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Meaning-Making of the Subjective Experience of Psychosis, When Subject to a Dominant Psychiatric Discourse: A Dynamic Phenomenological and Discursive Analysis

Portfolio for Professional Doctorate in Counselling Psychology

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For Mum

With many thanks to my supervisor, Professor Carla Willig for her patience, encouragement, expert guidance and knowledge throughout the research journey!

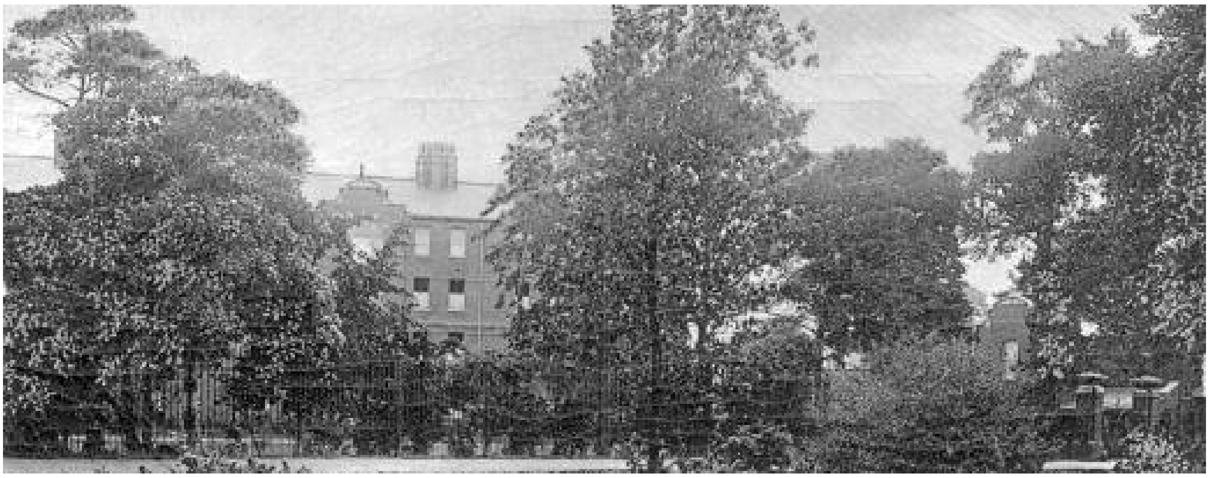
Preface

This course of study was inspired by the painful childhood experience of growing up with my mother, who was struggling to cope emotionally and was in receipt of psychiatric services. When I was six years old, she gave birth to my brother and subsequently became postnatally depressed, which escalated to the point that she started to develop unusual perceptual experiences. These experiences included seeing and hearing things that were not shared by the rest of the family, and she would frequently engage in conversations and behaviours that seemed to be related to some other reality and existence. I was aware that she was unhappy and that some of her behaviours were unusual, with claims that she was communicating with the Queen and royal family. She was also awake most of the night and napping in the daytime.

My mother reverted to speaking her first language, Greek, which infuriated my father who was already struggling to cope with her and the responsibilities of having a young family. My father, being Scottish, could not understand Greek, beyond greetings or menus – or my mother's seemingly bizarre behaviour – and he was becoming increasingly desperate for help with the situation. During this time, I was still able to communicate with my mother in Greek, which included some exciting stories about her involvement with royalty, complaints about my father, and missing Greece and her family. There were also some ordinary times where she seemed back to her usual self, playing the piano, shopping and cooking, reading with me, taking me to school and the park. However, being Greek in South London resulted in my mother receiving racist abuse in the street ("Greasy Greek, get back into your grease pot") in addition to being estranged from her family and friends who remained in Greece.

She had managed to make one new friend, Monique, who had three young children and was French. However, making friends was difficult for her, as a ‘foreigner’ and over time she became more isolated. The ordinary moments became less frequent as the unusual and bizarre increased, with it becoming more difficult to connect with her, although it was still possible at times.

However, help was at hand – or so I thought, before she was admitted to Tooting Bec Mental Hospital in 1969.



Tooting Bec Mental Hospital (1903-1995)

Visiting my mother at the hospital was like stepping into a scene from the film ‘One Flew Over the Cuckoo’s Nest’ (1975) – in fact much worse, with semi-naked people adorning the hallways, in varying states of consciousness, awareness and distress.

The Scottish Psychiatrist R.D Laing, who was living and working in London in the ’60s, was critical of both the psychiatric categorisation of mentally distressed people and the institutions in which they were housed. He objected to what he regarded as the inhospitable nature of mental hospitals, which was certainly congruent with my experience of visiting my mother. He opened a small residential unit, ‘Kingsley Hall’ in North London (1965), to provide an alternative experience and understanding, with humanity at the core. R.D. Laing’s progressive and controversial ideas were nowhere to be seen in South London, where treatment as usual (TAU) for my mother included being forcibly injected with neuroleptics, tranquilisers and courses of electroconvulsive therapy (ECT), which she referred to as “being tortured”.

On returning home after being given 13 ECT treatments, the last without anaesthesia, and a with a cabinet full of medications, she was unable to speak and sat in a somewhat dissociated state, dribbling into her lap. Any moments of connection were now impossible. Although she was physically present it seemed that she had disappeared. It was clear to me that the ‘treatment’ had not made her better, not by my estimation. When her doctor came to make a follow-up home visit, I spoke to him about my concerns that the treatment had not been successful or beneficial and that she had real problems in living which needed to be addressed. He responded with a dismissive statement, as he patted the top of my head, that my mother had a brain disease called ‘paranoid schizophrenia’ and this was as well as she could be now, as long as she took all of her medications for the rest of her life.

So began my journey to try and understand what had happened to my mother, and why my understanding was so different to the medical understanding I had been told as a child. As an adolescent, terrified of developing this condition myself, due to my alleged genetic predisposition, I did wonder whether I was in denial and the quest to learn more continued.

This led to a training in psychology and a life-long career as a chartered counselling psychologist with a specialist interest in ‘schizophrenia’ and psychosis, culminating in this doctoral research.

The process of working on the portfolio has been an immersive, challenging and illuminating experience. I have had the opportunity to learn more from other theoretical perspectives within the humanities, first-person accounts of psychosis, and from delving deeper into other disciplines, especially philosophy.

My appreciation of the methodological considerations when undertaking research has also increased, as I have attempted to familiarise myself with the ontological and epistemological concerns of combining Foucauldian Discourse Analysis (FDA) and Interpretative Phenomenological Analysis (IPA). Conducting these analyses required the reading of a variety of textbooks and research papers on qualitative research methods, as both of these qualitative methods were new to me.

The opportunity to study at this point in my professional career, as a practising psychologist of 25 years, has enabled me to increase both my academic knowledge and my confidence in supporting individuals to author their own experience.

Part one of the portfolio explores how the meaning-making of the experience of psychosis is affected when subject to a dominant psychiatric discourse. Five participants who had experienced psychosis were interviewed and the audio interviews were transcribed with four being coded for the purposes of analysis. Given my research question, a dual focus methodology was chosen, in order to shed an equal focus on both the embodied lived experience, for which Interpretative Phenomenological Analysis (IPA) was employed, and for the language used, a Foucauldian Discourse Analysis (FDA) was utilised.

Given the epistemological conflicts in combining these methods, a publishable paper was written and is presented at the end of the portfolio in part three. This paper examines the epistemological challenges of combining these approaches and how adopting a critical realist position as advocated by Bhaskar (1993) can enable their integration to good effect. This dual focussed approach is particularly pertinent when looking at areas of life that are deeply affected by both the embodied lived experience and how we speak, or how we are able to speak and make sense of experience, given the sociocultural and historical context. That is to say, that the discourses or interpretative repertoires available at any given time, construct experiences and are not simply portraying the truth or facts of experience. The paper was written for publication in the journal *Qualitative Methods in Psychology*, which I am hoping will encourage other researchers to use a combined methodology.

Part two, sandwiched between the academic pieces, i.e. the research and publishable paper, focusses on practice and includes two short case studies. The first is about a client who believed he was ‘the Messiah’, and did not want this belief challenged, but wanted help with depression and relationships. Working with his request, this case study illuminates the importance of the therapeutic relationship in alleviating mental distress.

The second is a case study of a client I met in the year of his 40th birthday and saw weekly for three years. He arrived at his first appointment saying he was a schizophrenic, who had been diagnosed 10 years previously and had been living a restricted life as a consequence, which left him feeling depressed and anxious about his future. He told me he felt unable to hold down a job, taking occasional short-term contracts as an IT specialist, and was of no fixed abode, sofa-surfing from one home to another. This was in stark contrast to his prior existence, working fulltime and living independently.

Together, we embarked on a journey to try and understand the restrictions he found himself living within and explore how it might be possible to improve his mood and quality of life.
We explored the question of what was creating and contributing to the felt restriction in living. Being diagnosed with schizophrenia? Severe and enduring distress related to trauma? A combination of both? Mental and emotional distress in personal and social relationships? Existential or spiritual crisis? Socioeconomic problems? Unusual perceptual experiences? What was the restriction in living about and was an improvement possible?

This case study is an example of the power of the dominant psychiatric discourse in influencing meaning-making of the subjective embodied experience of psychosis, and the impact of culturally available discourses in creating a multitude of realities.

This course of study has focussed on the impact of language on experience. The plethora of confusing and contradictory discourses on ‘madness’, including the various conceptualisations and terms used when referring to the individuals having these experiences with the consequent phenomena, present challenges for any communication on the subject.

Given the resulting impact on meaning-making, there are implications for practice. Insights arising from this research include the importance of averting the imposition of meaning on others by encompassing a multi-perspectival approach which embraces this diversity, in order to support individuals in self-determining and authoring their own experience.

Abstract

Objectives

This study investigated the subjective, embodied lived experience of individuals who had experienced psychosis, in addition to the interplay and impact of dominant psychiatric discourse on the meaning-making process. Constructions of psychosis deployed, experiential phenomena expressed, and therefore implications for subjectivity, selfhood, and meaning-making, were explored.

Design

A dual focus methodology combining Interpretative Phenomenological Analysis (IPA) and Foucauldian Discourse Analysis (FDA) was utilised to explore both language and experience. Despite arguments that combining IPA and FDA creates epistemological/ontological conflicts due to dissonant theoretical underpinnings, adoption of a critical realist position permitted an integration of these approaches.

Method

Four individuals with experience of both psychosis and accessing mental health services were interviewed. Focussing on both discourse and embodied lived experience, transcribed interviews were analysed using a dual focus of IPA and FDA simultaneously, followed by an integrative analysis.

Results

Individuals described a meaning-making crisis, affected by disorientating unusual perceptual experiences in a relational context. Themes emerged pertaining to loss, trust, agency and a fight for a meaningful existence, in both the embodied lived experience and socially constructed nature of reality. Dominant psychiatric discourse was experienced as generally limiting, with implications for levels of recovery and meaningful existence.

Conclusion

A combined methodological approach enabled a comprehensive understanding of the dynamic interaction between language and the situatedness of embodied experience, coexisting dynamically within our personal and social realities. Meaning-making, and participants developing their own personal meaning, were found to be fundamental in experiencing life as meaningful, thereby creating hope for the future.

Recommendations for practice include prioritising the subjective lived experience of psychosis *and* acknowledging the socially constructed nature of our reality by creating a therapeutic encounter in which personal meaning can be made by drawing on a variety of culturally available discourses, rather than the imposition of meaning associated with dominant psychiatric discourse.

Meaning-Making of the Subjective Experience of Psychosis, When Subject to a Dominant Psychiatric Discourse: A Dynamic Phenomenological and Discursive Analysis

Introduction

Acknowledging my personal history, outlined in the preface, is integral to being a reflexive researcher-practitioner but has also been a major motivating factor in my choice of career as a psychologist specialising in working with individuals experiencing severe emotional distress, in addition to the topic under investigation in this research study.

As a child, I was curious about my mother’s distressing experience and the treatment she received from medical professionals. Like many from a variety of disciplines in the mental health field, my inquiry into ‘madness’ has been inspired by my early experience and what appeared to me to be a failure in understanding what was happening for my mother and the context of her distress. This was my perception as a child and largely still is to this day, having come full circle from studying a Bachelor of Science in Psychology, in which I was taught the chemical imbalance theory of depression and the dopamine hypothesis for ‘schizophrenia’. These hypotheses were proclaimed scientific breakthroughs in mental illness, with the pharmaceutical industry developing medications to alleviate symptoms and restore any chemical deficiencies or irregularities in human physiology. The main premise then was that psychologists could help the ‘normal’ population with their upset or distress, but that the severely unwell required psychiatric treatment and medications to stabilise mental illnesses caused by faulty genes and biology. So, there it was, explained neatly via science! Now I just needed to worry about what type of predisposition I had inherited and when the ‘schizophrenia’ disease would be triggered in me, due to the existence of an ‘underlying genetic time bomb’ (Read, Mosher & Bentall, 2013, p. 4).

Fortunately for me, whilst attending my human physiology and psychopathology seminars I was also reading R.D. Laing’s *The Divided Self* (1960). This offered an alternative to the medical model of madness, illuminating inner conflict within the self and social relationships as causal factors for severe distress, as an individual attempts to live their life in the world. Furthermore, Laing argued that the verbal expressions and behaviours of those perceived to be mad, which were previously considered incomprehensible, could be understood as symbolic and metaphorical representations related to the life experience of the individual. This seemed to resonate with my personal experience of my Greek mother who, struggling to cope in South London with two small children, isolated from her culture, family and friends, mentally fled into a private world in which she felt special and conversed with royalty – a marked contrast to her otherwise stressful daily existence.

At that time, the mainstream understanding of madness, still largely influenced by Kraeplin’s view that it was a disorder from which individuals could not recover (Bentall, 2004), was characterised as a medical condition called ‘schizophrenia’ – best managed and treated with antipsychotic medication for life. A medical analogy often drawn by way of explanation references diabetes requiring medication to manage fluctuating insulin levels. So too were we to understand ‘schizophrenia’ as requiring management via medication, as postulated by the original dopamine hypothesis (Van Rossum, 1967). This compelling hypothesis remains popular to date – despite, some would argue, the lack of scientific evidence (Boyle, 1990; Hengartner & Moncrieff, 2018). Furthermore, critics of the medicalisation of distress claim that, ‘the heightened sensitivity, unusual experiences, distress, despair, confusion and disorganisation that are currently labelled ‘schizophrenic’ are not symptoms of a medical illness’ (Read, Mosher & Bentall, 2013, p.3) but legitimate human responses to adversity.

My professional journey to understand human beings, madness and how best to help has been a lifelong challenge, beset by contradictory theoretical models and professional opinions from a variety of disciplines. The first-person accounts filtering through the maze of scientific and medical models of madness all pointed to alternative conceptualisations, which placed the human being and the problems of living at the centre of those considerations. In my work with clients, it became apparent that the meanings made regarding their distress had direct implications for their beliefs and therefore behaviour and experience. This is recognised within social psychology, whereby our beliefs inform our behaviour with consequences for our quality of life. The social psychology conceptualisations include attribution theory, social cognition models, learning theory and locus of control, however these theories have been critiqued from a social constructionist perspective, which highlight the role of culturally available discourses in shaping beliefs (Willig, 2000).

So, how are we to understand madness and human beings experiencing psychosis amid the variety of concepts inherent in the available discourses within our western culture, all of which claim to offer viable explanations? Given the constitutive nature of culturally available discourses when making meaning of anything, as posited by social constructionist theorists, I will commence with a brief overview of the history of madness and humanism in order to map out the discursive field.

Madness

‘[B]efore anything else, madness is a word, a human artefact, a sign, stitched together to represent or echo something (abstract or concrete) related to human behaviour or one’s perception of this behaviour.’ (Gomory, Cohen, & Kirk, 2013, p.121)

Historians of madness agree that the most commonly used word for disturbing and, most often, socially unacceptable behaviours is the term ‘mad’. It is noteworthy that despite some claims by historians of madness (e.g. Roy Porter, Andrew Scull, Edward Shorter) that they are relaying an impartial account of madness, their underlying assumptions are evident in their framing of the term mad and the selection of words used to explain madness, ‘because it is a word first and foremost and, lacking immanence, its meaning is primarily determined by those responding to it’ (Gomory, Cohen, & Kirk, 2013, p.121). As Gomory, Cohen & Kirk conclude, ‘the consistent use of medical labels like mental illness, mental disorder, and mental disease by historians of psychiatry as substitutes for the older descriptors madness or insanity tends to reify the view of madness as medical disease’ (2013, p.132). So, even within the history of madness, it can be seen that the discourses mobilised impart a particular conceptualisation and understanding of madness, tending towards the medicalisation of distress.

Regardless of how we conceptualise madness, what it is and why it happens, or which words we use to speak about it, the experience of madness for humans exists and has been grappled with for centuries in an attempt to explain, understand and respond. There have been a myriad of aetiological explanations, words and definitions presented throughout history regarding the observable experiential differences between human beings, in what they believe, how they behave and how they appear to others within a society in any given sociocultural historical age. In turn, there have been a variety of responses and attempts to control the 'mad', and what is considered their 'mad behaviour'.

The variety of terminology used to describe madness is often used interchangeably in the literature, and is also often part of a binary concept with an implied or explicit polar opposite: e.g. sane – insane; abnormal – normal; well – unwell; mental illness – mental health. Other terminology includes mental disorder, mental disease, craziness, lunacy, psychosis, schizophrenia, and most recently, neurodiversity and mental, psychological or emotional distress. The words or terms used betray an underlying assumption about the nature of madness and, as Scull acknowledges, 'the concepts which we use to delimit and discuss any particular segment of reality inevitably colour our perceptions of that reality' (1993, p.376). I have found the metaphor of 'vantage points', as proposed by Davies and Harré (1990), particularly useful in understanding the effects of discourses and the positions created affording a particular viewpoint or perspective in understanding. This is pertinent to my research question, which seeks to explore how dominant psychiatric discourses influence and interact with the subjective embodied experience of psychosis, and it would appear from examining the literature on madness that subjectivity is always part of the creation of knowledge about madness.

