birth so it's important to carry on being that proactive support to mothers for a period of I believe at least a month. My breastfeeding journey has been so emotional and I feel so much guilt and this has had an impact on my mental health."

5.2.7 Conceptual model of analysis

Below is a visual model of the empirical study's themes captured through the RTA process in this chapter and which conceptualises them as circular and overlapping. I have highlighted the circle of 'the role of Islam during pregnancy and birth as all of the theme's experiences were expressed in context of the participants understanding within their Islamic ways of knowing and meaning-making.

Figure 10: Conceptual framework arising from RTA analysis.

Having presented the reflexive thematic analysis themes arising from the qualitative surveys during part I of this study, the next chapter presents a deep-dive focus into the narrative stories from the interviews which formed part II of my study.

Chapter Six: Analysis of Data Part II

This chapter presents the two composite case studies formed from the four interviews. They are detailed case studies that carefully construct and 'restory' the whole narratives from the interviews. Due to the sensitive nature of these composite stories and as they were few in number, in order to preserve anonymity, the rationale for which were discussed in chapter four, this chapter will have some aspects redacted/removed after examination of thesis. Hence the discussion around it is instead presented in chapter seven where I connect how the stories can be interpreted and what they offer the whole study; this included some analytic reflections and connected the case studies to the survey themes and systematic review.

Below is the first account of these two composite case studies. The case studies are narrated under a pseudonym* no real names are used).

6.1 Narrative Inquiry Analysis: Composite case study one

Due to ensuring an extra layer of anonymity and confidentiality aspects of the composite case study have been redacted/removed for the final version of this thesis post examination.

Sarah*

Sarah initiated the telling of her story by sharing how she may not recall everything of her pregnancies and births: *"They'll be bits that I'm not that clear about".* Sarah shares how difficult her experiences have been: "I don't think that my experiences of pregnancy and childbirth have been very positive."

She goes into describing her first experience, which she demarcated as her personal experience and then that with the healthcare system*: "Okay. Um, so first I'll start off with my first pregnancy. Um, um, well first of all, I'm going to say that overall all of my pregnancies themselves were okay in terms of how I was looking after myself and my own personal experiences of being pregnant."* Sarah was not inspired with confidence by the healthcare she received: *"But I, I've never really, um, had much faith in the system in terms of the treatment I had from doctors, midwives, the hospitals. Although there there've been a*

few very positive experiences I'd say on the whole, if I had to sort of put it in a nutshell, I would say overall the whole system, it didn't inspire much confidence in me."

Sarah goes to the beginning of her experience: *"Um, so if I start off from the beginning, so my first pregnancy was back in 2003, I was pregnant with twins and that was my first pregnancy. So I obviously had no experience to kind of measure it with when I got pregnant I was very, very sick. Um, for the first three months, very sick."* Sarah's experience of the first midwife she had contact with was lacking in support and empathy. She shared how she couldn't keep anything down and that the nurse: *"sort of laughed at me and said well you do know this is what happens in pregnancy love, you know, you, you do feel very sick, you know".* Sarah felt it was: *"almost to the point of saying, well, welcome to the world of pregnancy. And it did make me feel really silly, you know, made me feel like, well, what do I know? I've never been pregnant before".* When Sarah had her scan it emerged she was having twins, she then started reading about how there can be: *"excessive sickness and much worse sicknesses is very common when you have multiple pregnancies."* Sarah said: *"I felt like, I just want…to go back to that midwife and say, ha, I told you so. You know, I knew I wasn't imagining it kind of thing. But obviously it's, it's just part and parcel of the system. And you kind of just accept it, don't you?"* Sarah's experience was not validated and if anything felt mocking and dismissive.

Sarah moves on to say that after the initial sickness: *"I had a fairly uneventful pregnancy and the sickness died down after three months. Um, I didn't really have much need to see, um, any medical professionals apart from the normal scans and the normal midwife appointments that I was called to obviously because I didn't have anything to compare it with as well. I took every kind of help there was. So every time I got a letter or every time I got an invitation for a screening or a blood test or anything, I would take it because I didn't know what to expect."*

She moves along the stages of the pregnancy and starts recounting a significant period around 5 months into the pregnancy and how she had to have far more scans due to the twin pregnancy: "*I had more scans than normal pregnant women than you would have, normally for normal single pregnancies. And so for multiples I had, I had perhaps double the number*

of scans… So at one of the scans they picked up that twin two wasn't growing as fast as twin one, and they were a little bit concerned. So they told me that I needed to rest more, I needed to stop working and the doctor did me a sick note. So I did stop working. And at that point I was literally not on bed rest".

This was a worrying time for Sarah, she describes how she felt unnecessarily stressed out and anxious as a result of the appointments and what she was being told: *"I was very worried obviously and Mmm that the next few appointments they proceeded to really um, make me feel worried, anxious, quite stressed about the whole thing. And they were telling me things like, Oh, this is normal in twin pregnancies."* She was told it is normal for one twin to be taking more nutrition than the other but that they: *"were slightly concerned".* They wanted her to *"have some monitoring done."* Sarah had to go in weekly for scans: "*…the Doppler thing where they, they checked for the heartbeat and they would strap me to this machine and you know, they'd have to listen to it for about an hour. They would just listen to both heartbeats. Um, and although I could see that it was, you know, to help me, um, I felt like it was unnecessarily worrying me."*

Sarah shares how when the twins were born: *"they were absolutely fine…there were no issues… Twin two was only very slightly smaller than twin one, but she was absolutely fine. There were no issues whatsoever, and there were no follow ups at all afterwards. Um, so I feel like I was just kind of unnecessarily worried."* Sarah moves back in the story to talk about the actual childbirth describing when her waters broke: "so my water's broke 36 weeks and five days. Um, I then for about a whole day, nothing happened. I called hospital as soon as my waters broke and they wanted me to come in to be monitored. So I went in, um, they then sent me back home because nothing was happening. Um, I Um, I then I, yes, I had, I had a very uneventful 24 hours. I had no pain, I had no contractions, I had nothing all, um, so that, that following day they asked me to come back in after a few hours." When Sarah went back in the next when they wanted to admit her she still had: "no pain, no contractions, nothing's but I was admitted." She was placed in a ward and her husband sent home. Sarah found this upsetting: *"My husband was sent home, which I felt was again, a bit, um, uh, distressing for me cause I wanted him to be there and I couldn't understand why at such an*

important time, That at such a crucial time, Why all the women on the ward, their partners were sent home and there was no, there was no, um, provision for them"

(Reflections: The role of the father at birth and the lack of provision and inclusion of men came up for me again in relation to other comments in the survey and interviews and generally what I hear and the frustrations of women who recount their stories of unnecessary inflicted trauma and distress and feeling unsafe and disempowered. Something needs to change but how- how is this still an issue in 2021 I wonder).

Sarah had the same experience throughout all of her pregnancies where her husband was not allowed to stay: *"There was no provision made for partners to stay unless you'd had the baby or unless you were in, you know, you had some kind of a problem or you know, um, they weren't allowing partners to stay, which again, that wasn't, that wasn't a good experience for me throughout all of my childbirths."*

Sarah talked about how lonely it felt and how it felt being told when your partner could and could not come and made to feel like you have to do this alone: *"just that the lack of, you know, it's almost like you're in the hospital, you're alone until we tell you your partner can't come. So maybe when you're in birth your partner can be with you. But other than that, you know, all of this time you've got to be doing this on your own."* Sarah moves on to the birth itself and how though she was having some contractions they were "very far apart" so the medical stuff wanted to induce her due to a "a risk of infection". Sarah was told she would: *"need to have an epidural because the twin pregnancies, even if they are naturally born, sometimes one will turn and there may be a chance that an emergency C section is needed."* She said: *"I probably wouldn't have opted for an epidural, but I was told that I would need one and that was the way that it was done. So I just went along with it. I agreed with it."* She was given an epidural and put on a drip to quicken the contractions. It was at this point Sarah felt: *"...I'm completely out of control. Like everything is, I'm numb. I'm uh, on medication, I'm wired up to these drips. Um, I'm just listening to what they're telling me to do."* It was a very painful and long process. Sarah described how disempowering the whole process was for her: *"It was, I didn't feel in control. I wasn't, I wasn't distressed or upset. I was actually quite excited that I was having twins and I couldn't wait to meet them. But at*

the same time I was at the mercy of other people. I felt like I was totally in people's hands and I, I felt like I was not in charge of my body at all. I felt like I couldn't say anything, that I wanted, I felt like I, I felt like, okay, I need to just listen to what they're telling me and I need to do what they say and I, and you know, and that would be the best outcome that would, that is what I had in mind in my mind. Um, and I did, I followed every instruction they gave me."

Sarah shared details of the many interventions she was subject to and how it made her feel: *"also they gave me an episiotomy. So I had quite a lot of interventions. I had quite a lot of stuff going on. Um, so it was bad enough the epidural was awful. It was like not a very nice experience to have someone jab a needle into your back. Um, and then have to lie very still in, you know, kind of with this fear in your mind that if, if I move I might be paralyzed the rest of my life. Um, and then being wired up to all of these drips and being told what to do and how to breathe and how to, you know, move and where to sit and where to move my legs and everything. And then on top of that I was then I had, I had to be cut, so I then needed stitches…I found it really, really physically taxing."*

Sarah moves on to post birth and how the twins: "were sent off to a special care baby unit because they… were quite, they were quite small…" at that point Sarah was given a room which she appreciated especially as she had found the process undignified and public: *"just felt like the whole process was so undignified and so not private and so public. And there's so many people looking at me… and I didn't want to be this like painful bleeding mess in the middle of a ward. I was so appreciative of how they gave me my own room. And to this day I can't understand why women have to go through such undignified situations in wards full of…people".*

"visitors come in and out and you're there bleeding all over the floor and you're recovering from childbirth, which is like quite horrific really when you think about what your body's been through."

Having the room helped Sarah process and "get to grips" with everything and what her body was going through: *"So all the pain I was feeling from stitches and all this bleeding that I*

wasn't used to, the pain that I was feeling", having the room Sarah said: *"was probably one of the most positive aspects of, of my kind of childbirth experience."*

Sarah goes on to describe the lack of hygiene at the hospital, what she witnessed and how shocked it made her feel: *" I didn't feel like the hospital was particularly clean. ummm. Which I was quite shocked about…I just thought this is a, uh, you know, a maternity ward and women are having babies here and you're walking around and you're feeling that floor is sticky in places. And even when you went to the bathrooms, and of course there were lots of bathrooms on the ward because of being pregnant women, there were loads and loads of bathrooms, but everywhere you went you would see like little drips of blood and the toilets would have blood on the seats and even the bath were not kept that clean and they were telling me to do things like go and have a soak in the bath and soak your stitches. And I just thought how?"*

Sarah felt that the: "bathroom needs to be completely disinfected before I go in there" and how awful it was being told to go into a bath that was dirty with and be expected to bathe: "an open… wound into this bath where I don't know whose germs are in there." Sarah found a way around this by using the shower head in a cubicle next to the toilet as she couldn't bring herself to: "sit in the bath tub full of water when I didn't know how clean that bathtub was." Sarah highlighted that she: "had no means of cleaning it and… didn't even have the strength in me to clean the bath before I got in. So that was my way of dealing with the stitches and how I looked after myself in the hospital."

After five days Sarah was told she got go home but: *"they wanted to keep my twins in special care because they still hadn't gained the weight that they wanted them to gain."* This was distressing for Sarah: *"Again, that was a little bit distressing for me cause I just thought, hang on, you want me to go home without my babies?"* Because Sarah was visibly so distressed by this she was informed that there were transition rooms outside of the ward where people could stay and was offered that: "I was very thankful for that, um, um, facility because for the next two nights, so after I'd been discharged, um, we stayed in those rooms with the babies, which meant that we were attached to the hospital." They were discharged after two nights.

Finally at home with her babies Sarah shares the experience of midwife visits where they came to "check up on me several times". Sometimes they would turn up unannounced, Sarah found this odd but had a narrative for why this may be: "she just turned up on the doorstep, but they don't make appointments. They just turn up and which again I thought was a bit odd, but I could also understand that they perhaps, um, need to be sure that, you know, families are looking after the babies really well and so they just want to catch you out if you're doing something you're not supposed to be doing."

Though Sarah understood there may be this reason for the midwives turning up with arranging a time, she found it: *"quite intrusive because there were times when I was trying to sleep or I'd had a really bad night, um, or I was just emotional and these midwives and health visitors would just turn up at the doorstep wanting to see me."* This was a really struggle for Sarah who was trying manage her own recovery and care for her babies and while she was lacking sleep. It seemed really unthoughtful and inconsiderate: *"Um, and I think the first time I struggled down the stairs and then after that I just said to my husband, I can't do this. They're gona have to come upstairs if they want to see me and if I'm asleep, I'm asleep, you know, that's just, um, so the next few times they came to the house, my husband would bring them upstairs to my bedroom." Sarah had her sleep disturbed a number of times by the midwives: "I was asleep and they would wake me up to just say, you know, we want to check how you doing?*

Sarah shares her breastfeeding journey and the lack of support from midwives: *"Um, there wasn't a lot of support around breastfeeding. Um, I felt like right from the beginning they wanted me to not breastfeed".* One of the first questions she was asked was not what method of feeding she would like to try but: "what brand of formula milk would you prefer for your babies? That was one of the first questions I was asked. That was all, so immediately there was this, there was this assumption there that because she's got twins, she's not going to be breastfeeding. Definitely she's going to need formula. So, um, again, at that point, because I was a new mum, I just went along with everything as it happened and I just, I picked a brand, I picked a brand, funnily enough that I, I knew from my own childhood."

Sarah recalled how her mum: “gave us and my siblings cow and gate milk…so I picked cow and gate”. She did however attempt to breastfeed: “I also expressed milk for them, but I struggled and I think part of my struggle was I didn't have the right support…There was no one that say to me, are you okay? Do you need any help? You know, it was only when the health visitors and the midwives came to the house that they would actually ask, you know, what is the baby's latch like?” It was when Sarah got home she felt she did receive some support and was asked questions around how she was coping and if she needed any help and support: *“I was getting quite sore. Um, but it was only really when I was at home that I had the support. So I had someone, they had a breastfeeding advisor who came to visit me to give me advice and stuff, but by that point in the hospital, they'd already been giving them formula milk via bottles, so they weren't exclusively breastfed.” Sarah: “wished someone had really drummed into me the benefits of breastfeeding.”* She also wished for acknowledgement and that: “someone had said to me, do you know what? I know this is hard, but this is the best thing for your babies.” In hindsight Sarah feels: *“I would have loved to have tried harder to breastfeed them and I know there were two of them and it was hard. It was very difficult and I was very, very sleep deprived. But I feel like I could have done it for a bit longer.*

Sarah moved on to her second birth experience which “was nine years ago”. Sarah experience the pregnancy as: “again, the pregnancy was quite uneventful.” She did have: “a lot of sickness in that, in that pregnancy as well” She thought she may be having twins again but the scan sated one baby. The “pregnancy was fine. I was healthy, I was, well, I didn't have any issues. I was probably more active and more, probably healthier than I was in the first pregnancy. So I was, um, I was working up to a certain point. I was also doing other voluntary things in the community, so I was on my feet quite a lot.” Sarah also had her twins to look after and felt like a “busy mom running around”. She did not feel the *“need to slow down or anything like that. There were no complications. Everything was fine with all the scans.”* It was only towards the end of this pregnancy that she had pelvic pain and was referred to physiotherapy, “which I went for and didn't find helpful at all.” Towards the end of the pregnancy Sarah was told: *“that she was quite a big baby, um, and she was also back to back.”* Despite this Sarah was not given the support or information she felt she needed about this condition: *“they did not actually, they didn't actually, they didn't give me any exercises or anything to do. They didn't give me any advice on how to turn my baby or what I should be doing….I didn't even realize that back to back was more painful…so again, I*

didn't feel like towards the end of my pregnancy I had the right information or the right support. Mmm."

Sarah shares how her baby was *"overdue. So, Mmm. She was born at 40 weeks and 15 days. I think I've got that right. So she was 15 days overdue basically".* Sarah felt the midwives pushing her *"towards the C-section. They were saying that, um, because the baby still hasn't come yet and your, you know, this many days overdue, we would, we would advise you to book in for a C section... And I just, I just declined and I kept declining. I didn't want a C section. Um, when I got to about 10 days overdue, they said to me, we will have to bring you into the hospital and we will have to induce you because you know, your baby's getting bigger and bigger day by day and nothing's happening."*

Sarah shares how pressured she felt inti the c-section: "I think I then let them book me in for a date to induce me. Um, I can't clearly remember now exactly what happened towards the end. It's a bit of a blur, but, um, what I do remember is them pushing me to book…in for C-section and me and me saying, I don't want to do this. I don't want to do this. Um, I then reluctantly did book in, but Mmm. When I got to, Oh gosh, I think it was day 14. So I pushed it and pushed and pushed it as much as I could. They were really unhappy with how I was, how much I was delaying things. And they kept saying, look, there are risks involved and we can't let you go beyond a certain point and we would have to induce you. Which I thought was a bit weird. I just thought, how can you tell a woman what you have to do to my body? Sarah found it very disempowering and disrespectful how her bodily autonomy and rights to make decisions were being taken from her and the coercion she was experiencing.

Sarah had questions about how others have a right to tell a woman what she can do with her body and wondered what would happen if she made the choice, an autonomic decision about her body: "How can you tell me that you have to induce me? Because you know, what if I, if I don't want to be induced at all, what if I'm just going to go home right now and just have my baby on my own whenever she's ready to come." Sarah further explained how women are subject to fear mongering and guilt tripped into making decisions under what feel like coercive practices: *"But of course, because they also, um, put all these ideas into your head about how, you know, babies can die and you know mothers do die, you know, um, in these*

situations and it can, it holds a lot of risks, et cetera. And you think, okay, well they're the professionals. They know what they're talking about. Um, you kind of want to meet them halfway. Um, and so that's what I felt like I was doing. I felt like I was being reasonable. I was, I was doing what they wanted, but also partly on my terms". Sarah was partly able to asset some of her needs. Sarah tried a number of interventions around day 13 or 14 over due, from long walks, pessaries and birthing balls. She found the birthing ball "really helpful". She was trying to assist the turning of the baby from back to back then she states all of a sudden: "all I remember was a blur of examinations and them checking me and them wanting to admit me and still banging on about caesareans and me saying no. And it was all this sort of blur". Sarah felt "unclean from just being in the hospital on the ward. I wanted to pray, I wanted, there were things I wanted to do, I wanted to have my own food at home or I wanted my bed. And I said to them, I feel like I just want to go home and I just want to go have a shower and I'll come back." The staff said the "doctor won't approve it", at which point an exhausted Sarah remembers getting: *"quite upset and I remember saying, you know, if I'm saying I want to go home, how can you hold me back? How can you say I can't go home. I need to go home. I need to have a shower, I need to get fresh clothes, I need to have a sleep in my own bed."*

Sarah was in need for her autonomy and her self-knowledge of her needs and her body to be respected she was having to fight for it. She explained ot the staff: "when I'm feeling more energetic, I'm telling you myself that I will voluntarily come back in." The doctor then came in and spoke with Sarah and said: *"we can't advise you to go home, but if you're choosing to self discharge, then we need you to get, we need you to fill out form. And then we, and then you can go home and then come back. That's fine. So that's what I did. I filled out this self discharge form".* Sarah was so glad she made this decision and was allowed to go home despite their being tension initially with the staff over her exercising her choice: *"I went home and I'm really glad I did because, because I was able to have a two hour nap when I got home. I had a shower, I had clean clothes, I was able to pray. My husband made me some food to eat. Um, I was in my own, you know, I felt really comfortable, really relaxed at home."* Sarah went back in six hours later but *"still nothing was happening". Sarah* wanted to feel her labour: "a bit more than I had the previous time cause I, from the previous time I felt like I was completely out of control."

Various interventions were tried, one injection which made Sarah vomit. Sarah remembers: "being in absolute agony". Things were getting intense and hectic: "I kept pushing and I kept pushing and I kept pushing and nothing was happening again it was a very long labour…at one point that the, Mmm, the doctor came in and said…we will need to prep you for C-section". This was extremely distressing for Sarah who wanted a natural birth and was trying really hard and not feeling supported to go at the pace of her body and baby. Sarah shares her emotional journey: "at that point I started crying because this was going to be an emergency C section. And in my mind, I was thinking to myself, there's, there was, I had my first two naturally, there was no reason for me to have this C-section, I didn't want the C section Um, and I was, I remember being really, really upset. I was actually crying in pain and crying at the same time and saying, I don't want to have a C-section…then at one point, a really, um, like forceful midwife came and she was almost in my face and she was holding onto my shoulders and she said, I just remember her saying to me, listen, Mrs. [name], I need you to listen to me… and then she said, your baby's in distress and her heart rate is dropping and we can't wait any longer. We have to take you and you haven't, she was almost shouting at me in my face. Like, like it was the only way for me to comprehend what she was saying. Um, and it, it was quite unpleasant. The fact I remember it to this day, I remember the words, you know, she was kind of shouting in my face. I think she was trying to get me to see how serious it was. Um, my blood pressure was dropping, my baby's heart rate was dropping, and so they were quite concerned. Um, but again, I felt completely out of control. I don't feel like anyone asked me what I wanted. I felt like nobody, nobody had talked to me through these options beforehand. Nobody had said to me, there's a possibility that this might happen, that might happen…"

Sarah eventually had: *"*an emergency C section… it was a really awful experience. I hated every minute of it. The whole process, the whole, um, uh, not being able to feel what was happening cause um, they gave me a, a spinal block or something. Um, and then, um, and then the, the, the afterwards, the feeling numb and the having a catheter put in and not being able to feed anything, not being able to go off my bed, not being able to reach to get my baby. All of those things. I just remember it being a really awful experience. I didn't enjoy at all. Um, and then even afterwards, like the, the midwives had to come to my house and they had to okay, come and inspect my wound and um, the experience of having my staples taken out cause that's what I had."

6.2 Narrative Inquiry Analysis: Composite case study two

Mustafa* began by talking about the birth of one of his children. He described the experience as being good in terms of not knowing the gender and being happy with not knowing, relating this specifically to Islam and being grateful for whatever Allah gives and accepting whatever they are given. His first experience was emotional; he described crying in the hospital and also feeling excited. He further shared the significance of the first born and female especially and being a witness to the event and holding his wife's hand, encouraging her while she's pushing, reassuring her, seeing the relief on his wife's face and how he found that comforting. Mustafa spoke of their losses and also highlighted how he was there for all births bar one which holds the significant crux of the overall story and the shaping of the experience in this case.

Mustafa reflected on the quality of experience of pregnancy and birth being dependant on various circumstances and also in relation to family situation and how the wider context is different for everyone depending on what they are going through and what they have been through (this became apparent as the story unfolded: *"labour depending on the family, depending on the situation can be good or worse depending on what, how the, I don't know how to explain, but yeah, I mean everything, every birthing is different for every individual".*

He described how the experience of birthing lead to the shortening of labour and birth in later pregnancies, he felt the quicker the process the more convenient for the woman giving birth and the comfort of being in one's own home adding to the ease of the process. He moved on to explaining how one of their births was a home birth and a brilliant experience: *"Um, so Alhamdulillah that was good experience in itself. Um, so the second one was at hospital, the third one was at hospital the fourth one was a home birthing, I think, which is brilliant experience, honestly. Um, and when the the midwives, well w uh, yeah, the midwives come with all the facilities. Uh, literally you're in your own bed, in your own comfort zone. Um, you don't have to more or less, do nothing besides make tea or giving them snacks if they want."*

(Reflections: I was struck by how contrasting this experience was of offering hospitality to staff and how in hospital women are often not allowed to eat or drink when they are going

through such an enduring experience and require energy. Though there may be 'reasons' it is still striking. This also reflected the results of the survey where home birthing experiences were described as superior and offering an overall better experience. Further, I thought later in the writing how some experiences were expressed with intensity of emotion layered with deep reflections and philosophical thoughts that come out of tragic experiences so vastly especially when something goes wrong).

For Mustafa home birth represented comfort and familiarity, empowerment of being on one's own terms, autonomy, being able to pray and closeness to his partner. He gave the example of needing to pray during the labour and birth process: *"if you need to pray, you can pray, um, without having to worry to travel it through prayer, prayer room, a hospital, make it back and find out she had the baby kind of thing. So yeah, you're in kind of arms length at all times."*

He went back to the feeling of comfort and how being at home meant one could wear relaxed clothes as well as pray and overall be in control of the environment and personal needs. He also said he and his wife were told they were the first Muslim couple to home birth in their city, he was shocked at this especially because the demographic of the area was a highly Muslim population.

Mustafa shared how he: "*missed the one birthing because I was in hospital."* He makes an unexpected significant revelation of being in hospital at same time as his wife is giving birth – missing the birth and the emotional experience: *"Yes, we were in the same hospital, but I was an inpatient and I found out after she had given birth. So I went there and obviously I was sad I cried when I saw the baby cause I missed the bi[rth]. I missed the birthing..."*

(Reflections: I was stopped in my thoughts over this revelation, I could imagine perhaps something major happened and could feel something major about to emerge).

As Mustafa had been at the birth of each of his children missing this birth and having gone through what he later described was clearly a sad and emotional experience was really significant. It was also the birth of his first and only boy. Mustafa shared in jest how he felt solidarity as he is now no longer the only male in the house anymore. He talked about how

they are not sad to have girls and it's not like that for them, he also connected the family make up and patterns in terms of gender of siblings to his own family – it mirrored his own sibling dynamic, or 'trend' of being one brother with sisters.

(Reflections: I noticed as a Muslim how we talk about those things we know the outside world has stereotypes over and we have to justify or explain, gender being one. I wonder if this was an unconscious process when Mustafa was sharing how the gender of the child did not matter to them)

He shared how they chose the names and how important it was for them to connect to the Prophet (pbuh) and his family through emulating names: *"We thought, you know, uh, from the intention from day one that we'll keep the children's names of the Prophet salalahu alayhi salaam. Um, and lo and behold, yeah, we've got all the girls and we're just short of one boy's name… I mean, we've never planned Alhamudlillah. That's another thing we've never planned for our children. Yeah, we're ready for them, baby. You know, we're ready for the kids now whatever. So we've always, let, uh, whenever it's happening Alhamudlillah, it's happened."*

(Reflections: I was still struck by the significance of Mustafa being in hospital while his wife gave birth so I felt it important to acknowledge and empathise with how it must have been quite a difficult experience, this opens the door to Mustafa sharing in detail his incredible experience and how it over shadowed and affected the remainder of their pregnancy and birth while he was on his 'death-bed': *"Yeah, I mean ffffw it was complete. Um, so, Yeah, so basically my wife was [removed number of month] pregnant…. Yeah. So the baby was during [due date], I had, um, major, uh…accident. Um, I was on deathbed, basically, you can say, um, how's to live. Um, so it was hard on her, um, during the pregnancy as well, especially when the police turn up on your doorstep to say, you know, your husband's been involved in a…accident. Um, he's, he's being flown to the hospital for surgery, so she's panicking."* Mustafa stated how difficult and hard it was on his wife at this late stage in her pregnancy discovering that her husband had 72 hours to live and is on his 'death bed', having the police turn up and the shock and horror of it all.

