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Portfolio for Professional Doctorate in Counselling Psychology (Dpsych)

“Through that acknowledgement of weakness comes the strength”: The journey towards regaining control and achieving Good Enough

A portfolio of work including an interpretative phenomenological analysis of the experiences of middle-aged individuals with First Episode Psychosis

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List of Abbreviations/Acronyms

Acronym	Meaning
APA	American Psychiatric Association
ARMS	At Risk Mental State
CBT	Cognitive Behaviour Therapy
CBTp	Cognitive Behaviour Therapy for Psychosis
CORE-OM	Clinical Outcomes in Routine Evaluation
DNA	Deoxyribonucleic Acid
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
DUP	Duration of Untreated Psychosis
EIP	Early Intervention in Psychosis
EPPIC	Early Psychosis Prevention and Intervention Centre
FEP	First Episode Psychosis
GSP	Generic Social Processes
ICD-10	International Classification of Diseases, Tenth Revision
IPA	Interpretative Phenomenological Analysis
JTC	Jumping to Conclusion(s)
MHA	Mental Health Act
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PROQ3	Person’s Relating to Others Questionnaire
QPR	The Questionnaire about the Process of Recovery
QOLS	Quality of Life Scale
SRQR	Standards for reporting qualitative research guidelines
TA	Thematic Analysis
WHO	World Health Organisation

Acknowledgements

Most importantly, I am grateful to all the participants whose individual names I will not mention here for confidentiality reasons, who shared their memories and experiences with me; and without whom this piece of work would not have been possible. It was an honour to immerse myself in your narratives and to spend what seemed like forever making sense of your unimaginable and sometimes unwordable experiences. I have renewed respect for the courage and selflessness you all showed in rising above all odds to contribute to this research, being reminded about one of the most catastrophic times in your lives, so thank you.

I am forever indebted to my supervisor and morale booster, Dr Daphne Josselin, whose unwavering support and patience I could always count on, who made the writing of this thesis less daunting. Her clarity of thought and dedication helped me look forward to our meetings, especially when I felt like I was losing my way. I am truly grateful for her insights and guidance.

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This work would not have been possible at all without the continuous support and understanding of my husband Raf, who was, and always remained my default sounding board. He dedicated himself unfailingly and provided me with continuous encouragement throughout my many months of study especially through the process of researching and writing this thesis. As my devoted resourceful confidante, personal computer and IT specialist, he was always there to do whatever needed doing to support my writing, thank you Raf.

My daughter Ngaa and her husband Jon ensured that I was cushioned, housed, and well-nourished whenever I needed that, my deepest gratitude go to them both. Ngaa, you always knew the right questions to ask, how quickly you have grown, I am proud to have you as my daughter. My daughter Chido, your endless and well formulated questions even as a young person inspired my quest to focus on this piece of work, and my desire to continue to delve deeper every time, so I thank you abundantly. Raf, Ngaa, Jon and Chido, thank you all for being my cheerleaders, and for your understanding and acceptance of my preoccupation with my project, residing in my sometimes messy documents-ridden spaces which became my new home, as well as my perpetual focus on my thesis, often to the exclusion of everything. Thank you.

This thesis would have been unbearable without my good friends and colleagues, many of whom I made on the course, especially Esa, Jo and Varsha, so thank you all. I would like to thank Fungi, Angelika, Agnes T, and Laura B, for their commitment to our friendship, while I became a recluse… I promise to make it up to you once all this is done. Laura B, thank you for providing a different take to my sense-making, I am grateful. Esa, my companion especially as the heaviness of the topic of my study weighed down on me, I remembered I was not alone. You are such a brave individual, with the biggest heart ever possible. Thank you.

Dedication:

I dedicate this work especially to my talented and wise grandmother VaMudonzvo, who has been my shadow, overseeing and accompanying me everywhere even; this is for her. Also to my mother, who kept me on my toes in ways she will never know or begin to comprehend.

City, University of London Declaration

I hereby declare that the work presented in this portfolio is entirely my own, under the supervision of Dr Daphne Josselin.

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Preface

> ‘Ring the bells that still can ring
> Forget your perfect offering
> There is a crack in everything
> That’s how the light gets in.’
>
> (Leonard Cohen, ‘Anthem’, from the 1992 album The Future)

> “Perfectionism at its core isn't about high standards. It's about fear. Fear of failure. Fear of looking stupid, fear of making a mistake, fear of being judged, criticized, and ridiculed. It's the fear that one simple fact might be true:
>
> You're just not good enough.”
>
> (Marie Forleo)

The components of this portfolio map my journey to become a practitioner and a researcher psychologist at City University. Within each component, I demonstrate the level of knowledge and expertise I achieved through my training. What brings the components together is the concept of perceiving oneself as ‘not good enough,’ either in one’s own eyes or in others’ eyes. In the 20 plus years that I have worked in mental health services, from primary to secondary care, and acute to community care, I have seen individuals experiencing psychological distress, as a result of feeling ‘not good enough’. To curb this, individuals have often set unrelenting standards for themselves, working towards some abstract perfectionist outcomes, and becoming self-critical and/or low in mood when they perceived or feared that they had failed or could be seen as having failed to meet these standards.

Individuals that feel ‘not good enough’ in some way, internalised objects that resulted in them feeling that they could not measure up to theirs’ or others’ standards. Through different processes and situations, this resulted in, for example psychic pain. My client through psychodynamic therapy, and the research participants through being treated under the early intervention in psychosis service, all appear to have achieved versions of Winnicott’s ‘Good Enough Mother,’ which allowed them to live their lives in a more satisfactory way, with improved quality of life.

Portfolio Contents

This portfolio is divided into three sections: Section A containing the original research; Section B featuring the Publishable Paper; and Section C detailing the Combined Client Study & Process Report.

Section A: Original Research:

In this section, I present an original piece of qualitative research into the experience of middle-aged individuals with First Episode Psychosis (FEP). My interest in this research stemmed mainly from working within one of the Early Intervention in Psychosis (EIP) Services in Surrey. This EIP service is one of the few such services that provide specialist treatment for individuals aged 18 to 65 years nationally, with most services in the UK catering for 18 to 35 year-olds only. While working in this service, I realised how many resources catered directly to the needs of younger people, without a comparable equivalent for middle-aged individuals. I was aware that the service was developed from studies focusing on younger individuals with early-onset FEP, and I wondered how well the service was meeting middle-aged individuals' needs. Additionally, FEP was generally considered a condition for younger people, and I wondered how much was generally known about this group of individuals and how they perceived their interactions with other services, having heard from my clients about the unfair or even prejudicial treatment they had sometimes encountered before being taken on by the EIP service. Something resonated with me because, born as a female child in a culture where male children are deemed superior, and having migrated to live in a country where in some places, people from minority ethnic groups are considered inferior, I have had my fair share of experiential knowledge of prejudice and unfair treatment. There were, therefore, both personal and professional elements to my interest in this study. My fears that there was little qualitative knowledge about this group's experiences of FEP were confirmed during my literature search, where I could not find qualitative research focusing solely on late-onset FEP.

In the study, I interviewed six participants aged between 40 to 50 years whom I recruited from one EIP service. I analysed the data that I collected using Interpretative Phenomenological Analysis. This study identified five main themes around: the participants' loss of touch with reality; loss of the self with the shattering of identity; participants' experiences of exceptionality as persons of interest; participants feelings of being diminished and belittled; and ultimately participants' reframing of their experiences during the process of recovery.

The findings from this study highlight the devastating impact of FEP on the individuals' sense of self and identity, and indicate the importance of the restoration of identity after FEP. Shattering of individuals' identity by FEP resulted in individuals experiencing themselves as 'not good enough,' which influenced their inter and intra-personal interactions, sometimes feeling that they were not heard. The feeling of not having a voice or not heard is something I have experienced myself, and perhaps this gives me greater empathy for people in a similar position. Being exposed to the difficulties sometimes encountered by the participants made me realise how the role of helping others to exercise or find their voices mattered and that what I have been doing all along is quite essential. Now that I have done all this work, I want to pursue this more effectively once I qualify as a Counselling Psychologist, as I will be in a strategic position to influence how services are shaped.

Section B: Publishable Paper:

In this section, I present a publishable paper, where I showcase some of my findings about middle-aged individuals' experiences of FEP and their interactions with an EIP service.

I chose the '**Psychology and Psychotherapy Journal'** to present my findings in as this journal pays particular attention to the psychological features of mental health problems and well-being and psychological problems as well as their psychological treatments. Additionally, this journal invites qualitative papers and welcomes submissions of empirical research that have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. This journal is more likely to be read by a wider group of professionals working in mental health, especially those working with middle-aged individuals and with different psychoses.

The structure of my paper is in line with other published papers in this journal and follows the format stipulated for authors (Appendix Q). Due to space limitations, I have given details from two of the five superordinate themes as these appeared to cover the fundamental nature of my findings as well as show how such a disastrous process seemed to bring positive outcomes for most participants. Additionally, I felt like these results illustrated a clash between my participants' two 'mental worlds,' with several of the participants feeling special in one world, yet villains in another, and what appeared to be some resolution once 'the dust settled.' In my clinical experience such inner split is quite prevalent in FEP. I also considered that some of these results have not been written about in the literature reviewed, certainly not for middle-aged individuals as this group has not been researched qualitatively.

Section C: Combined Psychodynamic Client Study/Process Report

The Combined Client Study and Process Report is based on a piece of work that I completed while on placement in an NHS community mental health recovery team that offers psychodynamic therapy to adults of working age. The piece of work intended to demonstrate my in-depth understanding of appropriate concepts of psychodynamic therapy, my reflective abilities and how I integrated these in my clinical practice. The premise of psychodynamic therapy is that many emotional and/or psychological problems that people suffer with are the result of underlying conflicts and fears; therefore, during therapy, change comes from bringing the underlying unconscious into consciousness.

The focus of the process report is on a session with a female client named Bonita[1] who is in her mid-twenties. Bonita presented anxieties related to how difficult she found

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[1] Bonita is not the client's real name. It is a pseudonym to preserve her confidentiality and maintain anonymity

it to trust others, her fear of abandonment and of rejection, and her sense of unworthiness and low self-esteem. Bonita's sense of being 'not good enough' seemed to permeate her intra- and interpersonal interactions. She reported feeling empty, wanting to be like others in relationships, as if she had no identity of her own. I tuned in to the transference and counter-transferences, and how Bonita and I made sense of this helped her to understand and repair the bad internalised objects. My experience of emptiness from the first few sessions with Bonita made me feel like I had nothing to offer, and like I was not (good) enough to meet her needs. Using Winnicott's 'good enough' concept in the therapy room, I provided the holding environment wherein Bonita's true self began to develop. It appears that the safe base I provided for Bonita was vital for her healthy psychological development. The extract chosen is from session 8 of 40 sessions, which demonstrates the process of engaging which brought about change in our therapeutic work together. It is after this session that Bonita began to feel able to open up, to be present and express emotions, no longer fearing that I might abandon her once I saw her potentially unlovable and messy parts. This is when I felt that she let me in.

I believe that during our work together, Bonita and I achieved a good enough job, that enabled her to grow towards experiencing herself as 'a good enough person'. This was similar to my participants' interactions with the EIP service, who they felt had helped to restore their identities and consolidate their sense of selves, with some experiencing transformation through the process of FEP. Likewise, Bonita felt stronger for having expressed her vulnerabilities. As in Kintsukuroi, they 'experienced themselves as better for having been broken.'

Taken together, these three pieces illustrate the importance of the theme of "not good enough" and how I have worked with it and my growing understanding of the importance of feeling good enough in one's work and instilling this in clients.

Section A: Original Research

Battered, bruised and mended: an Interpretative Phenomenological Analysis of the experiences of middle-aged individuals with First Episode Psychosis

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Abstract

Research into first episode psychosis has developed considerably over the past two decades, mostly around experiences of younger people, with very little known about middle-aged individuals' experiences. Yet first episode psychosis in this age group is no rare event.

The purpose of this study was to gain a deeper understanding of how middle-aged individuals make sense of their experiences of becoming unwell and receiving treatment under the Early Intervention in Psychosis service.

Six participants (three females and three males) aged between 40 and 60 years were purposively sampled and interviewed using a semi-structured interview schedule. The interviews were audio-recorded and transcribed verbatim. The data were subjected to Interpretative Phenomenological Analysis.

Five superordinate themes emerged from the data: (a) "My Worst Nightmare," (b) "Not Myself," (c) Person of Interest, (d) Belittled, and (e) “Coming Out.” Together, these themes highlight the shattering of participants' identities, leaving them trapped in shame, and feeling like aliens. They also outline how a new self emerged as participants reframed their experiences and restored their identities.

The findings indicate how middle-aged individuals reflect on their first episode psychosis experiences with a mixture of wariness and gratitude suggestive of loss, growth and resilience, with what appears to be elements of Post Traumatic Growth being identified by several. They also suggest the need for all services that interact with these individuals to do so humanely and provide them with meaningful opportunities and resources to support the integrative processes following first episode psychosis. Additionally, there are implications for professionals and policymakers regarding the process of detaining individuals for hospitalisation, as the practices described by some of the participants appear to perpetuate the stigma of mental illness. Lastly, further clinical implications are for professionals working within Early Intervention in Psychosis services to consider incorporating restoration of identity as part of their treatment outcomes.

Chapter 1: Critical Literature Review

This study explores middle-aged individuals' subjective experiences of late-onset first episode psychosis (FEP[2]) from onset to recovery. Late-onset FEP is of interest for two main reasons. Firstly, compared to early-onset FEP, late-onset FEP has been reported to arise not so much in the context of emotional dysfunction, implying potential qualitative differences in its cause (Köhler et al., 2007). Secondly, due to the position middle-aged individuals hold in society and the impact any disturbances to their functioning could have on themselves and the rest of the people and systems that depend on them, socially, financially, and vocationally. However, as will be shown below, research into late-onset FEP has so far been limited and qualitative studies in particular remain largely lacking.

In this chapter, psychosis will first be discussed in general terms, focusing on its symptoms, its prevalence, and its impact. Theories about the risk factors and ways of conceptualising psychosis will follow. There will then be a discussion focusing on how the concept of FEP was developed and how FEP first became diagnosed and treated, in which particular attention will be given to the characteristics and challenges associated with FEP in middle-aged individuals. Thereafter, a review of existing qualitative research into the subjective experiences of FEP will follow. A final section will present the rationale for the present study.

1.1 How Psychosis is generally understood

According to the American Psychiatric Association (APA) (2013), the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) groups psychotic conditions together in one chapter. However, the term ‘psychosis’ still lacks a unified definition, and while it is not diagnostic in itself, it refers to a clinical construct composed of several

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[2] When an individual makes contact with statutory mental health services and fulfils the criteria for psychosis for the first time, as defined by the DSM-5 and ICD-10 (APA, 2013), they are said to have First Episode Psychosis (FEP).

symptoms of many psychiatric, medical, and neurological conditions (Arciniegas, 2015; Royal College of Psychiatrists, 2016). The DSM-5 classification (APA, 2013) highlights that psychotic conditions can be viewed as existing on a continuum, where schizoid personality disorder represents the mild end and schizophrenia spectrum disorders the severe end (Arciniegas, 2015). The schizophrenia spectrum disorders include schizophrenia, schizoaffective, delusional, schizophreniform, and brief psychotic disorders. Psychosis sometimes occurs in people with mood disorders and is also a frequent feature observed during either intoxication or withdrawal from substances (Arciniegas, 2015).

Psychosis is known to have positive and negative symptoms. Positive symptoms are those symptoms an individual suffers with during a psychotic episode, but which were not present before the onset of psychosis, and they include paranoia, delusions, hallucinations, disorganised thinking, and such unusual motor behaviours as catatonia. Negative symptoms are those symptoms an individual used to have but which become reduced or disappear with psychosis, and they include reduced expression of affect, poverty of speech, lack of or reduced motivation, withdrawal from social activities, or incoherence (APA, 2013; Mangalore & Knapp, 2007; Nuno et al., 2019). Psychosis is also characterised by cognitive dysfunction exemplified by deficits in executive function, working memory, and attentional deficits (Moran et al., 2016). These symptoms may be short-term, sporadic, or part of a longer-term underlying mental health condition (Arciniegas, 2015). While this wide range of symptoms can occur in various combinations, sufferers across the schizophrenia spectrum commonly experience impairments and restrictions in significant domains of life such as in relationships, education, work, or self-development and self-care (Ahmed et al., 2018). According to both the DSM-5 and ICD-10 (APA, 2013), impaired reality testing is a central element of psychosis, with delusions and hallucinations acting as evidence of impaired reality testing and lack of insight. Some other co-occurring features of psychosis include formal thought disorder, which refers to a presentation where thinking is disorganised, illogical, or to the presence of thought blocking, and tangentiality, or any combination of these (Wynn Owen & Castle, 1999). A diagnosis of schizophrenia is made when a person presents with positive or negative symptoms lasting at least six months, where symptoms are linked to impaired functioning in one or more areas (APA, 2013; Arciniegas, 2015).

1.2 Prevalence of schizophrenia and other psychotic disorders

There are significant variations in the reported prevalence of psychotic disorders. From their meta-analyses, Moreno-Kustner and colleagues (2018) reported a median lifetime prevalence of 7.49 per 1000 persons globally for schizophrenia and other psychotic disorders. This prevalence is higher than that given by Saha et al.'s (2005) of 4.0; and that of 4.8 in 1000 proposed by Simeone et al. (2015). In the UK, the Lost Generation report (2013) estimates that about 10 in 1000 people will have an experience of a psychotic nature in their life. According to the Psychosis and Schizophrenia document, though the lifetime prevalence of psychotic disorders and schizophrenia varies considerably between estimates, in the UK it is estimated to be 14.5 per 1000 (Psychosis and Schizophrenia in Children and Young People: Final Scope, n.d.). Charlson et al., 2018 report that worldwide, there are about 21 million people living with schizophrenia, a number that is anticipated to rise because of population growth and ageing.

1.3 The burden of psychotic disorders

Some literature reports that psychotic illness is a seriously debilitating condition, with an increasingly worsening trajectory, and considered to have potentially life-changing consequences (Lester et al., 2012). This is in line with Kraepelin's early description of 'dementia praecox', seen as a gradual and untreatable psychotic condition leading to irreversible disability (Adityanjee et al., 2002). However, this way of viewing psychotic disorders and their prognosis changed, when in 1908, Bleuler replaced Kraepelin's term 'dementia praecox' with schizophrenia. Bleuler's early understanding of schizophrenia, and mental illness for that matter, was that these conditions are biopsychosocially constituted. This gave room for therapeutic intervention on the three involved components, leaving the future of sufferers looking less bleak (Maatz et al., 2015).

In the past 20 years, there has been increased attention to early assessment, prevention, and treatment of psychosis when it first appears, resulting in better outcomes and prognosis for people with psychosis and psychotic disorders, their significant others, and their communities (Murru & Carpiniello, 2018).

While psychotic disorders are categorised as low prevalence disorders, different studies have estimated their financial burden to be between 0.02% and 1.65% of gross domestic product (Baxter et al., 2013). Mangalore and Knapp (2007) estimated the healthcare costs of schizophrenia in England as £6.7 billion between 2004 and 2005. Schizophrenia was ranked among the leading fifteen disorders that cause disability worldwide (Global Burden of Diseases, 2018; Moreno-Kustner et al., 2018), while the World Health Organisation (WHO) reported psychotic disorders to be among the top ten leading causes of disability (Saraceno, 2001).

Though outcomes differ among individuals, psychotic disorders are associated with substantial human suffering, disability, and premature mortality (Global Burden of Diseases, 2018; Jongsma et al., 2019; National Institute for Health and Care Excellence (NICE), 2014). It has been reported that the life expectancy of those diagnosed with schizophrenia can be reduced by between 10 to 25 years, mainly from preventable physical health problems (Saraceno, 2001). Employment for individuals with schizophrenia is reported to average 5 to 15%, which is considerably below the 71% for the general population (The Schizophrenia Commission, 2012). In their financial report on psychotic disorders in adults, the NICE guidelines (2014b) explain how these conditions impact people in many different ways, with the major economic costs arising from absenteeism or total inability to work.

1.4 Aetiology of psychosis and schizophrenia

Extensive investigations to identify the cause of psychotic disorders have been conducted in the last two decades worldwide, where different approaches were used, including magnetic resonance imaging, electrical encephalography, pharmacology, genetics, neuroendocrinology, and physiology, to name a few. In spite of all these efforts, effects were often difficult to reproduce, and most results were of little clinical significance and were not always unique to psychotic disorders (Scheepers et al., 2018). Part of what complicates psychotic conditions is that they are different from physical conditions in that the former do not have established and reliable biomarkers[3] that would allow clinicians to state categorically the presence of the condition (Cooke, 2014), as seen in conditions such as cancer, diabetes, or septicaemia for example. Therefore, it is important to take into account that the way we understand the 'causes' of psychosis is different from how we understand the 'causes' of physical conditions. While some parallels can be drawn, it is possible that various combinations of triggers are important to different individuals. According to the Early Intervention in Psychosis Network, there still exists heated debates about psychosis and its causes (Royal College of Psychiatrists, 2016). As for the DSM-5, it is ‘neutral with respect to theories of aetiology’ (APA, 2013; Royal College of Psychiatrists, 2016).

Still, several risk factors have been reported as possible causes of psychotic experiences, and while a full survey of the connections between biology and the environment are beyond the scope of this study, some of the risk factors and their interactions are discussed below.

1.4.1 The role of genetics in schizophrenia

The evidence about genetic risk and heritability of schizophrenia comes from adoption and twin studies, with the evidence indicating that the strongest predictor of the risk of developing psychosis is having a primary relative with psychosis (Gottesman et al., 2010; Sullivan et al., 2003). Different studies have reported conflicting heritability figures. According to some evidence, this genetic risk is estimated at between 80 and 90%, where some twin studies have shown that monozygotic twins are significantly

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[3] In this context, a biomarker is a characteristic that is objectively measured and evaluated as an indicator of normal biological and pathogenic processes (Robb et al., 2016).

more likely than are dizygotic twins to develop schizophrenia (Polderman et al., 2015). In other systematic reviews of twin and adoption studies, heritability has been indicated to contribute about 70% towards the development of schizophrenia (Zwicker et al., 2018), while Moran et al. (2016) report genetic contribution to be no more than 50%. Despite extensive genetic investigations being carried out, no single gene or variant has been identified as a necessary and sufficient causal factor for schizophrenia. While there have been some major breakthroughs afforded via the genome-wide association study data, over 100 independent loci are reported to be strongly associated with schizophrenia. These findings suggest that there are contradictory reports about the extent to which genes have a part in the aetiology of schizophrenia, where a major role has been indicated for developmental and environmental factors (Moran et al., 2016; Zwicker et al., 2018).

1.4.2 The role of environmental factors

Though Polderman and colleagues (2015) seem to suggest that the environment plays very little role in the development of schizophrenia, epidemiological studies strongly suggest a much smaller contribution of genetics and a consistently greater role of the environment (Zwicker et al., 2018). Some of the main environmental risk factors that have been well studied and are associated with the risk of developing psychosis include those affecting foetal growth. Examples are prenatal nutrition and maternal state of health, hypoxia-related obstetric complications, and paternal age. Others are social factors and include low parental socioeconomic status, migration, urbanicity, childhood abuse and neglect, chronic bullying (both as victim and perpetrator) and cannabis use (Moran et al., 2016; Zwicker et al., 2018). Many individuals who are diagnosed with psychotic disorders are subjected to a number of risk factors, which complicates the study of given environmental risk factors. Additionally, not everyone who is genetically predisposed and exposed to environmentally risky factors develops psychosis. Therefore, it can be concluded that psychotic disorders are not explainable from even multiple environmental factors alone, but perhaps from multiple genes interacting with multiple environmental factors (Zwicker et al., 2018).

1.4.3 Gene-environment interplay

Zwicker et al. (2018) explained how the interactions between genetic factors and the environment cause psychotic illness in particular individuals, where the combined contributary effects are termed ‘gene-environment interaction’. In this interplay, genes could predispose someone to environmental risk factors, thereby influencing how someone is likely to respond to certain environmental factors. For example, where some people cope well under stressful situations, others might develop mental disorders following such events. Studies have found that people with a high genetic risk for conditions such as schizophrenia are more likely to experience delusional thinking or hallucinations. Notably, not everyone is affected by this genetic vulnerability in the same way. Although there are no signs or symptoms for certain people at high genetic risk, others have symptoms that are serious enough for mental health disorders to manifest. Furthermore, Moran et al. (2016) observed that gene-environment interactions may also exist as environmental factors influencing methylation of DNA in schizophrenia, causing changes in how genes are expressed. Zubin’s (1977) stress-vulnerability model explains how the genetic predisposition exposes one to situations where they are likely to experience psychological distress (Figure 1.4). This can be modified by what are called protective factors. Therefore, those with high vulnerability and inadequate protective factors are more likely to experience distress, even with low levels of stress, and those with low vulnerability, at some level of stress, they will experience distress.

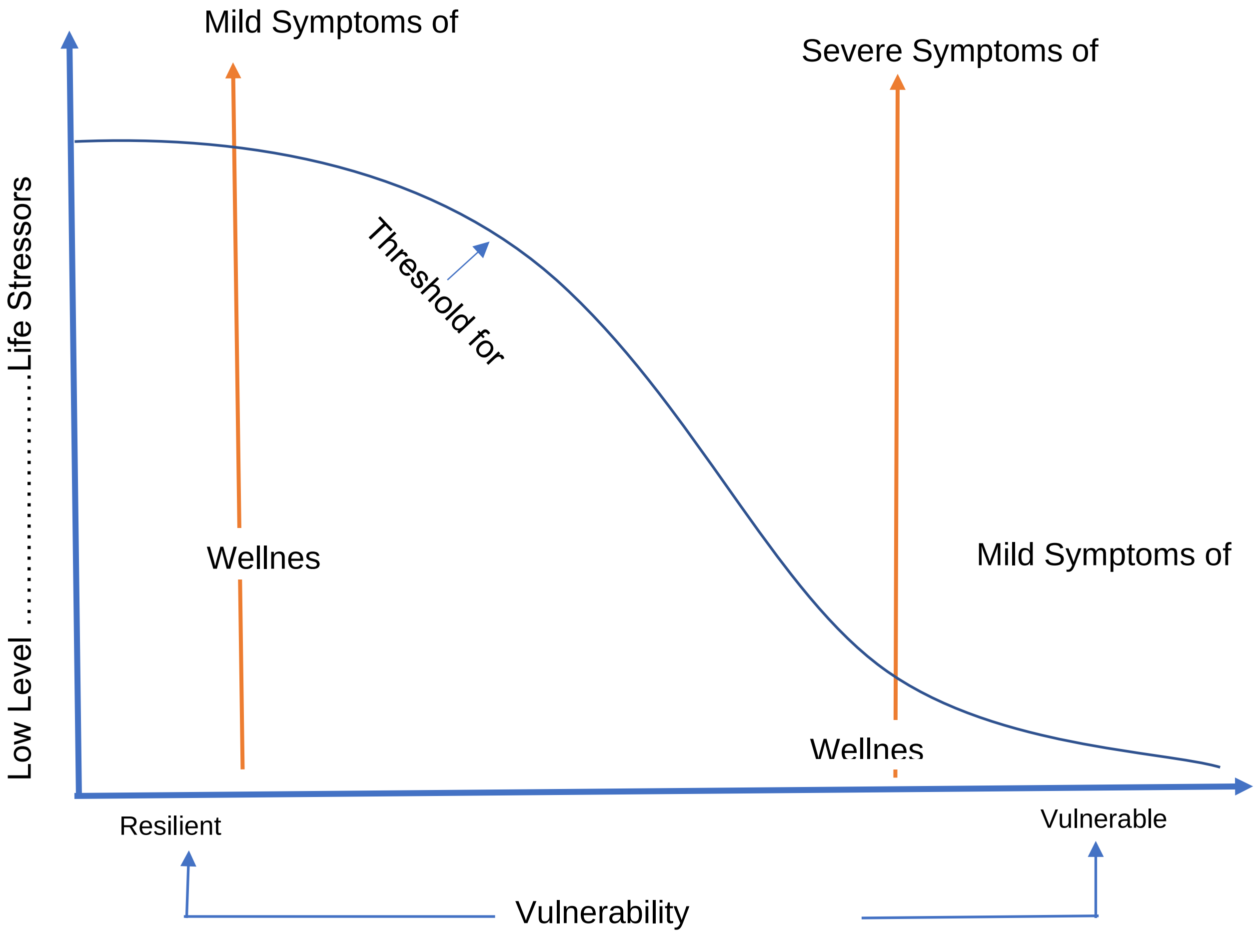
1.5 Making sense of Psychosis

Traditionally, the biomedical model, also known as the disease model, has been widely preferred in the interpretation of psychotic disorders, especially schizophrenia.

However, as yet, biomedical research has failed to conclusively unravel the aetiology of psychotic disorders, with different results laden with inconsistencies. Yet persuasive evidence exists for the relationship between psychotic disorders and stressful environmental factors, especially those that affect social interaction. Others have argued that psychosis symptoms can be viewed as a normal defense mechanism or protective response, and even an adaptive way to survive challenging, stressful, or traumatic situations (Scheepers et al., 2018).

Consequently, there have been huge debates about the most helpful way to refer to and understand psychotic experiences. The Understanding Psychosis Report argues in favour of viewing psychosis within the psychological context and integrating personal accounts (Cooke, 2014). Accordingly, the medical and psychological viewpoints will now be discussed to give the reader some idea about how each of these viewpoints makes sense of psychosis and other psychotic disorders. Other conceptualisations will also be discussed briefly.

Fig. 1.4: Stress Diathesis Model (adapted from Zubin & Spring, 1997)



1.5.1 The Biomedical Conceptualisation of Psychosis

The biomedical model primarily accepts that such psychiatric illnesses as schizophrenia are biologically based brain diseases. The key concepts of this paradigm consider that mental disorders are caused mainly by biological anomalies in the brain, that there is no substantial difference between mental illnesses and physical illnesses, and that pharmacological treatment is the answer (Deacon, 2013). As explained above, there has not been conclusive evidence about the aetiology of psychotic disorders; therefore, the stance that the biomedical model takes can be considered reductionist in that it minimizes the importance of psychosocial contributions to mental illness and claims that psychological phenomena can be entirely reduced to their biological causes (Deacon 2013). For many years, the biomedical model has overshadowed mental health systems in most western countries, where the majority of people believe that mental disorders are impacted by chemical imbalances, therefore should be treated with psychotropic medications. Antipsychotic medications were introduced for the treatment of psychosis in the 1950s, after which the dopamine hypothesis was reconceptualised to explain cognitive impairments (Howes & Kapur, 2009). With time, neuroimaging studies led to the conclusion that multiple factors such as genes, stress, and frontotemporal dysfunction act as modulators of dopamine regulation (Lau et al., 2013).

The main difficulty in defining psychosis as a mental illness is that it is not easy to separate our normal behaviours from those of people with psychosis, and experiences such as paranoia can be a part of normal development or they can exist on a spectrum as those experiences considered normal (Van Os, et al., 2000). As such, the biomedical conceptualisations have been critiqued for their lack of definite demarcations between psychotic disorder and 'normal functioning' (Bentall, 2009; Boyle, 2007/2014). Additionally, there are reports about the existence of cross-cultural variations in the prevalence of both positive symptoms and the diagnosis of psychosis, suggesting an interaction of social and ethnocultural factors in the presentation of FEP. Therefore, phenomena that may be considered to be psychotic within the Western settings may be more culturally accepted elsewhere (Schwartz & Blankenship, 2014; Vermeiden et al., 2019). Another example of difficulties in defining and diagnosing psychosis takes into account changes to diagnoses, for example, Kraepelin's dementia praecox, which no longer was recognised in 1952 when the DSM was published and to date (Berrios, 2011). Additionally, Cooke (2014) states that diagnosis can be unreliable, lacking in validity, and can be unhelpful. Therefore, there is need for alternative ways of understanding these experiences, and the British Psychological Society has accepted that the medicalisation of normal responses to situations that have distressing consequences misses the context of people's challenges.

1.5.2 Psychological Conceptualisation of Psychosis

Considering normal experiences as a psychiatric condition can be viewed as stigmatising in situations where individuals concerned do not find these experiences disturbing to them or if they attribute non-medicalising reasons for their experiences. Therefore, restoring meaning and making sense of a devastating yet seemingly meaningless experience is the most significant feature of any alternative to psychiatric diagnosis (Cooke, 2014). People's experiences and how they are affected emotionally is real, yet the explanation that they feel this way because of a psychotic illness may not be meaningful for, or resonate with the individual. Therefore, different researchers suggest developing psychological formulations, which take into account social contexts, life events, and the meanings that individuals attach to their difficulties (Cooke, 2014; Johnstone, 2017).

Johnstone (2017) defines formulation as *"the process of co-constructing a hypothesis or "best guess" about the origins of a person's difficulties in the context of their relationships, social circumstances, life events, and the sense that they have made of them*, p. 32". A formulation therefore offers the sufferer and the clinician a chance to collaboratively make sense of the sufferer's experiences as they together cocreate a narrative that allows the sufferer to move forward, with the clinician bringing their psychological or theoretical knowledge while the sufferer brings their experiential expertise. At its heart, unlike a psychiatric diagnosis, psychological formulation takes a personal, open-ended approach to all elements of distress, which enables the sufferer to feel that "at some level, it all makes sense" (Butler in Johnstone, 2017). A way forward, which may involve developing alternative ways to make sense of and cope with challenges, build on strengths, and live with or even overcome one’s difficulties, may be agreed on during formulation.

Some of the common psychological ways of understanding psychosis include the cognitive behavioural and the systemic way, with therapies based on both, that is Cognitive Behaviour Therapy (CBT) and Systemic Therapy. CBT will now be discussed briefly.

CBT is an evidence-based treatment approach that was developed by Beck to treat depression (Beck, 1976/2009). According to the CBT model, one’s thoughts, emotions, physical sensations, and actions are all interlinked, and change in one area can have an impact on the rest of the areas (Hardy, 2014). Generally, CBT helps by reframing one’s maladaptive cognitions and behaviours.

Based on the main CBT model is CBT for psychosis (CBTp). CBTp is recommended as the first line treatment for individuals with psychotic disorders (Lehman, 2004; NICE, 2009) and has been specifically recommended for individuals experiencing FEP (NICE, 2014b). The central tenet to treatment using CBTp rests on formulation, whose aim is to help the individual to understand the links between their early experiences, their core beliefs or core schema, the unhelpful thinking patterns and their behaviours that may be maintaining the distressing symptoms observed in psychosis.

Different CBTp models have been hypothesised, where they identify unhelpful appraisals of anomalous experiences about individuals themselves, others and the world, as crucial factors that influence the distress experienced by individuals with psychosis.

Individuals susceptible to experiencing delusions are observed to have a type of cognitive bias termed jumping to conclusions (JTC) which is more pronounced than it is in controls (Beck, 1976; Dudley et al., 2013; Huq et al., 1988). In people prone to psychosis, the JTC style of thinking is amplified during stressful times, resulting in, for example, persecutory or grandiose delusions.

One of the cognitive models of psychosis is by Bentall et al. (2001) who argue that persecutory beliefs originate from real life persecutory experiences, where delusions are a form of psychological defence against such underlying emotions as low self-worth and low self-esteem. In such cases, individuals make sense of anomalous situations by attributing blame externally, whether situations or others, to protect the ego.

Freeman and Garety (2000) claim that central to persecutory delusions are two main distressing concerns for people with psychosis, namely, that harm is inexorable, and that there is a perpetrator of this harm. Further, confirmation bias is said to provide the support the delusional belief in question, and this is believed to be important in the maintenance of delusional beliefs (Garety & Hemsley, 1994).

Morrison's (2001) integrative model to interpret intrusions in psychosis posits that psychotic phenomenon are one's unpleasant internal experiences that one misinterprets, according to one's prior beliefs and experiences. These faulty interpretations are influenced by the individual's highly active threat system instead of flawed perceptions. Auditory hallucinations for example are said to be a result of faulty attribution of intrusive thoughts to an external source. Of note about Morrison's model is the emphasis of misinterpretations in culturally unacceptable ways.

1.5.3 Trauma-informed psychological understandings of psychosis

Although there is no conclusive evidence about the specificity of the impact of trauma on psychosis, there is a wealth of epidemiological, phenomenological, and clinical research that supports the position that exposure to traumatic experiences in childhood represents a significant risk factor for the development of symptoms identified as those of psychotic disorders (Achim et al., 2011; Arseneault et al., 2011; Kessler et al., 2010; Longden et al., 2012; Matheson et al., 2013). Some studies have also given neuroscientific evidence that indicates how trauma and abuse during an individual's developmental phases are encoded in the brain and the autonomic nervous system, creating similar types of psychobiological states that can cause such long-term problems for people in adult life as voice hearing, suspiciousness and lack of trust, anxiety, and difficulties regulating emotions as seen in psychosis and other mental health conditions (Bentall & Read, 2012; Longden et al., 2012; Misiak et al., 2017). This in part has justified the rise of the psycho-socio-biological approach to making sense of psychotic disorders (Gerhardt, 2004; Read et al., 2001).

Concerning the correlation between childhood trauma and psychosis in adulthood, a dose-response relationship is reported between the frequency, severity, and range of traumatic experiences and the impact on one's psychological well-being. This means that those individuals abused as children and having endured more types of abuse are more likely to become psychotic compared to those who endured fewer types of abuse (Dillon et al., 2012; Shevlin et al., 2007).

In terms of how past trauma can manifest, childhood sexual abuse, as well as early memories of shame, defeat, and entrapment, are reported to be associated with hearing voices and suspiciousness in individuals, phenomena termed auditory hallucinations and paranoia respectively within the biomedical model (Trower et al., 2010). In other studies that review the relationship between past experiences and symptoms, emotional abuse and neglect have been associated with paranoia, negative beliefs about the self, and threatening appraisals of others and the world (Fowler et al., 2006; Hardy 2017; Morrison et al., 2003).

One of the mechanisms proposed to mediate the development and experience of psychosis involves dissociative mechanisms. Some authors have described these mechanisms as psychological defence responses that developed as ways to cope with childhood trauma to allow individuals to psychologically detach from experiences that were too overwhelming for the psyche to process (Read et al., 2001; Longden et al., 2012). However, this detachment then led to a disruption to the normal integration of psychobiological functioning (APA, 2000). The UK Hearing Voices Network explains voices as part of unintegrated dissociative traumatic material. In cases where normal integration of psychobiological functioning is disrupted, individuals may associate voices with an external source rather than identifying them as dissociative phenomena. Consequently, the network proposes a view of voice hearing as socially significant and psychologically interpretable (Dillon, 2006), a position which Longden and colleagues (2012) supported in their review paper. In other studies reviewing voice hearing in the general population, lifetime prevalences ranging between 1% to as high as 41% have been reported (e.g., Pearson et al., 2008). Therefore, as voice hearing is common in various clinical and non-clinical populations, adequately differentiating voice hearing characteristics between these groups becomes difficult. Additionally, due to the epidemiological associations between voice hearing and childhood traumatic life events, identifying voice hearing as a core indicator of psychosis needs to be reconsidered, with its dissociative origins given more weight. Psychosis therefore can be understood as being on a spectrum with other mental health conditions in terms of degree of dissociation. As such, where some individuals may experience a negative inner critic, as the trauma increases along the spectrum of dissociation, some may understand this as a persecutory voice. Considering all this, Longden and colleagues (2012) maintain that voice hearing experiences in different contexts can most appropriately be understood as reflecting dissociated or disowned components of the self or of relationships with others that result from trauma, loss, or other interpersonal stressors.

Manifestations of dissociation sometimes include symptoms like depersonalisation, derealisation, and identity confusion, phenomena sometimes reported by those diagnosed with psychotic conditions like FEP. Dissociative experiences have been reported to occur at different times of what is considered a psychotic episode, which can be part of the prodromal phase or the acute phase. While dissociation can be adaptive in the short term by reducing conscious awareness of intolerable experiences, severe dissociative intrusions as habitual ways of responding to anxiety or perceived threat can cause significant distress and functional impairment, both of which have negative implications on one’s quality of life (Dell, 2009).

This way of understanding psychosis has implications for treatment. Although abusive and derogatory voices can cause significant distress and demoralisation in those who hear them, the fact that voices are prevalent within nonclinical groups means they are not exclusively an indicator of psychotic illness, a point that can be used in normalising voice hearing. During treatment, regardless of at what point dissociation occurs, recognising and learning adaptive strategies to cope with the dissociation can make psychosis less disabling or more manageable. Therefore, practitioners delivering CBTp need to focus on normalising psychotic experiences and promoting a change in the appraisal of, and response to such experiences, rather than make attempts to work on the voices or try to eliminate these experiences, viewing them as symptoms of an illness (Morrison, 2017). Third-wave CBT approaches are more appropriate as they focus on and aim to address the meaning an individual gives to his or her experiences, as well as to the distress associated with self-perceptions (Chadwick, 2006).