This piece of research aims to explore the subjective experience of what I shall be referring to as *psychosis* throughout. I am aware that many other terms exist, and preferences expressed are related to the individual's personal and professional leanings. Although my preference would be to utilise the terminology of *severe emotional or mental distress*, as this makes the most sense to me from both personal and professional experience, there is a risk, due to the prevailing and current dominance of biological psychiatric discourse and practice, that this could be misunderstood as a reference to, e.g., clinical depression or anxiety. Therefore, I have decided to use the term psychosis, which is widely understood by health professionals and experts-by-experience to indicate the experience of unusual perceptual experiences and disruptions in mood, the usual orientation to the world, and the relationship to self and other, historically referenced and categorised as ‘schizophrenia’ for over a century now.

Madness has been variously conceptualised throughout history. Ancient Greek Philosophers Aristotle and Plato theorised that mental health was to be achieved through mental unity, owing to a lack of inner conflict with regard to moral concerns, the binaries at that time being related to vice and virtue. Although Socrates attributed some virtuous qualities to the ‘mad’, such as prophesising and creativity, the mad were predominantly perceived, at the time, to be purposeless and dangerous to society. Hippocrates took a more impartial stance, preferring to observe those individuals, recording their speech and behaviours, in the absence of any evidence of abnormality (Pilgrim, 2007). To some extent, the polarisation in opinion on the subject of madness is still evident today.

According to French scholar Michel Foucault, during the period of Enlightenment – the ‘Age of Reason’ – madness became separated from reason and the concept of un-reason was born. The General Hospital of Paris opened in 1656 to house the ‘mad’ and ‘unreasonable’, alongside others perceived to be engaging in ‘unreasonable’ behaviours such as begging, prostitution, stealing, vagrancy, homosexuality and anything deemed to be deviant by society. Unreason, during this period, referred to both the mad and bad (Foucault, 1965). However, towards the end of this period, confinement of the mad in such institutions was seen as barbaric and madness was no longer considered to be a criminal matter but an illness or disease requiring medical care. Nevertheless, the distinction between mad and bad remains a conundrum to date, with expert witnesses brought before law courts to give their professional opinion about motives for a crime and whether there is evidence of sanity or insanity in the accused, informing judgements about whether punishment or treatment is administered.

In Foucault's (1973) exploration of medical perception in *The Birth of the Clinic*, he observes that at the beginning of the nineteenth century classical medicine, with its focus on eliminating disease to restore health, was superseded by clinical medicine, with a focus on returning the patient to normal. Normality is thereby deemed to be the opposite of madness, with reason equated with psychological health and unreason with illness and abnormality. According to Foucault, this shift in knowledge and therefore power gave rise to the context in which psychiatry was born, with its discourses and affiliated practices.

The twentieth century is commonly referred to as the 'psychiatric age', with the medicalisation of madness and misery. However, the intellectual roots of the current paradigm date back to Kraepelin (1883), whose empiricist approach to classification identified two of the conditions – dementia praecox and manic depression – that are still considered valid today and referred to as 'schizophrenia' and bipolar disorder, respectively. Kraepelin believed these conditions to be chronic, physiological and degenerative diseases of the nervous system and brain, which would be confirmed scientifically as science and technology developed (Bentall, 2004).

The psychoanalytic turn by Freud at the beginning of the twentieth century focussed on conflict within the 'psyche' or mind as the causation of madness, and speaking was encouraged to heal the rift within. Persons suffering with conditions Freud identified as neuroses were encouraged to engage in talking therapies on his psychoanalytic couch, but persons with psychoses presented an uncomfortable challenge. In a letter in 1928 to his friend, Hungarian psychiatrist Istvan Hollos, Freud wrote, ‘I did not like these patients… they made me angry and I find myself irritated to experience them so distant from myself and from all that is human. This is an astonishing intolerance which brands me a poor psychiatrist.’ (Freud, 1928, p. 318-319).

Although Freud was able to reflect on his own process, the general feeling amongst psychiatrists at that time was the speech of the mad was unintelligible ‘word salad’, further evidence of a degenerative brain disease. Accordingly, the institutional and professional practices in psychiatry included confining the ‘mad’ in asylums, performing brain operations including lobotomies, insulin coma therapy, electroconvulsive therapy (ECT) and the use of psychoactive medications – neuroleptics, the first of which was chlorpromazine in the 1950s.

Scottish psychiatrist R.D. Laing, midway through the twentieth century, challenged the doctrine of the unintelligibility of ‘madness’ speech, finding it to be understandable and related to painful truths in the person’s life. He therefore advocated compassion and some metaphorical interpretation to reach an understanding, e.g., beliefs about being an alien may relate to feelings of alienation.

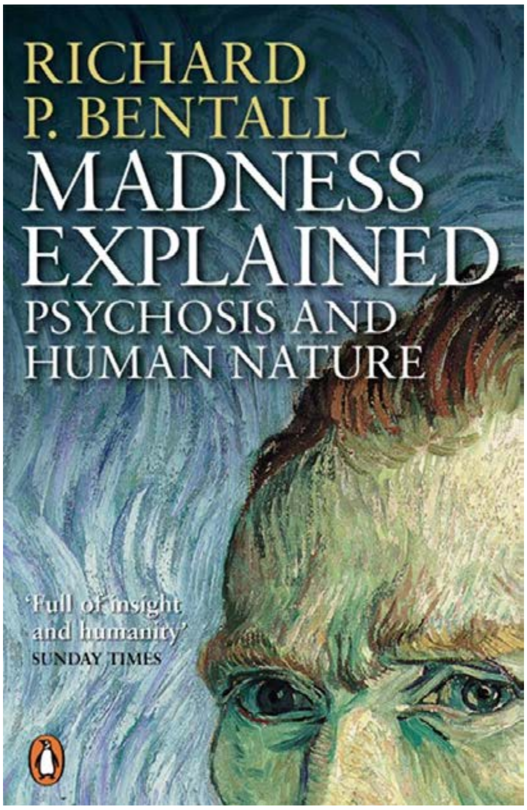
The struggle to understand those who were regarded as ‘mad’, the psychologically different and distressed, led to an effort to document classification systems. The most well-known, still used to date, was developed by the American Psychiatric Association (APA). *The Diagnostic and Statistical Manual of Mental Disorders* (DSM) was first published in 1952 and has been updated since. The current edition, DSM 5, was published in 2013 with amendments published separately in 2017. The APA claim:

> ‘*The Diagnostic and Statistical Manual of Mental Disorders* (DSM) is the handbook used by health care professionals in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders. DSM contains descriptions, symptoms, and other criteria for diagnosing mental disorders. It provides a common language for clinicians to communicate about their patients and establishes consistent and reliable diagnoses that can be used in the research of mental disorders.’ (2013)

Controversies and criticism about a classification approach to mental health problems date as far back as the 1940s, with psychiatrist Adolf Meyer promoting a holistic approach. His ‘psychobiology’ model considered both the biographical and social complexity of people’s problems, acknowledging biological predispositions yet not regarding them as solely responsible for the emergence of mental illness (Pilgrim, 2002). This model was developed further by Engel (1980), who took a systemic approach that encompassed the situatedness of human experience known as the ‘biopsychosocial’, still referred to in mainstream mental health services today despite being critiqued for masquerading as the ‘bio bio bio’ model with the psycho and social factors being overlooked (Read, Bentall, & Fosse, 2009).

Other controversies concerned the inclusion of homosexuality as a disorder in the second edition of the DSM. This was later removed after gay rights activists in the 1960s protested and lobbied the APA, claiming that homosexuality was not a disease~~,~~ but part of human variation.

Bentall (2004), in his award-winning book *Madness Explained: Psychosis and human nature,* sought to critically evaluate the medicalisation of psychological difference and distress with a specific focus on psychosis. The explicit reference to human nature and humanity can be seen on the cover, which includes Vincent van Gogh's self-portrait, painted when at the Saint Paul Asylum in France, May 1889 – May 1890. Aaron Beck, who reviewed the book, said, 'Bentall demystifies psychosis and restores the patient to a proper place with the rest of humankind.' (2004, 4th Cover).



The explicit use of the term 'human' – evident in terms such as human nature, humankind, humanity and humanitarian – in a book examining what is commonly thought of primarily as a symptom of psychiatric disorder, necessitating psychiatric treatment and medication, brings into consideration fundamental concerns regarding what it is to be a human being.

Humanism

I am using the term humanistic discourse to describe discourses that refer to universal aspects of what it is to be human and the commonality shared by human beings, irrespective of culture, history, race, religion, sexuality, disability and gender considerations. Humanist writer Dwight Gilbert Jones, on his *@humanism* website, defines humanism as, ‘inclusive sensibility for our own species, planet and lives with a creative appreciation for our own kind that is innate in all of us.’

Although essentialist ideas about human beings have been rejected by postmodernist and constructivist theorists who hypothesise that human beings are created from within their sociocultural surroundings and language, I argue that there is an essence to human beings that unifies us in our embodiment. This is evident in neonates who are socially dependent, emotionally responsive, and have basic needs for food, warmth and general care – features that are universally shared by babies irrespective of culture, time, place or language. Furthermore, before the reflective stage of development, a ‘pre-reflective self-awareness’ is apparent as a non-cognitive relation of the self to itself (Sartre, 1958, p.19) and therefore prior to language. Our biology and existence are in plain sight and our experience is both embodied and culturally influenced.

What it is to be a human being has been a central concern for philosophers and for Heidegger, ‘What human being is – or, as it is called in the traditional language of metaphysics, the “essence” of the human being – lies in his ek-sistence’ (1999, p. 247). Heidegger regarded existence as a way of being that is unique to humans, a ‘standing out’ mode of being, necessitating self-reflection and the meaning-making aspect of being. *Being* was central in Heidegger’s philosophy, with certain qualities regarded as fundamental for humanism, ‘[f]or this is humanism: meditating and caring, that human beings be human and not inhumane, “inhuman”, that is, outside their essence’ (1999, p. 244). Sartre, as an existentialist, believed that existence preceded essence, meaning, ‘man first of all exists, encounters himself, surges up in the world – and defines himself afterwards’ (2007, p. 28).

Regardless of the subtle variation in Heidegger and Sartre’s explications of what it is to be human, it would seem that an element of essentialism is evident in attempts to understand what it is to be human. Furthermore, essentialist and postmodernist concepts about what it is to be human do not appear to be mutually exclusive when considering humanity from a multi-perspectival and integrative position. I would argue that binary theories in general are reductive and of little utility in our current times, other than to chart the progress in thinking, from then until now. Examples of other binaries include mind and body, realism and relativism, male and female, normal and abnormal, sane and insane, which can all be reductive in our understanding of human existence if taken to delineate distinct and opposite categories.

My epistemological position is to align myself with an ontological notion of human existence, with the human being representing an essence and as pre-existing becoming, which I believe to be fundamental to the actuality of human reality. Furthermore, the concept of a unifying essence to human beings creates an ethics for how all human beings should be regarded, as equal and deserving of social justice in all spheres of life.

Human Rights

The varying categorisations of human beings, with consequent implications for treatments and rights, has been fraught with tension over the centuries – from Aristotle's distinguishing of the rights of 'Man' above that of women, slaves and children, to enduring civil rights struggles at the local, regional, national and global level regarding the need for equal opportunity and treatment, regardless of race, gender, sexuality, class, disability or 'madness'.

From the middle of the last century, the emergence of the human as an individual with an acknowledged unique potentiality, within a framework of a common humanity, facilitated the finding of a voice for oppressed groups and their subsequent uprising against discrimination. For example, the early civil rights movement in America for equal rights for African-Caribbeans in the 1950s-60s, to the gay rights movement's calls for dignity and equal treatment, resulting in the removal of homosexuality as a classification in the DSM in 1973 and the decriminalisation of homosexuality in the UK in 1967.

The expression 'human rights' gradually replaced the phrase 'natural rights' throughout the founding of the United Nations (UN) in 1945 and the adoption by the UN General assembly of the Universal Declaration of Human Rights in 1948. The Human Rights Act 1998, which incorporates the rights set out in the European Convention on Human Rights (ECHR), came into force in the UK in October 2000. These statutes set out inviolable social, civil and political rights that cannot be infringed or taken away by those states that have made signed declarations to be bound by the conventions and articles therein, including the means for citizens to assert these rights in courts of law. Examples of human rights particularly important for individuals experiencing ‘madness’ and in receipt of mental health services include: the right to life; freedom from torture and inhumane or degrading treatment; the right to liberty and security; respect for private and family life; freedom of thought, belief and religion; freedom of expression and protection from discrimination.

Critical and Alternative Perspectives

Within psychiatry, different opinions to the mainstream biomedical model began to emerge with psychiatrists such as R.D. Laing in the 1950s, who rejected the physiological explanation for ‘schizophrenia’ and offered an alternative, focussing on social factors and relationship dynamics and prioritising a humane approach. Although referred to as an ‘anti-psychiatrist’, Laing strongly rejected this categorisation, maintaining that he was voicing an opinion from within psychiatry as a psychiatrist formed from the clinical experience with his patients. Laing has been credited with repositioning the human being at the centre of concerns regarding mental health and popularising the idea that individuals are not themselves insane but responding to insane situations with adaptive responses to aid survival.

This sentiment has been echoed by those individuals with lived experience of psychosis who have found collective platforms from which to respond – uniting and sharing their experience to support each other, advance knowledge about the experience, and inform mental health service intervention and practice. Various groups of people and organisations – such as ‘experts by experience’, ‘individuals with lived experience’ and ‘mad activists’, as well as the service user movement which includes the Service User Research Forum (SURF) and Lived Experience Advisory Forum (LEAF) – acknowledge lived experience as of value to the discussion about the experience of psychosis and its contributory factors, thereby creating counter narratives and formulating alternative interventions of therapeutic benefit (which I will discuss further in the subsection A Therapeutic Approach). Collaborative approaches to mental health issues have developed in recent years, formed from experts by experience, carers and mental health professionals, including health professionals with lived experience.

The Hearing Voices Network was established in 1987 by psychiatrist Marius Romme and researcher Sandra Escher, who proposed that the experience of hearing voices is both part of the diversity of human experience, and also potentially a consequence of earlier traumatic experiences. Other groups offering alternative conceptualisations and involving the voices of those with lived experience include the Spiritual Crisis Network and Soteria Network. Inspired by R.D. Laing's Kingsley Hall community (1965), which promoted compassion and a person-centered approach for individuals experiencing psychosis, the Soteria Project was founded by Psychiatrist Loren Mosher in 1970 (and ran until 1992) to provide community-based approaches for the treatment of 'schizophrenia', as an alternative to mainstream psychiatric inpatient treatment.

Mad in America is a webzine dedicated to critical perspectives on modern psychiatry. It was founded in 2012 by Robert Whitaker, a medical journalist who published *Anatomy of an Epidemic* (2010), charting the long-term deleterious effects of psychiatric medications and the rise in mental health disability in America. Whitaker discovered that, unlike other areas of medicine, progress in mental health treatment was problematic and not advancing as it often claimed. *Mad in America* was founded to serve as a catalyst for rethinking psychiatric care in the United States (and abroad) in the light of this research.

Progressive views have also emerged from within the discipline of psychology, with the British Psychological Society's (BPS) Division of Clinical Psychology (DCP) publishing *Understanding Psychosis and Schizophrenia* (2017), which offers a multifaceted account and psychosocial model of psychosis, produced in collaboration with individuals with lived experience, carers and mental health professionals. In 2018 they went on to produce the *Power Threat Meaning Framework* (PTMF) for individuals who have experienced severe and enduring mental health problems. Within the PTMF, issues related to historical power differentials in life experiences are put forward as being significant contributory factors in the causation of severe emotional distress. The PTMF promotes therapeutic intervention, which includes a focus on the impact of power inequality in relationships and the potential sense of threat experienced by individuals, inherent in all forms of abuse. Understanding the threat response in the context of life experience, and developing a narrative around this, are seen as helpful in alleviating distress.

Critiques of Diagnosis

Inherent in many of the approaches and platforms referenced above is an effort to provide alternatives to diagnosis. The validity of psychiatric diagnosis was under scrutiny in the 1960s, amidst the work of R. D. Laing, the liberatory culture, civil rights struggles and a general rise in activist movements, which sought to demand greater respect, equality and humane treatment - It is still under scrutiny today.

The Critical Psychiatry Network, founded in 1999, stated, '[T]he DSM is incapable of capturing the full range of experiences of distress in the way that narrative formulation can' (2013). Critical psychiatrists Thomas and Bracken, who advocate understanding and interpretation as core approaches to psychosis, argue, ‘positivism is simply unable to deal with the complexity of social and cultural environments. In reality, these worlds are rich in meaning and resist linear causal models’ (2004, p. 363).

Psychiatric diagnostic systems have also been criticised for a lack of scientific evidence, with DSM categories being formed via consensus of professional opinion from the DSM committee to agree the criteria required for any given diagnostic category (Davies, 2013). As Dr David Kupfer, chair of the DSM-5 committee remarked, “we’ve been telling patients for several decades that we are waiting for biomarkers. We’re still waiting” (2013). Due to the lack of identifiable biomarkers of psychiatric disorders, circular arguments are also relied upon to confirm a diagnosis. For example, it is claimed that delusions are indicative of ‘schizophrenia’ and a ‘schizophrenia’ diagnosis is confirmed by the presence of delusions.