(Reflections: This feels like a remarkable story and talking to the man who shares the hurdles he overcame having been so close to death, I feel honoured to be speaking to him, for him to be sharing his story feels all the more remarkable given all that followed).

He spoke of the impact on his wife first, he didn't mention himself at this stage. He talked of her being heavily pregnant and having to be strong for his sake and not showing a sad face because he suffered significant brain injury: *"Um, I lost my skull. Um, I had broken bones, broken pelvis, broken knee, everything basically. So I got metal throughout my body, from the skull to pins in my spine to pelvis, on knee cap, I think. Um, so yeah, I mean, to think that you're pregnant with two children to look after pregnant with a third."*

(Reflections: I am amazed and astonished that someone who went through such horrific injuries is actually talking to me and what they must have gone through as a family with this happening at the late stages of pregnancy).

Mustafa talked further about the impact of the '72 hours to live' news and how at the time they did not know if he would come out of the coma and for the emotions and feelings his wife went through during these last months of pregnancy just not knowing whether she would have a husband at home, would she have to look after three kids as well as him in a coma. When he finally woke up the doctors said he would never walk again and: *"He's going to be vegetable basically. Again, that plays up thoughts in our mind. Okay. You know, spoon-feeding, changes - catheter etcetera, this idea, which is daunting, and it was not in the nicest thing we to experience when you kind of almost giving birth."*

(Reflections: I wondered how his wife would tell the story and about the impact on the unborn child of this shock as I listened to Mustafa's quite horrific descriptions of his accident and the timing of incidents with the pregnancy and birth. I was also struck by his calmness and the light heartedness and almost witty and good spirited tone with which he spoke about this).

Mustafa moved on to how he miraculously started to pull through and began physio during the last week of the pregnancy and that gave them both some relief and comfort. There was some confusion as he recounted the date: *"Um, then when her due date came and she was,*

she was oh my due date is today, whatever. And I think Eid was just within the next 10 days. I think it was back in 20 four. Yeah, back in 20. Oh damn. I forgot it. Yeah. 2014. Um, so initially my, my, my cognitive reaction was to say, inshallah you'll have the baby and on Eid day. Um, and in the process what I didn't know was my mum asked me to be transferred to [city] to be closer to home because I was, um, working and living in [another city] at the time." The hope from Mustafa that the baby is born on Eid becomes significant later in the story. The arrangements being made for his transfer to a hospital closer to his parental home became a point of stress and tension at the very late stage of pregnancy for his wife needing to pack and move home while heavily pregnant, with two other children and a husband - as Mustafa stated – at "dying stages and overdue date", (referring to his wife's due date and the doctors saying he didn't have long to live).

(Reflections: This experience of moving during pregnancy and the stress and upheaval reminded me of another account in the survey. However, this story of course tells a wider narrative and is driven by the accident and incapacitated state Mustafa finds himself in and the need for a wider familial network to help take care of the family unit as well as the intensely stressful impact on mother and unborn baby.

Finally, Mustafa found out about his baby having been born, he recounted the context: *"um, yeah, I woke up, um, I mean with, with my cognition, I, some days I didn't know what days was, what day it was kind of thing as well. So my family used to come visit me this, this is the day, this is what we're doing, this hour is, and this morning I woke up and the male nurse started to talk to me, you know, ah, you know, it's a lovely day today, you know. Yeah. This morning I, you know, had to get my three kids ready for school this that and the other, I'm thinking, I just woken up why you talking to me about your three kids, you know, let me freshen up, let me have breakfast, let me get with it then. And then all of a sudden he's jumped you into, Oh, congratulations. You got, you third child. And I said, what [shock surprise]?".* As Mustafa was in the same hospital where his wife gave birth, he was notified inter departmentally through staff and later wheeled to see his wife and baby by his brother-in-law. He focused on a point of relief for him, that despite all that was going on, his wife gave birth naturally and didn't have stitches and was able to go home a few hours later. Most significantly for Mustafa he highlighted it was the blessed and joyous day of Eid! *"it was*

Eid day Alhamdulillah the Dua came true! We had a joke about that as well". His earlier 'joke' had come true.

(Reflections: I was struck by Mustafa's gentle humour and light-hearted way of sharing what some may consider pretty horrific and life-threatening circumstances and experiences.)

He talked about how all the babies had been breast fed - this was important for Mustafa and is an important teaching in the Qur'an regarding the rights of a child and is seen as fulfilling a blessed role part of the process of creating a healthy attachment and bond. Part of his role he mentioned was in 'burping and playing with the kid's and taking care of them while his wife could attend to her basic self-care needs which in this circumstance, he was not able to do as with the previous babies. Another "daunting" situation occurred within a week of being discharged from hospital where his right hand became paralysed in relation to the brain injury he had sustained, he describes how difficult it was not being able to walk in the context of needing to help with the baby and children: *"So that was literally, um, one of the daunting thoughts what happened, what happened to my hand, or whatever. So my wife had to look after the three children, well, two children, one baby and her, husband".*

Mustafa spoke of how difficult he found it, and helpless he felt, witnessing what his wife was going through until he had a [body part] replacement procedure: *"seeing her kind of stressing about the kids as well as the baby as well as looking after me and I didn't feel too great, uh, looking at her, having to care for all four, um, because it was unfair, especially after you just given birth."* He described how courageous she was and that one regret was despite them having an open conversation relationship where they discussed 'what went good and what was bad' regularly, on this occasion that process did not take place and she bottled all her emotions and feelings up and was left out as Mustafa's serious injuries overshadowed the pregnancy and birth. He said his wife had to: *"show a brave face to everyone or, you know, because, and that's another thing. Um, she experienced and she, not too happy, but she was kind of left on the side, whereas obviously everyone came to see me in the hospital asking about or asking over the phone, you know, how's your husband or how, you know, um, from my mom and et cetera, uh, how's your son, whatever. And so whoever talked to her to ask about me, they forgot that she's pregnant".*

Mustafa shared how the traumatic impact of the circumstance of this pregnancy actually further took hold and played a part in affecting his wife's mental and physical health subsequently also affecting a pregnancy that led to miscarriage. He relayed how it was quite a difficult pregnancy due to her then health condition and some stress induced injuries that were exacerbated: *"the fact of being pregnant made that massively painful. Mmm.* Mustafa described how this experience impacted him, as his wife: *"would wake up screaming in the night and, um, it was very distressing actually. Mmm."*

He then shared that his wife miscarried: *"Um, and I think we, were reasonably confident that's what would happen because she had bled. Uh, and then that stopped. Mmm. Of course you get given all the most reassuring advice, you know, very normal and it doesn't necessarily mean it's a miscarriage so go home and relax."* Mustafa was trying to un-muddle the experiences in his mind, setting the context when they had to attend A and E: *"she was bleeding heavily and really, really, really desperately upset in public, you know, ready to bleed all over the seat. Mmm. So we did eventually get through reception at A and E and ushered to the waiting room. And she was in terrible pain and great sense of indignity".* He describes how they are "ushered" in by this nurse as they were not on the system and how the nurse found them an empty cubicle, which someone else tried to use 15 minutes later. He felt this was really lovely of her to help them out.

Mustafa highlighted how his wife was in extra pain due to the trauma she had experienced and her health conditions as well as the time it took going through the process which again was quite a muddled experience in his mind as he shared: *"you probably know that passing all the bits takes some time. Uh, so we kind of waited for that to take its course. And then I…think it was probably about three in the morning, perhaps, or two or something that we were released and we came home. Mmm. Yeah. So it was a very long, very long process as I recall, but Mmm…I do remember us coming home really, really late."*

Mustafa then proceeded to say he could share: "various other things, about our experiences in the hospital and stuff". He then moved on to the second miscarriage which was: *"perhaps nine months later. Mmm. Similar sort of story, but I guess we knew better what was going to go on this time and Mmm."* Mustafa checked in if I could hear him as "it's very quiet". He then shared how he: "always find it a bit difficult when I am emotional (? Said softly partly

audible) Mmm. I'll re position the laptop. Is that any better by the way?" I respond to say yes. We continue with Mustafa thinking out loud some questions: *"Okay, cool. Uh, so what else?... Mmm. How did that pan out?"* He then answers these questions by sharing how: *"most of the miscarriage occurred at home. I think possibly all of it. Mmm. Yeah. As good as all of it. I think we did go to the hospital. I think the ultrasound did check that everything was out… it was. Mmm. Yeah, that was, uhhf, it was good in that because we were at home and my wife was comfortable. But uh, maybe, maybe better all around, I don't know."* Mustafa described the raw experience of the: *"foetus sitting on the system? you know in a takeaway tub... Mmm. And then the hospital wanted to take that in so they took it in…"* He described the impact on his wife as for quite a long time his wife "didn't really want to think about it". Further, when the hospital called, they would not speak to him despite him being the father.

Mustafa spoke about the impact on him in the way they were being communicated to about the miscarriage experience by the midwife: *"that was quite a strange experience for me as a man Cause, um, throughout, she addressed my wife even when facing me and answering my question. So I can't give you examples now, but the, everything she said was as if my wife had said it, even though I had asked a question and she was facing me to give the answer. It was very odd."* While it was strange for him and felt dismissive of the father, he acknowledged the centring of the woman in the process - in this case - his wife: "*... in a way it was quite lovely because it was sort of, you know, it's about, yeah clearly the woman's gone through all the desperate pain and everything. Mmm."*

(Reflections: I felt the need to acknowledge Mustafa's experience in this moment which seemed to have been on the periphery or being lost or drowning out).

Mustafa described the way in which the foetus was handled: *"This mortuary technician came out with cardboard box and put it on the table. And then, uh, we were in the middle of a conversation with the Chaplain at the time who we know personally and she was, she was being absolutely so lovely, um, warm and compassionate and all the things you'd hope for. And then this mortuary technician came in with a cardboard box, put that on table and said, um, and then she and she got piece of a form and put that on top of the box."*

(Reflections: I found hearing this quite jarring and what a terribly undignified way of treating life).

Mustafa then continued describing the scenario emphasising that it was a paper form just propped on top of the box that contained the foetus and how they were just chatting to his wife "a bit about this and that" and then he had to fill in a question on the form which led to his wife collapsing into tears: *"I didn't see the form, but it said relationship. Mmm. And the mortuary technician said, Oh, just just put mother. At which point my wife just collapsed into tears and couldn't, you know couldn't put that on the form."* Mustafa was: *"not at all sure that's what was needed… I think it's relationship to the patient whose tissue you're collecting. Mmm. But maybe not. Perhaps it's for anybody that you collect and therefore you would say, Oh, this is my father, or whatever."* The point about lifting the form off the cardboard box seemed significant: *"at some point I sort of, I think I took the form, I lifted the form off the cardboard box."* The whole time this piece of paper – the form that had been sitting on the cardboard box that had a life in it, potential, a future, hopes and dreams, a child to parents, life - was so mechanically seemingly carelessly and or flippantly, bureaucratically treated. They spoke about it to the: *"chaplain afterwards and she said she would speak to the mortuary department about you know the dignity which Islam gives bodies and how they're to be treated. And you don't put paper, you don't put some bureaucratic form on top of a coffin thing."*

Mustafa shared the strangeness and dehumanising of the foetus being referred to as 'material' in the hospital system. Even though Mustafa understood that it was more than that, he was also concerned for his wife's' state and so refrained from insisting on it: *"And then there's this weird thing, with insisting its pregnancy material, they won't say it's a foetus… Mmm. So my wife was genuinely under the impression that what was meant was a bunch of placenta and umbilical cord and whatnot. And, and I was fairly sure that was a euphemism, but my wife was in such a state that I didn't want to really push that".* He shared how desperately sad he felt: *"so I was just desperate, desperately sad that this human being really had been on a shelf in [inaudible] poked and prodded passed about, and I get that that was necessary to an extent, but Mmm. It was very drawn out, very inhumane way of doing it. And so I was*

dismayed at, I hadn't asserted myself with my wife stronger to say, look what they mean is this…"

Mustafa reflected on the health system in relation to their experience and around death: *"It struck me as kind of symptomatic of the inability of the health system of the NHS to deal with death."* He further illustrated this through an experience relating to his grandfather: *"it reminded me when I was with my grandfather who was dying and it was quite clear he was dying, but the ward staff couldn't bring it, bring themselves to tell me in terms that he was dying. Mmm."* Furthermore, Mustafa continued to share his reflections on the NHS and dealing with death: *"It just seems like the NHS is very bad at dealing with death and I presume as a kind of self-defence. But I wonder also if it's not part of how general societies difficulty in, in facing void, because as far as the secular narrative goes it is just, that's it. You're oblivion. You never existed. You never will the world, the universe didn't notice. Um, and you get people saying, Oh yeah, well you go up and you're a star, all that stuff. But I think we all know that that's kind of just soppy nonsense. Mmm."*

This lack of respect and reverence for the human body and ignoring the reality of death was connected back to the foetus and how dismayed Mustafa was by the whole experience*: "I'm just dismayed at the lack of reverence for the human body and wherever that comes from, whether that's because it is just pregnancy material and not a foetus, or whether that is because Mmm. Uh, whether it's a kind of refusal to acknowledge the what's gone on, uh, emotionally, because they can't, they haven't got any language for it, or it may be just kind of a, a capitulation to the beliefs that we're just lumps of flash basically, and nothing more than that. So I'm not sure what it is about it".*

Mustafa stated that from his experience he believed that the: *"…NHS finds death really difficult and it was kind of just played out again with that mortuary technicians, uh, the way she went about stuff… she could have been the courier guy passing over parcel. Mmm."* This example of how it could have just been a courier highlighted the lack of respect and lack of dignity with which the foetus, and Mustafa and his wife were treated over their pregnancy loss and how no one wanted to acknowledge death: *"so nobody wants to be the person to say, by the way, you realise that in that papier mashay piss pot might be your baby".* Mustafa

shared how they had a medical friend working in the hospital at the time of their loss and how he came to visit them a couple of times and most significantly: *"we prayed Janaza over the bowl. It was really lovely actually".*

Again, Mustafa was disempowered by a system that did not seem to acknowledge the father's wishes, needs or even ask what he thought or felt. There was a sense of relief that prayer was able to be conducted, in this action was the acknowledgement of the life and loss. In relation to praying the *janazah* salaah (burial prayer) over the foetus Mustafa said: *"And that, that felt very good that we were able to do that, I remember sort of feeling cheeky transgressive that we've managed to sneak a bit of religion into this completely materialist machine that was treating all of us as lumps of flesh really…a hospital is there to cure the body and the mind and the spirit are no, don't come into it."* Mustafa connected this to the architecture of the hospital describing the functional layout referring to the positioning of both the chaplaincy and mental health units: *"I mean architecturally it's interesting… That chaplaincy is at the heart of that hospital, which is quite unusual. Um, and that's quite nice. Uh, but I don't think that really translates through anything more than the architecture. But the mental health unit for instance, is at the other end of the site. So. Mmm…Maybe that's good too. If you're a mental health patient, you don't want to be in with the other sickies, but I don't know. But it just, it's like, well there's mental health over there and there's physical health here."* The separation of physical and mental health in the hospital design is demarcated. Mustafa added how: *"then you've got the chaplaincy department, which is tiny, absolutely tiny."* While the physical and mental are acknowledged yet separated the spiritual is given the tiniest of importance at least space wise.

(Reflections: the connecting of pregnancy, loss and the significance and need of chaplaincy and mental health support and how these areas perhaps needed to be more connected and working together. I wonder about the role of spirituality needing to be part of healthcare for many and how this can be integrated and valued).

Mustafa felt that the medical system in the UK was: *"almost like a determined shutting the eyes of the system to religious needs. It's like, no, we don't do God."* Mustafa shared how: *"there was a kind of, you could call it kind of discrimination in the sense that in its determination to treat, everybody as a lump of flesh… things that are very important to*

people are not acknowledged." Being able to pray offered peace and relief for Mustafa: *"Certainly it was a moment of great peace in what was an extremely stressful time and yeah, the hospital's stress and we haven't slept for days and I was desperately hungry hadn't drunk for hours and hours and hours and you know, so it was, yeah, we were really run ragged… yeah, it's amazing. Yeah, prayer well done, it kind of gives you that sense of peace about stuff."*

(Reflections: I was really struck by how awful it could have felt and while experiencing grief and perhaps being jarred by some unexpected experiences there seems such little care where one may expect there to be in hospital. Basics like noticing and acknowledging the fathers' basic needs like food and water and rest are missing, yet there I am awed by the relief he felt in prayer despite all the other needs lacking, the peace and relief felt from the spiritual nourishment was striking).

Mustafa talked about the two nurses who helped them the most and how what they did was not part of their job yet was the most meaningful, most significant, humanising and helpful of all their experience during the pregnancy losses: *"she was going outside procedures and so was this Christian nurse going outside procedures to acknowledge our…Muslimness."* He also described the scenario with another nurse who helped them: *"she was Polish. Mmm. She put my wife in the Bay and uh, she's just just so lovely and said do you understand what's happening? Yeah. Uh, my wife said yes. And they said, do you understand that you're losing the baby and my wife said yes. Mmm. And then I can't, I barely caught this and I can't remember what the rest of the bits she said were. Then she said, well, said something like, well, sometimes God chooses… see what did she exactly? I wish I could remember that it was, but it w the, the, the meaning was something like, this is what God chooses sometimes, and then she apologized and she said, Oh, sorry."*

It was this connecting over religion that provided for the basic needs being met during this experience of pregnancy loss for Mustafa and his wife: "*She said, I'm religious, I'm Christian, I'm a Catholic. I can't remember which one she said, Mmm. Uh, and then my wife immediately said oh, you know, yeah, that's what we, we're religious too. That's what we believe or, or we're Muslim too. And that's what we believe. So that was, again, that was*

really, that was very meaningful. Um, and again, it was kind of, you know, to have the, the, the nurse sort of apologized for it. Mmm. We said how actually, how much we appreciated that."

(Reflections: the story about the nurse made me wonder how often this happens and how much staff may, (or have to) hide their beliefs and are careful not mention religion, would be interesting to know how much staff feel they can bring their whole selves into the hospital setting, also how perhaps this core element for some could be integrated as part of person centred care and be 'ok' to bring in for those who would value and benefit from it. I also thought about how some staff take the courage to overlook 'protocols' and connect to the needs of their patients and what feels human and right in the situation and just how tricky and risky this may be yet makes such a huge difference in what can otherwise be experienced as a cold bureaucratic system).

Mustafa used an analogy to describe the experience in the NHS and how it felt: *"it was this kind of, I think mechanical is, is the word I'd use for it. Okay. You are dealing with people, but you're not, you're just, it's like if I can use a really horrendous metaphor, you know, the meat packing lines where you see the sides of beef rolling along, uh, yeah. You know, tracks in the seating. Mmm. Uh, it is a bit like, ah, you know…it's an industrial process which has been refined and refined and refined and refined and refined. Mmm".*

He described in detail contrastingly the beauty of the hospital design in the early Islamic period and significance of nature in healing: "*its like a, like your typical Arab house has got a courtyard…has got a fountain in the middle, got pomegranate trees at each corner. Um, very pleasant place to be. Mmm. And you know my friend sent me a picture of a hospital [in…an Islamic country name]. You can say, well, they've got all the money that they like to throw at it, but it's not just that. It is about how it's decided".* Mustafa highlighted the choice and decision making that goes into hospital designs and that it is not just about finance. *"Again, huge green, green, green courtyard. And that's the centrepiece. And then the rooms in the hospital around that. So yeah. You know, we don't need to go into the theology of symbolism of gardens…but uh, you just need to notice that the hospital is designed around something living in something green and you face each other. So something communal about*

a courtyard, whereas the hospitals [here] are designed sort of …sections. They're cells, you know, you look at the fire map and they're sort of isolable cells of the hospital".

Mustafa had no support throughout the pregnancy and loss experience as the father he: *"found the whole pregnancy…really exhausting because I found it really traumatic when my wife would wake in the night and hear her scream, scream and scream. I was, I had, uh, I was already, I would bolt awake immediately. Mmm. As soon as that happens, I'd have months of light, sleep. Not particularly consciously, deliberately, but you know, just as a matter of the way it… way you work, you don't allow yourself to sleep deeply because Mmm. Because this person…they might need you…"* This was a difficult experience for Mustafa who shared how it impacted his relationship and how they both felt traumatised in their own way: "*to be honest, that has been quite a difficulty between the two of us that, Hmm. My wife feels like I'm not able to support her or not willing to, I'd feel like she makes it needlessly traumatic for me. So she deals with her pain by screaming out loud and I've tried to explain, well that's just deeply traumatizing for me because I cannot help you. So all you do is make me feel like, yeah, it's like a cry for help when she knows that I can't help and so I'm being told to help and that I can't".*

Mustafa shared his thoughts about the impact on his mental health: "*the first time around my mental health definitely did take…took a real hammering because I was not getting enough sleep, wasn't getting enough to eat because, you know, when you're stressed, you stop eating, stop preparing food and just snack and you don't notice that you're hungry and Mmm. You don't get exercise."* Mustafa was still recovering too: *"So I was, I was really stretched I think during that pregnancy, the first time round… to an extent the second. Mmm. Yeah. Uh, but in terms of the miscarriage itself, I don't know that that did make a big difference. Really. Um I didn't suffer from depression or anything that I'm aware of, well I say that, I think my wife was depressed, sort of postnatally depressed sort of thing. Um, and you kind of catch that sort of thing off each other. Um, obviously I was very sad. I was, I, I don't, always view depression as being pathological".*

Mustafa described how their loss was also not acknowledged in the community and how he felt that mental health was definitely not understood: "*My Muslim friends and nearly all of*

them [mentions an ethnicity]. And I remember… on [a] good several like three occasions, I think. And I just gave up afterwards. Mmm. I mentioned that my wife had a miscarriage, and they didn't respond at all. Mmm. They didn't. They didn't acknowledge… [they say] we don't talk about that sort of thing. Mmm."

Mustafa explained why this may be and how he had "zilch" support from his male friends: *"Their whole attitude to pregnancy to my mind is completely bizarre. Um, Victorian in that a woman mustn't, mustn't be, seemed to be seen to be pregnant because, because we know how she must've got pregnant. We mustn't allow that to be thought about. Mmm. So it seems like you can't talk about that. It just, they just didn't, one of my friends on the second or third time I mentioned it, you did say, Oh well make my duas, but basically I found that males support for me was zilch".* For Mustafa mental health was more about emotional support: *"I don't know how much I would call what I was saying about mental health directly, but in as much as emotional support from, yep. Okay. Yeah. Good friends is the best emotion... That's the best mental health treatment there is, I think. Yes. Both protective and prevent and treat".* Mustafa felt that there was no recognition of what had happened and *"there was a…determination not to recognize what had happened. There was a determination to pretend as if I haven't spoken. Um, and almost no, absolutely not spoken and maybe not even thought, but it felt as if it could be felt that I had committed a bit of a faux pas socially by mentioning this [the miscarriage]."*

Mustafa concluded how the experience could be improved in hospitals: "*in an ideal world we just need to complete redesign the hospitals and the desperate garden as they call it, the hospital, which is the concrete yard with a few people. [inaudible]. The first thing we need to do is completely redesign hospitals architecturally. But we're not going to bother doing that until we've redesigned what their intentions are. And we're not gona bother doing that until we've redesigned what they think that they're there for. And we're not going to do that until we've got a proper anthropology that knowledge is that a human being is more than just the body, that gets carted in the back of an ambulance. So that's... Yeah. I'd really want in my ideal world. That's what we'll do. Mmm. We probably as a culture need to accept that death is inevitable and stop trying so hard to stave it off."* Mustafa believed that the focus needed to change so that: *"we could then direct quite a lot of the resources we spend on*

keeping people alive in a pretty miserable state in palliative care, into holistic care, into, uh, much more community-based forms of, of, uh, therapy broadly conceived medicine. Mmm. So, you know, it's just, I guess I really, I feel very strongly about this, this experience of going to the hospital, it's a place of dread for many people and no wonder, you know, go in and it's a machine and you're in the bowels of the machine, the machine churns away. And, it's there on the outskirts of town, and that's not, it's where we used to put the lunatic asylums where we have things that we didn't want to think about and it's difficult to get to. So, your family don't visit. You know it's just all round. It's just really weird way of thinking about it all."

Mustafa believes that there is a lack of acceptance of death which significantly effects the support available: *"once you've accepted that people die and that a foetus is a life and has died, then you can start, then you can start supporting people where they are. But this because there's this kind of refusal to even contemplate that. Neither the death bit nor the life bit ironically, we refuse to acknowledge that we're going to die and especially doctors refuse to acknowledge that. As far as I'm under, I can understand, um, unless we're prepared to acknowledge that a foetus was a life in the first place, uh, completely stuck. I just don't see how you can maybe mitigate little bits around the edges, but basically the system is going to continue to behave the way it does."*

Having presented the detailed narrative composite case studies, I will now proceed to the final chapter which provides a discussion of the overall thesis and contextualises the meaning of these case studies within the wider remit of this study.

Chapter Seven: Discussion, Recommendations, and Concluding remarks

This chapter presents the concluding phase of this thesis through a final weaving of all the various 'elements' of this study, providing an overview discussion, strengths and contributions of the research, its limitations, recommendations, future research and implications, reflections and concluding remarks for the overall thesis.

The central aim of this study was to document British Muslims experiences of pregnancy and birth, using a decolonial, and trauma aware approach, mindful of centring Islamic ontology and epistemology. It was specifically intended that this qualitative explorative enquiry would offer insights and explore the multi-layered, nuanced complexities of experiences during the pregnancy and birth stages of life for British Muslims. I had wanted to contribute to the field through providing a platform for the sharing of stories and interpretation from an insider researcher lens that highlighted lesser heard voices. My contribution was in creating a space to gather some Muslim women and men's experiences in a mindful way that considered carefully the historical backdrop and colonial legacies on mind-body and soul, that could be shared, heard and affect change in a meaningful way. I was particularly looking to see if and how Islam played a role during the perinatal stages and how mental health was affected and experienced during the perinatal period, and the meanings given. I considered and highlighted the importance for Muslims in centring Islamic ways of knowing in key stages of life such as that of pregnancy and birth. Furthermore, the presentation of the collected data and resultant recommendations offered a nuanced understanding to those providing support and care for Muslims during this period. The data gathered offers a starting point for ongoing conversations within the Muslim community and in collaboration with healthcare professionals and providers interested in improving care and outcomes addressing inequalities Muslims' experience during the perinatal stages.