Screening for trauma and dissociation in individuals presenting with symptoms of FEP will allow treatment to focus on these aspects. During treatment, when voices are understood as disintegrated parts of the self, psychological methods can be used to support the integration of life events and understand the role voices may play in precipitating or maintaining the distress experienced by those hearing the voices.

1.5.4 Other Conceptualisations

Spiritual, religious, and cultural conceptualisations of psychosis

As there has been a rise in society’s religious and cultural diversity, there is a need to consider different cultures’ ways of perceiving their experiences, especially where non-western ways of making sense of psychosis are preferred (Menezes & Moreira-Almeida, 2010). When a psychotic diagnosis is made based on an individual’s cultural or religious beliefs been unfamiliar, multicultural communities may view these ways of being understood as pathologising. Additionally, one may view this as Western clinicians considering their views as superior to the sufferers’ who may have a different way of understanding their difficulties (Menezes & Moreira-Almeida, 2010).

Clinicians are advised to avoid pathologising religious attitudes as driven by psychotic conditions, since strong religious beliefs are not always indicative of a psychotic illness (Fallot, 2008; Lukoff, 2007). Blanch (2007) argues that appraising and expressing some psychotic disorders spiritually can be an effective way of reframing such conditions. In some sufferers' lives, religion has been reported to be part of either their problems or the solution (Mohr & Huguelet, 2004). As such, while some sufferers may feel their religion helps with recovery and that their religious communities are supportive, some may feel weakened and unwanted, which may affect their sense of self and belonging, which in turn may affect how they present (Menezes & Moreira-Almeida, 2010). As some spiritual experiences include being in contact with external forces and speaking in unusual ‘tongues,’ this may be considered a psychotic episode, as the person may be considered to exhibit beliefs in delusional elements and hallucinations, both of which are typical schizophrenia symptoms according to the biomedical model of psychosis (Menezes & Moreira-Almeida, 2010). The interpretation of how one hears voices and makes sense of other experiences, such as extra-sensory perceptions, can be affected by cultural and spiritual contexts. Within Western societies, the spiritual aspect of psychotic illness and the healing powers of prayer are said to be understudied and undervalued (Laroi et al., 2014).

Therefore, a holistic formulation approach is required, one that encompasses the biomedical, psychological, social, and spiritual aspects of an individual according to their beliefs. Importantly, sufferers and their significant others will benefit from a situation where services work collaboratively with them to understand their experiences in a way that is meaningful to them. To do so, there has to be an understanding of what it is like from individuals who have experienced psychosis, in their own words, from the onset till recovery.

As for me, in the context of this research, and as a Practitioner currently working in a service where a medical diagnosis is required to identify the care pathway under which a service user can access services, my own position is that medical diagnoses are one way, an inadequate way of making sense of individuals’ difficulties. I consider psychological formulation as an alternative to a standalone psychiatric diagnosis. The psychological formulation is about sense-making, being an ongoing collaborative process which gets updated as new information is discovered. I take the view that human beings are, and always have been meaning-making individuals, where meanings are influenced by individuals’ contexts. This way, my way of sense-making is more inclusive of culture specific ways of expressing distress.

I consider my preferred psychological way of sense making as integrative, specifically utilising the bio-psycho-social-spiritual model which I regard as a more comprehensive way to understand the full complexity of human experiences and their subsequent behaviours. This model guides my work with my clients. The four components of this model do not always have to be present in that order, and may each differ in their level of impact upon the individual’s difficulties. I am aware that some individuals using mental health services prefer to make sense of their experiences and challenges using the biomedical way, and I respect that, so I would continue to work with them to co-formulate their challenges in the more inclusive bio-psycho-social-spiritual way, if they wish or are open to alternative ways of sense-making. I do not consider my way of sense-making to be superior to my clients' preferred way of sense-making, but a more inclusive and exhaustive way.

1.6 First Episode Psychosis: definition and intervention

There has been a strong association between FEP and high rates of mood disorders, non-accidental harm, suicidality, and actual suicide (Saraceno, 2001). Furthermore, the risk of suicide is exceptionally high during the first year of FEP (Tarrier et al., 2007). It is necessary, therefore, to intervene in a way that results in treating FEP effectively.

Birchwood et al. (1998) came up with the 'Critical Period' hypothesis for psychosis after witnessing the Early Psychosis Prevention and Intervention Centre (EPPIC) program's results in Australia for those presenting with symptoms of FEP. The 'Critical Period' is the phase following the onset of psychosis and is said to present major opportunities for secondary prevention of the potential disabilities that may follow FEP, alleviating symptoms and reducing, and even preventing the development of treatment-resistant psychotic illness if optimally managed (Spencer et al., 2001). The 'Critical Period' is meant to provide a window during which there is a higher sensitivity to the illness and also a greater chance of responding to treatment if offered in time. In other studies, evidence also suggests that a long duration of untreated psychosis (DUP) negatively influences treatment outcomes (McGorry, 2008).

In the UK, this work led to public investment into specialist services nationally, with guidelines such as the Mental Health Implementation Guide and the Initiative to Reduce Impact of Schizophrenia (IRIS) recommending a focus on young people aged up to 35 years. By 2004, 50 early intervention in psychosis (EIP) services had been introduced, planned to increase to 200 shortly after (Department of Health, 2000). EIP services are specialist integrated and multidisciplinary mental health services focusing on the treatment of FEP. Since their establishment, EIP services have been reported to be the most positive and highly cost-effective development in mental health services since the closure of asylums and the beginning of community care (The Schizophrenia Commission, 2012). However, developing more such services could not continue as initially planned due to economic and political pressures, which saw repeated financial cuts to mental health services, in some cases amounting to a minimum of 50% to services' budgets (Birchwood et al., 2013; Marwaha et al., 2016; The Lost Generation report, 2014).

1.6.1 Late-onset FEP

1.6.1.1 Aetiology and Risk Factors in Late-onset Psychosis

The key to identifying the underlying pathological process of late-onset FEP and how this compares with early-onset FEP lies in identifying the risk factors for FEP in middle-aged individuals (Brunelle et al., 2012). Among individuals with late-onset FEP, more reports of significant past trauma and lower lifetime cannabis use are documented when compared to those with early-onset FEP. Other authors have cited a higher prevalence of late-onset FEP in women, with 60% of those diagnosed with FEP being women, implying a second peak of FEP onset in middle-aged women (Cotton et al. 2009; Tampi et al., 2019). In their review of late-onset psychosis, Tampi and colleagues (2019) reported that poor health status, hearing loss, visual impairment, cognitive decline, chronic adverse life events, and female gender appear to be risk factors for developing late-onset schizophrenia. In earlier studies, Selvendra et al. (2014) concluded that compared to their younger counterparts, individuals with late-onset FEP were more likely to have more metabolic morbidity and depressive psychosis, results that are similar yet different to those of Greenfield et al. (2018), who found that many of their 35 to 65 year-old participants had some form of physical health comorbidity with no predominant metabolic morbidity.

1.6.1.2 Late-onset FEP: Associated diagnostic challenges.

The challenges of diagnosing what is now referred to as late to very late-onset psychosis emerged early in the history of psychiatry. In 1896, Kraepelin coined the term ‘dementia praecox’ to refer to psychotic disorders in younger adults, with the term ‘praecox’ originating from Latin, which meant ‘very early.’ When he observed similar symptoms in middle-aged individuals, he called this ‘paraphrenia,’ although the symptoms of both conditions were very similar. In 1911, Bleuler described the kind of psychotic disorder observed in those over 40 as late-onset schizophrenia, a disease whose symptoms he considered direct responses to environmental factors (Adityanjee et al., 2002). However, both terms, Kraepelin’s ‘paraphrenia’ and Bleuler’s ‘late-onset schizophrenia,’ continued to be used for years, causing confusion within research, diagnosis, as well as in epidemiological studies (Pearman & Batra, 2012). Indeed, the prevalence and incidence of late-onset FEP are comparatively not well researched due to these diagnostic challenges, and to such disorders being believed to be rare in middle-aged individuals except where they are related to the ageing brain. That aside, under-reporting of late-onset cases was worsened by the implementation of inconsistent and relatively arbitrary age cut-offs in various diagnostic critical sets (Wynn Owen & Castle, 1999). Within the DSM-III-R, a separate category for psychosis-like symptoms was included for sufferers whose condition began after age 45 (APA, 1980; Castle & Murray, 1993/1998). In many countries, there was also a split in mental health services for over 60 years, resulting in geriatric psychiatry being considered a distinct subspecialty (Almeida et al., 1995). This confusion necessitated a way of reducing inconsistencies in diagnostic systems and nomenclature, thereby facilitating research. In 2000, the International Late-Onset Schizophrenia Group Consensus Conference agreed that FEP in individuals aged between 40 to 60 would be termed late-onset FEP, and very late-onset FEP in older adults with onset after 60 years (Howard et al., 2000). In line with this consensus, FEP in 14 to 39 year-olds would continue to be termed early-onset FEP.

1.6.1.3 Late-Onset FEP: Prevalence

As a result of the diagnostic inconsistencies explained above, prevalence rates for FEP in middle-aged individuals vary significantly. Some authors report rates of between 20 and 28% after 44 years (Wynn Owen & Castle, 1999), while others report

FEP in 40 to 60 year-olds as ranging between 15.4 and 32 % (Harris & Jeste, 1988; Howard et al., 2000), where the percentage of schizophrenia alone is cited as 23.5% (Harris & Jeste, 1988). Despite the differing prevalence figures, this indicates that psychotic symptoms starting in middle-aged individuals is no rare event.

There is a good chance that the prevalence rates given above are understated due to diagnostic challenges and due to the higher levels of positive symptoms, especially paranoia, observed in late-onset FEP, which may prevent middle-aged individuals from seeking help and consequently from being counted in clinical samples (Köhler et al., 2007; Wynn Owen & Castle, 1999).

To date, the current international consensus about the diagnostic criteria is that all cases, despite age of onset, belong to the same illness category if they satisfy diagnostic criteria for schizophrenia (Howard et al., 2000).

1.6.1.4 Late-onset FEP: Symptoms and presentation

Some researchers have maintained that early and late-onset cases are clinically more similar than different in terms of symptoms, with almost no differences up to age 60 (Pearman & Batra, 2012). However, other studies have reported that among individuals with late-onset FEP, there was a higher incidence of suicidal ideation and comparable rates of a history of aggressive behaviour when compared to those with early-onset FEP. Additionally, how late-onset individuals enter the psychiatric system is reported to be different, where most are referred to the EIP services by secondary mental health services (Greenfield et al., 2018). Jagger and colleagues (2020) had similar findings, adding that significant referrals were from the acute sector, while the younger people were mainly referred from within primary care settings. The way late-onset participants utilised the early intervention components of services further indicated that they might have different clinical requirements, or complexity of their needs or a different range of social or legal needs (Jagger et al., 2020).

Individuals with late-onset FEP are more likely than their earlier onset counterparts to complain of positive symptoms such as paranoid and persecutory delusions and hallucinations, are less disorganised, and display fewer negative symptoms (Howard et al., 2000; Wynn Own & Castle, 1999). The differences in symptoms and presentation are apparently not readily explicable in terms of societal gender-related role expectations, or gender differences in care-seeking, or better occupational and marital histories (Howard et al., 2000). Late-onset individuals are also reported to exhibit a relatively good premorbid adjustment and a more favourable disease outcome while being less likely to display formal thought disorder (Wynne Owen & Castle, 1999).

While 14 to 35 years is a crucial period in a person's development, middle-age is another critical stage of an individual's functioning in life (Rinaldi et al., 2010). Occupationally, functionally, financially, and socially, middle-aged individuals are autonomous. They have more social roles and responsibilities than younger people, yet the experience of FEP challenges all areas of autonomy and undermines one's sense of self-agency. Therefore, the impact of a psychotic breakdown at this stage can be profound, potentially resulting in the loss of social roles, leading to isolation, stigmatisation, and increased risk of suicide (Tarrier et al., 2007). It is reported that social isolation and interrupted employment is more prevalent in individuals with late-onset FEP compared to their age-matched peers, which might contribute to social exclusion, as one's job is reported to be the central hub from which many other areas of functioning emanate (Howard et al., 2000; Rinaldi et al., 2010). In their study where labour productivity was assessed as a function of age in the general population, Börsch-Supan and Weiss (2016) concluded that age-productivity profiles are highest between 25 and 65 years. In other studies, for social outcomes in late-onset schizophrenia, it was found that of the 84% of individuals who were homemakers or were employed when they became unwell, only 29% were employable five years after the first admission, indicating an overall 55% reduction in financial independence compared to 1% decrease in individuals with early-onset FEP (Hafner et al., 1998). To cater for individuals with late-onset FEP, the Department of Health and NHS England (2014) and the NICE Guidelines (NICE, 2015) recommended that EIP services be available to all individuals with FEP, increasing the upper age limit for individuals under EIP services to 65 years. For those EIP services that started to cater for 14 to 65 year-olds in April 2016, their first 'cohort' only 'graduated' from EIP service in April 2019.

As studies in FEP have increased in the past 20 years, what we learn so far is that late-onset FEP appears to have a different aetiology, different presentations, and to create different clinical needs. Furthermore, the extensive research on individuals with FEP developed so far has mostly focused on exploring the aetiology and prevalence of psychosis, and on medication efficacy and DUP, with outcomes including symptomatology, social functioning, and quality of life. These studies mainly adopted quantitative designs, while those exploring individuals' experiences did so through the use of standardised instruments, which do not detail how participants experience their FEP (Perkins et al., 2005).

Quantitative studies have been essential in advancing our understanding of FEP. However, in the process of matching questionnaire responses with preconceived categories we lose out on the opportunity to explore original and subjective meanings in participants' accounts. This is why this study aimed to gain a better understanding of 'what it is like' to have FEP for individuals with late-onset psychosis, and how their experience may differ from that of others. The Understanding Psychosis and Schizophrenia report details how, like with all individual experiences, different individuals utilise different coping strategies to cope with their challenges (Cooke, 2014). It is therefore important to understand individual experiences as reported by the sufferers themselves.

1.6.1.5 Double Jeopardy: Health-related stigma among middle-aged individuals with FEP

This subsection explains how the intersection of ageism and stigma around mental illness complicates the experience of mental health stigma among middle aged individuals accessing EIP services in the UK.

As a theory, intersectionality was first coined by Kimberlé Crenshaw, and in this case, it refers to the complexity and multidimensionality of people's lives, suggesting that the presence of more than one marginalised or oppressed identity marker overlapping with another negatively influences the experiences that the individual will have in a unique way (Crenshaw et al., 2013).

There is a lot generally written about ageism in health care and long term care, and in the available information about ageism in the provision of mental health services, many studies focus on older adults (Buttigieg et al., 2019). In healthcare, stigma has been shown to be more prominent in mental health services than in other areas of healthcare. Additionally, psychotic conditions are more stigmatised than other mental health conditions (see Butler, 1975; Rai et al., 2020). Generally, stigma is a socially constructed, multifaceted concept entrenched in complex areas of social inequality and organisational hierarchy, both of which are reported to mediate the process of othering of those who are stigmatised, as othering makes it easier to discriminate against those excluded (Weiss et al., 2006). When acts of discrimination and marginalisation are perpetuated by systems and organisations meant to protect and provide services for individuals, there is potential for severe social, psychological, and behavioural consequences for those affected (Seroalo et al., 2014). Furthermore, health-related stigma has been reported to not exist in isolation but to intersect with various types of social marginalisation due to identity markers such as race, gender, and age, for example. This results in intensified experiences of stigma for those affected, a concept termed 'multiple stigma' and in cases where age and mental illness intersect, 'double stigma' (Turan et al., 2019). Potential implications of intensified stigma include concealment of the condition, social exclusion and isolation, and reduced access to health services (Sharac et al., 2010) which in turn are strongly associated with suffering, disability, and economic losses.

1.7 Qualitative Literature on FEP

For the reasons explained above, I focused my literature search on qualitative studies; and since there is a lack of qualitative studies on FEP in middle-aged individuals, and I was also interested to know how late-onset FEP might differ from early-onset FEP, I included qualitative research on early-onset FEP.

To identify literature on individuals' subjective experiences of FEP, a systematic literature search of papers written in English between 1980 to 2020 was undertaken in the following electronic databases: CINAHL, PsycINFO, Cochrane, EBSCOhost, Medline, Web of Science, and PubMed to retrieve articles that: (1) examined FEP, (2) employed a qualitative methodology, (3) were about subjective experience, (4) were published in English, or (5) focused on EIP services and related services.

A combination of keywords was used to identify the literature on ‘first episode psychosis,’ ‘FEP,’ ‘schizophrenia’ or ‘psychosis,’ ‘experiences of’ and ‘late-onset,’ ‘very late-onset’ or ‘early-onset’. To increase the chances of retrieving articles focusing on FEP, different combinations of phrases were used in the search window. A total of 432 research study titles were identified. Studies that focused on the experience of significant others, siblings, or healthcare professionals did not meet inclusion criteria, resulting in 412 articles being excluded. This left 20 studies, two of which were review papers. These review papers covered between them 11 of the 20 papers identified separately.

Due to space limitations, both review papers (Boydell et al., 2010; and Hansen et al., 2018) will be summarised below while focusing on the experiences of sufferers only as the papers reviewed the experiences of young people as well as those of their significant others. Of the remaining papers, those that spoke more directly to my topic of interest by way of methodology, focus of study, and population being studied will be given more attention. There were only two papers that claimed to focus on late-onset psychosis, namely, Woodside and Krupa (2010) and Quin et al. (2009). These two studies will be discussed separately.

1.7.1 Early-onset FEP: sufferers’ experiences in their social contexts

During the prodromal phase, FEP sufferers experience non-specific symptoms which can initially go unnoticed by others. The sufferers are reported to be unsure about the meaning of their symptoms, and some actively disguise them. By the time individuals seek help, there will have been a protracted period of wondering what the symptoms mean, which can sometimes get in the way of seeking help, increasing the DUP. When sufferers eventually seek help, or when others do so on their behalf, they are sometimes put off pursuing services as others are dismissive or minimising of their symptoms. When they get in touch with healthcare staff, due to a lack of adequate mental health literacy some of the staff may not identify what causes the sufferers’ symptoms. Even when they finally get help, the process is not straightforward, with different challenges along the way including stigma from association with services. With time and different resources and interventions, sufferers start to make sense of their experiences, develop a sense of belonging, experience symptom relief and can achieve recovery.

In this subsection, I will discuss the findings of the two review papers, Boydell et al. (2010) and Hansen et al. (2018). Between them, they captured the full spectrum of individuals' experiences of FEP, from onset to recovery, according to individuals' subjective experiences. Boydell and colleagues (2010) include accounts by sufferers, their significant others and EIP staff, while revealing that there are many complex challenges associated with the process of seeking and receiving help. On the other hand, the studies reviewed by Hansen and colleagues (2018) only focused on sufferers, with results detailing their interactions with EIP services, including the impact the interactions had on their FEP experiences.

1.7.1.1 Early-onset FEP: Generic Social Processes

Understanding different aspects of the care, lives and experiences of those involved during the treatment of FEP is important. To do so, Boydell and colleagues (2010) carried out a descriptive review of the qualitative studies on FEP published between 1999 to 2009.[4] The FEP sufferers included in these studies were aged between 16 to 53; all had had early-onset FEP and two late-onset FEP. Among the participants whose gender was specified, the majority were male; and among those assigned an ethnicity, most were Caucasians, with Hispanics, black African/Caribbean, and Asians represented. The studies were conducted in different countries which include Australia, Canada, Denmark, Finland, Norway, Sweden, UK, and the USA.

The papers reviewed used a wide range of methodologies, such as Grounded Theory, Ethnography, Mixed Methods, IPA, Case study, Constructivist, and Interpretative Interactionist.

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[4] Boydell and colleagues search method is detailed on page 8 of their paper (Boydell et al., 2010).

Boydell and colleagues organised their findings in line with Prus'[5] generic social processes (GSP)[6], resulting in four GSPs: i) **achieving identity**, ii) **acquiring perspectives**, iii) **doing activity**, and iv) **developing relationships**.

To appraise Boydell and colleagues' (2010) review, emphasis will be given to the subjective accounts of sufferers only. While these GSPs are discussed separately, they are closely interlinked as they are about the impact of FEP sufferers' symptoms to related life processes and experiences.

In their review, Boydell and colleagues (2010) identified a GSP they called **"achieving identity,"** where they describe factors that caused interruptions to sufferers gaining a sense of self throughout their interactions with others, from the onset till recovery. There is an emphasis on how important identity work is as individuals' images of themselves and of others appeared to go through different phases depending on the level of anticipation, sense-making, resistance, and acceptance, the sufferers engaged with. The behaviour changes in sufferers were initially influenced by different features during the prodromal period such as disturbed sleep and cognitive problems. During periods of anxiety, fear, and heightened irritability, it is as if participants experienced the loss of self as they felt something was different within themselves, often withdrawing from social interactions. Due to the unusual experiences of FEP, there were emotional and social responses to different situations, with changes in personality, as individuals continued to seek meaning in their experiences, adopting explanations that often changed with time.

During the process of accessing help, sufferers interacted with different individuals, mainly professionals from the EIP service, and Boydell and colleagues' GSP of **"acquiring perspectives"** describes how sufferers perceived their interactions, and how, through the interactions, they built relationships and gained knowledge about their experiences, both of which helped them to make sense of and understand their

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[5] Prus, R. (1996). Symbolic Interactionism and Ethnographic Research: Intersubjectivity and the Study of Human Lived Experience. Albany, NY: University of New York Press.

[6] Prus identified GSPs as interpretive features of association and the activities that are involved in the 'doing' or accomplishing of human group life in the various situations. These are trans-situational elements of interaction, the trans-contextual formulations of social behaviour.

situations better, and to restore an identity and sense of self lost due to FEP. Participants also identified that during their engagement with EIP services, their experiences of FEP had been validated and not dismissed, resulting in them feeling they were worthy, as they were included in decision-making. This helped restore their self-esteem, and enabled them to find meaning in their situations, a step recognised as essential in recovery. As they interacted with their peers, they were able to normalise their experiences, potentially reducing stigma.

Although being supported by others brought symptom relief, sufferers identified that to start to feel better and achieve recovery, they needed to get involved in doing something about their experiences themselves. This is what the GSP of **“doing activity”** is about, where such actions as help-seeking and gaining and maintaining employment were involved. This ‘doing activity’ sometimes started soon after sufferers first noticed signs that something was wrong. Different activities are reported, such as actively hiding their symptoms, withdrawing from social interaction, or attempting to interact with healthcare professionals. During this process, both professionals and sufferers were reported to have sometimes struggled to make sense of what the symptoms signified, with the sufferers struggling to make themselves understood. Other activities involved were returning to work, which was a challenge for some sufferers, especially while experiencing symptoms. For some, the side effects of antipsychotic medication hindered their ability to effectively ‘do’ activities.

As they engaged with others, whether family members, professionals, or peers, some form of relationship was formed, and the GSP of **“experiencing relationships”** encapsulates this. This GSP is influenced by all the other GSPs mentioned earlier. During social interactions, there were elements of selectivity in relationships about who to associate with, as well as how to cooperate with others. Sometimes participants experienced isolation due to loss of friends and friendships, fear of stigmatisation, and misunderstood behaviour. For most sufferers, self-isolation and social withdrawal had started before psychotic symptoms were observed, and they sometimes lost contact with old friends, choosing to team up with those in situations where ‘unusual’ behaviour was more readily accepted, such as those who had been in similar circumstances, whom they felt had a better understanding, and therefore could express genuine empathy. Some young people lost friends during and after the psychotic phase due to paranoia and assumptions regarding stigma and fears of rejection.

Boydell and colleagues' (2010) findings illustrate the complexity, variety and intertwining of the participants' experiences of FEP and the impact of those experiences on their interactions and vice versa. The responses of their social worlds shaped their sense-making and in some cases influenced their experiences. The GSPs of achieving identity, experiencing relationships, and doing activity appear to be about how participants experienced themselves and others, with the loss of self, resulting in them withdrawing from social interactions; the importance of agency, and the central role of identity restoration for achieving recovery.

Unfortunately, the researchers' search method to identify relevant qualitative studies and papers and their screening process is not transparent enough for me to be able to comment on the rigor of their selection process. Their interpretations of the different study results appear good as these GSPs are applicable to different social situations as described in the studies reviewed. They did well in their report about the quality of the reviewed papers, where they identified that only a few studies met the basic quality standards required for qualitative studies.

Though they observed that the way methodological issues were reported was poor, they were not specific about in what way the reporting of the methodological issues was poor. Boydell and colleagues did not aggregate demographic details of their reviewed papers, though most of the participants' demographic details such as ethnicity, age at onset of FEP, and gender, were given in the original papers. They did not specify which of their papers lacked what demographic details either.

Looking through their review, their participants in the different studies were aged 16 to 53 years, where for those that were age specified only two were over 40 years. Of those whose ethnicities were given, there were more Caucasians than all other ethnicities put together.

From Boydell and colleagues' review, many interesting results are identified, but it is evident that there are very few participants in the age group I am interested in.

Additionally, their review includes service users, their significant others, and services; therefore, does not focus solely on subjective experiences of sufferers, which is what I am interested in.

1.7.1.2 Early-onset FEP: sufferers’ experiences of EIP service

Some individuals that are diagnosed with FEP are treated by the EIP service, and during their treatment, the way they are interacted with (real or perceived) may have an impact on their recovery processes. Hansen et al.’s (2018) meta-synthesis investigated how individuals diagnosed with FEP experienced their contact with EIP service and how this contact influenced their recovery.

To identify studies that met their research criteria, Hansen and colleagues (2018) conducted a comprehensive review of both qualitative and quantitative studies.[7] They included studies that focused on EIP service, addressed subjective experiences of FEP and processes related to recovery, used a qualitative methodology, and were published in English. They ended up with 17 studies, which they then analysed in a two-step process to come up with their themes. To appraise the quality of the papers, the research team was joined by a research assistant with experiential knowledge of psychosis. Cumulatively, there were 276 participants in the 17 studies they retained, aged 14 to 65 years, with all except three having had early-onset FEP.[8] Of those participants with gender assigned, there were more than twice as many male participants as there were females, with a small number of participants from two studies not gender specified. The majority of participants were Caucasian, but there were some Asians, African/Caribbean, and mixed races identified. The studies were conducted in Australia, Canada, Hong Kong, Norway, the United Kingdom, and the United States. Between them, the studies employed IPA, Grounded Theory, and Thematic Analysis.

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[7] They searched PsycInfo, PubMed, Web of Science, and CINAHL in June and July 2016, details about this available on Hansen et al. (2018, p 261).

[8] Three participants from Bjornestad et al.’s (2017) study were 40-58 (personal correspondence)

As they considered FEP sufferers' experience of EIP services, Hansen and colleagues (2018) identified five broad themes: (a) **something is wrong**, (b) **do for myself**, (c) **it's about people**, (d) **a price to pay**, and (e) **ongoing vulnerability**.

At the onset of FEP, the participants described an increasing sense of unease, a feeling that "**something is wrong,"** during which they found themselves unable to function in the usual way. Still, they were reluctant to get help, and it took significant others to contact the healthcare services when the participants' deteriorating functioning could no longer be ignored. This is similar to Boydell and colleagues' GSP of "doing activity", in that both reviews identify the vagueness of symptoms at the onset of FEP and the reluctance of sufferers to seek help.

On being taken on by the EIP service and engaging with staff, participants in Hansen and colleagues' (2018) review discovered their personal agency and that they were able to assert themselves. This discovery was identified as a crucial moment in participants' recovery, a theme Hansen and colleagues called **"to do for myself."** This theme is concerned with participants' self-agency.

The theme "**to do for myself"** is closely related to the theme they called **"it's about people"**, where participants realised how they benefitted from the support provided by the services and others, while at the same time realising that they had to devise their own solutions to achieve recovery. These results are similar to what Quin and colleagues (2009) discussed in their theme "*I would get on with it myself,*" details of which will be discussed later. During their interactions with EIP staff, their peers, families, and friends, participants identified that being treated humanely had a significant influence on their recovery, more so when they experienced relationships as a partnership, findings that are again similar to those identified by Boydell and colleagues in their GSP of "**acquiring perspectives.**"

Although the participants identified the benefits of acknowledging they had problems for which they needed help, they felt this acceptance came with **"a price to pay"** in different forms. For example, antipsychotic drugs were identified as successful in reducing positive symptoms, particularly during the early stages of FEP. Yet, many individuals identified side effects as getting in the way of social activities, thereby interfering with their recovery. Therefore, medication was viewed with ambivalence where participants felt it helped with acute symptoms but in later stages got in the way of their recovery. Secondly, though the participants had significant relationships to support their recovery, the stigma they perceived as being linked to seeking and getting this support from psychiatric services was deemed unhelpful. Nevertheless, some felt that EIP services supported them in dealing with the stigma and embracing their diagnosis. Still, some participants thought that there was a far greater stigma associated with the EIP service themselves, making them reluctant to engage.

Finally, some participants experienced an **"ongoing vulnerability**," which influenced their recovery process, with some feeling like they had to adjust to living with their illness. At the same time, some felt they had grown due to their experiences. They were now aware of their early warning signs and therefore were hopeful for the future. A few seemed to be resigned concerning their ability to lead a "normal" life, blaming themselves and their vulnerability.

Hansen and colleagues' (2018) study appears to be of good quality. The authors gave a thorough description of their study design, clearly explaining their inclusion and exclusion criteria. When searching for appropriate studies, they did not set any age restrictions which allowed them to capture a broader age range for those EIP services that included individuals older than 35 years. They give details about the demographics of their studies, being specific about proportions of males to females, and stating individuals' ethnicities, and what details were missing from the papers they reviewed.

However, they explained that they excluded studies whose specific focus was pathways into EIP services, therefore their synthesis may not adequately have captured the true experiences of participants prior to being taken on by EIP service. This means that the focus on DUP and potential opportunities to learn how to minimise it were missed. Yet their first theme partly captured the sufferers' experiences during the prodromal period, before they were taken on for treatment by the EIP service, and thus gave some attention to the period before individuals were taken on for treatment by the EIP services.

As for the samples used, most of the participants in their reviewed studies were Caucasian males, therefore their findings may not have captured differences and issues that are culture or gender based. Moreover, all the participants in their studies were individuals with early-onset FEP except three who were 49 to 53 years. So, like Boydell and colleagues' study, there are not many middle-aged individuals in the studies they reviewed.

Most importantly here, neither the review by Boydell et al. (2010), nor that by Hansen et al. (2018) included studies focusing on participants aged 40 to 60 years.

1.7.2 Experiences of early-onset FEP: From onset till recovery

Most of the studies presented so far focused on early-onset FEP. Some of the studies included in the two reviews, namely Woodside and Krupa (2010) and Quin et al. (2009), deserve more attention here because they identified their participants as having late-onset FEP, which appears to be a similar age group to my research participants. These are therefore discussed alongside additional studies also dealing with sufferers' experiences at different parts of their FEP journey. Together, these studies bring out important insights around pathways to care; the experience of psychosis, and the sense participants made of their experience retrospectively.

To assess the quality of the studies included in the review, the standards for reporting qualitative research guidelines (SRQR) (O'Brien et al., 2014) were followed. Using these, many of the shortlisted studies appeared to be of reasonable quality.

1.7.2.1 Early-Onset FEP: Pathways to care

Being part of a bigger study conducted in Norway, the study by Bay et al. (2016) aimed to gain knowledge about individuals' experiences at the onset of psychosis, focusing on factors that acted as barriers to early access to psychiatric services. The researchers used semi-structured interviews with four males and four females aged between 17 to 44 years, which were then analysed using IPA.

From their analysis, Bay and colleagues identified five themes, four of which are related to participants' experiences of FEP, namely 1) **participants failure to recognise symptoms of psychosis,** 2) **health-care professionals' failure to recognise symptoms of psychosis,** 3) **participants' difficulties expressing their experiences**, 4) **concerns about stigma.**

Bay and colleagues report that at the onset of psychosis, participants experienced non-specific symptoms, with the majority of them **'not realising that these were symptoms of psychosis,'** for which they needed professional help, sometimes attributing symptoms to the normal development associated with puberty. As such, sufferers expected their symptoms to subside or pass on their own. When participants were able to see mental health professionals, they had **'difficulties expressing their experiences',** sometimes causing their symptoms to be misinterpreted, which compounded their difficulties seeking help. Sometimes the problem around being understood was due to **'poor psychosis detection skills among health-care professionals',** resulting in sufferers getting discouraged from seeking help. Some participants had concerns about how others would react or think about their situations, compounding their reluctance to seek help. Bay and colleagues termed this theme **'concerns about stigma'**, and some participants are reported to have deliberately hidden their symptoms.

Bay and colleagues were relatively thorough in their explanation of the study design and participants demographics, ethical considerations, and data saturation. One limitation was the fact that some of the participants were still experiencing high levels of negative symptoms, which would have affected participants' ability to articulate themselves.

While they give some demographics for their participants, they do not mention their ethnicities. Additionally, they do not make it clear how many of their participants were above 40.

Bay and colleagues focus on barriers accessing healthcare and do not go beyond the entry into healthcare or any other phase during FEP. Therefore, the experiences they capture are limited to this early phase of FEP.

The critique about Bay and colleagues not mentioning their participants' ethnicities applies to another study, one by Anderson et al. (2013), whose study with 12 male and four female participants of Canadian nationality explored factors that promote or hinder help-seeking efforts. Anderson and her colleagues do not give the ethnic backgrounds of their participants, although they state that 12 were born in Canada while four were born elsewhere. They also state that five of the participants were 'visible minorities.' For their methodology, they used what they called a qualitative descriptive approach[9].

Their findings are similar to Bay and colleagues', where sufferers' fear of stigma and failure to attribute symptoms to psychosis were obstacles to seeking help. Anderson and colleagues (2013) emphasised participants' appreciation of the essential roles of carers in enabling the process of seeking help on their behalf, thereby bringing them and their families closer, a finding that is missing from Bay et al.'s (2016) results.

Another study similar to that of Bay and colleagues (2016) in terms of part of its focus is one by Jansen et al. (2018) whose aim was to investigate sufferers' experiences of pathways to care, as well as obstacles to necessary assessment and treatment. They organised their data in NVivo and analysed them data using Braun and Clarke's (2006) thematic analysis. Their sample comprised of five male and five female participants of Danish origin, aged 18 to 27. Jansen et al. (2018) report similar themes around stigma, but in their case, the stigma was about participants' fears of being associated with the 'psychiatric system', which made them reluctant to engage.

Jansen and colleagues (2018) do not mention the participants ethnicities though they mention that they were all Danish. However, their study appears to be of good quality, with the research team credentials being given, participants being given the choice of where they could be interviewed, and the same identified interviewer doing all the interviews for consistency. The researchers clearly explain the methodological orientation, the interview guide's development, and their inclusion and exclusion

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[9] Anderson and colleagues (2013) defined the qualitative descriptive approach they used as "… naturalistic enquiry which uses low inference interpretation Sullivan-Bolyai et al., 2005, p. 128)

criteria. They describe their sample characteristics and how saturation guided their sample size, and how they collected and analysed their data. They explicitly identify ethical considerations and anonymise their data while making it possible to locate the voices of the anonymised participants in the quotes. An added strength is that their findings brought forth the distinct voices of the participants.

1.7.2.2 Early-Onset FEP: Experiences of psychosis and impact of EIP service on FEP

While their topic of study was also covered by Hansen et al. (2018), the fact that Harris and colleagues (2012) conducted their study in the UK made it of particular significance for me. The researchers investigated sufferers' experiences of being cared for under the EIP service. They used purposive sampling to recruit five males and three females aged 21 to 37 years from an NHS EIP service. Five of their participants were white British, and three were mixed race. The interviews were then analysed using IPA.

From their analysis, they developed five superordinate themes, namely: 1) **Stigma**, 2) **relationships**, 3) **understanding the experiences**, 4) **sense of agency**, and 5) **impact on sense of self**.

Harris and colleagues' (2012) first superordinate theme captured stigma's multi-faceted nature, distinguishing between self-stigma, stigma from others, and the stigma of services. Self-stigma was about participants' shame and beliefs about psychiatric diagnosis. It was as if there was a hierarchy in the stigma from the different diagnoses, with psychosis viewed as a more severe and more shameful condition than other psychiatric diagnoses. This hierarchical nature of health conditions is similar to a finding by de Wet and colleagues (2015), who reported that physical health conditions were deemed less stigmatised than psychiatric conditions. Details about de Wet and colleagues' (2015) study will be discussed shortly.

Regarding stigma from others, Harris et al. (2012) reported that what their participants perceived as others' negative judgments of their diagnoses contributed to their reluctance to discuss their experiences. Lastly, the stigma surrounding psychiatric services was about sufferers' views, where they saw services as embodying power and exerting control over people. This had the opposite effect to the expected one, in that participants felt separated from services due to the shame of being associated with them. They felt that the service name, EIP service, exacerbated this. However, this view was not shared by all, with some sufferers viewing the service's powerful impact and approach as helping to overcome the stigma associated with mainstream psychiatric services.

Within the theme of sufferers' relationships during their time in the EIP service, therapeutic groups helped them to feel less isolated, and within these groups, their relationships with their peers enabled them to feel understood as well as to have a sense of belonging, which instilled confidence and helped to reduce feelings of shame. The sufferers' relationships with their care coordinators[10] were of particular value in that the sufferers felt this relationship facilitated their contact and engagement with other resources within the service.

Harris and colleagues' (2012) theme of understanding experiences summarises how participants made sense of FEP as a result of their engagement with the EIP service. This understanding enabled them to move on. Additionally, understanding there were others out there who had had similar experiences and were living within society, having overcome their FEP, normalised their experiences and instilled a sense of hope. Moreover, this helped the participants re-identify with the general public, realising that FEP can affect anyone. This view is related to the final theme regarding the impact on the sense of self, which will be discussed shortly. Another example of how the experiences of FEP were normalised through interacting with the EIP service was where sufferers considered that generally every individual is situated somewhere along the psychosis continuum, with some showing more symptoms than others. Therefore, they got the sense that we are all similar in that regard. Besides emphasising the significant role of the EIP service in helping sufferers of FEP to make

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[10] In an EIP service, a Care Coordinator is a named skilled clinician who is the main point of contact and support for a service user. Their role includes helping service users with self-management skills, social care issues such as housing or debt management, and relapse prevention work throughout their time in the service (Adamson et al., 2018).

sense of their experiences, this theme also shows how participants can be enabled to come up with their own interpretations of their experiences.

The ‘sense of agency’ theme encapsulated the conflicting perceptions of the participants as passive recipients and active agents. Within the subordinate theme of acceptance and control, participants moved from avoidance to acknowledging the existence of symptoms, which they felt the EIP service facilitated. Once they accepted what the symptoms signified, they were able to begin dealing with the symptoms themselves, which gave them a sense of agency, where they played an active role in their recovery.

Harris and colleagues’ (2012) last superordinate theme is about the impact of their FEP and of engaging with the EIP service as they made strides to re-establish their vocational and social roles, with some participants perceiving themselves as stronger for having FEP and engaging with the EIP service.

One potential limitation of this study is that initial contact with the participants was by care coordinators while they were still under the care of the EIP service. Due to this, the participants may have felt obliged to participate and they may have unwittingly left out experiences they may have considered difficult. The researchers did, however, state that they had explained confidentiality procedures in their participant information sheet.

1.7.2.3. Conceptualising Recovery: Looking back

Many studies have focused on recovery, exploring what factors facilitated recovery and what factors acted as barriers as individuals who have suffered with FEP looked back on their experience. Among those studies, some have focused on specific aspects of recovery, while some have considered recovery as a whole.

De Wet and colleagues’ (2015) study is among the latter, as it investigates how individuals experienced their recovery from FEP and presents recovery as a dynamic, evolving, and unique process. They conducted their study in South Africa and their sample comprised of three males and four females, aged 23 to 46, with three aged over 40 years. Six were mixed race and one was white. They interviewed participants in English and in Afrikaans and analysed their data using IPA. They identified what appear to be two superordinate themes though they do not use this term: 1) factors associated with participants' experience of recovery, and 2) the meaning of recovery. Among the factors associated with recovery, the participants identified that giving as well as receiving support were important contributors to recovery. While spirituality was usually considered to be a contentious topic, some participants highlighted its strength, claiming that it had played a greater role than medication. Spirituality was even considered to help develop resilience.

Stigma was considered to be entrenched and prevalent within the society, where physical health problems were preferable and considered less stigmatised. Their view of stigma was different from that presented in Jansen et al. (2018), and that of Harris and colleagues (2012), where participants' perceptions of stigma were linked to the fear of being associated with the psychiatric system.

Under the meaning of recovery theme, some of De Wet et al.'s (2015) participants discussed getting back into their past activities and roles, functioning like they used to before the onset of FEP, and needing less input from others as they regained self-confidence and trust. This way of viewing recovery as a personal process is where some participants experienced their agency and felt more prepared for relapses. This agency meant the ability to function again, at one's pace, becoming less dependent on others and taking back control of one's independence.

