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Exploring the experiences and impact of sexual  
problems in a sexual relationship; Black men with Type  
2 Diabetes

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A Portfolio Submitted for the Award of Doctorate in Counselling  
Psychology (DPsych)

City, University of London

Department of Psychology

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## 1. Preface

This doctoral portfolio is composed of three components: an empirical original qualitative research project, a publishable paper and a combined client study and process report and reflects the development of my clinical and research skills acquired as part of my training. I will outline first the inspiration for my research topic before providing an overview of each section of the portfolio in turn and highlighting connections between them and finally I will share my reflections on this process.

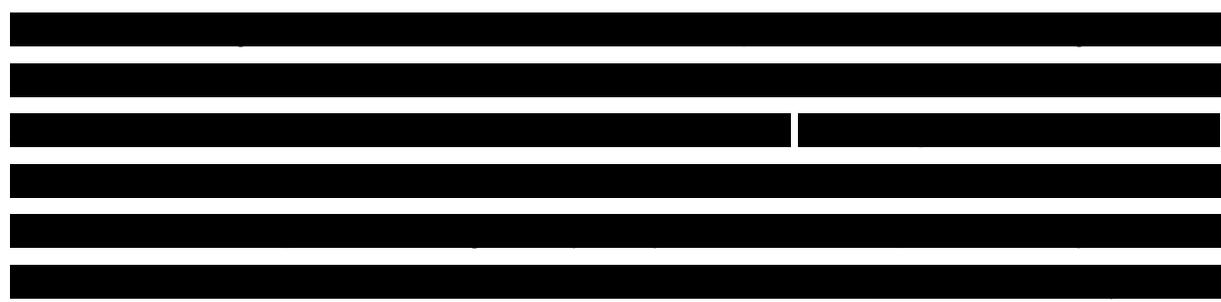
### Inspiration

The inspiration for my portfolio evolved from work that I became involved in more than 20 years ago. The year was 1999, I had a new job working in the policy department of a housing association in London and I was tasked with writing a new harassment policy and procedure for the organisation to adopt following the publication of the Macpherson Inquiry report (Macpherson, 1999) which had examined the Metropolitan Police's investigation into the horrific and tragic murder of the teenager Stephen Lawrence in 1993. This shocking report accused the Metropolitan Police of being institutional racist, outlined its serious failings and made 70 recommendations that included calls for changes to the law and the adoption of a new definition of racial harassment with the aim of clamping down on discrimination. This report, Stephen's murder and the significance of the task I was initially assigned to, was a defining moment, it shaped my role and the way that I subsequently reviewed and developed policies and services where I co-collaborated with a diverse range of tenants and it ultimately influenced my career.

Following this I worked for many years with a range of organisations in areas of deprivation, health and social inequalities working in disadvantaged neighbourhoods and consulting and engaging with disenfranchised groups. I compiled reports by demographics that included ethnicity, gender, age, education, class, sexuality, religion, and income and over time I was asked to distil findings further and while the aim was always to highlight and readdress the imbalance, I became sceptical about if and how the information was being used.

Fast forward 15 years [REDACTED] and I was astonished to learn about the impact diabetes has on daily life and the range and severity of complications associated with having the condition which includes sexual complications, [REDACTED]

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]



### **Part A: Overview of research study**

In the first part of this portfolio, I will present my research study, an exploration of what it was like for Black men living with Type 2 Diabetes Mellitus (T2DM) to experience sexual difficulties when in a sexual relationship using Interpretative Phenomenological Analysis (IPA). The research findings suggested that the men's experiences were often unexpected and unfamiliar, their sexual difficulties created strain in their relationship, and they struggled to find a solution which all contributed to the re-evaluation of their masculinity. The findings are discussed in relation to the existing literature and relevance to Counselling Psychology and the wider health sector.

Completing this research study as part of my training helped to refine my research skills. Carrying out the literature review was a valuable exercise as I developed an in-depth understanding of the subject area and research landscape and using IPA enabled me to hone my skills as an interviewer. The men's detailed accounts of their experiences offered valuable insight which will help my clinical practice in the future.

### **Part B: Publishable paper**

The second section of this portfolio consists of an article which I intend to submit to *Practical Diabetes*. This journal was selected because of its interest in all aspects of diabetes medicine. To do justice to the data, I decided to focus on one aspect of the men's experience for this article; Viagra is no quick fix. My decision was also influenced by my role as a reader I was often left feeling it was difficult to get a sense of the pertinence, salience, and depth of an issue from the qualitative studies I had previously reviewed. The offer of psychological support to people living with diabetes is currently limited, historically services have been based upon the medical model, for the findings of this study to have impact I felt it was important to highlight a theme that had physical and psychological implications. Finally, I felt it was important to bring to the attention of practitioners the physical, psychological and cultural implications of taking Viagra medication for Black men with T2DM with the hope that this information would be recalled during subsequent interactions as experiences of using Viagra rarely seemed to be followed up.

### **Part C: Case study and process report**

The final section of my portfolio comprises of a combined case study and process report outlining my work with Jason\*<sup>1</sup> at a community outreach drug service. We worked collaboratively to explore his low-self-esteem, anxiety and low mood using Fennell's' (1997) cognitive behavioural framework as a guide. The development of Fennell's low self-esteem model was informed and supported by rich descriptive case studies (Fennell, 1997, 2006). I decided to include my work with Jason in this portfolio because he had many strengths and despite difficulties in our relationship, he was resourceful, engaged and took risks and I wanted to celebrate this.

As part of my training, I worked across a range of psychological settings with diverse client groups with different types of presentations and this helped to refine my therapeutic skills. Through this work, I identified what excited and inspired me as a Psychologist, in terms of where I would like to work, who I would like to work with, how I would like to work and the type of supervision that I need to facilitate my work and growth. In addition to the reasons outlined above, my placement at a community drug service played such a key role in my learning and development, I felt it was important to include this experience within my portfolio.

### **Practice, tension and paradigms**

Working psychologically, I do not align myself with a particular model but endeavour to use the best approach for each client depending upon their preferences and circumstances, but from my placement experiences this is not always possible and challenging the status quo of a national institution like the NHS can seem impossible. Adding to this, I am drawn to working with health issues which tend be based in medical settings, and as part of a multi-disciplinary team and I am often faced with the challenge of working with colleagues who favour the medical model. Clients also tend to expect and are most familiar with this model, while I operate and promote the benefits of using a psychological approach and try to retain the underlying humanistic principles of Counselling Psychology.

While I do not align myself with a particular psychological model or approach, throughout my training I have valued the importance of the therapeutic alliance. One of the reasons I decided to highlight the work with Jason in my case study was because I found this particularly challenging to develop and I was aware that it can also act as bridge between the ethos of Counselling Psychology and cognitive behavioural therapy, especially as the two areas are not always easily affiliated. (Claessens, 2010). In terms of therapeutic practice, cognitive

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<sup>1</sup> Pseudonym

behavioural therapy has been criticised for being too directive and using standardised techniques in the pursuit of change (Sanders, 2012). In comparison, Counselling Psychology values are humanistic in essence where the focus is on an in-depth exploration of an individual's inner world and where change is a by-product. Despite these differences Counselling Psychology does not prescribe to a particular way of working and is committed to exploring a range of approaches and recognises the contributions of different traditions in psychology (Strawbridge & Woolfe, 2012). Cognitive behaviour therapy has also evolved as part of its third wave and has incorporated a range of heterogenous psychotherapeutic approaches which emphasise the collaborative nature of the therapeutic relationship and in doing so it has become more aligned with one of Counselling Psychology's core values, which recognises the importance of the helping relationship to facilitate and enhance wellbeing (Claessens, 2010).

Linked to this, within this portfolio, I refer to two distinctly different paradigms, theories and practices; phenomenology, hermeneutics and IPA and cognitive behavioural theory and therapy, so how can these differing philosophical and scientific streams be brought together? These paradigms are distinct in relation to the way types of knowledge are acquired, they make different claims about the world and use different language. Yet Smith & Osborne (2007) and Larkin, Eatough & Obsorn (2011) have suggested that there is also an element of overlap and a shared commitment in relation to cognition and thoughts and the role of meaning making in terms of what an experience or event means to a person and how this is shaped by the social, cultural and historical context. Similarly, the experience of engaging in the world is then relayed through communication and interpreted by another. They have also suggested taking this further, proposing that the two streams can work together to improve and enrich understanding, working at different levels. For example, a cognitive behavioural model can operate at a macro level focussing on the identification of key components and the relationship between cognition and behaviour. Whereas an IPA approach can work at a micro level through the detailed exploration of the meaning of an event or experience which can be developed into a phenomenological account and then relayed back to the existing theory. Such an approach would enrich a cognitive model, giving a sense of strength to a particular construct or not and this framework has provided the basis for the work contained within this portfolio.

### **Connections between the parts**

At first glance the three components that make up my portfolio seem quite distinct, but they link in several ways. First taking a wide lens, the three conditions experienced by the men:

sexual dysfunction, T2DM and substance misuse have all been perceived as highly stigmatised. Local Authorities are responsible for the funding and delivery of both sexual health and drug and alcohol services rather than the NHS and they have been subject to cuts and side-lined in recent years. Due to the stigmatisation, users of these services are unlikely to protest or demonstrate publicly about potential cuts in a way that say users of a green space or an arts venue might.

Looking more closely across the three pieces of work, some shared findings were evident in relation to: responsibility, control, strength, avoidance, implications of taking medication and substances and body and mind connection; although the meanings ascribed and the way they were experienced differed. A final common thread running through the portfolio was one of changing identity. As many of the men in the research study encountered sexual difficulties, they described re-evaluating their masculine identity and for some their identity appeared to influence their thoughts about taking Viagra medication. In the case study, Jason spoke of the importance of his various identities as a carer, provider, builder and step-father and the impact they had on his mental and physical wellbeing and sense of his self were explored during the therapy. While working alongside Jason I was also aware of my own changing identity as I too embarked on a new career at a similar life stage.

### **Final thoughts**

Within this portfolio I have attempted to bring together strands of my life that have been instrumental and inspirational in my journey of becoming a Counselling Psychologist and the work that I have presented reflects this. My identity as a Counselling Psychologist has been shaped by my placements, doctorate course and personal therapy. Through these processes I have been able to identify a clear set of values that I hold dear as a scientist-practitioner: kindness, fairness, equality, inclusion, connection, campaigning and community and keeping them in mind has been both motivating and grounding throughout my training.

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## Part A: Qualitative Research Study

Exploring the experiences and impact of sexual problems in a sexual relationship; Black men with Type 2 Diabetes

## **2 Abstract**

This qualitative study explored the subjective experiences and impact of sexual difficulties from the perspectives of Black men living with Type 2 Diabetes Mellitus (T2DM) who were in a sexual relationship. Semi-structured interviews were conducted with seven Black men living with T2DM and experiencing sexual difficulties. The Interview data collected was analysed using Interpretative Phenomenological Analysis (IPA) in order to understand and gain insight into the men's subjective experience of sexual difficulties and the meaning that this had for them. Four master themes emerged from the data: What is happening to me? Searching for meaning and answers; A changing relationship with my partner; Viagra is no quick fix; and Am I no longer a man? Each master theme is comprised of subthemes derived from my interpretation of the men's interpretation of their experiences of sexual difficulties. The findings reflected the men's journeys from their initial encounters of sexual difficulties and their attempts to make sense of what was happening to their bodies, not initially realising the impact of their diabetes; to experiencing communication difficulties and mistrust in their relationships; to being faced with the challenge of finding a solution and having to consider the implications of using medication; which culminated in the men re-evaluating their masculinity as they were no longer able to perform sexually in the way they once could as a consequence of their diabetes. These exploratory findings are discussed in relation to the existing literature. The quality of the study and its clinical transferability for Psychologists and colleagues working across the health sector are considered. Recommendations for future research are also suggested.

### **3. Chapter One: Literature Review**

#### **3.1 Overview of Chapter**

This chapter will begin by outlining the condition of diabetes and links to psychological wellbeing. To add context, a summary of key articles that examine the psychological impact of living with diabetes in general will be outlined initially before turning to studies that will explore sexual difficulties. Men's experiences are of particular interest and published studies that have predominately explored erectile dysfunction will be reviewed. Attention will then be directed towards research with Black men living with Type 2 Diabetes Mellitus (T2DM), evaluating the psychological impact of living with the condition before funnelling into the more specific area of sexual difficulties. Treatment interventions will also be reviewed. Throughout, the aim will be to develop an understanding of the subject area while also identifying gaps and limitations within the research field.

#### **3.2 Research Study**

As the reader considers the literature presented it may be helpful to understand the aim of this qualitative study which is to explore the subjective experiences and impact of sexual difficulties on Black men living with T2DM. Specifically, what it is like for a Black man with T2DM to experience sexual difficulties, the impact and meaning of this on himself in terms of the way he sees himself and how he feels, the impact on his sexual relationship and his wider relationships such as with family, friends and colleagues. In addition, I hope the research findings will also address how the men managed these particular aspects.

This area is of particular interest as diabetes is a chronic health condition that can be challenging to manage and the condition is associated with a range of life-changing complications including sexual difficulties. Studies have suggested that adults living with T2DM are at risk of diminished psychological wellbeing (Gask et al., 2011; Robertson et al., 2012) and yet less than a quarter receive psychological therapy specifically for their diabetes (Diabetes UK, 2015). The World Health Organisation considers sexual health to be a key component of well-being and living a fulfilling life (WHO, 1975, 2006a) and research studies have indicated that erectile dysfunction is at least three times more prevalent amongst men living with diabetes than the general population (Kouidrat et al., 2017). Yet it seems men experiencing sexual difficulties can be reluctant to report the condition to their GP (Fedele et al., 2000). In the UK, Black adults from Black African and African Caribbean backgrounds are up to three times more likely to develop T2DM than people of White European origin (DH, 2001; Public Health England, 2016). In addition, Black men are less likely to access mental

health care through a GP (Morgan et al., 2005) and more likely to wait until symptoms reach crisis point (Keynejad, 2008). There are relatively few research studies that have been conducted with Black men living with T2DM and if health inequalities are to be addressed there is a desperate need to establish an evidence base in the UK, addressing psychological needs can lead to improved clinical outcomes, quality of life, dietary control, overall prognosis and relationships with Health Care Professionals (HCPs) and others (NHS Diabetes & Diabetes UK, 2010; Alum et al., 2008).

To the best of my knowledge, the study proposed is the first to focus only on sexual difficulties rather than diabetes in general, and exclusively explore the experiences from the perspectives of Black men living with T2DM in sexual relationships in the UK.

### **3.3 What is Diabetes?**

There are different types of diabetes, Type 2 diabetes mellitus (T2DM) is the most common form representing 90% of diabetes cases worldwide. T2DM develops when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces (WHO, 2020). Insulin is a hormone which regulates blood glucose levels, as it enables glucose to enter the body's cells which is then converted into energy. Glucose is created when the body breaks down carbohydrates eaten, and it is released into the blood. Diabetes develops when the glucose cannot access the body's cells and too much glucose builds up in the blood and the body is unable to use it as fuel (NICE, 2015; Diabetes UK, 2019).

### **3.4 Prevalence of diabetes and associated complications**

463 million adults worldwide live with diabetes (IDF, 2019). It is a chronic condition associated with a range of complications including sight loss (Bourne et al., 2013), kidney failure (NIDDK, 2014), heart attacks, stroke (Sarwar et al., 2010), lower limb amputations (WHO, 2016) in addition to sexual complications.

### **3.4 Note on terminology: Sexual dysfunction & Sexual difficulties**

The terms sexual dysfunction and sexual difficulties are used interchangeably throughout the literature and within this thesis. Historically, sexual dysfunction was used when a clinical diagnosis was made, suggesting a clinical threshold had been met (Wincze & Weisberg, 2015). However, individuals with sexual difficulties may experience similar levels of distress but may not have sought help.

### **3.6 Development of sexual dysfunction with diabetes**

Erectile dysfunction is the inability to achieve or sustain an erection sufficient or satisfactory for sexual performance, but in practice it can also refer to weaker or softer erections (NIH, 1992; Hatzimouratidis et al., 2010). The literature tends to agree that the development of erectile dysfunction is complex, as it involves the co-ordination of psychological, endocrine, vascular and neurological factors (Melnik, Soares & Nasello, 2008) and living with diabetes can increase the risk of developing it (Hackett, 2009).

Erectile dysfunction is more common in men with diabetes because they may have high blood sugar levels accompanied by high blood pressure and cholesterol. This can cause the blood vessels to harden and narrow, damaging nerves in relation to receiving nutrients and sending signals around the body, thus restricting blood flow to sexual organs which is needed in order for a penis to become erect. Accompanying this maybe a loss of sensation in the penis contributing to erection difficulties and inability to achieve an orgasm (Edwards, 2013). Diabetes can also be associated with low sexual desire and ejaculatory difficulties occurring individually, alongside or as an outcome of erectile dysfunction. While there is no official definition of low sexual desire it has been linked with low testosterone which can be common in men with diabetes (Alto & Needle, 2017), whereas ejaculatory difficulties may also be due to nerve damage and a consequence of poor glycaemic control (blood sugar levels) (Ellenberg & Weber, 1966).

Episodes of hypoglycaemia where blood sugar levels fall can also impact on sexual functioning and cause short-term erectile dysfunction and ejaculative difficulties as the body attempts to save energy and diverts the flow of blood (Diabetes UK, 2019).

While thrush is not a sexual complication, a body with higher glucose levels and a weakened immune system enables bacteria to grow and thrush can develop on the genitals, making sex uncomfortable or avoided and this also appears prevalent in adults living with diabetes (Edwards, 2016).

There are many other factors related to diabetes that can increase the risk of developing sexual dysfunction including age of person, duration of diabetes, level of glycaemic control and side-effects of prescribed diabetes medication (Edwards, 2013; Hackett et al., 2018). Psychological factors such as feeling stressed and anxious about sexual performance also play their part. As well as general factors including being overweight, smoking and drinking alcohol (Mills, 2015).

### **3.7 Relevance of research with men**

Men are of interest, as they are slightly more likely to be diagnosed with diabetes (56%) and yet less likely to access health services in general (RCGP, 2014). Studies have suggested that men experiencing erectile dysfunction are reluctant to report the condition (Fedele et al., 2000), and yet may feel their sex life is not meeting their needs (Bjerggaard et al., 2015).

### **3.8 Relationship between diabetes and ethnicity**

Risk factors of developing T2DM include; being over 40, excess body weight, physical inactivity, diet, ethnicity, family history and lower socioeconomic groups (NICE, 2011). In the UK, Black adults from Black African and African Caribbean backgrounds are up to three times more likely to develop T2DM than people of White European origin (DH, 2001; Public Health England, 2016). A similar pattern is found in the USA, prevalence of diabetes amongst African Americans is 13.4% compared to 7.3% for White American adults (CDCP, 2017). Adults of Black heritage are also at an increased risk of developing T2DM ten years earlier and at lower body mass index than White Europeans (Paul et al., 2017). It is not fully understood as to why people from certain ethnicities are at greater risk (Goff, 2019; Nice, 2011; Tillin et al., 2013). In the UK, a long-term population study suggested higher body fat levels around the abdomen may lead to insulin resistance and a greater build-up in the body and consequently T2DM (Tillin et al., 2013). Conversely, a recent small study has suggested that Black African men have lower internal body fat, process glucose in the same way, but have higher levels of insulin to begin with than White European men, and the reasons for this remain unclear (Goff, 2019). However, cautious interpretation is required when considering the influence of biological factors as they can reinforce stereotypes and act as a distraction from sourcing solutions to reduce health inequalities, (Whitfield & McClearn, 2005) such as research findings in the USA which have suggested that African American men are more likely to experience health problems and less likely to receive good quality care (AHRQ, 2003; Satcher, 2003; Tucker et al., 2007), are more at risk of developing complications from diabetes and more likely to be hospitalized (OMH, 2014a; Hurt, Seawell & O' Connor, 2015) than White American men. In the UK, studies have also suggested that poor access to diabetes healthcare is a significant issue for non-White European ethnic groups (Healthcare Commission, 2007; Lakhani, 2008).

### **3.9 Note on terminology: Ethnicity**

Ethnicity is a difficult concept to define and there is no consensus of what constitutes an ethnic group. According to the Office of National Statistics (ONS, 2016) ethnicity is subjective and

multifaceted and its meaning depends on the person describing it. As it is self-defined it also evolves and shifts over situations and time (Vickers, Craig & Atkin, 2012). Due to its fluidity, attempting to measure it can be complex (Helms, 2005). However, some authors have suggested that ethnicity tends to refer to a group who share certain origins this may or may not include: country of birth, geographic region, nationality, language spoken at home, religion and cultural identity including shared beliefs, behaviours and traditions. An ethnic group can also be a political symbol and one that is a source of pride and belonging and also one that through definition is defined as excluded, by a powerful majority (Parekh, 2006; Platt, 2011; Institute of Race Relations, 2020; Salway et al., 2009).

Despite the complexity involved, the ONS developed a set of harmonised standards of ethnic group classifications (2013) to be used when conducting Government research. Their published guidelines for social researchers were referenced when conducting this study and participants self-identified as being from Black African, Black Caribbean or Black British heritage, and as such these terms are referred to throughout. The use of the term Black will at times also be used as an overall identifying statement encompassing all three groups. When referencing other research literature, the author's descriptions of participants are followed.

Ethnic groupings have been criticised as they are perceived to be crude, problematic and outdated labels which tend to homogenise people, ignoring the diversity of cultural heritage and masking inequalities (Boakye, 2019; Okolosie, 2015) and suggesting it is stable and discrete (Gunaratnam, 2003; Kalra, 2006). This gives rise to the question why carry out research in this way? Studies using ethnic classification can be useful, as they can highlight inequalities between groups, bringing them to the attention of policy makers with the hope of bringing about change in practices (Salway et al., 2009; Connelly, Gayle & Lambert, 2016). Salway and colleagues (2009) also suggested that undertaking research with a particular ethnic group can be justified when an issue disproportionately affects the population concerned and has not been adequately studied previously.

### **3.10 Ethnic identity development**

As the perspectives and experiences of Black men are of interest it is helpful to have an awareness of the development of identity in terms of ethnicity and masculinity. Cross and Fhagen-Smith (2001) proposed a model of ethnic development, informed by Cross's earlier influential Nigrescence model (Cross, 1971; cited in Jones-Smith, 2021). They conceptualised the progression of ethnic identity in various stages, beginning in childhood and influenced initially by family and historical events. It was proposed that ethnic identity was developed through a process of transformation whereby the values of a White dominant culture are rejected and through immersion and internalization, a healthy self-concept of identity as an

African American emerges. This influential model identified three types of identity: Black being the salient identity, bicultural Black identity which included integration with the dominant culture and a multicultural identity as Black, with the incorporation of other cultural identities such as gender and sexual orientation.

While emphasis of Cross's & Fhagen-Smith's model was on the development of African American identity, Jones-Smith (1985, 1991) proposed a tripartite model that was generic, applicable universally, across the lifespan and made no reference to oppression or conflict which conversely may also be interpreted as limiting its application. She proposed that ethnic identity was developed through an individual's identity and their unique response to life experiences. In addition to being equally influenced by the group, which seemed to work in a similar way to proposals made by Fhagen-Smith and Cross's (2001) through the structure of family and involvement with others. This element was also characterised by largely being unspoken and shaping the development of gender and professional roles. The final contribution feeding into the development of ethnic identity was the concept of universal influence, referencing a shared commonality as everyone is part of the same human race (Jones-Smith, 2014).

### **3.11 Masculinity**

Turning now to focus particularly on the development of masculinity and consideration of the meanings associated with Black masculinity. Early work by Hunter and Davis (1992) suggested manhood was shaped through self-determinism, accountability, family, pride, spirituality and humanism. They also suggested that men's relationships are important in defining manhood. Hunter and Davis proposed that Black men have a varying and complex understanding of manhood but there can be an expectation to conform to dominant gender roles e.g. to be successful and competitive, while also meeting cultural specific requirements such as co-operation, promotion and survival within the Black community. Franklin (1994) developed a triangle of socialisation to help understand how Black masculinity is shaped, sharing aspects as described by Hunter and Davis (1992). Franklin suggested Black masculine identity is developed through the navigation of three influential groups; the family's values, peer groups and mainstream society e.g. tv/radio messaging which idealises dominant White masculine traits such as competitiveness, aggressiveness and dominance that are different from the messages received from the previous two groups. This is similarly aligned with Cross and Fhagen-Smith (1991) model outlined earlier.

Hammond and Mattis (2005) expanded upon the earlier work of Hunter and Davis (1992) and explored the meaning of manhood with African Americans in the USA across the lifespan. This was an unusual study as the men were recruited as part of wider research examining social

experiences and sent a quantitative postal survey accompanied by a separate single qualitative question asking about manhood. Content analysis revealed 15 categories that described what it meant to be a man. Responsibility and accountability were the most heavily endorsed characteristics. Other categories related to the self, such as autonomy, personal growth, being grounded, survival, caring for and appreciating the self. Some categories connected the self and others for example expressing and connecting emotionally, gaining, and showing respect, using and showing leadership. Other categories were focused on family and the community and playing a central role as provider and protector. Finally, two categories centred around morals and spirituality. Research by Chaney (2009) shared similar findings, succinctly identifying 4 qualities that are used by Black men to describe manhood: maturity, responsibility, provider and self-awareness.

Adding to this body of work an interesting study was conducted with students who participated in focus groups and depth interviews by Mincey and colleagues (2014). A thematic analysis of the findings suggested masculinity consisted of three aspects: what it meant to be a man, what it meant to be Black man and influences on male development. Eight themes were identified of what it meant to be a man and included: responsibility, provider, mentor, to stand-alone, gradual process, sacrifice, family orientated and characteristics of father. Themes that emerged from the data of what it meant to a Black man included: strength to endure, prove to self and others, attitude which incorporated feelings of power and finally strength and honour in order to overcome stereotypes. Reflecting on these specific themes, they seemed to overlap, suggesting Black masculinity is multifaceted and fluid, however for the purposes of undertaking future studies, this might be challenging for researchers. The final aspect suggested by the authors that influenced masculine development included parents, friends, situations where milestones were met and the most prominent aspect was the influence of the self. These findings are consistent with Franklin's (Franklin, 2004) proposals that Black masculinity is shaped through the influence of different groups. The themes were generally consistent with those outlined earlier by Chaney (2009), Hammond & Mattis (2005) and Hunter & Davis (1992). In terms of exceptions Mincey and colleagues (2014) highlighted issues of spirituality, humanism and virtues were missing. The authors suggested the younger age of the men may have influenced this in addition to their exposure of different cultures at university. Nonetheless all of the studies suggest some consistency in the conceptualisation of what it means to be a man among African American men.

### **3.12 Summary**

The studies reviewed are aimed at guiding our understanding of Black masculinities and practices but they are diverse, performed differently and shift over time and space (Hammond & Mattis, 2005). In some ways Black men may conceptualise manhood in a way that is consistent with dominant male culture but in other ways its construction is nuanced through the intersectionality of race, class, age, sexual orientation and their gendered lives (Hunter & Davis, 1992; Dancy, 2012; Collins, 2005).

### **3.13 Psychological Models – Diabetes & Sexual Dysfunction**

A number of generic models have been used to understand the impact of living with diabetes but lack a specific focus on sexual dysfunction. As diagnosis can have an enormous impact on life and the ability to adjust (Adriaanse et al., 2004; Parry et al., 2004), Kübler-Ross's (1969) 5 stage grief model is a useful framework to understand the type and range of emotional responses involved in the processing of a diabetes diagnosis (Bateman, 2018). A range of psychological models have been used to assist adults in managing their diabetes with a focus on acceptance and change including the Health Belief Model (Becker, 1974), Transtheoretical Model of Change (Prochaska & Norcross, 2003), Mindfulness (Segal, Williams & Teasdale, 2002), Transactional model of stress (Lazarus & Folkman, 1984) and general Cognitive Behavioural models among others. Some of the integrated models have been criticised for being too generic, simplistic, lacking a philosophical basis and not incorporating a theory of personality with a focus on problem solving and the individual (Jones-Smith, 2019).

Turning to sexual dysfunction, diverse models have been developed from across the psychological spectrum including cognitive, behavioural, mindfulness, systematic, narrative and psychodynamic among others and as such sex therapy does not have one unifying or underlying theory (Binik & Meana, 2009) but the goals tend to be similar in relation to the presence of positive and sexual relationship functioning (Meana, Hall & Binik, 2014). While psychological models to address diabetes and sexual dysfunction have developed separately there are parallels in relation to the way both conditions are attended to with an emphasis on adaptation and change particularly those with a cognitive behavioural emphasis. Barlow (1986) and Nobre's (2009, 2010, 2013) conceptual models both emphasise the importance of cognition and negative appraisal of events in maintaining erection dysfunction.

The biopsychosocial model (Engel, 1980) is a comprehensive integrated model, conceptualising the body and mind as interlinked systems and has been applied to

understanding sexual dysfunction (Goodwach, 2005). The model hypothesized that sexuality is multifaceted phenomenon shaped by organic, hormonal and psychosocial factors (such as sexual attitudes, mental health, relationships and culture). As such effective treatments focus on these areas in combination (Bancroft, 2009; Hall, 2019). An interesting variation of this model called the Psychobiosocial has recently been proposed as an alternative for sexual dysfunction. Putting psychological issues at the forefront and led by psychologists with support from elsewhere. (McCarthy & Wald, 2012, 2017). Both variations of this model seem to be a good fit with diabetes in terms of understanding the impact of associated stressors and symptoms that can influence the adjustment and increase the chronic intensity of the condition (McCarthy & Wald, 2017; Hoffman & Driscoll, 2000).

### **3.14 Summary**

With the exception of the Psychobiosocial model there has also been a lack of consideration and integration of sexual complications and diabetes. While this model is to be commended for its fully integrated approach, as a generic model it can be easy to neglect aspects such as ethnic identity, culture, strengths and resilience that maybe particularly pertinent for Black men and in relation to understanding the meaning of illness. (Jones-Smith, 2019)

### **3.15 Evaluation of Pharmacological & Psychological Interventions**

Over recent years, there has been a heavy reliance on the use of pharmacological interventions for treating men experiencing erectile dysfunction and these have been considered alongside psychological treatments.

### **3.16 Medical & Pharmacological Interventions**

A range of medical interventions have been designed to address erectile dysfunction including vacuum erection pumps, intra-cavernous injection therapy and penile prosthesis (Porst, 1996; Rooney et al., 2009). However, Phosphodiesterase 5 inhibitors (PDE5Is), such as sildenafil, tadalafil, vardenafil and avanafil, also known more commonly by the brand name Viagra is recommended by National Institute for Health & Care Excellence (NICE) to be prescribed in the first instance. The medication increases arterial blood flow which leads to smooth muscle relaxation, vasodilation and a penile erection (Corbin, Francis & Webb, 2002). The endorsement by NICE of the use of PDE5Is implies a successful treatment, yet studies of men living with diabetes have suggested that efficacy rates are approximately 50-55% (Porst, 2012) and discontinuation rates are wide-ranging, 14-80%. Research is ongoing to understand reasons for discontinuation, but findings suggested treatment efficacy, satisfaction, side-

effects, safety concerns, cost and psychological factors (Corona et al; 2012, 2016). Interestingly Nice guidelines recommend one treatment of PDE5Is per week, yet in clinical trials adults were given significantly more medication to produce the reported effective responses (Hackett et al., 2018).

### **3.17 Psychological Interventions**

Early psychological interventions for sexual difficulties were devised by Masters and Johnson with contributions by Kaplan (Kaplan, 1974, 1987; Masters & Johnson, 1970) and their work was highly influential in the development of Cognitive Behavioural Therapy (CBT) models and techniques used for sex therapy (Goodwach, 2005). Their approach focused on psychoeducation about the sexual response cycle and on behavioural techniques such as sensate focus and systematic desensitization. (Heiman & Meston, 1998; Avery-Clark & Weiner, 2017). Since then the development of psychological interventions to manage sexual functioning have been diverse but few empirically validated studies have been undertaken (Althof, 2002) and it is unclear why so few studies have been published.

A systematic analysis as part of a Cochrane review selected just 11 studies to be evaluated between 1966 and 2007. Data pooled from 5 randomised trials suggested that group psychotherapy was more likely to reduce the number of men experiencing persistent erectile dysfunction in comparison to those on a waiting list who had yet to receive treatment (Kockott et al., 1975; Ansari, 1976; Price et al., 1981; Munjack et al., 1984; Kilmann et al., 1987). Men who received group therapy and sildenafil citrate also showed a significant reduction of persistent erectile dysfunction and were less likely to drop out than men receiving sildenafil alone. The authors concluded that group therapy may improve erectile functioning in some individuals, but the treatment responses varied. Interestingly, no significant differences were found according to age or severity of erectile dysfunction and ethnicity was not reported. A more recent systematic review (Fruhauf et al., 2013) of 20 randomised controlled trials (RCTs) compared the efficacy of a range of psychological interventions and found no statistically significant effects for erectile dysfunction. The author concluded that the studies were of low quality in relation to methodology and reporting. However, on re-examination of the data Nobre (2017) suggested that the patterns of responses were diverse for seven of the studies and he recommended that therapies should be reviewed that are of similar approach, specifically in relation to CBT, given its evidence elsewhere.

### **3.18 Summary**

Treatments for erectile dysfunction have become increasingly medicalised and yet they do not always meet men's needs. This seems an ideal opportunity for psychological interventions to be considered as an alternative or in conjunction with medication. However, the variety of psychological interventions may have hindered the development of a body of evidence and further research.

### **3.19 Parameters of the Literature Review**

Studies were initially selected because of their emphasis on the psychological impact of living with diabetes. Following this, studies were sought of men's experiences of living with diabetes and sexual difficulties with a focus on erectile dysfunction. Turning to the psychological experiences of Black men living with diabetes with regards to quantitative studies, primary consideration was given to large sample sizes where Black adults were the focus of the study. Only qualitative studies were found that discussed sexual difficulties with Black men with T2DM and they were mentioned briefly as part of a wider discussion about the general lived experience of diabetes but have been incorporated into this review. Databases searched included APA PsycINFO, APA PsycArticles, PubMed and Cochrane using a range of search terms including: Type 2 diabetes, sexual difficulties, sexual dysfunction, erectile dysfunction, Black men, African American men, African-Caribbean men and African men at various points between 2016 and 2021. A flexible approach was taken with regards to timeframe (approximately 20-25 years), as studies tended to be published on a sporadic basis. While Black men living with T2DM were of particular interest, not all research findings differentiated between types of diabetes and gender in some of the quantitative studies.

### **3.20 Psychological Wellbeing & Diabetes Relationship**

Prior to reviewing studies on sexual difficulties, it is useful to consider the links between psychological wellbeing and diabetes. Diabetes is a chronic and complex condition and it has been suggested those living with T2DM are at risk of diminished psychological wellbeing (Gask et al., 2011, Peyrot et al., 2005; Rane et al., 2011; Robertson et al., 2012). Yet, less than a quarter of people receive psychological therapy specifically for their diabetes (Diabetes UK, 2015) and the NHS spend an extra 50% on treating the physical health of someone who has T2DM and poor mental health in comparison to someone with good mental health (MHT, 2016). A possible explanation for this, is that poor mental health can reduce a person's ability to actively manage their diabetes and can be associated with poorer dietary and glycaemic control, lower adherence to medication and the development of complications (Vamos et al., 2009), which in

turn can lead to increase use of health services such as hospital admissions and GP consultations for physical health complaints (Das-Munshi et al., 2007).

### **3.21 Quantitative Research Studies - Psychological Wellbeing**

#### **3.21.1 Depression**

Quantitative studies have highlighted a complicated relationship between depression and diabetes. Some studies have implicated that adults with depression are at an increased risk of developing T2DM (Knol et al., 2006; Rotella & Mannucci, 2013). Other studies reported adults with diabetes are twice as likely to experience depression (Anderson et al., 2001; Roy & Lloyd, 2012). A world health survey across 60 countries with more than 200,000 participants suggested 9% of participants with diabetes experienced depression, significantly higher than for adults without diabetes (3.2%) (Moussavi et al., 2007). Having depression can impact on self-care and increase the risk of complications. The development of complications can in turn increase the risk of depression (de Groot et al., 2001; Winkley et al; 2012). However, interventions targeting depression do not always improve self-care or glycaemic control (Lin et al., 2006; Katon et al., 2004). Findings within the literature can be inconsistent and it has been suggested such differences are due in part to the application of terminology, measurements, reliance on self-reports and the confusion of depression with diabetes-specific distress (Gask et al; 2011).

#### **3.21.2 Anxiety**

Surprisingly, few quantitative studies have explored anxiety and diabetes (Smith et al., 2012). Studies reporting prevalence rates vary, one study implied 14% of people with diabetes experienced anxiety and 40% heightened anxiety symptoms (Grigsby et al., 2002), suggesting the experience of anxiety is within the normal range of the general population. However, a meta-analysis of 12 studies found a significant and positive association between diabetes and anxiety disorders as well as elevated anxiety symptoms (Smith et al., 2012). Studies investigating adults with co-morbid conditions of diabetes and anxiety have indicated they are more likely to report a heavier burden of diabetes symptoms such as an increase in complications (Collins, Corcoran & Perry, 2009), pain (Gore et al., 2005) and poorer glycaemic control (Anderson et al., 2002).

#### **3.21.3 Diabetes-Specific Distress**

Diabetes-specific distress (also referred to as diabetes-related distress) is a unique psychological response to managing diabetes (can include healthy lifestyle, medication regimen, blood glucose monitoring, complications, problem solving and interpersonal

relationships) against an appraisal of coping resources. Characterised by worry, frustration, guilt, anger, sadness, being overwhelmed and emotional burnout it can vary between individuals, in severity and over time (Fisher, Gonzalez & Polonsky, 2014; Tanenbaum et al., 2016).

Reported prevalence rates of diabetes-specific distress are wide-ranging from 18% (Snoek, Bremmer & Hermanns, 2015) to 80% (Carper et al., 2014). However, the first meta-analysis that included 55 studies with adults living with T2DM suggested an overall prevalence of 36% and identified that women and co-morbid depressive symptoms were significant factors affecting diabetes-specific distress (Perrin et al., 2017). Studies have consistently indicated diabetes-specific distress is associated with lower levels of self-care (Nicolucci et al., 2013), elevated levels of HbA1C (blood glucose levels) and lower quality of life (Gebel, 2013; Berry et al., 2015; Chew et al., 2015) while these studies do not suggest it is causal, interventions that have targeted elevated diabetes-specific distress have also demonstrated improvements across these measures (Sturt et al., 2015).

### **3.22 Qualitative Research Studies**

#### **3.22.1 Impact of Diagnosis on Self**

After being diagnosed with T2DM a range of emotional reactions have been quoted in the qualitative literature including; shock and surprise, fear and anxiety, sadness and hopelessness, frustration, anger and despair. Some have expressed self-blame, accompanied by feelings of shame and guilt as diabetes was perceived as a punishment. The literature suggested some downplayed and concealed their diagnosis, others felt challenged by it and for some, the diagnosis was perceived as traumatic as they described being in emotional turmoil, with their world ending (Stuckey et al., 2014, Gask et al., 2011). While being diagnosed with T2DM was completely unexpected for some, others suspected it and experienced a sense of relief as it was perceived as an opportunity to start afresh (Tanenbaum et al., 2016). While responses to being diagnosed were diverse, the recollection of the occasion was clear and vivid and the way in which it was delivered seemed to influence subsequent management (Stuckey et al., 2014, Gask et al., 2011). The impact upon identity after diagnosis was also referenced in the literature as some adults described a sense of loss with a desire to return to the past, others identified themselves as different to others while wishing to be similar, some developed a patient identity and viewed themselves as sick while in contrast others worked hard to maintain their existing identity and felt unchanged by their diagnosis (Manderson & Kokanovic, 2009; Stuckey et al., 2011).

### **3.22.2 Management of Diabetes**

While few qualitative studies have examined the impact of diabetes-specific distress those that have suggested living with T2DM can lead to feelings of great distress, frustration and exhaustion. Diabetes can be seen as a burden that requires fighting and adults with T2DM find themselves falling short when it comes to changing their lifestyle and maintaining their medication regimen (Tanenbaum et al., 2016). Consequently, some feeling defeated experience bouts of sadness which may be profound or transitory (Manderson & Kokanovic, 2009; Stuckey & Peyrot, 2020), alongside repeated worries about premature death and complications (Lustman & Clouse, 2005; Stuckey & Peyrot, 2020). Adding to this, some studies have suggested that stressful life events that are non-diabetes related interfere with daily management and diabetes no longer becomes a priority (Greenfield et al., 2011).

### **3.22.3 Support & Relationships with Others**

Some studies have suggested that family support can act as buffer against the development of psychological distress and is considered important in supporting the adjustment to living with diabetes (Gask et al; 2011; Stuckey et al., 2016; Stopford et al., 2013). While other studies highlight that family support can be insufficient or overbearing facilitating psychological distress (Tanenbaum et al; 2016., Gask et al., 2011). Encounters with Healthcare Professionals (HCPs) equally received polarised responses in the literature, some adults with T2DM were left feeling blamed and shamed about their diagnosis and management of diabetes so subsequently avoided appointments (Tanenbaum et al., 2016). While others felt appreciative of the challenge they received and the opportunity to think about their capacity to self-manage helped restore their sense of responsibility (Stuckey et al., 2014).