As a reminder, the overall main question being asked was: *'What are British Muslims' experiences of pregnancy and birth?'* The question emerged in response to the often, unrecognised traumatic context for this population (socio-cultural, political, religious, and psychological) on both an individual and collective level as a result of my engagement with the community through counselling therapeutic work, delivering lectures and seminars, and chaplaincy work as contextualised in the introduction. As discussed in chapter two, there had

been very little study on this specific topic in this context, which then led to conducting the systematic review to understand what the experiences were more broadly around pregnancy and birth for Muslims. The review looked at papers internationally; I wanted to look at the specifically British (Muslim) context following this hence my study pathway. The systematic literature review foregrounded and paved the path for the empirical study. There were no papers looking at British Muslims' experiences at the time of my conducting the searches for my study. An empirical study was conducted in two parts: qualitative surveys of 42 participants analysed using a Reflective Thematic Analysis framework and four narrative inquiry interviews presented as composite case studies. Drawing on ideas of critical thinking from decolonising research and the ideas posed in critical medical humanities, I was able to posit the need to look at power structures and health inequalities that can be enacted through the medicalisation of birth and through colonial knowledge production. In thinking about the implications of this study I am left asking how can we provide the appropriate care to Muslims if the most basic of their conceptualisation of and meaning of life rooted in Islam is not considered part of the healthcare they receive?

The introduction, literature review, and methodology provided a general broader framework to contextualise this study, with the reflexive thematic analysis and the narrative case studies providing new data gained through the qualitative studies carried out for this thesis. In this discussion, I have reflected on the themes that came to the fore through the Systematic Review, the Reflexive Thematic Analysis of the surveys, and the stories shared through the composite narrative case studies. The findings are discussed in relation to the literature review and decolonising approach, with consideration of what value this research has added, impact, limitations, implications for future research, education and practice, and recommendations. Finally, ending with personal reflections and a conclusion.

I address the concepts and points for reflection arising from the data based on my perspective having trained in counselling psychotherapy (drawing on psychodynamics, integrative, Islamic, critical, and trauma studies thoughts) and as a certified clinical trauma therapist working in a decolonial way, threading together what the contribution of this thesis all means. Here follows a summary overview of the main empirical findings presented.

7.1 Overview summary and interpretation of empirical research findings

A multitude of very personal, subjective, individually and collectively situated experiences around pregnancy and birth were shared by British Muslims'. Though the findings were presented as themes, I would like to highlight and acknowledge that they ought to be thought of as overlapping and interconnecting as per my analogy of the weaving rather than neatly compartmentalised separate categories.

The papers from systematic review provided an overview globally of the kinds of research being done around the question of Muslims' experiences of pregnancy and birth, though in different contexts and countries. I was able to discuss the coherent themes that came through on the role of Islam as a faith, a way of life and religious identity, mental wellbeing and jinn possession narratives, experiences of health care: discrimination and diverse needs, cultural dynamics and patriarchy, relationships and family and the transition to parenthood. Having learnt through the global literature of the systematic review the areas of significance in Muslims experiences during the perinatal period, I added to this, two further empirical studies that I conducted. Analysis of the qualitative survey and interview were not too dissimilar from the findings of the systematic review. The interview case studies provided an in-depth illustration of some of the themes developed through the reflexive thematic analysis. Overall, what we now know is discussed below. It can be seen visually how similar the themes were (and where they differed or themes that did not feature) that arose from the SR and the RTA:

Figure 1 (themes from SR)

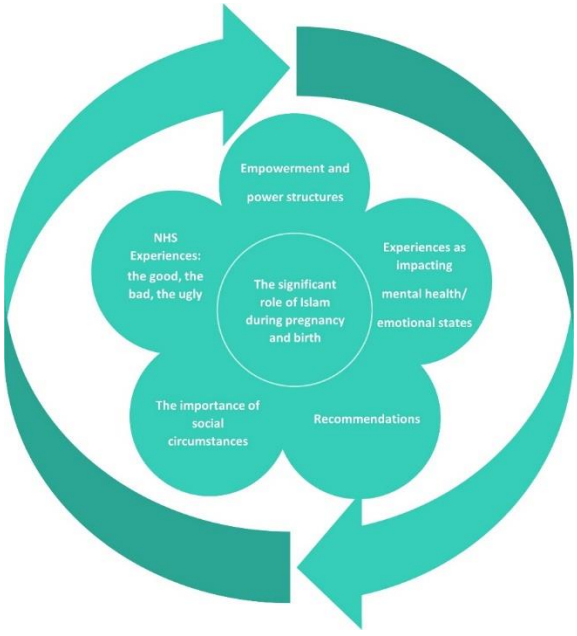


Figure 9 (themes from RTA)

Apart from transition to parenthood which came up in the SR and not in the empirical studies, the remainder of the five themes and sub themes echoed each other broadly and the nuances have been detailed in the writing that developed through the data collection for this study.

In summary, the empirical data indicated six core themes that were further illustrated in narrative form through the composite interview case studies. It was a challenging process to separate themes because ultimately participants' embodiment of Islam and its teachings were weaved through virtually all aspects of how they experienced life, how they made sense of and coped with challenges and how they experienced joy when things went well. The reflexive aspect of thematic analysis proved particularly helpful here as it allowed me to think through and write about my decisions and highlight where this occurred. The difficulty could be attributed to a limitation of the method in this application and or my own perception and internal worldview and way of making sense and connecting experiences which led to it feeling tricky to 'separate themes' out where everything felt more connected. It was incredibly challenging as discussed in chapter three to find the most appropriate method and RTA was the nearest 'ideal' for my empirical research. Despite feeling the content was interconnected on many levels for the sake of presentation and structure of a thesis, the role of Islam given its significance throughout, was developed as an individual theme and discussion is weaved into the other themes where it necessitated. Not being able to separate Islam out also highlighted the importance of understanding that a way of life and epistemology cannot be compartmentalised. This is the problem with categorising and compartmentalising Islam in the Western notion of religion. The 'whole' of the person and experiences needed to be kept intact, and meaning-making in the Muslim way, respected. This is where the Narrative composite case studies proved enlightening given the stories shared were more or less kept 'intact', went into depth and detail whilst not being dissimilar to those shared in the qualitative surveys. Connelly and Clandinin (1990)'s tools for narrative inquiry: broadening, burrowing, and storying and restorying were particularly helpful in allowing me to share knowledge and insights captured that were generally representative of the 'whole' despite being individualised cases. The narrative approach relayed real lived experience of a complex system of factors shaping experiences around the perinatal period and it is hoped these stories evoke empathy in health and social care providers (Wertz et al., 2011).

The first theme recognised that Islam plays a hugely significant and central role for Muslims during pregnancy and birth. It was given the title: the significant role of Islam during pregnancy and birth. The sub themes were:

1. Gratitude: Most beautiful and heart wrenching
2. The power of Qur'anic stories in particular Surah Maryam: Instead of doing positive affirmations I had done dhikr instead.
3. Modesty: The struggle between shyness, and accepting lack of choice at times
4. Closeness to God: Peace and seeking refuge
5. Islam played a vital role: My faith kept me going mentally

Gratitude was the key attribute for Muslims in all circumstances, whether things went well or were problematic or even seemingly traumatic. The concept of *shukr* (being in a state of thanks and praise) to God first and foremost was applied to all experiences. Even when things were challenging or traumatic, participants were still thankful and applied the concept of *sabr* which entails an active persevering patience. *Sabr* is considered the twin of *shukr* in the Islamic tradition. The theme in the SR that was most similar to this was the role of Islam as a faith, a way of life and religious identity. This theme also captured a feeling of gratitude, however, was more focused on the connection for women spiritually, feeling in a sacred state. In the SR there was discussion on faith increasing as pain and trials increased due to the reliance on God and the power in the strength of that relationship.

Another aspect to this theme in the RTA was how powerful the use of stories from the Qur'an were for participants and the way in which they utilised and applied them for their own wellbeing. Particularly, women drew on Surah Maryam (which details the story of Mary giving birth to Jesus) and the teachings from Maryam's (pbuh) experience of isolation and hardship. One such teaching drawn on in this story, is around feeling so strained and distraught that one wishes they did not exist and is sometimes referred to in helping Muslims when discussing issues of suicidal feelings. In The Holy Qur'an, in Surah Maryam, this experience is revealed: *"Then the pains of labour drove her to the trunk of a palm tree. She cried, "Alas! I wish I had died before this, and was a thing long forgotten!"* (Qur'an 19:23)[3], (This finding will be discussed in further detail in section below).

[3] https://quran.com/19

Some participants drew on *dhikr* (remembrance of God, reflection, meditation) and the names of Allah instead of affirmations or they created their own version of affirmations through drawing on supplications from within Islamic scriptures that provided a fortification, a strengthening and comforting. This theme also brought out the dilemma and negotiation of needs and environment regarding the need for privacy and differing levels of and understanding of modesty. Despite feeling their needs were not met at times for privacy or dignity, many of the participants accepted the lack of choice again drawing on teachings from Islam. Islam strongly advocates preservation of life and flexibility in situations such as if there is no female practitioner available and it is necessary for healthcare, then a male physician may attend. However, though there is flexibility, parameters for respect and dignity should be adhered to and this is where more dialogue needs to be had with healthcare providers about the preserving of dignity in general, and what it means for Muslims. There were participants who were emotionally and psychologically impacted by the consequences of situations that gave rise to feeling their dignity was violated. Preservation of dignity is a universally understood concept and not unbeknown to the NHS, however, what manifested through the participants experiences were in some instances the individual biases and discrimination of certain healthcare individuals perceived as using their power and position to antagonise (either subtle or overtly) during this vulnerable period giving birth.

Pregnancy and birth were seen as a time of closeness to God as the Creator and of being part of the process of creation. The womb *(rahm* - the meaning of which was discussed in chapter one but as a brief reminder - loving kind, compassionate, nurturing) is considered a deeply sacred and meaningful part of the process of creation. Thus the status of a mother and a pregnant woman is extremely high in Islam. This high status of women in Islam was not always given to pregnant women or mothers due to the elevation of cultural and various social and family dynamics over Islam.

In the second theme, pregnancy and birth brought with them various degrees of psychological and emotional affects. Theme two was titled: experiences as impacting mental health and emotional states. The sub themes were:

1. Intense experience of life
2. She wasn't emotionally available / conflict in views and mega stress.
3. Mental health on going impact and resiliency
4. Psychological “assault on the body”

For some, pregnancy and or birth evoked intense feelings, though that was not necessarily perceived as negative. External factors affecting participants where their mental health was impacted, included an emphasis on the availability or lack thereof an emotionally available mother. For example, those who were experiencing this major transition in life and had a mentally distraught, emotionally dysregulated mother were unable to draw on her for support as well as having to deal with their own stress and feelings of sadness. There were stressors from wider family dynamics where women were expected to continue with family chores despite feeling tired or discomfort and the change in their state as a pregnant woman were not accommodated for, or there were arguments and stresses with in-laws. There were experiences shared of being treated like a maid and expected to continue cooking, cleaning and doing chores as if nothing has changed and a denial of the state of the woman as pregnant which caused immense stress. These stressors had a detrimental effect. Nonetheless, women sought refuge and comfort through the empowerment that came from the knowledge they had through their Islamic ontological understanding that they are a conduit for creation and are in a sacred state during pregnancy, birth and the two years following suckling and weaning the child. One way of providing support for Muslim women could be through effecting change in the community through education about the importance of pregnancy and birth and how it may affect women and the family unit. Educational programmes and even khutbahs (Friday sermons that reach thousands of Muslims and mostly men) targeting the wider community would be one avenue of reaching a larger audience in the Muslim community. Many participants shared how Islam played a vital role and how the strength of their faith kept them going mentally no matter how low they felt. Feelings of utter extreme pain and injustices were shared; however the strength participants drew from their faith and knowledge base of Islam was a core pillar of support and resilience mentally for many.

Ultimately where a person's change in needs due to pregnancy or being a new mother or father were not being accommodated, they felt their mental health was strained from the pressure. There seemed to be little understanding and acknowledgment in the wider family and community of the profound impact of pregnancy and birth and the circumstances participants were in. Some of the consequences included the shock of the impact on their body, and, for some, the medical interventions felt intrusive and like something was being done to them and as captured in the words of it feeling like an "assault on the body". These were major experiences that felt abusive and traumatic for some but there was no awareness by those

around them, no acknowledgment of the impact on their mental and physical wellbeing and the need for support. There were also examples of incredible resilience in the face of very challenging experiences of pain and suffering, loss and grief, where participants drew on the teachings of their faith and prayer to give meaning to what they were going through and for support to help them continue going through. The accessibility of faith-sensitive support and counselling varied, and the majority felt mental health was poorly understood in the Muslim community. Some participants highlighted that the lack of awareness around mental health was a mainstream issue and not just one that affected the Muslim community. Furthermore, there was emphasis that perinatal mental health was even less known and accepted than 'mental health' more broadly. There was also recognition that awareness of men's mental health was near non-existent especially in relation to pregnancy and birth. Another interesting discovery was fewer participants spoke of mental health in terms of *jinn* (being possessed by unseen beings), *sihr* (black magic) and *ayn* (evil eye) than I had expected to find. This may be due to the changing dynamics around the globalisation of mental health language as well as general education around mental health being far more widely accessible and used to describe certain experiences. Some participants did however state clearly the distinction for them and what they attributed their experiences to whether they were *sihr* or *ayn* or mental health. However, this contrasted with the findings in the SR where mental health was more readily spoken of in terms of attribution of altered states and distress to jinn and with an interesting connection to intergenerational experiences of mothers (and siblings) having experienced the same. There was a sense that one had no control over becoming 'possessed' and that medical health was unavailable and dismissive of mental health/distressing emotions.

Thirdly, was the theme on the importance of social circumstances, which included family support, family-induced pressure and the husband's role. Theme three was titled: experiences as impacting mental health and emotional states. The sub themes were:

1. Family support and pressure
2. Husband's Role

The few men that took part mentioned their experiences in relation to their identity as the husband and supporter. The husband's support was perceived as calming and crucial for many of the women even citing that had their husband not been there for them they may well have developed postnatal depression/anxieties. This was different to what featured more prominently in the SR which was more a feeling of needing to protect the male from having to

witness the difficulties a woman goes through / stating a sort of helplessness and disempowerment of the man's role as not being able to do much. Though this was not the case at for all situations, there were multiple factors affecting the husband's ability and capacity to support his partner including policies and cultural in hospitals not being friendly to or inclusive the husband. This lack of inclusivity of the husband which featured in the SR was in some ways similar to the statements made in relation to the male experience during labour and birth in the RTA.

The level of family support or the pressure linked directly to how stressful experiences were during the time of pregnancy and birth. Some of these experiences included having to hide their pregnancy for the protection of their self and especially out of concern for the baby. There was also an expectation placed on the women participants to do as others advise, depriving them of agency and autonomy. These expectations and advice were relayed as coming from the mother/sister-in-law, and sometimes the mother – who most often than not seemed to be projecting their own anxiety of their own experience during pregnancy and birth on to currently pregnant daughter.

The lack of social support, and pressure, linked also to not receiving encouragement and the woman not being guided into her own knowingness and intuition of her body, and the empowerment that could come from that. Instead of empowering and encouraging Muslim women and men, certain cultural and hierarchical family dynamics that engaged in elements of power and control were being enacted, both at home and outside when seeking healthcare.

Contrastingly, and as is to be expected, those that received the support they needed and had supportive caring partners and family members fared well and generally narrated better experiences and more positive interpretations of events even if they were challenging and or involved pain and discrimination. This theme linked very closely with impact on mental health. The women whose husbands were supportive, despite any difficulties in the medical system and healthcare, coped better through having that core support. Many relayed how had it not been for their husband's support they do not know how they would have got through, even citing how they felt they may have had a mental breakdown. Fathers also stated how they saw their role, often citing how helpless they felt or were made to feel like they did not belong or were not wanted or cared for by the hospital staff. This was illuminated in depth with details in the illustrative composite case study of how such events unfold and how they make a man

feel as a spare part/easily dismissed/not having a say in decisions, as elucidated by one of the male interviewees. The negative experiences tied to impacting mental wellbeing and the supportive anchoring role Islam played as people drew on their faith to make sense of adversities and injustices, and how to deal with the behaviour of others.

What was interesting to note was there was more emphasis on the cultural community collective support in the SR and less mention in detail of community and collective support in the RTA, which may be as a result of the changing dynamics of family structures in Muslim communities becoming more nuclear and following the trends of the West, or it could be that families are not in the same country or there is as several sated lack of understanding and support from the wider family and community. The process of birth as medicalised as it is, is in some ways creating a disconnect to the deeper sacred, communal and spiritual connections that were more elevated.

Fourthly, the theme 'NHS experiences: the good, the bad, the ugly' elucidated the complex nature of experiences in relation to healthcare during pregnancy and birth. The sub themes were:

1. Discrimination and or disadvantage
2. Injury during birth: tears, tears and more tears
3. Mistreatment and neglect, shaming and humiliation by healthcare staff
4. The 'good'
5. Staff were so loving and caring

Many participants described incidents during the process of giving birth and how they were left with the impact; both positive and negative, though mostly negative. It was negative experiences that were re-told in detail as there is usually a story behind them. Negative experiences of giving birth in the NHS were one of the largest areas in terms of volume of data gathered before being broken down into themes. This was an interesting theme in that experiences were mixed; it was not all bad, which showed how and where things go well and should be noted going forward. Participants were careful to reflect on, and make distinctions between, experiences that were discriminatory and those that they felt were down to individual rude behaviour or ignorance on the part of individual professionals. It was interesting to note that some experiences which could be interpreted as discrimination were communicated by participants as being put at a 'disadvantage', quite graciously and giving benefit of the doubt.

Some of these experiences spoke of mistreatment, coercion, neglect, shaming and humiliation by healthcare staff. An example of the battle between power and control between birthing mother and the system was also illuminated in the composite narratives in detail, which helps us to see the nuanced ways in which these dynamics can be played out. The most similar of themes from the SR that related to this theme was the experiences of health care: discrimination and diverse needs, which included feeling judged, healthcare professionals making all sorts of judgements and being patronising. I was reminded of this in the writing of the RTA where one respondent had described how a healthcare professional had commented that she was here just to give birth to a British baby so she could get a passport, when she was in fact British and born here herself. It was just how she was dressed that judgements were made on. There were other subtleties where there was obvious Islamophobia and racism and surprise and change in attitude on the part of healthcare professionals initially but when the woman spoken in perfect English, they changed their attitudes and approach to care which is extremely disconcerting and worrying. There was an emphasised need for more understanding by healthcare staff of Muslim women and their needs across the SR and RTA themes around healthcare experiences. Even simple things like food preferences, need for privacy and basic wish for respect and not to be disadvantageously or (mis)treated because of religion, race or colour.

Within this theme, injuries during birth were captured. In the gathering of the data for this study I noted how the issue of tearing was coming up repeatedly. The words ‘tear’ or ‘tearing’ or ‘tore’ were used repeatedly across multiple participants stories. Although tearing affects all women, I wondered in the context of the points mentioned around power, control, discrimination and marginalised groups to what degree this was happening to Muslim women in particular and the reasons leading up to it specifically – is it happening the same, or more, for different reasons than in other communities? Further, thinking about the intersection is it happening more commonly to black Muslim women or disabled Muslim women or Muslim women in general. Although some details were given about individual contexts in which tearing occurred, I also wondered more generally about the circumstances in which Muslim women experience this. What is going on around them in terms of staff behaviour and environment and does it relate to issues discussed in chapter one around ‘obstetric violence’, coercion and control? Does it relate to biases and discrimination? Are they cared about less? Are their bodies valued less? Are they subject to cognitive biases? Are their concerns heard early on enough or at all? Are the reasons for tearing different and does it occur more often? All these are questions that could be addressed in further research. Tearing was something that

had ongoing lasting impact for the women, including impacting mental health and having consequences or the mother-baby bond, especially in terms of affecting or preventing breastfeeding which was so dear to many of the women who shared their pain in the difficulties that resulted from the pains they were in. For many Muslim women breastfeeding for them had sacred purpose and value and missing out on it had a profound impact including feelings of loss.

Examples of good experiences where staff were described as loving, and caring were shared. These were examples of how wonderful the experience of birth can be and how much of a critical difference it makes to have caring, positive midwives who are in a position of power and control yet needed as allies, companions and not enemies that prioritise a patriarchal system in this time. Those who had good care that was friendly and not hostile naturally fared better and coped better when things went unexpectedly, or they experienced traumatic birth. The care received or lack thereof was literally the difference between a positive and negative or traumatic birth experience. The relational aspect of having a safe supportive caring nurturing figure on the side of the birthing woman was critical. Sadly, many women had to be fighting a system and hostility while giving birth. Upon reflection, I noted that there was traumatic birth but also a traumatic context. Traumatic birth in itself that wasn't connected to staff mistreatment was coped with differently. Where there were external issues creating a feeling of lack of safety - discrimination, hostility, anxiety and fear induced through the language and actions of the system and the people who represented it - this type of birth trauma seemed like it needed another word to include the institutional and systemic role played in inducing or worsening and sometimes creating it in the first place. The trauma here seemed to cross section with racial trauma, systemic trauma and birth trauma.

The fifth and penultimate theme brought to the fore issues around 'empowerment' of the birthing women versus the 'power' of the system of healthcare. The sub themes were:

1. Alternative self-care and mental preparation
2. Breastfeeding successes and struggles
3. Power, astonishment and awe

The participants spoke of how they drew on their intuition and self-directed knowledge to utilise alternative self-care that felt right for them and how that helped in their mental preparedness during pregnancy and for birth. This was pitched against the power of the system

that could disempower women through issues of coercion, control and privileging the medical staff's knowledge and needs over the woman's'.

This theme also encapsulated issues of empowerment and feelings of failure in relation to breastfeeding. The successes and struggles were reflected on including how participants negotiated processing what felt like failures to them initially. Issues of power and who had it - the staff or the women, and what situations made the women feel in power were also highlighted. Women shared how astonished and awe-inspired they felt at their own bodies ability to give life and withstand such a remarkable process, overcome pain, near death feelings and emerge so powerfully.

Finally, there was the theme which captured 'recommendations', as given by the participants, in the hope for care improving around pregnancy and birth, what their needs are and what they would like to see. The sub themes were:

1. 'There isn't any information around this that is accessible'
2. A call for mosques to produce materials and be sources of support
3. Education, empowerment and the power of social support
4. 'I don't think mental health is considered at all in the Muslim community'
5. 'Birth trauma is not something that is spoken about or recognised'

This is one of the most powerful themes that emerged in terms of practical solutions that could effect change if taken on board by various stakeholders, NHS, mosques and community organisations, services and families. Recommendations were directed towards the NHS and healthcare and then to Mosques and the Muslim community in terms of mental and perinatal health support, needing to not just be on the agenda but to be at the top of it.

Recommendations were summarised under issues of lack of information that was accessible both in mainstream services and a desire (and, for some, a need) for Mosques and Muslim organisations to produce materials on perinatal mental health and be sources of support.

There was a request for these materials and information to be rooted in Islamic teachings and guidance; for education materials to be catered towards not just the mother but father and family members including in-laws and their roles in supporting and caring for the mother, and family unit. It was hoped that through education and awareness there could be a lessening of

and ultimately eradication of the pressures and stressors the wider family unit impose on the pregnant and new mother.

The recommendation for education was central in all its forms whether that be through mainstream services and or the Muslim community – many citing mosques but also highlighting that there is a bigger problem before we can get to supporting pregnant women and men as mosques still are not inclusive of women in general. Much work needs to be done in this area. It was felt that good social support had a powerful effect during pregnancy birth and after and played a critical role in empowering women and men. Where social support was lacking, it was difficult, there were more descriptions of strain and stress and ongoing difficulties. Most participants stated that mental health was not considered in the Muslim community and especially perinatal mental health was an almost unheard-of concept. Birth trauma was virtually unrecognised by the community though some women used the terminology to describe their experience as birth trauma. The question, in this lack of awareness, acceptance and recognition is, how can women and men be provided with the much-needed support and help they require, when the reality and concepts of perinatal mental health and birth trauma are hardly known about or dismissed. Attitudes from the wider family and community that dismiss mental health as not being a real thing, that it's a western concept, and that the person struggling just needs to have stronger faith/pray more, are deeply destructive. Other attitudes included displacing mental health distress on to narratives of possession and evil eye. The problem is there is little to no offer of the holistic support and healing that Muslim men and women are looking for. Muslim women and men are being failed when it comes to wider community and mainstream support around mental health, perinatal mental health and recognition of birth trauma and its lasting consequences and the impact on the family unit and child. Men were largely missing on the map of Muslims' experiences of pregnancy and birth. It is notable that in total only seven Muslim men took part in the survey and two in the interviews. This is reflective of the general population where males engage less with research particularly on topics widely perceived as women only. One of the composite narratives that case studied the Muslim male participants' experiences illustrated the challenges faced. Representation of Muslim men in this area is required. From the little insight that was gleaned, Muslim male participants were dismissed by the healthcare system and community. This was partly because the wider culture of perceiving the male partners involvement and presence at birth as less significant. This was echoed all throughout the RTA and SR. Culturally it was not considered the domain of men to be at birth or be witnessing the experience, this meant the

Muslim man's experience was mostly ostracised from the pregnancy and birth process. Muslim men need to be included. Providing education materials and engagement through dialogue are ways to combat many of the issues discussed that gave rise to the recommendations particularly around education and information.

The narrative composite case studies contribution to this study offered in depth descriptions by the participants themselves of the challenges they faced throughout the various stages of their pregnancy and birth experiences. The narrative case studies were intended to share the stories in their wider and whole context helping us to reflect on and gain some insight into all the various factors that played a role in the participants experience. These were complimentary to the RTA and SR in that they offered something beyond themes – they offered a whole illustrative picture.

Having shared an overview and my interpretations of the SR and empirical studies, I will move on to some of the key areas that emerged in this thesis that can help us make sense of what all this data collected means in context of a decolonial approach to research and healthcare. This is followed by a discussion on health inequalities and the role of healthcare providers in improving the perinatal experiences of Muslims'. I will then discuss issues of medicalisation, power and control over women's bodies, which featured significantly throughout the thesis, particular in relation to the treatment of racialised bodies, Islamophobia and women of colour. Considering all the aforementioned and the studies conducted, I will discuss the need for embedding cultural safety through the utilisation of faith sensitive health care for Muslims', and how this can significantly improve the healthcare experience of Muslims.