De Wet and colleagues (2015) are the only ones among researchers of early-onset FEP reviewed here whose participants associated spirituality with FEP.

The quality of de Wet and colleagues' (2015) paper is let down by some methodological shortcomings where the chief researcher is said to have approached the participants first. This does not give the participants the upper hand or chance to make an informed choice as they may have felt obliged to respond on the spot. This is especially important where participants are considered vulnerable. It is preferable for the participants to initiate contact. Additionally, they mention that there were two

interviews per participant, but there is no rationale given for conducting two interviews, neither are there details to explain how these interviews differed.
Also, for the sampling of prospective participants, they mentioned that they chose only those they felt “fared the best in treatment,” without giving a rationale for this. Such sufferers as those that did not fare well in treatment are therefore not given a voice, which is ironic considering the title of their study.

The exclusion of those who did not fare so well in treatment cannot be said of Eisenstadt and colleagues (2012), whose IPA study in Brazil explored the recovery from FEP regardless of participants’ recovery outcome as long as they met the inclusion criteria. Like that of de Wet and colleagues, this study with 12 male and four female participants of unspecified ethnicities, aged 15 to 37 described the recovery course as a gradual process, where improvement was viewed as the ability to function more independently again. Both studies, de Wet et al.’s (2015) and Eisenstadt and colleagues’ (2012) state that the participants were of low socio-economic statuses. Eisenstadt et al. (2012) viewed recovery as related to an improvement in positive psychotic symptoms, returning to social life, and establishing new social connections or improving the quality of existing social relationships. Besides symptom relief and the restoration of the self, the sufferers felt able to trust themselves and others more, having regained their sense of autonomy and independence.

This view of recovery was shared and extended by Windell et al. (2015), whose study in Canada explored individuals’ experiences related to recovery following a FEP. They interviewed 23 males and seven females of unspecified ethnicities, aged 17 to 33 years, with interviews ranging from one to three hours. They identified the following four themes: 1) **symptom recovery,** 2) **reckoning and reconciling meaning**, 3) **regaining control**, and 4) **treatment negotiation and acceptance**.

Like for Eisenstadt et al. (2012), Windell and colleagues’ (2015) **‘‘symptom recovery’’** was about either attenuation or elimination of the psychotic symptoms. Additionally, ‘‘**reckoning and reconciling meaning**” indicated the participants’ ability to recognise their psychological challenges and start to come to resolution and acceptance. Within the process of reconciling, participants went through a period of adjusting to having FEP and working through the perceived personal and social implications of the FEP episode. Within this reconciliation, the participants also had to come to terms with the numerous losses that came with acceptance, such as the loss of their former selves, for whom they had to grieve.

The “**regaining control”** theme contained the sub-themes of ‘‘discovering agency,’’ where some participants identified that they could take responsibility, influence their experiences, and develop their own strategies to promote recovery. The sense of agency was influenced by their beliefs about illness, related to perceived abilities to exert control over the illness and the resources available to them.

What seems to let down Windell et al.’s (2015) study down is the large size of their sample for IPA, and this may be responsible for the absence of representation of most, if not all of them in the quotations. With large sample sizes, it is not possible to have in-depth analyses of the data which will inevitably reduce the quality of the data. Additionally, while they use quotes to illustrate the themes, Windell and colleagues could have improved their study by using a way that would enable their anonymised participants to be locatable in the quotes as this would ensure that they are honouring participants’ voices.

The issue about their sample size can also be said about Connell et al. (2015) who recruited 20 participants of unspecified ethnicities from three EIP services in Australia. The participants were aged 18 to 25, where 14 were males and six were females. They analysed their data using IPA. Two superordinate themes were produced from the explication of the interview data, namely: 1) **self-estrangement**, and ii) **self-consolidation**. The theme of self-estrangement was about the participants’ experience of altered sense of self and the world, uneasiness, and experiencing the loss of self. Even as positive symptoms lessened, participants still felt vulnerable, and struggled with the stigma attached to the diagnosis of psychosis, especially with its threat to social and self-acceptance. Some of the participants identified that the diagnosis of psychosis itself contributed to self-estrangement.

The second superordinate theme about self-consolidation involved the strengthening of close relationships with others, making sense of the experience of FEP, and establishing a stronger self. The participants identified how family and friends’ reassurance helped alleviate fears that were based on stigma. These themes signify different phases of recovery and not all participants experienced all the stages.

This study has many strengths as Connell and colleagues (2015) are transparent about their recruitment and interview procedures, following steps that are recommended for IPA. Additionally, the interviews were close to the experience of FEP therefore the participants were more likely to better remember their experiences. What seemed to let the quality down besides the large sample size is their failure to identify the participants' ethnicities. Additionally, the researchers themselves identified that EIP staff were likely to approach clients who were more strongly engaged with the service, therefore sufferers not engaged well with the service were less likely to be recruited. They did not explain how they mitigated for this. Like Windell and colleagues' (2015) sample, they had more than twice as many male participants as female participants.

Taken together, these studies bring together similar themes to the ones from Boydell and colleagues (2010) and Hansen's et al. (2018). Their findings also added the multifaceted nature of stigma, including stigma associated with, and from psychiatric services. They also identified the role of spirituality in recovery. The idea that FEP can happen to anyone normalises participants' experiences as well as giving the sense of belonging to humanity, rather than being estranged for having FEP.

Like Boydell and colleagues' (2010) and Hansen's and et al.'s (2018) reviews discussed earlier, all the studies in this section have focused on early-onset FEP, where only a few participants had late-onset FEP. Below is a review of the studies that claimed to have focused on late-onset FEP.

1.7.3 Late-onset FEP: Experiences and impact on social activities

Two papers were identified that claimed to have focused their studies on late-onset FEP, namely, Woodside and Krupa (2010) and Quin et al. (2009). Their focii are so far removed that they will be discussed separately in detail below.

1.7.3.1 Late-Onset FEP: Work and Financial stability

Woodside and Krupa (2010) conducted a study to investigate the employment and financial experiences of individuals with late-onset FEP, using a constructivist Grounded Theory approach. Their primary sample of three females and five males was part of a larger study. Sampling was purposive, and participants were recruited through their case managers from three clinics in Canada, and an adult community treatment team in South Australia. Participants' ethnicities were not specified, although participants' nationalities were. From their results, three themes emerged that spoke to the impact of psychosis on employment and how this then influenced participants' financial stability and decision to return to work. These were: i) **Psychosis interrupts work and financial stability,** ii) **Recovery is driven by financial need**, and iii) **Negotiating work after psychosis.** The first theme identified by Woodside and Krupa (2010) was not exactly about the experience of FEP itself, but its effect on participants' ability to work, and its impact on their identities and financial stability. Earning a living and being autonomous were important aspects of the participants' identities before the onset of FEP, therefore FEP disrupted this. It was therefore necessary to re-establish their identities as soon as they could. This leads to the second theme, which is about returning to work and earning wages as priorities and markers of their recovery. The participants returned to work not because they had good control of their FEP symptoms. At the onset of FEP, the participants all had financial independence, with dependents to look after. Therefore, in a way, their indication of recovery was their capacity to honour their financial obligations. The third theme was about participants needing to make adjustments to their established careers, or retraining for new job roles. As they had returned to work while still experiencing symptoms of FEP, some participants could not function at the same level as before, or meet demands of their old roles at work.

While Woodside and Krupa (2010) identify their participants as having late-onset FEP, the participants were aged 27 to 39 years at the time of diagnosis. As mentioned earlier, the International Late-Onset Schizophrenia Group Consensus committee agreed that FEP in the under '40s is early-onset rather than late-onset (Howard et al., 2000). The researchers claim to have used Hafner et al.'s (1998) criteria for "LOFEP," yet Hafner et al. do not have any criteria for characterising or even identifying individuals with late-onset FEP. Instead, what Hafner and colleagues describe are social roles common to individuals with late-onset FEP. Additionally, Hafner and colleagues themselves refer to FEP in individuals under 40 as early-onset and in those between 40 and 60 as late-onset (Hafner et al, 1998, p. 357). Hafner and colleagues' reference to social roles is in the context of explaining their observations about the higher levels of social development achieved by individuals with late-onset FEP. The converse of their observation about the key social roles does not necessarily follow logically, where those individuals that have reached the same social development are middle-aged. The more appropriate way for Woodside and Krupa to describe their participants would have been 'late-onset like participants,' if they wished to incorporate Hafner et al.'s developmental factors. It is important to realise that not everyone who achieves those social roles is in the same age-group. Additionally, the objective of the International Late-Onset Schizophrenia Group Consensus committee was to avoid confusion about how different age-groups are identified.

It is also worth noting that Woodside and Krupa (2010) refer to participants as 'LOFEs,' short for 'Late-onset First episodes', which could be seen as reducing them to their illness, and possibly echoing the stigma so often described by FEP sufferers themselves.

1.7.3 2 "The subjective experience of late-onset FEP"

In this study, Quin and colleagues (2009) aimed to investigate individuals' experiences as well as psychological features of older adults[11] living with FEP. Their sample was comprised of three males and four females, aged between 61 to 84 at the point of diagnosis. One participant's age is unknown, and there is no mention of ethnicity. The study was conducted in Ireland, where participants from two Old Age Psychiatry Services who met the criteria for very late-onset FEP were identified and referred by their psychiatrist.

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[11] 'Older adults' is a term that will be used in this chapter to refer to adults over 60 years.

Quin and colleagues (2009) used a semi-structured interview schedule to conduct the interviews, which were carried out in the participants' homes. The data were analysed using IPA.

From their data analysis, Quin and colleagues (2009) report four themes, namely: i) "**the heaviness of being alone,"** ii) **"I'm not of this world",** iii) **"I would get on with it myself",** and iv) **"why me."**

The theme "**the heaviness of being alone"** summarised the participants' experiences of social isolation and what appeared to make it worse over time. Curiously, all participants had cared for relatives with age-related physical health or psychological problems, with whom they appeared to have had a very close connection. Those older adults who experienced delusions during FEP found the delusions comforting, feeling like they were offered a chance to recreate and relive their past caring roles. Some found company in the delusions; therefore, they did not consider the delusions distressing.

The second theme was around participants feeling like outsiders in their local environments, a theme captured as "**I'm not of this world**." This sense of not belonging appeared closely related to their premorbid personality and experiences. For some, the feeling of difference was intensified by having relocated to urban areas, resulting in the loss of social roles and their previous community ties. A common link was reported between the older adults' experiences of social isolation, earlier combative relationships in their families, and their sense of not belonging.

To cope with the experiences of FEP, the participants tended to utilise solitary strategies, giving rise to the theme **"I would get on with it myself,"** a finding similar to Hansen and colleagues' (2018), where participants identified activities they had to do for themselves to achieve recovery, as they developed a sense of agency. A number of researchers such as de Wet and colleagues (2015), Harris et al. (2012), and Windell et al. (2015), have identified a similar theme in their studies.

The participants' attempts to understand their experiences are captured by the theme "**Why me".** As they attempted to make sense of their experiences, participants gave different reasons, all of which seemed to be related to past relationships, with common links between their earlier life contexts and the content of their FEP delusions.

The first three themes are thus closely related and are around the development of very late-onset FEP in the context of isolation and loneliness, while the fourth focuses on participants' efforts to find meaning in their experiences of FEP.

This study has a number of strengths, which include ethical approvals as well as transparency about the recruitment and in their interviewing procedures. Participants' are honoured as their voices are locatable in the study.

However, the quality of their study is let down by a few factors such as participants' ethnicities not mentioned and having the participants' psychiatrist who is actively involved in their care being the referrer to the researchers. They do not mention how the psychiatrist or the researchers themselves mitigated for the potential of participants feeling they had no choice about participating or not. Lastly, the researchers identified their sample as having late-onset FEP, when in actual fact they have very late-onset FEP, limiting the findings' relevance for a middle-aged population.

Woodside and Krupa's (2010) and Quin et al.'s (2009) study yielded important results, however, they did not focus their studies on individuals with late-onset FEP as they claim, instead the former focused on early-onset FEP while the latter is for a sample with very late-onset FEP.

1. 8 Rationale for the current study

Taken together, the qualitative studies reviewed here give us a rich set of findings into the experience of FEP. However, they were largely concerned with individuals under 40 years of age, and the very few middle-aged individuals present in early-onset participants' samples appear to have been included coincidentally. Of the two studies purporting to focus on late-onset FEP experiences, one actually included younger participants and the other older ones. As a result, none of the qualitative studies identified here focused solely on middle-aged sufferers.

The studies presented above also display a wide range of focii, including experiences at the onset of FEP, recovery, social participation, activities and performance, perceptions about their illness, and views about services and engagement.

Finally, although EIP service are relatively recent, many studies have explored the experiences of those with early-onset FEP, as this literature review demonstrated. Yet, there is a paucity of documentation to date on how middle-aged individuals negotiate their experiences within EIP service.

Given these gaps in the literature, a focus on the experiences of middle-aged individuals with FEP seems long overdue. More than seven years after the Department of Health (2014) issued its recommendations, only a few EIP service in the UK cater for late-onset FEP. Yet as the older population continues to grow worldwide, the number of individuals with late-onset FEP is expected to increase, and clinicians must become well informed in the diagnosis and treatment of late-onset FEP (Pearman and Batra, 2012), in order to tailor treatment packages that are better able to meet the needs of middle-aged individuals (Selvendra et al., 2014).

Conducted in the UK, the present study hopes to be of value to those working in and with EIP service, so that services can better meet the needs of this particular age group. In turn, this should improve the outcomes for these patients, their significant others, and society as a whole.

1.9 Aims and research question

The present research study aimed to answer the following question: ***How do middle-aged individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis?***

Specifically, the research aimed to answer the following questions:

1. *What was it like for individuals to experience FEP from the time it started?*
2. *What sense did individuals make of their experiences of having FEP at the time?*
3. *What were their experiences of receiving treatment under the EIP team?*
4. *What sense do individuals make now of their experiences of FEP?*

This study aimed to explore the lived experiences of FEP among middle-aged individuals, and the impact late-onset FEP had on the individuals themselves, and how they negotiated the challenges to their reality and identity. It also aimed to give a voice to individuals who have often been marginalised and forgotten, and in the process, allow them to continue to make sense of their journey through FEP.

1.10 Relevance of topic to Counselling Psychology

Counselling Psychologists have a relational way of working where they concern themselves with individual contexts, subjectiveness, and diversity of experience (Orlans & Van Scoyoc, 2008). Until recently, subjective experiences have been largely absent in studies of FEP, and when studies started two decades ago, the subjective experiences were quantitatively evaluated, with the focus being on younger people. Being diagnosed with FEP at any point in life is devastating, and for middle-aged individuals who hold certain social roles, and command certain social statuses, this can have far-reaching effects (Hafner et al., 1998). Therefore, it is important to understand their subjective experience better, so that they can be supported more quickly to find their way back to having an improved quality of life.

Counselling Psychologists' work and their ethos of practice place them in a strategic position to help individuals with FEP regain trust and re-establish connections with their social environments. With their humanistic way of working and their non-pathologising stance, Counselling Psychologists can help to promote a therapeutic dialogue between the individuals and others so that they can regain and re-construct meaning in their lives (Windell et al., 2015), a step that has been reported to result in the alleviation of suffering for both the individuals and their families (Mangalore & Knapp, 2007).

This study and its focus may also be of direct interest to other mental health professionals working within EIP service.

Chapter 2: Methodology

This study aims to explore the experiences of middle-aged individuals with late-onset FEP and their experiences of receiving treatment under the EIP service. The study uses a qualitative research design and IPA methodology. The rationale behind the use of a qualitative design will be presented in the first section, with the ontological and epistemological considerations given next. Alternative methodologies are discussed briefly in terms of how they would not have been the best fit, after which IPA as the method of choice is given more attention, explaining its theoretical underpinnings and the rationale for using it. Methods of data collection and procedural aspects of the study are detailed next. Thereafter, details about ethical considerations and data analysis will follow. Reflexive aspects, including the central role played by reflexivity in IPA will conclude this methodology chapter.

2.1 Rationale for adopting a qualitative approach

To focus on middle-aged individuals' subjective experiences under the EIP service and understand how they made sense of their experiences of FEP, a qualitative approach was considered most appropriate rather than a quantitative one. Additionally, I considered a qualitative approach to align well with my epistemological stance, as discussed below. I do concede that psychosis, hence FEP, is a real psychological phenomenon with certain characteristics that allow it to be defined and described as a medical condition according to the ICD-10 and DSM-5 (APA, 2013), as noted in the literature review. However, my objective was not to ascertain the nature or validity of FEP, but to explore how middle-aged individuals suffering with FEP made sense of their experiences.

As was shown in the previous chapter, the positivist approach has its place in the study of psychosis, notably when trying to determine its aetiology and prevalence, to evaluate medication efficacy, and to explore the impact of DUP on outcomes, symptomatology, social functioning, and quality of life (Schooler et al., 2005; Trauelsen et al., 2015). Some quantitative studies have even attempted to explore individuals' experiences, which has been helpful in advancing our understanding of FEP (Perkins et al., 2005). However, such studies have been unable to explore participants' subjective meanings as the instruments used, such as questionnaires, have used preconceived categories that do not facilitate individual narratives of experiences. From the beginning of this research, I was aware that I wanted to get an in-depth understanding of what it was like for my participants when they were experiencing psychosis, and what sense they made of their experiences. It is acknowledged here that no one person's experiences are identical to anyone else's, therefore, it was essential to gain first-hand information about these experiences from the individuals themselves. More generally, as a Counselling Psychologist in training, my interest is to understand how my clients make sense of their internal and external worlds, and how they are impacted by their worlds (see Altmaier & Ali, 2011), in order to support them through the challenges they may encounter. This is reflected in my epistemological stance, presented in the next section.

2.2 Epistemological and ontological considerations

2.2.1 Ontology

Ontology is concerned with what reality is like or of what we think exists. According to Willig (2019), ontology can be defined as the philosophy of being that seeks to explain what is there, or what it means for something to be present. Similarly, Ponterotto (2005) explains that ontology is concerned with the essence of being and truth, focussing on the nature and form of life, and what it is that can be said about reality. Therefore, an ontological viewpoint expresses a researcher's views about the essence of the reality of their findings (Blaikie, 2007). Many ontological positions have been posited, including realism and relativism, which can be visualised as lying on opposite ends of a spectrum. Relativists question the ‘out-thereness’ of reality, and according to Cuthbertson and colleagues (2020), relativists believe that reality only exists in the perceptions of the individuals experiencing that reality. Therefore, from a relativist point of view, reality cannot be extricated from the individual's experience of it, and no other reality exists outside what is in people's minds. On the other hand, a realist believes in the existence of a real world that can be known objectively, one which is there independently from the human mind, experiences, perceptions, and constructions. This type of reality can be studied and understood and experienced as a 'truth' (Cuthbertson et al., 2020). Therefore, to the realist, the data that a researcher gathers, for example participants' accounts of their experiences, are considered to represent and describe the reality of the phenomenon under study.

My ontological stance is more aligned with the realist than the relativist. However, I believe that individuals experience their realities in different ways, and I therefore accept multiple perspectives determined by how participants make sense of their experiences (e.g., Cuthbertson et al., 2020). I believe in the existence of certain psychological and biological processes, but I do not think that we can observe them directly. I believe that people's reality and perceptions are influenced by their experiences and the way they view and understand their external and internal worlds. In terms of FEP, I believe that psychosis, and indeed FEP, exists as a psychological phenomenon regardless of culture or meanings, or indeed of our awareness of it, or how we make sense of it.

2.2.2 Epistemology

Willig (2019) explains that epistemology is concerned with the essence of knowledge: what we can learn, how we can acquire knowledge, and how certain we can be about the validity of the acquired knowledge. Madill et al. (2000) advise researchers to have clarity on their epistemological positions when conducting phenomenological research. To decide my epistemological vantage point, I needed to understand different epistemological positions first. Willig (2012) discusses three epistemological positions, namely realist, phenomenological and social constructionist, where the three are on a continuum, with realist and constructionist positions sitting on opposite ends. To a realist, what is going on in the world, whether physically, socially or psychologically, is bound by rules and is observable, implying that a seasoned researcher can gather accurate data about the events in the world. In other words, to a realist, the way research participants think or behave can be identified and communicated accurately. There is also an assumption that the phenomenon of interest exists whether or not the researcher is aware of it. By contrast, social constructionists believe that reality is always constructed, and that only the construction of that reality (or realities) can be studied, through paying attention to the way individuals describe their world and their experiences, and how they structure narratives of their reality. Most importantly therefore, to a social constructionist, the researcher can only focus on how knowledge is created, rather than seeking knowledge about how individuals experienced things, or how things are in the world (Willig, 2012).

My position is more aligned with the realist stance, in that I believe that there are psychological processes that are real and truly affect people in ways that can be understood. However, we can only approach these processes through what others tell us of them and what sense we make of what others tell us. This positions me as a critical realist, where I do not assume that people's experiences as they are directly reflect absolute reality; rather, the data need to be interpreted to enable an understanding of the structures that cause data to be generated in a certain way. As such, the research participants do not have to have the awareness of the underlying mechanisms, or of the conditions that inform their experiences or behaviours for that matter (Willig, 2012).

Where mental health conditions are concerned, I can see problems that I would encounter if I was to align myself with the social constructionist point of view. As argued by Mulvany (2001), social constructionism has failed to come up with a model of how to understand the origin and nature of distress, as well as how to empower and assist those individuals experiencing mental illness. Currently, the language they use appears to avoid recognising how affected individuals experience severe distress due to altered experiences and cognitive functioning. As a way of highlighting this issue, Busfield (2001) identified how, given its epistemological and ontological connotations, social constructionism might generate hostility from sufferers and their significant others, as well as from clinicians who feel it minimises or even rejects the reality of the pain and suffering involved in mental disorders. I consider medical diagnoses to be constructions of the medical profession, where the concepts of what they call mental illnesses can be understood in different ways, depending on many different factors. My position where FEP is concerned, therefore, is that of a critical realist, where I view the phenomenon of FEP not as a construction, but as a discoverable phenomenon that exists outside of people's perceptions. However, it is dynamic, complex, and experienced differently; therefore, to discover it or know more about its nature, we have to learn from those that experience it, as individuals' experiences of it are dependent on the interplay of many different layers that include biological, physical, cultural, psychological, chemical, social, economic (Bhaskar, 1978), developmental, experiential, functional, and spiritual.

2.3 Other Qualitative Methods considered

To identify which methodology to use, I reviewed various qualitative methods while holding in mind my epistemological and ontological vantage points, my research aims, and the compatibility of these with the different qualitative methodologies. I considered narrative analysis, thematic analysis, and interpretative phenomenological analysis, as they are among the most frequently used qualitative methods for exploring meaning making (Biggerstaff, 2012).

2.3.1 Narrative Analysis

My research questions were about what it was like to experience FEP, as well as what sense middle-aged individuals made of their experiences of FEP. In Narrative Analysis, the researcher explores how individuals construct stories out of their experiences to make sense of the world, and by so doing, harness the interpretative power of their stories for therapeutic effect and bring to light the meanings of their lived experiences (Burck, 2005; Willig, 2013). Narrative Analysis also focuses on verbal rather than on both verbal and non-verbal meaning making. Yet for me, individuals verbal and non-verbal experiences were equally important. Moreover, Narrative Analysis tends to be associated with a social constructionist epistemology, whereas my stance is that of a Critical Realist, as explained earlier. Therefore, my epistemological stance did not align with that of Narrative Analysis. I also felt that I needed an approach that would place a clearer emphasis on experiential knowledge, and include non-verbal experiences (see Smith et al., 2009).

2.3.2 Thematic Analysis

Thematic analysis (TA) is another method I considered for data analysis at the beginning of research, especially as I initially wanted to get a sense of what individuals experiences of FEP were. Among other things, TA is theoretically flexible, in that it can be used across different theoretical and epistemological approaches (Braun & Clarke, 2006). Braun and Clarke (2006) explain that TA is a method for the identification, analysis and reporting of trends within data, while Biggerstaff (2012) identifies it as the approach to use when researchers are interested in summarising, describing and categorising themes in their data. However, I soon realised that focusing on the similarities between individual themes from the start may result in the loss or misconceptualisation of some individual voices (see Javadi & Zarea, 2016). As my main aim was to understand how individuals make sense of their subjective experiences of a particular phenomenon, namely FEP, I needed to use an approach that was phenomenological and idiographic.

2.4 Interpretative Phenomenological Analysis (IPA).

IPA is a qualitative approach developed in the mid-1990s (Smith, 1996), and it advocates for psychological research to be more aligned with participant's experiences (Eatough & Smith, 2008). It concerns itself with how people understand their experiences and assign meanings to these experiences (Smith et al., 2009). IPA has three primary theoretical underpinnings, namely phenomenology, hermeneutics and idiography. Each of these theoretical underpinnings will be discussed in detail shortly.

Before presenting the rationale for choosing IPA, it is important to examine its epistemological and ontological viewpoints, to make sure that these are aligned with mine. Epistemologically, IPA concerns itself with individuals’ subjective experiences of a phenomenon, committing itself to understanding the quality of that phenomenon, from the interpretative sense-making of both the participant and of the researcher (Eatough & Smith, 2017). Therefore, in IPA, the belief is that there exists, within participants, a subjective reality that a researcher can explore. I considered this to closely align with both my epistemological and my ontological beliefs.

2.4.1 Theoretical underpinnings of IPA

IPA's idiographic perspective and its grounding in both phenomenology and hermeneutics allow it to be accessible to many, including those who do not have a philosophical background (Shinebourne, 2011). Larkin and colleagues (2006) explain how, with its commitment to communicate the insider's perspective, IPA aims to capture the participants' experiences within different contexts in which they occur and are understood. Furthermore, phenomenology is argued to be an in-depth study of conscious experiences, while hermeneutics studies interpretation (Cooke, 2014).

2.4.1.1 IPA and Phenomenology

Smith et al. (2009) describe phenomenology as the philosophical exploration of human consciousness, that is thoughts, memories and feelings as well as one's subjective experience of the world, giving the researcher access to participants’ inner worlds. Finlay (2013) goes on to explain how phenomenology as a general concept is about a way of being that investigates human situations that are usually taken for granted as they are encountered in daily life. The researchers’ main focus in phenomenology is exploring what it is like to have a certain experience, while considering participants to be the experiential experts. Eatough and Smith (2008) explain the interest of IPA as being that of clarifying how a particular individual within a certain situation interprets how they experience a particular phenomenon. The main focus is on individuals’ understanding of a phenomenon of interest and how they make sense of it, rather than understanding the details about the composition of the phenomenon itself. This study was interested in exploring individuals' experience of FEP, from the onset through to recovery. IPA aims to understand the importance that humans attach to their experiences, and explores individuals’ experiences in their own terms, in line with its phenomenological origins (Smith, Flowers, & Larkin, 2009). IPA goes further than just exploring the phenomenon-as-experienced in that it studies the person in their environment, as experiences are considered to be context-dependent (Eatough & Smith, 2008; Larkin et al., 2006). During IPA, the researcher merges the essential components of phenomenology and hermeneutics to give meaning to a participant’s lived experiences (Smith et al., 2009).

2.4.1.2 IPA and Hermeneutics

This study's main objective was to focus on the meanings that middle-aged individuals assign to their experiences of FEP. This involves the philosophy of interpretation, known as hermeneutics. In this study, the hermeneutic stance of IPA was achieved through rich description and interpretation, with the focus shifting between the participant's efforts to make sense of their experiences, to my interpretation and sense-making of those experiences. As IPA does not encode data into any specific chronology or plot, this offered a chance to capture the phenomenon in a more novel and nuanced way. Hermeneutically, IPA recognises that humans, therefore participants as well as the researchers, are sense-making organisms. This is known as the double hermeneutic circle: the researcher attempts to make sense of the participants as they try to make sense and interpret their experiences (Reid et al., 2005). Therefore, the intricate dynamics between the researcher and the participants whose experiences are interpreted are openly acknowledged. Further, the researcher’s understanding is considered to be fundamental to the data analysis process, as the researcher may rely on their own thoughts and feelings through which the participant reveals meanings that are not immediately apparent to the participant **(**Willig, 2012a**)**. Therefore, IPA identifies the researcher as essential to the process of discovering meaning and co-constructing knowledge together with the participants. Nevertheless, the researcher’s subjective involvement requires careful consideration throughout.

2.4.1.3 IPA and Idiography

Lastly, this study aimed to gain an understanding of individuals' idiosyncratic experiences. Therefore, an approach that is idiographic rather than nomothetic was necessary. Being idiographic in its dedication, IPA is interested on the particular and unique, instead of the general and universal (Smith & Shinebourne, 2012), therefore does not look to make universal claims (Smith & Osborn, 2008). It does so by thoroughly examining and analysing individual cases in depth, by focusing on each person’s sense-making in their specific contexts for a given phenomenon. Also, throughout the subsequent cross-case analyses, IPA stays committed to the individual and demonstrates how the lifeworld of individual participants correlates with more general themes (Smith & Eatough, 2006). IPA strives to access and make sense of individuals’ inner worlds. This applies to data collection, enabling the researcher to focus on aspects of experiences that individuals choose to discuss during the interviews; and to data analysis, which aims to ground the interpretations as close to the participants’ meanings as possible by quoting their words, thereby delivering the participants’ viewpoint which is essential to this type of research.

2.5 Rationale for choosing IPA

Outlined below are some of the reasons IPA was considered to be the most suitable method for this research. Firstly, IPA allowed me as the researcher to examine the participants' experiences and understanding of their FEP, focusing on their experiential and idiosyncratic reality. Additionally, it was important to utilise a methodological approach that is phenomenological, interpretative and idiographic when studying the kind of experiences I was interested in. Also, as a critical realist, both in my ontology and my epistemology, IPA appeared as a good fit.

IPA allows flexible data collection and analysis. By examining middle-aged individuals' experiences of FEP and allowing them to go into as much detail as they wished, I did not impose any predetermined hypotheses upon them or their data. While the interview guide gave the general direction about areas to explore, I was able to focus on aspects of experience that individuals chose to discuss during the interviews, thus giving clear precedence to internal or 'real' subjective experience. Last, compared with other phenomenological approaches, IPA prioritises interaction with the participant over bracketing.

However, I was aware that like other types of phenomenological research, IPA has some limitations. These relate to different areas, firstly, IPA has been said to give unsatisfactory recognition to the essential role of language as it does not give the use of language enough attention. To mitigate this, I paid attention to the contexts in which participants were explaining their experiences, being aware that language was the main tool to inform me of their experiences, however noticing that the primary focus was the experience. The second limitation focuses on whether the participants and the researcher have the required communication skills to effectively communicate an experience and its meaning. Linked to this is the issue about which participant accounts are deemed suitable. This is a limitation in that what is communicated may not completely describe the participant’s experience. To reduce the effect this could have, all the accounts were considered, as choosing some over other would imply those that could not articulate themselves will not be heard. I remained participant-led throughout the interviews and gave them time to add anything they felt they needed to add at the end of the interviews. During the data analysis process, I took special care to attend to the participants’ non-verbal communications, expressions, pauses and hesitancies, where they appeared to communicate something that they perhaps could not fully verbalise. I gave idioms and metaphors special attention as additional ways that the participants used to communicate their experiences. The third limitation is about the focus of IPA on perceptions of an experience, as this is not likely to advance our understanding of why these experiences occur. To this effect, as IPA’s idiographic nature, as well as its double hermeneutic approach, where experiences were explored from the understanding of the participants, I felt that this would explain the ‘whys’ of the experience, according to the participants. The final limitation is about the role of cognitions, where certain aspects cognition are said to not be compatible with phenomenological thought. I believe that participants’ meaning-making of their experiences involves reflection and consideration, and that these resonate well with cognitions (see Tuffour, 2017; Willig, 2013).

2.6 Procedural Aspects

2.6.1 Sampling and Recruitment

From the beginning of this study, I intended to recruit a small number of participants to ensure that I could give each participant a distinct identity while also giving room for investigating any similarities across the cases (see Robinson & Smith, 2010). Smith (2004) explains that nowadays, smaller samples are becoming more popular as an in-depth exploration of large samples may not be possible, resulting in superficial understanding. Additionally, Smith et al. (2009) maintain how idiographic research needs a small sample, suggesting about four to ten interviews for Professional Doctorate researchers using IPA, so that an in-depth analysis can be made, as well as to enable each participant to be given a voice that can be located within the study (Robinson & Smith, 2010). As IPA's main interest is with in-depth accounts of subjective experience, the focus is on quality rather than quantity (Smith, Flowers & Larkin, 2009). Most importantly, it is recommended that the sample be homogeneous, where it is clearly defined within the study (Smith et al., 2009). Through purposive sampling, participants can be sought out and selected because they have something to say about the phenomenon under study, – '...they 'represent' a perspective, rather than a population' (Smith et al., 2009, p. 49).

Once I was clear about my research ideas, I discussed them with the gatekeepers of local EIP teams who welcomed these and agreed that we would set a date for a presentation to the team after ethical permissions had been gained (details of permissions obtained are given in Appendix A, Appendix B, and Appendix C). With all the approvals obtained, I proceeded with the recruitment.

To raise the Surrey EIP team's awareness of this study, I presented the details of the study to the team members in one of their weekly multidisciplinary team meetings. The background and rationale of the study, as well as the details about prospective participants were discussed.

The Care Coordinators within the EIP service kindly agreed to do the initial screening process, for which I gave them copies of the research materials, namely the Pre-interview Schedule (Appendix D), and the Participant Information Sheet (Appendix E).

Further, Recruitment Posters (Appendix F) were displayed on Community Mental Health Recovery Centres' notice boards where individuals with FEP were likely to see them. This was to ensure that all the prospective participants interested in the research had access to the information.

Using purposive sampling, I was able to recruit six participants. The target population was middle-aged individuals within the Surrey area, who were under the care of one of the EIP service at the time.

2.6.1.2 Participants

Inclusion Criteria

Participants were eligible for this study provided they: (1) were English speaking; (2) were middle-aged (40 to 60 years)[12]; (3) met the DSM-5 criteria of FEP; (4) were receiving treatment (pharmacological or psychological) under the EIP team; (5) were deemed to have been mentally stable for at least three months as indicated by their Dialogue[13] (Priebe, 2007) and Process of Recovery[14] (QPR) (Neil et al., 2009) scores

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[12] This age group is what is identified as middle-aged individuals by Howard and colleagues (2000).

[13] Dialogue is a service user-rated outcome measure, which focuses on quality of life, care needs and treatment satisfaction (Priebe, 2007).

[14] The QPR is an outcome measure which asks about key aspects of personal recovery including connectedness, hope, identity, meaning to life and empowerment (Neil et al., 2009).

completed in the past three months; and (6) had their latest Crisis and Contingency Care Plans[15] completed collaboratively with their Care Coordinators in the past three months.

Exclusion Criteria

Individuals were deemed unsuitable for inclusion in this study if they were: (1) acutely mentally unwell, as they would not be able to give informed consent; (2) mentally stable for less than three months; (3) under 40 or above 60 years of age; (4) in need of an interpreter as this would add an extra layer of interpretation which was considered to not be compatible with IPA; or (5) unable to give informed written consent by virtue of not having capacity under the Mental Capacity Act 2005 (Department of Health, 2014c).

2.6.1.3 Initiating contact

Eight interested participants emailed me, while one forwarded his phone number through his care coordinator so I could phone him. I rang each of them on the phone numbers they provided so that we could agree dates, times and venues for the face-to-face interviews.

Of the nine participants, three could not be included for different reasons. The first one told me over the phone that he worried about his data being audio recorded and explained that he preferred to tell his story with no recording and no note-taking, which would only have allowed me to produce a summary of what his experiences were. I felt that this way of collecting data did not adequately align with IPA.

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[15] A Crisis & Contingency Plan lays out a service user’s early warning signs, helpful strategies, arrangements including details of who to contact; medication, including monitoring arrangements in the event of a crisis (Adamson et al., 2018).

The second one expressed anxiety about his command of the English language as he believed that it was not good enough, and that others may ridicule him on reading about him. He said he understood that his details would be anonymised but still felt he might be identifiable. Interestingly, during the past year of his treatment he had not needed any interpreter when engaging with staff from the EIP service. The third one went quiet after expressing his interest to his Care Coordinator in person and to me over the phone. He had said he needed to check his diary and would get back to me by emailing me to confirm the interview, which he did not do.

For the six that agreed interview dates with me, the dates we agreed were at least two weeks from the screening interviews with their Care Coordinators to allow them enough time to read the Information Sheet and consult with their significant others if they needed to. It was felt that this way, they would have enough time to formulate any questions they may have needed me to clarify before the interviews. Of the final six participants, four described themselves as White British, one firmly asserted she was White Scottish, and one described herself as Jewish Israeli. There were three males and three females. All had children, and while they were working before the onset of FEP, they had been made redundant or were on long-term sick leave (see Appendix G for the full participant demographics).

2.7 Data Collection

2.7.1 Interview guide and pilot

Data were collected during face-to-face interviews using a semi-structured interview guide (Appendix H). Semi-structured interviews are recommended to collect data when using IPA (Reid et al., 2005). One of the advantages of individual interviews is that it is easy for the researcher to build rapport with the participants, which supports the generation of in-depth discussions. Due to the flexible nature of the semi-structured interview guide, questions can be modified according to how the participants respond (Smith & Osborn, 2003). Also, using a semi-structured interview guide gave a consistent structure to the interview so that similar topic areas were covered, though the depth and breadth of these depended on what the participants chose to disclose. This flexibility was facilitated by the open-endedness of the interview questions. Since the interview schedule was semi-structured and open ended, this enabled the capturing of individuals' subjective experiences while limiting the risk of me directing where they went with their accounts.

The interview guide was developed by initially writing everything that I considered relevant to the topic based on my reading of the existing literature and my own understanding of FEP. Before using the interview guide with research participants, I piloted it with four volunteers who worked in the EIP service. This was to ensure that the questions asked were focussed, open-ended enough and that they enabled me to gather the required data. It was important for me to have a diverse enough group of volunteers when piloting the schedule. I had three females and one male, three Caucasians, and one black person. Professionally, one was the service manager with a nursing background, the second was a Clinical Psychologist, the third was a Psychological Therapist, and the fourth was a Social Worker. All were middle-aged, and two had children. Carrying out the pilot interviews helped me to adjust the interview guide so that it was more likely to capture rich, substantial, and relevant data while also having an adequate level of sensitivity for this delicate topic. Piloting also helped me improve the clarity of the questions and get a clearer idea about the interviews' average duration. The interview guide (Appendix H) was finalised after the four pilot interviews.

2.7.2 The face-to-face Interviews

The final six participants were interviewed in the mental health community centre they chose (one of three), close to where they lived, and where they sometimes met with the EIP staff. This was to ensure that they were in places they were familiar with and could access easily. Additionally, this was to ensure that I saw them in buildings where there were other professionals as per university and the NHS Trust lone working policy (see Appendix I). I ensured that I saw only one participant per day to allow me time to process the interview and ensure that that each interview could be approached with fresh eyes. On the day of each face-to-face interview, participants were made welcome and offered a drink (non-alcoholic hot or cold) of their choice with some biscuits before the interview started.

The interviews were audio-recorded with the participants' written consent. I showed them the recording device before the interview started, showing them how to pause or stop it at any time during the interview if they needed to. I also asked them where they wanted the audio recorder to be placed, whether somewhere they could see it and control it if they wished to, or out of sight. All of them except one (Chris) wanted it out of sight. After around 45 minutes, the participants were offered a break, which all of them took.

During the face-to-face interviews, prompting questions were used to allow further exploration and discussion where participants appeared to have difficulties with any of the questions I asked (see Lyons & Coyle, 2016). I closely monitored the participants' well-being throughout the interviews. As I conducted the interviews, it was apparent that some, if not all of the participants, were still processing their experiences. After asking all the questions I had, I invited the participants to ask further questions they had, or to add to their experiences of FEP. It was at that point that all of them spoke for an extra 25-40 minutes.

The participants did not receive any financial benefit for their participation, and they were aware of this before participating in the interviews.

2.8 Ethical Considerations

2.8.1 Ethical Approvals

This research aimed to comply with BPS ethical guidelines regarding informed consent, confidentiality, protection of the participants, well-being and debriefing (British Psychological Society, 2014), and NHS ethical guidance around studies involving potentially vulnerable populations (Health Research Authority, 2020). In line with this, full ethical approval to conduct the research was obtained from the North of Scotland Ethics Committee: Reference 19/NS/0028 (Appendix A), and the Health Research Authority (Appendix B), and the NHS Trust's Research as well as the Development Department' confirmation of Capacity and Capability (Appendix C). I started the study after all these ethical permissions had been gained.

2.8.2 Informed consent, confidentiality, and risk mitigation

Because Care Coordinators are more familiar with the participants, their involvement was a recommendation from the North of Scotland Ethics Committee. Therefore, before I had any contact with prospective participants, their Care Coordinators discussed my study's details with them and completed the initial screening process, using the Pre-interview Schedule (Appendix D) and going through the Participant Information Sheet (Appendix E) with interested participants who met inclusion criteria. The Participant Information Sheet gave details about the study, why it was being done, what would happen during the study, and how their data would be dealt with. Interested participants were left free to initiate contact with me, rather than the other way round, as I felt that this was a way of empowering them and giving them a choice. Eight interested participants emailed me, giving me their phone numbers, while one gave his Care Coordinators his number for me to ring him.