### **3.22.4 Summary**

Quantitative studies have attempted to establish prevalence and associations with psychological conditions and adults living with T2DM. Some concerns have been raised in relation to the application of definitions and measurements and prospective studies are needed to identify underlying mechanisms. While qualitative research has described some of the challenges faced by living with diabetes in general and it seems there is a need for more specific research as the condition progresses.

### **3.23 Sexual Health Research with Men Living with Diabetes**

The World Health Organisation (WHO) defines sexual health as a state that incorporates the physical (the absence of sexual dysfunction, disease and infirmity), the emotional and the mental and social wellbeing of a person, in relation to sexuality and sexual relationships (WHO, 2006a). It is also considered a key component in subsequently living a fulfilling life (WHO, 1975).

### **3.24 Quantitative Research**

#### **3.24.1 Physical & Psychological Influences & the Development of Erectile Dysfunction**

Studies have suggested that sexual dysfunction in men with diabetes is associated with older age, longer diabetes duration and multiple co-morbidities (Hackett, 2009). Nicolosi and colleagues (2002) conducted a secondary analysis on data initially gathered as part of an innovative worldwide study which examined sex lives. 26,000 adults from 28 countries, aged 40+ participated in a telephone, online or face to face interview, of which 10% of the sample were identified as living with diabetes. Their findings suggested that erectile difficulties were experienced more frequently by younger men (45-49 yrs.) and their experiences were similar to men aged 70+ living without diabetes. The authors noted the mix-methods used may have hampered some participants disclosing sensitive information. While an early study, this was important research covering many aspects of sexual life but it was funded by a pharmaceutical company that profits from the development of diabetes medication, so they had a particular vested interest in the orientation of the research and the subsequent published findings. Despite these limitations, Kouidrat et al's., (2017) recent meta-analysis concurred with the findings, suggesting that men with diabetes tend to develop erectile dysfunction 10-15 years earlier than those without.

Cummings & Rajendran's research (2015) supported the view that erectile dysfunction was more likely to be influenced by having diabetes than by performance anxiety or other psychological factors (De Berardis et al., 2007) although other studies have suggested the relationship between diabetes, sexual dysfunction and psychology is complex, relating to both the condition and treatment (Corona et al., 2004; Bhasin et al., 2007).

There seemed few studies that asked adults about their awareness of the relationship between sexual dysfunction and diabetes. A mixed-methods cross-sectional survey conducted by Rutte and colleagues (2016) in the Netherlands with adults living with T2DM suggested that while around six in ten men living with T2DM were aware of the connection, none had been informed

by a care provider and many felt their sexual dysfunction was due to ageing, mental health issues or their relationship. The authors acknowledged, a relatively low response rate was achieved from the postal survey conducted (155 returns) and the possibility of selection bias, as adults more open to discuss sexuality were more likely to respond. Nevertheless, this survey provided useful information on sexual dysfunction and highlighted the importance of the issue to men.

### **3.24.2 Prevalence of Erectile Dysfunction and Diabetes**

To understand the extent of the issue, many studies have focused on establishing prevalence and varying rates have been reported. Malavige and Levy's literature review (2009) found prevalence of erectile dysfunction among men with diabetes ranged between 35% and 90% in 10 worldwide studies. Koudrat and colleagues (2017) meta-analysis of 145 studies estimated an overall prevalence of erection dysfunction in men with diabetes was 53%. The authors concluded, prevalence differed significantly by country, ranging from the highest in studies conducted in South America (74.6% - 1 study), Oceania (74.4%; 1 study) and Africa (71.3%; 15 studies) and lowest in studies conducted in the USA (34.5%; 17 studies). While rates varied, there is consistency across findings that have suggested erectile dysfunction is at least three times more prevalent amongst men living with diabetes than the general population (Levy, 2002; Cummings, 2004; Koudrat et al., 2017).

### **3.24.3 Psychological Impact of Living with Diabetes & Experiencing Sexual Difficulties**

Studies that have examined the psychological impact of living with diabetes and sexual dysfunction have been conducted worldwide but authors have suggested that it is still a neglected area (Verschuren et al., 2010; Ramlachan, 2017). Having explored the literature, studies with a psychological focus are patchy and there appeared considerable time lapses between research studies. To date quantitative studies have mainly investigated the association of erectile dysfunction and diabetes with depression (Cummings, 2004; Cummings & Rajendran, 2015), diabetes-specific distress, anxiety (Debono & Cachia, 2007) and quality of life (De Berardis et al., 2005; Malavige et al., 2014).

Cummings and Rajendran's research (2015) has implicated that diabetes doubled the chances of developing depression and highlighted the correlation between depressive symptoms and incidence of erectile dysfunction among men living with diabetes as found by Anderson and colleagues earlier (2001). Koudrat et al's., meta-analysis study (2017) also concurred with this and reported significant positive associations between experiencing

depressive symptoms and erectile dysfunction in men living with diabetes. Research conducted by Ventura and colleagues (2018) on data collected as part of an online and postal survey in Australia with 3,338 adults used a univariate analysis that examined clinical correlations between diabetes, sexual dysfunction and psychological factors; reported sexual dysfunction was significantly associated with symptoms of depression with adults living with T2DM, albeit with small effect sizes.

Research has indicated there is an association between anxiety and sexual dysfunction but the direction and strength reported is variable. Some studies have highlighted that sexual dysfunction gives rise to anxiety and others suggested anxiety preceded the development of sexual difficulties in adults living with diabetes (Corretti & Baldi, 2007; Taştan et al., 2005; Yildiz, 2008). Erden and Kaya (2015) conducted a small-scale study with 150 men living with T2DM in Turkey and found a modest association between erectile dysfunction and trait anxiety whereas a larger study by Ventura and colleagues (2018) found a significant association between sexual dysfunction and anxiety symptoms among Australian adults living with diabetes.

Some quantitative studies have examined diabetes-specific distress and managing diabetes but few have done so in relation to experiencing sexual dysfunction (Ventura et al., 2018). De Berardis and colleagues (2005) conducted a large-scale study in Italy involving 1,460 adults living with T2DM over three years and found erectile dysfunction was associated with higher levels of diabetes-specific distress, a greater number of psychological problems which were experienced at a higher level and lower quality of life than men without erectile dysfunction. Interestingly, a recent study in Australia found diabetes-specific distress was associated with adults with T2DM who endorsed the belief that their sexual dysfunction was a consequence of their diabetes in comparison to others who did not hold such beliefs, but this was particularly so for females (Ventura, et al., 2018). The findings from this study were informative in establishing associations in relation to depression, anxiety, diabetes-specific distress, and sexual satisfaction but as this was an unplanned study, the authors did not use validated questionnaires for sexual dysfunction which they recognised was a limitation. Instead, respondents were asked if they had received a formal diagnosis and as not all adults seek help, they may have excluded potential participants.

The impact on quality of life was examined through a frequently cited cross-sectional observational study in Sri-Lanka. This study involved a random selection of 253 men with T2DM and univariate and multivariate analyses were conducted. The authors surmised that erectile dysfunction was a strong predictor of general quality of life (Malavige et al., 2014). Yet

older men with erectile dysfunction and T2DM reported lower emotional disturbance. The authors suggested older men may accept health issues more easily and cultural and religious factors may feature. In terms of limitations, the authors noted the research was conducted at a single clinic and further prospective studies were required to gain a more thorough understanding of the relationship between sexual dysfunction, diabetes and quality of life and yet since this study little has been published in this area.

#### **3.24.4 Sexual Activity – Frequency, Importance & Satisfaction**

Studies outlined have explored links between psychological impact, sexual dysfunction and living with T2DM, but it is also helpful to understand the role of sex. In terms of frequency, a large-scale worldwide survey indicated fewer adults living with diabetes had sexual intercourse in the preceding 12 months than adults without diabetes, amongst sexually active participants (Nicolosi et al., 2002). Another large-scale nationally represented in-home study in the USA concluded diabetes was associated with a higher rate of sexual inactivity for middle age and older men. While both men and women reported avoiding sex because of problems, the findings also suggested that two-thirds remained sexually active (Lindau et al., 2010).

Fewer studies have asked about the importance of sex and sexual satisfaction. In the same worldwide study (Nicolosi et al., 2002), the majority of men across the lifespan and living with diabetes considered sex to be important in their lives. A study by Bradley and Speight (2002) also found that when participants were asked to rank items that were impacted by diabetes, their sex life was ranked third out of 18 domains of life, surpassed only by dietary freedom and the enjoyment of food. Lower satisfaction levels in relation to sexual ability have been reported by adults with diabetes in comparison to those without (Nicolosi et al., 2002). These findings were supported by an Australian study which indicated 62% of adults with diabetes rated sex as important, but significantly fewer felt they could enjoy it, compared to others living with diabetes but without sexual dysfunction (Ventura et al., 2018). Rutte et al.'s (2016) findings from the Netherlands also implied men living with diabetes and experiencing sexual difficulties (41%) were notably more likely to have reported feeling sexually dissatisfied than women (28%).

#### **3.24.5 Seeking Help for Sexual Dysfunction**

Some men have continued to engage in sexual activity while others have not in the way they would like. As sex is perceived to be important it is interesting to understand what help men may have received. Lindau et al. (2010) conducted a logistic regression on a sub-set of data

from adults living with diabetes as part of a large nationally representative in-home survey on ageing in the USA. He found that men were twice as likely to have discussed their sexual issues with a physician (47%) than women, similarly Rutte's et al.'s (2016) study reported that 41% had contacted a care provider. While other studies have reported far lower rates of help seeking, in the region of 8-10% (De Berardis, 2002; Jiann et al., 2009). Interestingly a large-scale worldwide study indicated 14% of men living with diabetes had discussed their sexual problems with a GP but this is in contrast, to the 35% of men with diabetes who had a medical appointment in the previous month (Nicolosi et al., 2002). Some studies suggested men with T2DM were reluctant to disclose their symptoms to a doctor (Corona, 2016) and reasons cited for this included embarrassment, feeling unusual and unaware of treatments (Jiann et al., 2009; Lindau et al., 2010; Rutte et al., 2016). Other men have indicated that they would like their doctor to initiate a discussion about their sexual difficulties (Jiann et al; 2009; Nicolosi et al; 2002) yet findings in Lindau et al.'s (2010) study suggested only 10% had done so.

#### **3.24.6 Couple's Relationships**

In addition to exploring the psychological impact of sexual difficulties on the self, studies have investigated the impact on the sexual relationship. Rutte and colleagues (2016) indicated that partners expressed dissatisfaction and there was a lack of understanding of the sexual problems being experienced. Conversely, men in the relationship expressed guilt with regards to their sexual difficulties. An early, small cross-sectional study involving 80 couples, described lower levels of satisfaction in the relationship. The men with diabetes and sexual difficulties shared more conservative attitudes towards sex such as openness to sexual experimentation and more negative body image in comparison to men without diabetes (Schivai et al., 1995). Similarly, a later study described lower rates of satisfaction within the relationship and this was particularly so for men (Nicolosi et al., 2002).

#### **3.24.7 Summary**

Important groundwork has been undertaken to establish the prevalence of erectile dysfunction and the importance of sex in men's lives. Several studies have reported associations between psychological wellbeing measures and adults living with diabetes and experiencing sexual difficulties. Using mixed-methods studies and taking account of cultural influences would provide a more thorough understanding of the issues. In terms of limitations, many of the studies did not distinguish between types of diabetes and as many were cross-sectional in design, causation was unable to be established. However, perhaps there is a more important need for longitudinal research to understand the extent and progression of issues over time.

### **3.25 Qualitative Research**

#### **3.25.1 Sexual Functioning & Living with Diabetes**

Turning to qualitative research, as a starting point Stuckey's and Peyrot's (2020) literature review was considered, which explored the lived experience of people with diabetes from 74 studies over the past 25 years. The authors noted that many adults expressed concern about losing sexual function after being diagnosed with diabetes, however, they provided just two quotations and two sources in support of this, leaving it unclear if there were more studies that shared these findings. From a subsequent search of the literature, six qualitative studies have focused explicitly on the experience of sexual dysfunction. Studies have been undertaken in Brazil (Kolling, 2012; Coimbra & Teixeira, 2015), the USA (LeMone, 1993), UK (Jowett, Peel and Shaw, 2012), Sub-Saharan Africa (Cooper et al; 2018) and Sweden (Sarkadi & Rosenqvist, 2003). The studies have included participants living with Type 1 and Type 2 diabetes, both male and female, identifying as heterosexual, gay and bisexual, with some in sexual relationships and others wishing to seek a sexual partner. They seemed to suggest sexual functioning is a concern for men living with diabetes.

A comprehensive qualitative study (Cooper et al., 2018) was undertaken across locations in Malawi and South Africa. Adults living with T2DM participated in focus groups and depth interviews. This study was unusual as sexual functioning was not the intention of the study. Participants were initially recruited as part of a pre-trial evaluation of a sms text messaging initiative that encouraged treatment adherence. However, sexual functioning was mentioned spontaneously and repeatedly by participants that the authors felt it pertinent to pursue, conducting a thematic analysis on the findings and differentiating them by gender (Cooper et al., 2018). The findings suggested that men felt distressed as they experienced considerable changes in sexual functioning since their diabetes diagnosis including a reduction in sexual desire, the ability to obtain or sustain an erection and to ejaculate, all of which they felt limited sexual intercourse. These findings were consistent with quantitative research undertaken by Nicolosi et al., (2002) and Ventura et al., (2018) outlined earlier. The men cited older age as a possible reason for this change and some acknowledged diabetes but were left uncertain and confused over the role it played (Cooper et al; 2018), this was similar to the findings from Rutte's (2016) mixed-methods research.

The men in Cooper's study (2018) described feeling insecure, diminished, powerless and doomed when performing their sexual role. A shared sentiment expressed was that they were no longer real men and they equated this to being a child or friend of their wives. The authors

surmised as the men found themselves no longer being able to meet sexual expectations, they experienced a loss of their masculine identity.

This study also identified conflict and strain within the sexual relationship, communication was perceived to be difficult and so was avoided. Mistrust and accusations of infidelity were embedded in the men's accounts adding to their distress as they expressed fears of abandonment. The authors suggested this may have wider implications in relation to stress and the men's ability to manage their diabetes (Cooper et al; 2018). Quantitative studies have highlighted the negative mutual effects of sexual problems within a sexual relationship, for example Rutte's study (2016) found a lack of sympathy was expressed but did not report mistrust.

A lack of support from HCPs was also raised as key concern by some of the men in Cooper's study (2018). Many felt reluctant to raise the issue and cited embarrassment, and short appointment times. These findings are consistent with quantitative research outlined earlier (Lindau et al., 2010; Jiann et al; 2009). While a few men had sought help, their experiences were generally dismissed and were left feeling blamed and shamed. In terms of a way forward, many of the men expressed pessimism, despair and resignation citing there was nothing that could be done. Acknowledging the complexity of sexuality, the authors concluded their findings go beyond biomedical issues and comprised of psychological and relational influences impacting on gender identity (Cooper et al., 2018). There was a lack of detail about the demographic background of participants, in addition this study was unintended, participants were recruited for different purposes and this raises an ethical dilemma. Being asked to talk about sms text messaging is very different to being asked about a sensitive subject such as sexual difficulties. Nevertheless, by analysing and publishing the findings the authors enabled the men's voices to be heard and this study provided much needed insight into the lived experience of men living with T2DM and sexual difficulties in sub-Saharan Africa.

Jowett, Peel and Shaw (2012) carried out a thematic analysis after an exploration of the lives of gay and bisexual men living with diabetes in the UK and USA through in-depth interviews. Similar, to Cooper's study (2018) the men here were originally recruited as part of a wider study rather than specifically because of their sexual difficulties. Consistent with Cooper's findings (2018) the men in this study were unable to determine the cause of their weak erections and suggested factors such as age or stress. As the men in Cooper's study (2018) spoke of feeling insecure and diminished, likewise in this study the men expressed a loss of confidence and self-worth when engaging with a potential partner. In terms of difference, Cooper's study (2018) suggested there was consistency in the men's voices while in this

study, the authors concluded that the severity of the psychosocial impact was varied, some men were able to manage through medication and others described their social life being killed off, which played a key role in meeting a sexual partner. Interestingly some of men raised frustration with the changing relationship they had with their bodies and its lack of co-operation for example in being able to masturbate. Other unique findings included the men experiences of thrush which limited their sexual activity. While fear had been noted in Cooper's study (2018) in relation to being abandoned by a partner, here it was commonly expressed in relation to many aspects of life including: loss of an erection and loss of attracting a potential partner, gossip in the gay community, experiences of hypoglycaemia when having sex and in relation to discrimination when sexual matters were discussed with HCPs. Further description about the nuances between men who were single and those in relationships would have added to a deeper understanding of the men's experiences.

An ethnographic study incorporated 27 interviews and conducted in Brazil by Kolling (2012), highlighted similar findings to the studies previous reviewed. While change in a man's sexual performance was described as age related, interestingly in this study the impact of being in a long-term marriage was also mentioned. Most of the men talked of a reduction in the frequency of sex rather than in quality. Although there was a lack of clarity over the recruitment processes and it was uncertain if all the men had experienced sexual difficulties. Cooper's research (2018) suggested the men were questioning their masculinity and similarly Kolling (2012) concluded that some of the hesitancy illustrated by the men in talking about their sex life was perhaps connected to the prevailing socio-cultural notions of masculinity within Brazil, where potency was valued and is perceived as an enactment of masculinity. As such speaking about diabetes and sexual difficulties may be associated with stigma. However, Kolling (2012) quoted a participant who talked of feeling diminished, a shared feeling with some of the men in Cooper's study (2018) but here it was spoken about in a broader sense, in relation to the overall impact diabetes was having on all parts of his life including his sex life.

Another Brazilian study (Coimbra & Teixeira, 2015) involved 8 men with T2DM and used thematic analysis and the findings suggested that some men felt a lack of sex was normal and acceptable due to age and as such sex had become less of priority. Conversely, many of the men also spoke of the importance of sex in relation to health, wellbeing and for maintaining a relationship and these findings are in line with quantitative studies highlighted earlier (e.g. Nicolosi et al., 2002). As with Jowett's and colleagues study (2012), fear was also expressed but in this study it was in relation to relying on medication such as Viagra in order to have sex in the future. While there were some interesting findings from both Brazilian studies it was

difficult to get an overall sense of how much the men's lives have been impacted by sexual difficulties and the psychological implications of this.

### **3.25.2 Seeking Help for Sexual Difficulties**

Some men had sought help and were prescribed PDE5Is, but their experiences tended to be negative. They described them as having no effect or being unpredictable, difficult to use and unaffordable, some described fears of side-effects, others felt embarrassed about using them, some considered them unnatural and concerns were raised by partners. Dissatisfied, many discontinued treatment and they described never being asked for feedback about their experience at subsequent medical appointments (Rutte et al; 2016; Cooper et al; 2018; Kolling 2012; Coimbra & Teixeira, 2015). However, one study suggested that for some men the severity of erection difficulties and associated psychological impact became more manageable, but the quantity of the medication prescribed was inadequate for their needs (Jowett, Peel & Shaw, 2012).

### **3.25.3 Summary**

Few studies have explored the psychological impact of living with diabetes and sexual functioning. There appeared considerable time lapses between studies conducted and most standalone. It was challenging to think about improvements to the studies reviewed as many were unintended or formed part of a wider study. Overall, the studies conducted offered much needed insight into the lives of men with diabetes and sexual difficulties. However, some lacked clarity in relation to demographic information of participants and recruitment processes and it seemed participants were seldom recruited because of their shared experiences of sexual difficulties. Nonetheless, given the opportunity the men interviewed seemed keen to talk about sex, illustrating perhaps the impact it was having on their lives. There is now a need to consolidate these findings and help develop a much needed body of research in this area.

## **3.26 Overview of Sexual Health & Diabetes Research with Black Men**

Turning attention now to research with Black men. Many studies have explored Black men's sexual health in relation to sexual identity, sexual risk, substance abuse, and condom use (Jowett, Peel & Shaw, 2012). An extensive body of research has also been developed in the field of HIV, incorporating aspects such as prevention, disclosure, stigma, risk and interventions (Bowleg et al., 2013; Fields et al., 2013; Kelly et al., 2013) Within the field of

diabetes, research with Black men has focused upon healthy-eating, help-seeking, management and coping (DPPG, 1999-2004; Hurt, Seawell & O'Connor, 2015; Dodani & Fields, 2010), and often they are recruited as part of an evaluation of an intervention programme. Studies have predominately been undertaken in the USA and Africa.

### **3.26.1 Brief Historical Overview of Black Men's Participation in Sexual Health Research**

Black men's sexuality is historically, socially and culturally rooted (Alexander, 2010; Bowleg et al., 2017). In sexual health research, Black men have endured negative judgements that endorse racism and stereotypes such as hypersexual, hedonism and permissiveness and their sexuality is often perceived as problematic.

Awareness of historical events are important as it has been suggested that they have subsequently influenced the engagement and participation of Black men in sexual health research studies today (Sherman, et al., 2017), such events as the historical enslavement of African Americans which restricted and regulated Black bodies and behaviours, through violent control (McGruder, 2010; Nagel, 2004). Adding to this, the Tuskegee syphilis experience (1932) in the USA where the Public Health Service withheld treatment and allowed 400 Black men to suffer and, in many cases, die from untreated syphilis (Brandt, 1978). More recently the brutal murder by two White men of young Emmett Till (1955) in Mississippi who was falsely accused of flirting with a White shopkeeper (Pérez-Peña, 2017) and whose funeral was seen to galvanise the civil rights movement in the USA (Till-Mobley & Benson, 2003) and similar events continue to be repeated.

Few studies have showed Black men having a positive attitude towards sex (Bowleg et al., 2017). The way Black men have been portrayed in research has also been criticised for its biomedical and psychosocial emphasis that prioritise the individual while neglecting cultural (religion, spirituality and masculinity) and social-structural contexts (poverty, discrimination, inequality and class) that are influential in understanding the development of Black men's sexuality, health and behaviour (Bowleg et al., 2017; Alexander, 2010; Weber & Parra-Medina 2003).

### **3.27 Quantitative Research – Black Men's Perspectives of the Psychological Impact of Living with T2DM**

There is a paucity of research that has explored how Black men with T2DM experience sexual difficulties. Further challenges were encountered on widening the lens and searching for

studies that examined the psychological impact of living with diabetes in general. Black adults and in particular Black men have rarely been the focus of quantitative research, few studies with large sample sizes were found and those identified did not always distinguish between gender or type of diabetes. Black adults tended to be recruited alongside other minority groups with the intention of joining one homogenous sub-group for the purpose of comparing findings with White participants. Consequently, this section of the review seemed narrow in terms of examining psychological factors associated with diabetes that impact on the lives of Black adults. However, one area that has been reviewed, mainly in the USA is diabetes-specific distress and its associated components and this is explored in more detail in this section of the review.

### **3.27.1 Diabetes-Specific Distress**

Studies that have investigated diabetes-specific distress have consistently suggested that this is a particular area of concern for Black adults living with diabetes. The DAWN2 (Diabetes Attitudes, Wishes & Needs, second study) is a large-scale worldwide study and its objectives were to assess the level of current diabetes care and self-management among adults (Peyrot et al., 2014). The second wave of this study consisted of four parts and research was undertaken with adults living with diabetes, healthcare professionals, family members and of particular interest to this review a supplementary quantitative study was conducted in the USA with adults from four ethnic groups: African Americans, Hispanics, Chinese Americans and White non-Hispanics living with diabetes (Peyrot et al., 2014). The total sample size was 1055 and included 241 African American adults. The authors (Peyrot et al., 2014) used a multi-variate analysis to investigate differences in psychological outcomes such as wellbeing, quality of life and diabetes empowerment between groups. Their findings indicated African American adults experienced significantly higher levels of diabetes-specific distress than White non-Hispanic adults. This is a valuable finding as diabetes-specific distress has been associated with worsening diabetes status over time (Fisher et al., 2010). In addition, aspects of particular concern for African American adults included dietary restrictions, diabetes discrimination, frequent and severe hypoglycaemia and associated worry with this, which all were reported at significant higher levels in comparison to non-Hispanic White participants. These features are important as they contribute to the emotional burden in managing diabetes and overall levels of diabetes-specific distress (Peyrot et al., 2014).

Similarly, a recent quantitative telephone survey with 148 African American adults (65+) in Alabama also investigated diabetes-specific distress and the findings indicated that African Americans in comparison to White adults reported both higher levels of diabetes-specific

distress and this was associated with perceived higher levels of diabetes discrimination (Williams et al., 2020). In terms of limitations, the authors note the study was self-report and as a cross-sectional study unable to report causation. While the sample was modest and participants tended to be female, the findings provided a useful foundation for examining diabetes-distress over the lifespan. A larger earlier USA study conducted with a total sample of 615 adults of which 65% were Black males, concurred with these findings as they found perceived discrimination was significantly associated with diabetes-specific distress and the authors noted that this served as a pathway to influencing quality of life (Achuko et al., 2016).

Perceived severity of diabetes was suggested to be significantly associated with diabetes-specific distress in a smaller in-home survey of 180 African American adults with T2DM in the USA (Spencer et al; 2006). This finding was supported by a later study by Hausmann, Ren and Sevick (2010) who implicated that the severity of diabetes was also significantly associated with both perceived severity of the condition and an increase in interference in daily life for African American adults in comparison to White adults.

Hood and colleagues (2018) investigated diabetes-specific distress and its various dimensions in a mixed-method sequential explanatory study. The first phase comprised of 155 American African urban dwelling adults responding to a postal survey. Unlike previous studies quoted, the authors described finding moderate levels of diabetes-specific distress among participants. However, aspects of this measure yielded different results; regimen-distress rates were moderate to high indicating self-management was stressful and emotional burden scores indicated the need for clinical intervention. Understanding diabetes-specific distress is important as some studies have suggested it can influence glycaemic control, the progression of diabetes and associated complications and can contribute to the development of other psychological conditions including depressive symptoms (Carper et al; 2014).

### **3.27.2 Support – HCPs and Family**

Studies have examined the role of social support and this tends to be split between HCPs and family in relation to influencing diabetes management and diabetes-specific distress. In studies referenced earlier, Williams and colleagues (2020) suggested lower levels of physician trust was associated with higher levels of diabetes-distress. While no differences by gender were indicated for most of the findings in Hood et al.'s study (2018) interestingly, males significantly reported greater levels of physician distress, (this is a measure which refers to the feelings and concerns of a patient not being taken seriously by their doctor) than females. Similarly, Spencer and colleagues (2006) bivariate and multivariate analysis highlighted a lack of physician support and in their research the quality of health services were also significantly

associated with diabetes-specific distress. While a large proportion of the sample consisted of females the findings were not differentiated by gender and this was not mentioned by the authors, although they noted, due to a relatively small sample size, the findings lacked generalisability and possibly inadequate statistical power to detect other significant differences (Spencer et al; 2006). Unexpectedly the Dawn2 study findings highlighted that African American adults were notably more likely to have reported seeing a physician and accessed patient-centred care in comparison to both Hispanic adults and White adults, but again the results were not differentiated by gender. Yet, in the same study African American adults experienced higher barriers in paying for and accessing medication and testing supplies than White respondents (Peyrot et al., 2014). Reflecting on this finding, it would be expected that the benefits of accessing good care may well be negated if treatment cannot be accessed.

The perception of social support has appeared to have strong associations with psychological outcomes (Peyrot et al., 2014). While males reported more physician distress in Hood et al's., study (2018) in contrast they reported notably higher levels of social support from family and friends than females. Perhaps these high scores alongside high levels of engagement in education classes contributed to less interpersonal distress overall, which is a key aspect of diabetes-specific distress, which in turn may have influenced the overall rating of moderate as opposed to high diabetes-specific distress outlined earlier. Williams et al., (2020) also concurred with this, suggesting lower levels of social support were associated with higher levels of diabetes-specific distress. As with many of the studies reviewed, the authors noted caution with interpreting the findings as the sample sizes were modest. African Americans in the Dawn2 study (Peyrot et al., 2014) were notably more likely to have access to larger support networks and also have experienced more family arguments than White non-Hispanic groups, although the findings were not differentiated by gender. The role of arguments appeared complex and not fully understood as it has been suggested that it can improve diabetes self-management for some while creating greater psychological symptoms for others (Grzywacz et al., 2012).

### **3.27.3 Depression**

Findings in relation to the experience of depression amongst Black adults with T2DM did not appear straightforward. Some studies suggested that non-Hispanic Black adults experienced lower rates of major depression than non-Hispanic White adults, yet other studies have found no differences between the two groups (Roy & Lloyd, 2012). A cross-sectional study undertaken with 183 African Americans with T2DM in Baltimore examined psychological factors that may impact diabetes management and found depressive symptoms were

marginally associated with suboptimal levels of HbA1c (blood glucose levels) (Gary et al., 2003). Some authors have suggested depression is common in African Americans and particularly those with T2DM but it can often go undiagnosed and untreated as it is less likely to be reported (Fisher et al; 2004). Research carried out elsewhere has suggested that depression is negatively associated with diabetes self-management (Anderson et al., 2001; Lustman et al., 2000). The findings on depression may suggest Black adults may also express their experiences of mental health conditions such as depression in a different way and it maybe that they possibly connect more with aspects of diabetes-specific distress.

#### **3.27.4 Wellbeing, Empowerment & Quality of Life**

Surprisingly, African American adults who participated in the DAWN2 study (Peyrot et al., 2014) reported significantly higher levels of wellbeing, quality of life, diabetes empowerment and self-rated health than White non-Hispanic adults. African American adults also reported significantly higher levels of quality of life and diabetes empowerment than Hispanic adults and tended to rate their health significantly higher than for both Hispanic adults and Chinese American adults. Conversely as previously described they also reported significantly higher levels of diabetes-specific distress and aspects relating to the emotional burden of managing diabetes. The authors suggested the unexpected results may be due in part to the complexity cultural beliefs which for some can act as protective factors and for others act as risk factors in relation to influencing psychological outcomes such as wellbeing and quality of life. They also outlined limitations namely; online recruitment, reliance on self-reporting, social desirability and the use of individual psychosocial measures rather than fully validated questionnaires. In many ways this supplementary DAWN2 study was ground-breaking by including 4 different ethnic groups and focussing on the psychosocial aspects of diabetes. Yet the findings have created a dilemma, rarely studies have published positive findings in relation to the mental wellbeing of Black adults and they are not a homogenous group, but at the same time the data seemed unexpected and contradictory. It might be that experiences of diabetes-specific distress does not impact upon wider aspects of life, but as there has been absence of replicated studies, the findings remained neither challenged nor endorsed. As such perhaps qualitative research can offer an alternative and more meaningful way to unravel the issues raised.

#### **3.27.5 Summary**

Interesting work has commenced in the area diabetes-specific distress, as it is a complex construct further work and understanding of its long-term impact on the lives of Black adults

is required. It is also important to be mindful that diabetes-specific distress is a term most often used and applied by clinicians rather than individuals experiencing it. Establishing an evidence base is desperately needed through large-scale quantitative studies in relation to managing diabetes as this will enable appropriate treatments to be developed with the aim of improving both the psychological and physical health of Black men living with diabetes. However, having reviewed the literature, it is questionable how meaningful is it to measure psychological variables and compare findings between Black, White and other minority ethnic group participants.

### **3.28 Qualitative Research – Black Men with T2DM**

#### **3.28.1 Black Men’s Perspectives – Psychological Impact of Diabetes on the Self**

In similar vein to quantitative research, there is a lack of qualitative research that has explored Black men’s experiences of living with T2DM and sexual difficulties. Although some qualitative studies have examined what it is like to live and manage diabetes in general in the USA and Africa. The rationale adopted for selecting qualitative studies to review was based upon them predominantly being undertaken with Black men and exploring what it was like to live with T2DM. In addition, albeit briefly, spontaneous reference was made to experiencing sexual difficulties as part of the general lived experience (these findings are given specific attention in the next section).

The progression of diabetes and the development of complications was of key concern for many and frustration, anxiety, and stress were commonly expressed. Shiyabola, Ward & Brown (2018) conducted focus groups with African American city dwellers living with T2DM in the USA. Using inductive content analysis to examine perceptions of diabetes, many of the men described fears of losing their eyesight and the amputation of limbs. Similarly, Bhattacharya (2012) conducted a qualitative study with African American adults living in rural areas with T2DM and explored psychosocial factors that may influence self-management and suggested that fears about amputations developed from the moment of diagnosis. For many of the men this developed into anxiety and progressed into a sense of helplessness as they developed beliefs that negative outcomes were imminent and inevitable. The author suggested the high visibility of people with diabetes complications in the local community may have contributed to the development of such beliefs. In two studies undertaken with African American men in North Carolina, a thematic analysis indicated similar fatalistic beliefs were expressed by some men as well as preoccupied thoughts of early death and disability (Liburd et al., 2004, 2007). Alongside these findings Sherman et al.’s (2014) IPA study explored the

lived experience of African American men living with T2DM and suggested that many verbalised their fears of an early death, disability and complications. While complications were not specifically asked about in the quantitative studies reviewed earlier, severity of the condition was emphasised, and this may well link to fears expressed here.

Across the studies, many of the men described the challenges of daily self-management, it was referred to as tedious, complicated, demanding, relentless and frustrating, requiring regular attention and impacting on overall life (Sherman et al., 2014), this is in contrast to some of the unexpected quantitative findings identified by Peyrot et al. (2014). In the second stage of Hood and colleagues (2018) mixed-method sequential explanatory study, African American men with T2DM participated in focus groups and through an inductive content analysis the authors identified two main areas of frustration for the men; namely diet and medication. The men described their diet being limited, changes required clashed with their cultural traditions and overall sense of identity. Many men also described feeling frustrated and overwhelmed by the complexity and daily requirements of their medication regimen (Hood et al., 2018). Having undertaken focus groups and depth interviews in Tanzania to explore the co-existence of malaria and diabetes, Metta and colleagues (2017) through the use of Grounded Theory also surmised that men were living in a constant state of tension as their daily medication was a constant reminder of both the severity and longevity of their diabetes.

Loss of control was a common theme as the men commented on the controlling and intrusive nature of diabetes on their daily lives (Hood et al., 2018). Yet they also raised concerns about its unpredictable nature (Metta et al., 2017). Unable to see inside their bodies and the damage that diabetes was causing they expressed that they no longer felt in charge (Hood et al., 2018). Bhattacharya indicated that the men in her study (2012) felt responsible for taking care of their diabetes but at the same time perceived themselves to be helpless. In terms of lack of control other men expressed pressures in relation to their diet, blood sugar levels and the development of complications as highlighted earlier (Liburd et al., 2007; Hood et al., 2018).

Connected to the theme of control, for some men, living with diabetes symbolised a loss of independence, men expressed concerns of no longer being able to care for themselves and this had a negative impact on their identity. They described having to rely on others which meant they were no longer responsible to fulfil important roles of provider and carer and instead were left feeling a burden (Liburd et al., 2004, 2007; Metta et al., 2017). In Bhattacharya's study (2012) some of the men talked of giving up and putting their fate in God. Conversely, Liburd et al. (2004, 2007) surmised that men in his studies tried to maintain control at whatever cost even when detrimental clinically. Whereas Shiyanbola, Ward & Brown (2018) suggested the men in their study experienced a shift of locus of control, from feeling able to

influence diabetes outcomes to blaming outside evil forces for their condition, leaving the men with a sense of powerlessness in relation to their life.

A few men commented on the benefits of being diagnosed and described it as a wake-up call, an opportunity to embrace a new approach and expressed a sense of empowerment to successfully manage their diabetes (Liburd et al., 2004, 2007). Interestingly, empowerment featured prominently in the worldwide quantitative research undertaken by Peyrot et al. (2014).

### **3.28.2 Relationship with Others**

In many studies, friends, family and the community were viewed as critical support, offering encouragement and helping with the demands of self-management (Liburd et al., 2007; Sherman et al., 2014; Hood et al., 2018). However, some men spoke of disconnection, feeling distressed as they felt no longer able to bond with family and the community through the sharing of culturally relevant food (Bhattacharya, 2012; Metta et al., 2017; Shiyabola, Brown & Ward, 2018). In some ways these findings align with those from the quantitative research which reported relatively high levels of social support and large networks but also the tendency to have arguments.

In several studies, men talked of having kept their diagnosis confidential as they feared being gossiped about and ostracised, others did not want sympathy or to be perceived as sick person by the community (Bhattacharya, 2012; Liburd et al., 2007). Linked to autonomy outlined earlier, Liburd and colleagues (2007) suggested some men placed limits on the social support they would accept in an attempt to retain some control.

### **3.28.3 Summary**

Some of the men seemed preoccupied and fearful about the progression of the condition and what this would mean for them, while also facing challenges associated with daily management of their diabetes. The studies provided insight into how being diagnosed with diabetes impacted upon the self and encompassed their wider lives. While discrimination featured in the quantitative findings, it was noted for its absence here. Mapping and connecting the findings from quantitative and qualitative studies was not a smooth process. Research findings from different types of studies tend to stand alone, it would be useful if there could be more collaboration between the two areas, not in relation to how the research is carried out but in terms of the issues that are explored as this would enhance understanding and help provide a more in-depth view of life with diabetes.

### **3.28.4 Black Men's Perspectives – Living with T2DM & Sexual Difficulties**

When Black men living with T2DM were asked about their lived experience in general, as part of this conversation, some referred briefly to their experience of sexual difficulties. Authors represented their voices by incorporating one or two quotes within their overall findings and these are considered below.

Gaining and sustaining an erection and a decrease in sexual desire were commonly expressed experiences of the men in some studies (Liburd et al., 2007; Shiyabola, Ward & Brown, 2018) and for some this was noticed soon after being diagnosed (Metta et al., 2017).

Fear of developing sexual difficulties was expressed in two studies (Sherman et al., 2014; Walker, 2018) and this was felt by men regardless of how well their diabetes was managed (Sherman, et al., 2014). Walker's (2018) thematic analysis explored the lived experience of African American men over 40 living with T2DM in South Carolina suggested that this fear was a key motivator for making changes. Findings from supplementary in-depth interviews with HCPs concurred with this, as sex was perceived important in the men's lives and Walker (2018) suggested this was used as a fear tactic by staff to motivate men to change their relationship with diabetes.

Some of the men expressed dissatisfaction, frustration and dismay as diabetes impacted their sex life and they found themselves unable to sexually satisfy themselves or their partners (Liburd et al., 2004). The author suggested this left the men feeling diminished and some expressed a desire to return to the past before their diagnosis. Akin to feeling diminished, a thematic analysis following focus groups and depth interviews with men in Uganda suggested that diabetes had weakened their manhood (Mayega et al., 2014). A similarly designed but later study conducted by Mayega et al.(2018) suggested that when some men talked of their sex life they described a loss of manpower and gave the impression of lost hope. Concurring with this, a sense of lost hope and powerlessness was shared by some men in another study when discussing their sexual functioning (Metta et al., 2017).

Relationship difficulties were commonly referred to in connection with sexual difficulties. Some men described marital stress and conflict and seemed fearful about the possibilities of infidelity, separation and divorce (Liburd et al., 2007, 2014; Mayega et al., 2014). Men described no longer receiving attention from their partner in the way they once had and their relationship had become infantilized due to their partners involvement in the management of their diabetes and experiencing this loss of autonomy impacted on both their sexual relationship and sexual identity in Shiyabola, Ward & Brown's study (2018). Some also expressed fears about the community finding out and felt their lives would be ruined as a consequence. Early indications suggested

sexual difficulties not only impacted the self, but also relationships and the identity of the men within the community (Metta et al., 2017).

There is lack of knowledge about the treatment preferences of Black men living with T2DM and experiencing sexual difficulties. However, they have expressed their preferences for managing their diabetes in general and this potentially offers some insight. Previous findings have suggested that some like to take control of their treatment regimen and adjust it to meet their needs. Some also raised concerns over taking medication daily and sometimes alternatives such as over the counter medication and herbal remedies were preferred. The importance of God as a healer, guider and protector was also stressed by other men (Bhattacharya, 2012; Liburd et al., 2007; Shiyabola, Brown & Ward, 2018).

### **3.28.5 Summary**

Sexual issues seemed to be important as authors included them within their overall findings but without providing analysis or commentary, further research is needed to fully understand the impact and meaning for Black men living with sexual difficulties with T2DM.

### **3.29 Relevance to Counselling Psychology**

This review has explored the psychological impact of living with diabetes and experiencing sexual dysfunction. The aim of this was review was to develop an understanding of how Counselling Psychology could support the psychological wellbeing of Black men living with T2DM and experiencing sexual difficulties. Distress has been expressed by Black men regarding the daily management of diabetes and dissatisfaction with pharmacological treatments prescribed, yet specific references to psychological treatments were noted for their absence. By undertaking research in the area of diabetes and sexual difficulties with Black men it is hoped that awareness of the issues raised can be shared with other Black men living with T2DM and healthcare professionals involved in diabetes care.

Diabetes is complex and challenging and it is vital Black men gain confidence and skills to cope with the daily demands of self-management while being able to adapt to a lifelong cycle of changes if complications occur and psychological support can play a larger role in this. Counselling Psychologists are well placed to offer caring, non-judgemental and positive psychological services, giving space to process the impact of living with the condition and its associated stressors. We can also help develop and support the empowerment of Black men with T2DM to engage proactively with other services, giving them a voice by demanding the care they deserve. Learnings can also be shared with colleagues to support them in patient interactions to help readdress health inequalities.