7.2 Decoloniality

Decoloniality critiques the universality and superiority of western ways of knowing and concerns itself with the consequences of the powers and force of colonialism and its ongoing impact. This thesis posited the importance of considering an Islamic ontology looking at Muslims' experiences as part of an ongoing struggle of restoration of Muslim epistemologies. At the outset, I referred to the need for clinicians and healthcare providers to understand healthcare in their social, political and historical contexts rooted in colonialism and the need to be responding to how colonialism itself creates and sustains health inequities (Beavis et al., 2015). Using a decolonial approach was extremely helpful and provided me as a researcher a

platform within which to embed my research and allowed me to think critically across multiple influencing factors that shape research, researcher and researched. I was able to keep in mind the social, political, and historical contexts and the way in which the consequences of colonialism and ongoing health inequalities both create and perpetuate trauma.

Understanding the role and impact of epistemicide, the intellectual genocide that occurred as a result of colonialism (Grosofoguel, 2013 and Malik, 2019) was critical in understanding the root of the dismantling of knowledge structures and destabilising Muslim heritage and ongoing impact on knowledge, education, science and research. Being aware of this helped me be more sensitively attuned to how I carried out my research, the language I used, how I analysed and interpreted information. It is essential to be aware of the impact of intellectual genocide when doing research especially with certain communities who have historically and or continue to experience the power and control effects of epistemicide. In the research process it is important to be mindful of the lasting multi-layered psychological impact of epistemicide. It is critical to choose the right kind of research ontology, philosophical positioning and methodology for each group of people 'being researched', otherwise there can be intellectual dissonance and epistemic injustice which can have real world harmful consequences in research and healthcare practice and even policies.

Through understanding the detrimental impact of epistemic injustices and that a decolonial approach offered a way of creating social and cognitive justice, I was able to apply this in my thesis. I connected epistemicide to psychological trauma through presenting the historical example of the rape and massacre of Muslim women in 1947 (Kiran, 2017) and the real lack of research on the violent horrific impact of colonialisation imprinted on the bodies of Muslim women. Connections of this historic impact were not apparent obviously in the data and this may be due to stigma and shame we associated to these events and or lack of awareness of intergenerational trauma. This led to me weaving in an understanding of the neurobiology of trauma and the impact of how that violence and fear shapes an individual and potentially effects their experiences and health and how this could be linked to intergenerational trauma and affect periods like pregnancy and birth and what that may evoke. For me using a decolonising methodologies approach made sense for my individual research, at its heart it requires reflection and gives us 'space' to decolonise western research methodologies and ensures we do not compromise our identity whilst undertaking research (Martin & Mirraboopa,

2003). This is necessary in a world where stereotypes about Muslims continue to be perpetuated and re-enacted through medical assumptions. Medical scholarship has not received significant attention for its representations of minorities (Aggarwal, 2011). As discussed in chapter three prolific biases occur about the 'observant Muslim' in health research literature, how they create "problems" for service delivery, pose health risks, narratives and language that indicate blame for certain health conditions and health inequalities, the usual trope that Muslim women are passive and need a man to speak for them (Laird et al, 2007). Being an 'insider researcher' and reflective of the language and my interpretations helped me to provide a different lens into the not just the research process but also the interpretation of the meanings of the data. I was able to be more conscious of the impact of the Western orientalising gaze that misinterprets and constructs authoritative knowledge on a people that it also fears and perceives as the other that need 'civilising'. The consequences of orientalism in research lead to discrimination and disadvantage in practice – disease categories, and the interpretation of them are conceptualised through the oriental (Aull & Lewis, 2004) and or global north, Western, secular paradigms.

Having highlighted and brought to the fore the various themes and individual experiences (shared as quotes and case studies) this decolonial study created an environment that constantly required critical reflection and questioning of how perinatal health is felt, experienced and responded to (or not) through the lens of decolonising. I was also able to consider and reflect on where and how the western medicalised (sometimes racist and Islamophobic) context of healthcare during pregnancy and birth perpetuates and sustains health inequalities. It was extremely important and significant for me to use my time and position as a PhD researcher in a way that felt meaningful. I hoped that I could bring something different and add value, which is why after much consideration the decolonial approach seemed like the only way to truly do justice to my intention in this work, to be considering the impact of ongoing colonialisation of the mind, research, thought, theories, practice, and in people experiences. Transcending coloniality in the research process and health sciences is an important aspect of epistemic justice.

I will now share some reflections and dilemmas of my decolonising research journey brought with it many questions for me. I wondered if I could draw on the philosophies and methodologies of Muslim women. This became a long, reflective, and, at times, painful journey, as sadly, I could not find a single Muslim female philosopher whose works were documented in a way such as well-known male scholars and philosophers (for example

Ghazali, Ibn Khaldun, Al Balkhi). Why were most of the widely used theories and bodies of work produced by men and mostly White European men? Where are the works of the women of these times, the Muslim women, I wondered? Have they even been written down? Perhaps they are available, I hope, in their respective countries of origin, perhaps in some remote libraries in countries I do not know of, names of women I do not even know. I asked around, I emailed academics and scholars, but no one could even give me one name. Sometimes, in these conversations, people would mention Aisha - the prophet Muhammad's (pbuh) wife was a hadith scholar and the first female scholar in Islam, but this was not quite helpful in the way I was looking. I was looking for an Islamic methodology developed by a Muslim woman in social, health, or psychosocial sciences that I could follow and embed my thesis in. Perhaps if I was well versed in the Islamic sciences, I would know how to do this or have access to that information. Although there are some contemporary Islamic feminist scholars, I did not come across anything relevant to my thesis in the English language I did not come across a Muslim female philosophers' works in psychology, sociology or research methodologies related fields. It is not that Muslim women were not teachers, thinkers and philosophers, however, the era and culture in which they lived as well as later politics and culture made it difficult to preserve any works if they had written them down and certainly very little is available in the English language. Many may have shared knowledge orally and in languages or countries I have no access to. There are lists of 'notable', 'famous', 'powerful' women educators and thinkers in Islam. However, I was unable to find what I was looking for. This gap felt very powerful. I opted then for the use of multiple different theories from a diverse range of philosophers, theorists, and thinkers to draw on, intentionally avoiding using the same few European male voices that are oft repeated, to give space to something different and to centre 'other voices.

In conclusion decolonising has been a useful approach to my thesis. Drawing on the paper of Zocchi (2021) 'be brave but be smart', facilitated my thought around how to navigate the fine line in writing up my thesis between what I shared, the language I used and how I had to ultimately also abide by the conventions of doing a PhD. For example, I conducted a systematic review which for some may be considered part of a process of research that hierarchises and highly validates a SR over other ways of knowing and doing. However, I feel the SR was well aligned with the Islamic approach to knowledge gathering which has a strong emphasis on rigour, quality and traceability/authenticity. The decolonial approach helped me to see through and critique the methods of doing a PhD and the different types of methods available. While I acknowledge the hierarchy of evidence approaches can be problematic and even "stifle critical

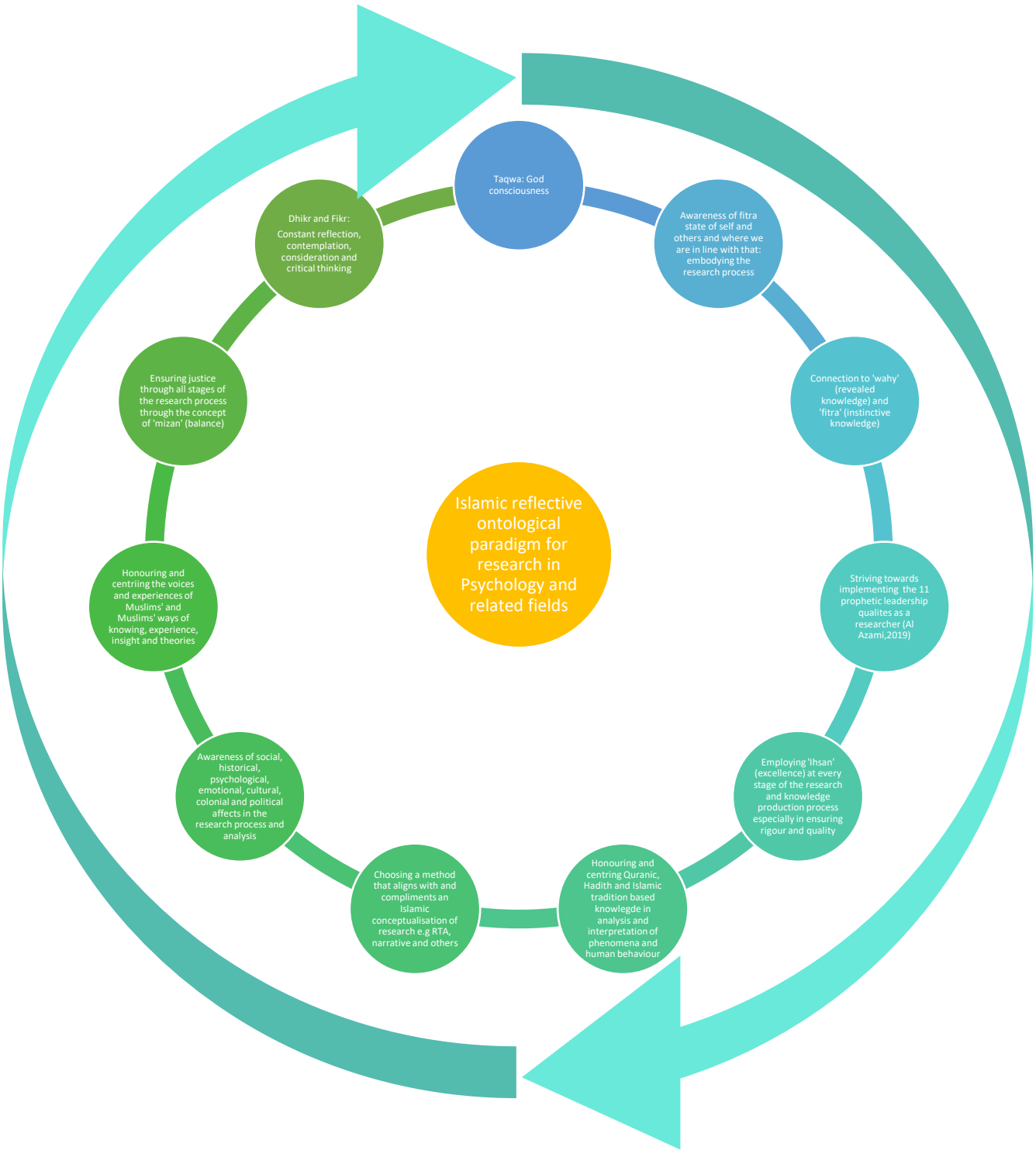
thinking" as O'Halloran, et al, (2010) states, if done reflectively and using the most appropriate method for each participant group of evidence gathering (which may be at the top of the hierarchy) then it can be helpful and add value. I did also use case studies, which can be perceived as low on the hierarchy of evidence base. Furthermore, carrying out a SR helped me to understand the research in the field on Muslims' experiences of pregnancy and birth that has been conducted to date. The research papers I looked at were also limited by conventions, dominant traditions and had elements that seemed disparate. I recall being frustrated at how some of the papers I came across lumped people together by ethnic minorities and were unclear. It is acknowledged that literature addressing health experiences among minority populations rarely provides data specific to Muslims (Laird et al., 2007b). It is crucial this changes going forward – religious beliefs play a critical role in shaping the lived experiences of people – leaving this out of the research process adds to epistemic injustice and perpetuates inequalities in care. How can we truly provide meaningful care/ do meaningful research, if we do not understand or acknowledge the people, we are purporting to provide services for? I would go as far as to argue that this creates a wasteful impact through economic and human cost – it is detrimental to the actual health experiences of certain populations.

Using the decolonial lens helped me to understand the health-related experiences and stories that came out of my own research and the ways in which I can understand people's way of being in the world and the difficulties they have because of the ongoing effects of colonialism, Islamophobia, racism, trauma and health inequalities and how I can relay that through my writing. I was able to learn from the process of the SR including what made a paper thorough and robust and where the flaws and weaknesses were in the papers. The decolonial approach also helped me to sensitively attune myself to my own perspectives and the importance of putting myself as the researcher as firmly located in and of the thesis and own that process of knowledge production rather than 'bracket' myself off, thus my lived experience, my history became an important part of the knowledge I produced. As a result of my research journey, I conceptualised a model of an Islamic reflective ontological paradigm for research which is shared below.

7.2.1 New conceptual model for an Islamic reflective ontological paradigm for research

Any scholarship endeavour is defined by its values and processes which are inherent in the researcher. As a result of my research process of considering the most appropriate philosophical and methodological underpinnings, I developed a model which is a visual representation of the elements I think could form an Islamic ontological centring paradigm for use in Health Psychology research and other closely related disciplines (mostly psychology and psychotherapy). This is a guidance ‘map’ of how it would look based on my process and understanding from the experience I gained through my research process (all of the elements are interconnected and circular in process):

Figure 7: Decolonising research methodologies approach: A Muslim researchers' process-based perspective, 11-pont model



Decolonising research methodologies approach: A Muslim researchers' process-based perspective, 11-pont model

Islamic reflective ontological paradigm for research in Psychology and related fields.

Below I discuss some aspects of my personal process of these points in my PhD journey.

- Taqwa: God consciousness

Being a Muslim means to submit or surrender oneself to God, to engage in a God-centred life. For me that means understanding the world through an Islamic ontological lens. An Islamic ontology in my understanding is a socially just and perfectly balanced model that involves a high degree of connectivism and holism. To make sense of our experience as humans and how we can improve our understanding of the world, contribute to and benefit humanity is at the centre of this way. To imbibe a sense of conscious awareness rooted in revelation, of reflecting on what my purpose is in this research, how do I understand a phenomena or experience. From the outset of my research, I was in a state of 'taqwa' (God consciousness) of every choice I made, every theory I looked at and every step I took and decision I made – It is an inherent part of who I am and how I function, it is not a separate part of me, it is a natural disposition. One of the ways this was part of my process was recognising the fundamental differences between the conception of methodology in health sciences and modern science, and the conception of a pluralistic holism in Islam-centred methodologies. When I found myself faced by challenges, uncertainty and in need of guidance I called upon God for insight, wisdom, guidance and help to navigate through alongside reflection and using the resources at hand. It was a more complex and nuanced process than there is capacity to detail here due to word count limitations and the application of God consciousness being so vast and deep an area.

- Awareness of fitra (innate disposition) state of self and others and where we are in line with that: embodying the research process.

Part of the reflection process for me included an awareness of my fitra state (innate disposition) and where I felt I was at any given time in line with that. When I was straying deep into a complex world of ideas and reading that were becoming so complex I felt I was losing myself in the process, I was able to reign myself back in by reconnecting to my source through prayer (connecting to God) and guidance, through reflection and turning to the Qur'an for support and comfort and remembering who I am and my ultimate purpose. When stuck, asking for guidance and to be shown the way. When deeply troubled and

anxious by the stress of the PhD process I was able to anchor myself by moving back along the spectrum towards closeness to God through reconnecting myself back to my 'fitra'.

- Connection to 'wahy; (revealed knowledge) and fitra (innate instinctive knowledge)

Connection to 'wahy; (revealed knowledge) through reading and reflecting on the Qur'an and asking people of knowledge to discuss ideas and connecting to my fitra (innate instinctive knowledge) and going with my 'gut' sense or intuition was a core part of the process of my research journey. It was not only when I felt at an impasse or frustrating juncture in my research that I turned to revelation. I continued with my studies and reflection alongside my research as part of my life. A crucial aspect of God consciousness in its Arabic term 'Taqwa' is far more expansive and includes to protect oneself / to guard oneself from harm through staying connected to the divine. When things do not make sense, become difficult and challenging we can look to the Qur'an and Sunnah for guidance, principles and applications that can be drawn upon.

- Striving towards the implementation of the 11 prophetic leadership qualities as a researcher.

I was required to undertake Prophetic leadership training which was accredited by the John Adair Leadership school in partnership with Murrabbi consulting as part of my scholarship. John Adair is one of the world's leading authorities on leadership and leadership development and developed the Action-Centred Leadership programme of which I am certified in. In our cohort we were engaged in interactive leadership qualities work drawn from the prophetic qualities identified by research carried out by Adair for his book *The Leadership of Muhammad* and consolidated and developed further by Al-Azami (2019) in his book: '*Muhammad 11 Leadership Qualities that changed the world'*, which considered the Prophet Muhammad (pbuh) as the most influential leader of all time. The 11 PLQ's (Prophetic Leadership Qualities) are: Integrity, Holistic justice, Spiritual Intelligence, Competence, Courage, Compassion, Servant Leadership, Practical wisdom, Resilience, Pragmatic Decisiveness, and Vision (Al-Azami, 2019). I drew on these qualities throughout my PhD research journey. It was helpful to check in with this list and understand its application, most of which is self-explanatory but for any researcher wishing to do this work they can use the book by Al-Azami as a thorough guide.

- Employing Ihsan (excellence) at every stage of the research and knowledge production process especially in ensuring rigour and quality.

I drew on the idea of *Ihsan* in the Qur'anic sense of going above and beyond and striving towards excellence in every act where possible within owns capacity. I used this as a guide in my mind that every stage, every search carried out, every article read, working through methods, ethics, theories, preparing questions, analysing data, that I was thorough as possible, and the quality of the process was high, and I gave my best. The quality of *Ihsan* is one a Muslim need to be striving towards in life generally regardless, as it is an ongoing process and when doing research that is true to Islamic epistemology this will be a necessary part of the process.

- Honour and centring Qur'an, Hadith and Islamic tradition-based knowledge in the analysis and interpretation of phenomena and human behaviour.

Despite the initial apprehensions about whether it would be accepted academically and institutionally I was able to take courage and honour and centre Qur'anic and Islamic based knowledge explaining why this was important and quoting verses from the Qur'an and discussing them and the importance for my topic and connecting it to the empirical research where it inevitably was also discussed given the central importance of the revelation in Muslims lives. I think it is crucially important for Muslim researchers to be able to draw on what the Qur'an (revelation) states given any particular phenomena and how we can understand and apply it.

- Choosing a method that aligns with and compliments an Islamic conceptualisation of research e.g., RTA, narrative and others.

Choosing a method that aligned with an Islamically rooted paradigm of research for me was of critical significance to the entire research process. Without the most appropriate fit there would be no Islamic ontological framework. This was a pain staking area initially in the exploration phase looking for a theory, a methodology in Health, Psychological and or Social Sciences that was rooted in an Islamic paradigm (particularly for me I also wanted to find something developed by a Muslim woman in history – the female counterparts of the Ibn Khaldun's, Razi, and Al Balkhi's of their time). Sadly, I was unable to find something appropriate that already existed and was accessible to me in the English language. During this process I was thinking about my processes of knowledge acquisition

in Islam, much of which has included contemplation, reflection and narratives. I settled on the Reflexive Thematic analysis as one method that complimented my approach particularly because it was suggested by the authors as atheoretical which made it easier for me to anchor my work in it. Similarly, narrative composite case studies were a complimentary and helpful method to share stories. Much of the Qur'an is centred around stories as methods of teaching and guidance for humanity.

- Awareness of social, historical, psychological, emotional, cultural, colonial, and political affects in the research process and analysis.

My research process was acutely aware of the implications of social, historical, psychological, emotional, cultural, colonial, and political affects in the research process and analysis which I have discussed significantly throughout my thesis. It would be unjust and missing a significant context to not include an understanding of how these areas impact the lives of Muslims and their experiences and is a critical part of the research process and analysis.

- Ensuring justice through all stages of the research process through the concept of balance *'mizan'* (balance).

Making sure that there was a balance and justice wherever possible in all aspects of the research helped me especially as this was a complicated research process for me. Reminding myself of where to draw the line was helpful. Understanding the concept of *mizan* through drawing on Qur'anic verses and Hadith is a crucial element of the research process as a Muslim researcher.

- *Dhikr* and *fikr*: consistent state of reflection, contemplation, consideration and critical thinking.

Being in a consistent state of reflections, contemplation, consideration and critical thinking was an inherent part of my journey and who I am as a person. It was this, perhaps, more than anything else that helped me develop the work that I did in the direction it did. *Dhikr* and *fikr* and at the heart of the research process and necessary.

- Honouring and centring the voices and experiences of Muslims' and Muslims' ways of knowing, experience, insights and theories.

> In my experience and throughout my life I can categorically say that Muslims' experiences and way of knowing, insights and theories have not been honoured or centred, if anything they have been disregarded, there has been disbelief, belittling, ignoring, invalidating. I believe that as researchers who are consciously Muslim and wish to contribute to understanding the human condition and providing solutions and new ways of thinking about problems we need to be invested in and committed to these steps as a basic. For me, I did this through centring through an Islamic lens and thus one that is socially just and rooted in an intellectually robust knowledge system (even though I as human may fall short of this – the point is to strive towards excellence and trust in Gods revelation and be open to learning) throughout my thesis.

This 11-point model provides a map for a potential research process that Muslim researchers could draw on and those collaborating with or researching issues impacting Muslims.

7.3 Health inequalities and the role of healthcare services and providers

The pandemic created a spotlight on health inequalities more generally (Bambra et al, 2020) with unequivocal evidence that people from Black and Minority Ethnic Backgrounds (BAME) in the UK are disproportionately affected by covid-19 (Hassan et al. 2021). British Muslims are at the centre of multiple intersections of social, health, economic and other disadvantages combined with discrimination, Islamophobia and otherisation. Interest in Muslims' experiences of pregnancy and birth are gaining traction as part of the wider debate in health inequalities and the concern over the worrying statistics regarding women of colour being more likely to die during childbirth as discussed in chapter one citing the MBRRACE report (Knight et al., 2014-16). As the author of this thesis, having spent over four years looking specifically at this area, I am left deeply concerned that despite the little traction Muslims' experiences of perinatal health care has gained, there is little else in terms of wider debate. There are insufficient discussion, research, practice, and policy changes occurring that are necessary for effecting change, providing support, and looking at solutions for improving health care during pregnancy and birth for Muslims in the UK. A solution to the lack of understanding and awareness of healthcare needs of Muslims during the perinatal period would be to take a collaborative community-based approach to reduce health inequalities. Working collaboratively can also help break down barriers and stereotypes, it can help humanise the dehumanised (Stonebanks, 2008). Turienzo et al., (2021) highlight how, *"the views and*

observations of service users and the research literature suggest that policymakers, the NHS, and local government need to take a community place-based approach to reducing maternal health inequalities, and to work in partnership with community leaders.". It is deeply concerning that British Muslims' needs around pregnancy and birth seem mostly missing from the 'map' of the wider debate on pregnancy and birth. I hope that this thesis highlights this and contributes to some of the knowledge gap in this area and acts as a springboard for further research and influences change in practice.

Best practice and where things are working well need to be learnt from more widely and standardised. One of the key determinants that was apparent in my empirical data was those who described having good, positive and even great experiences, were in an environment (hospital) and around people – family, healthcare providers who were facilitative, encouraging, collaborative, did not coerce or dominate, let women have a choice, emotions were positive, staff were caring and considerate. This was similar to Higginbottom et al., (2019) findings, that women with positive perceptions described healthcare professionals as *"caring, confidential and openly communicative in meeting their medical, emotional, psychological and social needs and those with negative views perceived health professionals as rude, discriminatory and insensitive to their cultural and social needs. These women therefore avoided continuously utilising maternity care.".* There was a distinct quote that stayed in my mind from the empirical research where a participant stated how she never wanted to have a hospital birth again after her traumatic and negative experience. The importance of the need for supportive provisions were in line with Ayers (2017) hypothesis that *"if women are in a perinatal environment where there is positive emotion, optimism, social support, where women actively cope, feel mastery and have a sense of purpose or meaning they will flourish".* For Muslims their belief system, and the sense of purpose that gave meaning to pregnancy and birth was a significant resiliency and growth factor, which can reduce and or prevent postpartum PTSD (Ayers, 2017). I note there were some quotes in the empirical studies I carried out, where Muslim women shared exactly how they felt their faith and the positive support they had prevented them from developing anxiety and or depression. Equally when support was lacking it created difficulties and stress. Support is associated with risk and resilience (Ayers et al., 2016). There is significant evidence that continuous support during labour is likely to *"improve outcomes for women and infants, including increased spontaneous vaginal birth, shorter duration of labour, and decreased caesarean birth, instrumental vaginal birth, use of any analgesia, use of regional analgesia, low five-minute Apgar score and negative feelings about childbirth*

experiences." (Bohren et al., 2017). This is an important finding particularly in that the improved outcomes through support and also connects to my earlier discussion in the thesis for the need to be bear in mind the impact on the baby - the research by Bohren et al., (2017) includes a low five-minute APGAR score rating.

One of the supportive factors noted in my empirical studies was the physical environment of the hospital. Those who experienced birthing suites that were described more like 'hotel rooms', or as 'private hospitals' had significantly better experiences, including giving them a sense of excitement and joy. The few participants who had experienced private medical care or shared their experience as 'feeling like a private hospital' where they were in a birthing suite, or a very good birthing unit naturally had better experiences and felt more in control and shared feelings of wellness. This finding is reflected in Leahy-Warren et al., (2021), study where they found that: *"Women who availed of private maternity care reported higher levels of choice and control than those who availed of public maternity care. This factor was the most influential factor on almost all choice and control measures."* This is a significant statement around quality of care and inequality of healthcare services. It was clear in the findings of this empirical research that those who had positive and good experiences felt better about their experience and those who shared stories of challenging or traumatic experiences were in a context of low quality of care, treated disadvantageously or discriminated against, felt disempowered, choice was not given to them, there was a lack of autonomy, disregard and or they were not listened to. Quality of care both in terms of hospital environment and attitudes of staff as well as other supportive factors such as partner, family and wider community played a role in the type of health care experienced and highlighted the inequalities. The quality of care put the spotlight on how powerful the environment and staff can be in shaping the experiences of labour and birth, making the need to tackle discrimination and negative attitudes and increase co-decision making and compassion vital in order to reduce health inequalities. One of the major issues relating to the role of health care providers in determining experiences was located in medicalisation, power and control which will be discussed in the next section.

