

MEANING IN LIFE FOR PEOPLE WHO HAVE
EXPERIENCED A FIRST EPISODE PSYCHOSIS:
AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

A Thesis Presented to the University of Dublin, Trinity College for
the Degree of Doctor in Philosophy

by

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DECLARATION

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and is entirely my own work.

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Because we are in the world, we are condemned to meaning, and we cannot do or say anything without its acquiring a name in history.

— Maurice Merleau-Ponty (1962) on the primacy on meaning in the context of human experience.

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SUMMARY

Background: The concept of Meaning in Life (MIL) is understood to be central aspect of service user defined recovery in mental health. MIL takes on renewed importance in the context of widespread endorsement of the recovery approach in mental health; as service development and reform are required to prioritise service user defined recovery. Psychosis appears to impact the degree to which a person experiences MIL. However, there is little research available that helps us understand how MIL is experienced in recovery in psychosis or how meaning making in psychosis experiences influences a person's perspective on MIL.

Aim: The aim of this study was to explore how people who experienced a First Episode Psychosis (FEP) approximately 21 years ago find, develop, and maintain MIL and identify the key factors that influence MIL.

Methodology: This qualitative study used Interpretative Phenomenological Analysis (IPA) and adopted a multiperspectival design. Participants were recruited from a cohort of people diagnosed with a FEP between February 1995 and February 1999. The study was carried out within a public/private mental health service based in Dublin in Ireland. Semi-structured interviews were conducted with 16 participants: 8 people 'In Remission' and 8 people 'Not in Remission' from psychosis, who were recruited using purposive sampling. Data were analysed according to IPA principles.

Findings: Data were coded as relating to either 'Meaning making in psychosis experiences' or 'Meaning in life in the context of mental health recovery'. 'Meaning making in psychosis experiences' formed the context and backdrop for participants finding, developing, and maintaining MIL in the recovery journey.

Five themes were developed to encompass 'Meaning making in psychosis experiences'. Firstly, psychosis experiences were found to erode MIL. This is reflected in the first three themes: Theme 1 *Living with the impact of psychosis on the self and identity*; Theme 2 *Reconnecting with time to move forward in time*; and Theme 3 *Navigating agency and powerlessness in chaos*. Psychosis experiences

were understood to threaten or damage a person's self, preferred identity, relationship with time, and control in their lives. Secondly, psychosis experiences were found to contribute to MIL by adding something that was not present in the person's life prior to psychosis (Theme 4 *Generating Meaning in Life in a vacuum*). Psychosis experiences offered a path to: establishing connection and understanding; contributing something of value to society; realising potential; and exceptionality. Thirdly, psychosis experiences disrupted narrative coherence and blocked the ability to narrate parts of life (Theme 5 *Trying to find a home for psychosis or not needing to*).

Five themes were developed to capture 'Meaning in life in the context of mental health recovery'. Participants found, developed, and maintained MIL by being aware of their connectedness to their context. Experiencing MIL through connectedness to context occurred in five main ways represented by five themes. Theme 1 *Being myself – de-othering and authenticity* involved participants being cognisant that they resided in a self (their identity). They sought to enact their identity by pursuing congruence between their true self and their actions. Theme 2 *Becoming significant where the self is witnessed* involved participants acknowledging that the self existed in relation to the self and others. They aimed to belong amid their life witnesses (including the self) to experience significance. Theme 3 *Generating meaning within and beyond systems* involved participants realising that the self existed in relation to systems. They used systems to generate MIL but also attained MIL from transcending them. Theme 4 *Shaping and being shaped by life* involved participants appreciating how their environment shaped the self and the self shaped their environment. Finally, Theme 5 *Integrating different perspectives of time* involved participants developing an awareness of how the self was experienced across time. They had to acknowledge that temporality changes depending on life circumstances.

Conclusion: The findings provide novel insight into the complexity of how MIL is experienced by people who have personally encountered psychosis. They also illuminate the influence of meaning making in psychosis experiences on MIL. The findings enhance the conceptual clarity of MIL in the context of mental health recovery in psychosis and contribute to meaning making and mental health recovery theory. In so doing, they also offer guidance for education, clinical practice, service provision, and future research and have practical relevance for therapeutic engagement, trauma informed care, and the recovery approach.

CHAPTER ONE: AN OVERVIEW OF THE THESIS

1.1 Introduction

Psychosis experiences are defined as: sensing things others cannot sense; having beliefs dissonant with consensus reality; feeling like thoughts, speech, and behaviour are muddled; having difficulty feeling emotions, experiencing pleasure, or speaking; and not having the desire to be social or the motivation to do the things people want to do (American Psychiatric Association, 2013; McCarthy-Jones et al., 2013; British Psychological Society Division of Clinical Psychology, 2014; Health Service Executive, 2019).

Epidemiological studies have yielded estimates of annual incidence of First Episode Psychosis ranging from as low as 15 per 100,000 to as high as 100 per 100,000 (Simon et al., 2017).

However, these figures only represent people who come in contact with mental health services and exclude people who experience what could be defined as psychosis (e.g. voice hearing) but do not seek help from mental health professionals.

The meaning of psychosis experiences is highly contested and poorly understood within the literature. The focus of this study is therefore on the activity of meaning making in the context of psychosis experiences and in Meaning in Life (MIL) generally. The aim of this introductory chapter is to provide a brief description of the background, rationale, and aim of the study. The chapter will also provide a concise overview of the contents of this thesis.

1.2 Psychosis experiences and meaning

Psychosis experiences and the meaning attributed to them have received little attention within the empirical literature. From the biomedical perspective, psychosis experiences have meaning as: symptoms of a psychiatric ‘disorder’ to be categorised according to psychiatric nosology (Kay et al., 1987); loci for the efficacy of psychiatric interventions designed to stop them from happening

(Harrow et al., 2014); and as features of pathology that require psychiatric epidemiology to determine its cause, course, and outcome (Dyckhoorn & Kirkbride, 2018). Critics of this standpoint argue that it ignores the primacy of meaning in the lived experience of human beings. In the context of recovery orientated mental health services, these critics contend that helping people live with, manage, and overcome mental health difficulties should (at its core) focus on what these experiences mean to the people having them (Thomas et al., 2012). They argue that if the process of recovery is to be promoted and service users' distress alleviated, it is vital to understand the meaning individuals attribute to psychosis experiences (Holt & Tickle, 2014). Service user meaning making, in this context, is viewed by practitioners as something to be targeted by interventions to progress these objectives.

For many people, the content of their psychosis experiences is of personal significance (Beavan & Read, 2010). Through autobiographical accounts (e.g. Chadwick, 2007) and published empirical data (e.g. Murphy, 2000), service users have expressed how they consider the meanings they ascribe to their own psychosis experiences to be fundamentally important in *themselves*. While meaning making can limit the perceived damage caused by psychosis on the lives of people experiencing it and instil hope for the future (Perry et al., 2007), it can also enhance distress. Encroaching images, ideas, and perceptions can have meaning in psychosis derived belief systems; which can erode a person's sense of self and their relationships with others (Binder, 2006). There is limited knowledge available on how people interpret and make meaning of their psychosis experiences and the impact of this on the recovery process.

One way that the process of meaning making in psychosis experiences may impact recovery is by influencing the degree to which a person experiences MIL. Finding meaning in psychosis experiences has been shown to lead to enhanced MIL and the development of a coherent life narrative (Roberts, 1999). Other studies have suggested that the experience of psychosis impairs MIL (e.g. Yarnell, 1971). How the meaning made in psychosis experiences can contribute to, or erode, MIL is poorly understood.

Individual qualitative studies (e.g., Jenkins & Carpenter-Song, 2005), qualitative syntheses (e.g. Leamy et al., 2011), and the autobiographical accounts of service users themselves (e.g. Scotti, 2009) suggest that MIL is a central aspect of service user defined (or personal) recovery in mental health. Successful implementation of the recovery approach to mental health service provision¹ requires the pursuance of both clinical recovery (remission of symptoms and social/occupational functioning) and personal recovery goals in services for people experiencing psychosis (Van Eck et al., 2017). In the context of this implementation, the concept of MIL takes on renewed importance in service delivery. There is little available literature on the process by which a person with experience of psychosis finds, develops, and maintains MIL in the recovery journey. Understanding this process can help guide providers in supporting it and bridging the gap between recovery ideology and its implementation.

1.3 Meaning making

Meaning making is a widely used term in qualitative research due to its focus on interpreting phenomena in the context of the meanings people attach to them. A consensus operational definition of meaning making does not exist in the psychology literature (Park, 2010; Steger et al., 2006); with different scholars developing different understandings of the term for diverse purposes. By taking an overview of the perspectives of these authors, meaning can be viewed as a multidimensional concept with multiple functions (e.g. cognitive or motivational) and many ways of interpreting the concept (e.g. the types, features, or sources of meaning; the search for, or presence of, meaning; as well as meaning made).

It was important to clarify meaning making prior to embarking on this study. However, this needed to be balanced with the requirement to limit the impact of a priori theoretical assumptions about meaning making on the research process itself. This is in line with the principles of Interpretative Phenomenological Analysis (IPA); the methodology adopted for the study.

¹ The recovery approach aims to integrate the input of service users and their family in order to optimise mental health service provision.

Many theorists have conceptualised meaning making in the context of adaptation to life changes and adjustment to stressful life events (e.g. Stiles et al., 1990; Neimeyer, 2001; Gillies & Neimeyer, 2006; Park, 2010). For some of them, meaning making is defined as ‘retaining, reaffirming, revising, or replacing elements of [one’s] orienting system to develop more nuanced, complex and useful systems’ (Gillies et al., 2014, p. 208). It is argued that our orienting system is what enables us to understand and respond to experiences and guide our perceptions of the self, the world, and how they interact. These orienting systems include: personal constructs; world assumptions; self-narratives; goals; beliefs; and schemas (Gillies et al., 2014). From this perspective, meaning making is the act of affirming the congruence among—or reconciling the discrepancies between—the appraised meaning of a particular experience and our orienting systems (Park, 2010). For example, receiving a new job offer is congruent with a self-narrative that one’s career is progressing *or* the sudden accidental death of a life partner is inconsistent with one’s assumption that the world is a safe place for one’s family. This perspective equates meaning making with sense making as ‘the process of building an explanation to resolve a perceived gap or conflict in knowledge’ (Odden & Russ, 2019, p. 178).

In the context of this study, meaning is defined as ‘a concept (conceptual frame or cognitive pattern) bound by a sign (word)’ (Melenteva, 2018, p 6). Meaning is understood as a mental representation of possible relationships among things, events, and relationships (Baumeister, 1991). Meaning making provides a framework for conceptualising, categorising, and mapping the outer world and connecting our life experiences in it to linguistic representations. These representations help us define, justify, and understand our thoughts and actions; they determine how we interpret reality (Melenteva, 2018). Meaning, therefore, is what motivates us; what drives our interpretation and application of knowledge (Krauss, 2005). Meaning making involves generating and placing a concept (e.g. agency) in a personally meaningful context (e.g. *my* agency in effecting change in *my* relationship status) (Antonellis, 2013).

However, meaning making is not just ‘epistemological in nature but is also ontological, phenomenological, axiological, and existential in nature’ (Kovbasyuk, 2013, p.15). Meaning making involves making assumptions about the nature and form of reality; focuses on the meanings things have in our experience; requires values and value judgments; and necessitates a meaning maker who is free to decide how meaning is made. This is why ‘the problem of personal meaning escapes any positivistic approach’ (Leontiev, 2005, p.6).

This study also conceptualises sense making as an aspect of the wider process of meaning making (Kopacz et al., 2019). Sense making is a cognitive process focused on comprehension:

a search for plausibility and coherence, that is reasonable and memorable, which embodies past experience and expectations, and maintains the self while resonating with others (Brown et al., 2008, p. 1038).

Sense making involves orientating effort toward coherence (i.e. detecting predictable and reliable patterns in one’s environment) (Heintzelman & King, 2014) and congruence (i.e. fitting new knowledge into existing knowledge frameworks) (Odden & Russ, 2019). Coherence and congruence converge to enable sense making and comprehension which render the self, the world, and one’s place in it understandable. While in many circumstances the meaning and sense made of a stimulus is identical (e.g. for most people, the meaning and sense made of the symbol ∞ is infinity); other circumstances result in a differentiation between the two activities. For example, making sense of a systematic review may necessitate rationalising, considering, and evaluating; while making meaning of it might involve interpreting the review as an effort to synthesise best available evidence (Mason, 2014).

In the context of this study, personal experiences are considered to be *embodied*. Personal experiences are viewed as situated in the context of meaning, relationships, and the lived world. Therefore, meaning making in such experiences is embodied, active, and situated (Larkin et al., 2011). This means that meaning is made through involvement and action; with the body as the

central point of reference. Our bodies shape how we know the world and make meaning (Merleau-Ponty, 1962). Meaning making is always situated in context fashioned by social influences, cultural history, language and how our body is attuned to the environment (Bahler, 2016). Meaning making is more than just the cognitive act of sense making; there are complex, bodily, and relational aspects of meaning making:

Meaning-making is not just an inner, personal process. Neither is meaning-making only a thought process. Instead, the making of meaning is a lived act, a bodily act; it can only be partly narrated, it happens between people, it is multimodal and it energizes and changes people (Østern, 2010, p. 47).

Thus, things become meaningful when we embody the world around us—making the external internal (Stelter, 2010).

1.4. Aim of the research

The overarching aim of the study was to explore how people who experienced a FEP approximately 21 years ago find, develop, and maintain MIL and identify the key factors that influence MIL.

The following research objectives were set:

- To explore the meaning participants attach to their experience of a FEP, as well as subsequent and current psychosis experiences;
- To identify if and how this meaning has influenced their current perspective on MIL;
- To explore participants' perspectives on MIL prior to and after a FEP;
- To explore the role of MIL in the recovery process;
- To identify participants' perspectives on the factors (barriers to, and facilitators of) that influence the finding, development, and maintenance of MIL;

- To explore if the perspectives of people in remission from psychosis differ to those not in remission

1.5 About the author of the thesis

To assist the reader in appraising the degree to which my preconceptions, assumptions, and experiences have influenced this thesis, I will now make some statements about myself.

In light of the fact that I am the author of this thesis, it is apparent that I consider MIL as deeply important aspect of existence. I view MIL as *the reason* why I value my life—because it is meaningful to me. I see it as the driving force behind much of my behaviour; why I decided to work in the area I do (mental health research), why I socialise, why I try to help others, why I cherish love, and why I regard my moral integrity so highly. At the same time however, I also see my focus on MIL as something that can distract me from the practicalities of living and surviving in the world.

From an academic perspective, I hold a Bachelor of Arts degree (Psychology, Anthropology, and Philosophy) and a Master of Science in Applied Psychology. As a researcher with over 12 years' experience in the mental health field, I view MIL as an important dimension of wellbeing and mental health. I have perceived much of the distress that service users have shared with me over the years as linked to difficulties experiencing MIL. This has led to an increased interest in reading about MIL for my own growth and development but also to inform my work when writing about mental health recovery in an academic context.

Since 2014, I have begun to research recovery in psychosis. I see the subjective lived experience of psychosis as something that warrants attention not just from an academic standpoint but from a societal one. I am aware that each person's perspective on MIL is a deeply personal thing and that I could be accused of appropriating the narratives of the people who took part in this research.

However, I am firm in my conviction that conducting this study is a correct and acceptable thing to

do as to ignore the concept of MIL in psychosis leaves people without support in a key area of their recovery. While, like all human beings, I have experienced challenges in life, I have not experienced psychosis myself.

1.6 Developing the research idea

In my research experience since 2006, I had developed some expertise in the recovery approach in mental health. I knew I wanted to conduct a study in this area as the focus of the recovery approach on justice, citizenship, and human rights spoke to my value system. I also worked with people with psychosis before and was motivated to continue to do so as I felt psychosis was an under researched experience. Having previously investigated psychiatric stigma with people who were diagnosed with schizophrenia, I was aware that people experiencing psychosis are often devalued by society. At times, I also saw this devaluing in some of the language used by academics to describe psychosis experiences and in the restricted nature of much psychosis research.

Over the course of my career, I was struck by the distress psychosis brought but also, at times, how some people viewed aspects of their psychosis in a positive light. This sparked my curiosity as my education in psychology had only described psychosis as something that was detrimental to wellbeing and quality of life. In my previous experiences of working with Principal Investigators and supporting them to coordinate two randomised controlled trials, I often felt very restricted when using quantitative measures to appraise outcome. Service users would frequently communicate a desire to explore the meaning of their experiences with me. This was not possible as it would be unethical to do so due to the context of my interactions with service users (i.e. assessing their outcome as part of a trial). However, my prior education in psychology had given me a yearning to explore the deeper aspects of life; what *really* matters to people.

Over the course of preparing my application for the PhD programme, I became aware of the presence of the concept of MIL within the recovery literature. Yet, the in-depth exploration of the construct in the context of mental health recovery in psychosis was lacking. In 2014, I had also

begun a role working with a Principal Investigator to coordinate a research study that sought to follow up with people 20 years after their First Episode Psychosis (FEP). Considering the amount of time this group of people had to engage in meaning making since their FEP and potentially experience MIL in their recovery journey, they seemed the ideal group to research. Thus, I decided that my PhD study should explore MIL with people who have experience of a FEP.

1.7 Format of the thesis

The thesis is presented in three sections. *Section 1* focuses on the literature that informed the study (Chapters 2 and 3). To contextualise the concept of MIL, the first chapter examines the various theoretical perspectives on MIL that have shaped our understanding of the concept in Western Europe (Chapter 2). This review was not used as a theoretical framework for the study but to develop theoretical sensitivity to assist me in understanding participants' perspectives on MIL. In Chapter 3, the broad range of literature and empirical research relating to MIL, meaning making, psychosis, and mental health recovery is considered, in order to provide the reader with an overview of the current state of knowledge in this area.

In *Section 2*, the epistemological, ontological, and methodological arguments underpinning the study are outlined (Chapter 4). This includes an overview of Interpretative Phenomenological Analysis (IPA), the methodology adopted for the study, with reference to IPA's theoretical, data collection, and data analysis principles. The rationale for selecting IPA as the methodology of the study is also given. Chapter 5 then details how IPA was operationalised for the study; with reference to its multiperspectival design, sampling, data collection, data analysis, and ethical considerations.

Section 3 presents study findings over two chapters. Chapter 6 addresses meaning making in psychosis experiences; while Chapter 7 focuses on MIL in the context of recovery in psychosis. A discussion of findings in the context of extant empirical and theoretical literature is given in Chapter 8. This includes an outlining of the study's strengths and limitations, as well as the

implications (for clinical practice, service provision, and education) and the suggestions for future research that emerged from findings. Chapter 9, the final chapter of the thesis, provides illustrative examples of how reflexivity was embedded in the research processes of the study. The thesis ends with an appraisal of rigour and quality of the study using Yardley's (2000) criteria of sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

CHAPTER TWO: THEORETICAL PERSPECTIVES ON MEANING IN LIFE

2.1 Introduction to the literature that informed this study

In order to contextualise ‘Meaning in Life’ (MIL), this chapter provides a wide-ranging synopsis of the theoretical perspectives on MIL that have shaped our understanding of the concept in Western Europe. The purpose of this chapter is to guide the reader through various perspectives on MIL found in the literature, as these positions are likely to inform how study participants comprehend and operationalise MIL as they navigate their existence in the world. It is not intended to review all of the published MIL literature; instead a reasonably comprehensive account of the differing theoretical positions adopted on MIL is presented. No value judgments regarding the theoretical perspectives presented are made, as all viewpoints are considered equally valid. Therefore perspectives are not presented in chronological order or as a progression towards ‘accuracy’ or ‘truth’ (e.g. from Supernaturalism to Existentialism). Each perspective presented has grown to prominence at different time points, in different cultural settings, to serve different functions. For the purpose of clarity, perspectives are presented as discrete categories; however, it is likely that each individual person draws on multiple perspectives when forming their specific and unique position on MIL. The focus of this chapter is on the dominant written perspectives that have impacted Western European culture as opposed to perspectives emerging from Eastern thought or from other forms of expression. For example, I do not elaborate on the Japanese idea of *ikigai* (a reason for being that necessitates a deep and time-consuming search for self) nor do I detail how MIL is represented in the visual arts. This chapter concludes with definitions of constructs that are similar and related to MIL in order to differentiate them from MIL.

2.2 Meaning in Life in the world today

Contemporary life in Western Europe is characterised by globalisation, neoliberalism, and environmental/climate uncertainty; with an increased prevalence of residential mobility, increased inter-group hatred and violence, and community disentanglement. In comparison to previous

epochs, contemporary life is typified by a decreased emphasis on shared goals and collective responsibility; with many people facing economic insecurity (e.g. pressure to compete for temporary work contracts) and having their free time dominated by technology contact (Nafstad et al., 2007; Kreyenfeld et al., 2012; Chopik, 2016). In recent decades, changes in the nature of society have resulted in the bond between religion and culture unravelling, with the attainment of enhanced scientific understanding and technical control over the environment (Roberts, 2007). Consequently, the erosion of religion and tradition (which provided structured, culturally sanctioned, and socially embraced sources of meaning) has left each individual with the primary responsibility of fashioning a meaningful life for themselves (Schlegel et al., 2014). Maslow (1964, p. 42) has referred to this as the pervasive ‘valuelessness’ in contemporary Western culture, signified by ‘A rather bleak, boring, unexciting, unemotional, cool philosophy of life’. Frankl (2004) described a similar state of meaninglessness as an ‘existential vacuum’ (p. 111) attributing it to non-commitment to one’s personal values. Such meaninglessness risks the development of a *crisis of meaning* and ‘noogenic neurosis’ (p. 112) defined by neurotic symptomatology² resulting from existential frustration.

Western European society has become increasingly secular over time marked by a decrease in the societal influence of religion (Sahgal, 2018). Commentators—such as psychologists Will Crescioni and Roy Baumeister (2013)—have argued that this shift has resulted in a ‘value gap’ (p. 4) internationally. They posit that today’s society presents opportunities to attain purpose, demonstrate efficacy, gain environmental control, and develop self-worth. However, they argue that contemporary society fails to provide a set of concrete, absolute, unchangeable values or sufficient guidance on how to determine which pursuits are more *meaningful* than others. There is no longer clear direction for how one should live a life of value and worth. Consequently, society falls short of meeting the human need to justify actions as they relate to moral standards. A similar case is made by Schlegel et al. (2009) who contend that the absence of consensus value bases means the modern human is confronted with more responsibility to develop their own personal

² Mental health difficulties including depression, anxiety, and obsessive thoughts/behaviour which are not the result of organic disease.

value system. Choices and actions are appraised in terms of their congruence with one's 'True Self' (Schlegel et al., 2009, p. 1). Those deemed harmonious are judged to be valuable or worthwhile; considered expressions of the True Self. Other authors have argued that modern culture has attempted to redress the decline of societal values with individualism (Bailey, 1990); consumerism (Burroughs et al., 2013); yoga retreats (Ponder & Holladay, 2013); and self-help books (Schueller & Parks, 2014).

Present-day citizens have to confront additional barriers to MIL; such as normalised precarious modes of living (Bidadanure, 2013) and unstable routes to efficacy and self-worth. For example, a labour market characterised by freelance work or short-term contracts, rather than permanent jobs. Modern paths to MIL are vulnerable to the whims of an unpredictable economy or a capricious lover (Vuolo et al., 2013; Hatchel & Subrahmanyam, 2016). Moreover, a decline in social capital in Western Europe—specifically, trust in others and group/association participation—has been documented (Francesco & Mikucka, 2015). MIL attained from social cohesion, in-person social intercourse, and *real world* social connectedness may not be as accessible as it was to previous generations (Stavrova & Luhmann, 2016). Modern life is embedded in global neo-liberal politics and ideology (Beresford, 2015) which privileges the free market and individual self-perception, power, and private ownership (Losev et al., 2003). MIL obtained from collective responsibility may be diminished if cultural discourses are dominated by competitive individualism (Neilson, 2015).

Considering these contemporary developments, it falls to each individual citizen of Western Europe to develop their own personal understanding of MIL and to try to live a life aligned to it. MIL is dependent on how human beings process and interpret their own reality (McKnight & Kashdan, 2009). The concept is grounded in an individual's character, personality, and outlook; as well as their self-defined schemata and personal paradigm. It is constructed across the lifespan as personal and socio-cultural history is integrated (Schnell, 2009). However, the facets of MIL can be difficult to identify as they are often represented subconsciously. Thus recognising and personally defining MIL in today's world necessitates introspective exploration (Leontiev, 2007).

2.3 Role of literature in Interpretative Phenomenological Analysis (IPA)

The utilisation of literature and established theoretical frameworks presents a particular challenge when conducting an IPA study, which is the methodology used in this study. Husserl's (2012, p. 56) concept of 'bracketing' is defined by an almost absolute exclusion of all external and internal beliefs and assumptions. This practice remains controversial. LeVasseur (2003) has criticised it as 'perplexing' (p.409) and likely to result in misunderstanding and misapplication; Snelgrove (2014) has noted the absence of practical guidance on how bracketing is implemented in IPA studies; and Fouché (1984) has queried the distinction between bracketing and attempts to reduce bias and enhance rigour. Advocates of IPA believe that it is impossible to identify unbiased cognitions as human beings form part of the world and are therefore inseparable from it. Consequently, we cannot divorce description from our own interpretation (Larkin et al., 2006). In IPA, 'bracketing' is something else: it is the researcher's *best efforts* to suspend critical judgment about the natural world in order to focus on the analysis of experience. It is the time limited refusal of critical engagement; to attempt to *temporarily* withhold and suspend the researcher's own preconceptions—including their knowledge of the literature and pre-defined theoretical frameworks—in the process of interpreting a dataset (Spinelli, 2005).

IPA utilises an 'enlivened form of bracketing as both a cyclical process and something which can only be partially achieved' (Smith et al., 2009, p. 25). IPA therefore adopts a constructivist-interpretivist perspective; a researcher's lived experience and values cannot be demarcated from the research process (Vachon et al., 2012). The 'phenomenological reduction'³ or 'bracketing' (p. 322) in IPA is interpreted as a commitment to researcher reflexivity and open-mindedness (Larkin, et al., 2011). The position and influence of the researcher is recognised and explored in analysis. As the

³ The scientific process involving the suspension of biases, assumptions, presuppositions, judgments, theories, and/or previous experiences in order to see and describe phenomena.

‘fore-structure’⁴ (which blocks interpretation) only emerges once the researcher commences interpretation, it is impossible to ‘bracket’ completely. Therefore, the reflexivity required in IPA is an ever-changing process; complex, dynamic, and iterative. Consequently, a key task for the IPA researcher is ‘to critically and reflexively evaluate how these pre-understandings influence the research (be it at data gathering or analysis phases) and to devise ways of containing their seductive power’ (Finlay, 2008, p. 17). This engages the ‘hermeneutic circle’ which involves the interplay between (i) interpreter and the object of interpretation and (ii) the dataset whole and parts (Shinebourne, 2001, p. 21).

In the context of this work, the literature explored in this chapter is utilised to develop a theoretical grounding on MIL and develop theoretical sensitivity⁵ as opposed to being used to impose a theoretical framework on the data. As such, it guided my interpretation of the data; assisting me to understand how participants might think about MIL and why they might conceptualise MIL in a particular way. This helped to sharpen my awareness, widen my empathy, and enhance my ability to detect and understated implicit (and often unconsciously communicated) subtitles in the data. The literature discussed in this chapter was read prior to study conceptualisation and refined over the course of conducting the study.

2.4 Difficulties in presenting divergent perspectives on Meaning in Life

When humankind contemplates the vastness of the universe, the tedium of daily life, and the inevitable expiry of humanity, individual lives can seem wholly meaningless. MIL is arguably one of the most difficult constructs to study. Its conceptual clarity has eluded philosophers and

⁴ Terminology used by Heidegger (1962). Comprises: (i) fore-having (practical familiarity or background practices from one’s world that enable interpretation); (ii) fore-sight (the point of view from which an interpretation is made); and (iii) fore-conception (the expectations of what might be anticipated in an interpretation).

⁵ In this context, theoretical sensitivity means my capacity to understand the data; my sensitivity to concepts, meanings, and relationships within the data; and my ability to separate data that are pertinent to the aim and objectives of the study from data that are not.

scientists for centuries; yet its importance, significance, and value as a construct is manifest. What is life for—if not the perpetual search for meaning in each living moment? The quest for its attainment is what defines the human condition. Frankl (2004) has argued that MIL is the single greatest motivating factor in human action; the search for it being *the* primary source of motivation to live. MIL can be why we get out of bed in the morning and engage with life (Bryan et al., 2013). For many, it is likely to be their final thought on earth (Wolf, 2012). While being complex (Cohen & Cairns, 2012), multifaceted (Dezutter et al., 2014), personal (Reker & Wong, 2012), dynamic (Halusic & King, 2013), elusive (Heintzelman & King, 2012), questionably ineffable (Heintzelman et al., 2013), and potentially unattainable (King et al., 2016); promising developments in the field of MIL research indicate that humankind may have the capacity to reach a shared understanding of the concept (Metz, 2011; George & Park, 2016; Martela & Steger, 2016). Although some authors exhibit more scepticism; considering MIL more of an ‘insightful metaphor rather than a sound scientific concept’ (Leontiev, 2013, p. 460).

There has been a paroxysm of research interest in MIL in the last 20 years. This flourishing of theoretical and empirical literature has been described as an ‘existential turn’ in modern science (Schnell, 2012, p. 5). It has been concluded that ‘there is now a critical mass of empirical evidence and a convergence of expert opinions that personal meaning is important not only for survival but also for health and well-being’ (Wong & Fry, 1998, p. xvii). MIL is now endorsed by academics and health professionals as a vital component of recovery in mental health (Leamy et al., 2011) and considered a keystone of wellbeing (Steger, 2012).

Although recent years have seen a surge in empirical and theoretical MIL research; the field has suffered from conceptual equivocality. To date, at times, it has utilised simplified approaches to study a nuanced construct; neglecting its conceptual range (Martela & Steger, 2016). Heintzelman & King (2013) refer to ‘the nagging definitional ambiguity of the construct’ (p. 471). Therefore, attaining conceptual clarity of MIL is a prerequisite to empirical and theoretical advancements. MIL has been conceptualised both subjectively and objectively. The meaning found in each individual’s life is specific and unique (Frankl, 2004) and created by the person themselves

(Battista & Almond, 1973); yet there are aspects of MIL that appear to exist across cultures and individuals (Steger et al., 2008a; 2008b). Research investigating MIL has been hampered by investigators using diverse terminology, operating in isolation in varied disciplines, reading different journals, and not engaging with each other to attain unanimity. Thankfully, conceptual clarity is now emerging through (i) debate and consensus seeking at international conferences (Wong, 2017); (ii) dimension integration in recent reviews (e.g. Martela et al., 2016); and (iii) efforts to measure MIL comprehensively and holistically (George & Park, 2016).

2.5 Framework of theoretical perspectives on Meaning in Life

MIL has been theorised and deconstructed in literature from a wide range of disciplines including philosophy, psychology, psychiatry, nursing, theology, anthropology, biology, and sociology. I have developed a conceptualisation of the various MIL perspectives using a framework based on (i) whether or not MIL exists and (ii) our capacity, efficacy, and agency to build MIL ourselves. The latter is subdivided into three categories—firstly, perspectives which deem MIL as a purely attainable from external sources; secondly, perspectives, which identify individual thought and action as the only well of meaning; and thirdly, theoretical positions that integrate these two perspectives. This framework is presented in Table 2.1. Engaging with these various perspectives can provide insight into the numerous political, cultural, and social influences that citizens of Western Europe are exposed to as they embark on the quest to live meaningful lives and understand MIL.

Table 2. 1 An overview of Meaning in Life perspectives

The absence of MIL	MIL as an external gift	MIL as individual capacity, efficacy, and agency	MIL as integration
MIL – fundamental nothingness	MIL – the presence of ultimate significance/justice	MIL – worldly action	MIL – embodied spirituality
MIL – a human delusion	MIL – literal/symbolic immortality	MIL – authenticity	MIL – belonging through connectedness
		MIL – creative acts of value	MIL – sense making, benefit finding, and action justification

2.6 The absence of Meaning in Life

Exploring the first MIL category (characterised by a rejection of the existence of the concept or any route to/source of its attainment) enables us to comprehend the deeply negative and inherently pessimistic perspectives which compel an individual to accept the incoherent, insignificant, and purposeless nature of their existence. Two discrete perspectives exist within this category: MIL – fundamental nothingness and MIL – a human delusion.

2.6.1 Meaning in Life – fundamental nothingness

In 1901, in *Will to Power*, Friedrich Nietzsche warned of the catastrophic emergence of a philosophical perspective so dangerous it could undermine all of humanity—Nihilism. According to Thielicke (1969, p. 27), ‘Nihilism literally has only one truth to declare, namely, that ultimately nothingness prevails and the world is meaningless’. This system of principles, characterised by a fundamental nothingness (i.e. absence of belief, epistemological failure, value destruction, and cosmic purposelessness) has significantly influenced how individuals have understood and conceptualised MIL in the 20th and 21st century. The position asserts that, as science has failed to establish the lawfulness of the world or that existence is intelligible or justified, we must refuse to acknowledge the concept of meaning or the presence of MIL in any form. The nihilist position is: as meaning is impossible to create, reason is powerless, all actions are equal in value, and all values

lack any form of foundation. Thus all of our value systems are essentially arbitrary; all life and the universe itself is purposeless and bereft of meaning (Nietzsche, 1968; Richardson & Gemes, 2013). Therefore there are no routes to MIL and all thoughts, actions, emotions, and forms of human suffering are hollow, senseless, and insignificant (Nietzsche, 1973). To exist honestly, we must embrace the reality of death, for both religion and metaphysics are just escapism from this reality (Storey, 2011). Nietzsche considered Nihilism an overwhelmingly destructive force. In a world where all truth is imaginary, reality perishes, and humanity is plunged into crisis. This forewarning is particularly germane to modern times. Consider the concept of ‘alternative facts’⁶ utilised by Counselor to President Donald Trump, Kellyanne Conway during a *Meet the Press* interview in 2017. Ultimately Nihilism concludes that human beings exist in a cold and inhuman world where nothingness triumphs (Rose, 1994).

2.6.2 Meaning in Life – a human delusion

Absurdism, a MIL theoretical perspective first presented by Albert Camus in *The Myth of Sisyphus* (1979), contends that any mode of meaning that is constructed in life is entirely illusionary and delusional. This theoretical position emanated from a desire to operationalise *meaninglessness* in order to develop strategies to confront and counteract the fundamental nothingness espoused by Nihilism and enable humanity to continue living in a cosmos devoid of meaning. It contends that the status of human existence is absurd and senseless and draws attention to the farcicality of the human quest for meaning in spite of this ‘truth’. Nihilism is defined by the multiple conflicts. Firstly, between the intrinsic human need, longing, and demand for a rational explanation of the cosmos—on one hand—and being confronted with its incomprehensible nature—on the other. Secondly, between identifying unity, order, and organisation in existence; while at the same time observing its incoherent character. Thirdly, at times perceiving a higher transcendent reality with cosmic universal meaning; while at other times being challenged by its absence. Fourthly,

⁶ Phrase used to defended White House Press Secretary Sean Spicer's false statement about attendance numbers at Donald Trump's presidential inauguration. When asked why Spicer would ‘utter a provable falsehood’, Conway responded that Spicer was providing ‘alternative facts’.

navigating the tension between believing in immortality or some form of permanence and believing that all action will come to nothing and all existence will end in oblivion. In this way, ‘the absurd is born of this confrontation between the human need and the unreasonable silence of the world’ (Camus, 1979, p. 31-32).

The solution presented by Absurdism is to have an honest confrontation with the bleak, grim, terrifying truth of our reality—that there is no MIL, while simultaneously being lucid, honest, and boldly refusing to allow this truth destroy us. We must accept that:

[life] will be lived all the better if it has no meaning. Living an experience, a particular fate, is accepting it fully (Camus, 1979, p. 53).

According to Absurdism, contempt and disdain for the meaninglessness of life brings a bizarre form of salvation. To confront the absurd, we must ignore the future and live for the moment, for the *now*, for our current experience. We must live life to the full; tackle everything in life with fervour, energy, and vigour; and push things to the limit: ‘The absurd man can only drain everything to the bitter end, and deplete himself’ (Camus, 1979, p. 55). This perspective differs substantively from Nihilism as it offers a rationale for living.

2.7 Meaning in Life as an external gift

In stark contrast to the *absence of MIL* category, supernatural theoretical perspectives on MIL conclude that MIL is attainable; however, they conceptualise it solely as an external object. In Western Europe, these MIL standpoints are predominately associated with Judeo-Christian dogma and belief frameworks. Engaging with this MIL category enables us to develop an understanding of how MIL has been theorised in terms of our relationships with entities of essential meaning (ultimate significance, ultimate justice, and immortality). Whether or not ‘God’ or the ‘soul’ exists is beyond our control as human beings. For these phenomena to bring MIL to us, they require unquestioning faith. Therefore, these perspectives are defined by our inability to bring meaning

into our own lives in the absence of the power to establish the presence of these entities. Whether or not they exist is wholly determined externally to us. From these theoretical positions, we have no agency or capacity to influence whether or not the potential for MIL exists in our lives. We can only affect how we relate to God/our souls (if we conclude they exist on faith alone). If we believe they do, then we are confronted by the societal expectation of gratitude for the *external gift* of MIL. This externally orientated MIL category has produced two distinct perspectives: MIL – the presence of ultimate significance/justice and MIL – literal/symbolic immortality.

2.7.1 Meaning in Life – the presence of ultimate significance/justice

The position of supernaturalism is that life is meaningful as a consequence of the existence of the external spiritual world. MIL from this perspective stems only from the manifestation of ultimate significance and/or justice (i.e. God and/or a soul). God is defined here as: an entity that is omniscient, omnipotent, all good, who has maximal greatness, and is responsible for the creation of the physical universe. A soul being: the spiritual immaterial essence, actuating cause, or animating principle of one's life. The standpoint of supernaturalism is that—if neither a God nor the soul existed and if we are unsuccessful in relating to them as we 'ought' to, in the 'correct' way—then life is bereft of meaning. Judeo-Christian dogma deems our lives are significant 'in virtue of immaterial properties such as a perfect being (God) or a perfect state of being (heaven)'; concluding that existence has value only in so far as its worth comes 'from beyond nature', from outside oneself (Metz, 2013, p. 407).

God can be considered the ultimate source of justice in the universe; the origin of invariant, binding, and universally applicable moral rules. Modern philosophers have argued that life is meaningless and nonsensical if there is no right or wrong (Craig 1994; Cottingham 2003). Thus, MIL comes from God existing and humankind having the capacity to relate to God through orthodoxy (a belief that is true) and orthopraxy (conduct that is correct). MIL also emanates from perfect universal justice derived from an afterlife made possible by the presence of a soul (Davis,

1987; Craig, 1994). These authors hypothesise that life is meaningless, insignificant, and nonsensical in the presence of superfluous evil, unpunished wickedness, and unrewarded virtue. They argue that—as such injustices are permitted to flourish on earth—righteousness, impartiality, integrity, and thus *meaning* must come from a higher order judgment made in the afterlife; which consequently requires a soul. This eternal rectifying of injustice allows only the moral and honourable of society to achieve their highest free and informed aspirations (e.g. maximal well-being, eternal flourishing, or ‘perfect happiness’⁷) (Goetz, 2012, p. 88).

The theoretical position being articulated is that God represents an entity of higher worth than human life—a manifestation of ultimate significance, value, and magnitude. Since the emergence of Judeo-Christian belief systems in Western Europe, the conviction—that we only exist on earth to fulfil the purpose God has decreed for us—has become prevalent among the faithful. The more closely our actions mirror God’s plan and the more they enable its full realisation, the greater meaning our lives have. Our purpose comes from the ‘reality’ of a supreme and definitive significance (God)—the only legitimate source of MIL. Deciding to reject God or attempting but failing to establish and maintain a relationship with God renders life meaningless; irrespective of whether or not there is an afterlife (Brown, 1971; Levine 1987; Cottingham 2003; Affolter, 2007). Simply worshiping or loving this ‘perfect being’ (in this life or the afterlife) constitutes such a relationship (Hartshorne, 1996). Therefore, human life has meaning in so far as it contributes to God’s *design*. Meaning can also originate from the immortalisation of our welfare in God’s everlasting memory (Hartshorne, 1984). The idea and significance of the soul is generated and valued across cultures (Brown, 1991); with some of us deeming it the most important of human considerations (Bett, 2006)—the most valuable and enduring emblem of our identity (Bryden & MacKinlay, 2003). From this viewpoint, it is the ultimate significance of the soul and our nurturing of its condition that brings MIL (Boyd, 1996).

2.7.2 Meaning in Life – literal/symbolic immortality

⁷ Interminable happiness comprising nothing but experiences of pleasure.

This MIL perspective contends that to manage the apparent meaningless of the suffering and perceived inadequacy inherent in the human condition and to confront the reality of our eventual demise—we need more than just a sense of efficacy within a framework of expected relationships—we need the promise of literal and/or symbolic immortality. Evolutionary psychology adopts the standpoint that all human behaviour (and consequently humankind’s search for MIL) can be understood as stemming from evolutionarily derived biological drives (Buss, 2000). From this perspective, MIL is confined to becoming better adapted to our environment, enhancing our fitness in evolutionary terms, and genetically passing this fitness on to the largest amount of offspring possible (Auhagen, 2000). Therefore having children (obtaining MIL externally) is the only genuine route to MIL as it endows human life with symbolic immortality. The contention here is that if we lack all agency and free will (due to our enslavement to natural selection), the pursuit of any other form of MIL is meaningless. Darwinistic naturalism contends that if all that exists is the ‘Big Bang’ and the physical and biological processes that emerged from it, then the brute and random nature of these processes render life meaningless. The universe is simply an arbitrary contingent succession of events. One valuable insight gained from evolutionary theory is that the search for MIL should not necessitate an examination of the origins of human life (Stanovich, 2004). The question has already been answered by Darwin. Instead, from an evolutionary perspective, MIL can be acquired in the transitioning of initially ‘mindless and pointless algorithmic processes’ to intelligence (Dennett, 1996, p. 205). As a result, from this perspective, MIL comes from the immortality in the form of ultimate progress of evolution, signified by an individual’s enhanced adaptation and evolutionary fitness.

Supernatural perspectives on MIL can emphasise immortality. The presence of a soul allows transcendence from the corporeal, finite, and mortal human condition to a state of permanence; and it is this immortality that imbues meaning into life. MIL therefore is ‘permanent difference’, ‘infinite effect’ or ‘ultimate consequence’ (Metz, 2002, p. 789). Leo Tolstoy (1987) asserted the perpetual impact of the spiritual/immortal self is the only way humankind can achieve something of worth with life; claiming meaning is impossible without worth. Life can become more meaningful,

as one increasingly orientates one's thoughts and behaviour toward the highest possible nature—God. It is the infinite nature of God that endows us with immortality and a belief that our lives have meaning (Nozick 1981; Tolstoy, 1987; Craig 1994; Cooper, 2005).

According to Terror Management Theory⁸ (Greenberg et al., 1986), we desire our lives to be imbued with meaning as the prospect that all that is us or indeed connected to us—our loved ones, the story of our lives, our mark on the universe—will ultimately be annihilated is simply too abjectly terrifying to accept. This terror is managed by a 'cultural anxiety buffer' (Salzman & Halloran, 2004, p. 236) which provides assurance of literal and/or symbolic immortality to those of us who meet the value standards set by cultural worldviews⁹ (i.e. a set of shared beliefs about the nature of reality). This in turn bestows us with self-esteem, personal worth, and safety in our existence. As a consequence, culture curtails terror by developing shared symbolic context that instils the universe with meaning; making it coherent and permanent (Harmon-Jones et al., 1997; Sullivan et al., 2013).

2.8 Meaning in Life as individual capacity, efficacy, and agency

This third MIL category is demarcated by our ability to effect change in our lives and seek out and obtain MIL for ourselves. From these perspectives, MIL is defined by the actions we engage in on earth. These theoretical positions are characterised by individual power and control; each of us demonstrating capacity, efficacy, and agency to construct our own personal, individualised, subjective MIL. They are secular and reject the idea of the external 'other' bequeathing meaning to life. My discussion of the contribution of these theoretical perspectives is presented under the headings: MIL – worldly action; MIL – authenticity; and MIL – creative acts of value. Examining these perspectives enables us to comprehend and interpret how people develop their own personal individual meaning systems.

⁸ A recently developed motivational account of the creation and defence of MIL.

⁹ An adopted perspective *on* the world and culturally imposed standards of being/acting *in* the world.

2.8.1 Meaning in Life – worldly action

Naturalism asserts the position that a significant, coherent, purposeful and thus meaningful existence is possible in a purely physical world. It does not contend that a supernatural realm does not exist; but simply that the natural universe we inhabit is sufficient for MIL—irrespective of the existence of a supernatural world. This perspective emphasises how meaning is constructed through worldly action and considers aspects of being that warrant esteem and purpose through pioneering exploits and courageous decisions (Sartre, 1948; Yalom, 1980; Maddi, 2013). Broadly speaking, there are two different schools of thought adopting this stance. The first is subjective naturalism (e.g. Sartre, 1975; Taylor, 1970); the perspective that whether or not one attains MIL is subjective; it depends on the person themselves, their attitudes, values, and disposition. Therefore wanting, choosing, having, and loving people/animals/things/values is sufficient for MIL and there is no MIL independent of the attainment of the objects of these ‘propositional attitudes’¹⁰ (Metz, 2013). The second is objective naturalism; the point of view that the basis of MIL can come from ways of *being-in-the-world* in their own right; that some thoughts, behaviours, and emotions can be deemed more meaningful than others; and that meaning (as a construct) can be measured across lives and experiences. MIL is fashioned from linking one’s life to mind-independent, inherently valuable conditions; which are more than just the result of our desires and choices. Something is considered meaningful by virtue of its intrinsic nature. Purists from this school of thought claim that certain actions provide MIL irrespective of our response to them (Singer, 1996). The more common position acknowledges that subjective factors play a role in meaning making; it just also maintains that we can make objective judgments regarding MIL (Wolf, 1997; Metz, 2013). While theorising MIL as worldly action alone does not categorically deny the possibility that there might be another route to meaning that allows us to transcend our corporeal appetites, it does substantially devalue it.

¹⁰ Mental states including desires, emotions, and goals regarding states of affairs.

2.8.2 *Meaning in Life – authenticity*

Existentialism discards reason as *the* source of MIL and rejects the universal meaning in metaphysical principles espoused by positivism, empiricism, and rationalism. Although existentialists regard rational clarity as desirable where feasible, they consider the most fundamental questions relating to human existence inaccessible to reason and science. These philosophers believe that human beings cannot be comprehensively understood in terms of science or moral theory categories. Instead existentialists conclude that a new pathway is necessary to comprehend the human condition—a categorical framework governed by the norm of authenticity. Authenticity is safeguarded by remaining true to our own character, essence, or spirit; despite encountering external forces, demands and influencing factors. ‘Absolute freedom’ is deemed a prerequisite to authenticity; we demonstrate this through creativity in our actions, by exhibiting truthfulness in sincerity, dedication, and intentions (Kant, 1929; Heidegger, 1962; Hegel, 1977; Rousseau, 1979; Sartre, 1992; Kierkegaard, 1985; Nehamas, 1999).

Existentialism constitutes the belief that free will, personal responsibility, and awareness can be integrated to allow one to fashion MIL within a world that intrinsically lacks meaning in and of itself. The existential MIL perspective is that that meaning comes from confronting death, suffering, and meaninglessness through innovative actions and brave choices (Yalom, 1980; Sartre, 1992). Each individual must take personal responsibility for themselves; to define and attain their own MIL. This is achieved by embracing existence and preserving our authenticity in order to offset the abject nothingness that comes with the absence of the transcendental. This perspective defines essence as meaning attributed to life (i.e. MIL) and holds that existence comes before essence. As Sartre (1975, p. 22) put it:

If man, as the existentialist conceives him, is indefinable, it is because at first he is not something. Only afterward will he be something, and he himself will have made what he will be. Thus, there is no human nature, since there is no God to conceive it.

Therefore MIL is not a contemplative theory but a consequence of a commitment to, and engagement with, life (Sartre, 1975).

2.8.3 Meaning in Life – creative acts of value

Throughout the 20th and 21st century, a small number of authors have argued that what humankind seeks primarily from existence is a mode of creativity that will make life meaningful; that the expression of creativity allows one to develop a personal sense of MIL by facilitating self-discovery and self-reflection (Singer, 1996; Yalom, 1980). The Creativity Account of MIL was only formally theorised recently by Taylor (1981). This theoretical perspective argues that MIL is derived from creative efforts that result in construction of value. Hence, it is only a creative life that is a meaningful one; all other acts and sources of *supposed* meaning are inane. An endeavour can only be deemed valuable by the individual performing it. What these writers emphasise is ‘meaningful creative activity’ defined as actions that achieve something of great consequence by virtue of them realising the purpose that the creator set out to achieve (Matheson, 2016, p. 76). It is only by creating something original that one can elevate ourselves and obtain MIL. Therefore, the pursuit of meaning is not a search for a prior reality we are hoping to unveil; but primarily a quest to identify a mode of creativity that will deem our lives meaningful (Singer, 1996). Metz (2011, p. 398) has extended this argument, contending that ‘the good, the true, and the beautiful confer great meaning on life insofar as we transcend our animal nature by using our rational nature in extremely creative ways’.

2.9 Meaning in Life as integration

A final MIL category, which has emerged in the last century, sought to reconcile the opposing positions of MIL as an external gift and MIL as individual capacity, efficacy, and agency. These

perspectives allow for engagement with the transcendental¹¹ without the prerequisite of the existence of a God or a soul (as we can achieve these dimensions of MIL without them). They draw on both the spiritual and natural world in our journey toward MIL. Value adoption, societal contribution, belonging, sense making, benefit finding, and action justification allow us to transcend the animal self, adverse life events, and actions/events incongruent to our value system or personal narrative. From this viewpoint, we have power regarding whether or not we have MIL; we construct it ourselves—the absence of external entities does not nullify our lives. Within this category there are three perspectives: MIL – embodied spirituality; MIL – belonging through connectedness; and MIL – sense making, benefit finding, and action justification.

2.9.1 Meaning in Life – embodied spirituality

Arguably the most influential of all writers on MIL in the 20th century, Viktor Emil Frankl (1905–1997) is credited with drawing substantial theoretical and empirical interest in the concept. Frankl (2004, p. 105) has described a person's search for MIL as the primary motivation for existence. This 'will to meaning' is equated with the motivation to satisfy the human need for self-transcendence; meeting this need constitutes fully functional flourishing as a human being (Fabry, 1994). Wong (2014, p. 156) describes Frankl's theory of MIL as relying on the 'spiritual core'; the 'noetic' dimension of human existence. The term noetic here refers to everything that is specifically human, what is distinct about human nature (i.e. that we are inherently meaning focused). Unlike animals, humans are driven by a yearning to understand and attain meaning from the universe in which they live. Frankl (2014) argues that the highest qualities of humanity (what is good and right about human life) lie in our spiritual nature. Meaning seeking arises from *embodied spirituality* (seeking and attaining MIL through creative, heuristic, and dispositional values).

¹¹ Transcendental is defined as experiences, objects, or ideas that are profoundly significant, special, and unusual, lie beyond the practical experience of ordinary life, and cannot be discovered or understood by conventional reasoning.

By ‘spiritual’ aspects of life, Frankl is referring to ‘our will to meaning, our goal orientation, ideas and ideals, creativity, imagination, faith, love that goes beyond the physical, a conscience beyond the superego, self-transcendence, commitments, responsibility, a sense of humour, and the freedom of choice making’ (Fabry, 1994, p. 18–19). The ‘embodied’ quality of this spirituality that brings MIL is characterised by how it is expressed in the physical world; how it is given a tangible or visible form. For Frankl, self-transcendence is the essence of human nature itself. This constitutes a philanthropic and unselfish orientation of our cognitions and actions ‘toward causes to serve or people to love’ (Fabry, 1994, p. xix). To attain meaning, one must decide for what, to what, and to whom one is responsible. It is by forgetting ourselves by being devoted to a person or (super)natural cause that we become fully human and actualised. Irrespective of a belief in a deity, higher order, or larger non-naturalistic realm, all humans have a spiritual nature that hungers for beauty, virtuousness, truth, and self-transcendence. Frankl’s standpoint is that this intrinsic motivation to transcend the physical self can be understood in either naturalist rational or supernatural terms. The construct is both vertically relational (it extends beyond the boundaries of space and time) and horizontally relational (it transcends egotism and self-regard). Self-transcendence can be facilitated by finding our niche in the world or identifying our unique calling that utilises our distinctive and inimitable aptitudes, personality, and life experience to utilise our full and true potential. This calling necessitates a worldly societal contribution (the MIL attained from answering it is mediated by social responsibility) but also allows us to go beyond the physical world (Wong, 2014).

2.9.2 Meaning in Life – belonging through connectedness

In the last 50 years, a new MIL perspective has emerged in the literature; one that defines MIL as belonging through connectedness with the self, other beings, nature, and the transcendental. This perspective is grounded in the understanding that we seek meaning through relationships with other people, the nonhuman environment, and the ultimate reality (Canada, 1980). It demarcated from other integrative standpoints by two arguments. Firstly, that for a life to have meaning it must

belong within a framework of connections. Secondly, rather than being a source, cause, or facet of MIL, MIL in its very essence, *is* inter-connectedness (Delle Fave & Soosai-Nathan, 2014) and the sense of belonging experienced finding our place in the patchwork of existence (Marris, 1974; Thompson & Janigian, 1988; Yalom, 1980; Richer & Ezer, 2000). The need to belong can therefore be understood as a core motive for meaning making (Stillman & Baumeister, 2009).

Manifesting MIL involves connecting with, accepting, and loving ourselves; through establishing our identity and experiencing self-growth (Missinne, 2000; Noviana et al., 2016). Self-belonging and self-awareness can be experienced through introspection, reflection, and meditation; ultimately requiring one to ‘go inwards’ to attain MIL. Rejecting the ‘superficial’ belonging of external attachment to people, places, and things, one version of this perspective stresses that true belonging is gracious receptivity of the self and the gift of life (O’Donohue, 1999). Another version defines MIL as connectedness with humankind—the sense of belonging within a physical, human, social structure. This position is founded on the assumption that the human hunger for belonging and the capacity to understand sizable and intricate systems of meaning are inextricably linked in our minds (Baumeister, 2005). Being a part of a larger symbolic entity (e.g. a friendship group, romantic relationship, or family) that transcends our corporeal limitations allows us to expand the boundaries and capacities of the self (Aron et al., 2001). Human relationships can offer love, stability, a shared social identity, and the opportunity to pursue important collective goals (Haslam et al., 2009). This social *belongingness* buffers against uncertainty and meaninglessness (Stillman & Baumeister, 2009).

Connectedness to other forms of life can also constitute MIL—such as bonding with pets or encountering nature (Noviana et al., 2016). Nurturing our relationship with the natural world can constitute MIL (Kellert, 1993; Verbeek & de Waal 2002; Frankl, 2004; Note, 2009; Schnell, 2009; Kjell, 2011). According to ecopsychology, we belong to the earth. One theory, the biophilia hypothesis, posits that we have an innate tendency to seek connection to nature due to our evolutionary development within it. Having contact with nature fosters our desire to care for the planet. When there is a disconnection in this relationship, it can result in distress and a sense of

meaninglessness (Wilson, 1984; Howell et al., 2013). Stepping into a forest brings MIL by affording the opportunity to transcend our ego-centric lives, to relate to something untouched by human hand, to go beyond the day to day mundanity of modern life—to connect with the earth itself (Moore, 2014). These encounters have been described as a ‘felt presence’¹², which can form a cornerstone of our self-identity in relation to others (Solomonova et al., 2011, p. 171). Thus, nature contact can provide an ‘oneness’¹³ or indivisibility; where a person’s sense of the separateness of the self dissolves (Terhaar, 2009, p. 312).

Belonging can be experienced through connectedness to the transcendental. This can be experienced by going inwards (Cook-Greuter, 2000); by connecting our existence to a higher framework of meaning (Braam et al., 2006); and by perceiving that we are linked to all life (Edinger, 1972). The routes to transcending the animal self—and situating our life—exist in the physical world and require human agency to enact. The transcendental is accessed through an altered state of consciousness attainable through meditation, sexuality, nature contact, REM sleep, psychotropic substances, hypnosis, ‘psychopathological’ states, and near death experiences (Sokol, 1986; Raković, 2000). Ultimately the *belongingness*—derived from being connected to the self, other beings, nature and the transcendental—bestows significance, value, worth, and importance to life as we recognise that our existence fits into a larger context (Yalom, 1980; George & Park, 2014).

2.9.3 Meaning in Life – sense making, benefit finding, and action justification

¹² The vivid sensation that someone/something animate is near you; often in the apparent absence of identifiable stimuli. Not an empirical, classifiable, scientific term; rather it denotes a subtle, emotional, ‘felt’ experience.

¹³ A core experience that likely occurs cross-culturally; characterised by an ultimate feeling of utter fusion, integration, unication, and wholeness.

A final integrative MIL perspective conceptualises MIL as how we make sense of ourselves and our environment (Proulx et al., 2013); how we identify and integrate the positive from adverse life events (Park, 2010); and how we justify our actions by our adherence to a set of personally defined moral standards (Crescioni & Baumeister, 2013). Generating MIL involves the mental process of linking ideas, memories, objects, and people together that are physically unrelated (Baumeister & Vohs, 2002). We then interpret and evaluate these connections to construct a coherent and comprehensive life narrative enabling us to make sense of our experiences to the degree that life becomes comprehensible (Baumeister, 1991; Reker & Wong, 1988).

Park (2010) has defined MIL as finding the benefit in exposure to negative events. Such benefits can include perceptions of growth; positive life changes; altered identity/integration of the stressful experience into identity; and the reappraising of the meaning of the event itself. Thus, making sense of what happened to us, finding the good in a harmful experience, and utilising this narrative to move forward in our lives is MIL.

Attaining MIL also involves meeting the need to rationalise, validate, and deem our actions in-line with what is just according to our own moral compass. This can involve reinterpreting events and altering memory so that our behaviour adheres to our personal rules (Crescioni & Baumeister, 2014). In this way, MIL enables a reappraisal and revision of values, beliefs, and goals, through mechanisms of meaning making that align our appraisals of threats with meaningful schemas (e.g. a guiding principle or comprehensive worldview) (Baumeister, 1991; Park, 2010).

2.10 Differentiating between Meaning in Life and similar/related concepts

There are two concepts that could be thought of as similar or related to MIL (*Meaning of Life* and *Purpose in Life*). In this section, I will discuss the distinguishing characteristics that differentiate them from MIL.

2.10.1 Meaning of Life

Meaning of Life (MOL) is a metaphysical concept that encompasses all forms of life and the cosmos at large. The construct questions whether or not there is any significance to any life existing (Schnell, 2014); contemplates whether or not there is a transcendental, universal, objective meaning of all reality (Singer, 1996); and eternally queries the origins of life and the significance/futility of all human endeavours in the face of certain extinction (Trisel, 2016). Such questions are ontological in nature. They consider all life, as a whole, and ask—what is the point of it? Why does it exist? What purpose does it serve? It has been argued that this form of meaning would have to come from knowledge that is independent of experience. MOL is concerned with ultimate and normative meaning that has a holistic and global orientation (Schinkel, 2015). MOL is a feature of the universe and is concerned with meaning in the wider context of humanity itself (e.g. arising from the origin of everything that exists or patterns exhibited by all life) (Metz, 2013; Tartaglia, 2015). Consequently, the term MOL represents a grand theory of all life; while MIL denotes a theory for the self. This is the subjective, embodied, personal experience of establishing what makes one's own life meaningful.

In this study, while I acknowledge the relationships between the two constructs, I do not adopt the position that studying MIL will necessarily bring insights into MOL. However, I do acknowledge that a universal objective MOL can bring MIL (that faith in ultimate meaning enables the unearthing of meaning in the moment). I also consider it possible to have MIL without endorsing a comprehensive, singular MOL.

2.10.2 Purpose in Life

Although Purpose in Life (PIL) and MIL have been used synonymously and interchangeably within the literature (e.g. Reker & Peacock, 1981); both terms can be clearly differentiated. Some

authors have argued for MIL and PIL to be treated as discrete concepts and have provided empirical support for this assertion (Heisel & Flett, 2014; George & Park, 2013). PIL is the subjective feeling that one has overarching aims and goals to work towards; objectives that provide a sense of direction in life and enthusiasm about what lies ahead. Having PIL involves intention and function; engaging in motivated planning and acting in order to achieve a positive future state (Yalom, 1980; George & Park, 2013).

McKnight and Kashdan (2009, p. 242) define PIL as a ‘central, self-organizing life aim that organizes and stimulates goals, manages behaviours, and provides a sense of meaning’. According to these authors, PIL is an overarching life aim directing targeted goals and the efficacy of a purpose is determined by where it sits on the three dimensional continuum of scope, strength, and awareness. Hill et al. (2010) have put forward three dimensions of PIL: (i) foundation and direction (the aspect that gives context and foundation for emerging goals); (ii) happiness (the element that brings profound satisfaction and deep fulfilment); and (iii) pro-social intentions (the facet rooted in a desire to contribute to something larger than oneself and make a difference in the world).

PIL has been theorised as just one aspect of the multifaceted construct MIL and as a dimension of MIL that has relationships with the other aspects of MIL (Martela & Steger, 2016). For example, significance in life (an aspect of MIL) could be derived from PIL (Weinstein et al., 2012). PIL is widely represented in the presented MIL theoretical framework—from a relationship with supernatural justice, to worldly action, to the unique calling necessary for embodied spirituality. Aspects of MIL not captured by PIL include: comprehending life as a coherent narrative (e.g. through sense making) and experiencing life as mattering (e.g. through the ultimate significance of the soul). Commenting on the direct relationship between the two concepts, Frankl (2004), Steger (2012), and Baumeister (1991) have contended that PIL is part of what motivates the development of MIL. Similarly, McKnight and Kashdan (2009, p. 242) have proposed that purpose originates from meaning but also creates ‘a self-sustaining source of meaning through continual goal pursuit and accomplishment’.

For this study, I have chosen to adopt the positions: PIL forms a part of the broader MIL construct (existing within its conceptual boundaries) and that the relationships between PIL and MIL are complex and bi-directional. Consequently, I anticipate that by exploring MIL in this study, I will also be examining PIL. However, this assumption may be contradicted by the accounts given by study participants.

2.11 Chapter summary and conclusion

In summary, this chapter examined the numerous theoretical perspectives that have fashioned our understanding of MIL in Western Europe including: Nihilism, Absurdism, Evolutionary Theory, Supernaturalism, objective/subjective Naturalism, Existentialism, the Creativity Account, Viktor Frankl's perspective, and MIL as belonging, sense making, benefit finding, and action justification. The perspectives presented detail a continuum of MIL theoretical perspectives from the *absence* of MIL, to MIL as a purely *external* phenomenon (a gift received), to MIL as an entirely *individual* experience (the consequence of human action), to MIL as *integration* of the passive and the active.