A final dilemma is the role of psychological well-being and its relationship to glycaemic control and self-care. While not overtly expressed, there is a sense within the literature, that if psychology is to be considered a serious alternative to traditional pharmacological interventions it needs to establish its impact in these areas of diabetes. Perhaps this tension is related historically to the substantial influence of biomedical research in the field of diabetes, although it too faces ongoing challenges on the same outcomes. Counselling Psychologists in their dual role of Scientist-Practitioner would be well placed in facilitating a new debate, unravelling the issues associated with glycaemic control and how this sits with psychological work, identifying improvements that can be made to models and thinking about how treatments can be evaluated in a more meaningful way.

### **3.30 Conclusion**

#### **3.30.1 Relevance & Importance of Proposed Research Study**

Across the literature, research studies tend to open with a statement that has included data on the prevalence of diabetes, the cost in managing diabetes and associated complications to healthcare services and reference is made to early death. I found myself following this set precedent, yet despite the consistency in reporting this harrowing data, there seemed to be a disconnect with the reader and somehow it lacks penetration, unable to gain traction with people who can influence and deliver change. So perhaps an alternative approach is needed, bringing the personal accounts of Black men living with diabetes to the fore might help the reader to connect and develop an understanding of what it is like to live with diabetes and experience complications and maybe this can be a starting point to facilitate a discussion around change in terms what type of care and psychological support can be offered and the impact this can have in helping people with T2DM lead a fulfilling life.

This review adopted a wider lens, focussing on the general lived experience of diabetes as relatively few psychological studies exploring the impact of sexual difficulties amongst Black men with T2DM had been conducted. From the few studies undertaken it seemed that sex was important, and sexual difficulties created distress and impacted upon relationships for some men and not all sought help. While studies have been conducted worldwide, most standalone.

Turning specifically to research with Black adults, if health inequalities are to be addressed there is a desperate need to establish an evidence base on the psychological impact of living with T2DM in the UK as there is a lack research and studies predominately have been undertaken in the USA or Africa.

Research that has been conducted on the lived experience of Black men with diabetes has tended to produce some wide-ranging but consistent themes such as the challenging nature of managing diabetes and fear associated with complications but there is a need for nuanced work with more symmetry between quantitative and qualitative studies in terms of similar issues being explored but through different approaches, so learnings can be shared.

While gaps across the literature have been identified, this study hopes to attend to one aspect that is sexual complications associated with diabetes. There have been few in-depth qualitative studies understanding the experiences of living with diabetes and sexual difficulties but none in the UK that solely focus on Black men with T2DM in a sexual relationship and it is hope the insight generated from this research will add to the existing body of work.

## **4. Chapter Two: Methodology**

### **4.1 Chapter Overview**

Within this methodology chapter, I have discussed the rationale for adopting a qualitative approach and choosing Interpretative Phenomenological Analysis and as part of this I considered the philosophical assumptions that underpin my research. In the latter part of the chapter, I have provided a detailed account of the way the data was collected and analysed and throughout I have included my personal reflections on undertaking this study, from the initial conception stage through to the interactional relationship with participants, culminating in the completion of the analysis.

### **4.2 Research Aims**

By carrying out this study it is hoped more knowledge and a deeper understanding would be developed about what it was like to experience sexual difficulties for Black men living with T2DM in sexual relationships. The findings intend to be shared with colleagues across the health discipline and as this is an exploratory study it is hoped it will act as building block for further studies in this area.

### **4.3 Rationale for Using Qualitative Research**

In terms of methodological considerations there has been a longstanding debate about the merits, values, scientific status and limitations to both quantitative and qualitative paradigms within the psychology field (Rawson, 2011). Traditionally a quantitative hypothetico-deductive approach relying on linear causal models was favoured, but there have been calls to replace or supplement this with a more qualitative, discovery oriented, non-linear approach to research (Seale, 1999; Barker, Pistring & Elliott, 2002; Silverman, 2006). Despite this debate, Randomised Control Trials (RCTs) appear to remain the gold standard within the health domain, although the qualitative paradigm fits well within the field of Counselling Psychology that values the uniqueness of individuals, inclusion, diversity, and the subjective and intersubjective experience.

Qualitative methodologies are a broad class of approaches designed to describe and interpret experiences in context-specific settings. Their advantage includes being able to explore more complex aspects of an experience in depth without being constrained by a hypothesis. They can also provide a rich and detailed description of a phenomena captured from the participant's viewpoint (Barker, Pistring & Elliott, 2002; Smith, 2003; Breakwell et al., 2010; McLeod, 2011). However, they have also been criticised for having too many distinct

frameworks with their own philosophical assumptions and terminologies, being unsystematic, limited in terms of theorizing (Barker, Pistring & Elliott, 2002) and for using small sample sizes which suggests the findings cannot be generalised to wider populations and hence the impact of qualitative research for some might be perceived as somewhat limited (Wadeley, Birch & Malim, 1997). Yet, the qualitative researcher considers many of these criticisms to be benefits, associated with undertaking qualitative research. Having a variety of philosophical frameworks to choose from gives the researcher freedom to select the most appropriate one to address the research question (Willig, 2013). By placing the individual and their experience at the heart of the research process the qualitative researcher aims to obtain a holistic and in-depth understanding (Guba, & Lincoln, 1994) while the development of a universal theory can reduce the complexity and multifaceted nature of the human experience and therefore holds little interest (Liamputtong, 2013). From my experience, qualitative researchers do not tend to claim their research findings can be generalisable, but the audiences who read and engage with the findings might well assume this, especially over time if findings get quoted out of context.

In terms of my own stance, over the last 20+ years working across housing, health and environmental sectors, I am aware of demand from colleagues, stakeholders and Government, for large-scale, robust and representative quantitative studies. Each time, the results show inequalities across, class, income, gender, education and ethnicity and yet little changes. When I have been able to convince others to adopt qualitative methodologies, a quote that expresses a feeling, or an experience or 'just tells it how it is', hangs in the air. While future change remains slow, it appeared to pack more of a punch.

The research question I am asking needed to capture the real worlds of participants in their own words and to do so required deep, rich and meaningful information and qualitative research methodologies are favoured because they are open ended and give people a voice (Ussher, 1999; McLeod, 2012; Scotland, 2012). The research field of diabetes is vast and traditionally there has been an emphasis on conducting quantitative research. There have been numerous quantitative studies highlighting how to improve control and the day to day management of living with diabetes. While some progress has been made, people living with T2DM continue to struggle with the day to day management of their condition and the number of people with living with T2DM is rising. There remains a gap in knowledge about what it is like to experience complications associated with T2DM and particularly in relation to sex. Therefore for this study, I have adopted a qualitative research design because I am interested in how Black men with T2DM experience sexual difficulties while in a sexual relationship, "with the aim to give a voice to those who tend to be marginalized' (Willig, 2013, p11) in a way that quantitative methods could not.

## **4.4 Philosophical Framework**

A paradigm is a belief system, it is made up of ontological, epistemological and methodological assumptions that are interrelated (McLeod, 2012; Scotland, 2012.) and provides a framework in order to guide the researcher about the social world (Guba & Lincoln, 1994; Denzin & Lincoln, 2000b) and this thus influences the development of the research question and how best it can be addressed (Hesse-Biber, 2007).

### **4.4.1 Ontology**

Ontology refers to beliefs about the nature of reality, i.e. what it is (Guba & Lincoln, 1994) and these assumptions are the starting point for any research study (Willig, 2012). Ontology operates along a continuum from realism to relativism and the researcher's ontological positioning determines the system used to gain knowledge. A realist ontology advocates the existence of one true reality, involving cause and effect relationships between objects (Willig, 2013), unconnected to human beliefs and behaviour. Research is approached in an empirical, objective and measurable way in order to ascertain the "truth" about reality that it accepts exists and in order to achieve this, favours traditional scientific methodologies found within a quantitative paradigm (Ponterotto, 2005). At the opposite end of the continuum, we find relativist ontology which subscribes there are multiple constructions of reality that exist, influenced by individual experiences, relationships, social worlds and contexts. Relativist ontology is concerned with the meaning of the individual experience and as each individual has their own reality their perspective can be developed using a qualitative research paradigm. However, Willig (2016) has suggested that when undertaking a qualitative research study, rather than being completely separate, realism and relativism ontologies are interwoven. Willig highlighted that with regards to IPA this might be reflected in the kind of research question that is posed by the researcher which can identify realist aspirations. For example by wishing to explore a particular phenomenon that has ontological status this suggests the researcher feels or assumes that it already exists in some format, as a mental, emotional or experiential structure and it would continue to do so regardless of whether an individual participated in a research study and shared their experience of it with a researcher. However, acknowledging this independent existence of a phenomenon does not mean the researcher can gain direct access it or provide an exact picture of what it is like, nor does it imply that there is only one universal truth about it, one interpretation of it or one way to make sense of it (Willig, 2016).

Thinking about my own research topic as a starting point my ontological position is one of critical realism. Critical realism (Bhaskar, 1978) adopts a realist ontology which posits that there is a stable and enduring feature of reality that exists independently of human

conceptualisation. In this study, I perceived diabetes and sexual difficulties to be 'objective' and 'real' conditions, in the sense they exist independently (Maxwell, 2011). Adopting this stance, I do not believe takes anything away from the experiences, interpretations or meaning making made by the participants, as critical realists also acknowledge that there is an inherent subjectivity in the production of knowledge (Madill et al., 2000). I interpret this as relating to the different meanings and experiences that participants ascribe to their 'objective' conditions (diabetes and sexual difficulties). This is considered possible because they experience different parts of reality which means that they can make sense of their diabetes and sexual difficulties in radically different ways (Willig, 2008). Adding to this, the way a participant perceives their 'objective' conditions particularly in the social realm is shaped and influenced by their thoughts, beliefs and expectations (Willig & Stainton-Rogers, 2008). By adopting a critical realist approach this means that different viewpoints of the participants can provide different understanding of the same phenomenon (Willig, 2001) and enhance the researcher's and others understanding of the topic. However, with regards to the participants data, from the critical realist viewpoint, this can tell us something about the reality of a participant's world but it is not viewed as 'direct mirroring' (Harper & Thompson, 2012), and as such the researcher is unable to fully access their world or provide a neutral account of it.

#### **4.4.2 Epistemology**

Epistemology is the study of knowledge and is concerned with how it is created, justified and evaluated (Schwandt, 2001) and is driven by ontological beliefs. Epistemology inquires about the relationship between the knower (the participant) and the would be knower (the researcher) (Guba & Lincoln, 1994; Ponterotto, 2005) and this influences how researchers go about finding out the knowledge and comprises of what methods are used, how they are used and what questions are asked.

Turning now to my research which aims to explore the experience of sexual difficulties of Black men with T2DM who are in sexual relationships, and considering my own assumptions made about the world, this has been shaped by a critical realist standpoint. Critical realism has been perceived as 'radical' and offering something different to the well-established paradigms of positivism and interpretivism (McEvoy & Richards, 2006). Critical realism locates itself somewhere between realism, that asserts results materialise from data and relativist beliefs that experience always involve an interpretative quality (Madill, Jordan & Shirley, 2000). In terms of reality, it assumes the world is differentiated by three key modes; the real, the actual and the empirical. The real consists of causal structures and mechanisms which generate phenomena, they may not be apprehended directly, as may not be available for observation but can be inferred. The actual, represents events that occur but may not be experienced or

interpreted. Finally, the empirical suggests a reality that is experienced by individuals either directly or indirectly. (Bhaskar, 1975, 1978; McEvoy & Richards, 2006; Hordyk, Soltane & Hanley, 2014).

Reflecting on my epistemological position and the knowledge that I hope to produce (Willig, 2008), the aim of this study is to explore and develop a deeper understanding about the sexual difficulties experienced by Black men with T2DM, in collaboration with my participants. In addition, I want to share the knowledge generated with others in the public health sphere. Within a critical-realist paradigm, the researcher's values and assumptions are acknowledged, as they will influence the focus and process of the research and interpretation of the data (Denzin & Lincoln, 2000b; Scotland, 2012; Parr, 2015). The findings produced are also dependent on the interaction and relationship with the participants.

I am aware of the influence of my own assumptions that impact on all aspects of this research study and that have been shaped by social, political, cultural, economic, ethnic and gender values (Denzin & Lincoln 2000b; Ponterotto, 2005). This comes from many years working with groups often defined as "hard to reach", and disenfranchised groups, without a voice. Although, I realise that these are my assumptions about the world and they may not reflect my participant's world in this study as they may experience different parts of reality and attach different meanings to their own experience.

Taking time to consider the knowledge I hoped to produce has been important and coincides with my critical realism stance where no methodological inquiry is favoured over another as the main priority is to answer the problem.

## **4.5 Methodology**

Methodology includes the description, explanation and justification of methods rather than about the individual methods themselves (Carter & Little, 2007; Rawson, 2011). Epistemology informs and modifies the methodology (Carter & Little, 2007).

### **4.5.1 Rationale for using Interpretative Phenomenological Analysis (IPA)**

This study adopted Interpretative Phenomenological Analysis (IPA), (Smith, 1996) as its methodological approach. IPA is a qualitative methodology with philosophical underpinnings in phenomenology, hermeneutics and idiography (Eatough & Smith, 2017).

IPA adopts an open stance, it does not claim a distinctive epistemological position. IPA's lens are directed at a research participant's phenomenological account and this is the focal point for all studies (Larkin, Watts, & Clifton, 2006). In line with a critical realist stance, IPA is centred

around open ended questions that generate rich and detailed descriptions covering issues of significant consequence for the participant (Breakwell et al., 2010) and it is expected that their accounts will tell us something about their private thoughts, feelings, beliefs and expectations that has shaped their experience (Willig & Stainton-Rogers, 2008).

#### **4.5.2 Phenomenology**

IPA's approach is phenomenological; concerned with understanding the experiences of an individual and interpretations of their world. Modern phenomenology was developed by Husserl (1931-1982) and its aim was to describe the meaning of the lived in experience of a phenomenon (Starks, & Brown-Trinidad, 2007), getting as close as possible and looking at the world in 'their eyes', uncovering the essence, in its totality (Willig, 2008). Husserl acknowledged the value of reflection and the bracketing of assumptions about reality (Smith, Flowers, & Larkin, 2009) while attempting to capture the essence of an experience. In order to achieve this the researcher has to lay aside their preconceived beliefs and assumptions and explore the phenomenon in an open and neutral way so it could be understood and then described in an unprejudiced manner (Dowling, 2005). Heidegger (1962), a student of Husserl, queried the scope to which a phenomenological approach could produce knowledge that captured the very essence of the phenomenon under investigation. Later, Smith's approach to IPA seemed to dilute Husserl's approach further as it aimed to discover "particular experiences as experienced by particular people" (Smith, Flowers, & Larkin, 2009, p16) rather than the very core of an individual's experience, acknowledging that the individual's experience cannot be directly entered into by the researcher nor can the researcher completely experience the phenomenon as the individual does. While acknowledging these difficulties, Smith's IPA still endeavours to uncover the individual's experience of the phenomenon from their perspective (Smith, Flowers, & Larkin, 2009).

The aim of this study is about knowledge generation in relation to the meaning and subjective experience, to understand what it is like to live with T2DM and experience sexual difficulties, how it makes a Black man feel and the impact it has on his sexual relationship with his partner and with others, by stepping into his world, while taking into consideration the limitations of being able to do this as outlined above by Heidegger and Smith and so my epistemological stance is also a phenomenological one (Willig, 2013). Phenomenology is aligned with my critical realist standpoint as the knowledge this study aims to produce, accepts there is more than one reality, more than one world and more than one way to experience an event (Willig, 2013). While phenomenology aims to capture the richness, the quality and the depth of an individual experience, it is not ideologically driven (Kvale, 1996). Phenomenology can produce

culturally, critical and emancipatory knowledge, but its focus is not on causes or processes (Willig, 2008).

### **4.5.3 Hermeneutics**

IPA is heavily influenced by hermeneutics, the study of interpretation (Eatough & Smith, 2017). While phenomenology focusses on uncovering the meaning, hermeneutics is about interpreting the meaning of the phenomenon under investigation (Bäckström & Sundin, 2007) and this distinguishes IPA from other phenomenological approaches in psychology such as descriptive phenomenology (Giorgi, 2009). Descriptive phenomenology aims to capture the experience as it is presented at face value and advocates an approach whereby interpretation is minimised (Giorgi & Giorgi, in Willig (ed.), 2013). This thus requires the researcher to adopt a phenomenological attitude which entails here, the bracketing of all past knowledge about the phenomena under investigation. While I support Giorgi's approach for portraying the experience naturally so as not to subtract or take anything away from it as a researcher, I am more at ease with having one step outside this experience, by considering the social, cultural and psychological meaning and using IPA will allow me to understand a participant's experience by relating these to wider constructs (Willig, 2013).

In contrast to Giorgi, Heidegger (1962) suggested that interpretation by the researcher was an integral part of the phenomenological process as the phenomenon being investigated can have concealed and unobvious meanings, as if under the surface and the researcher is required to examine both the noticeable as well as the veiled. As the bracketing of presuppositions was perceived to be unachievable, Heidegger instead advocated the researcher examined them, be open to them and make them apparent (Heidegger, 1962). He suggested that as researchers investigate, engage and interpret an individual's account with existing "fore- conceptions" that it may only be afterwards that they surface and the researcher becomes fully aware of what they are (Smith, Flowers, & Larkin, 2009). Willig (2013) also suggested it was virtually impossible when examining an account not to interpret and she proposed that all description in IPA comprises of some type of interpretation as comprehension cannot be made without the researcher making some preliminary assumptions about the meaning they are trying to uncover.

The impact of a researcher's prior understanding when examining new phenomenon was also of interest to Gadamer (1975), he highlighted the hermeneutic process, and suggested that the phenomenon under investigation influenced the interpretation made by the researcher which in turn can influence the "fore-standings" or presumptions the researcher already holds, which then in turn can further influence the interpretation (Smith, Flowers, & Larkin, 2009). The researcher can have many "fore-standings" which are continually attended to and

reviewed during the interpretation process as they come to forefront during the process of interpretation but are also realised afterwards. Gadamer, suggested by carrying out interpretation, through the hermeneutic process the researcher-the would-be knower, can reach a greater understanding of the phenomenon but this will never reach the level of the individual - knower.

Gadamer (1975) acknowledged that bringing a new interpretation to the forefront involved a complex interaction between the researcher as the interpreter, their assumptions and the interpreted and their account. His perceptions alluded to those of Heidegger's and the influential hermeneutic circle which identified the active relationship between the "part and whole". (Schleiermacher, 1998). In the course of meaning making it was suggested that "parts can only be understood from an understanding of the whole, but that the whole can only be understood from an understanding of the parts" (Schmidt 2006, p4 as cited in Willig, 2013, p86) In other words, to understand something in its entirety, the researcher needs to make sense and understand all the component parts that make it up. However, the researcher is unable to make sense of the phenomenon by examining the component parts in isolation as they may hold different meanings and so the researcher needs to access the whole phenomenon in order to do this, and understanding and sense making involves a circular movement, transferring back and forth between the two (Willig, 2013). My initial attempts at drafting emergent themes as part of the analysis process were too brief, enigmatic and did not capture the essence, these 'parts' seemed very much divorced from the 'whole' of the participant's account.

In terms of the types of interpretation, Ricoeur (1970) differentiates between two interpretative stances: hermeneutics of empathy and hermeneutics of suspicion. Eatough & Smith (2008) also recommended the implementation of 2 distinct levels of interpretations. The first level is aligned with hermeneutics of empathy and this is where most interpretations are made as they are grounded in the text and the researcher attempts to interpret in a descriptive and empathic way when trying to access the participant's world. The second level of interpretation always comes after the first and is more cautious, conjectural and explorative in its nature, as it comprises of the interrogation and questioning of a participant's account by the researcher with the aim of achieving further understanding into the meaning and origin. Smith talks of the hermeneutics of suspicion as permitting the researcher to make suggestions which the participant may not have been able to do or is willing to do. Making use of these two forms of hermeneutics facilitates a richer and deeper analysis, taking into consideration the totality of the person (Smith, Flowers, & Larkin, 2009). I felt apprehensive and unsure when making interpretations as I moved away from being grounded in the participant's data and I described

these moments as feeling 'wobbly', being on 'shaky ground' and 'fraught with danger' in my reflective diary (Appendix I). This process of making interpretations also highlighted the difference between being a therapist and researcher, as here I did not have the opportunity to check out my interpretations and understanding with the participants, which I would have been able to do in the therapy room.

In summary, IPA acknowledges the dynamic role of the researcher and the access and exploration of an individual's detailed inner world depends on and is also complicated by the researcher's own ideas, values and beliefs and something that she is unable to be disentangled from. This mirrored my experience, and this particularly came to the fore when I carried out the analysis and it felt troublesome. On the one hand, I had an insider's knowledge of diabetes [REDACTED] and [REDACTED] I felt emotionally connected to and on reflection my closeness to the subject matter meant I did not question further the meaning of responses in the interview room. Yet, on the hand I did not know what it was like to be a Black man experiencing sexual difficulties and at times I felt very lost and distant especially when re-reading the men's transcripts and trying to make sense of their experience. As part of this process, I felt drawn to highlighting parts of the men's experiences that were completely different to my assumptions and expectations, for example one of the reasons I was interested in researching Black men for this study was because I held the assumption that Black men would be less likely to engage in health services, but my participant's experiences showed this was not to be the case.

Willig (2013) has suggested far from having a negative impact on the research, the researcher's assumptions and prior experiences can expand and deepen the understanding and knowledge if they are worked with. These are also required in order to make sense of the participant's personal world which is through a two-stage process or double hermeneutics, whereby the participant is trying to make sense of their own world and the researcher in turn is trying to make sense of the participant trying to make sense of their world (Smith, 2003; Smith, Flowers, & Larkin, 2009; & Smith, 2010). The theory of double hermeneutics highlights the significance of the researcher's role in the research process and the construction of meaning and IPA involves examining both oneself as the researcher and the research relationship (Smith, Flowers, & Larkin, 2009).

#### **4.5.4 Idiography**

A third key component of IPA is idiography, relating to or concerning something, individual, unique, the particular. The researcher engages with the data collected on a case by case basis in a thorough, rigorous, and comprehensive way in order to reflect the uniqueness of an individual's experience. The same detailed attention is given by the researcher to each

participant's lived experience separately (Smith, Flowers & Larkin, 2009), in order to produce understanding and learning that reflect the substance and depth of an individual experience (Willig, 2008). This is achieved by only integrating individual cases at a much later stage of the analysis process.

IPA's idiographic nature is unique and it is not interested in interviewing a range or diverse populations (Starks & Brown-Trinidad, 2007) and is therefore well suited to small purposively select samples. This idiographic perspective is distinct from the prevailing nomothetic approaches favoured historically in the field of psychology that endeavour to determine laws about human behaviour. However, IPA's dual emphasis should not be overlooked and while its focus is on the unique characteristics of individual participants it also looks for patterning of meaning across participants, for both similarities and differences (Smith, Flowers & Larkin, 2009).

#### **4.6 Limitations of IPA**

A limitation of adopting an IPA approach is that in the current economic and political context there is a focus on being able to generalise and apply the findings. This is not possible with IPA as the focus is on understanding and exploring the phenomenon to gain more knowledge. However, Smith and colleagues point out, that findings from IPA research may have "theoretical transferability rather than empirical generalisability" (Smith, Flowers & Larkin, 2009, p51). Learning from one account to another of the same experience, the researcher may gain an understanding of a more general experience and in this way IPA findings can shed light on existing nomothetic data (Smith, Flowers & Larkin, 2009).

While IPA does give the participant a voice, it recognises the limitations in that individuals can struggle to express their thinking and feelings and also may not wish to self-disclose. As IPA relies heavily on the language of the participant to communicate the rich texture of their experience, the researcher may learn more about the way an individual talks about their experience within a context than the experience itself.

IPA and qualitative research in general is much more demanding for a participant, being asked about the meaning of a personal experience can be challenging to answer and particular so if participants are unfamiliar with qualitative research and the interview format and this is complicated further by discussing a sensitive subject matter. Their involvement requires deeper engagement and contemplation than a quick yes or no or ticking a box on a questionnaire as required in quantitative research.

## **4.7 Alternative Approaches**

As part of the rationale for justifying the use of IPA in this study, other approaches were considered.

### **4.7.1 Grounded Theory**

Grounded theory refers to both the method of analysis of the data as well as the theory that it produces (Barker, Pistring & Elliott, 2002). There have been many changes since it was first introduced by Glaser and Strauss (1967) as a set of principles to a more formalised and specified set of procedures (McLeod, 2012). The aim of grounded theory is to uncover the basic social processes that underlie behaviour (Smith & Osborne, 2003; McLeod, 2012). Grounded theory would be suitable for a number of reasons and it has been used by researchers with various theoretical perspectives. There are similarities to phenomenology in terms of data collection, the interview schedule and analysis (Starks & Brown-Trinidad, 2007). The researcher becomes immersed in the data and focuses on capturing the essence of the phenomenon and the experiences of these (Barker, Pistring & Elliott, 2002) and obtaining thick and rich descriptions (Smith, 2003). From a critical realist point of view, I think that the goal of producing an explanatory model fits with my research, because it may lead to the development of interventions. But it is unclear from my research project whether my phenomenon exists, hence an exploratory study is being recommended to investigate this.

There are some additional issues with a grounded theory approach, it requires saturation of the sample which is time consuming and the focus on sampling different conditions and experiences which does not sit with the aims of my project of working with a particular group of people to get their voices heard and in doing so valuing the uniqueness of the individual voice as equally as the group voice, paying particular attention to both subjective and intersubjective experiences (McLeod, 2012). My study feels like the building block which may lead to a Grounded Theory study.

### **4.7.2 The Narrative Approach**

As an alternative to IPA, narrative analysis was also considered. Narratives are concerned with how individuals make sense or bring order to an ever-changing world and how the stories connect to experiences. Bruner (1986/1990) introduced two forms of thinking, paradigmatic which refers to a science-based classification and narrative, everyday interaction and interpretation of the world which can either be real or imaginary, suggesting the existence of more than one reality. The appeal of a narrative approach is the focus on everyday social interaction, and how someone positions themselves within their story and develops an identity.

There have been some studies which link individual narratives to societal and social cultural ones, which also appeal to a critical realist. Narrative analysis covers a wide spectrum of methods and like IPA is interested in uncovering the meaning of experience and the interpretation of events (Riessman, 2008; Willig, 2008). However, narrative analysis also, seems to go beyond IPA in the sense that it is interested in how something is talked about, what is being talked about and why it is being talked about (Squire, 2008). As little research had been carried out previously with Black men with T2DM experiencing sexual difficulties, it felt important as a first step to solely focus on one aspect of my participant's experience in order to gain a better understanding and uncover the meaning of their subjective experience was of primary concern and an IPA approach was chosen on this basis. However, undertaking narrative analysis seems a logical next step in the future once the findings from this study have been established.

Finally, it is intended for the findings from this study to be shared with others working across the health spectrum in order to raise awareness and as little is known about the subject area it is hoped that others can become closer to the lived experiences of those participants and for this purpose IPA seemed more suitable.

#### **4.8 The Data Collection Procedure**

Having decided to take an IPA approach, I outline below the processes carried out as part of the data collection procedure.

##### **4.8.1 Methods – The Semi-Structured Interview**

Methods are the practical tasks carried out in order to collect and analyse information (Mcleod, 2003, 2012), they are pathways to the final research product and produce data that informs knowledge (Carter & Little, 2007), and the semi-structured interview is one path that can be taken. Semi-structured interviews with open-ended questions (Breakwell et al., 2010) are advocated within IPA because they enable the interviewer to stay close to the lived experience, allowing inner thoughts and feelings to be explored and show the problem from inside out (Willig, 2001; Smith, 2003, 2010).

Interviews are economical (Kvale, 1996; Seale, 1999) and in line with a critical realist slant questions are open-ended enabling participants to express their views and share their experiences without constraints. I have one interview, to delve deep into the interviewees' experience, and this will require all my therapeutic skills. As we live in an interview culture

(Silverman, 2006) interviews are familiar to many and this may assist with putting interviewees at ease.

As an alternative, focus groups were also considered, however it has been suggested that research undertaken in this way might become more about the group process and less about the interpersonal experience (Breakwell, et al., 2010). Smith (2003) suggested that IPA aims as a method is to produce in-depth and detailed analysis of participants subjective and personal experiences and that the semi-structured interview is more aligned to doing this than the focus group. Tomkins and Eatough (2010) reflected on the use of IPA with focus groups and concluded that focus on the group dynamic may represent a fundamental shift from the idiographic nature of IPA.

My initial preference was to carry out this research using focus groups as I felt this pathway would facilitate an atmosphere where participants felt able to speak freely and the sharing of experiences would become a beneficial by-product of the research. But I also am aware of group and power dynamics and on reflection I did not think a two hour focus group would produce enough depth from each participant, as a one to one face to face interview would with a researcher.

#### **4.8.2 Sampling of Participants**

In line with IPA, participants were recruited in accordance with '*purposive homogeneous sampling*' – selected according to criteria of relevance to the research question (Smith, Flowers, & Larkin, 2009). I recruited 7 participants for this study with the aim of producing in-depth information while completing the fieldwork and analysis within the timeframe.

The inclusion criteria included Black males, living with T2DM and at the time of recruitment had experienced sexual difficulties in their current sexual relationship with another adult (aged over the age of 18). Further details about the participants are provided in the pen portraits in Appendix H.

#### **4.8.3 Recruitment**

This study employed multiple recruitment strategies, participants were recruited from flyers advertising the research which were distributed using various channels. To inform my recruitment strategy, I used diabetes and census data to help identify areas in London where prevalence of T2DM was high and where larger populations of Black people reside. With permission of owners and managers, adverts were placed in a range of locations and venues; including barber shops, gyms, libraries, community centres, sports clubs and centres, takeaways, mini-cab offices, pubs, post-offices, churches and newsagents. Flyers were

handed out to members of the general public outside tube and overground stations, sexual health clinics and markets. Alongside this I used Facebook and asked friends and colleagues to promote my research and on receiving approval, I also posted messages online to men's groups and community forums. I attended numerous large-scale diabetes outreach events as well as more small-scale local groups to talk about my research. Finally, I also contacted a range of large employers including supermarkets, local authorities, housing organisations and transport companies [REDACTED] [REDACTED] and asked them to advertise my research using their internal communication channels.

All participants were recruited from the community as opposed to GP surgeries, Diabetes clinics or other NHS services. Participants responded to flyers advertising the study which had been distributed using the various channels outlined above. Initially nine men expressed an interest in taking part in the research and seven interviews were conducted in total. Following an initial conversation where further details about the research were provided, one participant decided not to take part in the research. Another potential participant initially expressed an interest in the research but I was unable to make further contact with him.

#### **4.8.4 Initial Contact**

All potential participants registered their interest in taking part in the study via email or left a voicemail message and were followed up with a telephone call. The aim of the follow up conversation was to provide further information about the study and clarify any queries. To ensure the participants met the sampling criteria I asked about the type of diabetes they had, their ethnicity, relationship status and to confirm they were experiencing sexual difficulties. The call was also used to ascertain motivation and assess emotional stability. Participants were asked what interested them to take part and as the researcher I listened out for coherence and psychological well-being in order to avoid causing any possible harm by asking sensitive questions and to ensure the safety of the participant and researcher. I also provided information about the approximate length of the interview, advised about confidentiality and that the interview would be audio-recorded and that the participant had the option to refuse questions or withdraw from the study if they wanted to. At the end of the telephone conversation, all participants met the criteria and were invited to take part in the study. Suitable dates to conduct the interviews and locations where participants could easily travel to were asked for. I also obtained their address to send the participation information sheet (Appendix C) and asked them to read it in advance of the interview.

#### 4.8.5 Location of Interviews

Once the locations, were secured, participants were recontacted to confirm the date, time and address for the interview. Seven interviews were conducted in hired rooms across three metropolitan cities in England. Finding private and confidential spaces to conduct the interviews without any religious, medical, therapeutic, or academic links in an attempt to readdress the power dynamics between the researcher and interviewee, while also being safe and secure and having reception/security staff on site was more challenging than I initially anticipated.

#### 4.8.6 Pilots Interviews

I carried out [REDACTED] pilot interviews [REDACTED] and this was useful for checking the applicability of the interview schedule and I obtained valuable feedback from those who took part. [REDACTED]

In terms of interview style, the pilot participants felt listened to, they liked the relaxed atmosphere that was created as this made them feel comfortable and able to discuss their experiences more freely and the emphasis within the interview on confidentiality was important in order to build up trust. They felt the resources pack provided as part of the debrief, was comprehensive and very useful to take away and all the paperwork associated with the research study was checked for clarity. The participants provided feedback on the recruitment flyer and felt it was generally too big and they suggested that some might feel embarrassed to pick it up in front of others, particularly in public places, so I arranged for the flyers to be printed in smaller versions. The participants also expressed an interest in hearing about other men's experiences in the interview and felt they needed more of a lead from me as the interviewer, into starting the conversation about their own sexual difficulties.

Reflecting on my role as the interviewer, I felt the need to bring the interview back to the research question as there was a tendency in the pilot interviews to move towards discussing diabetes, in general and this might have been because we shared a connection, as we knew

one another through the workplace, combined with talking about a sensitive topic. I also felt there was too much repetition in the interview guide, going back and forth, but the feedback differed and this was not the participant's experience as the structure of the interview, gave them time to think, to communicate their thoughts and open-up more about the issues they were experiencing as the interview progressed. At the end of the interviews, I asked about my difference, as a White woman researcher and all of the participants acknowledged this, but felt it helped them open up because I was not male, or a brother or sister.

#### **4.8.7 Data Collection**

Seven interviews were conducted in total. Each interview began with a recap of the information sheet (Appendix C) to check understanding. All participants were asked to sign the consent form agreeing to participate in the study (Appendix D) and were reminded about confidentiality and advised that their participation was voluntary and they could pause, stop or withdraw from the interview. As an introduction to the interview, we went through a brief questionnaire (Appendix E), confirming background information about the participant such as age, details of their relationship and when they first diagnosed with diabetes with the aim of helping them to feel at ease and build rapport.

Taking on board the feedback from the pilots and after discussion with my supervisor I shared with the men a brief summary of some of the sexual difficulties other men living with diabetes had reported experiencing.

As semi-structured interviews are perceived by many authors to be the most suitable method of enquiry for IPA (Landridge, 2007), a semi-structured interview guide was created (Appendix G). The aim of the guide was to enable space for insight to be gathered (Willig, 2001) and was produced in a format that was flexible to accommodate responses and changes from participants.

In an attempt to answer the research question, the interview guide focused on three aspects; what it was like for the participant to experience sexual difficulties, the impact and meaning of this on his sexual relationship, and on him in relation to wider relationships and an exploration took place about how the men coped and managed these three aspects.

At the end of each interview all participants were thanked for the valuable contribution they had made to the study. All the participants received a debrief and resources pack (Appendix G) and were asked for feedback about the experience of the interview and invited to talk about any concerns they had.

Each interview lasted approximate 90 - 120 minutes and was recorded using two digital recorders, one as a back-up device.

#### **4.8.8 Personal Reflexivity on Data Collection Procedure**

Initially I was unsure if the data that I had collected during the interviews was sufficient in terms of its depth and detail, I recalled many colleagues at the time having conversations about their IPA interviews and achieving enough depth, but how would I know if I had reached this point? On reflection, I also think that the questions that I asked were challenging to answer within the constraints of an interview, especially if they had not been considered and reflected upon before.

As with the pilots, I asked all participants about my difference as a White woman researcher and how this felt for them. The men responded that they had felt listened to and this had put them at ease and they all emphasised my gender. They explained they would have been less inclined to take part in the research if it had been conducted by a male, for fear of judgement and lack of understanding. Fewer comments on difference in relation my ethnicity were made, but all of participants spoke about being part of mixed raced friendships, families and work groups. The participants hoped they had been helpful in contributing to my research and they also wished they had heard of other men's stories when they first encountered sexual difficulties.

I am aware that I hold many identities, [REDACTED]

[REDACTED] At the beginning of the interview, I referred to these identities, attempting to address some of our differences. I wanted to be seen by the participant as someone who was serious, knowledgeable and had understanding about the subject matter, with the aim of showing them that I was non-judgemental and sensitive to the topic being discussed and a safe pair of hands, which in turn I hoped would build trust and rapport with the participants so they felt confident to share their experiences. I realised only when conducting the analysis, that I may have appeared an authoritative force and perhaps this impacted on the interview and reinforced the power imbalance.

#### **4.9 Data Analysis**

Having described the data collection procedure, below I detail the stages involved in analysing the data using IPA and I also refer to ethical practice and validity.

#### **4.9.1 Transcription & Confidentiality**

All interviews were recorded using a digital audio recorder and following each interview, they were transferred and stored in encrypted folders on a password protected computer. All consent forms (Appendix D) and paper copies of transcripts were stored in a locked filing cabinet.

Each interview was transcribed verbatim by the researcher. Transcribing the recordings was a prolonged process and during this time I tried to immerse myself as fully as possible trying to re-live each interview. All identifiable information including names and locations were removed from transcripts and confidentiality was ensured by assigning a pseudonym to all participants.

#### **4.9.2 Data Analysis Procedure**

There is flexibility in the way analysis is conducted within IPA and this reflects its epistemological positioning and as such there is no right way to write up IPA analysis, as it is a creative process that enables the voices of participants to be heard (Smith, Flowers & Larkin, 2009), but it has to be well structured and relate back to the phenomenological account of the participant (Larkin, Watts & Clifton, 2006). The focus of the analysis was not on generalisability, but on the unique subjective and intersubjectivity experienced by the participants (Kasket, 2012).

Within IPA, the researcher's role is to obtain an insider's perspective of an individual experience and understand how they make sense of their experience (Conrad, 1987) and as the focus is idiographic, the researcher begins with exploring one transcript in detail until a point of closure is achieved, prior to progressing to the next participant's transcript and so on (Smith & Osborn, 2003). I outline below the steps that I have taken in analysing the data using IPA following the flexible guidelines described by Smith, Flowers & Larkin (2009). These steps are just one possible way of analysing data and while on the surface this seemed a straightforward process, my experience of this process was one that was long, knotty and intricate.

##### **4.9.2.1 Reading and Re-Reading**

At the beginning of the analysis process it is advised to stay close to the text (Landridge, 2007) as this helps the researcher become more familiar with participants' accounts and enables

unexpected themes to surface throughout the process (Smith, 2004). I began by reading and re-reading the first transcript with the aim of getting a holistic account. I also accompanied this by listening to the audio recording so that my participant's voice remained present and this was carried out numerous times. Here I was really trying to understand what my participant was conveying and connect to his experience.

#### **4.9.2.2 Initial Noting**

The transcript was formatted in landscape with a margin at the left to record emergent themes and a margin at the right to record the individual steps outlined below using different colour pens. The lines were numbered for ease of reference throughout the analysis.

#### **4.9.2.3 Descriptive Comments**

This step consisted of close line by line reading, breaking up each sentence and focussing on the participants experience and my observations from the interview. I underlined words that stood out for me such as objects, phrases and emotions. I would then describe the subject of the talk as concisely as possible. In this moment, I was thinking of what stood out for my participant as part of his experience.

#### **4.9.2.4 Linguistic Comments**

I then examined the language my participant used to explain his experience. I enjoyed fully immersing myself in this stage, making a note of repetitions, hesitancy, metaphors, laughter, and the use of pronouns. This step felt as if it was creating an additional layer of richness to the participant's experience, but I was uncertain how it could be accurately captured later in the analysis write up.

#### **4.9.2.5 Conceptual Comments**

This stage marked a move away from the explicit claims of the participant but still remained grounded in the data. I began to note tensions, questions, similarities and differences within the text, adding additional texture to a participant's account.

I also began to make interpretations which aim to help understand the underlying meaning of experiences. My initial attempts saw me draw upon too "suspicious" interpretations, a consequence of making free associations, moving further away from the text and an empathetic reading (Willig, 2012). I discarded my free associations approach, and in latter attempts aimed to draw more empathic and tentative interpretations. Supervision helped me

recognise that my interpretations have been weighted towards my own professional knowledge as a therapist when using myself as a touchstone and in the process and I was losing my participant's experience. Being challenged here has been an important part of the process, but this felt a constant battle between the roles of therapist and researcher. A similar conflict was also experienced when trying to find the balance between description and interpretative comments while trying to draw out the meaning of a participant's experience. (Larkin, Watts, & Clifton, 2006).

#### **4.9.2.6 Decontextualisation/Deconstruction**

As a further step I also started to read paragraphs backwards, to see if anything new emerged. Interacting with an account in a different way was novel and engaging, but I did not feel that it added more depth to my participant's experience.

#### **4.9.2.7 Development of Emergent Themes**

I moved then to the left-hand margin of the transcript when developing emergent themes. I first looked at my initial comments and then referred back to the text. Emergent themes tended to be concise phrases (Smith & Osborn, 2003; Willig, 2008) that reflected the character of the text and involved a process of description and interpretation. As part of this process if two phrases were similar, I tried to combine where applicable. Carrying out this process I felt the emergent themes tended to represent parts rather than the whole of the participant's experience. My initial reflections after attempting to develop some of the emergent themes, was that they felt too abstract and a pithy phrase standing alone, felt too distant and lacked a direct connection back to the participant's text and would make little sense at a later stage.

#### **4.9.2.8 Cross-linking of Themes**

The next step involved the clustering and cross linking of the emergent themes from the participant's transcript. A list of all the emergent themes with accompanying quote and line number was printed out on coloured paper and cut into separate pieces, like individual labels and then laid out on a table. Cutting out and displaying the labels in this way was highly visual and enabled emergent themes to be easily moved, clustered and linked, facilitating new clusters and connections to be made and by doing it this way I found myself becoming more absorbed and immersed in the analysis process. This was an iterative process (Landridge, 2007) and continued until no further clusters could be made.