Criticism of psychiatric diagnosis for demonstrating a lack of validity, reliability, indications of causation, treatments or outcomes has challenged the benefit of the usage of the concept of ‘disorder’, leading to critical mental health professionals issuing a call to ‘drop the language of disorder’ in preference for an understanding that ‘distress is normal, not abnormal, and part of human life – that humans respond to difficult circumstances by becoming distressed’ (Kinderman, Read, Moncrieff, & Bentall, 2013, p. 2). Unfortunately, diagnosis is also involved as a means of accessing welfare benefits and support services in western society, so individuals rejecting the definition of themselves in diagnostic terms may find themselves excluded from forms of practical support. Nevertheless, leading members of the service user/survivor movement – e.g., Viv Lindow, Eleanor Longden, Ron Coleman, Rufus May, Jacqui Dillon, Rai Waddingham, Laura Delano, and many others – date their recovery from the moment they rejected their diagnosis.

Neoliberalism and Mental Health

But why were the alternative approaches focusing on the psychosocial aspect of experience, which had emerged in the ’50s and ’60s, phased out in the first place? Potentially we could understand this from two perspectives. One, more limited, relates to criticisms of pathologising or ‘blaming’ family members in the attempt to move beyond the individual and include the context of their experience. Approaches including the social context, as demonstrated in Laing’s work (1990), and exploring in-depth the impact of family relationships and expressed-emotion (EE) as ‘significant in mental illness’ (Leff, 1985), were received with scepticism.

The other way of understanding this, having wider reaching implications that continue to shape mental health services today, relates to the changing landscape of our politics in the 1980s where the rise of conservatism displaced the Labour left, along with the anti-establishment counterculture associated with the radical left, which had been supportive not only of feminist and anti-racist agendas but also the antipsychiatry movement. Activism in the area of mental health therefore also underwent a transformation in focus from critical evaluation of psychiatric institutions and practices, to an emphasis on the patient within the psychiatric system, now positioned as ‘self-empowered’.

The politics of our time saw neoliberalism emerge the victor, prioritising market forces and responsibilising individuals under the auspices of a reduction of state involvement in public life leading to liberation and ‘consumer’ choice. Consequently, this socio-political climate resulted in mainstream mental health services also adopting an individualist ideology, which presupposes that mental health problems exist within individuals that require ‘fixing’, via expert professionals and medication.

The need to identify disorders for treatment, in turn, has led to an expansion of psychiatric diagnoses, which could arguably be considered as social constructions accounting for experience. The medicalisation of human distress increased further, as the diagnoses are relayed as medical facts of personal pathology devoid of a social, economic and cultural context. Furthermore, as summarised by Esposito & Perez, ‘the tendency to treat ‘mental illness’ as a problem within the individual continues to be supported within the prevailing neoliberal logic that downplays the social realm, treats individuals as self-contained agents, and pathologises thoughts and behaviours that deviate from what the market defines as functional, productive or desirable’ (2014, p. 414).

It has been argued that mental health difficulties have been subject to a process of commodification, as ‘illnesses’ have been identified and labelled: ‘Once we have categorised states of emotional and behavioural deviance and these categories enter the market, they become the equivalent of brands’ (Timimi, 2011, p. 158). Furthermore, because psychiatric diagnostic categories are derived from subjective opinion without any corresponding physical markers, this means ‘they are ripe for exploitation as commodities’ (Timimi, 2011, p. 158).

The market society promoted by neoliberalism has dominated the western world since the 1980s. A focus on competition and productivity, ‘encouraging people to adjust their attitudes, habits, and behaviours to fit market demands is typically associated with functional/rational behaviour’ (Esposito & Perez 2014, p 416), whilst at the same time eroding social bonds and downgrading their importance. The medicalisation of distress is therefore a natural progression in a neoliberal society that individualises human beings, emphasising the need for productivity and consumerism as indicators of health and wellbeing.

Unsurprisingly, therefore, medication is the primary approach to mental and emotional distress in mainstream mental health services, with an emphasis on a biomedical understanding. Furthermore, within a neoliberal society, the delivery of any mental health care is treated as a commodity, with the distressed individuals positioned as customers and consumers responsible for their own problems, thereby providing a rich ground for the pharmaceutical industry to market and sell their products. So, not only are the mental health services adopting a biomedical approach to mental distress within a neoliberal society, but individuals identifying with the inherent concept of the 'biomedical self' (Esposito & Perez 2014, p. 422) present at services seeking diagnosis and medication to alleviate their distress. The question generated to make-meaning of experience is an inward facing one of 'what is wrong with me?' rather than a question with a contextualised focus such as 'what has happened to me?' The quest for meaning is therefore constrained by the dominant biomedical psychiatric discourses prevalent within a western neoliberal society that create a vantage point for developing individualised meanings, whilst obscuring others that contextualise experience in the social world within which we live. Self-reliance is thus elevated to a virtuous status and the consumption of medications normalised as the primary route to alleviation of distress. For Esposito and Perez, the consequence is the transformation of the psychiatric patient into a drug addict: 'in many ways this is the personification of the neoliberal consumer self' (Esposito & Perez, 2014, p. 430).

Mainstream Approaches to Psychosis in the UK

Mainstream mental health services operate within a biomedical paradigm, which is inextricably linked to the neoliberal agenda. Primary considerations, as summed up by critical psychiatrist Phil Thomas at the recent Soteria UK AGM (streamed online on the 30th of Jan 2021), are the ‘three E’s’: efficiency, evidence-based treatments and economics. A recent piece of ethnographic fieldwork exploring the impact of neoliberal policy on statutory mental health service provision found that, ‘prominent aspects of managerialism and marketisation disrupted attempts by mental health practitioners to sustain supportive and mutual structures with colleagues and engage service users in therapeutic and relationship-based forms of practice’, and furthermore, ‘biomedical orientations were remobilised in practice in spite of a purported shift in policy discourse towards more socially inclusive approaches’ (Moth 2020, p.133). Moth conceives the term ‘biomedical residualism’ to describe this phenomenon and provides a detailed account of the restructuring of mental health services on the basis of market forces, risk management and target driven approaches measuring the progress of clients and practitioners. This is explicitly evident in schemes such as ‘payment by results’ (PbR) introduced in 2013 accompanied by a new classification system – ‘clustering’ – to aid the assignment of treatments to a set of criteria, arguably a reductive approach to human beings in distress.

The neoliberal agenda can be seen to not only be shaping and constraining mental health services but also redefining the conceptualisation of mental distress, creating a mutually reinforcing cycle of ‘evidenced based’ practice. The systematisation of care, prioritising expertise in collating and in-putting data into this system to decide the treatment required, results in the downgrading of experienced mental health professionals in preference for experts in the system. These experts therefore do not require the same level of qualification and experience, making them more cost efficient to employ in delivering the care. The neoliberal agenda motivating the reorganisation of mental health care provision contributes to the resultant biomedical residualism evident in current mental health services.

This is particularly evident for individuals experiencing psychosis who are risk managed, diagnosed and medicated. The more recent development of early intervention services for psychosis (EIP), underpinned by the National Institute for Clinical Excellence (NICE) April 2016 guidelines for individuals experiencing a first episode of psychosis, has incorporated a more inclusive approach to psychosis, with medication being prescribed more cautiously and a range of therapies offered from individual cognitive behavioural therapy (CBT) to family therapy and social support. Research into outcomes for psychosis, comparing treatment as usual (TAU) as offered in generic services and the specialist support of an EIP, have concluded that the EIP has superior outcomes. Generic services, however, continue to be dominated by the biomedical model and are also underpinned by the 1983 Mental Health Act, which was amended in 2007 to extend authority and power to a wider range of mental health professionals. Coercive practices, with the prioritisation of risk management and assessment, could be argued to primarily serve the interests of the mental health institutions, rather than the needs of human beings in distress. One amendment, however, did increase power for patients by giving them the authority to give consent for ECT (if they were deemed to have capacity), where previously, authorisation by two doctors could result in ECT being forcibly prescribed against someone’s will. What is shocking here, beyond the use of ‘electro-shock’ administered directly to a person’s brain, with the potential side effect of brain damage, is the idea that in a civilised society this is still one of the ‘treatment’ options for a human being experiencing severe mental distress and that it continues despite a meta-analysis into research on the efficacy of ECT concluding the procedure should be suspended (Read et. al, 2019).

Concepts inherent in psychiatric systems shift the focus inwards to the personal and away from the social context in which we exist. The individualisation of distress associated with a neoliberal ideology provides a micro focus on the physiological structure of a human being and the relationship of that physiology to their behaviour as if it is somehow possible to by-pass the conscious human being. As Timimi explains, '[t]he focus on the narrow biomedical interpretations of patient's experience … means that "community mental health" collapses down to prescribing a pill, with the voices of patients and the general public, and the connection their experiences may have to social and political realities, going missing from the discourse' (Timimi 2011, p. 156).

A current illustration of these practices was apparent in a recent conversation (2021) I had with a local mental health team about a client of mine who was experiencing severe mental distress. The mental health team had diagnosed 'treatment resistant schizophrenia' as the main problem, thereby requiring immediate hospitalisation and a change of medication to Clozapine. Her keyworker called my practice, Psychology Sussex, to advise me of the plan to section her under the 1983 mental health act that afternoon. The context of my client's distress was not only not taken into account – it was not even known about. An exclusive focus on symptoms had dominated the conversation omitting any discussion of the effects of increased isolation due to 'lockdown' in a pandemic, two recent bereavements of her maternal aunts, and her being the sole carer for her mother with Alzheimer's. The increased stress due to the social context of her situation had certainly resulted in increased distress accompanied by an escalation in voice hearing and feelings of threat. However, in my opinion, a new medication was not the solution and in fact, enforced hospitalisation and medication would only have served to increase her sense of powerlessness and paranoia.

Fortunately, in this instance her keyworker, once informed of her circumstances, was able to avert the ‘treatment plan’ and together we made a new plan to communicate with the extended family to offer her support and for her to attend her weekly appointment with me as usual the following day. Her sister came to visit 10 days later for the Easter weekend as soon as she was informed of the crisis and the following week my client arrived at her appointment much calmer and told me how reassured and loved she felt. Sadly, without the fortuitous conversation beforehand, the mainstream mental health service approach of locating problems within individuals, thereby requiring sectioning to manage risk, would have continued without challenge.

Alternatives to Mainstream Approaches – Phenomena, phenomenology and discourse.

Critical approaches to mental health problems state that, ‘functional mental illness is a personal experience that does not have an underlying brain pathology’ (Double, 2019 p 61).

Furthermore, psychologist Lucy Johnstone, also a critic of psychiatric diagnosis for individuals suffering with severe distress, has proposed an alternative approach based on formulation (2018). She argues that severe distress is *not* best understood as a medical illness but as a complex mixture of social, emotional and relationship issues, meaning that the priority for any mental health professional is listening to people’s stories and adopting a collaborative approach to reach an understanding. The experiences of psychologist Eleanor Longden support the importance of giving individuals a choice about how they can understand their distress from the diverse range of culturally available discourses, and involving them as active participants, rather than imposing psychiatric diagnosis:

> ‘I got a diagnosis of schizophrenia. With this I got the message that I was a passive victim of pathology. I wasn’t encouraged to do anything to actively help myself. Therapy meant drug therapy. It was hugely disempowering and undermining, exacerbating all my doubts about myself. And the impact was devastating because it just served to make the voices stronger and more aggressive because I became so frightened of them. What started off as experience became a symptom… This all happened in a shockingly short space of time. I went into that hospital a troubled, confused, unhappy 18-year-old and I came out a schizophrenic. And I was a good one. I came to embody how psychosis should look and feel’ (2013).

Having recovered from her experience and trained in psychology, Eleanor has been an active campaigner in mental health for alternative approaches. She has collaborated with other critics in the field for a paradigm shift in order to improve mental health services and develop different understandings that privilege the distress experienced within the context of people’s life histories (Longden et al., 2012; Longden et al., 2016). The importance of a contextual understanding is also evident in writer and activist Jacqui Dillon’s first-person account of psychosis (2010), in which she attributes the causation of her voice hearing to the trauma of being subjected to ritualised child sexual abuse, her voice hearing experience being the voices of her abusers.

First-person accounts of lived experience have been central to the recovery movement, which grew out of the civil rights movement in the USA in the 1970s. Developments in information and communication technology have enabled individuals – as well as many of the lived experience groups mentioned in the subsection Critical and Alternative Perspectives – to publish their experiences on the internet, via social media or dedicated collective platforms, disseminating their message to a larger audience. This has also led to the increased awareness of the diverse range of perspectives regarding the experience of psychosis. This is especially important when considered against a backdrop in which, as Hornstein (2002) found in collating 300 first-person accounts, the patient voice is not just ignored but actively silenced. Research into the lived experience of psychosis is still growing and can help to redress the balance and correct potentially mistaken assumptions arising from positivist ways of knowing, in addition to the therapeutic action of shared experience between individuals experiencing psychosis.

Read and Geekie (2009) argue that new methods of research are required to understand the experience of psychosis and formulate useful therapeutic interventions. Research into first-person accounts of the lived experience of psychosis include qualitative studies exploring the lived experience of psychosis and its meaning in context. The focus on subjectivity has enabled an appreciation of the matters that concern, and are of importance to, the individual (such as existential concerns, relationships, sense of self and identity), which are a departure from the focus on measuring positive (i.e., auditory/visual hallucinations and delusions) and negative symptoms, often the central focus in mainstream mental health services.

Geekie (2004), in his research employing individual interviews on the subjective experience of psychosis, found existential needs to be a common feature of importance for his participants. Authoring one’s own experience, ontological insecurity and epistemological uncertainty, were shared themes that not only illuminated the experience of psychosis but created an informed foundation from which to develop a therapeutic focus for intervention. Authoring one’s own experience was perceived as validating and having it denied as invalidating, creating self-doubt, mistrust and uncertainty. For Geekie, the experience of psychosis alters the taken-for-granted aspects of everyday experience in which, ‘our fundamental ways of being in-the-world may be called in to question’ (2012, p. 87).

Other studies investigating published personal accounts of psychosis and recovery reveal self-experience or self-awareness, regaining a sense of identity and meaning in life as central components for recovery (Andresen et al., 2003). Making meaning was also found to be of primary importance and an active process in Larsen’s study (2004). Another qualitative study, based on the first-person accounts from recorded therapy sessions using a grounded theory analysis, concluded a core theme to be navigating issues related to selfhood (Dilks et al., 2010).

Other qualitative research has revealed the association between childhood adversity and the experience of psychosis (Read, 2012; Romme et al., 2009), including the connection between specific types of childhood abuse and experiential phenomena of mental distress, e.g. childhood sexual trauma resulting in hallucinations and bullying/victimisation leading to an increased risk of paranoid delusions (Read & Bentall, 2012). These research findings have been, at best, perceived as controversial within mainstream psychiatry (Murray & Dean, 2008) and, at worst, criticised by Murray at a London debate in 2006 for lacking a robust methodology (*New Scientist*, 2006). However, a recent study this year concluded, ‘[w]e found strong evidence that all forms of childhood adversity were associated with around a two to fourfold increased odds of psychotic disorder and that exposure to multiple adversities was associated with a linear increase in odds’ (Morgan et al., 2020, p.1).

This is in line with interviews undertaken with the public, individuals with lived experience and their families, which have revealed a preference for a broader psychosocial understanding appreciating the impact of adverse life events, rather than a reductionist approach focussed on biology and genetics (Read et al., 2005), as favoured within mainstream psychiatric practices and evident in dominant psychiatric discourse.

The phenomenological exploration – the study of lived experience – in the clinical work of Sass and Parnas (2001) with individuals experiencing psychosis (what they refer to as 'schizophrenia'), found anomalies in self-experience to be a key factor at the core of the subjective experience of psychosis. The self-disorder they identified, termed a disturbance in *ipseity*, refers to three aspects of disturbance within the self: hyper-reflexivity, diminished self-affection and disruptions in the conceptual and perceptual field (Sass & Parnas, 2003). The disconcerting changed experience of the self, with a sense of fragmentation of different aspects of the self, is considered a core feature of 'madness', which impacts the interpersonal world as well as the personal – the therapeutic aim being to attain integration. Their phenomenologically informed research endeavour from clinical work with clients resulted in insights for therapeutic intervention, with the subjective experience of the human being as the primary focus.

Phenomenological analysis has led to the development of a philosophical practice in mental health whereby the individual is not regarded as a patient, but a thinker suspending judgement on the concept of illness, and an active human agent collaborating in the pursuit of meaning and developing an understanding of the role and meaning of human suffering and a broader consideration of existing in the world (Dibitonto, 2014). This is summed up by Dibitonto: 'philosophical practice doesn't consist in patients becoming aware of their mental illness nor in learning to describe themselves in diagnostic or in psychopathological terms, but in becoming aware through dialogue of the problematic sense of human experiencing in general and not only of their own individual experience' (2014, p. 290).

A Therapeutic Approach

Prioritising the human being who is having the experience of psychosis, and responding to their individual needs, is a focus that is gathering some momentum via the various critiques of mainstream mental health services. Social Psychiatrists McCabe and Priebe, in their 2004 paper, 'The Therapeutic Relationship in the Treatment of Severe Mental Illness', revealed the importance of the therapeutic relationship in the patient-doctor relationship, and how different communication styles affected the relationship. McCabe and Priebe found that a good therapeutic relationship resulted in better outcomes in both the short- and long-term. The focus on the therapeutic relationship has been central in the field of counselling and psychotherapy, and a central tenet in person-centred therapy developed by Carl Rogers (1951). Rogers emphasised the importance of being person-centred and incorporating what he termed the 'necessary and sufficient' conditions into therapeutic practice, including unconditional positive regard, empathy, and congruence. In my professional experience with clients, these conditions are often reported as absent in their encounters with mental health professionals in mainstream services. Instead of listening to what they want to speak about, in terms of what has happened to them, there is a primary focus on discussing symptoms and risk with the 'psychiatric patient'. This can result in feelings of being disregarded, thereby eroding trust, which in turn increases a sense of threat, paranoia and suspicion, further damaging the potential for a therapeutic relationship.