All theoretical perspectives presented have been widely critiqued in the literature. The epistemology that underlies the 'absence of meaning' discourses is characterised by denial and a refusal to ascribe meaning to anything. From a nihilist's perspective, Nihilism itself is devoid of value, meaning, and substance. Nihilism nullifies the value of research on MIL. Therefore as a theoretical position it could be deemed self-contradictory, self-defeating, and consequently a fallacy. Absurdism equates the absence of MOL with the inability to create MIL. However, humankind not currently understanding the arrangement or disposition of everything in the universe may not necessarily mean that there is none. Humanity not being aware of a 'preternatural'¹⁴ reality does not mean that it cannot exist. In contrast, 'MIL as external' discourses are underpinned by an epistemology that acknowledges that knowledge related to MIL comes from the supernatural realm. From this perspective, we do not have the ability to shape MIL for

¹⁴ Apparently inexplicable by natural means.

ourselves. However, it could be argued that the nature of our relationships with supernatural phenomena negates this form of meaning—the existence of a soul may not necessitate a relationship with it, or indeed, God could simply be disinterested in us. The MIL attained (according to Evolutionary Theory) from the immortality derived from the ultimate progress of evolution may also be inconsequential if progress only means ‘better designed for an immediate local environment’ (Gould, 1977, p. 45) and our environment is constantly changing. Other critiques levelled at the contention that MIL is only drawn from immortality, include it: deprives humans of the choice to exist or not (which in itself can bring meaning) (Wollheim, 1984); removes exigency and vulnerability from life (Lenman, 1995); and would render life boring and consequently pointless at some point (Smuts, 2011). Moreover, Terror Management Theory has also been criticised on the grounds that it does not account for the fact that death is not universally feared; it is often welcomed (Chatard et al., 2017).

Polarised against this perspective—and associated with scientific rationality—Naturalism is defined by an epistemology informed by the belief that to know MIL we must collect evidence of our physical impact on earth. It is possible that conceptualising MIL as worldly action may neglect the human desire for more from existence than leaving a momentary footprint in space and time. If there is higher meaning beyond worldly action, it could transcend the meaning obtained from this mark. Existentialism deems living an authentic life the only route to MIL. However, it could be claimed that Existentialism concluding that the absence of evidence to confirm a universal MOL constitutes proof of its non-existence contravenes the scientific method¹⁵. Such a position may nullify the MIL that may come from MOL. Moreover, humanistic psychology directly challenges the ontological position of existentialism—that existence precedes essence—by maintaining that an individual (existence) must be who he or she really is (essence) (Decarvalho, 1991). Also, the position that inherent human values do not exist may be problematic; considering the presence of some meaning dimensions across cultures (Steger et al., 2008a; 2008b). It is possible that the Creativity Account—judging creative acts of value as the only source of MIL—is overly

¹⁵ According to Descartes (2006) we must reject as false all assertions that could be doubted; only then can we reach the truth.

reductionist. It may not account for meaningless creativity; where we aimlessly find ourselves creating something of no apparent purpose or significance. Camus (1979, p. 90) characterises this as ‘absurd work [art]’ bereft of meaning. One could also argue that there is no true creative act; that all creativity is a form of integration of influences and life experiences that have already occurred.

In order to assimilate both external and individual MIL theoretical perspectives, a distinct set of discourses has emerged; one that acknowledges both supernatural and natural phenomena in our quest for MIL. The epistemology that guided these discourse is one of openness to knowledge and acceptance of the unknown. These perspectives were borne out of a desire to integrate our knowledge and develop an inclusive, multi-dimensional, wide-ranging comprehension of MIL. However this position could be considered ambiguous regarding what aspects of the spiritual world it utilises. Frankl’s theory of embodied spirituality—transcendence through value adoption and societal contribution—may conflate what is uniquely human with what is spiritual in nature and what is altruistic with what constitutes transcendence. Authors have gone so far as to state that as Frankl’s main principles are defined in philosophical or metaphorical terms; his theory constituting a secular religion or value system. These critics contend that Frank’s theory requires individuals to acknowledge, on faith alone, that there is in fact MIL (Weisskopf-Joelson, 1975; Yalom, 1980; Wong, 1998). Meier (1973) has claimed that there is no *a priori* rationale or published empirical evidence to substantiate some of Frankl’s claims (e.g. that MIL happens in the ‘noological dimension’ distinct from the psychological dimension. The ‘belonging’ discourse may be confounded by belonging and MIL being related constructs¹⁶ rather than the same entity. Furthermore, some people choose to live lives of disconnectedness from self, other beings, nature and the transcendental yet are fulfilled (e.g. Blickem et al., 2014). Thus, the position that belonging is MIL by enabling transcendence may not be universally applicable to all human life. The argument that MIL is sense making, benefit finding, and action validation through moral standards is also open to critique. Some experiences cannot be made sense of (Janoff-Bulman & Thomas,

¹⁶ The relationship appears to be bidirectional (Stavrova & Luhmann, 2016). Interpersonal relationships increase the experience of MIL and the belief that life is meaningful aids the formation of new relationships (Stillman & Lambert, 2013).

1989); some acts of abhorrent destruction are so horrific that sense making or looking for the positive in them could be detrimental to wellbeing¹⁷. Finally not all actions need to be justified morally (Dorsey, 2016) and some of people live their lives in the absence of a moral code (Williams, 1976).

Positive psychology was intentionally excluded in this review as its contribution to the field of MIL research has been predominately empirical rather than theoretical in nature. While positive psychology has developed theoretical models of wellbeing that include the construct, the discipline's MIL research is largely quantitative and correlational in nature. Broadly speaking, positive psychology views attaining MIL as one of the routes to authentic happiness and wellbeing. This may overshadow the consideration of MIL in its own right and could be deemed problematic given the qualitative nature of meaning (Leontiev, 2013). According to Wong (2014, p. 153), this approach precludes the realisation that 'the pursuit of meaning might clash with the pursuit of happiness'. Positive psychology may also suffer as a consequence of measuring meaning and wellbeing in the abstract and lacking a comprehensive and coherent theoretical framework (Wong, 2014).

In conclusion, the history of the ever-changing ideas around MIL presented in this chapter implies that MIL transcends the binary categories that typify scientific approaches to defining phenomena—being equally subjective and objective; both cognitive and emotional; and equivalently a state and a trait (Leontiev, 2013). Overall, it appears that MIL is neither ever fully present or entirely absent; nor solely obtainable from external or personal sources. To operationalise the concept to utilise it empirically, it requires an integrative abstraction. The conceptual boundaries of the construct fluctuate in different lives, historical contexts, and cultures. It seems there is not one universal definition of MIL; but a wide-ranging array of perspectives that have shaped our understanding of MIL. What is of great consequence is how each perspective defined MIL—and in doing so—empowered or disenfranchised the individual regarding their

¹⁷ Recent evidence points to the need to re-evaluate theoretical arguments for the universal benefits of personal reflection for wellbeing. For a discussion see Greenhoot & McLean (2013).

power to construct it and exercise an internal locus of control. What we can conclude is that MIL is formed at the intersection between individual and collective belief systems. It is personal to each of us but can also be understood as existing on a continuum; its presence or absence being perceived in degrees. Therefore, it may be possible to ascribe more or less meaning to some phases of life than others and to consider some lives, as a whole, to exhibit more or less meaning than others. The meaning of MIL outlined in this chapter is a Judeo-Christian narrative demarcated within a Western European context. Therefore it is not the only narrative of MIL that could have been written.

The next chapter will explore the literature and empirical research on MIL, meaning making, psychosis, and recovery in mental health.

CHAPTER THREE: MEANING IN LIFE, MEANING MAKING, PSYCHOSIS, AND MENTAL HEALTH RECOVERY (A REVIEW OF THE LITERATURE)

3.1 Introduction

The previous chapter concentrated on a number of theoretical perspectives that have influenced the understanding of MIL in Western Europe. In this chapter, I employ literature and empirical research¹⁸ from a range of disciplines, in order to portray the inter-relationship between MIL, meaning making, psychosis, and mental health recovery. This inter-relationship is examined in order to establish how these constructs have been conceptualised, discussed, and investigated previously.

The chapter is divided into two parts. The first focuses on the divergent positions on MIL and meaning making within the mental health literature. Firstly, the medical narrative about psychosis is outlined and consideration is given to whether this narrative nullifies and invalidates personally constructed meaning. After this, how the construction of both MIL itself and the subjective meaning of the manifestations of psychosis permeates first-person autobiographical accounts is described. This part of the chapter concludes with a discussion of the literature on MIL and meaning making in mental health service provision. The second part of the chapter reviews the empirical data available on service user meaning making and service user perspectives on meaning in psychosis. This is followed by a review of the studies that quantified MIL among people with experience of psychosis. The chapter concludes with a review of the role of MIL in mental health recovery and an appraisal of research that has qualitatively explored MIL in psychosis.

¹⁸ Due to the study timeframe, it was not feasible to conduct individual systematic reviews in all of the areas relevant to the aim and objectives of the study. Therefore, the literature presented in this chapter represents my best efforts to identify all relevant published literature in the areas of MIL, meaning making, psychosis, and mental health recovery. Literature searches were conducted in PubMed, PsycINFO, CINAHL Plus, Psychology and Behavioral Sciences Collection, Web of Science, and Google Scholar.

3.2 Psychosis as understood through the medical narrative

The etymology of term ‘psychosis’ in psychiatric medicine can be traced back to the Greek word—‘psyche’ (meaning ‘life’ or ‘soul’) and the suffix ‘-osis’ (meaning ‘any illness of’) (Beer, 1996). With the advent of psychiatry, psychosis emerged as a concept used in asylums in 19th century Germany—*Einheitspsychose* (i.e. unitary psychosis). As a unifying term, it defined all forms of psychosis as surface variations of one underlying disease process (Berrios, 1987). It was not until the late 19th Century that Emil Kraepelin (1899) lay the foundations of the first diagnostic system for mental disorders. This framework guides how psychiatry conceptualises psychosis today.

Historically, psychiatric medicine has largely been disinterested in the meaning people attach to their psychosis experience. From this position, the meaning of psychosis is defined by psychiatry in isolation of the meaning making processes of the person confronting and experiencing it. Thus, psychosis has meaning only in so far as medical constructs can be operationalised to ascribe meaning to it; outside of this, psychosis has no meaning. Within psychiatry, psychosis is framed through the lens of diagnostic systems, as a symptom of a psychiatric ‘disorder’; delineated as a mental state characterised by a loss of contact with reality and substantial impairment in reality testing. From this perspective, psychosis means the positive and negative ‘symptoms’ of an ‘illness’ or ‘disorder’ (Kay et al., 1987, p. 261).

Within this medical view, positive ‘symptoms’ are demarcated by the presence of ‘abnormal’ features in human experience—phenomena of commission (i.e. cognitions or behaviours not exhibited by the general population). These are termed: ‘hallucinations’ (auditory, somatic, tactile, or olfactory); delusions (fixed beliefs not susceptible to modification despite conflicting evidence); disorganised thinking impairing communication (alternating between topics, providing unrelated answers to questions, or incomprehensible speech); and distinguishingly disorganised or ‘abnormal’ motor behaviour (including a marked decline in reactivity to the environment). Negative ‘symptoms’ are spoken of as the absence or substantial diminishment of ‘normal’

functioning (reduced emotional expressivity, goal-directed behaviour, interest in social engagement, frequency of speech, or capacity to experience pleasure).

From the medical vantage point, meaning in psychosis is derived in a number of ways. Firstly, psychosis has meaning for the clinician as a feature of specific diagnostic categories. Determining the frequency and intensity of psychotic cognitions or behaviours enables a psychiatrist to differentiate between diagnoses. Secondly, once classified, the different forms of psychosis become loci for psychiatric interventions designed to eliminate them. Thirdly, the medical focus on epidemiology gives meaning to psychosis in terms of its aetiology, prevention, course, and outcome. Course and outcome are typically appraised as the achievement of specific treatment goals at precise time points (e.g. remission and ‘adequate’ social/occupational functioning). This frame of reference is: if psychosis is a brain disease that leads to human suffering, then the construct has meaning in the context of the scientific goal of tracing its causality. By determining the predisposing, precipitating, and perpetuating factors that influence the development and progression of psychosis, psychiatric epidemiology endeavours to limit both the number of lives impacted by the ‘illness’ and the extent of this impact (e.g. averting prenatal exposure to influenza [O’Callaghan et al., 1991] or reducing/eliminating cannabis use following a FEP due to its detrimental impact on recovery outcomes [Madigan et al., 2013]).

In this way, meaning is defined by the clinician in isolation of the person experiencing psychosis. Thus, the meaning of psychosis is restricted to endeavours of categorising psychotic ‘symptomatology’; determining the prognostic significance of each ‘psychotic disorder’; establishing the biopsychosocial influences on course/outcome; tracing its causality; and accomplishing its diminishment or indeed annihilation (Bracken et al., 2012; Dazzan & Tansella, 2014; Pilgrim, 2014; Kar, et al., 2016).

3.3 Critique of the medical perspective on psychosis

Since their conceptions, the concepts of psychosis, schizophrenia, and other forms of psychotic ‘illness’ have all been contested. Clinical and social psychology theorists have posited that psychiatric diagnostic categories are not natural phenomena reflecting essential properties; but artificial in nature, defined by practical considerations rather than their ability to consistently individuate underlying essences (Zachar, 2000; Haslam, 2002). Modern commentators, such as philosopher Marc Roberts (2016) contend that the medical model is reliant on the ontological assumption of essentialism—the assertion that a psychiatric ‘disorder’ has an essential essence defined by psychiatric nosology mapping directly onto reality. Other academics have argued that psychiatry has failed to justify the validity of this assumption by not establishing the essential criteria of normality and order (in comparison to abnormality and disorder) in brain function, mental processes, and how cognition, emotion and behaviour is exhibited in human society (Patil & Giordano, 2010).

Others critique from the perspective of culture, which is defined as: ‘a set of behavioral norms, meanings, and values or reference points utilised by members of a particular society to construct their unique view of the world and ascertain their identity’ (Alarcón, 2009, p. 133). Therefore, they contend that what is collectively agreed as *reality* can shift over space and time. Larøi et al. (2014) argue that culture can influence what is and what is not identified as a psychosis. Thus, in their view the measurements of rates of psychosis in epidemiology may not reflect differing levels of experience; but theories of the world derived from different cultural models of reality. Most human beings acknowledge some degree of supernatural reality (Boyer, 2002); so determining what is real¹⁹ and what is psychotic based on the number of individuals sharing a belief or experience is an *argumentum ad populum*. Consequently, if reality can only be apprehended imperfectly (Ponterotto, 2005); and differences in the meanings people ascribe to experiences are possible because they experience different parts of reality (Fade, 2004); then the medical demarcation of psychosis as a deviation from reality in thought and action may be arbitrary.

¹⁹ In this context, ‘real’ means occurring or existing in actuality.

Postpsychiatry (as a new trajectory for mental health theory/practice) emphasises the limitations of evidence based medicine, and science itself, in producing a comprehensive account of ‘being’ and experience (Thomas et al., 2012). Postpsychiatry, seeks to modify the *modus operandi* of psychiatry to consider ‘a medical discourse about mental suffering that is sensitive to the issue of [service user constructed] meaning’ (Bracken & Thomas, 2010, p. 226). Postpsychiatry emphasises the social, political, cultural, historical, and ideological value systems that shape how we find meaning in and make sense of ‘madness’. Writers in this vein point out that our experiences are not discrete phenomena to be analysed empirically, in isolation but exist in multiple overlapping plexuses of meaningful relationships that are not captured by psychiatric classification or epidemiology. The proponents of Postpsychiatry also assert that psychiatric medicine ignores how meaning is constructed in its quest to test the efficacy of technical interventions (Bracken & Thomas, 2001).

Boyle (1990) goes further and suggests that psychiatry research may be biased towards form, rather than service user defined meaning, of the content of psychosis experiences. Thus, service users may experience oppression when—in order to avail of mental health care—they are compelled to accept the unimpeachable orthodoxy of the medical narrative of what is happening during these experiences. Should they rebel in defiance of it while adhering to treatment, and offer an alternative interpretation of psychosis, they are labelled as lacking ‘insight’ (Solbjør et al., 2011). Where psychosis is concerned, if there is widespread endorsement of the medical narrative among practitioners, then service user fashioned meaning is devalued and neglected in mental health care. This practice may be problematic as understanding the existential context of the speech and behaviour of people experiencing psychosis is likely vital to services facilitating and supporting recovery (Laing, 1960) as service user meaning making in psychosis experiences as well as MIL are part of mental health recovery.

3.4 The service user argument for the relevance of Meaning in Life and meaning making

The early stages in the emergence of the recovery oriented approach in mental health can be traced back to authors who wrote first-person narratives of their experiences of mental health problems, receiving diagnoses, and obtaining ‘psychiatric treatment’ (Deegan, 1993; Murphy, 1997). From the outset, service user defined recovery has been innately bound to MIL. From their perspective, writers with self-experience of psychosis saw MIL materialising out of their personal journey; they emphasised the centrality of MIL in recovery and how ‘mental illness’ experiences were intrinsic to MIL (Lovejoy, 1982; Chadwick; 1997; Scotti, 2009). Authors with self-experience of ‘mental illness’ defined recovery as a complex non-linear journey where one oscillates between a crisis of meaning—i.e. a ‘numbing succession of meaningless days and nights’ (Deegan, 1994, p. 152)—and ‘the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness’ (Anthony, 1993, p. 527).

In a seminal article, *Recovering our sense of value after being labelled mentally ill*, Patricia Deegan (1993) underlined ‘the need to find a way of making sense of what is happening to you that you can live with’ (p. 9). Deegan wrote of her disconnection to the roles valued by society and emphasised in the mental health system (e.g. parent or worker). From her personal experience of recovering with a diagnosis of schizophrenia, ‘functioning’ (like getting out of bed in the morning) was inconsequential in recovery unless imbued with meaning.

A central theme of autobiographical accounts is the profound need for, struggle to find, and the rewarding/frightening attribution of meaning within psychosis experiences. For example, Chadwick (2014) described the powerful longing to see significance within the perplexity of psychosis and life itself. This drive was shared by other authors. Reina (2009, p. 4) described this drive as causing her to see ‘hidden meanings in everything, from graffiti to architecture and to everyday speech’. Sometimes the overarching meaning of psychosis was found:

Perhaps... the psychosis of schizophrenia may bring about a fundamental reorganization of the self. The purpose of it may have been to transform my life—for indeed it has (Murphy, 1997, p. 543).

Other times it was not:

It was a permanent state of ‘there must be a meaning in what I have just observed—what is it?’ ... I was no longer able to discriminate what was relevant for me to process, to find meaning (Humpston, 2014, p. 241).

The longing propelling this search for meaning can be so powerful that it can define the totality of the experience of psychosis. One autobiographical account described this quest as cumulating in a sense of oneness and interdependence of everything in the universe (Clay, 1999). Another writer outlined how their psychosis offered the answer to life’s most pressing question—why they existed. Psychosis had shown them the devil and they had become ‘some sort of Jesus’ (Anonymous, 2010, p. 896). Another author detailed the MIL derived from the societal role provided by their psychosis: ‘I was a black panther... the highest position at the secret service... I thought that in order to save humanity I had to fight for it’ (Meijer, 2018, p. 469-470). Chadwick (1997, p. 169), in the following extract articulates how psychosis made his life meaningful:

From a meaningless life, a relationship with the world was reconstructed by me that was spectacularly meaningful and portentous even if it was horrific.

These extracts capture the MIL generated in the process of meaning making in psychosis experiences *themselves*.

For decades, authors with experience of psychosis have recounted how their interpretation of life events was directly challenged by practitioners who informed them that their understanding was illogical, absurd, and pathological (Clay, 1989; Anonymous, 2010; Dillon, 2011; SA, 2018). Some, like Dillon (2012) fought against this absolute dismissal of their interpretation of their experiences and the reductionist approach adopted by the mental health practitioners:

When I became upset and angry at having my experiences denied I was told that this was also a symptom of my illness (Dillon, 2012, p. 18).

Others sought to reclaim the primacy of their service user voice. Clay (1989), for example, concluded that in order for mental health services to truly support people in their recovery, they must give credence to personal meaning making and the transcendental properties intrinsic to altered states. Other authors, like Anonymous (2010), embraced the medical understanding of what had happened to them: 'I now know that this "saviour complex" is a classic delusion of schizophrenia' (p. 896).

Another theme present within these accounts is the integration of the subjectively defined meaning of psychosis experiences into a coherent overarching perspective on MIL. In the following extract, Colori (2018, p. 226) articulates this integration:

Once I developed the ability to freely analyze my experiences I started working with the meaning I had surrounding them and the meaning they had within my life. I discovered I have to find the truth that makes me function as well as I can, because ultimately my goal has been to function at my optimal levels.

Similarly, Lovejoy (1982) underscored the primacy of acknowledging how MIL can be derived from the recovery journey itself. For her, MIL came from success in her recovery acting as a beacon of hope for other people overwhelmed by psychosis.

For some people with experience of psychosis, like Scotti (2009, p. 844-846), MIL is the very definition of recovery:

This first person account describes recovery as discovery of new meanings and opportunities in life... a new birth emerged from within me that has made my life more meaningful and purposeful than before.

The cumulative impact of these accounts has been the limited acknowledgment within the mental health field that MIL is vital to psychological wellbeing and that its presence lessens psychological distress (Debats, 1996). These personal narratives have provided the impetus for the inclusion of MIL in a number of areas. Firstly, in the lexicon of practitioners who advocate for the consideration of meaning construction in treatment (Slade et al., 2019). Secondly, in the rhetoric of the international mental health policy landscape; as an aspect of personal (i.e. service user defined) recovery that providers need to prioritise in implementing the recovery approach (Slade et al., 2012²⁰). Thirdly, in the objectives of the World Health Organization's *Quality Rights*; as a concept to assist service providers in developing high quality mental health services (World Health Organization, 2012). The next section looks at the literature on the integration of this service user emphasis on MIL and meaning making into mental health care.

3.5 Meaning in Life and meaning making in mental health service provision

Today, MIL is attracting increasing attention as a nascent marker of the effectiveness of mental health services (Glaw et al., 2017). The idea has moved to the forefront of empirical research into recovery processes/outcomes internationally (Slade et al., 2012). Presently, there is a call for progressive service delivery to acknowledge that, in mental health, 'a more complete recovery requires understanding, learning from, integrating, assimilating and coming to terms with the whole experience' (Power, 2017, p. 332). Attending to meaning construction in treatment is likely to result in more clinically sensitive interventions and an orientation to person centeredness as meanings developed by service users impact their experiences of, and pathways to, care (Boydell et al., 2010). For example, Yeung et al. (2017) conducted a qualitative study with 14 people who had mental health difficulties and 16 of their family members. All had Chinese backgrounds but were

²⁰ This is a systematic review of mental health policies that identified a reference to MIL in 90 out of 105 policies reviewed.

living in England. They found that if cultural beliefs about mental distress are disregarded and invalidated by practitioners, then people are less likely to seek help from mental health services.

While Vos (2016) indicates that at least 30 different types of meaning centred psychological therapies can be found in the literature, Park (2010) suggests that there is a need within mental health services to recognise that meaning construction can be both: advantageous to a person's wellbeing (e.g. helping people adjust to a stressor) and upsetting (i.e. causing increased distress due to a *particular* interpretation of an experience). Consequently, she believes practitioners need to ask 'for whom, and under what circumstances, are particular types of meaning making and meaning made helpful and why?' (Park, 2010, p. 293). Park (2010) goes on to argue that the type of 'meaning made' likely determines its impact on wellbeing. For example, perceiving growth or positive life changes following a stressful event may be more beneficial to wellbeing than reappraising the meaning of the stressor.

Lonergan (2017) posits that the focus of modern day therapeutic approaches in psychosis has shifted away from pursuing 'symptom' reduction towards exploring the meaning people assign to psychosis experiences in order to alleviate the distress caused by them. From this perspective, service user meaning making is operationalised as an object to aid practitioners in delivering interventions to achieve a positive *change* in meaning making (i.e. a change that brings a reduction in distress); rather than something that is considered fundamentally important in essence.

To my knowledge, the degree to which a focus on service user meaning making in psychosis experiences and MIL is present in mental health care has not been explored in the literature. However, other literature sheds some light on why such an emphasis *may* not feature in mental health service provision in psychosis. Boyle and Johnstone (2014, p. 2) have argued that endorsing the 'illusory safe certainty' of psychiatric diagnosis allows practitioners to evade the reality of people's lives, their complex suffering, and the questions it raises. Moreover, the education system that supports the multidisciplinary team may not adequately equip clinicians to engage in the mutual dialogue with service users necessary to explore meaning making (Jones & Shattell, 2016).

This system may also privilege the medical discourse on ‘psychosis meaning’ and socialise practitioners in training/practice to this way of thinking (Newman et al., 2019).

Other studies point to why meaning making and MIL may not receive adequate attention in services. An international survey of 58 mental health practitioners and researchers found that 21% of respondents felt their work would be affected adversely should they attend to the *content* of ‘delusions’ and ‘hallucinations’ (Aschebrock et al., 2003). They feared they could lose their sense of job satisfaction; struggle to maintain a clear boundary (for themselves) between psychosis and reality; and risk ridicule from colleagues. Turnover/rotation of practitioners and restrictions on appointment time also limit opportunities to explore meaning (O’Keeffe et al., 2018). In addition, Hannigan & Allen (2011) suggest that as a practitioner, clearly demarcating what one has and does not have responsibility for is tantamount to survival in a demanding mental health system. Practitioners may not see service users’ MIL and meaning making as their responsibility.

3.6 Perspectives on meaning making in psychosis in the literature

From the early 20th century, two of the most influential authors in the psychosis literature writing from the medical perspective are Bleuler (1911) and Kraepelin (1919), who began documenting aspects of self-experience in schizophrenia. They both concluded that psychosis profoundly undermines a person’s capacity to engage in meaning making. These early perspectives characterise schizophrenia as disorganisation and instability of the self and catastrophic to relationships with both the self and others. Similar value judgments about meaning in psychosis are present in the design and conception of contemporary empirical studies (e.g. Werbart & Levander, 2005; Pinto & Pinto, 2019). These researchers contend that experiences and behaviours are defined as ‘psychotic’ precisely because they are impossible for clinicians to understand.

Davidson (2003) on the other hand is zealously opposed to neglecting subjective meaning in psychosis; positing that all experiences are innately understandable as they adhere to the laws of motivation. He asserts that deciphering meaning in psychosis experiences is simply a matter of

investing time/effort into unearthing the ‘motivational horizon’. From this perspective, it is through ‘meaningful relationships of motivation rather than through physical relationships of causality’ (Davidson, 2003, p. 96) that continuity and meaning emerges in life. This corresponds with Strauss’s (1969) finding that the degree to which ‘hallucinations’ and ‘delusions’ are comprehensible lies on a continuum. Strauss (1969) concluded that the assumption that psychosis experiences are meaningless may be related to narrative development and coherence rather than meaning itself. Davidson (2003) found that people with a diagnosis of schizophrenia experience their lives as lacking a personal story and not being of sufficient value to warrant a narrative; to the degree that they saw their experiences as pointless to share with others.

Dialogical psychology does not assert that schizophrenia automatically results in impairments in meaning making. Rather, this sub-discipline of psychology focuses on how people with schizophrenia can struggle to navigate ‘the intra- and interpersonal dialogues that lay the groundwork for sense of self’ (Lysaker & Lysaker, 2008, p. 337). Dialogical psychology has developed three models of self-experience in schizophrenia. The first, asserts that self-experience is compromised in schizophrenia due to difficulties maintaining dialogues among facets of the self in interactions with others. In schizophrenia, the absence of meaning in the interaction between aspects of self can result in experiencing the self as ‘empty’. In the second model, one or a small number of aspects of the self can dominate and self-experience is curtailed to those facets (e.g. *self-as-enlightened*). In the third, the person experiences information overload from all aspects of the self; to the degree that they become inundated, disorientated, or apprehensive; incapable of distinguishing what is meaningful from what is not (Lysaker & Lysaker, 2008).

Sass and Parnas (2003), in a review of phenomenological studies into psychosis ‘symptoms’ in schizophrenia, suggest that schizophrenia is characterised by profound challenges in meaningfully engaging the world and intersubjectively situating a ‘sense of self’. As a consequence, they argue that this leads to the perception of the *self-as-absent*. Studies utilising phenomenology to grasp the essential structures of the service user experience have defined schizophrenia as an excessive form of extreme self-awareness characterised by ‘hyperreflexivity’ and estrangement from others (Sass,

2000) or dysfunctions in perceptual processing that limit a person's ability to merge stimulus elements into meaningful and coherent object representations (Uhlhaas & Mishara, 2006). Other phenomenological research indicates that some people with schizophrenia find the self and the world incomprehensible because the 'disorder' essentially destabilises common sense (Blankenburg, 2001; Stanghellini, 2004).

In sum, Part 1 of this chapter has considered the medical narrative on the meaning of psychosis; critiques of this perspective; the service user viewpoint on MIL and meaning making in psychosis; the focus on MIL and meaning making in mental health service provision; and perspectives found in the literature on meaning making in psychosis. Part 2 focuses on the empirical quantitative, qualitative, and mixed methods research that has investigated MIL, meaning making, psychosis, and mental health recovery.

3.7 Quantitative appraisal of service user meaning making in psychosis

Little quantitative research has investigated service user meaning making in psychosis. Studies found in this area focus on appraising the meaning making process in two ways: categorising a service user's 'recovery style' (McGlashan, 1987, p. 681) and measuring meanings assigned to psychosis using the Subjective Sense in Psychosis Questionnaire (SUSE) (Klapheck et al., 2012).

According to McGlashan (1987), a person's 'recovery style' characterises how they cope with psychosis and is determined by their desire to find meaning in the experience. Thus, some people feel they do not need to find meaning in their experience of psychosis to progress in their recovery journey. While many people are interested and curious to learn about their psychosis, seek to integrate psychosis experiences into their life/identity, and have an awareness of continuity between experiences pre- and post-psychosis; others do not. In their quantitative research into how people live with schizophrenia, they conclude that people 'seal-over' and struggle to recall or describe phases of acute psychosis; engage in cognitive and behavioural avoidance to prevent an exploration of meaning; and may deny the existence and/or severity of their psychosis (McGlashan,

1987). In their view, these differing strategies allow for a restoration of coherence after the collapse of meaning. From the medical perspective, integration in psychosis is associated with: mental health service engagement; less relapse/readmission rates, general psychopathology, negative ‘symptoms’, and depression; as well as an increased likelihood of employment, social functioning, and quality of life (McGlashan, 1987; Thompson et al., 2003; Tait et al., 2003; O’Donoghue et al., 2011).

One German research group developed a self-report instrument—the *Subjective Sense in Psychosis Questionnaire (SUSE)*—to assess service users’ subjective experiences and the meanings they ascribe to their psychosis (Klapheck et al., 2012). The authors categorised meaning by temporal perspective (past, present, or future) and valence (positive or negative meaning of psychoses). ‘Psychosis meaning’ was then classified as: coherent/ incomprehensible psychosis emergence (e.g. understanding why psychosis happened or psychosis occurring by coincidence); positive/negative ‘symptom’ experience (e.g. psychosis being enriching or frightening); long term positive/negative psychosis effects (e.g. psychosis bringing a new perspective on life or psychosis leading to loss of MIL).

However, the methods applied to the development of this instrument are unclear, obscure, and unreproducible. Questionnaire items considered to represent the effects of psychosis on the future relate to its impact on the present. The questionnaire also explicitly cites types of psychosis experiences (e.g. telepathy) and not others (e.g. voice hearing). The SUSE’s construct validity is also questionable; it focuses more on the subjective experience of responding to psychosis than the perceived *meaning* of psychosis experiences.

A recent randomised controlled trial found that an individualised metacognitive intervention enhanced meaning making (measured by the SUSE) in people with schizophrenia (Moritz et al., 2017). Interpreted through the medical lens, data was understood to indicate that people actively experiencing ‘positive symptoms’ perceived psychosis experiences in a less adverse light than other participants. The authors posited that psychosis ‘symptoms’—via an external-personal

attributional style for blame—may unintentionally reduce self/ideal discrepancies and increase self-esteem. However, as this research categorises meaning making solely for the purpose of improving outcome in psychosis, it is detached from the perspectives of service users themselves. The next section reviews qualitative studies exploring service user perspectives on meaning in psychosis

3.8 Research into service user perspectives on meaning in psychosis

It is striking that the devaluing of the meaning people ascribe to their experiences of psychosis was so prevalent in the 20th century that the first qualitative study exploring meaning making in psychosis, from the service user perspective, was not published until 2000 (Murphy, 2000). Since then, to my knowledge, eight other qualitative studies exploring service user perspectives on meaning in psychosis have been published. This research took place in Sweden (Strand et al., 2015); the United Kingdom (Hirschfeld et al., 2005; Holt & Tickle, 2015); Australia (McCann & Clark, 2004); Israel (Araten-Bergman et al., 2016); the United States of America (Murphy, 2000); Denmark (Larsen, 2004); China (Liu et al., 2012); and Finland (Bergström et al., 2019). The authors used a range of methodological approaches including: interpretative phenomenological analysis; social constructionist grounded theory; descriptive phenomenology; a reflective lifeworld phenomenological approach; thematic analysis; ethnography; constant comparative analysis; and thematic narrative analysis.

Two studies explored sense making and psychosis experiences, two explored meaning in ‘illness’ in psychosis, and five explored meaning and psychosis experiences. Four of the nine studies were published over a decade ago. No study explored ‘meaning *making*’ in psychosis experiences as its primary objective. Neither did any study examine how the meaning made in psychosis experiences influence a person’s perspective on MIL. Four studies were conducted with people diagnosed with schizophrenia; two with people diagnosed with a FEP; one with people diagnosed with schizophrenia, schizoaffective ‘disorder’, or bipolar ‘disorder’; one with people who displayed psychosis ‘symptoms’; and one with people who had experience of being distressed by voice hearing.

The themes developed from these nine studies cluster into three main categories: identifying an explanation for, or the cause of, psychosis; recognising the negative impact of psychosis *on* life; and determining the function of psychosis *in* life. Although the authors of these studies failed to elaborate adequately on (or clearly define) the themes developed from their analyses. One key aspect of meaning (found by seven studies) concerned service users seeking to identify a reason why they had experienced psychosis. These reasons were described as causes (Liu et al., 2012; Strand et al., 2015); explanations or systems of explanation (Larsen, 2004); self-aetiologies (Araten-Bergman et al., 2016); frameworks (Holt & Tickle, 2015); relationships (Hirschfeld et al., 2005); or a crisis (Bergström et al., 2019). Reasons for psychosis included: trauma; genetics; drug use; social isolation; organ dysfunction; punishment for moral failings; attachment or adjustment difficulties; spirituality or fate; witchcraft, evil spirits, or demons; stress, anxiety, or depression; and negative relationships, harassment, or bullying (Larsen, 2004; 2007; Hirschfeld et al., 2005; Liu et al., 2012; Strand et al., 2015; Holt & Tickle, 2015; Araten-Bergman et al., 2016; Bergström et al., 2019). Establishing a reason or reasons for psychosis gave service users comfort and a sense of control in their lives. It also made them feel like life was understandable and helped them reconstruct their identity in the aftermath of psychosis (Larsen, 2004; 2007; Araten-Bergman et al., 2016). Holt and Tickle (2015) found that service users made sense of their voices by considering their view of the self, their relationships with others, and how voices were a part of them but beyond their control. Service users' perceptions of agency, experience of stigma, and sense of hope impacted their ability to explain voice hearing. However, the authors did not clarify how.

Three studies found that service users saw psychosis experiences as giving them something positive that was absent from their lives (Murphy, 2000; Hirschfeld et al., 2005; Strand et al., 2015). These additions to life included: help to overcome life challenges, coping strategies, and the perception that one was growing and maturing beyond psychosis. Experiencing psychosis gave service users: company, social support, and reassurance. The 'self-value' and 'special abilities' they had when within psychosis helped them defend against 'low self-worth and powerlessness' (Strand et al., 2015, p. 110). Voices gave 'advice in stressful life situations' (Strand et al., 2015, p.

112) and at times were encouraging and supportive (Murphy, 2000). Psychosis also positively altered service users' outlook on life; helping them reconnect with their faith, appreciate difference in people, and defend against discrimination. In addition, psychosis imparted beautiful images; often interpreted as divine in nature (Murphy, 2000). Hirschfeld et al. (2005) found that service users viewed *overcoming* psychosis as giving them confidence, wisdom, and enhanced self-awareness/self-understanding. Unfortunately, the authors did not elaborate on how this occurred.

Four studies found that service users made meaning in psychosis experiences by recognising the negative impact they had on their lives (Murphy, 2000; McCann & Clark, 2004; Hirschfeld et al., 2005; Liu et al., 2012). Psychosis damaged participants': temporality; social/romantic relationships; 'normative' life course; and sense of safety, independence, and control in life. Psychosis also hampered participants': social/occupational competence; resilience to stress; optimism about the future; achievement of life goals; and trust in their own perceptions and judgment. These negative effects resulted in some service users struggling to: engage socially, find the motivation to keep living, and cope with day to day life (Murphy, 2000; McCann & Clark, 2004; Hirschfeld et al., 2005; Liu et al., 2012).

McCann & Clark (2004) found that service users viewed psychosis as a 'catastrophic experience' that adversely affected 'temporality' (p. 787). However, within their article, this theme was not clearly explained. The authors stated that psychosis brought unpredictability into service users' lives which altered their perception of present circumstances and future events. No further information was given. Bergström et al. (2019) explored meaning in the context of the life stories of people who were treated for a FEP 10 to 23 years ago. However, they excluded four participants' accounts from their analysis because they concluded these participants struggled to remember events prior to and after their FEP and thus 'lacked continuous plots' (p. 4). These four accounts did not fit into either theme developed in the analysis. This exclusion is unethical and constitutes scientific misconduct as the authors excluded data that undermined their findings (Anthony et al., 2019). (Table 3.1 displays further detail regarding the methodology and findings of the nine studies).

Table 3. 1 Characteristics and main findings of qualitative studies exploring service user perspectives on meaning in psychosis

Author(s) and year	Study aim	Context and sample	Data collection and analysis method	Main findings
Studies exploring sense making²¹ and psychosis experiences				
Strand et al., (2015)	To explore how people make sense of the content of their psychosis 'symptoms'	Sweden 12 service users who had experience of psychosis 'symptoms' attending a psychosis specific outpatient unit	Semi-structured interviews Interpretative phenomenological analysis	Participants viewed psychosis experiences as harassment and caused by abusive/ intrusive relationships, trauma, or guilt Psychosis was seen as a substitute for social relationships and as a way to redress perceived helplessness (through 'grandiose' beliefs) Psychosis was also understood as a strategy for coping with life (e.g. commanding voices told participants what to do when uncertain).
Holt & Tickle (2015)	To develop a theory of how voice hearers make sense of the origin and maintenance of distressing voices	United Kingdom 8 people who self-identified as a person who was distressed by their experience of voice hearing No further context given	Semi-structured interviews Social constructionist grounded theory	Participants made sense of their voice hearing by linking it to stress, trauma, attachment difficulties, anxiety, depression, and spirituality Participants drew upon three frameworks when trying to understand why their voices began and remained in their lives. These were: <i>interpersonal</i> (interpreting voices through the view of self); <i>intrapersonal</i> (understanding voices through relationships or communication between people), and <i>parapersonal</i> (perceiving voices as being beyond participants' control yet attributed to being a part of them—e.g. spiritual or biological interpretations) The ability to utilise these three frameworks was determined by participants' perceptions of agency, stigma, and hope(lessness)
Studies exploring meaning in 'illness' in psychosis				
McCann & Clark (2004)	To explore how people experience schizophrenia as an embodied phenomenon and find meaning in their 'illness'	Australia 9 young adults diagnosed with schizophrenia No further context given	Unstructured interviews Descriptive phenomenology	Participants constructed meaning in schizophrenia by acknowledging how the 'illness' can interrupt their temporality, act as a mediator of social relationships, and undermine their ability to establish and maintain sexual relationships
Araten-Bergman et al. (2016)	To explore how older people diagnosed with schizophrenia give	Israel 18 people over the age of 60,	In-depth semi-structured interviews	Participants viewed schizophrenia as: genetic; a decree of fate; a punishment from God; a result of witchcraft; and a consequence of personal trauma

²¹ Sense making, in my study, is understood to be an aspect of meaning making. However, in these two studies meaning and sense are considered synonymous; although only sense making is mentioned in their aims.

	meaning to their 'illness' by developing 'self-aetiologies' (i.e. explanatory models of illness and health causal attributions)	diagnosed with schizophrenia before 40, living in the community	A reflective lifeworld phenomenological approach	'Self-aetiologies' can give meaning to 'illness' experiences. This meaning can establish closure (in order to move past 'illness'), lessen ambiguity (by focusing on one or a small number of interpretations of 'illness'), and reduce the feeling that life is an enigma (making life comprehensible).
Studies exploring meaning and psychosis experiences				
Murphy (2000)	To present a thematic analysis of the meaning of psychosis according people with experience of psychosis	United States of America 8 psychosocial rehabilitation centre attendees who had experienced psychosis and received a diagnosis of schizophrenia; schizoaffective 'disorder'; or bipolar 'disorder'	Data collection and analytic approach unclear—'thematic analysis' and 'interviews' referenced but not defined	Participants understood psychosis experiences as: a demonic attack; an assault on their moral integrity; a threat to their life; a source of strength, beauty, and encouragement; and a reason to accept, and advocate for, others with disabilities
Larsen (2004)	To examine individuals' attempts to generate meaning in psychosis experiences by drawing on their cultural repertoire	Denmark 15 young people diagnosed with a FEP participating in an early intervention for psychosis programme	Participant observation documentary analysis, individual interviews, and focus group interviews Ethnography	Participants used their own agency and different systems of explanation to find meaning in psychosis experiences and render them more controllable Participants' explanations for psychosis were culturally determined and embodied narratives that allowed them to reconstruct their identities and their lives after receiving early intervention
Hirschfeld et al., (2005)	To explore the meaning young men ascribe to their subjective experiences 3-5 years after their FEP	United Kingdom 6 young men diagnosed with schizophrenia; in contact with community mental health services; receiving psychosocial support through keyworkers	Semi-structured interviews Social constructionist grounded theory	Meaning was made by connecting psychosis to difficulties adjusting to age-related milestones, social isolation, and drug use or interpreting psychosis as punishment for prior actions. Meaning in psychosis experiences came from the personal and interpersonal changes in participants' lives that occurred following their FEP (e.g. loss regarding life goals, such as financial independence) and the self-development experienced by overcoming the challenges these changes brought (i.e. confidence, insight, and maturity)
Liu et al., (2012)	To enhance understanding of the meaning of 'psychotic phenomena' for people with schizophrenia	China 16 people diagnosed with schizophrenia attending a psychiatric hospital outpatient department	Semi-structured interviews Constant comparative analysis	Meaning in psychosis experiences was derived from being confused by it and its consequences; establishing its cause; and feeling powerless from experiencing changes to the self, being controlled, and perceiving a pessimistic future
Bergström et al. (2019)	To explore how people give meanings to their psychosis	Finland 12 people who were treated for a	Semi-structured interviews Thematic narrative	Participants <u>either</u> viewed psychosis experiences as a crisis that disturbed the 'normative' course of their life (such as gaining employment and entering a

	experiences and included these experiences in their life stories	FEP 10 to 23 years prior to study participation	analysis	romantic relationship) <i>or</i> as a crisis that was an ‘expected’ reaction to early childhood adversities (such as bullying from peers or the absence of security at home).

Meaning from the service user perspective has rarely been explored in the qualitative FEP literature. Larsen’s (2004) and Hirschfeld et al.’s (2005) studies were the only studies located that explicitly mentioned ‘meaning’ in their aims. However, other FEP qualitative studies that reference meaning making do so for other research aims—e.g. investigating the experience of receiving information from practitioners (Kilkku et al., 2003); exploring the socio-cultural processes involved in early intervention (Larsen, 2007); establishing how people recognise changes from and respond to a FEP (Judge et al., 2008); understanding the influences on hope (Perry et al., 2011); and comprehending adaptation to, and growth from, a FEP (Attard et al., 2017). These studies highlighted the need to understand service users within their own explanatory frameworks of meaning and to recognise the interrelationship between meaning, belonging, hope, adaptation, identity, and recovery.

Taken as a whole, this body of qualitative research suggests service users comprehend psychosis experiences in diverse ways. The meaning of psychosis for service users came from: identifying an explanation for it; surviving its impact; taking advantage of the help it gave them in life; and reaping the benefits of the positive change/growth experienced in its aftermath. These forms of meaning impact how service users they view themselves; their relationships with others; their past, present, and future; and their perception of the world. Also, service users can assign both positive and negative psychological values to psychosis experiences. For example, the joy in witnessing divine beauty or the fear in realising one’s life is under threat. Thus, recovery in psychosis is congruent with multiple understandings and beliefs about these experiences and finding personal meaning in them appears to constitute ‘one of the keys to recovery’ (Thornhill et al., 2004, p. 195). Other qualitative studies have highlighted service users’ longing for opportunities with practitioners to discuss the content and meaning of psychosis experiences and for the personal

meaning that they ascribe to these experiences to be given credence (Coffey & Hewitt, 2008; O’Keeffe et al., 2018). The next section reviews the empirical research on MIL in mental health.

3.9 Empirical studies on Meaning in Life in mental health: mixed outcomes

It is only since the 1980s that MIL has become empirically investigated in the context of recovery and wellbeing in mental health. Within the literature, there is broad endorsement by researchers that the *presence* of MIL is positively related to psychological wellbeing, defined as life satisfaction, happiness, and positive affect (Debats et al., 1993; Hicks & King, 2007; King, et al., 2006). MIL has been found to be positively related to quality of life (Stolovy et al., 2009), empowerment (Roberts, 2008), identity (Heine et al., 2006), and internalised stigma (Or et al., 2012); all of which influence life satisfaction in the face of ‘psychiatric illness’ and ultimately recovery (Davidson et al., 2010). However, quantitative data obtained from undergraduate psychology students suggest that the *search* for MIL is associated with negative affect, poor life satisfaction/self-esteem, and neuroticism (Steger et al., 2006).

Steger et al. (2008c) conducted a study to examine the relationships between meaning, wellbeing, cognitive style, and personality among undergraduate psychology students. They found that seeking MIL was correlated with rumination (i.e. repetitive focusing on negative and distressing feeling), enforcing fatalism and helplessness (i.e. being unable influence current circumstances), and perceiving that the past in a negative light (i.e. wanting to change history). These findings suggest that the destination of MIL attainment is deeply rewarding; but the ‘in the moment’ experience of actively pursuing MIL and not attaining it—detrimental to wellbeing. However, recent research utilising lagged analysis has challenged this deduction, suggesting that greater search for MIL on one day leads to greater presence of MIL the next (Newman et al., 2018). These findings indicate a temporal factor mediating the relationship between seeking MIL, finding/developing it, and its advantageous consequences. In other words, seeking MIL today may act like a savings account; the rewards of which can be ‘withdrawn’ at a later date.

3.10 Measuring Meaning in Life in psychosis: assessment instruments

A wide range of assessment instruments have been utilised to measure MIL in the empirical literature (Brandstätter et al., 2012); albeit these are predominantly utilised in physical health conditions (Czekierda et al., 2017). Prior to discussing the research, a brief overview of the four self-report questionnaires used in psychosis research is presented. This overview informs the reader of how, to date, MIL (or the drive to attain MIL) has been measured among people with experience of psychosis.

The Purpose in Life Test (Crumbaugh & Maholick, 1968) was designed from Frankl's (1967) MIL theory (that the 'will to meaning' is the main source of human motivation) to appraise the degree to which meaning and purpose in life are experienced. The Life Regard Index (Battista & Almond, 1973) was created to make operational Battista and Almond's (1973) phenomenological 'relativistic' theory of MIL (that beliefs differ regarding what makes life meaningful). The instrument equates MIL with Positive Life Regard (defined as the extent to which a person has a framework or a philosophy of life and lives a life congruent with it). The Seeking of Noetic Goals Test (Crumbaugh, 1977) was developed to assess a person's motivation or need to discover MIL from Frankl's (1967) theoretical perspective. Finally, the Meaning in Life Questionnaire (Steger et al., 2006) assesses the presence of MIL and the degree that a person strives for MIL. This measure conceptualises MIL as the sense made of, and seeing significance, in life. (Table 3.2 displays further detail on each measure).

Table 3. 2 Instrument details, how MIL is conceptualised by each, and frequency of use in the psychosis literature

Measure name, author(s), and year published	Aspect(s) of MIL measure appraises	MIL definition and theoretical perspective	Item/scale details	Number of articles measure used in
Purpose in Life Test (Crumbaugh & Maholick, 1968)	The degree to which MIL/PIL is experienced MIL and PIL considered the same construct Cognitive, affective, and behavioural symptoms of	MIL/PIL is 'the ontological significance of life from the point of view of the experiencing individual' (Crumbaugh & Maholick, 1964, p. 201). Derived from Frankl's	20 items 7 point Likert scale No sub-scales	9/16

	pathological meaninglessness in clinical settings	(1967) theoretical perspective: the 'will to meaning' is the primary and most robust source of human motivation		
Life Regard Index (Battista & Almond, 1973)	The extent to which 'Positive Life Regard' (PLR) is experienced PLR deemed synonymous with MIL	MIL/PLR is having a framework/philosophy of life and experiencing fulfilment by living in harmony with it Grounded in Battista & Almond's (1973) phenomenological 'relativistic' theory of MIL: no predetermined values should be applied to MIL measurement as beliefs differ about what is meaningful	28 items 5 point Likert scale 2 subscales: Framework (14 items); Fulfilment (14 items)	5/16
Seeking of Noetic Goals Test (Crumbaugh, 1977)	The level to which a person holds attitudes that motivate them to find PIL/MIL	PIL/MIL are defined in the same manner as the Purpose in Life Test Oriented towards Frankl's (1967) theoretical perspective	20 items 7 point Likert scale No subscales	1/16
Meaning in Life Questionnaire (Steger et al., 2006)	Both the presence of MIL and the extent that people strive for MIL MIL and PIL are not equivalent	MIL is 'the sense made of, and significance felt regarding, the nature of one's being and existence' (Steger et al., 2006, p.81) MIL is <i>comprehension</i> (devising a life framework) and <i>purpose</i> (crafting long-term self-defined life goals)	10 items 7 point Likert scale 2 subscales: Presence (5 items) Search (5 items)	2/16

3.11 Quantitative research on Meaning in Life in psychosis

A number of studies were located that measured MIL among people with experience of psychosis. Sixteen articles representing 14 discrete quantitative studies investigating MIL in psychosis were identified. Eight articles focused on comparing MIL levels in people diagnosed with psychosis with those of the general population and other people with psychiatric 'diagnoses' (e.g. borderline personality 'disorder'). Studies infer that people with experience of psychosis exhibit more MIL (e.g. Roberts, 1991) or less MIL than the general population (e.g. Huguelet et al., 2016). Other studies conclude that those diagnosed with psychosis exhibit more MIL (e.g. Crumbaugh, 1968) or less MIL (e.g. Chaudhary & Sharma, 1976) than people with other psychiatric 'diagnoses'.

Five identified articles compared MIL with different variables (such as personality traits, hopelessness, and empowerment) and attempted to mathematically model the relationships between MIL and these variables (Crumbaugh, 1968; Yarnell, 1971; 1972; Chaudhary & Sharma, 1976; Roberts, 1991). MIL was associated with treatment characteristics (Duration of Untreated Psychosis [DUP], duration of hospitalisation); clinical variables (depression levels, psychosis ‘symptoms’, medication adherence); and more wide ranging life factors (post traumatic growth, quality of life, coping self-efficacy appraisal²², spirituality/religiosity, and personal recovery). Two articles examined the effect of interventions (social recovery therapy and recovery oriented clinical programme) on MIL (Young et al., 2014; Fowler et al., 2018). Both demonstrated that interventions are capable of enhancing MIL. One article investigated MIL change over time and concluded that MIL may be more or less important in recovery at different time points (Snyder et al., 2015).

Some articles use archaic, disparaging, and racist language to categorise people, such as ‘Schizophrenics, hospitalized, Negro’ (Crumbaugh, 1968, p. 75). Psychiatric stigma permeates this lexicon, which reflects an antiquated medical lens and socio-cultural context that devalues the lived experience of mental health difficulties. Some studies made value judgments about the lives of people experiencing psychosis and deemed some forms of MIL more meaningful than others. For example:

the schizophrenic may think that life has meaning and purpose even though to the external eye this meaning is shallow, inadequate, distorted and unsatisfactory (Crumbaugh, 1968, p. 77).

(Table 3.3 presents a detailed overview of these studies).

²² The appraised ability to manage environmental demands and personal functioning following stressful or traumatic or events.

Table 3. 3 Characteristics, samples, and key findings of quantitative studies assessing MIL among people with experience of psychosis

Author(s) and year	Study aim	Psychosis sample and comparison sample	MIL measure used	Main findings
Studies comparing MIL in psychosis samples with other samples				
Crumbaugh (1968)	To validate the Purpose in Life Test in six 'psychiatric patient' and four 'non-patient' groups	230 business people/ professionals 142 Protestant parishioners 417 undergraduate students 16 non-psychiatric inpatients 225 outpatient 'neurotics' 13 hospitalised 'neurotics' 38 hospitalised 'alcoholics' 11 black hospitalised 'schizophrenics' 41 non-black hospitalised 'schizophrenics'	Purpose in Life Test (Crumbaugh & Maholick, 1968)	Psychiatric patients displayed significantly lower MIL than 'normal' subjects The inpatient 'schizophrenic' groups displayed higher MIL than any other psychiatric group No tests appraising statistically significant differences were carried out
Yarnell (1971)*	To examine the relationship between Purpose in Life Test scores and measures of personality in 'normal' and 'schizophrenic' participants	40 Air Force men 40 hospitalized male 'schizophrenics'	Purpose in Life Test (Crumbaugh & Maholick, 1968)	'Schizophrenics' exhibited lower MIL than 'normal' males No tests examining statistically significant differences were conducted
Yarnell (1972)*	To validate the seeking of Noetic Goals Test with 'schizophrenic' and normal participants	40 male 'schizophrenic' participants 65 'normal' Air Force members (25 female; 40 male)	Seeking of Noetic Goals Test (Crumbaugh, 1977)	'Schizophrenic' male participants were more motivated to find MIL than 'normal' male and female participants No significant differences were found between groups
Chaudhary & Sharma (1976)	To compare PIL in 'psychiatric patients' and 'normals'	60 'schizophrenic' males 60 'neurotic' males 60 'normal' males	Purpose in Life Test (Crumbaugh & Maholick, 1968)	'Schizophrenic' participants presented with significantly lower MIL than both 'normals' and 'neurotics'
Gonsalvez & Gon (1983)	To compare PIL in 'psychopathological' and 'normal' groups.	30 'schizophrenics' 30 'psychoneurotics' 30 nonpatient college students 30 nonpatient seminarians	Purpose in Life Test (Crumbaugh & Maholick, 1968)	'Psychopathology' groups had significantly lower MIL than non-clinical groups No significant differences in MIL scores were found between the two 'psychopathology' groups or the two 'normal' groups
Roberts (1991) ¹	To compare the strength of perceived MIL among a group of 'chronically deluded' participants with three comparison groups	17 People Diagnosed With (PDW) schizophrenia/ schizoaffective 'disorder' with longstanding 'delusional' belief systems 17 matched 'previously deluded' service users in	Purpose in Life Test (Crumbaugh & Maholick, 1968) Life Regard Index (Battista & Almond, 1973)	People with active 'delusions' displayed significantly more MIL than those in remission The actively 'deluded' group also reported more MIL than psychiatric nurses Anglican Ordinands recorded the

		remission following treatment 16 psychiatric nurses 33 Anglican Ordinands		highest levels of MIL For some people, there may be satisfaction in psychosis, psychosis itself may give MIL, and delusional formation is adaptive
Huguelet et al. (2016)**	To test a model of the determinants of MIL	75 PDW schizophrenia/other 'chronic' psychoses 38 PDW borderline personality 'disorders' 28 PDW anorexia nervosa 35 PDW with type I or II bipolar 'disorder'	Life Regard Index (Battista & Almond, 1973)	Similar levels of MIL were found across groups; no statistically significant differences were found between groups. Psychosis sample MIL was significantly lower than general population MIL levels
Weibel et al. (2017)	To explore if childhood maltreatment has a direct or indirect effect on MIL in people with psychiatric 'disorders'	73 PDW schizophrenia or other 'chronic' psychoses 28 PDW borderline personality 'disorder' 30 PDW anorexia nervosa 35 PDW type I or II bipolar 'disorder'	Life Regard Index (Battista & Almond, 1973)	The highest degree of MIL was found in the bipolar disorder group followed by the anorexia nervosa, schizophrenia/'chronic' psychoses, and borderline personality disorder groups No tests investigating statistically significant differences were performed
Studies looking at the relationships between MIL and other variables				
Turner et al. (2007)	To assess and compare 'symptomatology', PIL, and DUP in FEP	54 PDW a FEP who presented to community/inpatient psychiatric services	Purpose in Life Test (Crumbaugh & Maholick, 1968)	Sample MIL was lower than studies using non-clinical (Zika & Chamberlain 1992; Moomal 1999; Edwards & Holden 2001) and clinical (Vaughn & Kinnier 1996) samples High MIL was significantly negatively associated with a long DUP and high depression scores
Hasson-Ohayon et al. (2014)	To explore MIL among people with 'serious mental illness' and variables that may influence it	80 PDW schizophrenia/schizoaffective 'disorder'	Life Regard Index (Battista & Almond, 1973)	Results supported a mediation model in which self-clarity affects self-stigma, self-stigma impacts MIL, and MIL influences personal recovery
Stolovy et al. (2009)	To investigate the relationship between MIL, quality of life, medical adherence, and duration of hospitalization among 'inpatients'	60 inpatients diagnosed with schizophrenia (49 male; 11 female)	Purpose in Life Test (Crumbaugh & Maholick, 1968)	MIL significantly correlated: (i) positively with quality of life, medication adherence, and the duration of the current hospitalisation and (ii) negatively with depression scores
Huguelet et al. (2016)**	To explore spiritual MIL in relation to values and mental health among 'psychiatric patients'.	74 PDW schizophrenia 37 PDW borderline personality 'disorders' 29 PDW anorexia nervosa 35 PDW bipolar 'disorder'	Life Regard Index (Battista & Almond, 1973)	Among PDW schizophrenia, those who deemed spirituality/religion essential to their lives pictured their existence from a more meaningful perspective
Mazor et al. (2016)	To further understand the relationships between psychosis and post traumatic growth	95 PDW schizophrenia/schizoaffective 'disorder' 9 PDW with bipolar 'disorder' with past psychosis 'symptoms'	Meaning in Life Questionnaire (Steger et al., 2006)	Post traumatic growth was mediated by MIL Higher MIL was generally related to higher post traumatic growth, higher coping self-efficacy

		17 PDW personality or affective 'disorders' with psychosis 'symptoms'		appraisal, and fewer negative and total psychosis 'symptoms' A marginal negative non-significant correlation was found between MIL and positive psychosis 'symptoms'
Studies testing the efficacy of interventions in increasing MIL				
Young et al., (2014)***	To test the effectiveness of a recovery oriented clinical programme	104 PDW psychotic spectrum 'disorder' diagnoses	Purpose in Life Test (Crumbaugh & Maholick, 1968)	A recovery oriented clinical programme based in a therapeutic community resulted in statistically significant improvements in MIL
Fowler et al. (2018)	To test the efficacy of social recovery therapy plus early intervention services among people diagnosed with a FEP	155 PDW non-affective psychosis	Meaning in Life Questionnaire (Steger et al., 2006)	Social recovery therapy in combination with early intervention services had a statistically significant effect on MIL
Studies examining the dynamics of MIL change over time				
Snyder, et al., (2015)***	To examine the rates and correlations of change in 'symptoms, functioning and personal recovery within a recovery oriented clinical programme	104 PDW psychotic spectrum 'disorders'	Purpose in Life Test (Crumbaugh & Maholick, 1968)	MIL and clinical recovery occur over time along idiosyncratic and heterogeneous pathways An emphasis on MIL may be more or less valuable in recovery depending on the individual and the recovery trajectory time point

*/**/*** = articles reported on the findings from the same study

¹ This study used quantitative and qualitative methods; quantitative findings are reported on here

While these studies tell us something about the levels of and variables related to MIL; they do little to inform us about the subjective experience of service users. The next section reviews published qualitative syntheses of service user perspectives on recovery in order to identify if (and how) MIL features in their understanding of 'recovery'.

3.12 Service user perspectives on the role of Meaning in Life in mental health recovery

A number of studies have aimed to synthesise service user understandings or the concept of recovery and the influences on recovery. Six qualitative syntheses of service users' perspectives on 'recovery' in mental health and psychosis were identified (Andresen et al., 2002; Leamy et al., 2011; Soundy et al., 2015; Stuart et al., 2017; Jacob, et al., 2017; Wood & Alsawy, 2017). As some

syntheses were not explicit about the number of service user perspectives synthesised or where original studies were conducted, it is not possible to give an overview of this information. The findings of these syntheses concluded that MIL is central to how recovery is conceptualised by service users. MIL was experienced as something of value to pursue in the recovery journey; as part of the recovery process itself; and as what motivated people to continue living as they dealt with the challenges of ‘mental illness’. MIL was understood as finding meaning in ‘mental illness’ experiences; engaging in meaningful activities; adopting social roles; and achieving life goals. Attaining MIL was also connected to: spirituality, identity transformation, reputation, belonging, developing new perspectives on life, caring for others, as well as taking responsibility for, and rebuilding life in the aftermath of ‘mental illness’. (The characteristics and meaning related aspects of recovery found in these articles are displayed in Table 3.4).

Table 3. 4 Characteristics of syntheses of service user perspectives on recovery in general mental health/psychosis and their findings regarding *meaning*

Author(s), year, and synthesis method	Synthesis aims	Findings related to meaning
Andresen et al., 2002) Systematic review and constant comparison	To develop a conceptual model of recovery meaning, stages, and outcomes for people with schizophrenia and other serious ‘mental illness’	MIL is a pivotal component process of recovery; meaning sources can vary between individuals and over time MIL involved: • Reassessing/expressing life values/goals; • Finding what motivates and makes life valuable/enriching; • Recovery work giving MIL; spirituality giving meaning to struggling; • Developing a new world view
Leamy et al. (2011) Systematic review and modified narrative synthesis	To develop a conceptual framework of service user defined recovery journey characteristics, processes, and stages in general mental health	MIL is a predominate recovery process MIL included: • Meaning of ‘mental illness’ experiences; spirituality; quality of life; meaningful life/social roles/goals; and rebuilding life
Soundy et al. (2015) Systematic review and thematic synthesis	To identify the factors that influence recovery in individuals with schizophrenia	Social support, close relationships, and belonging supported recovery: • Caring for others provided MIL
Stuart, Tansey, &	To determine how service users with	MIL is a central facet of the recovery process

Quayle (2017) Systematic review and best-fit framework synthesis; with Leamy et al.'s (2011) model providing the exploratory framework	severe/enduring 'mental illness' experience the recovery process	MIL was derived from: • Participating in society/rewarding activities and helping others; • Positively evaluating 'mental illness' experiences • Taking responsibility for physical health
Jacob et al., (2017) Systematic review	To establish—and determine the differences between—how recovery and factors influencing it are viewed by service users, carers, and service providers	Recovery according to service users is: • A transformation of self from an 'illness' to an identity marked by meaning • Finding personal meaning in experiences, engaging in meaningful activities, and having MIL Service users perceived not having the capacity to develop MIL in their communities as humiliating and antagonising Carers only mentioned meaning in recovery terms of 'meaningful activities' Service providers did not reference meaning as a part of recovery
Wood & Alsawy (2017) Systematic review and thematic synthesis	To synthesise the 'recovery from psychosis' qualitative literature examining service user perspectives	MIL related to reconciliation, integration of psychosis into identity, and making sense of life following a psychotic episode People learned from, developed a coherent explanation of, and found a personal meaning for, psychosis experiences and their implications for the future Meaning was linked to social activities, self-image/esteem, and social connection Faith/spirituality assisted meaning construction for psychosis experiences

These syntheses underscore the powerful need for MIL and meaning in 'mental illness' experiences in mental health recovery. The next section looks at individual qualitative studies that explored 'recovery' with people with psychosis and also found that MIL was a feature of 'recovery' in psychosis from the service user standpoint.