On meeting with the participants, I made all of them aware that their privacy and confidentiality were guaranteed while at the same time explaining the limits of this confidentiality in the event of a risk of self-inflicted harm, harm to others, violence, abuse, or criminal activity came up. I also explained that while I would use direct quotes from their data in the final thesis and the journal article, all potentially identifying details about them would either be anonymised or removed altogether. I informed them that my academic supervisor and other academic members of staff identified by my university would have access to the anonymised transcripts for the purpose of grading my work. I then confirmed that they had read the Participant Information Sheet (Appendix E) and gave them a chance to ask questions. I then provided them with a copy of the Consent Form (Appendix J), which we went through together. Participants' understanding of what was involved and their willingness to be involved in the study were confirmed by them signing the consent form. They completed the Demographics Questionnaire (Appendix K) on the day of the face-to-face interviews.

2.8.3 Well-being

Due to the sensitive nature of the topic under study, I was mindful that painful memories could be evoked, thereby causing distress in the participants. I hoped that due to my extensive experience of working with diverse client groups in the NHS and the private sector, and particularly with people with psychosis in mainstream psychiatry as well as in EIP services, the chances of the participants feeling unduly distressed would be minimised. Furthermore, I was careful to phrase all the questions sensitively. The questions were open-ended and broadly framed so that the participants were in total control of how much detail they chose to share. During the interviews, I informed the participants that if they felt that any questions were too invasive or difficult, they had the right to not answer. To mitigate the participants' possible distress, I stated clearly what the rationale for the study was in the Participant Information Sheet (Appendix E) and at the beginning of the interviews. I hoped that participants would feel that they were contributing to the development of greater understanding and that by telling their experiences, they had a chance to have their voices heard, which has been reported to reinforce a sense of identity and human potential (Eatough & Smith, 2017). I reminded the participants at the end of each interview of their support systems, their emergency care plans, and their crisis and contingency plans, should they need to use them. I also reminded them that at any point up to two months after the interviews they could withdraw from the study without any adverse consequences. On completing each interview, I gave the participants a Debrief Sheet (Appendix L), which summarised the study's details and provided contact details if they had any questions about the research. The Debrief Sheet also informed them about how to access extra support if they needed it.

2.8.4 Data Storage

What would happen to participants' personal information and data was clearly explained to them in the Participant Information Sheet, in line with GDPR and BPS guidelines (British Psychological Society, 2014). The participants' anonymity and confidentiality were guaranteed as all data was encrypted for transfer and storage, and pseudonyms were used when the study was written up. The anonymised data was stored on secure servers on NHS computers, and will be kept for 10 years post-publication as per City, University of London guidelines, after which the data will be destroyed.

2.9 Data Analysis

Guidelines for IPA follow different methods (see Smith & Osborn, 2003/2009; Willig, 2001), which shows how versatile and flexible IPA typically is (Reid et al., 2005). According to Smith and colleagues (2009), there are no hard or fast rules of doing IPA, and researchers are encouraged to be creative in their approach. This ability to be flexible explains why although IPA recommends six steps, my data analysis is in seven steps.

2.9.1 Steps for Data Analysis

The following steps are recommended by Smith and colleagues (2009) and have been used by other researchers (e.g., Larkin & Thompson, 2012). Nevertheless, Smith et al. (2009) allow researchers to make adaptations to this, and I personally strongly felt that there was an overlap of my data analysis and data collection during the interview stage.

Step1: Reading and re-reading the transcribed data
Step 2: Initial noting
Step 3: Initial themes- Identifying emergent patterns
Step 4: Developing a structure illustrating the relationships between themes
Step 5: Clustering and Theme development

Step 6: Finding patterns across different cases

2.9.2 Process

Following the above recommendations, below are details about how I analysed my data.

Step 1: During the participant interview breaks, I held in mind my initial impressions about the participants and our interactions[16], and at the end of each interview, as soon as I possibly could, I wrote in my reflective diary what my initial thoughts and feelings were. I documented my thoughts as the interviews progressed, what was stirred in me, and any comments about how I felt the interview went.

Step 2: I listened to the first recorded interview over and over, immersing myself in the data while continuing to make further comments in my reflective diary.

Step 3: I typed up the first transcript verbatim, including non-linguistic features like sighs, laughter, uncomfortable pauses, hesitancy, body posture changes, gestures, and observable physiological states, including tearfulness[17]. My first interview was with Happi, which was the most challenging of all as she had a heavy and unfamiliar accent. Additionally, she swore a lot, something I am not used to, so I had to listen to the interview several times before completing the transcript. For Happi, it took me 23 hours to transcribe 114 minutes of data. After transcribing the interview verbatim, I read the transcript repeatedly while listening to the recording to ensure that I stayed with the data. Thereafter, I started coding by closely analysing the transcript, line-by-line, noting the participant's experiential claims, concerns, and understandings.

Step 4: As I continued coding, I converted the text into a two-column table instead of what is suggested by Smith, as I found this easier to work with and more intuitive for me, making notes in one column from reflections about the descriptive and linguistic observations, marking these in different colours (see Appendix M). Using

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[16] This was mainly about whether the person that attended for the interview was as I had imagined them to be like.

[17] During the interview I had taken notes and timings with every participant’s consent whereby I noted times whenever I observed non-linguistic features and any particular change in body language.

contextualisation and taking some words out of context (decontextualization), I created a list of what I later developed into themes. I was careful to bracket off my initial thoughts and impressions as much as I could, and I found it helpful to have my reflective diary next to me throughout this process. Some of the initial thoughts I encountered were similar in different interviews; therefore, I could not bracket them all off. I made a list of participant's idioms and metaphors to let them shed light on my interpretation. There were statements and words that I felt carried complex meaning or left me with questions, so I highlighted these to work on them further.

Step 5: As themes began to develop, I grouped similar ones into overarching categories. I interpreted the coded data utilising my psychological understanding about potential meanings of sufferers' concerns in their different contexts. These nuanced themes were highlighted in a different colour. It is possible that my psychological understanding and interpretation of the participants' data may have differed from participants' meaning-making during this sensitive topic, as my approach is positioned between emphathic and suspicious interpretation, when compared to IPA's empathic interpretation. I organised the data in a table of themes where direct quotes from different participants were included in a way that enables coded data to be identifiable all the way in the analysis, from initial coding to the final themes (Larkin & Thompson, 2012). An example of such a table of themes though incomplete is shown in Appendix N. By way of interpreting what the participant may have meant without saying, looking for the experiential components in what they were saying, further themes were developed, which helped with the overarching categories. Smith and Osborn (2008) refer to this as the double hermeneutic circle, as I, the researcher tried to make sense of the participants trying to make sense of their world. As recommended by IPA, I moved from each part of the interview, to the whole and back, meaning that I needed to check and recheck every theme against the data it stemmed from, and also against the whole transcript. I continued to remind myself to stay close to the data throughout, being tentative in my interpretations. During my interpretations, I consulted and used the notes I made during the interviews to help in the development of the themes as a way to enhance the rigor of the analysis.

Step 6: I moved on to the next interview, following the same steps 2 to 5. As I did so, I noted similarities and differences, with some opposites and contradictions. I maintained clarity about the steps so as to remain systematic in my analysis and grounded in the data for each participant.

Step 7: I looked for patterns across my six cases, using each participant's overarching themes to guide me, and developed sub-themes. To ensure that I could work across cases and maintain a clear visual of my cases at all times while I worked on them, I used the double 2m by 1.5m whiteboard in my conservatory to move subthemes across overarching themes where I felt they fit better in one than the other (see Appendix O). Smith et al. 's (2009) six ways of clustering emergent themes were utilised as much as the available data allowed, with abstraction being the most straightforward and most intuitive to use. Contextualisation was another intuitive method I frequently used as all the six participants had similar social roles, and had gone through the first four decades of their lives already, where they had passed through similar contexts such as in their work, families, and social interactions and functions. While many of my participants had experiences that could be represented on the same continuum, some of Chris' experiences were the opposite of the rest of them, resulting in polarisation being utilised in such situations. Two such examples include where Chris felt that being labelled with FEP was pathologising, medicalising a normal situation, while the other participants had felt that diagnosis brought them relief as they could then understand why they experienced themselves and others the way they did. Another example was where others were grateful for EIP staff support where Chris felt it was unwanted attention that he felt had resulted in him being viewed as different.

Throughout the analysis I closely consulted with my research supervisor to test and develop the coherence and plausibility of the interpretation, and to explore reflexivity. This also helped with analytic rigor and as a credibility check. A narrative was developed whose aim was to take the reader through theme by theme interpretation.

Chapter 3:

2.10 Reflexive Aspects

The researcher needs to be reflexive to ensure that their experiences, values, and assumptions are considered, as well as how these may impact the research process (Langdridge, 2007). Since being totally and meaningfully detached from the data was not possible, I attempted to be continually aware of how I may be impacting on the data. For purposes of integrity, I made all possible attempts to take ownership of my perspectives by using reflexivity regarding my theoretical vantage point and my personal interests in this topic of study. This way, the reader is granted transparency about my interests and motivations (Cunliffe, 2009). IPA places the researcher centrally in the research process. The way in which I understood the participants' experience of their FEP was influenced by how I engaged with and interpreted the participants' accounts throughout. I endeavoured to remain open-minded, maintaining an unconditional positive regard to the participants narratives, in order for the participants' narratives about their experiences to impact me.

2.10.1 Recruitment and data collection

At the first meeting, some of the participants looked different from how I imagined they would look. I wondered whether this sense of difference was something that they felt in their lives. When completing the demographics questionnaire (Appendix K), Happi commented that no section accurately described her as she is 'White Scottish,' not 'White British,' quickly adding 'not that it matters' and apologising 'that she had to be different.' As I continued her interview and went on to analyse her data, I did get the sense that she was indeed different, with her unusual accent and her way of articulating herself.

During the interviews, where appropriate I tried to adopt the participants' own language especially how they referred to their experience. However, I struggled with Happi's

language as swearing and using expletives was how she appeared to communicate. I found it difficult to use her language and be sincere about it, but I noticed that her way of using language felt less unfamiliar to me and less difficult the more I listened to her. As I carried out the interviews at the EIP service bases for the participants' convenience, this could have created an association in their mind between me and the EIP team members. To minimise the effect of this association, I made participants aware of my role as a Trainee Counselling Psychologist, rather than me being one of the workers in the EIP service. However, Sharon had been one of the clients I worked with before leaving the EIP team for my counselling psychology training, and I had to be very clear about my role. I was aware that she might feel the need to edit the experiences she shared with me, or to veto the language she used to describe her experiences of FEP and of EIP services. Interestingly, she was very complimentary of the EIP staff and the services she had received, as if she wanted to please and reassure me, perhaps wishing me to see her as a good client. It is possible that while she understood I no longer worked for the EIP service, there was still some bias and that she unconsciously felt she had to show my former colleagues and I gratitude.
During the interviews, I also worried that for those participants who had been in hospital, especially involuntarily, coming to the mental health centre may create discomfort and perhaps prevent them from carrying out the interviews, but as it happened, being there seemed merely to reignite their memories of their experiences. During a break in the interviews, Finn described 'how it felt good to come back,' while Randy said he 'did not expect to be reminded of so much,' which he said helped him to remember details for the interview. Both denied that they felt distressed as a result of returning to the centre.

Despite all the precautions I had taken around participants' recruitment and well-being, I also worried lest being asked to remember details of some of their most vulnerable, devastating and chaotic moments would send them reeling back into that dark place again, hoping they were as resilient as they had said they were. Hearing Fatimah, Finn, Happi and Randy tell me that they felt clearer about their experiences as a result of their interviews with me felt reassuring. Listening to Chris telling me “it was really good to talk about that period” encouraged me to think that perhaps there had been something in the interview for his benefit. As for Sharon expressing her gratitude for being given “all the time to tell her story” it left me feeling even more grateful for her time and perseverance as like with Happi, I had needed to refocus her attention and ask her to dwell on experiences that she said had shattered her world.

Generally, in qualitative research, participants are anonymised and nobody else knows they are doing the research unless the participants disclose this themselves. In this study, there is a chance that Care coordinators could potentially identify participants in the analysis. While it is hard to quantify the impact this may have on the participants, they were aware that their Care Coordinators knew of their potential participation, yet the competing needs for anonymity, having participants' voices heard, and them being able to access extra support if needed had to be balanced.

2.10.2 Data analysis

Having worked within the Mental Health Services for so long, I was mindful that I needed to be constantly reflexive as each individual I met was unique and had their own experiences, regardless of how similar their situations may be to some past experiences I might have come across.

Personally, I shared certain similarities with all my participants, more so with some than others. Like all the participants I am middle-aged, and like Happi, Sharon, and Chris, I have grown up children while like Happi, Fatimah, and Sharon, I am a woman. It is possible that these similarities may have influenced how I approached the participants' data. I noticed that for Fatimah, I was more affected by her, and perhaps I was more attentive when analysing her data. I wonder whether I felt this way as she appeared to be all alone in her local community as the member of an ethnic minority and an immigrant in a foreign country. However, I noticed the same with Happi, perhaps because she was my first participant. Though Happi was challenging to analyse, I noticed that she became my point of reference when analysing the rest of the participants' data. While I was aware of these similarities, I was also mindful with all the participants of our potential differences in gender, age, culture, and life experiences, considering how all this may privilege certain disclosures while potentially censoring others. I continued to utilise formal and peer supervision to consider my potential influence on the data I was analysing. I found myself continuously asking whether participants meant what I thought they meant and whether I was stretching the meaning too far, thereby failing to authentically represent what they meant. I also found myself agreeing with some of the observations they had made as I shared the same views, which led me to query whether I sometimes overidentified with them. With the aid of supervision, these reflections allowed me to interpret the participants' meanings with a good degree of confidence.

As a black woman, I have experiential knowledge of prejudice and unfair treatment, so I needed to be aware of the risk of imposing my own meaning to what some of my participants were saying about the unfair or discriminatory treatment they had received. I continued to keep a reflective diary, where I documented my own beliefs and identified potential unjustified or unsubstantiated conceptions and processes during the analysis of the data.

While I had not felt at risk from my participants, I found that I felt distressed by what they were sharing, both during the interviews and on analysing the data. As I immersed myself into my participants’ worlds during the countless weeks of data analysis, trying to feel what it was like to fill their shoes, and viewing the world through their eyes, I realised how imperative it was to self-care. Immersing myself into my participants’ worlds often left me feeling quite upset, occasionally needing to take time off the data. On a couple of occasions, I felt so heavy-headed and foggy that lying down was the most effective way to get back to feeling like myself again. I must add here that entering my participants’ worlds affected me more for some than for others. When I felt that I needed support to self-care, I sought this from my personal therapist and from a very close friend who became my informal therapist and sounding board. Additionally, I sought supervision from my research supervisor when I needed to.

During data analysis, I also realised that I was closely drawn to all my participants who all felt very special to me. I was respectful of all of them, and therefore I struggled to choose whose data extract to present as an example for the write-up. To be fair to them all, I designed a system which considered the number of subthemes each one identified with. The participant identifying with the highest number of themes was chosen to represent the rest of them as this was felt to be a fair and non-discriminatory way. This participant was Fatimah, hence an extract from her data is used (see Appendix P).

As I could not use all the data I had gathered during the interviews, it felt sad to leave behind some of the data that the participants had so generously shared with me. It felt uncomfortable, like I was not respecting what they shared with me. Perhaps this was the therapist in me wanting to use everything that was brought to me.

The findings from this study will be shared with the participants according to the wishes they expressed during the interviews. Three of them said they would like to know if there is a difference between their experiences of FEP compared to those of early onset FEP, one wanted to know if she could read the whole thesis once it is completed, one wanted to know what the next steps were after the study findings, and one stated that he did not mind not knowing about the findings. As the participants are now no longer with the EIP, the researcher will establish contact with them by phoning them, to confirm their wishes concerning knowing about the findings from the study. Thereafter the researcher will share the findings as agreed.

Chapter 4: Findings

This chapter reviews the themes generated by the analysis of the data from the experiences of middle-aged individuals with FEP. Where direct quotes from the transcript are used, the quote is specified by inserting the participant pseudonym at the end of the quote (e.g., Fatimah)[18].

From the wealth of transcribed data obtained during the eleven and half hours of interviews, thirteen subordinate themes emerged which were organised into five interrelated superordinate themes. The superordinate and subordinate themes are shown in Appendix 2.

Attempting to present the data in separate and neatly organised themes was a huge challenge mainly because FEP experiences are not stand alone or neatly organised experiences. Instead, they are closely interwoven and move backwards and forwards throughout the experience of FEP. Additionally, 'data mining' and making sense of the details from the minds of people who are trying to make sense of their sometimes chaotic and disjointed, illogical, or indescribable and confusing experiences was not only intense, but confusingly difficult, and mind boggling.

The superordinate themes identified are centred around how the participants made sense of what was happening around and within them at the onset, during, and as they were recovering from FEP. The superordinate themes also cover how participants perceived others' responses and reactions towards them; how what they were going through impacted their lives, and what sense they made then and now of their experiences.

The five superordinate themes are given in Table 1 below.

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[18] To maintain the participants' confidentiality, all names of participants and places are anonymised via the use of pseudonyms, and any potentially identifying details are either anonymised or omitted altogether.

Table 3.1: Table of Themes

Superordinate Theme	Subordinate Themes
1. “My Worst Nightmare”	1.1) “Too much”
	1.2) “Petrified”: The lack of agency
	1.3) “A shock and a Half”
	1.4) Becoming Untethered
	1.5) “I lost it, lost it completely”
2. “Not Myself”	2.1) “My Crazy Mind” and the self
	2.2) Wrestling
3. Person of Interest	3.1) Superhuman
	3.2) “Alonely”: Participants’ desperate need to hide from the terror of being targeted and hunted down
4. Belittled	4.1) “Like I was Defective”
	4.2) “A Lesser person”
5. “Coming Out”	5.1) Being Understood and Gaining Understanding
	5.2) “It’s like I’m… I’m a man, a new man”: Participants’ sense of development and growth

3.1 Theme 1: “My Worst Nightmare”

According to all the participants, the phenomenon diagnosed as Psychosis[19] was experienced as a dynamic process happening in a non-linear fashion over some time, and not as a fixed event. The first superordinate theme, “My Worst Nightmare” is around participants’ awareness that something within their internal and external worlds

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[19] Psychosis is used here as a medically defined set of symptoms according to the DSM-V; and all participants in this study understood their experience as having been a psychotic episode except for Chris. I will continue to use this term for brevity and simplicity’s sake. Though he did not subscribe to it, Chris allowed its use even where he is concerned.

was shifting. It is also about how the participants made sense of this shift before healthcare professionals became involved. All the participants describe this shift and its realisation as taking them to a vaguely (if at all) familiar realm. Within this realm, the participants continue to attempt to make sense of situations and experiences that sometimes appear ambiguous. They have not been there before, and as their levels of discomfort and distress reach a crescendo, a point of no-return, they feel ungrounded and uncontained; they appear to have ‘nothing left to lose’ except their minds.

3.1.1 “Too Much”

Throughout the participants’ narratives, the onset of symptoms of FEP is preceded by periods of intense stress. In some cases, this stress is accompanied by pressure (perceived or real) to achieve certain levels of competency, with uncertainties and challenges in different areas of their lives. While the duration of the process is variable for each participant, the participants appear to see the process as having a beginning, a middle and an end:

> It seems like an Arc that I went through, and then I came out the other side […] but there's a definite beginning, you know, leading up to that point, a time -a moment when I suddenly realised ‘Oh, I am, I am unwell’ (Finn).

> I can’t tell you exactly when it was, but it started gradually and when-, then it got worse and worse. I am a lot better now, but at the beginning I didn’t even know that I was becoming sick (Randy).

Both Finn and Randy’s descriptions of their experience of FEP sound dynamic, analogous to journeying, transitioning through time to a different state of being. In both cases there was total lack of awareness that they were becoming unwell.

Finn’s idea about an Arc can be used to symbolise the FEP process. As an Engineer, it is likely that Finn’s longitudinal view of the Arc observes its two ends resting on a horizontal plane while the apex is higher up above the horizontal plane.

All six participants identified that at the onset of FEP, they experienced several adverse life crises, with periods of isolation, interpersonal and occupational stressors, or physical health issues. This is how Randy describes this period:

> I was in debt, quite…quite a large amount […] I still had a house and I was still paying the mortgage and bills on that. I was -, work was quiet. […] I think last year it got even quieter because of Brexit […] Also with my sister, we used to be quite close - I had - we had we had a falling out. (Randy).

All the challenges identified by Randy above appear to have had an impact on his sense of personal control of his life and his financial affairs.

Like Randy, Happi identified stressors, some of which were external, and she may have felt a lack of control:

> I had two massive court cases going on with the Metro Police, errm one historic, no, two historic, one being a Doctor. Err, my oldest son who'd always been a support had moved out of our home…and my daughter had decided to go and live with friends in [X- name of a place] at the age of 15…(Happi)

Happi's stress was influenced by what sounds like serious court cases, exacerbated by reduced social support. She may have felt like she was being rejected and abandoned by her children when she most needed support. It may also be that it left her doubting her position and competency as a mother.

Like Randy and Happi, Chris describes external stressors, with additional physical health difficulties:

> this is something that started, that started as this stress at work really. […] I had other things going on as well, erm my - (sighs), my eldest son was at Sydney University abroad […] my only daughter was travelling; and you know, you hear about things happening don't you when young people are out there, so I was worried about all that. […] I've had a heart condition as well […] and so I was thinking you know, is this gonna cause that again (Chris).

Chris had work-related stress like Randy, and worries about his children's welfare away from home. The way Chris sighs and appears to hesitate when enumerating his circumstances is as if returning to this memory was uncomfortable for him. He refers to his daughter as his only daughter, which gives the sense that perhaps he has a special relationship with his daughter. He appears to have feared for his daughter's safety as well as worrying about not being there for her, all of which seems to have compounded existing worries around his health.

There is a sense that all participants perceive the causes of these difficulties as being out of their control.

Apart from the external stressors, some of the stresses experienced appear to have been influenced by the participants' temperament with perfectionist tendencies, and their attitude towards their work as Sharon explains:

> I'm like the sort of person who is determined to keep going and push myself to the limit […] which is probably what I did. Errm, I'm not a workaholic- I suppose, maybe I am, I don't know. I like to help people out. […] I used to work till seven {pm} […] because I was the sort of person that wouldn't say 'no' […] Then it will be a question of getting home late, too tired to do anything else. (Sharon).

Appearing to be working beyond her contracted hours, as well as being an over-achiever, doing jobs for others, not feeling able to assert herself, and perhaps intending to please her boss and pushing herself to do so, all seemed to have influenced Sharon's stress levels. Consequently, she appears to have been unable to maintain a good work-life balance.

Fatimah shares a similar disposition, even pushing herself beyond her physical limits:

> In order to get perfection, sometimes I'd push myself beyond my physical limits, working too hard […] because when you work too hard, don't sleep well enough don't eat properly, you're more susceptible to anything from the flu to psychosis, I think (Fatimah).

Like Sharon, Fatimah does not appear to know when to draw the line. Instead, she appears to deprive herself in other areas of necessary activities of daily living. Due to pushing herself beyond her limits Fatimah appears to imply that her perfectionism triggered the psychotic episode.

A different dimension of the stress the participants experienced resulted from what appears to be time-sensitive deadlines, or expectations from the participants themselves or others, whether perceived or real:

> I found the pressure of, you know, trying to be happy for Christmas, […] to cope with the whole sort of Christmas festivities and spirit, that was almost-, like … buying- going out and buying presents…just too much. (Finn).

Finn alludes to how perhaps he did not feel cheerful to match the spirit of Christmas, and so there is a sense of forced cheer in order to match the Christmas spirit, and the need to 'be happy'. One wonders whether he viewed others as expecting of him to be cheerful and do Christmassy things.

In Chris' case:

> Work was busy, you know, there was a lot of pressure. […] The airline industry is quite pressured. I mean, everything has, everything has quite tight timeframes and things have got to be done by certain times otherwise people don't make the money, and yeah, it's it's about, it was up to me…to get it right (Chris).

However, it sounds like there are personal consequences to Chris, and a sense of guilt, if deadlines are not met. From his language, emphasising the pressure he felt from his workplace, he used the word "pressure" twice, and "tight", which appears to convey what was happening to and within him, and the sense of responsibility he experienced. Just before he mentioned "it was up to me… to get it right" he stumbled then stated it was his responsibility, as if he is still grappling with the idea of the pressure and the implied responsibility.

All the participants identify that their stress levels reached unprecedented levels, which appears to have worsened how they felt physically, either directly or due to how they processed their experiences:

> it was so stressful I was worried thinking- 'am I gonna have a heart attack now' because of all this stress. I don't think I have been so stressed in my whole life. (Chris).

> I have not been under so much pressure, so much stress before, and I would have headaches, […] I think I put it down to being under the most stress I can ever remember having in my life. (Randy).

> everybody has tough periods but I never had periods quite as tough as that, and not having any time to self-care. […] I had other incidents in my life that were quite extreme but nothing was on such a prolonged timeframe […]. I had to make sure everything was done, even when I felt physically unwell. I took last place in the pecking order, so I didn't look after myself properly. (Fatimah).

While all the participants identified their stress levels as reaching record highs, Fatimah identified that her worst stress levels were over a protracted period of time, leaving her with no time to prioritise her own needs. Fatimah’s use of the idiom “the last place in the pecking order” gives the impression that she perceives her position in society or at home as being below others, or that she prioritised other people’s needs over her own.

As their stress levels continued to rise, all participants reported experiencing mood and emotional changes, and disruptions in cognitive processes related to perception, attention, recollection, or decision-making:

> It became harder and harder for me to focus at work. […] my work output and quality of work had gradually become almost barely worth me coming in because I just couldn't focus. […] I was making mistakes. I wasn't paying attention all the time. I was distracted and I couldn't control it as much as I tried. Fatimah).

Fatimah seems to identify the experience as something that was gradual and inexorable, as if she was being ground down yet it was out of her control.

While Finn, like Fatimah, observed that he could not focus, he also observed that he was struggling to make sense of his thoughts, and his distress appears to have been worsened by his struggle and failure to process his thoughts:

> I was finding it really hard to focus on anything, […] And I had lots of thoughts rushing, going through, sort of in my head. I I couldn't process them. I couldn't understand all my thoughts. Because of that I couldn't, I couldn't work properly, I couldn't think properly. I couldn't, I couldn't do normal daily activities. I couldn't I couldn't concentrate on the actual, the actual… (Finn).

Finn speaks of “lots of thoughts rushing, going through”, as if there is a force driving and pushing them, causing them to be faster than usual. In the quote, he also uses the word “couldn’t” nine times, as if his use of language mirrors how stuck and trapped in some form of infinity loop he felt, where he could not see a way out. Additionally, it is as if he cannot go beyond the looping of his thoughts as he attempts to do activities. Even as he attempts to explain himself in the interview, it appears he ‘couldn’t’ articulate himself, with his use of language appearing to mirror his sense of cognitive entrapment.

3.1.2 “Petrified”: The lack of agency

Participants described how they noticed changes in their performance, with some reporting being unable to physically mobilise themselves to do different tasks; it was as if they were paralysed. Some identified how time either passed by without their awareness, or was experienced as having stood still. The extent to which this happened varied from person to person. Some noticed a reduction in their work-output, or erratic ways of behaving, while some stopped doing activities altogether:

> I’d just get up and go to bed in the night-time, wake up and sit in the chair day after day after day. […] I wouldn't go out of the house. I couldn't go out of the house. I didn't want to leave the front door. […] I just didn't want to do anything, didn’t want to go anywhere I didn't want to get up. […] I just didn't, didn't realise - functioning wasn't happening. (Sharon).

Where she explains that she would “sit in the chair day after day after day,” it is as if Sharon is repeating this to show how repetitive this part of the process was, as if it was automated. She initially sounds like she chose to not leave the house by saying “I wouldn’t”, while in the next breath she sounds like she is planted in place and therefore *could* not leave the house even if she wanted to. Therefore, on one hand it sounds like it was her choice not to leave the house though she was capable of doing so, and on the other, it was not her choice to not go out as if she lacked the ability. There appears to be an interplay between choice and lack of choice, ability and lack of ability, agency, and lack of it. Perhaps Sharon herself was not sure which was which, both at the time, and during the interview. This shifting between agency and lack of it continues to be seen elsewhere in carrying out activities and pursuing her hobbies.

In her narrative, Sharon then appears to change her speech to passive when she says “functioning wasn't happening”, as if something else or somebody else was responsible for her to function, again indicating this lack of agency.

This idea of being frozen into inactivity is taken further by Finn who initially expresses lack of ability rather than desire or motivation, later mixing the ability and lack of it, just like Sharon:

> I used to go to work and I'd just sort of freeze, and I just sort of I couldn't, couldn't cope. So I'd just sort of stop everything just like that. […] I didn't do anything really because that's what that's when I couldn't, and then I started pacing. And I wouldn't wouldn't go out of the house. I couldn't do anything social. […] I found myself doing nothing, I I couldn't do tasks. (Finn).

While participants identified being petrified and not doing activities, it was also as if time was experienced differently, either as racing or as having come to a standstill:

> Martyn {Sharon's husband} would go out to work, and he would come back, a lot of times I would still be sitting in the same chair, thinking it's the same time. […] This went on for - for what I will call months. (Sharon).

When Sharon speaks about her husband going and returning from work, whatever time he spent at work appears to have stood still for her, as if it was both herself and time that were frozen into place, as if all was 'petrified'. Additionally, Sharon appears to be aware that she does not know exactly how long the state of 'petrification' lasted, stating "this lasted for what I will call months", appearing to be aware that other people may quote a different time frame.

In contrast, for Happi, time seemed to be moving too quickly for her to make sense of it or even perceive it:

> all I can say is I think it lasted a year, I think it started about the year before, I had no sense of time […] because it was Christmas then it was Christmas, that's all I remember-a whole year of my life was just a blur basically. (Happi).

Being petrified and having no sense of time deprives one of their usual bearings in time and space. These two, time and space give us an idea about the 'when' and 'where', locate us as humans; they give us landmarks to relate to each other and to the environment around us, and to make sense of our experiences. Once the participants lost their sense of both time and space, it is almost as it they lost part of their humanity too, something that is further discussed in the subordinate theme ‘Becoming Untethered’.

3.1.3 “A Shock and a Half”

Though the participants could tell something was not right within themselves or their worlds, they sometimes appeared unable to identify what exactly it was, which led to unanswered questions and bewildered confusion, as Fatimah explains:

> I could sense there was something wrong because I stopped driving without my license being taken away. […] I just wasn't sure what it was that was wrong (Fatimah).

While the participants can now look back and talk about becoming untethered, at the time their state of mind appears to have crept up on them without them realising it:

> I guess I pushed myself to breaking point, without realising it. […] when I did, to say it was distressing is an understatement. I was scared, horrified, I couldn’t believe I was ill, that I was - I was -, I don’t know (she looks down then away). It was my worst nightmare (Sharon).

Sharon says “I guess” as if to say she is not sure and therefore is reluctantly agreeing that she pushed herself beyond what she could take. In her attempt to describe what it was like for her when she realised she was unwell, Sharon appears unable to find the right words that would enable her to fully explain what it was like for her. As this is something she had never experienced in all her life, the best way to put it across was it was her “worst nightmare”.

This sense of perplexity and unreality was experienced by Randy too, perhaps contributing to his confusion:

> because I was err, I was having strange thoughts and errr I wasn't sure what was real - what was reality and what wasn't […] I kept I kept thinking backwards and forwards through time. (Randy).

Randy mentions having strange thoughts, as if his mind has become unfamiliar to him. Struggling to know what is real or not gives the sense that one is left in a state of uncertainty, not being able to make decisions that they can trust. He mentioned that he “kept thinking backwards and forwards through time,” giving the sense of being stuck, and perhaps lost, or losing himself, unable to focus his thinking, with his mind going everywhere yet nowhere, which gives a disorienting sense even.

When the participants started to realise what was happening to them, there was a sense of shock, as if they did not expect these things to happen to them:

> I was quite shocked by what happened...to be honest […] It felt like, like a switch was pressed… I couldn’t believe that I was going down that road. (Happi).

> I felt very, I was, it was like, I mean, I just felt very sad, was confused, I was scared and angry, I couldn’t even say what it was like. I felt like I was not myself anymore, it was horrifying, horrendous. […] you can't, you can't imagine it ever happening to you when it did. It was a shock and a half (Sharon).

On realising that something in her had shifted, it sounds like Happi was not the one who pressed the switch, indicating lack of agency, a thread that appears to run throughout her interview as well as throughout her life. Additionally, Happi expresses her disbelief of her experience in past tense, as if she does not feel so shocked now, being reflective and perhaps taking an observer viewpoint.

On the other hand, Sharon starts so many sentences which she does not finish, sounding like she is realising that going through FEP was not something she could use words to describe. For Sharon, when she realised she was becoming unwell, not only did it shock her, but it is also as if it went beyond shock, it was *“*a shock and a half”.

3.1.4 Becoming Untethered

As discussed earlier under the subordinate theme ‘Petrified: The lack of agency’, it is as if the participants’ experiences left them feeling untethered, no longer grounded in space and time. Additionally, all the participants appear to have experienced a sense of profound loneliness and isolation. During such moments, participants described feeling existentially separated from others and sometimes from their own feelings. It is as if they were from another race, and could not relate to others as human beings.

Finn expresses this powerfully:

> And I remember taking my daughter to school, and I just felt outside of everyone as though I was not normal and everyone else was normal. (Finn).

These other people whom Finn experienced being outside of seemed to fit in, looking as if they knew who and where they were:

> It looked as though everybody else was getting on with their life and you know, they didn't have problems and they're they're coping well and there was me thinking, ‘I can't I can't hold it together, I really can’t’. (Finn).

Not only did he feel like he did not belong, it appears that Finn felt like he was falling apart, and experiencing a possible sense of inferiority, or being less able, weaker, a sense of failing at being human.

While being alienated sometimes gets in the way of functioning, there is the idea of feeling misunderstood, and of being unable to share one’s experience or reach out for help:

> It just felt really errm, alienating {not being able to share her thoughts with ward staff}, it was a lonely time, I just felt like I was alone and misunderstood, and that it was pointless to try to explain to anyone since they believed otherwise. (Fatimah).

Fatimah appears to believe the perceptions staff already hold about her are not from her own experiences, feeling staff prejudged her.

Being unable to discuss one’s concerns with anyone either due to lack of trust or a sense of not belonging, when coupled with strange thoughts, and doubting their surroundings' veracity, seems devastating. Additionally, feeling misplaced in time and space sounds like it adds to further destabilisation. Participants’ distress appears to have been worsened by their perceived inability to control anything in their lives, as Randy’s quote illustrates:

> I felt that everything was spiralling out of control and I was literally spinning round physically spinning round in the house and uhm […] and my mind would be spinning at what felt like a million miles an hour. (Randy).

It sounds like both Randy and his world, both internal, that is symptoms and his surroundings, were spiralling out of control. Within this kind of situation, it is unlikely that one can stay or feel connected to themselves or to others.

Randy speaks of literally spinning around, as if this was an attempt to re-establish some control, some form of re-grounding. He further appeared to think he could establish grounding by being literally on the ground:

> It was at one point when I had been spinning, I felt, I was disorientated. I remember 'cause I went outside and had to lie down afterwards. (Randy).

Fatimah explains her sense of becoming untethered this way:

> I just had had enough, and nothing made sense to me anymore. Everything was strange - I started feeling like I have no control over what's happening to me anymore. I felt very strange. (Fatimah).

The above quote suggests that 'everything' that Fatimah knew was gone, and she is in an unfamiliar world, where she herself feels "very strange," not just strange, giving the sense of someone totally misplaced. She uses the word strange twice, as if to emphasise how disconnected from herself and from her world she was. It would appear that the incomprehensibility of Fatimah's state is what she experienced as distressing and destabilising for her.

Some participants describe how they felt at their breaking point, appearing no longer able to contain their anguish within themselves, or to bear their pain:

> I felt like I was going to explode soon from all the stuff I was feeling and not being able to express it […] I felt overwhelmed, […] I just felt like my world had turned upside-down. The pain was …-, I can't describe it… I couldn't bear it. (Fatimah).

Fatimah reports that her "world had turned upside-down", everything that was once familiar no longer so. Like Sharon, Fatimah could not find words to explain her experiences at the point of realising what was happening, however, she appears to know that she could not handle it. She mentions "not being able to express it," as if indicating that she felt the need to squeeze some of "the stuff" and perhaps emotions and feelings out, to stop herself from exploding, given the unbearable pain she was in.

Like Fatimah, Happi could identify when it was that her tipping point was reached too:

> I had, the court cases had been a year previous, when they reopened, my son moving out and my daughter moving out was an instant switch, which is when I would say was the pinnacle point that I broke down. […] I would say it was a trigger point there. […] them {her children} leaving like that …it was the last nail in the coffin. (Happi).

After the stresses with the court cases as she explained earlier, Happi seems to have continued to function, appearing to reach the tipping point when her children left her. She spoke as if she could lose everything else and still function, but after losing what appeared to matter most to her, her children, there is a sense that she may perhaps have felt that there was nothing else left to lose, which is the point at which she "broke down" especially as she said her children leaving "was the last nail in the coffin". Happi's collection of expression "instant switch," "pinnacle point," and "trigger point" all give a sense of suddenness, and the fact that she felt that all of a sudden, she lost control. There is a precise moment in time where she felt things went wrong, depicted by the idiom "last nail in the coffin" as if to mean that this was what ultimately caused her FEP. However, there is a disparity here as the process of her children moving out is not something that happens in an instant, but it is as if in her recollection everything is sudden. Pinpointing the moment when she lost it gives the sense that the suddenness of it all left her without any time for preparation, to work out what was happening, and to adjust to the new situation.

3.1.5 "I lost it, lost it completely"

Once that point of no return had been reached, it is as if there was only one way to go, as the participants entered a different realm. This realm sounds like an alternative reality, and it has been referred to by participants as a 'breakdown,' 'a different type of stress', 'an episode,' or just psychosis.

This is what Happi said in an attempt to explain her experiences:

> I lost it, it was -, I felt like I'd been -, that's when I lost it, it was …. I felt like I'd been – oh no! I felt like I was on another planet, I jus… […] I just …I was in La-la land, I lost it, lost it completely … I was on a different wavelength. (Happi).

When attempting to explain what happened to her after the point of no return, Happi's account is fragmented and chaotic, which may mirror her profound sense of disconnection, perhaps from herself and from her surroundings, as she entered this new realm. Her speech is hesitant, and she seems to struggle to articulate her experience, as she attempts to describe something that perhaps cannot be put into words. Happi mentions "lost it" four times in the quote, ending by indicating she lost it completely. The way she repeats this is as if she after losing it she was no longer herself. Happi then speaks of 'losing it', as if this 'it' was a separate entity with a character to it. She needed it, and after she lost it, it is as if she was incomplete and could not function adequately. After losing "it" there is a feeling of being teleported as if to another planet. She speaks of being on a different wavelength, in La-la land, perhaps expressing her total loss of control, and her loss of agency. She exclaims "oh no!" as if realising and resenting the loss but being unable to adequately describe it.

Similarly, Randy demonstrates this failure to describe an indescribable moment when he attempts to explain what it was like for him:

> Well it was it was after- when I started, before I started feeling better, feeling more normal -because I didn't -because I -we left -we yeah, mom -my dad arrived, then my mom and my fiancée, I mean my mother and sister and I had the dogs as well in the van, but I don't normally take them to work. (Randy).

It is difficult to follow what Randy is attempting to say here. Like in Happi's case, his sentences are incomplete and fragmented. It is as if there is some confusion in what he is attempting to express, perhaps even portraying a disorganised way of thinking as he revisits perhaps an unfathomable state in the past, resulting in muddled up speech.

While Fatimah's speech is more intact and better, what she recalls of the moment when she 'lost it' evokes a sense of psychological collapse nonetheless:

> I was just talking nonsense. […] and then after being at home for a short while I tried to commit suicide. […] I just had had enough and nothing made sense to me anymore.

> […] I started feeling like I have no control over what's happening to me anymore. […] I started coming to the conclusion that I have nothing more to live for and that I'm better off dead really. (Fatimah).

Fatimah appears to be saying she felt that she lost her voice, she had no choice and was not in control of anything. She saw no other options, and it is as if the only thing left that she felt she had control over was her life. There is desperation, hopelessness, and an inability to contain her despair. There is a profound sense of meaninglessness, where Fatimah appears unable to see meaning in actions, relationships, or the world around her. At what seems to have been her point of no return, Fatimah "tried to commit suicide". She does not say she 'tried to kill herself, or take her own life', as if committing suicide gives a different type of weight to the action.