7.4 Medicalisation, power and control over women's bodies

Issues of power, choice and control in the medical system emerged in the empirical studies of this thesis. In approaching the changing needs and wishes for women and 'minority' communities it is important to understand the power and history of the system within which

birth is taking place. Though it was not easy many of the Muslim respondents brought in their spiritual framework into the labour and birthing process even when there was resistance by the 'system'. There was a constant negotiating and, power and control in the process of labour and birth. A pregnant or birthing woman is essentially a 'patient' in a hospital for the sick, rooted in a patriarchal model (Cahill, 2001). The medical model of birth perceives women as *"abnormal, as victims of their reproductive systems and hormones…and defines pregnancy as inherently pathological - a clinical crisis worthy of active intervention"* (Cahill, 2001). The birthing woman is a subject of the male physician who performs surgical interventions such as caesareans – something is being done to her rather than her actively doing. The context of labour and birth matters a great deal. With a system that already pathologises women's experiences how much worse does it get for 'minoritised' women who have to contend with race, religion and other intersections as well as being a woman. According to Cleese et al., (2018) "the majority of births are performed in institutions in westernised societies, birth medicalisation is associated with the generalisation of surgical interventions. Pregnancy and birth has somewhere in its history with industrialisation and patriarchy gone from a natural intuitive power – a domain and knowingness of women of what to do with their bodies when it feels right – to a highly technocratic process losing its 'soul', embodiment and connection to the divine and feminine ways of knowing and empowerment. Johanson et al., (2002) states that in the *"past few centuries childbirth has become increasingly influenced by medical technology, and now medical intervention is the norm in most Western countries".* Johanson et al. (2002) argued that perhaps normal birth has become too "medicalised" and that *"until the 17th century, birth in most parts of the world was firmly in the exclusively female domestic arena, and hospital birth was uncommon before the 20th century".* This shift in environment of birth to a well-constructed hospital 'system' that hierarchises professional (usually male physicians) over the birthing women has for many led to feeling a lack of choice or lack of involvement in decision-making which has also been highlighted by Ayers and Nicholls (2007). The medicalised labour and birth process can be disempowering woman, as needing something done to them, and for them, having choices made for them such as the timing of an induction, rather than empowering them to draw on their inner knowingness. This was a feature in my empirical study - the lack of choice in decision-making was apparent and sometimes perceived as being a result of discriminatory, racist or Islamophobic behaviour on the part of healthcare staff. Not being able to choose or be pushed into making sudden decisions with the threat of life and death (by healthcare professionals) or fearing being judged as unsafe mothers, sometimes forced women into agreeing with professionals on timing of birth. There were also

Muslim women who shared how they resisted as much as they physically and mentally could and tried to birth on their terms. Smith (2003) discusses Illichs' (1974) works in particular his three iatrogenesis, I will focus only on one here for the relevance for this thesis - cultural iatrogenesis, which he describes as the destruction of traditional ways of dealing with and making sense of death, pain, and sickness. This is where Muslims have held on to their traditional practices because it is rooted in their religious belief system. Muslim participants in this research shared how despite difficulties, they made sense of labour, pain, birth, mental health, illness, loss, grief and death in the context of their belief system including performing rituals in the hospital setting. The way we understand our experiences is dictated by the discourse already in circulation around how we ought to experience mental health, stress, pregnancy, labour, birth. Through this illusory presentation of choices (discussed in chapter one) are women losing agency and bodily autonomy in the decision making process of labour and birth? This study explored how Muslims as a marginalised group at the intersection of many vulnerabilities experienced abusive or disrespectful care and how this affected their mental health. It also highlighted the push-back of some Muslim women who used their strong sense of self rooted in their faith to push for their needs and choices to be accepted.

7.5 Birth trauma: language, meaning and the need for recognition

It is worth noting and reflecting on the terminology of 'trauma' and how the experiences relayed in my studies may not have used words like trauma but could potentially be understood as traumatic experiences. In the systematic review, and even in my qualitative study, experiences that may well be described as traumatic, were not always framed in that way, using that terminology. On reviewing the literature, it was clear that trauma as a term and concept were not named as such by participants instead, they framed the experience with other language and metaphors. This could be to do with the changing landscape of language as I am working in a live context where this study was formed over a four-year period pre and spanning the pandemic. This makes it ever more critical that healthcare providers are updated with the dynamics around how trauma is felt, shared, experienced, verbalised and the language used if they are to identify needs and offer support. The events of the pandemic have shifted the collective dialogue around mental health and trauma. There is a greater sensitivity to the language of trauma and a notable shift in mainstream and Muslim discourses, with an increase in talks and online events since the start of the pandemic using the word trauma and or mental health in the title – this is and will shape the language we use to give meaning to our

experiences. The papers I drew on in the systematic review themselves analysed papers spanning several years and the shift in language and terminology used was more apparent in my study which is most recent. It was notable that the global north dominant discourse on mental health and the recently increasing widespread use of 'trauma' / mental health language is being used to relay difficult experiences around mental health (illness, wellness and disturbances). What I noticed specifically as a Muslim researcher was the reduced attribution of mental health and traumatic disturbing experiences to *jinn / ayn / sihr* which has been widespread language used to describe distress and disturbance for Muslims. It is also worth thinking what this may mean for people, if people start to use the more globalised dominant language, does that then transform their understanding of their experience? Does the vocabulary open up a new world of education and research that helps people to think differently and perhaps give different meaning to their original wounds i.e., traumas, and become a helpful resource? The shift in vocabulary could be potentially limiting and also liberatory. Most significantly, I reflect in terms of my study, how will the use of words like 'birth trauma' shape ongoing narratives and experiences in the British Muslim community and does it cover the continuum of experience that may be initiated or triggered by a birth? This made me reflect on my therapeutic work over the years where I heard the stories of women who, a decade and more later, were impacted by 'birth trauma'. What language does one use several years after a traumatic birth to talk about the ongoing trauma? Does there need to be a different term that encapsulates the longer-term impact, does it turn into the label of PTSD? It is important to think about terms like trauma and the western construction of the phrases 'mental health', 'mental illness', 'mental disorders', and if they could be partially limiting our understanding. In reflecting on and critiquing the use of mental health language we can ensure wider narratives around the distress of the whole body-mind-soul-eco system, and giving space to indigenous narratives, are included in our dialogues. Without critiquing the meanings do we risk the experiences becoming narrowly defined by purely neurobiological, psychological or even socio-political constructs – the parameters of which are 'fed' to people?

Conversations around trauma-informed work are relatively recent and are limited to certain circles (for example in academia, education, psychology and mental health). Experiences are generally not framed using trauma language in lay discussions, though this seems to be gaining traction. Are Muslim women who experience perinatal trauma and explaining it in terms of being possessed (or even using commonly understood English language descriptors such as depression, anxiety and trauma) more likely to be pathologised and diagnosed or medicated?

In thinking about solutions and effecting change, the healthcare system and professionals within it require a core shift in attitudes and approach. One way to tackle this is through decolonising healthcare and acknowledging how systems and structures may perpetuate harm or dissociated from it. An awareness of the multi-dimensional conscious and unconscious intergenerational and historical traumas, which could be embodied and triggered by current experiences such as pregnancy and birth could pave the way forward for in building trust with marginalised communities, creating opportunities for healing and positive experiences.

Physical, emotional, psychological, and spiritual states of mothers and fathers have been found to impact their mental health and wellbeing (House and Ridgway, 2006). Consequently, the states' parents are in can affect the emotional availability and quality of attachment they have with their children (House and Ridgway, 2006). This thesis provided some insight to how some British Muslims were impacted by their physical, emotional, psychological, and spiritual 'states' during pregnancy, labour and or birth. Further to this, I posited that adverse foetal and early childhood experiences and stressful events can affect the brain architecture and physiology of a developing child (Harvard Child Study Center), resulting in poor physical and mental health outcomes. It is important to know how these experiences may be premediated through early experiences including the event of birth and the time in the womb and the state of the mother and father and how these interact with complex intergenerational trauma and a history of colonial violence etched into the unconscious bodies and minds of Muslims. I pose more questions to think about around birth trauma and its potentially lasting effects: What happens to the quality of life of Muslim children? How do potentially fear and anxiety-inducing states during labour and birth affect the start of a child's life and the parents? What insight can we gleam though knowing the circumstances a child was born in through their parents' stories? Ultimately, it was beyond the scope of this study, but I had initially wanted to combine this study with looking at the effects of experiences during pregnancy and birth on the developing child. A longitudinal study is something I hope to pursue if circumstances permit as an ongoing enquiry following this thesis.

I began with the words of Perry (2001) in the Introduction chapter to the thesis, regarding the capacity of human beings to: "create, nurture, protect, educate and enrich" but also denigrate: "degrade, humiliate, enslave, hate, destroy and kill". I intended to emphasise the importance of understanding early development and health outcomes in the context of potentially discriminatory, possibly violent, fear and anxiety-inducing healthcare provision and

experiences of Muslims with a backdrop of colonialism. Simultaneously I was hopeful of the possibility of healing through education and the potential to nurture protect and enrich. I connected the concept that violence has played a role in shaping our sociocultural evolution (Perry, 2011) to the use of obstetric violence and the impact on mother, child and family unit of early trauma. I used this specific opening as a reflection of and connection to the violence with which birth can take place in and the resultant trauma. This connection came about as a result of the many stories I had heard of (before conducting this study) in what felt for women like medically induced violence and aggression on their bodies and minds, which also exacerbated and or triggered previous traumas which were not understood or connected by healthcare providers. For many Muslim women including the responses shared in this study, a lack of faith sensitivity to their experience of mental health and trauma, combined with being treated as 'less-than', created a disconnect with healthcare services and providers.

7.6 The need for faith sensitive (Islamically rooted) healthcare provision and research

This thesis identified the factors that hold most meaning and relevance as shared by the participants of their journey navigating pregnancy and birth. As has been clearly established, Islam played a definitive role in Muslims experiences of pregnancy and birth. The theme on the significant role of Islam during pregnancy and birth in my study was one of the largest and the analysis highlighted the various ways in which the Islamic worldview was weaved into the lives of participants and their experiences. This theme contained the greatest number of quotes, stories and references to Islam, Islamic teachings, principles, ethics, values and beliefs as told in relation to pregnancy and birth. It was also closely linked to the theme arising from the SR: 'the role of Islam as a faith, a way of life and a religious identity'. What it highlighted was the need for a faith sensitive, Islamically rooted approach to the healthcare of Muslims during pregnancy and birth.

The way in which mental health was experienced and responded to, including how and where sources of support were accessed, was also influenced by how people understood mental health within their worldview as Muslims. The provisions of the required faith sensitive support and knowledge required to meet needs within the community and in mainstream services was clearly lacking. I argue that a faith sensitive approach rooted in Islam is necessary for the holistic care of Muslims during the perinatal period and can enhance and improve their experiences significantly. Religion and spirituality have been found to be an important

resiliency and protective factor against mental health in several studies. Depression is one area that has been studied in connection with the role of religion and spirituality and has been correlated with positive outcomes as indicated by clinical and neurobiological outcomes (Svob et al, 2019). According to an article by the Yale School of Medicine (2019) Dr Weissman studied the effect of religion or spirituality on rates of depression in mothers who self-identified as highly religious or spiritual and found that 81 percent were less likely to have depression 10 years after the start of the study. This also influenced their children who showed a 75 percent lower rate of depression over a 10-year span and the importance of religion or spirituality to a parent correlated with a 20-year lower risk of suicidal behaviour in their children (Yale School of Medicine, 2019). If we think about how this could connect to perinatal mental health and developmental outcomes, we see the interpretation and application of religion and spirituality holds important implications for health psychologists, psychiatrists, and clinicians in relation to health outcomes (Svob et al, 2019).

There remains a distinct lack of knowledge of the requirements and needs of Muslims in healthcare. I was reminded of Rodrigues (2011) statement I shared in chapter two that the publications they reviewed unanimously referred to the lack of knowledge of the Islamic culture and the implications this has for treating Muslim women and that the cultural requirements of 'Islamic women' regarding health services remained poorly understood. It is worth highlighting here the terminology 'Islamic women' is not a conventional descriptive term for Muslims who follow the Islamic faith and can have different connotations. I highlight this because as a Muslim it struck me as unusual. The usual terminology would be 'Muslim women'. Islam is the religion – Muslim refers to the believers of that religion. However, the point of Muslim women's needs being poorly understood was and continues to be a matter of concern.

The importance of establishing more holistic models of care have been proposed by many researchers yet it does not seem to have gained sufficient traction in practice. A belief that *dua* (supplication or sometimes referred to as prayer) helps emotionally, physically, and mentally plays a significant role in difficult situations for Muslims, and as my study has shown it was of central importance to Muslim participants during labour and giving birth. Healthcare professionals working with Muslim women and men during labour and birth could draw on this knowledge and be facilitative of women wanting to listen to or play the Qur'an during labour and birth for example. Support could come in the way of having knowledge on Islamic

healing practices such as breathing in and out using Allah's names. This reminds me of the concept of the biopsychosocial model first proposed by Engle in his 1977 seminal work and mentioned in the Midwifery Network Units comparison model. Despite its recognition and usefulness, it has still - over four decades later - not been implemented or integrated into everyday healthcare practice and the medical industrial models continue to prevail perhaps for political and economic reasons, though reductionist and arguably short-sighted. I argue for an extension to Engels' biopsychosocial model to include spiritual. Wade and Halligan, (2017) highlight how, *"the (biomedical) model was incomplete in not being able, even in 19th century, to account for well-recognized illnesses, such as 'hysteria' and 'neurasthenia', where there was no evidence of disease."* They refer to the Journal of the American Medical Association *which says, "one hundred years ago highlighted the weaknesses of the scientific approach to medical care".* They further make a pertinent statement: *"Collaborative healthcare for chronic illness can be effective and requires the patient and the healthcare team to share a common understanding of the illness – to use the same model; when the models differ, management may fail."* This further highlights the need for collaborative healthcare. In midwifery, researchers have called for a 'salutogenic' health-promoting approach to care that includes the emotional and spiritual aspects of health rather than a purely pathogenic approach (Magistretti et al, 2016, Mathias et al., 2021). My study centred meaning, which is an important component of the salutogenic approach, it is important that the meanings that are understood are taken onboard and further investigated by healthcare researchers and applied in practice.

Healthcare professionals being aware of the spiritual aspects of health and making sincere efforts to deal with structural racism and being mindful of the overall disadvantages experienced by certain groups in society can support Muslims better. Fernandez Turienzo et al., (2020) highlight the need for addressing health beyond biomedical factors alone. They suggest the need for *"integrated and holistic long-term public health strategies that address societal and structural racism and overall disadvantage in society"*, which must be implemented collaboratively in partnership with local communities (Fernandez Turienzo et al, 2020). They further point out that fear and lack of trust in services could result in reluctance to seek prompt care, which is something that emerged in my findings where Muslim women lost trust and felt cultural and faith insensitivity (Fernandez Turienzo et al, 2020). This reduced motivation to attend follow up appointments or welcome midwife visits, especially in the face of everyday demands and conflicting pressures of being a new mother or having a new baby to care for. There is a clear need to implement cultural competency as has been highlighted by a

number of researchers including Kaihlanen et al., 2019, Truong et al., 2014 and the National Institute of Health. I argue that along with this cultural sensitivity a faith-based sensitivity is required for the care of Muslims particularly during pregnancy, birth and postpartum.

One of the key concepts I started with was the idea of 'Cultural Safety' (CS) and competence. Lokugamage et al., (2020) concept of CS is one that *"aims to address systemic racism through dismantling barriers faced by colonised people".* I believe it was a useful framework in assisting my thinking around the need for antiracist and decolonising approaches to research and healthcare. The notion of CS helped me to centre and propose the need for faith sensitive perinatal care for Muslims. A critical element of CS is allowing the recipient of care to define and decide what feels safe for them. The critical importance of the power dynamic and who decides and defines care and experiences, and what constitutes safety and or risk, featured in the empirical studies with the battle between the need for women feeling empowering and the power of the healthcare system. Even in circumstances where participants felt disempowered by the system of healthcare, they drew on their understanding and belief in Islam for support, strength and meaning making. It was clear that the role of Islam during pregnancy and birth especially the passage of birth was significant.

Islam for British Muslims was weaved through virtually every aspect, of story relayed, particularly how helpful and supportive it was for participants to draw on their faith tradition of Islam. It featured in all aspects from making sense of trauma, in coping with mental health difficulties, with pain and suffering, even when being mistreated by staff some Muslims were able to draw on their values and teachings through Islam to either not take it personally, as a source of comfort and support to be able turn to supplications and prayers, or as providing the strength and resilience to know that they will be rewarded for their hardship, that there is goodness for a believer in all circumstances, a knowingness that there is higher justice involved even if it may not seem apparent in the current moment.

The study showed what matters most to Muslims during pregnancy and birth and that for many this was the role of Islam and their faith particularly in how they navigated adversity, challenges and their mental health. This study provided a rich nuanced account of British Muslims experiences of pregnancy and birth which is currently lacking in broader literature around pregnancy and birth, particularly in terms of our understanding of how they are impacted and what can be done to improve experiences.

7.7 Strengths and key contributions of this research

As there were no previous in-depth studies (to my knowledge) qualitatively exploring British Muslims experiences of pregnancy and birth using a decolonial approach, this study offered an important and unique contribution. Despite the difficulties in trying to navigate this methodological area which was new to me, and I was carefully laying the foundations for the study as I went a long, this thesis demonstrates how it is possible to centre non mainstream, Eurocentric secular voices and bring in lesser utilised philosophical underpinnings. I had not come across another thesis in health psychology attempting to embed research mindful of an Islamic ontology. I think this was a unique contribution. This study has contributed to the much-needed discourse required in understanding Muslims experiences of the perinatal period and how a faith sensitive approach to healthcare and service delivery would be of immense benefit to all involved in the process. It also has brought to the fore the need for Muslims and mainstream services to be collaborating to produce literature and information that is accessible and relevant. This research highlighted the need to push for a wave in education both on a community level, within mosques, in academia through research, in healthcare practice and policies to give importance to the needs and service provision for the healthcare of Muslims, for the improvement of experiences particularly during pregnancy and birth.

The objective of this thesis was not to offer a theory or explanation as such but to present and platform voices and nuanced experiences in their complexity and context to gain some insight. The thesis was mindful of the historical backdrop of a large migrant community whose worldview is constantly persecuted. A community who have experienced the effects of being a colonised people, cross-generational traumas, discrimination: racism, Islamophobia and socio-economic disadvantages. I feel this objective was achieved in the gathering of all the data in all the phases of this research from the systematic review, being mindful of the decolonising approach, and the process of the empirical data and writing the analysis through constant reflection.

The development of the Islamic reflective ontological paradigm for research in Psychology and related fields was an original contribution that I made through this thesis. It was the conceptualisation of a visual model of my research process that can be used by other students and researchers who wish to apply an Islamic ontological aware research paradigm in

understanding human behaviour and experiences. Particularly, the argument for using an Islamic ontology and being mindful of and centring Muslim ways of knowing through a decoloniality approach is a contribution to research in the field of health psychology. I hope others will also brave paths like this and critically question the research process and methodologies and their origins. Despite the difficulties in trying to navigate this methodological area which was new to me, and I was carefully laying the foundations for the study as I went a long, this thesis demonstrates how it is possible to centre non-mainstream, Eurocentric secular voices and bring in lesser utilised philosophical underpinnings. I had not come across another thesis in health psychology attempting to embed research mindful of an Islamic ontology. I think this was a unique contribution.

This thesis attempted to add to the scarce knowledge base in this area by bringing together first-hand accounts and information that could provide insight into how Muslims and particularly Muslim women felt. It further identified their needs particularly at the time of pregnancy and birth and consequently this did provide us with a rich content base where participants not only shared their difficult sometimes traumatic, physically, mentally and spiritually taxing, or discriminatory experiences and what worked really well, they also shared recommendations that could help improve services and decision-making processes in health care. This study provided direct raw data with first-hand accounts of what Muslims who experienced pregnancy and birth needed, wished for, what they felt could be improved and how, which could have direct policy implications, could be useful in education and teaching and paves the way for multiple branches of further research.

The application of the Reflexive thematic analysis method used for the empirical phase of this research was the most appropriate and closest method I found in that in provided the structure for the elucidation of very rich accounts and continual reflection, whilst also aligning Islamically with core ideas of reflection and themes which are central in Islamic and Qur'anic education – The Qur'an itself is full of themes and there are even thematic based translations of the Qur'an in the English language. The narrative approach was also ideal in that it worked closely with how Islamic knowledge is often shared even in the Qur'an as stories, narratives as case studies for human reflection. The systematic review strictly adhered to guidelines and was conducted in a thorough methodical way capturing a wide range of international papers that themselves drew on first-hand accounts of Muslims experiences of pregnancy and birth.

Despite sharing what I believe to be the strengths and contributions of this study, I had my own self-doubts throughout the process about whether this thesis was adding value to the world of knowledge. What eventually became a strength – the methodological approach I took – was initially and throughout the process one seeped in uncertainty and the vulnerability that I discussed at the outset of chapter one. I wondered if the findings were clearly obvious such that Islam played a significant role in Muslims experiences of pregnancy and birth and the way in which they approached life, and whether the significance of this would ever materialise in terms of healthcare support and provision, and in how research is conducted. I also wondered if the need for Muslims to have mental health provision rooted in a faith-based approach would ever be actualised and the critical importance recognised. The 'mental health' of Muslims was nowhere nearly addressed or supported as needed, in the Muslim community or in mainstream service provision. This thesis has highlighted the urgency for fast tracking conversations, educational material and service provision that is holistic and genuinely rooted in an Islamic paradigm that offers Muslims meaningful support particularly around perinatal mental health. Another area I wondered if I had done justice to was the context of what led to birth trauma for Muslim women, which could be perceived as seeped in discrimination, health inequalities, and Islamophobia, and the vulnerability that comes with being at the intersection of multiple stressors. Do people not know this already I wondered? This can be for a number of reasons: because I have inhabited this world for so long, immersed in this area not just for the last four years but also prior to that. What seems obvious and known to me may well not be known 'out there' so to speak. Certainly, enough data is not available on the perinatal experiences of Muslims'. I hope my study will be of value to various stakeholders; especially those who care for Muslims' and provide services such as the NHS. Muslim community organisations can use these findings and learnings to inform education and support resources. We need to put Muslims' experiences of the perinatal period on the map, particularly experiences of perinatal mental health and birth trauma and its ongoing implications. This thesis has highlighted some of the nuanced ways these experiences have an impact, how they are continuously weaved through the past and their impact on the future. We also need to think about how the environment around the earliest experiences from the time in the womb and birth are internalised and experienced for the developing child and the impact on the next generation. One contribution of this thesis was holding in mind and repeatedly making that connection of not just difficult and or traumatic experiences around pregnancy and loss for the mother and father but also the impact on the baby and ongoing developing child and what that may mean for their mental and physical health.

To create optimal circumstances for future generations we need to heal the effects of our complex pasts which are steeped in colonialism and disconnected from our own worldview and healing traditions. The intersection of the physical, mental and spiritual health of Muslims needs to be given space, time, resources and funding to be researched further. Taking this decolonial approach to health and mental health could also be a way to understand Muslim women's health concerns especially the high prevalence of chronic 'psychosomatic' conditions which could be emanating from the effects of trauma in the body but may be (dis)missed as we saw in chapter three through, or through a reductionist biomedical clinical model that does not have the answers alone. Instead, I believe a holistic model of care that is inclusive of mind-body-soul is required and the approach allows a more expansive knowledge base from which to draw on which could assist healing.

Spiritual health is often neglected but it matters a great deal too, especially to Muslims. As I understand it, Islamically the spiritual cannot be separated from the physical and mental. One can utilise their spirituality as a supportive factor which encourages resiliency and growth as has been discussed throughout this thesis. However equally people can question their existence and faith and be deeply troubled through their distress and traumatic experiences especially without the right support, compassion and knowledge, hence their spiritual health can also be impacted by the mental suffering / traumas they may be experiencing. Having non-judgemental guidance, support and knowledge rooted in their faith can be help people reconnect and heal. It is crucial for the health and wellbeing of Muslims for the wider community and healthcare to break stereotypes and negative perceptions of Islam and Muslims and actually engage with what it can offer particularly in healthcare for Muslims. It is a 'tool' that can be used, a 'tool' that has a rich tradition of healing and teachings, a rich tradition of psychology and health. For hundreds of years the works of Ibn Sinna (Avicenna) formed the canon of medicine taught in the West, which is largely ignored now. The disconnect and colonisation does not negate the reality of the influence and enmeshment of knowledge and commonality of values. Commonality and values that can be used to enhance healthcare.

I came across papers on de(colonial) research that were looking through feminist, gender, race and indigenous perspectives but interestingly I did not come across any papers on Islam/religion and decolonising research for example how to use an Islamic ontology within the decolonial research methodologies literature in health or psychology. Though religion is a

protected characteristic it is not mentioned as much in research papers looking at the experiences of people and it seems like religion is conflated a lot with race/ BAME, which makes me wonder are we accurately thinking about religion – peoples world views in research.

7.7.1 Limitations

There were several limitations of the overall study. Though the systematic review was conducted as thoroughly as possible adhering closely to the guidelines and referring to the quality appraisals, literature may have been missed due to the limitations of the key word searches applied. It is also regrettable that it was not possible to register the systematic review with PROSPERO at the time as the systematic review process was affected by my having to take time out due to an unexpected need for surgery. By the time I was able to consider registering it the time had lapsed. Another limitation is that papers not written in the English language were excluded, a more thorough review could take place that includes non-English sources. Due to time constraints and limitations of a PhD I myself could not take on this endeavour and the resources it would take to get help with translating. Sampling and recruitment for the empirical study was inevitably limited due to its targeted reach, though every best effort was made to ensure the notice of research being conducted was shared in the Muslim community across the UK, it was limited by the circles in which it was likely shared. Though it was shared widely on the internet beyond my initial scope as it snowballed, I think it was still skewed to certain networks of mostly middle class educated Muslims who had access to the internet and capacity to engage in research.

Given that the data gathered was qualitative and analysis based on interpretation of a relatively small sample of the wider population of Muslims it still would not be generalisable or represent all Muslims' experiences. For example, as mentioned there were very few Muslim father's voices, and there was a glaring absence of Black African Muslims' voices. This could partly be due to my lack of connections to a number of communities and not having had that reach, though I know the survey link and study information were shared on multiple groups via my connections which did include communities of Muslim men and African Muslim communities. There is certainly scope for and I would suggest an urgent need for a study looking specifically at the intersections of British Black African Muslim perinatal experiences, especially given the stark findings of the MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential enquiries |across the UK 2018-2020) report of Black women being five times more likely to die in childbirth. Given the multiple negative experiences shared in my empirical research of Muslim women experiences of discrimination, I am left wondering how much more dire and concerning experiences may be of Muslim women who are of Black African heritages. This research could look at the links between intersectional experiences of differently positioned Muslims, for example, the intersections of anti-Black racism and Islamophobia,

which were absent in this thesis sample. The study did however elucidate recurring themes and it is hoped that this empirical data acts as a steppingstone for further research in the ample areas already mentioned.