3.13 Service user perspectives on mental health recovery and Meaning in Life in psychosis

Since the early 2000s, investigators have explored the concept of 'recovery' according to people with experience of psychosis. Qualitative studies have found that core aspects of service user

defined recovery for this group relate to MIL; that, from their perspectives, part of the recovery construct is (re)discovering and (re)engaging with MIL. For participants, recovery meant constructing MIL by increasing the amount of meaningful activity engaged in; adopting meaningful roles valued by family and society; having faith in spirituality; and regaining one's spirit (O'Sullivan et al., 2013; Windell et al., 2012; Spaniol et al., 2002). One service user led study found that recovery in psychosis involved rebuilding life (by creating purpose through rebuilding social support) and rebuilding self (by making sense of distress) (Pitt et al., 2007). A 2014 Delphi study found MIL to feature in three definitions of recovery with very high levels of consensus among persons with experience of psychosis ($\geq 83\%$) (Law & Morrison, 2014).

Service user interpretations of recovery underline the process of sense/meaning making in 'mental illness' experiences. Understanding and integrating these experiences can result in positive changes (Jordan et al., 2018) including learning; maturity; emotional/personal growth; insight into self/increased self-awareness; benefit finding; a broader perspective on life; and becoming a 'better' person (Eisenstadt et al., 2012; Spaniol et al., 2002; Romano, McCay, & Boydell, 2012; O'Sullivan et al., 2013; Roger et al., 2008). This aspect of recovery can help people accept the totality of their experiences; develop new skills; make better choices; establish more fulfilling relationships; and buffer against the diminishing impact of psychosis on their sense of self (Romano et al., 2010).

According to people living with psychosis, meaning is also factor that influences recovery. The absence of routes to meaningful community engagement hinders recovery (i.e. available occupations/structure). Recovery is supported by spirituality and nature contact affording meaning; family offering meaningful roles/connection; teachers and bosses providing meaningful opportunities for success; mental health services encouraging meaningful role participation; and society helping people to engage in socially valued activities that give meaning, purpose, and self-worth (O'Sullivan, 2013; Jenkins & Carpenter-Song, 2005; Romano et al., 2012; Windell & Norman, 2013). The next section looks at qualitative studies that explicitly aimed to explore MIL or Meaning of Life in psychosis.

3.14 Exploring Meaning in Life and Meaning of Life in psychosis

Little published qualitative research exists exploring Meaning of Life (MOL) or MIL among people diagnosed with psychosis. Three articles examining these concepts were identified; representing three discrete studies, conducted in Taiwan (Lan & Su, 2007), Sweden (Eklund et al., 2012), and an unspecified location (Roberts, 1991).

The first, carried out in Taiwan using semi-structured interviews with inpatients with schizophrenia (N = 9), focused on MOL content in participants' life narratives (i.e. the meaning of suffering, life and death, life goals, and values) as well as life meaning sources (Lan & Su, 2007). Data were coded to quantify these aspects of life meaning using content analysis. Findings indicated that attaining mental health care, being altruistic, and life experience (e.g. living peacefully and in the moment) gave participants' lives meaning. The authors concluded that the experience of schizophrenia and 'drug therapy, psychotherapy, and folk therapy'²³ (Lan & Su, 2007, p. 479) influenced the meaning of suffering, which affected attitudes to death, which—in turn—impacted participant's MOL perceptions. The extent to which participants could experience life meaning was greatly restricted by living in an inpatient hospital.

The second, a Swedish study, utilised semi-structured interviews with people with a diagnosis of schizophrenia (N= 10) in supported housing (Eklund et al., 2012). Content analysis was employed to quantify five MIL sources: social contacts; engagement in occupations; experiencing health; precious memories; and positive feelings. The authors concluded that, for their sample, MIL was derived from doing, being, and belonging, but not from shaping a future identity. Findings indicated that, for participants, MIL comprised: engaging in occupations; having everyday routines; experiencing positive emotions from investing in personal interests; belonging to a work context (in the past); and attaining balance in life from managing distress.

²³ Not defined by the authors.

A third paper provided qualitative data from a mixed methods study performed by Roberts (1991). The study's qualitative component explored the 'meaning and significance' of quantitative MIL and depression assessment instruments²⁴ for people with schizophrenia/schizoaffective disorder described as 'chronically deluded' (N = 17) (Roberts, 1991, p. 22). Delusions were interpreted by the author as giving participants: an identity; a duty/responsibility; hope; purpose; relationships/connectedness; value in the eyes of others; freedom/protection from the past; positive affect; and a reason to live. Participants described thinking about the possibility of losing their 'delusional' beliefs as painful and envisioned this potential loss as 'catastrophic'.

These qualitative findings were used by the author to explain the study's quantitative result that 'chronically deluded' people with a diagnosis of schizophrenia/schizoaffective disorder exhibited more MIL than matched 'previously deluded' (Roberts, 1991, p. 23) service users in remission, psychiatric nurses, and Anglican Ordinands. Roberts concluded that for some people, there may be satisfaction in psychosis, psychosis itself can give MIL, and delusional formation is adaptive. (Further detail regarding each study's methodology and findings is given in Table 3.5).

Table 3. 5 Characteristics and main findings of qualitative studies exploring MOL and MIL for people diagnosed with psychosis

Author(s) and year	Concept(s) explored	Context and sample	Data collection and analysis method	Main findings
Lan & Su (2007)	MOL content in participants' life narratives and 'life meaning' sources	Taiwan 9 inpatients with schizophrenia living in a long-stay ward No further context given	Semi-structured interviews Content analysis to quantify aspects of 'life meaning'	Acquirement of care, altruistic behaviours, and life experience gave participants meaning Past meaning was derived from meaningful support and work ability; present meaning was limited to participation in treatment; and future meaning emerged from realising the goals of being discharged from hospital, obtaining a 'disease-free' status, and returning to work
Eklund, Hermansson, & Håkansson (2012)	The sources of MIL	Sweden 10 people with schizophrenia residing in	Semi-structured interviews Content analysis to quantify MIL	Five sources of MIL were identified: social contacts (socialisation, existing in a social context, feeling accepted); engagement in occupations (having structure and routine, investing in interests, envisioning work);

²⁴ The Purpose in Life Test (Crumbaugh & Maholick, 1968), the Life Regard Index (Battista & Almond, 1973), and the Beck Depression Inventory Shortened Form (Beck & Beck, 1972).

		supported housing No further context given	sources	experiencing health (physical and mental); precious memories (forming memories and reflecting on how life was richer in the past); and positive feelings (feeling safe and needed). Positive feelings were generated by all MIL sources; occupation engagement and experiencing health mutually reinforced each other
Roberts (1991) ¹	The meaning and significance of quantitative MIL and depression findings	Country not specified 17 people with schizophrenia/schizoaffective disorder (described as 'chronically deluded') No further context given	Semi-structured interviews Analytic approach unclear	'Delusions' provided a new sense of identity; a clearer sense of responsibility, hope for the future; a higher purpose; freedom and protection from past hurts; a feeling of being peaceful, enthusiastic about, and interested in life; and a reason to live. 'Delusions' may offer people a preferred reality where they are protected from depression and experience greater MIL.

¹ This study used quantitative and qualitative methods; qualitative findings are reported on here.

In sum, studies that focused on MIL or MOL from the viewpoint of people diagnosed with psychosis found that meaning was dependant on societal perceptions; societal value/responsibility; memory formation; mood; hope for the future; and the restrictions on freedom intrinsic to psychiatric care. Findings also suggest that 'delusional belief systems' (Roberts et al., 1991, p.19) offer an abundant source of MIL. Two of the three published studies (Lan & Su, 2007; Eklund, et al., 2012) did not explore MIL with people in the community living independently. Both studies adopted a reductionist approach; classifying meaning in an instrumental manner by detailing the sources of MIL important in recovery: roles, relationships, goals, and activities. The third study (Roberts, 1991) did not investigate MIL in an open ended way; instead focusing on the meaning arising from 'delusion' content. It also failed to make its analytic approach, epistemological/ontological grounding, and the context of data collection explicit. None of these studies provided an in-depth understanding of how MIL is constructed in recovery in psychosis and what supports and hinders this process.

3.15 Chapter summary and conclusion

This chapter considered the literature on meaning making, MIL, psychosis, and mental health recovery. Historically, the meaning of psychosis experiences has been a key site of discordance, dispute, and struggle for human rights. In this context, it becomes a political act of defiance for a person to search for meaning in such experiences. Such a quest risks being labelled as ‘a lack of insight’, if the meaning constructed is not aligned to the meaning assigned by practitioners. In the past, psychiatric services have actively sought to diminish the value of the subjective interpretation and meaning making of people experiencing psychosis. The uncritical application of diagnostic systems allowed clinicians to manage responsibility, by delimiting what was ‘meaningful’ in terms of psychiatric categorisation, and ignore the innumerable aspects of lived experiences. The recovery model, adopted by contemporaneous services, seeks to redress the assumption that psychosis experiences have no meaning beyond the medical narrative and research conducted in line with recovery principles reflects this.

The literature is equivocal regarding whether or not schizophrenia and other forms of psychotic ‘illness’ necessarily result in impairments in meaning making. Mixed findings link psychosis to both increased and decreased MIL. This may be the result of psychosis itself; an epiphenomenon of treatment depriving a person of psychosis derived MIL; or due to other unexamined factors. It is difficult to unpick these findings as no study assessed individuals who had disengaged from, or indeed, decided to recover outside of, the mental health system. On the one hand, both attachment to institutional settings and antipsychotic treatment adherence/efficacy appear implicated in the process of MIL attainment in psychosis. If MIL is positively correlated with short DUP, long duration of hospitalisation, and medication adherence; then service providers need to be cognisant of risk when treatment is ceased. On the other, if mental health services are successful in reducing the frequency/intensity of psychotic phenomenology, treatment may inadvertently be hindering service user defined recovery if it deprives the person of the MIL drawn from their psychosis.

The evidence gleaned from this review points to a number of deductions. Although available data are largely from descriptive qualitative studies, research conducted internationally has confirmed the desire for, and the value of, MIL among individuals with experience of psychosis. Many people

managing psychosis in their life explain recovery as attaining a sense of self-coherence and individual meaning in the world. Research has suggested that service users deemed deciphering 'psychosis meaning' an important outcome of treatment. Studies indicated that meaning is shaped by a person's personal narrative, social context, culture, and the ideologies present in their environment. However, not all people needed to find meaning in psychosis and engaging in meaning making can be both advantageous and detrimental to wellbeing.

The majority of qualitative studies exploring service user perspectives on meaning in psychosis either focus on one or a small number of diagnostic categories (e.g. schizophrenia) or one type of psychosis experience (e.g. voice hearing). No study examined the impact of remission status on meaning making in psychosis. Many were over 10 years old. Themes presented often lacked clarity and elaboration. Thus, there is a need for modern research conducted with rigour on meaning making in psychosis experiences across psychosis experience type, diagnosis, and remission status. No study was found to examine how meaning making in psychosis experiences influences service users' perspectives on MIL.

In spite of the considerable discourse on the prominence of MIL as a dimension of recovery in psychosis and its impact on outcomes, what is apparent from this review is the scarcity of research seeking to enhance the conceptual clarity of MIL from the perspective of people with psychosis. What is published comprises small, surface level, qualitative studies that either quantified categories of meaning or lacked transparency in methods. No study was found that explored MIL and the factors that influence MIL in an in-depth manner. In addition, no study was identified that qualitatively compared the MIL process between groups based on their remission status.

Endeavouring to capture this process and identify relationships and nuances between accounts using quantitative methods was deemed incongruous. It was considered more appropriate to explore this subject from an idiographic perspective, using the methodology of Interpretative Phenomenological Analysis. Therefore, the overarching aim of this study was to explore MIL and the key factors that influence MIL from the viewpoints of people who experienced a FEP 21 years

ago. In this way, rather than constructing a theory, this research strived to obtain a deep and rich understanding of the nature and meaning of the lived experience of meaning making and MIL in mental health recovery in psychosis. The next chapter will discuss the theoretical and philosophical standpoints that guided the research process.

CHAPTER FOUR: EPISTEMOLOGICAL, ONTOLOGICAL, AND METHODOLOGICAL ARGUMENTS UNDERPINNING THE RESEARCH STUDY

4.1 Introduction

This chapter begins with an explanation of terms used to clarify the assumptions that influenced the research process. A brief description of interpretative phenomenological epistemology is then provided; followed by an explicit outline of the specific epistemological, ontological, and theoretical standpoints adopted by the study. The theoretical, data collection, and data analysis principles underpinning Interpretative Phenomenological Analysis (IPA) are then discussed. After this, a critique of IPA and a discussion on the assessment of quality and rigour in IPA research is provided. The chapter concludes with the rationale for selecting IPA as the methodology of the study.

4.2 Defining terms: Epistemology, ontology, and theoretical perspective

Epistemology considers the nature and scope of knowledge; how it is generated, acquired, and utilised; and its relationships to similar constructs such as truth, belief, and justification (Topping, 2006). Epistemology examines how we can know, what is the meaning of knowing, and whether or not certain knowledge can be validated or considered ‘true’ (Montfort et al., 2014). *Ontology* concerns assumptions made about the nature and form of reality (Guba & Lincoln, 1994). It considers whether reality is objective and external to us or subjective and constructed by each of us—resulting in multiple realities (Long et al., 2000). A *theoretical perspective* constitutes a philosophical standpoint reinforcing and guiding a methodology. It provides context for the research process itself; grounding its criteria and logic. Distinct from epistemology, a theoretical perspective is an approach to comprehending and elucidating the human social realm that goes beyond empirical knowledge (Crotty, 1998; Hesse-Biber & Leavy, 2004). According to Staller

(2012), a logical research study must demonstrate integration among, coherence of, and an interrelationship between these three concepts.

Prior to embarking on a research project, it is vital to clarify explicitly (not just to the reader but to oneself) one's assumptions regarding epistemology, ontology, and theoretical perspective. Being transparent enables the reader to judge appropriately rigour and quality; determine if methodology and methods are justified; and establish if outcomes are plausible and helpful to the field (Crotty, 2003). This requirement is particular germane to qualitative researchers, as their work is likely to confront what sociologist George Steinmetz describes as 'epistemological unconsciousness' (Steinmetz, 2005, p. 109)—the privileging and institutionalisation of objectivist epistemological philosophy in academic life. This clarity can assist qualitative researchers in robustly defending their work from misplaced critiques emerging from conflicting paradigms. As IPA is the methodology used in the study, the remainder of the chapter will present the epistemological, ontological, and methodological arguments that underpinned its use.

4.3 The Interpretative Phenomenological Analysis (IPA) epistemological stance

Adopting an IPA philosophical orientation means embracing an interpretative phenomenological epistemology. This orientation involves the researcher adopting a number of assumptions to enable them to comprehend each participant's *relatedness* to the world through the meanings they make from their experiences in life. An IPA researcher accepts that human beings cognise, interpret, and conceptualise the world by understanding *experience*; with this understanding occurring in the context of ongoing personal and social relationships (which includes the researcher). The researcher also acknowledges that people engage in embodied meaning making while being 'always-already immersed in a linguistic, relational, cultural and physical world' (Larkin & Thompson, 2011, p. 102). While experience cannot be accessed directly from participants' accounts, through the processes of intersubjective meaning-making and reflexivity, a researcher

can become ‘experience near’²⁵ (Eatough & Smith, 2017, p. 206). Accepting these suppositions necessitate an idiographic approach to enable a fine-grained focus on the particular, with interpretation being required at all stages of an IPA study. IPA researchers must also commit to reflecting on their role in generating interpretations and grounding these interpretations in participants’ accounts (Larkin & Thompson, 2011).

While an interpretative phenomenological epistemology is fundamental to IPA and certain theoretical underpinnings are standardised across studies²⁶, the IPA approach is nonetheless flexible; being compatible with a range of ontological/epistemological perspectives in the continuum between positivism and constructionism²⁷. As Wagstaff et al. (2014, p. 8) has described:

IPA has integrated diverse philosophical perspectives that are not always easily reconciled with one another. With different emphases on different intellectual roots of IPA, the paradigmatic appropriation of the methodology can vary.

Typically IPA is grounded on realist ontologies²⁸ with contextualised relativist²⁹ epistemologies (Larkin et al., 2006). The current research study is guided by the ontological/epistemological underpinnings of critical realism³⁰ and contextualism³¹ and informed by an integrated theoretical

²⁵ As an IPA researcher can never directly access other people’s experiences, he/she can only aim to get *experience near*. This necessitates encouraging participants to attend to the experience in question.

²⁶ Phenomenology, idiography, and hermeneutics.

²⁷ For example, researchers have used contextualism (Madill et al., 2000), critical realism (Fade, 2004), and ‘a light constructionist stance’ (Eatough & Smith, 2006, p.485) as the ontological and epistemological foundations of IPA research.

²⁸ Ontologies which assert the view ‘that entities exist independently of being perceived, or independently of our theories about them’ (Phillips, 1987, p. 205).

²⁹ The stance that knowledge of the world is gained through mental constructs; thus the truth/falsity of an assertion is relative to an individual or social group.

³⁰ The philosophical position that reality exists but the process of knowing modulates what is known.

³¹ The understanding that knowledge is relative to context.

perspective of phenomenology³², idiography³³, and hermeneutics³⁴.

4.3.1 Critical realism

The positivist paradigm assumes a direct relationship between the world and the human perception of it. Reality is demonstrated by collecting unbiased objective data. Knowledge is conceptualised as something that accumulates and as a consequence improves understanding. Further research is justified on the grounds that it will contribute to what is currently known and this accumulation of knowledge enhances one's ability to successfully predict outcome in the world (Denzin, 2016).

While the positivist paradigm is dominant, it has been argued that it entirely fails to tackle elementary questions regarding meaning in human life:

... this [positivist] science has nothing to say to us. It excludes in principle precisely the questions which man, given over in our unhappy times to the most portentous upheavals, finds the most burning: questions of the meaning or meaninglessness of the whole of this human existence (Husserl, 1970, p. 6).

The naturalistic paradigm sits in stark contrast to positivism. From this position, the accumulation of studies in a research area does not in itself impart an advancement in, or development of, knowledge. It simply indicates a research area of particular human interest, signifies the playing out of the positivist paradigm, and may not reflect an improvement in the actual understanding of phenomena (i.e. events, processes, or relationships). In contrast, naturalistic research seeks to enhance understanding of the social world, the 'sense of things'—in order to enrich academic and societal discourse and generate concepts that aid in comprehending human behaviour. Such understanding can facilitate anticipation but not prediction. This standpoint assumes there are

³² The study of the structures of consciousness as experienced from the first-person perspective.

³³ Analysis focusing on the particular and the individual in trying to understand individual behaviour.

³⁴ Analysis being interpretative.

multiple realities; that the researcher and participant interact and influence each other; and that research is subjective and interconnected with the values of the researcher (Noblit & Hare 1988).

The interpretivist research tradition that characterises this paradigm, however, has many shortcomings. It has been argued that interpretativism performs an ‘epistemic fallacy’³⁵ (Bhaskar, 1975, p. 158) by prioritising epistemology over ontology (considering them one and the same); being blinkered on how to acquire knowledge rather than the nature of reality itself. It may privilege agency by neglecting the real causal mechanisms and structures in nature and society that affect change and give rise to certain meanings and experiences. Furthermore, it is claimed that if actions cannot be explained by the intentions of the humans concerned; they are left unexplained (Tikly, 2015). Critical Realism is an ontological/epistemological position that has the potential to transcend limitations of both positivism and interpretivism.

Critical Realism argues that there are consistent and lasting features of an objectively knowable reality that are independent of human beings; however reality can only be apprehended imperfectly; therefore the roles of perception and cognition must be recognised when generating knowledge (Fade, 2004; Ponterotto, 2005). The fact that the real world cannot be wholly detectable or observable by human beings does not make it any less real or present (Bhaskar 1975). According to Sayer (2000, p. 12) ‘observability may make us more confident about what we think exists, but existence itself is not dependent on it’. This perspective integrates, on the one hand, the recognition that real objects/events exist and, on the other, the acknowledgment that all experiences /interpretations of the world are imperfect, partial, and not fully representative of the external world (as they can have multiple meanings) (Shipway, 2010). Knowledge, therefore, is acquired through construction and meaning making.

From the critical realist perspective, there are three interconnected ontological domains or knowledge strata. Firstly, the ‘real’ (the world independent of human thought, awareness, and

³⁵ The assumption that whether something exists is the same question as whether there is human knowledge that it exists.

existence; this comprises structures and phenomena generating mechanisms). Secondly, the ‘actual’ (all events/phenomena produced by the interaction of these structures/mechanisms; regardless of whether humans experience them or not). Thirdly, the ‘empirical’ (the world comprising human perceptions and experiences alone) (Bhaskar, 1975). For science, this means that a human perception or supposition (in the empirical domain) is regarded as a fallible representation of the real domain (Clark et al., 2008). However, it is unlikely to disclose reality entirely or result in full comprehension of any social situation (Easton, 2010). Still, the aim of science is to develop knowledge about the real domain while recognising that interpretive knowledge and scientific theories are socially produced (Bhaskar, 2008).

Critical realism contends that ontology affects epistemology (i.e. the way things are affects the way in which we know them and the extent to which they can be known). Thus, different research methods reveal disparate aspects of knowledge. Critical realism is compatible with IPA as IPA is greatly influenced by the philosophy of Martin Heidegger (1962). Heidegger’s ontological position is synthesised by Larkin et al. (2006, p. 32) as: ‘What is *real* is not dependent on us, but the exact meaning and nature of *reality* is’.

4.3.2 Contextualism

Located in the space between essentialism and constructionism on the ontological continuum lies contextualism—a philosophical position congruent with critical realism (Willig, 1999). This position reconciles how people make meaning of their experiences, on the one hand, with the limits of reality on the other. It understands meaning making as being impinged by social context (Braun & Clarke, 2006). Contextualism adopts the epistemological stance that standards of knowledge and justification vary depending on context³⁶. Therefore, study results will vary depending on the setting in which data were collected and analysed (Larkin et al., 2006) and all knowledge is relative

³⁶ From the IPA position, *context* refers to the ‘worldly circumstances in which meanings are made’ (Larkin et al., 2011, p. 324).

to its milieu; it is local, provisional, and dependant on context (Jaeger & Rosnow, 1988). Hence, the social, cultural, and theoretical environments from which research emerges impact research output.

This perspective corresponds to Heidegger's (1962) conceptualisation of the human being as person-in-context or 'Dasein'³⁷ (p. 67). The idea that we are all always and inherently somewhere; located and engaged with meaningful context (of some form). By implication, *relatedness* is an indelible part of our constitution (Larkin et al., 2011) as 'it is not actually possible—even if it might be desirable—to remove ourselves, our thoughts and our meaning systems from the world, in order to find out how things “really are” in some definitive sense' (Larkin, 2006, p. 106). Research with a contextual orientation aims to gain an understanding of specific persons-in-context and how they comprehend a particular phenomenon in situ (Braun & Clarke, 2006). Contextualism is integrated with critical realism by 'grounding discursive accounts in social practices whose underlying logic and structure can, in principle, be discovered' (Parker, 1998, p. 4). Contextualism is compatible with IPA due to their shared focus on as the construction of intersubjective meaning (Larkin & Thompson, 2011)

4.3.3 Phenomenology

Phenomenology is a core theoretical underpinning of IPA. Phenomenology is a branch of philosophy concerned with the study of meaning and experience (Cohen, 2000). It focuses on 'the meaning, structure and essence of the lived experience of this phenomenon for this person or group of people' (Patton, 2015, p. 115). This philosophical approach is interested in the experience of being a human in the world and the process of understanding what the world is like (with a particular emphasis on what is important to people). Husserl (1982) argues that as experience is the only lens one has from which to gain access to and perceive the world, so knowledge is limited to

³⁷ Meaning 'there being' or 'being there'.

that which one can obtain from how things appear in one's experience. In the context of phenomenology, science develops knowledge from the structures and components of the experience itself rather than knowledge gained from the objects of experience. To be phenomenological, one must go 'Back to the things themselves!' (Husserl, 1982, p. 35) and focus on phenomena in their own right—the experiential content of consciousness—rather than force experiences into predetermined, pre-existing categories. He asserts that one can identify the essential qualities of experience through a comprehensive in depth and rigorous examination process and arrive at true knowledge of one's own experience.

According to Husserl (1970), a central aspect of phenomenology is the practice of bracketing granted assumptions about the nature of the phenomena in question. One *brackets* what is taken for granted in the world³⁸ in order to distinguish the essential structures and characteristics of human experience. The practice of 'phenomenological reduction' involves removing oneself, one's world view, values, and preconceptions and focusing on the essence of a phenomenon (Husserl, 1983, p. 66). The essence being its *meaning* in lived experience. One seeks to establish what it is about a particular phenomenon that makes it recognisable as such. This is achieved by attending to experience itself and describing its essential and particular features.

Heidegger (1962) conceptualised the individual and the act of being human as enmeshed with pre-existing world of language, culture, relationships, and objects. From this standpoint, an individual must be viewed as a 'person in context', constantly interconnected to the world. Thus, *Being-in-the-world* is dependent on time, perspective, and being-in-relation-to something else. For Merleau-Ponty (1962), knowledge is gained from one's own world view—from one's particular experience of the world; there is a situated and interpretative quality to our world knowledge. Our relationship with the world, therefore, is subjective and embodied. For Sartre (1992), our self-consciousness is driven and directed by action and meaning making. He asserts that human nature involves becoming oneself in an on-going process. Humans have agency and freedom to make decisions and

³⁸ Acceptedness of the unexamined everyday.

should be held accountable for their actions. These choices should be judged by their context, the life history of the person who chooses, and the social environment the choice is made in. The differing perspectives on phenomenology offered by these philosophers are compatible with each other.

Phenomenology and critical realism are also congruent. Both posit that reality is simultaneously more than (and distinct from) sense experience (Budd, 2010). Examining essence can illuminate the multiplex detail of intersubjective interrelationship between structures and mechanisms that lead to action. Operationalising this integration to enhance understanding of a phenomenon requires a method ‘that is recursive, that urges the perceiver/analyser to examine both the thing as it occurs and the act of perceiving and analysing’ (Budd, 2012, p. 80). This involves the merging of the phenomenological focus on things as they exist with the critical realist emphasis on the nature, structure, and working of consciousness.

IPA can assimilate these priorities by situating embodied individual experience within the context of meaning, relationships, and the lived world. In this way, IPA can aid our understanding of consciousness by contributing to the cognitive science movement of embodied, active, situated cognition (Larkin et al., 2011):

[Embodied, active, situated cognition] foregrounds the fact that cognition is a highly *embodied* or *situated activity*—emphasis intentionally on all three—and suggests that thinking beings ought therefore to be considered first and foremost as acting beings (Anderson, 2003, p. 91).

4.3.4 Idiography

Idiography is an essential theoretical underpinning of IPA. Idiography is concerned with the systematic, thorough, and deep analysis of the detail of the particular (i.e. an individual experience) and the understanding of phenomena from the perspective of specific people in certain contexts.

The focus of idiography is identifying the meaning of unique, contingent, and frequently subjective phenomena for *this* person in *this* context. The theoretical justification for the idiographic focus is that idiography can: describe something that is fundamentally, scientifically, and humanly interesting; disconfirm preconceptions and expectations; identify flaws in existing theory; and direct how theory can be revised to accommodate a new finding (Smith et al., 2009). Within idiographic research, no attempt is made to quantify variables or control context. The aim is to capture how phenomena are *experienced*. All forms of idiography do not abstain from making generalisations; some offer a different way of establishing them. These generalisations are grounded in the particular and, as a result, developed consciously in a painstaking manner. This argument is well articulated by Harre (1979, p.137):

I would want to argue for a social science ... which bases itself upon an essentially intensive design, and which works from an idiographic basis. Nevertheless such a science is aimed always at a cautious climb up the ladder of generality, seeking for universal structures but reaching them only by a painful, step by step approach.

Consequently, ‘the particular eternally underlies the general; the generally eternally has to comply with the particular’ (Hermans, 1988, p. 785). The detailed, deep, and extensive examination of the particular brings one closer to the universal (Warnock, 1987). However, to ensure continuity and harmony between the contextual and idiographic positions adopted by this research study, I am cautious in claiming the transferability of results to wider populations.³⁹ Idiography and phenomenology are compatible as the essential qualities of experience can be distilled by focusing on each person’s individual experience of them. When IPA is described as idiographic, this is referring to IPA’s primary focus on providing a detailed and nuanced analysis of particular individual instances of lived experience.

4.3.5 Hermeneutics

³⁹ In line with the curtailed ambitions of IPA articulated by its developers (Smith & Osborn, 2003).

Hermeneutics is a fundamental theoretical underpinning of IPA. Hermeneutics is the theory of *interpretation* which originated from the study of text rather than data (the focus of IPA).⁴⁰ It is concerned with how one interprets text in one's own context when the text has been created in another (i.e. time and place). When applied to data collected from eliciting participants' accounts of a phenomenon, this means that interpretation can provide insights that transcend and exceed the explicit claims of participants. The novel perspective of the interpretative analyst comes from extensive analysis of the data itself, identifying connections that emerge across the entire dataset and the interaction with—and integration of—the data into current theory. Consequently, hermeneutics deepens and broadens the first-person perspective of phenomenology and idiography by situating it within a language specific framework of symbolic meanings (Smith & Osborn, 2008; Graham, 2011).

Heidegger (1962) defines phenomenology as hermeneutic; with its dual focus on how a phenomenon appears and the role of the interpretative analyst in enabling and making sense of this appearance. From this standpoint, there is a duality to all phenomena; visible meaning and hidden meaning. As Morgan (2000, p. 229) explains:

Phenomenology is seeking after a meaning which is perhaps hidden by the entity's mode of appearing. In that case the proper model for seeking meaning is the interpretation of a text and for this reason Heidegger links phenomenology with hermeneutics. How things appear or are covered up must be explicitly studied. The things themselves always present themselves in a manner which is at the same time self-concealing.

Heidegger identified the considerable influence of 'fore-structure' on interpretation. Fore-structure describes the preconceptions, assumptions, and experiences that an analyst brings to the

⁴⁰ Text is words/characters formatted a particular way on a page. Data comprises information pieces linked to variables and identifiers. In IPA, the process of interpretation involves analysing data (both the text of a transcript and the variables/identifiers linked to that text).

interpretation process. Due to this colouring or bias, fore-structure acts as a barrier to successful interpretation. Fore-structure however may only emerge when one is in the process of interpretation and therefore it is complex and ever changing (Smith et al., 2009).

For Gadamer (1960), the person who understands a text is always projecting one of many interpretations of the meaning of the text. When one is making sense of and identifying the meaning within text, one compares, contrasts and amends one's conceptions. The risk is that one's preconceptions may block the text from communicating its own truth and message. This can be addressed by maintaining a commitment to openness and curiosity when interpreting. It is by dialoguing between the context in which the text was created (the past) and the context of where the interpretation take place (the present) that new knowledge emerges.

According to Ricoeur (1970) there are two discrete strategies for comprehending meaning in the process of interpretation. Firstly, a hermeneutics of empathy (of empathic engagement)—reconstructing experience in its own terms. Secondly, a hermeneutics of suspicion (of critical engagement)—illuminating a phenomenon by utilising outside theoretical perspectives. In IPA, both modes of hermeneutic engagement are drawn on to enlighten our understanding of lived experience (Larkin et al., 2006). Interpretation aims to create both 'rich experiential descriptions' and to evaluate critically 'in ways which participants might be unwilling or unable to do themselves' (Eatough & Smith, 2017, p.189). The theoretical perspective of hermeneutics can be reconciled with the critical realist ontological perspective. Both share the principal that it is rational to believe in determinate meaning in the presence of interpretative disagreement.

4.4 Interpretative Phenomenological Analysis: Theoretical principles

IPA is a qualitative methodology that gives the person's experience of life primacy (Holloway & Todres, 2003). IPA facilitates researchers to examine experience—the way it occurs and in its own terms—rather than through predefined category systems; focusing on understanding the everyday experience of reality, in great detail, so as to gain understanding of a particular phenomenon. IPA

assumes that data can inform us of a person's involvement with—and orientation towards—the world; as well as how he/she makes sense of their experiences (Smith et al., 2009). In other words, IPA enables the development of a deeper and richer understanding of the nature and meaning of everyday lived experience. The methodology seeks to develop a phenomenological account of experience by identifying, describing, and understanding participants' experiential claims and key objects of concern in the world⁴¹ (Smith et al., 2009). This account allows for a detailed exploration of how participants are making sense of their personal and social realm (Smith & Osborn, 2003).

By focusing on participants owning their experience, the phenomenological aspect of IPA explores what is important to them, how they are orientated in the world, and how they have understood the phenomenon in question. An IPA researcher must make sense of, understand, and give voice to their participants' claims and key concerns. By engaging in sense making (from a psychological perspective), the interpretative element of IPA contextualises the accounts of participants within their environment. The approach goes beyond descriptive phenomenology to make sense of a described phenomenon relative to wider social, cultural and theoretical contexts (Larkin et al., 2006). IPA studies examine the relationship between participants and the world they live in; honing in on the meaning of a concept for *this* person in *this* context.

While description and interpretation are centred on the status and discrimination of meaning; they fundamentally differ. Description is the offering of an account of a person, object, or event in which participants' views are presented in their own terms. It is the 'use of language to articulate the intentional objects of experience within the constraints of intuitive or presentational evidence' (Giorgi, 1992, p. 121-122). One communicates the meaning of an object of experience precisely as it is experienced; portraying something exactly as it appears; without adding or taking anything away (Giorgi, 1992). Interpretation, on the other hand, is the attempt (motivated by the absence of clarity) to develop a plausible but conditional (i.e. not exclusive) line of meaning attribution to

⁴¹ Experiences, events, and states.

account for a phenomenon. It has been argued that interpretation is necessary in qualitative research because of the existence of the unconscious and the fact that humans are self-interpreting beings (Giorgi, 1992). IPA necessitates the researcher to adopt both an empathetic and questioning stance; requiring both description *and* interpretation (Smith et al., 2009). Differing levels of interpretation include identifying key processes participants are engaging in; deciphering the meaning of metaphors used; and unpacking how identity is constructed over time (Smith, 2004).

Phenomenology is utilised to reveal meanings and hermeneutics is used to interpret this meaning (Bäckström & Sundin, 2007). Both components assist the researcher to gain insight into a particular phenomenon; enlightened by how each participant is related to and engaged with the subject under investigation (Larkin et al., 2006). Conducting IPA research involves a double hermeneutic; there are two levels of interpretation. Firstly participants—in loop one—are making sense of who they are (their identity in space and time) and their experiences. Secondly, the researcher—in loop two—is trying to make sense of the participants' sense-making (Smith, 1996). The meaning making process can often be hidden and obscure; not just from the researcher but from the participants themselves (Sawadkar & Ayalasomayajula, 2017). Meaning can reside in the subtleties, pauses, and colloquial phrases present in participants' accounts (van Manen, 1990); lying beneath immediate experiences. Attitudes, beliefs, emotions, and values affect individual meaning making and shape how an experience is understood (Zepke & Leach, 2002).

The IPA approach is inductive (it is 'bottom up' not 'top down') and idiographic (it can be conceptualised as a series of integrated case studies). The hermeneutics of empathy⁴², so central to IPA, necessitates the assumption that if you talk to someone and are empathetic, they will likely open up to you and share their experiences and how they are making sense of them. IPA research aims to offer up a nuanced multi-layered interpretative narrative of participant experience, sense making, and identity (Smith et al., 2009). Identity, in this context, refers to both the social category a person places themselves in and the socially distinguishing features they believe they exhibit. The

⁴² Trying to understand a phenomenon from another person's perspective.

overall outcome of an IPA study is ‘renewed insight into the ‘phenomenon at hand’; informed by the participant’s own relatedness to, and engagement with, that phenomenon’ (Larkin et al., 2006, p. 117). Although theory building is not a primary aim of IPA; findings can, nonetheless, affect (and add to) theoretical formulations (Pringle et al., 2011). IPA can systematically make formal theoretical connections (Smith, 2004) and dialogue with general laws and theories (Larkin et al., 2006; Smith et al., 2009). An IPA study can thus offer guidance to health professionals by illuminating processes occurring within a sample that may be relevant to their work.

4.5 Data collection principles in Interpretative Phenomenological Analysis

4.5.1 Data collection methods in IPA

The key focus of data collection in IPA is to elicit rich, nuanced, comprehensive, and first-person accounts of the experiences/phenomena under inquiry; to collect high quality experiential data⁴³. Adopting an IPA stance necessitates obtaining data that illuminate what experiences matter to participants. These data afford researchers the opportunity to gain an understanding of participants’ perspective on these experiences. This priority is aligned to Heidegger’s notion of ‘care’ or ‘Sorge’⁴⁴ (Heidegger, 1962, p. 405). Therefore, data collection in IPA allows participants (to a certain degree) set parameters around what they want to disclose in term of what matters to them.

An IPA researcher may utilise a variety of data collection methods to achieve this, including; telephone, online, video, and email interviews; focus groups; observational notes; diary entries, auto-biographical accounts/poetry; and face-to-face unstructured/semi-structured interviews. Focus groups present a specific concern for IPA researchers as they have the potential to dilute the capturing of a detailed exploration of personal experience (Smith, 2004). Larkin and Griffiths

⁴³ This is data that is *experience near*.

⁴⁴ For Heidegger, the essential basis of *being-in-the-world* is ‘care’ or ‘Sorge’. It is the innate concern that *Dasein* has with the states of affairs that it is thrown into.

(2002, p. 309) have claimed that analysing observational notes using IPA can offer the plausible ‘insider’s perspective’ well-grounded in data. The use of diary entries as a data collection method in IPA is almost non-existent in the literature. Other IPA researchers have used published autobiographical accounts (Williams, 2004) and autobiographical poetry (Spiers & Smith 2016) as data sources. Unstructured face-to-face interviews are another alternative. Ultimately, irrespective of what data collection method or mix of methods is chosen, it is vital that an IPA researcher acknowledges and reflects on their impact on data yielded (Brocki & Wearden, 2006).

4.5.2 Face-to-face semi-structured IPA Interview

This study collected data using a face-to-face semi-structured IPA interview. Multiple factors distinguish the IPA interview from those used in other forms of research—its primary aim being to generate descriptions of experiences that are not generalised but situated in time and space. Interviewing in IPA necessitates the development of a topic guide focused on participants’ accounts of their experiences; which is not a fixed set of questions, but a guide of foci related to the phenomenon under investigation (accompanied by appropriate prompts). While the initial focus of participants’ talking is determined by the questions asked, interviews are also led in part by participants’ interests/concerns as they are viewed as the ‘experiential expert’ on the subject at hand (Smith & Osborn, 2003, p 59). Interviews follow the direction participants wish to take them in (allowing access to the participant’s psychological and social world), while periodically being reoriented by the researcher back to the experiences under inquiry. Unprompted data is considered extremely valuable in IPA as it is likely to have significant importance to the participant (Smith et al., 2009). When designing the topic guide, it is important that questions elicit open and expansive responses, encourage elaboration, and seek to probe deeply.

Participants are encouraged to linger on recounting experiences longer than a typical interview and only after this are they permitted to drift into sense making of the phenomenon in question.

Participants are urged to share situated/concrete details in addition to the sense of the phenomenon

as it is lived and made sense of. The IPA interviewer attends to the ‘more’ of what is typically said about an experience. This ‘more’ is defined by Todres (2007, p. 21) as:

This whole experience is carried by the body and is ‘more’ than just heat, ‘more’ than who you were with, ‘more’ than other times and places that resonate with the hot summer night.

Each interview seeks to gather and carry understanding from experiential experts. Participants are seen as storytellers not respondents. To identify modes of understanding, the IPA interviewer enters into and shares each participant’s ‘life-world’⁴⁵ (Husserl 1970, p. 382) rather than investigating it. Hence, the IPA interviews can last for one hour (or even more) and require audio recording and verbatim transcription (Pietkiewicz & Smith, 2012).

The face-to-face semi-structured IPA interview was selected to gather data for the current study due to it: (i) cohering with the aims and philosophical underpinnings outlined; (ii) facilitating rapport (by enabling participants to describe their subjective experiences) and capturing these accounts in rich detail; (iii) allowing for collaboration between interviewer and participant; (iv) being flexible; and (v) affording the opportunity in real time to follow up on remarkable and pertinent issues raised by the participant without removing all structure. This method has been cited by the developer of IPA as exemplary (Smith & Osborn, 2003) and allows for interpretation in data generation and not just data analysis (Brocki & Wearden, 2006).

4.5.3 Critique of the semi-structured IPA interview

Hammersley and Gomm (2008) have cautioned about the risk of socially desirable responding in semi-structured interviewing. They argue:

⁴⁵ The realm of immediate human experience.

what people say in an interview will indeed be shaped, to some degree, by the questions they are asked; the conventions about what can be spoken about;... by what time they think the interviewer wants; by what they believe he/she would approve or disapprove of (p. 100).

Variables such as interviewer age, gender, and disclosed personal and professional experience, as well as demand characteristics⁴⁶ influence engagement, disclosure, and response content in an interview. Nonetheless, these issues are likely to be addressed in researcher reflexivity and minimised by ensuring anonymity/confidentiality (where feasible) (Gomm, 2004; Newton, 2010). Participants only disclose in an interview the experiences, perceptions, and beliefs they want to disclose and therefore the accounts provided may be substantially divorced from ‘reality’.⁴⁷ However, IPA does not seek to get to some ‘objective truth’ of what is real or to verify participants’ claims; rather its focus is on *sense making*. It is irreverent to whether participant sense making is grounded in the actuality of what has happened in their lives. What is relevant is that they *experienced* it. From a phenomenological perspective, reality does not need to be shared in order to be considered valid (Kalish & Reynolds, 1973).

Face-to-face semi-structured IPA interviews can also be critiqued on the grounds that how the data generated from them is vulnerable to interpretative bias. There is a risk that participants’ claims about their experiences can become decontextualized from the context of the interview itself. Reporting can often delete the interviewer entirely when presenting data or indeed fail to consider interviews as interaction. However, these concerns can be addressed by representing the interviewer’s questions and interjections (where appropriate) (Potter & Hepburn, 2005).

4.6 Sampling and sample size in Interpretative Phenomenological Analysis

⁴⁶ What participants perceive the situation requires.

⁴⁷ This is particularly relevant to this study in the context of the reality distorting effects of psychosis.

According to Smith and Osborn (2003), decisions regarding how to sample participants for an IPA study are principally driven by the need to give full and sufficient attention to each participant's account in order for analysis to retain its idiographic nature. There is 'no right answer to the question of sample size' in IPA research (Smith et al., 2009, p. 51). The number of participants required for an IPA study varies widely⁴⁸. Typically, IPA studies utilise a small purposeful homogenous sample⁴⁹—in order for a study to retain its idiographic focus and allow for an in-depth examination of a specific phenomenon. Homogeneity is contingent on the accessibility of participants sharing one defined characteristic and the extent of sameness/dissimilarity contained in the analysis of the phenomenon under investigation (Pietkiewicz & Smith, 2012). This, however, does not prevent the IPA researcher for exploring differences between groups (Palmer et al., 2010).

IPA sample size is dependent on resources available and the richness in—or depth of analysis possible for—each person's narrative (Smith & Osborn, 2003). Purposive sampling is used in IPA in order to generate an analysis about specific people who share a particular relationship to a certain phenomenon in a given context. Determining whether or not sufficient data have been collected for an IPA study is a question of 'quality, not quantity' (Smith et al., 2009, p. 51). A sample size target is set *a priori*, then modified depending on an assessment of the richness of each interview (Larkin, 2017). Practical and resource related considerations as well as a researcher's commitment to the case-by-case approach are also taken into account (Smith & Osborn, 2003).

According to Van Manen et al. (2016, p. 5) 'saturation' is not a relevant concept in hermeneutic phenomenology:

In phenomenological inquiry, you open up a question, which becomes bottomless –so it does not make sense to say that you caught all the meaning or meaningfulness of a human phenomenon.

⁴⁸ The number of interviews included in IPA research studies can vary from 1 (Robson, 2002) to 30 (Collins & Nicolson, 2002)

⁴⁹ The goal of sampling in IPA is to find a defined group that the research question has relevance and personal significance for. The term *homogenous* here refers to all participants being alike in terms of sharing a specific characteristic.

Every phenomenological topic can always be taken up again and explored for dimensions of originary meaning and aspects of meaningfulness.

Therefore, saturation does not apply to IPA—as everyone’s experience is going to be different at some level.

4.7 Data analysis principles in Interpretative Phenomenological Analysis

The goal of analysis in IPA is to explore how participants assign and attribute *meaning* to their experiences as they interact with their environment—to develop an in-depth understanding of participants’ accounts of the *process* by which they attempt to, struggle with, and succeed in making sense of their life experiences (Smith, et al., 2009). Analysis commences with a detailed examination of each person’s narrative separately, but then carefully shifts to an investigation of agreement and divergence across narratives. This process produces meticulous, detailed, in-depth accounts of patterns of meaning—representing participants’ understanding of a shared experience. Analysis is focused on the life-world. From the IPA perspective, the scientific world presupposes the life-world (Husserl 1970).⁵⁰ If one wants to understand the complexities of human beings and their lives, then one must begin with trying to understand a person’s experience (their life-world)—because the scientific world is an abstraction. An IPA researcher is interested in understanding a person’s *relatedness* to the world through the meanings they make and how a person connects to the world through meaning making. Our experiential world has a quality of ‘mineness’⁵¹ (Zahavi, 2008, p. 124) or ‘first-person givenness’⁵² (Schraube, 2013, p. 22) and this is what one is endeavouring to get close to when conducting IPA. One understands experience from the first-

⁵⁰ An argument first put forward by Edmund Husserl (1970) in *Crisis of European Sciences*. The life-world is the world as lived, perceived directly without reasoning, before any reflective analysis or representation. The contention is that every scientific theoretical construction necessitates its particular historical life-world.

⁵¹ ‘Mineness’ is a fundamental characteristic of first-person experience—for every person, current experience is unequivocally ‘mine’.

⁵² ‘First-person givenness’ is the first-person standpoint of experiences (i.e. all experiences are *my* experiences to someone).

person perspective and treats the research participant as the experiential expert regarding the phenomenon under investigation.

All people are situated which influences how they make sense of the world and the events that happens to them. This requires the IPA researcher to acknowledge their own and their participants' *situatedness* and reflect on their role in producing interpretations by maintaining a commitment to grounding them in participants' claims and concerns (i.e. what was said in their interviews). IPA also compels the researcher to stretch, what can be considered, the *interpretative elastic*. One begins analysis by making low level interpretations (clearly substantiated by participants' descriptions). Subsequently, the IPA researcher offers their own more abstracted interpretations and understandings; in order to foreground their voice as a researcher. However, interpretation is always tethered, to some degree, to participants' accounts. This hermeneutic process is enabled by epoché and bracketing.

4.7.1 Epoché and bracketing

In order to elicit meaning from participant's accounts, an IPA researcher must endeavour to temporarily withhold and suspend past knowledge and personal/professional experiences relating to the topic of inquiry (Van Manen, 2016). Subsequently, in data analysis, this knowledge/experience can be legitimised or refuted by connecting it interpretatively to participants' articulated meanings and evaluating the significance of any bias in data interpretation. In light of this, successful IPA research necessitates the operation of both epoché and bracketing. Although, at times, considered interchangeable in literature (e.g. Gearing, 2004); both concepts differ. Epoché is the *process* of, and bracketing is the *act* of, time limited suspension of judgment regarding the natural world in order to focus on analysing experience. Bracketing occurs on multiple occasions at each interpretation; it is a moment of interpretative fusion. Epoché is 'an-ongoing analytic process' (Patton, 1990, p. 408), a practise of thinking, a mind-set, and a place for biases and assumptions to dwell—that is comprehensively integrated into all stages of the research process.

Importantly, these biases are reintegrated into the interpretative process at a later stage. This involves ‘the unbracketing and subsequent reinvestment of the bracketed data into the larger investigation’ (Gearing 2004, p.1434). Personal dispositions and values ‘held in epoche’ (Bednall, 2006, p. 125) are permitted to synthesise observations of the data to form as interpretative conclusions. This process of epoché does not eliminate researcher bias; instead it facilitates insight and reflexivity. The act of bracketing enables the researcher to converge their attention on the meaning of the phenomenon being explored (Bednall, 2006). IPA emphasises that it is the best efforts of the researcher that is required here;⁵³ recognising that it is impossible to entirely prevent one’s past from influencing interpretation.

4.7.2 An explanation of IPA theme terms

IPA uses a specific typology to categorise themes developed in analysis. This will now be outlined. Superordinate themes are higher order interpretations that are developed through the clustering of emergent themes (Smith et al., 2009). Emergent themes are defined as the ‘basic building block of inductive approaches to qualitative social science research... derived from the lifeworlds of research participants through the process of coding... grounded both empirically (in the data) and conceptually (linked to the wider analytic context)’ (Given, 2008, p. 248). In IPA, they are concepts, ideas, and statements that are a synergy of description and interpretation (Smith et al., 1999). Subthemes are themes within emergent themes. Person specific or group specific themes are those that capture the experiences of one participant or one group of participants (Larkin & Thompson et al., 2011; Larkin et al., 2019).

4.8 Critique of Interpretative Phenomenological Analysis

Within the literature IPA has been criticized on a number of fronts. Giorgi (2010) has questioned

⁵³ What is described in IPA as an ‘enlivened form of bracketing’ (Smith et al., 2009, p. 25).

the scientific rigor of IPA arguing that science requires prescription and the specification of rules. His contention is that as IPA is not prescriptive; that it is a non-scientific personal way of working; as science requires an interpersonal or intersubjective approach with rules regulating it. In his view, IPA does not meet these criteria as ‘there is no single, definitive way to do IPA’ (Smith & Osbourne, 2003, p. 54).

Smith (2010) has countered this assertion by distinguishing between two concepts which he believes Giorgi inadvertently merged in his critique: replicability and checking. Smith (2010) highlighted: that the concept of *replicability* itself is not a criterion that the majority of qualitative researchers would aspire to or desire their work to be judged against; that replicability itself is derived ‘from paradigmatic assumptions [i.e. positivism] which do not necessarily apply in, or sit easily with, human science’ (p. 189). *Checking*,⁵⁴ however, according to Smith, is a valid quality criterion in qualitative research. The results of IPA research reports can be checked and how results were arrived at examined through supervision, independent audit, and a person reading an IPA manuscript confirming that methodological steps have been adequately described and that the write up and argument presented is supported by evidence and coherent. This can ‘ensure that the account produced is a credible one, not the only credible one’ (Smith et al., 2009, p. 183).

Smith (2010) has pointed out that IPA does not advocate total freedom as the IPA researcher is constrained by needing to: (i) achieve a level of proficiency in the skills necessary for IPA (e.g. interviewing, analysis, interpretation, and writing) and for this competence to be monitored in supervision; (ii) take an ordered set of research steps; and (iii) adhere to quality appraisal criteria congruent with IPA research. Hence while there is flexibility in *how* an IPA approach is implemented there is no flexibility regarding *whether or not* certain steps are taken.

Giorgi (2010) has also targeted the theoretical and philosophical underpinnings of IPA in his

⁵⁴ This is the checking of a final report/manuscript being prepared for publication that involves judging if the document produced is plausible and credible account of data collected and if a step by step process of logic has been recorded supported by evidence.

critique, advocating that the methodology is not grounded in phenomenology and/or hermeneutics. Smith (2010) asserts that this criticism is unfounded as a body of work has been published which explicitly outlines the relationship IPA has to key ideas in phenomenology and hermeneutics (Smith, 2004; Smith, 2007; Larkin et al., 2006; Smith et al., 2009; Eatough & Smith, 2017). It is my interpretation of this debate that—with this response—Smith (2010) has provided a robust defense of IPA; highlighting the selectivity of Giorgi's critique and his narrow perspective on the methodology.

Pringle et al. (2011) have queried if the idiographic nature of IPA limits its contribution to theory. They argue that generalisations cannot be made when an idiographic approach is adopted and therefore the usefulness of the findings of IPA studies are in question as they are likely to be subjective, intuitive and impressionistic. Research adopting an IPA approach sets out to examine convergence and divergence among small samples to generate insight regarding specific research questions. IPA is thus concerned with 'theoretical transferability' rather than 'empirical generalisability' (Smith et al., 2009, p. 51).

IPA studies have been utilised to contribute to and dialogue with theory (e.g. Flowers et al., 1997) and to generate theoretical insights in and of themselves (e.g. Smith, 1999). IPA is primarily concerned with the micro-analysis of individual experience and not theory generation. However, macro level claims/insights can arise from IPA studies to complement and enrich micro level accounts, but it is not the principal focus of IPA. Insights developed from IPA studies have applicability to some people with experience of the same phenomenon as study participants; therefore theorized ideas arising from IPA are of value (Smith, 1999). IPA research should be judged primarily on the degree to which it sheds light on the experience of a phenomenon for a group of study participants, not on theory contribution or development. However, the inductive nature of IPA enables an engagement with current psychological approaches, models, and theories (Brocki & Wearden, 2010). It has been argued by that using a small homogenous narrow sample limits the transferability of IPA research (Pringle et al., 2011). However, such samples are essential for the rich, in-depth, comprehensive analysis and idiographic focus required by IPA (Smith,

2009).

Another criticism of IPA is that it is dependent on the ‘the representational validity of language’ (Willig, 2013, p. 63); meaning that IPA does not recognise or account for the role language plays in how we (as human beings) construct and shape meaning in our lives. Therefore, IPA researchers cannot be certain that data collected reflect actual experience; data may simply mirror the way participants *talk* about experience, for language might precede and consequently shape experience itself (Ware & Raval, 2007). I adopt the pragmatic position that language is the best means available for communicating human thought. I therefore contend that language is an adequate mechanism for participants to convey how they are making sense of their identity and experiences.

Advocates of Discourse Analysis have challenged IPA. Potter and Wetherall (1983) have questioned one assumption underpinning the social cognition paradigm, an assumption also made by IPA researchers. They contest the supposition that verbal reports given by participants reflect, or can be easily related to, underlying cognitions and assert that participant accounts may be principally dependent on the environment and demands of the social occasion of a qualitative research interview. In addition, they argue that participant responses to interview questions are contingent on the discourses available to them in their culture. Smith (1996) addresses these concerns by presenting IPA as a bridge between the divergent positions of Discourse Analysis and the social cognition paradigm; as it recognizes the importance of language and context in shaping participant responses and shares assumptions with symbolic interactionism. These premises being that: humans interact with and respond to things on the basis of what things mean to them; this meaning occurs in and is derived from social interactions in society; and meanings are managed and adapted through interpretation (Blumer, 1969).

The rich descriptions of participant accounts required by IPA have also been the subject of critique. Willig (2013) argues that the descriptions provided by IPA studies do not explain why experiences happened or why participants differ in their descriptions of the same experience. This is correct as the focus of an IPA study is not developing explanatory frameworks but offering a detailed

exploration of sense making in participants' social and personal worlds. While this criticism is valid, I adopt the position that 'no method provides the tools to find all the answers to all the questions' (Langdridge, 2007, p. 167).

4.9 Appraising the rigour and quality of Interpretative Phenomenological Analysis research

In the context of appraising IPA research, I understand rigour to be an aspect of quality. Rigour relates to the degree to which research processes result in trustworthy findings. Quality is how good or bad a research study can be deemed to be. A study's rigour directly impacts its quality. By appraising a study's quality, its rigour is also assessed. Demonstrating rigour by outlining the steps taken to reduce bias is vital to justify the scientific merit of qualitative research. Doing so increases the likelihood that research is seen by stakeholders (in the field being investigated) and the general public as legitimate and worthy of attention. A researcher can defend their work and demonstrate its value to the scientific community and society by showing how a qualitative study has established rigour and proven its quality.

Rigour is achieved by a qualitative researcher being thorough and careful in the selection and application of research processes. A qualitative study can be endorsed as trustworthy if researchers disclose these processes and their execution with enough detail to enable the reader to determine whether findings are credible. Trustworthiness also requires data collection methods to be appropriate to the methodology selected and data analysis to have been conducted in an exact, exhaustive, and consistent manner (Tracy, 2010).

There is much debate in the literature regarding whether it is useful or indeed desirable to develop criteria to assess rigour and quality in qualitative research (Barbour, 2001; Morse et al., 2002). Nonetheless, I contend that any study that does not consider these cannot be deemed science (Descartes, 2006). Criteria used to appraise rigour and quality in quantitative research (such as objectivity, reliability, and generalisability) are inappropriate benchmarks to judge qualitative research by (Yardley, 2000; Spencer et al. 2003; Madill et al. 2000). Thus, rigour and quality must

be assessed by criteria that are more consistent with the philosophical constructs underpinning qualitative inquiry. How this appraisal should take place is the subject of much discussion (Lincoln & Guba, 1985; Elliott et al. 1999; Yardley, 2000; Spencer et al. 2003; Walsh & Downe, 2006). However, there is emerging consensus that such assessments should not be simplistic box ticking exercises incapable of considering the complexity of qualitative research (Spencer et al., 2003).

It was important that both the rigour and quality of this study be evaluated. By conducting such appraisals, I hoped to demonstrate that study findings were arrived at by rigorous methods in order for them to be considered trustworthy and of value to society. The challenge was to identify criteria to appraise rigour and quality that were philosophically consistent with IPA. A range of criteria sets were considered (see Lincoln, 1995; Mays & Pope, 1995; Morse et al., 2002; De Witt & Ploeg, 2006). In this study, I used Yardley's (2000) quality criteria for qualitative research: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. These criteria were selected as their application is advocated by the originator of IPA (as well as other senior IPA researchers) as an appropriate method of appraising quality in IPA research. This is due to their broad ranging and accessible nature, the variety of ways they permit the establishing of quality, and the fact that they can be applied to any qualitative research study irrespective of its theoretical orientation (Smith et al., 2009; Shinebourne, 2011). Yardley's (2000) criteria are also widely used in published IPA research (e.g. Krzeczowska et al., 2019) and they capture the essence of my understanding of quality in IPA. Therefore, they fitted the study's methodology. A detailed evaluation of the study using Yardley's (2000) criteria is presented in Chapter 8.

4.10 Rationale for the selection of Interpretative Phenomenological Analysis

I selected IPA as the methodology for this study due to (i) its compatibility with the study central aim and objectives; (ii) the growing body of IPA research exploring the experience of, and recovery in, psychosis (including 'delusions', stigma, suicide, hope, trauma, and the personal meaning of recovery) (Rhodes & Jakes, 2000; Knight et al., 2003; Perry et al., 2007; Windell,

Norman, & Malla, 2012; Dunkley et al., 2015; Gajwani, et al., 2018;); and (iii) its methodological strengths (specifically its flexibility and accessibility). Thus, I deemed IPA as a methodology that would enable me to extend and complement the existing MIL, meaning making, psychosis, and mental health recovery knowledge base.

As a methodology IPA offered clear data collection and data analysis guidelines; yet, was flexible enough to enable me to take ownership over how I applied them (Smith, 2010). As a researcher, I could execute the required IPA research steps; but do so in a manner that felt right for me (e.g. I could hand code data). IPA would also allow me to get as close to participants' experiences as possible (i.e. experience near) and enable me to obtain a deep and rich understanding of participants' perspectives on meaning making in psychosis experiences and MIL. It also had the potential to provide me with the tools I needed to limit the impact of my preconceptions on my interpretations of these experiences. I considered IPA to be congruent with my beliefs, values, and priorities (i.e. that all people should be treated equally and justly in a manner that acknowledges their inherent value) and hoped that it would help me report on participants' lived experience in a way that was respectful of the trust they had given to me.

4.11 Chapter summary and conclusion

This chapter outlined the main epistemological, ontological, and methodological standpoints that guided my decision making in the process of conducting the study. In particular, I set out an argument, suggesting that these standpoints are congruent with each other and with IPA. Within this chapter, I highlighted what I understood to be the central tenets of IPA and justified its use as the methodology of the study. I endeavoured to defend IPA against the critiques levelled against it in the literature. I also discussed the importance of rigour and quality in qualitative research and identified the criteria to be used to evaluate this study. The next chapter (Chapter 5), drawing on the concepts and positions presented in this chapter, details how IPA was operationalised in the conduct of the study.

CHAPTER FIVE: OPERATIONALISING AND APPLYING INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

5.1. Introduction

This chapter describes how IPA was operationalised in the conduct of the study. The chapter begins with a description the study's aims and objectives and then moves to a description of the study design. This is followed by an outline of how participants were sampled and recruited, and how data were collected and analysed. Finally, the process of obtaining ethical approval is outlined and ethical considerations for study are discussed. While the research procedures used are presented linearly, many research processes were dynamic and iterative.

5.2 Focus, aim, and objectives of the study

IPA research questions are explicitly open and process-orientated (i.e. they are typically prefixed by 'how'). The researcher is generally orientated towards his/her object of interest from a standpoint of exploration. The aims of IPA studies are to *explore* participants' understandings, experiences, and sense making activities related to a named phenomenon (Smith et al., 2009). Establishing a precise research question from the outset may not be possible in an IPA study. Research questions, aims, and objectives can be modified over the course of an IPA study due to the dynamic and iterative processes involved in operationalising the methodology. Nonetheless, it was essential that the study begin with a 'realizable goal' (Smith et al., 2009, p. 48) that may or may not change as analysis progressed. Therefore, the following aim and objectives were developed:

Aim:

- To explore how people who experienced a First Episode Psychosis (FEP) approximately 21 years ago find, develop, and maintain Meaning in Life (MIL) and identify the key factors that influence MIL.

Objectives:

The objectives were:

- To explore the meaning participants attach to their experience of a FEP, as well as subsequent and current psychosis experiences;
- To identify if and how this meaning has influenced their current perspective on MIL;
- To explore participants' perspectives on MIL prior to and after a FEP;
- To explore the role of MIL in the recovery process;
- To identify participants' perspectives on the factors (barriers to, and facilitators of) that influence the finding, development, and maintenance of MIL;
- To explore if the perspectives of people in remission from psychosis differ to those not in remission

5.3 The multiperspectival design

The study adopts a multiperspectival design. Multiperspectival IPA research seeks to expand on the one-dimensional perspective offered in traditional IPA studies as it extends the potential reach and impact of findings by combining two or more perspectives of different groups on a phenomenon.

While multiperspectival IPA retains a commitment to idiography in data collection and analysis it also aims to generate insight by exploring relational and intersubjective perspectives between groups (Larkin et al., 2019). In Larkin et al.'s (2019) view, by analysing and synthesising multiple perspectives, IPA researchers can develop stronger and more persuasive analytic accounts of participants' experiences.

Larkin et al. (2019) have developed a typology of multiperspectival IPA study designs which consists of four design types (see Table 5.1). The design type ‘Directly related groups’ was used in this study as two groups of participants were used to explore the ‘same experience’: MIL in the context of recovery in psychosis. The two groups consisted of: (i) participants In Remission and (ii) participants Not in Remission from psychosis at 20 year follow up. Roberts (1991) asserts that psychosis can impact the degree to which MIL is experienced. Therefore, the extent to which participants were *experiencing psychosis* (defined by their remission status) was thought to result in both groups having different views on MIL in the context of recovery in psychosis. Thus, the differing perspectives needed to be understood in order to develop stronger and more persuasive analytic accounts of participants’ experiences (Larkin et al., 2019) that would inform practice.

Table 5. 1 Typology of multiperspectival IPA study designs

Design type	Distinctive features	Metaphor
Directly related groups	When subsamples are immersed in the same experience, but are likely to have different views of it.	‘All surfing the same wave’
Indirectly related groups	When people are linked by some underlying quality of two which bridges between otherwise distinctive phenomena	‘Sharing the breeze’
Families, teams and other cohorts	When people are involved in a system or group, and have shared an experience.	‘Tangled in the same web’
Dyads	When the research is concerned with shared and distinctive features of an experience which is important to two people (e.g., doctor and patient; service-user and carer; siblings; couples)	‘Two sides to every coin’

(Larkin et al., 2019, p. 186)

5.4 Study context

The study was conducted within a public/private mental health service based in Dublin in Ireland.