Like the rest of the participants and as seen before for other participants, after his tipping point, Randy went into a space that appeared to have no words:

> And then that's that sort of tipped the scales in a way because I thought, 'Oh, no! it's in the family'. Yeah, then my mind went crazy […] because - well who believes these – who understands, who thinks these thoughts and- hearing voices and seeing things. All those -all that- that's what I mean that's what I mean. (Randy).

As Randy attempts to explain what he meant when he said his mind went crazy, his language fails him, and he speaks as if he was back in the moment when he lost it, even though he is now in a much better place mentally. It is as if even as the participants are better mentally, they sometimes struggle to express themselves, as if getting in touch with the moment when they 'broke down' takes them back there.

3.2 "Not Myself"

This superordinate theme captures two subordinate themes, where on one hand, some of the participants appeared to have a specific relationship with their minds, where they appeared to consider that their minds were separate entities functioning independently to their 'selves.' This comes as all the participants attempted to make sense of what they recognized as a disconnect in themselves.

On the other hand, while some participants accepted the diagnosis of FEP with a sense of relief, some appeared to wrestle with the idea. The internal conflict, and the continued struggle to own the experience of FEP fully, results in some participants pretending to be well, minimising or hiding their symptoms.

3.2.1 "My Crazy Mind" and the self

Four of the participants appeared to consider their minds to be the ones affected by FEP, not 'them.'

Reflecting on his experiences and attempting to make sense of this, Randy speaks in a way that gives the impression that he considers that his mind was the one affected, not him:

> I think my mind, my crazy mind, my mind sort of my mind just went a little crazy. (Randy).

The interesting thing is while he is separating himself from his mind, he is still owning it, despite it being crazy, when he states, "my mind, my crazy mind."

This separation and owning of the mind is something that Finn also shares:

> That's when I felt like this glitch, like my brain like in my brain there was something not, a glitch, like this failure to do what brains do, to work with me. (Finn).

There is an impression that his brain was doing its own thing and not working with him. When he speaks of a "glitch", one gets the sense that perhaps his brain is like a mechanised equipment, which gets a sudden malfunction resulting in a faulty output. Finn's language as an Engineer is seen in his symbolisms. As a glitch, perhaps Finn views his crazy mind's behaviour as a random malfunction therefore it is tricky or difficult to know how to fix it himself.

In some participants, there appeared to be ambivalence about the separateness of their minds and their 'selves,' where at times the mind appeared to be integrated with the persons they were, and at other times, 'mind' and 'self' became separate entities. To demonstrate this, Happi has this to say:

> I just can’t believe that my mind went along those lines. I can’t believe I broke, that my mind broke. (Happi).

It is as if Happi initially considered her mind to be the one affected when she could not “believe that my mind went along those lines.” Yet in the next breath, it is as if she considers that the whole person broke, before she steps back again to her mind breaking, perhaps as a self-protective move, seen in the distancing of the self from the broken mind.

This distancing is also seen in Finn who appears to consider that his experiences altered his sense of self in an undesirable way, and appears uncomfortable with or even embarrassed by being identified as ever having been *that* person:

> That's why I when I look back, I think that that person is not me now. Because, because I'm not like that person (Finn).

It is as if Finn’s sense of self and his identity when he was experiencing the FEP are incompatible with his current persona. He says “that person” twice, using distancing language, and emphasising by repeating, perhaps to let the interviewer realise that he was a different person.

In contrast to how Happi and Finn relate to their separate minds, Randy appears understanding of his mind’s failure to cope, and its need for a break:

> I think my mind could not deal with it, it was too much … it's like coming – like I would come back to my senses… I think the result was my my mind went. My mind was err, I think, my mind needed a break (Randy).

Randy mixes his tenses, first using “could,” then going to the present continuous tense in “it's like coming,” as if it is still happening, before going back to another tenseless verb “would.” It is as if Randy’s thinking changes during the interview, and goes back to the past, which he appears to bring to the present, accepting that his mind could not continue with the challenges it was faced with. Like Finn and Happi, Randy speaks of himself and his senses as if they are separate entities. However, Randy appears to take a compassionate stance towards his independent mind. Additionally, it is interesting to note that in the separateness of the mind and the self, Randy’s quote seems confused and is fragmented, as if to denote the fragmentation between the self, the mind, and the senses.

In sharp contrast to Randy’s compassionate stance towards his mind, Happi and Finn have different relationships to their minds, with Happi appearing almost angry with her mind for breaking, perhaps feeling betrayed by the mind, as if the very sense of who she is being compromised. Finn on the other hand sounds embarrassed that his mind showed him up to be an inadequate person.

3.2.2 Wrestling

While some participants accepted the diagnosis of FEP with a sense of relief, some participants appear to struggle to fully own the experience of FEP, giving the sense that there is something uncomfortable about it, or about how they perceive others to view it. These participants have had a full life meaningful to them until then, and appear to be fighting against anything that may taint the memory of their lives to date.

Holding onto the sense of his former self, perhaps to protect his ego, Chris normalises and minimises his struggles:

> So mistakes like that you know happened. […] I forgot a couple of times. But then your mind wanders off sometimes … again, everyone does that, errm .. that does not make it an, an episode. (Chris).

Chris also minimises his cognitive difficulties, using a passive voice saying: “mistakes like that you know happened”, as if he was not ready to take ownership of his struggles. When Chris says “everyone does that” it is as if he is normalising this and is trying to hang on to his former (‘normal’) self-concept. Additionally, Chris talks of his mind wandering off, and pauses as he does so, as if there was something difficult about the experience, before denying that his mind’s behaviour demonstrates the experience of “an episode.”

In addition to minimising and normalising his experiences, Chris also rationalised them, as if viewing them all as part of his personality:

> I mean they’re calling it psychosis. I’ve gone through a lot of crap you know, a lot of shitty things have happened to me […] I just call it stress really. […] It wasn't really an episode. I think it's just part of who I am. (Chris).

By rationalising and normalising what had contributed to what he experienced, Chris is rejecting the idea of his experience being psychosis. He appears to be saying that anyone would have experienced the same as he did, had they gone through the stresses he went through. This way, he was not different to anyone else. While the rest of the participants appear to subscribe to a disease narrative, Chris preferred instead to consider his experiences as normal reactions to highly stressful life situations. He uses the word “really,” twice perhaps as a qualifier. He positions himself as the expert in his experiences, and asserts himself by saying “they’re calling it psychosis,” and “I just call it stress really,” as if to portray that since he is the one experiencing it, he knows better. Minimising can also be his attempt at maintaining self-esteem. When Chris uses the word “crap,” to describe the nature of his experiences, and when he then states “a lot of shitty things have happened to me” he uses the passive voice, as if to show that he has been on the receiving end of unpleasant or even terrible experiences, which perhaps he had no agency to directly do anything about.

Similar to Chris in terms of struggling to own the experience fully, Finn differs in that he admits that there is a conflict; however, he would not admit that to others as he wanted to maintain appearances and perhaps to preserve his dignity:

> And so I, so this is a conflict that I, that I knew something was wrong with me, but I didn't want to tell anyone, that something was wrong with me because […] going to a doctor is an admission that there's something wrong with you, so don’t. (Finn).

There seems to be that kind of wrestling within, whereby Finn admitted to himself that something was wrong, yet could not accept help for it. It is as if seeing a doctor will make it real, while if he continues to deny that it is a problem, he is still his old self. He says “so don’t” as if commanding himself about the right action to take.

A similar struggle is seen from Sharon’s dilemma with psychotropic medication, as she perhaps viewed herself as strong enough to do without it, yet knew she needed it:

> I didn't like to think that my mind-my brain had been affected to this extent. I consider myself different, strong. And to just have tablets, medicine, just to make me better, you know, I‘m not weak, I…- (Sharon).

Sharon speaks in the past about her preferences “I didn't like to think”, with a reflective tone, taking the vantage point of an observer, immediately switching to present tense “I consider myself different, strong”, as if she would like me to know that it is perhaps all in the past now. Additionally, she says she is different as if there is a certain set of attributes which she does not possess but associates with those whose minds get affected this way. Although she does not complete the statement “I‘m not weak, I…,” she appears to be saying that taking tablets to make her better is something that would contradict the view that she is strong, a view she appeared keen to preserve. There is something reflective about how she says this, as if accepting on recognising and taking the position of someone who needs tablets. She does want to see herself as strong, there is a tension, it is hard to accept, yet she appears willing to hold the tension between sickness and strength in mind.

The reluctance to take psychotropic medication was shared by Chris too, however it appears his reluctance was for different reasons:

> I just think it’s not right. You are a fraud; you want others to think you are normal by taking head medication. And for a 55-year-old man, that is not what I want, who I want to be. (Chris).

As he has been known as a particular person until now, Chris appears to want to preserve this identity which he perhaps thinks will shift if he was to start “taking head medication.” He appears to view this person who uses head medication as not authentic, but one who leads others into thinking he is one way when in actual fact it is the medication making him that way. Perhaps this way of thinking is as a result of Chris considering FEP not as a medical condition but a normal response that anyone can experience therefore does not need to be medicalised or medicated.

Finn, who was also reluctant to take medication for fear of being seen as weak appears critical of his additional ways of attempting to cope:

> I felt very -, part of me felt like ‘I don't need medication. I can cope on my own, I am strong’. And another part was like ‘I'm just being like, acting like a silly child here’. I was just not, I was not coping well at all. ‘I'm just regressing back, back into my childhood acting like, well as a child refusing to take medication’ (Finn).

Finn acknowledged that something was wrong, and he appears quite perceptive in how he identifies the three different and conflicting parts of himself: a ‘silly child’, the struggling self, and a more responsible ‘parent’. This shows that there are also differences in the way participants relate to or understand their episode.

While Finn spoke about acting as “a silly child,” Randy described a similar experience about acting a certain way, ‘pretending’, for others not to know exactly how he was feeling:

> it was like I was acting …and then I sort of felt I had to pull myself together and pretend everything was fine […] and I thought I needed to continue to hold it together (Randy).

Randy however goes further than pretending as he felt like a character in a play. Acting means that it is a game, where he is in character and can come out of it. There is a sense of minimising or even rejecting how bad things are, and by turning it into a game, it gives one the sense of being in some sort of control.

The idea of minimising what is actually happening during FEP by way of acting or considering it a game seems to also be shared by Happi:

> I made it that everybody was playing a game with me, that it was part of some game we were all playing, I don’t know what we would win in the end, but I just felt like, everybody that was-, I was approaching neighbours- anyone like that we were all part of some game. (Happi).

Being a game player perhaps gives Happi a sense of belonging, perhaps helping her to achieve what she felt she lacked in her other reality. Here the game sounds somewhat delusional, perhaps an escape from Happi’s perceived reality when that reality stopped making sense.

The struggle to own the experience of FEP appears to be depicted in other ways such as through masking and pretence:

> I was trying to hide it. I was trying to put this sort of pretence on and that I can cope. And it's almost like I felt like I put a front on, that, like yes. That I'm fine. I'm happy. I'm okay. But inside I wasn't. (Finn).

Although he put on the front, this does not appear to have been given Finn the sense of safety he was looking for.

In her wrestling with the fact that she got FEP, Sharon continues to take the viewpoint that it should not have happened to her, like she should have been spared because she did not deserve to experience FEP since she is a particular type of person who does particular things, and behaves in particular ways:

> Well, when you hear psychosis, psychosis, you think young people, drug users and people who are not like me, maybe people who don't look after themselves, and people who have it in their family. (Sharon).

Sharon appears to believe she had many characteristics that should have excluded her from being a candidate for psychosis. It is as if there is also a sense of 'why me', which gives the idea that Sharon views having FEP as an injustice to her. It is as if there is a type of individual she attributes to being the right fit to develop psychosis, not her.

3.3 Person of Interest

This superordinate theme captures how participants somehow set themselves apart, seeing themselves in ways that appear both grandiose and wretched. Seeing themselves as grandiose, they possess special powers, which gives them a superhuman or superhero status, thereby enabling them to engage with the universe in ways that normal humans cannot. They also experience themselves as people of high social status or a Person of Interest, who interact with others and with organisations in ways enabled by their status. This is the Superhuman subordinate theme.

As wretched, there is a sense of being targeted or hunted down by some unspecified organisations or bodies. Consequently, being a superhero or a person of interest gives a paradoxical sense of victim fragility to the sense of superiority, which causes the participants to seek self-preservation by isolating themselves or actively hiding away. By doing so, they feel within themselves a sense of loneliness. This type of self-isolation by actively hiding is because they feel their lives are in danger and while they want others around them, they cannot risk it. This way of being is herein termed "Alonely," a separate subordinate theme. The state of being alone is located both externally and within the individual.

3.3.1 Superhuman

Some participants experienced themselves as connected to something special, which appears to have raised their human profile to a higher status, a superhuman status leaving them feeling exceptional. This appears to give them extra-sensory perceptions, which no other humans have:

> in a way I felt I could see something that nobody else could see, that in some ways I was specially connected to something […] some spiritual connection, some sort of connection to something that nobody else had, I felt special like I was one step ahead of everyone. (Happi).

When Happi says "in a way," this gives the impression that she is not completely certain of what she is saying, or that what she is saying is true in all respects. This therefore reduces the force of her statement now, which may indicate that she is in a different place of believing.

Additionally, although there is passivity on her part, it is as if this special spiritual connection empowered her, giving her agency, or a competitive advantage over others.

Like Happi above, Randy experienced himself as having elevated and extra-sensory perceptions:

> all my senses were heightened. I could smell more-, I could smell better. That's the thing. So yeah my hearing and my sense of smell got really heightened. […] I would

> hear some things on TV, […] The news was carried in between special messages, which only I could hear. (Randy).

Due to his heightened sensory improvements, there is a sense of both quantitative and qualitative improvements in his sense of smell. In addition, his sense of hearing sharpened, he was the chosen one hearing these messages, which makes him both special and isolated in his experience.

Randy's superhuman abilities continue with him experiencing himself as a message decoder, raising him a step above others:

> I was aware enough sometimes to know that it was all nonsense what was being said on TV, because I knew- because I know that I knew what type of program it was. […] it was all maybe, maybe, it was something that I thought I'd had in the past or something I knew what it was and it wasn't completely strange and alien so to speak. And it was- I could understand it that way, because it was all meant for me. (Randy).

Randy appears to have added abilities as his superhuman senses enabled him to realise that the messages were especially meant for him. His use of the word alien when in this parallel reality perhaps gives the sense that he felt like he belonged and was not an alien there, and was not an alien in this world either. There is also a sense of déjà vu, a feeling of having experienced this before, when he says, "maybe, it was something that I thought I'd had in the past." This gives the sense of in betweenness, where he had one foot in each world, one in the world of familiar TV programmes and that of special messages.

Happi shared a similar experience, where being privileged to see what others could not see, there is a sense that she was ahead of others, and saw things for what they really were:

> I could see flaws in the reports …. […] Like when they were making it like they were reporting news from Scotland, to me it was just a backdrop, […]. Every time the news came on you know it was full of flaws (Happi).

Seeing what others could not see, nothing could be hidden from her, which perhaps empowered her even more. Being able to spot fake news gives the impression that she was better placed to predict situations, and perhaps maintain order in her life. It is as if in this parallel reality, Happi could have the sense of importance and order that she lacked in her real life.

In terms of being special, Fatimah felt like she had been elevated to a Goddess state as she was directly interacting with, and being wanted by a Demigod for a romantic partner:

> He {her ex-boyfriend} was like a Demigod, very powerful, with so much influence. […] I really loved the idea {of being linked to a Demigod}, I must have felt – I felt like a Demigoddess I guess, I don’t know (she looks down and laughs lightly). (Fatimah).

Fatimah was interacting with her ex-boyfriend who was now, in her world, a Demigod. She was receiving messages directly from the universe that he sent her and was understanding them. It sounds like within the human race there is not much power beyond this, or even equal to this. These experiences were not learnt, she just had them. She says “I felt like a Demigoddess I guess” as if to indicate that she thinks she felt that way but cannot be sure now of how she felt. Looking down and laughing lightly appears to show some embarrassment, perhaps at the fact that she thought this way. The feeling of being special, important and powerful people is one that several of the participants experienced. In this capacity, they interacted with international dignitaries:

> I heard like voices, people talking to me. […] Like the government type. I also saw, you know, people in power. I thought of Donald Trump a few times. […] I mean I it was like I was the British government. (Randy).

While Randy does not make it clear where he was when he heard and saw the “government type” of people talking to him, it sounds like he was somehow in their company. Randy’s sense of importance appears to have given him the idea that he represented the British government, which would make him influential and visible to others, perhaps as he felt unrecognised and invisible in this life.

Due to how special they felt they were, some participants believed they had the power and ability to decode special meanings in seemingly mundane items. Examples included the ability to decode hidden messages from car registrations and street markings:

> It’s who they were as people- you know, ‘it’s a very important person in that car’, […] it just read back to me as ‘you know they’re police, they’re this important person, they’re that’, you know. […] I had to think about what car number plates meant, I thought they all meant something, the letters of the number plates translated something to me. (Happi).

> every street sign was a message to me. […] Every car number plate was a message to me. To me the whole thing was orchestrated like a theatre (Fatimah).

Both Happi and Fatimah’s experiences of being able to decipher hidden meanings from day to day items sounds like it made their lives very busy, perhaps more so for Fatimah as she sensed the messages were especially meant for her, and she therefore perhaps had the responsibility to decipher them all.

Being able to perceive important people in unmarked cars, without even seeing them or being introduced to them perhaps shows how special and important Happi felt she was, especially since no one else around her could tell who was in what car, or what the meanings of car registrations were. It also creates a world laden with meaning, where everything becomes meaningful, perhaps to compensate for a life that had started to be meaningless for her.

Being as special as the participants felt they were, it appears they experienced certain other people as having a desire to learn more about them. To this effect, the participants experienced their day-to-day activities within their homes and how they behaved or interacted within their environments as being monitored and recorded, perhaps so that certain insights about them could be gleaned, or studied, or identified. It was as if they were wanted for something, by someone, they were being followed, and tracked. This is what made them persons of interest:

> I thought my video recorder was videoing me, the TV video recorder […] I thought the Blackbox, I thought someone's watching me on that. I also thought people were watching me in the street and following me. (Sharon).

> I started thinking that I was being followed by satellites; that I was getting messages from the TV and the radio even car number plates I was reading, everything had double meaning […] I thought all my conversations were recorded and analysed (Fatimah).

Being followed or monitored or recorded all sound like they have elements of intrusion and invasion of privacy, therefore may represent unwanted attention. Having said that, this may indicate the participants' desperate need to be 'seen' perhaps, when they felt overlooked or invisible in their real lives.

One other special experience of being wanted which some of the participants had was that of a fairy tale nature:

> And I thought they {Radio 2 songs} were all chosen by him specially for me. I'd read a lot into the words of the songs like it was personal messages from him to me […] I thought Radio 2 was taken over by him and every song was meant directly for me. (Fatimah).

Having songs dedicated to you is something special for most people, and to have all the songs by the whole of the radio station being special messages sounds even more romantic. Coincidentally, while Fatimah was relishing in this fairy tale-romance involving an ex-boyfriend, her marriage was falling apart, something that appears to have been difficult for her to accept. This alternative world was perhaps an escape, to make her love life easier. It is as if her mind was trying to compensate for what she lacked.

The idea of compensating is seen in Randy's life where it appeared like he lacked control. The ability to be in control, to maintain order in a world that is orderless is taken further when he experiences himself as having the power to control even cosmic activities:

> I felt like I could control, I could control the weather. […] as in if I changed my mood from being- if I could sort of feel, sort of make myself feel happy, I'd then get the sun out, the sun would come out and hide the clouds when the sun came out. And then when - and then when I was -and if I was thinking negatively it would go dark. You know the clouds would come over. (Randy).

There is something magical about Randy's way of thinking, where his emotional state or just his mood would influence such conditions as the weather. There is a sense that Randy had some form of psychic power, or perhaps he felt he had agency over what he was unlikely to objectively control.

3.3.2 “Alonely”: Participants’ desperate need to hide from the terror of being targeted and hunted down

The participants to whom this subordinate theme speak are targeted and hunted down by unspecified entities. Such participants therefore struggle to know who to trust, therefore, to protect themselves, they end up on their own, and outside of everyone else. They are with superhuman powers, yet paradoxically, their power sounds intoxicating yet also horrifying. The idea of being singled out and hunted down has paranoid undertones. They like to be with others but need to be alone to stay safe, giving a sense of forced choice. The participants feel lonely, and the situation is termed “Alonely”.

Sometimes the power that some of the participants felt they had was such that it was omnipotent and God-like, yet also destructive, like in Randy’s case:

> it was like I was I was in control of the world, and I was going to end, to end the world– if I wanted (he looks up, changes the tone of his voice, as he sat up in his chair and raised his shoulders). (Randy).

Randy sounds pleased to have so much power, and as he speaks about it, it is possible that he is even flattered about the destruction he can cause with his power. Judging from the tone of his voice and his shoulder movements and body language, he sounds rather proud to have such power. It is as if he is saying it was up to him to spare the world. While this amount of power makes him special, the destructive nature of the power bestows a sense of responsibility on him when used.

Randy further believed he had caused an earthquake:

> and on the way there I was -I was thinking that I -like an earthquake had happened and I'd caused it from that afternoon when I was spinning and my my fian- when my fiancée was on the telephone. (Randy).

Triggering an earthquake would make Randy responsible for any destruction the earthquake may have caused, possibly creating feelings of guilt.

While it is not always clear why they would be targeted, some participants felt that they were being hunted down. There is both the superiority as well as the victim fragility to their superhuman strength.

> I thought that … maybe the authorities, the authorities were coming to sort of take, like abduct me […] I just had a sense that there was something they may want me for, I don’t know what it was, it was all very unclear. Maybe they also didn’t know why they had been sent for me. (Randy).

There is a lack of clarity about who it was or what the reason for this was when Randy was being hunted. However, what is clear is the mix of grandiosity (it is all preordained as the abductors may not know why they have been sent) and paranoia. Being abducted has something aggressive about it, while the participant has no control over it.

Sharon shared similar experiences too:

> I thought I might be taken somewhere. […] I don't know I just said just overwhelming feeling of being snatched and abducted by somebody. I don't know why. (Sharon).

There appears to be a profound sense insecurity, as if Sharon was constantly at risk of losing her freedom, and perhaps herself.

Additionally, there is a sense of responsibility and perhaps guilt, due to Sharon believing that it was not just herself targeted, but her husband too:

> I was absolutely terrified Martyn {Martyn is Sharon’s husband} was going to get snatched, absolutely petrified that was going to happen. It would seem that the helicopters used to fly over the roof, what I thought was the police, trying to get out to me. (Sharon).

There is a sense that she would be violently taken against her will, and the same would be done for her husband. Sharon mentions her extreme fear that her husband will “get snatched”, where there is a sense of Martyn being grabbed quickly, so that he could not prevent this from happening. During the interview, Sharon spoke of Martyn as her rock, therefore if Martyn was to get snatched, Sharon would lose her main ‘anchor’ to the world, her secure base, which would leave her exposed. In the quote is also a sense of powerlessness and helplessness, which appears to have been a common thread in Sharon's narrative.

Similar to Sharon, Randy shared the sense that his superhero status may have put his family at risk:

> because I thought -I thought he {Randy's father} was angry and like it was like, yeah I was potentially going to cause trouble for myself or for him and the family, with the helicopters and all. (Randy).

While Randy does not elaborate in what way he was going to cause trouble for his father and his family, one gets the impression that him being a targeted person of interest, this may cause his significant others some form of collateral damage, again potentially reflecting a profound sense of responsibility and guilt.

Most participants reported increased perceptive abilities, and for Randy, being a superhero with heightened senses, he could sense how endangered he was, yet remained unable to safeguard himself:

> I'd then hear the helicopters in a movie kind of way in the distance. So it was like everything was closing in on me. […] everything was getting uh, like out of control. I could hear more, more vehicles, and and like I could hear helicopters and everything closing in on me. (Randy).

When he talks of everything "closing in" on him, it is as if he is talking about the symptoms of psychosis were closing in, and that he was getting full-blown psychosis. Being closed in feels suffocating, with nowhere to turn within oneself, therefore one cannot help oneself. Randy repeats "everything" three times, as if he is referring to the extent of his internal experiences getting out of control and the absoluteness of the psychosis controlling his mind.

The idea of being targeted or being seen as a threat did not end in the participants' communities, but extended to mental health centres where the participants should have felt safe:

> I was thinking 'this is a new place, I have not been here before, yet they already have these measures in place'. […] I felt that I could be seen as a potential risk to other

> people even though I hadn't I hadn't-. So the glass that goes up and down {in the mental health’s building waiting room} was to stop me hurting other people. (Randy).

It was as if Randy believed that measures had been put in place to protect others from him, suggesting that perhaps he senses that something about him is dangerous, out of control or that what he senses of others could also reflect his sense that his mind is a danger to himself.

There appears to exist a degree of ambivalence in the attitudes of the participants, on the one hand they are attracted to the idea of being the centre of attention, and on the other hand, they are fearful of attention being directed at them.

For Fatimah, her need for self-preservation was borne out of the sense of threat to the self, which she felt on receiving too many messages from the universe:

> Every time I stepped outside I'd get dizzy, every time I answered the phone to anyone I started feeling dizzy and sick and panicky. I felt I couldn't talk to anyone about it. I had to be away because I felt like I could collapse and die […] It was scary, I felt, I was, it was just alonely time (she mumbles) (Fatimah).

Inasmuch as she appears to have enjoyed her elevated human status, Fatimah was finding this experience overwhelming, with her physical health being negatively affected. As she mumbled, it sounds like she joined the words alone and lonely to say “alonely,” which appears to be a potent way to portray her aloneness and loneliness. The interplay between the superhuman status and the targeted victim status appears to create a special type of aloneness and loneliness. So, it is as if their superhero status is both a gift and a curse.

3.4 Belittled

This superordinate theme captures how the participants’ perceived others as judging them negatively, therefore not treating them as full human beings anymore. As such, they sometimes could not exercise their agency or feel connected. The participants feel like they are lesser people or are lacking that which made them the people they believed they were before FEP. This suggests a shift in their views of the self and of their identity.

The extent of this ‘diminishment’ varies in different participants. When this happens, the participants are ashamed and embarrassed, they doubt themselves, they experience reduced dignity, and self-esteem.

Some participants in this superordinate theme felt isolated at times, however the flavour of their loneliness here is different from that in the “Alonely” subordinate theme discussed earlier in that there is no sense of paranoia or impending doom. They are not actively alienating themselves to stay safe, rather loneliness is a secondary outcome.

3.4.1 “Like I was Defective”

All the participants appear to have felt that FEP caused others to interact with them as if they were directly or indirectly reduced from their former selves, or that their experiences diminished their humanness to some extent. Some participants felt that they were treated in patronising ways even by mental health professionals:

> I felt they {Home Treatment Team} treated me like I was a bit remedial, like ‘here's your pill. Put it in your mouth’ and then they'd stand and watch […]–‘**you can talk to me like an adult you know, I have a mental illness, I am not stupid’**. […] then they would say, ‘we come every day, then we go to two days, then three days and then theeeen …’(she imitates in a slow childlike voice) (Happi).

Describing how she felt the Home Treatment Team treated her like, it was as if she perceived their treatment of her as inferior in some way, or was of a compromised mental capacity. Happi found this patronising, it was as if staff from the Home Treatment Team did not consider her as a full-grown adult. This gives a sense of being disempowered with no rights to privacy, and respect, and there is something humiliating about the treatment. Yet it is as if she cannot do anything about it. When Happi described being spoken to in a childlike voice which she imitated slowly, there is mockery, as if she is repeating how she felt about the Home Treatment Team’s treatment of her. The way she brings the conversation to life was when she spoke in the present tense, emphasizing “**you can talk to me like an adult you know, I have a mental illness, I am not stupid”** as if the memory of this interaction stirred her up.

This sense of being treated as an inferior person was sometimes when participants were interacting with family members too:

> she {Finn’s fiancée} was trying to make me take my medication, and I wouldn't take it. […] And it got to the stage where she was trying to put a pill in my mouth, as if I was a child. (Finn).

Finn appears to feel that his partner treated him like someone who could not make his own decisions about his medications, leaving him feeling like she was infantilising him. When one is treated like a child, or as someone inferior, it is as if the fact that they are adult human beings is not considered or is disrespected.

Other ways in which some participants felt like they were not treated as self-governing human beings was when they were not given adequate information, or when they lacked information that would have allowed them to exercise their right to choose and to make meaningful decisions:

> I think if they had discussed it with me rather than come and what felt like hijack me from my home, so if they had sat with me, adult to adult and explained […] to try and get me to agree to go rather than use a warrant and say ‘you're coming with us now whether you want to or not’. […] the warrant means you have no choice. I would have preferred to have the choice (Fatimah).

When Fatimah was removed from her home, it was as if what she wanted or her opinions did not matter. Fatimah’s language “rather than come and what felt like hijack me from my home” gives the sense that she was forcibly removed from her home without warning, choice or information. It was as if her views did not matter or that they were not needed. As she specifies, she would have wanted to have her voice heard. She felt that she was not treated like the adult she was.

Not having a voice and not being given a choice was also shared by Happi:

> I didn’t want to let them into my house, […] and I said ‘I’m not interested you know […] I don’t want to speak about it I’m not interested I’m not ready to think about it I’m not

> ready to talk about it'. […] so I shut the door on her and next thing errr they barged into my house. (Happi).

Happi's experiences encapsulate how intimidated she appears to have felt when she was suddenly surrounded by strangers, with no choice and no voice. She did not decide to let unnamed people into her home, yet "they barged into my house," a phrase reflecting violent intrusion, portraying her as a passive participant. It is as if she was helpless, powerless, with her autonomy and right to privacy not respected. Her collection of negatives in "I didn't want to let them in", "'I'm not interested," "I don't want to speak," "I'm not ready to think," and "I'm not ready to talk about it'," all speak of someone who was opposed to any type of interaction or engagement at the time, it was as if she shut the world out, an action she completed with the shutting of her door. Fatimah described this situation further: being surrounded by strangers, given no information, and taken to hospital in the company of emergency and law enforcement services, with no prior warning and no explanation given:

> ten minutes later a whole big team of people came into the house, police officers, ambulance crew err five or six of them and one of the ladies, I think a social worker, took me upstairs and said to pack a bag. They put me in an ambulance and took me to an assessment unit. (Fatimah).

Fatimah's use of words like "a whole big team", and the enumeration, convey her sense of being outnumbered as if suffocated even. There is passivity in the actions she had to take, "took me upstairs and said to pack a bag", "They put me in an ambulance and took me to an assessment unit" as if almost forced to do as they wished, without involving her as an adult.

Fatimah's sense of lack of fairness and respect in how she was treated was also shared by Happi:

> Once I'd been what I call reprimanded by the mental health people…getting Sectioned in front of my neighbours ...and put back into my community to deal with it, […] And you can see it being a small neighbourhood you know it becomes a pain. I was refused to join the Community Board, (Happi).

Being reprimanded gives the idea that there was something that she had deliberately done wrong, or that she had been deliberately inappropriate. Happi appears to view the lack of respect with which the mental health people treated her as having influenced how her community later treated her. It was as if the community had been warned to view her as someone to be careful about. Being refused membership of the Community Board suggests she was considered an outsider, someone who did not belong, all this because she had had FEP.

Nevertheless, while being rejected by the community must have been hurtful, when she was then rejected by a friend, someone who should have been understanding and lenient, Happi must have felt betrayed:

> whereas **she judged me** and **didn't want to be my friend anymore**, […] now I just think you know **'f**k off!!'** do you know what I mean? I can't... I really don't have time in my life to... you know **–'you're not so special that I need you in my life'**. I don't need people like that in my life you know. (Happi).

The intensity of Happi's emotions about this betrayal is perhaps emphasised by the tone of her voice and the swearing when she says, "I just think you know **'f**k off'**." Even when she recalls this betrayal by a friend, it is as if her fragmented language reflects how she struggled to put herself across. Happi does not complete her sentences, as if there are unnameable things that come to her mind. It is as if she is talking directly to this friend, when she says, **"you're not so special that I need you in my life**," after which she appears to return to the room and to me.

It is important to mention here that Happi frequently employed swearing as a way of communicating, possibly to relieve her pain, or as her own revenge, to get back at people she felt had wronged her; as well as perhaps to regain a sense of power and control over situations where she felt she had been powerless.

FEP seems to have the effect of causing sufferers to experience embarrassment, or shame; or it somehow stirred up emotions that left the participants feeling unsettled. This was exemplified by Happi who uses an earlier experience when explaining about earlier episode related to FEP:

> I've had to think, other episodes…, I mean when he took me to the GMC he wasn't like a criminal, **…** and he ripped me into shreds … (Happi).

While Happi had not yet experienced psychosis at that time, she references “he ripped me into shreds,” as if the breakdown brought back memories of being vulnerable, victimised and betrayed and the subsequent public humiliation.

Fatimah’s experiences of FEP and its aftermath sound similar to Happi’s “being ripped to shreds”:

> It was very embarrassing, I felt like I had been undressed, like I was defective in some way. […] I just wanted to sink into the ground in shame […] I couldn’t look anyone in the eye. It was like being stripped of all your clothes (she looks down, breaking eye contact with me). (Fatimah).

While she “couldn’t look anyone in the eye,” at the time it was as if there was a parallel process in the room where she broke eye contact with me. Her downward gaze when describing this moment of shame, made me wonder whether by describing this moment she felt that I could somehow see her intimacy or nakedness as the people she was describing had done. Being in the room with her as she said how she felt, one could sense her shame at being undressed and being totally exposed, with the exposure sounding actively violent, “being stripped of all your clothes”. For the Jewish woman she was, and judging from the way she was dressed in the interview, and what I imagine of her culture, she was quite a conservative woman. Her manner of dressing was as if to protect her intimacy. Feeling undressed and revealing her body like that, it must have been unbearably shameful, explaining why she **“**just wanted to sink into the ground in shame**.”**

From what Fatimah says below, there is a sense of total loss, and being utterly devastated:

> It's a disaster because at the moment I'm only getting visitation rights with my daughter. […] I've lost my job for what is err the longest period of time I've ever not worked. I'm about to lose my home. My confidence has taken a huge knock. […]. I’m just a shell of my former self. So yeah, everything that mattered to me is gone. […] it’s like I was stripped to the bone. (Fatimah).

Fatimah’s depiction of her experience of FEP as a disaster does sound catastrophic as she describes social and psychophysiological losses. The sense of being “stripped to the bone” and having nothing left on or with her gives the sense of someone left in absolute and painful nakedness, with the personal attributes that made them who they are lost. Being “just a shell of my former self” implies everything of substance is removed, the person she was is no longer there.

This sense of total loss continues for Fatimah:

> When I was left in the room {at the hospital} and the door was closed behind me and my shoelaces were taken away from me […] they took my cable away. They took everything away (Fatimah).

The sense of having everything taken from you sounds inhuman and dehumanising. Like Fatimah, Happi appears to have experienced similar inhuman treatment at the hands of the Police, after which she viewed this treatment to be fit for criminals or someone who needed to be controlled or was seen as a threat:

> They {the Police} cuffed me, they threw me out of my house, cuffed me- no it was ten officers actually and several stood out of my house with the neighbours watching; they locked down Myborough, errr, CS gassed me, sectioned me brought me here for a week. […] I got 47 bruises from where I've been sectioned. When they came round and CS gassed me I was traumatized by that. I don't want to ever- that traumatized me they affected me. (Happi).

Seeing her local road being locked down, and being treated in what sounds like a brutal way gives the sense Happi was seen as a threat to her community, a threat which needed to be contained. This may have left Happi feeling trapped and vulnerable. The sense of being viewed and treated as unsafe, and as someone who needed to be contained and controlled, appears to have left Happi with lasting effects long after the FEP had subsided as seen when she stated “I was traumatized by that”.

This long lasting effect of trauma is also mentioned by Fatimah:

> It was shocking, scary, I cannot find the right words to describe the experience, the trauma, in either case […] it’s a feeling that's never going to leave me. I’m now worried every time someone knocks on the door. (Fatimah).

Because Happi and Fatimah found themselves hospitalized involuntarily, they felt their free will was stripped away from them, and as such, they felt like they had no options and no power over their day-to-day lives, stuck against their will, like someone imprisoned. As such, being incarcerated for no crime gives the feeling that one's natural rights as a human being are denied.

> Oh, I felt like I was in a prison, it was very - in fact had I been in a prison then I would've had access to a lot more stuff had I been a criminal. I'd have had a better time for a week locked up. (Happi).

> I was now basically a prisoner. That's what I felt like with no control over my life. […] This lack of freedom got to a terrifying new level. […] being somewhere where I didn't want to be, with no ability to leave. (Fatimah).

Being in a psychiatric ward seems to have been experienced as a worse experience than being in a prison, where perhaps individuals have access to better resources or are treated more as humans.

Having been intruded upon, one gets the idea that Happi also viewed the police's behaviour as having exposed her to her neighbourhood, as if they had branded her:

> It was all a big- like someone had shone a spotlight on my house to the neighbourhood and it's a very- it's a little village which is very judgemental. (Happi).

Happi uses an idiom "shone a spotlight" which gives the sense that the Police had exposed her to the neighbourhood. She mentions the size of the village, as if to say that due to its size, everybody knows everybody, creating a higher risk of exposure for her.

Fatimah simply felt violated, not just intruded upon:

> I felt violated, and I had no say, and it was so unfair. I did not like it […] And that was partly why I resented being sectioned as well because it was my thing and they were constantly trying to get information from me and I felt that was an invasion of privacy. (Fatimah).

Fatimah continues to speak about how things were done to her, without her involvement, or her voice, and how her human attributes of choice and autonomy were denied her.

3.4.2 “A Lesser Person”

This subordinate theme is about participants’ feelings of being less than or not as good as others, feeling like one has less value or is lacking in what they can contribute to the world compared to others, and is the result of many different complex interactions. Interestingly, this perception appears to pre-date their experience of FEP, though it seems to have exploded during the psychotic episode.

During the process of FEP, when some participants became aware that something was wrong, they still struggled to openly admit it, believing this would show them to be weak and vulnerable, with Finn appearing to have identified his bottom line, the fear of being “seen as a lesser person.”

> I felt like I didn't deserve it. I felt I didn't deserve that help. […]. I just felt I wasn't worthy. I wasn't worthy of that attention. […] I didn't allow anyone else in because I feared they’d see my vulnerability and maybe see it as like a weak characteristic of myself. […] if that was to be the case, then I'll be I'll be …(looks down) seen as a lesser person. (Finn).

Finn’ sense of undeserving permeates different areas of his life, and affects his way of interacting, needing to hide himself and what he perceives as his shortcomings. The concept of deserving that he mentions is as if some people deserve to be helped while some do not, perhaps depending on their worth. His repetitive use of phrases “I didn't deserve it” and “I wasn't worthy” gives the sense of someone with low self-esteem, and someone who is self- critical and perhaps lacking self-compassion. His downward gaze at the end is as if he is self-conscious, perhaps about all the time I have given him.

Other participants appear to judge themselves unkindly too:

> it makes me cringe to think that I even thought along those lines... […] I shudder, I just can't believe how much I lost reality. […] I’m quite err quite strong minded, strong person- I see myself as – err, and to break like that you know- it’s - a lot of people judge me (Happi).

As if inferring that those who develop mental illness are perhaps weak-minded, Happi appears to feel too awkward to associate herself with the experience, since she views herself as strong-minded, therefore should not have broken down. Her mention of cringing at the thought that her mind broke sounds like she is perhaps ashamed, disgusted, or even revulsed by the thought that she and her mind broke, meaning she became that person who is weak. She also mentions she shudders at the thought of how much she lost reality, giving the sense that she perhaps gets a physical response to this as something she finds unpleasant and triggering. While all along Happi sounded like she perceived herself as judged and treated unfairly by others, she also sounds like she is judging herself unfairly, being self-critical.

Being self-critical is something that was shared by Finn, who saw himself as someone who is not good enough:

> I felt that I was not normal, that I'd let let people down and that sort of self, not self-loathing as such, but just erm was is it worthlessness? I think, I think that’s what it was (Finn).

It is as if Finn has certain expectations of himself, or what he believes others expect of him. He mentions that it was “not self-loathing as such”, which gives the impression that what he feels towards himself is similar to self-loathing but there may also be part of him identifying that what he feels is actually self-loathing but not wishing to admit it in my presence, in case I see him as weak, which is one of his fears as discussed earlier. When he identifies what he feels as “worthlessness” he does not sound sure about it, stating “I think that’s what it was,” sounding like he is not convinced that it was exactly worthlessness, perhaps as a protective move.

Being self-critical seems to be a characteristic within him as he enumerates his other areas of weakness:

> In a way I didn't feel I was good enough, I felt, I didn't feel confident enough in in my lifestyle, in my career, for the man I was. […] So I didn't talk to anyone about it. […] I just thought, Oh, it's just me being immature. I just need to like, again, like I said, ‘Man up, be an adult’. Like, ‘this is what middle-aged men are meant to be like’. (Finn).