The Muslim male voice was not substantial, with few men responding to the survey and two interviews. I felt throughout my writing that I had to keep checking in, that I was including men and not always referring to women only where appropriate. I had wanted to include Muslim father's experiences from the outset as they are rarely if ever included on this topic hence why I did not make this a Muslim women/mothers' only study. However, in reality many men did not respond to the survey or interview call. In general, this study did not capture the wider range of Muslim men's experiences that are critical to the debate. The few captured voices may be an opening for further directed work specifically on Muslim men's experiences of pregnancy and birth however there may be challenges in getting Muslim men in large numbers to speak on this specific topic which culturally is not seen as 'men's business'. Nonetheless, there is great potential and an exciting opportunity for further work in this area and perhaps as above also linking the intersectional challenges that may present between racism and Islamophobia for Asian and African Muslim men and how these experiences may be different or similar.

The narrative case study approach while ideal for capturing rich data and in line with Islamic ways of imparting knowledge had its limitations. The limitations were mainly due to the few numbers of interviewees - the case studies had to be composited to further protect anonymity and as it was still too few numbers some aspects of the narrative case study section have been redacted/removed post thesis examination. I also initially found it quite difficult to find methods of applying narrative inquiry as the literature is quite sparsely documented. It was difficult to navigate best practise in conducting narrative research – it was quite a challenge to know how to analyse and present the interviews as narrative method applications are interpreted very differently in different contexts. Another limitation of applying narrative is the limitation of experience to words only.

7.8 Future research and implications

There are several areas for potential future research and work arising from my study. In terms of the topic of study itself, Muslims experiences of pregnancy and birth, many areas can be

pinpointed for further research looking more in depth at the issues arising from this thesis. There were areas that were not captured fully within the empirical research but nonetheless will be helpful to look at, such as perinatal loss, issues of coercion during perinatal care and service delivery, resilience of Muslims through faith sensitive approaches, perinatal mental health of Muslim mothers and fathers. Research on the impact of the pandemic on Muslim women and families who were pregnant or gave birth during the lockdown and restrictions would be important given how acutely the pandemic highlighted health inequalities as a result of fractured and fragmented systems which reflect in the quality of care and health of 'minority' communities. Though this research was conducted very early on in the pandemic (and hence only a couple of people referred to a covid related experience and one of which was pregnancy where there was uncertainty around how the birth may be), the consequences of women being denied their partner at the birth in the very early stages of the pandemic (followed by a partner being allowed only at the time of the actual birth), has had an impact on many women and families.

Future research should most certainly address Muslim men's experiences around pregnancy and birth. It was difficult to reach or connect with many Muslim men but this could be because I am a female researcher, and perhaps few men saw the notice looking for research participants or they did not have time or this was not an area they felt was connected to them – I feel the latter played a role significantly, certainly from the few that did take part, it was apparent that men felt left out of the process of birth by the healthcare system and culturally thus this is a wider issue that can be looked at. I do not however think that Muslim men would be difficult to 'engage' as such, I think it is about the who and how it is done. I think someone who is representative of, a good role model, and inspiring, would be able to have those conversations. I would urge that a Muslim male attempt to conduct research in this area. Additionally, to this it is necessary to involve birth partners and especially provide education in the Muslim community targeted at fathers to be, both from within the community and NHS mainstream services working collaboratively with mothers and fathers to be ensuring their needs are understood and then creating services and or attitude shifts within those services.

One area of interest to me which was what led to my PhD itself was my interest in looking for correlations between the mothers' experience of perinatal trauma (including exposure to intergenerational trauma) and the babies health, and if we can use early indicators such APGAR scores, attachment styles and other markers along with the mothers experience to predict the

possibility of developmental trauma, an increased likelihood of adverse childhood experiences and health conditions. A study of this kind could also explore questions of the following kind: are we doing everything we can to give Muslim children the best start in life or are they seeped in a world of health inequalities and social injustices (that go unnoticed) before they are even born? How does being born through a hostile and or violent process (such as for those who experience obstetric violence) go on to affect the developing child and their life experiences, physical, mental and spiritual health. This was all too much for one study with its limitations but that was my ultimate dream idea which I hope to pursue through a post doc or other research opportunities.

Further research should most certainly be carried out on Muslims experiences of trauma and intergenerational trauma. This research should include an attempt to understand and provide insight into the differing ways distress may be communicated such as through somatic descriptions, or, ideas of possession, evil and black magic, to make sense of pain and suffering. It is important to understand how people are making sense of their distress and to discover if it is being located in a particular paradigm more, whether that be more medicalised due to the widespread globalisation of mental health, spiritual or holistic or a combination.

The other area of inquiry that I believe leads to the potential for future research is through decolonising work that brings in a faith sensitive approach centring the ontology and epistemology of Muslims' in understanding human behaviour and in doing research. As a result of the process of this PhD journey, and due to the difficulties, I experienced treading a path that seemed to have no map and the challenge of drawing on and integrating an Islamic ontological approach within a Health Psychology PhD, I had the idea for a group like the decolonising research study group which I then set up with my supervisor (GL). This is a group that has been running bimonthly for over a year now and I hope will continue when I leave.

During the PhD I was asked to co-author and edit a report using my skills and knowledge gained through my PhD for a community interest grassroots mental health initiative on Muslim mental health. It was a landmark report with 926 Muslims surveyed on their views and experiences of mental health. I was also asked to write a chapter for the first book on British Muslims and health inequalities being published by Edinburgh University Press. The chapter was directly inspired from my methodology chapter in this thesis and is on the relevance of research methodologies used in Health Psychology for British Muslims, providing an

epistemological critique on the colonisation of knowledge production. I am intending to write a paper based on the Islamic reflective ontological paradigm for research in Psychology and related fields that I created as a result of my work on this thesis. I hope this will be helpful for other researchers and students. A model like this is what I was in need and search of all throughout my PhD. It would have been helpful for me, to guide my study, to have a research model that was embedded in an Islamic paradigm. Through my work, I realised after writing up, that actually there was a model in my thesis through the process I had followed as a Muslim researcher. Hence, I created the 11-point model in the hope it may also be helpful to others. Further to this, I hope to publish the findings from my systematic review and empirical study in journals. There is also possibility for me to share my thesis results through webinars and lectures with the Muslim community through grassroots organisations that I am connected to and more widely. I am also hoping to share my process as a Muslim researcher and hope to connect with fellow Muslim researchers and academics and incoming students to share how I went about my work and the research model I created, perhaps through public lectures or webinars.

This study suggests that Islam plays a central guiding role in participants lives during pregnancy and birth, it acts as a rich source of guidance in dealing with life, the good and the challenging. Participant's faith, belief system and the teachings they were able to draw on from Islam were significant in giving hope and supporting their mental health. The problematic aspect around mental health was the lack of education on psychological and emotional issues and understanding of how they can be made sense of in the Muslim experience. Recognising the importance of a faith based perinatal mental health service for Muslims as well as the need for psychoeducation around perinatal mental health for Muslim men and women and the wider Muslim community is a key area that has clinical implications, can impact health outcomes and is an opportunity for intervention (done in collaboration with the community, not exclusive of).

What was also apparent was the lack of critical engagement around mental health. I posit that this could be in part attributed to, as a community, being in the early stages of grappling with getting mental health recognised and destigmatised and the use of Western medicalised terminology to describe mental health. I argue the use of globalised and medicalised notions of mental health including language can be detrimental if not thought of in the wider critical debates around metal health which are taking place. Using common language also reduces risk of being judged for occupying a further minority view as a critical thinker and as a 'minority'

person. There is a lack of understanding in mainstream healthcare services of the significance for Muslims in needing to have their worldview understood and a part of therapeutic support and care.

This study highlighted the struggle in power dynamics between participants own needs, own knowingness and values rooted in Islam, with that of the system of the NHS which works within its own narrowly defined parameters and history though there seems to be some awareness of the need for change.

This study points to the need for integrating an Islamic faith sensitive approach to perinatal healthcare and wellbeing of Muslim mothers, fathers and the family unit.

7.9 Recommendations

The below are several recommendations arising from my research that can be considered by healthcare providers, policy makers, mosques and the Muslim community:

- Reform is required in research processes, education and policy that is decolonised, trauma aware and faith sensitive regarding Muslims experiences and needs of healthcare.
- Research ‘about’ Muslim’s should be ‘with’ Muslims’.
- Consult with Muslims in the interpretation of behaviours, phenomena and experiences of Muslims, do not assume all Muslims experience in the same way.
- Re-evaluation of structural determinants of health that impact the perinatal experiences of Muslims.
- Honestly tackle institutionally racist, colonial and sexist systems which disadvantage healthcare provision for Muslims.
- Improve the lack of understanding around perinatal mental health and the need to recognise and know what birth trauma is in the Muslim community.
- Healthcare practitioners / hospital staff / midwives to provide proactive support, advice and create a Culturally Safe relationship with Muslims they are providing care to.
- Muslim community, mosques, community centres and healthcare providers, to collaborate holistically providing materials around pregnancy and birth that are tailored for Muslim families, bringing together Islamic tradition and modern science.

- Mental health to be normalised and for there to be education from an Islamic paradigm about the experiences of pregnancy and birth and perinatal mental health including related topics of parenting, emotions, and shame.
- Mosque centred social network for mothers and father aiding spiritual and mental struggles related to motherhood and fatherhood.
- Muslim men to be provided with more information and education around what women experience during pregnancy, labour and birth, including referring to and embedding the teaching through the Qur'an and Sunnah sources creating a point of holistic education and connection.
- Education around the sex of the baby and addressing cultural preferences for the male child with the Islamic teachings that reprimand preference of gender of a baby.
- Providing specific support initiatives for Muslim men who can feel dismissed by the process.
- Support groups for Muslims experiencing perinatal mental health challenges.

7.10 Final Reflections

This thesis has considered the historical context of knowledge production and value, the impact of colonialism and epistemicide, explored western domination of research science. I acknowledge the canon of reference for most research in the West is white male. I journeyed through thinking about research models incompatible to the socio-religious realities of the Muslim world and posited the need for creating relevant mindful research processes. Furthermore, I suggested that our knowledge is far more enmeshed across cultures and ontologies than we acknowledge. There is perhaps more by way of similar values than is recognised and that perpetuating a dialogue of the 'other' and difference adds to this polarising. I took us through the decolonising methodologies approach, with a historical example of the legacy of colonisation of Muslim women's bodies, with a discussion of the neurobiological impact of intergenerational trauma of a colonialised people and how that can affect the lived experiences of health and psychology.

I am acutely aware of the voices that are not directly represented in this thesis. As I write I keep in mind all those stories I know and hold space for. We must not forget the stories of those who do not have the privilege and access to let anyone know their pain, who will never be seen or known by research, by healthcare, be represented in policy and research, who are in

circumstances where mental health is obliterated, where physical health is disregarded by families and communities. We must not forget the stories of women who are expected to carry the burden of their families and are not allowed to prioritise themselves, their children, their or her own needs, her pain and suffering, and is expected to continue working for the family and home despite having just given birth and or be suffering mental and or physical health concerns. We have a lot of work to do if we want to ensure the health and sanity of all people equally, if we want to make sure we provide safe nurturing environments and relationships for people from prebirth and through the life span to grow well and be well. Right now, it is not equal. I will end in full circle borrowing the words of Savransky (2017): *"there is no social and cognitive justice without existential justice, no politics of knowledge without a politics of reality".* Without a commitment to truth and connections with the realities of Muslims there will be no justice, we will continue to live with health inequalities. The number one priority needs to be a commitment to creating genuinely safe spaces, places, relations and connections and exchange ontologies and ways of knowing and being that can of benefit to all. Normalising faith sensitive, Islamically rooted healthcare and psychological support for Muslims during the perinatal period is necessary. This PhD journey feels like a point at a juncture and one that does not conclude; hence I will end perhaps unconventionally, with a question: how do we think about ideas of healing that include epistemic pluralism and critical consciousness that challenge the existing hegemony of the way research evidence is presented, understood and affects change in healthcare practice?

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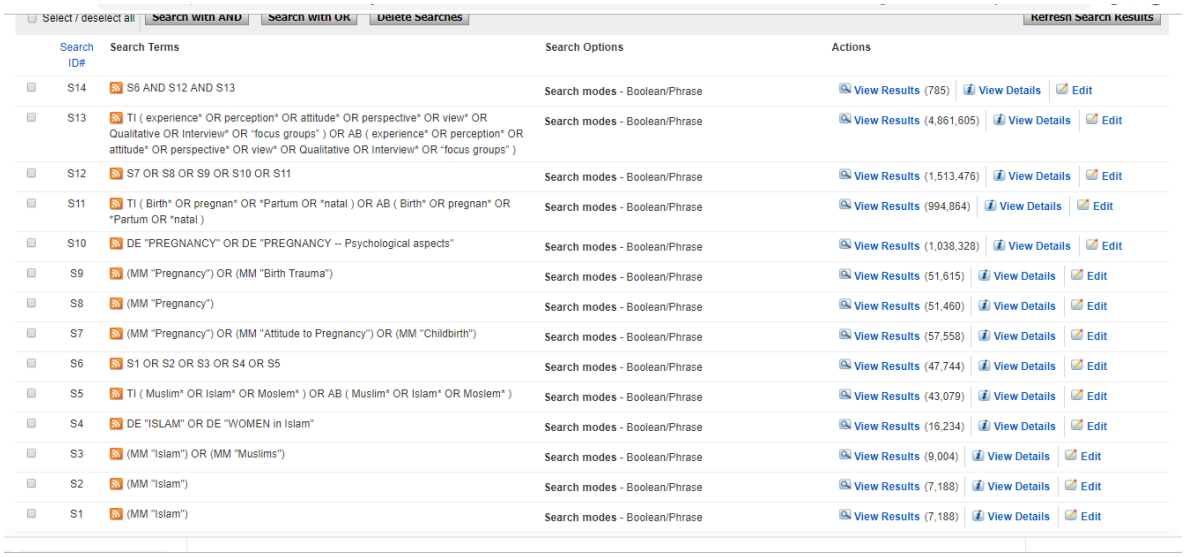
Appendices

Appendix (1): Search syntax and results

Search syntax used on EBSCOHOST:

In EBSCOHOST each MesSH was used in 'Advanced search' selecting 'Map to tree. Followed by key word searches using the PEO.



Select / deselect all | Search with AND | Search with OR | Delete Searches | Refresh Search Results

Search ID#	Search Terms	Search Options	Actions
S14	S6 AND S12 AND S13	Search modes - Boolean/Phrase	View Results (785) | View Details | Edit
S13	TI (experience* OR perception* OR attitude* OR perspective* OR view* OR Qualitative OR Interview* OR "focus groups") OR AB (experience* OR perception* OR attitude* OR perspective* OR view* OR Qualitative OR Interview* OR "focus groups")	Search modes - Boolean/Phrase	View Results (4,861,605) | View Details | Edit
S12	S7 OR S8 OR S9 OR S10 OR S11	Search modes - Boolean/Phrase	View Results (1,513,476) | View Details | Edit
S11	TI (Birth* OR pregnan* OR *Partum OR *natal) OR AB (Birth* OR pregnan* OR *Partum OR *natal)	Search modes - Boolean/Phrase	View Results (994,864) | View Details | Edit
S10	DE "PREGNANCY" OR DE "PREGNANCY -- Psychological aspects"	Search modes - Boolean/Phrase	View Results (1,038,328) | View Details | Edit
S9	(MM "Pregnancy") OR (MM "Birth Trauma")	Search modes - Boolean/Phrase	View Results (51,615) | View Details | Edit
S8	(MM "Pregnancy")	Search modes - Boolean/Phrase	View Results (51,460) | View Details | Edit
S7	(MM "Pregnancy") OR (MM "Attitude to Pregnancy") OR (MM "Childbirth")	Search modes - Boolean/Phrase	View Results (57,558) | View Details | Edit
S6	S1 OR S2 OR S3 OR S4 OR S5	Search modes - Boolean/Phrase	View Results (47,744) | View Details | Edit
S5	TI (Muslim* OR Islam* OR Moslem*) OR AB (Muslim* OR Islam* OR Moslem*)	Search modes - Boolean/Phrase	View Results (43,079) | View Details | Edit
S4	DE "ISLAM" OR DE "WOMEN in Islam"	Search modes - Boolean/Phrase	View Results (16,234) | View Details | Edit
S3	(MM "Islam") OR (MM "Muslims")	Search modes - Boolean/Phrase	View Results (9,004) | View Details | Edit
S2	(MM "Islam")	Search modes - Boolean/Phrase	View Results (7,188) | View Details | Edit
S1	(MM "Islam")	Search modes - Boolean/Phrase	View Results (7,188) | View Details | Edit

Population Terms

S1 is from CINHAL MESH

S2- Medline MESH

S3 Psychinfo MESH

S4 socio index MESH

S5 key word search TI (Muslim* OR Islam* OR Moslem*) OR AB (Muslim* OR Islam* OR Moslem*)

S6 all of the above (S1 OR S2 OR S3 OR S4 OR S5)

Exposure Terms

S7 CINHAL MESH

S8 Medline MESH

S9 Psychinfo MESH

S10 Socio index MESH

S11 key word search TI (Birth* OR pregnan* OR *Partum OR *natal) OR AB (Birth* OR pregnan* OR *Partum OR *natal)

S12 all of the above (S7 OR S8 OR S9 OR S10 OR S11)

Outcome Terms

S13 key word search TI (experience* OR perception* OR attitude* OR perspective* OR view* OR Qualitative OR Interview* OR "focus groups") OR AB (experience* OR perception* OR attitude* OR perspective* OR view* OR Qualitative OR Interview* OR "focus groups")

Final combination

S14- S6 AND S12 AND S13 = 785 results

OVID SEARCH syntax

1. OVID Online accessing:

- AMED (Allied and Complementary Medicine) 1985 to February 2019, Database Field Guide (Results 2) (2-1 duplicates= 1 left)

- Embase 1974 to 2019 Week 07, Database Field Guide (Results 432) (432- 392 duplicates= 40 left)

- Global Health 1973 to 2019 Week 06, Database Field Guide (Results 189) (189- 76 duplicates= 113 left)

- Maternity & Infant Care Database (MIDIRS) 1971 to December 2018, Database Field Guide (Results 109) (109- 101 duplicates= 8 left)

- Ovid MEDLINE(R) 2015 to February Week 2 2019 (Results 52) (52- 46 duplicates= 6 left)

Total 2+432+189+109+52 = 784

After duplicates removed: 1+40+113+8+6 = 168

784 -616 duplicates= 168 left

Each database within OVID was searched individually.

OVID AMED

1 Islam/ 48 MeSH

2 (Muslim* or Islam* or Moslem).ab. or (Muslim* or Islam* or Moslem).ti. 111 keyword

3 1 or 2 120

4 Pregnancy/ 1362 MeSH

5 (Birth* or pregnan* or Partum or natal).ab. or (Birth* or pregnan* or Partum or natal).ti. 2344 keyword

6 4 or 5 2859

7 (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ab. or (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ti. 42911 keyword

8 3 and 6 and 7 2

OVID EMBASE

1 Islam/ 1187 MeSH

2 (Muslim* or Islam* or Moslem).ab. or (Muslim* or Islam* or Moslem).ti. 10761 keyword

3 1 or 2 11126

4 attitude to pregnancy/ or pregnancy/ 560333 MeSH

5 (Birth* or pregnan* or Partum or natal).ab. or (Birth* or pregnan* or Partum or natal).ti. 873558 keyword

6 4 or 5 1080045

7 (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ab. or (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ti. 2749238 keyword

8 3 and 6 and 7 432

OVID GLOBAL HEALTH

No MeSH was available for Islam.

(Muslim* or Islam* or Moslem).ab. or (Muslim* or Islam* or Moslem).ti. 3881 keyword

2 pregnancy/ 77302 MeSH

3 birth/ or childbirth/ or postnatal development/ or pregnancy/ 80538 MeSH

4. (Birth* or pregnan* or Partum or natal).ab. or (Birth* or pregnan* or Partum or natal).ti. 141198 keyword

5 2 or 3 or 4 151021

6 (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ab. or (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ti. 303161 keyword

7 1 and 5 and 6 189

OVID MATERNITY AND INFANT CARE

1. Islam.de. 157 MeSH

2. (Muslim* or Islam* or Moslem).ab. or (Muslim* or Islam* or Moslem).ti. 383 keyword

3. 1 or 2 414

4 (Pregnancy or Pregnancy outcome or Birth or Attitude or POSTNATAL).de. 60960 MeSH

5 (Birth* or pregnan* or Partum or natal).ab. or (Birth* or pregnan* or Partum or natal).ti. 134707 keyword

6 4 or 5 149334

7 (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ab. or (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ti. 49051 keyword

8 3 and 6 and 7 109

OVID MEDLINE

1.Islam/ 955 MeSH

2. (Muslim* or Islam* or Moslem).ab. or (Muslim* or Islam* or Moslem).ti. 1381 keyword

3. 1 or 2 1734

4. Pregnancy/px [Psychology] 230 MeSH

5. (Birth* or pregnan* or Partum or natal).ab. or (Birth* or pregnan* or Partum or natal).ti. 86555 keyword

6. 4 or 5 86581

7. (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ab. or (experience* or perception* or attitude* or perspective* or view* or Qualitative or Interview* or focus groups).ti. 319719 keyword

8. 3 and 6 and 7 52

Total OVID: 2 + 432 + 189 + 109 + 52 = 784

(Total EBSCOHOST) 785 + 784 (Total OVID ONLINE) = 1569 total combined records for screening.

270 ebscohost after duplicates +168 after duplicates = 438 to screen

1569- 1131 duplicates- leaves 438 to screen

Database records and screening numbers:

Database	Results	Results- Deduplicate	Final result
CINHAL complete (Results)	193	(193- 109)	84
MEDLINE complete (Results)	358	(358- 245)	113
PsycINFO	133	(133- 97)	36
SocioINDEX with Full Text	101	(101- 64)	37
AMED (Allied and Complementary Medicine)	2	(2-1)	1
Embase	432	(432- 392)	40
Global Health	189	(189- 76)	113
Maternity & Infant Care Database (MIDIRS)	109	(109- 101)	8
Ovid MEDLINE(R)	52	(52- 46)	6
	1569 Records	1131 Deduplication	438 Screening

Appendix (2) Detailed account of papers included and excluded with reasons and criteria

	Papers	Inclusion Criteria
1	Abushaikha, L. and R. Massah (2013). "Perceptions of Barriers to Paternal Presence and Contribution During Childbirth: An Exploratory Study from Syria." Birth: Issues in Perinatal Care **40**(1): 61-66.	(Meets inclusion criteria 1-7) 1. Raw first-person narratives 2. Qualitative research only and focused on Muslims' experiences of birth. 3. Any country was included as long as Muslims' experiences were documented in the form of interviews or focus groups. 4. Men's voices. 5. Peer reviewed journal papers 6. No date limitation criteria applied 7. Papers selected were all in the English language.
2	Bawadi, H. A. and Z. Al-Hamdan (2017). "The cultural beliefs of Jordanian women during childbearing: implications for nursing care." International Nursing Review **64**(2): 187-194.	(Meets inclusion criteria 1 2 3 5 6 7)
3	Bawadi, H. A., et al. (2016). "The role of fathers during pregnancy: A	(Meets inclusion criteria 1 2 3 4 5 6 7)

	qualitative exploration of Arabic fathers' beliefs." Midwifery **32**: 75-80.	
4	Hanely, J. and A. Brown (2014). "Cultural Variations in Interpretation of Postnatal Illness: Jinn Possession Amongst Muslim Communities." Community Mental Health Journal **50**(3): 348-353.	(Meets inclusion criteria 1 2 3 5 6 7)
5	Heidari, T., et al. (2015). "Maternal Experiences of Their Unborn Childs Spiritual Care." Journal of Holistic Nursing **33**(2): 146-160.	(Meets inclusion criteria 1 2 3 5 6 7)
6	Khalaf, I. and C. L. Clark (1997). "Cultural meanings of childbirth: Muslim women living in Jordan." Journal of Holistic Nursing **15**(4): 373-388.	(Meets inclusion criteria 1 2 3 5 6 7)
7	Miller, T. (1995). "Shifting boundaries: exploring the influence of cultural traditions and religious beliefs of Bangladeshi women on antenatal	(Meets inclusion criteria 1 2 3 5 6 7)

	interactions." Women's Studies International Forum **18**(3): 299-309.	
8	Missal, B. (2013). Gulf Arab women's transition to motherhood. *Journal of Cultural Diversity*, *20*(4), 170. Hand searched	(Meets inclusion criteria 1 2 3 5 6 7)
9	Mustafa, K. N. and M. J. Kittleson (2016). "Pregnancy-Related Experiences of Bangladeshi Immigrant Women in the U.S." Global Journal of Health Education & Promotion **17**(2): 4-16.	(Meets inclusion criteria 1 2 3 5 6 7)
10	Parvin, A., Jones, C. E., & Hull, S. A. (2004). Experiences and understandings of social and emotional distress in the postnatal period among bangladeshi women living in tower hamlets. *Family Practice*, *21*(3), 254-260. doi:10.1093/fampra/cmh307 Hand searched	(Meets inclusion criteria 1 2 3 5 6 7)
11		

	Tsianakas, V., & Liamputtong, P. (2002). What women from an islamic background in australia say about care in pregnancy and prenatal testing. *Midwifery*, *18*(1), 25-34. doi:10.1054/midw.2002.0296 Hand searched SCOPUS	(Meets Inclusion 1 2 3 5 6 7)
	Papers	Exclusion Criteria
12	Adulyarat, M., et al. (2016). "Development of a culturally-based care model for Muslim mothers in a rural community in southern Thailand." Journal of Population and Social Studies **24**(2): 49-65.	(Meets point 4 and 6 of Exclusion criteria) 4. Conflation of culture with religion; papers which may have had Muslims as part of a sample or grouped with Asian as a cultural group or other faiths, or where Muslim voices were not separately identified or where it was not clear what participants' religion was. 6.Voices of professionals and not first-person accounts of women and or men experience pregnancy and birth.
13	Al Bustan, M. A., et al. (1995). "Maternal sexuality during pregnancy	

	and after childbirth in Muslim Kuwaiti women." Archives of Sexual Behavior **24**(2): 207-215.	(Meets point 5 of Exclusion criteria) too narrow a focus – the subject matter being prenatal testing specifically.
14	Badissy, M. (2016). "Motherhood in the Islamic Tradition Rethinking the Procreative Function of Women in Islam." Muslim World Journal of Human Rights **13**(1): 131-156.	(Meets point 3 of Exclusion criteria) Papers that were quantitative or had quantitative elements or mixed methods or are not explicitly qualitative methods.
15	Cross-Sudworth, F., Williams, A., & Herron-Marx, S. (2011). Maternity services in multi-cultural britain: Using Q methodology to explore the views of first- and second-generation women of pakistani origin. *Midwifery*, *27*(4), 458-468. doi:10.1016/j.midw.2010.03.001 Hand searched SCOPUS	(Meets point 3 and 7 of Exclusion criteria) Not clearly focused on Muslims lived experiences differentiated from cultural or regional and country contexts This criteria would be needed to fulfil the aim of this review and the absence of it would be out of this remit.
16	El-Tomi, N. F., et al. (1992). "Maternal sexuality during pregnancy and after childbirth in Kuwait." **13**(2): 163-173.	(Meets point 3 and 5 of Exclusion criteria) Papers that were quantitative or had quantitative elements or mixed methods and too narrow a focus.