The catchment area of this service is a largely affluent urban region that had a population of

approximately 165,000 at the time of cohort inception. Today, the population of this region has expanded to 195,000. Treatment modalities and support services available within the research site catchment area included outpatient psychiatric review, inpatient hospitalisation, an acute day hospital, medication management, community mental health nurse home visits, residential rehabilitation, day centres, occupational therapy, and a range of psychological interventions, social work, and family supports. In Ireland, recovery oriented policy and legislation came into effect in 2006⁵⁵ and services were adapted in response to these. The philosophy of care in the catchment area's service was underpinned by a Christian tradition and the values of hospitality, compassion, excellence, justice, and respect. Moreover, the study was carried out in the context of the external pressures and constraints that come with PhD research with a sample of people who were diagnosed with psychosis 21 years ago. The study timeframe had to be strictly adhered to, the study budget was limited, and recruitment was challenging.

5.5 Sample and access to sample

The study participants were recruited from a pool of individuals who had taken part in another study, within the service, called the iHOPE-20 study. The iHOPE-20 study was a prospective 20-year follow-up study of a FEP epidemiologically complete incidence cohort known as the Dublin FEP Cohort⁵⁶ (N = 171) (Clarke et al. 2006). Participants were first recruited to iHOPE-20 using data from the previous follow up research. First contact with cohort members was made when the iHOPE-20 research team (of which I was a member) requested: the persons' clinical teams/GPs to

⁵⁵ With the publication of A Vision for Change (2006).

⁵⁶ The Dublin FEP cohort was established when, at time of first contact (between February 1995 and February 1999), all referrals to a public/private mental health service in a Dublin catchment area were screened by a team of psychiatrists. Individuals were included if they were aged ≥ 12 and diagnosed with a FEP using the SCID-IV (Structured clinical interview for DSM-IV axis I disorders) (First, 1995). FEP was defined as first presentation with acute psychotic symptoms to any psychiatric service for service users who, if they had been prescribed antipsychotic medication prior to presentation, had been receiving such treatment for no more than 30 days. At initial presentation, participants included also met DSM-IV criteria for schizophrenia; schizophreniform disorder; delusional disorder; bipolar disorder (on the basis of a first episode of manic symptoms); major depressive disorder with a first episode of psychotic features; substance-induced psychosis; psychosis due to a general medical condition; and psychosis not otherwise specified. No cases of schizoaffective disorder or brief psychotic disorder were identified.

contact the person by phone; or posted registered letters to persons' last known address; or met the person at their next clinical appointment. If a person expressed an interest in the iHOPE-20 study, they were invited by phone to meet, to discuss participation, and consent to the study if they wished. At this point, written informed consent to be contacted for future research was also obtained.

To be involved in my study, participants had to fulfil the following *inclusion criteria*:

- Provided verbal consent for their details to be passed on to me;
- Be able to provide informed written consent to participate in the study;
- Had only participated in the quantitative component of iHOPE-20.

Potential participants were not included if they were:

- Diagnosed with an organic illness or an intellectual disability;
- Deemed likely to become unduly distressed from talking about their experiences; or
- Had participated in the qualitative component of iHOPE-20 or participated in research conducted within the Saint John of God Hospitaller Ministries during the previous 4 months⁵⁷.

5.6 Recruitment

A four month period was allowed to elapse following participation in iHOPE-20 before contact was made about the MIL study. Prior to any contact being made, the Clinical Gatekeeper reviewed each potential participant's medical file. This was in order to establish if they were experiencing a mental health crisis at the time and determine if they were likely to become unduly distressed from study participation.

⁵⁷ These criteria were applied to limit participant burden.

Following this, the Clinical Gatekeeper made phone contact with an iHOPE-20 participant who had agreed to be contacted about further research and who met the inclusion criteria. The Clinical Gatekeeper informed the person about the MIL study and obtained verbal consent for their contact details to be shared with me. Once I received their details, I phoned the person. If the person continued to express an interest in the study, I posted them an information pack containing the MIL study Letter of Invitation and the Information Leaflet (see appendix 1). One week later, I made a follow up telephone call. If the person was still agreeable to continue with participation, verbal consent was sought over the phone and a time and location for the interview was agreed. When speaking to potential participants themselves, I checked to see if they felt that they were up to taking part or if they thought it might be too upsetting. No potential participant was excluded from participation on the grounds that they were deemed likely to become unduly distressed by taking part. Recruitment for the study occurred on a rolling basis, once I had completed an interview and a preliminary analysis of that interview, I contacted the clinical gatekeeper who then contacted another person.

5.7 Sampling

In total, 80 people who had taken part in the iHOPE-20 study were considered for inclusion in my study. Of these 80, 20 were excluded as they had taken part in the qualitative component of iHOPE-20 and 1 was excluded as he/she had taken part in other research in within the Saint John of God Ministries during the previous 4 months. This left 59 potential participants. From these, 18 individuals were contacted and 16 agreed for their information to be passed on to me. All 16 iHOPE-20 participants who received the information pack from me agreed to participate in the study. In line with IPA data collection principles, purposive sampling (Smith et al., 2009) which considered homogeneity, idiography, and richness of data was used to select participants. The Clinical Gatekeeper reviewed iHOPE-20 study variables for each potential participant in order to purposively select who to sample. Three variables were considered: (i) the degree to which the

person was still *experiencing psychosis* (In Remission or Not in Remission) at 20 year follow up⁵⁸; (ii) age at time of FEP onset; and (iii) gender. Deciding who to contact was based on the desire to increase the variation across these three variables within the sample. Thus, a conscious effort was made to recruit a group of people balanced across remission status and gender; who had experienced their FEP at different time points in their lives. However, due to the multiperspectival study design, sampling an equal number of participants In Remission and Not in Remission was prioritised.

To assess remission status in this study, data from the iHOPE-20 study (from which the participants were drawn) were used. In the iHOPE-20 study, participant's remission status was assessed by a clinically trained researcher⁵⁹; using the Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987). The PANSS is a widely used, 30 item clinician/researcher rated instrument, designed to assess psychosis symptom severity (see appendix 2). It comprises 7 items appraising 'positive symptomatology' (e.g., suspiciousness/persecution); 7 items measuring 'negative symptomatology' (e.g., emotional withdrawal); and 16 items rating 'general psychopathology' (e.g., guilt feelings). All items are scored between 1 (not present) and 7 (severe) (Kay et al., 1987). The PANSS is an internationally recognised, reliable, and valid measure of current state psychosis symptoms (Kay et al., 1987; Kay et al., 1988; Kay, 1990).

Excluding the 6-month duration component, the remission criteria advocated by Andreasen and colleagues (2005) were used to determine remission status. 'In Remission' was defined as meeting Andreasen et al.'s (2005) criteria; 'Not in Remission' as not meeting them. According to these criteria, to be categorised as being *In Remission* of positive and negative symptoms, a person must score 3 or less on 8 PANSS items: delusions; unusual thought content; hallucinatory behaviour;

⁵⁸ These variables were measured for iHOPE-20 (from 2014 – 2017) approximately 1 year prior to MIL study participants being interviewed (from 2017–2018). Mean duration from baseline to iHOPE-20 quantitative follow up was 19.68 years (SD = 0.82) (O'Keeffe et al., 2018). Mean duration from baseline to MIL study qualitative interview was 20.74 years (SD = 1.11). Thus, remission status could have changed from iHOPE-20 data collection to MIL study data collection.

⁵⁹ Roisin Doyle (Clinical Research Assistant, DETECT Early Intervention in Psychosis Service).

conceptual disorganisation; mannerisms/posturing; blunted affect; social withdrawal; and lack of spontaneity. Although remission is defined as a temporary diminution of the severity of disease or pain (Oxford Dictionary of English, 2010) and thus is a concept which may not apply to all the FEP cohort members (as some people experienced a once off psychotic episode); it was nonetheless considered the most valid measure of this variable.

Age at time of FEP onset was also relevant as, compared to younger service users, people with experience of a late onset FEP have divergent needs in their recovery (Selvendra et al., 2014). Therefore, their perspectives on recovery will likely differ. Gender was also deemed significant as there is some evidence to suggest gender differences in the recovery process (Schön et al., 2009). Age and gender data were obtained by iHOPE-20 participants self-completing the Client Socio-demographic and Service Receipt Inventory – European version (Chisholm et al., 2000) at 20 year follow up (see appendix 3).

5.8 Determining sample size

Adhering to IPA data collection principles necessitated striking the balance between the need for sufficient participants to meet the study aim/objectives and the volume of data I could manage whilst remaining true to IPA's idiographic commitments. The approach I adopted was aligned to the position of Sim et al. (2018)—that specifying a priori, the number of participants needed to create sufficient understanding of what is as yet unknown, is essentially illogical. Therefore, as study participants were being interviewed and their data analysed, I was constantly evaluating when recruitment should stop. A decision to stop interviewing was made after 16 interviews were completed following an appraisal of the *richness*⁶⁰ of the dataset in its entirety. Richness was based on a decision that the data sufficiently illuminated participants' explicit meaning making—their

⁶⁰ Considering dataset *richness* when deciding when to stop conducting interviews was prioritised following guidance provided by IPA expert Dr Michael Larkin on 24th April 2017 to the community of researchers who use the internet forum set up by the originators of IPA (Larkin, 2017).

beliefs, understandings, reasoning, and interpreting. In addition, data were rich enough to enable me to explore patterns of similarity and difference across the dataset.

5.9 Data collection process

Data were collected using a face-to-face semi-structured interview informed by an interview guide (appendix 4).

5.9.1 Developing the interview guide and its content

All questions were developed with the explicit goal of eliciting data that I hoped would enable me to meet the study's aim and objectives. Developing the guide involved constructing questions that participants could answer to provide me with these data. Throughout this process however, I was conscious of keeping questions as open ended as possible to avoid me framing participants' responses in a way that reflected what I considered were the issues at stake; as opposed to focusing on participants' concerns and how they were making sense of their personal and social world.

The first step in developing the interview guide was to define psychosis to ensure that participants and I were speaking about the same thing when discussing 'psychosis experiences'. From consulting a wide range of literature (e.g. American Psychiatric Association, 2013; McCarthy-Jones et al., 2013; British Psychological Society Division of Clinical Psychology, 2014; Health Service Executive, 2019), I developed a definition that I believed was without medical jargon and therefore would be accessible and understandable to participants. The definition of psychosis used for the interview was:

Sensing things other cannot sense; believing things that others find strange; feeling out of touch with reality; having difficulty feeling emotions, experiencing pleasure, or speaking; or not having motivation to be social or to do the things you want to do.

From the outset, I decided the content of interview guide needed to cover three separate areas: MIL, meaning making in psychosis experiences, and factors that influence MIL. I began constructing the guide by focusing on the first part of the interview: MIL. I developed open ended questions that aimed to elicit participants' overarching perspective on MIL. These focused on how MIL was experienced and the aspects of life participants viewed as giving their life meaning. The next questions sought to explore what participants understood the role of MIL in recovery in psychosis to be. Subsequent questions sought to elicit participants' thoughts on whether their perspective on MIL changed as a result of experiencing a FEP. If their perspective changed, I wanted to understand how it changed. If their perspective did not, I wanted to understand why not.

The second part of the interview guide focused on meaning making in psychosis experiences and its impact on MIL. These questions had a temporal ordering. Questions began with participants' FEP, then moved to subsequent psychosis experiences, and then current psychosis experiences. These questions aimed to capture the meaning making that occurred in the context of psychosis experiences. I wanted to elicit how participants understood psychosis experiences, what meaning (if any) was derived from them, and how participants dealt with, and felt about, them. The final set of questions in this section centred on if and how participants perceived psychosis experiences impacting their perspective on MIL.

The third part of the interview concentrated on factors that influence MIL. Questions tried to elicit the broad range of barriers to, and facilitators of, MIL that participants had experienced. These questions aimed to bring participants back to the aspects of life they had cited as giving them MIL (e.g. activities, relationships, goals) and then explore what supported and hindered them engaging with these. Questions then examined the help experienced, and desired from, mental health services in relation to MIL. The final set of questions in this section focused on the role of the other health services and community supports in participants' experience of MIL. Questions aimed to elicit how help with MIL offered by these services and supports differed from the help offered by mental

health services. The interview guide ended with an open ended question asking if there was anything else participants would like to add.

5.9.2 Refining and piloting the interview guide

The content of the interview guide was modified and revised over time. Refining the guide was supported through academic supervision; with the objective of enhancing the clarity of interview questions (through supervision meetings and email correspondence). This process was also supported by the piloting of the interview guide with Barry Hurley,⁶¹ a service user and employee of the Irish Advocacy Network. While Barry did not have experience of psychosis, he did have extensive experience of integrating service user perspectives into research and mental health system development/reform. I considered this experience to be more valuable in this context than the experience of psychosis itself.

The first step in the piloting process was for Barry to critique and suggest amendments to my draft interview guide by email. Barry's comments drew attention to a number of implicit assumptions I had made regarding participants' experiences and the language that I had used to explore them. He questioned whether these assumptions applied to service users' lives. For example, it was questioned if 'psychosis' is a term that could be contested by participants as a descriptor for their life experiences. However, I deemed its use necessary as I could identify no other catch all word to capture the scope of my research topic. As a resolution, we agreed that I would provide a lay person's definition of 'psychosis' at the start of the interview and if a participant did not identify with the term we would use aspects of this definition instead. Nonetheless, if participants described their experiences of psychosis using their own lexicon, I adopted it due to the personal meaning of specific words/phrases to participants. It was suggested that approaching interviews in this manner would enhance participant's engagement in the process.

⁶¹ Barry has given me permission to name him in this thesis and in any publications arising from the study.

Subtle but important changes were made to language. ‘Diagnosed with a FEP’ became ‘when you first experienced psychosis’ and ‘becoming mentally unwell’ became ‘developing difficulties with your mental health’. The terms used to describe support —‘mainstream’ and ‘other services for mental health’—were deemed ambiguous. Instead, a distinction was made between ‘formal mental health services’ and ‘other health services/community supports’. An open ended question was also included at the end of the guide allowing participants to add anything else they thought was relevant.

I was advised that, when interviewing, I should endeavour to create a safe environment so trust can be built, rapport and openness can be fostered, and respectful/reciprocal relationships can develop. To this end, Barry recommended that we pilot the interview, alternating as interviewer and interviewee, in order to experience the questions directly, their style, and how they were delivered. In this process, we identified an issue with the flow of the interview. When role playing, I found that being asked about ‘my’ psychosis experiences at the start of the interview was too soon (as rapport within the interview had not developed yet). Consequently, we decided to move the general MIL section first and then to transition to the meaning of psychosis experiences later in the interview. The final interview guide is included in appendix 4.

5.9.3 Interview process

I entered the data collection process fully cognisant that skill in qualitative interviewing is something that is built over time and that my experience in qualitative interviewing was somewhat limited; albeit with the same population (people with experience of psychosis) (O’Keeffe et al., 2018). To remedy this I consulted the literature and reviewed online resources provided by academic institutions and qualitative research experts. This gave me the awareness that fruitful interviewing involves listening assiduously; endeavouring to understand what is being communicated; negotiating meaning when aspects of narratives appear unclear, ambiguous or

abstract; and responding to participants in a manner that deepens the exploration of the essence of their words.

Prior to beginning each interview, I obtained written informed consent to take part in the study from participants using a consent form (see appendix 5). I opened each interview by welcoming participants and thanking them for giving me their valuable time. Prior to the interview, I prioritised building genuine rapport and gaining/respecting participants' trust. When I met each person on the day of the interview, I took some time to get to know them individually and sought to reduce any tension they might have been feeling. This involved speaking to participants about their life in general, how they spent their time day to day, and what their interests were. I then introduced the focus of the interview (MIL and psychosis experiences), offered a definition of psychosis using lay language, and commenced the interview. I found this definition resonated with all participants; they identified with the experiences it listed. Some participants described how they found it easier to discuss these experiences rather than 'symptoms'.

Throughout the interview, I was sensitive to and tried to be aware of all verbal, nonverbal, and non-behavioural communication. As this was my first IPA study, I had to orientate myself to assume an IPA stance by focusing on participants' experience, sense making, and identity in the interviewing process (Pietkiewicz & Smith, 2012). To progress the interview, I used questions that looked to clarify participants' thoughts and sought to explore and elaborate on participants' experience. I was also specific at times and looked to elicit data by requesting participants to use metaphors and images to capture their experience. In the interview, I also reflected participants own words back to them and used silence to allow participants to dwell in their story and what they were telling me. In line with IPA practice, participants themselves also directed the interviews, allowing me to delve into their concerns and interests (Smith & Osbourne, 2003). Interview style was non-directive and open-ended. At times, however, I found it challenging to balance this openness with the interview guide structure. I strove to ask questions free from my explicit/implicit presumptions. This allowed participants to tell their own story in their own words (Smith et al., 1997).

I approached each interview with a consciously naïve and open stance; being receptive to change and ambiguity as sense making can be an ambiguous process. I conceptualised the interview as a human to human relationship (Fontana & Frey, 2000). In the process of data collection, I allowed participants to set the parameters about what mattered to them in the context of the phenomena at the centre of this study (psychosis experiences and MIL). To enable this, I began with open questions. I then sought to find equilibrium between following participants when they opened up a new avenue of enquiry and directing them toward its stated focus. This necessitated constant oscillation between guiding and being led. In this way, my role was not simply to ask questions but ‘to wander together’ with participants (Kvale, 1996, p. 4). Often I sought to bring participants back to their experience and to assist them in putting their experience into words. When participants gave a word (e.g. pain) to describe their experience, I would stay with that word for a while. I would ask them: What does this *pain* feel like? Is *pain* actually the word that best describes what you are feeling? Frequently participants would say ‘no’ and identify another word that best reflected and captured their experience.

I sought to ask participants to attend to the *more* of experience by dwelling on the detail of their experiences. For example I would ask: ‘Can I just take you back, what was the room like, how were you sitting?’. This encouraged participants to take themselves back to a moment in time and to re-invoke the experience; which in turn, helped me to tap into their sense making. My priority at this stage of the interview was to get participants to stay with the experience before making sense of it. This allowed me to get experience near,⁶² to capture the quality and texture of participants’ existence, and to place them in-relation-to events, objects, others, and the world (Boden et al., 2019). I sought to elicit understandings which were concrete and situated rather than general opinions. This assisted participants to talk about *themselves* and *their own* experience rather than rushing to discuss sense making and abstract concepts. I was aiming for a description of participant experience that was situated in time and space not an abstract generalised account. The early stages of the interview needed to focus on ‘what’ not ‘how’ or ‘why’.

⁶² No one can ever directly access another person’s experience.

Participants offered me a story that they had likely already made sense of at an earlier time.

However, in some interviews, there was a remaking of a narrative within the interview context. As a consequence, it was important that I was responsive to the aliveness of the experience and the real time nature of the interaction. In interviews, I adopted the role of an enabler; my goal was to enable the participant to evoke and bring to life the phenomenon being explored. Conducting the interviews felt natural to me. I felt privileged to be trusted with participants' life stories.

I closed each interview by thanking participants for sharing their perspective and experiences with me. I reiterated that the data that had provided would be treated with respect and anonymised so they would not be identifiable. I then provided participants with a €20 One4All voucher to defray the costs of their travel to the interview location. Our interaction ended after I checked in with them to see how they were feeling after the interview. All 16 semi-structured interviews were audio-recorded using a Zoom audio recorder and lasted between 23-76 min. The interviews were conducted in a place of convenience for participants. This was a booked room in a hotel, a local health centre, or the community mental health service connected to the study.

5.10 Process of data analysis

5.10.1 Data transcription, cleaning, and organising

Data analysis begun from the moment the first interview participant began their interview as I was interpreting participants' accounts while they were being shared with me. The next stage of analysis involved the generation of verbatim transcripts from the interviews. This was achieved by commissioning an experienced transcriptionist who had signed a confidentiality agreement. As I did not transcribe the interviews myself, I compared each transcript with each audio recording and fixed any inaccuracies I identified. During this process, I also cleaned the interview transcript of any personal identifiers (e.g. names of individuals and groups) and used a pseudonym for each

participant. Once cleaned, all transcripts were then organised so that In Remission Group and Not in Remission Group data were stored separately.

5.10.2 Manual or electronic coding

A key decision in the analysis of interview data was whether or not to use computer software to facilitate analysis or to rely solely on hand coding. The originators of IPA are not prescriptive regarding this issue. There are benefits of, and challenges in, using software (e.g. potentially saving time through cross referencing codes but requiring time to become familiar with software). For the study, I decided to code data manually by hand.

James (2012) has cautioned against the use of software packages in qualitative analysis, contending that its use decontextualizes and disembodies codes; tethering the researcher to interpret data through the computer system context. Researchers can also have problems recalling all codes used; this inhibits conceptualisations and interpretations. According to St John and Johnson (2000):

Using technology in qualitative research may strip away the meanings with which inflection and body language imbue words. The codes may become objects manipulated by the researcher, with a life and meaning of their own, divorced from their contexts. Consequently, computer technology can distance the researcher from intimate interaction with their data' (p.396).

Others are of the view that these programmes can overemphasize coding and retrieval and consequently increase the likelihood of meaning being missed in the data (Tallerico, 1991; Miles & Huberman, 1984).

Considering the importance of meaning in IPA, I hand coded data in order to ensure that I had made every effort to preserve the meaning of words used by participants. This approach circumvented the potential de-contextualising and dehumanisation of the data. It also enabled me to

engage with data using pens and highlighters, which was more conducive to me interacting with and interpreting data.

5.10.3 Data analysis in multiperspectival IPA

Data analysis was informed by the multiperspectival design type ‘Directly related groups’ recommended by Larkin et al. (2019). Analysis in multiperspectival IPA begins by a researcher endeavouring to comprehend each participant’s understanding of their experiences within their lifeworld and then attempting to synthesise these idiographic analyses not only *within* a group but also *between* groups. Thematic development begins with the first unit of analysis (Phase 1: an idiographic analysis of each case or individual interview); then moves to the second unit of analysis (Phase 2: an analysis of data within each group [In Remission and Not in Remission]); then continues to the third unit of analysis (Phase 3: an analysis of data between the two groups), and finishes with Phase 4 (an analysis of data across the entire dataset).

5.10.4 Phase 1: An idiographic analysis of each case

The first phase of analysis considered each participant’s interview separately. All transcripts were printed on paper with wide margins on either side of the page. One by one, each transcript was analysed separately in order to develop a set of case specific emergent themes for each participant. This process began with me reading and rereading each transcript while taking unfocused notes of initial thoughts and observations. This enabled me to sit and dwell with the data.

Analysis then proceeded to ‘phenomenological coding’ (Larkin & Thompson, 2011, p. 106); a close line by line coding of each transcript. In this stage, I aimed to identify objects of concern (what mattered to each person individually; e.g. relationships, events, values) and then look for experiential claims (narrative and linguistic clues that suggested what these objects meant to the

person). I then began initial noting by hand (recording preliminary analytic observations of the data) and exploratory phenomenological coding (recording descriptive, linguistic, and conceptual comments on the data). These *phenomenological* notes and codes were written on the left hand side of the transcript. During this process, I maintained a balance between staying close to the data and generating tentative possible interpretations of the data. This allowed me to map out, in detail, the phenomenological core of each transcript.

I then moved on to the process of interpretative coding. I began to question, speculate, and develop tentative emerging ideas regarding the meaning of objects of concern for participants. Initially, I endeavoured to remain open to possible meanings by avoiding unfounded assumptions, reaching premature conclusions, or making too much of a leap in interpretation. Throughout this process I tried to acknowledge my fore-conceptions and rein them in as they were informing my work. I was being reflexive; turning away from the analysis and dialoguing with myself. I was aware that meaning could be indirect, enigmatic, complex, and multiform and that surface meaning could both hide and express a deeper meaning. I recorded *interpretative* notes and codes on the right hand side of the transcript. An example of the process of phenomenological and interpretative coding described above is provided in appendix 6. This example illustrates how analysis was undertaken and case (individual) level emergent themes were developed at an idiographic level. I then copied all hand written phenomenological codes and interpretative codes into Microsoft Word 2010.

Once recorded in a Word document, I then searched for connections across codes and grouped them into clusters. This introduced structure into the analysis as I was searching for patterns among, as well as connections and tension between, these codes. Code clusters were the raw material that I then used to generate a set of emergent themes for each participant. These emergent themes were concepts that captured the experiential quality of each person's descriptions of their lives and how they made sense of their objects of concern. A separate Word document was created for each person and each one was colour coded so that different colours corresponded to different participants. This idiographic analysis was then repeated for each of the 16 participants. To help me attend to each transcript in isolation of the rest of the dataset and minimise the likelihood of

previous transcripts influencing the analytic process, I only analysed one transcript on any given day.

5.10.5 Phase 2: An analysis of data within each group

The second phase of analysis examined the data for each group (In Remission or Not in Remission) separately. As the study adopted a multiperspectival design and collected data on two main topics (meaning making in psychosis experiences and MIL), the entire dataset was split into four smaller datasets after phase one was completed. Firstly, data were coded as either meaning making in psychosis experiences data or MIL data. Secondly, a distinction was made between In Remission Group data and Not in Remission Group data. Individual Word documents were then combined to create four master Word documents (datasets) that were linked to each participant by a colour.

To analyse data in this phase, I firstly generated emergent themes for each of the four datasets. This process involved searching for relations, associations, and patterns, as well as conflict, tensions, and contradictions between ideas within each group. How the phenomenological and interpretative codes (developed in the idiographic analysis) were used to develop emergent themes is illustrated in appendix 7.

Secondly, I developed group level superordinate themes. To do this, I considered abstraction (integrating emergent themes due to their likeness); subsumption (turning an emergent theme into a superordinate theme as it captured related themes); polarisation (identifying an oppositional relationship between emergent themes); contextualisation (identifying temporal, cultural, or narrative elements in emergent themes); numeration (reviewing emergent theme for frequency in each transcript); and function (considering each emergent theme's function within each transcript) (Smith et al., 2009).

5.10.6 Phase 3: an analysis of data between the two groups

The third phase of the analysis sought to understand the relationship between the data provided by each group (In Remission and Not in Remission). In particular, each groups' differing 'characterisable stances or positionalities' (Larkin et al., 2019, p. 191) as well as the perspectives they shared. I aimed to identify pattern, connections, conflicts, and differences between the two groups. My aim was to generate an interpretative account that was comprehensive enough to exploit the multiplicity between the groups while offering a plausible interpretation of how participants' lifeworlds interacted and overlapped. This was not a pooling of data to construct an artificial consensus; but an exploration of how the perspectives of both groups related to each other and a consideration of how they could exist together. I analysed the two meaning making in psychosis experiences datasets (In Remission Group and Not in Remission Group) in this way first; then repeated the process for the MII datasets. The analytic strategies for multiperspectival IPA recommended by Larkin et al. (2019) were employed to synthesise the group specific analyses (Table 5.2).

Table 5. 2 Analytic strategies for multiperspectival IPA

Analytic strategy	Explanation
Identify <i>consensus overlap or conceptual overlap</i>	Participants may explicitly express the same concerns and make similar experiential claims. Sometimes the overlap between the meanings made by participants speaking from different perspectives will be implicit, and the analyst may be able to suggest a concept which underpins the participants' concerns
Identify <i>conflict of perspectives</i>	Sometimes there will be a clear disagreement between the different perspectival samples. In these cases, theme titles can capture this conflict, and the analysis can explore the variations in experience, and the contexts from which they emerge
Identify <i>reciprocity of concepts</i>	Participants may express concerns which complement each other very well
Identify <i>paths of meaning</i>	Sometimes we notice shared experiences with divergent meanings, or shared meanings attributed to different experiences
Identify ' <i>lines of argument</i> ' (after Noblit & Hare 1988).	This involves "storying" the most important dimensions drawn from the preceding strategies to provide an analytic narrative to the audience which captures the structural

(Larkin et al., 2019, p. 191)

5.10.7 Phase 4: an analysis of data across the entire dataset

The fourth phase of analysis focused on the dataset as a whole. I engaged the hermeneutic circle (the idea that my understanding of the dataset as a whole was established by reference to the individual parts and vice versa). In the analysis, the whole transcript and parts of it informed each other; the entire dataset and one transcript enlightened each other. I interpreted the hermeneutic circle as a dialectic, referential process (i.e. that we come to understand something by comparing it to something else). I got closer to participants' experiences by comparing them to my own. I was bringing and coming to an understanding of participants' sense making in an organic slowly evolving process due to my immersion in the data. In this way, I was able to come to 'possibilities of understanding' (Kidd & Eatough, 2017, p.2) for the entire dataset.

Interpreting the entire dataset involved deconstructing each transcript and rebuilding the meaning participants attached to their experiences and trying to determine how they made sense of their lives. This was achieved using participants own concerns, claims, and words and putting them together differently with my interpretations. Data analysis was carried out as a non-linear, iterative, back and forth process; analysing part and whole. To get experience near I used my own life experiences as a benchmark. For example I thought: 'I have not had an experience of psychosis myself but have I had a similar one?' Or 'Can I imagine what psychosis is like?'. My goal was to open up credible interpretations. I developed framing and structure in the analysis of the dataset as a whole by asking: 'In what way might themes fit together/differ?'. I defined my role as to retain and embed the richness, text, and texture of the individual experience in more abstract theoretical articulations about the entire dataset.

I integrated each In Remission Group level superordinate theme with its corresponding Not in Remission superordinate theme. Therefore, all superordinate themes offered in study findings represent a synthesis of data from both groups. I then developed a core concept for each superordinate theme. This was done by distilling the essence of each superordinate into as few words as possible in order to aid their interpretation. Emergent and subthemes for both groups were developed by identifying consensus or conceptual overlap; conflict of perspectives; reciprocity of concepts; or paths of meaning. Where possible, efforts were made to modify themes so that they were flexible to account for the perspectives articulated by both groups. However, in many cases this was not possible. Where consensus or conceptual overlap was identified—a shared emergent or subtheme was developed. Where conflict of perspectives existed—group specific emergent or subthemes were created. Sometimes, group specific emergent or subthemes reflected reciprocity of concepts or shared paths of meaning between the groups. Consequently, differences identified between groups were preserved at the emergent or subtheme level. Thus, study findings reflect the thematic development within the group unit of analysis, between groups, and across the entire dataset.

5.10.8 '*Gems*' in IPA

Throughout the analytic process I actively sought, and maintained openness in order to find, what Smith (2011) describes as a 'gem' within study transcripts. Gems were single words, phrases, or extracts; things that said something about the bigger picture of what was going on for participants. Gems offer the IPA researcher 'analytic leverage' (Smith, 2011, p.7), clarifying the phenomenon being explored, coating the transcript and entire dataset in a new light. Gems provided me with a window to access the experience of participants; providing depth to themes as they emerged. In locating and analysing all gems discovered in the dataset, I was aware of the interaction between the object in the participant's consciousness that the gem represents, my role in interpreting the gem, and the participant's awareness of the gem's meaning. I used gems to deepen my interpretations and understandings.

This extract is an example of a gem I found in the transcript of Annie's interview:

I could drink 20 cans of Carlsberg per day, if allowed, and it wouldn't bother me but it bothers other people. I used to think that I was being poisoned in my own home by my own mother, I used to think that. And I used to use the alcohol as an antidote for this. So when I'm drinking today now, it is into a habit, I am not an alcoholic, I can do without drink, but I use it as an antidote to what I used to think was the poison.

This gem illuminated how Annie engaged in meaning making in an experience of psychosis. In the extract, she describes trying to make sense of why she believed her mother was poisoning her when she was younger. Annie viewed psychosis as influencing the degree to which she could be held responsible for her excessive drinking. Psychosis enabled Annie to justify her drinking, relinquish personal responsibility for her life, and attribute her behaviour to the actions of others. This gem gave me analytic leverage that helped me understand psychosis experiences in the context of responsibility for life.

5.11 Ethical considerations

Operating ethically as a qualitative researcher is particularly challenging as ethical issues arising from their work are difficult to identify prospectively and can sometimes be overlooked by review boards (Kendall & Halliday, 2014). This is because ‘By its nature, qualitative research is flexible, emergent and negotiated: the direction of enquiry and even the research question cannot be precisely anticipated in advance, and may alter in response to emerging findings’ (Pollock, 2012, p. 4). Consequently, it has been argued by Schrag (2011, p. 128) that prospective ethical review in exploratory research makes little ‘sense’ and does not address ethical problems as they emerge. For example, a researcher planning on conducting an interview does not know in advance what topics or insights will emerge or what direction the arising discussion will take and thus cannot accurately predict what ethical problems they will encounter.

In the absence of a research specific code of ethics provided by the organisation governing my discipline in Ireland (the Psychological Society of Ireland), ethical decisions were guided by the British Psychological Society (BPS)’s Code of Human Research Ethics (2014). The ethical framework presented by BPS comprises: (i) respect for the autonomy, privacy and dignity of individuals, and communities; (ii) scientific integrity; (iii) social responsibility; and (iv) maximising benefit while minimising harm. It is in consideration of these ethical principles that the following section details the ethical issues that arose during the study and delineates how these were addressed.

Another key challenge for me was my concern that the ethical review board might assess my qualitative study using risk assessment frameworks necessitated by biomedical and clinical research (Pollock, 2012). Being aware of the extensive inconsistencies in the positions adopted by

different ethics committees on specific issues,⁶³ I was concerned that the import of unmodified bioethical principles⁶⁴ could lead my study to be appraised using an incongruent framework.

While I acknowledged these dilemmas, I adopted the pragmatic approach of exercising my best efforts to anticipate ethical challenges and meet review board requirements while also cultivating what Pollock (2012, p. 3) describes as ‘ethical mindfulness’. This involved the consideration of micro ethics based on judgment and ultimately adopting a process rather than a procedural approach.⁶⁵ This necessitated me acknowledging in my application how qualitative research requires engagement and collaboration with participants; not just their cooperation. While identifying the power differential inherent in the research process (Mishler, 1991); I highlighted how I viewed my interaction with participants as a reciprocal exchange⁶⁶ characterised by the coproduction of data; something that was much more than a simple contractual relationship outlined in a consent form. This also compelled me to, over the study lifetime, constantly assess and re-evaluate the degree to which I was treating participants with sensitivity, respect, and consideration.

5.11.1 Obtaining ethical approval

Ethical approval to conduct the study was firstly applied for to the Faculty of Health Sciences Research Ethics Committee, University of Dublin, Trinity College and subsequently to the Saint

⁶³ A study conducted by Roche et al., (2012) revealed that in Ireland alone there is substantial variation on how the issue of payment to research participants is dealt with.

⁶⁴ Ethical principles designed specifically for medical research by the American philosophers Beauchamp and Childress (2008), namely: respect for autonomy, beneficence, non-maleficence, and justice.

⁶⁵ Procedural ethics focuses on context ignorant and abstract principles and formulaic rules. Micro or process ethics is based on judgments that consider context and acknowledge diverse epistemological and methodological research paradigms.

⁶⁶ While study participants received financial compensation for giving their time to provide data, participants also described other benefits of participation. They communicated being happy to contribute to something they considered valuable and worthwhile; they deemed interview itself ‘therapeutic’ (allowing them to formulate and articulate previously unexplored thoughts); and were grateful for the opportunity to give back to the mental health system and help others with experience of mental illness.

John of God Hospitaller Ministries Research Ethics committee—the committee responsible for the Dublin FEP cohort and approving all research conducted within the Health Service the cohort was established in. A prerequisite of approval was the submission of a comprehensive ethics application form for each committee which outlined my plans to identify and contact participants, interview them, and analyse the data generated. The former had to be approved prior to the latter being considered for review. I was cognisant of the contingent nature of ethical regulation (e.g. General Data Protection Regulation⁶⁷ (2016) came into effect across Europe mid study (31st May 2018). I was aware that that review boards may believe that that people with experience of psychosis have an increased propensity for harm/violence (O’Keeffe et al., 2016). I was also conscious that ‘vulnerability’⁶⁸ is a pivotal concept in psychiatric research ethics (Bracken-Roche et al., 2016). Therefore, I paid particular attention to completing sections on protection from harm, consent, and data storage/destruction. I was meticulous responding to all questions presented and supported the answers I provided with references to the literature.

The University provided a list of additional questions their committee required clarification on that I answered by email. The Health Service required me to attend a meeting with committee members which provided an opportunity to directly address any ethical concerns raised by my application (see appendix 8 and 9 for letters of approval). Although responding to the extensive ethical critique proved challenging; it was valuable in helping me anticipate study specific ethical dilemmas.

5.11.2 Informed consent and capacity to consent

⁶⁷ European Union regulation that protects citizens' personal data and harmonises how data are gathered, processed, stored, and used.

⁶⁸ ‘Vulnerability’ is a controversial concept in the mental health field. While it is utilised to protect people who may be at risk of being abused or manipulated due to psychiatric disability; it can also be used to implement paternalistic practices and deprive people of their right to be considered equal to others in society. There is a risk that once a person had received a diagnosis of psychosis, they are deemed interminably vulnerable; irrespective of their current remission status of functioning.

The ethical issue of informed consent concerns the duty of researchers to explain the nature and purpose of the study, the procedures/risks/benefits involved in participation, the alternatives to/time needed to participate, the freedom to withdraw/refuse participation without consequence, and whom to contact for answers to questions regarding the study and participant rights (Nijhawan et al., 2013). Adopting a micro ethics approach meant that, from the outset, consent was conceptualised as an ongoing process; consistently validated over different study stages by building trust with participants and appraising their motivation to take part (Usher & Arthur, 1998).

When conducting this study I rejected the privileging of autonomy and individualism espoused by bioethics (Pollock, 2012); rather I viewed decision making on the part of the research participants as an embedded process of enacting agency within their multifaceted personal and wider social networks; their choices being limited by the obligations imposed by, and the consequences of, certain decisions to these networks (Broadstock & Michie, 2000). I was also conscious that people make decisions on much more than just logic; many decisions are intuitive and based on habits, inclinations, values, and emotions (Karel et al., 2010). Nonetheless, I endeavoured to provide full ‘neutral’⁶⁹ information on the study to participants and at all times sought to prevent undue influence. This involved me underlining the *voluntary* nature of participation; clarifying that cohort members’ decision regarding participation would not impact them personally or socially; and explaining that I was not involved in clinical care in any capacity and that the study was not a component or an adjunct to medical care. Therefore, refusing to take part or withdrawing from the study would have no consequence for them.

How I was to provide adequate information to and appraise capacity to consent in people with experience of psychosis were key issues raised in the ethical review. I ensured information was communicated as clearly as possible by presenting information repeatedly, asking questions, and using probes/prompts to aid interpretation of information. Capacity to consent was assessed using the following four criteria (Foster, 2013): (i) does the person understand the study; (ii) can they can

⁶⁹ As far as possible, information imparted to participants was impartial.

weigh up the benefits and risks of participation; (iii) can they retain the information provided long enough to process; and (iv) can they communicate their decision to participate or not. No concerns about capacity to consent were identified.

One review committee asked: ‘Will only those considered [clinically] ‘recovered’ and hence with capacity to consent be included?’. In order to address this concern, I confronted the assumption that capacity to consent was synonymous with social/occupational functioning and the absence of psychosis symptoms. I argued for the inclusion of ‘non recovered’ participants on two grounds. Firstly, on any given measure of decisional capacity, the majority of patients with a diagnosis of schizophrenia, for example, perform as well as matched comparison subjects without mental disorders (Grisso & Appelbaum, 1995). Secondly, their involvement may promote their interests; offer an opportunity to shape service developments; and may draw attention to aspects of their care and treatment that might otherwise remain hidden (Seymour & Skillbeck, 2002). I posited that excluding this group could be perceived as unethical as not involving them would deny them of the benefits that research can confer and disadvantage research in an already under researched area.

5.11.3 Protecting participants and myself from harm

It has been argued that the risks posed by being a participant in a qualitative study are minimal; commensurate with those encountered in everyday life (Dingwall, 2008). However it would be imprudent to minimise this risk by discounting it. One considerable risk is the potential for qualitative research to induce negative psychological states in participants (Hadjistavropoulos & Smythe, 2001). This stems from the vulnerable position that a participant is placed in by allowing an exploration of their psyche and personal experience. I was cognisant that interviews could result in the eliciting of negative emotions through a recounting of distressing or traumatic events (e.g. a FEP, psychiatric hospitalisation, tormenting symptoms).

To reduce the likelihood of participant distress during the interview, a number of steps were taken. It was possible for the Clinical Gatekeeper to make a judgment regarding whether or not potential participants were experiencing a mental health crisis at the time of recruitment. This was not out of a paternalistic desire to determine ‘readiness’ to participate (O’Keeffe et al., 2016, p. 84); rather it was an effort to protect participants from the intrusion of research during a crisis and the possible impact of this on their mental health. By speaking to potential participants themselves, I was also able to determine if they did not feel up to taking part or if they thought it might be too upsetting. No concerns were identified for any of the potential participants.

A protocol was developed to address distress if encountered in the interview. If distress was detected, I used my skills to manage the situation and respond in a supportive and empathetic manner in the first instance. The participant was also given the option to have the audio recorder turned off and the interview terminated. While I have over 12 years’ experience of working in the mental health field, this has all been in research roles. Therefore it was paramount that I worked within the limits of my professional competence. All incidents of identified distress were to be discussed with my Clinical Supervisor. A system was in place whereby with participants’ consent, they could be referred to a health professional (i.e. the participant’s Clinical Team or GP). No such distress occurred during study interviews.

I was aware of the possibility, that during the interview, participants may disclose a risk of harm to themselves or others⁷⁰. All such disclosures were to be deliberated with my Clinical Supervisor. Potential participants were informed prior to consenting that confidentiality may be broken in these circumstances and informed that disclosure would take place if it occurred. All effort was made to communicate this caveat to participants so that they would have the autonomy to choose whether or not to disclose risk to me.⁷¹ Participants had consented to me disclosing this risk to their Clinical

⁷⁰ A context specific issue relates to the mandatory reporting of child sexual abuse by researchers in Ireland enshrined in the Children First Act 2015.

⁷¹ While I was aware that people can disclose risk without being aware that it is risk, my best efforts to prevent this happening involved me detailing the wide range of risks that would meet this criteria.

Team, GP, the Health Service Executive⁷², An Garda Siochana⁷³ if such risk was identified. If risk was disclosed, I was to link participants in with their Clinical Team, the mental health service in their catchment area, or their GP. None of these actions were ever warranted.

The protection of PhD students as they conduct research field has been described as a ‘deficiency in university risk management’ (Bloor et al., 2010, p. 45). Traditionally the safeguarding of participants has been awarded pre-eminence over researcher welfare by ethics committees (Dickson-Swift et al. 2008). However, this was not my experience. Both review committees underlined the importance of my welfare. I believe the risk assessment of the potential hazards involved in the study conducted by me (in consultation with my academic/clinical supervisors) and the safeguards we put in place adequately ensured my safety.

I considered there to be a reasonable element of risk associated with conducting research alone (albeit supervised). Examples of such dangers include: psychological trauma from actual/threatened violence or the nature of interview disclosures; the study necessitating me being placed in a situation (i.e. being alone with participants) that risks accusations of illegal/immoral actions; the impact (on me) of potential psychological or physical harm caused to participants as a result of my interactions with them (Dickson-Swift et al., 2008). To protect my personal safety and welfare, the study adhered to the University’s Faculty of Health Sciences Lone Worker Guidelines (see appendix 10). Steps taken include being aware of the signs of danger; alerting colleagues when leaving for and returning from an interview; and not releasing my personal telephone number to participants. I also decided not to conduct interviews in people’s homes and had access to Clinical Supervision if I was distressed following the interviews.

One review committee queried: ‘Should there be someone else present at the interview – given stated risk?’. I presented a robust case against this recommendation. I argued that the risk of being

⁷² The national health service of Ireland.

⁷³ The Police Service of Ireland.

accused of improper behaviour was less than the importance of developing rapport with participants and not stigmatising them or undermining my competence by requiring an additional individual to chaperone the interview. I argued that although there is an association between violence and schizophrenia (for example), only a small proportion of societal violence can be attributed to people who receive this diagnosis (Hodgins, 2008). Epidemiological data suggest the relationship between ‘severe mental illness’ and violence is due to an accumulation of historical, dispositional, clinical, and contextual risk factors⁷⁴ linked to a psychiatric diagnosis rather than the diagnosis itself (Van Dorn et al., 2012). Most of the violence propensity in mental health service users appears to be mediated by substance use (Elbogen & Johnson, 2009). Psychosis is also uncommon among people who are repeatedly violent and it inconsistently predicts violence among this group (Skeem et al, 2016).

5.11.4 Confidentiality and anonymity

In 2019, confidentiality and anonymity has taken on renewed importance in European research due to high profile data breaches (most notoriously the Facebook–Cambridge Analytica data scandal⁷⁵) and the implementation of GDPR. However, prior to this, these concepts have long been core tenets of research ethics. Although often considered synonymous, both concepts are discrete, albeit related (Christians, 2000). Confidentiality concerns the right to privacy and the disclosure of personal data. It denotes the commitment to not disclose to other parties information gathered in the research process. Anonymity involves the right for a research participant to remain unidentified and for researcher to protect this right (Clark, 2006). Anonymity is one way in which confidentiality is operationalised; it is a tool used by researchers to achieve confidentiality. However, it is inaccurate to assume that anonymity guarantees confidentiality (Tilley & Woodthorpe, 2011) or indeed that all

⁷⁴ Such as a having a parent with a history of depression, binge drinking, being male, or recently fired/divorced.

⁷⁵ The Facebook–Cambridge Analytica data scandal arose from over 87 million Facebook users having their personally identifiable data harvested and used without their consent in order to influence voter opinion in specific political battle grounds.

research participants desire both (Baez, 2002). I concur with the argument of Singleton and Strait (1999)—that complete anonymity in most social research is impossible due to the researcher participant relationship. Therefore, I focused my efforts in preserving participants' anonymity in report writing and upholding their confidentiality throughout the research process.

In comparison to other types of research, qualitative social science research, by its very nature is full of clues to participants' identities, and has an increased risk of breaches in confidentiality. Thus additional effort and care is required to protect the confidentiality and anonymity of participants (Hewitt, 2007; Kaiser, 2009). If a participant is identified from a quote presented or their personal information is disclosed in a report without consent, they may risk sanctions, prejudice, reprisal, or reputation damage (Kylmä et al., 1999). In this study, it was my responsibility to protect participants from this risk. Confidentiality was maintained using the following procedures.

Participants' names did not appear on the audio recording or the written transcript. I chose to irrevocably anonymise study data to remove it from the bounds of GDPR. I elected to assign a pseudonym rather than a number to each participant, in order to 'give more life to interview excerpts' (Schilling 2013, p. 253), to make participants more memorable, and to help the reader navigate their way through the analysis. Using pseudonyms prevented depersonalisation. Demographic characteristics of the study sample were not displayed in a table individually but presented as group data. I balanced the idiographic/phenomenological foundation of IPA with the need to protect participants. This was achieved by ensuring themes were abstracted beyond the individual yet not losing sight of individual accounts and searching the dataset for, and changing, identifiers (e.g. other people's names, place/service names, group names) without damaging the integrity of the report (Morse & Coulehan, 2015). Furthermore, if any participant withdrew their consent mid study, I planned to destroy all data linked to them. This never occurred. All hardcopy data were stored in a locked filing cabinet in my home. All electronic data were stored on a password protected database.

5.11.5 Power relations in the research process

Power relations in qualitative research are complex. While the researcher-participant relationship is always defined to some degree by power asymmetries; how qualitative studies are conducted can curtail these. IPA seeks to minimize the detachment and segregation between researcher and participant (Karnieli-Miller et al., 2009). It emphasises the researcher–participant coproduction of knowledge where ‘the division between researcher and subject is blurred, and control over representation is increasingly shared’ (Gergen & Gergen, 2000, p. 1035). Unlike other approaches, IPA researchers do not explicitly aim to actively remove such power inequity (e.g. Feminist research [Ropers-Huilman, et al., 2011]). Instead, they endeavour to conceptualise the ‘knower and the known as fundamentally interrelated’ (Larkin et al., 2006, p. 116). Thus, elicitation and interpretation of participant accounts compels balanced and iterative work.

I was conscious that each interview was a one-way dialogue of participants answering my questions. I had defined the situation; framed the interview topic; (at times) guided its course; and determined when engagement ended. However, successful application of the semi-structured interview topic guide enabled ‘multifaceted power shifts’⁷⁶ between the interviewee and myself (Edwards & Holland, 2013, p. 78). As far as possible, I sought to present the interview as a collaborative (rather than directive) exercise in knowledge generation. I aimed to be continually receptive and responsive to participants’ emotional needs. This entailed: explicitly attending to their verbal/nonverbal responses; seeking clarification or additional information from them in a compassionate manner; altering the pace of each interview depending their requirements; accepting their perspectives without judgment; and avoiding the disclosure of my own stance on topics. I was also aware that I had ‘monopoly of interpretation’ (Kvale, 2007, p. 15); the power to interpret, frame, and report what I believed participants’ *really* meant in interviews. Supervision, the phenomenological grounding in IPA, and the process of epoché helped redress this.

⁷⁶ Depending on interview requirements/stages, I modified my role. For example, if I deemed that the participant was going grossly off topic, I guided them back. This involved shifting from the role of vulnerable knowledge seeker to competent scientist.

5.12 Presentation of findings in Chapter 7 and Chapter 8

Prior to continuing this thesis, an outlining of how findings are displayed in Chapter 7 and Chapter 8 is warranted. The superordinate themes offered are not presented in a logical, sequential, or developmental order. No value judgment is applied to them; therefore, all have equal value. Each superordinate theme stands alone; although there are relationships between themes. When I state that both groups experienced something, this does not mean that all participants in both groups experienced it. Or when I say one group experienced something, this does not mean all participants in that group experienced it. Rather, findings are my best efforts to present the diversity of perspectives present in the sample. In order for a theme to be included in the presented analysis, at least three participants' accounts needed to provide support for that theme. In the analysis offered, I am not endeavouring to develop a theory or a framework. Instead, I am displaying the diversity of ways people made meaning in psychosis experiences and found, developed, and maintained MIL.

5.13 Chapter summary and conclusion

This chapter concentrated on detailing how the philosophical, theoretical and methodological propositions inherent to (and selected by me to complement and underpin) IPA were operationalised in this study's context. Practical considerations relating to access, sampling, and recruitment were considered, as were the real-world steps involved in collecting and analysing data. The rationale for decisions made and processes utilised was also presented. Peppered throughout the chapter, I sought to encapsulate key ethical, methodological and personal challenges I encountered and record my reflections on addressing these in the scholarship process. A detailed discussion of reflexivity, rigour, and quality is presented in Chapter 8. The following chapters (6 and 7) outline the findings of the MIL study. Findings are presented over two chapters. The first chapter (Chapter 6) addresses meaning making in psychosis experiences and its impact on MIL and the second chapter (Chapter 7) examines the experience of MIL in the context of mental health recovery in psychosis.

CHAPTER SIX: MEANING MAKING IN PSYCHOSIS EXPERIENCES AND ITS IMPACT ON MEANING IN LIFE

6.1. Introduction

This study aims to explore MIL and the key factors that influence MIL from the perspectives of people who experienced a FEP 21 years ago. This chapter, the first chapter of findings, addresses meaning making in psychosis experiences and its impact on MIL. Prior to presenting findings, an explanation for why the focus of this chapter is *meaning* making (and not *sense* making) *in* psychosis experiences (and not *of* psychosis experiences) is warranted. This study conceptualises sense making as an aspect of the wider process of meaning making. Therefore by focusing on meaning making, this chapter is also presenting data on sense making. ‘In’ psychosis rather than ‘of’ psychosis is used as ‘in’ refers to ‘in the context of’. This captures both retrospective meaning making (*of* psychosis experiences) and the meaning making that occurs when participants are *in* psychosis experiences. Also a number of participants were having psychosis experiences at the time of their interview; therefore meaning making *in* psychosis experiences encompasses the meaning making that was occurring during the interview itself.

Meaning making, in this context, means how participants construe, understand, cohere, interpret, and make of sense of psychosis experiences; and if and how they identify the purpose, point, significance, importance, and value of them. Meaning making refers to how psychosis experiences are conceptualised, categorised, and mapped; what the words participants use to describe them signify; the relevance psychosis experiences have to participants’ lives; and why participants think they occurred.

This chapter begins with a description of participant demographic characteristics. Following this, an overview of the five superordinate themes developed in the analysis and the core concepts produced to capture their essence is provided. This is accompanied by a diagrammatic

representation. Findings are then presented and supported with key extracts from participants' interviews. The chapter ends with a summary of the findings.

The analysis presented aims to provide an interpretative account of how the lifeworlds of participants, including the lifeworlds of different participant groups, interact and overlap. The analysis detailed in this chapter does not aim to develop a theory or present a stage or process account. Rather it aims to generate, in a clear manner, insight into meaning making in psychosis experiences and its impact on MIL; while portraying the ambiguities and different perspectives present in the dataset.

6.2 Demographic profile and diagnoses of participants

In total, 16 participants took part in the study: 8 in the In Remission Group and 8 in the Not in Remission Group. At the time of their FEP onset, participants' mean age in years was 26.94. When completing their MIL study interview, their mean age in years was 47.68. All participants were Caucasian. The majority were male ($n = 11$). Schizophrenia was the most common SCID-IV diagnosis given at baseline (i.e. the time of participants' FEP). Most were unemployed, single, and recorded their Leaving Certificate⁷⁷ as the highest level of education attained. More information on participant demographics and psychiatric diagnoses are displayed in Table 6.1.

Table 6. 1 Demographic characteristics and diagnoses of entire study sample

Characteristic, M(SD)/n (%)	Entire Sample	In Remission Subsample	Not In Remission Subsample
<i>Age in years at time of FEP onset</i>	26.94 (8.32)	28.30 (9.28)	25.57 (7.61)
<i>Age in years at time of MIL interview</i>	47.68 (8.34)	48.72 (10.03)	46.64 (6.79)

⁷⁷ Educational qualification awarded in Ireland following successful completion of the Junior Cycle of secondary education and the achievement of a minimum standard. It is typically required to progress to Higher Education.

<i>Ethnicity</i>			
Caucasian	16 (100%)	8 (100%)	8 (100%)
<i>Gender</i>			
Male	11 (68.75%)	7 (70%)	4 (50%)
Female	5 (31.25%)	1 (30%)	4 (50%)
<i>Baseline SCID-IV Diagnosis (1995-1999)</i>			
Schizophrenia	10 (62.5%)	4 (50%)	6 (75%)
Bipolar Disorder with Psychotic Features	2 (12.5%)	2 (25%)	0
Delusional Disorder	1 (6.25%)	0	1 (12.5%)
Major Depression with Psychotic Features	1 (6.25%)	0	1 (12.5%)
Drug Induced Psychosis	1 (6.25%)	1 (12.5%)	0
Psychotic Disorder Not Otherwise Specified	1 (6.25%)	1 (12.5%)	0
<i>Employment status</i>			
In paid employment or self employed	4 (25%)	3 (37.5%)	1 (12.5%)
Engaging in voluntary work	1 (6.25%)	1 (12.5%)	0
Unemployed	10 (62.5%)	3 (37.5%)	7 (87.5%)
Retired	1 (6.25%)	1 (12.5%)	0
<i>Relationship status</i>			
Single	13 (81.25%)	6 (75%)	7 (87.5%)
Living with partner	1 (6.25%)	0	1 (12.5%)
Married	1 (6.25%)	1 (12.5%)	0
Separated/divorced	1 (6.25%)	1 (12.5%)	0
<i>Highest level of education attained⁷⁸</i>			
No qualification ⁷⁹	2 (12.5%)	0	2 (25%)
Junior Certificate ⁸⁰	1 (6.25%)	1 (12.5%)	0
National Framework of Qualifications Level 5 Certificate ⁸¹	1 (6.25%)	0	1 (12.5%)
Leaving Certificate	6 (37.5%)	3 (37.5%)	3 (37.5%)
Advanced Certificate/Higher Certificate	4 (25%)	3 (37.5%)	1 (12.5%)
Master's Degree/Postgraduate Diploma	1 (6.25%)	1 (12.5%)	0
Unknown	1 (6.25%)	0	1 (12.5%)

⁷⁸ Education level measured using the Irish National Framework of Qualifications. <http://www.nfq-qqi.com/>

⁷⁹ Participants in this category had not received education past the Junior Cycle of secondary education.

⁸⁰ Educational qualification awarded in Ireland following successful completion of the Junior Cycle of secondary education and the achievement of a minimum standard.

⁸¹ A vocation specific qualification that allows a person to start working in their chosen field or progress to Higher Education in the absence of a Leaving Certificate.

All participants continued to reside in Dublin at the time of the MIL study interview. Participants obtained varying degrees of support in mental health settings in Dublin following their FEP and 5/16 lived in accommodation managed by a mental health service.

6.3 OVERVIEW OF MEANING MAKING IN PSYCHOSIS EXPERIENCES

Meaning making in psychosis experiences focuses on what the experiences of psychosis mean to participants, how and why this meaning is assigned, and the impact of this meaning on their perspective on MIL. Five superordinate themes and their emergent themes were generated from the IPA together with their associated core concepts. The superordinate themes are as follows:

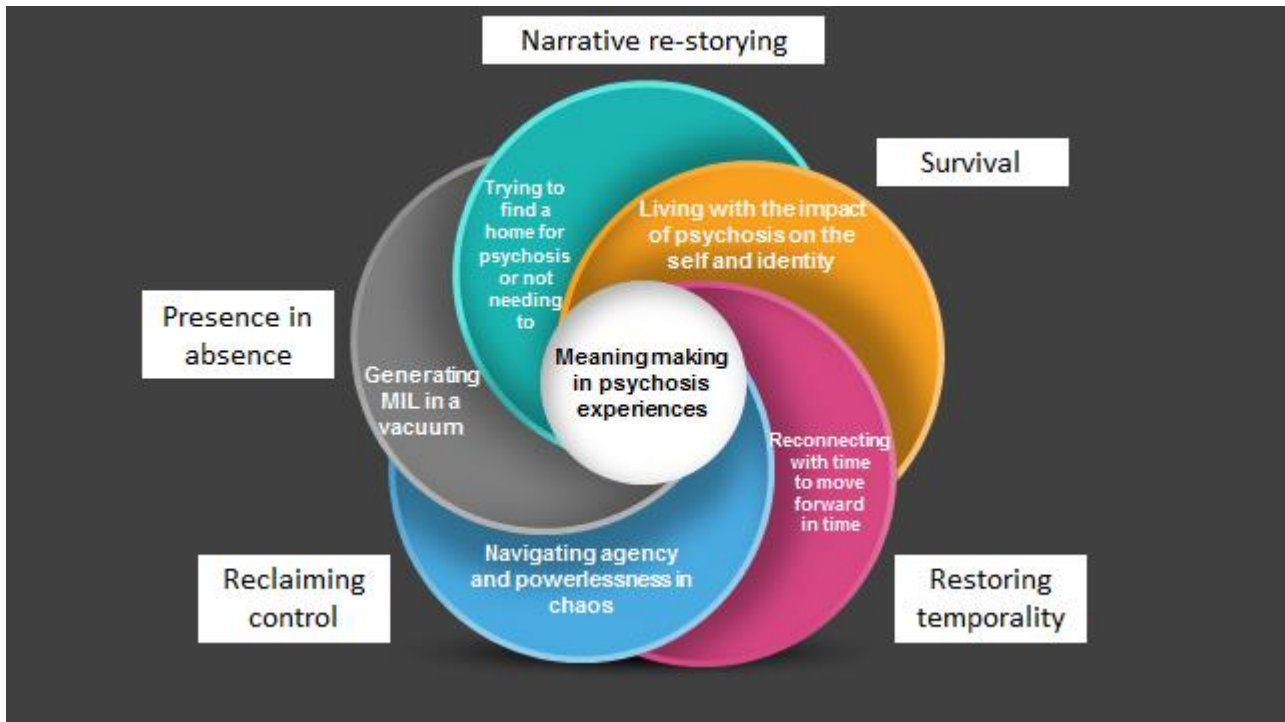
- Living with the impact of psychosis on the self and identity
- Reconnecting with time to move forward in time
- Navigating agency and powerlessness in chaos
- Generating Meaning in Life in a vacuum
- Trying to find a home for psychosis or not needing to

The five core concepts, which represent the essence of each superordinate theme, are as follows:

Survival; Restoring temporality; Reclaiming control; Presence in absence; and Narrative re-storying respectively. Although each superordinate theme is recognisably different in nature from the others, there is a degree of conceptual overlap between them.⁸² The overarching thematic structure is illustrated in Figure 6.1. In line with IPA principles, the structure presented is not explanatory; nor is it a model of what is ‘out there’ (Larkin & Thompson, 2011). Rather, it is a visual representation of the patterns of meaning identified in the dataset as a result of the analysis.

⁸² For example, experiencing psychosis as altering their relationship with time impaired participants’ ability to re-story a coherent life narrative.

Figure 6. 1 Diagrammatic representation of *Meaning making in psychosis experiences*, its superordinate themes, and their related core concepts



6.4 SUPERORDINATE THEME 1: LIVING WITH THE IMPACT OF PSYCHOSIS ON THE SELF AND IDENTITY

The first superordinate theme *Living with the impact of psychosis on the self and identity* describes participants' perception that the self and identity is under threat from psychosis experiences.

Participants viewed psychosis experiences as damaging (or potentially damaging to) the self and identity. This perception made participants question if the self existed, if they knew or trusted the self, if the self was constant and stable, and if psychosis experiences were part of the self.

Participants' description of the self aligned with Leary and Tangney's (2003) understanding of the self as the 'I' that thinks and the 'me' that is the content of thoughts. Participants thought consciously about the self and observed the self as the object of their own attention (e.g. *'I feel I am unresponsive when I myself am not advancing'* [Eddie]). They experienced the self. They perceived, thought about, and felt the self. In order to survive, participants had to continue to live

despite how (in some cases) the threat of psychosis experiences resulted in annihilation or alienation of the self.

In addition to placing the self under threat, participants' viewed psychosis experiences as impacting identity. Identity was viewed by participants as who they understood themselves to be. Identity was defined by what they shared with specific groups (e.g. service user identity), what social roles they adopted (e.g. husband identity), and what differentiated them from others (e.g. resilient identity). Participants formed identity by reflecting on their life narratives, different social discourses, and their many life experiences. Identity was constructed when something continuous and secure that defined the self emerged from this reflection. Participants saw psychosis experiences as superimposed on their budding identities, if the person was in adolescence or early adulthood when they had their FEP, or their well-established identities, if they had their FEP at a later stage in life.

Participants described having a pre-psychosis identity (the person they understood themselves to be before experiencing psychosis) and a preferred identity (an identity they valued above all others). They viewed psychosis experiences as a threat to both of these. Participants questioned if they could have continuity in identity before and after psychosis experiences. They also questioned if psychosis experiences blocked them from becoming, and living as, the person they desired to be. In order to survive, participants had to continue to live despite how (in some cases) the threat of psychosis experiences resulted in the loss of pre-psychosis identity or the inability to develop and enact their preferred identity.

Participants' made meaning in psychosis experiences by interpreting psychosis experiences as a threat and engaging in efforts to survive this threat. Participants responded to the damage caused by psychosis and took proactive steps to mitigate the threat of damage. Meaning making thus focused on ensuring the continued existence of the self and identity in the face of this threat. This focus enabled participants to live with the impact of psychosis on the self and identity. Thus, the core concept of **Survival** defines this superordinate theme.

Within this superordinate theme, there are five emergent themes (Table 6.2). Three relate to the self: *Responding to the threat of self-alienation* (In Remission Group); *Responding to the threat of self-annihilation* (Not in Remission Group); and *Proactively protecting the self* (Shared by both groups). Two relate to identity: *Preserving aspects of pre-psychosis identity* (In Remission Group) and *Overcoming barriers to identity development and enactment* (Not in Remission Group).