It can be validating to have concerns around identity, selfhood, personhood, and relationships within the self and others listened to, resulting in the experiential feeling of ‘being seen’. As Dillon puts it, ‘What people want is to be believed and acknowledged. It’s that simple’ (2019, p.1). The potency of the experience of ‘being seen’ resonates with studies researching early human development and behaviour, in which ‘being seen’ is regarded as fundamental in developing secure attachments in relationship to others. The act of seeing each other, and responding to the other, forms the beginning of language and of communication. In secure relationships, the reciprocal dynamic of seeing and responding is referred to as ‘mirroring’. The devastating impact of not ‘being seen’ is illustrated well in the Still Face Experiment (2009) by Dr Edward Tronick,[1] conducted with mothers and their preverbal children. He instructed the mothers to start by communicating with their child as usual, and then stop responding to their child in order to ascertain the child’s response. Video clips show how the child becomes very distressed as the mother, still present physically, stops responding.

Attachment theory, as developed by Bowlby (1969), proposes that early relationships with significant others have a profound impact on later interpersonal relationships and attachment styles. Although Bowlby did not perceive attachment theory as contributing to the understanding of psychosis, Berry et al., argue that, ‘[u]nderstanding the role of attachment in psychosis allows us to make the fundamental shift from treating psychosis to working with the person with pronounced interpersonal difficulties’ (2020, p.1).

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[1] See https://www.youtube.com/watch?v=apzXGEbZht0

Dominant Discourses Obscuring Meaning and the Person?

‘Although awareness of the arbitrary and constructed quality of psychiatric diagnoses is on the increase, the prevalence and use of medical discourses within mental health provision and society at large, remains dominant, when it comes to understanding human behaviour and experience’ (Rosenberg, 2006, p. 417).

Discourse analysis is utilised across many disciplines and, despite variability in how it is conceptualised, the common theme is a social constructionist view related to the contextual, functional and constructive nature of language (Wetherell et al., 2001). In recent decades the social constructionist movement in psychology has developed discourse analytic approaches to mental distress in order to acknowledge the sociocultural and historical context of the discourses present in language – which it is theorised, construct realities, in contrast to mainstream positivist approaches theorising language as representing an objective reality (Burr, 1995). Foucauldian approaches to discourse analysis emphasise the historical production of discourses through interpersonal, institutional and social processes, which constitute our experience, knowledge and practices (Burman & Parker, 1993).

Social constructionist research into the categorisation of individuals experiencing mental distress – wherein they are assigned a psychopathological category from the dominant classification system in psychiatry (the DSM) – problematises the taken for granted aspect of diagnostic categories, resultant knowledge, and associated practices. Social constructionist research therefore raises some challenging questions about how mental distress can be understood, critiquing the emphasis on individualist approaches that locate the problem within the individual, who in turn is identified and labelled. Instead it illuminates the socially produced nature of the categories of mental distress, which can be regarded as discursive complexes that construct reality and subject positions.

Willig explains the implications of subject positions as follows: ‘positionings constitute ways of being through placing the subject within a network of meanings and social relations which facilitate as well as constrain what can be thought, said and done by someone so positioned’ (2000, p. 557). It can therefore be understood that the linguistic categories and discursive constructions present in dominant discourses legitimate a particular version of reality and experience, excluding alternative versions. Parker posits that ‘[d]ominant discourses ratify the existing order of things, make them seem natural and unquestionable and they conceal patterns of power’ (2015, p. 28). Foucault explored the historical conditions of conceptualisations over time and the ‘modes of objectification which transform human beings into subjects’ (1982, p. 777) placed in complex power relations. He observed that the scientific status of medicine, the episteme of our time as evident in mainstream psychiatric systems and practices, can bestow ‘uncontrolled power over people’s bodies, their health and their life and death’ (1982, p. 780).

Parker and colleagues co-authored a book, in 1995, titled *Deconstructing Psychopathology*. This was a revolutionary text at the time, deconstructing expert discourses in psychopathology to reveal new understandings including how subjectivity is shaped and identities are constructed, and recommending changes for practice – the aim being to enable more empowering and beneficial ways of understanding and managing mental distress. The deconstruction of expert discourses on mental distress exposes how mental distress has become separated from mental health by operation of the abnormal/normal dichotomy, which consequently results in ‘dividing practices’ (Foucault, 1982, p. 777) by mental health professionals engaged in separating the normal from the abnormal. This practice is promoted by our western education system, which still promotes the teaching of ‘abnormal psychology’ despite the excellent publication of *Psychology, Mental Health and Distress* (Cromby, Harper & Reavey, 2013), which offers knowledge based on understanding the complexity of human experience, rather than pathologising experience and diagnosing disorders.

The practice of dividing normal from abnormal is associated with what is referred to as the ‘psy-complex’, a network of theories, practices and systems in society individualising minds and behaviours for social regulation purposes (Ingleby, 1985; Rose, 1985). The most oppressive implementation of psychological knowledge is considered to be within the psychiatric system and institutions (Parker et al., 1995), which have been aligned with systems of social control. For Parker, discourse analysis is a method that, ‘efficiently homes in on the representations of pathology circulating outside psychology as well as inside it’ (2015, p. 3).

In addition to the discourse analysis of the psychiatric classifications, experiences regarded as symptoms of disorder have been critically analysed from interviews with service users – e.g., paranoia (Cromby & Harper, 2009), psychotic speech (Parker et al., 1995) and hallucinations (Blackman, 2001). The concept of delusions has also been problematised for drawing from a naïve realist perspective that denies the very reality of the individual (Georgaca, 2000, 2004, Harper, 1995, 2004).

Other forms of discourse analytic research have involved examining professional accounts in mental health to investigate how discursive strategies are employed to justify certain practices – e.g., diagnosis (Harper, 1995), medication (Harper, 1999; Liebert & Gavey, 2009) and ECT (Stevens & Harper, 2007). Insights from this research demonstrate how practitioners conceptualise the service users as severely medically ill and position themselves as objectively applying medical interventions whilst assessing risks and benefits.

Public texts on mental health issues have also been a focus for discourse analytic research. This has identified the prominence of medical discourse and the discourse of dangerousness in both the media (Bilić & Georgaca, 2007) – where it perpetuates a negative view of individuals experiencing mental distress – and in policy documents containing legislation that emphasises the concept of risk, consequently promoting restrictive measures in the interest of public safety, such as Community Treatment Orders (CTOs) (Harper, 2004).

Willig has pressed the importance of ‘moving beyond critical deconstruction of health-related discourses and practices’ and ‘beginning to explore the ways in which these are appropriated, modified and challenged by individuals’ (2000, p. 554) in an attempt to manage and cope with their experience, which in turn shapes selfhood and embodied subjectivity. Henriques argues that a discursive focus alone cannot theorise subjectivity (2002). Furthermore, Willig states that to attain a full understanding we need to include, ‘how discourses of health and illness are interleaved with our material bodies’ (2000, p. 559) and that the relationship between discourse and embodied subjectivity requires more in-depth research, potentially requiring new methods that include a focus on both aspects of experience. A research collective with an interest in qualitative research was formed in the UK in 1999, to explore how to rebalance the turn to language in psychology by including a focus on embodiment. Memory work, a methodological approach focussing on rich sensory descriptions and details of circumstances surrounding a past event, was used with the aim of illuminating ‘the “being in” aspect of experience’ and the role the body plays in subjectivity and selfhood to, ‘do justice to the complexity of embodied experience’ (Brown et al., 2011 p. 512). The collective agreed that despite the difficulties in researching embodied subjectivity, it was important to continue exploring methodological approaches on the subject.

Taking into consideration the advances in understanding the constitutive nature of dominant discourses in shaping subjectivity, and the phenomenological focus in illuminating aspects of lived experience, the research presented in this thesis comprises a dual focus qualitative research study utilising both FDA and IPA. This methodology has been utilised in order to benefit from the analytic insights from both methods, which include the personal and social aspects of our existence, so as to attain a more in-depth understanding of the meaning-making of the embodied lived experience of psychosis when subject to a dominant psychiatric discourse.

Qualitative Research in Psychology

When I was studying for my undergraduate degree in psychology during the 1980s, quantitative research was regarded as the gold standard. Nevertheless, in recent years qualitative research has begun to be valued for the rich understanding of human beings it can afford. In 2005, with the rise in the use of qualitative methods, the Qualitative Methods in Psychology section (QMiP) of the British Psychological Society (BPS) was formed to promote and develop qualitative research with an appreciation of human interpretation as a core consideration. The methods used are diverse and incorporate discursive, phenomenological and feminist approaches that seek to illuminate meaning-making and the situatedness of human existence in the context of social processes, the personal and material world. The departure from a positivistic focus on individual cognitions and behaviour by ‘changing the subject’ (Henriques et al., 1984) enabled the exploration of what it is to be human within a social context, without which human beings do not exist. However, despite the rise in acceptance and popularity of qualitative methods, the current regulatory systems evaluating and governing quality in research utilise criteria applicable to quantitative research, creating a discriminatory bias that undermines the progression of qualitative research (Riley et al., 2019), so there is no room for complacency!

Given my critical stance, interest in phenomenology, discourse and placing the whole human being at the centre of any research focus (including the researcher), a qualitative methodology was essential. Furthermore, an integration of phenomenological and discursive methods was required to explore the meaning-making of the lived experience of psychosis when considering the wide range of discursive resources available, although the dominant discourse in mainstream mental health services at this point in time continues to be the medical psychiatric discourse.

Contemporary Qualitative Research on the Experience of Psychosis

The language around the subject of mental health has been changing in recent years, so I will give a brief overview of some of the contemporary qualitative studies published in the last five years on the topic of psychosis from a discursive and/or lived experience perspective. A literature search was undertaken using the City University Library Psycinfo database (October 2015 - October 2020) for published qualitative research using the search terms: ‘qualitative research on the lived experience of psychosis’; ‘IPA psychosis’; ‘FDA psychosis’; ‘phenomenology psychosis’; ‘discourse analysis psychosis’; ‘meaning-making psychosis’; and ‘dual focus analysis psychosis’. Sixteen studies were found and, after reading the abstracts, twelve selected as most relevant. Notably, I did not find any qualitative dual focus studies on the subject of psychosis.

I found one UK study utilising FDA on how the experiential phenomena associated with psychosis are written about and understood in expert case reports. It identified two predominant discourses, namely biomedical and a counter discourse (Kaselionyte & Gumley, 2019). The context was related to 'extreme mental states' experienced in meditation and whether that experience can be best understood as a spiritual emergency or psychosis. The authors also stated they were using Vanderkooi's term 'extreme mental states' (1997) instead of psychosis as they wanted to adopt a neutral position outside of a medical approach. The biomedical discourse identified was imbued with psychiatric symptoms and a variety of treatments including involuntary hospital admissions, electroconvulsive therapy (ECT) and antipsychotic medications, with the individual positioned as a nameless passive recipient and mental patient. The counter discourse by contrast offered a range of different constructions including spiritual, cultural and psychological phenomena experienced by a named individual in crisis, whose experiences were not pathologised, but tentatively understood from a reflexive stance. Kaselionyte & Gumley theorised that the discursive divide evident in the expert reports is reflected in the trainings of mental health professionals and concluded that a cross disciplinary approach integrating multi-perspectives might be more beneficial: '[w]e suggest that efforts should be made to create a supportive environment for people to integrate their extreme experiences and find meaning congruent with their values, beliefs and cultural background' (Kaselionyte & Gumley, 2019, p.1110). This was an interesting piece of research which valued the power of language to shape experience, however, expert discourses being analysed does not tell us how individuals with the lived experience construct their experience, which discourses they are mobilising and therefore what they might find most useful in a mental health service.

A narrative analysis conducted in Sussex, exploring young people's narratives of hope following an experience of psychosis, resulted in the identification of some significant themes: sense of belonging, social inclusion, a future oriented idea of improvement from information, planning and occupation, and recommendations of beneficial foci when offering therapeutic interventions to aid recovery (Bonnett et al., 2018). However, although this piece of research drew on lived experience following individual interviews of 10 young people, it was focussed on cognitions with hope' conceptualised as a cognitive process without an emotional component and the achievement of goals influencing emotions to create more hopeful thinking. Even though this is a piece of qualitative research, the absence of a phenomenological exploration of hope, or discursive focus to consider discursive strategies used to negotiate meaning or the constitutive nature of discourse – with the assumption that talk reflected a single objective truth of the experience rather than one knowledge amongst others – is in line with positivist psychological research. Research on the phenomena of the subjective experience of hope may have yielded richer insights beyond the narrow cognitive formulation in addition to a discursive analysis.

Another narrative analysis of individual interviews investigated the lived experience of recovery in people who hear voices in the UK (de Jager et al., 2016) by adopting a single complaint approach as defined by Bentall: outlining specific difficulties individuals experience (Bentall 2004); investigating voice hearing in relation to a broader conceptualisation of recovery as a personal process; regaining a positive sense of self, agency, hope, occupation and improved quality of life. Two narratives were identified –

‘*turning toward’*, characterised by a curiosity and integration of voice-hearing experience in a process of self-transformation, and ‘*turning away’*, which was focussed on symptom reduction and management, consigning the experience to the past. Although the authors did not want to engage in judgement, they were able to offer the following observation from their research findings: ‘the stories that participants told about themselves were more restrictive in turning away narratives and more liberative for those who turned toward’ (de Jager, 2016, p.1417). They also noticed that a ‘turn toward’ was accompanied by a ‘turn away’ from the dominant biomedical discourse theorising voice hearing as a symptom of illness requiring antipsychotic medication. They therefore concluded that integration of alternative explanations of voice hearing could be beneficial when working with individuals who hear voices, however, the subjective embodied lived experience of voice hearing was not included, which could potentially have shed some light on the development of a ‘turn toward’ or ‘turn away’ narrative.

Another single complaint (Bentall, 2004) study conducted using semi-structured interviews with 12 participants in the UK, and subsequently analysed using thematic analysis to explore dissociative experiences in psychosis (Černis et al., 2020), did include a focus on the phenomenology of dissociation experience and meaning. Conclusions resulting were that the central feature of dissociation was a ‘felt sense of anomaly’ (FSA) characterised by a feeling of strangeness and disconnection that was exacerbated by a lack of information in how to understand the experience. Recommendations for practice included psychoeducation on dissociation to increase making sense of the experience, thereby reducing fear of the unknown and leading to positive consequences in the management of dissociative experiences, in addition to practical exercises focussing on a return to the body and grounding.

An IPA conducted in Belgium, exploring meaning-making of individuals with lived experience of psychosis using individual interviews and focus groups, found that meaning-making was composed of *aha* and anti *aha* experiences (Sips et al., 2020) – '*aha'*, referring to moments of restructuring in understanding which feel like a breakthrough, and '*anti aha'* being a form of insight that is undermining, contradictory and destabilising in every sense, disrupting fundamental aspects of reality and identity. A tension between these experiences during the lived experience of psychosis was noted, which was concluded as significant for clinical work. Therefore, including a focus on the subjective and existential experience of psychosis during any therapeutic encounter was recommended, in order to enhance understanding of what is happening for a person and 'not merely on a supposed underlying discrete neurological process' (Sips et al., 2020, p.10). The specific focus in this research study may have been influenced by the first author's lived experience of psychosis, creating a narrower focus of enquiry, however, this could be interpreted positively given the progress in mental health research of including first-person perspectives in qualitative research to advance treatments for psychosis.

Another IPA study looking into the relationship of emotions and psychosis, colourfully named 'Emotional earthquakes in the landscapes of psychosis' (Hutchins et al., 2016), looked to explore the lived experience of emotions before, during and after psychosis. This UK study using semi-structured interviews with eight participants had a broader perspective than the previous studies discussed here and resulted in the generation of four themes: struggling with life distress; transformed world and intense emotion; blame and guilt after the breakdown; and confusion, despair and hope. The three researchers worked closely together to discuss the themes and reach agreement, which seems advantageous in terms of advancing knowledge and increasing a multi-perspectival understanding. They concluded that whilst the sense of self remained fragmented following an experience of psychosis, a meaningful future was aspired to with a reintegration of self.

Two further IPA studies, '"She is more about my illness than me": A qualitative study exploring social support in individuals with experiences of psychosis' (McGuire et al., 2020), and, 'Service users' experiences of the treatment decision-making process in psychosis: A phenomenological analysis' (Stovell et al., 2016), both conducted in the UK, highlighted the role of relationships in influencing meaning-making and personal recovery, with 'illness' and a medical framework being central to explanations considered requiring negotiation in attaining an understanding. Furthermore, in the former study (McGuire et al., 2020), although social support was associated with positive outcomes in terms of safety and inclusion, the role of patient and 'illness' were normalised, potentially closing down the opportunity for other identities outside 'illness'. Conclusions reached included that further research would be important in finding ways to empower individuals and foster a sense of connection, apart from concerns about their 'illness', in addition to shared decision making and peer support to promote recovery and selfhood. The need to feel listened to was echoed in the latter study with the issue of power a core theme (Stovell et al., 2016). References were made to the power of negative constructions of psychosis, e.g. danger and abnormality, resulting in stigma negatively impacting a sense of agency and empowerment. Given the consideration of power relations emanating from the latter IPA, an additional FDA could have been appropriate in affording a more detailed investigation of the discourses and constructions present in the accounts of treatment decision-making encounters. Especially given the references to the dominance of a medical framework in these encounters and the different conceptions of recovery present.

Stigma associated with negative constructions of psychosis was explored in a thematic analysis completed on 193 respondents to an online US survey titled, ‘Lived experience perspectives on reducing the duration of untreated psychosis: The impact of stigma on accessing treatment’ (Hardy et al., 2020). Two higher order themes were identified: firstly, negative perceptions of being diagnosed with a psychotic disorder resulting in shame and fear, and secondly the actual consequences of potential discrimination and rejection by others. This research was conducted by a multidisciplinary team with a variety of experiences in an attempt to avoid bias, which is a strength in this study. However, its recommendations for ameliorating the effects of stigma when there has been a delay in accessing treatment would seem to indicate that addressing stigma on a broader society wide scale is required, as is discussion about the types of stigma experienced prior to accessing mental health services and possibly how this is reflected in the culturally available discourses.