17	Ghubash, R. and V. Eapen (2009). "Postpartum mental illness: Perspectives from an arabian gulf population." Psychological Reports **105**(1): 127-136.	(Meets point 1 of Exclusion criteria) No first-person narratives/quotes included.
18	Hatamleh, R., et al. (2013). "Birth memories of Jordanian women: findings from qualitative data." Journal of Research in Nursing **18**(3): 235-244. Hand searched SCOPUS	(Meets exclusion criteria 2 mixed methods)
19	Haque, K. N. (1994). "Attitudes and beliefs of Muslim mothers towards pregnancy and infancy." Archives Of Disease In Childhood **71**(6): 559-560.	(Meets point 1 of Exclusion criteria) No first-person narratives/quotes included.
20	Hussein, Suha Abed Almajeed Abdallah, Dahlen, H. G., Ogunsiji, O., & Schmied, V. (2018). Women's experiences of childbirth in middle eastern countries: A narrative	(Meets point 6 of Exclusion criteria) Voices of professionals and not first-person accounts. Not the aim of this review It is a narrative review.

	review. *Midwifery, 59,* 100-111. doi:10.1016/j.midw.2017.12.010 Hand searched SCOPUS	
21	'Muslim women experience poor-quality maternity care'. Practising Midwife **8**(1): 9-9	No record for it with abstract /full text. Not primary research. No author for contact.
22	Rosnah, S. and M. Hazlina Mohd (2012). "Psychosocial impact of perinatal loss among Muslim women." BMC Women's Health **12**(15).	(Meets point 5 of Exclusion criteria) too narrow a focus – the subject matter being prenatal testing specifically.
23	Tehrani, S. G., et al. (2015). "Pregnancy experiences of first-time fathers in Iran: a qualitative interview study." Iranian Red Crescent Medical Journal **17**(2).	(Meets point 2 of Exclusion criteria) Does not mention Muslims
24	Tsianakas, V. and P. Liamputtong (2002). "Prenatal testing: the perceptions and experiences of Muslim women in Australia." Journal	(Meets point 5 of Exclusion criteria) too narrow a focus – the subject matter being prenatal testing specifically.

	of Reproductive and Infant Psychology **20**(1): 7-24.	

Appendix (3) CASP checklist cross tab

Papers/ **CASP checklist questions**	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Abushaikha, L., & Massah, R. (2013) Perceptions of Barriers to Paternal Presence and Contribution During Childbirth: An Exploratory Study from Syria,	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes somewhat**	**Somewhat-** permission gained from Human Research committee but no discussion	**Yes**	**Yes**	yes, highlights policies and practices that create barriers to paternal involvement.
Bawadi, H. A. and Z. Al-Hamdan (2017). "The cultural beliefs of Jordanian women during	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**no**	**Yes**	**Yes**	**Yes**	very relevant, accounts of Muslim women's experiences

childbearing: implications for nursing care." International Nursing Review **64**(2): 187-194.										and feelings which can cross cultures and are overarching. more about a shared faith contextualisation than cultures. lessons can be learnt across.
Bawadi, H. A., et al. (2016). "The role of fathers during pregnancy: A qualitative exploration of Arabic fathers' beliefs." Midwifery **32**: 75-80.	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Can't tell** they gave choice for the setting of the interviews.	**no**	**Yes** 4 reviewers	**yes**	Very valuable/ rare voice of Muslim men in this area. One of only 2 papers.
Hanely, J. and A. Brown (2014). "Cultural Variations in Interpretation of	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	No-acknowledgement of researchers being Non-	**Yes**	**Yes**	**Yes**	Really crucial research, unique in comparing

Postnatal Illness: Jinn Possession Amongst Muslim Communities." Community Mental Health Journal **50**(3): 348-353.						Arab and Non-Muslim but the relationship is not discussed in the paper				the different expressions and use of language for the same phenomena.
Heidari, T., et al. (2015). "Maternal Experiences of Their Unborn Childs Spiritual Care." Journal of Holistic Nursing **33**(2): 146-160.	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**no**	**Yes**	**Yes**	**Yes**	important for understandin g different behaviours and patterns of care given to Muslim women by midwives. documents how religious beliefs penetrate all aspects of maternal life, how to provide holistic

										prenatal supportive care for mother and unborn child according to the mother's religious, spiritual, and cultural sensitivities. The results of this study can also provide part of educational content of care and may be used in training.
Khalaf, I. and C. L. Clark (1997). "Cultural meanings of childbirth: Muslim women living in Jordan." Journal of Holistic	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Can't tell**	**Yes**	**Yes**	highlights areas for improvement and awareness in care

Nursing **15**(4): 373-388.										
Miller, T. (1995). "Shifting boundaries: exploring the influence of cultural traditions and religious beliefs of Bangladeshi women on antenatal interactions." Women's Studies International Forum **18**(3): 299-309.	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	very important highlighting hidden voices, matters of concern and importance to Muslim women and cultural nuances and barriers in experiencing health care systems
Missal, B. (2013). Gulf Arab women's transition to motherhood. *Journal of Cultural*	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	provided a means for the Gulf Arab women to tell their rich stories about their lives and

Diversity, *20*(4), 170.										joys in becoming mothers. Women who are seldom heard were given a voice that this nurse researcher was permitted to see, hear, and experience. These findings are important for nursing, family, and culture. Families were one of the major influences on the transition to motherhood. study provides

										information for nurses working with Gulf Arab women. The new mothers shared their feelings and experiences which are helpful in providing culturally appropriate care. Findings of this study can assist nurses to provide culturally appropriate and supportive care to new mothers, babies, and their families in not only the Gulf

										region but in other countries where Gulf Arab families live and work.
Mustafa, K. N. and M. J. Kittleson (2016). "Pregnancy-Related Experiences of Bangladeshi Immigrant Women in the U.S." Global Journal of Health Education & Promotion **17**(2): 4-16.	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**no**	**Yes**	**Yes**	highlights useful recommendations and issues of disempowerment and various systemic structures as inhibiting e.g language, patriarchy, discrimination.
Parvin, A., Jones, C. E., & Hull, S. A. (2004). Experiences and understandings of social and emotional distress	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Not clear**	**Yes**	**Yes**	clear conclusions about role of services and families in social and emotional

in the postnatal period among bangladeshi women living in tower hamlets. *Family Practice, 21*(3), 254-260. doi:10.1093/fampra/cmh307										distress in the postnatal period
Tsianakas, V., & Liamputtong, P. (2002). What women from an islamic background in australia say about care in pregnancy and prenatal testing. *Midwifery, 18*(1), 25-34. doi:10.1054/midw.2002.0296	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**no**	**Yes**	**Yes**	may lead to sensitive and culturally appropriate antenatal care and prenatal testing services for women from migrant backgrounds in general, and for

										Muslim women

Appendix (4) Study context and characteristics

Study	Aim	Setting	Method	Sample
Abushaikha, L. and R. Massah (2013). "Perceptions of Barriers to Paternal Presence and Contribution During Childbirth: An Exploratory Study from Syria." Birth: Issues in Perinatal Care 40(1): 61-66.	to explore Syrian parents' perceptions of barriers to paternal presence and contribution during childbirth.	postpartum unit in a major public maternity hospital Syria	descriptive phenomenological approach rooted in qualitative philosophy	23 mothers and 14 fathers
Bawadi, H. A. and Z. Al-Hamdan (2017). "The cultural beliefs of Jordanian women during childbearing: implications for nursing care." International Nursing Review 64(2): 187-194.	To determine the cultural and religious beliefs and practices about childbirth among Jordanian women and to indicate how these beliefs and practices can be integrated into the maternity care of Muslim women in general, especially those immigrating to Western countries.	Jordanian Muslim women who had given birth to one or more healthy children in Jordan Informants were identified in the communities where they lived through social networks of the authors.	qualitative research design with an interpretative phenomenological approach	9 Jordanian Muslim mothers
Bawadi, H. A., et al. (2016). "The role of fathers during pregnancy: A qualitative exploration of Arabic fathers' beliefs." Midwifery 32: 75-80	to gain a deeper understanding of Arabic fathers' involvement in maternity care during their wives' pregnancy, and to give a descriptive interpretative explanation of their lived experience.	Saudi Arabia and Jordan. Aimed to enrol Arabic fathers living in either country whose wives had experienced pregnancy and childbirth within the previous 24 months.	a phenomenological study	19 Arabic fathers
Hanely, J. and A. Brown (2014). "Cultural Variations in Interpretation of Postnatal Illness: Jinn Possession Amongst Muslim Communities." Community Mental Health Journal 50(3): 348-353.	To determine the cultural and religious beliefs and practices about childbirth among Jordanian women and to indicate how these beliefs and practices can be integrated into the maternity care of Muslim women in general, especially those immigrating to Western countries.	Muslim community in an Arabian Gulf state.	qualitative research design with an interpretative phenomenological approach	10 married Muslim mothers who had given birth during the past year and personally identified themselves as currently being possessed with a Jinn. All mothers were aged between 14 and 44 years.
Heidari, T., et al. (2015). "Maternal Experiences of Their Unborn Childs Spiritual Care." Journal of Holistic Nursing 33(2): 146-160.	Exploration of maternal behaviours associated with the spiritual health of the unborn child.	Tehran city, Iran	Qualitative approach based on naturalistic paradigm. The study was conducted using conventional content analysis.	22 Iranian mothers in Tehran city (Iran) who were pregnant or had experienced pregnancy in 2012-2013.
Khalaf, I. and C. L. Clark (1997). "Cultural meanings of childbirth: Muslim women living in Jordan." Journal of Holistic Nursing 15(4): 373-388.	study on the experience of childbirth for Muslim women living in Jordan.	Jordan- women were recruited in clinics, acute care settings, and refugee camps. Interviews	descriptive, ethnographic study	32 childbearing women were interviewed in the early postpartum weeks.
Miller, T. (1995). "Shifting boundaries: exploring the influence of cultural traditions and religious beliefs of Bangladeshi women on antenatal interactions." Women's Studies International Forum 18(3): 299-309.	to examine how cultural and religious beliefs may influence use of maternity services amongst Bangladeshi women living in Britain, and the impact of a highly developed system of antenatal care on the "private" and "public" spheres of the women's lives.	Community group	qualitative informal, in-depth interviewing And focus groups	10 Bangledeshi women living in the UK

Missal, B. (2013). Gulf Arab women's transition to motherhood. *Journal of Cultural Diversity, 20*(4), 170.	The aim of this study was to describe the Gulf Arab primiparas' transition to motherhood within their culture. The long-term goals of the study were to provide pertinent information for nurses, other health providers, and the broader Arab community; and to contribute to culturally appropriate nursing care of new Gulf Arab mothers	There were two cohorts in this study. The first cohort of seventeen women had obstetrical care at a private hospital in the UAE in 2001. The second cohort included seventeen women in Nizwa, Sultanate of Oman in 2009.	A qualitative study	34 total- 17 participants in the first cohort. The first interview was conducted during the ninth month of pregnancy, A second interview was held between 14 and 28 days after delivery, and a third interview was conducted at forty days after childbirth.
Mustafa, K. N. and M. J. Kittleson (2016). "Pregnancy-Related Experiences of Bangladeshi Immigrant Women in the U.S." Global Journal of Health Education & Promotion 17(2): 4-16.	to discover What are the experiences of immigrant women from Bangladesh living in a large U.S. metropolitan area during pregnancy	The first four participants were recruited through the primary researcher's personal network, and the remaining six were referred by participants. All lived in the New York metropolitan area. Three of the 10 participants had been living in the United States for 2 years, six participants between 3 and 6 years, and one participant for 9 years. interviews, observations, and hospital documentation. Most of the interviews were held in the participants' homes while their husbands were away.	A qualitative study was conducted in a specialist centre among Muslim mothers who had experienced perinatal loss. qualitative study open-ended, semi-structured interviews.	10 participants
Parvin, A., Jones, C. E., & Hull, S. A. (2004). Experiences and understandings of social and emotional distress in the postnatal period among bangladeshi women living in tower hamlets. *Family Practice, 21*(3), 254-260. doi:10.1093/fampra/cmh307	The purpose of this study was to explore first-generation Bangladeshi women's understandings and experiences of postnatal distress, and to describe coping strategies during the postnatal period.	community groups in Tower Hamlets, London.	qualitative study using focus groups. Thematic content analysis was used to explore and present the data.	25 women
Tsianakas, V., & Liamputtong, P. (2002). What women from an Islamic background in Australia say about care in pregnancy and prenatal testing. *Midwifery, 18*(1), 25-34. doi:10.1054/midw.2002.0296	: to examine satisfaction with care and services in relation to antenatal care and prenatal testing and to present what women say about what can be done better to improve antenatal care for women from an Islamic background.	Melbourne Metropolitan Area, Victoria, Australia.	Qualitative approach, in-depth interviews of women's perceptions and experiences	15 women of Islamic background living in Melbourne.

Appendix (5) The eMERGe meta-ethnography reporting guidance

Author checklist: Muslims experiences of pregnancy and birth: A systematic review and meta-ethnography

No.	Criteria headings	Reporting criteria	Number in document indicated by [x] (highlighted)
Phase 1—Selecting meta-ethnography and getting started			
Introduction			
1	Rationale and context for the meta-ethnography	Describe the gap in research or knowledge to be filled by the meta-ethnography, and the wider context of the meta-ethnography	[1]
2	Aim(s) of the meta-ethnography	Describe the meta-ethnography aim(s)	[2]
3	Focus of the meta-ethnography	Describe the meta-ethnography review question(s) (or objectives)	[3]

No.	Criteria headings	Reporting criteria	Number in document indicated by [x] (highlighted)
4	Rationale for using meta-ethnography	Explain why meta-ethnography was considered the most appropriate qualitative synthesis methodology	[4]
Phase 2—Deciding what is relevant			
Methods			
5	Search strategy	Describe the rationale for the literature search strategy	[5]
6	Search processes	Describe how the literature searching was carried out and by whom	[6]
7	Selecting primary studies	Describe the process of study screening and selection, and who was involved	[7]
Findings			

No.	Criteria headings	Reporting criteria	Number in document indicated by [x] (highlighted)
8	Outcome of study selection	Describe the results of study searches and screening	[8]
Phase 3—Reading included studies			
Methods			
9	Reading and data extraction approach	Describe the reading and data extraction method and processes	[9]
Findings			
10	Presenting characteristics of included studies	Describe characteristics of the included studies	[10]
Phase 4—Determining how studies are related			
Methods			

No.	Criteria headings	Reporting criteria	Number in document indicated by [x] (highlighted)
11	Process for determining how studies are related	Describe the methods and processes for determining how the included studies are related:	[11]
		- Which aspects of studies were compared	[11]
		AND	
		- How the studies were compared	[11]
Findings			
12	Outcome of relating studies	Describe how studies relate to each other	[12]
Phase 5—Translating studies into one another			
Methods			

No.	Criteria headings	Reporting criteria	Number in document indicated by [x] (highlighted)
13	Process of translating studies	Describe the methods of translation**:**	[13]
		- Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies	[13]
		- Describe how the reciprocal and refutational translations were conducted	[13]
		- Describe how potential alternative interpretations or explanations were considered in the translations	[13]
Findings			
14	Outcome of translation	Describe the interpretive findings of the translation.	[14]
Phase 6—Synthesizing translations			

No.	Criteria headings	Reporting criteria	Number in document indicated by [x] (highlighted)
Methods			
15	Synthesis process	Describe the methods used to develop overarching concepts (“synthesized translations”)	[15]
		Describe how potential alternative interpretations or explanations were considered in the synthesis	[15]
Findings			
16	Outcome of synthesis process	Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis	[16]
Phase 7—Expressing the synthesis			
Discussion			

No.	Criteria headings	Reporting criteria	Number in document indicated by [x] (highlighted)
17	Summary of findings	Summarize the main interpretive findings of the translation and synthesis and compare them to existing literature	[17]
18	Strengths, limitations, and reflexivity	Reflect on and describe the strengths and limitations of the synthesis:	[18]
		- Methodological aspects—for example, describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted.	[18]
		-Reflexivity—for example, the impact of the research team on the synthesis findings	[18]
19	Recommendations and conclusions	Describe the implications of the synthesis	[19]

Appendix (6) Evaluating the methods, methodology, and analysis: Using the Guidelines for reviewers and editors evaluating thematic analysis manuscripts**. Produced by Victoria Clarke and Virginia Braun (2019)**

Evaluating the methods and methodology	**Notes**	**Reference in [ ]** can be found in the main text throughout this chapter
1. Is the use of TA explained (even if only briefly)?	Yes	[1]
2. Do the authors clearly specify and justify which type of TA they are using?	Yes, I am using Reflexive Thematic Analysis.	[2]
3. Is the use and justification of the specific type of TA consistent with the research questions or aims?	I have explained the reasons for using the Reflexive Thematic Analysis (RTA) type as a method which offers many advantages for a qualitative study interested in exploring experiences such as I am looking at. As an approach it worked conceptually well with the aims of this study given it is independent of a methodology.	[3]
4. Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (conceptual coherence)?	The RTA method is embedded within the conceptual framework of the decolonising approach. I have explained the specific context of the research design, how it is positioned and situated in relation to the original research question and the type of study. I also discussed the importance of the embodied, organic approach of RTA; at its core is	[4]

	constant reflection and recognition of researcher influence in decision making and processes which also linked to the Islamic research model I developed as a result of my research process. The analysis tells *'stories'* through interpreting and creatively engaging with the data. It also worked well with hearing the experiences of marginalised voices and provided a foundational structure for me to transition from the methodology to a method that provided a conceptual framework which I used as a guide to analyse my data [4]	
5. Is there a good 'fit' between the methods of data collection and the specific type of TA?	Data was collected through online surveys and interviews. All data collected was qualitative and pertaining to subjective experiences. This worked well in line with RTA.	[5]
6. Is the specified type of TA consistently enacted throughout the paper?	I made every attempt to check back throughout my writing process to ensure consistency. I also repeatedly consulted the papers of Braun and Clarke, their FAQs document and checked with my supervisors to make sure that the consistency was enacted throughout my writing.	[6]
7. Is there evidence of problematic assumptions about TA? These commonly include: • Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures.	I closely following Braun and Clarke guidelines to avoid any of these assumptions. I understood the philosophy of the method and I checked to the best of my ability that my writing does not in any way make such assumptions. I have distinguished between the types of TA. I have not made any connections to grounded theory concepts or procedures. I do	[7]

• Assuming grounded theory concepts and procedures (e.g., saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification. • Assuming TA is essentialist or realist, or atheoretical. • Assuming TA is only a data reduction or descriptive approach and thus has to be supplemented with other methods and procedures to achieve other ends.	not state anywhere that my approach of RTA is essentialist or realist, or atheoretical. I have discussed the point about RTA not being atheoretical. I do not engage with line-by-line comparison. At no point have I stated or engaged in a process that would demonstrate TA is data reduction of descriptive approach or brought in supplementary methods to valid my data.	
8. Are any supplementary procedures or methods justified and necessary or could the same results have been achieved simply by using TA more effectively?	I have not applied any supplementary procures or methods. There was no need for this within the approach I took.	[8]
9. Are the theoretical underpinnings of the use of TA clearly specified (e.g., ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?	Yes, I have clearly stated in multiple junctures throughout the chapter (three and four) the underpinnings of the use of RTA and have specified the ontological, epistemological assumptions, and guiding theoretical framework. I also addressed the point about TA not existing in a theoretical vacuum.	[9]
10. Do the researchers strive to 'own their perspectives' (even if only very briefly); their personal and social	I have explicitly acknowledged and stated my own perspectives, thoughts, and my personal and social standpoint throughout the thesis.	[10]

standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)		
11. Are the analytic procedures used clearly outlined?	I discussed the six phases and how I engaged with them and navigated the analytic procedures.	[11]
12. Is there evidence of conceptual and procedural confusion? For example, reflexive TA (Braun and Clarke, 2006) is the claimed approach, but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).	I did not refer to any different procedures such as the use of a codebook or coding or analytic inputs. I carefully used this checklist to make sure there was no confusion or inclusion of procedures that did not belong with RTA. I used the word 'nodes' from the NVivo programme to distinguish it from being misinterpreted or confused as a coding frame per se. Nodes/codes for me are categories or lists for the sake of gathering similar data as part of making sense and the interpretive process.	[12]
13. Have the authors fully understood their claimed approach to TA?	I think this is demonstrated in the way I have approached it and in the analysis.	[13]

Evaluating the analysis		
14. Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?	The themes are clearly identified and available in chapter fice Braun and Clarke suggest a summary of themes before the detailed writings, so these are placed as a visual Figure at the start of analysis in chapter five.	[14]
15. Are themes reported domain summaries rather than fully realised themes? • Have the data collection questions been used as themes? • Are domain summaries appropriate to the purpose of the research? (If so, if the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified?) • Would the manuscript benefit from further analysis being undertaken and the reporting of fully realised themes? • Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA (e.g., coding reliability or codebook)?	No, the data collection questions have not been used as themes.	[15]

16. Is a non-thematic contextualising information presented as a theme? (e.g., the first theme is a domain summary providing contextualising information, but the rest of the themes reported are fully realised themes) Would the manuscript benefit from this being presented as non-thematic contextualising information?	No	[16]
17. In applied research, do the reported themes give rise to actionable outcomes?	No, however there are recommendations partly drawn on from the data where participants were asked.	[17]
18. Are there conceptual clashes and confusion in the paper? (e.g., claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours)	No	[18]
19. Is there evidence of weak or unconvincing analysis? • Too many or two few themes? • Too many theme levels?	I have tried to ensure the analysis is robust and follows a rigorous process. There was overlap between themes. They were all connected in	[19]

• Confusion between codes and themes? • Mismatch between data extracts and analytic claims? • Too few or too many data extracts? • Overlap between themes?	some way as part of a whole. I do not think this could be avoided or was necessary.	
20. Do authors make problematic statements about the lack of generalisability of their results, and implicitly conceptualise generalisability as statistical-generalisability?	I do not make any statements about lack of generalisability or implicitly conceptualise generalisability as statistical generalisability.	[20]

Appendix (7) Ethics Decision, Approval for ETH1920-1345

From: Research Ethics Online
To: Ayers, Susan
Subject: (CC) Decision - Ethics ETH1920-1345: Aaliyah Shaikh (Medium risk)
Date: 06 April 2020 15:48:25

City, University of London

Dear Susan

The following notification has been sent to **Aaliyah Shaikh** and is copied below for your information.

Dear Aaliyah

Reference: ETH1920-1345

Project title: British Muslims' experience of pregnancy and birth

Start date: 6 Jan 2020

End date: 29 Oct 2020

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the School of Health Sciences Research Ethics Committee. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

Please ensure that you are familiar with City's Framework for Good Practice in Research and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

- Change or add a new category of participants.
- Change or add researchers involved in the project, including PI and supervisor;
- Change to the sponsorship/collaboration;
- Add a new or change a territory for international projects;
- Change the procedures undertaken by participants, including any change relating to the safety or physical or mental integrity of research participants, or to the risk/benefit assessment for the project or collecting additional types of data from research participants;
- Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;
- Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or carers;
- Change to the insurance or indemnity arrangements for the project; Change
- the end date of the project.

Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

a) Adverse events

b) Breaches of confidentiality

c) Safeguarding issues relating to children or vulnerable adults

d) Incidents that affect the personal safety of a participant or researcher

Issues a) and b) should be reported as soon as possible and no later than five days after the event. Issues c) and d) should be reported immediately. Where appropriate, the researcher should also report adverse events to other relevant institutions, such as the police or social services.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the School of Health Sciences Research Ethics Committee, I do hope that the project meets with success.

Kind regards

Nicolas Drey

School of Health Sciences Research Ethics Committee

City, University of London

Ethics ETH1920-1345: Aaliyah Shaikh (Medium risk)

Appendix (8) REC Number ETH1819-1208 Study 1: Online Survey, Participant Information Sheet, Informed Consent, demographics, list of support organisations.

Online (Study 1): Participant Information Sheet

السلام عليكم ورحمة الله وبركاته
As-Salaamu alaykum wa rahmatullahi wa baraktuh

Welcome to our research study!

PARTICIPANT INFORMATION SHEET

Title of study Understanding British Muslims' experiences of pregnancy and birth.

We would like to invite you to take part in a PhD research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
This research is being conducted as part of a PhD study in Health Psychology and aims to understand and explore experiences of pregnancy and birth in British Muslims who have been born and raised in Britain. This is to help create an understanding of the specific experiences, challenges and needs of the British Muslim community in Britain and discover what is significant for them during this life stage.

Why have I been invited?
You have been invited because you are a British Muslim, who may have experience of pregnancy and birth.

You can take part if you meet the following Inclusion Criteria:
- I identify as Muslim.
- I was born / raised in Britain (or have experience of pregnancy or birth in the British context)
- I am male or female (mothers or fathers, including if you lost a child).
- I am over 18 years of age.
- I or my partner have been pregnant or had a baby in the last seven years.

Do I have to take part?
No. Participation in the project is voluntary, and you can choose not to participate. If you do decide to take part, you will be asked to sign a consent form before starting the online survey. At any point if you decide not to complete the survey or you exit the form your data will not be included in the study. Once you have pressed submit it would not be possible to withdraw from the study as the data is anonymised and we are not collecting any identifiable information.

What will happen if I take part?
Participation involves sharing your story and experiences in an online form.
You will first be taken to a consent form after this page and if you agree you will then be able to proceed to the main form. There will be some guided open-ended questions for you to answer and a space for you to write your story. You will then be asked to answer some basic demographic information. Your story will form part of the study which will then be analysed and written up as part of my PhD thesis. The summary findings of which will be made available at https://blogs.city.ac.uk/impact

What do I have to do?
If you are interested in taking part, please continue to the next pages of this form. The time it will take to complete entirely depends on how much information you wish to share and how long it takes to write your story. It is a detailed survey and the information being gathered is valuable, so it is longer than an average survey. You may want to think about it and come back to it and or set some uninterrupted time aside to ensure you are able to fully write your in-depth experiences.