Not only will he be letting people in general down, it appears that Finn considered himself as not man-enough. It is as if he feels responsible to uphold certain ways of being as a man and represent men adequately. Additionally, Finn appears to have been feeling that he could not be an adult who could fulfil adult roles.

The socially constructed norms about men that Finn appears to subscribe to appear to be shared by Chris as well, who seems to feel he has to be autonomous all the time:

> It's not the sort of think blokes tell their wives. I didn't want her to see me as a snowflake, I am the husband for Christ's sake. I would expect her to tell me about these things because this is what husbands do, support their wives, not the other way round. I should be able to do all this you know (Chris).

While Chris was in a situation where he needed to accept that he needed support, his beliefs about men appear to get in the way. His use of the slang term "bloke" connotates the stereotypical maleness in terms of superiority. It is as if should he fail to live up to it, then he has failed as a man. His referral to "snowflake" appears to mean that Chris did not wish to be seen as someone who perhaps was fragile, or too emotional, or cracking under pressure, as if this would mean he has failed as a husband. "Snowflake" is also used as a derogatory term to mean someone who cannot survive in extreme social weather.

All the participants perceived themselves as failures because of FEP. This perceived failure was in different domains of life, one of which was the parenting domain:

> I saw myself as someone that had failed. This is how I felt. […] I was finding it really difficult to just be a dad and do dad things if you like, I couldn't take my daughter out places, sort of playing with her, you know, engaging with her, just being a dad. (Finn).

Finn uses the word dad, rather than father, who perhaps relates to their child as a figure of authority, and is related to the child biologically. When he says "just being a dad" it is as if he is considering this as the basic role of a father which he was failing to fulfil. For someone who is a dad, there is a sense of intimacy, of doing fun things together, going beyond what a father does. Finn appears to be judging himself negatively for failing to have the quality of relationship he wants, and perhaps considers that it is horrible that he cannot do that anymore. Perhaps he even feels guilty that he cannot be close to her in that way.

Similarly, with Chris, who has adult children, there seems to be guilt for not being there for them:

> and my son he was stressed out he was doing lots of hours and he was he was struggling a lot and I didn't really get to see him, and of course I couldn’t see my daughter, all of which made me blame myself for not being a good father. (Chris).

Even with his adult children, Chris appears to blame himself for failing to be emotionally available for them. Chris does not observe his behaviour as being what fell short, rather it was the person he was.

Happi’s sense of failure as a mother seems to have had a drastic effect on her, especially since her sense of being was centred around who she was as a mother:

> I felt like a failure as a mum. […] like I failed at my attempt of one thing that I have always been proud of, which is how both my kids have turned out … (Happi).

How her kids had turned out had been the way she appeared to define herself. If this was no longer there, who was she? If she could not see that their behaviour was that of children who have been raised well, then she had failed as a mother.

As symptoms of FEP were subsiding and participants were returning to their day-to-day activities within their communities, it appears that some found it difficult and that the feeling of being lesser people continued:

> I was ashamed to go out, I was ashamed to go shopping, I was ashamed to go anywhere, I couldn’t even drive my own car. I couldn’t even go to the local shop, I couldn’t ‘cause I thought everybody knew about it, that everybody was judging me. (Happi).

Happi appears to be limited in her ability to engage freely in activities within her community. It is as if she is trapped by shame, so much that she appears to view herself as unworthy of even being seen outside. Happi repeats “I was ashamed” and “I couldn’t” three times in the quote above, as if she is stuck or trapped in this bubble of shame. She also uses the absolutes “anywhere” and “everybody,” which perhaps display how she views things, not seeing a middle ground.

If Happi’s confidence has taken a knock, then she is not alone, as other participants struggle with reduced confidence too:

> I am second guessing myself all the time now. I worry that when I am very convinced about something that it may not be true, that it may err, not be- it’s not reality. (Randy).

> Well before that I was a very confident person. […] I don't feel that I have much to contribute to an employer.[…] I feel much more vulnerable now, I doubt myself, I just feel quite fragile. This broke who I thought I was. (Fatimah).

Both Randy and Fatimah identify how their confidence has been affected by FEP so much that they struggle to trust the quality or even robustness of the decisions they make. Randy seems to go a lot further than overall confidence, as he no longer trusts his ability to know what is ‘real’. Also, Fatimah extends this lack of confidence to indicate how even when she thinks about her next career, self-doubt about her abilities and competencies are getting in the way of her concluding her decisions. When she mentioned that “This broke who I thought I was,” there is a sense that she feels she is no longer the same person, perhaps in her autonomy and ability to be herself. It is as if her very identity had been broken by the experiences of FEP.

Similar struggles about reduced self-belief and confidence were voiced by Chris:

> I think I doubt myself very much, my confidence and my ability to be – to sort things out myself…I worry that people will think I am becoming errr… well unwell again, so that worries me. And now I take time to conclude anything. (Chris).

Chris appears to be a lot more cautious about asserting himself now when he has to, for fear that he will be considered to be unwell again. While he has not spoken about his condition as an illness all along, calling it a different kind of stress, or ‘just who he is’, here his mention of “people will think I am becoming errr… well unwell again” gives the impression that to a certain extent he does consider his condition to be an illness. In the whole quote, it is interesting to note that he also struggles to complete his sentences, as if he is no longer trusting his own words.

Considering these viewpoints, it appears that all the participants' global meaning about the self, how they positioned themselves within their world and their families was destroyed by their experience of FEP.

3.5 "Coming Out."

This fifth superordinate theme captures concepts that fall into two threads, where the first is concerned with how the participants take stock as they look back in time, reconsidering their positions and their interactions with others. In the second thread, the participants decide where their experiences of FEP have left them, and how this influences their intra-personal interactions. Strength and vulnerability appear to be finely balanced in negotiating new positions and new relationships with the self and with others. There is a sense that the participants are still meaning making. For most participants, as they are "coming out" of the fog of FEP, it is as if the experience of FEP was some form of private journey, at the end of which they 'came out' only to those they chose.

3.5.1 Being understood and gaining understanding

While some participants still appear to be grappling with the idea that they could get as ill as they did, some reflect on where they now fit in their societies, and on their roles within their families, with what appears to be gratitude and some satisfaction. Losing family members, work colleagues and friends, appears to have enabled some participants to forge a new type of relationship with themselves and their significant others, having reached a different understanding:

> … in a funny sort of way, I don't know if good is the word, but it is a – it was a good thing when it happened, because I don't know what would have happened to me, or others. I gained all this knowledge and understanding all because I had the psychosis you know. […] and my family is more tight, tighter, because of my, you know, of psychosis. (Randy).

This reframing is shared by Sharon, who considers that her relationships with some people changed or were lost, which she is not regretful about, but sounds grateful for, as it left her with those who understood and genuinely cared about her:

> I've been sick- I've never stood as a victim, and a lot of people don't know my history or my past you know. Err and I'm very selective you know I don't see it as a weakness […] People judge, you know, people judge you and they know nothing about you (Happi).

While it is unclear what it is that she does not see as a weakness, it is possible that this is about being selective, or about having had FEP. When she states, "people judge you and they know nothing about you," there is a sense that Happi values it when people take time to know her and treat her as a unique individual. This was apparent when she was an inpatient on a psychiatric ward:

> The bloke who did the dinners would come and ask 'have you eaten' and really being nice. He was the only person that took time out of all the staff {on the psychiatric ward}, he was the one person. I really liked him, and he asked me what I liked. He spoke to me as a human being (Happi).

Being treated humanely, like someone who matters shines through what Happi said about the treatment she received from the dinner man and about her engagements with EIP staff, whom she felt went beyond just doing their jobs:

> They {the EIP staff} have more consideration, and they think of people that they are involved with in the original sense. […] They treat you as an individual and as as somebody with feelings, they're not just going there to tick a box and they know you're different (Happi).

Happi seems to be saying that EIP *staff* **dealt with her humanely***,* not *as a* person suffering with psychosis when she said, "they think of people that they are involved with in the original sense." There is also a sense that she identifies their attention to her as a unique person as an important component of her treatment.

This is something that Fatimah shared too as she made a comparison with those healthcare professionals who had interacted differently with her:

> And unlike all these others, the early intervention people have just been nice, and they talk to me like I am someone who matters, someone with a brain (Fatimah).

While the way EIP interacted with Fatimah seems basic, this appears quite meaningful and well appreciated especially when she felt like she was treated inhumanly by others in earlier interactions. Being treated like someone with a brain may include being involved in decisions to do with her care and treatment. Fatimah gives the impression that the EIP staff interacted with her as an adult.

Being informed and being given a choice is viewed as important during one’s care by most of the participants:

> they {EIP staff} explained my medication, they explained the why, and coming down and coming off it and you know they really genuinely care. I was allowed to have a say about how long I wanted to take the medication. […] I just didn't really understand what I was taking and why, which you know -and it was explained to me by them, about imbalances in my brain and stuff and you know. I wasn't scared to say if I didn’t understand (Happi).

While Happi started taking medication in hospital and on returning home, she appeared to say that the first time she was given information about her medication in a way she understood was by the EIP staff, who took over after her discharge from hospital and from the Home Treatment Team. She appears to say she could openly and honestly discuss with them, without worrying that she would be judged perhaps as lacking in knowledge. She also seems to have enjoyed being involved in decisions about when she could stay on what dose of medication, or when she could come off her medication altogether.

Being given information about her condition involved her as a partner, working with her collaboratively. She appears to be saying that she gained more understanding about her condition by working this way.

Being understood and gaining understanding was something that Randy valued too from his interactions with the EIP staff:

> I suppose knowing that they have -a will have a better understanding of what I'm experiencing, […] Well it's – I can ask questions without worrying they will think I’m crazy. […] That has, it’s helped me to understand what had happened better. (Randy).

Randy appears to be saying that he managed to make sense of his experiences better due to how the EIP staff interacted with him, whereby they engaged with him in a way he felt was non-judgemental.

3.5.2 "It's like I'm… I'm a man, a new man": Participants' sense of development and growth

Generally, participants explained how they gained new perspectives as a result of how the EIP service interacted with them. They observed that there was a shift in their expectations, and they had started to be hopeful about the future. Some observed how the way they reframed their experiences helped them to come to terms with what had happened to them.

Being honest during interactions with others in general was something Finn identified as one of his achievements after his experiences of FEP, as a parallel in how EIP staff interacted with him:

> I'm more open to understanding others, I have the ability to talk to people in a more open way, you know, with more openness, I have no need for pretence, for putting on a front, I can be myself. I don't feel I have to make up make up my person, my persona (Finn).

Finn considers his new identity to be even more authentic. It is interesting to note his repeated his use of the words "more open" and more openness", and the point about not needing to put on a mask, as if needing to emphasise to me what this new authentic 'him' is like.

Similar to Finn above in terms of being open-minded, Happi goes further to explain how getting FEP has made her more insightful and knowledgeable about mental illness, something she did not even realise she lacked before:

> It left me more open minded because as much as I said and believed to have understood mental health, in fact I had no clue about mental health until I experienced it myself. So, it left me more open minded, more aware, and more supportive of anybody with mental health issues. […] I can sit down with anybody and say, 'I know what you mean, I went - I lost it last year'. (Happi).

Like with Finn, there is a repetition in Happi’s speech as she reflects on her newfound open-mindedness, with a repeated use of the word “anybody.”

While some participants who were involuntarily hospitalised felt angry about the process and the fact that they were detained, there appears to be a softening of their attitudes about that as they get further and further on their recovery journey:

> the balance is: I needed to come into hospital, but the way in which I came into hospital, I don't think it was acceptable. I don’t think somebody who is mentally ill like myself has to be treated that way, I’m not a bloody criminal you know. (Happi).

Fatimah expresses similar sentiments, mentioning how being detained and hospitalised involuntarily initially had the opposite effect to what was desired and expected, though improving her situation overall:

> So in hindsight I'm better now. So sectioning me must have been the right thing. But how they went about it, and while I was going through it -it definitely didn't feel helpful as it was much more scary than helpful. It made me retreat even further. (Fatimah).

Besides the newfound inclusiveness and understanding mentioned above, Happi has also become more resilient, and perhaps she is talking about something more than resilience, that she has grown psychologically:

> It made me a stronger person and gave me more knowledge into something I didn’t understand. (Happi).

Another participant that reports benefits from FEP is Sharon who considers FEP as something that helped her to identify her limits, and also acted as a wake-up call:

> I resent that I had to have the psychosis, but I know that I was bound to have it, […] I think pushing myself meant that I did not give myself a break, perhaps that is what caused it, contributed to it, […] I think I am more aware now, I know myself better. I know to listen to my body, and I know, what are they called, early warning signs. [...] I understand now that I can't take on the whole world and I can't fix my brother's battles. (Sharon).

Although Sharon appears to consider it unfortunate that she suffered psychosis, she appears to put things into perspective. She appears to have identified her vulnerabilities and how to deal with them. She now knows to assert herself and prioritise her own needs now, as if FEP was a wake-up call.

Like Sharon, Fatimah identified that, among other things, she now knows how far she can push herself too:

> Well I found my limits. I've discovered how much stress I can and can't take. […], And also now if I do get psychosis again I'll know hard to recognize it. […] I'm a lot less of a perfectionist now. I let things slide more because it's not the end of the world. I think that's a good thing that came out of it. (Fatimah).

All this speaks to her development and growth as a person, as she also knows how far to push her perfectionism. Letting things slide may mean that Fatimah can put things aside without needing to work on them obsessively. Both Fatimah and Happi discuss their ability to identify early warning signs, which speaks of newfound strength and personal growth. There is also a sense of having regained control over something that temporarily shattered their worlds.

This emphasis on personal development and growth is also shared by Finn:

> I have been, that's that's what's changed a lot actually now- is that I don't have that that faffiness, that indecision. So this whole process, that that's what's really helped me this whole process. […] It's like I'm… I'm a man, a new man. (Finn).

Finn emphasises the change he has undergone, by adding “actually,” as if drawing my attention to this. He has become more decisive, perhaps feeling more confident in himself and more trusting of his decisions. He states he is now not just a man, but a new one. This is in sharp contrast to how he had expressed feeling like a failure as a man as shown in subsection 3.4.2 “a lesser person”, becoming a man again would have been an improvement already, but he is a new man.

Not only has he stopped dwelling on options**,** but Finn also identifies that he has become reflective, and there is a sense that he has developed a new sense of internal coherence and wisdom, with improved self-awareness and renewed hope:

> So yeah, it's just made me a more well-rounded person I think, and I don't dwell on the past now so much. … I can reflect on the past but not dwell on it. […] now I'm much

> more like I- I've become the person I've always wanted to be…I'm much more in the present now. (Finn).

There are other fundamental beliefs that appear to have changed too in Finn's life. Throughout his interview, it was clear that being seen as a strong person, a strong man, and an able father was important to him and that he would do everything possible to portray this front even if he did not feel that way inside. After FEP, his take on this appears to have shifted, and he seems to take the view that there is strength in vulnerability:

> I think the belief that that helped me, I think, was just the understanding that it's okay to be weak. It's okay to like show your emotions. […] So yeah, it's okay to be a man, and weak. And through that acknowledgement of weakness comes the strength. (Finn).

Finn appears to be saying that he came to the realisation that as a human being, there are times when one gets vulnerable, and that it is acceptable to show the vulnerability as this is part of being human. There is also a sense that he is realising that being a man and being vulnerable can co-exist.

While Finn makes this realisation and insight, other participants made similar and different insights too:

> I think I needed to check who I was for a while. You know I needed help for a while. I needed it. I don't want to be ashamed to ask for help if I needed it again. […] I won't be ashamed to ask for help, I never never want to go there again. (Happi).

Happi's mention of 'shame for asking for help' as discussed earlier appears to be as a result of her previous judgemental attitude about having others' support. Stating, "I think I needed to check who I was for a while" gives the sense that perhaps she is reflecting back on her FEP, and acknowledging that she was no longer certain who she was for a while as it had lasted a long time before getting the support.

It is striking that with all the devastating effects of FEP, the following appears to be a narrative of regained control as in: if you know what makes you sick, you can prevent it:

> I think when I said about being mentally stronger, I meant I will be able to recover quicker if I was to start being ill again. I am now aware of early signs and symptoms .[…] That puts me in a better place than somebody who is not aware of mental illness, psychosis, because then I can nip it in the bud. I have people who love me, I need to use them for me to understand better when when I am you know, losing the plot […] (Randy).

However, it is also possible that there could be something defensive at play too. It is also as if both Happi and Randy above are sort of taking stock, identifying best way forward, rather than acting alone in the moment.

What seemed to add to most participants' insights is their realisations that FEP can happen to anyone:

> Just the understanding that I you know, it's not just me it's other people who have problems as well. And that was not not relief as such but of course that it's not all about me. (Finn).

> That's when you realise we've all got everyone's got issues in some way, and that it shouldn't have happened to me but it did […] that it can affect anyone. you don't think it will happen to you, but it can happen to anybody. (Sharon).

From both Finn and Sharon's narratives, there appears to be something of a repair of the self going on, a restoration of the participants' self-image as whole, human, and as equals. There is no doubt that the experience of FEP is considered difficult, and many people struggle to accept, own or talk about it.

Together, these themes highlight the devastating effect of FEP on identity in middle-aged individuals, and the lengths to which individuals go as they wrestle with the changes they experience within themselves and how they perceive both their internal and external worlds. The themes also feature the restoration, and in some cases transformation of participants' identities as they interact with the EIP service, which allows them to review their priorities as they develop new perspectives. There is, however, one participant who felt that in spite of his experiences, he continued to be who he was and did not change at any point, although he identified that he had become more reflective and restrained in his approach to what matters in life.

Chapter 5: Discussion

Chapter 3 above attempted to give the reader an insider's perspective into middle-aged individuals' experiences of FEP, their subsequent interactions with healthcare staff and other professionals, and their journey to recovery. The data analysis yielded five superordinate themes and 13 subordinate themes. In this chapter, a summary of the findings will be given first, tying the themes together as an intertwined, complex process that the participants went through. The themes will then be reviewed in detail in light of the existing literature on FEP. From a Counselling Psychologist's perspective, I will discuss such psychological concepts as 'identity,' 'the self,' 'not belonging,' and being 'not good enough,' adhering to the different ways in which these concepts were experienced by or apply to the participants.

The general implications of this study for research and clinical practice will then be reviewed, with special emphasis given to its relevance to Counselling Psychology, and the strengths and limitations of the study will be considered. A final summary and personal reflections will conclude this chapter.

4.1 Overview of the findings: the participants' journey through FEP

FEP was portrayed by all the participants as a journey, one with a beginning, a middle, and an end, corresponding to what are termed the prodromal, the acute and the recovery phases.

During the prodromal phase, the duration of which varied from one individual to the other, participants reported protracted periods of intense stress in their workplaces, their families, or within their social lives. Some felt they were expected to perform or behave in certain ways, which they experienced as pressuring for them.

All participants described how they then started noticing a gradual reduction of their trust in others, especially at work and in their homes, doubting themselves as well, and realising how hard it was to optimally perform their activities of daily living. Eventually they found themselves withdrawing from society. While they felt that something was not right, they could not clearly comprehend it, or articulate what it was, as they did not associate their gradually intensifying symptoms to FEP. They therefore did not initiate contact with healthcare professionals or discuss their symptoms with their significant others. As symptoms gradually intensified, they noticed that they started to feel like strangers to themselves and within their surroundings. They also started to lose control of different aspects of their lives. When they started to realise that the symptoms they were experiencing were those of a psychotic breakdown, most describe experiencing a feeling of being lost, losing hope and being in what seemed to be a "nightmare." They reached their 'breaking points' at different times, and once this point was reached, they found themselves in alternative worlds with alternative realities. In this alternative realm, some perceived themselves as having superhuman powers, with exceptional abilities and extrasensory perceptions. Some felt that their superhuman status was causing them to be targeted and hunted down, while others felt that their superhuman powers caused destruction. This left such participants feeling like they had to hide themselves to stay safe. Being so different to the rest of the population made them outsiders, while some felt like outsiders as a result of feeling inadequate or being unfairly singled out. Consequently, they all felt socially isolated, and even alienated because of these experiences.

All participants described feeling like failures in their roles as parents, while some expressed feelings of failure just as humans. Some explained how they had to put on a mask or pretend so that others would not see their inadequacies, with some expressing profound shame. There was a sense of hopelessness, helplessness and loss of self.

When first seen by healthcare professionals, all participants initially denied that what they were experiencing were symptoms of psychosis. Those who had to go into hospital involuntarily under the Mental Health Act described that they were interacted with by social workers, the Police and acute care professionals in demeaning ways, which left them with feelings of powerlessness and lacking a voice. Some explained that they felt that they had been infantilised, while some felt they had been treated like criminals or in inhumane ways.

Even after beginning treatment, some continued to feel that the person they were was not their usual self, with some eventually accepting and finding relief in the diagnosis of FEP as it helped them to understand their unfamiliar experiences, while some continued to wrestle with this diagnosis. During their interactions with the EIP service, they started to make sense of their experiences in ways that enabled an understanding of what they had gone through. Many of them experienced their interactions with the EIP service as empowering, and as a form of partnership that supported them to find their voice and enabled them to exercise their agency. However, one of the participants viewed interactions with the EIP service as unwanted, explaining how his experiences and subsequent behaviours were a normal reaction in response to the severity of the stress he had undergone, rather than being symptoms of FEP. He viewed others' responses towards him, including healthcare professionals as unjustified, and poised to position him as different.

As participants started to regain control, practicing their agency and consolidating their lives, they reported experiencing symptom relief, re-establishing their social roles and reconnecting with their worlds. Many of the participants explained that when they looked backed at the persons they used to be even before the onset of FEP, they could see that they had become stronger, wiser, more tolerant, more understanding, good decision makers with "no faffing about," and were now all rounded persons. While some of them identified an ongoing vulnerability and fragility as a result of FEP, they still considered themselves to be in situations that enabled them to beat the condition, should they get it again, and overall, they considered themselves better for having had FEP.

4.2 "My Worst Nightmare"

In this theme, the main finding is about all the participants experiencing themselves as struggling to find meaning, wondering whether their experiences are real or not, and losing control, as if they were in a nightmare. Initially, they experienced symptoms that they had never experienced before, being unable to clearly make sense of or communicate what was wrong, lacking the awareness that they were experiencing something treatable.

4.2.1 "Too Much"

All the participants identified and described in great detail how, during the time leading up to them developing acute symptoms of FEP, they experienced unprecedented levels of stress. Time-sensitive deadlines and expectations (perceived or real) from themselves or from others added pressure onto their stress. Participants experienced gradual mood and emotional changes, and disruptions in cognitive processes related to perception, attention, recollection or decision-making, without having the awareness that what they were experiencing was the onset of FEP. This is understandable, because while they may cause psychological distress, on their own these symptoms do not constitute psychosis. Bay and colleagues (2016), Connell et al. (2015) and Hansen et al. (2018) reported similar findings where participants experienced non-specific symptoms and the sense that something is wrong, without being clear what it was they were experiencing, during the prodromal phase in individuals with early onset FEP.

In line with Bay and colleagues' (2016) findings, some of the participants in my study had difficulties explaining their symptoms to others. Participants' failure to realise that what they were experiencing was something treatable is echoed in studies focusing on early onset, with symptoms in adolescents being associated with the normal developments noticed in puberty. Freeman and Garety et al. (2000) identified non-specific emotional and cognitive symptoms as being among the most prominent symptoms at the onset of FEP.

The participants' detachment from their immediate surroundings, leading to being isolated and alone in their experiences, appears to lead to feelings of alienation[20], a feeling that appeared to continue throughout the process of FEP as will be described

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[20] Alienation as a general concept is described by Jaeggi and colleagues (2014), where individuals feel estranged from society and sometimes from their authentic selves.

in more detail in sections 4.3 and 4.4. Similar results are echoed in Quin and colleagues' (2009) theme of the heaviness of being alone in individuals with very late onset FEP as detailed in Chapter 1.

All the participants experienced loss of control over their lives as their symptoms intensified with the increase in life's challenges. Life's challenges and biological factors have been identified as significant factors in the development of psychosis (see Gispen-de Wied, 2000; Gispen-de Wied & Jansen, 2002). This is reminiscent of Zubin and Spring's (1977) stress-vulnerability model (Figure 1.4), that, confronted with enough stress in their lives, everybody would experience psychological difficulty.

4.2.2 "Petrified": The lack of agency

As participants' symptoms were intensifying, they got to a stage where they felt unable to physically do anything, as if they were paralysed, frozen, turned to stone even, with some identifying how time passed them by without their awareness, while others felt like they were standing still. Some participants experienced reduced emotions, and there was reduced spontaneity in some. Lack of motivation, being apathetic, and lacking spontaneity are common negative symptoms observed in psychosis and psychotic disorders (Foussias & Remington, 2010). Being petrified into inaction was expressed by some participants in ways that made it difficult to know whether it was their choice to not do anything, or that they felt unable to do anything. It is as if they themselves were also unsure about their agency over their actions and inactions. This shifting between agency and lack of it permeated all participants' narratives, and is similar to Harris et al.'s (2012) findings, as detailed in Chapter 1. This is also in line with Jones and colleagues' (2016) findings in their investigation of participants' experience of agency in FEP where they reported multiple ways in which participants experienced their own agency.

4.2.3 "A Shock and a Half"

The participants sense that something was not right within themselves or their worlds, is similar to those of Hansen et al.'s (2018) and Boydell and colleagues' (2010), where, at the onset of FEP, the participants in both reviews described an increasing sense of unease, a feeling that “something is wrong,” without knowing what it was as the symptoms were vague. Connell and colleagues (2015) reported similar results as well, with participants feeling a strong sense of something being wrong with themselves and their surroundings as detailed in Chapter 1.

Some participants’ minds become unfamiliar to them, and there is confusion between what is real and what is not, resulting in disorientation which left them feeling alienated from themselves and from their environments. Similar feelings of estrangement from self and surroundings were reported by Connell and colleagues (2015) in their study to explore factors associated with the experience of early onset FEP.

Realising what their symptoms signified pushed participants beyond shock, where it became “a shock and a half.” In this study, realising what was happening as passive observers was surprising for participants as they were used to reacting to situations. This led to participants’ struggles to find meaning in things, leaving them with a sense of misunderstanding, and being misunderstood.

4.2.4 Becoming Untethered

All participants reported that they experienced people they knew, and everything around them, including themselves, as different, strange, or questionable, therefore difficult to trust. Failing to trust themselves and others compromises how individuals position themselves and function within their societies, especially since trust is a crucial component needed for social interactions. This reduced trust in these findings is in line with Lemmers-Jansen et al.’s (2019) report where they explored what helped to build trust in individuals with FEP.

During the acute phase of FEP in this research study, as the participants experienced their world as strange and unfamiliar, with their usual understanding of reality contradicting their prior beliefs about themselves, others and the world; they felt threatened and ungrounded. Lacking a sense of space and time, they also felt they had lost part of their humanity. This experience of being disconnected from a shared world and being ungrounded is reported elsewhere in literature, where Zafran and colleagues (2017) described how their participants with early onset FEP appeared to experience a disconnect from a shared world, giving the sense of being untethered from their daily rhythm, and of not being part of their world. It is as if they were thrown into stuckness, experiencing time as being slowed or static. This closely related concept of frozen temporality was explained in subsection 4.2.2, indicating how this sense of becoming untethered is closely intertwined with these earlier themes. Feelings of being untethered gave participants a profound sense of aloneness and isolation, a sense of existential separateness not only from others, but from themselves. Additionally, feeling unable to relate to others in your own specie speaks of difference, and perhaps inferiority. Feeling unable to trust and to be disconnected from others in those with FEP sounds to be paranoid in nature. Paranoia, a disconnect with reality, and impaired reality testing are all reported to be central elements of psychosis (APA, 2013; Mangalore & Knapp, 2007; Nuno et al., 2019).

The implications all this had on participants' sense of self will be discussed in more detail in section 4.5.

4.2.5 "I lost it, lost it completely"

After reaching their breaking points, all the participants describe entering a different realm, which they refer to in different ways, such as 'breakdown,' 'a different type of stress', 'an episode,' La-la land or 'just psychosis.' Even after this happened, all participants described how they could not articulate their experience in a coherent manner, as if it was unwordable or indescribable. Their accounts became hesitant, fragmented and chaotic, their speech muddled, and their narratives became difficult to follow.

When participants lost it, they also felt they lost their voices, and that their choices were limited or taken from them. No longer being in control of anything left them feeling desperate and hopeless, in a world where everything seemed meaningless. One of the participants felt that there was nothing left to live for, resulting in her making an attempt to take her own life.

While none of the qualitative literature on FEP reviewed in Chapter 1 reported similar results around sufferers' failure to articulate themselves during a psychotic breakdown, a presentation where thinking is disorganised, illogical, or incoherent are reported as negative symptoms of psychosis (APA, 2013; Mangalore & Knapp, 2007; Nuno et al., 2019). Additionally, as explained in Chapter 1, FEP is associated with high rates of suicidal ideation, with the risk of suicide being exceptionally high during the first year of FEP (Saraceno, 2001; Tarrier et al., 2007).

4.3 "Not Myself"

As all the participants attempted to make sense of what they recognised as a disconnect in themselves, some of them expressed their ways of interacting and relating with their minds in a manner that seemed to indicate that they considered their minds to be separately functioning from their 'selves.'

4.3.1 "My Crazy Mind" and the self

Participants reported experiencing a variety of deviations from how they usually experienced themselves and how they carried themselves around others, from the moment they started to realise that something was wrong, to when they lost touch with reality. They experienced themselves as "strange," not like their usual selves. This resulted in changes in how they interacted, on their own and with others, and in temporary changes in identity. Similar results are reported by Conneely et al. (2021) in their systematic review about understanding identity changes in psychosis, with some views considering identity change to be an essential path to recovery.

Considering their minds to be separate entities to their selves, it was as if some participants believed that one of the entities could leave the other and each can function independently, or the entities could work together as an integrated system. Where entities are functioning separately, the situation is not considered to be harmonious, where the self feels lost without the mind. These views about the separateness of the mind and the self echo McGrath's (1984) account where she, as a person with a psychotic disorder, grapples with the separateness of the different parts of herself in times when she is in the acute phase of her condition, which she seems unable to grasp or understand, and she feels like she has moments where she has lost herself.

During the acute phase for individuals suffering with FEP, the self is experienced as strange, and therefore unfamiliar, especially since the individual has not had this experience before. This morbid self-experience is such that the individuals sometimes wish to keep a distance to their altered self, as portrayed by statements such as "because I'm not like that person," (Finn, page 28, line 32); or through the conditional "as if" statements, such as "It is as if I was someone else," (Finn, page 28, line 11). In some individuals, there appears to be ambivalence as seen in statements like "I can't believe I broke, that my mind broke" (Happi, page 5, line 16). In their paper where they presented the phenomenological manifestations of unusual experiences identified in the prodromal phases of psychotic conditions, Parnas and Handest (2003) made similar observations where the self is considered to possess a mental reality of its own.

From the narratives of participants in this study, it appears that the participants related differently to their minds. The sense of separateness or distancing of the mind from the self is as if participants recognised uncomfortable shifts in their identities. FEP has been reported to have a dramatic effect on participants' sense of self and identity, where they perceive that the person they used to be is no longer there (Conneely et al., 2021). This idea of identity shift was repeatedly expressed by participants, all the way from the onset of FEP, through to being a 'Person of Interest' to feeling 'Belittled.' Ben-David and Kealy (2020) report how important it is for sufferers to restore their identities during the process of recovery from FEP. Similarly, Boydell and colleagues' (2010) GSP called "achieving identity," is about how participants experienced the loss of self, often withdrawing from social interactions, and how important it was for them to restore their identities during the "achieving identity" GSP. Overall, the present findings suggest that FEP causes difficulties in preservation of identity. Additionally, individuals experienced disruption to their sense of self continuity, even at the beginning of psychosis. These findings about loss of identity are similar to those reported by Ben-David and Kealey, (2020), Connell et al. (2015), Lester et al. (2011), Tan et al. (2014), and Windell et al. (2012) in their studies about early-onset FEP.

Still, some participants in this study experienced identity changes that they associated with growth and intrapersonal transformation. This process of identity restoration is discussed in more detail in the theme “Coming Out” in section 4.6.

4.3.2 Wrestling

While some participants accepted the diagnosis of FEP with a sense of relief, some appeared to wrestle with the idea. The dilemma of diagnosis, where on one hand the diagnosis helps individuals to make sense of their experiences, while also potentially running the risk of being stigmatised was reported by Hansen and colleagues (2018). The struggle to fully own the experience of FEP was evidenced by the ways participants grappled with what they had gone through and what they were still dealing with. These ways of wrestling and rejecting FEP include denial, minimising, pretence, masking, acting, normalising, rationalising, and sometimes using euphemisms for their experiences of FEP. Similar results were reported by Jansen and colleagues (2018), where the fear of stigma and the fear of the psychiatric system resulted in some individuals with early-onset FEP rejected that they had FEP by normalising or rationalising their symptoms.

The internal conflict, and the continued struggle to own the experience of FEP fully, results in some participants pretending to be well, or hiding their symptoms so that others did not see their suffering. Griffiths et al (2019) reported how participants’ awareness of the society’s stigma about psychiatric problems resulted in participants hiding their “true” identity to maintain social acceptance.

In this study, sometimes participants’ inner conflict showed up as a reluctance to take medication. Denial of having FEP was discussed by Gerretsen et al. (2015), where they linked this with impaired illness awareness in individuals with schizophrenia. This impaired awareness of having a treatable condition, also termed lack of insight, was said to lead to poor medication compliance. According to Echebarría and colleagues’ (2010) review of the main factors that contribute to lack of insight in FEP sufferers, denial of their psychotic symptoms or of having psychosis is reported as a coping mechanism related to reduced insight.

4.4 Person of Interest

4.4.1 Superhuman

Several of the participants experienced themselves as having special powers and abilities that enabled them to maintain a sense of superiority over others, putting them ahead in different situations. These experiences of exceptionality have been identified as grandiose delusional beliefs, a form of positive symptoms of FEP and other psychotic disorders. Bortolon and colleagues (2019) define delusions of grandeur as false beliefs about possessing an inflated worth, or a special identity, all strongly maintained even with indisputable proof to the contrary. Delusions are a well known positive symptom of FEP (APA, 2013; Arciniegas, 2015; Mangalore & Knapp, 2007; Nuno et al., 2019).

In the present study, the grandiose beliefs appeared to give the participants such statuses as they perhaps lacked but longed for in their real lives. I understood from their narratives that they felt powerless, invisible, unloved, victimised, or simply not good enough, as depicted by the following “I wanted to be appreciated and understood and loved and cared for, but I wasn't getting it, and I wasn’t portraying that as I saw that as a weakness,” (Randy, page 34, lines 8-9). Their grandiose delusional beliefs may have counteracted this to some extent, thereby giving them a sense of security and importance.

For some participants, their superhuman status enabled them to maintain some order in a world that seemed chaotic, and as they could predict and control situations, this gave them a sense of control. Where the participants read meaning and made sense of situations that others considered mundane, denying themselves opportunities to consider explanations that may have been more rational, they seemed to fall prey to cognitive bias, something also documented in Dudley and colleagues’ (2013) meta-analysis about decision making in individuals with nonaffective psychosis. Dudley et al.’s (2015) meta-analysis concluded that people with nonaffective psychosis need less evidence to make decisions than controls, including making more extreme decisions, a phenomenon he called jumping to conclusions. While we all jump to conclusions sometimes without having psychosis, in the case of FEP, this is in the form of jumping to extreme conclusions. This JTC thinking style was also described by other researchers as explained in Chapter 1 (see Beck, 1976; Dudley et al., 2013; Huq et al., 1988).

In this study, one participant identified her superhuman connection as spiritual, which perhaps gave her agency. This finding is related to that of de Wet and colleagues' (2015), and that of Quin et al.'s (2009), where it was considered that religious faith and spiritual forces are crucial to most participants' coping, with some participants considering these forces to be even more important than medications in building resilience.

4.4.2 "Alonely": Participants' desperate need to hide from the terror of being targeted and hunted down

Some of the participants who experienced grandiose delusional beliefs also viewed their superpower as having a destructive element to it. They therefore feared that due to their destructive powers, they had inadvertently put members of the public in danger, or their families, perhaps by association. In their mind this had resulted in others targeting them, while other participants just felt targeted for no reason they could identify. Such persecutory beliefs are explained by Bentall et al.'s (2001) cognitive model of psychosis, where the delusions are described a form of psychological defence against such underlying emotions as low self-worth and low self-esteem. Additionally, the distress from being targeted echoes what is explained in subsection 1.6.2 by Freeman and Garety (2000), as central concerns for individuals with persecutory delusions. In the current study, the perceived victim fragility had paranoid undertones and elements of guilt. These paranoid and persecutory delusions in individuals with late-onset FEP are also reported by Howard et al. (2000), and Wynn Own and Castle (1999). As seen in Chapter 1, similar persecutory beliefs were reported by Quin and colleagues (2009). Freeman et al. (2016) reported that over 70% of individuals presenting with a FEP have a persecutory delusion.

4.5 Belittled

All the participants perceived that others interacted with them as if they considered them to be reduced from their former selves due to having FEP. Participants perceived themselves to be unfavourably judged, controlled, or dealt with in ways that were disrespectful, infantilising, belittling or dehumanising. They also perceived themselves to be less than or inferior to others, when they looked through others' eyes as well as through their own.

4.5.1 "Like I was Defective"

Reports about being treated in patronising ways even by mental health professionals, as well as by their significant others resulted in participants sometimes getting the sense that they were inferior persons. Sometimes feeling like they were infantilised by professionals or by family members especially around their treatment and decision-making are findings reported by other researchers. In their study with individuals experiencing early-onset FEP, where individuals described what they went through and how they understood their relationships with their families, and how they related to their recovery, Boden-Stuart and colleagues (2021) reported individuals initially feeling infantilised by family members. For the participants that went into hospital under the Mental Health Act ("legislation.gov.uk," 2007), there was the perception of a lack of control and a sense of powerlessness, even helplessness. How participants were treated, especially by Police was reported to have caused trauma in the participants, especially due to how the Police used force. The finding about trauma experienced as a result of involuntary admission practices involving the Police is in line with what was reported by Gorrell et al. (2004) in their audit of treatment for individuals receiving treatment for FEP in the mainstream services, before introduction of EIP services. Sentiments of being hijacked from their homes, or of being treated as if they were less than humans, especially when acutely unwell and treated in psychiatric hospitals, where individuals feel humiliated can leave individuals feeling discouraged and hopeless. This is observed and reported by Deegan (1990) when she discussed how human services sometimes dehumanise and depersonalise sufferers who receive services. In her paper, Deegan described how helping professions have, in some cases, been responsible for breaking the spirits of those they are supposed to empower and give hope.

Like Jansen et al.'s (2018) finding about participants' stigma and fear of the psychiatric systems, some participants in this study expressed their fears in quite some vivid ways with one explaining, "I had these images of being locked up and being, you know, sort of put away forever in a straight-jacket or something like that." Finn, page 8, lines 8-9) implies total loss of control and hope.

To the author's knowledge, these experiences of feeling infantilised or dehumanised have not been reported in previous literature on late-onset FEP.

Even where interactions with others were not violent or aggressive, the rest of the participants described themselves in ways indicating that they perceived themselves as deficient in the eyes of others, with obvious impact on their self-esteem. FEP thus left them with an unfavourable identity and reinforced participants' sense of exclusion from their communities, and their social isolation.

Where participants felt that they were treated as if they were defective in some ways, they were also left with a deep sense of shame. Shame was also core to the participants' experience of themselves away from social interactions, as discussed in the next sub-section. Some participants appear to be limited in their ability to engage freely in activities within their communities. It is as if they are trapped by shame and view themselves as unworthy of even being seen outside their homes. This experience of FEP had serious implications. At some point on their FEP journey, several participants struggled to fully engage with their social world. In their systematic review of studies about FEP and sources of distress, Griffiths et al. (2019) explain how an altered sense of self may act as an obstacle for how individuals engage in social and recreational activities they value. Miller and Mason (2005) explain how individuals societal ideals and values as well as stereotypes perpetuated by the media may be internalised by individuals, therefore when one gets FEP, the internalised stigma may be accompanied by feelings of shame and guilt.

4.5.3 "A Lesser Person"

On an intrapersonal level, the participants saw themselves as lesser people. All expressed how they felt either less than or not as good as others in areas such as their contributions to the world, their positions within their families, and more generally. They not only felt harshly judged by others, as explored earlier, they also seemed to judge themselves in the same way, resulting in a pervasive sense of shame, related to disruption of the self.

While none of the participants in this study mentioned the word 'stigma', all participants perceived that they were treated as an 'other,' or excluded due to being seen as not belonging. Sometimes this idea of being seen as different was also perceived from mental health professionals.