Recent discussions in changing the way neuroleptic medication, most commonly referred to as antipsychotic medication, is used in the treatment of psychosis or ‘psychotic disorders’ is reflected in the contemporary information being published in mental health journals and in qualitative research. A grounded theory research study analysing interview transcripts of 12 participants in Northwest England, ‘Personal Accounts of Discontinuing Neuroleptic Medication for Psychosis’ (Geyt et al., 2017), emphasised the importance of the quality of the relationship with mental health professionals and the need for, ‘empathic, collaborative, non-judgmental alliances with clients’ (p 569). A biomedical discursive construction of ‘mental illness’ as necessitating the use of antipsychotic medication was found to be the dominant understanding amongst the participants. Recommendations for practice included practitioners supporting formulations tailored to the needs of each individual in order to empower them in their recovery, and for the option to discontinue antipsychotic medication to be openly communicated so individuals can make an informed choice. Further research was also recommended into the interface with mental health professionals and their understandings, in order to facilitate service user empowerment and reduce the dominant practice in mental health services of risk assessment and the promotion of medication adherence.

The importance of agency and autobiographical power in recovery is a prominent theme in contemporary research. A piece of ethnographic research using individual interviews and field research, ‘No one ever asked me that before: Autobiographical Power, Social Defeat, and Recovery among African Americans with Lived Experiences of Psychosis’ (Myers & Ziv, 2016), highlighted the needs of individuals with lived experience of psychosis to take charge of their lives and have their personal explanations recognised and listened to. Being heard and recognised was concluded to be beneficial for recovery in rebalancing the power in the therapeutic encounter and empowering the individual to author their own experience.

The final piece of research I will reference was conducted in Belgium and is pertinent to authoring one’s own experience. Pete Tomlinson narrates his own lived experience of psychosis, specifically the variety of diagnoses, psychiatric treatments and talking therapies he has had over the years, in his qualitative research study, ‘A narrative of my lived experience of a whole series of psychiatric diagnoses and their impacts on me, ending with a discussion of clinical recovery from psychosis’ (Tomlinson, 2020). His aim was to problematise the over reliance and confidence in diagnostic categories, and what is subsequently assumed about a person, preferring an approach which prioritises the person and their unique story. This was a touching account to read with much to be learned in terms of recommendations for practice.

It can be seen from this review of contemporary qualitative research that the language in mental health is starting to change, as is the level of prominence and inclusion of accounts from people with lived experience of psychosis. Explorations into the lived experience of psychosis, meaning-making and the language used to speak about the experience are evident in contemporary qualitative research. However the interplay between language and experience seems only to be given a light touch approach, in preference for a single methodology that privileges one slice of reality. Given my work as a practising counselling psychologist working with individuals who have experienced or are experiencing psychosis, and what appears to be a gap in the research literature, I decided to explore the interplay between language and experience.

My Approach

[E]xploring personal recover[ies] have been closely rooted in constructivist and phenomenological approaches, and have been more exploratory and open to capturing nuances in subjective experience, which may allow for a broad understanding of what is important to people with mental illnesses like psychosis' (Jordon et al., 2020, p. 290).

My research title includes the word 'subject', in recognition of the 'power which makes individuals subjects' (Foucault, 1982, p. 781), and the 'subjective', which is informed by self-knowledge and experience. The dominant psychiatric discourse, with medical concepts at its core, was the predominant explanation my participants encountered when accessing mental health services for psychosis. Although I would agree with the statement that language constructs objects, I argue that it is not solely responsible for how we understand human beings in the social, personal and material world. Co-existence of language and the situatedness of our embodied experience mean that these exist together naturally in the actuality of our reality.

I therefore wanted to pay equal attention to the discursive and non-discursive aspects of experience, including the embodied phenomena of psychosis and subjectivity. I explored the dynamic interaction between discourse and subjective experience with regard to meaning-making of the experience of psychosis and the implications for what can be thought, said and done, influencing being in the world and recovery. Exploring how individuals mobilise discourses and the relationship to the subjective experience of psychosis was a key focus. A critical realist methodology was used to deal with the conflicts in epistemology arising from realist and relativist assumptions about the world, by integrating ontological realism, epistemological relativism and judgemental rationality, referred to by Bhaskar as the holy trinity of a critical realist philosophy (2018). Qualitative research has been criticised for concerning itself with one side of a false dichotomy, where there is an exclusive focus on language or experience. However, a combined methodology can aim to explore the experiential and constructed aspect of reality. As Latour (1993) suggests, it is important to recognise the connections between nature and culture rather than seek distinctions in the pursuit of objective knowledge, which he argues is not possible.

My approach to knowledge is integrative, not privileging one slice of reality over another. A multi-perspectival focus, in addition to an individual approach to each participant, is a non-homogenising endeavour enabling both the knowledge of what might be universally experienced in addition to the diversity in experience between participants. Appreciating the uniqueness of individual experience is central to my clinical work with clients, where the search for meaning is prevalent. Seemingly, it is even central for those experiencing severe emotional distress, leading to deeper existential concerns which reach beyond ordinary everyday experience and the trials and tribulations of living. It was important, given my critical approach, for this stance to be maintained throughout the research process, regardless of my primary role of researcher in this study rather than that of a counselling psychologist.

The following chapter contains a detailed description of the methodology, followed by a chapter outlining the methods used. The analysis section of the thesis proceeds with the IPA chapter, then the FDA chapter, and finally the blended chapter integrating the findings from both analyses, before drawing my conclusions with the implications and recommendations for practice.

A Dual Focus Methodology

It was clear to me that an exploration of meaning-making of the experience of psychosis when subject to a dominant psychiatric discourse, would require a focus on both discourse and embodied phenomena. Furthermore, it felt imperative to give equal focus to both the subjective, embodied lived experience and the available discourses deployed in meaning-making of the experience of psychosis, including the dynamic interplay that exists between language and experience. From my clinical work, it was apparent to me that my clients were often struggling to make sense of their experience from their own personal perspective and what they might be aware of within the sociocultural context and mainstream mental health services.

It was therefore a natural progression to consider combining an IPA and an FDA, and I anticipated that this was something that many researchers before me would have undertaken. Indeed, I expected to find appropriate reference materials regarding a dual focus methodology incorporating IPA and FDA, to guide me in my endeavour. However, what I was not aware of, as a practising clinician, was that within academia these were regarded as theoretically incompatible. This position, which I shall discuss in more detail later in this chapter (including how I overcame this stalemate), seemed to have put off most researchers from conducting this form of analysis, with the exception of a handful of studies, e.g. Colahan, 2014; Cosgrove, 2000; Willig, 2011; Johnson et al., 2004. However, there was some precedent in terms of methodological pluralism, which emerged as an option earlier on in the development of qualitative research, as assumptions about epistemological differences precluding the~~ir~~ integration of different approaches were challenged in order to provide richer knowledge about the complexity and multifaceted nature of human experience. Langridge

(2004) and Del Busso & Reavey (2013) are examples of such research, encapsulating a diversity of interests including lived experience and the constitutive role of language. These could be considered as precursors to dual focus approaches in qualitative research, looking to provide separate readings which are not mutually exclusive and that can be integrated to provide a coherent understanding with enriched meaning.

Fortunately, my supervisor Professor Willig, an expert in the field of qualitative research methods in psychology, encouraged me to continue with the proposed dual focus methodology and recommended I start by reading a research paper by Colahan et al., (2012) ‘Understanding lived experience and the structure of its discursive context’, and her paper on the, ‘[p]henomenological repercussions of being positioned within dominant constructions of cancer’ (2011). So began my research journey to conduct a dual focus analysis on the same data set about the meanings arising from the subjective experience of psychosis, utilising IPA and FDA.

The primary focus for IPA is the meaning and texture of subjective experience, whilst FDA explores the discursive resources individuals access and deploy in speaking about their experiences. It was anticipated that integrating the results from both would enable an appreciation of the interplay between language, culture and experience, thereby affording a more complete understanding of the experiential phenomena and meaning-making of the experience of psychosis.

Although the primary focus for IPA concerns accessing the life-world of an individual as it has been experienced and appeared to them, the context and the conditions for that appearing are also a fundamental consideration. As Smith points out, ‘[t]here are entities, discourses pre-existing, there is a social order that strongly influences the person and it's the symbiosis between the individual trying to make sense of what's happening to them and the resources they have to do that' (Smith, 2012, p. 213) – thereby claiming IPA as a social constructionist endeavour. He also expresses the potential for combining IPA and discourse analysis explicitly, to attain a full consideration of the uniqueness of individual embodied experience embedded in a sociocultural context. Smith's IPA therefore seemed an appropriate method, especially given my interest in paying close attention to first-person accounts of emotional distress, the phenomenality of experience, embodied subjectivity, relationship to self, others and being in the world.

Furthermore, the claim that IPA focusses on experience in its 'own terms, rather than predefined category systems' (Smith, Flowers, & Larkin, 2009, p. 32) seemed a good match for the purpose of my research looking to explore meaning-making of the embodied subjective experience when subject to a dominant psychiatric discourse infused with category systems. Additionally, having been inspired by phenomenological psychiatry developing therapeutic interventions that extend beyond psychiatric classifications (Sass & Parnas, 2003) and exploring the structural changes in subjectivity, basic relation to the world, affective changes and unusual perceptual experiences, including how they all dynamically interact with each other, suggested IPA as a good fit for the purposes of this study.

However, philosopher Dan Zahavi, prolific writer of texts on phenomenology (2003, 2012, 2015, 2017, 2018, 2019), has raised some interesting objections regarding the use of IPA for qualitative research in health, which I have considered. Zahavi argues in his paper, 'Getting it quite wrong: Van Manen and Smith on Phenomenology', that a phenomenological approach cannot be reduced to an exploration and description of phenomenality alone, but must also, ‘disclose, disentangle, explicate, and articulate those components and structures that are implicitly contained in the pre-reflective experience’, and, ‘understand the transition between our pre-reflective and pre-conceptual grasp of the world and our subsequent conceptualization of and judgment about it’ (2018, p 5). I have taken into account these valid points raised by Zahavi in my study, the aim of which was multi-perspectival, incorporating a dual focus approach designed to attain a rich and more complete understanding of both the meaning-making of the subjective embodied experience of psychosis – by adopting a phenomenological approach – and the context – by expanding further in considering the discourses mobilised by the participants in their pursuit of meaning. As a result, there were some interesting insights generated from utilising IPA, regarding subjectivity, embodiment, agency, emotions, the relationship with self, other and the world, in addition to the socially constructed nature of reality, as participants deployed a variety of discourses to articulate and convey their understanding of their lived experience.

The debate amongst academics in the field regarding the status of IPA in qualitative research, and whether or not it satisfies the criteria to claim being a phenomenological approach, is as yet unresolved and no doubt will continue. However, from my perspective primarily as a practising critical clinician, the emphasis has always been on first-person accounts of experience and the dynamic interaction between myself and my clients’ being-in-the-world. The adoption of a phenomenological approach in my work with clients has been fundamental to understanding their attempts to make sense of their distress from the ‘pre-reflective to their conceptual grasp’ (Zahavi, 2018). Whether or not it can be concluded that IPA involves a phenomenological approach, I will leave to the academic experts to debate. Nevertheless, there is much to be gained in qualitative research by moving beyond psychiatric diagnostic classifications of experience and paying attention to the phenomenological, in the knowledge that psychiatric classifications are socially constructed and therefore interpretations of experience, rather than facts with ontological status.

Given my critical stance and therefore critical analysis of psychiatric categorisation and labelling of individuals, it would have been somewhat perverse to conduct a piece of research that sought to homogenise the data and exclusively consider shared themes, potentially losing the uniqueness of the individuals and the differences between them. The benefits of multi-perspectivity – by which I mean attending to both language and experience – in addition to the idiographic commitment in IPA, have been highlighted for research looking to explore a variety of perspectives concerning experience and meaning. The range of options includes, ‘a case study for each participant’ (Larkin et al., 2019, p. 190). A single case analysis seemed appropriate for this study given the dual focus, to facilitate an appreciation of the points of convergence and divergence between the participants whilst also maintaining a respectful stance towards them by presenting them individually.

The summary grid table of the IPA master themes (appendix 7) enabled a view of each participant within a column and the shared themes along the rows. It was from this exercise that the differences between the participants were noticeable in addition to the themes shared between them. It became apparent that the differences were potentially attributable to a variety of meanings made about the experience of psychosis, which were associated with a diverse range of discursive resources deployed by the participants in speaking about their experience. The various constructions of psychosis, and subject positions resulting, created contrasting implications for what can be thought, said and done. Conflicting positions were also apparent within each participant’s individual account as different discursive resources were mobilised to articulate their understanding and experience.

Willig highlights the impact of discourse on meaning in her paper, ‘Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer’ (2011), making the point that the meaning made has a direct impact on options for living and subjectivity. A previous paper about her experience included excerpts from her reflective diary providing a phenomenological glimpse of living with a diagnosis of cancer, whilst also evaluating the impact of various constructions of cancer on meaning-making, including her own. This enabled a binocular view of the experience of cancer diagnosis and the pursuit of personal meaning, with an imposition of meaning from others via contrasting discourses – e.g. moral – being experienced as painful (2009, p. 185). In her first-person account, the therapeutic relationship and the presence of an empathic other were experienced as important for making and retaining a personal meaning in the ‘thrownness’ of being (Heidegger, 1962) amidst the plethora of constructions of cancer.

Emphasising the role of language in mental health services, Walker states, ‘[t]he mental health profession’s isolation from other disciplines such as history and philosophy, as a whole, has left it with only a superficial understanding of the power of language’ (2006, p. 77), and therefore how its constitutive nature is overlooked. Social constructionist approaches have sought to elucidate the impact of language on subjectivity in a variety of fields including mental health.

Social constructionist research examining the impact of discourses in psychopathology (Parker, et al., 1995) has critically evaluated the detrimental and disempowering effects on those seeking help from mental health services and how dominant discourses serve to maintain institutional practices. However, discursive psychology is not without critique in our pursuit to understand the social world and our relationship within it, '[t]he 'discursive psychologists' now guard their own domain of study very carefully, stipulating exactly how speech should be transcribed and most importantly how the researcher should avoid straying into talking about anything else. In this way discursive psychology buys into the worst of academic specialisation in which each compartmentalised area of work refuses to have anything to do with other areas' (Parker, 2007, p. 136). This observation aligns with my own views. Namely, although I agree that discourses have a profound and powerful impact on subjectivity, language cannot solely be responsible for experience. Integration of other theories and conceptualisations is therefore required to gain a more complete understanding of our being-in-the-world. This emphasises the need for psychologists to spread their focus further afield to include other disciplines such as philosophy, sociology, history and anthropology, in order to enable a more comprehensive understanding of human beings, in addition to a contextualisation of human experience.

I shall begin by clarifying my use of the term 'discourse', which acquires different meanings within different disciplines, as is commonplace for many terms. Parker, who is an exponent of FDA, defines the term 'discourse' as a set of 'statements that construct objects and an array of subject positions' (1994, p. 245). The emphasis for Parker is on the constitutive nature of discourse and the inherent power contained within, to constrain and condition human subjectivity. Furthermore, the affiliation of certain discourses with powerful institutions and the propagation of certain practices sets up a mutually reinforcing dynamic, thus maintaining the dominant position in both the conceptualisations possible and practices evident at a certain point in our sociocultural history. In conducting a Foucauldian discourse analysis, these are core considerations.

Within discursive psychology there is a focus on how individuals use language for intersubjective benefits, and do so from an agentive position. The emphasis in Foucauldian discourse analysis is on the prevailing dominant discourses and the consequences for what can be thought, said and done, thereby directly influencing subjectivity. My focus is to examine how dominant discourses are pervasive in participants' communication about their experience and how that affects their subjectivity. As a critical psychologist, this form of analysis is appealing as it enables the scrutiny of the taken for granted concepts and theories in mental health and thereby creates the possibility for considering alternative formulations that can in turn inform recommendations for different therapeutic interventions. The inclusion of a wider range of discourses, I argue, can also be experienced as empowering and liberating, as the meaning contained in first-person accounts of the experience of psychosis and the voices of lived experience are considered in their entirety, rather than reduced to medical symptoms of biogenetic disease emanating from a classification system within dominant psychiatric discourse.

In order to clarify my thoughts about the discourses and the inherent statements which construct experience, that is to say the 'constructed as' components of the discourse, I made tables for each participant identifying the quotes that indicated a dominant discourse and the constructions associated with those discourses, as a preliminary exercise to start organising my thoughts and the interpretative process. I subsequently utilised a Foucauldian informed discourse analysis as outlined in Willig's six stage model to map the culturally available discursive resources deployed by the participants, constructions and subject positions, which can constrain or facilitate what can be thought, said and done (2013).

The focus for both the phenomenological and discursive aspects of subjective experience was in relation to meaning-making, so before I go on any further it is worth explaining meaning. Viktor Frankl (1962), writing about his experience of surviving the Auschwitz concentration camp, concluded that meaning is essential for life and went on to develop a therapeutic approach with meaning as a core focus – Logotherapy. Merleau-Ponty (2014) stated that we are ‘condemned to meaning’ as human beings and that meaning-making is fundamental to our existence. So how are we to understand meaning? Meaning and meaning-making in this study refer to the subjective experience of *felt* meaning for the individual for whom life and experience are making sense. An existential focus includes higher–order, value-laden components of life-purpose and significance, with a directedness in life related to a person’s future aspirations, accompanied by a sense that life matters and is worthwhile. From a psychological perspective, feelings can be seen as information about a person’s experience in the world, embedding subjective feeling states in the context of an embodied experience in response to life and the world.