What are the possible disadvantages and risks of taking part?
There are no disadvantages or risks of taking part as such, however it is possible that the nature of the questions may include thinking about sensitive topics, but you are free to not answer any questions, to pause and come back or withdraw at any time up to the point of pressing submit. If you find it brings up certain difficult emotions or distress please contact your G.P or one of the signposting organisations on this link: resource sheet signposting support organisations

What are the possible benefits of taking part?
Although there are no direct benefits from taking part in this research study, the research aims to add to the knowledge around British Muslims' experiences of pregnancy and birth which may inform healthcare professionals and community led services. It will also potentially create a reference point for future research. It is an opportunity to share your voice about experiences that matter to you in relation to the study topic.

What will happen when the research study stops?
Personal data relating to the study (email addresses, contact details etc) and any other data will be kept securely within City University London and will be destroyed after the minimum archiving period (10 years). All transcripts will be anonymised. Direct anonymous quotations may be used in the dissemination of results.

Will my taking part in the study be kept confidential?

Only the research team will have access to information relating to this study. Information you share will be kept confidential. However, should you share any information that may present harm to yourself or others, this will be disclosed by the interviewer to the supervision team to decide an appropriate plan of action and support and this may not stay confidential to the study.

What will happen to results of the research study?

The research will be written up as part of the requirements for the PhD thesis. The research may also be written up for publication in academic journals disseminated to health and social care professionals and academics interested in maternal and child health and shared within the Muslim community. If you would like to view a summary of the findings of this study please keep an eye out on https://blogs.city.ac.uk/impact/ where they will be released.

What will happen if I do not want to carry on with the study?

You are free to withdraw from the study without an explanation or penalty while completing the form. Your data will not be included. However once you click submit as it is an anonymised form it will not be possible to know whose form it is to extract individual data from the study.

How is the project being funded?

The PhD student researcher has received a scholarship for the overall PhD from the Aziz Foundation, though they have no influence on the research topic, process or outcome.

Conflicts of interests

There is no conflict of interest.

Insurance

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: British Muslims' experiences of pregnancy and birth.

You could also write to the Secretary at:
Anna Ramberg
Research Governance & Integrity Manager
Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

Who has reviewed the study?

This study has been approved by City University of London's School of Health Sciences Research Ethics Committee.

Further information and contact details:

Aaliyah Shaikh
PhD Student Researcher, School of Health Sciences
Email: [email removed]

Supervisors of this study:

Professor Susan Ayers: [email removed] and Dr Grace Lucas: [email removed]

Thank you for taking the time to read this information sheet.

جزاك اللهُ خيراً
Jazak Allah Khayr

Online (Study 1): Consent Form

Title of Study: British Muslims' experiences of pregnancy and birth

Please select the box:

1.	I confirm that I have read and understood the participant information sheet (above) for this study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.	
2.	I understand this will involve writing responses to questions online on this form	
3.	I understand that my participation is voluntary, that I can choose not to participate and that I can withdraw from the study without an explanation or penalty at any time up to the point when I click submit on the form. As it is an anonymised form it will not be possible to extract individual data from the study once submitted.	
4.	I agree not to disclose any identifiable information	
5.	I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
6.	I agree to the use of anonymised direct quotes in publication	
7.	I agree that my anonymous data will be made open access if required by journals at point of publication.	
8.	I agree to take part in the above study.	

Online (Study 1): Recruitment text to be used in WhatsApp, email contacts, social media comms: British Muslims' experiences of pregnancy and birth

WE WANT TO HEAR FROM YOU, YOUR VOICE IS IMPORTANT TO US!

"PARTICIPANTS NEEDED FOR RESEARCH STUDY: BRITISH MUSLIMS' (MOTHERS OR FATHERS) EXPERIENCES OF PREGNANCY AND BIRTH"

As a PhD student, I am looking for British Muslims (born and raised in the UK, men and women) to write their story (through an online anonymous survey) and answer some questions about their experiences of pregnancy and birth. This is to help create an understanding of the specific experiences, challenges and needs of the British Muslim community in Britain and discover what is significant for them during this life stage.

You are eligible to take part if you meet all of the following criteria:

- I identify as Muslim
- I was born and raised in Britain
- I am male or female, (mother or father, including if you lost a child)
- I am over 18 years of age
- I had a baby in the last seven years

As a participant in this study, you would be asked to take part in an online questionnaire. This is an in-depth piece of research so may take some time to complete. Your voice is really important, there are very few academic studies on this specific topic. There will be a phase 2 of the study conducting interviews so keep a look out for that if interested instead of the online survey in coming months please register your interest at [email removed].

Will the information I provide be safe and secure?

Data protection, confidentiality, anonymity and ethics are all taken very seriously. Please read the Participant Information Sheet for further information [INSERT LINK TO QUALTRICS FORM].

This study has been reviewed by and received ethics clearance through the School of Health Sciences Research Ethics Committee, City, University of London.

For more information about this study, please read the Participant Information Sheet [INSERT LINK TO QUALTRICS FORM] and if you still have and questions please contact Aaliyah Shaikh, Centre for Maternal and Child Health Research, School of Health Sciences, City, University of London. Email: [email removed]

Social media text: Understanding British Muslims' experiences of pregnancy and birth

British Muslims' experiences of pregnancy and birth - Interested in sharing your experiences and views for a study? If you would like to write your own story with some guided questions through an anonymous online survey tool please click here: [INSERT LINK TO QUALTRICS FORM]
There will be a phase 2 of the study conducting interviews so keep a look out for that if interested in coming months and for any information contact [email removed]

Online (Study 1): Demographics questionnaire: British Muslims' experiences of pregnancy and birth

Demographics sheet

Please see Qualtrics form.

Thank you for taking part in this survey. It is appreciated.
If you feel that anything distressful came up for you during writing/ filling out the survey that you would like support with please do contact your G.P and see the list of organisations that may be of some support [INSERT LINK TO PDF **List of Useful Organisations**]

Once again, we thank you for taking part in this research study.
جزاك اللهُ خيرًا
Jazak Allah Khayr

List of Useful Support Organisations

If you are feeling anxious, depressed, or distressed, you could consider contacting the organisations below for information and / or support.

UK

Organisation:	The **Muslim Youth Helpline** (MYH) is an award winning registered charity which provides pioneering faith and culturally sensitive services to Muslim youth in the UK.
Website:	https://www.myh.org.uk/
Contact:	0808 808 2008. The helpline service is open 7 days a week, 365 days a year including Bank Holidays and Eid. Current opening hours are Monday to Sunday 4pm-10pm. They have live web chat and email support as well as the phone support service.
Organisation:	**IPPA (Islamic Psychology Professional Association)** Has a directory available to search for Muslim counsellors utilising or experienced in working with Islamic models of therapy and faith sensitive ways of working.
Website:	https://www.ippa.org.uk/ippa-directory
Contact:	info@ippa.org.uk
Organisation:	**Aanchal Women's Aid**, supports Asian women affected by abuse. Languages spoken: English, Hindi, Punjabi, Urdu, Tamil, Bengali, Gujarati and Eastern European languages.
Website:	www.aanchal.org.uk
Contact:	0845 451 2547 (24 hour); 0203 384 9412 (office hours).
Organisation:	**PANDAS Foundation**, Pre- and Post-natal depression advice and support.
Website:	www.pandasfoundation.org.uk
Contact:	0843 28 98 401 (telephone helpline weekdays 9am-8pm, calls cost 5p per minute plus your phone company's access charge).

Organisation:	**Anxiety UK**, provides information and support for those living with anxiety and anxiety-depression.
Website:	www.anxietyuk.org.uk
Contact:	03444 775 774 (telephone information line weekdays 9.30-5.30pm, calls cost no more than to landline numbers and are included in free minutes packages).
Organisation:	**The Association for Post-Natal Illness (APNI)**, provides support to mothers suffering from post-natal illness.
Website:	www.apni.org
Contact:	020 7386 0868 (telephone helpline weekdays 10am-2pm).
Organisation:	**Samaritans**, provides support and information if you are having a difficult time and struggling to cope.
Website:	www.samaritans.org
Contact:	116 123 (open 24hrs, 7 days a week).
Organisation:	**MIND UK**, provides information about and sources of support for mental health.
Website:	www.mind.org.uk
Contact:	0300 123 3393 (Monday-Friday 9am-6pm; closed on bank holidays).
Organisation:	**IAPT Services**, provide psychological therapy for people experiencing anxiety and depression. You can refer yourself (often online) to your local IAPT service for psychotherapy. Find the IAPT service nearest to you using the website below.
Website:	https://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008
Organisation:	**Tommy's**, midwife-led support and information for pregnant women, and those who have suffered the loss of a baby.
Website:	www.tommys.org/mentalhealth
Contact:	0800 014 7800 (Monday to Friday, 9am to 5pm), or email midwife@tommys.org.
Organisation:	**NCT**, provides practical and emotional support about pregnancy, birth and early parenthood, including feeding.
Website:	www.nct.org.uk
Contact:	0300 330 0700 (telephone helpline weekdays 8am-midnight including bank holidays).
Organisation:	**Maternal OCD**, provides information and support to pregnant women and mothers who may be experiencing OCD.
Website:	www.maternalocd.org

Organisation:	**Action on Postpartum Psychosis**, provides information and support for those recovering from postpartum psychosis.
Website:	www.app-network.org
Organisation:	**Netmums**, information about anxiety, depression and mental health in pregnancy and after birth.
Website:	http://www.netmums.com/parenting-support/depression-and-anxiety

Appendix (9) REC Number ETH1819-1208. Study 2 Interviews, Participant Information Sheet, Informed Consent, Topic guide, advert, demographics, list of support organisations.

Interviews (Study 2): Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Title of study Understanding British Muslims' experiences of pregnancy and birth.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

This research is being conducted as part of a PhD study in Health Psychology and aims to explore experiences of pregnancy and birth in British Muslims who have been born and raised in Britain.

Why have I been invited?

You have been invited because you are a British Muslim, who may have experience of pregnancy and birth.

You can take part if you meet the following Inclusion Criteria:

- Have not taken part in the previous online survey for this study
- Identify as Muslim.
- Must be born and raised in Britain.
- Male or female that are mothers or fathers (including if you lost a child).
- Be over 18 years of age.
- Had a baby in the last seven years.

Do I have to take part?

No. Participation in the project is voluntary, and you can choose not to participate in part or all of the project. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time up to the point of data analysis and without giving a reason.

What will happen if I take part?

Participation involves one interview with a researcher for approximately 30-60 minutes. The semi structured interview will be conducted over Skype for Business online. The interview will be audio-recorded and you will be asked to answer some basic demographic information. Your answers will form part of the study which will then be analysed and written up as part of my PhD thesis. The summary findings of which will be made available at https://blogs.city.ac.uk/impact

What do I have to do?

If you are interested in taking part, please contact Aaliyah Shaikh (email [email removed]). I will send you a Participant Information Sheet, arrange a time convenient for you to take part in the interview and ask you to complete and return the consent form. It is estimated that it will take between 30-60 minutes to complete the interview depending on your responses and how much you wish to share.

What are the possible disadvantages and risks of taking part?

The interview will take up to a maximum of 60 minutes of your time. The researcher will make sure that they know how much time you have available and ensure the interview runs accordingly. It is likely that the nature of the interview may include the discussion of sensitive topics, but you are free to not answer any questions, to pause the interview or withdraw at any time up to the point of data analysis. If you find it brings up certain difficult emotions or distress please contact your G.P or one of the signposting organisations provided along with this Participation Information Sheet.

What are the possible benefits of taking part?

Although there are no direct benefits from taking part in a research interview, the research aims to add to the knowledge around British Muslims' experiences of pregnancy and birth which may inform healthcare professionals and community led services. It is also an opportunity to share your voice about experiences that matter to you in relation to the study topic.

What will happen when the research study stops?

Personal data relating to the study (email addresses, contact details etc) and any other data will be kept securely within City University London and will be destroyed after the minimum archiving period (10 years). All transcripts will be anonymised. Direct anonymous quotations may be used in the dissemination of results.

Will my taking part in the study be kept confidential?

Only the research team will have access to information relating to this study. Information you share will be kept confidential. However, should you share any information that may present harm to yourself or others, this will be disclosed by the interviewer to the supervision team to decide an appropriate plan of action and support and this may not stay confidential to the study.

What will happen to results of the research study?

The research will be written up as part of the requirements for the PhD thesis. The research may also be written up for publication in academic journals disseminated to health and social care professionals and academics interested in maternal and child health and shared within the Muslim community. If you would like to view a summary of the findings of this study please keep an eye out on https://blogs.city.ac.uk/impact/ where they will be released.

What will happen if I do not want to carry on with the study?

You are free to withdraw from the study without an explanation or penalty at any time up to the point of data analysis.

How is the project being funded?

The PhD student researcher has received a scholarship for the overall PhD from the Aziz Foundation, though they have no influence on the research topic, process or outcome.

Conflicts of interests

There is no conflict of interest.

Insurance

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal

rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Privacy notice

You're providing your name and contact details, so that we can contact you about the research study as necessary. We will use the minimum personal-identifiable information possible.

We will need to share your information with relevant staff and departments within City, so that we can undertake the research. We may also need to share your information with companies that process data on our behalf, or because the law requires us to.

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. City will usually rely on the Academia Exemption under Paragraph 26, Part 5, Schedule 2 of the Data Protection Act 2018 to process research personal data and special category data (e.g. health data).

You can read more about how we process your data in our **Privacy Notice** (https://www.city.ac.uk/about/governance/legal/data-protection)**.**

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *British Muslims' experiences of pregnancy and birth.*

You could also write to the Secretary at:

Anna Ramberg
Research Governance & Integrity Manager
Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB
Email: [removed]

Who has reviewed the study?

This study has been approved by City University of London's School of Health Sciences Research Ethics Committee.

Further information and contact details:

Aaliyah Shaikh

PhD Student Researcher, School of Health Sciences

Email: [removed]

Supervisors of this study:

Professor Susan Ayers:

[removed] and Dr Grace Lucas: [removed]

Thank you for taking the time to read this information sheet.

Interviews (Study 2): Consent Form

Title of Study: British Muslims' experiences of pregnancy and birth

Please initial box:

1.	I confirm that I have read and understood the participant information dated [INSERT DATE AND VERSION NUMBER] for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily. I understand this will involve: • Being audio recorded for an interview	
2.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw from the study without an explanation or penalty at any time up to the point of data analysis at which point it will not be possible to extract individual data from the study.	
3.	I understand that the information I provide is confidential (unless relating to disclosure of risk of harm), and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
4.	I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City	

	complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
5.	I agree to the use of anonymised direct quotes in publication	
6.	I agree that my anonymous data will be made open access if required by journals at point of publication.	
7.	I agree to take part in the above study.	

Other related documents for this application:

Interviews (Study 2): Topic Guide: British Muslims' experiences of pregnancy and birth

Online questionnaire

1. **Introduction**

- Participation information sheet
- Consent information sheet including information on
    - confidentiality and anonymity – quotes will be used but de-identified
    - data storage issues
    - consent issues explaining they can withdraw, and do not have to answer any questions they do not want to.

Check whether they have any questions – provide email [removed]

-
- if they are happy to continue, they have ownership of the process and can terminate, withdraw or pause during the interview and withdraw up to the point of data analysis.
- Ask for verbal consent and recorded consent via tick box on consent sheet emailed to participant prior to the interview taking place.
- Explanation of aims and objectives

2. **Background**

Aims: To understand how British Muslims experience pregnancy and Birth.

Some of the broad sub areas for exploration:

- How religion specifically Islam plays a role in how pregnancy and birth and healthcare are experienced.
- How British Muslims specifically encounter healthcare services of the NHS in the context of a discriminatory political climate and the PREVENT agenda?
- How much participants are aware of their own birth story from their own parents i.e having been born and how if it at all any of their experiences or trauma if any have impacted how they experienced being pregnant /giving birth?
- How participants feel their experiences might shape those of their children and their future health and wellbeing?
- How participants feel their experiences have impacted their mental health?
- How their experiences have shaped their parenting?
- Their own stories in their own words

Interviews (Study 2): Recruitment text to be used on WhatsApp, email contacts, social media comms: Understanding British Muslims' experiences of pregnancy and birth

WE WANT TO HEAR FROM YOU, YOUR VOICE IS IMPORTANT TO US!

"PARTICIPANTS NEEDED FOR RESEARCH STUDY, INTERVIEWS: BRITISH MUSLIMS' (MOTHERS OR FATHERS) EXPERIENCES OF PREGNANCY AND BIRTH"

As a PhD student, I am looking for British Muslims (born and raised in the UK, men and women) to be interviewed about their experiences of pregnancy and birth. This is to help create an understanding of the specific experiences, challenges and needs of the British Muslim community in Britain and discover what is significant for them during this stage and is following on from a previous online survey.

You are eligible to take part if you meet all of the following criteria:

- Did not take part in the online survey
- I identify as Muslim
- I was born and raised in Britain
- I am male or female, (mother or father, including if you lost a child)
- I am over 18 years of age
- I had a baby in the last seven years

Your voice is really important, there are very few academic studies on this specific topic.

As a participant in this study, you would be asked to take part in one interview (online video or audio with audio recorded) lasting between 30 and 60 minutes with a researcher from City University of London. For more information about this study, or to volunteer for this study, please contact Aaliyah Shaikh, Centre for Maternal and Child Health Research, School of Health Sciences, City, University of London

Email: [removed]

Will the information I provide be safe and secure?

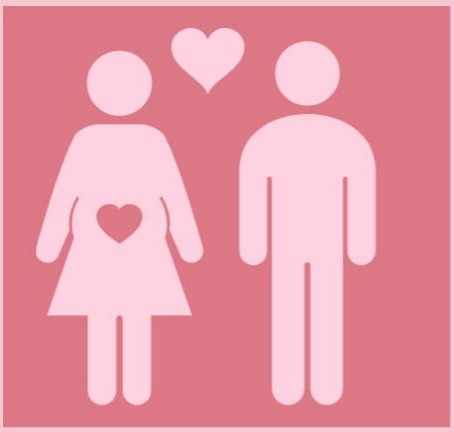
Data protection, confidentiality, anonymity and ethics are all taken very seriously. You will be sent a Participant Information Sheet with further information once you make contact to take part in the study.

This study has been reviewed by and received ethics clearance through the School of Health Sciences Research Ethics Committee, City, University of London.

For more information about this study, or to volunteer for this study, please contact Aaliyah Shaikh, Centre for Maternal and Child Health Research, School of Health Sciences, City, University of London Email: [removed]

Social media text: British Muslims' experiences of pregnancy and birth

British Muslims' experiences of pregnancy and birth - Interested in sharing your experiences and views for a study? If you would like to be interviewed please contact [removed]



WOULD YOU LIKE TO SHARE YOUR STORY?

THE IMPACT STUDY: BRITISH MUSLIMS' EXPERIENCES OF PREGNANCY & BIRTH

CITY
UNIVERSITY OF LONDON
EST 1894

Who?

You can take part if you identify as Muslim, were born and raised in Britain, are male or female (mother or father), over 18 years of age and had a baby in the last seven years.

What?

British Muslims' (men & women) are being asked to share their experiences of pregnancy & birth. Interested in sharing your experiences and views for a study?

How?

IF YOU WOULD LIKE TO BE INTERVIEWED PLEASE CONTACT

AALIYAH.SHAIKH@CITY.AC.UK

Interviews (Study 2): Demographics questionnaire: British Muslims experiences of pregnancy and birth

Demographics sheet

1.	Current age	
2.	Gender (male, female, other (please state), prefer not to say)	
3.	Do you identify as British Muslim?	
4.	Where you born and raised in Britain?	
5.	What is your ethnic group/heritage (as self described)?	
6.	Occupation (as self-identified, paid or unpaid)	
7.	How many children do you have?	
8.	What are the ages of your children?	
9.	Where did you give birth to your last child? • In a hospital • Birth Centre • Home • Other…	
10.	Do Islamic rituals and or values inform your day-to-day routine? In all areas	

	Significantly but not always Sometimes Not much Not at all	

Thank you for taking part in this survey. It is appreciated.

If you feel that anything distressful came up for you during writing/ filling out the survey that you would like support with please do contact your G.P and refer to the below list of organisations that may be of some support.

Once again, we thank you for taking part in this research study.

جزاك اللهُ خيرًا

Jazak Allah Khayr

List of Useful Support Organisations

If you are feeling anxious, depressed, or distressed, you could consider contacting the organisations below for information and / or support.

UK

Organisation:	The **Muslim Youth Helpline** (MYH) is an award winning registered charity which provides pioneering faith and culturally sensitive services to Muslim youth in the UK.
Website:	https://www.myh.org.uk/
Contact:	0808 808 2008. The helpline service is open 7 days a week, 365 days a year including Bank Holidays and Eid. Current opening hours are Monday to Sunday 4pm-10pm. They have live web chat and email support as well as the phone support service.
Organisation:	**IPPA (Islamic Psychology Professional Association)** Has a directory available to search for Muslim counsellors utilising or experienced in working with Islamic models of therapy and faith sensitive ways of working.
Website:	https://www.ippa.org.uk/ippa-directory
Contact:	info@ippa.org.uk
Organisation:	**Aanchal Women's Aid**, supports Asian women affected by abuse. Languages spoken: English, Hindi, Punjabi, Urdu, Tamil, Bengali, Gujarati and Eastern European languages.
Website:	www.aanchal.org.uk
Contact:	0845 451 2547 (24 hour); 0203 384 9412 (office hours).
Organisation:	**PANDAS Foundation**, Pre- and Post-natal depression advice and support.
Website:	www.pandasfoundation.org.uk
Contact:	0843 28 98 401 (telephone helpline weekdays 9am-8pm, calls cost 5p per minute plus your phone company's access charge).

Organisation:	**Anxiety UK**, provides information and support for those living with anxiety and anxiety-depression.
Website:	www.anxietyuk.org.uk
Contact:	03444 775 774 (telephone information line weekdays 9.30-5.30pm, calls cost no more than to landline numbers and are included in free minutes packages).
Organisation:	**The Association for Post-Natal Illness (APNI)**, provides support to mothers suffering from post-natal illness.
Website:	www.apni.org
Contact:	020 7386 0868 (telephone helpline weekdays 10am-2pm).
Organisation:	**Samaritans**, provides support and information if you are having a difficult time and struggling to cope.
Website:	www.samaritans.org
Contact:	116 123 (open 24hrs, 7 days a week).
Organisation:	**MIND UK**, provides information about and sources of support for mental health.
Website:	www.mind.org.uk
Contact:	0300 123 3393 (Monday-Friday 9am-6pm; closed on bank holidays).
Organisation:	**IAPT Services**, provide psychological therapy for people experiencing anxiety and depression. You can refer yourself (often online) to your local IAPT service for psychotherapy. Find the IAPT service nearest to you using the website below.
Website:	https://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008
Organisation:	**Tommy's**, midwife-led support and information for pregnant women, and those who have suffered the loss of a baby.
Website:	www.tommys.org/mentalhealth
Contact:	0800 014 7800 (Monday to Friday, 9am to 5pm), or email midwife@tommys.org.
Organisation:	**NCT**, provides practical and emotional support about pregnancy, birth and early parenthood, including feeding.
Website:	www.nct.org.uk
Contact:	0300 330 0700 (telephone helpline weekdays 8am-midnight including bank holidays).
Organisation:	**Maternal OCD**, provides information and support to pregnant women and mothers who may be experiencing OCD.
Website:	www.maternalocd.org
Organisation:	**Action on Postpartum Psychosis**, provides information and support for those recovering from postpartum psychosis.

Website:	www.app-network.org
Organisation:	**Netmums**, information about anxiety, depression and mental health in pregnancy and after birth.
Website:	http://www.netmums.com/parenting-support/depression-and-anxiety

Appendix (10) Free text based questions from Qualtrics Survey

Q1 - Please write your story in your own words of your experiences of pregnancy and or birth (It can be as long and detailed or little as you like)

Q2 - What was your experience of the place you gave birth? E.g NHS or birth centre, home, other

Q3 - What were your experiences in relation to the healthcare providers (staff, midwives, doctors, nurses, doulas, any other healthcare professionals involved in your care)?

Q4 - Did you feel understood (language, religious needs, personal preferences etc) and that your needs were met?

Q5 - In your opinion, did you at any point feel disadvantaged or discriminated against even if subtly due to your Muslimness?

Q6 - If you answered yes/unsure can you explain how (if at all) this impacted on the care you/your child received?'

Q7 - What were your experiences of those with you (e.g partner, family friends)

Q8 - How did Islam play a role in your experience of pregnancy and or birth?

Q9 - How (if at all) did cultural traditions play a part in your pregnancy and or birth experience (positive or negative experiences).

Q10 - How do you think if at all your physical and mental health were impacted during the pregnancy and or birthing period? (Including if you felt effects of Jinn/sihr (supernatural), or if you felt it was related to social or relationship difficulties, or any other factors)

Q11 - Did you experience any trauma during the pregnancy or birth? (If so please share your story below if you like and have not already covered it elsewhere on this form)

Q12 - Do you think mental health around pregnancy and birth is understood and recognised in the Muslim community in Britain?

Q13 - If you answered no to the above question (or would like to elaborate), what do you think could be done to improve the understanding and recognition of mental health around the time of pregnancy and birthing? What would be supportive based on your experience?

Q14 - How do you think if at all these experiences have impacted your child(ren's) physical and mental health?

Q15 - How do you feel if at all your pregnancy and or birth experiences impacted how you parent / your attachment to your child.

Q16 - What was the month and year of the pregnancy and or birth story you wrote about?

Q17 - Are you aware of your own birth story from your parents and details of how you were born and the circumstances? If so, please share any of your story below.

Appendix (11) Interview schedule prompt questions (not including demographics)

Q1 - Please share your story in your own words of your experiences of pregnancy and or birth.

Q2 - What was your experience of the place you gave birth? E.g NHS or birth centre, home, other

Q3 - What were your experiences in relation to the healthcare providers (staff, midwives, doctors, nurses, doulas, any other healthcare professionals involved in your care)?

Q4 - Did you feel understood (language, religious needs, personal preferences etc) and that your needs were met?

Q5 - In your opinion, did you at any point feel disadvantaged or discriminated against even if subtly due to your Muslimness?

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Q15 - How do you feel if at all your pregnancy and or birth experiences impacted how you parent / your attachment to your child.

Q16 - What was the month and year of the pregnancy and or birth story you wrote about?

Q17 - Are you aware of your own birth story from your parents and details of how you were born and the circumstances?