In line with Harris and colleagues' (2012) and de Wet et al.'s (2015) findings about self-stigma, where participants appeared to have harboured negative perceptions about psychosis, some participants in the current study did not feel comfortable being identified as having had FEP; they did not even want to be associated with people on a psychiatric unit, as indicated here: "I kept saying I don't know what I'm doing here. I don't belong here. I don't want to be around these people," (Fatimah, page 14, lines 25-26). Some feared returning to work and having to explain that they had been off work due to FEP. There was also a sense of guilt associated with failing to satisfy different roles.

Looking back on their journey before their recovery, even where the participants did not consider that they had been directly belittled by others, they nonetheless experienced themselves as diminished due to having FEP, using dramatic expressions such as "ripped to shreds" (Happi, page 7, line 34) and "stripped to the bone" (Fatimah, page 7, line 14). Some no longer trusted the robustness of their decisions, and reported feeling more vulnerable. Some doubted they would have much to contribute to future employers. These findings are in line with those of Connell and colleagues (2015), Hansen and colleagues (2018), and those of Sandhu et al. (2013), where participants were reported to have a sense of ongoing vulnerability related to the fear of relapse after FEP.

4.6 “Coming Out”

As participants looked back in time as they came to the end of their FEP journey, reflecting on their intra and interpersonal interactions, they attempted to understand how their strengths and vulnerabilities were balanced. This in turn allowed them to negotiate new relationships with themselves and with others. Several participants negotiated this process with what appeared to be gratitude and some satisfaction, identifying how to reposition themselves in their families and communities.

4.6.1 Being understood and gaining understanding

Five of the participants in the current study were initially relieved to have their experiences named. It meant that this was a known condition, and that they were going to receive a treatment; it also meant that they were not alone as there was a known team associated with their condition.

Although the participants identified different losses that they had to contend with due to FEP, all of them reframed their experiences, with many identifying how their experiences left them in a better place than they had been before becoming unwell. Interestingly, the way all except one explained their understanding of their experiences of FEP appeared to have been influenced by the biomedical way of conceptualising FEP.

All of them identified as helpful their interactions with some healthcare professionals, where they were treated humanely and as partners, being involved in decisions about their care and treatment rather than being patronised or partenalised. Having open and honest relationships with EIP staff, without worrying about being judged for lacking in knowledge; being given a voice; and working collaboratively with the staff were all supportive of identity recovery. These findings are in line with those of Boydell et al. (2010) and Hansen et al. (2018), where participants identified that gaining identity as well as being treated humanely had a considerable influence on their recovery, more so when they experienced their relationships with professionals as a partnership.

Being understood and gaining more understanding about their condition and their experiences of FEP enabled several of the participants to make better sense of their experiences during interactions with the EIP staff. They identified the EIP service's non-judgemental stance as having enabled them to express themselves in open and honest ways, where the risk of being seen as ignorant was minimised. These gains from interpersonal interactions benefitted them intrapersonally as will be explained in more detail in the next subsection. These results are similar to Harris and colleagues' (2012) findings about how participants made sense of FEP and how their engagement with the EIP service influenced this understanding. Additionally, understanding there were others out there who had overcome their FEP, normalised their experiences and instilled a sense of hope. Moreover, this helped the participants re-identify with the general public, realising that FEP can affect anyone. These results echo those of Boydell and colleagues (2010), where participants identified that during their engagement with EIP service, their experiences of FEP had been validated and not dismissed, resulting in them feeling they were worthy, as they were listened to and were included in decision-making. This helped restore their self-esteem, and enabled them to find meaning in their situations, another step recognised as essential in recovery.

Participants also reported becoming more understanding towards others, and interacted more openly with others, without feeling the need to pretend or put on a mask. Participants further felt they had become more tolerant of difference.

Last, their experiences with EIP service provided some participants with an opportunity to review their lifestyle, findings that are consistent with those of Boydell and colleagues (2010) and of Quin et al. (2009).

4.6.2 "It's like I'm… I'm a man, a new man": Participants' sense of development and growth

Those participants who lost relationships with some family members, work colleagues and friends, identified that some of their relationships also strengthened, which allowed them to realise who genuinely mattered in their lives. This reframing of loss appears to indicate personal growth, self-discovery, and renewed life perspectives. Although some participants resented having FEP and viewed their breakdowns as inevitable, it was as if they were acknowledging their fragility and reframing it in the context of their humanness. This ability to reframe may be an indication of psychological flexibility, or just of a general openness and readiness to consider new perspectives. Both psychological flexibility and openness to new perspectives have been identified as necessary for recovery and psychological well-being, in line with findings identified by Hansen and colleagues (2018).

There is a sense that some participants developed a new sense of internal coherence, while for some, FEP appears to have catalysed the development of their ideal selves. All the participants appeared to have developed a sense of wisdom, improved self-awareness, and renewed hope. Many spoke of being more resilient now they were able to identify their early warning signs and had developed strategies to cope with new symptoms. Realising that they were not alone and that there were other individuals out there who had challenges appeared to have brought about a restoration of the participants' self-image as human beings. Different areas of growth were identified, including self-confidence, compassion for self and for others, more open-mindedness, and empathy for people suffering with mental health issues. Therefore, each in their own ways, the participants appeared to have developed a stronger sense of self, and what seemed to be restored identities. This process of identity restoration was also identified in individuals recovering from early-onset FEP (e.g., Connell et al., 2015; Lester et al., 2011; Windell et al., 2012).

Considering how devastating their experiences of FEP had been, and the losses they had encountered along the way, it is noteworthy that most participants' narratives of where FEP left them were around regained control. This echoes the findings of Bjornestad and colleagues' (2017), Eisenstadt et al. (2012), and Windell et al. (2015) where some participants identified that they could take responsibility, influence their experiences and develop their own strategies to promote recovery, where recovery was seen as symptom relief and the restoration of the self, having regained their sense of autonomy and independence.

Having said that, one participant in this study did not express the same sense of having reconstructed himself in the same way as the rest of them. Nonetheless, at the end of the interview he stated “Well, I’ve become more - I feel that I am more reflective now, I don’t rush to make decisions, which my wife seems to like.” (Chris, page 30, lines 7-8).

Some participants expressed their desire not to be identified as having survived FEP, with one participant directly denying that she was either a victim or a survivor. It seemed as if her recovery had taken her beyond just surviving her experiences, and now she did not wish to have her new identity to be defined by her past. Lee and colleagues (2020) explained how individuals that did not identify themselves as victims or survivors of their past differed from those in the survivor mode who lived with mild depressive symptoms.

Further, while there was evidence of restoration of identity and resilience, some participants indicated they had gone beyond the restoration of their past selves, and that new selves appeared to have emerged (“It’s like I’m… I’m a man, a new man.”) This reminds me of the Kintsukuroi fable of the Japanese (Coffin, 2013), where broken bowls were mended with gold, leaving them looking more beautiful than the original bowls, akin to my participants who appeared to consider themselves ‘to be better individuals for having been broken.’

The emergence of transformed identities also echoes what Tedeschi and Calhoun (2004) termed Post Traumatic Growth (PTG).

> *The individual has not only survived, but has experienced changes that are viewed as important, and that go beyond what was the previous status quo. Posttraumatic growth is not simply a return to baseline-it is an experience of improvement (p.4).*

The findings thus suggested that middle-aged individuals perceive a positive identity shift after FEP, and a transformation akin to PTG. For middle-aged individuals with

FEP, this is a new finding, which is in marked contrast with what has been observed among younger individuals, whose identity changes after FEP were mainly perceived as negative (see Connell et al., 2015; Lester et al., 2011; Windell et al., 2012). Though new for FEP in middle-aged individuals, this finding echoes what has been observed in other studies when people are confronted with major and life-changing illnesses, and is reminiscent with Arthur Frank's (1995) narrative of quest around cancer.

4.7 Contribution and clinical implications

The Department of Health (2014) issued its recommendations about EIP services increasing the age limit to 65 years in order to accommodate individuals with late-onset FEP. Since then, many qualitative research studies have continued to focus on early onset FEP, although it is now understood that late onset FEP is no rare event. It has also been concluded that current EIP services are gender and age inequitable, being skewed towards males and younger individuals (Lappin et al., 2016). To the author's knowledge, the present study is the first to provide an in-depth exploration of middle-aged individuals experiences of FEP.

The novel findings from this study are mainly around agency, control, the self, and identity, concepts that are intertwined in intricate ways as detailed in earlier sections. Therefore, this study fills a gap in the research literature, providing a valuable contribution to the knowledge about experiences of FEP among middle-aged individuals.

The findings from this study highlight the debilitating impact of FEP on the individuals' sense of agency, control, the self and identity. They also show the importance of the restoration of all these after FEP, an area where the experience of middle-aged individuals seemed to differ from that of younger sufferers. Engaging with professionals in the EIP service and reframing their experiences helped the participants to regain control, restore their agency, as they develop a new and valued self, one in which the vulnerabilities revealed by FEP could also bring new strengths.

From a clinical standpoint, this research supports earlier findings regarding the impact of FEP on the lives of individuals and outlines potential areas of intervention during treatment, such as psychoeducation, problem-solving and grounding at the onset of FEP. However, as highlighted both in the analysis and in the discussion chapters, the experience of FEP also raises questions around personal and interpersonal identity, and the related concepts of control, agency, the self as well as those of belonging, stigma, shame, and guilt. Most therapeutic approaches to psychosis focus on symptom reduction and meeting functional goals. Yet in this study, while the participants described their struggles with distressing symptoms, there was further distress from their non-psychotic internal processes, some of which related to interpersonal interactions. Additionally, the participants valued working in partnership to consolidate their agency and to regain control; and to re-establish their selves and their identities. From the findings above, therefore, during treatment, interventions that promote the creation of a new narrative, such as narrative treatment, are recommended here.

It is the author's suggestion that services intervene even earlier, before individuals need the EIP service. To achieve this, a dedicated service could be located within primary care, such as within GP surgeries and have close liaison with EIP services. The role of this service could be to ameliorate symptoms related to the onset of FEP in middle-aged individuals that are observed and assessed to have an 'at risk mental state.'[21] The at risk mental state is often abbreviated ARMS (Fusar-Poli et al., 2012). Currently, the ARMS service is available only to 18 to 35 year-olds, and is located within EIP services, and there is no equivalent service for individuals over 35 years. It is suggested here that the ARMS service for middle-aged individuals be located in primary care for three reasons: firstly, not everyone who has ARMS develops FEP, therefore if treated earlier the number of middle-aged individuals that go on to develop FEP may be reduced as research has shown that individuals with a shorter DUP experience better outcome and may not develop FEP (see McGorry, 2008/2015;

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[21] Characteristically, before the FEP, individuals go through a relatively long period, the prodromal phase, experiencing non-specific symptoms, termed at risk mental state, shortened (ARMS) (Fusar-Poli et al., 2012).

Schooler et al., 2005; Trauelsen et al., 2015). Secondly, as they will be seen during the prodromal stage, those individuals who hold jobs could be supported sooner to stay in their jobs, and this could be done through liaising with Richmond Fellowship for employment support, instead of waiting to support individuals after they develop FEP and need to take time off work (see International First Episode Vocational Recovery Group, & International First Episode Vocational Recovery Group; 2010). Thirdly, placing this service within primary care instead of within the EIP service is likely to reduce potential stigma for middle-aged individuals with ARMS since psychosis is a stigmatised condition; since the individuals would not be treated within EIP service, the risk of stigma by association to psychiatric services would be reduced (see Hansen et al., 2018). While they could be cared for under the GP positioned ARMS service, individuals would receive bibliotherapy and psychological treatment to ameliorate prodromal symptoms (see Ben-David & Kealey, 2020).

To support individuals with FEP, an additional important area to focus on during treatment within the ARMS service, and indeed within EIP services, could be around the restoration of agency, control and identity as all these are critical aspects of the recovery process (see Ben-David & Kealy, 2020; and Boydell et al., 2010). For psychological therapy, EIP services currently offer CBTp and Family Interventions according to NICE guidance (NICE, 2014), therefore working in partnership for the restoration of all these and to re-establish identity could be added to the treatment focus. This could focus on individuals' self-image, interpersonal roles as well as a reconstruction of one's narrative. This would support the reconsolidation of identity for recovering individuals.

The results from this study suggest the need for all services that interact with middle-aged individuals with FEP to do so in a humane way, and to provide meaningful opportunities and resources to support self-reconstruction following FEP. Additionally, there are implications for professionals and policymakers regarding the process of detaining individuals for hospitalisation, as the practices described by some of the participants indicate lack of choice and voice, and behaviours (towards those with FEP) that appear to perpetuate the stigma of mental illness.

4.8 Limitations

This research contributes knowledge in form of subjective experiences about a population that has been less represented in studies. One of the limitations is that, while the sample comprises equal numbers of male and female participants, five of the six participants identified themselves as white, with only one identifying herself as Jewish Israeli. Therefore, this sample is not representative of other ethnicities. It was curious that there had been a poor representation of individuals from other ethnicities within this study, a limitation that had been observed in other studies as reported earlier. Therefore, the researcher decided to review the whole EIP case load that she recruited from as a way to understand some of the possible reasons for the poor representation. It was striking to note that of the 226 service users under this EIP service at the time, only seven were from black and Asian ethnicities, with the rest being of Caucasian ethnicity. This explained in part some of the challenges of recruiting a more ethnically diverse sample from a population that is already underrepresenting these ethnically diverse populations. The sample was also idiosyncratic in other ways, with all participants holding jobs or being self-employed as well as all being in long term relationships at the onset of FEP.

All of the participants for this study were recruited from one EIP service, therefore there is a chance that the sample was skewed towards how this particular EIP service interacts with sufferers. On the other hand, the population from which the participants were drawn was diverse, including from a socio-economic standpoint.

Moreover, while having prospective participants initiate contact with the researcher was meant to empower them, it also required participants to be adequately assertive and confident. Therefore, the participants who were less so may have not volunteered to take part, with the result that their voices were not heard.

It is also worth noting that the interviews were retrospective: the participants were asked to remember, and describe in detail, experiences during a disastrous and extremely distressing time in their past. This may have led to inaccuracies in their recollections and their subsequent descriptions. The impact of this is likely to have been minimal, as the interviews were quite proximal to the individuals' experiences of FEP.

Another possible limitation of this study is that initial contact with the participants was by care coordinators while participants were still under the care of the EIP service. The participants may have therefore felt obliged to participate and they may have unwittingly left out experiences they considered difficult so as not to appear ungrateful. To mitigate this, the researcher clarified in the participant information sheet as well as before the interviews what the confidentiality procedures were.

Lastly, some of the limitations of IPA include its dependence of participants' ability to articulate themselves in such ways that they can clearly communicate their experiences (Willig 2013). To mitigate this, the researcher remained participant-led throughout the interviews and gave them time to add anything they felt they needed to add at the end of the interviews. During the data analysis process, the researcher took special care to attend to the participants' non-verbal communications, expressions and pauses, where they appeared to communicate something that they perhaps could not fully verbalise. Idioms and metaphors were given special attention as additional ways that the participants used to communicate their experiences.

4.9 Quality assurance

IPA places the researcher at the centre in the research process, with data interpretation being dependent on the researcher's sense making. Therefore, the researcher ensured that her interpretations stayed as close to the participants' meanings as possible.

To ensure the rigour of this research, Meyrick's (2006) standards for conducting good qualitative research were utilised as far as was possible. Transparency and systematicity were maintained all the way through. The researcher clearly stated both her epistemological and ontological positions as well as her proximity to the topic and to the data through reflexivity. She identified the research question and the aims of the study, where a robust literature review indicated the rationale the study. Ample information was given for recruitment and sampling of participants. Trustworthiness was achieved by maintaining transparency throughout the data gathering phase where the methods and rationale for gathering data are fully described. Throughout the data analysis process, all the steps followed from data collection to conclusions are clearly stated and explained. In the findings, all the participants' voices are represented, including one participant whose experiences and sense-making appeared different to the other participants'. The researcher closely consulted with her research supervisor throughout the analysis to ensure coherence and reliability of her interpretations, and to explore reflexivity, which helped with analytic rigor and acted as a credibility check. On presenting the findings, rigour was maintained through transparency, where direct quotes were used to ground the themes within the participants' words. To demonstrate the way the data is related to the conclusions, cross referencing was used to demonstrate the link between these two. Since being totally and meaningfully detached from the data is not possible in IPA, reflexive engagement was maintained by the use of reflexivity, in addition to the use of a reflective diary that was kept for the duration of the research process.

4.10 Areas for Future Research

As there are not many studies that have focused on middle-aged individuals with FEP, it would be worth looking at how late-onset FEP is experienced in more diverse samples, such as those with different ethnic groups, as well as individuals in diverse relationship statuses. Furthermore, research into those individuals who have different ways of understanding FEP (i.e., those who do not follow a disease narrative) would add a cultural dimension to the work and enrich our understanding of how more diverse populations experience the condition medically known as FEP.

On a more specific point, as described in section 4.4 both the delusions of grandeur and persecutory delusions are closely related to the JTC bias as explained by Dudley et al. (2015). This JTC bias may be an area of focus during the ARMS treatment interventions, in the hope that modifying it may reduce individuals search for meaning, which is what has been suggested to leads to delusional ideation. This may take the form of qualitative research, with especially those individuals who have the JTC tendency.

4.11 Personal Reflexivity

Throughout this research, I was aware of the way my participants spoke about what they viewed as their inadequacies, their feelings of generally being ‘not good enough,’ and their sense of being different. For me this related back to diversity, and how it could be embraced without making it stick out like something to be embarrassed about. I often thought about how these individual differences could be honoured, especially in the field of Counselling Psychology and in my own role as a Counselling Psychologist in training. My awareness of myself as someone different (yet similar in some ways) to my participants, often led me to wonder how my experiences compared with theirs, bearing in mind that my sense of difference made me feel somewhat special and privileged, especially having bounced back from several personal tragedies and now pursuing my studies at doctoral level.

The experience from this study confirmed to me what I have known about myself for as long as I can remember; that where there appears to be injustice or unfairness, I will look out for those that are being prejudiced against. I have found that doing this research has made me more determined to push for changes, to help people who are denied their voice find and exercise it. The feeling of not having a voice, or not being heard, is something I have experienced myself, and perhaps this gives me greater empathy for people in a similar position. Being exposed to the difficulties sometimes encountered by the participants made me realise how the role of helping others to exercise or find their voices mattered, and that what I have been doing all along is quite essential. Now that I have done all this work, I want to pursue this in a better and more influential way, once I qualify as a Counselling Psychologist. I consider that qualifying as a Counselling Psychologist will enable me to have an influence over how services are shaped, as qualifying as a Doctor of Psychology will give me more legitimacy and will give my voice more authority. I plan to dedicate myself to pushing for change at an organisational level and addressing injustice where it exists wherever I will happen to work.

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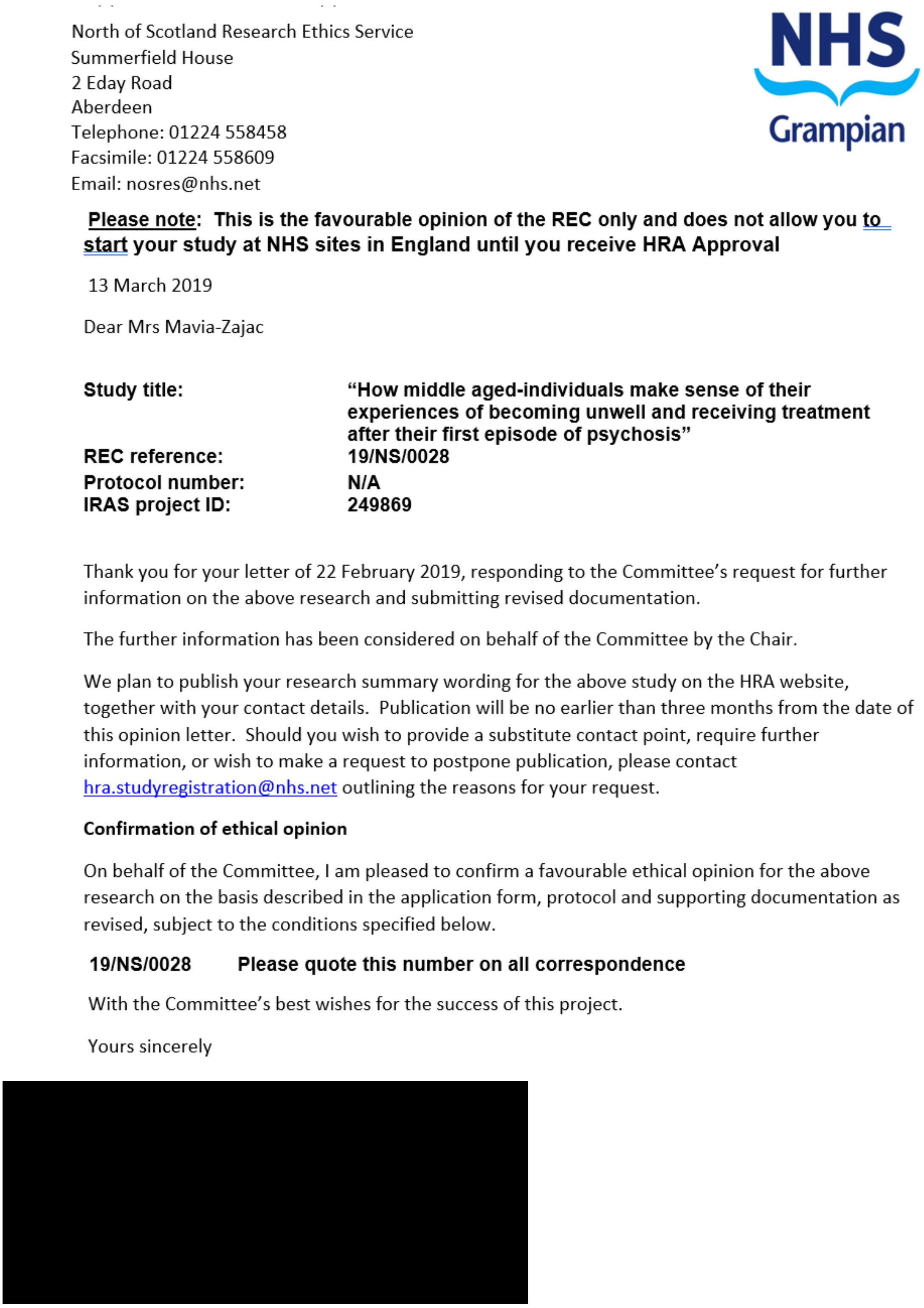
Appendices

Appendix A: NHS Ethics Approval



North of Scotland Research Ethics Service
Summerfield House
2 Eday Road
Aberdeen
Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

13 March 2019

Dear Mrs Mavia-Zajac

Study title:	**“How middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis”**
REC reference:	**19/NS/0028**
Protocol number:	**N/A**
IRAS project ID:	**249869**

Thank you for your letter of 22 February 2019, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

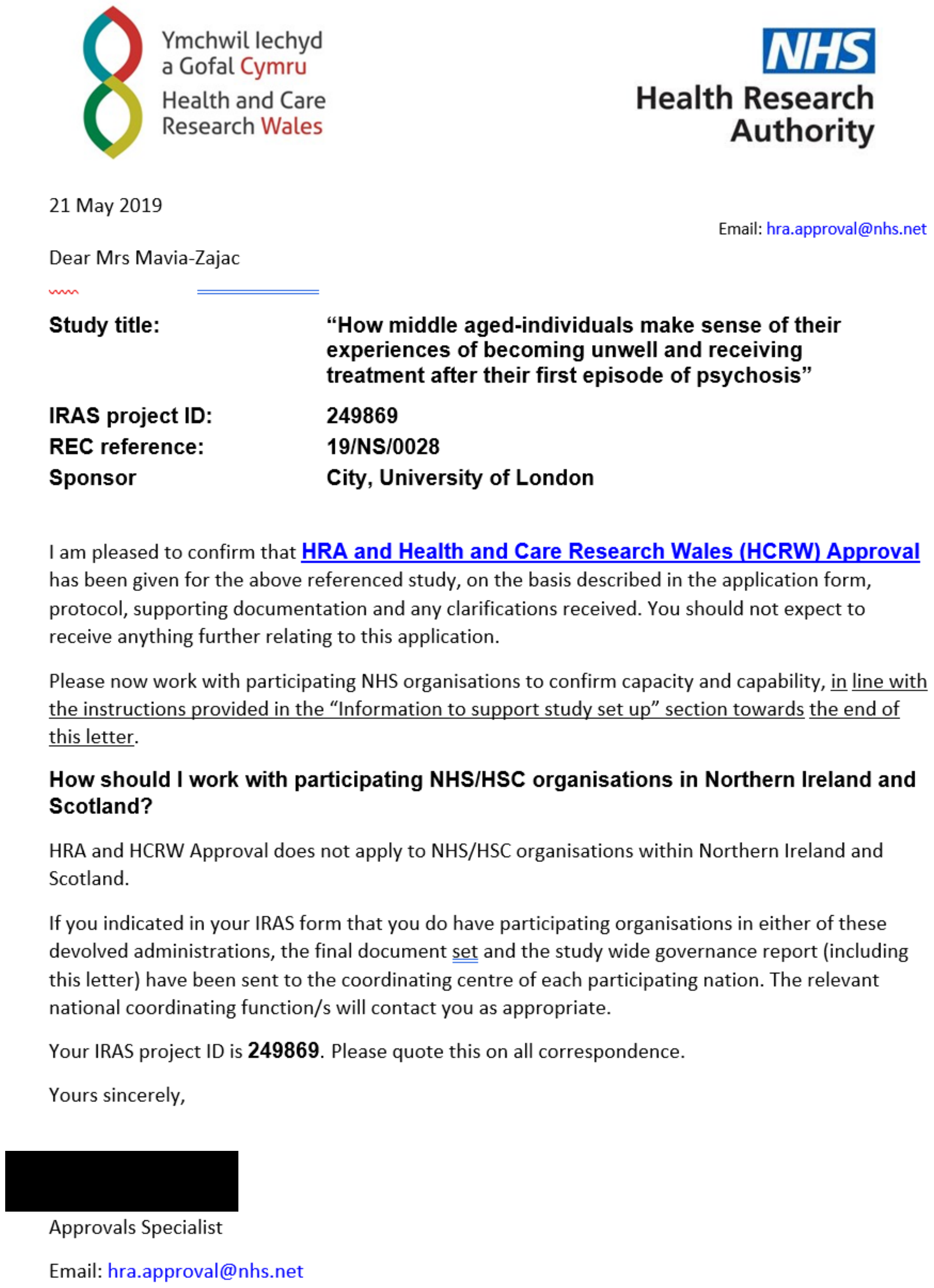
19/NS/0028 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

[redacted]

Appendix B: Health Authority Approval (NHS Research)



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

21 May 2019

Email: hra.approval@nhs.net

Dear Mrs Mavia-Zajac

Study title:	**"How middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis"**
IRAS project ID:	**249869**
REC reference:	**19/NS/0028**
Sponsor	**City, University of London**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Your IRAS project ID is **249869**. Please quote this on all correspondence.

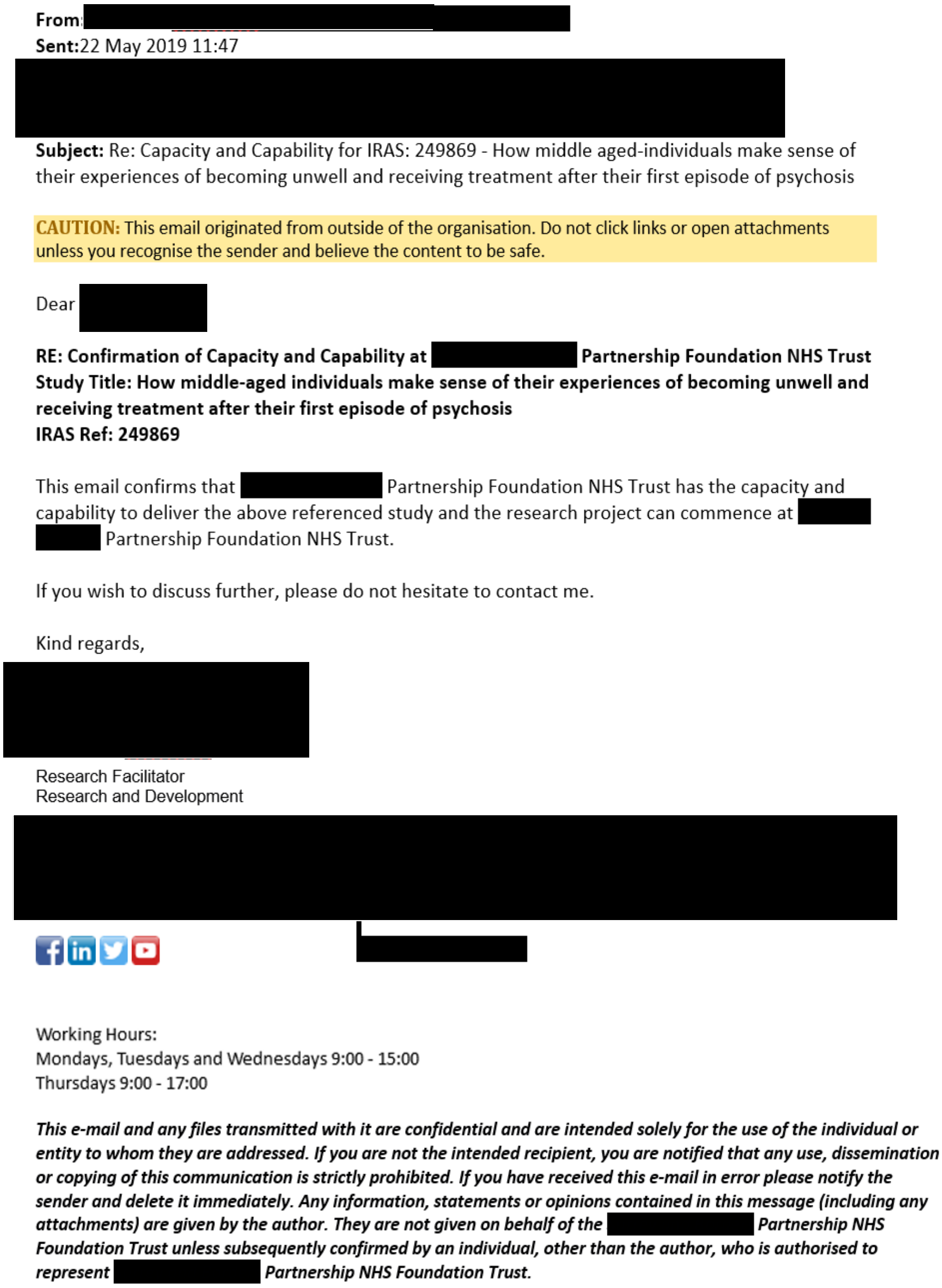
Yours sincerely,

[redacted]

Approvals Specialist

Email: hra.approval@nhs.net

Appendix C: NHS Foundation Trust's Capacity, Capability and Permission



From: [redacted]
Sent: 22 May 2019 11:47
[redacted]
Subject: Re: Capacity and Capability for IRAS: 249869 - How middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis

CAUTION: This email originated from outside of the organisation. Do not click links or open attachments unless you recognise the sender and believe the content to be safe.

Dear [redacted]

RE: Confirmation of Capacity and Capability at [redacted] Partnership Foundation NHS Trust
Study Title: How middle-aged individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis
IRAS Ref: 249869

This email confirms that [redacted] Partnership Foundation NHS Trust has the capacity and capability to deliver the above referenced study and the research project can commence at [redacted] Partnership Foundation NHS Trust.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards,

[redacted]

Research Facilitator
Research and Development

[redacted]

[redacted]

Working Hours:
Mondays, Tuesdays and Wednesdays 9:00 - 15:00
Thursdays 9:00 - 17:00

Appendix D: Pre-Interview Guide

IRAS ID: 249869 **(**Version 2)

Care Coordinators will thank participants for their interest in taking part in this study. They would let them know that their comments and responses will be held confidentially and that my final report will be written in such a way that it will be impossible to identify individual participants.

Care Coordinators will explain the rationale for process, which is to assess their suitability for the face to face interview. He/she will clarify that this suitability takes into account their well-being as well as meeting the inclusion criteria as specified on the Participant Information Sheet.

Care Coordinators will go through their emergency plans for support are and what their general support network is like. Through these discussions Care Coordinators will get an idea about how able they can express themselves, where they are on their recovery journey and their suitability for the study.

Risk assessment: I will liaise closely with their Care Coordinators to understand their risks to self and/or others in the past and any indicators thereof. I would also like to understand more about their engagement with supportive systems and how they cope in a crisis.

If they meet the inclusion criteria for this study, they will initiate contact with me and we will agree a date for a face-to-face interview. As the Care Coordinators and Psychiatrists are the first gate-keepers to ensure suitability, those that do not meet the inclusion criteria will have most likely been excluded already.

This is the end of the Pre-Interview Schedule

Appendix E: Participant Information Sheet

Version 2 IRAS ID: 249869

Title of Study: How middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis

Principal Investigator: Miriam Mavia-Zając

Supervisor: Dr Daphne Josselin

My name is Miriam Mavia-Zając, and I am a trainee for the Doctorate in Counselling Psychology degree at City, University of London under the supervision of Dr Daphne Josselin.

We would like to invite you to take part in a research study but before you decide whether you would like to take part in the study, it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

I am interested in exploring the experiences of individuals who were diagnosed with First Episode of Psychosis in middle age, that is between 40 and 60 years of age. In particular, I would like to understand what your experiences were from when you were becoming unwell, during the time you started treatment and after your mental health condition stabilised. It is hoped that the study will highlight what mental health professionals and Early Intervention in Psychosis services may need to do differently in supporting middle-aged people with First Episode in Psychosis.

Why have I been invited?

You have been invited because you are an individual aged between 40-60 years and you were diagnosed with First Episode Psychosis. You are receiving treatment under the Early Intervention in Psychosis Service and you have a Care Coordinator who oversees your treatment and recovery needs. You are not currently being treated in hospital and you are not detained under the Mental Health Act. As you appear to be doing well on your recovery journey, you will make a good candidate for this study if you wish to take part.

Do I have to take part?

Participation in this study is totally voluntary, and you can choose not to participate in part or the entire project. If you do decide to take part, you will be asked to sign a consent form. You can withdraw at any stage or avoid answering questions which you feel to be too personal or intrusive, and this will not affect any future treatment and you will not be penalized if you choose to withdraw. If you decide to take part, you are still free to withdraw at any time and without giving a reason. It is totally up to you to decide whether or not to take part. If you choose to take part, any information likely to identify you will be anonymised. You will be able to withdraw your data for two months following the interview, after which the analysis will be under way.

What will happen if I take part?

These are the steps we will follow:

If you are interested in taking part in this study, you will have an initial screening interview with your care coordinator, during which your care coordinator will check that you meet the requirements for participating in the study.

In this interview, you will discuss your travel requirements and your care coordinator will answer any questions you may have.

You can then initiate contact with me either over the phone or by email to express your interest. We will then agree when, where and at what time the face-to-face interview will be held.

The face-to-face interview will be with myself as the researcher and will last between 60 - 90 minutes and will take place in a place appropriate for you such as your GP surgery or community centre where your Care Coordinator and Psychiatrist usually see you, wherever is convenient for you.

During the face to face interview, I will ask you questions about your experiences of becoming unwell

I will audio record the face-to-face interview and transcribe the interview word for word.

We can have a short break during the interview if you wish to take a break. This will be the only face-to-face interview we will have and after this there will not be any further meetings.

During this face-to-face interview, I will collect basic information about you such as your marital status, your ethnic origin, your age and whether or not you belong to any faith or spirituality groups.

Expenses

Your travel expenses will be paid for your round trip

Some refreshments will be offered

There is no financial reward offered for your participation in this study

What do I have to do?

On the day of the face-to-face interview, you will be asked if you have any questions, and confidentiality will be explained to you again, and your consent will be requested in writing. The data will then be analysed for themes which may have arisen from the discussions. Your name will not appear anywhere in the written transcripts as pseudonyms will be used at all times throughout the report to maintain your anonymity.

What are the possible disadvantages and risks of taking part?

There is the potential for distress to arise from this sensitive topic, and I would like you to know that if this is the case and you feel unable to continue with the study, you are able to withdraw from the study at any time, and seek support from your care coordinator, your support network or any other advisory agencies whose contact details are given below. If during the interview you feel that any of the questions sound too invasive or difficult, please realise that you have the right to let me know or not to answer.

Your care coordinator and consultant psychiatrist are aware of your participation in this study, so they are on the look-out should you need extra support.

What are the possible benefits of taking part?

I hope that your participation in this study will contribute your unique experiences and add to the body of knowledge that is already available. I also hope that the study will highlight what services may need to do better in supporting middle-aged people and lead to helpful discussions around how Early Intervention in Psychosis Services in Surrey can be more supportive of middle-aged people with First Episode in Psychosis. Additionally, you will have the opportunity to reflect and get your story heard which has been identified by some authors as cathartic.

What will happen when the research study stops?

At the end of the research, I will write out the recorded interviews word for word and analyse the data according to the method suitable for this study. The information will be stored on encrypted servers of the NHS and my university which is City, University of London. The results of this analysis will be presented for my thesis and after my academic results are out, all the potentially identifying data from the interviews will be destroyed. The processed and anonymised data from which you cannot be identified will be kept for 10 years as per my university's data storage guidelines.

Will my taking part in the study be kept confidential?

My supervisor Dr Josselin and I will have access to the information both before and after anonymising, which will include the audio recordings and the transcribed data. After the data is anonymised, access to this will be by other identified members of the academic committee for purposes of grading my work. However, at this stage all data will be anonymised, and it will be impossible to identify you.

If there is any further need to use your personal information in future, further consent will be sought from you.

All information you provide will be kept confidential according to GDPR regulations, except under specific circumstances such as for reporting of violence, abuse, self-inflicted harm, harm to others, or criminal activity.

The results of the proposed research will be presented in a Thesis that will be kept by the University in the library and other people may have access to this.

What should I do if I want to take part?

If you want to take part in the research, talk to your Care Coordinator to express your interest or contact me on the following email address:

[redacted]

What will happen to the results of the research study?

The results of the proposed research will be presented in a Thesis which will be made available in the City Research Online repository where other people may have access to it. There will also be a publication where the data is anonymised and it will be impossible to identify you.

Who has reviewed the study?

This study has been reviewed and approved by the North of Scotland Research Ethics Service, Ref 19/NS/0028.

Further information and contact details

Should you have any further queries about the research, please do not hesitate to contact my supervisor [redacted]

Data Protection Privacy Notice: Your rights under the data protection legislation

City, University of London is the data controller for the personal data collected for this research project. Your personal data will be processed for the purposes outlined in this notice. The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees.

Further, City considers the processing of special category personal data will fall under Article 9(2)(g) of the GDPR as the processing of special category data has to be for the public interest in order to receive research ethics approval and occurs on the basis of law that is, inter alia, proportionate to the aim pursued and protects the rights of data subjects.

The rights you have under the data protection legislation are listed below, but not all of the rights will be apply to the personal data collected in each research project.

- right to be informed
- right of access
- right to rectification
- right to erasure
- right to restrict processing
- right to object to data processing

- right to data portability
- right to object
- rights in relation to automated decision making and profiling

For more information, please visit www.city.ac.uk/about/city-information/legal

What if I have concerns about how my personal data will be used after I have participated in the research?

In the first instance you should raise any concerns with the research team, but if you are dissatisfied with the response, you may contact the Information Compliance Team at dataprotection@city.ac.uk or phone [redacted], who will liaise with City's Data Protection Officer [redacted] to answer your query.