The subjective feeling state of meaning provides feedback about the reliability and coherence of any information being processed, regardless of its origin. Positive affect tells us things are going well and negative affect tells us there is a problem to be solved, while the subjective feeling of meaning tells us whether experiences make sense (Heintzelman & King, 2014) and therefore directs behaviour in adaptive ways. It could be theorised that a combination of the cognitive, ‘conceptual grasp’ and existential foci give rise to the feeling state of meaning, creating a sense of stability. Layers of meaning, from the literal to the existential, have been identified by Smith (2019) as important in conducting IPA and understanding the different levels of meaning present for an individual making sense of their experience. Smith’s aptly titled paper, ‘Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis', suggests a typology for levels of meaning associated with five core questions, beginning with: the literal - *What does that mean?*; pragmatic – *What do they mean?*; experiential – *What does it mean?*; existential – *What does it mean for my identity?*; and finally, existential purpose – *What does my life mean?*

The process of IPA in qualitative research is not that dissimilar to the process of counselling psychology or many therapeutic approaches that look to make-meaning of experience, in so far as clients are looking to answer *their* questions in pursuit of meaning, e.g., *what is this experience?*, *Why is this happening to me?*, *Why do I feel so bad?*, *What does it mean about me and my future?*, *Who am I?* Often clients arrive with some ideas they may be considering in answer to the questions they bring, arrived at in a multitude of ways; in conversation with others, in self-awareness and self-reflection, and inevitably informed by the culturally available discourses. The similarity is self-evident and the point of divergence it would seem is related to the stage of meaning-making an individual has attained. That is to say, an individual arrives for therapy with their questions potentially to engage in the co-construction of meaning, but in IPA research the focus is on the meanings the participants have already made. This factor created a curiosity for me about the specific questions the participants may have considered in making meaning of their experience of psychosis, and these questions in turn became the organising principle in presenting the integrated analysis of IPA and FDA.

It was evident in this research study that participants were conveying the meaning-making felt experience both during psychosis and subsequently – the former being strongly affiliated to the embodied sensory phenomena of psychosis and the latter a dynamic integration of the subjective experience and the socially available discourses from which to make meaning of their experience, a motivating factor being the attainment of a meaningful life in the world.

The use of the term ‘world’ also requires some explanation and, as Willig (2016) elucidates in her paper ‘Constructivism and ‘The Real World’: Can they co-exist?’, it is important to be clear about the aspect of the world I am concerned with in relation to meaning-making of the experience of psychosis. The ‘social world’, which is the product of social interactions within a ‘material world’ context, results in a range of culturally available discourses which constrain and shape what can be thought, said and done. However, there is also an internal, personal, ‘phenomenal world’ which is related to the internal subjective experience. My position is an integrative one, where the various dimensions of our experiences of the ‘world’ meet and dynamically interact with each other, as they exist naturally in our subjective experiences and are real. So, an exploration of both the ‘social’ and ‘phenomenal’, or language and experience aspect of meaning-making of the experience of psychosis, seemed to be pertinent, with an integration of FDA and IPA an appropriate combination for this research study. However, arguments that combining IPA and FDA creates epistemological/ontological conflicts, due to the dissonant theoretical underpinnings and the relativism/realism debate, required further exploration and explication before I could commence securely.

The primary focus in this study, like most qualitative research, is on meaning-making and is therefore concerned with the construction of meaning by the participants and the researcher. This focus lends itself naturally towards a constructivist approach which is most often associated with relativism and an anthropocentric view that reality is produced by the minds of individuals from their subjective experience, resulting in multiple versions of reality and therefore an indication of ontological relativism. Although, this position on an epistemological level can be seen to be respectful of participants’ accounts of their experience, the consequent premise that an objective reality beyond the minds and verbal articulation of human beings does not exist appears somewhat naïve. Reducing the materiality of the world to our knowledge about it, Bhaskar (2016) called the ‘natural attitude’, an attitude adopted by human beings in ordinary day-to-day existence. However, in terms of advancing knowledge, he coined the term ‘epistemic fallacy’ to indicate that the ontology of the world and what can be known about it are distinct matters for concern. Pilgrim (2020) uses the psychiatric claim of the existence of ‘schizophrenia’ to illustrate an epistemic fallacy, whereby symptoms and criteria created and agreed on by a group of psychiatrists (Davies, 2013) are referred to as evidence of ontological status, despite the lack of scientific evidence (Boyle, 1990) – this example being particularly relevant to the subject of my research.

Regardless of the variability in the way individuals may interpret their personal/phenomenal worlds or the material and social structure of the world consistent with epistemological relativism, the directedness and intentionality of that interpretation in the pursuit of meaning involves attention towards something pre-existing our perception of it. I argue that this pre-existence comprises a form of objective reality with a separate ontological status, made up of more than we can know or have to say about it, therefore conferring an ontological realism. Examples in this study include the embodied sensory experience of psychosis given in the detailed first-person accounts by the participants regarding the unusual perceptual experiences encompassing visual, auditory, and temporal changes accompanied by alterations in self and other relation. The experiential dimension of psychosis was evident as lived embodied phenomena that were subsequently attended to by mobilising culturally available discursive resources in order to make meaning. This fits with Zahavi’s notion of the self in which he argues, ‘that the experiential notion of a core or minimal self is both more fundamental and a presupposition to the narrative self’ (2008, p. 8), thereby regarding these two notions of self as complimentary. A pre-reflective experience constituting a primary presence in the world seems to confer an ontological status of the self as real, with self-consciousness being an essential feature comprised of 'non-observational self-acquaintance'. Furthermore, Sass and Parnas make the point that, '[i]pseity or vital self-affection may verge on ineffability; it is nevertheless something quite real, having very real consequences' (2003, p. 430). The personal given-ness and for-me-ness of the experience as described by Heidegger (1962) also suggests the existence of an essential aspect to subjective experience as an integral component of conscious life, prior to any conceptual or linguistic interpretation. Additionally, the out-there-ness of the material world as a mind-independent entity, and our relationships with actual others in the social world, I argue, point towards a realist ontology.

It would seem, therefore, that our understanding of ourselves in the world includes realist assumptions, however, relativists refute any realist ontology. Edwards et al., (1995), for example, having argued the importance of relativism as, 'potentially liberating, dangerous, unsettling, with an appeal that it is enduringly radical, nothing ever *has to be* taken as merely, obviously, objectively, unconstructedly true', and rejecting realist assumptions as, 'bottom-line arguments against relativism', nonetheless appears to smuggle in realist assumptions that seem to be foundational, stating that there is, 'no contradiction between being a relativist and being *some*body, a member of a particular culture, having commitments, beliefs and a common sense notion of reality' (1995 p. 35). Willig's (2016) assertion appears to be true, that any lack of explicit acknowledgement of realist assumptions does not mean they are not there. Furthermore, Willig suggests that, 'most qualitative research is actually based upon a position of ontological realism together with epistemological relativism. It seems to me that epistemological relativism constitutes a form of intellectual self-awareness and concomitant humility, and ought to characterise all research endeavours whilst ontological relativism is probably not actually compatible with doing research in the first place' (2016, p. 2-3). From my experience as a clinician this approach is compatible and appropriate in terms of honouring the relative nature of human interpretation and understanding, whilst also acknowledging the presence of an objective material and social reality, with real consequences prior to our interpretation of it.

It would seem that, despite declarations of theoretical relativist allegiances, we are predisposed to realist assumptions, as we inhabit the world as human beings within an experiential dimension and hermeneutic perspective. So, how can we accommodate the constructed and personal experiential dimension of reality, beyond a binary conceptualisation of realist or relativist understandings, creating a dilemma and a pressure to choose between them, even though within the lived world they coexist naturally?

Roy Bhaskar, a philosopher and comprehensive, radical thinker working in recent decades, has advanced novel and convincing solutions particularly applicable to the human and social sciences in developing his own philosophy – critical realism. His aptly named book, *Reclaiming Reality*, (1st ed. 1989, 2011) provides a rich and detailed explanation of his critical realist philosophy, which incorporates a realist ontology and a relativist epistemology – thus resolving the tension of the either/or position of having to choose between a realist or relativist perspective in our endeavour to understand our personal, social and material worlds and attain knowledge closer to the state of the truth of our existence. Bhaskar importantly reinstates the 'things' we refer to in our 'sensing of, judging and interpreting of the world', and expresses a, 'disgrace of postmodernism in how it removed the things we refer to when we begin to think about the world' (2018).

In a series of lectures edited by Gary Hawke and posthumously published in *The Order of Natural Necessity* (2018), Bhaskar spoke with clarity about the importance of embracing critical realism, the aim being to, ‘remove the rubbish that prevents us knowing the world’ (9% kindle). He also emphasised the need for ‘seriousness’ in our exploration of the world, in that a workable overlap between theory and practice is required, and warned against ontology being reduced to epistemology in modern philosophy. The three main principles of critical realism, he named the ‘holy trinity’: ‘*Ontological Realism*, that is realism about the world, *Epistemological Relativity*, that is the idea that the beliefs about the world are socially produced, fallible, unchangeable and changing so our knowledge is relative. And the third principle is that of *Judgemental Rationality* and this says that even though our knowledge is relative, we can produce in particular contexts strong arguments for preferring one set of beliefs, one set of theories about the world to another’ (14% kindle).

Adopting a critical realist approach for my research study provided the requisite solution to claims of theoretical incompatibility, permitting an integration of IPA and FDA, enabling the exploration of meaning-making of the experience of psychosis from both the phenomenological and discursive perspectives. Indeed, it became clear to me that a dual focus methodology, drawing on the strengths of both methodologies, was indeed a critical realist endeavour whereby the phenomenology of the lived experience of psychosis illuminated in IPA, and the constructed aspect of reality explored in FDA, together provide a more complete knowledge about the experience of psychosis and its meaning.

Interpretation and meaning are of central concern to both IPA and FDA. Smith et al., (2009) have stated that IPA can adopt a central position whereby the hermeneutics of empathy and suspicion (Ricoeur, 1981) can be incorporated to explore meanings in the text, which, in this case, have been produced in dialogue with the participants, transcribed, read and subsequently interpreted.

IPA is associated more with the hermeneutics of empathy, focussing as it does primarily on subjective experience, with the suspicious approach looking to question and explore meanings. By contrast, the hermeneutics of suspicion utilised in FDA looks to examine the socially constructed content of text, drawing on external theoretical frameworks to elucidate meaning. Furthermore, dominant discourses containing the material traces of history as identified by Foucault (1965) influence our meaning-making, whether we are aware of it or not, due to the taken for granted status of the culturally available discourses, which imply a truth in knowledge claims often underpinned with empirical evidence. Although, IPA and FDA have distinct foci, there are overlaps in the approaches due to their focus on meaning and language. Moreover, as Smith is keen to point out, although there are claims that IPA ‘is essentialist and individualist… it’s not, it’s social constructionist’ (2012, p. 213) – i.e., IPA includes a consideration of the linguistic resources accessed to communicate and articulate experience.

The relationship between experience and discourse is complex and it is important for me to explain the conceptualisation underpinning my research focus and methodology. Broadly speaking, due to my realist assumptions with regards to the ontology of the self and the world, and my relativist epistemological position, I argue that experience pre-exists discourse but that discourse both constrains how experience can be spoken about *and* shapes the experience due to the context created by the discourse. This position is a combination of Willig’s ‘phenomenological conceptualisation’ of discourse and experience, and the ‘middle position’ (2017, p. 18). A dual focus methodology is therefore required to investigate the relationship between discourse and lived experience. IPA provides in depth information about the subjective experience, while FDA acknowledges the role of language in how the experience can be spoken about, and the consequent impact on subjectivity as meaning-making is pursued.

Meaning-making is mediated through language and, as Willig astutely points out, there is an ‘intimate connection between the process of meaning-making and the use of language’ (2012, p. 65). My position appreciates that language is both expressive and performative, i.e., that language is used to both describe what we are experiencing, in addition to playing a constitutive role. Different epistemological positions make different assumptions about the role of language in meaning-making, hence my adoption of a critical realist approach to knowledge facilitating the integration of the data from IPA and FDA, enabling an understanding of both the quality and nature of experience and the construction of versions of reality. Human experience exists interwoven in a world of language, social relationships and culture. Therefore, any study on the meaning of human experience, in my opinion, is enriched by an appreciation of the complexity encountered in language use and what it represents for meaning.

A dual focus methodology is therefore extremely compatible with and advantageous to the area of investigation in this study exploring subjectivity, discourse and meaning-making of the experience of psychosis. I also anticipate that a dual focus is applicable to many qualitative research aims in achieving a more complete understanding of human experience. However, as Willig notes, ‘[d]ual focus methodology is a very recent development and there are, as yet, not many published studies available for inspection. It will be interesting to see how researchers use this approach in future work’ (2017, p. 18).

At the 2017 Qualitative Methods in Psychology conference, Aberystwyth, a symposium on advancing dual focus methodology – with my supervisor Prof. Willig and fellow researcher Sophia Ledingham – was followed by many questions including why a dual focus might be more beneficial than an in-depth IPA or FDA alone (Willig et al., 2017). Although it seemed to make complete sense to me, the conference attendees were curious and had many questions before they could be persuaded. I was convinced that a dual focus methodology was needed both for my research, in order to do justice to my enquiry, but also to explore in more detail what had been apparent in my clinical practice – that many clients diagnosed with severe and enduring ‘mental illnesses’ seemed to be living within the confines of what they thought a particular diagnosis meant. For example, certain categories of disorder (psychotic and bipolar) were often understood to be biomedical diseases requiring long-term use of antipsychotic medication, and involving limitations in the capacity to work, achieve independence or to develop long-lasting relationships and have a family.

A year on from the 2017 conference, it was encouraging to read a paper – ‘Active Ink: Analysing the experience and construction of tattoos as therapy using a dual focus methodology’ – co-authored by Sarah Riley and Sarah Black (2018). They proposed a dual IPA and FDA methodology, drawing together Langdridge (2007) with Willig (2001), so it seemed the symposium had not only been persuasive but convincing too!

Methods

Design

A qualitative design using a combined methodological approach was utilised in order to explore the dynamic between experience and discourse regarding the experience of psychosis and meaning-making. Both Foucauldian discourse analysis (FDA) and Interpretative phenomenological analysis (IPA) were applied to the same data to gain an understanding of both the socially constructed nature of experience and embodied, lived experience. Although IPA and FDA originate from different epistemological positions that are potentially contradictory, there are ‘in between’ positions (Willig, 2013) that can be adopted within both, e.g., between relativist and realist – i.e., critical realist – and between constructed and experiential – i.e., phenomenological.

Adopting an integrative position that does not privilege language over experience, or vice versa, made it possible to combine the FDA and IPA methods as they are compatible with the methodological approach in this research, which aims to explore the different forms of knowledge inherent to both phenomenological and discursive perspectives. This affords an opportunity to gain insight into the interplay between experience and language occurring naturally together in our everyday reality. The proposed ‘dynamic approach’ aims to explore the experiential aspect of psychosis and meaning-making, when the individual is situated within a biomedical psychiatric construction of psychosis and the diversity of meanings available from the deployment of alternative constructions.

Service User Consultation

I consulted with the Service User Research Forum (SURF) about my research proposal, which was positively received, and they were keen to share their guidelines for research participants. Guidelines for the recruitment of research participants from their group – a ‘research forum for service users who access Sussex Partnership NHS Foundation Trust Early Intervention in Psychosis services’ (SURF, 2020) is that £10 per hour is paid for their time in addition to any expenses incurred in taking part. Renumeration is seen as a demonstration of valuing the participant’s time, regarded as especially important for a group who have been marginalised in our society. I agreed with their guidelines and included information about payment in my participant information form, which stated explicitly that participants would be paid for their time to express their opinions. Participants recruited were paid £10 per hour in addition to any expenses.

Interview Schedule Development

A semi-structured interview was developed in consultation with my supervisor Prof. Willig at City, University of London, and an individual from Soteria Brighton who had experienced psychosis and received a diagnosis of schizophrenia. Questions were aimed at facilitating discussion around themes related to the subjective embodied experience of psychosis and the interface with mental health services including psychiatric diagnosis and treatment. The foci concerned: the language used; conceptualisations; beliefs and understanding of their subjective experience of psychosis; the impact of their meaning-making on the relationship to self and others; hope, recovery and a meaningful future. Enquiry into their recommendations for improvement to their care was also explored. The full interview schedule can be found in appendix 4.

Ethical Approval

An application for ethical approval of the professional doctoral research proposal was made to the Psychology Department at City University on the 6th of July 2015 (appendix 1), after appropriate amendments had been made in consultation with my supervisor Prof. Willig. Approval was granted on the 24th of September 2015 by the Psychology Research Ethics Committee (appendix 2), which meant I could begin the participant recruitment process. The posters advertising for participants and the participant information forms (appendix 3) were sent out to the Sussex Psychosis Research Interest Group (SPRiG) and Soteria Brighton, in addition to Psychology Sussex, an independent psychological healthcare practice where I am the clinical director.

Sample

The sample originally purposed was adult individuals who had recovered from a first-episode of psychosis in the preceding five years. However, advertising resulted in enquiries from adults who had experienced psychosis in excess of five years previously and had experienced more than one episode. I decided to proceed with the individuals that had expressed an interest in participating with the research, as it was apparent that interviewing them would produce relevant data pertinent to my research, irrespective of my original intention. The participants were at various levels of recovery, from partial to full, both in terms of medication and quality of life. All five participants had experienced psychosis, been hospitalised, medicated and diagnosed. Some received a variety of diagnostic labels during their involvement with mental health services.

Safety of Participants

I was aware that participants were speaking about events from their experience in which psychological and emotional distress had reached crisis point, so there was potential for them to experience emotional distress as they reconnected with, and described, their experiences during the interview. Although they had all recovered from the acute phase of psychosis, events preceding the psychotic experience were evidently still emotionally painful and, for some, unresolved – e.g., prior trauma, difficult relationship dynamics etc. Also, it was clear that the psychotic experience itself was still painful to reconnect with and talk about.