Table 6. 2 *Living with the impact of psychosis on the self and identity*

In Remission Group		Not in Remission Group	
Superordinate theme 1 <u>Living with the impact of psychosis on the self and identity</u>			
Core concept <u>Survival</u>			
Emergent theme 1 <i>Responding to the threat of self-alienation</i>		Emergent theme 2 <i>Responding to the threat of self-annihilation</i>	
Emergent theme 3: <i>Proactively protecting the self</i>			
Emergent theme 4 <i>Preserving aspects of pre-psychosis identity</i>		Emergent theme 5 <i>Overcoming barriers to identity development and enactment</i>	

The emergent and subthemes relating to the self will now be outlined.

6.4.1 Emergent theme 1: Responding to the threat of self-alienation (In Remission Group)

Responding to the threat of self-alienation describes the In Remission Group's perception that by experiencing psychosis they were at risk of self-alienation. Self-alienation was viewed by participants as the experience of no longer trusting the self or perceiving the self as fragmented or engulfed. Participants were frightened as the self was not the unified known trusted self anymore. They felt detached, estranged, and separated from the self. In their view, the self had become something else or had broken into parts or become lost in the 'cloud' of psychosis. This experience was deeply painful as it meant grieving the loss of the pre-psychosis self. Participants made

meaning in psychosis experiences by endeavouring to live with the threat of self-alienation in order to survive. Within this emergent theme there are three subthemes: *Developing self-mistrust*, *Fearing self-engulfment*, and *Experiencing self-fragmentation*.

Subtheme 1: Developing self-mistrust

Developing self-mistrust describes the In Remission Group's perception of the self as no longer trustworthy due to psychosis experiences. Participants experienced this perception as frightening as life became highly unpredictable. They were not able to see or protect themselves from risk in their surroundings, as psychosis experiences were not just frightening in themselves but they also rendered benign stimuli threatening. Perceiving constant threat led to a high state of arousal and continuous fear. When within a psychosis experience itself, there was no calm safe space, consequently participants constantly felt exhausted and on the verge of giving up life. In order to survive, they had to develop an awareness (in the aftermath of psychosis experiences) that that it was the self that was a threat to the self; not their environment. Self-mistrust acted as a barrier to MIL undermining participants' thoughts and actions.

Lou viewed psychosis experiences as the self misinterpreting stimuli and distorting reality. As a consequence, she mistrusted her senses and felt impaired in her ability to discriminate threats to the self from benign stimuli. Thus her competence as an interpreter of her surroundings was compromised. The constant state of fear that she inhabited led to her developing self-mistrust. For Lou, psychosis experiences represented the uncontrollable uncontainable self. Her inability to anticipate what the self was going to do next or to manage the consequences of the actions of the self was frightening. In the absence of self-trust, she could not trust anything or anyone. While she could not trust the self, she nonetheless endeavoured to protect the self in order to survive. In the following extract, Lou details how psychosis led her to misinterpret one look from her sister as a threat to her own life:

I actually nearly remember a click in my brain that went ‘click’ and I looked at my sister and she looked as if she was just about to kill me. She looked as if she was really annoyed with me, really angry. And it is only years later I realised she wasn’t angry. It was my brain.

In a similar manner, Conor engaged in meaning making in psychosis experiences by identifying relationships between the content of his psychosis and his life in general. When experiencing psychosis, he was convinced the police were hunting him. He found links between himself and an imagined crime when there were none; fabricating connections and patterns; misinterpreting the meaning of information; causing what he described as a ‘*misapprehension of guilt*’.

In the following extract, Conor explains how he developed self-mistrust through the active participation of the self in the worsening of his psychosis. He viewed the self as out of control, jumping from one conclusion to the next, generating more and more evidence supporting his belief that he was not safe. He experienced this as the self locked in a cycle of self-destruction:

I don’t know how sick I was [during his FEP] but obviously I was sick but I was making myself sick as well... I was actively engaged in this [being terrified of the police] and it wasn’t like I was just sick and there was nothing I could do. I was actually compounding it by looking for more problems that I’d done.

Conor understood this uncontrollable cycle as the self inflicting damage on the self. In order to survive, he had to become aware of this cycle and find a way to break free from it. In the following extract, he likens the act of breaking free from this cycle to surviving a dangerous storm:

This is the storm we are in here, it is probably the worst storm we are ever going to be in, if we can just calm it and the weather calms down, we might find some clear blue water somewhere through it.

Subtheme 2: Experiencing self-fragmentation

Experiencing self-fragmentation describes the In Remission Group's experience of feeling as though the self was disintegrating and losing cohesion. Self-fragmentation was experienced as the self becoming weaker by breaking into small pieces and aspects of the self no longer fitting together to form a united whole. The participants felt like life was falling apart as for them, the self was not one thing but many. This resulted in deep confusion for participants as different fragments of the self were engaged in different thought processes at different times. In order to survive, participants had to accept the self as divided and as a consequence their efforts to generate MIL would also be fragmented.

Eddie perceived the self as fragmented as a result of different thought processes occurring within and outside of psychosis experiences. He perceived a clash between the thinking required to engage with psychosis experiences and those required to function in the world outside of them (as a consequence of one thought process constantly interrupting the other). To survive, he had to '*move away*' intentionally from one thought process and focus on another, depending on his environment. If Eddie's environment required him to perform a function, he directed his thinking away from his psychosis experiences. If his environment did not put functional demands on him, he directed his thinking towards his psychosis experiences.

To illustrate this, he provides a hypothetical example:

If I was working in a supermarket at a till, what would the thought process I would be thinking about have anything to do with? Working at the till? No! And I had to move away from those thought processes.

Eddie experienced the impact of psychosis on his cognitive functioning as the core defining feature of his personal definition of psychosis. Psychosis experiences hijacked his cognitive focus; requiring huge amounts of energy to understand something he could not understand. While he

endeavoured to accept the self as divided, in order to survive, he longed to replace the self-fragmentation (described as '*that mess in the mind*') with a unified self:

This is my definition of psychosis. If I was reading a newspaper, and I was able to concentrate on it, and perceive what it is saying, I am in a good frame of mind. If I am reading it, but my thoughts are cloudy or interrupted by psychotic processes, I am not really just reading the newspaper, I am split sort of thing.

Subtheme 3: Fearing self-engulfment

Fearing self-engulfment describes the In Remission Group's experience of being afraid that the self would become overwhelmed, enclosed, or swallowed up by psychosis. For the participants, this was not a death or an absence of the self but the experience of the self being absorbed into psychosis where the self still existed but was disconnected and hidden from the participant. This perception led participants to experience a feeling of incompleteness and a sense that life was only being half lived; as aspects of life were blocked and inaccessible. In order to survive, participants had to experience this fear and progress forward with their lives.

For Conor, he understood that if he fully engaged with psychotic phenomena he was risking the self being consumed and trapped outside of consensus reality forever. Conor perceived his allowing of psychosis experiences to take over his life as blocking him from sensing beauty in life. He commented: '[during previous psychosis experiences] *I couldn't see all those nice pictures* [the beauty of nature and family connectedness] *that I outlined to you before and that hurt me*'. Psychosis also deprived him of efficacy: '*I couldn't actually perform in things I was meant to do*' and self-understanding: '*I couldn't actually say: 'what's wrong with you and why is this* [that he was experiencing psychosis induced distress]?'. Psychosis experiences alienated him from aspects of selfhood and consequently limited the MIL that was available to him. In the following extract, Conor articulates his fear of self-engulfment:

The thing [a psychosis experience] knocked me for six because the sadness that overcame me was so enveloping, it was like being in a cloud. I couldn't get out of it and I was saying: 'this is very strange'.

6.4.2 Emergent theme 2: Responding to the threat of self-annihilation (Not in Remission Group)

Responding to the threat of self-annihilation describes the Not in Remission Group's experience of perceiving parts of the self as dead or the self as absent entirely. The threat of self-annihilation was perceived as a hollow feeling of uncertainty regarding participants' own existence. This perception was experienced as being on the precipice of life and death. If participants understood parts of the self to be dead, they experienced immense suffering and grief. If they perceived self as absent, this distress was experienced but minimised. In order to survive, participants made meaning in psychosis experiences by endeavouring to live with the threat of self-annihilation. Within this emergent theme there are two subthemes: *Grieving partial self-death* and *Living with self-absence*.

Subtheme 1: Grieving partial self-death

Grieving partial self-death describes how the Not in Remission Group participants acknowledged that a part of the self had died and consequently sought to find a way to progress through life with this awareness. To do this, they needed to grieve the partial loss of the self. Grieving did not mean that participants moved past the pain of this loss. Grieving meant this pain stayed with them throughout their lives but was accepted. In order to survive, participants also had to accept that aspects of the self were gone forever.

For Adam, partial self-death was felt as deep regret at the extinguishing of the '*fire in [his] belly*'; something he attributed to his psychosis experiences. Adam equated this '*fire in [his] belly*' with both his fervent determination for success (where he is '*flying towards*' his life) and the wild abandon of youth (when he was exuberant, unable to stay still, and unwilling to be controlled).

Accepting this part of himself being extinguished changed his perspective on MIL. In the aftermath of psychosis, MIL no longer meant that he passionately pursued achievement. In the following extract, Adam describes how the loss of the '*fire in [his] belly*' required grieving the integrity of his pre-psychosis self and accepting that he was no longer whole because of the hollow space carved into the self by psychosis. The pain of this loss stayed with him throughout his life:

Interviewer: What does having a fire in your belly mean to you?

Adam: Well it is only a term I use to explain it [part of the self], I always felt like... even when I was what 35... I always... like my chest would fill up with an energy or something, it is like youthful exuberance. When you are enthusiastic about things and you are flying towards things. That's as it was. That is what it means to me, my meaning.

Interviewer: And how did experiencing psychosis impact on the fire in your belly, that youthful exuberance?

Adam: Extinguished it.

Interviewer: How did it do that?

Adam: The aftermath... because of my illness I had to go through years of depression after my psychosis.

Adam made meaning from partial self-death by focusing on his survival. Survival was excruciatingly difficult for him, as in the past the '*fire in [his] belly*' was his only source of perseverance. Although he has accepted that '*the fire*' was '*extinguished*', he nonetheless persevered without it; somehow finding determination elsewhere to survive:

Well I talked about when I was young and I had the fire inside me that always made me want to be doing something. I think that would have fired me to keep going. Like I remember the last time I

was with you when you were doing your research before [when participant took part in the iHOPE-20 study] and one of the questions you asked me was why do you think, I can't remember your exact words, but you asked me what sort of kept me going and I said 'perseverance'.

Subtheme 2: Living with self-absence

Living with self-absence describes how the Not in Remission Group participants viewed the impact of psychosis experiences as the realisation that the self was absent. For them, realising the self was absent was characterised by a sense of emptiness and a lack of ownership of thoughts, perceptions, and actions. Participants were not distressed by their awareness of self-absence. From their perspective, there was no need to grieve the self as it never existed in the first place. In order to survive, participants had to accept self-absence and then direct their energies towards remaining in existence and continuing to live on despite this awareness. Finding MIL was still possible, even though the meaning made in psychosis experiences meant the self was perceived as absent.

Natasha's psychosis derived belief system gave her a unique perspective on MIL. In her interview, she recounted a psychosis experience where *'the television was talking about... had I invented eternal life?'* Natasha was able to become aware of a *'form of eternal life for atheists'* achieved through the replication of the self. At first, this realisation was frightening; but overtime it became fascinating and exciting to her. She realised it was not her but aliens who made replication of the self possible. From Natasha's perspective, by taking *'video footage'* or *'footage of the electricity of someone's brain'*, the self could be copied. When applied by Natasha, this belief system negates the existence of the self. If an identical self can be generated, then the self ceases to exist. The 'I' becomes the 'we' that thinks and the 'me' becomes the 'us' that is the content of thoughts. Thus the self is no longer the self; it is absent. In the following extract, Natasha describes this belief system:

Think about it, if you make a replica of someone, like you can already clone the body so just making a really similar body is not really that difficult. And all you have to do is essentially make the mind think exactly like someone who may not be dying or maybe dead or whatever... And so

you have essentially made someone who thinks identically to the deceased person... So it is like a form of eternal life.

Natasha's life demonstrates that it was still possible to find MIL without the self, although it was much more difficult to do so. This was because, even though she experienced thoughts, perceptions, and actions; they were not anchored to anything; they existed outside of her. Yet she still found MIL in the act of surviving self-absence. Her life was remarkable because she kept living it despite being aware she had no self. As a result, she felt enlightened, unique, and resilient. Survival required Natasha to avoid focusing on the absent self and '*just go with things [life] and be happy and distracted*'.

6.4.3 Emergent theme 3: Proactively protecting the self (Shared)

Irrespective of whether participants viewed psychosis experiences as a threat of self-alienation or self-annihilation, they reported *Proactively protecting the self*. *Proactively protecting the self* describes how both groups engaged in proactive strategies in order to mitigate the impact of psychosis experiences on the self. These actions reduced distress and participants could take comfort in knowing that they were doing all they could to defend, preserve, and save the self from the threat of psychosis. Participants made meaning in psychosis experiences by endeavouring to act in anticipation of potential damage to the self to prevent or limit it in order to survive. Within this emergent theme, there are two subthemes shared across both groups: *Maintaining self-continuity* and *Rejecting the unwanted self*.

Subtheme 1: Maintaining self-continuity

Maintaining self-continuity describes how both groups interpreted psychosis experiences as a threat to the constant stable self. Participants interpreted experiencing psychosis as risking irreversible changes in the self, if efforts were not engaged in to maintain self-continuity. This interpretation

meant participants proactively pursued self-coherence before and after psychosis experiences. Participants endeavoured to link remembered selves so they were coherent over lived time. If efforts to link these selves were successful, participants experienced continuity and consistency in their thoughts and behaviours. Such a process was challenging at times; there was always a threat that the self could be altered forever. In order to survive, participants had to keep motivated in their pursuit of self-continuity. If self-continuity was maintained, then participants experienced the self as having an unbroken and consistent existence. Self-continuity gave life coherence as participants perceived the self as the same person over time.

Following over two decades of psychosis experiences, Ian comprehended the self as inherently bound to psychosis. Regarding the presence of psychosis in his life, he stated that: *'it became a part of me, whether I liked it or not'*. To Ian, assimilating psychosis into the self meant becoming whole and undivided in order to uphold the integrity of the self. Assimilation allowed Ian to maintain self-continuity but required him to run *'a marathon'* (by tolerating the pain of psychosis over time). Linking the self over different time periods made his life coherent. In the following extract, Ian describes how he was able to link the past, present, and future self by enduring pain in order to keep the self *'going'*. Maintaining self-continuity was possible due to, what he describes as, *'cold water and the pain going away'*. Ian anchored the self over time to the certainty of *'release'* from the prison of psychosis induced pain:

You have to kinda keep 'you' going... I felt so bad at one stage [he thought]: 'it has to change, it can't really get any worse, I would be dead'. I just pushed myself—a really low feeling. It was kind of like a marathon or something like that. But there were rewards... even if I was a few days going the same... really bad... it could always be a release. I could kind of feel cold water and the pain going away... Sometimes when it happens in your head, you think: 'this is never going to go away'. And it is very easy to think that but it is actually wrong. It tricks you in a way and then with the cooling off phase you are fine again.

Subtheme 2 Rejecting the unwanted self

Rejecting the unwanted self describes how both groups interpreted psychosis experiences as the unwanted self. Participants viewed psychosis experiences as undesirable, something to be shameful of, or something not applicable to participants' current lives. In order to survive, participants had to proactively reject psychosis as part of the self before it could inflict damage.

For Trevor, psychosis was something he rejected by avoiding thinking and talking about it. In his interview, he refused to answer the question: '*Are you still experiencing psychosis?*'. From his perspective, embracing psychosis experiences as an aspect of the self risked readmission to psychiatric hospital and reversal of '*moving forward*' in his recovery.⁸³ Embracing them risked re-exposing himself to the abject pain he wanted to avoid at all costs. Rejecting psychosis experiences as part of the self enabled Trevor to defend the self from risks to personhood and societal value. These forms of social status were aspects of MIL that he could have been deprived of if he did not reject psychosis as part of the self. Trevor's act of rejection enabled him to be seen by others as someone '*doing his best*'. As a result, he did not have to fight against the othering of psychiatric stigma:

The whole idea of getting back to reality, trying to comply with normality, because otherwise no one is going to take you seriously in your life if you're going on [acting psychotic]; plus in a way, there is still stigma I am sure. It's probably not as bad now as it was 30 years' ago.

The two emergent themes relating to identity will now be outlined.

6.4.4 Emergent theme 4: Preserving aspects of pre-psychosis identity (In Remission Group)

⁸³ Note Trevor was not distressed by the interview; nor did he feel that discussing his psychosis experiences during the interview risked him becoming psychotic.

Preserving aspects of pre-psychosis identity describes how the In Remission Group perceived psychosis experiences as a threat to their pre-psychosis identity. In the aftermath of psychosis, participants endeavoured to preserve (by targeting, investing in, and expressing) specific traits that they viewed as defining them prior to their FEP. These were aspects of their pre-psychosis identity that they believed could endure psychosis experiences (e.g. self as strong, self as good, self as of societal value, and self as normal). Their aim was to ensure continuity in identity before and after psychosis experiences. This was an emotional fight to prove to themselves and others that they were not permanently altered by psychosis. This is not to say that participants rejected psychosis as an aspect of their identity. For example, Conor stated: *'It [psychosis experience] may not be something that will be on your CV but I think it should be on your CV, it's a chapter'*. Rather, participants' meaning making was dominated by categorising psychosis as a threat to their pre-psychosis identity. Continuity in identity brought coherence in life but it also made participants feel that they were living an authentic life; a life true to the person they saw themselves as before psychosis. Participants made meaning in psychosis experiences by endeavouring to preserve aspects of pre-psychosis identity in the aftermath of psychosis in order to survive.

Jack described how, through the commendation he received from his family for successfully overcoming the challenge of psychosis, he was able to safeguard and consolidate his pre-psychosis identity as *'a fighter'*. Jack made meaning out of his psychosis experiences by interpreting them as undermining his efforts to achieve his life goals. The backsliding that occurred when psychosis experiences interrupted him progressing toward these goals was heart-breaking for him. However, constantly overcoming the adversity that psychosis brought affirmed his perseverance and strength. The social recognition of this was a source of immense pride:

Jack: My mum and dad think the world of me and if I hadn't got sick they wouldn't know that side, they wouldn't know that side...

Interviewer: Because you came back [recovered].

Jack: I did but I always had the power to fight back, I was always a fighter and I didn't let anything get in my way. I am afraid of no person.

Some participants viewed psychosis experiences as extreme deviance from the '*normal*' self; often considered a shameful weakness. Conor described how his psychosis derived belief (that others believed he had committed an unforgivable crime and deserved punishment) was harshly polarised against his understanding of himself as an inherently '*goodish*' person with moral integrity which was an aspect of his pre-psychosis identity. Within his psychosis, '*going to jail and letting everybody down*' was a certainty. He was convinced that the police had evidence that linked him to this crime; evidence that would result in his incarceration. This certainty terrified him to his very core as it represented the realisation of his worst fears. In order to survive, Conor sought to maintain coherence in identity and to protect his reputation by establishing a legacy of moral integrity which aligned to his pre-psychosis identity. Post his FEP, this became his '*raison d'être*' and the primary justification for his actions:

And I say to the kids: 'look, be straight with people, don't tell any lies because then you have nothing to look back on, you have free conscience, and free movement and you just move forward'. I don't know, maybe that [his central focus on moral integrity] has helped me.

6.4.5 Emergent theme 5: Overcoming barriers to identity development and enactment (Not in Remission Group)

Overcoming barriers to identity development and enactment describes how the Not in Remission Group perceived psychosis experiences as hindering their preferred identity. Participants viewed the identity they valued the most as stunted as psychosis deprived them of psychological space to nurture and grow their preferred identity. At times, psychosis experiences dominated their thinking patterns. This imbalance meant participants were unable to invest their time and energy into enacting their preferred identity, putting it into practice, and living it in the world. Having an identity forced upon them by psychosis experiences was the source of great conflict for

participants. Forming and enacting identity both within and outside of psychosis experiences was challenging. At times, participants did not know who they were. This perception was distressing and a source of great anxiety for them. Life was seen as almost impossible when anchoring experience to a preferred identity was blocked. Participants were unable to attach (or anchor) their thoughts, perceptions, and actions to their preferred reference point (the identity they valued above all others). Participants made meaning in psychosis experiences by endeavouring to protect a selected preferred identity from the threat of psychosis in order to survive.

William understood psychosis as fundamentally altering his identity as it blocked the MIL he could obtain from his individuality and social interaction. He understood psychosis experiences as the cause of isolation. They deprived him of valuable time in his youth; time that he regretted he was not given to develop and enact his preferred identity. It is only when psychosis experiences decreased in frequency and intensity that he was afforded this time. While experiencing psychosis, he longed to deliberately create his preferred identity over time and to manifest and represent it through his actions. To survive, William had to overcome the barrier of lost time in order to develop and enact his preferred identity. This required him to make his preferred identity visible so it could be witnessed. In the following extract, William speaks of a key life turning point after his FEP where this development and enactment was witnessed. He uses the metaphor of a shell to signify his transition from self imposed isolation to living as the affable, funny, social person he sees himself as:

William: When I was first sick I wouldn't talk to no one [anyone]. Then one day a woman said to me at the bus stop, me and my friends were messing, and she goes: 'Would yous [you three] ever calm down'. And I said: 'It wasn't me messing'. And she goes: 'You are coming out of your shell'. That snapped me out of it. That brought me right back around, the way she said it to me, and she said it with a smile: 'You are coming out of your shell'. And she was a little old woman and she was from here, but it was just the way she said it, and I thought: 'Gee... that's a good one'. It made me think and I moved on from there and I just kept going ever since.

Interviewer: It was just like your personality was coming through.

William: Yeah it was probably shut away for a long time.

For Annie, reconciling pre- and post-psychosis identities presented a significant challenge. Psychosis experiences offered an identity so meaningful to her that it eclipsed any identity held prior. At the time of her interview, when within her psychosis experiences, she perceived herself as Jesus. When outside of psychosis experiences, she perceived herself as a worshiper of Jesus. Annie was unable to reconcile these. To survive, she had to accept the absence of this reconciliation. She struggled to make meaning out of this identity conflict; longing for a '*normal*' identity. This was not her pre-psychosis identity (a pagan) or her identity within her psychosis (Jesus) but her non psychotic post FEP identity (a '*normal*' worshiper of Jesus). Consequently, psychosis experiences acted as a barrier that prevented Annie from developing and consistently enacting her preferred identity:

In 2005 Jesus came into my life, when I got sick in 2005, because I was pagan before that for four or five years. Then in 2005, Jesus came into my life and I was thinking: 'Jesus, am I Jesus?'. I pray to Jesus... My life is gone now, gone basically when you think something like that [that she was Jesus]. That was nearly 22 years ago, my life was taken away then when I thought that. Because you cannot get back to normal [being a worshiper of Jesus] when you do something like that.

6.4.6 Summary superordinate theme 1 – Living with the impact of psychosis on the self and identity

This superordinate theme describes how participants made meaning in psychosis experiences by understanding them as a threat to the self and identity that necessitated action. This action involved responding to the damage to the self caused by psychosis, proactively engaging in strategies to prevent or lessen damage to the self before it occurred, endeavouring to keep pre-psychosis identity

alive, and safeguarding space in life for a preferred identity. For participants, psychosis experiences meant learning how to live with and survive and their impact on the self and identity.

6.5 SUPERORDINATE THEME 2: RECONNECTING WITH TIME TO MOVE FORWARD IN TIME

The second superordinate theme *Reconnecting with time to move forward in time* describes participants' perception of psychosis experiences altering temporality by blocking the fullness of lived time. In this context, temporality refers to the state of existing within or having some relationship with time. Psychosis experiences caused participants to struggle to engage with the physical world around them; losing time that could have been spent generating MIL. Participants made meaning by trying to restore the temporality ruptured by psychosis experiences. They desired to progress goals and objectives (within time) but were often stifled by psychosis induced inertia. Psychosis caused participants to feel like they were stuck and that their life would remain unchanged. Participants interpreted psychosis experiences as severing their relationship with time and removing their situatedness in time; decontextualizing them from their temporal context. They endeavoured to restore temporality by re-establishing this connection and situatedness. If temporality was restored, participants could moving forward in time and experience the fullness of lived time. Thus, the core concept of **Restoring Temporality** defines this superordinate theme.

Within this superordinate theme, there are three emergent themes (Table 6.3). The first two emergent themes are group specific: *Breaking free from and progressing past psychosis* (In Remission Group) and *The view from rock bottom – life outside of time* (Not in Remission Group). The third emergent theme is shared across both groups: *Accepting the worthlessness of time destroyed by pain*.

Table 6. 3 Reconnecting with time to move forward in time

In Remission Group		Not in Remission Group	
Superordinate theme 2 <u>Reconnecting with time to move forward in time</u>			
Core concept <u>Restoring Temporality</u>			
Emergent theme 1 <i>Breaking free from and progressing past psychosis</i>		Emergent theme 2 <i>The view from rock bottom – life outside of time</i>	
Emergent theme 3 <i>Accepting the worthlessness of time destroyed by pain</i>			

6.5.1 Emergent theme 1: Breaking free from and progressing past psychosis (In Remission Group)

Breaking free from and progressing past psychosis describes the In Remission Group's experience in relation to how they perceived time as continuous despite the loss of MIL due to psychosis. Participants responded to this loss by balancing the need to salvage and restructure MIL with the need to move on from their psychosis experiences. Attaining this balance enabled them to cohere their life experiences across time, break free, and progress past psychosis. Participants made meaning in psychosis experiences by restoring temporality. This meaning making involved finding a way to resituate themselves in, and experience the fullness of, lived time.

Conor viewed psychosis experiences as rupturing his connection to time. In order to cohere his experiences across time and advance past psychosis, he had to resituate himself in time; binding himself to his past, present, and future. Restoring temporality required him to embrace the pain of his past and strike a balance between erasing and reclaiming aspects of MIL damaged by psychosis. As a result he could accept the past, appreciate the present, and look forward to his future. By achieving this balance, Conor was able to savour starting afresh, as prior sources of meaning were no longer relevant to his life (e.g. his secure yet isolating career). He was also able to intentionally repair or buttress MIL across time (e.g. strengthening his relationships with his wife and children).

In the following two extracts, Conor articulates the internal struggle between grieving loss of MIL and salvaging or restructuring MIL following his FEP. By restoring his temporality, these two actions enabled him to break free from and progress past psychosis:

[Telling himself] ‘you must build up from here [the aftermath of his FEP], you can’t go back there [his FEP]’ ... ‘drop, jettison the old life, it hasn’t been good for me’.

I feel I am strengthened and those parts of the foundation [of MIL] that are creaking have been re-founded, they have been put back into place and built stronger.

6.5.2 Emergent theme 2: The view from rock bottom – life outside of time (Not in Remission Group)

The view from rock bottom – life outside of time describes the Not in Remission Group’s experience in relation to how they perceived time as disintegrated due to the loss of MIL due to psychosis. Consequently, participants adopted the vantage point of the view from rock bottom. They felt disconnected from everything; including time itself. Participants responded to the loss of MIL to psychosis by expressing sadness and anger at the injustice of their disconnectedness to time and the pain caused by this. They engaged in an ongoing struggle to cohere their life experiences across time and advance past psychosis. Participants understood their life as being situated outside of time. They longed to restore temporality by re-establishing their connection to time. This was an ongoing process that was never fully achieved.

Polly expressed anger at being stuck in time due to the inertia brought on by psychosis experiences. Psychosis forced her to allow time to progress without her. Polly measured time—not by a clock—but by the degree of success she experienced in achieving her goals, such as being well liked and having a career that was respected by others. Success in achieving her goals is what bound her to time. Without success she was lost, adrift in life, and disconnected from time. To Polly, inertia in time was stagnancy in achievement. Psychosis experiences gave her a new perspective on MIL and

temporality. In her view, by passively allowing time to pass her by, Polly could achieve success and then temporarily reconnect to time:

There was [a change in her perspective on MIL before and after her FEP] because I could see there was an outlook. I could see there was something. Sometimes you have to wait, and patience is a virtue, and that is one thing I do have, is patience. And you just have to sit there and wait, you could be there for like six months, six years but something good will happen. It has to happen. You can't go through hell for the rest of your life, something has got to happen. It might only be one good day, a job might come up, or they [her family and friends] might appreciate you more than they used to... but something has to happen.

For Annie, the intensity of her psychosis derived belief system ruptured her connection to time. The all-encompassing significance of *'being Jesus'* did not compensate for this rupture in temporality (i.e. the loss of past, present, and future). Annie experienced time as disintegrated and the world as alien. She viewed life through a window that could not be opened. This window separated her from the world and blocked the fullness of lived time. This rupture in temporality saddened and angered Annie as psychosis experiences meant that she lived outside of time; unable to realise her dreams of working, enjoying life, and having a family. As a result, her perspective on MIL was fundamentally altered. Due to Annie's psychosis experiences, she only partially lived her life. There was a limit on the degree of her engagement with the world. Time progressed without her. Consequently, she experienced certain aspects of MIL as forever out of her reach:

It is not nice being mentally ill and you are looking out your window and you see everybody working away, doing their job, going to the shops, bringing up their children. And you are stuck inside as I am in here as well, looking out and seeing this, and you can't do anything about it. You can't live like that.

6.5.3 Emergent theme 3: Accepting the worthlessness of time destroyed by pain (Shared)

The shared emergent theme *Accepting the worthlessness of time destroyed by pain* describes both groups' perception of their connection to time being ruptured by pain. Pain was experienced by participants as intense physical and mental suffering. Participants understood pain as the cause of both inertia in, and disconnection with, time. These experiences were understood by participants to hamper their ability to generate MIL. Pain was seen to dominate their thinking processes to the degree that they struggled to be situated in time focusing on MIL. Participants made meaning in psychosis experiences by endeavouring to reconnect with time. A necessary prerequisite to this reconnection was accepting the worthlessness of time destroyed by pain. By doing this, participants acknowledged that parts of their past were of no value to them. For some participants, the pain caused by psychosis experiences was so overwhelming that they were unable to accept it. Consequently, they experienced the self as existing outside of time. Others could accept the pain of the past in order to move forward in time.

For Natasha, the combined abject pain inflicted on her by her FEP, the grief from her mother's death at a young age, and the alienation she felt within society due to her experiencing psychosis was the most severe pain she had ever endured. This was a hopeless, sad, and lonely pain; rupturing her connectedness to time. In order to have the possibility of moving forward in her life through time, she needed to accept that the time destroyed by pain was of no value to her. In the following extract, Natasha describes how she viewed certain aspects of her past as worthless. In order to progress in time, she needed to accept this worthlessness. However, within this acceptance, she still questioned why such abject pain happened to her and why she lost this time. This questioning focused on the motivations for the actions of the aliens she believed controlled her life and the world:

Well I think I'm a classic case of you know people whose lives are so fucked up at the beginning, you learn to accept things [the pain Natasha experienced during her life], and you learn to appreciate things more I suppose. Yeah my life was totally fucked up; you wouldn't take anything good from it... Why would they [aliens] do that [inflict pain on her]]?

6.5.4 Summary superordinate theme 2 – Reconnecting with time to move forward in time

This superordinate theme describes how participants interpreted psychosis experiences as disrupting their relationship *with* and situatedness *in* time. It captures participants' efforts to restore this temporality in order to experience the fullness of lived time. This involved resituating the self in time or situating the self outside of time, while endeavouring to re-establish a connection to time. Accepting the worthlessness of time destroyed by pain was a necessary prerequisite to participants reconnecting with time. Reconnecting with time allowed participants to move forward in their lives through time

6.6 SUPERORDINATE THEME 3: NAVIGATING AGENCY, POWERLESSNESS, AND RESPONSIBILITY IN CHAOS

The third superordinate theme *Navigating agency, powerlessness, and responsibility in chaos* describes participants' struggle to exist in the disorder and confusion caused by psychosis. Participants experienced their environment as chaos defined by unpredictability in the world around them. They interpreted psychosis experiences as loss of control in their lives as it shattered their understanding of themselves and their relationship to the world; causing them to question their ability and capacity to effect change in their environment. Participants made meaning in psychosis experiences by embracing the powerlessness of, and engaging in efforts to, reclaim control in psychosis induced chaos. They endeavoured to recover the ability or power to influence life course and outcome. Participants engaged in these efforts both within and in the aftermath of psychosis experiences. Thus, the core concept of **Reclaiming control** defines this superordinate theme.

Within this superordinate theme, there are three emergent themes (Table 6.4). All three are shared across both groups: *Embracing powerlessness*, *Enacting agency in chaos*, and *Perceiving personal responsibility as dependant on free will and agency*.

Table 6. 4 Navigating agency, powerlessness, and responsibility in chaos

Not in Remission Group	In Remission Group
Superordinate theme 3 <u>Navigating agency, powerlessness, and responsibility in chaos</u>	
Core concept <u>Reclaiming control</u>	
Emergent theme 1 <i>Embracing powerlessness</i>	
Emergent theme 2 <i>Enacting agency in chaos</i>	
Emergent theme 3 <i>Perceiving personal responsibility as dependant on free will and agency</i>	

6.6.1 Emergent theme 1: Embracing powerlessness (Shared)

Embracing powerlessness describes participants' experience of perceiving the self as not effective within their environment due the chaos caused by psychosis experiences. As a consequence, participants felt like they were helpless; unable to influence, and at the mercy of, a capricious world. They described inhabiting a place of trepidation; characterised by uncontrollability, unpredictability, and uncertainty. While within this chaos, participants perceived they could not control their circumstances. However, by deciding how to respond to these circumstances, they could engage in efforts to regain control of their emotional landscape. Participants made meaning in psychosis experiences by striving to embrace powerless in order to reclaim control.

In her interview, Natasha described how, on the one hand, she believed that all life was a computer simulation run by aliens. This belief deprived her of a primary route to meaning in her day to day life: her free will. On the other hand, Natasha believed there was meaning to life as all life had the free will to '*spontaneously generate itself*'. This belief meant that life had a '*point*'. These two beliefs formed the basis of Natasha's overarching perspective on MIL—that outside of her decision to self-generate, she had no free will, and experienced limited MIL as a result. Thus, in order to continue to exist, Natasha had to embrace powerlessness and manage her own emotional response

to this powerlessness. For Natasha, self-generation gave life meaning. It acted as a buffer against perceived meaninglessness; giving her a reason to live. Self-generation also meant she could embrace powerlessness without a complete loss of MIL. In the following extract, Natasha outlines these two beliefs:

You can never have a situation in science where, you know, you can essentially divorce yourself from your functioning to have free will; it can't be facilitated within science. It can't stop and go: 'which path will I take?'. It just takes the path it takes, if you get me. So, 'Day One', you don't have free will and it is all planned out [embracing powerlessness]. You get that. But when it really starts to get complicated is... the beings that made us [aliens], they can't have free will, nothing can. So I say: 'everything is designed'. So for all intents and purposes, the hills are as designed as the buildings. But actually it flips it on its head then; actually nothing is designed. Somehow conscious experience did spontaneously generate itself. And then eventually you get us. But actually, it's not actually designed... basically all conscious experience generated itself or there wouldn't be any point in anything.

When asked about how she dealt with being powerless in her day to day life, Natasha stated that she accepted powerlessness as reality, was not distressed by it, and just got on with living. For her, powerless was *'Just c'est la vie'*. However, Natasha did have to manage her emotional response to her powerlessness. In order to reclaim control in her life, she actively decided not to engage with her emotions. She understood this action as what protected her from depression. In the following extract, Natasha describes how she responded to her powerlessness:

I just get on with it [life]. I guess other people would be emotional or whatever and I knew well not to. I used to think I was more wrong about things and now... Well I didn't get depressed in spite of all the stuff [pain, grief, and alienation] that was happening to me [in her youth].

6.6.2 Emergent theme 2: Enacting agency in chaos (Shared)

Enacting agency in chaos describes both groups' experience of perceiving the chaos caused by psychosis as compatible with agency. Although, following psychosis experiences, there was an awareness of the unpredictability of life, participants could still effect change in their environment. This was experienced as a gradual process over time where powerlessness was challenged through individual action. Participants endeavoured to find ways to put some order on life through their own agency in order to reclaim control.

From the moment Isaac experienced his FEP, he struggled to control his life. For him, MIL was the fulfilment, realisation, and achievement of his goals and objectives. For example, he longed to '*achieve self-actualisation*' through academic and professional success. Isaac understood psychosis experiences to be the cause of overwhelming circumstances that blocked him from attaining such aspects of MIL. Due to his experience of psychosis, Isaac realised that even with his intelligence and best efforts, achieving his goals and objectives would be extremely difficult. He sought to effect change in the chaos that his life had become by questioning his response to negative circumstances (e.g. his FEP forcing him to drop out of his PhD programme). In the following extract, Isaac wonders if he could have been more effective at influencing his life in the past if responded to negative life events differently:

Whether I could have been more objective or more forthright in the way that I dealt with those circumstances... could I have handled them better and more deliberately to prevent things getting out of control at the time? But retrospectively, the circumstances were so severe it was very difficult to overcome those circumstances or to act more decisively at the time because things had gone out of control so quickly.

Participants also enacted agency in chaos by reframing their interpretation of psychotic phenomena. Polly described how she actively altered her experience of hallucinating. Through meaning making, she was able to reframe something she initially considered distressing (a hallucination) into something that enhanced her life. Polly decided to interpret this hallucination as her grandmother taking care of her from the afterlife. Consequently, the hallucination became a

positive experience; something that reduced her stress levels. Prior to her hallucination she felt unprotected; after she reframed her experience, she felt safe:

Or sometimes you would see somebody like my grandmother in my brain, but I know, I sometimes try and think there is a good way: 'Is she looking after me?' 'Is she saying something is about to go wrong?'. That is the way I look at it.

Polly believed her FEP caused her reputation to be tarnished in her hometown. A rumour began circulating that she had committed an unspecified act during this psychosis experience. Although Polly did not clarify what this rumoured act was, she indicated it was something she considered immoral; something that would deprive her of a '*clear conscience*' if she had committed it. Her internal battle against this rumour became a fight for her moral integrity. In the following extract, Polly describes reclaiming control of her life by revisiting her hometown to defend her moral integrity and erase the negative '*meanings*' connected to the place. In this way, Polly effected change in how she understood both herself and this psychosis experience:

My aunt turned around and said: 'God you are very brave to come to [town in Ireland]'... And they were asking me questions and I was like: 'That is not true, I never did that [rumoured act]'. But the funny thing was, when I came home from [names town in Ireland], those thoughts weren't there anymore about [names town in Ireland] whereas before I went, I would have a lot of meanings in [names town in Ireland].

6.6.3 Emergent theme 3: Perceiving personal responsibility as dependant on free will and agency (Shared)

Perceiving personal responsibility as dependant on free will and agency describes both groups' perception that personal responsibility required free will and agency. Participants believed that if actions were not freely chosen, and they did not have impact on the world, then they could not be held responsible for them. Participants made meaning in psychosis experiences by seeing their

psychosis as influencing the degree to which they could be held responsible for their actions. For some, psychosis experiences caused a relinquishing of responsibility for life. For others, psychosis experiences brought immense and overwhelming responsibility. In order to reclaim the control in life lost to psychosis experiences, participants adopted a particular philosophical stance on free will and agency that impacted how they perceived responsibility in their lives. If participants were not held responsible for their actions, the MIL attained from making the choice to perform them was diminished. Action (or inaction) mattered less, if they occurred without consequence and accountability.

Natasha's psychosis derived belief that the spontaneous generation of life was the only form of free will meant that she could act without consequence. It also meant she could justify relinquishing responsibility for other people. Thus the absence of free will in her day to day life was liberating for Natasha. She played a '*game of let's pretend*', knowing that her day to day actions were inconsequential; she believed they did not matter, impact, or alter the world. Therefore she was accountable to no one. In the following extract, she asserts that trying to help others is pointless. In the past Natasha struggled with guilt from not helping others. At the time of her interview, this guilt had vanished because of her psychosis experiences:

[The world being a simulation] means you can't help other people and you want to help other people but then it is like well isn't it better, if you actually care about other people instead of them having your own screwed up attempts to help them, that things are actually controlled. It's like better and that kind of works out.

Natasha believed that the aliens she thought controlled human life were restricted in their power. They could not decide to inflict extreme pain on human beings. This belief provided Natasha and the people she loved with a certain degree of protection; irrespective of whether or not she took responsibility for her life. There was a safety net in place within the system that produced the computer simulation of the world and human life; there were '*limits on pain*'. In the following extract, Natasha details how these '*limits on pain*' were evidenced by her experiences in life. No

matter how bad things got, she never experienced agony. These '*limits on pain*' allowed Natasha to live a life without responsibility:

Natasha: Basically picture a computer simulation run by aliens, so they have limits on pain, they have limits on how badly wrong things can go.

Interviewer: Who puts those limits in place?

Natasha: There just have been limits in my life, no matter how shit things have got, there is like loads of reasons like I wasn't bullied in school and things like that, there are loads of things that never went wrong.

Psychosis experiences also gave participants responsibilities that they found impossible to meet. Due to psychosis, participants became responsible not just for their own lives but for something much more significant (e.g. the entirety of humanity). For example, when Annie was Jesus, she felt that the inhabitants of the entire world were dependent on her for MIL. Annie made sense of '*being Jesus*' by seeing this responsibility as a gift, giving her the power to face evil, to be able to '*laugh at the devil*'. This gift was also seen as an overwhelming burden:

What can I do, what can I say for people?... You have the worries of the world sitting there.

By believing that she lacked the agency to produce the effect on the world required of Jesus, Annie was able to reclaim control over her life. She knew she would not be held accountable if she failed to meet this responsibility. Annie felt the role of being Jesus lost a certain amount of meaning in the absence of accountability. This feeling made it easier for Annie to occupy other roles (e.g. being an employee):

Then I heard a voice: 'I have joined you with my son, don't worry if you can't [meet the responsibility of being Jesus]... you won't be blamed, you are a guardian in the church'. So that

was grand, that was '95, but after thinking these things over the years I forgot about the work experience in the few years until '95. I was working in '95 as a sales assistant manager.

6.6.4 Summary superordinate theme 3 – Navigating agency, powerlessness, and responsibility in chaos

This superordinate theme describes how participants interpreted psychosis experiences impairing their ability and capacity to effect change in their environment. Psychosis experiences caused participants, at times, to view the world as chaotic and something out of their control. To respond to this, participants embraced powerlessness as an agentive act and found ways to challenge chaos through agency. The positions they adopted regarding their free will and agency determined their interpretation of responsibility. Participants viewed psychosis experiences as both causing a relinquishing of responsibility and giving immense responsibility. Through meaning making in psychosis experiences, participants sought to reclaim control; to re-establishing influence on the course and outcomes of life.

6.7 SUPERORDINATE THEME 4: GENERATING MEANING IN LIFE IN A VACUUM

The fourth superordinate theme *Generating Meaning in Life in a vacuum* describes participants' perception that MIL was absent in certain areas of life and that this was redressed by psychosis experiences. MIL could be produced or created by using psychosis experiences. Participants viewed psychosis experiences as deeply meaningful; filling a vacuum in MIL that, in the past, was a source of anguish and distress. Psychosis experiences felt like the missing piece of a puzzle in participants' lives; they made participants whole and gave their lives value, significance, purpose, and connectedness. This feeling brought immense relief and reduced suffering. Participants felt that something was missing in their lives in terms of meaning and that psychosis experiences gave them MIL in this absence. This often gave rise to intense gratitude for psychosis experiences. Thus, the core concept of **Presence in absence** defines this superordinate theme.

Within this superordinate theme, there are three emergent themes (Table 6.5). The first two are shared across both groups: *Something in the void* and *The mark of exceptionality*. The third emergent theme is group specific: *Developing spiritual networks in the absence of social connection* (In Remission Group).

Table 6. 5 *Generating Meaning in Life in a vacuum*

In Remission Group	Not in Remission Group
Superordinate theme 4 <u>Generating Meaning in Life in a vacuum</u>	
Core concept <u>Presence in absence</u>	
Emergent theme 1 <i>Something in the void</i>	
Emergent theme 2 <i>The mark of exceptionality</i>	
Emergent theme 3 <i>Developing spiritual networks in the absence of social connection</i>	

6.7.1 Emergent theme 1 Something in the void (Shared)

Something in the void describes both groups' experience of perceiving certain aspects of MIL as absent in their lives. Participants experienced life as a void of value, significance, purpose, connectedness, and coherence. This void was distressing as participants felt like they were missing something in their lives. Participants made meaning in psychosis experiences by interpreting them as something that redressed the nothingness of this void in order to generate presence in absence. Psychosis experiences substituted for the MIL that was missing in participants' lives.

For example, the MIL vacuum felt by Thom when he reflected on his perceived 'wasted' life (from not being able to 'achieve something' of value in his lifetime) was a source of intense pain. He was devastated by not having utilised his untapped potential and achieved his definition of success, by making a contribution and demonstrating societal value. This was, in his view, a cause of

depression. For Thom, his psychosis experiences filled a vacuum of significance and purpose. In his interview, Thom juxtaposed his perceived failure at not pursuing his yearning to work as a detective solving '*disappearances*' with his role as the 'Solver'. In order to redress his MIL deficit, Thom adopted the role of the 'Solver'. The 'Solver' could predict the future and solve '*certain things*'. '*Certain things*' were tests Thom set for himself to demonstrate his prescience. In the following extract, Thom gives an example of one these tests:

I like predicting or figuring out what someone is going to say before they come in or figure out who is coming before I see them. For instance ... I was in the coffee shop, I wasn't looking out the window, I couldn't see out the window, I was sitting at a particular point and there was another chap in there and next minute somebody walks in the front door you see. No sound is mentioned at all. And I said immediately, I said: 'Hello [peer]'. And she answered. And the chap who was in the room with me was amazed: 'How did you know, can you mind read?'.

By positioning himself as the 'Solver' of impossible problems, Thom was able to demonstrate his own significance by accomplishing something of worth. He compared his achievements as the 'Solver' with those of the professional sports players he cited as his understanding of someone who actualised their potential:

Interviewer: When you do that [predicting the future], when you have that talent, why is that important to you?

Thom: I feel it is something achieved, achieving something, a difficult shot, whether you win the game or not, playing a difficult shot.

Throughout her interview, Polly communicated the helplessness in isolation she experienced prior to her FEP. She found meaning in voice hearing through, what she described as, a loneliness-psychosis-loneliness cycle. Polly perceived loneliness as the cause of her voice hearing and socialisation as a method by which she could prevent it; yet she lacked self-efficacy in building and

maintaining social networks. She struggled with boundaries in friendships and often experienced social rejection when newly made friends would break contact with her. Polly had difficulty understanding why this rejection kept happening to her. To her, this rejection was incoherent with her understanding of herself as an inherently social person who loves: '*getting out every day... meeting people*'. Polly's voice hearing restored this coherence as she understood her voices as making sense in the context of her loneliness. She viewed her voices as vital in redressing the absence of people in her life who truly understood her. Polly's voices represented something in the void; adding connectedness and coherence to her life:

And then the loneliness came in, the loneliness is a big thing. And then the depression thing got more. And then because I had no one there, that is when the voices happened. That is when the voices happened. That is a good point actually... Yeah because it wasn't just you wake up one morning and you have voices in your head... And then I would meet new people and I would become obsessed ringing them and wanting to meet up with them and they would bar their numbers, you know, so there was a lot of loneliness and no understanding.

6.7.2 Emergent theme 2: The mark of exceptionality (Shared)

The mark of exceptionality describes both groups' perception that psychosis experiences made life exceptional. They understood psychosis as giving their life significance. Participants' viewed their existence as rare, unusual, and atypical, because their psychosis experiences deviated so drastically from what was considered by others as 'normal'. In their view, psychosis experiences were unlike anything else in the world. As a result of experiencing psychosis, life became important and valuable to participants. This perceived significance was more than participants developing a new identity; they felt marked by exceptionality. Participants made meaning in psychosis experiences by interpreting psychosis as giving their life something others did not have. This interpretation made life significant and gave them a reason to keep living. Thus, participants experienced presence in absence.

Natasha's psychosis made her life significant by making her unique. From her absence of belief in free will (in day to day life), to her invention of a '*form of eternal life for atheists*', to her emotional insensitivity, to negative life events acting as a form of resilience, to her rejection of her diagnosis of schizophrenia. Due to Natasha's psychosis derived belief system, she refused to entertain the possibility that she may be experiencing mental illness. In the following extract, Natasha articulates her belief that there is no point in comparing her to other mental health service users. Doing so would be meaningless due to mark of exceptionality that psychosis experiences have left on her life:

I don't think like other people so putting it [realising the world was a simulation] in the context of comparing it [her accepting that the world was a simulation] to how someone else would deal with it does nothing... You see you don't believe that you've had mental health issues because of the whole psychosis thing... I knew I couldn't have [had mental health issues]. It's [her experience of life is] a whole different... [thing] so different, it's not the same... I don't have anything in common with their [other mental health service users'] experiences.

6.7.3 Emergent theme 3: Developing spiritual networks in the absence of social connection (In Remission Group)

Developing spiritual networks in the absence of social connection describes the In Remission Group's experience of perceiving the self as disconnected from the social world. In the participants' view, psychosis experiences contributed to breaking social connections and shrinking their social networks. As a result, they diminished the significance of life and damaged participants' sense of connectedness and belonging. Consequently, participants felt alone, rejected, alienated, and frustrated; feelings which were, for some, compounded by paranoia and mistrust of others. These feelings of aloneness and isolation were experienced as a crisis characterised by the absence of social connection. Participants longed to generate MIL in social relationships but struggled to do so. However, they made meaning in psychosis experiences by endeavouring to

forge stronger bonds with the spiritual world in order to develop spiritual networks (i.e. the connections between participants and the spiritual world). In this way, participants restored their sense of life significance, connectedness, and belonging through their psychosis experiences. Participants used the spiritual networks derived from psychosis experiences to generate presence in absence. These spiritual networks brought aspects of MIL into existence where they were absent before.

Matt valued the social part of himself but, during his FEP, he was unable to connect to others in the social world. The psychosis experiences that characterised his FEP were perceived as preventing him from articulating his thoughts. Matt prized intuition (i.e. the ability to understand something instinctively) above all other ways of connecting to others. To him, intuition *is* telepathy. Through telepathy, Matt established his connectedness to the spiritual world by generating a spiritual network. This spiritual network gave him a mechanism by which he could redress the absence of social connection in his life. He could use his spiritual network to connect to human beings in the social world. In the following extract, Matt communicates gratitude for his ability to integrate social and spiritual worlds through telepathy:

Matt: It is kind of pretty normal for me now to think people communicate telepathically other than speaking. The thing is that they talk as well, but at the time [during his FEP] all I was capable of was in my head. Or I wasn't capable of talking. So any stuff like that, spiritual stuff, nothing would surprise me.

Interviewer: And what is the meaning behind telepathy for you?

Matt: I think it's just communication, we are spiritual and physical and that is just part of... There is great awareness or there is intuitive, being intuitive, developing, becoming intuitive. Intuitive is as good a thing as you can get... I think it's just that we are spiritual as well as physical. It is the spiritual dimension to our lives.

6.7.4 Summary superordinate theme 4 – Generating Meaning in Life in a vacuum

This superordinate theme describes how participants interpreted psychosis experiences as providing the raw material that enabled them to generate MIL when MIL was absent in their lives.

Participants made meaning in psychosis experiences in order to form something where there was nothing before; creating presence in absence. This involved developing spiritual networks in the absence of social connection; actively engaging with the form and content of psychosis experiences in order to fill MIL gaps; and understanding psychosis experiences as what made participants unique and their lives significant.

6.8 SUPERORDINATE THEME 5: TRYING TO FIND A HOME FOR PSYCHOSIS OR NOT NEEDING TO

The fifth superordinate theme *Trying to find a home for psychosis or not needing to* describes participants perception of psychosis as alien or in other words unlike anything they encountered before. Psychosis diminished participants' capacity to coherently narrate their lives, or at least, delayed the process until coherence could be reconstructed. This coherence was important as it gave the reassurance that participants were safe if life adhered to recognisable patterns. Participants had to decide if they should try to understand psychosis experiences and position them within a broad coherent life narrative. Reconstructing coherence in this way meant endeavouring to re-story narrative.

This narrative re-storying involved participants searching for and trying to locate a home for psychosis; somewhere they could situate psychosis within their narrative so it could be made sense of. However, for some participants, psychosis experiences entirely prevented the narration of certain time periods in their lives. Able participants, who chose to do so, sought to restructure life narrative so that psychosis had a place in it. For participants who had multiple psychosis experiences, narrative re-storying was more challenging depending on the degree to which each

new psychosis experience differed from previous ones. The core concept of **Narrative re-storying** defines this superordinate theme.

The following extract from Ian's interview illustrates the increased difficulty involved in narrative re-storying when new types of psychosis experiences were encountered. Each new type of psychosis experience required a new home in order to make sense of it:

You feel 'I don't know anything about that or had that feeling before... oh no, damn! I don't like that, what is that?' and it can trick you again but it is not the same. It is still a bad maybe psychosis feeling but it is not the same one.

Within this superordinate theme, there are four emergent themes (Table 6.6). The first three are shared across both groups: *Justifying narrative disruption and suffering*, *Using culture to explain psychosis*, and *Navigating life in an incomprehensible mist*. The fourth is group specific *Surviving and thriving with little meaning* (Not In Remission Group).

Table 6. 6 Trying to find a home for psychosis or not needing to

In Remission Group	Not in Remission Group
Superordinate theme 5 <u>Trying to find a home for psychosis or not needing to</u>	
Core concept <u>Narrative re-storying</u>	
Emergent theme 1 <i>Justifying narrative disruption and suffering</i>	
Emergent theme 2 <i>Using culture to explain psychosis</i>	
Emergent theme 3 <i>Navigating life in an incomprehensible mist</i>	
	Emergent theme 4 <i>Surviving and thriving with little meaning</i>

6.8.1 Emergent theme 1: Justifying narrative disruption and suffering (Shared)

Justifying narrative disruption and suffering describes both groups' experience of perceiving psychosis experiences as impairing their usual ability to narrate life and seeking a justification for this disruption. For participants, if the ability to coherently narrate life was interrupted, it had to be for *something* (the significance of which also needed to outweigh the suffering caused by psychosis). Participants made meaning in psychosis experiences by finding such justification through narrative re-storying. Narrative re-storying gave a home for psychosis in their life narrative. Thus, making life itself coherent.

The justifications found by participants for narrative disruption and suffering varied depending on what was important to them and their circumstances. Psychosis experiences unveiled the presence of evil in the world; bringing to participants' awareness the immoral and wicked realities of life (e.g. society's abandonment of the homeless). Psychosis experiences were necessary for the enactment of justice and the redressing of inequality (e.g. by bringing universal alienation to all life). They alerted participants to their own resilience; their hardiness in, and adaptability to, extreme stress; brought spiritual salvation (e.g. by facilitating transcendence from a perceived meaningless corporeal life); and made the universe comprehensible and coherent. Psychosis experiences also preserved MIL (by preventing participants from engaging in meaningless action).

In order to justify psychosis experiences, participants engaged in benefit finding (i.e. searching for positive life changes caused by psychosis). These benefits included: deriving MIL from the recovery journey itself; perceiving a positive shift in life orientation; developing an enhanced sensitivity to the world; meeting a life partner because of mental health system contact; finding purpose in the act of availing of mental health services; experiencing the comfort of being guided in life; having both humanness and spiritual awareness enhanced; gaining insight into the self; obtaining balance in relationships; and witnessing enriched family bonding.

In the following extract, Annie is trying to make sense of why her mother, who she knows loves her, was in her view poisoning her:

I mean the Virgin Mary gave seven secrets, said there was a war between Lucifer and Jesus but I suppose me believing I am Jesus, I suppose I was given the liquid substance to make the war evil. I know loads of people like me and they think the exact same as me but I suppose it's God's war to make it even or something. Because no mother in her right mind would give a person poison. So I could have been very ill... And then actually walking around the city centre I used to think there was little hells and little houses and there was even a fire hell. And every type of hell you could think of, well I don't know but I was thinking: 'But I seen [saw] it'. I was sitting at [beach] on my own, I seen [saw] the end of the world.

Annie viewed her psychosis experience (her fixed belief in her mother poisoning her) as necessary to both unveil the presence of evil to her and ensure justice in the world. To understand this experience she utilised the idea of an eternal battle between good and evil: '*God's war*'. This, she interpreted, was the reason why she was being poisoned. She was given a liquid substance by Lucifer⁸⁴ to '*make the war evil*'. This realisation then made her aware of evil everywhere. However, Annie also believed that the purpose of God's war was to '*make it [the war itself] even*'. Earlier in her interview, she made a point of sharing a central value in her life: equality.

I am from a land of equality, you are just as important to me as I am to you, everyone is equal.

Within this context, the term even now takes on new meaning, that of the importance of egalitarianism to Annie. This value was strengthened through years of feeling devalued by society as a homeless person. This inequality was remedied when Annie became significant in this fight for ultimate justice (*because* of the poisoning). Her life now had a role in the most important of all narratives: the fight between good and evil. This belief allowed her to accept the abhorrent heart breaking reality of being poisoned by someone she loved; giving her justification for the narrative disruption she experienced and the suffering she endured.

⁸⁴ With her mother as an intermediary.

6.8.2 Emergent theme 2: Using culture to explain psychosis (Shared)

Using culture to explain psychosis describes how both groups interpreted psychosis experiences by connecting them to pre-established culturally endorsed, coherent, and consistent meaning frameworks (i.e. explanatory models and cultural discourses). These were culture derived propositions that had explanatory power; held by participants about how things are in the world and how things will be. They offered a home for psychosis experiences in the person's narrative, situating them in a larger framework of meaning, rendering them comprehensible. Participants used culture to decipher meaning in psychosis experiences. By using culture in this way, participants were able to re-story their narrative, so that psychosis experiences could have a place in it. Consequently the narrative disruption caused by psychosis was confronted.

Participants used a wide range of explanatory models and cultural discourses to make sense of psychosis experiences. The cultural context in which participants were situated influenced how psychosis experiences were interpreted and how they were seen to impact MIL. Eddie considered psychosis as mattering only in terms of it being something to be prevented. To him, psychosis was a medical illness, a sign of imminent danger that should trigger urgent treatment. Psychosis was an aberration or a '*mess in the mind*' as he put it. To understand psychosis experiences, Eddie endorsed the medical explanation of them. He believed his mind was broken and needed to be fixed by a doctor. From Eddie's perspective, psychosis experiences had no role to play in MIL. James interpreted psychosis as a reawakening of his spirituality. From his standpoint, he had found Jesus *through* his psychosis. James adopted a spiritual interpretation of his psychosis experiences; he understood them as an expression of heightened spiritual awareness or enlightenment. James highly valued this exceptionality and he built his understanding of the meaning of his life around it. If James nurtured his spirituality, his life was meaningful. Polly viewed her psychosis as caused by her circumstances (i.e. her loneliness in the absence of friendship). Thus, she used an explanatory model that focused on her environment to interpret her psychosis experiences. For her, the degree of MIL she experienced was determined by her environment. Lou saw herself as at fault and to blame for her psychosis; she believed it was caused by her actions. By assimilating the cultural

discourse of personal responsibility and applying it to her life, Lou made sense of psychosis by interpreting that it was caused by her taking on too much stress in her life. This understanding meant that Lou viewed herself as responsible for protecting time and space in her life for so that MIL could be nurtured. No participant applied an abuse or emotional trauma explanatory model in understanding their psychosis. By participants applying these culturally derived methods of interpretation; they could engage in narrative re-storying so that their psychosis experiences became culturally meaningful. Matching psychosis experiences with cultural expectations made them more acceptable and understandable; thus participants' narratives became more coherent.

For years, Adam struggled to comprehend the meaning of the term '*psychosis*' and thus was alienated by mental health professionals trying to help him understand his experiences. In order to operationalise the concept, he sought to apply his own definitional parameters around it. This allowed him to link his experiences with a broader framework of meaning: the lexicon of psychiatry. Following an interaction with a doctor, Adam concluded that psychosis meant an absence of awareness of his troubles and feelings. This characterisation of psychosis resonated with him as the defining attribute of all of his psychosis experiences. He had found one potential meaning for these ambiguous events and thus a home for psychosis in his life narrative:

The psychiatrist and registrars I have seen as part of the mental health services, like never actually explained the meaning of the word [psychosis] to me. So you have to come up with your own definition of the term. But it is only when I got sick there about 2010 that something, a doctor had said to me, well she was asking me direct questions. Now that is the type of doctor I liked, someone who asks you direct questions. But she asked me a simple thing, like of all the trouble I was going through, all the feelings and stuff I was going through when I wasn't well, she asked me: 'Was I aware of it?'. And my answer was: 'No'. And it was only then I realised that is what I think psychosis is, part of it, you know, it is not to be aware of... So my understanding of that term would be just... that part of its meaning is that I wasn't aware of what was going on.

Initially, James found the anomalous experience that characterised his FEP (i.e. his visual field being taken over by a '*beautiful blue light*') difficult to explain. However, when within this psychosis experience, he connected it to a dominant cultural discourse in Ireland: Catholic doctrine⁸⁵. James's interpretation of his psychosis experiences as finding Jesus matched cultural expectations in Irish society (i.e. the importance of a relationship with God). By linking his unusual experiences with cultural expectations, he was demonstrating to the world (through narrative re-storying) that he is not 'mad' but *privileged*. Privileged to be granted access to the spirit world in order to cultivate this relationship with God. This made his life comprehensible; enhancing his social status rather than diminishing it. In the following extract, James describes his use of culture to explain psychosis experiences:

But I will never forget it as long as I live, that April day in '96 when I found Jesus again in my life. Or I found him maybe for the first time.

Throughout James's life, this perspective was not left unchallenged. For example, according to his psychiatrist his psychosis experiences were a manifestation of a medical illness. In order to reconcile these two conflicting explanations, he resigned himself to acquiescing to her pathologising his '*religious thoughts*' in order to receive mental health treatment. Nonetheless, James maintained throughout his life that his psychosis experiences were the embodiment of Catholic doctrine.

6.8.3 Emergent theme 3: Navigating life in an incomprehensible mist (Shared)

Navigating life in an incomprehensible mist describes how both groups perceived psychosis experiences as blocking clarity of thought, damaging life narrative coherence, and preventing the narration of certain time periods in life (i.e. when participants were acutely psychotic). Participants

⁸⁵ In the 2016 census, 78.8% of the population of the Republic of Ireland identified as Catholic.

understood psychosis experiences as an incomprehensible '*mist*' obscuring their understanding of themselves and their relationship with the world. They experienced the mist of psychosis experiences as incoherence in life narrative. The unfathomable nature of some psychosis experiences meant that participants struggled to decipher their obscured meaning; eventually accepting that fully exploring and understanding them was impossible. Participants made meaning in psychosis experiences by accepting not just that narrative re-storying was impossible but that some parts of their lives will never be narrated. Instead of finding a home for psychosis experiences, participants sought to navigate through them and move on with life.

Conor did not need to find a home for psychosis experiences or restore life narrative coherence. He simply needed to escape them. In the following extract, Conor describes successfully navigating '*the mist and the fog*' of psychosis experiences. He equated this with surviving a '*storm*'; a metaphor utilised in his interpretation of the unpredictability of illness which was given to him by a doctor who treated his child in the past:

I wasn't at the point where I was through the mist and the fog and I was talking and saying: 'Is this helping me at all?' And then I remember one time a doctor explained to me when one of the children had been sick and I said: 'What is this all about, this child was sick at birth, and then she was well, and now she is sick again?'. He said: 'Consider this as an upset on a stormy sea, that is what life is going to be like for you, your children and everybody in the world. If you can understand that and get through the storm'.

Adam was unable to recollect what occurred during certain times when he was intensely experiencing psychosis. He understood these times as lost memories. This was distressing as psychosis experiences prevented him from narrating parts of his life. He had to accept them as incomprehensible memory blanks. This acceptance was disconcerting and frightening as it meant that his ability to understand who he was and judge trustworthiness in others was compromised. Others could have harmed or tried to manipulate him during these time periods and he would not

know. In the following extract, Adam discusses the impact this had on his relationship with his mother:

Now I will always love my mum no matter what she does. I don't always trust her, I think she keeps more things from me and tells me lies sometimes but I am willing to forgive that because she is my mum and what she has done for me. But I haven't got a complete handle on that situation. Because, well a factor would be that my memory isn't great so I don't tend to reflect back too much on the relationship.