#### **4.9.2.9 Selection of the next Participant/Transcript for Analysis**

I then started the process outlined above for each new transcript, particularly keeping an eye out for new themes and divergence.

#### **4.9.2.10 Developing Themes across Participants**

Only on completing each transcript individually Smith (2004) recommends carrying out a cross case analysis that involves developing a table of themes and looking for patterns of both convergence and divergence. All themes for each participant with accompanying quote and line number were then reprinted as labels on different coloured paper for each participant and displayed on a table, and this enabled me to immerse myself in the data once more in a sensory way with fresh eyes, as I began the clustering process again. To help identify patterns between the themes, I engaged in a number of clustering processes including abstraction - identifying pattern between themes, polarisation - connecting themes that had distinctively opposing relationships, function – seeking themes with similar purpose, numeration - noting the frequency of themes and subsumption – absorbing closely related themes into one another (Smith, Flowers & Larkin, 2009). I continued with this approach until I felt the themes could not be further integrated (Willig, 2008). All sub-themes were placed in individual envelopes and labelled with their provisional theme name. Master themes were then developed and represented by grouping envelopes of sub-themes together on the kitchen table.

A table was then created of master themes (superordinate) and subordinate (sub-themes) that included quotes from across participants with the aim of portraying the shared experiences of the participants but also their differences and this table was used as the source for writing up the analysis. During the write up, the structure of themes including the themes names were continually refined and as part of this I checked any changes against the transcripts.

#### **4.9.3 Reflection on the Analysis Process**

As the researcher plays a central role in the development of interpretations, trying to make sense of the participant's sense-making (Smith & Osborn, 2003) they become an inclusive part of the participants world they describe (Smith, 2004). As this relationship is complex the researcher must demonstrate "sensitivity and responsivity" (Larkin, Watts & Clifton, 2006) in attempting to reveal the experience of participants and one way to do this is through reflexivity which generates openness and curiosity to enhance the quality and depth of the analysis.

Despite feeling passionate about this research and connected to the participants after conducting the interviews and transcribing the data, it took much longer to fully connect to the participant's data and what they were telling me. Fearing that I lacked enough depth, my initial

attempts at making descriptive comments were far too detailed. The detail, did not necessary add to my understanding of the participants experience or make their voice any clearer or louder but I felt torn, if I missed a particular phrase, would I be missing out on capturing their full experience?

Throughout the analysis process, I found it incredibly difficult to separate out my role as therapist and my role as a researcher, it felt counter-intuitive and perhaps working as the sole researcher contributed to this. For example when making an interpretation of the data, I found myself asking 'why' and looking for an explanation, thinking about the wider context rather than staying with the 'how'.

Also at times when carrying out the analysis, as an outsider researcher I felt distant from the men's experiences and as a way to connect, sometimes I found myself becoming fixated upon their language as this felt a tangible approach and helped me to stay grounded in the data. However, in order to remain aligned with IPA, I had to remind myself that while language is important, it is one aspect and not the complete focus. To help with this when analysing the men's transcripts, I repeatedly asked the question, what are the men trying to tell me? and I tried to stay with the phenomenological process and the men's meaning-making of their experience. This often involved widening the lens, moving away from examining a particular sentence to re-listening and re-reading the men's transcripts as a whole. As an additional check, I also shared my analysis interpretations with my supervisors, fellow students and local IPA group and asked for feedback which sometimes generated similar interpretations to the ones that I had made and at other times a range of different interpretations were suggested which I then reflected upon. Through the local IPA group I also became aware of a number of research projects being conducted by 'outsider' researchers and hearing about their IPA projects, their progress as well as their struggles seemed to help me connect with my participant's experiences.

#### **4.9.4 Ethics – Data Collection & Analysis**

The study was granted full ethical approval by City, University of London and full due consideration was given to the ethical implications of the proposed research in accordance with BPS Code of Conduct Ethical Principles and the HCPC Guidance (2014) on conduct and ethics for students.

As this research was a qualitative exploratory study and the topic discussed was sensitive, prior to carrying it out great thought was given to the participant's wellbeing. Taking part may give rise to unpredictable learning experiences as participants would be asked to discuss

issues of a sensitive nature that may result in heightened awareness and may cause emotional distress. To minimise any risks to my participants, I put into place the following framework:

All research associated paperwork given to participants was piloted for clarity prior to the research taking place. Telephone screening to check for well-being took place before the interview and the participant was also given contact details for myself and my supervisor, to contact at any time with queries. I was clear about the expectations of participants from the outset and I explained in detail how the research process would unfold. At various stages of the project, the participant was reminded their participation was voluntary and they can refuse to answer questions, halt the interview and withdraw from the process.

The aim of the research was to gain an understanding of participant's experiences and I approached each interview sympathetically in line with IPA philosophy. At the end of the interview, there was an opportunity for participants to feedback on their experience and talk about any concerns they had. All participants were given a full debrief and offered support measures and advised to contact their GP if any issues arose.

All electronic documents were encrypted with a password and all hard copy documents (such as consent forms) were kept in a locked cabinet, and the information will be stored for five years in line with the General Data Protection Regulation (2018) and destroyed after this time.

#### **4.9.4.1 Ethical Reflexivity**

I am unsure how the analysis may impact my participants and it feels presumptuous that I would know. It has been important to have my participants' voice at the forefront of the analysis, but how could I make sure all my participants' voices were equally heard? Reading research and commentary by Black writers, I am struck by the phrase "I am somebody". (Smitherman, 1994). This phrase is rooted in African American slave history (Franklin, 2004) and presumes the experience of somebody is with unlimited worth, who has the ability to make a meaningful contribution to the community (Johnson, 2016). Throughout the analysis process it has been important for me to remember all my participants in this way.

As a White woman researcher, I am aware that the way I have designed this research study, in terms of the approach taken, the questions asked, the interpretations made and the findings reported and ultimately I decided what becomes known about the participants and this could preserve the western bias and enforce neo-colonialism to dominate and influence, thus hindering meaningful engagement in the research process (Sultana, 2007). Thinking more about the findings and the interpretations who owns this? The men who generated it, or me who interpreted it? (Willig, 2012). The aim of this research was to understand what it was like for Black men living with T2DM to experience sexual difficulties and in doing so raise

awareness of this through sharing this knowledge but from the processes described above, so far, the power relations have been reinforced. In terms of how I can redress this imbalance of power moving forward, I feel the format of the findings and the engagement with [REDACTED] other Black men with T2DM with diabetes at the next stage will be key.

There is a possibility that other men may feel silenced by my research. The language that I choose to relay the findings is based on my own cultural and societal experiences, may not match the target audiences. The experiences I choose to extract and meanings that I decide to make may also not connect with different audiences. Thinking of how I can address these concerns, perhaps by using the language of my participants, but this creates a dilemma as not all my participants share the same points of reference. During the writing up process, I tried to address this by bringing out individual nuance as well as collective experiences.

I am also aware by carrying out not only descriptive analysis but interpretative analysis, the people I present the findings of this study to will also make their own interpretations and I will not be able to influence what they take from it or how they reinterpret. There is a possibility that their reinterpretations may impact negatively on the participants.

#### **4.9.4.2 Quality of the Approach**

Rigour, quality and validity can be contested within qualitative projects. A benefit of carrying out qualitative research is that it enables the researcher to interact with an individual participant at a deeper level and for both to influence the research process (Smith, 2004), yet this very process and experience can make it difficult for other researchers to replicate, which can lead to findings being queried. The paradox here is that for many researchers who adopt a qualitative approach the replication of findings is not of primary concern. IPA has also been described as 'evidenced-based' as findings are based on the words of participants and the direct use of quotes (Smith, Flowers & Larkin, 2009). Reflecting on these issues when conducting the literature review as a reader, I found some published qualitative studies lacked detail in relation to the steps taken concerning the methodology and analysis, which are important components of the research process and this is an area which requires addressing and warrants further discussion amongst qualitative researchers.

Approaches such as triangulation and feedback checking with other researchers or participants have been introduced to negate some of these issues, although these procedures are not always best placed to fit with an IPA approach where the experience of the interview cannot be relived with an independent researcher or the whole of the interpretative analysis process with an interviewee. To aid qualitative researchers in their strive for quality, Yardley (2000) developed four principles and my approach to meeting these are outlined below:

#### 4.9.4.3 Sensitivity to Context

This principle applies to the careful management of all stages of the research including the methodology and interpersonal nature of the interview process (Yardley, 2000). One way to do this is through evaluation of the interviewer and participant relationship. Prior to conducting and throughout the study, I was aware of the power imbalance. I tried to address this by arranging the timing and locations of interviews to suit the participant and spent time considering the type of venue that would put them at ease. In terms of language, I addressed the possibility of embarrassment by the talking about sex and tried to match my language with the participant throughout the interview.

The literature review has identified a gap in the research which this study aimed to address. In terms of the research question, I did hold prior assumptions, I was shocked to hear how diabetes can impact and cause complications and in particular sexual complications. I was also aware that people of certain ethnic backgrounds (Black and Asian) are more likely to develop T2DM at an early age and the reasoning for this is still not fully understood and I felt both of these aspects were unjust. [REDACTED]

[REDACTED] However, I did not hold assumptions about my participants experiences of sexual difficulties, what this was like for them or if or how it had impacted them, as this was very much an exploratory study. I was really interested to hear about my participant's experiences, and it was important to me that they felt listened to in a non-judgemental and empathic way. The open-ended interview guide was designed to give all my participants a voice, and they were encouraged to convey what was important to them regarding the topic and in keeping with this approach the analysis included a notable number of verbatim quotes drawn from all the interviews (Smith, Flowers & Larkin, 2009).

Gadamer (1975) described a cyclical interpretative process by which the researcher constantly returns to their subjective preconceptions during analysis stages (Smith, Flowers & Larkin, 2009), so before making an interpretation I followed this guidance and asked myself what is my assumption about this issue? how does the view of the participant agree or disagree with my own? by continually having this open and reflexive dialogue it helped me become aware of my own interpretative lens and how it affects the interpretation of the participants words. Being able to translate the participant's experience into an empathic write up without losing the richness or accuracy of their voice and to write in a way that they would not feel blamed for their experience was testing.

#### **4.9.4.4 Commitment & Rigour**

Yardley's second principle refers to the full engagement with participants and to the completeness of the data collection and analysis processes (Yardley, 2000). Prior to embarking on data collection, I attempted to become more familiar with IPA, I attended IPA lectures, joined a regional IPA support group and engaged with an online group, while also reading around the subject area. Repeated listening to interview recordings and the re-reading of transcripts helped me engage with participants' experiences. Full immersion of the data took time and was a demanding process, there was a prolonged cycle as I the researcher tried to make sense of the participants making sense of their experiences and this tested me in ways I had not expected. Standing back and trying to see a bigger picture when in the midst of a participants' data was challenging when re-engaging in the hermeneutic circle, as was allowing for tentative themes to be continually developed, revised and refined until they could be no more.

#### **4.9.4.5 Transparency & Coherence**

The third principle refers to the overall clarity of the research so that the reader can see what has been done and why (Yardley, 2000). From the inception stage, I endeavoured to be clear about the research aims and the required involvement for participants. I have provided detailed account of the data collection and analysis process in the hope the reader could replicate the stages if they chose to. The data analysis stage was a continuous and iterative process rather than a linear one and which paid particular attention to convergent and well as divergent experiences of my participants. I reflected on my assumptions, intentions and actions as the researcher and attempted to be clear about the motivation which led me to carry out this study and how my work has influenced the research.

#### **4.9.4.6 Impact & Importance**

This final principle concerns the usefulness and importance of the research (Yardley, 2000). From the outset, consideration was given to how the research findings may be used in practice. In terms of relevance, Counselling Psychologists are ideally placed to understand the different perspectives of experiencing sexual difficulties and the meaning and impact this has when living with diabetes and offer psychological support. In terms of fully meeting this criterion, this work is ongoing. The aim is to share the findings with those working in the field of diabetes and health and with other Black men living with diabetes and this is outlined in the discussion chapter.

## 5. Chapter Three: Analysis

### 5.1 Chapter Overview

This chapter presents the four master themes and their related sub-themes which emerged through an Interpretative Phenomenological Analysis (Smith & Osborn, 2008) of the transcribed participant interviews.

**Table 1: Summary of Master Themes and Sub-themes for the Group**

Master Theme 1 & sub-themes	<b>What is happening to me? Searching for meaning and answers</b> <ul style="list-style-type: none"><li>• Suddenly, I am no longer in control of my erection</li><li>• I am left feeling frustrated</li><li>• Diabetes was overlooked</li></ul>
Master Theme 2 & sub-themes	<b>A changing relationship with my partner</b> <ul style="list-style-type: none"><li>• Talking is not easy</li><li>• Trust feels like it is being eroded</li></ul>
Master Theme 3	<b>Viagra is no quick fix</b>
Master Theme 4	<b>Am I no longer a man?</b>

In this chapter, verbatim quotes from the interviews have been incorporated throughout. This was done with the aim of enabling the men's own voices to be heard clearly, to provide the reader with a transparent analysis and to support the discussion of the emergent themes. While it aims to highlight the full range of individual experiences, practical constraints meant that it was not possible to present all relevant data within each sub-theme. Therefore, the quotes presented were chosen to highlight both similarities and differences in the men's experiences, and to ensure all participants were present in the analysis in some way.

Verbatim quotes have been reported in italics followed by a line number from the original transcript and referenced using a pseudonym to ensure anonymity. Three dots: "..." have been

used to indicate a pause in the speech, two dots in brackets: [..] to indicate words were missing in the transcript and three dots in parentheses: {...} to indicate that less applicable parts of the quote have been removed.

For the men’s accounts to remain at the forefront, a decision was made to include no references to literature or theory within the analysis section. The findings will be discussed in the context of the extant literature in the next chapter.

The 7 participants were all aged over 40, of Black ethnic origin and reported experiencing sexual difficulties in their relationship. They had been living with T2DM for varying lengths of time. Additional pen portraits are provided in Appendix H.

**Table 2: Demographic summary of the participants**

<b>Name*<sup>2</sup></b>	<b>Age</b>	<b>Relationship Type</b>	<b>Number of children</b>	<b>Age at diagnosis of Type 2 Diabetes</b>
Des	61	Married	3	50
Justin	48	Co-habits	1	38
Marcus	57	Married	2	41
Carlton	49	Co-habits	1	45
John	47	Married	2	44
Ade	46	Married	4	44
Victor	51	Married	2	41

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<sup>2</sup>Pseudonym used

## 5.2 Master Theme One: What is happening to me? Searching for meaning and answers

This master theme presents the ways in which the men described and understood their initial experiences of sexual problems. Their discussion involved how they experienced the first moments of such difficulties, their attempts to make sense of what was happening to their erections, and the challenges, emotions and questions that were evoked as a consequence.

### 5.2.1. Sub-theme One: Suddenly, I am no longer in control of my erection

Many of the men described feeling that they were no longer in control of their erection during sexual contact and reported feeling confused about what was going on with their body, as if it was unexpected.

Talking about his erection, John described feeling a loss of confidence in how his body behaved:

*“Now I can’t control it, it’s just like spontaneous and I can’t control it... I can’t tell if it will like get erect and stuff, I can’t say it will work or whichever, it’s just like uncontrollable”* (John, 38-44).

John emphasised feeling a lack of control over the way his body functions, repeating the phrase *“I can’t control it”*, and there was a feeling of panic and confusion with *“it”* being implied to have its own power, and being something separate and strange. John’s explanation of this as happening *“now”* gave the impression as if he had felt a marked change in the transfer of power to *“it”* which was working in *“spontaneous”* and *“uncontrollable”* ways, making his experience even more distressing.

Justin spoke of similar difficulties and the impact they were having:

*“Not being able to um get and sustain an erection at will, it is never good.”* (Justin, 112-113).

Justin does not talk of *“my erection”* and thus like John, he gave the impression of something detached from himself. Justin’s account also implicated both his lack of control and sense of powerlessness, mentioning what he is not able to do *“at will”*. His statement that this was *“never good”* is noted for its finality.

Victor shared the impact of the thrush medicine needed in diabetes management causing his skin to thin and leading him to fear tears. He conveyed feelings of fear and despair as he described the unexpectedness of not being able to gain an erection:

*“I never had a problem getting it up before, but the tears, I was fearful, what’s going on? I’m frightened of it splitting, in my head it is going to tear and I cannot get excited ... well in terms of traumatic it’s like not again.... this is not going away, so it’s like powerlessness”* (Victor, 1274-1278).

Some of the men described not knowing what to expect from their erection from one occasion of sexual activity to the next. For example, Des seemed doubtful about how his body might behave:

*“Looking down now and you’re thinking what’s going on, you know and will it be alright? But it’s not what you remember, you know it use to be the right size, firm and erect”* (Des, 238-243).

Des’s question *“will it be alright?”* suggested that he was not aiming for brilliant or fantastic but something satisfactory and he intimated that he might have lowered his expectations from how his erection *“use to be”*. Des’s use of *“it”* was reminiscent of some of the other men’s accounts and suggested he felt it was divorced from himself, no longer under his influence and perhaps it was too painful for Des to name. It is as if Des had lost confidence in his body and it no longer seemed recognisable, as he reflected *“it’s not what you remember”*. There is a strong sense of loss.

John spoke about the unpredictability of his erection which caused him to question what would happen during sex:

*“When we are engaging in sexual activity, what’s going to happen? sort of thing, it is sort of unpredictable, ... whether I’m going to be able to perform or not.”* (John, 73-76).

John use of *“we are engaging”* suggested that he sees sex as a joint endeavour with his partner. However, his experience of his erection as *“unpredictable”* suggested that he feel he cannot depend on it and again leads to a sense of lack of control.

Several men described the impact when they lost control of their erections in a sudden way. For example, Des described losing his without warning:

*“We’d be making love and suddenly the erection would go and I thought well this is nonsense.”* (Des, 1374-1375).

Like some of the other men, Des did not speak of *“my erection”* but *“the erection”* as if it was something that was clinically detached and distant from being fully absorbed in the process of *“making love”*. Des dismissed his sexual encounter as *“nonsense”*, as if he had never experienced anything like this before and was left feeling vexed by it.

Victor described how he found himself unable to sustain an erection:

*“You believe you’re 100% on fire and then the next minute you’re lukewarm, that in itself is like wow really, now of all times, nothing happening, I can’t do anything, I know you want to do something, I know I want to do something, but not tonight Josephine?”* (Victor, 510-515).

Here Victor described feeling sexually “*on fire*” and then experiencing an unexpected loss of control in his erection “in the next minute”. Like Des, Victor also seemed to describe feeling perplexed, saying, “*wow, really*”. It is as if both men feel not attuned with their bodies. Victor’s use of the phrase, ‘*Not tonight Josephine*’ leads one to wonder if perhaps he used humour as a way of coping with such devastating and confusing moments.

Marcus also talked of being taken by surprise by the onset of his erection problems, but he described feeling a more permanent sense of loss, as if bereft:

*“You cannot get an erection or sustain it, I thought my sexual life would go on until my seventies....It’s a bit like losing your leg or losing an arm, that’s the sort of thunderbolt, because it’s just like part of your body, that’s no longer functioning anymore, so that’s what you feel like”* (Marcus, 185-195).

Marcus likened his difficulties to a “*thunderbolt*” as if an external force had unexpectedly descended upon him in a destructive way. While some of the men intimated their erection felt like it was operating as a separate entity, Marcus stresses, that despite feeling his penis was redundant, it was still very much connected to his body, reminding him of his loss. Marcus drew a striking similarity between losing control of his erection and losing an arm or leg, illustrating the life-changing loss he was feeling, for something that he once relied upon so heavily.

Ade also inferred he felt a more permanent absence of sexual activity as a result of his erection difficulties:

*“Within me, I wanted to do it, but the tool itself is not active, it’s not active, so there’s nothing I can do, we don’t really believe in oral sex, ... we don’t really believe in that, so it’s just penetration most of the time”* (Ade, 282-286).

Ade suggested his situation was made evermore challenging by the sexual beliefs he held dear, leaving him with few alternatives. Ade described his penis as “*the tool*” which implied that he felt it was something both external and mechanical, as if it had a special function that

was no longer working. Ade communicated his sense of helplessness as he exclaimed “*there’s nothing I can do*”, echoing Victor’s experience.

The men shared feelings of shock, disbelief and confusion as they found themselves no longer in control of their erections. As the men described feeling no longer attuned to their bodies, they described feeling uncertain about how their erection would perform and their sex lives appeared to be in jeopardy.

### **5.2.2. Sub-theme Two: I am left feeling frustrated**

Most of the men expressed feeling frustrated with aspects of their sexual performance and spoke of their exasperation as they struggled to address their sexual difficulties. The men’s experiences of feeling frustrated appeared to be unfamiliar and relentless. Des described feeling his frustration intensifying during sex:

*“I didn’t think I was performing properly, so mentally, I’m getting annoyed and frustrated and thinking well, you know, ‘Is there any point? Because I’m not getting much out of this, I am not reaching orgasm, having to withdraw, and I’m getting more and more frustrated, it’s all a waste of time”* (Des 402-409).

Des’s evaluation of his performance suggested he was used to receiving so much more from sex. His annoyance appeared to manifest into a sense of defeatism, as he described writing off his sexual encounter: “*it’s all a waste of time*”, suggesting he felt as if his efforts had been for nothing.

Marcus described feeling gripped with frustration, as he was unable to meet his sexual expectations:

*“With our sexual activities, you can’t go the full way, it feels frustrating, yeah it is frustrating, because you know it’s just something that you would want to do, but unfortunately you can’t do it really. So you feel frustrated, you feel frustrated with yourself, because you’re thinking, well why can’t I? as I want to do it but I can’t”* (Marcus, 345-350).

Marcus described feeling irked by his sexual performance. He clearly conveyed his irritation with his sense of his mind and body being misaligned, leaving him with feelings of confusion.

Victor described feeling at his wits’ end as he failed to be able to successfully address his sexual difficulties:

*“Nothing is working, so frustrated and experiencing pain, nothing worked, so there’s frustration there, you’ve tried everything and you physically can’t do anything, it’s all failed and you’ve*

*got three conditions running rampant and it does your head in... it's exasperating"* (Victor, 1286-1292).

It was as if Victor felt he had no options left, and he shared the terrible frustration he felt as he struggled with pain and felt incapacitated.

Carlton also found "*nothing was working*" and spoke of the profound impact it was having on his whole life:

*"Trying different things, but nothing is working, you feel frustrated, like nothing is going right for you and your feeling frustrated, and it impacts on your whole life, not just your partner, but work, your family and friends, you keep yourself to yourself, not really socialising. I wasn't depressed, I don't like that word, but I felt frustrated, I was missing out on life"* (Carlton, 340-348).

Carlton powerfully explained how the impact of his difficulties were not confined to himself or his sexual relationship but were dramatic and widespread, leading him to extensively modify his behaviour and losing the valuable wider relationships he once had. Carlton described "*missing out of life*". It is interesting that Carlton is keen to distinguish his feelings from those of being depressed; one might wonder what the implications would be for Carlton if he labelled the impact of his difficulties in this way?

Some of the men talked of experiencing unwelcome angry outbursts as a result of their frustrations as John recalled:

*"I am dealing with it by myself, ... so the nights after, if I've not been um like erect, that's when it affects me, I might have some sort of outburst...and then I try and correct myself quickly"* (John, 186-191).

John described how the full impact of not being erect during sexual contact emerged sometime after. It was as if he feared a possible escalation of these unacceptable, angry outbursts, which he hurried to correct as if embarrassed.

Justin also shared his experiences of managing unacceptably intense feelings:

*"Your sexual performance, is confusing and you're conflicted on how to deal with it and you jump around trying to and you're not really dealing with it, it's like that pressure release valve you have, I try not to, I try and be calm and not sort of blow off steam, and say the wrong thing, but under pressure you do."* (Justin, 539-546).

Justin's use of "*confusion*", "*confliction*" and "*jumped around*" described almost a sense of panic which fostered his feelings of impatience at his lack of progress. His talk of a pressure release valve implied he was able to reduce the intolerable pressure he felt, by "*blowing off steam*", although his disdain for doing this was palpable.

Marcus appeared determined not to let such unwelcome feelings take over:

*"Some people who probably go through this actually would change a lot...because the anger would creep in that's beside you, because you're feeling the way you are really, but I've not let it get that far"* (Marcus, 273-277).

Marcus's talk of "*go through this*" described his sense of his circumstances as something similar to an ordeal, where the impact was profound. It was as if Marcus felt proud that he had been able to constrain his anger, by "*not letting it get that far*".

As the men continued to battle with their sexual problems, many also struggled to manage accompanying feelings of frustration which seemed unfamiliar, unfair and unwanted. The men described having little respite from their feelings as they impacted on their behaviour and wider lives and as some described their feelings reaching intolerable levels it seemed important to try and constrain them. One might wonder as to the impact of trying to suppress and control such angry feelings on the participants' psychological well-being.

### **5.2.3. Sub-theme Three: Diabetes was overlooked**

The men described how they initially attributed their sexual difficulties to work stress, not realising their diabetes might have been impacting things until they visited a healthcare professional.

Carlton reflected on the influence of his working pattern:

*"Initially I thought because I was working long hours, because of work, stress maybe that was the reason"* (Carlton, 9 -10).

Justin made a similar connection:

*"I was working ...where I was travelling away a lot... my sleep patterns were all over the place [...]the intimacy issues came back again, significant loss of libido, definitely performance issues as well, when we did go to have sex"* (Justin, 160-165).

Des made sense of his sexual difficulties in a similar way, which led him to taking drastic action:

*“I retired early... I put it down to work you see, not having diabetes, so once I stopped working but I was still experiencing those symptoms” (Des, 21-23).*

Des’s sexual problems were negatively impacting his life to such an extent that he decided to give up work, assuming this would be the answer. Having carried out such decisive action there was a sense of exasperation as Des explained ‘those symptoms’, too painful to name, “*still*” remained.

While diabetes was not at the forefront of Justin’s mind as the reason for his sexual problems, he was motivated to visit his surgery:

*“I wasn’t really thinking it could be diabetes..... when I did go and get checked, I realised my blood sugars were all over the place and then started to realise, yeah, actually, it’s causing all these other problems, and impacting other areas of my body and health, and that’s taken a while to get used to” (Justin, 167-179).*

Justin did not say what triggered his visit to the surgery, but receiving his results seemed to be a catalyst, as he “*realised*” his diabetes was causing “*all these problems*”, suggesting there were many. Justin described feeling something like a revelation, recognising the power of diabetes and its wider implications seemed a momentous discovery, as he concluded it had “*taken a while to get used to*”.

Carlton expressed astonishment after being given diabetes as an explanation from his GP:

*“He [the GP] explained everything to me and that’s when I began to realise hey, that’s exactly what’s happening to me .... he just explained the symptoms of loss of erections and low sex drive so on, I mean you say to yourself, I didn’t know this, I didn’t know this” (Carlton, 448-449).*

Carlton’s repetition of “*I didn’t know this*” illustrates the shock of his discovery of the cause of his sexual problems. Listening to the GP’s detailed description that covered “*everything*” and discovering his symptoms were mirrored “*exactly*”, was an unexpected breakthrough, recalled in a similar way to Justin receiving his test results. After experiencing sexual problems for more than a year, Carlton finally has a reason for the distressing difficulties he has been experiencing.

Des recounted how it felt to hear about the connection from his GP:

*“He said yeah you’ve got diabetes, this is why, you know, you can expect it... I said oh I’ve got erection problems... he said, oh you’re a diabetic okay, that was all he said...I thought well this is a bit of a relief, it is as if it seems normal practice when you have diabetes”* (Des, 1404-1411).

Des recalled his GP’s response as brief, but being told to “*expect it*” seemed just as powerful, as Carlton’s “*full explanation*” and left Des feeling reassured that he was not abnormal. Noting “*it seemed normal practice*” might have helped Des feel less alone with his erection problems.

Like many of the men, Marcus described learning about the link between diabetes and sexual problems from a health-care professional. Marcus remembered being made aware of this when first diagnosed:

*“When I first was diagnosed with diabetes they did actually give you a leaflet for um, dysfunctions of sex itself...I just thought I would never need that leaflet”* (Marcus, 21-25).

Most of the men shared the sense of relief they felt when they uncovered the association between their diabetes and sexual difficulties. Marcus’s response suggested he felt differently:

*“At the time well I laughed at it, I just thought it was just like it would never happen to me”* (Marcus, 159-161).

Marcus’s laughter seemed to almost have a protective quality. His emphasis on “*never need*” and “*never happen*” was striking in its absolute nature, as if the information was so far removed from his sexual experiences at that time, it was unthinkable.

The impact of diabetes was often initially overlooked as the reason behind the men’s sexual difficulties and for many men becoming aware of this was a meaningful discovery.

### 5.3 Master Theme Two: A changing relationship with my partner

This second master theme presents the mens' accounts of how experiencing sexual problems placed a strain on their relationship with their partner, specifically in relation to communication and trust.

#### 5.3.1. Sub-theme One: Talking is not easy

Some men reported feeling uncomfortable talking about sex and they described not feeling equipped to express what was happening to their bodies. The men reported feeling reticent to talk about their sexual problems with their partners, with some describing that they feared a negative response and others simply feeling overwhelmed with anxiety. All the men described drawing upon various strategies to avoid having to talk about their difficulties.

Marcus talked about the challenge of how to share his sexual problems with his wife and expressed concern about where it might lead:

*"It is very difficult, for that conversation, to say I physically can't have an erection, I can't keep an erection, I can't climax as much as I used to before, it's the case well, why can't you? really and then it's trying to explain that reason, it's not an easy thing to explain"* (Marcus, 478-483).

Marcus anticipated a difficult question of *"Why can't you?"* rather than a compassionate response and he gave the impression that he would feel overwhelmed, grappling to find an answer. One might wonder if Marcus' fear of his partner's potential questions reflects his own difficulty in making sense of things himself at that time.

Victor expressed an uneasiness in talking about his difficulties in gaining and sustaining an erection and his low libido:

*"To explain why you can't have sex and that in itself is not easy, it's not the best conversation to have"* (Victor, 111-112).

Victor seemed troubled by having to provide a reason for being unable to engage in sex, as echoed in his words *"not the best"*. Adding to Victor's sense of discomfort, he also described feeling sceptical about the merits of talking itself:

*"You've got no answers, you've tried everything and it's all failed and you can talk until Doomsday it's not going to change what happens downstairs"* (Victor, 1325-1330).

Victor did not define the change he would like to see “*downstairs*” but he seemed certain and demoralised when he stated “*it was not going to change*”. His hopelessness about engaging in conversation was palpable when he says that he had “*tried everything*” and it had “*all failed*”.

Justin had visited his GP for a prescription, but shared how he was used to keeping things about sex to himself:

*“My wife obviously knew I had thrush as she saw creams around as it was hard to hide, but I didn’t talk about the other sex stuff. No-one else knew, I didn’t really talk to the doctor or my wife, I didn’t really talk to anyone, because it’s not something you do talk about”* (Justin, 826-832).

Justin described making a distinction between communicating about thrush and “*other sex stuff*”. Justin indirectly disclosed he had thrush, as his wife “*saw creams around*”, but this felt like an exposing situation, as if not by choice. Justin seemed very much alone with his sexual problems as talking about sex was something that had always been kept private in his life, and perhaps this was in part why Marcus and Victor were also finding conversations difficult.

Some of the men described sharing similar approaches to avoiding talking about their sexual problems. As Marcus continued to worry about responding to questions about his sexual performance, he described using an avoidance technique to help him:

*“To talk to my wife about sex, that you can’t perform its difficult because it always going to be why can’t you?...It’s very hard to express what’s going on....both physically and mentally within myself.. so, it becomes an avoidance, instead of having to have a tricky conversation that could end up in an argument, you try to avoid it as much as possible”* (Marcus, 914-920).

Marcus felt fearful, as if threatened by the prospect of talking about sex. His account hints at the psychological challenges his situation was creating for him and his avoidance of conversation about sex, perhaps was resulting in the avoidance of opportunity to talk about how he also felt about himself, his relationship and his life.

Ade described changing the subject in attempts to avoid talking about his sexual difficulties, but berated himself for doing so:

*“ I can’t sexually satisfy her and when she talks about it, I try to divert the topic to something else and she always said okay, I just told you something and you’re telling me something else... it’s not good I just digress and divert, It is selfish... I am being selfish, because it is going to be a continuous occurrence”* (Ade, 889-897).

Ade described feeling guilty as he used diversionary tactics to protect himself from conversations about his sexual difficulties. He described feeling selfish as a result, perhaps showing that he appreciated that resolving these difficulties would be important for his partner as well as himself and avoiding addressing them will impact significantly on them both ongoing.

Carlton described going to great lengths to avoid a conversation with his partner:

*"I wouldn't talk about it, I would just avoid the subject all along, and just probably avoid her... coming up with excuses, like I've been working long hours and trying to get away for weekends, so she doesn't ask me all these questions ... it didn't feel right, it felt all wrong, that I'm not being honest"* (Carlton, 592-598).

Carlton does not define the "*subject*" or the type of questions he felt were too risky to discuss, but his reference to "*all these*" suggested that he expected many, and he felt sufficiently worried that he ended up withdrawing from the relationship. His "*trying to get away*" is reminiscent of Ade's account as he "*diverted*" and "*digressed*" and they both indicated a sense of feeling trapped in managing the situation in their relationships. Like Ade, Carlton shared that he felt unease about his avoidance of intimacy, emphasising it was "*all wrong*", it is possible he might have been felt that he was not living up to his own expectations of being a partner in an intimate relationship.

In contrast, John had spoken about his sexual problems with his wife but only after a resulting accusation of him being unfaithful (please see the next sub-theme 3.2 for further relevant analysis). He described how the talk neglected important aspects of his experience:

*"We're not really talking about it, it's just more practical talking, like oh are you seeing the doctor?"* (John, 307-309).

He elaborated further on the reserved quality of their talk:

*"Kind of like practical talk, but nothing, nothing about oh, how are you feeling about it?"* (John, 436-438).

John implied that "*really talking*" would have involved talking at a deeper level. His repeated emphasis on "*nothing*" suggested he was hoping for something more, perhaps greater intimacy with his wife, but it felt to John that his needs were left unmet.

Many of the men found the task of talking about their sexual difficulties to be especially daunting. The men had shared how they developed avoidance strategies to deal with any potential talk but these too had consequences, seemingly limiting intimacy in their relationship

and leaving them feeling uneasy, selfish, guilty and isolated and seemingly limiting intimacy in their relationship.

### **5.3.2. Sub-theme Two: Trust feels like it is being eroded**

The men described experiencing changes in dynamics of trust in their sexual relationships. Many noted how their partners questioned their fidelity after having noticed the change in their sexual behaviour. This resulted in several of the men questioning their partner's loyalty and left them feeling fearful about the robustness of their relationship.

For example, Marcus felt deeply offended by his wife's checking up on him, after she had doubts about their relationship due to them having less sex:

*"There's distrust there for someone to creep down on your phone and have a look. She's snooping around, so we're married but I still think it's an invasion of privacy It feels hurtful because the distrust is there and I think in every relationship, it's all about the trust, once the trust is gone it becomes difficult then really, we're not actually having sex much now and her insecurity becomes even more"* (Marcus, 569-584).

Marcus described his wife's actions as "*creeping*" and "*snooping*", as he feels under suspicion. He suggested his wife's actions had crossed an unacceptable boundary that had left him feeling distressed. Marcus describes his fears for his relationship once the trust had been broken, as relationships are "*all about trust*". He does not specify what "*difficult*" would look like but there is a sense of hopelessness in his assessment of his wife's feelings, suggesting he feared that his relationship was fundamentally changing.

Like Marcus, John described his wife doubting his fidelity:

*"The problems getting the erection even reached a point that my wife actually thought I was cheating, so I had to sort of like convince her, she didn't believe me, she thought that I was engaged in sexual activity with someone else"* (John, 21-26).

Being confronted by his wife, signified to John, that his erection difficulties were having a profound on his relationship. John concluded that his wife "*didn't believe me*", leaving him almost with a sense of powerlessness.

Some of the men repeatedly talked of the pressure they felt to provide evidence of their fidelity. Marcus described feeling despair as a result:

*"If you're not making love to your wife you're getting it somewhere else, but that's not the case at all with my relationship but she really feels this way, but it's like somebody accusing you of*

*armed robbery but you know you didn't do it. And it's trying to prove it and it's very difficult to prove and that's hurtful to me, I know for a fact that I'm innocent, but my wife has doubts ... I'm not one of those, I totally disagree with any man who does actually have affairs" (Marcus, 520-532).*

Marcus vividly likened his experience to being a criminal. His frustration and sense of injustice is palpable as Marcus found himself being judged and feeling triply wounded: feeling not believed by his wife, trying to "*prove*" that he was "*innocent*" and having his belief about the importance of faithfulness in his marriage severely tested.

While Marcus found it impossible to provide proof of his fidelity in the way he felt was needed, John was able to obtain evidence that his sexual difficulties were connected to his diabetes:

*"She was like oh is there another woman? and I was like well that's rubbish, I was just ignoring it and saying like whatever, but I could see that she was being serious and I'm like are you really serious? They said I've got erection problems and it's associated with diabetes and I had to like physically show her proof on the internet" (John, 404-413).*

Despite initially feeling his wife's worries about his fidelity were implausible, John felt compelled to respond and "*physically show her proof*". His exasperation at having to do so was tangible, as talking did not seem to feel enough.

Victor offered his partner physical evidence for why he was unable to have sex:

*"If there wasn't going to be any sex and I said no, this is why, so I was able to show her, there were scars there, so it's not like I was lying" (Victor, 1118-1119).*

In "Talking is not easy" (sub-theme two), Victor described finding it difficult to talk about his libido and erection problems, but shared that it was easier for him to reveal certain aspects of his sexual difficulty, in particular physical, medical symptoms. He described how he showed the scars on his penis to his wife, following a severe bout of thrush that he suffered as a consequence of his diabetes. His actions seemed almost to be a shorthand way of communicating that there would be no sex and perhaps indicated there were indeed legitimate exceptional circumstances reasons to turn down sex. Victor reflected "*it was not like I was lying*" showing that perhaps it was important for him to feel believed.

Whereas some of the men described feeling distressed when questioned about their own fidelity others expressed feeling insecure, fearing their partners being unfaithful as a result of their sexual difficulties. For example, Carlton shared:

*"I don't feel that confident anymore, I'm not fulfilling the other person's sexual desires, and you probably think, oh are they going to go to someone else because my partner is pretty much younger than I am, so yeah that comes into your head"* (Carlton 65-70).

Carlton implied his confidence was tied to meeting someone else's "sexual desires". He describes his partner as being "pretty much younger" and this seems to suggest the age gap between the two seems more acute in light of his sexual difficulties and this adds to his concerns about her being unfaithful.

Ade described feeling afraid for the future of his marriage:

*"I am putting her in a situation whereby she is not happy and that might affect the relationship because she says to me: Do you want me to go and see somebody that's outside? and if she continues to repeat that, tries it and if whoever she meets outside and that one can satisfy her, then my marriage is in the process of crumbling"* (Ade, 1048-1054).

Ade described feeling responsible for his wife's happiness on some level and hearing her apparent threat and imagining her acting on it, felt like he risked losing his relationship. Ade's account illustrates that he seems to place great importance on trust within the marriage and that infidelity has serious repercussions.

In contrast to the other men, Des expressed absolute confidence in the trust between him and his partner:

*"There's never a question that she or I preferred somebody else or anything like that"* (Des, 196-199).

Trust seemed to be challenged within many of the relationships as the men faced accusations of infidelity and felt pressured to provide evidence to the contrary. Many men were left feeling hurt and vulnerable sharing fears that their partners might feel tempted to look outside of their relationship for sexual satisfaction.

#### 5.4 Master Theme Three: Viagra is no quick fix

Within this theme, the men's experiences of taking GP prescribed Viagra were explored as they reflected on the physical and psychological impact of using medication to manage their sexual difficulties. The men had been prescribed Viagra by the GP and they described how the decision to take Viagra appeared complex as it seemed to conflict with their sex needs.

Many of the men who had tried Viagra to address their sexual difficulties described feeling reluctant to use it again as they expressed concern about its safety. Marcus shared his fears about the physical side effects:

*"I don't think it is something at the moment I really want to be involved with, it can be dangerous as well, because depending on your heart, it excels the heart rate faster than it used to be, so obviously taking Viagra will play on your mind and at the same time it's just adding more pressure to yourself, by doing that"* (Marcus, 218-224).

Marcus's account conveyed how he worried that taking Viagra might be at the expense of other aspects of his physical health. Marcus described how the worry of physical side effects would potentially lead to psychological consequences, almost suggesting that he feared it would lead to more problems for him that it would fix.

Victor recalled being "*advised to take Viagra*" (Victor, 320) as a way to manage his sexual difficulties; he too indicated concern about its physical impact:

*"The side effects is the raised heartbeats and so forth when does that stop? Do you know what I mean? And I don't want to be playing about on that"* (Victor, 562-566).

Victor described feeling fearful of "*raised heartbeats*" and did not want to '*play*' or gamble with his heart. Victor's uncertainty about when an elevated heart rate would subside, suggested he was afraid he could be managing the serious after-effects of Viagra for far longer than a single sexual encounter.