As an experienced counselling psychologist, I felt confident that I was able to maintain an appropriate level of careful, empathic listening in order to provide a level of containment of distressing emotions, whilst also adopting a researcher position aiming to obtain data for the purposes of IPA and FDA. A confidential space at my private practice – Psychology Sussex in Hove – was selected as an appropriate place for the interviews, as it utilises all the necessary insurance policies, including a general health and safety policy to protect the public.

Setting

Psychology Sussex is an independent psychological healthcare practice in Hove, East Sussex.

There are four consulting rooms, a waiting area and reception, located on the second floor of a semidetached Victorian building, located conveniently near public transport links, local shops and parking facilities. The setting is welcoming, quiet, private and confidential. Individuals who expressed an interest in participating were contacted and a mutually convenient time to meet on the premises was arranged. Follow-up confirmation of the appointment time, location and contact details was also emailed to the participants along with the participant information.

Recruitment and Participant Selection

Five participants were interviewed with audio recording that was transcribed. However, the decision to analyse in full four interviews out of the five was taken when the initial listening and coding revealed that one account, although rich in discursive information, was lacking in experiential information pertaining to the embodied experience of psychosis. Considering my research question, it became apparent that the interview, although interesting and informative from a discursive viewpoint, did not provide data relating to the phenomenological enquiry of the embodied experience of psychosis.

Despite my attempts during the semi-structured interview to elicit responses regarding the embodied experience of psychosis, the participant in question repeated assimilated viewpoints from the knowledge gained from reading critical psychological and psychiatric literature. Furthermore, a retreat into metaphorical explanations utilising technological equivalents from hardware and software in computing to express his understanding of the biomedical focus of psychosis, as compared to the psychosocial understanding proposed by the BPS’s DCP, was an alternative response to questions aimed at a phenomenological enquiry. In this instance, the participant's narrative was adhered to, irrespective of the question asked. It seemed this account had been of major importance to the participant in making sense of, and finding ways to cope with, the experience of psychosis in addition to the treatment accessed and received from mental health services. It might have been that another interview method, such as object solicitation, would have enabled access to accounts of embodied experience, bypassing the familiar narrative. However, it may be that at this point in his journey this account was readily available to him and a priority in meaning-making of his experience.

Either way, this interview did not provide the information I was looking for to answer my research question. If I had been undertaking an FDA only, this interview would have been relevant and useful. However, it would have been discarded if the sole purpose was an IPA looking to focus on the subjective experience of psychosis. The absence of reference to 'the things themselves', fundamental to a phenomenological enquiry, in preference for cognitions and intellectual conclusions would not have afforded access to the lifeworld, structure of experience or the conditions of their appearing (Heidegger, 1962). Since my research question is focussed on the intersection between the embodied experience and the discursive reality, I made the difficult decision not to use this interview.

The Participants

The participants included three females and two males who had experienced psychosis and had accessed mental health services for help.

1T - a British white male in his early 30s.

2A - a female, descending from an African father and a British white mother, in her early 30s.

3L - a British white female in her 50s.

4L - a British white female in her 40s.

5M - a British white male in his 50s.

The participants, all of British nationality, self-identified their gender as being concordant with their biological sex. I have decided to use pseudonyms for the participants in the write-up to preserve a personal reading, instead of the codes ascribed to them in the transcripts and results tables for confidentiality purposes. Additionally, brief case studies are included in the body of the text, rather than the appendix, to facilitate a smoother read, uphold the personal nature of this project and foster a connection with the people at the heart of this endeavour.

Case Studies

What follows provides a context for the participants' interest and engagement in the study, and a useful reference point from which to understand their responses to the semi-structured interview. I have decided to include this information in the main body of the research rather than the appendix as I regard the participant involvement and meaning-making as central to my research endeavour.

Jo - Code 1T

Jo is a British white male in his 30s who experienced a first episode of psychosis whilst in the third year of his physics degree at the age of 20. He did not mention any siblings but did say his parents were together and that he had chosen to study away from home to escape the *drug culture he had become involved in and his depressed feelings, however this plan had 'backfired on him'. He described being collected by his parents from the university and brought back home to Sussex where he accessed mental health services and eventually received a diagnosis of 'Schizophrenia/schizoaffective disorder', having initially been told his experience was a drug-induced psychosis.*

Jo has accepted his diagnosis and continues to take antipsychotic medication for a condition he believes is biogenetic, based on the medical opinions he has received when accessing services. He did not express any religious beliefs. Jo has experienced a couple of repeat episodes of psychosis since then, but reports feeling well at the present time, and able to attend to his basic needs despite leading a restricted life. He attends a lived-experience advisory forum and a support group for individuals with severe and enduring mental health problems. Jo is currently single and unemployed.

Maria – Code 2A

Maria described herself as a mixed-race woman in her 30s, having a British white mother and Nigerian father. Her parents have separated but she reported having a very close relationship with her mother. However, she expressed deep anxieties about losing her mother prematurely due to her mother's advancing age. Maria did speak about having a half-brother on her father's side, saying she visits occasionally and enjoys looking after his children. She alluded to ambivalent feelings regarding a sense of belonging, due to her mixed heritage and the lack of contact and familiarity posed by the distance – he is five hours away.

Maria first experienced psychosis in her 20s following a period of depression triggered by concerns about her identity and existential concerns. She received inpatient treatment, *antipsychotic medication and a variety of diagnoses during her contact with mental health services – including bipolar disorder, psychotic depression and schizoaffective disorder, which is her current diagnosis. Although Maria expressed some uncertainty about how to understand her experience of psychosis, she felt her experience as a person within society and what she had been through as a mixed-race woman were key factors. A near death experience from taking one of the prescribed psychotropic medications led to her prioritising surviving and putting her meaning-making quest on hold. Maria did not express any religious beliefs.*

Recently, Maria had started seeing a therapist to explore the meaning of her experience and address some of her concerns around identity and existence. She is aware that the biomedical explanation she was given for her experience of psychosis, by statutory mental health services, is one of a number of potential opinions or viewpoints alongside psychosocial and spiritual concerns. Maria is currently living in a house share, applying to college for a graphic design course and attending weekly psychotherapy. She is taking a low-dose antipsychotic medication but would like to discontinue at some point in the future.

Doreen – Code 3L

Doreen is a British white woman in her 50s, divorced with two adult children. She lives on her own and works at a psychological training organisation, which teaches a variety of theoretical models regarding human mental health and distress.

Doreen has had two episodes of psychosis and has received a diagnosis of Psychotic Depression, which she accepts. She continues to take low-dose psychotropic medication, she explained, as a preventative measure as recommended by her psychiatrist. Doreen related *that several other diagnoses had been considered including Post Traumatic Stress Disorder (PTSD), Borderline Personality Disorder (BPD), Bipolar Disorder and Schizophrenia, which she fears receiving due to 'Schizophrenia' being, in her words, "a dustbin diagnosis… where you go and don't come back".*

Doreen has a strong Christian faith, which she felt helped her through her previous two episodes of psychosis, which she understood to be related to spiritual crises. Although Doreen did disclose experiencing some traumatic events in her past, including a difficult relationship with an ex-partner, she did not want to understand her experience in the context of that, preferring a spiritual crisis as a way of making sense of her experience. She felt a diagnosis of PTSD would have pushed her towards an understanding of her psychotic experience pertaining to earlier trauma, which she did not want to do. Doreen was clear~~,~~ that meaning-making of the experience of psychosis, for her, was very much about exercising her choice regarding what was important.

Jacky – Code 4L

Jacky is a British white female in her 40s, married with two daughters. She is a psychotherapist and also teaches on a psychotherapy training course.

Jacky had a first episode of psychosis at 18 years old, during her A-level exams. This resulted in her making a suicide attempt and being sectioned and detained in a psychiatric hospital. She received a diagnosis of Schizophrenia from the psychiatrist at the hospital and was prescribed high-dose antipsychotic medication for her symptoms. Although initially this experience made her feel special, where previously she had felt somewhat ignored, the side-effects from the medication interfered with her ability to live her life to the full. With the help *of her parents, she sought a second opinion from her local GP who helped her withdraw from all psychotropic medication slowly. Jacky remembered feeling able to continue with her life and gain employment. However, her experience taught her to conceal her diagnosis in order to be able to progress with the full quality of life that she desired.*

Jacky has not had any repeat episodes of psychosis since. However, she has experienced depression, which she felt was at the heart of her psychotic breakdown as a teenager. Through her training in psychotherapy and her own personal therapy she has made meaning from her experience, in the context of her family of origin, her lack of power and confidence as an individual and the consequent inability to integrate with her peer group whilst at college. Jacky did not express any religious beliefs and was strongly aligned with the psychosocial approach to understanding psychosis as advocated by the Division of Clinical Psychology (DCP) of the British Psychological Society (BPS).

Simon – Code 5M

Simon is a British white male in his 50s who is recently divorced and has two school-age children. He has experienced a couple of episodes of psychosis in the last few years, which resulted in him losing his job as an engineer and eventually the breakdown of his marriage. Simon now lives alone and is unable to work, although he is teaching himself web design.

As an engineer and scientist, Simon had used his knowledge in those areas to try and understand his experience of psychosis and correlate his knowledge of computers with his understanding of how the brain works. Furthermore, he spoke at length about the use of antipsychotic medications for psychosis and that the medications did not cure psychiatric illnesses but can alleviate some of the symptoms. Simon did not express any religious beliefs *and found it difficult to speak about the phenomena he experienced during psychotic episodes, preferring to access his knowledge on the similarities between the brain and computers. Simon had made some meaning from his experience of psychosis which related to stress in his life, mostly in the workplace and some difficult dynamics with females in his life, however his current focus was very much about the interface with mental health services and how those treatments cause more harm than good. There were many references to a sense of powerlessness within his own life and futile attempts to regain power, which may be reflected in the semi-structured interview, where it seemed important for him to express his knowledge of scientific concepts despite questions aimed at the embodied experience of psychosis.*

Procedure

The participants were provided with an information sheet about the research study in advance of the interview in order to make an informed decision. They were offered the opportunity at the beginning of the interview to ask any questions before proceeding. Additionally, there was an opportunity at the end of the interview to ask any questions and a debrief information sheet was given for discussion before ending the interview. Participants were also asked if they required anyone to be contacted for support on completion of the interview.

The data was collected by audio recording the 50-90-minute semi-structured interview between the participant and myself in a confidential and private setting convenient for the participant. Notes were not taken during the interview in order to attain a personal, attentive stance, respectful of participants and their accounts of subjective experience. The audio recording of the interview was transcribed using Atkinson and Heritage’s (1984) guide for notation (Appendix 5) and the transcript was subsequently used for analysis.

Interviews

My approach included adopting both an empathic and suspicious stance during the interview. Listening empathically enabled the phenomena of the lived, embodied experience of psychosis and diagnosis – as described by the participant – to be explored. The suspicious stance involves adopting a curious position in which interpretation of what is being communicated includes what might exist beyond the explicit content, which the participant may not be aware of themselves. This includes the meanings contained in the structure of language – the discourses which construct objects and subject positions. This stance informed the questions asked, which sought to elicit responses regarding the embodied phenomena and the language used to speak about the experience of psychosis, e.g., ‘*what was the experience of psychosis like and how were you affected?’* and *‘how did you decide which words to use to speak about this?’*. See appendix 4 for the full semi-structured interview schedule.

The interview schedule also contained questions regarding the participants’ position in relation to the available dominant discourses they were aware of in mainstream mental health services and the sociocultural domain, e.g., *‘how do you feel about how other people talk about this subject? e.g., family, friends, health professional, media etc.’*. The scope of the interview from the standpoint of phenomena, language and the participants’ position in relation to dominant discourses required the adoption of a ‘relaxed awareness style’ (Colahan et al., 2012, p.53). This enabled my attention to be mindful of the subjective accounts of psychosis in addition to tensions and contradictions arising from the deployment of a variety of discourses constructing psychosis in different ways, giving rise to a multitude of contrasting positions and vantage points for experiencing.

My aim throughout the interviews was to be mindful of maintaining a researcher position, whilst working sensitively and compassionately with the participant and the personal information they were disclosing. Additionally, I aimed to maintain a reflective awareness of context and the participant's involvement in the study, in addition to adopting a reflexive position monitoring my own personal contribution to the relationship dynamic and the research study.

Ethics of Interpretation

Interpretation is a process by which we give meaning to some 'thing' which already exists and attempt to convey an explanation that may be altering or transforming what was originally said. Such processes are commonplace in human communication and an essential component of any psychological therapy, as we attempt to clarify meaning in a conversation to arrive at a mutual understanding. Although there is an overlap in the process of research and psychological therapy, once the interview phase of the research has been completed, the capacity to clarify understanding with the participants is lost. That is to say, the participant's opinion on the interpretation made by the researcher is absent, and the researcher subsequently focusses primarily on the audio recordings, transcripts, and the memory of the interview encounter. This difference requires acknowledgement in the presentation of the analysis of results, or to state more accurately, the *researcher's* interpretation of results. I have attempted to present an analytic interpretative account of the participant's understanding of their experience as expressed to me, which is grounded in what was said during the interview. This is referred to as a double hermeneutic, where the researcher engages with the participants' interpretations of their experience and is the cornerstone of IPA.

Furthermore, the preservation of the participants’ voices was of utmost importance to me, hence the liberal inclusion of quotes (from the transcribed audio recordings of the interviews), throughout the analysis, in order for their words to be read alongside my interpretation. This was important in doing justice to their accounts and maintaining an ethical stance.

Willig emphasises that, ‘the act of interpretation is both a responsibility and a privilege’ (2012, p. 165) and that ethical ways of engaging with the data in the process of making interpretations include preserving the voices of the participants, reflexivity and modesty about any claims being made (2012). These have all been important factors informing the research process in this study in order to mitigate against the inherent power of interpretation when deviating from a purely descriptive account of human experience. Willig warns against the risk of ‘interpretive violence’ and emphasises the need for sensitive interpretation when reflecting on the questions a researcher might be entertaining when searching deeper for meaning – the ‘why’ and ‘how’ aspect of what was said (2012), which I have attempted to consider carefully in making my interpretations.

Arguably, the psychiatric classification system of diagnosis could be regarded as a psychiatric interpretation of experience, which results in the imposition of a medicalised meaning that pathologises the other. Given my critical stance in this regard, it is important for me to emphasise my openness to possible interpretations of the data other than my own and welcome the opportunity to discuss my findings with others interested in this piece of research!

Analysis

Following the interviews, I listened to the full audio recordings twice, without interruption, prior to transcription. This was to enable an appreciation of the whole interview and to reflect on the experience of meeting the participants. Initially, I noticed a broad range of themes, and the dynamic between me and each participant. I was satisfied with the interviews and was reassured by my responses in the recordings, which chimed with my thoughts when listening back through. I also made some brief notes in my reflective journal about my initial impressions.

Transcription was a laborious and lengthy process. However, it provided an opportunity to listen again, paying specific attention to the detail of what was expressed and how, including the tone of voice, rate of speech, pauses, emotional expressions of laughter, tears, sadness, frustration, in addition to the language used to speak about meaning-making of the experience of psychosis.

Once the transcription process was completed, IPA tables were compiled with three columns, as recommended by Smith et al., (2009). The transcript was positioned in the centre column, with my initial hand-written comments noted in the third column on a line-by-line analysis. The emergent themes were noted by hand in the first-hand column, which were then listed for the process of clustering together to arrive at the superordinate themes for each participant. This was repeated for each participant and the superordinate themes were grouped together to form the master themes applicable to all participants.

A master table was subsequently created to display the master themes shared between the participants, as recommended by Smith et al., (2009). Due to the idiographic commitment of IPA, a master theme summary grid table was also produced in order for the shared themes and individual differences to be revealed (appendix 7). This summary grid table enabled a view of each participant within each column and the shared themes across the rows. It was from this exercise that the differences between the participants were fully noticeable in addition to the themes shared between them. Therefore, presenting the data in an IPA single case analysis format seemed most appropriate in order to illuminate both the universalities and differences contained in the data and the differences creating a focus for the FDA.

Following the IPA analysis, I began the FDA on the same transcript. I formed a table of three columns with the IPA superordinate themes in the right-hand column and psychosis ‘constructed as’ in the left-hand column, either side of the transcript. This process created a dynamic interpretation of the transcript as the emerging constructions from the FDA could be seen alongside the superordinate themes from the IPA. This was an informative process that exposed the impact of the constructed aspect of experience on the phenomenological experience of psychosis and subsequent consequences for living. This was something that has been apparent in my clinical practice with individuals over the last three decades – through which awareness of, and access to, alternatives to the dominant psychiatric discourse has afforded a broader range of perspectives from which to understand their experience. This process has been reported as a liberating experience by many individuals with lived experience of psychosis as new understandings and meanings, associated with the different discourses, come into view. In order to clarify my thoughts about the discourses and the inherent statements which construct experience, that is to say the ‘constructed as’ components of the discourse, I made preliminary tables for each participant identifying the quotes that indicated a dominant discourse and constructions of psychosis associated with those discourses. This was an interesting exercise to help create a framework for beginning the FDA and resulted in a Venn diagram (diag. 3) of dominant discourses in the UK 2020.

The ‘constructed as’ components emanating from a variety of culturally available discourses were explored further for what can be thought, said, and done. These were considered, alongside the potential subject positions that can be resisted or accepted by the individual. Although a full genealogy of humanistic discourse and the discourse of madness were completed to anchor the ‘constructed as’ aspect of the data, this has not been included in the write-up due to the limitations in the scope of this study.

The results from the IPA and FDA were written up in separate chapters in order for them to be read independently prior to the integration of results. Subsequently, the dual focussed analysis incorporating results from both IPA and FDA was undertaken in order to home in on the intersection of language and experience and the dynamic interplay influencing meaning-making of the experience of psychosis. The question for me was, how to do this?