6.8.4 Emergent theme 4: Surviving and thriving with little meaning (Not in Remission Group)

Surviving and thriving with little meaning describes the Not in Remission Group's experience of believing that life holds little meaning and engaging in advantageous avoidance of meaning making as a result. This involved not needing to find a home for psychosis experiences so that they could be made sense of. Narrative re-storying was actively avoided due to participants' primary perspective that life was largely meaningless.

Natasha saw little meaning to anything; therefore she directed her efforts towards surviving in a world mostly devoid of meaning. With no free will beyond self-generation, she resigned herself to going along with what she saw as society's delusion of meaningfulness. This was a pragmatic decision; life was easier if she was not constantly confronting others with this harsh existential reality. In the following extract, Natasha describes how she lied to others; faking a belief in a deeply meaningful world in order to endure. For her, flow, happiness, and distraction overrode meaning. She was able to attain these things and thrive (i.e. enjoy her life and experience wellbeing) in the absence of coherence in her life narrative:

It's a bit of a game of let's pretend. Because I don't think I am really helping people so I don't know. As long as I am happy and distracted by things, I just kind of go with it really.

6.8.5 Summary superordinate theme 5 – Trying to find a home for psychosis or not needing to

This superordinate theme describes how participants interpreted psychosis experiences as disrupting narrative coherence and blocking the ability to narrate parts of life. Participants responded to this by trying find a home for psychosis in their life narrative in order to make sense of it; accepting the meaningless of such efforts; or deciding that making sense of psychosis was impossible. Some participants had to accept not being able to narrate certain time periods in their lives. If a home for psychosis was found, a re-storied life narrative was generated and narrative coherence was preserved.

6.9 Summary and chapter conclusion

This chapter presents an exploration of how participants engaged in meaning making in the context of psychosis experiences. For some participants, psychosis experiences occurred continuously throughout life following their FEP. For others, the presence of psychosis experiences in their life was time limited. Other participants experienced psychosis experiences unpredictability entering and leaving their life at different stages. This meant that psychosis experiences were not just seen as events that called into question, or needed to be reconciled with, previous patterns of meaning making. At times, psychosis experiences defined life itself; they shaped how participants understood life events, relationships, and the self. Participants universally perceived psychosis experiences as unlike anything else. Finding meaning in them brought elation, comfort, completeness but also fear, sadness, and anxiety. Not being able to find meaning in psychosis experiences or not desiring to were also perspectives present in participants' accounts. Every act of meaning making in psychosis experiences impacted participants' overarching perspective on MIL. This impact occurred in three main ways.

Firstly, psychosis experiences eroded MIL. They were understood to threaten or damage a person's self, preferred identity, relationship with time, and control in their lives. The self was eroded by psychosis experiences risking self-annihilation, self-alienation, as well as discontinuity in, and rejection of, the self. Identity was eroded by psychosis experiences impairing identity development, enactment, and preservation. Temporality was eroded by psychosis experiences severing participants' relationship with time, removing their situatedness in time, and blocking the fullness of lived time. Control was eroded by psychosis experiences depriving participants of the ability to effect change in their environment; rendering life chaotic.

Secondly, psychosis experiences contributed to MIL by adding something that was not there before. This addition allowed participants to fill a MIL vacuum that was in their lives. Psychosis experiences gave life value, significance, purpose, coherence, and connectedness. In the extracts presented providing evidence of this, psychosis experiences offered a path to: integrating the physical and spiritual world; establishing connection and understanding; contributing something of value to society; realising potential in life; and living an exceptional life.

Thirdly, while psychosis experiences eroded MIL by disrupting narrative coherence, they also prevented participants from narrating certain time periods in their lives. They created incomprehensible memory blanks that meant that participants struggled to construct a life narrative and understand themselves and their relationships. If memories of psychosis experiences were there, and if participants chose to do so, they could endeavour to re-story their narrative in order for psychosis to have a home. If not, they focused on moving on and accepting the likelihood that they would always have gaps in their life narrative. This was because they either did not understand (and believed it was unlikely that they ever would understand) some psychosis experiences or had no memories of some psychosis experiences to narrate. This acceptance of the absence of narrative meant that participants would forever be deprived of the aspects of MIL connected to those lost time periods as well as the MIL that come with narrative integrity.

Among the sample, meaning making processes in psychosis (or indeed the decision not to engage in meaning making) were influenced by personality and individual predisposition; the perspectives of family, friends, and peers; understandings communicated by the mental health system; the cultural and religious epoch in which they lived; and the degree that psychosis altered their physical and spiritual perception. The allostatic load⁸⁶ (Clarke et al., 2007) increasing over multiple psychotic episodes also made meaning making more difficult in time; especially if the content and form of psychosis experiences changed. Whether or not participants were in remission from psychosis prior to their interviews 20 years after their FEP also influenced the degree of the impact of psychosis experiences on MIL.⁸⁷

The analysis presented accommodates convergence and divergence within individual accounts, within each group, and between groups. While the claims both groups made about their experiences clustered around the same superordinate themes, distinct sites of difference were identified within the emergent and subthemes. This chapter has explored meaning making in psychosis experiences and how the array of meanings assigned to psychosis experiences impact participants' overarching perspective on MIL. How participants interpreted their psychosis experiences formed the context and backdrop for them finding, developing, and maintaining MIL in the recovery journey.

The next chapter will examine the much broader question of how participants experience meaning in their *lives* in the context of mental health recovery in psychosis.

⁸⁶ The damage to the body that accumulates through chronic exposure to stressful life events.

⁸⁷ Generally speaking, participants in remission at 20 year follow up perceived psychosis experiences impacting MIL to a lesser degree than participants not in remission at that time point. There were exceptions to this. E.g. the In Remission Group reported *Developing self-mistrust*. The Not in Remission Group did not.

CHAPTER SEVEN: MEANING IN LIFE IN THE CONTEXT OF MENTAL HEALTH RECOVERY IN PSYCHOSIS

7.1 Introduction

This chapter presents the second part of the findings and examines how participants experience MIL in mental health recovery in psychosis. Recovery, in this context, means the personal, unique, non-linear process by which a person can develop a positive sense of self, cope with challenges, and build a life that they define as meaningful, satisfying, and contributing; with or without the presence of psychosis ‘symptoms’ or other mental health difficulties. In this chapter MIL refers to anything that participants perceive as giving their *life* meaning. Specifically, this chapter examines how participants found, developed, and maintained MIL as well as the factors that influenced this. *Finding* MIL means purposively discovering MIL or accidentally happening to come across MIL. *Developing* MIL means creating, producing, or evolving MIL over time. *Maintaining* MIL means preserving MIL from decline; keeping MIL in an existing state; or helping sustain MIL against threats, opposition, or danger by defending it. *Experiencing* MIL means having been affected by, or gained knowledge through, interacting with MIL.

The chapter begins with an overview of the five superordinate themes developed in the analysis and the core concepts produced to capture their essence. This overview is accompanied by a diagrammatic representation. Findings are then presented and supported with key extracts from participants’ interviews. The chapter concludes with a summary of the analysis offered.

7.2 OVERVIEW OF MEANING IN LIFE IN THE CONTEXT OF MENTAL HEALTH RECOVERY

Analysis of the findings in relation to *Meaning in life in the context of mental health recovery* resulted in the following five superordinate themes:

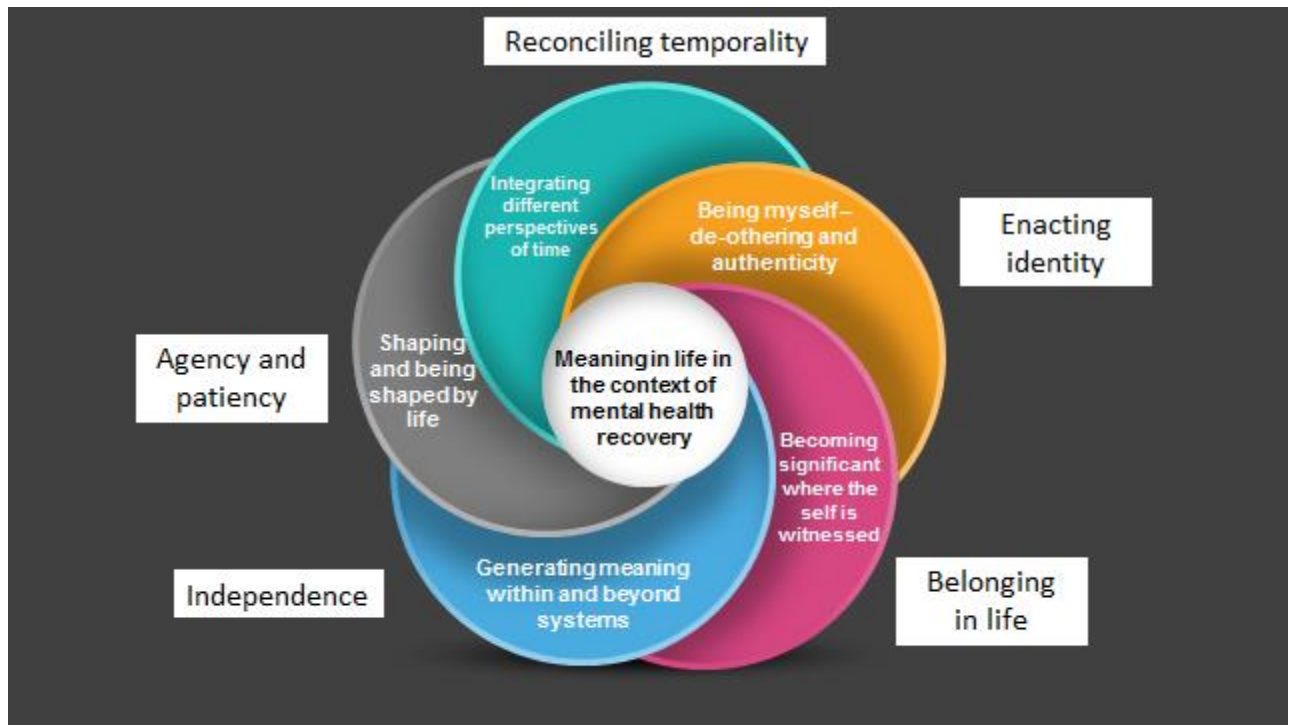
- Being myself – de-othering and authenticity
- Becoming significant where the self is witnessed
- Generating meaning within and beyond systems
- Shaping and being shaped by life
- Integrating different perspectives of time

Core concepts were developed to represent the essence of each of the superordinate themes. The five core concepts are as follows: *Enacting identity*; *Belonging in life*; *Independence*; *Agency and patiency*; and *Reconciling temporality*.

As in the previous chapter, each superordinate theme is different in nature from the others; however a degree of conceptual overlap does exist between them.⁸⁸ This conceptual overlap mirrors the multifaceted quality of MIL; as well as the complexity of the interview data collected. The overarching thematic structure is illustrated in Figure 7.1.

⁸⁸ For example, generativity (the experience of contributing towards the betterment and wellbeing of others) was understood by participants as them contributing something of value to the world *and* transcending time.

Figure 7. 1 Diagrammatic representation of *Meaning in life in the context of mental health recovery*, its superordinate themes, and their related core concepts



7.3 SUPERORDINATE THEME 1: BEING MYSELF – DE-OTHERING AND AUTHENTICITY

The first superordinate theme *Being myself – de-othering and authenticity* describes how participants endeavoured to develop MIL by *being* themselves. This involved them engaging with the world as the person they understood themselves to be. Participants were able to *be* themselves in two main ways, through de-othering and authenticity.

Participants described psychosis experiences as leaving a mark of shame or discredit on their lives. Due to their diagnosis, they felt like they had become flawed or damaged in the eyes of others and marked as different and ‘other’. Being ‘other’ meant being seen as of less value to society.

Participants sought to de-other themselves and remove or lessen the degree of this differentiation by fighting for their humanness and equality (and for some of the female participants in the sample, their femininity).

‘Being myself’ also involved authenticity. Participants sought to live a life true to their own essence—their intrinsic nature. Existing in this way involved them living a life congruent with the true self. De-othering and authenticity are related as participants viewed the act of de-othering as one way they could live a life aligned to the true self. Participants considered the true self to be who they really were at their very core, regardless of their outward behaviour. Through their actions, participants sought to reveal to the world their true self by acting in accordance with it. In the context of recovery in psychosis, participants found maintaining this congruence challenging.

For participants, ‘being myself’ meant putting their identity into practice and representing their identity in action. This identity was that of a person who had the same status as other people and who lived a life congruent with the true self. MIL was developed and maintained by participants fighting for their identity and preserving it over time so that they could enact it in their day to day life. Thus, the core concept of **Enacting identity** defines this superordinate theme.

Within this superordinate theme, there are four emergent themes (Table 7.1). The first three emergent themes are shared across both groups: *Restoring lost humanness*, *Defending egalitarianism*, and *Actualising values*. The fourth emergent theme is group specific: *Reclaiming femininity* (Not in Remission Group).

Table 7. 1 *Being myself – de-othering and authenticity*

In Remission Group	Not in Remission Group
Superordinate theme 1 <u>Being myself – de-othering and authenticity</u>	
Core concept <u>Enacting identity</u>	
Emergent theme 1 <i>Restoring lost humanness</i>	
Emergent theme 2 <i>Defending egalitarianism</i>	
Emergent theme 3	

<i>Actualising values</i>	
	Emergent theme 4 <i>Reclaiming femininity</i>

7.3.1 Emergent theme 1: Restoring lost humanness (Shared)

Restoring lost humanness describes both groups' perception of the need to fight for their human status in order to enact their identity as a human being. Participants saw dignity as the very essence of humanness. Possessing dignity meant being valued, respected, and treated justly by others; as well as having one's worth as a human being recognised. They longed to be treated with dignity so they could *be* human. However, psychosis was understood by participants as severing them from their humanness; both in their own eyes and in the eyes of other people. Dehumanisation stripped them of their dignity. It manifested itself in a sense of personal loss, a change in peoples' behaviour towards them, and a devaluing of who they were by others. Participants often felt objectified and put down. They experienced their perspective on issues (such as family conflict or their mental health treatment) being ignored by family, friends, and clinicians as a consequence of their psychosis. The negative treatment from others also made participants question their own human status which was deeply unsettling as it made them feel worthless. Participants aimed to develop MIL by engaging in de-othering through fighting for their humanness and enacting their human identity. In this way, they could *be* themselves.

Annie considered her true self as human. She described her '*species*' as '*soft*' and sought to be kind and empathetic to others in her actions in order to embody this humanness. However, psychosis, in her view, made her feel and act like an '*animal*'. This dehumanisation of Annie was also compounded by the mental health system (administering anti-psychotic medication), homelessness (depriving her of dignity), and trauma (making her feel unsafe). Annie positioned these factors against her '*soft*' '*human*' identity:

You see I would actually, the species I am, I would give up medication to find my species again which is very soft but when I take this medication it makes me hard which is what they [the mental

health system] want me to be... I am very religious. I even sometimes... I've thought I was Jesus, like many people do in mental illness. But it is difficult to get over thinking these things, to get back to normal, to get human and start acting and behaving human.

In order to develop MIL in her recovery journey, Annie sought to restore her humanness in the aftermath of psychosis by not taking her medication. Humanness was also restored by her acknowledging and helping others:

Interviewer: That is what Meaning in Life is to you, coming back to the human being state?

Annie: It is yes, it is about that, it is about getting back, reading the paper, acknowledging people, have a bit of heart for people, helping people. Helping people I think is most important. You help yourself but when you know you can help others you are better off because you can actually make a person feel normal by being nice to them.

7.3.2 Emergent theme 2: Defending egalitarianism (Shared)

Defending egalitarianism describes both groups' experience of fighting to defend their belief that all people are equal and deserve equal rights and opportunities. For participants, egalitarianism meant that everyone deserved respect, integrity, and the protection of their reputation. However, in their view, psychosis experiences undermined their right to equality. They were disenfranchised by the actions of others, blocked from taking on social roles (e.g. being a spokesperson for their family), excluded from group decision making, and, at times, insulted. Participants aimed to de-other the self by redressing the self-esteem and social status consequences of psychosis through fighting for their equality.

From family, friends, clinicians, and other members of their community they sought recognition for their achievements, acknowledgment of their intrinsic worth, and respect. De-othering involved fighting against coercion, rejecting other peoples' interpretation of their vulnerability, and

reclaiming responsibility for their life. By defending egalitarianism through de-othering, participants experienced the self as becoming more liked, respected, and valued by others. This enabled them to *be* themselves and enact their identity as an equal member of society. Participants generated MIL by pursuing equality.

For Polly, MIL was connected to social status, functioning, and confidence. She had dealt with social rejection her whole life; she was often rebuffed when attempting to form new friendships. Polly expressed a need to defend against the loss of social status she has encountered as a result of psychosis. In her interview, she referred to four separate occurrences (across the social realms of community, friendship, family, and work) where her lesser social status was made evident to her. Polly recounted how her father debased her publically by telling her community that '*she [Polly] is simple*'; opting to insult her intelligence in order to avoid the shame of disclosing her experience of psychosis. Similarly, she remembered a friend describing her as a '*sandwich short of a picnic*'. She was also chastised when she attempted to represent the family at a funeral:

I went to the church and I just went: 'Thanks very much to everyone for coming'. And she [family member] was like: 'That wasn't your place to say it'.

On a separate occasion, another family member struggled to accept how Polly, someone who experienced psychosis, could be employed in a private healthcare service⁸⁹:

I met her [family member] in [Polly's place of employment] and then she was like: Why are you here?' 'I work here'. 'You can't be working in a place like this, why are you here?'... Because I used to work in public [healthcare services], this is private, but she was kind of going: 'But you work *here*'? And I am like: 'Yeah' 'How long have you been here?' 'Eight years'. And then I just walked off. And I got upset then, I wasn't tearful but I was upset because I was like: 'am I that bad?'.

⁸⁹ From Polly's perspective, working in a private service meant she was held in higher esteem by society than when she worked in the public system before.

Polly sought to redress this relegation and de-other the self by defending egalitarianism. Firstly, by demanding equality and respect in her relationships:

Sometimes [another family member] would say: ‘You’re weird’. Or she would be like: ‘You have gone off the point’. And I’d be like: ‘Listen to what I have to say!’.

Secondly, by establishing that she was capable of performing a valued social role; that she was justified in her claim to—and thus deserved—her social status. Polly described how a different family member observed her working with adults with special needs but ignored her; walking by her on the street. Despite being ignored, she took pride in being seen performing this valued social role:

It is being acknowledged. I was kind of delighted: ‘Look now, I am doing it! Oh for God’s sake!’.

7.3.3 Emergent theme 3: Actualising values (Shared)

Actualising values describes both groups’ efforts to engage in actions congruent with their true values. These values were higher order ideals that acted as a guiding force in life and centred on balance, justice, and morality. Developing MIL involved aspiring to actualise these values in reality. If values were actualised, participants experienced pride and experienced *being* themselves. They felt like they were living a life true to themselves and that they were sincere and genuine in how they interacted with the world. This was a form of MIL.

Lou grew up in a family that was well respected in her community. When she was in her 30s she set up a charity. This allowed her to develop social status in her own right and afforded her opportunities to connect with people across the world; all for a the shared purpose of ‘*doing good*’. In the following extract, she describes how the charity’s emblem inspires her:

It means peace and freedom, charity... that's number one, and charity, try and be kind to others in every way but also try and do a little bit. You can't do much as one human being but you can do an awful lot.

To Lou, this emblem signified collective action against injustice. The values of charity, peace, and freedom (all central to her identity) were actualised by her working with the charity. Through her charity, she was effecting small changes in the world and *being* more herself overtime. Lou describes one such change her charity contributed to by deciding where to direct the funds it raised:

So last year it was in [country]. He [the person who set up the organisation that Lou's charity donated to] decided, when he was a teacher there, he realised women needed more education so he set up this [organisation] to fund girls so that they wouldn't have to, at 13 and 14, go and get married, basically sold off for slavery. It is not marriage; it's sex abuse.

William perceived his experience of long term homelessness as abandonment by society. He viewed his life as being worthless and insignificant in the eyes of others. Over the years, he felt consistently undermined by society; his homelessness being the reason in his mind for this devaluing of him as a person. This treatment contravened a strongly held value of William's—that of justice. Actualising this value involved directing his anger towards the injustice he perceived in the housing system. However, doing this also risked contravening another strongly held value—that of peace. To reconcile this conflict, William aimed to strike a balance between his values; allowing himself to experience this anger while maintaining his peaceful nature. In this way, he could *be* himself. This reconciliation was achieved by William communicating his anger to the housing authority in a respectful manner. In adopting this approach, he also endeavoured to ensure that he did not unintentionally contribute to his own subjugation, by acting submissively and allowing his dignity to be violated:

William: There should be proper housing put in place and people who can't afford it shouldn't be looked down upon. That is what I think.

Interviewer: You have to be treated with respect.

William: Yeah and not be looked down on like a piece of shit on the end of someone's shoe. It is not nice... That is one of my perspectives... You have to have a level or people will just keep shitting on you. And you can't be violent and you can't be verbally abusive or nothing like that. You just have to walk away and take a deep breath and keep going.

7.3.4 Emergent theme 4: Reclaiming femininity (Not in Remission Group)

Reclaiming femininity describes the experiences of female participants in the Not in Remission Group. Participants reclaimed femininity for themselves either by rejecting societal stereotypes of femininity or by restoring what they perceived to be as their feminine qualities in the aftermath of psychosis. Reclaiming femininity was an act of de-othering. Participants endeavoured to ensure they themselves felt feminine and that other people saw them as feminine. Fighting for this status brought MIL. Reclaiming femininity meant participants could *be* themselves.

Firstly, reclaiming femininity involved challenging dominant societal narratives about what it is to be female and viewing being female as the only criterion for femininity. This meant defying society superimposing a single idealised image of femininity on the diversity of *all* women. Simply being a woman therefore was enacting a feminine identity. Secondly, psychosis and its treatment were viewed by participants to result in them feeling disconnected from the feminine aspects of their identity. They perceived themselves to be emotionally stunted, unattractive, and harsh in their interactions with others. Reclaiming femininity, in this context, involved reconnecting to lost feminine attributes.

Natasha's mother died when she was a teenager. She also grew up without anyone at home to model what femininity was to her as she lived with her father and younger sister. She rejected the understanding of femininity presented to her in the media; that of an emotional person eager to discuss her feelings with others:

It is easier for women to completely open up or whatever... I mean you see it on TV and people are a bit overzealous that 'all women have to think like me' or if you have got a food problem you are emotionally eating because you could be such a cretin that you wouldn't fit into some stereotype.

Natasha made meaning out of the incongruence between what she perceived society's expectations of femininity to be (i.e. emotional and open) and her detached closed predisposition by redefining and thus reclaiming femininity as resilience:

I guess other people would be emotional or whatever and I knew well not to. I used to think I was more wrong about things and now, well I didn't get depressed in spite of all the stuff that was happening to me. Years ago, I would have thought that wasn't even a good thing because it is the '90s and you are kinda spoon-fed, everyone is supposed to be emotional and if you are not, that is like a bad thing, and you can't even take from it now... it is good that you are not getting depressed—you are strong. I couldn't even take that from it. The '90s were a crazy time and you know things about psychology and men should have emotions and something so I kind of fell into that trap that I'm supposed to be emotional and now I can sit back and say I should have taken from the fact that I was strong and that was good.

Annie viewed her femininity as innately bound to her sexuality and viewed expressing her sexuality as a way of enacting her femininity. Annie believed taking anti-psychotic medication deprived her of the opportunity to enact her femininity by being in a romantic relationship which allowed her to '*be a woman*'. From her perspective, the medication de-sexualised and de-gendered her. Annie reclaimed her femininity when she felt human again later in her recovery journey and could express her sexuality again:

But the thing I notice with me is when I take my medication... it puts a fungus on your tongue and then when I didn't take medication it was clear. So every woman likes to be a woman but the medication can make you feel dirty and your tongue dirty so you can't have a [romantic] relationship with anybody. It is like it is not vanity. I can't go off medication anyway. It is not vanity it is just like... the human being comes back to itself.

7.3.5 Summary superordinate theme 1: Being myself – de-othering and authenticity

This superordinate theme describes how participants experienced MIL by *being* themselves. *Being myself* involved participants engaging in behaviours that decreased their differentiation from the rest of society and reflected their true self. To de-other the self, participants sought to reclaim their femininity (if female), fight for their humanness and dignity, and defend their entitlement to equal rights and opportunities within society. To be authentic, participants aimed to actualise their values in their daily lives. Actualising values meant aligning thoughts and actions to the values participants viewed as defining the true self. By *being* themselves, participants enacted their identity which made them feel their life and essence were aligned.

7.4 SUPERORDINATE THEME 2: BECOMING SIGNIFICANT WHERE THE SELF IS WITNESSED

The second superordinate theme *Becoming significant where the self is witnessed* describes how participants endeavoured to find a witness to their life. A witness was any entity (either in the physical or spiritual world) that was cognisant of the fact that participants existed and to some degree understood them. Examples of witnesses include the self, friends, other people with mental health difficulties, the spirits of the deceased, or spiritual entities. Through the experience of being witnessed, participants felt acknowledged and fully seen. This in turn enhanced the significance of their life, as it made them feel that life had value and was worth living, because they were important enough to be worthy of attention from others. When participants experienced the self

being witnessed, they viewed the self *as* significant, mattering, and important in the context of the existence of all things. This significance gave life meaning in the recovery process.

Having the self witnessed also enabled participants to develop a web of connectedness with witnesses in their life. They had a sense of personal involvement and a purpose—to maintain and develop this web. Thus, they became an integral part of the web, developed an affinity to it, and consequently felt like they had a rightful place in it (i.e. a home). They felt included, valued, and accepted. Participants found, developed, and maintained MIL by forming, forging, and strengthening connections with witnesses over time. Thus, the core concept of **Belonging in life** defines this superordinate theme.

Within this superordinate theme, there are five emergent themes (Table 7.2). The first four emergent themes are shared across both groups: *Unearthing the hidden self*, *Being lost in human disconnection*, *Connecting to transcend the self*, and *Seeking a home amid connectedness*. The fifth emergent theme is group specific: *Owning the self – being the subject of experience* (In Remission Group).

Table 7. 2 *Becoming significant where the self is witnessed*

In Remission Group	Not in Remission Group
Superordinate theme 2 <u>Becoming significant where the self is witnessed</u>	
Core concept <u>Belonging in life</u>	
Emergent theme 1 <i>Unearthing the hidden self</i>	
Emergent theme 2 <i>Being lost in human disconnection</i>	
Emergent theme 3 <i>Connecting to transcend the self</i>	
Emergent theme 4 <i>Seeking a home amid connectedness</i>	
Emergent theme 5 <i>Owning the self – being the subject of experience</i>	

7.4.1 Emergent theme 1: Unearthing the hidden self (Shared)

Unearthing the hidden self describes both groups' perception that aspects of the self were hidden from family members, friends, and mental health professionals. Unearthing, in this context, means bringing to light and making known the hidden parts of the self. Participants spoke of keeping certain thought processes (e.g. interpreting a hallucination as a threat), beliefs (e.g. believing the self was Jesus), emotions (e.g. feeling anger at a loved one), and behaviours (e.g. not sleeping) secret or hidden from others. However, they craved for these parts of the self to be known and consequently witnessed. Some participants were unable to articulate these parts of the self. Others did not share these parts of the self with people, as they believed no one was interested or they wanted to protect their family and friends from their psychosis experiences. For example, Jack experienced the overemphasis on social and occupational functioning and absence of depth in conversations with mental health professionals as alienating. This caused him to hide the truth and disengage at clinical appointments, and just say: '*It [his mental health] is fine, fine, fine*'. As a result mental health professionals failed to understand and witness Jack's self.

Participants experienced this absence of understanding as detrimental to MIL. Without the hidden aspects of the self being witnessed, they only ever felt partially known by others. Participants' hidden self remained unwitnessed and unconnected to other people; its value ignored. Thus, participants felt like the hidden self did not belong anywhere. MIL could be generated by unearthing this hidden self and by sharing it with others so participants' entire self could belong in a web of connectedness. However, this was not always possible.

Natasha experienced isolation due to the absence of opportunities in her life to unearth hidden aspects of her thinking and feeling in the presence of others. In her interview, she expressed surprise when I sought to engage her about her understanding of life as '*a computer simulation*' run by aliens; having not had a meaningful conversation about it before. During her interview, Natasha

experienced the hidden self being witnessed for the first time. By me engaging with her psychosis derived belief system with respectful curiosity, Natasha felt valued and thus significant. For the brief duration of the interview, she could belong somewhere and experience this aspect of MIL:

Interviewer: And why do you think, what are their [the aliens] motives for having the simulation?

Natasha: Why are you asking me intelligent questions?

Interviewer: Sorry, you are okay answering them, are you?

Natasha: No it's okay, it's just I have literally never spoken to anyone who has in any way asked intelligent questions or had any understanding of what I am saying whatsoever, ever.

Polly viewed the hidden self as a core part of the self. The fixed beliefs she held and the voices she lived with, although fluctuating in both their intensity and frequency, remained permanent in her life. Their presence was stable and constant throughout her life. She could not detach psychosis from the self; psychosis was the self. Polly commented: *'delusions is the voices and I know that they are there, I will never be rid of them'*. She longed for the hidden self to be witnessed. Polly viewed MIL as obtainable from meaningful relationships; relationships where people were there for her, valued her, and understood her. For her, the hidden self remaining hidden was a barrier to MIL. This was a place of entrenched isolation and deep loneliness as Polly experienced almost nobody witnessing her entire self. She felt like she could never be fully herself and or fully accepted by others. Thus, without a witness to her whole self, she did not fully belong anywhere. Part of the self was left disconnected from others. This eroded MIL, making her feel less significant, less valuable. Only Polly's partner (who also experiences psychosis) witnessed her hidden self. He helped normalise psychosis, supported her socialising, and made her feel valued and understood:

I have only got very few [friends] and I could never turn around and say to them, if I was in a restaurant with them, ‘oh sorry, I got [schizophrenia]... this [psychosis experiences] could happen’. So I can’t explain it [the hidden self] to them so the only person I could really explain it [the hidden self] to is my partner because he has got the same thing as me.

7.4.2 Emergent theme 2: Being lost in human disconnection (Shared)

Being lost in human disconnection describes both groups’ experience of loneliness, abandonment, and isolation. When participants struggled to find witnesses to their lives, they did not feel significant which impacted their experience of MIL. Participants felt adrift in the absence of connections with the social world; longing to belong somewhere and to be interconnected with other human beings. They felt alienated, not understood or cared about by others, and grappled with the realisation that they required others to experience certain aspects of MIL (e.g. the accomplishment of a shared goal). Participants viewed life experiences as meaningless unless shared with others. Thus, they longed for a shared life. When isolated, participants felt powerless, incapable of developing friendship or romantic love; uncertain, not knowing if they would always be alone; and vulnerable without support. Some participants struggled to socialise even though they wanted to. They avoided social contact and community because of the emotional effort required to connect. Participants accepted this loss of connectedness as a barrier to MIL.

Jack struggled with romantic loneliness which was blocking him from realising his dream of having a family. This was a dream that helped alleviate some of his fears of aging alone and wasting the abundance of love that he had to give other people. He described his capacity to ‘*love [others] to bits*’. Jack’s dream of having a family at some time in the future offered him hope for enhanced MIL. Someday, he hoped, his life would be highly significant as it would be deeply valued by his future wife and children.

In the following extract, Jack contrasts his life to that of his brother who is interconnected to his new born child through love and commitment. He longs for his self to be witnessed by others in the same way, to be a '*real dad*', to belong as a father and husband:

Jack: I have got this far but I would like to have my own place, my own house, and a wife and two kids.

Interviewer: If you look at a potential relationship, how would that bring meaning?

Jack: A relationship with a woman? I wouldn't be as lonely, you do things together, we could love each other and have a little kid together that I could just adore.

Interviewer: And what would having a child mean to you?

Jack: A big responsibility, huge, but I am up for it. My little brother, he is only 31, he had a little kid there last [date] and you should have seen him. He brought the baby over at Christmas, they live in [names country] and they came over, but he's such a real dad. You just have to look at him and he is so committed to the baby. And so is she [his brother's wife]. I look at them and go... I am never going to let my age get to me. I am 37, I could be 49 and turn around and say I would love to be 37 again. So use your youth.

7.4.3 Emergent theme 3: Connecting to transcend the self (Shared)

Connecting to transcend the self describes both groups' experience of the process of connecting the self (across the boundaries of time and space) to the spiritual world. For participants, self-transcendence meant going beyond their ordinary, everyday, habitually conditioned ways of experiencing and *being-in-the-world*. This process took participants outside of their normal experience of consciousness and allowed for connectedness to something that could not be experienced by the senses. Self-transcendence involved participants reaching out beyond their

individual lives to try to connect to something they viewed as having higher value than the self. Participants viewed the self as significant by virtue of the self acting as a springboard to connect to something greater. If successful, participants were witnessed by this entity they highly valued. They experienced this connectedness as a sense of belonging; finding their place in the greater scheme of life. Participants realised they were only one small part of a greater whole and modified their behaviour accordingly.

To develop MIL, Isaac pursued self-transcendence by endeavouring to connect with the transcendental. His belief in '*the Other*' afforded him access to the a reality beyond what is perceptible to the senses, something he describes as the '*metaphysical world*'. He understood '*The Other*' as the existence of something beyond the world horizon; something outside of the limits of possible human sensory experience or knowledge. However, Isaac could still connect to '*The Other*' through his spirituality. In order to do this, he began forging deep connections with the '*natural physical world*' so that he could experience harmony with his environment. Once this congruence was attained, Isaac felt he had an anchor from which he could then attempt to situate his life purpose within the '*metaphysical world*'. He endeavoured to find a place for his core goals, aims, and direction in life within all existence. Once found, Isaac experienced the self as being witnessed by '*The Other*'. In his view, his life was seen, acknowledged, and, in some way, understood by an entity he could not sense. This, he felt, enhanced his connectedness and made him feel complete. From Isaac's perspective, his purpose and thus his life became significant because he had found a place to belong in the network of the existence of all things. This sense of significance made him feel alive and fulfilled; living a meaningful life:

Interviewer: What does the word transcendental mean to you?

Isaac: Metaphysical, esoteric use of therapy, and belief in the Other, and in a greater sense of purpose, a greater sense of being that simple earthly beings would have, that earthly sense of being that simple earthly beings would have and a sense of peace, harmony... I suppose with yourself

and the world and of the nature of the world around us as well that leads to a sense of purpose and fulfilment in life as well.

Interviewer: And how does a belief in the Other give you meaning in life?

Isaac: That connection to the Other, that connection to the Other and that connection to the natural physical world around us and circumstance can give us a sense of your place in it or objectives and your place in it as well and your objectives, your purpose, your place in it and your goals and your purpose and your place in it as well as you go and develop what you're into; become more a fuller and a more comprehensive person as well.

In a similar way, Matt was able to operationalise spirituality on earth through jazz drumming. Drumming provided him with the mechanism by which he could inhabit the spiritual world on earth by embodying a spiritual flow state. This was a state of being where Matt had little conscious control over his actions and the distinction between the self and the act of drumming dissolved. His attention to his surroundings was narrowed; he focused on drumming and little else. When in this state, he was of the view that he did not need anything else to motivate or sustain him in life, as nothing else mattered. His responsibilities, life goals, relationships were temporarily unimportant. He could quiet his mind. This focus gave Matt a sense of immense satisfaction and gratification; achieved by connecting to the spiritual world.

In this state, Matt viewed himself as a vessel for deceased jazz musicians that, at a moment in time, could impart a gift to the audience. He transcended time, space, and the self. When drumming in this way, Matt *experienced* the self. He knew it was him drumming, yet the self also felt extrinsic, like it was temporarily not belonging to him; as though he was '*being played*' by the jazz masters that inspire him. Matt's spirituality acted as a bridge to spiritual world connectedness; temporarily making him more than human. When drumming, Matt experienced the self as not just witnessed by his audience but also by the deceased jazz musicians that played through him. When experiencing this time limited self-transcendence, he saw himself as a spiritual being. The temporary nature of

self-transcendence for Matt meant he struggled to maintain the MIL derived from it over time. In his view, he could not preserve his connection to the jazz artists he valued so highly. Matt could not predict when he would enter the flow state. When the flow state ended, he became '*completely human again*':

Interviewer: And you spoke about your drumming, your love of it, and I am just wondering, does the creativity that is attached to that, does that give your life meaning?

Matt: Huge meaning, playing is like being in heaven. Now it can be very difficult and there is lots of stuff you have to deal with in your head as you are playing but when you are actually, as sports men would say, 'in the zone', it is definitely other worldly again. It is like you are being played but really you are not, you are kind of watching yourself and you have all the spirits, the jazz spirits, the jazz musicians. Jazz is the music I'm into. But I think... spiritually at work... that music is maybe the most spiritual kind of thing. And I have definitely experienced other people, great jazz musicians, they are dead now, but their spirits being in me and you are playing and it is like the music is, you are given it or something, it is a gift for the time. And you go away afterwards and go: 'that was really good like'. And then you go back to being completely human again and it is kind of: 'I can't play drums anymore'. You go from there to playing out of your skin and it is really, really good, to: 'oh, I can't play'. You can't take it for granted; it is a very special thing that happens. I just say: 'thank you God'. I find jazz music is more, you need to have that little bit of extra spirituality or something to play it properly.

Jazz music allowed Matt to engage in self-transcendence by connecting him to the land, people, and time that originated it; giving him a sense of belonging and thus MIL.

7.4.4 Emergent theme 4: Seeking a home amid connectedness (Shared)

Seeking a home amid connectedness describes both groups' search for somewhere to call home. Home, in this context, is not so much a physical dwelling but a set of relationships and shared

commitments. These relationships were with participants' family members, friends, peers, mental health professionals, and their wider community. Examples of shared commitments included the wellbeing of a family unit, the cohesion of a peer group, participants' own mental health, and the caretaking of a community centre. Home existed *amid* participants' connectedness. Home was a place where they could form relationships; be witnessed and accepted; belong, share and learn from others; have their identity reinforced; and develop solutions to life's challenges. Home was where MIL could flourish.

Matt found home in Alcoholics Anonymous (AA). The experience of AA as home transcended a physical place for him; home was whatever AA meeting he attended. An AA meeting was a place of self-growth fostered by unconditional acceptance, learning, and sharing. For Matt, the shared objective of sobriety gave community, belonging, and significance to his life. AA meetings offered a path to mentorship, guidance, and human connection; as well as access to real world knowledge and wisdom about mental health and life. From Matt's perspective, his life had to have some value if his sponsor had chosen to mentor and guide him. Being chosen meant he was witnessed; seen by another human being who decided to invest their time and energy in him. Matt experienced MIL because he viewed himself as worthy of this investment:

Listening at meetings people accept me when I wasn't talking, they were kind to me just telling me I am okay, very encouraging. My sponsor was an amazing man, he died last year and I miss him. He was a very intuitive person, mentally very sharp in the right way. I have never met anybody like him in my experience in life, anybody... monks... anyone. And he helped a lot of people, a very gentle person... He wouldn't have to know... he would just say the right thing... He was my person like that and he was an inspiration... He would have been this father to me.

7.4.5 Emergent theme 5: Owning the self – being the subject of experience (In Remission Group)

Owning the self – being the subject of experience describes the In Remission Group's perception of the self as both unwanted and alien. At times, participants saw themselves not as observers of life but as objects to be observed and acted on by others. Consequently they struggled to own the self and their actions. They saw their thought processes as distant; being outside of logic and reason or involving a different mode of thinking than their usual thoughts. They were not fully experiencing joy, feeling pain, or dealing with the difficulties they encountered. Developing MIL involved reclaiming ownership of the self. Owning the self meant observing life, being the subject of experience (i.e. having an awareness that one was the *experiencer*), and reclaiming ownership of thoughts, feelings, and actions.

Participants viewed the self as unpredictable and potentially destructive; something that needed to be accepted or contained in order to own the self. They accepted the self by overcoming the shame of what they saw as negative aspects of the self (e.g. anger, viciousness, intolerance), acknowledging that there was good and bad in everyone, and internalising the acceptance they experienced from others. Participants contained the self by seeking to purge the mind of '*psychotic thinking processes*' or by taking medication to experience stability. Once they accepted or contained the self, they could own and consequently witness the self. This self-witnessing gave participants a sense of belonging as they were at home within themselves.

Following his FEP, Conor saw psychosis as a part of the self. This understanding was challenged by other people in his life, like his General Practitioner who '*knew the personality he was*', telling him '*it [his psychosis] is not you*'. According to Conor, his psychosis was defined by a fixed belief that others were convinced he had committed a morally corrupt act. Although in his interview, he did not specify what this act was, he believed it warranted his incarceration. The possibility of being imprisoned was in such stark contrast to the good person that Conor saw himself as, that he gradually began to reject ownership of this fixed belief. He described this belief as '*a misapprehension of guilt*'; a mistaken interpretation that he was guilty of a crime and deserved to be punished. To own the self in the aftermath of psychosis, he had to purge the self of his psychosis (i.e. this guilt). This purging involved a process of removing what he described as '*shadows*'; the

'issues inside [his] head that create disturbances [in thinking]'. Once this purging was completed, Conor experienced his mind, body, and relationship with his family as purified. This was felt as a freedom from undesirable guilt and the impact of this guilt on his family (i.e. the sorrow they experienced seeing him distressed). He described this purging process as becoming *'clear'*. Becoming *'clear'* allowed him to own and witness the self in its newly cleansed entirety. In his own words, by being honest, open, and *'straight'* with others in his life, Conor's *'conscience comes back to [a] clear level'*:

Now I feel, as I said to you earlier, I tell the truth about everything and I don't want any shadows in my mind or my head about what is going to cause something to make me trip up... And then, at home, I make sure that everything is clear.

The act of purging and the consequent purification of the self permitted Conor to re-establish the self as the subject of his experiences. He could reclaim full ownership of his thoughts, feelings, and actions. This allowed him to witness the self by fully acknowledging it and not rejecting parts of it anymore. He was more connected to the self as a consequence. This enhanced MIL as the self belonged somewhere because of this connection. This connection enhanced the significance of Conor's life; it felt more valuable to him and worth living. He could now be fully present in his life experiences:

As soon as it was over [Conor's FEP], I was back into the thing of saying: I love the open space, I love the brightness, I do like bright days... [he could] see beautiful things, even if it is a small river or stream, it is birds, it is trees, it is open space and that means a lot to me.

7.4.6 Summary superordinate theme 2: Becoming significant where the self is witnessed

This superordinate theme describes how participants experienced MIL by identifying witnesses for the self and then connecting the self to these witnesses. This process involved participants: sharing

previously unshared aspects of the self with others; connecting to the spiritual world to transcend the self; seeking a home (somewhere to belong through relationships with others) amid this connectedness; and owning their own thoughts, feelings, and actions in order for them to witness themselves. Participants also had to, at times, accept the feeling of being lost without other people in their lives to connect to. MIL was found, developed, and maintained by identifying, establishing, and preserving connections with witnesses. The self became significant because it had a place in the web of interconnectedness. As a result, participants experienced a sense of belonging in life.

7.5 SUPERORDINATE THEME 3: GENERATING MEANING WITHIN AND BEYOND SYSTEMS

The third superordinate theme *Generating meaning within and beyond systems* describes how participants experienced MIL both inside and outside of systems. Systems included: the family system; the mental health system; and the system of Irish society. These systems were used to generate meaning from experiences in order to enhance MIL. Systems were utilised by participants to make sense of their experiences; develop goals, aims, and direction in life; and perceive their life as being of value to others. For example, the family unit was used to form a life narrative (by family members helping them remember experiences); the mental health system was used to find purpose (by engaging in a vocational rehabilitation programme); and society was used to deem certain achievements significant (such as securing employment). Participants gleaned whatever MIL support was available to them within systems and then embarked on a quest to transcend them. They managed their dependence on systems, exercised autonomy within their constraints, integrated MIL from within and beyond systems, and found freedom from systems entirely. Thus, the core concept of **Independence** defines this superordinate theme.

Within this superordinate theme, there are six emergent themes (Table 7.3). The first two emergent themes are shared across both groups: *Managing dependency on systems and exercising autonomy within their constraints*, and *Building shallow foundations*. The other four are group specific: *Experiencing freedom untethered to systems* (In Remission Group), *Locating meaning outside of*

systems to complement meaning within them (Not in Remission Group), *Repairing Meaning in Life damaged by the mental health system* (In Remission Group), and *Renegotiating the social contract* (Not in Remission Group).

Table 7. 3 Generating meaning within and beyond systems

In Remission Group		Not in Remission Group	
Superordinate theme 3 <u>Generating meaning within and beyond systems</u>			
Core concept <u>Independence</u>			
Emergent theme 1 <i>Managing dependency on systems and exercising autonomy within their constraints</i>			
Emergent theme 2 <i>Building shallow foundations</i>			
Emergent theme 3 <i>Experiencing freedom untethered to systems</i>		Emergent theme 4 <i>Locating meaning outside of systems to complement meaning within them</i>	
Emergent theme 5 <i>Repairing Meaning in Life damaged by the mental health system</i>		Emergent theme 6 <i>Renegotiating the social contract</i>	

7.5.1 Emergent theme 1: Managing dependency on systems and exercising autonomy within their constraints (Shared)

Managing dependency on systems and exercising autonomy within their constraints describes both groups' experience of using systems as a source of MIL but sacrificing some aspect of their freedom to do so (e.g. taking on the responsibility of caring for a parent). Thus, they had to accept certain constraints. At the same time, participants had to curtail their dependency on systems in order to generate MIL beyond them.

The social rejection and loneliness described by Polly throughout her interview was a source of great pain. During periods of psychosis, she became convinced that everyone hated her and, in her own words '*there was no meaningful then*'. For her, other people were needed in her life to give it

meaning. Polly expressed an intense longing for her social needs to be met through friendship. She was aware that she could use the mental health system to substitute for this absence through her interactions with mental health professionals. However, it was of paramount importance to her that she managed her dependency on these relationships to protect her independence. Polly was able to exercise her independence within the constraints of the mental health system (i.e. she did not overburden it) which gave her MIL:

But I know I have here [mental health service] and I never ring up. We always say to each other, because [partner] has got the same thing as me [psychosis], so we always say we'll give it two weeks and within the two weeks it [psychosis] goes.... I have never rung here in years but I know there is somebody at the end of the line.

Similarly, James detailed his dependency on the family system as a source of MIL. He too longed for friendship and experienced intense loneliness at times. James had difficulty separating his emotional experience from his mother's, describing enmeshment in the relationship, viewing her wellbeing as a prerequisite to his. In the following extract, he elaborates on how this relationship was both protective and all consuming. As an adult, he was reliant on her to ensure that his basic needs were being met:

My mother is always mentioning: 'I hope you are clean, I hope you washed up, I hope everything is right now'. I got a stain on my trousers the other day and my mam said: 'Vanish, you want Vanish, use Vanish and steep them [participant's name] and don't be skimping it! Put the trousers in the dyer on its own. Don't be putting anything else in with them!'. She's always protective of me... once my mam is right I am all right, she is me [my] whole life.

James sought to manage this dependency and be independent but struggled due to the absence of a wider social circle.

Experiencing the traumatic unexpected deaths of three of his immediate family members left William deeply angry at society for the pain he had experienced. When asked about how he managed this anger, he described how he abused alcohol and substances. However, his most valued coping mechanism was listening to music. Hip hop gave him an outlet, a way to channel his anger and release it, in a manner that adhered to society's rules:

Interviewer: What is it about music?

William: I just love it, different acts and that of different music that I like. Some of it is aggressive but I think that releases the adrenaline without harming anyone, it just gives you a free flow of the music. I thrive on it.

Music offered William a safe space where he could release his adrenalin and anger. As a result, he could independently exercise autonomy within society's constraints (i.e. society requiring him to not harm other citizens). Finding a way to express himself within these constraints gave William MIL.

7.5.2 Emergent theme 2: Building shallow foundations (Shared)

Building shallow foundations describes both groups' experience of MIL being only partially explored within the mental health system. Participants expressed an awareness of efforts on the part of mental health professionals to examine the degree to which their life was meaningful to them. However, these attempts were understood to lack depth. Participants were given initial support, such as information on how to enhance their own motivation to attain MIL. However, this support was perceived as insufficient to provide the foundations needed to rebuild MIL in the aftermath of a FEP and other psychosis episodes. This rebuilding had to be done independent of the mental health system.

While, in the past, Natasha had experienced mental health professionals trying to open up a conversation with her about MIL; she described being consistently '*shut down*' when she sought to explore her psychosis derived belief system. She strongly contested what she viewed as a reductionist approach to helping her (defined by services seeing no meaning in this belief system outside of its pathological label). Natasha longed for mental health professionals to engage with her beliefs in an open, critical, and empathetic manner. She desired to engage in a collaborative process of meaning making with clinicians about her experiences in life. In the absence of this, Natasha felt devalued and alienated. She had to go outside of the mental health system (to take part in this research study) for this collaborative meaning making to occur. Natasha viewed '*moving forward*' in this process as facilitating MIL:

I have been in the day hospital. They try and get a conversation going... It is kind of taking in a lot that maybe things will get more articulate and more into that side of things [Meaning in Life], it is kind of hard to see how maybe they would progress with that... I don't know, I guess it is like I said, there has been a conscious thing that I would be shut down when I would try to talk about what I believe and you are literally the only person to.... like I'm saying something and you are getting it and moving forward.

Shallow explorations of MIL in the mental health system were also reported by Matt. His belief in God was of such importance to his perspective on MIL that he felt alienated by the automatic pathologising of spiritual ideas by mental health professionals. This perceived close-mindedness was seen as limiting the potential for MIL exploration in clinical settings. Therefore, from his perspective, mental health services were incomplete and depriving him of hope if they failed to adequately consider his spirituality and its role in MIL:

For good or bad there is still a stigma with mental health professionals which maybe doesn't encompass the whole picture... Emm... I think mental health people [professionals]—maybe wrongly—like they frown upon the God thing and they would be more into the responsibility thing, which is a huge thing... Even though they are spiritual beings themselves and they are quite

aware ... For better or worse, I get help from the God thing. When people mention God and even just saying there is a meaning to life, that gives me a bit of hope. And okay, I can go through this for another little bit.

7.5.3 Emergent theme 3: Experiencing freedom untethered to systems (In Remission Group)

Experiencing freedom untethered to systems describes both groups' desire to transcend meaning generated through systems. Transcending these systems gave participants independence from other people, sovereignty in relation to their own life choices, and liberty from constraints.

Although Lou's family were involved in politics, she grew up '*poverty stricken*'. She was determined to break free from this poverty trap; to transcend the quality of life limitations she had experienced in her childhood. Early in her life, MIL was defined by Lou, almost exclusively by this goal. She worked diligently to amass wealth in order to escape the poverty she had experienced within her family. She desired significant social standing in order to be free, independent, and not to have to rely on anyone. Lou was able to maintain and enhance this freedom by fostering a respect for, and understanding of, social power:

I was always determined. I grew up with parents who had huge difficulties, there was no money there and I didn't want to be poverty stricken, I grew up in it... We had nothing. So the Meaning in Life was so I wouldn't be a burden on anybody but to be able to sustain myself. So that was working hard and I did want a nice house. I didn't want to rely on people. The Meaning in Life for me is to be independent... And go to, for example, I was obviously always very interested in [political party] and politics because my [relative] was in it, the family were in it... To be able to go to these different events, to be able to learn and understand them... learn about politics.

In a similar way, Conor, during his FEP, sought to use mental health services temporarily (as a shelter to enable him to regain his freedom) and then sever his bonds with them. In the following extract, he describes how, once he had restored his capacity for reasoning following mental health

treatment, he was free to continue his recovery journey independently. Conor was now both resilient and untethered to the mental health system:

After that [his capacity for reasoning being restored]... I felt I could get the ship back out on the sea which was calm, or even if it wasn't always calm, I could deal with it ... And at some stage obviously my mind had settled and then I was free to get back on the boat and move again in life and here I am. So happy days! And I am a stronger person.

7.5.4 Emergent theme 4: Locating meaning outside of systems to complement meaning within them (Not in Remission Group)

Locating meaning outside of systems to complement meaning within them describes the Not in Remission Group's longing to integrate meaning they developed within and outside of systems.

Amelia underscored the importance of having purpose in her life. Having never worked, she craved something to do, to occupy her, to redress the constant boredom she experienced at home. Although she deeply loved her immediate family (her sister, mother, and father), she nonetheless wanted more from life than these relationships; yearning for meaning outside the family system:

Well if I was just hanging around the house in [town in Ireland] or hanging around the house at home with my mum and dad and my sister, I would get very very bored. I would find that extremely boring, just hanging around doing nothing all day... I would hate that.

This meaning was found by independently accessing sites of social inclusion—physical locations (cafes, pubs, and restaurants) where Amelia had access to life outside of both her family unit and the mental health services. In these places, she had opportunities to develop new social connections. Visiting these locations offered her a means to embody an essential aspect of her identity. She viewed herself as '*a very social creature [who loved] meeting up with people*'. Experiencing these places afforded Amelia access to life outside of her restricted social network.

These locations gave her a window to view the lives of new people through. This act of observing other lives beyond her family and mental health service was MIL to Amelia. It allowed her to experience excitement and activity not present in these systems:

Most weeks I go to the [pub] for dinner and I always reserve it for [a time]. And I love it there in [the pub], I love [the pub]. I just think it is a great place to relax, it is lovely, I love it... Yeah I love it when it's busy especially; I love it there when it's extremely busy. There is a great buzz a lot of the time in the [pub].

7.5.5 Emergent theme 5: Repairing Meaning in life damaged by the mental health system (In Remission Group)

Repairing Meaning in Life damaged by the mental health system describes both groups' experience of redressing the harm caused to MIL by the mental health system and viewing the mental health system as blocking pathways to MIL.

Isaac described his frustration at mental health services not taking into account his intelligence and potential. He rallied against mental health professionals '*putting objectives in people's way*'.

Certain people '*in administration and certain medications or certain therapies or certain points of action or certain accommodation arrangements*' were considered by Isaac to be damaging to MIL.

At times, he experienced the mental health system as both irresponsible (e.g. not engaging with him urgently when he was in crisis) and inaccurate (e.g. not keeping his medical file up to date). He deemed some psychiatric medication as having a '*malign effect*' on MIL. Isaac understood himself as being unable to achieve success in social and academic contexts due to anti-psychotic medication:

Interviewer: And how did the medication act as an obstacle [to Meaning in Life]?

Isaac: [By] preventing emotionally... cognitive functioning in academic or social settings; emotional cognitive functioning; a sense of fulfilment or development; and they are always the environments which I was faced with.

To redress this blocked potential and repair the MIL damage done, Isaac became more determined to achieve his dreams. He defined MIL as success in the face of limitations (many of which he saw as imposed on him by the mental health system):

Interviewer: What would achieving those goals and objectives mean to you?

Isaac: A sense of purpose, a sense of fulfilment, a sense of realisation, a sense of actualisation, and achievement of what you are capable of and what standards you can achieve in the case of putting your mind to achieving those realistic standards and life as well given personal or environmental constraints as I said.

Emergent theme 6: Renegotiating the social contract (Not in Remission Group)

Renegotiating the social contract describes the Not in Remission Group's experience of the social contract. The social contract required participants to submit to authority (i.e. democracy and the Irish legal system) in order to be afforded basic human rights. However, participants witnessed the deterioration of the social contract as a consequence of the society's dehumanisation of people with psychosis. As a result, they experienced the unravelling of the social order as they felt their rights were left unprotected. Renegotiating this 'failed' social contract was one way participants pursued MIL.

William felt abandoned by society. He experienced social exclusion to such a degree that he was barred from eating in the local psychiatric hospital where many of his homeless friends went for food. This was due to an argument he had with hospital management. Living with the constant fear of being unsafe that comes with exposure to trauma, homelessness, and poverty meant that he did

not see violating society's laws (like illegal drug use) as him breaking the social contract. In his view society had broken the contract first by abandoning him. In the following extract, William highlights the absence of a safety net in his life. In the case of an emergency, he lacked the ability to contact anyone for help as he could not regularly charge his phone. He generated MIL by fostering self-reliance and surviving outside of this safety net:

If I had a base, but I don't have that, no stability, no hot water, no electricity, nowhere to charge my phone. If I need to fucking ring 999! Ask God to drop a white phone out of the sky, do you know what I mean? The Samaritans... ask them to reverse the charges to the nearest [police] station on God's white phone. Reality!

For William, renegotiating the social contract meant society endorsing his rights to stability, safety, and a permanent home: *'I am willing to keep going until I do get help... stay on the list until I get housed'*.

7.5.6 Summary superordinate theme 3: Generating meaning within and beyond systems

This superordinate theme describes how participants' experienced MIL by transcending the systems that they used to make meaning out of experiences. This MIL came from exercising independence. Transcending systems gave participants a sense of freedom, allowed them to integrate MIL attained from within and beyond systems. Transcendence meant they repaired the aspects of MIL damaged by the mental health system and renegotiated the social contract damaged by dehumanising them. Transcendence also involved participants managing dependency on, and experiencing autonomy within, systems; while acknowledging that mental health services only partially supported them generating MIL.

7.6. SUPERORDINATE THEME 4: SHAPING AND BEING SHAPED BY LIFE

The fourth superordinate theme *Shaping and being shaped by life* describes how participants understood their role in their own lives. Sometimes, they viewed themselves as an active constructor of their life; other times, they saw themselves as a passive experiencer of life. Participants developed MIL by adding to or influencing their environment. This involved both efficacy (achieving the intended result of an action) and agency (exerting power over one's environment). However, participants also found MIL by allowing themselves to be shaped by their surroundings, context, and circumstances.

To experience MIL participants had to exercise either agency or patiency. Exercising agency meant participants viewed themselves as being able to act in and effect their environment by exerting power over it. Enacting patiency meant being passive; enduring life without resistance. Participants oscillated between the two approaches, with each event warranting an evaluation of the degree to which agency or patiency should be applied. Thus, the core concept of **Agency and patiency** defines this superordinate theme.

Within this superordinate theme, there are six emergent themes (Table 7.4). The first two emergent themes are shared across both groups: *Positioning the self between human responsibility and spiritual exoneration*, and *Individualising, or struggling to operationalise, Meaning in Life*. The other four are group specific. Two are In Remission Group specific themes: *Maximising the effect of the self on the world* and *Overcoming barriers to efficacy* and two are Not in Remission Group specific themes: *Contributing something of value to the world* and *Balancing determination with acceptance*.

Table 7. 4 *Shaping and being shaped by life*

In Remission Group	Not in Remission Group
Superordinate theme 4 <u>Shaping and being shaped by life</u>	
Core concept <u>Agency and patiency</u>	

Emergent theme 1 <i>Positioning the self between human responsibility and spiritual exoneration</i>	
Emergent theme 2 <i>Individualising, or struggling to operationalise, Meaning in Life</i>	
Emergent theme 3 <i>Maximising the effect of the self on the world</i>	Emergent theme 4 <i>Contributing something of value to the world</i>
Emergent theme 5 <i>Overcoming barriers to efficacy</i>	Emergent theme 6 <i>Balancing determination with acceptance</i>

7.6.1 Emergent theme 1: Positioning the self between human responsibility and spiritual exoneration (Shared)

Positioning the self between human responsibility and spiritual exoneration describes both groups' experience of placing responsibility for life somewhere on the continuum between taking full responsibility for their actions and their consequences (human responsibility) and assigning all responsibility to a higher power (spiritual exoneration). Participants viewed responsibility as something that was placed on their shoulders as a result of being a human being in society. Human responsibility meant meeting one's obligations and being held accountable for one's conduct. For example, Isaac asserted: *'the patient is in control of his or her own destiny and has to take responsibility for his or her illness, his or her own responsibilities'*. Participants understood spiritual exoneration as being relieved of responsibility, obligation, and blame due to spiritual beliefs. For example, Adam stated: *'I am not a professional photographer so somebody else [God] made that decision'*. MIL was generated through agency (if participants endorsed human responsibility) or patency (if they pursued spiritual exoneration) or both.

For the majority of Ian's lifetime, he had lived with psychosis. Since his FEP, his family had been against his use of antipsychotics; yet he viewed taking this medication as a core responsibility of his. During his interview, Ian vividly described an accident he had shortly after his FEP. When abroad, he fell off a high wall and badly injured himself. Ian viewed this as the most traumatic event of his life. He attributed his fall to his failure to meet his responsibility to take his medication. Following this event, he decided to take pride in self managing his psychosis. In the following

extract, Ian describes how, since his fall, he endeavours to fight the pain of psychosis alone in order to not burden his family with it:

I don't tend to dwell on the pain as much but I know it is there. I don't start telling my mum or telling my brothers I have it, I want to fight it myself... When you start doing it yourself, taking control yourself, that's actually a good thing. Even if it's just the beginning. Taking control of it yourself rather than expecting other people... I am not talking about help, you obviously need help but it's good to take the initiative yourself as well as other people.

However, sometimes Ian experienced the pain of psychosis as overwhelming and turned to God. Ian expressed a fear of taking on the '*tough world*' alone and relief at sharing responsibility for his life with a higher power (i.e. God). Ian's belief in God offered him spiritual exoneration as the '*burden*' of managing the pain of psychosis alone was removed from him:

It is important to believe because it is good to believe in some greater being to help you rather than to believe there is none, you have to do it all yourself. It is a tough world if you have to do everything by yourself... It takes the burden away sometimes for me, that is why I believe in God... Some things you can place it in God's hands, if you believe you actually do that, you actually place it in his hands.

7.6.2 Emergent theme 2: Individualising, or struggling to operationalise, Meaning in Life (Shared)

Individualising, or struggling to operationalise, Meaning in Life describes both groups' experience of encountering challenges when seeking to understand the concept of MIL and its relevance to their lives. Operationalising MIL meant that participants engaged with the concept, made it relevant to their life on a practical level, and used it to enhance their experience of life.

Individualising MIL involved participants adapting the concept of MIL to their own needs and unique circumstances. Struggling to operationalise MIL meant participants encountered significant

difficulties in seeing how the concept was applicable to their lives. All participants who operationalised MIL individualised the concept.

Trevor was both indifferent to, and unable to apply, the concept of MIL to his life. He saw pursuing MIL as impractical; opting instead to live in the moment, attain balance, and do the best with every day. To achieve this, he invested his energy in his local community by attending church services, volunteering with children with disabilities, and working in a mental health service run social club; while keeping his mind and body healthy through diet and exercise.

In his interview, Trevor concluded that the concept of MIL in all likelihood was not applicable to him. While he could shape his life (by deciding where to invest his time), he struggled to develop MIL. Instead he embraced patience by not pursuing MIL:

Having Meaning in Life, emm... I don't know, I would say it is different for different people. I suppose maybe in a way I am only getting my head around it these days but definitely like we are all different. I don't know if I do have meaning in my life as such. It is a tough one... It's kinda out there. If you just take things day to day and just try and do your best with the day and stuff like that.... Having meaning, it is just such a big one. Okay, Meaning in Life... I don't know... you need a bit of balance; you need to mix things up and all that... Meaning in Life... I just can't get my head around it at the moment.

For other participants, operationalising MIL involved individualising the concept. This meant acknowledging that MIL was individually shaped (i.e. self-defined, personally constructed, location and culture specific). Thus, MIL meant something different for everyone.

For Adam, developing MIL entailed a process of tailoring the concept so that it was of value to his own life. He could exercise agency to define what MIL was to him and then shape his life by actively pursuing this individualised concept:

There is so many different meanings to it [Meaning in Life] and of course I imagine people from different countries and cultures all have different ideas to what it is as well. As I said, the meaning of life for me for the last so many years has been education.