Finding a remedy to manage their sexual difficulties was not easy for the men and this process become even more challenging as they then had to consider potential adverse consequences of using it. Viagra had given Des the erection he wanted, but he was apprehensive about its interaction with his existing medication:

*“When I use a Viagra like tablet...my erection it is like how it used to be, it’s better, it’s bigger, it’s firmer, but I take enough tablets already, I’m not sure what the side effects are of Viagra apart from getting the erection” (Des, 248-254).*

Both Des and Carlton were prescribed an alternative to Viagra which had the same purpose and effect. They could not recall the exact name of this medication and interchangeably referred to it as “*Viagra*”, “*Viagra substitute*”, and “*Viagra like*”. The benefits of having an erection did not appear to Des to have satisfied him in quite in the way he would have liked, as he described taking “*enough tablets already*”. Des was left feeling unsure about using Viagra as if there was something ominous about it, other than fixing his erection.

Deciding to take Viagra was complex, and Ade shared his worries about the impact of taking Viagra on his heart and of adding more medication to his regimen:

*“I’m taking medication for diabetes, I don’t want to be taking that one for sexual problems, that would be too much for me ...When I’m taking three or four medications to swallow, I can’t be going through the pain and stress, it’s an additional burden... on my body taking too many medications” (Ade, 1216-1222).*

Taking medication to Ade was not a soothing or alleviating experience, but one that caused him concern. His description “*too much for me*” almost suggests a sense of Ade feeling as if he could be overpowered by the “*sexual*” medication feeling too much for his body to bear. While some of the men expressed fears about Viagra’s immediate safety, others felt unsure about long-term dependency.

For example, Carlton reported: “*I can’t just rely on the Viagra substitute on its own, ... I didn’t really want to take it at first, but obviously I did and it does help with the erection, but it’s just a short-term solution you know, because you can’t keep taking it, taking it, you can’t rely on it for the rest of your life*” (Carlton, 623-627).

Carlton suggested his sexual problems were ongoing and long term and taking Viagra was just not feasible.

Several of the men expressed unease about using Viagra to treat their sexual difficulties because of their age. For example, John stated:

*“To be reliant on medication, Viagra and stuff, because you associate it with older people, I wouldn’t take it, I don’t think, I should, um, I should be at that point in life” (John, 1336-1341).*

John also did not see Viagra as a viable solution, fearing he would “*be reliant*”, perhaps highlighting his struggle with not being in control of his own erection. He shares his perception that sexual difficulties at his age were not to be expected; Carlton too describes how age played on his mind about using Viagra:

*“I’m still relatively quite young, you don’t want to just depend on Viagra alone”* (Carlton, 618-619).

One might wonder what the implication was for both men’s self-esteem given that they seemed to construct such sexual problems as primarily being the domain of older adults.

In addition to describing their worries about the side effects of Viagra, some of the men expressed dislike with the fact that taking Viagra meant that they had to plan when they would have sex and this involved changing expectations of how sexual contact might unfold. Victor explained his predicament:

*“Viagra, its putting you down to timeframes for me...this will happen at 10 o’clock and between 10 and 2, but if I don’t want to and I’ve taken it, what happens then? Yeah for me or if anyone of us decided not tonight Josephine, then what do I do with myself? I can’t walk around or hide my erection”* (Victor, 565-572).

Victor’s worry of “*If I don’t want to*” and “*not tonight Josephine*” suggested that he might run the risk of his body not being aligned with his mind and level of sexual desire and that this might leave him feeling quite powerless as he alluded to in Theme 1, sub theme 1: Suddenly I am no longer in control of my erection, when he described initially experiencing sexual difficulties.

As with the other men, deciding to take Viagra did not appear an easy decision for Des as it seemed to elicit mixed emotions. On the one hand, Des described how he liked the way his erection appeared after taking Viagra, however his belief that taking it would need to alter the way he had sex seemed to fill him with what appeared to be dread:

*“There’s a cure, there’s a cure but then of course you get four tablets, so you’re thinking, one’s not going to last me a week, so I’m thinking God, I’m going to have to manage these now, that means I’m going to literally have sex in a different way”* (Des, 1426-1431).

Des seemed overjoyed by the prospect of finding a “cure” to his sexual difficulties, but this feeling became eclipsed, as he realised his prescription would not meet his sexual needs. It was as if, his sex life had been reduced to “four tablets” and this sense of feeling restricted echoed Victor’s experience of his sex life being restricted by pre-arranging and planning “timeframes” for sex. Des described that instead of Viagra feeling like an easy quick fix, it involved re-evaluating, planning and changing the way he managed his sex life. It was as if the tablets did not give Des agency over his erection but rather left him with additional worries to contend with.

Like Victor and Des, Carlton conveyed displeasure with the way sex was turned into a premediated act:

*“I don’t want to reach a point whereby I need it every time I want to have sex with my partner... you want to do things on the impulse without relying on the Viagra, as it gets in the way because you’re not connecting, you have to think oh I have to take that tablet now, but you want things to happen naturally, not think to take that pill, it feels like a mechanism”* (Carlton, 651-669).

Carlton described wanting sex that was on “impulse”, “natural” and “connecting”, suggesting a longing for sex that was fluid and an unfolding organic process. His sexual desires seemed in contrast to his associations with taking Viagra, which he described as “like a mechanism” and his interrupted thoughts about remembering to take the pill, suggested sex changed into something that was planned, technical and that involved thinking about. It was as if for Carlton, using Viagra took him away from having a bonding encounter with his partner.

Victor, Des and Carlton described feelings of dissatisfaction with Viagra as it required them to change the way that they managed their sexual lives, rather than the Viagra merging with their sexual needs and easily slotting into their existing lives. This disparity also seemed noticeable in some of the men’s accounts when they interacted with their GP about their sexual difficulties, as Ade recalled:

*“I’ve been to my GP, the Viagra he gave doesn’t work for me... I want to know his expertise and knowledge, to advise and prescribe whatever, but I’m just hoping for something natural, not on medication because it’s going to be a continuous process”* (Ade, 1205-1211).

Des recounted his disheartening experience of receiving his prescription from his GP for his sexual difficulties:

*“They only give you four a month of the Viagra substitute, so is that suggesting you only have sex once a week, which even that for me you know is not enough”* (Des, 85-87).

There was a shared quality in Des’s and Ade’s accounts when prescribed Viagra, as Des stated *“for me you know it is not enough”* and Ade reflected it *“doesn’t work for me”*, it is as if they both received a generic and impersonalised offering that did not fit with their individual desires.

For many of the men, Viagra did not seem to be the longed-for quick fix as the implications of taking it were complex. The men expressed fears about the dangerous consequences it could have on their body and it meaning that they would have to change the very essence of the way they engaged in sex. They seemed to experience Viagra as being offered in a generic and mechanical *‘one size fits all’* way rather than being responsive to their individual needs. From these men’s accounts, it seems that Viagra did not allow the men to regain control of their erections in the way they wanted or give them the hoped for agency in their sexual lives.

## 5.5 Master Theme Four: Am I no longer a man?

In this final master theme, the men described how they no longer felt like a man in the same way that they had previously. This led them to re-evaluate their masculinity in relation to being a sexual performer, sexually satisfying their partners, their sexual strength and how others perceived them as a result of their sexual difficulties caused by living with diabetes.

The men's experience of finding that they could no longer control their erections and the associated uncertainty regarding their sexual performance, appeared to challenge their ability to live their lives in line with their long held sexual beliefs and expectations. Some of the men described how their beliefs about sex which had been influenced by their communities and their upbringing seemed to have played an important role in how they saw themselves as men, John explained:

*"In Black communities and stuff you're especially like within males and stuff, everyone is prided on their sexual relationships, and everyone seen to be always has to be basically be on their game ..., it's uncommon among friends or within the community to have this issue and not be able to perform and stuff"* (John, 804-811).

John defined "on their game" to mean "sexually active in relationships" (John, 826). In this extract, he suggested that this is an attitude or behaviour expected of Black males. John's use of the word "prided" suggested a sense of achievement related to sexual activity and gave the impression of shared notions of sexual identity within his community. Repetition of the phrase "everyone" when he described his sexual expectations John suggested how pervasive this belief was within his shared community and this only served to highlight John's sense of his own difference as a result of his current erection problems. Furthermore, John described performance issues as "uncommon" which suggested that his belief that erectile difficulties were rare amongst his peers and again highlighted how John viewed himself as different and it is possible isolated from his peers and one might wonder how this might have impacted on how John felt about himself.

Marcus recalled how his sexual beliefs and what it meant to be a man developed as he grew up:

*"Yeah as an image of a man as you grow up actually, is um, as most boys, when you start growing up, then past puberty, most men just think about, well, let's go out tonight and I'm going to have sex, you always feel that you know that is part of being a man, to go out and have sex really or meet a partner and have as much sex as you can"* (Marcus, 955-961).

Marcus seemed to suggest that having frequent sex was an important part of the transition from boyhood to manhood. His use of the phrase *'let's go out tonight and I'm going to have sex'* was suggestive of conquest and like John, he presented a belief that having sex was a key achievement. Marcus referred to *'as most boys'* and *'as most men'* suggested that he thought that his sexual beliefs were standard and shared by others. It seemed that it might be a challenge for Marcus to continue feeling like *'most men'* as he now experiences sexual difficulties and raises questions about the impact of this on his identity as a man.

Many of the men spoke of being a sexual performer as being central to their concept of manliness. For example, Des scrutinised his sexual performance:

*"You feel inadequate if you can't perform it's a sense of inadequacy, a sense of lack of manliness, you can't perform,..... sort of like a Delta male almost sort of thing, you know, you're not your Alpha male"* (Des, 416-419).

Des felt performing was an essential part of making him feel manly. The term *"Alpha male"*, inferred dominance, pride and success and Des' use of it, suggested these qualities that he associated with being a sexual performer were important in affirming his masculinity.

Marcus made comparisons with the place that sex held in the past for him:

*"As a man to perform sex and have sex actually used to be the reason of life but when you're not sexually active as you used to be you're trying to justify yourself, and why can't you be as you were?"* (Marcus, 949-953).

There is a profound sense of loss as Marcus poignantly expressed himself in the past tense when he described performing sex as a man *"used to be"*, almost as being the reason for existence and this appeared consistent with his earlier comments where he seemed to imply that having sex symbolised an important milestone into manhood. Marcus's life appeared to be very different to how it once was and finding it difficult to *"justify"* himself, he lamented for a return to the past with an almost plea like desperation: *"Why can't you be as you were?"*.

As Marcus expressed a desire to return to his sexual past, Justin continued to wrangle with his sexual abilities, alongside his diabetes:

*"As a male there are aspects of your life that you want to count on...certainly your sexual appetite and ability to perform, you want to feel there is no problem there and be that confident and invincible person, not sexually being able to do the things you once could do, it knocks your confidence and then having to consider you're diabetic, you can't treat your body in the same way, it shakes your confidence, your battling with yourself and it's a challenge"* (Justin, 302-316).

Performing sex seemed to deliver additional benefits for Justin, shaping how he felt about himself as a man; “*confident*” and “*invincible*”, perhaps echoing how Des imagined an “*Alpha male*” to be. No longer being able to rely on his body in the way he once could appeared to have left Justin feeling unsure about who he is now and adjusting to these changes seemed an ongoing battle for him.

Victor compared his perception of his own masculinity when sexual performance was a ‘natural’ one, against a Viagra “enhanced” one:

*“I take the Viagra, the Viagra takes control of me as it will allow for me to have an erection for whatever length of time...so once I’ve taken it and I’ve taken and I’ve taken it and it’s fantastic, what happens when I don’t have any and I’m in the mood and nothing happens?... I know what that can do as opposed to what I can do naturally and that’s why I say I would be half a man, as I would be thinking that”* (Victor, 587-606).

The men’s experiences of Viagra have been explored previously, but here Victor seemed fearful of the drug taking “*control*” of him and he alluded to being left feeling like “*half a man*”.

Having natural and instinctive sex was also described by some as a fundamental part of masculine identity. For example Marcus shared that:

*“A man has sexual urges and needs to perform...that’s basically what most men think they should be doing”* (Marcus, 130-133).

Des felt this was particularly pertinent and important for Black men:

*“For Black men sex is natural, you know, you have this feeling about you... and I’ve taken all that for granted.”* (Des, 219-222).

Des’ experience of sexual difficulties appeared to have given him cause for reflection. He appeared to express experiencing a conflict between long standing sexual beliefs held as a Black man and his current experience of sexual difficulties.

Many of the men described feeling less manly because they were less able to sexually satisfy their partners in the way that they would like. Carlton shared how this felt for him:

*“The lack of erections and um lack of sex drive are linked, it makes you feel a bit less of a man... you’re not fulfilling your partners desires, and you just want to make them happy and you’re not satisfying their needs and left feeling a bit worthless as a man”* (Carlton, 84-91).

Carlton seemed to suggest that his worth as a man was based upon his partner’s sexual happiness.

Ade reflected on the wider implications of not being able to sexually satisfy his wife:

*“It doesn’t feel like I am a man when I’m unable to satisfy my wife in bed... it has affected my confidence because I think what’s the point of doing it again? (Ade, 53-59).*

Ade like Carlton described feeling his manliness as linked to his ability to sexually satisfy his wife and for Ade the consequences of feeling he cannot in the way that he would like to seemed to be long lasting. He seemed demotivated and hopeless, asking, *“What’s the point?”*, almost as if by trying again it might reinforce the view he has of himself as no longer feeling like a man.

Des appeared disillusioned, as he was finding it difficult to sexually satisfy his wife:

*“When I am not performing as a male should, I feel that I’m letting her down... it upsets me greatly and you think well why should I bother?, is it worth having sex if I’m not going to satisfy my partner?.... because it’s not going to be good enough” (Des, 755-767).*

Des did not specify how a male should perform but not matching up to his expectation, fostered a sense of hurt and sadness which culminated in him questioning the rationale for sex and he gave the impression he was on the verge of giving up.

A few of the men described the importance of having children as an indicator of being a man, Carlton expressed the pressure he felt to comply with this expectation:

*“You’re brought up to be sexually active. I come from a big family, so I’ve only got one kid culturally we’re meant to have big families... your meant to have quite a few kids, you’re meant to show you’re a real man” (Carlton, 707-715).*

Carlton shares a tangible sense of the pressure he felt and his use of the word *“show”* gave the impression of the importance of displaying this to others, fearing that instead it was visible that he was some way off being a *“real man”* by having only one child.

In a similar vein to Carlton, John commented:

*“And everyone keeps saying to us oh when are you guys going to have your third? You need a girl, blah, blah, and um its pressure, because ... in our circle we were the first to shoot out the boys and.... it is like everyone’s had kids and gone past us” (John, 1048-1054).*

Both Carlton and John described feeling that there were strong cultural expectations of them having more children. This cultural pressure adds an extra challenging additional dimension for the men to negotiate when trying to manage their sexual problems and maintain their sense of masculinity.

Justin also described the pressure of sexual performance being important for procreation purposes:

*“Sex is a big part of your manhood and being able to easily have sex is a big part of that, but it hasn’t impacted as much as it could have because it’s not been at a critical time, if I’d been suffering from performance issues and feeling pressure to perform when we were trying to conceive our child 5 years ago, it would have been much harder to deal with, so I am really lucky it wasn’t happening then”* (Justin, 772-773).

Justin described how he believed having effortless and readily available sex was an integral part of being a man. Given his sexual beliefs one might have wondered how his difficulties might have impacted upon his own sense of himself as a man but his reflections suggested that in part this seemed to have been mediated by having a family and considering himself as lucky.

When talking about their sexual difficulties some of the men made links between their sexual performance and their strength and manliness. For example Carlton recounted:

*“It feels like your strength has been taken away, but you know, that’s what it is and there’s nothing you can do about it, you feel less of a Black man because as I said, like the way you’re brought up like your peers oh you have to be this, you have to be a man, there’s certain stereotypes you have to be like”* (Carlton, 178-182).

Carlton intimated that part of him had been removed by an inescapable external force, leaving him feeling defeated. Feeling strong to Carlton appeared inextricably linked to being a Black man. The removal of his strength might have signified that he no longer felt aligned with his peers and his difference was sharply felt.

Carlton continued to describe how it felt for his sexual strength to have been stripped away:

*“It’s not working down there, ... you feel like weak, not physically weak but in yourself, you just feel like I’m weak and you know, I’m less of a man”* (Carlton, 636-639).

It seemed important to Carlton to define the “weakness” he felt and for it to be understood, as it appeared to be more potent than a “*physical weakness*”.

Ade spoke frankly about the distinction between the “*physical*” and the “*sexual*” weakness he felt as a man:

*“I see myself as a weak man when it comes to bed, it’s not that I am physically weak, like if I had a heart problem and I am unable to perform, this is a different thing entirely, it’s not about physical strength, when it comes to bed I’m not sexually strong”* (Ade, 124-131).

Like Carlton, Ade shared his belief that his reduced sexual strength seemed to him to be incompatible with feeling like a man.

Des shared how he felt that the physical strength of his erection impacted on the way he felt about himself as a man:

*“Women want a man with a strong penis and a strong erection. That’s my mental image and when my penis is not doing that, I’m, thinking I’m not a man and my worth is diminished”* (Des, 730-735).

Des implied that having a “strong” penis and erection is what all “women want” as if this was universally accepted and it is as if almost no other aspect of him as a man mattered. It seemed that Des’ well-defined “mental image” of what makes a man might reinforce his sense of feeling devalued.

In contrast to many of the men, John spoke of being the “same person” (John, 684), with sexual difficulties not impacting on how he saw himself:

*“I haven’t thought anything negative, like I’m a failure, I haven’t dwelt on it in that way, it’s a situation that I’m just trying to address and I’m not seeing as permanent, so I don’t look at myself differently”* (John, 240-248).

John described his “situation” as temporary and this seemed influential in maintaining the view he has of himself as a man, suggesting that his difficulties could be remedied.

While John has described not thinking of himself differently, he seemed to suggest earlier that some Black communities hold widely accepted sexual beliefs about Black males being sexually active in relationships, who associate sex with a sense of achievement and where sexual difficulties are generally unheard of. Here he provided more detail about how others may see him as a result of his sexual difficulties:

*“Not being able to perform sex will probably be looked down upon, this would be a negative... I don’t think they’d understand, they’d wouldn’t even care it’s related to diabetes, it’s like oh you can’t perform, you can’t perform. Its worrying that people would look at me that way, I’m going to be looked down upon. But I think I’m sort of for now in a safe place where it’s just kept indoors at the moment”* (John. 838- 849).

John shared that he expected to be judged by others and his repetition of “it’s like oh you can’t perform” brings to mind childhood taunting and ridicule. The ‘outdoors’ seemed risky and John appeared to feel comforted and protected by keeping his difficulties “indoors”. However John’s reflection that this was “for now” and “at the moment”, suggested that he was fearful that it might not possible to keep the difficulties private ongoing and one might wonder what impact that would have on how John would see himself in that situation.

Carlton also talked of keeping things to himself, worried about others’ reactions:

*“I haven’t spoken to any of my brothers or my friends because I’m thinking oh what are they going to think of me?, that I’m less of a man now?, because the way we’re brought up is to be strong and there are certain things you don’t really talk about, it’s a bit hard as I said you know there’s certain stereotypes you have to be this way and that way, you know as Black man”* (Carlton, 259-270).

Carlton expressed his anxiety that he would be seen as “*less of a man*”, because he was experiencing sexual difficulties. Carlton’s emphasis on “*now*” implied others might not have viewed him this way before and sharing his sexual problems would change this. It seemed for Carlton there were many expectations required to being a man, and a Black man, which were developed as part of his upbringing and have remained ever present since. He was finding them particularly challenging to uphold as he experienced sexual difficulties and in the meantime he appeared to be alone with his problems.

Marcus described the weight of society’s expectations about what it means to be a man:

*“Society puts a lot of pressure on people .. there’s an expectation your supposed to be, if you’re sexually active you’re a great guy and if you’re not, you’re not a full person, you are not a man anymore because you’re not doing as much as everyone else is doing, now I’m not having sex, I’m no longer that person that I used to be”* (Marcus, 970-976).

Marcus painted the unforgiving way in which he felt society defined men, based on their sexual activity. He suggested that a man’s sense of worth, completeness and manliness was based on how much sex he was having. This complete reduction of a man’s identity to sexual virulence is reminiscent of Des’s assertion about what “*women want*”. For Marcus this is what society expected. There is a great sense of loss, as Marcus reflected “*I’m no longer that person that I used to be*” and it is as if he has been unable to escape from society’s definitions of what makes a man, no longer seeing himself qualifying in the “*great guy*” category.

Many of the men shared that no longer being able to perform sexually in the way they once could led them to reappraising their sense of themselves as men and for some as Black men. Their masculine identity and beliefs and expectations about sex seemed to have been shaped by their experiences of growing up in their families, their communities and among their peers and these core influences have remained throughout their lives.

Often the men evaluated the different qualities that made up their masculinity in a dichotomic way as if they were passing or failing a test, so maintaining their male identity seemed particularly challenging under these circumstances. For many of the men how they viewed their sexual performance, sexual desire, sexual strength and sexual gratification seemed to be highly influential in shaping their overall feeling of manliness.

## **6. Chapter Four: Discussion**

### **6.1 Chapter Overview**

This chapter will review the research findings from each theme, in relation to the research aim and the existing literature. Master theme findings will be explored in the same order in which they appeared in the analysis chapter. The study will then be evaluated and recommendations for future practice and research will be suggested.

### **6.2 Discussion of findings**

#### **6.2.1 What is happening to me? Searching for meaning and answers**

This study aimed to understand what it was like for Black men living with T2DM to experience sexual difficulties and the impact it had on them. The findings explored the men's responses when engaging in a sexual encounter and their attempts to make sense of this.

##### **6.2.1.1 Suddenly, I am no longer in control of my erection**

The men talked of no longer being able to obtain or sustain an erection and experienced difficulties reaching an orgasm. A few men felt their sexual difficulties were complicated by experiencing thrush and generally the men's sex lives seemed under threat. Similar sexual difficulties were commonly expressed by men living with T2DM in other studies (Liburd, Namageyo-Funa & Jack, 2007; Shiyabola, Ward & Brown, 2018; Metta et al., 2017).

As the men encountered difficulties with their erections, many intimated their penis felt separate and detached from their body and their bodies and minds no longer felt aligned in the way they once did. This was not the case for Marcus who described his sexual difficulties as life-changing, similar to losing an arm or a leg, yet he felt his penis remained connected to his body although it no longer worked sexually in the way he would like, and possibly a constant reminder of his loss. These experiences were generally not captured elsewhere with the exception of Jowett, Peel and Shaw's study (2012) where some gay and bisexual men reported a changing relationship with their bodies, they commented about its lack of co-operation for example when they tried to masturbate. Biopsychosocial models conceptualise the body and mind as interlinked systems and they are applicable to understanding sexual dysfunction (Goodwach, 2005) which seemed in line with the men's thinking about their own sexual functioning.

The men described losing their erections as unexpected and unfamiliar. They expressed feeling shocked, and surprised and were left confused and in disbelief as they no longer felt attuned with their body. These responses are similar to those outlined in stage 1 of the Kubler-Ross (1969, 2005), 5 stage grief model which proposed that they are protective in order to cope and survive a loss, where lives have changed in an instant and are incomprehensible. Men's reactions to a change in their erections seemed not to have been reported in other studies. However, in some ways the men's experiences in this study were evocative of how other men reacted when receiving their diagnosis of diabetes which have been outlined in a number of studies with general populations (Stuckey et al., 2014; Gask et al., 2011; Tanenbaum et al., 2016) and recollections in this study when first encountering sexual difficulties were equally vivid and strong.

Many of the men talked of their erections as being unpredictable and changeable and some commented on how this happened in a very sudden way and they described not knowing what to expect when engaging in sexual activity. With the exceptions of Marcus and Ade who both described experiencing a more constant absence and they seemed to endure a more permanent sense of loss. Some of the gay and bisexual men in Jowett, Peel and Shaw's study (2012) also spoke of the changeable nature of their erections and they expressed fear when trying to attract a sexual partner and in relation to hypoglycaemia when engaging in sex, although this particular side-effect of living with diabetes was not raised in this study.

The men's experiences of erection difficulties appeared to symbolise that they were no longer in control and as their minds and bodies seemed no longer aligned the men were left with a sense of powerlessness and a loss of confidence in their performance abilities. Associated with this, a few of the men shared thoughts that there was nothing they could do and their words evoked a sense of hopelessness. Some of the Black men with T2DM in Metta et al.'s study (2017) also shared similar feelings of powerlessness and lost hope when they discussed their sexual functioning and lost hope was also expressed in Mayega et al.'s study (2018). Consistent with this study's findings, the gay and bisexual men in Jowett, Peel & Shaw's study (2012) also described feelings of powerlessness and this too seemed to be connected with a loss of confidence and self-worth. Whereas hopelessness was emphasised by the men who took part in Cooper et al.'s study (2018) as they felt doomed when performing their sexual role and also conveyed pessimism, that there was nothing that could be done.

When the men talked of losing control there seemed to be similarities with the findings from the wider literature and diabetes management in general. Many Black men with T2DM expressed fears about complications and described the unpredictability and intrusiveness of

diabetes and some were left feeling unsure of the damage it was causing (Bhattacharya, 2012; Hood et al., 2018; Metta et al., 2017; Shiyabola, Ward & Brown, 2018).

The men's focus on their erectile response can be understood using both Barlow's (1986) and Nobre's conceptual cognitive models (2009, 2010, 2013). They proposed that specific attention on erection arousal and response, combined with a negative appraisal of the sexual experience intensified the distress experienced and directed attention away from erotic stimuli which contributed to the maintenance of erectile dysfunction. Interestingly, there was an absence of talk about erotic stimuli within the men's accounts.

Although not specific to a sexual context, within the Black masculinity literature, qualities such as self-determinism, accountability, autonomy and responsibility among others have been suggested as being influential in defining what it means to be a Black man (Hunter & Davis, 1992; Hammond & Mattis, 2005; Chaney, 2009; Mincey et al., 2014). While it is unknown if the men in this study identified with these characteristics in the same way, it is possible that valuing similar qualities or being expected to meet them may contribute to further tension within the self when faced with the unpredictable nature of erections and the mind and body no longer being aligned.

#### **6.2.1.2 I am left feeling frustrated**

The men emphasised feelings of frustration accompanied by exasperation, panic and anger outbursts when they tried to engage in a sexual encounter. They seemed to suggest these feelings were unwanted, uncomfortable and unjust. The men described experiencing such feelings from different parts of the sexual experience: when they tried to obtain and maintain an erection, reach orgasm, sexually satisfy the self and their partner and when they recognised their body and mind were no longer aligned as outlined earlier. They also manifested when some of the men felt they were unable to find a solution to their sexual difficulties. Feelings of frustration seemed to be experienced as powerful as they continued to be felt for some time after their sexual encounter, spilling over into family and social life. At times, the men described their feelings as reaching unbearable levels and it felt important to constrict them. Black masculinity literature has suggested that qualities of what it means to be a Black man may include being grounded and having strength to both endure and overcome (Hammond & Mattis, 2005; Mincey et al., 2014). While we do not know if the men in this study ascribed to the same qualities, the feelings the men have expressed seemed contrary to feeling grounded and some men in this study despite their best efforts had been unable to find a solution to their sexual difficulties. It is possible that the men may experience more acute emotional turmoil

and conflict if they share similar beliefs of what it means to be a Black man that has been highlighted in the literature.

The feelings expressed by the men are also akin to those outlined in stage 2 of Kubler-Ross's (1969, 2005) grief framework which identified, anger, irritation and frustration as natural responses to grief. A tendency at this stage is to redirect these feelings onto others, however others did not seem to be blamed by the men in this study, but they found their feelings had encroached into other domains of their lives. In Liburd et al.'s study (2004) some of the African American men expressed their frustration, dissatisfaction and dismay with the way diabetes had impacted upon their sex life. However, again diabetes was not blamed by the men in this study, and they were more likely to have described feeling perplexed over what was happening to their body.

Within the wider diabetes literature, it has been consistently reported that African Americans living with T2DM experienced relatively high levels of diabetes-specific distress (Nicolosi et al., 2002; Peyrot et al., 2014; Spencer et al., 2006; Williams et al., 2020). In another study of men in Italy higher levels of diabetes-specific distress was also associated with erectile dysfunction (De Berardis et al., 2005). Diabetes-specific distress is a wide ranging and complex construct, a unique psychological response to managing aspects of diabetes such as complications against an appraisal of coping resources (Polonsky, 2005; Tanenbaum et al; 2016). Diabetes-specific distress is characterised by range of emotions and some of these appeared to be experienced by the men in this study such as frustration, worry, anger and a feeling of being overwhelmed but the men in this study did not seem to blame their diabetes for causing their sexual difficulties but were more likely to direct their feelings inwards and berate themselves for no longer being able to engage in sexual activities in the way they once could.

Interestingly, Barlow's (1986) and Nobre's (2009) models placed emphasis upon the role of cognition in maintaining erectile dysfunction rather than emotions. Although Nobre noted that depressive affect can act as a maintaining factor and the men he researched also reported high levels of fear, sadness and disillusionment about their predicament (Nobre & Pinto-Gouveia, 2006b). But it seemed here the men struggled to deal with their emotions associated with their sexual difficulties.

### **6.2.1.3 Diabetes was overlooked**

Many of the men recounted how initially they thought that perhaps work and associated stress was at the root of their sexual problems. It was not until they visited a HCP at a later point that the connection with diabetes was made.

Rarely in diabetes research have men been asked about the cause of their sexual difficulties, despite sex being valued by adults with diabetes (Nicolosi et al., 2002, Bradley & Speight, 2002; Ventura et al., 2018). Of the few studies that have asked, a general lack of awareness about the influence and impact of diabetes was reported and many men felt ageing was responsible for their sexual difficulties as well as relationship and mental health issues (Kolling 2012; Coimbra & Teixeira, 2015; Rutte et al., 2016; Cooper et al., 2018). Interestingly, none of these reasons were cited in this study.

Many men in this study had initially sought help from their GP on more than one occasion as they experienced thrush which is often connected with diabetes. The men described their appointments as brief, conversation was kept to a minimum and their sex life was not enquired about. All the men had experienced sexual difficulties for more than a year before they sought help at their surgery, some of the men decided they had to take action as they felt they could no longer continue as they were, some were motivated to do this because of their relationship difficulties and for others it was unclear what prompted their visit.

The men described receiving information about the connection between diabetes and sexual difficulties in a variety of formats, but all felt it was a meaningful discovery, a momentous occasion and an unexpected breakthrough which offered a sense of relief and reassurance and also the recognition for a few of the powerfulness of diabetes. Like the other men, Marcus received information about the link between diabetes and sexual difficulties from a HCP but he was the only man to have been made aware of this at the time of his diagnosis. However, his response suggested that at this point in his life, the information was so far removed from his sexual experience it seemed difficult to connect with.

This study was one of few where all the men had interacted with a HCP and so in other studies, emphasis was placed on the reasons for not seeking help, which included embarrassment, perception of sexual difficulties as unnatural, short appointment times and fear of discrimination (Cooper et al., 2018; Lindau et al., 2010; Jiann et al., 2009; Jowett, Peel & Shaw 2012; Rutte et al., 2016). A shortfall perhaps of this study was that the men were not asked

about what had prevented them from seeking help for their sexual difficulties sooner as many had lived with their sexual difficulties for more than a year.

## **6.2.2 A changing relationship with my partner**

The men described how daunting it felt to talk about their sexual difficulties and consequently their relationship with their partner seemed to be under strain as they conveyed a breakdown of trust.

### **6.2.2.1 Talking is not easy**

Within the existing literature there was relatively little mention about the communication of sexual difficulties in a relationship, yet adults living with diabetes had expressed concern about their sexual difficulties and reported lower levels of satisfaction in their relationship, in both quantitative and qualitative studies (Schiavi et al., 1995; Nicolosi et al., 2002; Ventura et al., 2018; Cooper et al., 2018).

Many men in this study described feeling challenged as they did not know how to communicate their experience of sexual difficulties. Some seemed to feel overwhelmed with anxiety at the prospect of having a conversation, this may have been influenced by not fully knowing what damage diabetes had caused to their bodies as many were unaware of the connection. Adding to this, the men's hesitancy seemed related to their anticipated thoughts that their partner's response would be negative and non-compassionate, and they expressed fear about where it would lead to and seemed sceptical of the benefits of talking. Justin shared that sex was never talked about and was something kept private. While other men did not communicate this, they seemed to lack confidence to know how to describe what was happening with their bodies suggesting that talking about sex was also unfamiliar to them.

The men in this study developed a range of avoidance strategies that included ignoring their partner, changing the subject when the issue was raised, limiting intimacy, working long hours, going away and withdrawing from the relationship to avoid any discussion about their sexual difficulties. On reflection they seemed to regret doing this as they reported feeling guilty, incongruent, selfish and uneasy and their approach appeared to further limit intimacy in their relationship and they were left alone with their ongoing sexual difficulties. The use of avoidance in relation to having sex rather than communicating about it, was found elsewhere in the literature (Lindau et al., 2010), although in the same study two-thirds of adults also remained engaged in sexual activity. Cooper et al.'s (2018) qualitative research also

suggested that the men coped with their sexual difficulties through avoidance but did not provide detail on how this manifested.

#### **6.2.2.2 Trust feels like it is being eroded**

As the men described that they found it difficult to talk about their sexual difficulties and their partners noticed a change in their sexual behaviour, mistrust developed as the men faced accusations of infidelity. This was a shared finding in other studies which lead to conflict and strain within relationships (Cooper et al., 2018; Liburd et al., 2004; Mayega et al., 2014).

In Rutte's (2016) mixed-methods research, partners expressed dissatisfaction with the sexual relationship and were perceived to have a lack of understanding about the men's sexual difficulties, while the men expressed guilt about their problems, but mistrust was not reported. In the present study the men described feeling under suspicion, of their partners crossing unacceptable boundaries and they were left seemingly powerless when their partners had doubts about their relationship. Some expressed distress and were offended as their beliefs about faithfulness within a marriage were being severely tested and they appeared fearful about the robustness of their relationship to survive. Others spoke of feeling pressured to provide evidence of their fidelity and they described their dislike at having to do this but being believed felt important. Elsewhere in the literature it is unknown how the men experienced or managed the conflict and strain in their relationship.

Some of the men also expressed fears that their partners may be tempted to be unfaithful to obtain sexual satisfaction as the men felt they were unable to fulfil this role. Consequently, the men described feeling insecure and experienced a loss in confidence as they were concerned that such actions could have serious repercussions for their relationship. Similar expectations were shared in other studies, fears of men being abandoned by partners and couples separating or divorcing because of sexual difficulties were reported (Cooper et al., 2018, Liburd et al., 2004; Mayega et al., 2014).

There has been little attention within the literature to the role of communication in the relationship when living with diabetes and experiencing sexual difficulties. The findings here highlighted the possible repercussions of finding it difficult to talk that included the erosion of trust, worries about indefinitely and potential breakdown of relationships. Other studies shared similar findings in relation to fears of mistrust and couple separations (Cooper et al., 2018; Liburd et al., 2004; Mayega et al., 2014).

The findings highlighted the importance of attending to the relationship when living with diabetes and sexual difficulties and this corresponds to the psychological and social elements of the Psychobiosocial therapeutic model (McCarthy & Wald, 2012, 2017). The aims of the therapy include the pursuit of good enough sex as this would allow men to regain their confidence and remove the pressure of trying to fulfil their own and their partners sexual expectations while working as a team to address the difficulties experienced. However, this therapeutic model is dependent on both members of the couple agreeing to attend therapy which is not always possible. A huge paradigm shift is also required on behalf of both partners to adjust to having good enough sex especially if they have engaged in sex in a particular way, for a long time that has previously brought sexual satisfaction and that was based upon arousal, erections and orgasms.

### **6.2.3 Viagra is no quick fix**

From the existing literature little was known about the experiences of Black men living with T2DM who had used Viagra to address their sexual difficulties, although we knew something about their views towards taking diabetes medication in general. Viagra was not specifically asked about in this study, but it seemed pertinent to the men as they spoke about it spontaneously and in-depth.

The men have described feeling distressed as they experienced sexual difficulties impacting upon themselves and their relationship with their partner, they talked about their efforts of trying different things and longed for a solution. Decisions about using Viagra seemed complex and it was not an easy answer as the men reflected on both the physical and psychological impact of using medication to manage their sexual difficulties. Some of the men felt they were taking enough medication which was not emphasised in the existing literature. Concern was also raised about the safety and side-effects of Viagra and some men felt it could cause further pain and stress. A few men also expressed fears about becoming reliant upon it and there was sense of potentially becoming overpowered by the medication. There seemed to be similarities here with how Black men felt about their diabetes treatment regimen in general which has been described as demanding, complex and overwhelming (Hood et al; 2018). Findings from Liburd et al.'s (2004) study suggested some Black men adapted their treatment regimens to their individual needs as a way to maintain control, the importance of which has been highlighted in Master Theme 1, sub theme 1: Suddenly I am no longer in control of my erection. Shared concerns about side-effects, safety and desire for something natural were also raised by other men with diabetes and experiencing sexual difficulties (Coimbra & Teixeira, 2015; Kolling, 2012; Rutte et al., 2016).

Difficulties in using Viagra were fleetingly mentioned as a reason for dissatisfaction and discontinuation in quantitative research with men living with diabetes (Corona et al; 2016) In this study, difficulties conveyed with taking Viagra included changing the way the men had sex into something that was thought about, re-evaluated and planned. Some of the men described sex as a bonding and connecting experience and this seemed to jar with having to take pill which was associated with interrupting sex and turning it into a mechanical activity. Interestingly and contravening Viagra's purpose, these thoughts are aligned to those outlined in both Barlow (1986) and Nobre's (2009, 2010, 2013) conceptual models which suggested that being distracted and directing attention towards a non-sexual stimuli can inhibit sexual arousal.

In this study, Des expressed enthusiasm about finding a solution to his sexual difficulties in Viagra in contrast to many of the other men. His elation seemed to be short lived as he described feeling disheartened and dreaded the prospect of being rationed to one tablet per week and having to plan sex around this. Some of the gay and bisexual men in Jowett, Peel and Shaw's study (2012) felt that the psychological impact and severity of erectile dysfunction was also mediated by medication, but they too felt their prescription was not enough to meet their needs.

A few men in this study felt, as they were young, Viagra was not a viable option and they appeared to be fearful about the ongoing nature of their sexual difficulties and dependency on it long-term. Perhaps it would be a constant reminder that they were no longer in control of their bodies as referenced earlier. For some of the men, there also seemed a natural association between erectile dysfunction and being older and as they did not consider themselves to be so, there was an unease about using Viagra and it is possible this association made it even more challenging for them to accept their sexual difficulties.

Quantitative studies have reported that Viagra does not work in around 50 percent of cases of men living with diabetes. Both quantitative and qualitative studies reviewed suggested some men discontinued using Viagra because it had no effect or its effects were unpredictable. However, this was not mentioned in this study, all the men described Viagra giving them an erection but the implications of using it did not meet with their individual desires. In other studies additional reasons cited for dissatisfaction with Viagra and subsequent discontinuation included affordability, embarrassment and partners raising concerns about an erection being a sign of real attraction (Coimbra & Teixeira, 2015; Kolling, 2012; Cooper et al., 2018) but these were not expressed here.

The findings from this study provided an in-depth view of how Viagra as an intervention was experienced by Black men living with sexual difficulties and T2DM. While Viagra enabled the men to have an erection it did not merge with their lives as it altered the very essence of the way they engaged in sex. These findings are broadly consistent with negative views expressed in previous studies about Viagra. Erectile dysfunction has become increasingly medicalised and NICE recommends Viagra as first-line therapy. Yet in this study and others, many have expressed dissatisfaction and discontinued using it and feedback was rarely sought by HCPS. This research adds to existing studies to suggest that Viagra is not a suitable option for some men and it is reasonable to advocate that they should be offered alternatives and choice.

#### **6.2.4 Am I no longer a man?**

The men in this study suggested that as they encountered sexual difficulties they questioned their masculinity which was challenging. The reappraisal of their masculinity is discussed here first in relation to the self, followed by partners and finally in relation to others.

No longer feeling like a man was a salient finding in this study and in other studies with Black men and other men living with T2DM and experiencing sexual difficulties. However, several new findings came to the fore in this study, as it seemed the men reevaluated their masculine identity on a range of sexual dimensions. The men's descriptions of this included, being a sexual performer and actively having sex with their partner was expressed as a central concept of manliness and the men spoke of a sense of inadequacy when they found themselves unable to perform. They felt they were falling short of meeting their own sexual expectations as they were no longer able to reach sexual satisfaction.

Some men suggested their manliness was shaped by their sexual strength, distinguished from physical strength as being more potent. They felt this had been stripped away and it appeared to leave them feeling powerless and defeated and this seemed incompatible with feeling like a man. Research on Black masculinity conducted by Mincey and colleagues (2014), suggested that meanings associated with being a Black man included strength to overcome and endure, and having an attitude which incorporated feelings of power. If the men in this study shared similar values it is possible that this could have added to their struggle and might have promoted the re-evaluation of their masculinity as they experienced sexual difficulties. The findings here are also consistent with Connell's (1995) claims that gender identity can be vulnerable when the body's performance cannot be sustained due to illness.