If you are dissatisfied with City's response you may also complain to the Information Commissioner's Office at www.ico.org.uk

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the title of the project is: **How middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis.**

You could also write to the Secretary at:

[redacted]
Research Governance & Integrity Manager

Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB

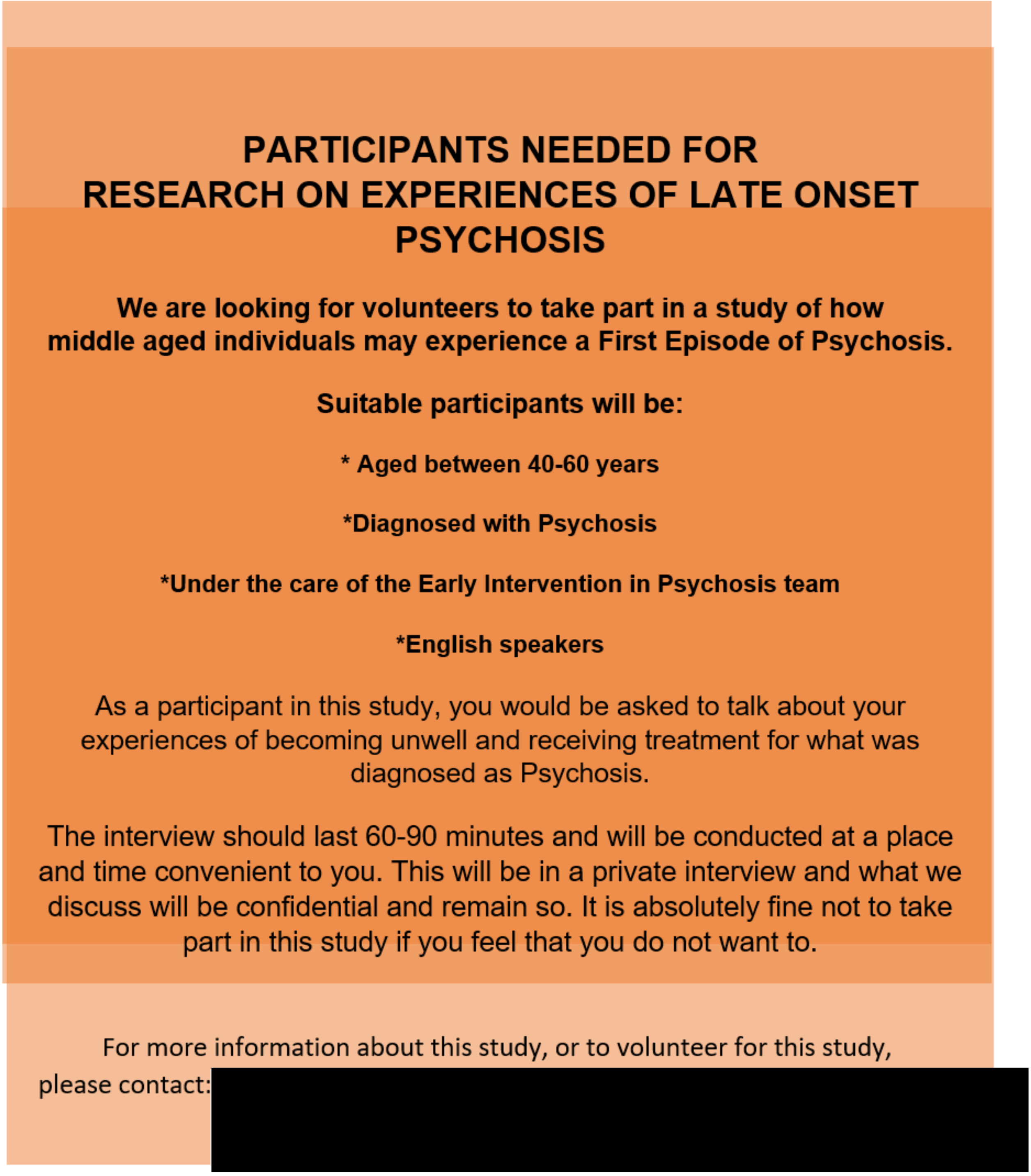
Email: [redacted]

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Thank you for taking the time to read this Information Sheet.

Appendix F: **Recruitment Poster.**

CITY
UNIVERSITY OF LONDON
EST 1894



PARTICIPANTS NEEDED FOR RESEARCH ON EXPERIENCES OF LATE ONSET PSYCHOSIS

We are looking for volunteers to take part in a study of how middle aged individuals may experience a First Episode of Psychosis.

Suitable participants will be:

*** Aged between 40-60 years**

***Diagnosed with Psychosis**

***Under the care of the Early Intervention in Psychosis team**

***English speakers**

As a participant in this study, you would be asked to talk about your experiences of becoming unwell and receiving treatment for what was diagnosed as Psychosis.

The interview should last 60-90 minutes and will be conducted at a place and time convenient to you. This will be in a private interview and what we discuss will be confidential and remain so. It is absolutely fine not to take part in this study if you feel that you do not want to.

For more information about this study, or to volunteer for this study, please contact: [redacted]

Appendix G: Participant demographic information

Participant Name	Gender	Age	Ethnicity	Employment Status	Marital Status	# of Children & age in years
1.Happi	Female	47	White Scottish	Unemployed	Separated	3 ≥ 18
2.Randy	Male	44	White British	Self-Employed	Married	2 ≤ 17
3.Finn	Male	45	White British	Self-Employed	Married	1 step-son ≤18
4.Sharon	Female	52	White British	Long term sick leave	Married	2 ≥ 18
5.Fatimah	Female	42	Jewish Israeli	Unemployed	Separated	1 ≤ 6
6.Chris	Male	55	White British	Long term sick leave	Married	2 ≥ 18

Appendix H: Interview Guide

IRAS ID: 249869

Thank you for volunteering to take part in this study.

Opening questions: What motivated you to volunteer for this study?

Can you tell me about your experiences when you first had the difficulties for which you are under the EIIP team?

(Prompts)

(I will adopt the terms they use for their condition in further communication)

What was happening in your life at the time?

What was that like for you? (I will explore details to elicit feelings, emotions, thoughts)

Besides that first episode, have you had any other episodes? (If yes) Can you tell me about the most recent or the most significant one?

Prompts

Do you remember when this was?

What was happening around you at the time?

How did this compare to the episode resulting in you being under the EIIP? (again I will elicit feelings, emotions and thoughts)

How did you make sense of this/these experience/s at the time? How would you make sense of them now?

During the most recent/most significant episode, were you with anyone when you realised something was happening?

Prompts

What was that like?

I will establish who they were with, and how these others responded.

5. Who did you turn to for support?

I will make sure I help the participants to explore all possible sources of support, and all aspects of this.

6. What have your experiences been of receiving treatment under the EIIP team?

Prompts

How was the treatment identified?

What was it like to receive this treatment?

7. What did you find most unhelpful/helpful from others around you during this time?

8. Looking back, what could others have done to provide you with better support?

Prompts

If above question is not responded to fully- I will ask about what, if anything else, they wish EIIP staff had done differently or offered

9. Considering all the experiences you have had since (year they will have given as start of condition) where has that left you as a person?

Thank you very much. Is there anything you would like to ask, or to add about your experiences?

Appendix I: Risk Assessment

Date of assessment: ………………………………………………. Assessor(s)…………………………………………….

Hazard/ Type of Injury	People affected & any specific considerations	Risk level	Existing Control Measures	Extra control measures
**Risk of attack or allegation by Participant	Researcher	Low	• In these situations, the researcher will follow the safe practice guidance issued by City, University of London • The screening interview will be by telephone therefore risk in this case is low. These interviews will take into account any risk histories people may have and appropriate risk management measures will be taken if such participants are suitable for 1:1 interviews. • Interviews will be only on mental health or GP premises. • The Lone Working procedure and 'buddy system' will be used as described in detail under data collection and analysis.	Other people such as the service manager/lead, individuals' Care Coordinator & Psychiatrists will be aware of researcher's presence on their premises. • There will be other people in the buildings when the interviews are done. • The researcher's buddy will know the starting & expected finishing times for each interview.

Contacts

School Safety Liaison Officer: [redacted]

University Safety Manager: [redacted]

Appendix J: Consent Form

IRAS ID: 249869

Title of Study: How middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis

Please put your initials in the box

1	I confirm that I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.	
	I understand this will involve:	
	being interviewed by the researcher	
	allow the interview to be audiotaped	
	complete questionnaires asking me about personal details and my religion	
2	This information will be held by City as data controller and processed for the following purpose(s): Public Task: The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be	

	scrutinised and approved by one of City's Research Ethics Committees. I understand that the following special category data will be collected and retained as part of this research study: [*ethnic origin, age, gender, number of children]* City considers the processing of special category personal data will fall under: Article 9(2)(g) of the GDPR as the processing of special category data has to be for the public interest in order to receive research ethics approval and occurs on the basis of law that is, inter alia, proportionate to the aim pursued and protects the rights of data subjects and also under Article 9(2)(a) of the GDPR as the provision of these personal data is completely voluntary.	
3	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.	
	I understand that the researcher's thesis will be made available in the City Research Online repository.	
4	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 stage of the project without being penalised or disadvantaged in any way.	
5	I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
6.	I agree to the arrangements for data storage, archiving, sharing.	

7	I agree to the use of anonymised quotes in publication.	
8	I agree to take part in the above study.	

Name of Participant Signature Date

Name of Researcher Signature Date

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix K: Demographic Questionnaire

IRAS ID: 249869

Date ……………………………………

To begin, I would like to get some basic information about you (such as your age and occupation). The reason that I would like this information is so that I can show those who read my research report that I managed to obtain the views of a cross-section of people. The information that you give will not be used to identify you in any way because this research is entirely confidential. However, if you don't want to answer some of these questions, please do not feel that you have to.

Are you male or female?

(Tick the appropriate answer)

Male __ Female __ Other __ (please specify:_______________)

How old are you? [ ] years

How would you describe your ethnic origins?[22]

(*Choose one section from (a) to (e) and then tick the appropriate category to indicate your ethnic group or background)*

White

---

[22] The format of this question is taken from the 2011 UK census.

(b) Mixed/multiple ethnic groups

White and Black Caribbean __

White and Black African __

White and Asian __

Any other mixed background, please write in below

____

Asian or Asian British

____

Black/African/Caribbean/Black British

African __

Caribbean __

Any other Black/African/Caribbean background, please write in below

____

Other ethnic group

____

What is your current occupation (or, if you are no longer working, what was your last occupation?)

____

What is your current *legal* marital status?

(tick the one that applies to you)

Single __

Married __

Civil partnership __

Divorced/separated __

Widowed __

a) Do you have any children?

(tick the appropriate answer)

Yes __ *(go to part b)* No __

b) How many children do you have?

[ ]

c) What age range are your children?

Below 18 ………………………. Above 18 ……………………….

What is your religion (if you have) ……………………………………………….

You have reached the end of this questionnaire. Thank you.

Appendix L: Debrief Sheet

IRAS ID: 249869

Title of Study: How middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis

Thank you for taking part in this study. Now that it is finished we would like to tell you a bit more about it.

In this study we explored how middle aged-individuals make sense of their experiences of becoming unwell and receiving treatment after their first episode of psychosis. It is hoped that this study will be of use in understanding your experiences better, which will hopefully result in better providing for your needs and developing greater relationships between mental health professionals/services and any other services that you find supportive.

This study has received ethical approval from the North of Scotland Research Ethics Service, Ref 19/NS/0028.

We hope you found the study interesting. If you have any other questions, please do not hesitate to contact us at the following: [redacted]

[redacted]

If you would like to further discuss any issues that arose within the interview, or for further support, please contact the organisations below:

Your Care Coordinator in the first instance (name of Care Coordinator & work mobile number)

Your GP at (telephone number of GP surgery will be given)

The Crisis Helpline on 0300456834 if it is outside the working hours of your team, or on Bank Holidays.

The Samaritans on 01252 513222/01483505555 outside working hours if you feel suicidal.

If you have any concerns about the research or if at any point you wish to complain about how you have been treated during the research, please do not hesitate to ask me. Alternatively, you may wish to contact my supervisor whose contact details are below:

Dr Daphne Josselin

City, University of London

United Kingdom

[redacted]

Appendix M: Coding example & development of Themes

Happi (not her real name) Interview 1

** All names of people and places have been changed to protect the individuals' anonymity.

Research Question: How do middle -aged individuals' make sense of becoming unwell with Psychosis & receiving treatment under the Early Intervention in Psychosis Team

A little about Happi: Happi female, 46, separated. I'm a 'person', you can call me white British, but I'm Scottish, 'not that it makes any difference' she says at the beginning of completing the demographics questionnaire.

** My initial thoughts even before the interview: She surely sounds different. I am struggling to understand her accent, I wonder how this will go.

She uses the word 'victim' 15 times

Happi's idioms and metaphors are underlined. Descriptive understanding is in green. My sense making is in Red Decontextualising is in Blue	Gems are highlighted in this colour. Themes or categories are CAPITALISED & ARE IN PURPLE. MMZ is me, the interviewer/researcher
Happi: I would say while I experienced what I would call a breakdown, errm, believing I was somewhere else, something else, somebody else, the whole- I had moved to an unrealistic world but I genuinely believe in it, you know	She believed herself to be someone else in a different place to where she was in reality. She honestly believed what her new reality was at the time. She called her experience a breakdown, where she believed she was someone else, so she was no longer herself Has how she views herself changed? When something breaks down, it ceases to function. She is being tentative in how she is viewing her experience, as if she is looking at it as an observer, being reflective, and calling it a breakdown now, as if this is not what she would have called her experience at the time. In chemistry, the result of a breakdown is decomposition of the product, sometimes giving rise to something with undesirable properties.

	Is she considering that she became someone with undesirable characteristics? Is there LOSS OF SELF/IDENTITY RUPTURE. Did she get a sense she did not belong to the current reality? DISCONNECTEDNESS
MMZ: hmm, hmm	
Happi: Err, it's like a switch which err ...I couldn't believe that I was going down that road, I couldn't believe me-	Perhaps her light was switched off & she could not function like herself. She could not believe that she was having a breakdown, she could not believe herself. It is as if she saw the breakdown as an unlikely scenario, that she was now on the road that she would not have chosen under normal circumstances. It feels like there is an element of UNBELIEVABILITY within her. She compares how her experience started to a **sudden** change, such as when a switch is pressed. A switch changes states from darkness to light & vice versa. In one state things are easier to work with & in the other there is need to stop functioning in the usual way. She had been feeling different for some time, yet she speaks of a switch, is this how she felt, that it was sudden? I there an element of losing track of time?
MMZ:- hmm	
Happi:-that that it happened basically, the whole thing it was just shocking (she looks away as she says this).	Happi states that in short, she cannot believe that she had the breakdown. It was shocking for her to have the breakdown =it caused a feeling of surprise, maybe even disappointment, panic and even dismay. It sounds unexpected and perhaps even unbelievable. She could not believe herself. It appears she is surprised that she had an experience that 1 in 4 people experience. Is she considering herself too special to have a breakdown? Should she have been spared? She looks away as she says 'the whole thing was shocking', is she ashamed that she had a breakdown? Is she trying to hide her shame, does she feel like others view her as someone with undesirable characteristics for having the breakdown? SHAME/UNBELIEVABILITY She repeats this, this sense of disbelief must be something important for her. She looks away as she said this, breaking eye contact. What is this about? Is there SHAME that she experienced this?
MMZ: right, right. Okay, when you first started to experience what you called this breakdown, what was happening around you at that time?	
Happi: I had 2 massive court cases going on with the X (a Place) Police, errm 1 historic, no, 2 historic, one being a Doctor. Err, my oldest son who'd always been a support had moved out of home. My daughter had decided to go and live with friends in Y (a place) at the age of 15, and I think the whole-, nothing was familiar in my	She had 2 court cases from the past reopened without warning therefore was unprepared. One of the cases was with her former Doctor. She thought she had put this behind her. Her main source of support was unavailable when her son moved out; and her daughter who was a child at the time had moved out to go & live with friends. Nothing in her surrounds felt familiar to her anymore. Did she feel like a stranger in her surroundings- did she feel lost?

surroundings…no people nothing, I shut myself away and I would say it was a trigger point there. I was left vulnerable basically, and weak.	Did she feel that her children had betrayed and/or abandoned her? Does she feel that who she sees herself as a mother is changing? She later mentions that she felt abandoned by her children, does she feel betrayed by others too, look out for this. The people she mentions are close to her- her children, then the Dr, was he also close to her? Being betrayed by people close to you -what was that like for her? DISCONNECTEDNESS/LOST/DESTABILISED/UNWANTED
	Her new reality, which she did not choose for herself, which she suddenly found herself in, had no one in it, so she socially withdrew even further. This left her feeling weak & vulnerable. This was acted as the trigger that activated her breakdown. She had been EXPOSED/WEAKENED/SUSCEPTIBLE She speaks of a trigger point, she can pin-point the exact point at which change happened. Again, there is this suddenness. There is something about the sense of time.
MMZ: Okay, okay. So all this happened around the same time – you said you had these 2 massive court cases	
Happi: Uhuh, it went on for years but the, they had reopened them both within a week of each other	The court cases had gone on for a long time which she does not specify, then within a week of each other, they reopened the 2 cases. I wonder if she had had chronic stress as a result of the court cases not being concluded, which would have made her feel re-wounded to reopen these cases.
MMZ: right, hmm. Were you aware that they were going to be reopening these cases?	
Happi: No, no. I'd myself where - myself mentally I felt a lot quite hard done by a lot of my life for different reasons…but I had told myself- and said 'that's it, you can't be a victim all your life'; I'd put -I'd dealt with it, it had been dealt with.	The re-opening of the court cases was out of her control. She had felt that she had been treated in an unjust manner and unfairly, but had dealt with it in her own way and had moved on. She had liberated herself by putting the matter to rest. However, someone else decided to bring her back to a place where in the past she had been a victim- where she felt injured, harmed, hurt because of others' actions. When the cases are re-opened, she is a passive participant, her power to keep the victim status in the background is removed from her. Old wounds are being re-opened. PASSIVITY/INJUSTICE/NO VOICE
MMZ: hmm, hmm	
Happi: -then when they knocked on my door, they opened it, something I wasn't ready for, but I couldn't say 'no' to because …I'd fought so hard you know, they were both found guilty in the end, so…	When they knocked her door, they let themselves in. She did not make a decision to let them in, again she was being a passive participant, for something she was not ready to deal with, she is being victimised again. She could not say 'no' because it sounds like she was not given an opportunity to make that choice; control was taken away. When a door is closed nothing is allowed in, & opening a door allows all & sundry in, especially as she had not opened the door herself. She must have felt angry realising again how unfairly she was treated. Up to that point she had fought hard to be in the

	state she was in. Her efforts had paid because the perpetrators had been found guilty. POWERLESS/INJUSTICE/NO VOICE
MMZ: Right, were they found guilty at that point of the breakdown or before?	
Happi: Well, it was …the Doctor was found… at the GMC …that was supposed to be the General Medical Council-	She starts a sentence about the Doctor and does not finish it & tells me what GMC stands for. Did she lose her train of thought, or is she wanting to put a context to the cases she is referring to?
MMZ: hmm	
Happi: -that was 10 years ago, I was torn to pieces, it was absolutely horrific, err he was found guilty I think of 3 out of 6 of my charges. So I was part of him being struck off, he was struck off from practising	Ten years ago at the GMC she was criticised in a very harsh & angry way, leaving her feeling horrified, terrible, and unfairly treated. The Doctor was found guilty after that horrific treatment, treatment which would have brought back past memories of being victimised by the Doctor. REVICTIMISATION. Her claims had been upheld & resulted in some justice done when the Dr was struck off the GMC register. As he was found guilty, she was not to blame for what happened to her. Is she wanting me to see that she was credible? Struck off- this indicates the use of force to remove someone from a position of power. Torn to pieces, did the experience with FEP feel the same, like it tore her to pieces? Does this situation help her to articulate herself better regarding her FEP? The Doctor being struck off, is that similar to the FEP being treated and her being freed from it, so it would not 'hurt her anymore?'
MMZ: Mhmm mmm	
Happi: But the police just did- apparently… I couldn't understand why it wasn't a criminal offence that he'd been- ss he'd been… do you know what I mean, I… I, the whole reality of how the GMC, the police and everything deal with a Doctor who's abused a patient errm, was quite …and I had no support, I had nobody else for support I could- (she becomes tearful)	She starts a statement about the police and does not finish it, she does this a few times. She points at her lack of understanding why the Dr was not tried in a criminal court. She feels there is injustice perpetuated even by statutory systems meant to maintain fairness & justice. She says 'do you know what I mean', as if she believes I am already understanding what she is saying. She points at the abuse by someone and the system meant to protect her and uphold her rights, then states how she had no one supporting her. Apart from the immediate family (her children), the justice system seems to not care. She is hurting as she remembers. PREJUDICE/INJUSTICE/DISCONNECTEDNESS/ISOLATED
MMZ: hmmm, okay (I offer her a box of tissues; we sit in silence for 13 seconds. Then she looks up and I continue). So there was this wound reopened with- with no warning on your part.	When she looks up, I take it to be an unspoken message for me to continue
Happi: Uhuh	
MMZ: -and there was no support provided.	
Happi: Uhuh	
MMZ: The person who had been supportive- your son, moved out	

Happi: Uhuh. He'd had a car accident drink driving as well, which is something I wouldn't,… can't tolerate can't accept- can't, my dad was a drunk, I don't like- you know. For him to go drink drive-	Happi sounds angry with her son, perhaps not so much for him having the accident, than him having been drinking. It's as if she is reminded of her father who used to abuse alcohol. Is she seeing herself through her son? Does she feel like her son's behaviour defines her? Does she feel her son let her down? Is her identity as a person &as a mother changing because of how her son has behaved? BETRAYAL/SPOILT IDENTITY Again, she starts sentences she does not complete, is she feeling fragmented recalling this moment which she mentioned as a trigger point earlier?
MMZ: Mhmmm.	
Happi: -so (she looks down, there is silence 10 secs)	She just said one word, then goes quiet while looking down so I cannot make eye-contact or read her face. Is she reminded of her painful past? Or is she ashamed of something, looking down as if this will limit what parts of her she exposes to me? EMBARASSMENT/SHAME
MMZ: When your son moved out, were you aware that this was his plan -to move out?	
Happi: Yes and no, it was just sudden, it was, he didn't come home from hospital after the accident. He decided that it was… I'm good with him now	It was an unplanned move by son, sudden removal of source of support. He decided to go and live away from his mother after his accident but Happi has made peace with him & has accepted it now. She described her son moving out as sudden yet moving out is not something that happens suddenly. Perhaps this is how she felt. This is something recurring- this suddenness, the loss of time. SUDDENESS She does not complete her statement about his decision, I wonder how it felt for her, this must be the time the son needed support after an accident, and Happi needed support too, so they could support each other. But her son chose to not go back to his mother. Did she feel he blamed her for his accident? LACKING/NOT A GOOD ENOUGH MOTHER/SHAMED?
MMZ: hmmm. You also said your 15-year-old daughter moved out to be with friends	
Happi: I think it was the age, she said she was going for study, she had a friend who she is no longer friends with, Becky, she was very influential over her you know… 'you're better here, it's easier here this and that'. She stayed for about 6 months and moved back, back home. She'd been, she admitted it was ..something she shouldn't have done but at the time you know she was a child it wasn't her, up to her, to sort of see my situation …it was <u>the last nail in the coffin,</u> I <u>felt like a failure as a mum</u>.	Attributing her daughter's behaviour to her age & friend's influence. Happi sounds pleased that her own daughter was sensible enough to return home after 6 months, but at the time she felt like a failure as a mother. She sounds like she felt like her daughter was influenced to betray her, and does not blame the daughter for this. It is as if her daughter is a reflection of what kind of mother she is -as if her daughter is her extension- that she is defined by her daughter's behaviour. Her daughter leaving home was the last nail in the coffin meaning that her daughter leaving home is what caused the breakdown that had already started to happen. Happi can identify the trigger of her psychosis. BREAKING POINT/FAILURE/DIMINISHED ABILITY Happi's sense of failure as a mother seems to have had a drastic effect on her identity, especially since her sense of being appears to have been centred around who she was as

	a mother. ?SHATTERED IDENTITY. Look for evidence of this elsewhere in her narrative Last nail in the coffin- is the FEP the coffin?
MMZ: Right, right. Hmmm. You felt like a failure-	
Happi: uhuh	
MMZ: can you tell me a bit more about that?	
Happi: It made me feel, you know I'd struggled, fought very very hard all my life – all my kids had all turned out amazing, they're honest , they have no criminal records, they've decent morals you know, I'm very proud of that.	She devoted all her time & energy to raising her children, which is a source of pride for her, as she initially felt rewarded & it appeared to have paid when they turned out to be well-behaved & pro-social. I wonder whether she feels like her children are not respectful of her sacrifices, sensing some BETRAYAL. Does she feel like her identity as a mother is being diluted because the children are no longer abiding by the standards she set for them. FAILURE/TAINTED IDENTITY
MMZ: hmmm	
Happi: Err, but it was like a (inaudible) in the teeth at the time from- coming from a 15-year-old.	Whatever she said, it sounds likes she did not expect it from her 15-year-old daughter; she sounds upset & irritated. Is she thinking that such behaviour must have come from some other person- maybe an older person, or someone raised by a different mother? ? Kick in the teeth- BETRAYAL & UNBELIEVABILITY. How dare you do that-it sounds like there is some anger in this

Appendix N: Table of Superordinate Themes and Themes

(All names of people and places have been anonymised to maintain the participants' confidentiality).

Themes	Page/Line	Phrases/Sentences
1. "My Worst Nightmare"		
"Too Much"	11/11	I was in debt, quite…quite a large amount
	11/17-18	I still had a house and I was still paying the mortgage and bills on that. I was -, work was quiet.
	11/19	I think last year it got even quieter because of Brexit […]
	15/17	My sister, we used to be quite close - I had - we had we had a falling out. (Randy)
	1/22-24	I had two massive court cases going on with the Metro Police, errm one historic, no, two historic, one being a Doctor. Err, my oldest son who'd always been a support had moved out of our home…and my daughter had decided to go and live with friends in (X- a place) at the age of 15…(Happi)
	29/5	I guess I pushed myself to breaking point, without realizing it.
	23/18-20	when I did, to say it was distressing is an understatement. I was scared, horrified, I couldn't believe I was ill, that I was - I was -, I don't know (she looks down then away). It was my worst nightmare (Sharon).
	2/2	this is something that started, that started as this stress at work really.
	9/3-4	I had other things going on as well, erm my - (sighs), my eldest son was at Sydney University in China
	9/5	my only daughter was travelling; and you know, you hear about things happening don't you when young people are out there, so I was worried about all that. (Chris)
Petrified	7-18	I'd just get up and go to bed in the night-time, wake up and sit in the chair day after day after day.
	5/18-19	I wouldn't go out of the house. I couldn't go out of the house. I didn't want to leave the front door.
	1/25	I just didn't want to do anything, didn't want to go anywhere I didn't want to get up.
	1/26	I just didn't, didn't realise - functioning wasn't happening. (Sharon)
	3/6-7	I used to go to work and I'd just sort of freeze, and I just sort of I couldn't, couldn't cope. So I'd just sort of stop everything just like that.
	4/3-4	

	2/5	I didn't do anything really because that's what that's when I couldn’t, and then I started pacing. And I wouldn't wouldn't go out of the house. I couldn't do anything social. I found myself doing nothing, I I couldn't do tasks. (Finn).
“A Shock and a Half”	30/30	I could sense there was something wrong because I stopped driving without my license being taken away.
	3/6-7 5/8	because I was err, I was having strange thoughts and errr I wasn't sure what was real - what was reality and what wasn't I kept I kept thinking backwards and forwards through time (Randy).
	1/4 1/16	I was quite shocked by what happened...to be honest It felt like, like a switch was pressed… I couldn’t believe that I was going down that road (Happi).
Becoming Untethered	4/27-28	And I remember taking my daughter to school, and I just felt outside of everyone as though I was not normal and everyone else was normal.(Finn).
	17/36-37	I felt overwhelmed… I just felt like my world had turned upside-down. The pain was …-, I can’t describe it… I couldn’t bear it. (Fatimah).
	17/4-5	Yeah, then my mind sort of went crazy […] because - well who believes these – who understands, who thinks these thoughts and- hearing voices and seeing things. All those -all that- that's what I mean that's what I mean. (Randy).
	3/21-22 35/25	I lost it, it was -, I felt like I’d been -, that’s when I lost it, it was ….I felt like I’d been – oh no! I felt like I was on another planet, I jus… I just …I was in La-la land, I lost it, lost it completely … I was on a different wavelength. (Happi).
2. Not Myself		
My Crazy Mind and Myself	16/34	I think my mind, my crazy mind, my mind sort of my mind just went a little crazy. (Randy)
	3/12-13	That’s when I felt like this glitch, like my brain like in my brain there was something not, a glitch, like this failure to do what brains do, to work with me. (Finn)
Wrestling	2/7 12/5	I mean they’re calling it psychosis. . I’ve gone through a lot of crap you know, a lot of shitty things have happened to me I just call it stress really… It wasn't really an episode. I think it's just part of who I am. (Chris).
	15/29-30 15/31	And so I, so this is a conflict that I, that I knew something was wrong with me, but I didn't want to tell anyone, that something was wrong with me because going to a doctor is an admission that there's something wrong with you, so don’t. (Finn).
3. Person of Interest		

Super-human	9/32-33 9/35-36	in a way I felt I could see something that nobody else could see, that in some ways I was specially connected to something some spiritual connection, some sort of connection to something that nobody else had, I felt special like I was one step ahead of everyone (Happi).
	4/13 4/34-35	I felt like I could control, I could control the weather… as in if I changed my mood from being- if I could sort of feel, sort of make myself feel happy, I’d then get the sun out, the sun would come out and hide the clouds when the sun came out. And then when - and then when I was -and if I was thinking negatively it would go dark. You know the clouds would come over. (Randy).
	19/32 19/34	every street sign was a message to me. Every car number plate was a message to me. To me the whole thing was orchestrated like a theatre (Fatimah).
	1/27 1/30	I thought my video recorder was videoing me, the TV video recorder I thought the Blackbox, I thought someone's watching me on that. I also thought people were watching me in the street and following me. (Sharon).
“Alonely”	6/28-29	“and on the way there I was -I was thinking that I -like an earthquake had happened and I'd caused it from that afternoon when I was spinning and my my fian- when my fiancée was on the telephone. (Randy).
	5/21 5/23	I thought I might be taken somewhere. I don't know I just said just overwhelming feeling of being snatched and abducted by somebody. I don't know why. (Sharon)
4. Diminished		
“Like I was Defective”	13/29-33	whereas **she judged me** and **didn’t want to be my friend anymore**, […] now I just think you know **‘f**k off!!’** do you know what I mean? I can’t... I really don’t have time in my life to... you know **–‘you’re not so special that I need you in my life’**. I don’t need people like that in my life you know.(Happi).
“A Lesser Person”	32/11 32/13 32/15-16	I felt like I didn't deserve it. I felt I didn't deserve that help. I just felt I wasn't worthy. I wasn't worthy of that attention. I didn't allow anyone else in because I feared they’d see my vulnerability and maybe see it as like a weak characteristic of myself… if that was to be the case, then I'll be I'll be …(looks down) seen as a lesser person. (Finn).
	13/4 19/29-30	it makes me cringe to think that I even thought along those lines... I shudder, I just can't believe how much I lost reality…I’m quite err quite strong minded, strong person- I see myself as – err, and to break like that you know- it’s - a lot of people judge me (Happi).
		them {her children} leaving like that …it was the last nail in the coffin. I felt like a failure as a mum. […] like I failed at my

		attempt of one thing that I have always been proud of, which is how both my kids have turned out … (Happi).
	12/28-29	No, I didn't say or show anything. I wouldn't have said anything to them, no, it's just not the sort of thing, I just kept it to myself, in case they thought, you know, that there was something wrong with me. And I didn't want them thinking that of me. (Chris).
5. Coming Out		
Transformed	39/4 39/6 39/33	Well I found my limits. I've discovered how much stress I can and can't take. And also now if I do get psychosis again I'll know hard to recognize it. I'm a lot less of a perfectionist now. I let things slide more because it's not the end of the world. I think that's a good thing that came out of it.(Fatimah).
	33/26-27	It left me more open minded because as much as I said and believed to have understood mental health, in fact I had no clue about mental health until I experienced it myself. So it left me more open minded more aware, and more supportive of anybody with mental health issues. […] I can sit down with anybody and say 'I know what you mean, I went -I lost it last year'. (Happi).
	35/18	It made me a stronger person and gave me more knowledge into something I didn't understand. (Happi)

Superordinate Theme	**Subordinate Theme**	**Data**	**Participants identifying with theme**
1. My Worst Nightmare	**Too much**	Worst stress ever	**H, S, R, Fa, Fi, C**
		Quite Pressured	
	Petrified	Paralysed	**S, H, Fa, R, Fi**
		No sense of Time	
		Totally Blank	
	A shock and a half	Is this Real?	**S, R, Fi, Fa, H**
		Why Me?	
		Fragmented	
		Incredulity	
	Becoming Untethered	Paranoid	**R, H, Fa, S, C, Fi**
		Spiralling out of Control	
	Fully Untethered	Nothing left to lose	
		Ready to Explode	
2. Not Myself	**My crazy Mind and I**	Embodiment of the Mind	**R, Fi, H, S, Fa**
		Brain Glitch/the switch	
	Wrestling	Denial	**C, Fi, H, R, Fa,**
		Conflicted	
		Not Me	
		Games	
3. Person of Interest	**Special**	Special/Demigoddess	**Fa, H, C, Fi, Ra**
		Universe whisperer	
		Magical thinking	
	Alonely	Vulnerable	**Fa, R, H, S, C**
		Fragile	
		Responsible	
		Outside	**Fa, H, C, Fi, Ra**

		Not normal	
		Alonely	
4. Diminished and Marginalised	**Dehumanised**	Judged	**H, S, C, Fa, R, C**
		Violated	
		Pathologised	
		People become a danger to you	
		Excluded	
		Separated	
		Traumatised	
		Betrayed	
		Infantalised	
		No voice	
	A lessor Person	Emasculated	**Fi, Fa, H, S, C, R**
		A lessor person	
		Not good enough	
		Ashamed	
		Weakened	
5. Coming out	**Inter-personal:**	Humanised	**S, H, R, Fa, Fi,**
		Given a voice	
		Open and honest	
	Stronger within	Knowing own limits	**H, S, Fa, Fi, H**
		Wake-up call	
		No more ‘faffiness’	
		Stronger	
		Altruistic	

Appendix O: My White Board

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Appendix P: Example of Superordinate & Subordinate themes (Fatimah)

Superordinate Theme	Subordinate Theme	Codes	Relevant Data
1. “My Worst Nightmare”	**Too much**	Worst stress ever	In order to get perfection, sometimes I’d push myself beyond my physical limits, working too hard. because when you work too hard, don't sleep well enough don’t eat properly, you're more susceptible to anything from the flu to psychosis, I think
		Quite Pressured	Work was very stressful. I was under a lot of stress basically. Just a very steep learning curve and no time to process it really because every minute of my day was I was under pressure all the time.
		Attenuated stress	I had other incidents in my life that were quite extreme but nothing was on such a prolonged timeframe
		Excruciating Pain	The overload of information was causing me to have severe headaches on a daily basis, it was excruciating pain.
		Cognitive problems	It became harder and harder for me to focus at work. I was making mistakes. I wasn't paying attention all the time. I was distracted and I couldn't control it as much as I tried.
		Reduced Performance	my work output and quality of work had gradually become almost barely worth me coming in
		Self-Neglecting	I had to make sure everything was done, even when I felt physically unwell. I took last place in the pecking order, so I didn't look after myself properly. I mean I was forty nine kilos when I was admitted. I had I stopped eating properly. I was starting to look like a skeleton with skin on, I neglected myself.

	“A shock and a half”	“Something is wrong”	I could sense there was something wrong because I stopped driving without my license being taken away. I just wasn't sure what it was that was wrong
		Fragmented	
		Incredulity	I just had had enough and nothing made sense to me anymore. Everything was strange - I started feeling like I have no control over what's happening to me anymore. I felt very strange
	Becoming Untethered	Paranoid	
		Spiralling out of control	I felt like I was going to explode soon from all the stuff I was feeling and not being able to express I just felt like my world had turned upside-down. The pain was …-, I can’t describe it… I couldn’t bear it.
		Overwhelmed	I felt overwhelmed,
	“I lost it, lost it completely”	Nothing left to lose	and then after being at home for a short while I tried to commit suicide.[…] I just had had enough and nothing made sense to me anymore. […] I started feeling like I have no control over what's happening to me anymore. I started coming to the conclusion that I have no control over it and feeling that I have nothing more to live for and that I’m better off dead really.
		Falling apart	I disintegrated completely, I just didn’t know what else to do or how to feel. I really fell apart.
		Ready to Explode	
		La-la land/Fantasy	I was just talking nonsense. […]
		Lost it	
2. “Not Myself”	**My Crazy Mind and I**	Mind Embodiment	
	Wrestling	Denial	
		Conflicted	
		Not Me	
		Acting	
3. Person of Interest	**Super-human**	Special	I started thinking that I was being followed by satellites that I was getting messages from the TV and the radio even car number plates I was reading everything I had double meaning

		Universe whisperer	
		Magical thinking	
		Message decoder	every street sign was a message to me. Every car number plate was a message to me. To me the whole thing was orchestrated like a theatre Every car number plate was a message to me to me the whole thing was orchestrated like a theater. At the time it was like- I had special- I felt special, like he had sent me some decoder for these messages somehow
		Demigoddess/Demigod	He {her ex-boyfriend} was like a Demigod, very powerful, with so much influence. […] I must have felt – I felt like a Demigoddess I guess (she looks down and laughs lightly)
	“Alonely”	Victim	
		Fragile	Every time I stepped outside I'd get dizzy, every time I answered the phone to anyone I started feeling dizzy and sick and panicky. I had to be away because I felt like I could collapse and die […] It was scary, I felt, I was, it was just alonely time (she mumbles and it sounds like she joined the words alone and lonely
		Paradox of power	
		Hunted Down	
		Monitored	
4. Diminished	**Dehumanised/they took everything/left me with nothing**	Judged	
		Violated	I felt violated, and I had no say, and was so unfair. I did not like it […] And that was partly why I resented being sectioned as well because it was my thing and they were constantly trying to get information from me and I felt that was an invasion of privacy.
		Traumatised	It was shocking, scary, I cannot find the right words to describe the experience, the trauma, in either case it’s a feeling that's never going to leave me. I’m now worried every

			time someone knocks on the door
		Imprisoned	I was now basically a prisoner. That's what I felt like with no control over my life. This lack of freedom got to a terrifying new level. being somewhere where I didn't want to be, with no ability to leave
		Hijack/taken against will	I think if they had discussed it with me rather than come and what felt like hijack me from my home, so if they had sat with me, adult to adult and explained to try and get me to agree to go rather than use a warrant and say 'you're coming with us now whether you want to or not'. the warrant means you have no choice. I would have preferred to have the choice
		Betrayed	
		Alienated	It just felt really errm, alienating {not being able to share her thoughts with ward staff}, it was a lonely time, I just felt like I was alone and misunderstood, and that it was pointless to try to explain to anyone
		Retreated/withdrew	I just isolated myself completely didn't answer the phone for a few months before that I did not see any messages. I didn't even read them. it {the process of compulsory admission to hospital} definitely didn't feel helpful as it was much more scary than helpful. Made me retreat even further.
		Stripped/They took everything	I've lost my job for what is err the longest period of time I've ever not worked. I'm about to lose my home. My confidence has taken a huge knock. I'm just a shell of my former self. So yeah, everything that mattered to me is gone. it's like I was stripped to the bone When I was left in the room {at the hospital} and the door was

			closed behind me and my shoelaces were taken away from me …they took my cable away. They took everything away
		Infantalised	They treated me like I was a child, like I couldn’t make sensible choices on my own. and they were checking that you were swallowing it
		No voice	a whole big team of people came into the house, police officers, ambulance crew err five or six of them and one of the ladies, I think a social worker, took me upstairs and said to pack a bag. They put me in an ambulance and took me to an assessment unit. I didn't feel I had a choice.
	“A lesser Person”	Emasculated	Well before that I was a very confident person.
		Not good enough	And I kept missing deadlines and it just <u>wasn't good enough</u>. at this point I wasn't even good enough […] And for me to not even be able to achieve the minimum was very hard to take, I would say it was a blow to my ego.
		I have nothing to offer	I don't feel that I have much to contribute to an employer. I have nothing to offer anyone
		“Sink into the ground in shame”	I just wanted to sink into the ground in shame It was very embarrassing, I felt like I had been undressed, like I was defective in some way. I couldn’t look anyone in the eye. It was like being stripped of all your clothes (she looks down, breaking eye contact with me) It was embarrassing, you see because I have always thought of myself as clever and rational, and balanced, as I said 2 feet planted on the ground
		Weak/Vulnerable	I feel much more vulnerable now, I doubt myself, I just feel quite fragile. This broke who I thought I was. Because the psychosis in a way was a better place to be because I was hopeful, and I felt I was wanted. Whereas realizing what's

			really happening really takes all the hope away. That's a much worse place to be.
5. Coming out	**I matter**	Humanised	And unlike all these others, the early intervention people have just been nice, and they talk to me like I am someone who matters, someone with a brain
		Benevolent	I do think it just makes me feel good helping other people so you can look at it as a slightly selfish benevolence. […] doing research and analysis will add to the pool of knowledge that people have about my condition in my age group
		“The right thing to do”	So in hindsight I'm better now. So sectioning me must have been the right thing. But how they went about it, and while I was going through it -
		Open and honest	
	Reframing	“I found my limits”	Well I found my limits. I've discovered how much stress I can and can't take.
		Wake-up call	
		No more ‘faffiness’	I'm a lot less of a perfectionist now. I let things slide more because it's not the end of the world. I think that's a good thing that came out of it.
		Hopeful	if I do get psychosis again I'll know hard to recognize it.
		Self-Aware	I feel much more vulnerable now, I doubt myself, I just feel quite fragile. This broke who I thought I was. But also much stronger than I was 6-12 months ago. I learned a lot about myself.
		Picking up the pieces	{I am} reestablishing social contacts rather than just sitting at home and feeling sorry for myself to get me out of the house, get me back used to getting up and going somewhere every morning.
		Stronger	

# Section B:	Publishable Paper

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Section C: Combined Psychodynamic Client Study/Process Report

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