Adam viewed his education as giving him time-limited structure and purpose. In the past, it offered the potential to bring him closer to his dream of being a professional photographer.

7.6.3 Emergent theme 3: Maximising the effect of the self on the world (In Remission Group)

Maximising the effect of the self on the world describes the In Remission Group's experience of observing the impact of their actions on the world and trying to increase this impact. Participants were aware that their actions had consequences for others. However, they sought to maximise this ripple effect; to expand their impact and thus enhance their significance in life. Participants aimed to augment the degree that they influenced the lives of others. They exercised agency by shaping their own life through their impact on other people.

Conor described the process of maximising the effect of the self as '*doing something you love effectively*'—seizing opportunities to exercise agency; be that pursuing business prospects, being '*good with kids*', or acting '*just in life*' (i.e. treating people with respect and dignity). Following his FEP, he had left a secure, albeit isolated, job to establish his own business that he worked diligently at to make a success. This new business increased the degree of contact Conor had with other people; increasing the chances that he could positively impact the lives of others:

In [the] normal work that I do... I meet people who have problems but I find that I can bring them around to getting the objective of the trip over by chatting to them or calming them. I carry a pack of cigarettes and say: 'Would you like two cigarettes?' And they say: 'Oh you are very good'. I might have just found the packet.

The MIL Conor attained from this interaction came from the self impacting the lives of others. Altruistically offering a cigarette in the context of humanised engagement meant he had exercised agency. Conor had demonstrated the power to, in a small way, change the world.

7.6.4 Emergent theme 4: Contributing something of value to the world (Not in Remission Group)

Contributing something of value to the world describes the Not in Remission Group's desire for their actions to be considered by others as being of value. They yearned to have their capability (efficiency and ability), capacity (ability to produce), and untapped potential (functioning not yet exploited) fully utilised in order to contribute to the world. Untapped potential was potential that, if developed, could lead to future usefulness for society. Ultimately, participants wanted to make a contribution, to add something to the world, something valued by society. If this contribution was made, participants felt they had exercised agency and were shaping their life.

Loneliness was a central concern peppered throughout Thom's interview. In general, he felt his life did not contribute to lives of others. Thom had spent his days largely in isolation from society; save for his close relationship with his mother (who is now deceased) and his attendance at a rehabilitation day centre run by his mental health service. Throughout his life he struggled to find employment. Thom yearned to have his intelligence utilised and applied to a purpose; something that truly interested and occupied him. He viewed himself as languishing in the absence of this purpose. He compared his situation to the achievements of the sports stars he revered and the financial success of his brother and father. Thom viewed the cognitive impact of psychosis (his poor memory and difficulty maintaining attention on tasks) as well as the absence of mentorship in his life as contributing to his lack of purpose. In the following extract, Thom describes how he aches to '*do more*' in life and to '*give something*' to the world. He felt deprived of the MIL that would come from this contribution. As a result, he experienced the patency of being shaped by

life. Thom passively endured life in the hope that he would experience MIL from this potential contribution in the future:

Before I kick the bucket, as we all will [laughs], I would like to do more than I am. I would like to see if there is... other things, other ways. I believe that I am smart in certain ways and if that could be brought forward, if that could be brought out. And if I could do something that I really am into that can *give* something... I really mean this when I say this that I would like to do something good which achieves... I feel at home doing certain things.

7.6.5 Emergent theme 5: Overcoming barriers to efficacy (In Remission Group)

Overcoming barriers to efficacy describes the In Remission Group's experience of navigating life in such a way that they were able to surmount the difficulties they experienced. Participants were able to harness their ability to produce an intended result from their actions despite environmental constraints, such as poverty, disenfranchisement (e.g. having choices made about their life by others), and isolation. The intended result from their actions was the achievement of their life goals (e.g. career success). If these barriers or environmental constraints were overcome, participants demonstrated the capacity to achieve the intended result of their actions (efficacy) and thus exert power in their circumstances (agency). Consequently, they felt like they were shaping their life. Participants developed MIL by adding to or impacting their environment.

Isaac is highly educated scholar who was unable to complete his PhD due to his FEP occurring during the course of his PhD programme. During his interview, he communicated his respect of human resilience and the ways in which humanity can overcome seemingly insurmountable obstacles. This respect was reflected in his reverence of space exploration; seeing it as a symbol of transcending the limits of the capability and capacity of the human race. For Isaac, space exploration was an exemplar of how life could be shaped; signifying the human potential to exert

power over the environment. In the following extract, Isaac explains why space exploration was meaningful to him:

The optimistic vision for the future, the fact that anyone who devotes themselves to that growth area of pushing their physical limits and the most extreme to develop and design research and engineering and engineering capabilities and medical and psychological abilities for the pursuit of space travel and space exploration as well; probes and rockets that can help us explore beyond earth and help reach the outer solar system and even beyond as well.

Isaac had a similar interest in Latin America. In the following extract Isaac communicates a deep respect for the difficulties the people of Latin America endured in the past. This is a respect for how they overcame their political disenfranchisement and exploitation by political powers to rise from the ashes of such hardships:

Interviewer: And your interest in Latin America, what does that mean to you, why is that important to you?

Isaac: The countries were held up and they were abused and manipulated by multinational organisations and irresponsible dictators and Cold War powers and difficult economic and political systems for the duration of the 20th century as well that's only now being undone; being reformed over the last few years. The manipulative organisations, the exploitation by ecclesiastical groups, multinational organisations, large corporate players, and as I said irresponsible dictators that abuse them and prevented the economic and social development of those countries. For, as I said, the duration of the Cold War and for so many years during the 20th century has become to be reformed and undone during the last few years. And they are now emerging countries as well as I said and those travel investments, as I said, development and tourism potential of those countries are now emerging and was not realistic beforehand.

Both interests reflect Isaac's own personal journey of recovery from psychosis. The obstacle of psychosis *'proved somewhat insurmountable and difficult to deal with at the time* [during his FEP]

but [he] *overcame it*’ by ‘*proper application or through proper planning or proper objective goal setting*’. In order to develop MIL, Isaac had to, just like space explorers and the people of Latin America, overcome barriers to efficacy (in order to shape his own life).

7.6.6 Emergent theme 6: Balancing determination with acceptance (Not in Remission Group)

Balancing determination with acceptance describes the Not in Remission Group’s experience of striving for equilibrium. This equilibrium was between the drive that helped participants achieve their goals in the face of obstacles and the motivation to endure obstacles without protest.

Sometimes participants strove with determination to achieve their goals. Other times they accepted their inability to actualise goals. Acceptance required participants to let go of their drive to succeed and not stay focused on outcomes. In this way, they pursued the balance between agency and patency; between shaping and being shaped by life.

Central to Adam’s understanding of MIL was his determination to achieve his dream of becoming a professional photographer. Adam described how he was ‘*always trying to prove something*’, his capability and capacity, to himself and others. This, however, dwindled in the aftermath of repeated psychosis experiences. As a consequence, he had to accept life as shaping him. Over time, life altered the essence of who he saw himself to be. He was no longer an aspiring photographer, he was someone who used education to give him hope for a better future and protect himself from depression. In the following extract, Adam describes how he resigned himself to the likelihood that his dream would not be realised:

And at a certain time in my life over the last ten years when I sort of came to a certain search where I became unwell and I felt that I had failed once again about becoming a photographer. But I have come to the realisation since that, the only answer, I can come up with is—‘it wasn’t meant to be’.

Yet, this determination for success still burned strongly. Adam saw recovery in psychosis as distinct from MIL. Recovery involved maintaining stability, accepting his current circumstances, and trying to move forward in uncertainty. However, developing MIL involved fighting for his dream of success. For Adam, MIL was more than mere survival:

I thought I had failed. That was part of just ‘feeling sorry for myself’—is the way I look at it now. And there are certain individuals where recovery is when you become stable again. So I have sort of achieved that but... Meaning in Life... there has to be more than just basic existence. But are you going to achieve that? Not everyone is going to achieve the same.

Adam’s adopted perspective on MIL reconciled these conflicting motivating forces. He aimed to see his life as a journey, to live mindfully in the moment, while still holding on to his determination to succeed:

Meaning for life is, I think, for anyone is... going day to day, doing whatever you do, having the health to get up every day, have enough to eat, drink. So you know, try your best to be happy... For me, at the moment, it’s just day to day... I understand now when they said: ‘It is about the journey’... I have to constantly keep fighting and striving. But I am sort of getting too old for that now.

7.6.7 Summary superordinate theme 4: Shaping and being shaped by life

This superordinate theme describes how participants’ experienced MIL by deciding whether agency or patency should be applied to events in life in order to make meaning. This decision making resulted in participants having the experience of either shaping or being shaped by life. Sometimes acceptance was preferred; sometimes barriers to efficacy and agency were overcome; sometimes responsibility was abdicated or embraced. In their fullest forms, agency was expressed by individualising MIL and patency by not attempting to operationalise the concept.

7.7 SUPERORDINATE THEME 5: INTEGRATING DIFFERENT PERSPECTIVES OF TIME

The fifth superordinate theme *Integrating different perspectives of time* describes how participants had many different understandings of time and their relationship to time. These perspectives included: participants not seeing themselves as progressing forward in time; feeling stuck in, outside of, or left behind by time; and experiencing life progressing parallel to time. Some participants viewed time as a scarce fleeting resource and as a consequence believed how time was used determined the presence or absence of MIL. To develop MIL, participants had to make these different temporal perspectives compatible with each other. This reconciliation involved accepting that time can be experienced differently in different circumstances. Thus, the core concept of **Reconciling temporality** defines this superordinate theme.

Within this superordinate theme, there are three emergent themes (Table 7.5). All three emergent themes are shared across both groups: *Unsticking the self*, *Accepting inertia and change*, and *Transcending time through legacy generation*.

Table 7. 5 *Integrating different perspectives of time*

In Remission Group	Not in Remission Group
Superordinate theme 5 <u>Integrating different perspectives of time</u>	
Core concept <u>Reconciling temporality</u>	
Emergent theme 1 <i>Unsticking the self</i>	
Emergent theme 2 <i>Accepting inertia and change</i>	
Emergent theme 3 <i>Transcending time through legacy generation</i>	

7.7.1 Emergent theme 1: Unsticking the self (Shared)

Unsticking the self describes participants' desire to progress through time by actively engaging with their life. Engaging with life meant committing to achieving goals and objectives (within time). If these goals and objectives were achieved, participants could break free from unwanted inertia caused by psychosis. Inertia disconnected them from time and either made them feel like they were stuck in time or stuck outside of time entirely. When participants were experiencing inertia, time still progressed but *they* could not progress alongside time. By achieving their goals and objectives, they could alter their perception of their own temporality through their action. This achievement allowed participants to move forward in time as they had utilised time to progress themselves. To develop and maintain MIL, participants had to reconcile being stuck in or outside of time with progressing forward in time.

For Matt, this bond to inertia in time (something he describes as mundanity, repetition, and purposelessness) was broken by him chasing newness through creativity. Matt considered newness the essence of jazz—the music genre he had devoted his life to mastering. His creativity was heightened by opening himself up to the influence of other musicians. He endeavoured to always take a fresh perspective in his playing. Matt considered time a precious commodity; the raw material necessary for the creation of newness. During his interview, he commented: *'We are only here a short time; we are gone pretty quickly'*. This deeply valued newness altered his temporal experience. Its generation was seen as the metric of progress through time; not the passing of time itself. Matt developed MIL by generating newness. To maintain MIL he had to reconcile the periods in his life when he was not creating (i.e. being stuck in time) and the periods when he was creating (i.e. progressing forward in time). In the following extract, Matt describes how he values newness:

I have a couple of gigs in the [music festival] coming up so I am looking forward to them and I am playing with a new person. So anything new that happens, newness is a very good thing. And [AA sponsor], my sponsor, would say: 'Be new every day... be a beginner, be a newcomer every day'.

William had spent some time in prison. While incarcerated and reintegrating into the community, he believed the prison and probation services failed to help him with MIL. In prison, when unoccupied and not progressing his goals and objectives through activities, William experienced time as slowly passing him. However, when keeping busy with activities, he could alter his perception of time. In order to develop MIL, he had to reconcile these two experiences. In the following extract, he describes how he perceived time as speeding up when he was progressing alongside time. To develop MIL, William had to utilise time to generate something meaningful from it:

Interviewer: And did they [the prison and probation services] help you with meaning in life at all?

William: No I done [did] it all myself; I went in and I got out myself.

Interviewer: What did you do yourself to help yourself?

William: Played football, reading and writing; that got me through a few prison sentences... playing football, pool, reading, and writing. Time flew by.

This MIL allowed William to unstick himself from the inertia inherent in prison life; he could accelerate his progression forward through time and lessen the distress caused by the incarceration.

7.7.2 Emergent theme 2: Accepting inertia and change (Shared)

Accepting inertia and change describes participants' experience of acquiescing to time. Participants viewed time as taking place in an irreversible sequence from past, through present, to future yet they perceived themselves as not advancing alongside time. They saw everything around them change over time and were forced to accept this. To maintain MIL, participants had to reconcile the absence of change in their progress with the constant changes in their environment over time.

Thom saw the absence of meaning in his life as slowing down time: ‘*What people do in the day; if they are not doing much time will drag*’. Yet he yearned to reverse time; to begin his life again in order to achieve something of value with it. He wanted to advance through time but felt unable as he was stuck in inertia. He was unable to realise his goal of achieving something of value. This made him feel like he was not fully appreciating life. In the following extract, Thom describes his desire to reverse time in order for him to re-experience his life and appreciate it more. To reconcile temporality and maintain MIL, he had to accept the inertia in time he experienced from not achieving his goal. This acceptance occurred while Thom was witnessing constant change around him and watching humanity progressing through time. Although Thom lamented the fact that did not advance through time like others did, he nonetheless accepted the pain of languishing in inertia:

But if it was possible to reverse the aging process! Now how do you reverse the aging process? Instead of when a year comes you go back or something like that. Is it possible? We are here at this moment and time goes... I believe... we age with time, we can't see the air that we breathe... If you look at a baby, that baby will grow into a young child, become a teen, then become an adult, and then advances... I felt my life was wasted, if I understand it correctly.

7.7.3 Emergent theme 3: Transcending time through legacy generation (Shared)

Transcending time through legacy generation describes how participants endeavoured to rise above or go beyond the limits of time. This transcendence was achieved through legacy generation which involved extending the impact of life beyond death. Legacies took many forms, such as charities, businesses, children/grandchildren, artistic contributions, and the positive changes made to the lives of others. To develop MIL, participants had to reconcile the realisation that they were going to die with their anticipated relationship with time after death.

Annie viewed her legacy as improving the lives of the people she loved (e.g. making them feel valued). For her, to ‘*see [her family and friends] happy was the most important thing*’. Throughout her interview, Annie referenced her dream to have children so she could teach them this way of being in the world (i.e. being benevolent towards others). Annie viewed procreation as a central route to MIL. She longed to ‘*love a child properly and bring them up well*’ yet raising a child in this way (when experiencing psychosis, alcoholism, and homelessness) presented an almost impossible challenge to her. While realising this was painful, this pain was ameliorated by her belief in reincarnation. Through reincarnation, she saw the possibility of continuing to improve the lives of others after her death:

For people out there it [Meaning in Life] is actually about procreation and proceeding on and then you are reborn again in your child. Well I think... I could have existed before this. I could have had children and a family before this... I could have seven children for all I know in reincarnation.

Annie’s belief in reincarnation offered her a path to transcend time. Being ‘*reborn again*’ allowed her to integrate two perspectives of time. She could reconcile her belief that time would stop once she died with her belief in reincarnation which allowed her to transcend time by experiencing time indefinitely. For Annie, this act of reconciliation was MIL. In her view, she could potentially continue her legacy of benevolence in the *next* life.

7.7.4 Summary superordinate theme 5: Integrating different perspectives of time

This superordinate theme describes how participants’ experienced MIL by merging different understandings of time and their relationship to time. Examples of these different perspectives included participants: perceiving they could break free from inertia and progress through time (by unsticking the self); accepting inertia and change (by acquiescing to time); and believing they could transcend time (through legacy generation). Within each of these perspectives, participants

experienced an internal conflict in how they interpreted time. MIL emerged in the reconciliation of this conflict.

7.8 Chapter summary and conclusion

This chapter offers an in-depth interpretative account of the multifaceted ways by which people with experience of psychosis found, developed, and maintained meaning in their lives. For many participants, experiencing MIL occurred without conscious awareness. This was something brought to their attention by participating in this study. For example, Conor commented: *‘And it’s only when you ask me to think about it [Meaning in Life] I have to say, God I didn’t realise it was all connected to the meaning’*. For others, it was intentionally defined, consciously operationalised, and actively pursued at different time points. For example, Adam stated (of his life prior to psychosis): *‘...to me the meaning of life would have been to be successful, like financially successful, and get on in life like other people that you hear about’*. Consequently, he pursued success with fervour.

Even when operationalising MIL was seen as infeasible, participants interpreted and engaged in meaning making of their positionality, thoughts, emotions, actions, and life events. No participant endorsed the standpoint that MIL does not exist. Participants experienced MIL as the intersecting concepts: *Enacting identity; Belonging in life; Independence; Agency and patiency; and Reconciling temporality*. The MIL concepts developed can guide future policy, research, education and clinical practice in the underdeveloped and under researched area of MIL in psychosis. They represent potential targets for intervention in mental health care and treatment.

Participants found, developed, and maintained MIL by being aware of their connectedness to their context. ‘Context’ refers to the interrelated conditions that participants existed in. Experiencing MIL through connectedness to context occurred in five main ways. MIL involved participants being cognisant that they resided in a self (their identity). They sought to enact their identity by pursuing congruence between their true self and their actions. MIL related to participants’

acknowledgment that the self existed in relation to the self and others. They aimed to belong amid their life witnesses (including the self) to experience significance. MIL concerned participants realising that the self existed in relation to systems. They used systems to generate MIL but also attained MIL from transcending them. MIL included participants appreciating how their environment shaped the self and the self shaped their environment. They had to accept that a balance was required between exerting power over one's surroundings and being passive and accepting one's life conditions. Finally, MIL meant participants had to develop an awareness of how the self was experienced across time. They had to acknowledge that temporality changes depending on life circumstances.

Remission status (at 20 year follow up) did not exclude participants from using particular MIL concepts to generate MIL. However, remission status did determine whether or not certain aspects of these concepts were used (some emergent and subthemes were group specific). Remission status also influenced how MIL concepts were operationalised. For example, the lives of the In Remission Group became significant by *maximising* the effect of the self; the lives of the Not in Remission Group by *contributing* something of value. The analysis presented strives to capture these group differences, offering a comprehensive interpretative account of the entire dataset, while never losing adherence to the idiographic principles of IPA.

This study, therefore, makes a contribution to the literature because it is the first time MIL in psychosis has been studied in depth. Study findings offer exclusive insights into the process of MIL generation in psychosis; that account for both temporal changes in meaning making over time and heterogeneity in frequency, intensity, and form of psychosis experiences. The next and penultimate chapter in the thesis will discuss, interpret, and consider the findings presented in Chapter 6 and 7.

CHAPTER EIGHT: DISCUSSION OF THE FINDINGS, STRENGTHS, LIMITATIONS, AND IMPLICATIONS

8.1 Introduction

This chapter, the penultimate chapter in the thesis, aims to discuss the findings as they relate to the literature. The chapter begins with a brief overview of study findings. This is followed by a discussion of how the study enhances the conceptual clarity of MIL in the context of mental health and contributes to meaning making and mental health recovery theory. Following this, the implications of study findings for trauma informed care and the recovery approach are considered and the strengths and limitations of the study are outlined. Then whether the aim and objectives of my study were met is discussed. The chapter ends with the implications and recommendations for education, clinical practice, service provision, and future research.

8.2 Overview of study findings

This is the first study to explore *both* MIL in psychosis and the impact of meaning making in psychosis experiences on MIL. The study offers, as far as I am aware, the first in-depth understanding of the process of finding, developing, and maintaining MIL in the context of recovery in psychosis. Research findings offer up a new way of seeing MIL that challenges previous conceptualisations and consequently unveils new potential routes for research and education for people experiencing psychosis, their families, and clinicians. The study highlights how people's perspectives on MIL in recovery in psychosis are coloured by meaning making in psychosis experiences. In almost every aspect of the MIL discussed by participants, psychosis experiences were implicated. Findings demonstrate that, for people diagnosed with a FEP, there are many paths to MIL, and that this attainment is possible; even when people are actively experiencing what might be considered non-consensual reality or what others might call psychosis.

Participants perceived psychosis experiences as eroding MIL, in terms of: impact on the self, preferred identity, relationship with time, and control in life. They viewed psychosis experiences as contributing to MIL by filling a vacuum of meaning in their day to day existence; giving their lives value, significance, purpose, coherence, and connectedness. Participants also understood psychosis experiences as requiring them to accept their inability to narrate certain time periods; thus removing the potential to generate MIL from these lost chapters of their life.

MIL can be understood through study findings as the experience of connectedness to one's context. Participants experienced MIL by being aware that: they resided in a self (their identity); the self existed in relation to the self and others; the self existed in relation to systems; their environment shaped the self and the self shaped their environment; and the self was experienced across time. Thus, for participants, MIL was about enacting identity; experiencing belonging in life; demonstrating independence; exercising agency and patience; and reconciling temporality.

8.3 Conceptualising Meaning in Life in the context of mental health

The study involved a detailed exploration of the various dimensions of MIL from the perspectives of people with experience of psychosis. Findings offer a different understanding of the concept of MIL than that been presented in the literature to date, as discussed in Chapter 3. In so doing, the study provides novel insight into the complexity of how MIL is experienced by people who have personally encountered psychosis.

The study helps us understand, give clarity to, and enhance our ability to conceptualise MIL in context of recovery in psychosis. Study findings indicate that MIL is not a discrete concept that (combined with other concepts) forms personal recovery. Rather, findings suggest that in recovery in psychosis, MIL is a multifaceted higher order concept that encompasses other aspects of personal recovery, such as Leamy et al.'s (2011, p. 448) 'recovery process' concepts of Connectedness, Identity, and Empowerment, which have been presented as discrete concepts. In my study, these concepts mapped on to what study participants considered aspects of MIL. This

apprehension of MIL contrasts with previous conceptualisations of the construct in the context of mental health that view MIL as distinct from other components of personal recovery (Andresen et al., 2002; Leamy et al., 2011; Jacob et al., 2017; Stuart et al., 2017).

Findings also indicate that previous efforts to conceptually refine MIL so it can be operationalised for empirical investigation may have neglected the complexity of the concept. My study identified five core concepts that encompass how participants found, developed, and maintained MIL; namely *Enacting identity*; *Belonging in life*; *Independence*; *Agency and patiency*; and *Reconciling temporality*. However, others have developed tripartite conceptualisations of MIL—such as coherence, purpose, and significance (Martela & Steger, 2016) or comprehension, purpose, and mattering (George & Park 2016)—which do not capture the wide array of MIL perspectives expressed by my study participants. Thus, there may be qualities of MIL that can only be experienced by people with disabilities, mental health problems/illness, or psychosis (such as the MIL derived from sharing thought processes, beliefs, emotions, and behaviours linked to these experiences with others). Therefore, researchers indiscriminately importing (into the mental health context) conceptualisations of MIL developed with people who have not experienced these challenges may be problematic.

Developing the conceptual clarity of MIL in the context of mental health is a key challenge for service providers as MIL is a central aspect of service user defined (i.e. personal) recovery (Leamy et al., 2011). Enhancing our understanding of personal recovery and its various aspects can help guide service providers in bridging the gap between recovery ideology and its implementation (Roberts & Boardman, 2013). Without such understanding, service providers run the risk of viewing their role in supporting MIL only in terms of helping service users attain meaningful social roles (Petros et al., 2016) and realise meaningful life goals (Mabe et al., 2016). This limited understanding of MIL in the context of mental health is ubiquitous in the literature (e.g. Wood & Alsawy, 2017). The absence of conceptual clarity of the MIL construct also means providers run the risk of confusing concepts *related to* MIL with MIL itself. For example, Leamy and colleagues (2011, p. 448) conflate MIL with ‘quality of life’ and view ‘meaning of mental illness experiences’

as an aspect of MIL; rather than something that influences a person's perspective on MIL (the argument supported by my study's findings).

The five MIL core concepts identified in my study augment the conceptual clarity of MIL in the context of mental health and will now be discussed with reference to the existing literature.

8.3.1 Enacting identity

Study participants developed MIL by enacting their identity through gaining an awareness of how they resided in a self. This awareness enabled participants to enact their identity by *being* themselves through their actions. Enacting identity occurred through de-othering and authenticity. De-othering involved reducing the degree to which participants felt differentiated from others (due to experiencing psychosis) by challenging psychiatric stigma. Authenticity involved participants ensuring their actions were congruent with their true values. In other words, they sought to be sincere and genuine in how they interacted with the world. What is unique about the understanding of identity offered by these findings is that for study participants MIL was not so much derived from group membership (i.e. social identity) or from having idiosyncratic characteristics (i.e. personal identity). Rather MIL came from being like everyone else—a human of equal status and feminine (if female) and from living a life true to one's own essence.

One method of de-othering involved participants fighting for their *humanness*. The experience of dehumanisation can be a feature of the experience of mental health service use (Williams & Tufford, 2012; Eirksen et al., 2012; O'Keeffe et al., 2018). In psychosis, this perceived dehumanisation may be the result of how psychosis itself (and treatment for it) can dislodge a person from active participation in everyday life (Chase, 2011). Haslam et al. (2008) have described two ways a person can be dehumanised by others: animalistic dehumanisation and mechanistic dehumanisation. Animalistic dehumanisation seeks to deprive a person of their human nature by disputing their civility, refinement, moral sensibility, rationality, and maturity.

Mechanistic dehumanisation aims to deny a person of their human uniqueness by challenging their emotionality, warmth, openness, agency, and depth. Both forms of dehumanisation were described by my study participants. For example, participants reported how others communicating how they perceived their thoughts as irrational or their mood as blunted resulted in them feeling dehumanised. This raises the question of how the mental health system can exert power and control over how society understands ‘normative’ humanness and challenges us all to adopt a more positive perspective on difference and deviance. Society acknowledging that diversity is the essence of humanness may generate conditions that make it easier for people experiencing psychosis to develop this aspect of MIL.

Equating authenticity with MIL corresponds to Leontiev’s (2015) view that the experience of involvement (defined as the feeling of authenticity and owning one’s actions) is a central facet of MIL. Martela and Steger (2016) argue that authenticity should be interpreted as a key source of MIL rather than an aspect of MIL due to the relationship between MIL and authenticity (Martela et al., 2015). This is fallacious reasoning as if the concept of authenticity is indeed a part of MIL, therefore it would be expected that both would correlate. For the participants in my study, MIL was experienced *as* authenticity. It is possible that Martela and Steger (2016), in their desire to offer up a succinct tripartite conceptualisation of MIL, chose to interpret the literature in this way. Doing so ignores the existential perspective on MIL (Kant, 1929; Heidegger, 1962; Hegel, 1977; Rousseau, 1979; Sartre, 1992; Kierkegaard, 1985; Nehamas, 1999), which for the study participants was reflected in their drive to remain true to themselves through their actions despite external factors (such as poverty) making this difficult.

8.3.2 Belonging in life

Participants in my study experienced MIL by perceiving they were connected to witnesses in their life (including the self, other people, and spiritual entities). MIL was derived from their connections with these witnesses as this web of interconnectedness (and their place in it) made

them feel significant and gave them a sense of *Belonging in Life*. Having witnesses meant participants were witnessed (i.e. seen, acknowledged, and understood). The study presents a novel perspective on belonging in mental health recovery. Participants described the experience of partial belonging; feeling included, valued, and accepted while hiding parts of the self from others or rejecting ownership of the thoughts, feelings, and actions linked to psychosis. These findings suggest that people may struggle to experience the *Belonging in Life* aspect of MIL if they do not have at least one person in their life who they feel understands their entire self (including their psychosis) or if they reject psychosis as part of the self.

Social connectedness can be defined as experiencing closeness with others, sharing identities, valuing human relationships, as well as feeling cared for, accepted, and socially involved in society (Hare-Duke et al., 2019). However, having a sense of belonging is different. For participants in my study, belonging extended beyond the human world and involved connectedness to things other than people. Witnesses existed in both the physical and spiritual world. This finding has implications for people supporting someone experiencing psychosis in their recovery as the distinction made between spirituality and psychosis is culturally defined (Clarke, 2010). A belief could be a culturally sanctioned collective ‘religious’ thought in one culture and a symptom of psychosis in another. Differentiating between what is a *spiritual* from what is a *psychosis* experience can be challenging for clinicians; especially when service users interpret their psychosis as a spiritual emergency (Kaselionyte & Gumley, 2019). It can be difficult to reconcile this ambiguity with the scientific ‘objective’ rationality that influences much of the mental health system. Some participants in my study understood their psychosis experiences as arising from (what they considered to be) a crisis caused by the absence of spiritual connection.

Spirituality was experienced by study participants as something much broader than religious faith. If spirituality is ignored in mental health care or if spirituality is siloed into the remit of chaplaincy guided by a particular religious doctrine, then service users may be left without support in attaining a key area of MIL (i.e. belonging through spiritual connectedness). This is particularly important in the context of modern society where immigration has resulted in increased spiritual diversity within

communities (Nelson-Becker & Canda, 2008). Clinicians considering a spiritual understanding of people's experiences and developing an openness to how people self-define spirituality may be important initial steps in addressing this issue.

8.3.3 Independence

Independence, in the context of my study findings, refers to the independence of participants to take whatever MIL support was available to them within systems (the family system; the mental health system; and the system of Irish society) and then endeavour to transcend these systems by generating meaning outside of them. The isolation that can accompany mental illness can mean that many service users can rely heavily on mental health services to have their social needs met (Davidson et al., 2004). This was reflected in my findings with some participants desiring to increase their attendance at their rehabilitation day centre as it was their only social outlet. Therefore, isolation can profoundly restrict opportunities people have to experience MIL and may overburden the mental health system by service users placing expectations on it to be a dominant source of meaning in their lives.

For mental health professionals, supporting independence as an aspect of MIL means assisting service users to live a life—and have experiences—beyond mental health services. Many people experiencing psychosis have restricted social networks (Allison et al., 2013). The social world of service users becomes immensely restricted if (outside of family) it is confined to relationships with clinicians, peer supporters, or indeed other mental health service users. Although participants in my study valued these relationships (and saw them as meaningful), they also craved relationships with people outside of the mental health system. Without these external relationships, independence in MIL generation may remain out of reach for many people experiencing psychosis.

The introduction of early intervention services and the evidence for their effectiveness (Correll, 2018) suggest that many people living with psychosis today will be able to experience fully life

beyond the mental health system. People with experience of psychosis becoming independent from the system by demonstrating full functional recovery is common (Álvarez-Jiménez et al., 2012; O’Keeffe et al., 2019). Despite this evidence, many health professionals remain pessimistic about recovery in schizophrenia (Björkman et al., 2008; Magliano et al., 2017) and hold negative attitudes towards the community integration of people with serious mental illness (Moldovan, 2007). Clinicians can inadvertently place limits on people’s potential for independence because service users can internalise their recovery pessimism; making their expectations a self-fulfilling prophecy (Hampson, 2018). My study participants saw exercising independence by generating meaning beyond the mental health system as MIL. This means that pessimistic clinicians may inadvertently erode people’s potential for MIL.

8.3.4 Agency and patency

For study participants, agency meant seeing oneself as being able to act in and effect one’s environment. Patency, on the other hand, meant being passive in life. Study participants derived MIL from deciding whether they should apply agency or patency depending on life circumstances. Study findings offer a nuanced understanding of how this aspect of MIL was experienced by people in mental health recovery. MIL was not just about success in exerting power; MIL involved negotiating the relationship *between* agency and patency. The fit between participants’ actions and their circumstances gave them MIL. For some participants at certain times, one or the other gave MIL. For others, experiencing MIL meant achieving the balance between them (e.g. reconciling one’s determination to ‘succeed’ in life with accepting things as they are).

The concept of agency is ubiquitous in the mental health recovery and psychosis literature (Lysaker & Leonhardt, 2012). Its omnipresence is likely linked to two things. Firstly, a key tenet of the recovery approach—that people are not passive entities whose recovery outcome is determined by the interplay between biological and social forces; but agents who engage in interpretation and meaning making which impacts recovery outcome (Roe & Davidson, 2005). Secondly, the

difficulty that people with experience of psychosis have displayed in perceiving themselves as active agents in their lives (Dimaggio et al., 2009).

While it is unsurprising that exercising agency was one way participants in my study viewed MIL, it was unexpected that exercising patiency (i.e. being passive as one is acted upon) was another way MIL was experienced. The recovery approach asserts that all service users should be empowered to direct their treatment and their lives and thus not be positioned in the mental health system as 'passive recipients of care' (Hamm et al., 2018, p. 2). There is an emphasis on putting responsibility for, and control of, the recovery process in the hands of the service user; thus promoting agency (Frese et al., 2001). However, what the participants in my study tell us is that, for some people with psychosis, exercising patiency (enduring life without resistance) is how they experienced MIL. Therefore, they may be marginalised if they attend a recovery oriented mental health service that adopts a one size fits all approach privileging agency (Lal, 2010). Mental health services forcing agency on these service users may erode their MIL.

8.3.5 Reconciling temporality

From the perspectives of study participants, temporality meant their understanding of time and their relationship to time. To generate MIL, participants had to adopt multiple temporal perspectives (such as progressing through time; accepting inertia and change; and transcending time) and endeavour to reconcile these. For example, inertia was not desirable; yet finding a way to reconcile inertia and progress through time was experienced as MIL. It was the act of *Reconciling Temporality* that gave participants MIL; finding a way to live with these conflicting temporal perspectives as they altered with changes in life circumstances. Adopting multiple perspectives on time may be more prevalent in people with psychosis due to the extent to which psychosis experiences can erode a person's relationship to time.

My study participants experienced psychosis as severing their relationship with time, removing their situatedness in time, and blocking the fullness of lived time. For example, Annie described how she lost MIL as she became uncoupled from her lived engagement with the world and thus time itself. At times, she experienced the world as alien; as if she was viewing life through a window. Denischik's (2015) argument concerning temporality and psychosis may help explain these findings.

Denischik (2015) describes the impact of psychosis on a person's temporality as the 'loss of lived time in an alien world' (p. 148). She argues that people can experience a disruption in temporality if traumatic stimuli are not successfully incorporated into the mind. This inability to incorporate trauma necessitates them modifying their sense of time as time ceases to exist as continuous, meaningful, lived time. Denischik (2015) contends that psychosis can render fully experiencing time inaccessible which—in turn—reduces the degree to which life is meaningful. From her perspective, this disconnection from time arises from the need to gain control over the impact of the pain caused by past trauma; which if not dealt with, dominates the experience of time to the degree that it diminishes the significance of both the present and the future.

For the participants in my study, psychosis had a severe impact on temporality. Some felt stuck in, outside of, or left behind by time entirely. This finding contrasts with the milder impact of mental health difficulties on temporality reported by O'Doherty et al. (2012). These authors found that *Reconnecting with time* was a central feature of mental health recovery for a sample of Irish mental health service users. This reconnection involved: coming to terms with and explaining the past; living in the here and now; finding hope for a positive future; and looking forward to, planning, and moving on with, their lives. These contrasting findings suggest that reconnecting with time may be a more difficult challenge to overcome if psychosis is one of the mental health difficulties that disconnects a person from time.

8.4. Contribution to theory

Critical realism espouses the goal of empirical work as supporting, elaborating, or refuting extant theory in order to aid the construction of the most precise explanation of reality available to humanity (Fletcher, 2017). Findings of my study can make a contribution to meaning making theory (the Meaning Making Model) and mental health recovery theory (the understanding of recovery styles). Park's (2010) Meaning Making Model is the most widely cited and influential model for meaning making in the context of mental health and adaptation to stressful life events, therefore it is within the context of this model that my findings are first discussed. This is followed with a discussion on the findings as they relate to McGlashan et al.'s (1976) construct of Recovery Styles.

8.4.1 The Meaning Making Model (Park, 2010)

According to Park's (2010) Meaning Making Model, individuals have orienting systems that provide the cognitive frameworks they use to interpret their experiences. These can include personal constructs, world assumptions, life narratives, goals, beliefs, and schemas. When confronted with an event (e.g. a loss) that has the potential to challenge their orienting systems, people appraise and assign meaning to the event (referred to as situational meaning). When the appraised meaning of a situation is discrepant with their orienting systems, people attempt to change or distort their views of events to incorporate them into their orienting systems (i.e. assimilation) or change their orienting systems to integrate that situation (i.e. accommodation). Park (2010) argues that meaning making tries to align the two and restores a sense that the world is comprehensible and that peoples' lives are worthwhile.

My study findings challenge Park's (2010) Meaning Making Model. For some participants, in the process of meaning making in psychosis experiences, orienting systems were destroyed. The self was perceived as absent. Life narrative, as a whole, was experienced as disintegrated. Situational meaning was impossible to assign to psychosis experiences as they were either unexplainable or not in a person's memory. As a result, alignment between orienting systems and the situational

meaning of psychosis experiences could not take place. However, these participants could still experience MIL. For example, MIL could be generated by participants even when the self was perceived as absent; by deriving MIL from the act of surviving self-absence. Also not being able to make sense of or remember certain psychosis experiences erodes MIL but does not destroy it. Thus, study findings indicate that MIL differs from an orienting system and that Park's Meaning Making Model (2010) may not be fully applicable to the lives of people experiencing psychosis.

8.4.2 Recovery styles (McGlashan et al., 1976)

Recovery style is frequently used as a quantitative variable in mental health research and is generally conceptualised as a personality trait that is stable across time (McGlashan, 1987). The theory underpinning its use proposes that people typically use two general strategies to adapt to their experience of psychosis and heal (McGlashan et al., 1976). People with an integrative recovery style will be curious about, and accepting of, their experience of psychosis. They may also actively search for personal meaning in their psychosis experiences. In contrast, people with a sealing over recovery style will endeavour to see psychosis experiences as isolated, intrusive, interruptive events; that are best forgotten. Thus, they endeavour to keep psychosis experiences separate from the rest of their lives.

My study findings undermine the assumption that recovery style is a stable personality trait that remains consistent over time. Findings suggest that different recovery styles can be adopted for different aspects of psychosis experiences. They also indicate that MIL may play a role in determining the recovery style adopted. In my study, whether or not a person actively sought meaning in psychosis experiences was not stable over time or across participants. People assigned multiple meanings to a psychosis experience and then decided to value and integrate some parts of the experience and devalue and reject others. Multiple meanings were required if one explanation did not sufficiently account for the experience or if people were having new types of psychosis experiences that needed to be integrated alongside previous ones. Integration was easier for

participants if they were able to resolve the dissonance between these meanings. At certain points in their lives, participants were highly motivated to understand what happened to them when they were psychotic (e.g. when reflecting on life in retirement). At other times, participants actively sought to block the experience out (e.g. when trying to get on with life and find employment). On the whole, it was the experiential quality of the experience that determined if it was worth their effort to find meaning in it. If participants deemed psychosis experiences to be potentially relevant to MIL, they tended to actively search for meaning within them.

8.5 Trauma Informed Care and psychosis as trauma

Trauma Informed Care (TIC), in the context of mental health service delivery, acknowledges the presence of trauma in the lives of many service users (Isobel & Delgado, 2018). TIC recognises that all people may have experienced trauma; seeks to educate clinicians to be cognisant of the effects of trauma; and aims to minimise re-traumatisation by services inadvertently re-enacting traumatic dynamics (Miller & Najavits, 2012). TIC also seeks to enhance awareness that: trauma can become manifested in response to stimuli unrelated to past traumatic experiences (Reeves, 2015); clinicians themselves can be traumatised in their work and personal lives (Isobel & Edwards, 2017); and trauma can be implicated in causing psychosis (Tong, 2018).

TIC focuses on reducing the risk of re-traumatisation within the mental health system and considering how exposure to trauma can help explain mental health difficulties. While the participants in my study described dehumanising practices in services and not being listened to by clinicians, they did not report being re-traumatised in mental health settings. In addition, no participant described using a trauma explanatory model to understand their psychosis experiences. However, participants described psychosis experiences *as* trauma. They viewed psychosis experiences as an event or series of events that were threatening or damaging to the self, their preferred identity, and temporality; as well as their ability to control their lives and effect change in their environment. Consequently, psychosis experiences shattered participants' beliefs about the self, others, and world. These events caused overwhelming stress that exceeded participants' ability

to cope; thus, they saw them as a threat to their psychological integrity. Psychosis experiences had lasting adverse effects on participants' functioning and their emotional, social, or spiritual well-being. In other words, they were *traumatising* to participants. For many, the pain of this trauma was still present in their lives.

Study findings correspond with a recent systematic review and meta-analysis concluded that a person's FEP is often a highly traumatic experience (Rodrigues & Anderson, 2017). In the pooled sample analysed, 42% of FEP service users experienced PTSD symptoms and 30% met diagnostic criteria for PTSD in relation to psychosis. This understanding of psychosis *as* trauma is absent from the TIC literature. Service providers need to be sensitive to the trauma caused by psychosis itself. This involves being aware that service users may be entering the mental health system as shattered forms of their former selves who have lost connection to themselves, to others, and to time. Psychosis caused trauma can consequently impact clinicians interactions with service users. Therefore, they need to be offered a physically and emotionally safe, caring, and respectful environment in order to be supported in re-forming the self and re-establishing these connections. Thus, TIC involves being sensitive to the fact that trauma is not just a precipitating factor for psychosis but is *within* the experience of psychosis. Study findings indicate that the trauma of psychosis erodes MIL.

In the past, people diagnosed with psychosis have been excluded from trauma treatment in clinical and research contexts (van den Berg et al., 2015). Clinicians being mindful of how psychosis is potentially traumatic in and of itself will likely lead to an increased focus in services on how psychosis can lead to post traumatic growth. This is defined as pervasive, stable, and transformative positive psychological, social, or spiritual change in people following trauma (Jordan et al., 2017). TIC could consider how interventions offered can foster this growth by facilitating engagement with the pain of psychosis caused trauma. Engagement with trauma induced pain is of value as it can enhance MIL (Kashdan & Kane, 2011) and help people progress in their recovery journey after their FEP (Tedeschi & Calhoun, 2004).

8.6 The recovery approach: explanatory models, cultural discourses, and living with psychosis

Recovery based mental health services are asked to: review how they understand and respond to people experiencing mental illness; critique traditional values, beliefs, and practices regarding treatment and aetiology; and prioritise supporting service users to live lives that are meaningful to them (thus experiencing MIL). Such services require practitioners to collaboratively consider, interpret, and discuss the meaning of mental illness experiences utilising a multiplicity of biological, psychological, social, and spiritual perspectives (Higgins, 2008; Davidson et al., 2009; Le Boutillier et al., 2011; Commonwealth of Australia, 2013).

My study findings indicate that multiple explanatory models can be used by people simultaneously to understand—and make peace with having experienced—psychosis. These explanatory models are complex and idiosyncratic; as well as stable or fluid over time. By attending to service user meaning making, clinicians can aim to minimise the damage caused by psychosis while supporting people to use the explanatory models and coping mechanisms most helpful to them. This involves challenging the impetus to deem anyone who does not interpret psychosis through the medical lens as ‘lacking insight’. My study participants described the distress they experienced at having many of their explanatory models viewed by clinicians as misguided or ill-informed belief systems that need to be replaced with medically ‘correct’ experience interpretations in order to promote adherence to treatment. Therefore, adopting a recovery orientation requires openness on the part of clinicians to considering multiple experience interpretations; setting their ‘expert’ knowledge alongside (not over and above) service users’ own explanations (Kleinman & Benson, 2006). Findings also suggest that clinicians need to be mindful of how some people do not need to use such models as they have no desire to explain (or find a home for) psychosis experiences.

The findings of the study draw attention to the question of how can different cultural discourses relating to, and explanatory models of, psychosis be accommodated in mental health services. They underscore the role of culture in shaping how psychosis experiences are interpreted. For example,

by linking hallucinations to cultural discourses, my study participants could view hallucinations as culturally acceptable; thus reducing their own distress and isolation. Participants were able to use culture to bridge the gap between the *consensus* interpretation of reality and *their* interpretation of reality. This finding is consistent with previous research highlighting the power of using cultural interpretations of hallucinations to promote wellbeing (Larøi et al., 2014) and how culture shapes the degree to which hallucinations are considered an assault on the self (Luhmann et al., 2015). Study findings suggest that any recovery-oriented treatment would benefit from considering a person's cultural context and engaging with the cultural discourses they have used to cope with and make sense of their psychosis experiences.

Finally, by continuing to experience psychosis years after initial FEP diagnosis, my study participants had to engage in ongoing efforts to live a life of personal meaning despite the continued presence of psychosis and disability. This meant that, even 21 years later, they continued to struggle to stop psychosis from eroding aspects of MIL. The fact that study participants were able to continue to pursue lives of personal meaning despite this constant damage contributes to the evidence base supporting the recovery approach.

8.7 The medical narrative about psychosis and therapeutic engagement

Historically, a person's thoughts and behaviour have been deemed psychotic by virtue of the fact that they are deemed by others to be incomprehensible or impossible to understand (Heinimaa, 2000). This perspective of psychosis as being beyond the reaches of rational thought remains present in modern day mental health treatment. The diagnostic manuals—the DSM-5 (American Psychiatric Association, 2013) and ICD-10 (World Health Organization, 1992)—currently in effect in 2019 still retain this absence of *understandability* as a defining characteristic of psychosis. For example, in the DSM-5:

Delusions are deemed bizarre if they are clearly implausible and not understandable to same-culture peers and do not derive from ordinary life experiences (p. 87).

The in-depth exploration of meaning making in psychosis experiences presented in my study contravenes this assumption. Findings from the study affirm Davidson's (2003) proposition that that all human experience is innately understandable. In the study, all psychosis experiences that participants could understand themselves were rendered comprehensible to me (as the researcher) by attending closely to participants' context and their unique perspective on MIL. For example, Thom's adopted role as the 'Solver' of impossible problems makes sense in context of his view that MIL is derived from utilising his potential and contributing something of value to the world. No matter how 'bizarre' or 'illogical' participants' accounts of their psychosis experiences *appeared* to be; by being attentive and engaging in a detailed idiographic analysis of each interview, I was able to get close to understanding how participants made sense of them.

My study findings underscore the value people place on exploring meaning making in psychosis experiences with others. Prior to the study, there was an awareness of this value because of service users' emphasis on narrative (e.g. Onken et al., 2007) and meaning (e.g. Colori, 2018) within the recovery process. However, following the study we can now understand this desire in the context of therapeutic engagement in mental health services. For participants, one aspect of MIL was *Becoming significant where the self is witnessed* and feeling a sense of *Belonging in life* as a consequence. Experiencing this aspect of MIL was hindered by the need to hide thought processes, beliefs, emotions, and behaviours linked to psychosis from others. If these hidden parts of participants' self were not witnessed (i.e. shared with others) they did not belong anywhere. Participants hid these aspects of the self from clinicians as they perceived clinicians as viewing them solely as symptoms of a disorder that lacked value and meaning outside of psychiatric nosology. In order for this witnessing to occur in mental health services, clinicians may need to nurture in themselves a critical self-reflexivity so they are able to open up spaces for a genuine dialogue with the people who come to mental health services seeking help. This could involve reflecting on: what is defined as expertise and knowledge in mental health; why we consider that there is privileged knowledge and a singular truth in mental health that clinicians have access to; and whether we are reducing the embodied, encultured, and complex reality of people's

experiences to categories. This may support clinicians to develop the trust of service users so that people are given the right conditions to disclose these hidden parts of the self in order to experience significance and belonging and thus MIL.

If the medical narrative about psychosis is the dominant narrative within services, then psychosis experiences may only be viewed in a negative light by clinicians working in those services (Slade & Longden, 2015). There is substantial evidence in the literature that a FEP can result in positive life changes for service users and their families and friends (Jordan et al., 2018). If meaning making in psychosis experiences is not explored by clinicians, then service users' hidden self may remain unwitnessed and devalued by the world. My study findings indicated that the perception of not belonging in mental health services increases the likelihood that service users will disengage from treatment.

By clinicians being open to how psychosis experiences can contribute to MIL during assessment and treatment; they will likely talk to service users about psychosis in a different way. By seeing the value of psychosis to the person they are trying to help, clinicians will likely communicate through their affect, behaviour, and their words that the person's entire self is of value. Such an approach will likely prevent clinicians inadvertently communicating fear, reinforcing stigma or engaging in dehumanising practices. By adopting this openness, clinicians will rely less of traditional formulised questions that label and contain complex multifaceted experience and instead seek to understand the meaning of these experiences in the context of people's lives and cultures. This openness is central to building a relationship with someone who may already be feeling distrustful of others. It would be helpful to all mental health system stakeholders to look at how the core concepts that the study identified as central to meaning making in psychosis experiences can be integrated into conversations with service users: *Survival*; *Restoring temporality*; *Reclaiming control*; *Presence in absence*; and *Narrative re-storying*.

8.8 Are findings psychosis specific?

One question that arises from study findings is whether insights gained pertain to all disability, all mental health problems/illness, or just psychosis. There are patterns in how MIL is understood across all individuals (Steger et al., 2008a; Steger et al., 2008b) and all forms of disability and mental illness are likely to influence a person's perspective on MIL. However, findings suggest there are unique experiences of MIL that only people with psychosis can perceive.

This uniqueness is evident in reflecting on findings through the lens of the MIL theoretical perspectives discussed in Chapter 2. When within their psychosis, study participants were protected from perceiving *The absence of MIL*. This is because accepting consensus reality is a prerequisite to accepting meaninglessness in life. By engaging the world of psychosis (i.e. an alternative interpretation of reality) participants opened up a new path to MIL which, for some, was their only one. Other participants saw *MIL as an external gift* as psychosis gave them MIL from a supernatural source. For example, God's war provided Annie with a route to ultimate justice. Psychosis also altered participants' perception of reality to such a degree that they could only understand them by using a supernatural belief system.

Participants viewed *MIL as individual capacity, efficacy, and agency*. They described internalising the societal perception that they lacked the capacity to create change in their lives. This finding may reflect how being diagnosed with a 'psychotic illness' can cause a person to be defined as a passive host of a brain disorder that profoundly restricts their control over their lives (O'Keeffe et al., 2016). Finally, participants saw *MIL as integration*. This offered them scope to move past psychosis experiences that were incongruent with their value system or personal narrative; and concurrently effect change in their lives and transcend the self.

8.9. Policy and practice guidelines

Study findings highlight the importance of developing a deep understanding of the meanings people ascribe to their psychosis experiences in order to facilitate their engagement in clinical care. This 'meaning orientation' is in line with the recovery approach that now forms the cornerstone of

mental health policy internationally (O’Keeffe, 2018). The essence of the recovery approach is the valuing of service users’ perspectives on their own experiences in order to redress the undervaluing of their subjective experience that took place within the mental health system in the past (Anthony, 1991; Warner, 2010).

Following years of preparation, the Irish health service recently published the new model of care that will guide their National Clinical Programme for Early Intervention in Psychosis (Health Service Executive, 2019). While this is to be welcomed (as for decades a postcode lottery determined whether people experiencing a FEP received specialised early intervention), it is disappointing that the document gives primacy to the medical understanding of psychosis. The service user perspective is absent from the document save for one small positive account of a person’s experience of a technical intervention; which seems in conflict with the concept of ‘Public and Patient Involvement’. Therefore, this publication is a lost opportunity to include a phenomenological understanding of the experience of recovery in psychosis in a document that will guide service provision in Ireland for years to come. This is particularly disheartening in light of my study’s findings that that people with experience of psychosis have a strong desire for how they interpret and understand their psychosis experiences to be given credence in services. It is also discouraging that the aims and objectives for the model of care make no reference to MIL when my study has demonstrated the centrality of MIL in mental health recovery in psychosis. Future policy and practice guidelines could benefit from considering these issues.

8.10 Meaning in Life study strengths and limitations

The study has a number of strengths and limitations that need to be considered in the context of reading the findings and discussion. In terms of strengths, in meeting its aims and objectives, the study reached beyond the scope of the largely descriptive qualitative studies on MIL in psychosis previously published. As my study is an IPA, it is idiographic. Therefore, it privileged depth over breadth and hence utilised a small to enable this. A key strength of the study is that it managed to maintain this idiographic focus while using a larger sample than is typical for IPA research.

Participants were sampled from a larger more representative sample (iHOPE-20) and recruited across remission status and demographic characteristic/diagnostic groups. Participants described many different types of psychosis experiences and displayed a wide variation in approaches to meaning making and perspectives on MIL. The presence of psychosis in participants' lives also varied over time. Psychosis experiences occurred in different frequencies, durations, and intensities. Thus, these factors enhance some aspects of the transferability of findings.

There was a long time period for participants to make meaning from their psychosis experiences as, when they were interviewed, many years had passed since their FEP. This meant the study captured the range of meaning making efforts at different time points. Also, a multiperspectival research design was adopted that looked at similarity and difference between groups (In Remission and Not in Remission). This allowed for a triangulation of viewpoints. Finally, the study did not just look at MIL in isolation; it also considered the impact of psychosis experiences on MIL.

While study findings offer novel insight into *Meaning making in psychosis experiences* and *MIL in the context of mental health recovery*, the following are limitations:

1. *Transferability*. The study participants were sampled from an epidemiologically complete FEP incidence cohort representative of FEP referrals in a Dublin catchment area. However, only 16 out of 171 cohort members took part in the study. Participants were mostly male, unemployed, and single; the majority had a diagnosis of schizophrenia. In addition, there was no ethnic variation among the sample. Also individuals may have been more likely to participate in the study if they had more positive/easier experiences of meaning making in psychosis experiences or generating MIL. In addition, people with a pre-established interest in MIL and those not existentially indifferent (Schnell, 2010) may have been more likely to take part. These factors impact the transferability of findings to other contexts.

2. *Validity of cut off used to define groups.* In the study Andreasen et al.'s (2005) remission criteria were used to distinguish between participants by the degree to which they were experiencing psychosis. However, applying these criteria in sampling for the study meant that people who were still experiencing what may be described as 'low level' psychosis symptoms could be recruited to the In Remission Group. This may have limited the exploration of the extent to which psychosis impacted participants' perspectives on MIL. In addition, participants, on average, completed their interview for the MIL study one year after their remission status was assessed. Thus, their remission status could have changed over this time period.
3. *Recall bias.* Memory of experiences typically becomes less accessible over time (Schacter, 1999). Participants retrospectively reported on psychosis experiences up to 21 years old. Therefore, participants may have struggled to remember the meaning making that occurred during early psychosis experiences (particularly their FEP). Some studies suggest that cognitive impairment can be a feature of psychosis and its treatment (Lepage et al., 2007; Wood et al., 2015). This cognitive impairment is linked to difficulties representing goal information in working memory to guide behaviour; the side effects of antipsychotic medication; comorbidities associated with psychotic illness (e.g. metabolic syndrome and substance abuse); and accelerated or exaggerated aging (Barch & Sheffield, 2014; Harvey & Rosenthal, 2018). While not minimising participants accounts, narration of their meaning making may have been influenced by fluctuations in psychosis symptoms and these factors impairing the retrieval of life memories. Moreover, the differences found between the In Remission and Not in Remission groups may reflect the impact of psychosis on participants' mood and emotional state and thus their memory retrieval rather than differences in perspectives (Ochsner & Schacter, 2012).
4. *Participant social desirability and articulation.* For various reasons, during interviews participants may have hidden aspects of meaning making and MIL from me and responded to questions in a way that did not reflect their 'true' perceptions. For example, social

desirability may have led participants to omit details from their narratives if they believed that this disclosure would portray them in an unfavourable light. In the interview, some participants found it easier than others to communicate. It is possible that the accounts of articulate and open participants may have had a disproportionate impact on study findings.

5. *Researcher related bias.* The study is a PhD study. As such, it was a learning experience conducted in the context of me getting my wings as a qualitative researcher. My foregrounding in quantitative research methods may have acted as an additional barrier to overcome as I had to ‘unlearn’ previously adopted positivist perspectives on knowledge and reality. At times, there were aspects of conducting an IPA study that I found difficult. These were a challenge for me but other more experienced IPA researchers may not have found them demanding.
6. *Cultural context.* The study was conducted in Ireland. As a result, participants’ narratives reflected Irish culture and the influence of Judeo-Christian thought on MIL that exists in Ireland. Thus, findings are limited in the degree to which they can shed light on how MIL is experienced in other cultures. For example, findings may reflect the privileging of individualism in Western countries (Bayetti et al., 2016).

8.11 Meaning in Life study aim and objectives

The study explored MIL and the meanings participants attached to psychosis experiences; identified the impact psychosis experiences had on participants’ MIL perspectives; investigated if participants FEP changed this; and examined if MIL viewpoints among people in remission from psychosis 20 years after their FEP differed to those not in remission. While the factors that influenced MIL and the role of MIL in recovery in psychosis were not made explicit in the analysis presented, the superordinate themes and the associated concepts representing *Meaning in life in the context of mental health recovery* nonetheless illuminate these. Thus I believe that the study largely met its aim and objectives.

8.12 Implications and recommendations

Bearing in mind the limitations of the study, the following implications and recommendations for education (for people experiencing psychosis, their families and clinicians), clinical practice, service provision, and research are put forward. Implications refer to the relevance of study findings to these areas and recommendations are the specific actions that are advised to be taken as a result of study findings.

8.12.1 *Education of people experiencing psychosis, their families, and clinicians*

- Findings point to steps that people experiencing psychosis can take to facilitate MIL. It is recommended that service users and their families be educated about these steps in clinical settings to foster optimism for MIL attainment in the recovery journey.
- My study found that psychosis experiences can be extremely valuable to people and can contribute to MIL. For some participants, they were the most important experiences of their life. This suggests that psychosis is not just characterised by suffering and pervasive loss. It is recommended that these insights be communicated to people recently diagnosed with a FEP to offer them hope for MIL and awareness that others have successfully navigated through suffering.
- The study findings identified how clinicians failing to consider the positive aspects of psychosis experiences hindered participants' engagement with mental health services. In the context of the high rate of disengagement among people with a FEP from treatment⁹⁰ and the importance of continuity of care for this group (Doyle et al., 2014); mental health

⁹⁰ Approximately 30% of FEP service users disengage from services before they complete treatment.

services need to prioritise their engagement. To improve this, it is recommended that clinicians be educated that psychosis experiences are not always detrimental to wellbeing and that the mental health system can negatively impact MIL.

- Study findings concluded that MIL from the perspective of people with experience of psychosis was much broader than the restricted understanding of the concept prevalent in the mental health literature (i.e. meaningful social roles and life goals). Educating clinicians about the broader nature of the concept may help them to support people in generating MIL.

8.12.2 Clinical practice

- My study found that participants expressed a strong desire for opportunities to explore meaning making in psychosis experiences with clinicians but felt these opportunities were generally lacking in their mental health care. It is recommended that these opportunities be offered to service users.
- The study findings indicated that participants often perceived that the explanatory models they used to understand their psychosis experiences were regarded by clinicians as expressions of their psychosis. It is recommended that how people use explanatory models at different stages in their recovery journey is *explored* in an open non-judgmental manner in clinical practice; rather than conducting a once off assessment that simply categorises explanatory model type. This exploration could provide valuable information to aid successful understanding of the person's context and their beliefs about their experiences, support treatment negotiation, and enhance the efficacy of interventions (if people feel their explanatory models and thus parts of themselves are understood).

- Findings underscore the central role of spirituality in connectedness, transcendence, and MIL. Participants described how spirituality provided comfort; made them feel connected to others and the universe; and helped them understand and come to terms with psychosis experiences. It is recommended that spirituality be considered in clinical practice in psychosis but not reduced to religiosity. Service users' spiritual beliefs need to be respected and not automatically pathologised as symptoms of psychosis.

8.12.3 Service provision

- My study found that while psychosis erodes MIL, it also contributes to MIL. This means that in some cases, service providers are inadvertently diminishing MIL by reducing psychosis experiences within service users' lives or by removing them entirely. It is recommended that providers consider delivering interventions to replace psychosis experiences with sources of MIL that are less costly to service users' psychological wellbeing. For example, these interventions could focus on fostering significance, connectedness, and belonging through: supporting socialisation; increasing peoples' capacity to develop romantic relationships; or enhancing their community engagement. Thought could also be given to whether it is less stigmatising to link service users in with resources already available in their community.
- Findings suggest that the culture and structures of mental health services can damage MIL. It is recommended that service providers consider how they may be inadvertently contributing to hopelessness among service users and the feeling that MIL will forever be out of their reach. The emphasising on symptoms, 'deficits', limitations, and 'problematic' past behaviours in clinical team meetings and in clinical notes can make it difficult for clinicians to see service users' potential for MIL.

- My study developed MIL concepts that capture how people with psychosis experience MIL: *Enacting identity; Belonging in life; Agency and patiency; Reconciling temporality; and Independence*. Study findings highlight the need to repair the damage done by psychosis to MIL and to replace the MIL that psychosis gives service users. It is recommended that these concepts be considered as potential targets for prevention and treatment of psychosis and that any interventions designed to target them should be provided with the same emphasis on urgency of delivery that underpins the early intervention model.
- My study identified how psychiatric stigma greatly hampered participants' experience of MIL. Therefore, it is recommended that population based anti-stigma campaigns systematically targeting psychosis and schizophrenia would be engaged in. Also, interventions to address self-stigma among service users would be helpful in this regard.

8.12.4 Recommendations for future research

The literature review conducted for this study suggested there was a dearth of qualitative research exploring MIL in psychosis. What is available are small, surface level, qualitative studies that either quantified categories of meaning or lack transparency in methods. While my study has begun the process of investigating in an in-depth manner an aspect of recovery considered to be of vital importance by mental health service users, the findings suggest a number of areas that warrant future investigation.

- Findings suggested that MIL is a much broader construct than previously considered in the mental health recovery literature. It encompasses aspects of personal recovery previously seen as separate from MIL (i.e. connectedness, identity, and empowerment). Therefore, it is recommended that systematic and narrative reviews of MIL in the context of mental health recovery be used to help refine and enhance its conceptual clarity and disentangle

these constructs.

- As the focus of my study is on service users' perspectives, and given the important role that family members and health care practitioners play in supporting people's recovery, it is recommended that research into family member and clinician perspectives on MIL in the context of psychosis and their views on prioritising MIL in mental health services be carried out. Further study into services users' views on prioritising MIL in mental health services is also warranted.
- My study only used interview techniques. Given my earlier comment on the challenges people can experience with articulation, it is recommended that future studies in MIL broaden the data collection methods and incorporate innovative techniques such as visual research methods (e.g. drawings or photographs) as they may help service users express and process their experiences (Attard et al., 2017) and better illuminate meaning making.
- My study was cross-sectional; participants were asked to reflect back on their life experiences from one position in time. Therefore, it is recommended that qualitative longitudinal studies be carried out to illuminate how meaning making in psychosis experiences and perspectives on MIL may change over time.
- The interviews for my study were completed approximately 21 years after participants had experienced their FEP. It is recommended that future research be conducted just after a person's FEP as it may offer different insights into meaning making and MIL and findings may be a more accurate representation of the FEP experience.
- Findings indicated there are aspects of the experience of MIL uniquely perceived by people with experience of psychosis. Therefore, it is recommended that future research aims to develop a MIL questionnaire specifically for this group.

- I utilised service user involvement in order to refine my study's interview guide. It is recommended that service user led research be conducted as it may reveal insight into MIL unobtainable by someone who lacks lived experience of psychosis. This could generate new knowledge on how MIL is experienced and what facilitates it.

8.13. Chapter summary and conclusion

This study offers an in-depth exploration of the perspectives of people with experience of psychosis on MIL. The study examined how MIL was found, developed, and maintained by this group; but also investigated how meaning making in psychosis experiences and remission status impacted MIL perspectives. By doing this, the study enhanced the conceptual clarity of the concept of MIL in mental health recovery, contributed to theory, and generated recommendations for education, clinical practice, service provision, and future research.