Consistently across studies, men with T2DM appeared to question their masculinity as they experienced sexual difficulties, but an overview was provided rather than a granular description of the men's experiences. In these studies, diabetes was perceived to weaken the men's masculinity and they spoke of a loss of manpower and manhood which they associated with powerlessness, and of lost hope (Metta et al., 2017; Mayega et al., 2014, 2018) as did the men in this study. Frequently the men considered themselves no longer real men as they found their sexual functioning limited and referred to themselves as being diminished but rarely was the meaning of this explored (Cooper et al., 2018; Kolling, 2012). Jowett, Peel & Shaw (2012) described some of the gay and bisexual men in their study also sharing thoughts of being diminished and experiencing a loss of confidence and self-worth in relation to attracting a sexual partner, but in this study emphasis was placed on some of the men feeling pressured to conform to certain gay identities and stereotypes rather than questioning their sense of manliness.

In this study many of the men reappraised the qualities that contributed to their masculinity in a dichotomic way as if they were passing or failing a test and maintaining their masculine identity seemed particularly challenging when experiencing sexual difficulties, but this was not something noted in other studies. However, Black masculinity literature suggested that Black men can develop varying and complex understandings of manhood but there can be an expectation to conform to dominant gender roles (Hunter & Davis, 1992). Franklin's (1994) socialisation framework also proposed that Black masculine identity was shaped in part by the influence of mainstream society and media which idealises dominant masculine traits and which may potentially conflict with influences received in the home and community.

Findings from studies that explored the experience of managing diabetes suggested that for some Black men this had a negative impact on how they viewed themselves, as they felt a loss of autonomy and were no longer fulfilling roles of protector and carer which were important to their identity (Liburd et al., 2004; Liburd, Namageyo-Funa, & Jack, 2007; Shiyabola, Ward & Brown, 2018). These qualities among others have been identified as important in the shaping and meaning of Black masculinity across various studies (Hunter & Davis, 1992; Hammond & Mattis, 2005; Chaney, 2009) Shiyabola, Ward & Brown (2018) suggested that some Black men in their study felt their diabetes had impacted more broadly across their sexual, social and employee identities. In other studies, some Black men were described as no longer feeling invincible, sexual or proud as they once did and expressed a desire to return to their past identity (Liburd et al., 2004; Liburd, Namageyo-Funa & Jack, 2007; Metta et al.,

2017). Some of these challenges were also shared by the men in this study when they re-evaluated their masculinity.

Many of the men described feeling less manly as they no longer felt able to sexually satisfy their partners. Some of the men seemed to suggest that being able to fulfil their partners sexually made them happy and their sense of worth appeared connected to this. Consequently, they were left feeling demotivated and questioning the point of sex when no longer able to do so, culminated in thoughts about no longer being a man. These findings are consistent with the men in Cooper et al.'s study (2018) who suggested that as they were no longer living up to sexual expectations of their partner, the men perceived this as form of emasculation.

Kimmel, Hearn & Connell (2005) claimed that in addition to considering the inferences of masculinity and male roles in relation to health processes it is also necessary to be mindful of the 'plurality of masculinities' and the intersections among gender, ethnicity, race, class and sexual orientation. Findings from this study suggested that as the men re-evaluated their masculinity their cultural values seemed to come to the fore, something that was not emphasised in other studies. In relation to their culture influences, some of the men seemed to describe a range of qualities, beliefs and behaviours that were expected and that symbolised what it meant to be a man and a Black man in some Black communities. The men suggested that it was expected for males to be sexually active when in a relationship and to have a family. Some described that when engaging in sex in a relationship it was expected to be effortless, regular, natural, organic, a connecting experience that was also associated with a sense of achievement. Other men felt having sex represented a milestone of turning into a man, playing a key role in feeling like a man and giving men a feeling of confidence and invincibility. A few men perceived these aspects to be more of a societal view that was generally expected and accepted. It is possible that these cultural influences may well have contributed to the development of a well-defined sense of the self and masculine identity, and therefore experiencing sexual difficulties may have been more acutely felt. However, as outlined earlier by Bowleg et al. (2017) many of the cultural values highlighted represent positive aspects of healthy sexual behaviour that contribute to an overall sense of wellbeing which is to be aspired to in order to live a fulfilling life (WHO, 1975). While not specifically referenced in relation to a sexual context, the cultural influences highlighted by the men are similar to qualities among others suggested by Hunter & Davis (1992), Franklin, (1994), Hammond & Mattis (2005), Chaney, (2009) and Mincey and colleagues (2014) of what it means to be a Black man that are centred around family, the community, reaching milestones,

having confidence and striving for achievement; all were considered important in shaping identity.

In this study cultural and societal influences seemed important in the way sexual difficulties were experienced but it is unknown if the findings are unique or consistent with the way other Black men living with T2DM and experiencing similar problems may feel. In the findings, cultural influences were not always distinct in relation to their meaning and association with being a man and a Black man, but these two aspects of identity seemed to overlap somewhat and this was consistent with the masculinity literature outlined in the literature review chapter. IPA does not enable underlying mechanisms to be identified so it is also unclear how cultural expectations exactly interact with masculine identity and psychological wellbeing. Relatively little attention seemed to be given the role of culture in other studies. Kolling (2012) briefly suggested that men in her study were possibly reluctant to speak about their sex life because of the prevailing socio-cultural notions within Brazil where potency was valued and is perceived as an enactment of masculinity.

Sexual difficulties were not often talked about to others and sex as a topic was rarely discussed. There was an expectation by many men in this study that their experiences would be viewed negatively rather than in a compassionate way and consequently they would be thought of as less of a man. To help understand these findings it might be useful to consider Cross & Fhagen-Smith (2001) developmental model of ethnic identity and Jones-Smith's tripartite model (1985, 1991) and Franklin's model of socialisation (1994). All three models posit the important and influential role peers play in shaping an individual's identity and it might be that when growing up some men learnt that issues such as sexual performance and sexual difficulties are not talked about. In this study many of the men described their struggle to maintain their masculine identity. Although this was not so for John who described not seeing himself differently as a man but he seemed to suggest that his masculine identity also felt safe as his sexual difficulties were unknown to the outside world, which supports the suggestions made above.

The influence of culture was not widely emphasised within the existing literature, but some Black men appeared fearful of other people finding out about their sexual difficulties as they felt they would be ostracised, gossiped about and their lives would be ruined, but it was unclear if others referred to were friends or shared a similar culture (Shiyanbola, Ward & Brown, 2018; Metta et al., 2017).

The findings from this study suggested how important sex is and how beneficial it can be to a man's confidence, their sense of wellbeing and how they feel about themselves as man. This research has highlighted the intricacies of masculinity that can be impacted upon when men experience sexual difficulties.

### **6.3 A Summary of the Novel Findings from this Study**

The findings from this study provided an in-depth view of how Viagra as an intervention was experienced by Black men living with sexual difficulties and T2DM and prior to this research little was known about their experiences. Sex was of key concern for the men in this study and they wanted to find a solution for their sexual difficulties. From the men's descriptions it seemed that Viagra was not a quick fix, as there were number of psychological and physical implications of using the medication and the decision to do so was complex. In particular, the men conveyed that taking Viagra involved changing the way they had sex into something that was planned, thought about and re-evaluated. These processes seemed very different to how some of the men described sex as a bonding and connecting experience and one that was fluid, impulsive and organically unfolded. From some of the men's descriptions having to take a pill seemed to jar with their experience, as it involved interrupting sex in the moment and turning it into a mechanical or technical activity and in doing so altered the very essence of the way the men engaged in sex. Interestingly and contravening Viagra's purpose, these thoughts are aligned to those outlined in both Barlow (1986) and Nobre's (2009, 2010, 2013) conceptual models which suggested that being distracted and directing attention towards non-sexual stimuli as opposed to sexual stimuli can inhibit sexual arousal and maintain erectile dysfunction. Within the men's account there also seemed to be an absence of talk about erotic stimuli. From this extract of the findings, Viagra did not seem to give the men agency or meet their needs and this has implications for psychological therapy which does emphasise the unique needs of the individual and can facilitate growth and self-actualisation (Maslow, 1970).

In the study, the men's accounts of their sexual difficulties intimated that their penis and erection felt separate and detached from their body, and their bodies and minds no longer felt aligned in the way they once had. Interestingly if we link this to the previous findings in relation to men's experiences of taking Viagra medication, while most of the men described Viagra giving them an erection it did not seem to reconnect the men's bodies with their minds but reconfirmed and reinforced this separation. As some of the men described having an erection but not necessary being in the mood for sex or they described sex as having to be undertaken within a certain timeframe which they felt was restrictive. Adding to this, when the men described their sexual experiences and the distress they felt, they did not tend to talk about

carrying out sex alone or through masturbation for example, but they repeatedly talked about sexual encounters with their partner. It is difficult to conceptualise the men's experiences of their sexual difficulties without incorporating their partner and the relationship. This suggests when attending to the men's concerns a more holistic and integrative approach is required taking account of the psychological, social and cultural impact alongside the biological implications of experiencing diabetes and sexual difficulties (McCarthy & Wald, 2012, 2017).

The men described losing their erections as unexpected and unfamiliar. They expressed feeling shocked, and surprised and were left confused and in disbelief as they no longer felt attuned with their body. The men's recollections of their sexual encounters were vivid and strong and were evocative of how other men responded when initially receiving their diagnosis of diabetes which has been reported elsewhere (Stuckey et al., 2014; Gask, MacDonald, & Bower, 2011; Tanenbaum et al., 2016). It is possible that some of the men are re-experiencing something akin to a trauma as their identity is challenged repeatedly in an unexpected and unintended way. Diabetes is a chronic, complex and progressive condition impacting on all areas of the body, this might then become a regular occurrence for the men. Which could lead to an increase in long term psychological distress and have wider implications in relation to the men's overall lives. Psychological support could help in terms of adjustment, integration and the acceptance of the ongoing changes experienced.

In this study many of the men re-evaluated their masculinity as they experienced sexual difficulties and as part of this, the men's sexual and cultural beliefs came to the fore, and the questions the men posed to themselves suggest they were not meeting them in the way they were expected to. These findings are consistent with the ideas posited by Nobre's (2009, 2010, 2013) cognitive conceptual model which hypothesized that having similar, strong beliefs, and expectations about sexual performance and masculinity for the self and the partner can act as both predisposing and maintaining factors for erectile dysfunction. In this study many of the men reappraised the qualities that contributed to their masculinity in a harsh dichotomic way, as if they were passing or failing a test and maintaining their masculine identity seemed to be particularly challenging as they felt their body no longer functioned sexually in the way they would like. Changes to identity as someone adjusts to living with diabetes can be testing, particularly as it is not usually through choice, so perhaps it is unsurprising that some of the men when experiencing sexual difficulties are reluctant to embrace further changes to their identity as they perceive their sense of their self to be under attack once again, causing psychological distress. The men described not talking to anyone about their sexual difficulties and experiencing sexual difficulties seem to be unheard of

amongst their peers and in their communities and one would expect this only added to their levels of distress.

#### **6.4 Clinical/Psychological Implications for Counselling Psychologists – 1-1 Therapeutic Work**

Psychological interventions are not systematically offered to men living with diabetes and experiencing sexual difficulties and care is not always integrated. Many of the men expressed dissatisfaction with taking Viagra and discontinued using it and yet this was rarely followed up or discussed with their GP and it might be that men are left alone to find their own solutions. This is particularly significant for men with T2DM who engage only with Primary Care and who may have sporadic contact with their local surgery. Access to psychological support via psychosexual services can be complex if men are unaware of the services on offer.

In the literature it is generally agreed that the management of diabetes is complex. Within this section I recommend a range of therapeutic interventions based on the specific findings from this study with the aim of informing and supporting the therapeutic work of Counselling Psychologists working with Black men living with T2DM and sexual difficulties:

**Counselling Psychologists develop greater understanding and empathy.** A granular account of the men's experiences has been provided when being in the sexual moment and when they do not seem to feel in control of their erections and it is hoped that this could enable Counselling Psychologists to develop greater empathy and understanding of what it is like for some Black men with T2DM to experience sexual difficulties.

**Support processing of emotions.** Thinking about the conceptualisation of erectile dysfunction and how it is maintained for the general population, Barlow's (1986) and Nobre's (2009) models placed great emphasis upon the role of cognition but it seemed the men in this study struggled to deal with their emotions associated with their sexual difficulties and it is not only cognition that required attending to but a safe space to explore the unfamiliar feelings experienced by the men in order to process them. Counselling Psychology could support Black men with T2DM to process emotions associated with their sexual difficulties, normalise their experience and help adjust to living with sexual difficulties.

**Help develop communication skills.** Counselling Psychologists could support men to develop a language, in how to talk about sex, enabling them to become confident and to access the services they might need. This work could also help them engage in conversations

with their partners as this was a pertinent issue and particularly daunting and challenging for many of the men, placing their relationships under strain. This work would be particularly important if the partner is unable to join or engage with psychological therapy.

**Working with both partners therapeutically.** It is important to consider the role of the partner with regards to contributing to and maintaining sexual difficulties within the relationship and it is recommended that psychological therapy is a joint endeavour with both parties. If adopting a Psychobiosocial approach (McCarthy & Wald, 2012, 2017), both partners are required to be equally engaged and the aim of the therapy is to work towards for example 'good enough sex' that would allow men to regain confidence and remove the pressure of trying to fulfil their own and their partners sexual expectations. Participating in therapy together would also enable some couples to work around communicating effectively. It might be that partners may not wish to join or engage with psychological therapy, nevertheless it is still important to consider their role in the relationship and leave the invitation open for them to join the therapy at a later stage.

**Explore masculine identity.** The findings from this study suggested that some Black men when they encountered sexual difficulties questioned their masculine identity. Counselling Psychologists would be well placed to support men process the changes and threats to their identity while taking into consideration the men's strengths and the importance of their cultural values, helping them to adjust to living with sexual difficulties while considering their individual preferences for their sex lives.

**Trauma focussed therapy.** It is possible that when experiencing sexual difficulties the trauma of being diagnosed with diabetes might be retriggered for some men and Counselling Psychologists can provide a safe space to explore and reprocess the trauma in more depth.

**Establish peer support groups.** Counselling Psychologists are encouraged to set up Black support groups for men. Findings from this study, and elsewhere suggest Black men with T2DM enjoyed being part of a collective group and found it beneficial to talk about their sexual difficulties, sharing their experiences while also listening to others.

**Summary of Psychological Interventions.** There are many different interventions a Counselling Psychologist can use when working with Black men living with T2DM and experiencing sexual difficulties and the psychological approach taken depends on the needs of the client, where they are in their journey and what they would like to focus on. Some guiding principles for practice, could for example involve the processing of the sexual complications, associated emotions and trauma, the provision of psychoeducation in relation

to the connection between diabetes and sexual difficulties, the exploration of beliefs and roles of medication and psychological therapy and how they can work together, the introduction of behavioural interventions such as sensate focus, desensitisation and the re-evaluation of sexual and cultural beliefs and scripts. The psychological approach to take would be explored through a clinical assessment and agreed with the client and this would be reviewed as the work progressed.

## **6.5 Evaluation**

This section of the discussion will consider the strengths, limitations, researcher's role and service level implications. Yardley's (2000) guidelines for conducting qualitative research will be referenced throughout. Recommendations for future research will also be suggested.

### **6.5.1 Strengths**

The study had a number of methodological strengths. This research purposely set out to recruit Black men with T2DM who were experiencing sexual difficulties and they were recruited based upon a shared experience and they were asked about their experiences specifically. Studies conducted elsewhere have tended to be concerned with the general lived experience of diabetes. Few studies have been conducted exclusively with Black men in the areas of diabetes and sex and their experiences remained at the forefront throughout. The research also generated rich data suggesting that sex is important and sexual difficulties are of concern and as such other Black men living with T2DM might find it useful to hear about others' experiences.

This research also provided an in-depth and granular account of men's sexual encounters, increasing understanding of how sexual difficulties are experienced and the psychological impact on the self and the sexual relationship. A final strength of this study is in relation to meeting Yardley's (2000) second principle of commitment and rigour and I feel that has been reflected in both the literature review and discussion chapters. I have tried to show the depth and breadth of research that has been carried out worldwide in the fields of diabetes and erectile dysfunction to inform and add context to the research findings from this study.

### **6.5.2 Limitations**

Several limitations were identified, the most pertinent included the focus of the study, methodology and researcher role. Using existing literature as a guide alongside the men's emphasis of their experiences, this study predominantly explored erectile dysfunction and this

narrow focus has perhaps failed to capture the full experience of living with other sexual difficulties. Therefore, the insight gained will add to existing literature rather than create new research insight in other neglected areas of sexual dysfunction.

A criticism of sexual health research with Black men is that it is deficit-focussed suggesting experiences are problematic and negative (Bowleg et al., 2017). This study is centred around experiences of sexual difficulties and it too can be perceived as adding to this narrative. The rationale for conducting an exploratory study was based upon a lack of research in this area and at the time it was relatively unknown what the men's experiences would be like. On reflection, men whose sexual difficulties were not a cause for concern may well have felt less inclined to take part in this study.

In terms of methodology, the sample was small, and the findings cannot be generalised and are reflective of the experiences of the participants only. However, Smith, Flowers & Larkin (2009) point out, that findings from IPA research may have "theoretical transferability" rather than empirical generalisability and in this sense may enable others to find some useful ideas and information from findings (Smith, Flowers & Larkin, 2009, p51). The men were all in heterosexual relationships, so the findings have not captured experiences of Black men with other sexual identities.

Much has been written about the ethnic matching of participants and researcher insider-outsider status and the importance of clarity about research motives, ethical representation and reflexivity (Gunaratnam, 2003; Salway et al., 2009). Reflecting on Yardley's (2000) first principle of sensitivity to context, that encompasses attending to the interviewee-researcher relationship, I felt as an outsider my relationship with the participants was complex. As a White woman researcher, I asked the men explicitly about my difference and they responded by saying that they had friends and family from a range of ethnic backgrounds. More was made of my gender, as the men stated that this had helped them to open-up about their experiences which they had found cathartic. All the men communicated that if I had been a male researcher they would not have participated in the study. Reflecting on the men's comments, my gender identity seemed to be a strength of this research study as it helped the men share their experience and facilitated the generation of rich data.

However, I felt my outsider status return to the fore when conducting the analysis, particularly when the men questioned their masculinity and what it meant to be a Black man. I struggled to connect with this, and it highlighted my difference and distance. My identity as a woman came into sharper focus, of how important and much loved my gender identity is to me and I

started to reflect on how I would feel if this part of my identity became threatened in an unexpected and unwelcome way. This helped, together with further reading around what masculinity means to Black men and hopefully this brought me closer to catch a glimpse of the men's experiences and what it was like for them to question their masculinity through my distorted lens of otherness.

The #BlackLivesMatter movement (<http://blacklivesmatter.com>), the events of 2020 and the calls to uproot racism, brutality and injustice embedded within society made me rethink about the work I was doing in terms of some of the assumptions that I set out with as a White researcher and in relation to the ethical representation of the participants (Oguntokun, 1998; Salway et al., 2009). The design, questions asked, analysis extracted, commentary and recommendations is my interpretation and reflects who I am and my interests and assumptions and in doing so this highlights my difference. A Black researcher possibly would have designed a different type of study, asked different questions, found other aspects of the men's experiences interesting and drawn alternative conclusions.

### **6.5.3 Final Reflections**

Looking back over my research journey, I have mixed feelings about what I thought this research could achieve. My [REDACTED] background motivated me to undertake this research with the aim of helping others to be heard. Modifying my [REDACTED] voice when writing up the findings to one that more accurately reflected the men's experiences and that was tentative and more aligned with IPA felt incompatible at times. IPA is a flexible methodology and its premise easily grasped but transforming this into action was complicated and restrictive. I found it impossible to shake off my practitioner role, automatically asking why about the men's accounts rather than staying focused on the how.

### **6.5.4 Future Research**

Writing up this research I have kept in mind Yardley's (2000) third principle of transparency and coherence in the hope it will encourage researchers to build on this research. The next step could involve mixed-methodology research to see if the issues raised are salient across a wider population of Black men with T2DM. Capturing the impact of sexual difficulties that also include positive experiences related to coping and adaptation, with Black men of different sexual identities and in different types of relationships would provide a more comprehensive picture.

The narrow focus on erectile dysfunction might be perceived as a criticism of this study, however, I would recommend future research continues with this approach as a review of existing literature has illustrated that many diabetes and erectile dysfunction studies stand alone, and as they have not been brought together under one umbrella this limits their usefulness with regards to informing the work of the scientist-practitioner and this is a missed opportunity to share valuable learning.

Following on from this, collaboration with Black men through participatory action focus groups would facilitate the development of interventions that are tailored to their specific needs. Further phases could then be expanded to incorporate partners and other types of sexual difficulties.

### **6.5.5 Service Level Applications**

Reconsidering Yardley's (2000) fourth principle of impact and importance, the findings from this study support existing findings and identify new ones that require attention. Findings related to specific 1-1 therapeutic work have been outlined earlier, in addition Counselling Psychologists would make a valuable contribution to other service areas and these are described below.

#### **6.5.5.1 Counselling Psychologists Leading the Debate – Connecting Diabetes & Sexual Health**

Within the academic and clinical literature, diabetes and sex are often considered separately. A recommendation would be for Psychologists working in these fields to come together to share learnings and debate the role of psychology, glycaemic control and self-care, to review existing psychological theories and models that could help understand the experience of living with diabetes and sexual difficulties, to make recommendations for future theoretical development and appraisal, while also identifying priorities for research, to deliberate on how to build a body of respected evidence while discussing the most meaningful way to evaluate psychological interventions.

These discussions need to give due consideration to the diverse nature of men with T2DM, addressing barriers to support for Black men and how their strengths, needs and cultural values could be fully incorporated into any psychological offering, areas that have often been neglected.

As part of these discussions, it is also important to consider the medicalisation of erectile dysfunction and the preference for prescribing Viagra. This requires a collective response and there is a desperate need for more psychological research so that it can be considered alongside biomedical research.

#### **6.5.5.2 Counselling Psychologists - Helping to Develop Services**

Counselling Psychologists could work alongside colleagues in health and charitable sectors using their skills and knowledge to help inform and contribute to messaging that is aimed at raising awareness of the connection between diabetes and sexual difficulties, that would encourage Black men to seek help sooner and that highlights treatment options and routes to access.

#### **6.5.5.3 Counselling Psychologists – Consultation & Supervision & HCPs requirements**

A Department of Health (DOH) report calculated that people with diabetes spent approximately three hours with a HCP annually (DOH, 2007), suggesting adults are mainly left to self-manage despite the complexity of diabetes. Lobbying with HCP colleagues is obviously required to increase access to care and psychological support, as it is rare for adults to be offered therapy.

In the meantime, Counselling Psychologists could support HCPs to make the most of the short interactions by helping them to develop a language that will enable them to become more empowered and confident in order to initiate conversations about sex, while also considering cultural values and sexual beliefs of the client.

In this study and in Jowett, Peel & Shaw (2012) research the men experienced Thrush, alongside sexual difficulties and while the men sought help for Thrush, their sex lives were not enquired about at the same time by their GP, this felt like a missed opportunity. Psychologists can raise awareness with HCPs about sexual complications associated with diabetes, how appointments about Thrush might act as a calling card and the psychological impact sexual problems can have.

In this study and across the literature, Viagra was often prescribed but rarely enquired about in subsequent appointments. HCPs require support to revisit sexual issues that have been presented previously while also having awareness of clear pathways for patient referrals for psychological support and information about the role of a Psychologist in terms of what they

do and how they can help and support a client. Psychologists are encouraged to develop stronger local networks with HCPs and they would be well placed to work more closely with HCPs who undertake annual health checks with people with T2DM and as part of this exercise incorporate questions about sexual difficulties and psychological wellbeing.

#### **6.5.5.4 Dissemination of Findings Plan**

The intention is to publish the research findings in various academic journals taking a staged approach. By focusing on the findings from one master theme at a time, I will be able to tailor articles to different audiences and journals in order to have maximum impact.

In the first stage, I hope to publish the findings from Master Theme Three: “Viagra is no quick fix” in a diabetes focussed journal. Traditionally diabetes research has tended to be quantitative and based on the medical model, whereas my research is qualitative with a psychological focus. I thought in the first instance, publishing the findings from the Viagra master theme would act as bridge as it has both physical/medical and psychological implications. There is currently a heavy reliance on prescribing Viagra for erectile dysfunction but the findings from my study suggested that this does not work in a number of ways for Black men with T2DM. The findings from this study are novel and it is important to try and publish them in order to help bring about change. By focussing on one particular issue it is hoped the key take home messages from the article will remain front of mind for HCPs when considering the prescription of Viagra and engaging in future interactions about sexual difficulties with patients. The reason for deciding to publish initially in a diabetes focussed journal such as *Practical Diabetes* is that it has a broad readership of health clinicians, this seemed particularly pertinent as many adults with T2DM, depending where they are on their journey may only have sporadic interaction with HCPs and this will mainly be with their GP or nurse at their local surgery in primary care, as current access to psychological support is very limited.

In addition to publishing the findings, I also plan to attend health care professional conferences to present the findings to HCPs such as those organised by Diabetes UK, the International Diabetes Foundation and the European Psychosocial Diabetes Group. By attending conferences I also aim to network and make necessary connections with members of local primary networks with the hope of being invited to present the findings from my study and engage in workshops at a local level. Finally a number of universities in the UK offer postgraduate diabetes courses and this might be another forum that I can utilise to disseminate my findings to a clinical audience.

A key part of the dissemination plan is also to involve Black men with T2DM [REDACTED]  
[REDACTED]  
[REDACTED]

and to work collaboratively, to agree the most effective way to share the research findings with other Black men living with T2DM so that they have maximum impact. The aim is to share the experiences of the participants from this study, to raise awareness of the connection between diabetes, sexual difficulties and psychological wellbeing and to identify and signpost to relevant support resources.

## **6.6 Conclusion**

This research set out to understand the subjective experiences and impact of sexual difficulties in men as there had been relatively little research in this area. This study presented findings that were more granular and enabled a much deeper understanding of what it was like for Black men with T2DM to experience sexual difficulties than existing studies which tended to briefly mention issues without delving further. The findings have provided a picture of what is like for the men, broken down moment by moment during a sexual encounter but one that also includes the wider impact on their sexual relationship and their identity as a man. We now know from this study that sex was described as important by participants but was not necessarily meeting their needs. Trying to address and adjust to their sexual difficulties seemed to be psychologically challenging for the men and this appeared to subsequently lead to strain and conflict within their relationship and the men continued to be alone with their ongoing difficulties as they had not found or been offered a suitable solution. All of these aspects impacted on the men's sense of their self and many described feeling their masculine identity had become endangered. There were some parallels between Black men's experiences of being diagnosed with diabetes and experiencing sexual difficulties although a note of caution is required as few studies have been conducted and it is important to not lose the nuances between the different experiences. Rarely has sex and diabetes been considered together in a research study with a psychological focus with Black men. I have a number of hopes for this research; that it will be of interest to Psychologists who will feel inspired to conduct research in this area and build on these findings, it will give Psychologists and HCPs a deeper understanding of the salient issues of what it is like to experience sexual difficulties, that it will generate debate about the provision of psychological support for Black men living with T2DM and experiencing sexual difficulties, that it will increase awareness of and add to existing concerns about the use of Viagra and finally it is hoped that these experiences will be shared with other Black men living with T2DM.

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Appendices  
Appendix A: Ethics Approval Letter and Ethics Form



Psychology Research Ethics Committee  
School of Arts and Social Sciences  
City University London  
London EC1R 0JD

3<sup>rd</sup> March 2016

Dear [REDACTED] and [REDACTED]

**Reference:** PSYETH (P/L) 15/16 181

**Project title:** Exploring the experiences of intimate relationships among Black African Caribbean men with Type 2 diabetes

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

- (a) Recruit a new category of participants
- (b) Change, or add to, the research method employed
- (c) Collect additional types of data
- (d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee ([REDACTED]) in the event of any of the following:

- (a) Adverse events
- (b) Breaches of confidentiality
- (c) Safeguarding issues relating to children and 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 5 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 then please do not hesitate to get in touch.

Kind regards

[REDACTED]  
Student Administrator  
Email: [REDACTED]

[REDACTED]  
Chair  
Email: [REDACTED]



## Psychology Department Standard Ethics Application Form: Undergraduate, Taught Masters and Professional Doctorate Students

This form should be completed in full. Please ensure you include the accompanying documentation listed in question 19.

<b>Does your research involve any of the following?</b> <i>For each item, please place a 'x' in the appropriate column</i>	<b>Yes</b>	<b>No</b>
Persons under the age of 18 <i>(If yes, please refer to the Working with Children guidelines and include a copy of your DBS)</i>		x
Vulnerable adults (e.g. with psychological difficulties) <i>(If yes, please include a copy of your DBS where applicable)</i>		x
Use of deception <i>(If yes, please refer to the Use of Deception guidelines)</i>		x
Questions about potentially sensitive topics		x
Potential for 'labelling' by the researcher or participant (e.g. 'I am stupid')		x
Potential for psychological stress, anxiety, humiliation or pain		x
Questions about illegal activities		x
Invasive interventions that would not normally be encountered in everyday life (e.g. vigorous exercise, administration of drugs)		x
Potential for adverse impact on employment or social standing		x
The collection of human tissue, blood or other biological samples		x
Access to potentially sensitive data via a third party (e.g. employee data)		x
Access to personal records or confidential information		x
Anything else that means it has more than a minimal risk of physical or psychological harm, discomfort or stress to participants.		x

**If you answered 'no' to all the above questions your application may be eligible for light touch review.** You should send your application to your supervisor who will approve it and send it to a second reviewer. Once the second reviewer has approved your application they will submit it to [psychology.ethics@city.ac.uk](mailto:psychology.ethics@city.ac.uk) and you will be issued with an ethics approval code. You cannot start your research until you have received this code.

**If you answered 'yes' to any of the questions, your application is NOT eligible for light touch review** and will need to be reviewed at the next Psychology Department Research Ethics Committee meeting. You should send your application to your supervisor who will approve it and send it to [psychology.ethics@city.ac.uk](mailto:psychology.ethics@city.ac.uk). The committee meetings take place on the first Wednesday of every month (with the exception of January and August). Your application should be submitted at least 2 weeks in advance of the meeting you would like it considered at. We aim to send you a response within 7 days. Note that you may be asked to revise and resubmit your application so should ensure you allow for sufficient time when scheduling your research. Once your application has been approved you will be issued with an ethics approval code. You cannot start your research until you have received this code.

<b>Which of the following describes the main applicant?</b> <i>Please place a 'x' in the appropriate space</i>	
Undergraduate student	
Taught postgraduate student	
Professional doctorate student	x
Research student	
Staff (applying for own research)	
Staff (applying for research conducted as part of a lab class)	

<b>1. Name of applicant(s).</b>
Charlotte Dent
<b>2. Email(s).</b>
████████████████████
<b>3. Project title.</b>
Exploring the experiences of intimate relationships among Black African Caribbean men with Type 2 diabetes
<b>4. Provide a lay summary of the background and aims of the research. (No more than 400 words.)</b>
<p>The aim of this study is to explore sexual and intimacy difficulties experienced by Black men who are in relationships and living with a long- term health condition – Type 2 diabetes. Males of Black African and Black African Caribbean ethnic backgrounds are more likely to experience Type 2 diabetes and at an earlier age. In addition, men with diabetes can also experience sexual difficulties including a lack of sexual desire and erectile dysfunction; although it is unknown whether the participants interviewed will have experienced the same difficulties. Despite this situation men and Black men in particular are less likely to access health services.</p> <p>By carrying out this study it is hoped more knowledge and a deeper understanding about the sexual difficulties encountered in relationships by Black men with Type 2 diabetes will be developed. The findings will be shared with stakeholders across the health discipline. In addition it is hoped the findings of this research will act as building block for further studies in this area.</p>
<b>5. Provide a summary of the design and methodology.</b>
<p>A qualitative design will be adopted for this research. 6-8 participants will be recruited for the study, this will enable in depth information to be obtained and enable the fieldwork and analysis to be undertaken within the timeframe. Adverts for the study will be located in areas of where prevalence of Type 2 diabetes is high and in areas where large populations of Black residents live. In line with IPA, participants will be recruited in accordance with 'purposive homogeneous sampling' (Smith et al, 2009, p49). Semi structured interviews and an interview guide will be developed focusing on the experience and meaning of the participants. Interviews will be last approximately 90-120 minutes and be undertaken near to the participant's place of home or work. The research will be undertaken using IPA and analysis will be conducted in line with Jonathan Smith's guidelines.</p>

**6. Provide details of all the methods of data collection you will employ (e.g., questionnaires, reaction times, skin conductance, audio-recorded interviews).**

Once participants have registered their interest for the study, their contact details will be recorded and securely stored (encrypted and with a password). These contact details will be secured separately from the interview transcripts.

Participants will be asked to take part in one face to face interview with the researcher. The interview will be audio-recorded and the script transcribed for analysis purposes. The interview will last approximately 90-120 minutes. The audio-recordings will be secured safely on the University's secure server and password protected.

At the beginning of the interview a short questionnaire will be administered with the aim of obtaining background information from the respondent, for example their age, their employment status and the year they were diagnosed with diabetes (see appendix 10).

As this study is using IPA, a semi structured interview guide will be used for the main part of the interview (an example is provided in appendix 11). Due to the nature of IPA, the questions may change depending on the nature of the responses from participants. Following each interview the guide will be reflected upon and reviewed.

**7. Is there any possibility of a participant disclosing any issues of concern during the course of the research? (e.g. emotional, psychological, health or educational.) Is there any possibility of the researcher identifying such issues? If so, please describe the procedures that are in place for the appropriate referral of the participant.**

Yes there is a possibility. The participant may disclose issues of concern and the researcher may also identify issues of concern during the interview. However, recruitment for this study is with the broad general public. While members of the general public will be asked to share and think of relationship experiences which are potentially emotional, they are not being recruited from NHS or private clinics or therapeutic settings. It is unknown if members of the general public interviewed will have specifically experienced erectile dysfunction or a lack of sexual desire but they will have experienced some kind of difficulty in their sexual and intimate relationships.

The participant will be verbally told prior to the interview starting they can refuse to answer a question, halt or end the interview at any time and withdraw from the research study, up to four months after the interview. This information will also be given in the information sheet prior to the research and their understanding of it will be checked.

At the end of the interview, the participant will receive a debrief, they will have the opportunity to feedback on the experience of the interview and talk about any concerns or queries they have following it. In addition as a Trainee Counselling Psychologist, I will note and be aware of signs and changes in body language and I will discuss these at the end of the interview with the participant. The client will be provided with further information about support services (see debrief sheet, appendix 7). In addition the participant will be notified that they can also contact their local GP for support.

**8. Details of participants (e.g. age, gender, exclusion/inclusion criteria). Please justify any exclusion criteria.**

Inclusion criteria for this study includes: Black men (Black British, Black African, Black African Caribbean heritage), who have been diagnosed with Type 2 diabetes. At the time of recruitment the participants also will have to be involved in a sexual relationship with another adult (i.e. over the age of 18) and have experienced sexual difficulties.

Males have been chosen for the study because they are slightly more likely to be diagnosed in the UK than females (56 per cent). Adults with a Black African and Black African Caribbean ethnic background are the focus of this study because they are up to three times more likely to experience Type 2 diabetes in comparison to adults from White ethnic backgrounds in the UK and are also more likely to develop Type 2 diabetes at earlier age, generally about 10 years earlier.

While South Asian populations are also more likely to experience Type 2 diabetes and at an earlier time, they have been excluded from this study because an IPA approach recommends in depth, small scale studies with homogenous participants if possible.

Single adults not in relationships have been excluded because the focus on this research is to explore experiences and difficulties of being in a relationship rather than seeking a partner.

## **9. How will participants be selected and recruited? Who will select and recruit participants?**

As the researcher I will be solely responsible for recruiting and selecting participants for this study. Please see appendix 2 for an example recruitment flyer, I intend to use a range of flyers to advertise this study, in order to attract a range of participants. Adverts will be placed in London boroughs which have highest prevalence of Type 2 diabetes and Black residents. The study will be advertised in a range of places including (although, not exhaustive); barber shops, gyms, community centres, sports centres, local shopping areas, cinemas, local football clubs, mini cab offices and takeaways (with prior permission of owners). Online social media forums and Black groups will also be used to publicise the study, this will be undertaken using a secure server and the information will be taken down and removed on completion of the study. Budget allowing, adverts may also be taken out on local radio stations and newspapers/magazines such as the Metro, Evening Standard and The Voice. Flyers advertising the study will also be handed out on street corners.

Once someone has registered their interest in taking part in the study, either by voicemail message or email, I will undertake a follow up telephone call with the potential participant, during this conversation I will cover the following points:-

- Introduce who I am
- Introduce the study/aim of it
- Ask where they saw the study advertised
- Explore what interested them about the study
- Explore/establish motivations for taking part
- Introduce requirements to the study (interview /duration/location)
- Ask about the type of diabetes they had
- Ask when they were diagnosed with diabetes
- Ask for their ethnic origin
- Ask their age
- Ask if they are in a relationship with another adult (over 18)
- Check their availability to take part in an interview within the time frame
- Ask their location/where they are based within London
- State the interviews will take place in a public/open building (close to their place of work or home) – address to be confirmed
- Take their contact details
- Advise the information sheet will be sent to the potential respondent with further information about the study
- Ask if they have any further questions
- Advise I will be back in touch to confirm time of interview/venue of interview
- Reiterate contact details should they need to get back in contact in the interim period or change their mind about participating in the study
- Thank them for their interest

During this telephone conversation I will use my therapeutic skills and experience developed from working in a psychosexual placement, specifically in relation to engaging in conversations around sex and sexual difficulties. In addition I will draw on my experience of working for a diabetes charity for the last 5 years and being in contact with people with diabetes and those who have experienced complications as a result of their long term health condition.

At the end of the telephone conversation, if I as the researcher have no concerns about the motivations of the potential respondent to take part in the study and they meet the inclusion criteria (male, described themselves as of Black British, Black African & Black African Caribbean heritage and have Type 2 diabetes and are in a relationship with an adult over the age of 18 and have difficulties in their sexual and intimate relationships) and are able to undertake the interview within the allocated timeframe, they will be invited to take part in the study. Respondents will be recruited on a first come first served basis and sent the information sheet (appendix F). Those who don't meet the criteria will receive a thank you letter for their interest and be provided with a list of support organisations, as will potential participants who make contact once the target number of interviews for this study (6-8) have been reached.

During the initial telephone conversation, should I the researcher be concerned or become uncomfortable in relation to the language, story, motivations, coherence or become aware of any psychological issues being expressed by the potential participant or should the participant become distressed, I will use my therapeutic skills making use of the core conditions to bring the telephone conversation to an end and this will also signify the end of the research process for this potential participant. While bringing this conversation to an end I will also signpost to their local GP, A&E, and alternative support services as provided in the debrief sheet (appendix J) and I will also seek advice and support from my supervisor.

**10. Will participants receive any incentives for taking part?** (Please provide details of these and justify their type and amount.)

No

**11. Will informed consent be obtained from all participants? If not, please provide a justification.** (Note that a copy of your consent form should be included with your application, see question 19.)

Yes, informed consent will be obtained from all participants stating they fully understand the purpose, procedure and risks of the research – please see Appendix G. This will be completed once the participant received introduced to the study and the information sheet has been given and reviewed with them.

**12. How will you brief and debrief participants?** (Note that copies of your information sheet and debrief should be included with your application, see question 19.)

Please see appendices F and J for information sheet and debrief information.

On response to the recruitment advert, potential participants will be contacted via telephone. During this initial conversation, the points outlined in section 9 of this ethics form will be covered, this includes asking them about their diabetes, their ethnicity and their age, their motivations for taking part and their interest in the study. They will be given a brief outline of the project and requirements and provided with a copy of the information sheet.

If they meet the criteria for the study and agree to take part in the study, at the beginning of the interview the information sheet will be referred to again and read out. Any questions raised will be answered at the beginning and at the end of the interview. The information sheet will be piloted with colleagues prior to conducting the fieldwork.

At the end of the interview, participants will receive a debriefing. Participants will be asked for feedback on how they found the interview and if it raised any concerns for them. As a Trainee Counselling Psychologist throughout the interview I will look out for any signs of distress or anxiety and note the body language of the participant. The participant will have an opportunity to explore any issues with me that have arisen during the interview. In addition the participant will be given a debrief sheet which I will go through with them, this provides details of a range of organisations across London that can provide further support if needed. In addition I will remind the participant that they can also contact their local GP.

From the beginning of the process to the end, all participants will have the contact details of me, the researcher and supervisor.

Once the research project has been completed, respondents will also be offered a summary of the research findings.

**13. Location of data collection.** (Please describe exactly where data collection will take place.)

To be agreed depending on location of participants. Interviews will take place close to a participant's place of work or home. Due to the sensitive nature of the areas to be discussed, the interviews will take place in private rooms but within open spaces for example (but not exhaustive) community centres, local halls, libraries, community organisations, charity organisations, gyms and universities. The locations to be researched and finalised once the respondents have agreed to take part. The researcher will visit the venue prior to interviews to check access of the room, to familiarise herself with the layout of the building and check exits. During the interview another adult will be on site during all times such as a security guard or receptionist who will be aware of the interviews and timings and remain in close proximity for the duration of the interviews. All rooms chosen will be well lit, with a window pane in the door frame and easy accessible. Security guards/receptionists will be asked to patrol past the room. The researcher will follow the participant into the room and sit closet to the door, should they need to exit the room quickly. There will be a clear path between the researcher's chair and exit to the room. In advance of the interview the researcher will agree with the security guard/receptionist the process for summoning help in an emergency for example, the researcher will make their way to the reception area, or call/text an internal number on speed dial to summon help or agree a code word to be shouted in order to summon help.

**13a. Is any part of your research taking place outside England/Wales?**

No		x
Yes		If 'yes', please describe how you have identified and complied with all local requirements concerning ethical approval and research governance.

**13b. Is any part of your research taking place outside the University buildings?**

No		
Yes	x	If 'yes', please submit a risk assessment with your application or explain how you have addressed risks.

Risk assessment attached – see Appendix 8

**13c. Is any part of your research taking place within the University buildings?**

No	x	
Yes		If 'yes', please ensure you have familiarised yourself with relevant risk assessments available on Moodle.

**14. What potential risks to the participants do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.**

While there is no risk of physical harm for taking part in the research and no psychological harm is expected, due to the nature of the topic (intimate relationships and difficulties) being discussed, talking about these experiences may cause participants to become embarrassed, upset or distressed and participants may not have adequate support networks in place.

I will also need to consider ethical issues and be mindful of the ethnic identity of participants and historical relationship with mental health services, this group has experienced in the past (i.e. people from Black and minority ethnic backgrounds are more likely to be diagnosed with Schizophrenia, compulsorily detained under the Mental Health Act, held by Police under Section 136 of the Mental Health Act, given higher doses of medication and not referred for psychotherapy). As this may make participants more suspicious of the interviewing process.

However, this research is with the general public and while the men recruited maybe asked to think about their relationship experiences and difficulties they are not being recruited from an NHS clinic. As this is an exploratory study, the study is not recruiting men who have known psychological problems as a consequence of their sexual problems and for the men interviewed this may not be an issue or their experience. The interview schedule will be referred to throughout the interview to ensure it stays on track.

I will also seek to minimise any other risks by being clear about expectations from participants in the recruitment adverts as will the information sheet which will be provided to all participants prior to the research commencing. The aim of the research is not for the questions to be challenging but to gain an understanding of participant's experiences and I will approach the interview sympathetically. During the interview, participants will have the option of refusing to answer a question, halting the interview or ending/withdrawing from the study at the time of interview and afterwards, up to 4 months after the interview has been conducted.

As the researcher if I become aware that the participant is visibly distressed, I will also reiterate these options to them. At the end of the interview, participants will be able to raise any concerns they have and will be given a debriefing (including debrief sheet) and a list of support sources they can access and advised they can contact their local GP. I will also use my skills as a Counselling Psychologist trainee to hold any distress expressed. I will keep the client safe and make contact with other health professionals if required.

I will adhere to BPS ethical guidelines and will be sensitive to the power dynamics between the researcher and participant. Throughout this process I will also seek support from my supervisor.

**15. What potential risks to the researchers do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.**

There may be some issues around personal safety when meeting unknown participants and of an opposite gender to myself and given the nature of the discussion. Prior to the interviews, I will conduct a telephone conversation with potential participants. As part of this I will check their criteria for the study, explore their motivations for taking part in the study and use my therapeutic skills to monitor for any signs of psychological distress or incoherence on behalf of the potential participant. [REDACTED]

I will purchase, carry and use a personal alarm with me at all times during the interviews. Interviews will be arranged close to participants home or work but will be conducted in a private room in a public space i.e. library, community centre, local hall, community organisation or charity. The rooms will be visited and assessed prior to the interview to ensure they are well lit, visible and accessible. During the interviews I will arrange for another adult such as a security guard or receptionist to be on site and inform them of the interview and duration. I will ask them to patrol past the room every 20 minutes. In advance of the interview the researcher will agree with the security guard/receptionist the process for summoning help in an emergency for example, the researcher will make their way to the reception area, or call/text an internal number on speed dial to summon assistance or agree a code word to be shouted in order to obtain help in addition to sounding her personal alarm.

A personal (safety) contact will be contacted before and after each interview. The researcher will inform the safety contact of date, time, anticipated duration and location of interview with the participant. The researcher will provide contact details of respondent/interviewee to the safety contact that is password protected and only to be accessed in the case of an emergency in relation to safety of researcher. If the safety contact has not heard from researcher within 3 ½ hours of the beginning of the interview, they will contact the respondent and the police. Alternatively, if interview has been completed without harm to the interviewer, the contact details of the respondent will be destroyed by safety contact.

Emergency contact numbers will be listed on speed dial on my personal mobile phone. Following a review of risks should I feel unsafe during the interview, the interview will be terminated and risk assessment procedures followed as outlined in appendix I.

Due to the nature of the topics being discussed, issues may arise during the interviews in relation to my age, gender, and ethnicity in comparison to the respondents. Prior to the research starting I will review my experience of the subject matter and explore my relationships with these groups in personal therapy. During the interviews should further issues arise I will use supervision and personal therapy to work through these.

**16. What methods will you use to ensure participants' confidentiality and anonymity?** (Please note that consent forms should always be kept in a separate folder to data and should NOT include participant numbers.)

*Please place an 'X' in all appropriate spaces*

<b>Complete anonymity of participants</b> (i.e. researchers will not meet, or know the identity of participants, as participants are a part of a random sample and are required to return responses with no form of personal identification.)	
<b>Anonymised sample or data</b> (i.e. an <i>irreversible</i> process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates.)	
<b>De-identified samples or data</b> (i.e. a <i>reversible</i> process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location.)	<b>x</b>
<b>Participants being referred to by pseudonym in any publication arising from the research</b>	<b>x</b>
<b>Any other method of protecting the privacy of participants</b> (e.g. use of direct quotes with specific permission only; use of real name with specific, written permission only.) <b>Please provide further details below.</b>	<b>x</b>

As this is an IPA study, an integral part of the analysis and discussion will be to include quotes from participants in order to illustrate a particular experience and viewpoint but the quotes will be anonymised- the participant's real name will not be used. Information will be given about this as part of the information sheet for participants so that they are aware of this prior to the interview taking place.

**17. Which of the following methods of data storage will you employ?**

*Please place an 'X' in all appropriate spaces*

<b>Data will be kept in a locked filing cabinet</b>	<b>x</b>
<b>Data and identifiers will be kept in separate, locked filing cabinets</b>	<b>x</b>

<b>Access to computer files will be available by password only</b>	<b>x</b>	
<b>Hard data storage at City University London</b>	<b>x</b>	
<b>Hard data storage at another site. Please provide further details below.</b>		
<b>18. Who will have access to the data?</b>		
<i>Please place an 'X' in the appropriate space</i>		
<b>Only researchers named in this application form</b>		
<b>People other than those named in this application form. Please provide further details below of who will have access and for what purpose.</b>	<b>x</b>	
<p>To minimise risk of lone working during the interview period, one safety contact will be given contact details of participant on day of interview with a password to be accessed only in case of an emergency i.e. serious harm to interviewer. If the safety contact has not heard from the interviewer within 3 ½ hours of the interview commencing, they will contact both the police and the participant.</p> <p>If the interview is completed without harm, the safety contact will be informed following the interview and they will destroy the contact details safely.</p>		
<b>19. Attachments checklist.</b> *Please ensure you have referred to the Psychology Department templates when producing these items. These can be found in the Research Ethics page on Moodle.		
<i>Please place an 'X' in all appropriate spaces</i>		
	<b>Attached</b>	<b>Not applicable</b>
<b>*Text for study advertisement</b>	<b>x</b>	
<b>*Participant information sheet</b>	<b>X</b>	
<b>*Participant consent form</b>	<b>x</b>	
<b>Questionnaires to be employed</b>	<b>x</b>	
<b>Debrief</b>	<b>x</b>	
<b>Copy of DBS</b>		<b>x</b>
<b>Risk assessment</b>	<b>x</b>	
<b>Others - topic guide for interview,</b>	<b>x</b>	

## 20. Information for insurance purposes.

(a) Please provide a brief abstract describing the project

This qualitative research study will involve semi structured interviews with 6-8 adult participants. The research will have a phenomenological focus and make use of interpretative phenomenological analysis. The research will explore the subjective experiences of sexual relationships among Black men since they have been diagnosed with Type 2 diabetes. This population has been chosen for the study because males, of an African Caribbean ethnic background are more likely to experience Type 2 diabetes and at an earlier age. The focus of the study will be to explore sexual difficulties experienced. Men with diabetes are more likely to experience sexual difficulties such as lack of sexual desire and erectile dysfunction which can impact on relationships, although it is unknown whether these exact problems will be experienced by the participants interviewed. Despite this situation, men and Black men in particular are less likely to access health services. Most of the diabetes literature to date is of a quantitative nature and focuses on the medical aspects of the condition rather than a psychological perspective. By carrying out this study it is hoped more knowledge and a deeper understanding of Black men's sexual relationships when living with a long term health condition will be developed. The findings will be shared with stakeholders across the health

discipline. In addition it is hoped the findings of this research will act as building block for further studies in this area.

*Please place an 'X' in all appropriate spaces*

<b>(b) Does the research involve any of the following:</b>	<b>Yes</b>	<b>No</b>
Children under the age of 5 years?		<b>x</b>
Clinical trials / intervention testing?		<b>x</b>
Over 500 participants?		<b>x</b>
<b>(c) Are you specifically recruiting pregnant women?</b>		<b>x</b>
<b>(d) Is any part of the research taking place outside of the UK?</b>		<b>x</b>

If you have answered 'no' to all the above questions, please go to section 21.

If you have answered 'yes' to any of the above questions you will need to check that the university's insurance will cover your research. You should do this by submitting this application to [REDACTED] before applying for ethics approval. Please initial below to confirm that you have done this.

I have received confirmation that this research will be covered by the university's insurance.

Name ..... Date.....

## 21. Information for reporting purposes.

*Please place an 'X' in all appropriate spaces*

<b>(a) Does the research involve any of the following:</b>	<b>Yes</b>	<b>No</b>
Persons under the age of 18 years?		<b>x</b>
Vulnerable adults?		<b>X</b>
Participant recruitment outside England and Wales?		<b>x</b>
<b>(b) Has the research received external funding?</b>		<b>x</b>

## 22. Declarations by applicant(s)

*Please confirm each of the statements below by placing an 'X' in the appropriate space*

I certify that to the best of my knowledge the information given above, together with accompanying information, is complete and correct.		<b>x</b>
I accept the responsibility for the conduct of the procedures set out in the attached application.		<b>x</b>
I have attempted to identify all risks related to the research that may arise in conducting the project.		<b>x</b>
I understand that <b>no</b> research work involving human participants or data can commence until ethical approval has been given.		<b>x</b>
	<b>Signature</b> (Please type name)	<b>Date</b>
<b>Student(s)</b>	[REDACTED]	<b>080116</b>
<b>Supervisor</b>	[REDACTED]	<b>11.01.16</b>

Appendix B – Recruitment Flyer Example

**Are you a Black man and do you have Type 2 diabetes?**

**Have you experienced sexual difficulties as a result in your sexual relationships?**

**If you are currently in a relationship and would be willing to talk to me about your experiences, I would love to hear from you.**

**Please contact me, to find out more:** [REDACTED]

[REDACTED]

This study is being carried out as part of a DPsych in Counselling Psychology at City University, London. Further information can be obtained from my research supervisor, [REDACTED] Senior Lecturer and Registered Psychologist.

This study has been reviewed by, and received ethics clearance through the Research Ethics Committee, City University London

(PSYETH (P/L) 15/16 181).

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on [REDACTED] or via email: [REDACTED]

## **Appendix C: Participation Information Sheet**

### **Information sheet**

#### ***Exploring the experiences of sexual difficulties in sexual relationships among Black men***

#### ***with Type 2 diabetes***

Thank you for your registering your interest in this study. Before you decide whether you would like to be involved, it is important you understand why I am carrying out this research and what will be required.

This information sheet provides further information about my study. If you have any questions or if anything is unclear please contact me directly (details at the end of the sheet).

#### **Why am I carrying out this research?**

As part of my professional doctorate Counselling Psychology course at City University I would like to explore how Black men with Type 2 diabetes experience sexual difficulties in relationships.

#### **Why have you been invited to take part?**

I am looking to recruit approximately 8 men who have experienced sexual difficulties and are:-

- Black – Black African, Black African Caribbean men
- Living with Type 2 Diabetes
- In a current sexual relationship

If you answered yes to all the above points, I would like to hear about your experiences. To date there have been very few studies in UK interviewing men like you on this topic.

#### **Do you have to take part?**

The study is voluntary, so you do not have to take part. If you do agree to take part you will be asked to sign a form agreeing to this (a consent form). You can withdraw from the study at any time and you do not need to give a reason.

#### **What will happen if you agree to take part?**

I would like you to take part in a face to face interview with me that will last approximately 90-120 minutes at an agreed time and location.

I will start by asking you a number of short questions about your background, for example asking your age, your occupation and when you were diagnosed with diabetes. I will then ask you more in- depth questions, these questions will be more informal but will be about the sexual difficulties you have experience as a man with diabetes. I will ask questions like “Can you tell me about your experience?” or “What was this like for you”, rather than a question that asks for a yes or no answer.

The interview will be audio recorded so that I have an accurate record of our interview. The recording will be transcribed and I will use it to review the feelings and views you hold.

**What are the possible disadvantages and risks of taking part in the research?**

As the interview is about your personal relationships and sexual/intimacy difficulties, it is possible that during or after the interview you may become upset or distressed by talking about them with me. If this happens, I will explore this with you and will provide details of organisations that can provide further support. In addition the interview can be halted or terminated if required.

**What are the possible benefits of taking part in the research?**

By carrying out this study it is hoped more knowledge and a deeper understanding about the experiences and sexual difficulties in sexual relationships for Black men with Type 2 diabetes will be developed. The findings of this research will help inform future research in this area.

Some adults also find it helpful to speak to someone on a one-to-one basis about their personal experiences who is willing to listen, is independent, and offers confidentiality.

**Will my taking part in the study be kept confidential?**

Yes. All information collected during the research will be kept confidential. Contact detail information about you, such as your name, telephone number and email address will be kept separately from the information you give as part of the interview.

When I am writing up the interviews into a report, any personal information which identifies you will be removed. While quotes will be included in the report as they highlight personal experiences, your name and age will not be used, I will ask you to choose an alternative name/age to be used in the report.

To ensure safe working when conducting the interviews, I will share your contact details with another adult (safety contact) and include the time and location of our interview but these will be destroyed by this adult after the interview. If during the interview, I become concerned about safety, harm or violence to you or others, I would be required to let someone else know and break confidentiality. If this is the case, I will let you know and what action I will take.

**What will happen to the results of the research study?**

The overall findings of this research project may be presented at conferences or to interested organisations that work or provide services for Black men or people with Type 2 diabetes. A summary of the research carried out may also be published in a science or academic journal (magazine).

**What will happen when the research study ends?**

In line with the requirements of the Data Protection Act, all the data collected from interviews on this project will be stored securely for 5 years on City University' secure computer server and password protected. After which time it will be destroyed

**What will happen if I don't want to carry on with the study?**

You can withdraw from the study up to four months after the interview and you don't have to give a reason, just let me know. Any data that can be identified as yours will be removed from the findings if you require.

**What if there is a problem?**

If you have any problems, concerns or questions about this study, you can contact me in the first instance to discuss and following this my supervisor. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone [REDACTED]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them of the name of the project: *Exploring the experiences of intimate relationships among Black African Caribbean men with Type 2 diabetes.*

You could also write to the Secretary: [REDACTED]  
[REDACTED]

City University London 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.

**Who has reviewed the study?**

This study has been approved by City University London Psychology Department Research Ethics Committee.

**Further information and contact details**

If you have further questions or would like to take part in the study, I would like to hear from you, please contact me, [REDACTED]

Further information can also be obtained from my research supervisor, [REDACTED]  
[REDACTED]

## Appendix D: Participant Consent Form



Title of Study: Exploring the experiences and impact of sexual problems in a sexual relationship; Black men with Type 2 diabetes

Ethics approval code: PSYETH (P/L) 15/16 181

Please initial box

1.	<p>I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.</p> <p>I understand this will involve:</p> <ul style="list-style-type: none"> <li>• Being interviewed by the researcher about my sexual difficulties that I have experienced</li> <li>• Allowing the interview to be audiotaped</li> </ul>	
2.	<p>This information will be held and processed for the following purpose(s): in order to answer the research question of how Black men with Type 2 diabetes experience sexual difficulties in relationships.</p> <p>I understand that any information I provide is confidential, 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.</p>	
3.	<p>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 at any point between agreeing to take part in an interview and up to 4 months after the interview has been conducted without being penalized or disadvantaged in any way.</p>	
4.	<p>I agree to City University London 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 the University complying with its duties and obligations under the Data Protection Act 1998.</p>	
5.	<p>I agree to take part in the above study.</p>	

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Background Information Questionnaire

To start with I would like to ask some questions about your background. This will help me get to know you better and build up a picture about you, your health and your relationships.

**So, first of all, some questions about your background.....**

- 1) Can you tell me how old are you? \_\_\_\_\_
- 2) How would you describe your ethnicity? (show census list if need to) \_\_\_\_\_
- 3) What is your current occupation (if not currently working, what was your previous occupation)? \_\_\_\_\_
- 4) What, is the highest qualification you have? \_\_\_\_\_
- 5) How many children do you have? \_\_\_\_\_
- 6) If applicable, what are their ages & genders? \_\_\_\_\_

**Now thinking about your health and diabetes.....**

- 7) Can you confirm the type of diabetes you have? \_\_\_\_\_
- 8) Can you remember when you were diagnosed with diabetes? \_\_\_\_\_
- 9) How do you manage your diabetes on a daily basis?(medication/exercise/diet/nothing)? \_\_\_\_\_

**Moving on to you and your sexual relationship.....**

- 10) How would you describe your sexual orientation (gay, bisexual, heterosexual/straight, other – please state)? \_\_\_\_\_
- 11) Are you in a current relationship? \_\_\_\_\_
- 12) How long have you been in your current relationship? \_\_\_\_\_
- 13) Do you live with your current partner? \_\_\_\_\_
- 14) If yes, is that all the time or part of the time? \_\_\_\_\_
- 15) Are you married, or in a civil partnership with your current partner? \_\_\_\_\_

## Appendix F: Interview Schedule

*Please note as the nature of this project is an IPA study, the questions asked are flexible and may change reflecting on responses given by participants.*

Now, I have found out a bit about you and your background, I am moving onto the second part of the interview, where I want to ask you some more in depth questions about your intimate relationships.

---

Some men with diabetes report a wide range of sexual difficulties such as lack of sexual desire, sexual dysfunction, erection problems and many others.

- Can you start by telling me about the kind of sexual difficulties you have experienced?
- Explore the frequency and length of time difficulties have been experienced by the participant
- What it is like to have these difficulties?
- Thinking about these difficulties, how does this feel?
- How have these difficulties impacted:
  - on the way you see yourself?
  - on the way you feel about yourself?
- How have these difficulties impacted on your current relationship with your partner?
- Can you tell me more about any changes you have noticed?
- What has this felt like for you?
- Have these sexual difficulties been present with all previous partners since you were diagnosed with diabetes?
- In what ways did your sexual difficulties impact on previous relationships?
- What was that like for you?
- How do these sexual difficulties impact on other wider relationships in your life?
- Probe if necessary: such as with family, friends, work colleagues, other men groups, other black men, other important groups to participant.
- How do you see yourself in relation to these groups when experiencing sexual difficulties?

- What does it feel like?
- Now focussing back on just you and the sexual difficulties you have experienced, how have you coped on a daily basis?
- How has this made you feel about yourself?
- When coping, how do you see yourself?
- Probe: What have you done or not done as a result?
- Moving to thinking about your partner(s), when experiencing sexual difficulties, how have you managed this with your partner(s)?
- What has this been like for you?
- Probe: What have you done or not done as a result?
- Now moving onto those important groups you mentioned earlier, how have you coped with those relationships in light of your sexual difficulties?
- What has that been like for you?
- How has it made you feel?
- Probe: What have you done or not done as a result?

Ending:

- We are coming to a close now, is there anything else you would like to add?

Final comments:

- Thank you for coming today and sharing your experiences with me.
- Have you been left with any concerns following the interview we have just had?
- Explore any anxieties before ending.
- If you do have them now or after the interview, there are a number of sources who can help you, including your local GP.
- I have prepared a sheet with a list of advice, support and counselling organisations across London that you can contact (provide debrief sheet & go through).
- Repeat what will happen with results & secure storing of information

## Appendix G: Debrief Sheet

# Debrief - Support and Contact Organisations



Thank you for taking part in the interview.

Once the research has been completed, I can share with you a summary of the findings.

If you need further support following the interview you can contact your local GP or one of the organisations listed below who offer support, advice or counselling.

### **SUPPORTLINE**

A preventative service geared to providing support to individuals on any issue – before the point of crisis is reached.

[www.supportline.org.uk](http://www.supportline.org.uk)

Helpline: 01708 765200

Admin: 01708 765222

Email: [info@supportline.org.uk](mailto:info@supportline.org.uk)

Address: SupportLine, PO Box 2860, Romford, Essex RM7 1JA

### **RELATE**

Providers of relationship support – with the aim of strengthening that relationship.

[www.relate.org.uk](http://www.relate.org.uk)

Helpline: 0300 100 1234

Direct: +44 (0)20 7554 2892

Email: [enquiries@relate.org.uk](mailto:enquiries@relate.org.uk)

Address: Premier House, Carolina Court, Lakeside, Doncaster, DN4 5RA

### **TERRENCE HIGGINS TRUST**

Provider of HIV and sexual health services. Services range from long-term condition management to advice on benefits, housing, employment and counselling.

[www.tht.org.uk](http://www.tht.org.uk)

Helpline: 0808 802 1221

Direct: 020 7812 1600

Email: [info@tht.org.uk](mailto:info@tht.org.uk)

Address: 314-320 Gray's Inn Road, London WC1X 8DP

## **SEXUAL ADVICE ASSOCIATION**

Aimed at improving the well-being and sexual health of men and women and to raise awareness of how sexual conditions affect the general population. Runs a helpline providing support on any sexual issues including erection problems.

[www.sda.uk.net](http://www.sda.uk.net)

Helpline: 0207 486 7262

Direct: 020 7486 7262

E-mail: [info@sexualadviceassociation.co.uk](mailto:info@sexualadviceassociation.co.uk)

Address: 59 Knowle Wood Road, Dorridge, West Midlands, B93 8JP

## **LGBT SWITCHBOARD**

A listening service for LGBT, providing information, support and referral services.

<https://switchboard.lgbt>

Helpline: 0300 330 0630

Direct: 020 7837 6768

E-mail: [chris@switchboard.lgbt](mailto:chris@switchboard.lgbt)

Address: LLGS PO Box 7324, London, N1 9QS

## **THE SAMARITANS**

Support for anyone in distress.

[www.samaritans.org](http://www.samaritans.org)

Helpline: 08457 90 90 90

Direct: 020 8394 8300

E-mail: [admin@samaritans.org](mailto:admin@samaritans.org)

Address: The Upper Mill, Kingston Road, Ewell, Surrey, KT17 2AF

## **MIND**

Support for people with a range of mental health problems.

Also campaigns to improve services, raise awareness and promote better understanding

[www.mind.org.uk](http://www.mind.org.uk)

Helpline: 0300 123 3393

Direct: 020 8519 2122

E-mail: [contact@mind.org.uk](mailto:contact@mind.org.uk)

Address: 15-19 Broadway, Stratford, London E15 4BQ

## **COLLEGE OF SEXUAL AND RELATIONSHIP THERAPISTS (COSRT)**

Was previously called the British Association for sexual and relationship therapy.

A membership organisation that can help with finding therapists specialising in sexual and relationship issues

[www.basrt.org.uk](http://www.basrt.org.uk)

[www.cosrt.org.uk](http://www.cosrt.org.uk)

Direct: 020 8543 2707

E-mail: [info@cosrt.org.uk](mailto:info@cosrt.org.uk)

Address: The Administrator COSRT, PO Box 13686, London, SW20 9ZH

## **TAVISTOCK CENTRE FOR COUPLE RELATIONSHIPS**

Offers 1-1 counselling and couples counselling for sexual and relationships difficulties and carries out research to support couples.

[www.tccr.ac.uk](http://www.tccr.ac.uk)

Direct: 020 7380 1975

Address: 70 Warren Street, London W1T 5PB

## **SEXUAL HEALTH LINE**

Free confidential information and advice on sexual health.

Helpline: 0300 123 7123

## **BRITISH PSYCHOLOGICAL SOCIETY**

The representative body for psychology and Psychologists in the UK. Can be accessed to find a Psychologist.

[www.bps.org.uk](http://www.bps.org.uk)

Direct: 0116 254 9568

E-mail: [enquiries@bps.org.uk](mailto:enquiries@bps.org.uk)

Address: St Andrews House, 48 Princess Road East, Leicester, LE1 7DR

## **DIABETES UK**

Charity offering support for people affected by and at risk of diabetes. Offers advice, support, helpline and peer support groups.

[www.diabetes.org.uk](http://www.diabetes.org.uk)

Helpline: 0345 123 2399

Direct: 0345 123 2399

E-mail: [info@diabetes.org.uk](mailto:info@diabetes.org.uk)

Address: Macleod House, 10 Parkway, London, NW1 7AA

## **THE NAZ PROJECT**

Provides sexual health and HIV prevention, support and counselling services for Black and Minority Ethnic communities in London.

[www.naz.org.uk](http://www.naz.org.uk)

Direct: 0208 741 1879

Email: [naz@naz.org.uk](mailto:naz@naz.org.uk)

Address: 36 Black's Road, London, W6 9DT

## **BEMDA (BLACK ETHNIC MINORITY DIABETES ASSOCIATION)**

Provides support, education and workshops for people with diabetes from black and minority ethnic communities. Runs forums and peer support groups. Offers telephone support

Monday to Thursday 12-6.30pm. Operates a drop in service on Fridays 12-6pm at Voluntary Action Westminster, 37 Chapel Street, London, NW1 5PD.

[www.bemda.org](http://www.bemda.org)

Direct: 020 7723 5357

Email: [info@bemda.org](mailto:info@bemda.org)

Address: St. Paul's Church Centre, Rossmore Road, London NW1 6NJ

## **SEXUAL HEALTH CLINICS**

Throughout London there are a number of sexual health clinics, these tend to be operated by the NHS or charitable organisations. Most offer walk in appointments or you can telephone to make an appointment and you don't need to live in the local area and the services are usually free of charge. Each clinic offers a range of different services such as testing, information, advice or counselling and they offer a non-judgmental space. I have listed the contact details of some of these clinics below.

### **CENTRAL LONDON**

#### **56 DEAN STREET – SOHO**

NHS Sexual health clinic offering a range of services including testing, information and support.

Direct: 020 3315 6699

Address: 56 Dean Street, Soho, London, W1D 6AQ

#### **MORTIMER MARKET CENTRE**

NHS sexual health clinic offering a range of services including testing, information and counselling.

Direct: 020 3317 5100

Address: Mortimer Market, Capper Street, Off Tottenham Court Road, London, WC1E 6JB

#### **MARGARET PYKE CENTRE**

Based near Kings Cross. Offers a range of free NHS contraceptive and sexual health services, includes information, support to couples and counselling.

Direct: 020 3317 3737

Address: 44 Wicklow Street, Kings Cross, London, WC1X 9HL

### **EAST LONDON**

#### **HOMERTON SEXUAL HEALTH SERVICES – HACKNEY**

Offers a full range of sexual health services at Homerton University Hospital, and the community based clinic, the Ivy Centre.

Direct: 020 7683 4103

Address: St Leonards Hospital, Nuttall Street, London, N1 5LZ

## **THE AMBROSE KING SEXUAL HEALTH CENTRE- WHITECHAPEL**

The Ambrose King Sexual Health Centre provides a number of sexual health services, including testing, contraception, sexual health and HIV advice and support.

Direct: 020 7377 7307

Address: The Royal London Hospital, Whitechapel Road, London, E1 1BB

## **NORTH LONDON**

### **THE ARCHWAY CENTRE FOR SEXUAL AND REPRODUCTIVE HEALTH – ISLINGTON**

The centre is a sexual and reproductive health (GUM) clinic offering a range of free, confidential services, including contraceptive services and STI and HIV testing.

Direct: 020 3317 5252 – Appointments

Address: 681 - 689 Holloway Road, London, N19 5SE.

### **WILLESDEN CENTRE FOR HEALTH & CARE: SEXUAL AND REPRODUCTIVE HEALTH CLINIC - BRENT**

The centre offers confidential reproductive health and family planning services. These include contraceptive services (including emergency contraception), cervical screening, testing and referrals.

Direct: 020 8438 7085

Address: Robson Avenue, Willesden, London, NW10 3RY

### **ST ANN'S HOSPITAL SEXUAL HEALTH SERVICES - HARINGEY**

Screening for sexually transmitted infections and treatment. HIV testing, care and management.

Direct: 020 8442 6536

Address: Sexual Health Centre, St Ann's Hospital, St Ann's Road, London, N15 3TH

## **WEST LONDON**

### **JEFFERISS WING CENTRE FOR SEXUAL HEALTH – PADDINGTON**

Diagnosis, treatment and care of people with sexually transmitted infections (STIs), including HIV.

Direct: 020 3312 1225

Address: St Mary's Hospital, Praed Street, London, W2 1NY

### **WEST LONDON CENTRE FOR SEXUAL HEALTH – FULHAM**

The West London Centre for Sexual Health is a discrete and free NHS sexual health clinic based at Charing Cross Hospital, West London. Offers, full sexual health tests, outpatient HIV clinics, HIV treatment and more specialised sexual health services, support and counselling.

Direct: 020 8846 6699

Address: Ground Floor, Charing Cross Hospital, Fulham Palace Road, London, W6 8RF

## **SOUTH LONDON**

### **GUYS HOSPITAL – LONDON BRIDGE**

Sexual health clinic offering, checks, treatments, information, advice and counselling.

Direct: 020 7188 6666

Address: Guys Hospital, 2<sup>nd</sup> Floor, Southwark Wing, Great Maze Pond, London, SE1 9RT

### **MAUDSLEY HOSPITAL - PSYCHOSEXUAL SERVICE –DENMARK HILL**

Treatment for individuals and couples who are experiencing difficulties with their sexual functioning, psychological, or where it has developed due to a physical condition. Referral required from GP, counsellor, mental health team or other health professional

Direct: 020 3228 2458

Address: Psychosexual Service, 1st Floor, Mapother House, De Crespigny Park  
London, SE5 8AZ

### **COMMUNITY SEXUAL HEALTH CLINIC - STREATHAM HILL CENTRE- STRETHAM**

Delivers free and confidential sexual health services to women and men, including: contraception, testing, and sexual health information.

Direct: 020 3049 4006

Address: 41a-c Streatham Hill, London, SW2 4TP

## **Appendix H: Pen Portraits**

### **Victor**

Victor lives in a metropolitan city and works in the care sector and is a well-known figure in his community. Victor is in a long-term relationship (30 years) and married his wife 15 years ago. He has two grown up daughters in their early 20s. He was diagnosed with T2DM, 10 years ago and manages this with a combination of diet, exercise, and medication. He has been experiencing sexual difficulties for the last 12-18 months. Victor had been experiencing a range of sexual problems, including loss of libido, softer erection, difficulties in gaining and sustaining an erection, thrush, foreskin tears and bleeding. He described his sexual difficulties as being linked to one another, as if in a cycle. Initially, Victor felt his sexual problems were due to his working patterns and tiredness, and he was unaware of the connection with diabetes. Victor sought help from his GP for recurrent bouts of thrush before later seeking help for his sexual difficulties. Since his visits to the GP, Victor felt his sexual difficulties were related to his diabetes medication and medication for thrush. Victor described being very focused on trying to find a solution for his sexual difficulties.

### **Justin**

Justin lives with his partner and has been in a relationship for 8 years and has one young daughter. He lives in a large city but spends lots of time travelling with work. He was diagnosed with T2DM when in his 30s and over the last year has started taking medication to manage his diabetes, prior to this he managed it through diet and exercise. Justin experiences a range of sexual difficulties including difficulties in gaining and sustaining an erection, bacterial infections and low libido. He felt his sexual difficulties appeared at various times over the last few years. Initially he associated his sexual problems with the stress of running his business, working away from home and disrupted sleeping patterns. He described feeling lucky that he and his wife were able to have a child before his sexual difficulties developed.

### **Des**

Des previously worked in education and retired early as a consequence of his sexual difficulties which he initially felt were related to work stress. Des had been experiencing a number of sexual problems including gaining and maintaining an erection, being unable to climax, bacterial infections and associated foreskin tears and bleeding which have been ongoing for the last few years. Over the last 18 months he has no longer been able to engage in frequent penetrative sex. Des has been married for 30 years and lives with his wife and three teenage children in a metropolitan city. He was diagnosed with T2DM, 11 years ago but recalled having few symptoms at the time. He manages his diabetes on a daily basis through

exercise, diet and medication. Throughout the interview Des described the importance of being able to sexually satisfy both himself and his wife.

### **John**

John is a project manager and in his 40s. He had been married to his wife for 8 years and they have 2 young boys and live in a metropolitan city. He would like to have another child. He was diagnosed with T2DM, 3 years ago by his GP and manages this through medication, diet and exercise. For almost a year John has been experiencing frequent difficulties in gaining and maintaining an erection. He described associating Viagra medication with being an older man, and did not feel it was a viable option. John explained that it was important to keep upbeat and remain focussed on seeking a solution for his sexual problems as he did not feel they were permanent.

### **Marcus**

Marcus works in retail and has been married for a number of years. He lives with his wife and grown-up children in a metropolitan suburb. He was in his early 40s when he was diagnosed with T2DM and manages his diabetes through medication. Up to 2 years ago Marcus was engaging in regular sex with his wife. Marcus described experiencing difficulties in sustaining an erection and climaxing every time he tries to engage in sex and as a consequence he also experiences low desire. When Marcus was initially diagnosed with diabetes he was given a leaflet outlining sexual difficulties as a possible complication of diabetes that he might experience. He recalled receiving this leaflet and described feeling that he would never need it. Marcus described how he found it difficult to communicate about his sexual difficulties and he was concerned about the impact this was having on his relationship with his wife. He also shared his experience of growing up and described how having sex was seen as important milestone in becoming a man.

### **Ade**

Ade is in his mid-40s and works in IT. He was diagnosed with T2DM about 2 ½ years ago and manages it through a combination of medication, diet and exercise. Ade was divorced from his first wife and has been married to his second wife for 6 years. He has 4 children from the two relationships. Ade started to experience sexual difficulties about 2 years ago and finds it difficult to gain an erection most of the time and he also experiences low libido. Prior to this he was engaging in frequent sex with his wife. Ade had been to see his GP about his sexual problems and tried medication but stated this had not worked for him and that he was still looking to find something that would meet his needs. He expressed concern throughout the interview about the impact of his sexual difficulties on his relationship with his wife. He was

unaware of any support services to help him address his sexual difficulties and was very grateful for the resources pack.

### **Carlton**

Carlton is in his late 40s and works in sales. He has been in relationship with his partner for the last 3 years and has one child from a previous relationship. He was diagnosed with T2DM approximately 4 years ago and manages this through medication, diet and exercise. He experiences low sex drive and a lack of erections, that have been ongoing for 2 years. He has tried various medications to address his sexual difficulties including Viagra and Testosterone Therapy prescribed by his GP. Carlton was concerned about experiencing sexual difficulties in his current relationship, as he felt his partner was much younger than him and he associated taking medication such as Viagra with old men. As a consequence of his sexual difficulties Carlton felt he was missing out on socialising with friends and seeing family members. He also felt pressured to have a larger family

## **Appendix I: Excerpts from my reflective diary**

My reflections on the research process (transcribed from my diary)

### **Recruitment**

Spent all day walking around [REDACTED] handing out flyers. People are really friendly and happy for me to leave them at their venue. Exhausting day but exhilarating at the same time, really enjoyed talking about my research with others – realised my confidence is growing about my research topic, spent quite a bit of time in barber shops - people seem interested in my research but they think I am there to give them a test for diabetes (interesting about the perception of me...) lots of talk of having the 'sugars'. Everyone seems to know someone with diabetes.

### **Recruitment**

Great day at [REDACTED] event handed out lots of flyers, a good day, people are interested to hear about my research, and positive about it – it is really encouraging, lots didn't realise the connection with sexual difficulties – let's hope I get some interest.

### **Recruitment**

Managed to get hold of [REDACTED], had a good chat with [REDACTED] they are really interested in my research as lots of their employees have diabetes – and this is an issue for them, they are happy for me to send my posters and to advertise internally to their employees, ... feels promising, they want to keep in touch about how it goes.

### **Recruitment**

Went to talk to [REDACTED] today, lovely bunch of people, they really wanted to know more and were supportive of my studies. Ended up being asked lots of questions about everything and anything to do with diabetes – as the diabetes guru?? (Not sure I am this...another interesting perception of me..).

### **Interview**

Hurrah first interview booked – feel relieved. Why is it so difficult to find an interview room..... spending a lot of time looking for somewhere suitable – hard to book for just a few hours.

### **Interview -1**

Day of the first interview-,.... excited and nervous at the same time – let's hope [REDACTED] turns up.

Feels like a lot of paperwork to go through – need to make it engaging, hope my tape works.  
Wow – really interesting, [REDACTED] was really open and chatty – plenty of time to talk.

## **Interview 2**

Interview 2 – Arhh engaging interview [REDACTED], shared lots. What a lovely man. He felt it was really useful to open up about what he had been going through.

Makes me think how [REDACTED] is not doing a great job in connecting with men with diabetes.

From the 2 interviews I have done, am I getting enough depth for IPA?, are the men answering the research question? - feeling unsure and worried.

Staying on track in relation to answering the research question –v- allowing the discussion to flow and for the men to share any aspect of their experience.

Interviews seem to be taking a pattern where the men start off by talking about the impact of their partner – wondering about influence of my gender on this process?

## **Interview-5**

That was a trek – feeling urghhh,.has been a nightmare trying to find a neutral location close to where [REDACTED] works, interview had been cancelled several times by him and rearranged. I wasn't at my best and felt tired, the time of the interview was late. Felt a lack of connection with the participant, hmmm not sure how much was shared in this interview – felt a lot was left unsaid, seemed like it really did lack depth and detail. Interview didn't feel like it was working? Felt irritated by this. Shorter interview than the rest.

## **After final interview**

All really interesting and engaging - but also really different

Resources pack well received – unaware of services.

Been a pleasure to interview the men – really pleased they shared their stories.

## **Transcribing**

Loving this, feels a concrete task - takes time though, interviews are long. Difficulty in formatting.

## **Transcripts**

Mountains of paper, so much to go through. Re-reading [REDACTED] transcript – why didn't I pick up on that in the interview? And that and that – missed opportunities.

Arrh really moved by [REDACTED] words – I feel awful that I didn't think the interview went well and it lacked any sort of depth or detail and our distant – his words are very emotional – he did share – I just couldn't listen at the time.

## **Analysis**

Where to start..... holding on to following Smith's guidelines and some good advice from my supervisor in terms of the first steps to take – this is important to keep me grounded.

Going over each line slowly - worried I am going to miss that nugget of gold.... how do I know when I have found it? – making too many notes.

Words are failing me, why can't I describe the essence of the men's talk????? – They are telling me I just don't seem to be able to do their words justice.

Will I ever get this - feel really stumped..... Feels exasperating....

Interpretations – wobbly, scared, fearful – I don't know what I am doing, this is shaky ground and I can't check out with the men??? This is so different to my clinical work. Lost my confidence in being able to do this.

Feeling distant – my difference is so apparent – how can I accurately reflect what they are saying?

Some respite in reading....

What to do with the data that doesn't address the question? – feels disloyal not to use it.

Will this ever come together???, it feels a never ending process and is very slow.

Re-engaging with the IPA group, need to feel part of something...

## **Lit Review**

Where is the literature? – struggling to find relevant studies – all based on the medical model – where is the psychology???

So many papers lack clarity about the type of diabetes or whether interviewing men or women -too general, missing information...

Why do titles not reflect the content of the research?

So a bit of a turnaround today, now have a number of studies and it is coming together – worldwide studies, but with a focus in the USA and Africa – surprising wasn't expecting this – real drought in the UK – wonder why this is? Govt cuts?

Yes at last found some great articles about masculinity, being a man and being a Black man - this is promising and making sense in relation to my research.

Bingo – found a study like mine – the findings are similar despite different cultures....

Had to force myself to stop – could have carried on– found some great articles. Why so little research focusing on sex?....

Really enjoyed this in the end – very inspiring, reconnecting with my research but as usual have generated too much material.

## **Writing up**

Having difficulty pulling it all together, making sense taking too much time. Having a break from it takes so long to re-engage – don't seem to be able to hold any information for long.

Missing my clinical work, .....need to finish.