What is apparent from study findings was the importance of meaning making to study participants. Meaning making involved participants developing an awareness of their life experiences grounded in their own personal perspective on MIL, which universally was altered in some way by psychosis. Their unique MIL perspective provided a foundation that guided their thoughts, feelings, and actions; determining what was meaningful to them in their lives as they progressed or struggled to progress in their recovery journey. Participants were able to make meaning in their psychosis experiences and in their lives in ways that worked for *them*.

Findings challenge how meaning making and MIL are understood in the mental health field. They point to the need for service users to not just have their meaning making modified by technical interventions to reduce their distress but rather for them to engage in a much richer, open, phenomenological dialogue with others about their experiences. In order for us to help people to experience MIL, we need to understand their priorities; values; aspirations; identity; level of connectedness; sense of agency and independence in their lives; and how they view time. This

involves us thinking about people's experiences in a way that gives full consideration to their culture, context, and personal meaning making processes. People need to be supported to respond to their psychosis, cope with its aftermath, and make sense of it in a way that respects their MIL perspective. By being open to the array of possible meanings people attach to their experiences and how MIL is unique for every individual, service users can be supported by clinicians to navigate the impact of psychosis on MIL and clarify what MIL is to them.

The next, and final chapter in the thesis, will consider the issues of reflexivity and how rigour and quality was appraised in the study.

CHAPTER NINE: REFLEXIVITY AND QUALITY APPRAISAL

9.1. Introduction

This chapter, the final chapter in the thesis, begins with an overview of the process of reflexivity. This is followed by illustrative examples of how reflexivity was embedded in the study. Using Yardley's (2000) criteria the chapter then concludes with a discussion of the rigour and quality of the study.

9.2. Defining reflexivity

Positivist research privileges objectivity by viewing subjectivity as a threat to validity (Newton et al., 2011). The researcher enacts procedures without needing to develop self-awareness; positioned as either neutral or absent; decontextualized from their interpersonal, social, and institutional context (Mauthner & Doucet, 2003). Typically, qualitative researchers are more concerned with how their values, beliefs, experience, and context influence every stage of the research process. The qualitative researcher has a more active and involved role in shaping findings (Darawsheh, 2014). Thus, they need to be more self-aware and cognisant of their role in knowledge construction. Becoming self-aware means developing the capacity to recognise and utilise one's self for analytic purposes; as the researcher is a part of—and integral to—the social world that they study (Ackerly & True, 2010). This self-awareness can be fostered through reflexivity.

Reflexivity is this 'thoughtful, conscious self-awareness' (Finlay, 2002, p. 532); the process of introspection concerning the role of subjectivity in research. Being reflexive involves the recognition that a researcher's partial and positioned perspective shapes the creation of the knowledge they produce (Cohen & Manion et al., 2011). Reflexivity constitutes a form of critical thinking; the researcher aims to communicative the contexts that fashion research processes (Lazard & McAvoy, 2017). When carrying out qualitative research 'our subjectivity becomes entangled in the lives of others' (Denzin, 1997, p. 27). Therefore, subjective elements of study

processes need to be made explicit in qualitative reports as the researcher acknowledges and discloses their own selves within the research.

Willig (2001) has suggested that there are two types of reflexivity: personal reflexivity (reflecting on how our selves affect and are affected by the research process) and epistemological reflexivity (reflecting on how the assumptions about the world and knowledge made in the research process impact findings). However, it must also be acknowledged that there may be limits to reflexivity. Developing the level of self-awareness required to unveil *all* of the unconscious filters that we view the world through is likely beyond our reach. Therefore, it may be best to view reflexivity in terms of degrees; some influences are easier or more difficult to identify and some only become apparent years after the research is published (Mauthner & Doucet, 2003). Nonetheless, reflexivity adds to the rigour and quality of qualitative inquiry as it enhances the transparency of the subjective role of the qualitative researcher (Jootun et al., 2009).

9.3. Illustrations of reflexivity within the research processes of the study

To provide a reflexive account of all aspects of my experiences conducting the study is beyond the scope of this thesis. However, in order to illustrate to the reader how the process of reflexivity was embedded within the study, I have offered a reflexive account of two aspects of the study. Namely: (i) utilising service user involvement to enhance reflexivity and (ii) operationalising the philosophical and theoretical propositions adopted.

9.3.1 Utilising service user involvement to enhance reflexivity

Service user involvement in research can act as an aid in reflexivity (Veseth et al., 2017). Having co-founded Ireland's first mental health service user research committee in 2006—Source of User

Research Collaboration and Expertise (SOURCE),⁹¹ I have always seen this involvement as justified on multiple grounds: ethically/morally, politically, and methodologically. From the outset I was required to reconcile the desire to engage in the entire gamut of service user involvement in research⁹² (Shippee et al., 2013) with the need to have ownership over and direct my PhD study. I considered it unethical to share responsibility for developing my research idea, designing study procedures, and executing operational components when I would be the primary beneficiary of its success. I therefore chose one aspect of the study to expose to service user scrutiny: the development of the interview schedule used in data collection.

Engaging in a consultation process with a service user on the interview guide made me cognisant that there was a risk (within the interview process) that service user perspectives could inadvertently become subverted by my desire to contribute something new to the literature. I became aware that if a participant provided a novel insight within the interview that challenged the literature, my enthusiasm for exploring this could blind me to other aspects of MIL important to the participant. The consultation taught me to balance my own respectful curiosity with the priorities of the participants. I linked this realisation to the phenomenological aspect of the study; placing the exploration of experience and its perception at its centre. Thus, I sought to elicit participants' embodied, situated, and lived process of developing perspectives and assigning meaning to that experience.

The focus on openness I took from the service user consultation helped me to avoid applying pre-established ideas about MIL and psychosis onto participants' accounts before meaning and interpretation were even elicited. For example, prior to the consultation I held the philosophical stance (derived from the biomedical perspective) that there would be some aspects of psychosis experiences that would be impossible for me to understand. The consultation made me realise that

⁹¹ A service user research committee based in the Cluain Mhuire Mental Health Service (County Dublin) which operated from 07/2006 - 10/2012. In that time, SOURCE was successful in securing €305,000 in research funding.

⁹² Service user involvement in research can occur at the preparatory, execution, and translational phase.

all experience is potentially comprehensible which gave me the confidence to probe further during the interviews. When designing the interview guide, I realised that I was struggling to empathise with the experience of psychosis as I have never experienced it. This was distressing as it made me question the position of authority I would adopt when representing participants' accounts. The consultation taught me that I could choose to empathise with the participant themselves, and not the 'illness' they were diagnosed with. I believe this enhanced the richness of the data collected in the interviews. An example of how the consultation enriched the data can be seen in Natasha's interview. In part, due to the open nature of the questions in the finalised questionnaire, Natasha shared a rich, in-depth, and comprehensive first-person account of her experience of living with her belief that all life was a computer simulation.

9.3.2 Operationalising the philosophical and theoretical propositions adopted

My experience of working in mental health research roles since 2006 (particularly in the areas of supported socialisation, psychiatric stigma, and recovery in psychosis) drew my attention to how marginalised, excluded, and isolated people experiencing mental health difficulties can be in Irish society. Over the years, I became disenchanted with the quantitative paradigm in its ability to represent sufficiently peoples' experience of psychosis in academic discourse. Prior to commencing my PhD study, I realised that this perceived limitation was due to the philosophical and theoretical underpinnings of positivistic quantitative research. Hence, I decided to embark on a qualitative PhD. However, the diverse yet complementing perspectives on knowledge, reality, and theory I adopted (see Chapter 4) and incorporated into IPA presented significant challenges.

The initial exhilaration of escaping the confines of positivism allowed me to select philosophical underpinnings more aligned to my personal worldview. For example, I could conduct research congruent with my belief that objective science is not possible in the mental health field. However, it took me time to relinquish the lingering positivist stance from my past, to fully respect IPA's grounding in hermeneutics, and to not ascribe to the assumption that qualitative research simply

‘gives voice’ to participant perspectives. At the early stage of the research process, this desire to *give voice* blinded me from my own subjectivity. On commencing data analysis, I began by applying the distance and neutrality that had been advantageous in previous quantitative research roles. I saw my initial interpretations of participants’ experiences as direct reflections of these experiences. It was only after dwelling on the data that I realised that there were many possible interpretations available to me; that it was *my* subjectivity that determined findings. I realised I had been attending to participants’ narratives through a filter of my past experiences. I was assuming that *all* participants experienced psychiatric stigma and that their struggle against it would dominate their experience of MIL. This was not the case.

Critical realism permits qualitative research to explore the values and meanings participants assign to the world without arguing that knowledge is solely limited to these (Lipscomb, 2008).

Consequently, in the study I did not aim to unearth a single universal truth. Adopting a critical realist stance meant that the narratives elicited in data collection were viewed as doors onto reality; reflected by participants’ thoughts, behaviours, emotions, and experiences. I found adopting this stance particularly challenging due to the disconnect I perceived between my reality (and what I viewed as consensus reality) and the reality experienced by participants who I (from my education and training) had previously construed as ‘floridly’ psychotic. For these participants, I struggled to not interpret the majority of their experiences as *symptoms* of psychosis. This influenced whether data were coded as relating to ‘meaning making in psychosis experiences’ or ‘MIL’.

I aimed to address the influence of context on interpretation by ensuring interpretations were grounded in, and based on, actual descriptions of phenomena provided by participants. However, from the contextualist standpoint, in research, the intrinsic subjectivity of both researcher and participant accounts means that such accounts are not necessarily invalidated by conflicting alternative perspectives (Madill et al., 2000). Given that data obtained in research is a construction between the researcher and participant, I could not use IPA to produce an indisputably first-person account. Thus, I aimed to contextualise all data in my analysis so that each participant’s claim could be interpreted accordingly. Providing this level of detail was challenging considering the

volume of data analysed. In presenting findings, I struggled to strike a balance between explaining a theme, offering evidence from transcripts for the theme, and contextualising data presented; without overburdening the reader.

My relatedness to MIL and psychosis as well as to the participants themselves⁹³ also impacted study findings. My own personal perspective on MIL is that meaning largely arises through others; from helping others, learning from others, developing close relationships/a wider community; and treasuring and celebrating life with others. Although this perspective was temporarily withheld and suspended in my attempt to be true to the operation of epoché and bracketing, it may have resulted in me unconsciously privileging the social aspects of MIL in the analysis. This is a potential bias as asociality is a core feature of psychosis (Kasanova, 2018).

Prior to conducting this PhD study, I understood psychosis to *only* be detrimental to a person's life (damaging their health and wellbeing). Having spent years immersed in the culture of, and advocating for, Early Intervention in Psychosis, I was unaware of the profound value that people ascribed to their psychosis experiences. For some, they were the most important experiences of their lives. My unawareness of this meant, in the analysis, I may have inadvertently privileged how psychosis experiences eroded MIL. While I believe the themes developed are an accurate reflection of the dataset, this bias could possibly be reflected in how the majority of 'Meaning making in psychosis experiences' themes relate to this erosion.

I had a pre-established relationship with participants before they took part in the MIL study. I had met them to collect data for another study. While this meant that rapport was easier to establish, it also may have influenced the accounts participants shared with me. For example, participants may have presumed I had a prior understanding of their circumstances; therefore may have omitted details in their accounts.

⁹³ What Heidegger (1962) describes as fore-structure.

To ensure the study maintained an idiographic positioning, I consciously worked to minimise the risk that essential individual differences were obscured by my efforts to identify common experiences and generate themes across the entire dataset. While I understood experiences as idiographic, I also assumed that (when considered collectively) multiple accounts produced a common pool that reflected a shared experience of the world as it appears. Although engagement in the hermeneutic circle helped, I personally found it difficult to balance these conflicting priorities. I hope that I have conducted a nuanced detailed analysis of specific examples of lived experience in order to unpack the complexity of MIL and illuminate extant knowledge.

9.4 Appraising the rigour and quality of the study

9.4.1 Is the study an Interpretative Phenomenological Analysis?

While there are various versions of phenomenology, IPA is a unified field. This may appear counter intuitive as IPA allows ‘more room for creativity and freedom than other approaches’ (Willig, 2013, p. 99). While the originator of IPA stresses its non-prescriptive and adaptable nature (Smith et al., 2009), this plasticity does not infer inconsistency or the absence of rigour. Although IPA can be conducted using a wide variety of different data collection techniques (Smith et al., 2009; Brocki & Wearden, 2006) and IPA has the capacity to engage with research that adopt theoretical frameworks⁹⁴ as well as those that do not (Reid et al., 2005), the approach does not lack consistency. According to Smith (2010, p. 189), ‘there are a set of research steps that need to be made and these do need to be made in the appropriate order’. If one follows these steps, stays true to the philosophical underpinnings of IPA, and focuses on experience and sense making, then an IPA study is actualised. If any of these are deviated from, then an IPA study is not realised. By meeting these three requirements, the study can be deemed an IPA.

⁹⁴ For example, Green et al (2004) used the self-regulation model as a framework for analysis in IPA.

9.4.2 Yardley's criteria for rigour and quality

In the study, I used Yardley's (2000) criteria of: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. These criteria enabled me to appraise quality and rigour while remaining congruent with the epistemological, ontological, and methodological arguments outlined in Chapter 4.

9.4.3 Sensitivity to context

According to Yardley (2000) high quality qualitative research should demonstrate a sensitivity to the multifaceted context in which it is situated. Within the study, this sensitivity related to multiple factors: an in-depth understanding of the theoretical discourses on MIL; the empirical literature relating to MIL, meaning making, psychosis, and mental health recovery; and the philosophical underpinnings of IPA. This sensitivity enhanced the analysis presented (by enabling an in-depth examination of MIL) as I was grounded in the philosophy of IPA and I had an awareness of the concepts that had been applied to MIL by previous investigators. The findings presented both echo published research in this field and suggest new ways of conceptualising MIL in the context of recovery in psychosis. Sensitivity to the tenets of phenomenology (e.g. its focus on experience in its own right) allowed the interrogation and unpicking of assumptions that underpin the intellectual history of academic work in this area. For example, the assumption (within the medical narrative) that psychosis has no meaning outside of the medical constructs operationalised to ascribe meaning to it.

Sensitivity to context was demonstrated by attending to how the socio-cultural milieu in which the study took place influenced the course and outcome of the study. Language, culture, and social interaction were seen to shape the meaning participants ascribed to their experiences.

Understanding the 'normative, ideological, historical, linguistic and socioeconomic influences on the beliefs, objectives, expectations and talk of all participants' (Yardley, 2000, p. 220) was

privileged. In doing so, the constant interaction between participants and their environment was recognised. For example, I reflected on how Catholicism within Irish society and the Catholic ethos of the mental health service (in the research site) might impact participants' interpretation of their psychosis experiences. Data collection processes were also conducted in a manner that was sensitive to participants' individual context. During interviews, participants were put at ease, treated empathetically, and any interactional difficulties were identified and responded to.

The study participants and I (as the researcher) were also placed in context. Participants' demographic characteristics and their 'psychiatric diagnoses' were presented. In interpreting study findings, how these factors may have influenced the accounts participants provided was discussed. My positionality was disclosed and how it affected every stage of the research process was considered. As I have not experienced psychosis myself, my professional experience of working with people with psychosis has been described. How this experience has influenced my expectations of the study and how it was conducted has been reflected on.

The social context of my relationship with participants within the study has also been considered. Participants' speech in their interviews was seen as an act of communication intended to have a specific meaning for and an effect on *me* (Yardley, 2000). Therefore, I reflected on how the interactional nature of the research interview itself determined the content of participants' accounts (i.e. social desirability may have led to omissions of important aspects of meaning making). The power differential present in our relationship was closely attended to and how this was managed over the study lifetime was discussed in Chapter 5. Thus, the role of context in shaping the narratives participants imparted to me was acknowledged. Ethical sensitivity was shown in the detailed examination of specific ethical issues relating to researching people with experience of psychosis (Chapter 5). The sensitivity of the study to the data is demonstrated by my attempt to ground my analytic claims in participants' accounts and supporting them with quotes (Smith, 2015), while acknowledging that my interpretation is just one of many possible interpretations. It is hoped that an appropriate level of contextual detail (for the extracts presented, study participants, the researcher, and the study itself) has been provided to the reader (Larkin & Thompson, 2011).

Ultimately, the degree to which sensitivity to context was achieved will be determined by the reader judging if the study offers compelling and convincing findings.

9.4.4 Commitment and rigour

Yardley (2000) has defined commitment as developing competence in research methods used, engagement with the research topic, and full immersion in theoretical and empirical data relevant to the study. I was committed to realising the skills necessary to carry out the study. I completed an introductory and an advanced workshop in IPA at the Qualitative Research Summer School in Dublin City University. These were delivered by experts in the field (Prof Paul Flowers and Dr Virginia Eatough). The literature was also widely searched in order to enhance my understanding of IPA, my competence in executing IPA, and knowledge of the ways in which data in IPA could be analysed and presented. How competence in qualitative interviewing was developed has also been described. Commitment was demonstrated through perseverance in selecting and recruiting a sample of participants who are known to be difficult to engage in research (Patterson et al., 2014). Triangulation of data collection and analysis was employed (by exploring the perspectives of two groups) in order to achieve a grounded multilayered understanding of the research topic (Yardley, 2000). Immersion in relevant data has been demonstrated in the theoretical, empirical, and discussion chapters of this thesis. Commitment was also demonstrated by my engagement in the academic supervision process through my openness to the study being extensively critiqued and my dedication to revising this thesis to address these critiques.

For Yardley (2000), rigour refers to completeness of data collection and analysis. In IPA this completeness is describes as ‘thoroughness of the study’ (Smith et al., 2009, p.181). Thoroughness is determined by carefully and appropriately selecting a sample to provide a dataset that is sufficiently rich in order to answer the research question posed to it; ensuring data collection is performed to a sufficient standard to elicit such a dataset; and engaging in a detailed, meticulous, and comprehensive analysis of the dataset (Smith et al., 2009; Larkin & Thompson, 2011). During

interviews, I was highly attentive to what participants were saying, the nonverbal cues indicating how they were feeling, and their level of comfort.

In the analysis, effort was made to elucidate the distinctiveness of individual experience as well as the similarity among participants regarding their experience of the phenomenon in question. The analysis presented sought to sufficiently represent the entire dataset by making sure that the extracts offered in support of themes was derived from all participants interviews and not just a select few. Where possible, the depth and breadth of each theme presented was demonstrated by providing multiple extracts per theme to show the convergence, divergence, representativeness, and variability within the dataset. The nuanced description of themes offered shows how participants manifested the same theme in specific and diverse ways. The aim was to provide an analysis that transcended the interview guide used; balanced phenomenological detail with interpretation; and focused ‘on how things were understood rather than on what happened’ (Larkin & Thompson, 2011, p. 112). The goal was for the research findings presented to: attend to both analytic and reflexive aspects of the research process; be pitched appropriately; and engage sufficiently with theory in making sense of the analysis (Larkin & Thompson, 2011). Academic supervision was also used to enhance study rigour as the study’s methodology and findings were extensively critiqued and refined in the supervision process.

9.4.5 Transparency and coherence

Yardley (2000) understands transparency as the degree to which all relevant aspects of the research processes are disclosed and the clarity of the description of such processes. In the context of an IPA study using interviews, this means clearly explaining how participants were sampled, how the interview guide was constructed, how the interviews themselves were conducted, and how each stage in the analysis was performed (Shinebourne, 2011). In the methodology and methods chapters I have provided this clarity and explained the arguments underpinning the methodology used and methodological decisions made.

Extensive effort has been made to be as transparent as possible in showing how study findings were arrived at. The extracts presented (and the commentary offered on them) in the results chapters allow the reader to discern if the themes developed are a reasonable representation of participants' accounts. Findings were reviewed to ensure that: all claims made were referenced to data, extracts were never allowed to speak for themselves, and that there was substantive engagement with and commentary on some large data extracts (Larkin & Thompson, 2011). I have made relevant disclosures regarding research processes in my reflexivity statement. In it, I have disclosed my own predispositions, discussed the experiences and motivations that led me to undertake the study, and detailed the external pressures and constraints that impacted the study (Yardley, 2000; Shenton, 2004).

Coherence, in the context of an IPA study, refers to the persuasiveness and rhetorical power of the arguments presented. Qualitative research requires a researcher to construct a version of reality in a manner that is meaningful for the reader. This reality should resonate with, and be believable to, the reader (Yardley, 2010). Coherence was pursued through careful writing, flagging arguments for the reader, and critique and revision through academic supervision. Attaining coherence also required the integration of ambiguities and contradictions within the dataset in the analysis (Smith et al., 2009). The superordinate theme *Finding a place for psychosis or not needing to* is an example of how this integration was achieved. For the study, coherence also reflected the degree to which its aim was congruent with the philosophical perspective adopted, the research methods utilised, and the analysis conducted. It is hoped that from reading the thesis in its entirety, the reader can conclude that this fit is present and that the study has been carried out according to the principles of IPA.

9.4.6 Impact and importance

The final quality criterion put forward by Yardley (2000) concerns the utility of a piece of research.

Utility is judged in terms of a study's value in meeting the objectives it set out to achieve; its application in the ways it was intended to be used; and the audience to which its findings were meant to influence. A good piece of research is impactful; it should alter the beliefs and actions of other people by informing them of something interesting, important, and useful (Smith et al., 2009). A full appraisal of this criterion cannot be made at this stage as it is only once research is published and in the public realm that an extensive appraisal of its resonance can be made (de Witt & Ploeg, 2006).

Nonetheless, at this stage it is possible to point to the potential impact of the study on academic thought, policy, and clinical practice. Recommendations for research, policy makers, and mental health practitioners have been made. An objective of IPA research is to cautiously make claims to theoretical transferability (Smith et al., 2009). These claims constitute the external validity of IPA research. The evidence for theoretical transferability is accessed by the reader using their experiential knowledge (and professional knowledge if working in the field being investigated) to appraise whether ideas developed and insights gained from the study can be transferred to other contexts (Smith et al., 2009). To facilitate this, participants' characteristics and experiences as well as the study context, setting, and time period were described.

The study aimed to demonstrate its theoretical worth by offering a novel and original perspective that opens up new ways of understanding meaning making and MIL in the context of recovery in psychosis. It is for the reader to interrogate findings to determine whether they cause a revaluation of what is considered known or understood about this topic. Findings should be appraised in terms of how they enhance insight, contribute to or challenge existing theory, and generate new research ideas (Yardley, 2000). The reader can make this appraisal by considering the future research recommendations and the argument (presented in Chapter 8) that findings contribute to theory and the conceptual clarity of MIL in mental health.

It is also envisioned that study findings may have a socio-cultural impact (Yardley, 2000). If disseminated broadly they might (in some small way) alter how people talk about psychosis; both

within and outside of mental health services. Specifically, that we (as a society) adopt a more balanced understanding of the impact of psychosis on MIL; that psychosis is recognised for *both* the destruction it causes to MIL but also the positive contribution it makes to MIL. The importance of the study is also evident in the presence and primacy of MIL in service user defined recovery (e.g. Deegan, 1998).

9.5 Chapter summary and conclusion

This chapter, the final chapter in the thesis, defined reflexivity and provided examples of how reflexivity was engaged in over the course of the study. The chapter also discussed the steps taken to promote rigour and quality within the study. In Smith et al.'s (2009) view, an IPA study should satisfy Yardley's (2010) criteria of sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. In doing so, it should be able to generate new insight about participants' experience of the phenomenon being investigated (Larkin et al., 2006). It is hoped that study findings will enable health professionals, researchers, and policy makers to develop a greater understanding of the impact of meaning making in psychosis experiences on MIL and the centrality of MIL in recovery in psychosis. In this way, we can begin the process of reversing the devaluing of psychosis experiences within the mental health system and better support people to live meaningful lives.

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APPENDICES

APPENDIX ONE: PARTICIPANT INFORMATION LEAFLET



TRINITY COLLEGE DUBLIN
COLÁISTE NA TRÍONÓIDE

THE
UNIVERSITY
OF DUBLIN

Participant Information Leaflet

Title of Study:

Meaning in Life Study

Thank you taking the time to read this leaflet.

Introduction:

Meaning in Life can come from live goals, social roles, values, relationships, work, purpose, a life philosophy, spirituality, art, and nature. Meaning in life is seen as part of recovery in mental illness, however very little research has been done to explore what gives people meaning in life and how that meaning helps people in their recovery. Learning about meaning in your life may help us improve how we educate mental health professionals so they can better support peoples' recovery in the future. It may also help us to develop new ways of helping people.

The aim of this study is to explore your perspective on

- a) meaning in life,
- b) the meaning of your experience of psychosis,
- c) and how meaning in life has influenced your recovery,

This study is being conducted by me, Donal O'Keeffe. I am a PhD candidate in the School of Nursing and Midwifery, Trinity College Dublin. The study is being supervised by Prof Agnes Higgins, Dr Brian Keogh, and Prof Mary Clarke. This study has received full ethical approval from the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin and the Saint John of God Hospitaller Ministries Research Ethics Committee.

What is involved?

I am asking you to complete an **Interview** with me, which will last between 30-90 minutes. This interview will take place in a place of convenience for you (e.g. a room in a hotel, a local health centre, Trinity College Dublin, a mental health service). During the conversation I will ask you open ended questions or ask you to elaborate on your answers. I will also request your permission to audiotape these interviews. Questions will focus on meaning in life, your experience of psychosis, and recovery. There are no right or wrong answers I

am only interested in your views. After the interview, you will be given the opportunity to review the interview transcript.

Benefits and Risks

Participating in this study may help improve the mental health services in Ireland for people with experience of psychosis. The only risk involved in participating is that you may become upset by discussing meaning in life, your experience of psychosis, and recovery. If you do, I will ask you if you wish to stop the interview and the audio recorder. I will also offer you information on support services. If you are very distressed, I will look for your permission to contact a health professional and/or a voluntary agency. If you think that talking to me about this subject might upset you or cause you any sort of distress then I would prefer that you did not take part in this study, as I do not want to cause any distress that may interfere with your treatment. If you don't feel well enough to talk to me about your experience then I would prefer if you did not participate in this research.

Voluntary Participation

Your participation is entirely voluntary and you may withdraw at any time, without giving a reason and without this decision having any consequence for you. Not consenting to taking part or dropping out will not affect your future treatment or medical care in any way. If you do decide to withdraw from the study, the information you have given me will be destroyed. Likewise, if deemed necessary to protect your welfare, I may have to withdraw your participation in the study without your consent.

Confidentiality

Your identity will remain confidential at all times. Your name will not be published and will not be disclosed to anyone. I will keep the information you share in your interview strictly confidential. However, I may be required to inform a health professional or other relevant people (including An Garda Síochána) if you disclose that there is a risk of harm to yourself or others. If I have to make such a disclosure, I will inform you that it is taking place. The results of this study will be published in a PhD thesis and may be published in journal articles. However, there will be no way of identifying you; no personal details will be included in any published material.

Data Protection

All data will be stored securely and in line with the Data Protection Acts 1988/2003. All tapes, hardcopy transcripts and interview notes will be stored in a locked filing cabinet in a secure office. The information you give us will be entered into a computer for analysis. Electronic data will be stored on a password protected computer in a way that prevents you from being identified. After the study, your information will be held securely by Saint John of God Community Services Ltd. After 5 years, all study data will be destroyed.

Insurance

This study is covered by standard institutional indemnity insurance provided by Trinity College Dublin. Nothing in this insurance policy restricts or curtails your rights.

The Next Step

If you are willing to participate or want to hear more or have any questions about the study, please complete the Expression of Interest Form enclosed in this information pack and return it to me in the stamped addressed envelope provided? The form asks for your name, phone number, a preferred contact day and time. Once I receive, it I will call you to discuss the study further with you. If you are willing to take part, I will then set up a time and a place to (a) run through the enclosed Consent Form with you, (b) take your consent, and (c) conduct the interview.

Thank you for taking the time to read this leaflet. If you have any questions about the study, please get in touch.

Yours sincerely,

Donal O'Keeffe

PhD Candidate
Lead Researcher (Meaning in Life Study)

Contact Details

Address: DETECT Early Intervention in Psychosis Service, Avila House, Block 5, Blackrock Business Park, Blackrock, Co Dublin.

Phone: 01 279 1701 / 087 906 1730. **Email:** donal.okeeffe@sjog.ie

APPENDIX TWO: THE POSITIVE AND NEGATIVE SYNDROME SCALE (PANSS) (KAY ET AL., 1987)

POSITIVE AND NEGATIVE SYNDROME SCALE (PANSS) RATING CRITERIA

GENERAL RATING INSTRUCTIONS

Data gathered from this assessment procedure are applied to the PANSS ratings. Each of the 30 items is accompanied by a specific definition as well as detailed anchoring criteria for all seven rating points. These seven points represent increasing levels of psychopathology, as follows:

- 1- absent
- 2- minimal
- 3- mild
- 4- moderate
- 5- moderate severe
- 6- severe
- 7- extreme

In assigning ratings, one first considers whether an item is at all present, as judging by its definition. If the item is absent, it is scored 1, whereas if it is present one must determine its severity by reference to the particular criteria from the anchoring points. The highest applicable rating point is always assigned, even if the patient meets criteria for lower points as well. In judging the level of severity, the rater must utilise a holistic perspective in deciding which anchoring point best characterises the patient's functioning and rate accordingly, whether or not all elements of the description are observed.

The rating points of 2 to 7 correspond to incremental levels of symptom severity:

- A rating of 2 (minimal) denotes questionable or subtle or suspected pathology, or it also may allude to the extreme end of the normal range.
- A rating of 3 (mild) is indicative of a symptom whose presence is clearly established but not pronounced and interferes little in day-to-day functioning.
- A rating of 4 (moderate) characterises a symptom which, though representing a serious problem, either occurs only occasionally or intrudes on daily life only to a moderate extent.
- A rating of 5 (moderate severe) indicates marked manifestations that distinctly impact on one's functioning but are not all-consuming and usually can be contained at will.
- A rating of 6 (severe) represents gross pathology that is present very frequently, proves highly disruptive to one's life, and often calls for direct supervision.
- A rating of 7 (extreme) refers to the most serious level of psychopathology, whereby the manifestations drastically interfere in most or all major life functions, typically necessitating close supervision and assistance in many areas.

Each item is rated in consultation with the definitions and criteria provided in this manual. The ratings are rendered on the PANSS rating form overleaf by encircling the appropriate number following each dimension.

PANSS RATING FORM

		<u>absent</u>	<u>minimal</u>	<u>mild</u>	<u>moderate</u>	<u>moderate severe</u>	<u>severe</u>	<u>extreme</u>
P1	Delusions	1	2	3	4	5	6	7
P2	Conceptual disorganisation	1	2	3	4	5	6	7
P3	Hallucinatory behaviour	1	2	3	4	5	6	7
P4	Excitement	1	2	3	4	5	6	7
P5	Grandiosity	1	2	3	4	5	6	7
P6	Suspiciousness/persecution	1	2	3	4	5	6	7
P7	Hostility	1	2	3	4	5	6	7
N1	Blunted affect	1	2	3	4	5	6	7
N2	Emotional withdrawal	1	2	3	4	5	6	7
N3	Poor rapport	1	2	3	4	5	6	7
N4	Passive/apathetic social withdrawal	1	2	3	4	5	6	7
N5	Difficulty in abstract thinking	1	2	3	4	5	6	7
N6	Lack of spontaneity & flow of conversation	1	2	3	4	5	6	7
N7	Stereotyped thinking	1	2	3	4	5	6	7
G1	Somatic concern	1	2	3	4	5	6	7
G2	Anxiety	1	2	3	4	5	6	7
G3	Guilt feelings	1	2	3	4	5	6	7
G4	Tension	1	2	3	4	5	6	7
G5	Mannerisms & posturing	1	2	3	4	5	6	7
G6	Depression	1	2	3	4	5	6	7
G7	Motor retardation	1	2	3	4	5	6	7
G8	Uncooperativeness	1	2	3	4	5	6	7
G9	Unusual thought content	1	2	3	4	5	6	7
G10	Disorientation	1	2	3	4	5	6	7
G11	Poor attention	1	2	3	4	5	6	7
G12	Lack of judgement & insight	1	2	3	4	5	6	7
G13	Disturbance of volition	1	2	3	4	5	6	7
G14	Poor impulse control	1	2	3	4	5	6	7
G15	Preoccupation	1	2	3	4	5	6	7
G16	Active social avoidance	1	2	3	4	5	6	7

APPENDIX THREE: CLIENT SOCIO-DEMOGRAPHIC AND SERVICE RECEIPT INVENTORY – EUROPEAN VERSION

CLIENT SOCIODEMOGRAPHIC AND SERVICE RECEIPT INVENTORY (CSSRI - IE)

Centre ☐ Patient Study Number ☐☐☐☐☐☐ Date ☐☐☐☐☐☐
d d m m y y

1. SOCIODEMOGRAPHIC INFORMATION

1.1	Date of birth	Date	☐ ☐ ☐ ☐ ☐ ☐ d d m m y y
1.2	Sex	1 Female	
		2 Male	☐
1.3	Marital status (From a legal perspective)	1 Single/unmarried	
		2 Married	☐
		3 Separated	
		4 Divorced	
		5 Widow/widower	
		9 Not known	☐
1.4	What is your ethnic group? (Refer to manual for assistance)	Ethnic group	_____
1.5	Country of birth	Country	☐ ☐ ☐
1.6	Mother tongue	1 National language	
		2 Other language (but having <u>good</u> Knowledge of national language)	_____
		3 Other language (and having <u>poor</u> or <u>no</u> knowledge)	☐
1.7	Number of years of schooling in <u>general</u> education	Number of years schooling	☐ ☐
1.8	Highest completed level of education	1 Primary education or less	
		2 Secondary education	
		3 Tertiary / further education	
		4 Other general education	
		9 Not known	☐
1.9	What <u>further</u> education or vocational training have you completed or are doing now? (Tick all boxes that apply)	1 Specific vocational training (< 1 year)	☐
		2 Specific vocational training (> 1 year)	☐
		3 Tertiary level qualification /diploma	☐
		4 University degree (undergraduate)	☐
		5 University higher degree (postgraduate)	☐
		6 Other vocational training	☐

1.10	Diagnosis	_____	
1.11	Current legal status	_____	
1.12	How much time in total spent in hospitals (days)?		
1.13	How many times has the person been compulsorily admitted?		
1.14	How many mental health tribunals has the person had?		
1.15	How many occurred after the admission order was revoked?		

2. USUAL LIVING SITUATION

2.1	What is your usual/normal living situation now?	1 Living alone (+/- children) 2 Living with husband/wife (+/- children) 3 Living together as a couple 4 Living with parents 5 Living with other relatives 6 Living with others 9 Not known	

2.2 What kind of accommodation is it? (Refer to manual for definitions)

<u>Domestic / family</u>	1 Owner of own flat/home 2 Parent / relative owned flat or house 3 Privately rented flat or house 4 Rented from local authority/municipality or housing association/co-operative	
<u>Community (non-hospital)</u>	5 Overnight facility, 24-hour staffed 6 Overnight facility, staffed (not 24-hour) 7 Overnight facility, unstaffed at all times	
<u>Hospital</u>	8 Acute psychiatric ward 9 Rehabilitation psychiatric ward 10 Long-stay psychiatric ward 11 General medical ward 13 Homeless / roofless	
	14 Other _____	

2.3 If domestic accommodation:

How many adults live there? (over the age of 18)	Number of adults	
And how many children? (under the age of 18)	Number of children	

Note: If hospital or community accommodation:

Complete the final sheet of the schedule after finishing this interview.

2.4 Have you lived anywhere else in the last 12 months? Yes = 1; No = 2 ☐

If yes: please complete table:

Accommodation type (see Q. 2.2 for code)	Number of days in last 12 months

EMPLOYMENT AND INCOME

3.1 What is your employment status?

1 Paid or self employment
2 Voluntary employment
3 Sheltered employment
4 Unemployed
5 Student
6 Housewife/husband
7 Retired
8 Other ☐

3.2 *If employed:* state occupation:
(Refer to manual for definitions)

1 Manager/administrator
2 Professional (e.g. health, teaching, legal)
3 Associate professional (e.g. technical, nursing)
4 Clerical worker/secretary
5 Skilled labourer (e.g. building, electrical etc)
6 Services/sales (e.g. retail)
7 Factory worker
8 Other ☐

How many hours a week do you work? ☐

How many days have you been
absent from work owing to illness
within the last 12 months? ☐

Days absent from work ☐

3.3 *If unemployed:*

Number of weeks unemployed
within the last 12 months ☐

Number of weeks ☐

3.4 Do you receive any state benefits? Yes = 1; No = 2 ☐

If yes: What benefits are received?
(Please tick all boxes that apply)

International categories

National variants

Unemployment /income support

1 Jobseeker's allowance or benefit (Unemployment assistance 'dole')
(Supplementary welfare allowance if self-employed) ☐

2 Back to work allowance ☐

Sickness/disability

3 Illness Allowance (Disability allowance) ☐

4 Illness Benefit (Disability benefit) ☐

5 Invalidity Pension (Disability pension) ☐

Housing

6 Rent allowance ☐

7 Fuel allowance ☐

8 Household benefits ☐

Other benefits

9 Living alone increase ☐

10 State pension ☐

11 Child benefit ☐

12 Medical card ☐

13 Travel allowance (bus pass) ☐

14 Other ☐

3.5 Do you have health insurance? Yes = 1; No = 2 ☐

3.6 What is your main income source?

1 Salary/Wage

2 State benefits

3 Pensions

4 Family support (e.g. from spouse or parents)

5 Other ☐

3.7 What is your total personal gross income from all sources?

CSSRI - IE (CB)

Final version: Sep 2014

4

(Note: if gross income not known, please give net income, i.e. after tax and other deductions)

<u>Weekly</u>	or	<u>Monthly</u>	or	<u>Yearly</u>	
1 Under €149		1 Less than €649		1 Less than €7,785	
2 €150 - €204		2 €650 - €885		2 €7,786 - €10,635	
3 €205 - €279		3 €886 - €1,208		3 €10,636 - €14,504	gross income ☐
4 €280 - €392		4 €1,209 - €1,699		4 €14,505 - €20,394	or net income ☐
5 More than €393		5 More than €1,700		5 More than €20,395	

4. SERVICE RECEIPT

4.1 Please list any use of **inpatient hospital services** over the last 12 months

(Note 1: please enter '0' if service has not been used; Note 2: see manual for definitions)

Service	Sector (1 = public; 2 = private, 3= Voluntary)	Admissions	Total number of inpatient days (over the last 12 months)
Acute psychiatric ward			
Psychiatric rehabilitation ward			
Emergency / crisis centre			
General medical ward			
Other _____			

4.2 Please list any use of **outpatient hospital services** over the last 12 months

(Note 1: please enter '0' if service has not been used; Note 2: see manual for definitions)

Service	Sector (1 = public; 2 = private, 3= Voluntary)	Unit of measurement	Number of units received (over the last 12 months)
Psychiatric outpatient visit - consultant		Appointment	
Psychiatric outpatient visit – Senior Registrar		Appointment	
Psychiatric outpatient visit - Registrar		Appointment	
Psychology outpatient visit		Appointment	
Social worker outpatient visit		Appointment	
Occupational therapist OPD visit		App / Session	
Community psychiatric nurse OPD visit		Appointment	
Depot clinic		Appointment	
Other hospital outpatient visit (incl. A&E)		Attendance	
Day hospital		Day attendance	
Clozapine Clinic		Appointment	
Other _____			

4.3 Please list any use of **community-based day services** over the last 12 months

(Note 1: please enter '0' if service has not been used; Note 2: see manual for definitions)

Service	Sector (1 = public; 2 = private, 3= Voluntary)	Number of attendances	Average duration of attendance

Community mental health centre / Day centre			
Group therapy			
Sheltered workshop			
Specialist education			
Other _____			

PRIMARY AND COMMUNITY CONTACTS

- 4.4 Please list any other **primary and community care contacts** over the last 12 months (*Note 1: enter '0' if service has not been used; Note 2: see manual for definitions*)
ANY SERVICE NOT INCLUDED IN ANY CATEGORY ABOVE IE NOT WITHIN THE HOSPITAL/OPD SYSTEM

Service	Sector (1 = public; 2 = private, 3 = Voluntary)	Total number of contacts over the last 12 months	Average contact time (minutes)
Psychiatrist			
Psychologist			
Individual counselling /therapy			
Group counselling / therapy			
General practitioner			
Public health nurse			
Community psychiatric nurse / case manager			
Other nursing services			
Social worker			
Occupational therapist			
Home help / care worker			
Support services e.g SI, GROW, etc.			
Community care			
Other _____			
Other _____			

- 4.5 Over the last 12 months, has the patient been in contact with the **criminal justice services**? Yes = 1, No = 2 ☐
- Were the Gardai required to assist any admissions? Yes = 1, No = 2 ☐
- If yes:** How many contacts with the police Contacts ☐
- How many psychiatric assessments whilst in custody? Assessments ☐
- How many (criminal or civil) court appearances? Criminal courts ☐
- Civil courts ☐

5. MEDICATION PROFILE

- 5.1 Please list below use of any drugs taken over the last year:

Name of drug	Dosage (if known)	Dosage frequency	Depot (1 = Yes; 0 = No)
1.			
2.			
3.			
4.			
5.			
6.			

6. CARER PROFILE

Independent Yes = 1, No = 2 ☐

Who is the main caretaker?

1 Parent

2 Partner

3 Other family member

4 Other ☐

How many days off work has the carer needed to take when the person has been ill in the last 12 months? ☐

Has the carer had to take time off work to transport family member to appointments Yes = 1, No = 2 ☐

Has the carer given up employment to look after the person? Yes = 1, No = 2 ☐

Has the carer had to spend any of their own money in expenses? Yes = 1, No = 2 ☐

How much in the last 12 months? _____

7. INVESTIGATIONS RECEIVED in the last 12 months

MRI Yes = 1, No = 2 ☐

CT scan Yes = 1, No = 2 ☐

EEG Yes = 1, No = 2 ☐

Other _____

Other _____

Thank You

APPENDIX FOUR: INTERVIEW GUIDE

Introduction

Thank participant for agreeing to take part in your study and for giving you their valuable time.

‘In this interview I am going to ask you about your experiences of Meaning in Life generally and your experiences of psychosis. By ‘psychosis’ I mean: *sensing things other cannot sense; believing things that others find strange; feeling out of touch with reality; having difficulty feeling emotions, experiencing pleasure, or speaking; or not having motivation to be social or to do the things you want to do*’.

Questions

Meaning in Life and its role in recovery

1. Thinking about Meaning in Life...

- a) How do you experience meaning in your life generally?
- b) What gives your life meaning?
- c) Do you think Meaning in Life has a role in your recovery? Y/N ?
 - If so, what role?
 - If not, can you tell me why?
- d) Do you think your experience of a first episode psychosis changed your perspective on Meaning in Life? Y/N

Ask either (i) OR (ii):

- i)
 - If so, how?
 - Before you experienced a first episode psychosis, what gave your life meaning?
 - After you experienced a first episode psychosis, what gave your life meaning?
- ii) Can you tell me why it didn’t change your perspective?

The meaning of psychosis experiences

2. Thinking about your experience of developing difficulties with your mental health 21 years ago...

- a) How do you understand what happened to you at the time you were experiencing psychosis and had first contact with mental health services?
- b) Have you tried to find meaning in that experience? Y/N
 - If so, what does it mean to you?

- If so, how did you find meaning in the experience?
- c) In your day to day life, how do you deal with having had that experience?
 - How do you feel about it?

3. Thinking about your mental health over the last 21 years...

Have you experienced episodes of psychosis since? Y/N

If so,

- a) How do you understand what happens to you during these experiences?
- b) Have you tried to find meaning in these experiences? Y/N
 - If so, what do they mean to you?
 - If so, how did you find meaning in the experiences?
- c) In your day to day life, how do you deal with having had these experiences?
 - How do you feel about them?

4. Thinking about how things are now...

Are you currently experiencing any symptoms of psychosis?. Y/N

If so,

- a) How do you understand what happens to you as you are experiencing psychosis?
- b) Do you try to find meaning in this experience? Y/N
 - If so, what does it mean to you?
 - If so, how do you find meaning in this experience?
- d) In your day to day life, how do you deal with having this experience?
 - How do you feel about it?

(For questions 2, 3, and 4: if needed, refer back to the definition of psychosis in the Introduction)

Role of meaning of psychosis experiences in current perspective on Meaning in Life

5. Thinking about the impact of these experiences on your life...

Ask either (i) OR (ii):

- i) Has the personal meaning you have found in these experiences influenced how you view meaning in your life today?
 - If so, how?
- ii) Has the absence of meaning in these experiences influenced to how you view meaning in your life today?
 - If so, how?

Influences on engagement with what gives the person Meaning in Life

6. Thinking about you being involved in what gives your life meaning...

(NB only ask questions for what participant communicates gives their life meaning)

- a) What would make it easy for you to engage in/engage with /set/achieve/find/develop/maintain X
- b) What would make it hard?

How mental health services can best promote Meaning in Life

7. Thinking about the contact you have had with mental health services over the last 21 years...

- a) Do you think the mental health service helped you experience meaning in your life? Y/N
 - If so, how?
 - If not, how did it not?
- b) Is there anything that the mental health service could have done better regarding this?
- c) How can the mental health service support you now regarding this?
- d) What questions would you like mental health professionals to ask you about meaning in life?
- e) What would you like to ask mental health professionals about meaning in life?

How other health services or community supports can best promote Meaning in Life

8. Did you access any other health services or community supports?

- If so, what?

- a) How did you become aware of these services?
- b) Did they help you experience meaning in your life?
- c) Is there anything they could have done better to support you in this regard?
- d) How can they support you now to experience meaning in your life?
- e) How did the help offered here differ from help offered by formal mental health services?
- f) How might formal mental health services incorporate this type of help?

9. Is there anything else you would like to add?

Ending the Interview

- Thank the participant for sharing their perspective and experiences with you.
- Reiterate that all data provided will be treated with respect and anonymised – so they will not be identifiable.
- Ask the participant how they are feeling after the interview.

Prompts for Questions

Prompts Question 1, 2, & 3: Meaning of psychosis experiences

- Do you accept it, normalise it, or block it out?
- Do you integrate, live with, or move on from it?

Prompts Question 4: General sources of MIL

- Activities?
- Relationships?
- Social roles?
- Goals?
- Values?
- Wellbeing?
- Meeting basic needs?
- Voluntary work?
- Work-related activities?
- Education?
- Spiritual beliefs?
- Environments?
- Nature?
- Art? E.g. drawing or painting a picture?
- Creativity? E.g. writing a short story or a poem?
- Meaning in the recovery process itself?
- Resuming daily activities and-routine?
- Developing new skills?

Prompts Question 5: MIL

- What does your life mean to you today?

Prompts Question 6: Engagement in things that give MIL:

- What makes it easy for you to do these meaningful activities? What makes it hard for you?
- What makes it easy for you to develop and maintain relationships? What makes it hard for you?
- What makes it easy for you to take on and maintain social roles? What makes it hard for you?
- What makes it easy for you to set and achieve goals? What makes it hard for you?

Prompts Question 8: Other health services or community supports MIL

- GP;
- Peer support;
- Online information, online communities, online services, online counselling, mobile phone apps;
- Counselling;
- Other community supports (church, sports club etc).

APPENDIX FIVE: CONSENT FORM



TRINITY COLLEGE DUBLIN
COLÁISTE NA TRÍONÓIDE

THE
UNIVERSITY
OF DUBLIN

PROJECT TITLE:

**Meaning in life for people who have experienced a first episode psychosis:
An Interpretative Phenomenological Analysis**

PRINCIPAL INVESTIGATOR:

Donal O'Keeffe

BACKGROUND:

Participating in this study involves taking part in an interview that explores meaning in life, recovery, and psychosis and having this interview recorded and transcribed. After the interview, you will be given the opportunity to review the interview transcript. The results of this study will be published in a PhD thesis and may be published in journal articles but you will not be identifiable in any published material. Information discussed in this interview will remain confidential unless it relates to disclosures outlined in the information leaflet. The researcher may be required to inform a health professional or other relevant people (including An Garda Síochána) if you disclose that there is a risk of harm to yourself or others.

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement. I understand that the results of this study will be published in a PhD thesis and may be published in journal articles.

PARTICIPANT'S NAME:

CONTACT DETAILS:

PARTICIPANT'S SIGNATURE:

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:..... **Date:**.....

APPENDIX SIX: AN EXAMPLE OF THE PROCESS OF PHENOMENOLOGICAL AND INTERPRETATIVE CODING

The aim of this appendix is to provide an account of ‘Phase 1: An idiographic analysis of each case’ to illustrate (as far as is practicable) the process of phenomenological and interpretative coding in my study. A section from Matt’s account has been used as a case example. This section focuses on Matt’s experience of using mental health services during his FEP.

Phenomenological coding

Participant uncertain why experience happened

Mental health treatment as ‘get off me’

Self as the subject of an experiment, a specimen, a ‘lab rat’

I did have an interview one day where I had the top twelve psychologists in Ireland in the room and I mean thinking they could get me or something or make me see some point of life which wasn’t... and maybe I just wasn’t available, ready to receive what they were trying to help me with. But I still don’t understand why I was there that day with the twelve of them, this was in [psychiatric hospital] in a room as if I was some specimen. You’re kinda going ‘get off me!’ I am sure they are all good but there was a certain kind of nastiness, that is not the right word, but a kind of experiment like you were a lab rat or something. That was the only thing but other than that you have been very helpful to me, thank you.

Commentary

The left hand margin illustrates phenomenological coding in the first phase of the analysis of Matt’s account. His confusion as to why he was treated like ‘a lab rat’ during a mental health evaluation signifies psychosis damaging his identity as a human being. The analysis is the beginning of my interpretation of the social consequences of psychosis for Matt. He wishes to be treated with dignity and for the clinicians assessing him to stop interfering with him. Matt feels like an animal in a cage.

Commentary

The comments in the right hand margin illustrate interpretative coding of the extract. This coding is at a higher level of abstraction. At this stage codes are cautious and provisional. You can begin to see Matt's desire to fight to restore the humanness and dignity he lost in this experience. He seeks to protect his identity as a human being by rejecting how he was treated by mental health professionals during this experience (i.e. his objectification). The experience fundamentally altered his way of *being-in-the-world*.

I did have an interview one day where I had the top twelve psychologists in Ireland in the room and I mean thinking they could get me or something or make me see some point of life which wasn't... and maybe I just wasn't available, ready to receive what they were trying to help me with. But I still don't understand why I was there that day with the twelve of them, this was in [psychiatric hospital] in a room as if I was some specimen. You're kinda going 'get off me!' I am sure they are all good but there was a certain kind of nastiness, that is not the right word, but a kind of experiment like you were a lab rat or something. That was the only thing but other than that you have been very helpful to me, thank you.

Interpretative coding

Experience of no value to participant. Self objectified as knowledge for the mental health system

Mental health treatment: an invasion of the self and an assault on dignity

Protecting identity in process of being dehumanised

APPENDIX SEVEN: AN EXAMPLE OF HOW EMERGENT THEMES WERE DEVELOPED FROM PHENOMENOLOGICAL AND INTERPRETATIVE CODES

The aim of this appendix is to show how the phenomenological and interpretative codes (developed in the idiographic analysis presented in the case example in appendix 6) were used to generate emergent themes. Below see the colour coding (green refers to Matt) as well as the number used beside each phenomenological code to refer to a transcript section. Phenomenological codes are in lower case; interpretative codes are in capital letters. Examples of data from other participants used to develop the emergent theme are coded in pink, grey, and navy.

Emergent theme:

Restoring lost humanness

52 understanding and welcoming



Phenomenological code

PROTECTIVE OF HUMAN STATUS



Interpretative code

72/73 self as the subject of an experiment a specimen a 'lab rat'

PROTECTING IDENTITY IN PROCESS OF BEING DEHUMANISED

72/72 Participant uncertain why experience happened.

EXPERIENCE OF NO VALUE TO PARTICIPANT. SELF OBJECTIFIED AS
KNOWLEDGE FOR THE MENTAL HEALTH SYSTEM.

72/73 Mental health treatment as 'get off me'

MENTAL HEALTH TREATMENT AN INVASION OF THE SELF AND AN
ASSAULT ON DIGNITY

57 AA... a site of inspiration

57 place to experience humanity, gain a understanding of human nature, and intuition
connected to how to help others

VALUING HUMANITY AND ALTRUISM

66 Seen as valuing service user experiences as objects of knowledge ‘people are learning off them’; you have to ‘go through it to know it’.

ACCEPTING OBJECTIFICATION

55 Considered helpful, caring, and thoughtful - having your ‘best interests at heart’

EMBRACING PERSON CENTRED HUMANISING CARE FOCUSED ON SERVICE USER PRIORITIES

16 Being seen as a person – desire for personhood over social status/achievement

DEFENCE OF IDENTITY (PERSONHOOD) - PROTECTING WELLBEING BY DEVALUING SOCIAL STATUS/ACHIEVEMENT

41 services considered lacking in humanity/human connection – no desire to know my ‘self’

41 described as avoidant of participant’s central concerns – their wellbeing

ENFORCED DEHUMANISING SHAME – ‘SELF’ AS UNWANTED BY OTHERS

APPENDIX EIGHT: TRINITY COLLEGE DUBLIN ETHICAL APPROVAL LETTER



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin

Ollscoil Átha Cliath | The University of Dublin

Donal O'Keeffe
School of Nursing & Midwifery
University of Dublin, Trinity College
24 D'Olier Street
Dublin 2

Ref: 150401

Title Of Study: Meaning in life for people who have experienced a first-episode psychosis: An Interpretative Phenomenological Analysis

Dear Donal,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in June 2015, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely,

Dr. Ruth Pilkington
Chairperson
Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte
Foirgneamh na Ceimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

APPENDIX NINE: HEALTH SERVICE ETHICAL APPROVAL LETTER



Saint John of God *Hospitaller Ministries* *Hospitaller Ministries Headquarters*

Mr. Donal O'Keeffe,
Research Assistant and Research Administrator,
St. John of God Community Services Limited,
DETECT Early Intervention in Psychosis Service,
Avila House, Block 5, Blackrock Business Park,
Blackrock,
Co. Dublin.

7th February, 2017

Dear Donal,

Saint John of God Hospitaller Ministries Research Ethics Committee Research Application
“ID629” Meaning in life for people who have experienced a first episode psychosis: An Interpretative Phenomenological Analysis.

Thank you for sending the duly approved and completed Research Agreement that was requested in our letter of 5th August, 2016 you now have the permission of the Research Ethics Committee to proceed with the aspect of your research that seeks to use Saint John of God Hospitaller Ministries, as a potential source of participants for your study.

This permission is valid for the period of 12 months from the date of this letter. If further time is required to gather data, you must reapply to the Committee to have the decision renewed setting out clearly the reasons for the extension. We cannot guarantee that such extensions will be granted. Ethical approval is granted on the condition that you ensure that you are in compliant with the Data Protection Acts 1988 and 2013 all data (if applicable) will be destroyed or archived in accordance with your application.

Furthermore, the Committee reminds you that you have agreed to the following, as indicated on the Applicant's Checklist:

- To fully acknowledge the role of Saint John of God Hospitaller Ministries, in facilitating this research in any written papers, posters and/or conference presentations.
- Any publication of the findings will a) include Saint John of God Hospitaller Ministries as a contributor and b) incorporate the logo where possible (a jpeg file will be provided upon request)
- To forward a copy of your findings and/or any publications/research posters to Saint John of God Hospitaller Ministries Library upon completion, to be made available to all staff.
- To permit your findings and/or any publications to be made available to the general public on the www.sjog.ie website upon completion, as deemed appropriate
- Upon completion you will be expected to present at the annual Saint John of God Hospitaller Ministries Research Study Day, as agreed with the Research Department.

Hospitaller House, Stillorgan, County Dublin, Ireland. | Tel: +353 1 277 1500 | Fax: +353 1 283 1257
Email: communications@sjog.ie | www.sjog.ie

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Lone Worker Guidelines

The following pages are guidance for researchers (staff and students) who are working alone or in small teams. They are intended to provide guidance to researchers in the field, irrespective of whether they are working on independent research projects or externally funded ones.

Who is this guidance for?

Members of staff or students who:

- work by themselves without close or direct supervision,
- or in small teams
- who may be vulnerable to the physical environment,
- lone travelling either by public transport or on foot and
- in particular for unaccompanied home visits.
- Researchers are expected to follow these guidelines and to use their professional judgement at all times.

Safe working arrangements for staff who work alone

Lone working on campus should also be considered to have a reasonable element of risk, particularly when working in the evening, after dark and early in the morning.

You should have permission from your Head of Department or Supervisor and notify security to let them know when you are working late or any other time where you feel vulnerable.

Ensure that you have a telephone close to you at all times and the Campus security number to hand.

It is your responsibility to ensure that you alert a named co-ordinator/colleague, when your work involves you working alone, in vulnerable situations or undertaking home visits, so that an effective process is put in place to ensure your safety.

This includes:-

Basics –

Good common sense should prevail and all researchers should carry the following items each time they conduct research away from the University:

- Carry an official **identity card** (with photograph).
- Carry a **comprehensive map** of the area.
- Carry a **torch** (and spare batteries).
- Carry a **mobile telephone** and **phone cards** (for areas with poor mobile reception).
- Carry a **personal alarm** (to be kept in an accessible place).

In addition, each researcher should:

- Maintain a **visit proforma** (Appendix 1) as well as their personal diary as a means of logging visits. The visit proforma must be easily accessible by colleagues who are monitoring your visit.
- Never carry large amounts of **money or valuables**.
- Always have familiarisation sessions on home visits with an experienced member of staff during their induction period and only complete a home visit on their own when they, and their more experienced colleague, agree that they are ready. A formal risk assessment should be undertaken prior to new staff undertaking lone working.
- Ask a colleague to accompany you if you feel at all uneasy about conducting a home visit on your own.
- Obtain information about where you are visiting before the visit. Ask how many people will be at the visit.

Risk assessment – ensure that there is opportunity to feedback relevant information from a lone visit – e.g. if you felt at risk or if there was an incident. This should be formally recorded and reviewed with your Supervisor/ Head of Department and other members of your team to ensure appropriate follow up action is taken and to minimise any risk in subsequent visits.

Use of private cars

- Researchers or staff using their own cars for travel:
- Should where possible become a **member of a national breakdown service**.
- Ensure that car users have the appropriate level of insurance cover.
- Drivers should travel with **doors locked and windows closed**. If windows are open, handbags and briefcases should be kept out of sight.
- At night, the car should be **parked in a well-lit and busy place**. Multi-storey parks, or car parks where the car and the user will not be easily visible, should be avoided.
- If a driver thinks they are being followed, they should keep driving until they reach a busy area - Garda station or a garage, etc.
- Staff should avoid taking research participants as passengers unless they know them.

Pre visits

- Make and keep pre-arranged appointments, and notify the participant if you cannot keep them.
- Try to arrange home visits during daylight hours whenever possible. During winter months, weekend visits may be more suitable than evening appointments.
- Consider the purpose of the visit. Does it pose a higher than usual potential of bringing about a violent response e.g. an interview in connection with emotional matters? If so, consider asking a colleague to accompany you or arrange to interview the person at the workplace.
- Ensure that an appropriate room is available and there is financial support to cover participants' travel expenses if necessary.

During a visit

1. **Do not** enter someone's home, if you don't feel comfortable or safe.
2. **Do not** enter a house if the person you have arranged to see is not there. Be aware of, and maintain, personal safety at all times during visits.
3. Always explain your research role clearly and the conditions of confidentiality.
4. If the participant is anxious, consider encouraging them to have a carer/friend within sight/hearing.
5. Never meet aggression with aggression.
6. Your safety is the primary concern, which should be placed above completion of research tasks.

Home visits

- If you are late arriving for your appointment, advise your nominated colleague who will record the revised time on the visit proforma.
- When visiting people's homes, try to let the tenant lead the way. Avoid being the first to go into any room. Be extra careful when alone with participants e.g. fetching something from a handbag, comforting participants. You should always make sure that the exit from the room is clear.
- Animals in the home: if you are in any doubt about the behaviour of animals in the home, ask for it/them to be locked away while you are visiting.
- Never undertake an interview or assessment in the bedroom.
- Do not give your personal telephone number or address to clients.
- You should not interview anyone who is under the influence of alcohol or drugs.
- If you feel uncomfortable while in a person's home, you should take steps to leave immediately.
- A professional and friendly attitude should be adopted but over familiarity must be avoided.
- Remember that the interviewee may also feel anxious about the interview and your visit.
- You should bear this in mind whilst also ensuring your own safety.

Be alert for signs of DANGER

- Raised voice, rapid speech and babbling indicate rising tension.
- Changes in tone and pitch as the conversation progresses may suggest anger, frustration or impending violent behaviour.
- Keep your distance. Each of us has a personal space, which we defend when we feel it is being invaded.
- Be alert for body language that may indicate developing anger – e.g. flushed face, fidgeting, pointing, folded arms.

Awkward or potentially threatening situations

If an awkward or potentially threatening situation arises, this should be reported to a colleague as soon as possible. The facts should also be recorded in a specific "untoward incident" file. Formal arrangements should be in place for staff to be accompanied by a colleague for subsequent visits if there have been any incidents giving cause for concern on the first occasion. If, for any reason, you are concerned for your personal safety once you arrive at your appointment venue, then do feel able to cancel your appointment. On return to the office, make alternative arrangements when another member of staff experienced in working on their own undertaking home visits can accompany you.

Adapted from Keele University Lone Worker Guidelines

Process for monitoring researcher visits

When visiting the home of a participant, you should leave the following details with a nominated colleague (complete a visit proforma) who **has formally agreed to monitor the duration of your visit**. The onus is on you, the researcher, to ensure that a colleague is aware of the details of your visit and has agreed to monitor during the visit and when the visit is completed. Ensure that your nominated colleague is available on the phone and contactable by you for the duration of your visit. Keep your nominated colleague adequately informed by leaving the following details:-

- Sign/make colleagues aware that you are leaving the office and make sure that a named colleague is aware of your visit and details provided on your visit proforma sheet.
- State clearly the name and address and telephone contact for where the interview will take place (and where the interviewee lives, if different) – take care about interviewee confidentiality.
- State the time of the appointment, when you expect the visit to be completed and when to expect you back in the office or the time you expect to contact your nominated colleague to let them know that your visit is safely completed.
- State the make, model, colour and registration of the car you will be driving and the route you will be taking.
- Contact your nominated colleague if you are late for your appointment who will note this on the visit proforma.
- If an appointment or the deadline for contact is after 5pm, the researcher must make other arrangements for someone (colleague/partner/friend/family) to undertake the departmental role in monitoring the researcher's whereabouts. These details should be noted on the pro forma. Your nominated person should also be briefed on these procedures and given details of who to contact in the unit (Head of Department or nominated Deputy), in the case of your failure to return on time.
- Leave your mobile telephone switched on during the interview.
- It is the responsibility of the researcher to ensure that he/she has stated clearly the details about the visit. Where appropriate, a nominated colleague will monitor who is out of the office and when they can be expected to return. It is important that the office are aware of the whereabouts of the researchers, including, wherever it may be practicably possible, the travelling time between the visited site and the office.
- Prepare yourself for difficult meetings by finding out everything you need to know before arriving and planning in your mind how you are going to deal with the situation.
- It is the responsibility of the nominated colleague to ensure s/he is available to receive a call and monitor the time when the visit should be over. If circumstances change, s/he should arrange for another colleague to monitor the visit.
- If the interview is still in progress as the deadline for contacting the department approaches, the researcher should excuse him/herself and call their nominated colleague to inform them.
- If the deadline passes and the researcher has not contacted the nominated colleague, the nominated colleague should ring the mobile telephone number of the researcher.
- If there is no answer, the nominated colleague should inform the Head of Department (or Deputy) immediately and ensure the police are informed immediately.
- If researchers decide that they are not going to return to the office after their last visit, they should ensure that the appropriate person in the office knows about that by telephoning in. The visit pro-forma can then be completed accordingly.