## **Appendix J: Summary of master themes and sub-themes**

1. Master Theme 1: What is happening to me? Searching for meaning and answers

1.1 Sub-theme: Suddenly, I am no longer in control of my erection

1.2 Sub-theme: I am left feeling frustrated

1.3 Sub-theme: Diabetes was overlooked

2. Master Theme 2: A changing relationship with my partner

2.1. Sub-theme: Talking is not easy

2.2 Sub-theme: Trust feels like it is being eroded

3. Master Theme 3: Viagra is no quick fix

4. Master Theme 4: Am I no longer a man?

## Appendix K: Figure 1: THEMATIC MAP OF FINAL THEMES

### **Master Theme 1: What is happening to me?**

#### **Searching for meaning and answers**

- Sub-theme 1: Suddenly, I am no longer in control of my erection
- Sub-theme 2: I am left feeling frustrated
- Sub-theme 3: Diabetes was overlooked

### **Master Theme 2: A changing relationship with my partner**

- Sub-theme 1: Talking is not easy
- Sub-theme 2: Trust feels like it is being eroded

### **Master Theme 3: Viagra is no quick fix**

### **Master Theme 4: Am I no longer a man?**

**Appendix L: Table of master themes, sub-themes and quotations**

<b>Master Theme 1 – What is happening to me? Searching for meaning and answers</b>		
<b>Sub-theme 1: Suddenly, I am no longer in control of my erection</b>		
John	38-44	“Now I can’t control it, it’s just like spontaneous and I can’t control it... I can’t tell if it will like get erect and stuff, I can’t say it will work or whichever, it’s just like uncontrollable”.
Justin	112-113	“Not being able to um get and sustain an erection at will, it is never good”.
Victor	1274-1278	“I never had a problem getting it up before, but the tears, I was fearful, what’s going on? I’m frightened of it splitting, in my head it is going to tear and I cannot get excited ... well in terms of traumatic it’s like not again.... this is not going away, so it’s like powerlessness”.
Des	238-243	“Looking down now and you’re thinking what’s going on, you know and will it be all right? but it’s not what you remember, you know it use to be the right size, firm and erect”.
John	73-76	“When we are engaging in sexual activity, what’s going to happen? sort of thing, it’s sort of unpredictable, ... whether I’m going to be able to perform or not.”
Des	1374-1375	“We’d be making love and suddenly the erection would go and I thought well this is nonsense.”
Victor	510-515	“You believe you’re 100% on fire and then the next minute you’re lukewarm, that in itself is like wow really, now of all times, nothing happening, I can’t do anything, I know you want to do something, I know I want to do something, but not tonight Josephine?”.
Marcus	185-195	“You cannot get an erection or sustain it, I thought my sexual life would go on until my seventies....It’s a bit like losing your leg or losing an arm, that’s the sort of thunderbolt, because it’s just like part of your body, that’s no longer functioning anymore, so that’s what you feel like”.
Ade	282-286	“Within me, I wanted to do it, but the tool itself is not active, it’s not active, so there’s nothing I can do, we don’t really believe in oral sex, ... we don’t really believe in that, so it’s just penetration most of the time”.
<b>Sub-theme 2: I am left feeling frustrated</b>		
Des	402-409	“I didn’t think I was performing properly, so mentally, I’m getting annoyed and frustrated and thinking well, you know, ‘Is there any point? Because I’m not getting much out of this, I am not reaching orgasm, having to withdraw, and I’m getting more and more frustrated, it’s all a waste of time”.
Marcus	345-350	“With our sexual activities, you can’t go the full way, it feels frustrating, yeah it is frustrating, because you know it’s just something that you would want to do, but unfortunately you can’t do it really. So you feel frustrated, you feel frustrated with yourself, because you’re thinking, well why can’t I? as I want to do it but I can’t.”.

Victor	1286-1292	"Nothing is working, so frustrated and experiencing pain, nothing worked, so there's frustration there, you've tried everything and you physically can't do anything, it's all failed and you've got three conditions running rampant and it does your head in... it's exasperating".
Carlton	340-348	"Trying different things, but nothing is working, you feel frustrated, like nothing is going right for you and your feeling frustrated, and it impacts on your whole life, not just your partner, but work, your family and friends, you keep yourself to yourself, not really socialising. I wasn't depressed, I don't like that word, but I felt frustrated, I was missing out on life".
John	186-191	"I am dealing with it by myself, ... so the nights after, if I've not been um like erect, that's when it affects me, I might have some sort of outburst...and then I try and correct myself quickly".
Justin	539-546	"Your sexual performance, is confusing and you're conflicted on how to deal with it and you jump around trying to and you're not really dealing with it, it's like that pressure release valve you have, I try not to, I try and be calm and not sort of blow off steam, and say the wrong thing, but under pressure you do."
Marcus	273-277	"Some people who probably go through this actually would change a lot...because the anger would creep in that's beside you, because you're feeling the way you are really, but I've not let it get that far".
<b>Sub-theme 3: Diabetes was overlooked</b>		
Carlton	9 -10	"Initially I thought because I was working long hours, because of work, stress maybe that was the reason".
Justin	160-165	"I was working ...where I was travelling away a lot... my sleep patterns were all over the place [...]the intimacy issues came back again, significant loss of libido, definitely performance issues as well, when we did go to have sex".
Des	21-23	"I retired early ... I put it down to work you see, not having diabetes, so once I stopped working but I was still experiencing those symptoms".
Justin	167-179	"I wasn't really thinking it could be diabetes..... when I did go and get checked, I realised my blood sugars were all over the place and then started to realise, yeah, actually, it's causing all these other problems, and impacting other areas of my body and health, and that's taken a while to get used to".
Carlton	448-449	"He [the GP] explained everything to me and that's when I began to realise hey, that's exactly what's happening to me .... he just explained the symptoms of loss of erections and low sex drive so on, I mean you say to yourself, I didn't know this, I didn't know this".
Des	1404-1411	"He said yeah you've got diabetes, this is why, you know, you can expect it... I said oh I've got erection problems... he said, oh you're a diabetic okay, that was all he said...I thought well this is a bit of a relief, it is as if it seems normal practice when you have diabetes".
Marcus	21-25	"When I first was diagnosed with diabetes they did actually give you a leaflet for um, dysfunctions of sex itself, ...I just thought I would never need that leaflet".

Marcus	159-161	"At the time well I laughed at it, I just thought it was just like it would never happen to me".
<b>Master Theme 2: A changing relationship with my partner</b>		
<b>Sub-theme 1: Talking is not easy</b>		
Marcus	478-483	"It is very difficult, for that conversation, to say I physically can't have an erection, I can't keep an erection, I can't climax as much as I used to before, it's the case well, why can't you? really and then it's trying to explain that reason, it's not an easy thing to explain".
Victor	111-112	"To explain why you can't have sex and that in itself is not easy, it's not the best conversation to have".
Victor	1325-1330	"You've got no answers, you've tried everything and it's all failed and you can talk until Doomsday it's not going to change what happens downstairs".
Justin	826-832	"My wife obviously knew I had thrush as she saw creams around as it was hard to hide, but I didn't talk about the other sex stuff. No-one else knew, I didn't really talk to the doctor or my wife, I didn't really talk to anyone, because it's not something you do talk about."
Marcus	914-920	" To talk to my wife about sex, that you can't perform its difficult because it always going to be why can't you?...It's very hard to express what's going on....both physically and mentally within myself.. so, it becomes an avoidance, instead of having to have a tricky conversation that could end up in an argument, you try to avoid it as much as possible".
Ade	889-897	" I can't sexually satisfy her and when she talks about it, I try to divert the topic to something else and she always said okay, I just told you something and you're telling me something else... it's not good I just digress and divert, It is selfish... I am being selfish, because it is going to be a continuous occurrence".
Carlton	592-598	"I wouldn't talk about it, I would just avoid the subject all along, and just probably avoid her... coming up with excuses, like I've been working long hours and trying to get away for weekends, so she doesn't ask me all these questions ... it didn't feel right, it felt all wrong, that I'm not being honest ".
John	307-309	"We're not really talking about it, it's just more practical talking, like oh are you seeing the doctor?".
John	436-438	"Kind of like practical talk, but nothing, nothing about oh, how are you feeling about it?".
<b>Sub-theme 2 :Trust is being eroded</b>		
Marcus	569-584	"There's distrust there for someone to creep down on your phone and have a look. She's snooping around, so we're married but I still think it's an invasion of privacy It feels hurtful because the distrust is there and I think in every relationship, it's all about the trust, once the trust is

		gone it becomes difficult then really, we're not actually having sex much now and her insecurity becomes even more".
John	21-26	" The problems getting the erection even reached a point that my wife actually thought I was cheating, so I had to sort of like convince her, she didn't believe me, she thought that I was engaged in sexual activity with someone else".
Marcus	520-532	"If you're not making love to your wife you're getting it somewhere else, but that's not the case at all with my relationship but she really feels this way, but it's like somebody accusing you of armed robbery but you know you didn't do it. And it's trying to prove it and it's very difficult to prove and that's hurtful to me, I know for a fact that I'm innocent, but my wife has doubts ... I'm not one of those, I totally disagree with any man who does actually have affairs".
John	404-413	"She was like oh is there another woman? and I was like well that's rubbish, I was just ignoring it and saying like whatever, but I could see that she was being serious and I'm like are you really serious? they said I've got erection problems and it's associated with diabetes and I had to like physically show her proof on the internet".
Victor	1118-1119	"If there wasn't going to be any sex and I said no, this is why, so I was able to show her, there were scars there, so it's not like I was lying".
Carlton	65-70	"I don't feel that confident anymore, I'm not fulfilling the other person's sexual desires, and you probably think, oh are they going to go to someone else because my partner is pretty much younger than I am, so yeah that comes into your head" .
Ade	1048-1054	"I am putting her in a situation whereby she is not happy and that might affect the relationship because she says to me: Do you want me to go and see somebody that's outside? and if she continues to repeat that, tries it and if whoever she meets outside and that one can satisfy her, then my marriage is in the process of crumbling".
Des	196-199	"There's never a question that she or I preferred somebody else or anything like that".
<b>Master Theme Three: Viagra is no quick fix</b>		
Marcus	218-224	"I don't think it is something at the moment I really want to be involved with, it can be dangerous as well, because depending on your heart, it excels the heart rate faster than it used to be, so obviously taking Viagra will play on your mind and at the same time it's just adding more pressure to yourself, by doing that"
Victor	320	"advised to take Viagra".
Victor	562-566	"The side effects is the raised heartbeats and so forth when does that stop? Do you know what I mean? And I don't want to be playing about on that".
Des	248-254	"When I use a Viagra like tablet...my erection it is like how it used to be, it's better, it's bigger, it's firmer, but I take enough tablets already,

		I'm not sure what the side effects are of Viagra apart from getting the erection".
Ade	1216-1222	" I'm taking medication for diabetes, I don't want to be taking that one for sexual problems, that would be too much for me ...When I'm taking three or four medications to swallow, I can't be going through the pain and stress, its an additional burden... on my body taking too many medications".
Carlton	623-627	"I can't just rely on the Viagra substitute on its own, ... I didn't really want to take it at first, but obviously I did and it does help with the erection, but it's just a short-term solution you know, because you can't keep taking it, taking it, you can't rely on it for the rest of your life".
John	1336-1341	" To be reliant on medication, Viagra and stuff, because you associate it with older people, I wouldn't take it, I don't think, I should, um, I should be at that point in life".
Carlton	618-619	"I'm still relatively quite young, you don't want to just depend on Viagra alone".
Victor	565-572	"Viagra, its putting you down to timeframes for me...this will happen at 10 o'clock and between 10 and 2, but if I don't want to and I've taken it, what happens then? Yeah for me or if anyone of us decided not tonight Josephine, then what do I do with myself? I can't walk around or hide my erection".
Des	1426-1431	"There's a cure, there's a cure but then of course you get four tablets, so you're thinking, one's not going to last me a week, so I'm thinking God, I'm going to have to manage these now, that means I'm going to literally have sex in a different way".
Carlton	651-669	"I don't want to reach a point whereby I need it every time I want to have sex with my partner... you want to do things on the impulse without relying on the Viagra, as it gets in the way because you're not connecting, you have to think oh I have to take that tablet now, but you want things to happen naturally, not think to take that pill, it feels like a mechanism".
Ade	1205-1211	"I've been to my GP, the Viagra he gave doesn't work for me... I want to know his expertise and knowledge, to advise and prescribe whatever, but I'm just hoping for something natural, not on medication because it's going to be a continuous process".
Des	85-87	"They only give you four a month of the Viagra substitute, so is that suggesting you only have sex once a week, which even that for me you know is not enough".
<b>Master Theme 4: Am I no longer a man?</b>		
John	804-811	"In Black communities and stuff you're especially like within males and stuff, everyone is prided on their sexual relationships, and everyone seen to be always has to be basically be on their game ..., it's uncommon among friends or within the community to have this issue and not be able to perform and stuff".

Marcus	955-961	"Yeah as an image of a man as you grow up actually, is um, as most boys, when you start growing up, then past puberty, most men just think about, well, let's go out tonight and I'm going to have sex, you always feel that you know that is part of being a man, to go out and have sex really or meet a partner and have as much sex as you can".
Des	416-419	"You feel inadequate if you can't perform it's a sense of inadequacy, a sense of lack of manliness, you can't perform,..... sort of like a Delta male almost sort of thing, you know, you're not your Alpha male".
Marcus	949-953	"As a man to perform sex and have sex actually used to be the reason of life but when you're not sexually active as you used to be you're trying to justify yourself, and why can't you be as you were?".
Justin	302-316	"As a male there are aspects of your life that you want to count on...certainly your sexual appetite and ability to perform, you want to feel there is no problem there and be that confident and invincible person, not sexually being able to do the things you once could do, it knocks your confidence and then having to consider you're diabetic, you can't treat your body in the same way, it shakes your confidence, you're battling with yourself and it's a challenge".
Victor	587-606	"I take the Viagra, the Viagra takes control of me as it will allow for me to have an erection for whatever length of time...so once I've taken it and I've taken and I've taken it and it's fantastic, what happens when I don't have any and I'm in the mood and nothing happens?... I know what that can do as opposed to what I can do naturally and that's why I say I would be half a man, as I would be thinking that".
Marcus	130-133	"A man has sexual urges and needs to perform...that's basically what most men think they should be doing".
Des	219-222	"For Black men sex is natural, you know, you have this feeling about you... and I've taken all that for granted".
Carlton	84-91	"The lack of erections and um lack of sex drive are linked, it makes you feel a bit less of a man... you're not fulfilling your partners desires, and you just want to make them happy and you're not satisfying their needs and left feeling a bit worthless as a man".
Ade	53-59	"It doesn't feel like I am a man when I'm unable to satisfy my wife in bed... it has affected my confidence because I think what's the point of doing it again?".
Des	755-767	"When I am not performing as a male should, I feel that I'm letting her down... it upsets me greatly and you think well why should I bother?, is it worth having sex if I'm not going to satisfy my partner?.... because it's not going to be good enough".
Carlton	707-715	"You're brought up to be sexually active. I come from a big family, so I've only got one kid culturally we're meant to have big families...you're meant to have quite a few kids, you're meant to show you're a real man".
John	1048-1054	"And everyone keeps saying to us oh when are you guys going to have your third? you need a girl, blah, blah, and um its pressure, because ...

		in our circle we were the first to shot out the boys and.... it is like everyone's had kids and gone past us".
Justin	772-773	"Sex is a big part of your manhood and being able to easily have sex is a big part of that, but it hasn't impacted as much as it could have because it's not been at a critical time, if I'd been suffering from performance issues and feeling pressure to perform when we were trying to conceive our child 5 years ago, it would have been much harder to deal with, so I am really lucky it wasn't happening then".
Carlton	178-182	"It feels like your strength has been taken away, but you know, that's what it is and there's nothing you can do about it, you feel less of a Black man because as I said, like the way you're brought up like your peers oh you have to be this, you have to be a man, there's certain stereotypes you have to be like".
Carlton	636-639	"It's not working down there, ... you feel like weak, not physically weak but in yourself, you just feel like I'm weak and you know, I'm less of a man".
Ade	124-131	"I see myself as a weak man when it comes to bed, it's not that I am physically weak, like if I had a heart problem and I am unable to perform, this is a different thing entirely, it's not about physical strength, when it comes to bed I'm not sexually strong".
Des	730-735	"Women want a man with a strong penis and a strong erection. That's my mental image and when my penis is not doing that, I'm, thinking I'm not a man and my worth is diminished".
John	240-248	"I haven't thought anything negative, like I'm a failure, I haven't dwelt on it in that way, it's a situation that I'm just trying to address and I'm not seeing as permanent, so I don't look at myself differently".
John	838-849	"Not being able to perform sex will probably be looked down upon, this would be a negative... I don't think they'd understand, they'd wouldn't even care it's related to diabetes, it's like oh you can't perform, you can't perform. Its worrying that people would look at me that way, I'm going to be looked down upon. But I think I'm sort of for now in a safe place where it's just kept indoors at the moment".
Carlton	259-270	"I haven't spoken to any of my brothers or my friends because I'm thinking oh what are they going to think of me?, that I'm less of a man now?, because the way we're brought up is to be strong and there are certain things you don't really talk about, it's a bit hard as I said you know there's certain stereotypes you have to be this way and that way, you know as Black man".
Marcus	970-976	"Society puts a lot of pressure on people .. there's an expectation your supposed to be, if you're sexually active you're a great guy and if you're not, you're not a full person, you are not a man anymore because you're not doing as much as everyone else is doing, now I'm not having sex, I'm no longer that person that I used to be".

## Appendix M: Example theme table - Des

<b>Participant: Des</b>		
<b><u>What is happening to me? My search for meaning &amp; answers</u></b>		
<b>No longer in control of my erection</b>		
	<b>Line number</b>	<b>Quotation</b>
	238-243	"Looking down now and you're thinking what's going on, you know and will it be alright? but it's not what you remember, you know it use to be the right size, firm and erect".
	711-714	"I mean when we had the loss of erection and I was thinking I need to sort this out because you cant be intimate if you cant make an erection".
	246	"And your thinking, what's happening to it now?".
	224	"And suddenly I'm not performing well".
	633-642	"And the tearing, so you know you sort of have intercourse and the other thing is that having sex affects my foreskin so that impact its quite scary and going into bathroom and bleeding, it is quite something I couldn't understand why I was cut, it was not very nice, I thought what is going on? and um, it is horrible really".
	719-721	"What's going on you know, why is it like this? I should be able to do this and its in my head all the time".
	1374-1375	"We'd be making love and suddenly the erection would go and I thought well this is nonsense."
<b>Frustrated</b>		
	267-268	"When I'm not getting my full erection it does annoy and frustrate me".
	397-400	"Well, I've just had to settle for... a lower er erection, a softer erection. Well, I felt it was quite annoying it could be quite upsetting, yeah definitely".
	402-409	"I didn't think I was performing properly, so mentally, I'm getting annoyed and frustrated and thinking well, you know, 'Is there any point? Because I'm not getting much out of this, I am not reaching orgasm, having to withdraw, and I'm getting more and more frustrated, it's all a waste of time".
	828-829	"Frustration well, I'm thinking why aren't we having sex? what's going on?".

	1088-1090	"Waiting with the creams, you wait, so it's frustration not having intercourse because you've got to wait for the foreskin to settle down".
	1388-1390	"Frustrated getting up, I've not reached orgasm so that's been a waste of time, I haven't come, she may or may not have come, so what's the point?".
<b>Diabetes overlooked</b>		
	10-14	"I put a lot of that down to my job because I was getting it was quite stressful at work and when I was having sex it was very difficult and a problem".
	21-23	"I retired early... I put it down to work you see, not having diabetes, so once I stopped working but I was still experiencing those symptoms and even now".
	48-50	"So when I gave up work and the stress levels went down, ...but I was still not maintaining an erection".
	112-116	"I put it down to work or the stress and then once I'd finished it carried on and I thought well I'd better sort this out, you know because I'm not very happy".
	1376-1378	"I think about a year and I thought, I have got to get it sorted out, I couldn't work out what the problem was".
	1403-1411	"I went to the doctor and he said yeah you've got diabetes, this is why, you know, you can expect it... I said oh I've got erection problems... he said, oh you're a diabetic okay, that was all he said...I thought well this is a bit of a relief, it is as if it seems normal practice when you have diabetes".
	1412-1416	"The doctor, so you know and said don't worry because I was worried and he said well because literally all he said was you know you've got diabetes okay then we can give you these Viagra like tablets".
<b>No talking about sex</b>		
	362-364	" Well, I get quite frustrated, but I don't say anything, I must admit, we haven't discussed it".
	475-479	" Well we haven't talked about it, well no, we haven't and um well a conversation, a conversation. We don't make time to talk about things like this".
	601-607	"And you know, I'm not sure a restaurant is the best place to talk about sex, but, no we haven't done. I think we could do it, I think we could, but it's just how we do it, ummm".

	691-703	"Erections... and going to bleed again, because I don't say anything and it is not very nice, quite upsetting because you know you keep things from your wife".
	704-709	"I mean she doesn't, well, she tells me most things, if she's got a smear test she say, she doesn't like them but she decided to go, but we tell each other most things but I haven't talked to her about it. Which is unusual for us because usually we'll talk about all other things and talk about other ailments quite openly but not sexual ones".
	831-833	"I don't talk about it, I haven't discussed it, I have kept it private".
	886-888	"I find it difficult, we don't talk about things like that".
	1226-1228	"Um.. I mean you see all these programmes about people talking about sex. It tends to be women who talk more about sex than men I think, it is difficult to talk about it".
	1290-1291	"Yeah, yeah, I think is there any point?, I think well there's no point in talking about it".
<b>Viagra is no quick fix</b>		
	54-59	"He (GP) gave me some um, well it wasn't called Viagra but it's called something else but it is the same thing as Viagra, a Viagra substitute and I cant remember what its called so you get four tablets and that's it .. but it gave me a firmer erection".
	65-66	"If I take a tablet and not say anything and she is tired, I felt like I wasted a tablet".
	76-80	"We have intercourse in the sense that we're ready you know, we sort of have an unwritten thing we know it is not a contractual thing more consensual by mutual consent".
	85-87	"They only give you four a month of the Viagra substitute, so is that suggesting you only have sex once a week, which even that for me you know is not enough".
	123-127	"Most of the time my hard-on it isn't as firm without the pill, I think the Viagra substitute makes you a little bit larger and you feel a little larger and a litter stiffer and you feel more confident when you go to bed".
	248-254	"When I use a Viagra like tablet...my erection it is like how it used to be, it's better, it's bigger, it's firmer, but I take enough tablets already, I'm not sure what the side effects are of Viagra apart from getting the erection".

	270-272	"If I take a tablet to gain an erection and I feel like I have to use the penis straightaway and forcing sex".
	388-392	"You know yeah, I think the problem is because you have only got four tablets you think I've only got four days of it. I waste one I've only got one left".
	410-412	" I haven't talked to the Doctor about it again because he said well I've given you the tablets you know, I just assumed he'd say well you have the tablets you should be all right, just take them and have sex".
	413-414	" I'm not sure the doctors appreciate you know, you cant take a tablet every night on the prospect of having intercourse".
	738-740	"Yeah so with the tablets you think well yes that the solution but you've then got this problem that if you take a tablet you have to have sex then and it's the wrong time".
	1137-1140	"If I could have predicted if I could predict when we were making love, then probably take a tablet half an hour every time, but that's the thing, I cant".
	1143-1145	" I worry using the tablets stretching that you know when you have a full erection your foreskin is now so tight with the thrush so it could cause more damage" .
	1426-1431	"There's a cure, there's a cure but then of course you get four tablets, so you're thinking, one's not going to last me a week, so I'm thinking God, I'm going to have to manage these now, that means I'm going to literally have sex in a different way" .
	1462-1470	"So it's a problem really in the sense that I've got the tablets which will give me an erection whenever I want it but it means I am demanding sex and I'm not happy about that or not having the tablets and having a less of an erection and she not being satisfied and me not being satisfied because I'm not performing I am in a bit in difficult place".
	1505-1508	" In my view as soon as somebody says yes this is when we make love you know in advance than the whole dynamic would change, well I think it will".
	1536-1540	"I think that's the thing at the moment its consensual. As soon as you start saying on Wednesday night have sex, on Friday night or Sunday night and if neither party is ready or in the mood, then you're forced but you still have to honour the contract that how I feel".

Am I a man?		
	16-19	"Because my erection wasn't strong, I didn't think it was as strong, so I felt that I was under performing, basically the level of performance was not what it should be as a man".
	128-131	"My hard-on is not always firm, so I mean, I know women will say that it doesn't really matter, but I always feel that as a man, I feel that I'm not manly enough unless it is larger and firmer".
	180-181	"Well as a male, I think well yeah, I do feel, because males for me, performing sex is very important to me".
	195	"Yeah, you know, I feel that I'm not manly enough to do it, you know".
	212-216	"Would she want an active sex life with someone who is underperforming? ...well I think as a man, I do feel less manly if I'm not".
	219-222	"For Black men sex is natural, you know, you have this feeling about you... and I've taken all that for granted."
	225-229	"Black men have a reputation of being a performer, you know and suddenly I'm not performing well, so I'm sort of questioning myself as a male".
	263-265	"I want to have sex, I don't want to feel that I'm going to be inadequate because I do feel inadequate sexually".
	416-419	"You feel inadequate if you can't perform it's a sense of inadequacy, a sense of lack of manliness, you can't perform,... sort of like a Delta male almost sort of thing, you know, you're not your Alpha male".
	421	"You don't feel like a man anymore".
	715-717	"I've got these images of Black males to sort of give me some incentive to perform thinking that umm, I should be like that and I'm not at the moment".
	730-735	"Women want a man with a strong penis and a strong erection. That's my mental image and when my penis is not doing that, I'm, thinking I'm not a man and my worth is diminished".
	749-754	" So um, so you know I feel that, er we, with men, with Black men, we've got this stereotype, okay it may be a little bit exaggerate but it's still there and um you want to feel part of that".
	755-767	"When I am not performing as a male should, I feel that I'm letting her down... it upsets me greatly and you think well why should I bother?, is it worth having sex

		if I'm not going to satisfy my partner?.... because it's not going to be good enough".
	790-795	"I like to think that even if she doesn't see it in the same way, that I am performing as a Black male and when I don't, when I'm not, because my erection isn't strong enough, I feel that I'm letting her down and myself as well".
	1574-1580	"I've not done a good job or been a good lover, then I am upset with myself .... I feel annoyed because um, I've not performed particularly if I don't reach orgasm and I go limp, I feel I'm not satisfied. I've not been a man in the way you expect a man to be".
	1584-1587	"And if I've not been a man in the way that you expect a man to be, she may well be disappointed if she has not felt me ejaculate, I'm sure that's significant".



had that sort of conversations, really, really. I never had that sort of conversation with my parents.

C *No so not something you have spoken about*  
M It's never been one of those of things. I always find it's sometimes a taboo subject to talk really, you know. I used to watch TV and there'd be sex on TV with my parents in the same room and I used to feel very uncomfortable really, yeah. That's your upbringing really.

C *Arhh ok, so then, talking about it to your wife feels...*  
M I find it, I find it difficult to talk about it, yeah, yeah, to talk about sex itself as a an act. You can have that conversation but to talk to my wife about sex that you can't perform, it's difficult because it's always going to be why can't you?.. It's, very hard to express what's going on... both physically and mentally within myself.. so, it becomes an avoidance, instead of having to have a tricky conversation that could end up in an argument

you try to avoid it as much as possible really

C *Mmm... so you've been kind of avoiding, have I got this right because you don't feel comfortable to talk about sex and finding it hard to find those words to have that type of discussion?*  
M Yeah, yeah.  
C *Ok and the avoidance makes you feel?*  
M Once again I've let her down really, um, but um, it's not really letting myself down, it's letting my wife down really.

C *Hmmm*  
M But the emotional feeling, actually and sex actually, um, it is very difficult, really, it's difficult to put into words, it's also very difficult to justify as well.

C *Tell me more about that to justify?*  
M Well, you're justifying it, trying to justify to yourself why you cannot have, you can't make love to your wife or keep an erection or why you cant climax really and that and um, unless someone really has read up about it or spoken to some professional about it, they can't then understand what you're relating to them, so the only way you can get to justify it would be to have someone between the two of you sitting down and talking about it, really now, for them to give er professional advice on why it happens or

um, what is happening within the body of a person itself, really.

Um, but from a one to one basis with someone, a wife or partner, it's actually more difficult, because you're not a professional yourself, all you can talk about is the emotional side of it within yourself, what's happening and how you feel, really.

C *And you talk about justifying it to yourself, how does that, erm, how does that feel, trying to justify it to yourself?*

M It's a difficult thing, because as I said growing up, as a man to perform sex and have sex actually used to be the reason of life but when you're not sexually active as you used to be you're trying to justify yourself and why cant you be as you were? And the why cant you keep an erection up really now?

C *So tell me growing up, you had an image of a man...*

M Yeah, as an image of a man as you grow up actually is um, as most boys, when you start growing up then past puberty most men just think about, well, let's go out tonight and i'm going to have sex you always feel that you know that is part of being a man, to go out and have sex really or meet a partner and have as much sex as you can.

So um, you know there's always those jokes about did you have a good night, you know and last night was it all right? kind of thing yeah, but umm, ... as you get older it's not as, it's not as much as that anymore, really, so you are sexually active but not as much, not like as you used to be when you were a youngster yourself really.

C *And what is that like for you having erection difficulties, and as you get older?*

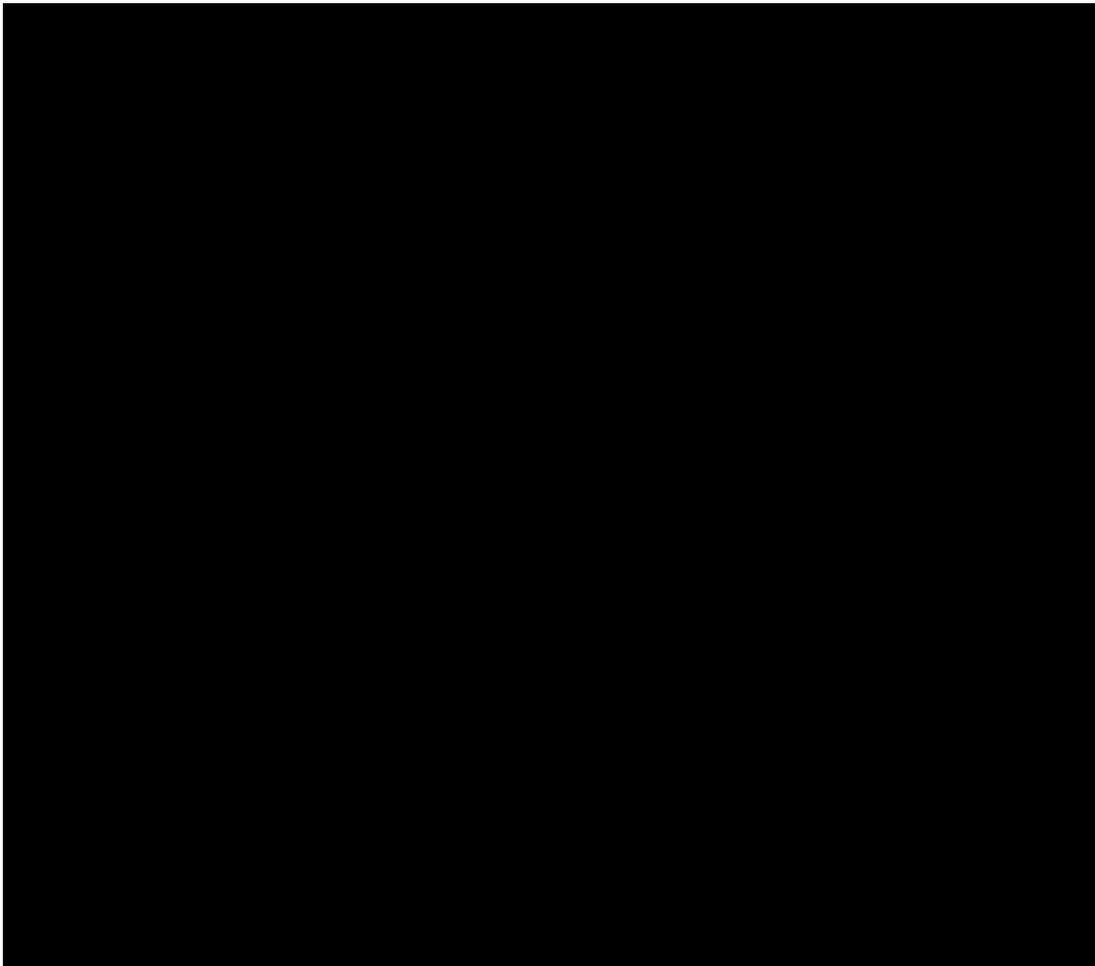
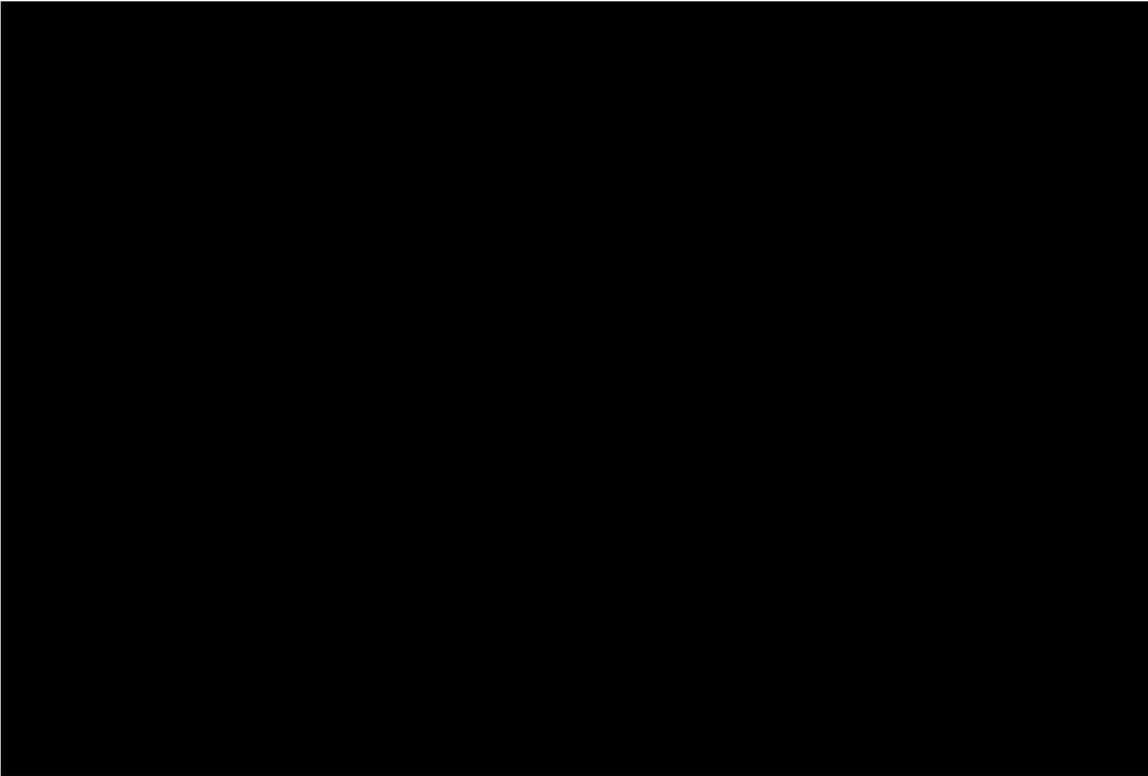
M I feel that society puts a lot of pressure on people ... there's an expectation your supposed to be, if you're sexually active you're a great guy and, if you're not, you're not a full person, you are not a man anymore, because you're not doing as much as everyone else is doing, now I'm not having sex, i'm no longer that person that I used to be really.

C *And how do you manage that right now?, you have talked about the image you had when growing up and no longer being that person you once was and how do you manage it now in your life and no longer gaining an erection?*

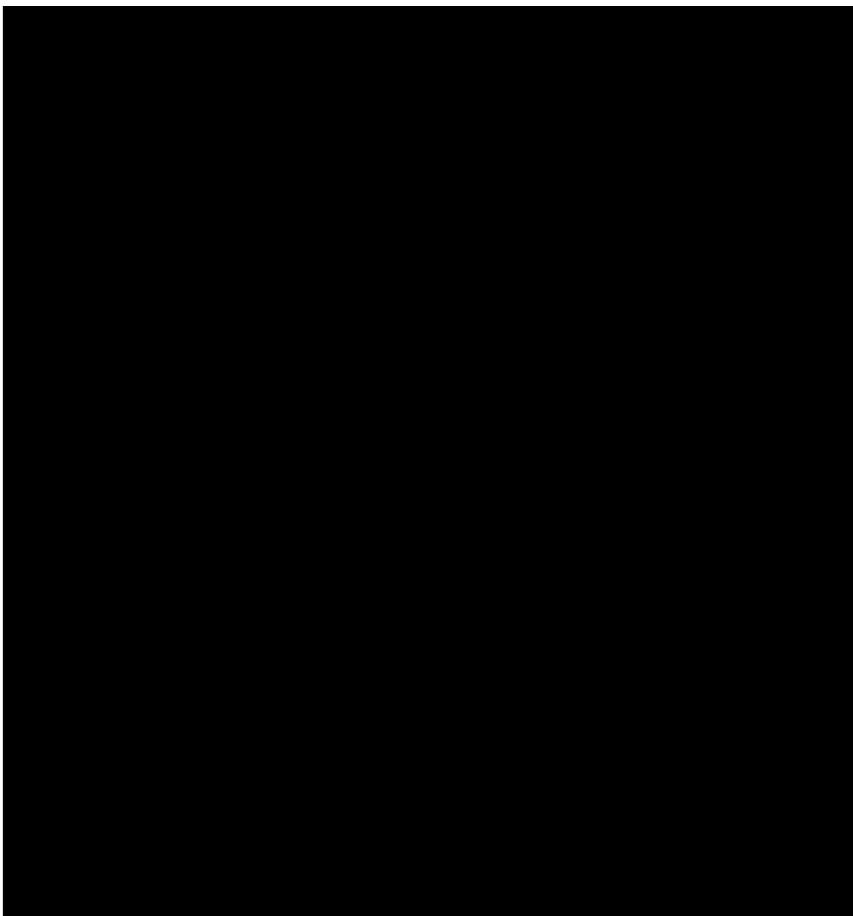
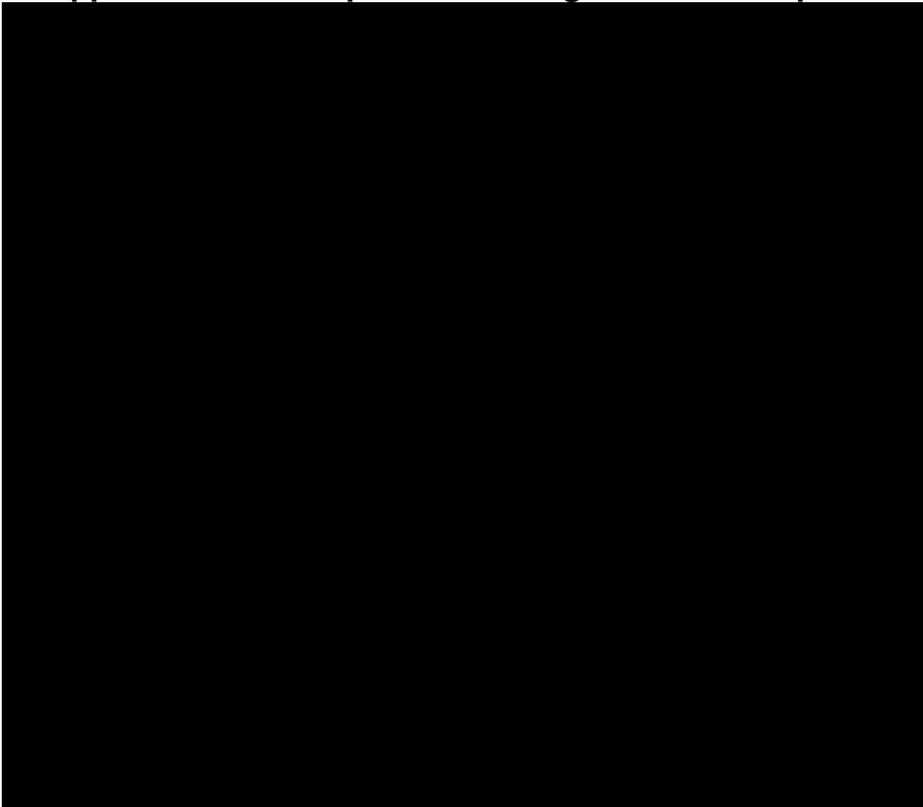
M Um, maybe in a realistic way I'm hoping that things will either get better, improve, um, but it's probably the case of actually seeing how things go, if things to continue the way they are, then I think as I said, my wife and I need to seek some help, but I think

9	only help in the case that from her understanding a little bit more
9	of um <u>how diabetes affects you in a sexual way</u> . how not having a
9	full erection itself um and I think <u>between</u> the two of us, actually,
9	if we had the conversation ...of the reason why this is happening for
9	my wife to properly understand it. so I thought that would probably be
9	
9	the next step, really, um, if things, you know, I'm in my xxxx next year,
9	so obviously I don't want to go into my xxxx year with that
9	pressure mounting up, because over the last couple of years
9	
9	things have not got any better, so I think something would have to
9	be done with it, otherwise um, it would probably <u>destroy</u> the
9	
9	relationship that we have, really.
9	<i>Arhh, mmmm, so you have been really feeling the pressure and you are</i>
9	<i>hoping for improvements and more understanding but if you don't mind</i>
9	<i>can you tell me a little more about that, the possibility of destroying</i>
9	<i>the relationship r?</i>
100	It feels very disheartening that if it went down that road, really, so
100	
100	I'd rather say that we would do something about it, but it's just a case of wait
100	
100	and see, do things improve or if it doesn't then
100	we need to take some action and have that conversation.
100	Hopefully we can overcome it <u>but I don't know really</u> because we've never had
100	conversation really.

**Appendix O – Example 1 clustering themes as part of the analysis**



**Appendix P – Example 2 clustering of themes as part of the analysis**



**Appendix Q – Labels from original transcripts ready for clustering**