The Questions

As a practising counselling psychologist, my work with clients involves supporting them in making sense of their experiences and arriving at their own meaning. Although there are similarities in the process of IPA and counselling psychology, in that there is a focus on meaning-making, the fundamental difference pertains to the level of meaning already attained by an individual. A participant taking part in a research study is primarily recruited to speak about the meaning they have already made about the topic being researched. I would argue this cannot exclusively be so, because as sense-making individuals we are constantly making-meaning, and any encounter can of course trigger a meaning-making process – an example being a participant making-sense in the present moment during a research interview about pain (Smith, 2019). This participant brought the interview to a premature close, and I wondered to what extent that was related to being asked a question they did not feel prepared for with a meaning already made?

When clients come for therapy, by contrast to participants, they primarily attend with their questions ready for collaborative exploration and, to some greater or lesser extent, are prepared for uncertainty. So, the balance of questions to meanings made arguably tips towards the latter in research and the former in psychological therapy.

Knowledge from my work as a clinician, accompanied by inspiration from Smith’s layers of meaning in IPA being connected to certain questions (2019), created a curiosity about the questions my participants may have already asked themselves before seeing the recruitment poster. Their answers to my questions in the semi-structured interview regarding language and experience, and the results from both analyses, gave rise to my conception of the questions they may have considered in their search for meaning prior to our meeting. A handful of questions became apparent to me in an ‘aha!’ moment one morning when reflecting on the wealth of information I had gathered in the research process.

The questions identified and subsequently used as the organising principle for the presentation of the analyses (IPA – meaning of embodied experience, and FDA – dominant discourses constructing experience), are a synthesis of core existential concerns and the culturally available discourses pertaining to psychosis. These questions included a curiosity about both the meaning of the embodied experience and the language used to speak about the experience, thereby providing a focus on the convergence of language and experience. These questions were a useful analytic strategy for facilitating a coherent summary of the results from both analyses and enabling a focus on the intersection of language and experience, inevitably intertwined in our existence as humans.

Quality

Where quantitative methods were once regarded as the gold standard in psychological research, qualitative methods now occupy centre stage. Criteria and guidelines have been created to enable the production and evaluation of good quality qualitative research (Yardley 2008; Henwood and Pidgeon 1992; Williams and Morrow 2009). The Society for Qualitative Inquiry in Psychology (SQIP) has produced guidance for assessing quality in qualitative research (Levitt et al., 2017) condensing ideas from previous recommendations and developing some key principles applicable to a range of qualitative methods and traditions. These principles have been adopted by the *British Journal of Health Psychology* in assessing research for publication. Since my research is focussed on mental health, I decided to utilise the SQIP guidelines and principles in the design and evaluation of my research.

The core principle of the guidance concerns *methodological integrity*, where compatibility of the methodology to the research question is of key importance. This means that creativity and flexibility are required in adapting traditional research method approaches in order to attain the best fit to answer a research question, rather than restricting inquiry to fit the method. Since my research question contained an exploration of language and experience, a dual-focussed methodology incorporating FDA and IPA seemed the most appropriate option, irrespective of the scarcity of previous IPA and FDA dual-focussed research or method guidance. This presented several challenges in choosing how to analyse the transcripts, which involved multiple attempts with various print outs of the transcripts, highlighter pens, coding attempts and a variety of tables for both the IPA themes and discourses identified for the FDA, including the psychosis ‘constructed as’ components, before a satisfactory procedure was arrived at, as outlined in the analysis section above. Every step taken was traced, which importantly also affords opportunity for alternative interpretations.

Methodological integrity concerning trustworthiness of the research for this framework contains two core constituents: *fidelity* to the subject and *utility* in achieving research aims.

Fidelity

In terms of data collection, four participants were selected in order to explore the phenomenon in depth, but also to allow potential for variation within the phenomenon to be researched. Since the transcripts were going to be analysed firstly with IPA and secondly FDA, a sample of four participants appeared adequate for the research aims and also the word allowance for the write-up. Self-awareness of my critical perspective was managed by self-reflection and documentation of my thoughts and feelings in a journal during the research process. This approach facilitated transparency and openness to the data as I sought to manage a limitation – *bracketing* – of my perspective informed by theory and practice, but subsequently incorporating this awareness in the analysis and discussion of my findings. Direct quotes from the transcripts were used to illustrate the themes identified for IPA and the ‘constructed as’ components for the FDA, demonstrating a grounding of the findings in the data.

Utility

The quotes selected were presented both within the context of the participant's individual and shared history, and the context of the interview question they were responding to, thereby embedding the findings in the data. A semi-structured interview designed to elicit responses regarding language and experience, followed by a dual-focussed analysis, enabled insights into the interplay between language and experience, thereby appropriately addressing the research question. Both divergences and convergences in the participants' accounts were utilised to maximise insights and a meaningful contribution to the field of mental health, including recommendations for practice.

Reflexivity

A reflective journal was kept throughout the research process to capture emerging thoughts, feelings and ideas, in addition to maintaining self-awareness of my own assumptions in order to bracket them, albeit not withstanding fallibility. These reflections have been incorporated throughout the research process and are integrated in the write-up.

As a practising psychologist, I was aware that language has a profound effect on experience. It was apparent in my work that discourses mobilised by clients contain particular constructions about their experience leading to subject positions that can be accepted or resisted. Their response to the constructions subsequently impacts what can be thought, felt, said and done, impacting the meaning-making of the experience of psychosis – an experience characterised by unusual perceptual changes in addition to severe emotional distress in all aspects of life.

The main focus of my work as a psychologist is with individuals who have experienced psychosis or are experiencing psychosis and have often been involved in mainstream mental health services. Increasingly however, some clients seek help directly by self-referral, or through a friend, family member or General Practitioner (GP). It appeared to me there were some notable differences between individuals seeking help directly and those who had been involved in mental health services. This difference did not seem to equate to the severity of the embodied experience of psychosis but related more to discourses, constructions and meaning-making of the experience. A natural progression for me was to undertake a piece of research to explore this in depth.

As a critical psychologist, I am aware that I have reservations about biological psychiatry and broadly agree with the criticism that it essentialises certain mental and behavioural differences, projecting them into the minds of individuals, which has an impact on meaning-making. Hence, the focus in my research question. Although I was originally hesitant about using the word 'dominant' in the title, due to my already critical stance, supervision with Prof. Willig enabled me to become more familiar and confident with social constructionist approaches focussing on discourse. Reading that dominant discourses, 'ratify the existing order of things, make them seem natural and unquestionable, and they conceal patterns of power' (Parker, 2015, p.28), confirmed 'dominant' as the correct term applicable to exploring the impact of the language used in mainstream mental health services.

Additionally, my involvement in Soteria Brighton – an organisation looking at developing compassionate approaches to psychosis and alternatives to mainstream psychiatric services – has provided awareness raising events to the local community, offering different perspectives and conceptualisations of psychosis including treatment options. Speakers have included Robert Whitaker, Joanna Moncrieff, Dave Harper, Peter Kinderman, Lucy Johnstone, John Read, Jim Geekie, James Davies, Mohammed Rashed, Robin Murray, representatives from the Hearing Voices Network and Spiritual Crisis Network. Attendees have often approached me after Soteria events to express their surprise at hearing that there were alternatives to the biomedical model of psychosis in understanding their experience, which consequently creates new considerations for them with respect to diagnosis, treatment, medication, and options for being and living.

IPA Results

Introduction of Findings

> *I think it was that* <u>*desire for a future*</u> *that gave me hope that I could recover, that I could get better because I couldn't have got better without actually wanting to (Jacky 34/9-11)*

All four participants had experienced psychosis and now identified themselves as having 'recovered' from the experience, or perceived it to be an experience that was now in their past. However, whilst a universality was expressed in regard to the subjective, embodied experience of psychosis, it was evident that there were both similarities and differences in their respective experiences with regard to meaning-making. I will begin by introducing the master themes and superordinate themes to illustrate the similarities, followed by an exploration of how they apply to each participant, an idiographic bottom-up approach, to illuminate the differences and variability in meaning-making.

The sense of having been taken over by an overwhelming and powerful change in their taken for granted reality, in addition to the powerlessness associated with accessing services, presented the participants with many challenges which were grouped together around four master themes. The first master theme, *Fight: managing the experience*, incorporated superordinate themes relating to a struggle for personal meaning and identity in addition to coping with 'the system', fear about the diagnostic possibilities being considered, the stigma associated with having a mental health diagnosis, and the 'work to do' as a consequence.

Relationships within the self, and with others were evident within the master theme *Trust: experiential issues around trust.* Both the intrasubjective and intersubjective dimensions of trust were the focus of interest in this study. Levels of trust and mistrust present, and an evaluation of trustworthiness, were a major factor for participants in determining what was possible within relationships. Accompanying these were intense emotions of fear and anxiety. Trust, as defined by the Oxford English Dictionary, is the 'firm belief in the reliability, truth, or ability of someone or something' (2019). Trust is therefore of central importance in the development of relationships, with distrust leading to pessimism and paranoia.

The master theme *Agency: experiencing oneself as the agent*, referred to feelings of agency, power and influence within the individual. This was central to personal meaning, choice of narrative, knowledge from personal experience and collaboration with others, which were the superordinate themes contained within this master theme and shared by all four participants. However, the superordinate theme *lack of agency – others decide* was shared by three of the four participants.

Loss: loss and powerlessness in relation to others and the experience, was a master theme with the most superordinate themes, eight in total, shared amongst all four participants. This was related to powerlessness both with regard to the lived experience of psychosis and the interface of accessing mental health services. Loss of identity in relation to the self and others was experienced as disorientating, adversely affecting hope for the future and further complicating a challenging situation.

These master themes appeared to be more explicitly stated, by which I mean they were manifest in the participants' accounts and therefore required less interrogation to notice and interpret meaning. The hopes, desires, and fears contained within the themes appeared more subtly and suggestively, expressed in an implicit form in the participants' accounts. The drive towards a meaningful existence, as a motivating factor, was also more subtly embedded in the accounts, requiring a deeper connection and exploration of the material to reveal meaning.

Smith (2011) uses the terms 'suggestive', 'manifest' and 'secret' in his discussion on 'gems' in IPA and from my analysis it would seem that these terms are also useful in expressing the prominence or hidden quality of the meanings present in the participants' accounts. A 'gem' refers to a quote or extract in a transcript that is understood by the researcher to be fundamental to the meaning made by an individual and also relatable to the whole account. A researcher is able to identify gems, as they become more familiar with the transcripts and can move dynamically from the micro to macro meanings contained in the accounts. In so doing, it is possible to notice how one comment is integral to meaning made in relation to the whole interview and potentially across all the data.

The 'gems' present in this IPA were surprising and appeared gradually as a more detailed reading of the transcripts was conducted. Each participant expressed a similar notion of *choice and ownership* in making their own meaning, in the superordinate theme *choosing a narrative* within the *Agency* master theme. The introductory quote to this chapter illustrates the 'gem' in Jacky's account. Each single case analysis of the participants' meaning-making begins with a quote to illustrate the 'gem' contained in their accounts.

What constitutes a meaningful existence was delineated by the individual. That is to say that what constitutes 'a life' originates from the individual within the context they find themselves. Although individual variation was evident, the drive towards a personally meaningful existence was of paramount importance in all participants' accounts.

The diagram below illustrates the connection between the suggestive, more subtle quality of the themes, implicit in expression, with the master themes manifest and expressed more explicitly in the participants' accounts.

Master Themes shown in the central box of the diagram below are as follows:

Fight: managing the experience

Trust: experiential issues around trust

Agency: experiencing oneself as the agent

Loss: loss and powerlessness in relation to others and the experience

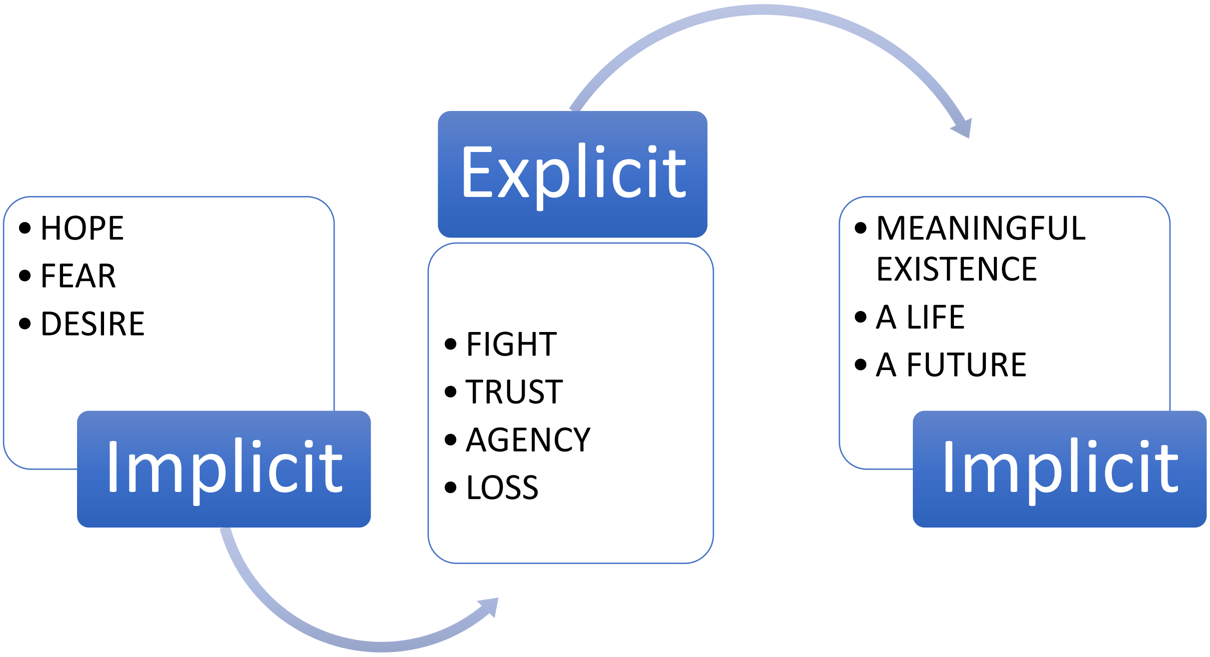

Diagram 1: Connection between the implicitly expressed meanings (suggestive) and explicitly expressed meanings (manifest) represented in the master themes

Each master theme contained several superordinate themes. The first master theme *Fight: managing the experience* contained four superordinate themes. The second, *Trust: experiential issues around trust* and the third, *Agency: experiencing oneself as the agent* both contained five. The final master theme*, Loss: loss and powerlessness in relation to others and the experience*, contained the most superordinate themes at eight. The table below outlines the superordinate themes identified in each master theme.

Table 1. Master Table of Themes

Master Themes	**Superordinate Themes**
1) Fight: managing the experience	i. Fight/struggle for personal meaning
	ii. Fight for self
	iii. Fight others/cope with the system
	iv. ‘work to do’
2) Trust: experiential issues around trust	i. Lack of trust in others
	ii. Lack of trust in self
	iii. Distrusted by others
	iv. Trust in self
	v. Trust others with knowledge of oneself and psychosis
3) Agency: experiencing oneself as the agent	i. Agency in personal meaning
	ii. Collaborating valued
	iii. Choosing a narrative
	iv. Agency from knowledge and experience
	v. Lack of agency others decide

4) Loss: loss and powerlessness in relation to others and the experience	i. Powerlessness when accessing mental health services
	ii. Powerlessness when experiencing psychosis
	iii. Loss of ‘taken for granted’ reality
	iv. Loss of ‘taken for granted’ future
	v. Loss of ‘taken for granted’ sensory perception
	vi. Loss of function
	vii. Loss of personhood
	viii. Loss of selfhood

The Participants’ Meaning-Making

‘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.’ (Merleau-Ponty, 1962, pxix)

I have attempted to stay close to the phenomenological accounts of the participants and how they have been making meaning of their subjective, embodied experience of psychosis, including at the interface of accessing mental health services. This empathic understanding has been essential in giving each participant a voice in describing their experience, as it appears to them. I have also attempted to adopt a position of consciously bracketing my assumptions – ‘the natural attitude’, as posited by Husserl, who argued that bracketing is essential in order to glimpse the phenomenological experience of the other (Husserl, 2012).

I will be exploring the master themes and superordinate themes in detail, how these relate to the whole account, and vice versa. This is referred to as the ‘hermeneutic’ circle of understanding, where both the parts and whole are dynamically related and inform each other (Heidegger, 1962). This will involve incorporating quotes from the transcripts to enable an understanding of the participants’ experiences.

I have also incorporated what is referred to as a suspicious, or critical, approach (Ricoeur, 1981) and engage in my interpretation of the participants’ meaning-making experience in a double hermeneutic process. This involves a dynamic relationship with them and their understanding, and myself and my understanding of their understanding, which is influenced by my personal and professional experience.

The single case analyses will include a focus on aspects of convergence and the individuality contained in the accounts. This will incorporate my interpretation of their meaning-making of their experience of psychosis when accessing mental health services, and therefore the inevitability of being subject to a psychiatric discourse, with an imbued medical meaning. The benefit of focussing on the differences between individuals, in addition to commonalities, was evident in the IPA Master Theme Grid Table (Appendix 7) where the differences in meaning seemed to be related to the deployment of a variety of discourses. The single case focus thereby provides a useful bridge to the Foucauldian discourse analysis (FDA) following on from the IPA, before an integration of both analyses and discussion, focussing on the intersection of language and lived experience.

For all participants there was a commonality in their experience in terms of their meaning-making and perceptions, represented in the master and superordinate themes, however it was also apparent that their accounts included contradictions and conflicting feelings about how to understand and interpret their experience: what was psychosis and why had it happened? There was also a variability, in terms of their quality of life and sense of wellbeing, which seemed to be associated with differences in their understanding of psychosis. In order to illustrate the diversity in these findings I have structured the IPA by attending to each participant in turn in a single analysis of each case, to illuminate the uniqueness and variability in their meaning-making, whilst also distilling the shared themes. As Smith (2018) emphasises, ‘The articulation of meaning as being of a particular thing, for a particular person, within a particular context, also speaks to IPA’s idiographic commitment’.

What was clear for all participants was the importance of arriving at their own understanding of their experience from the range of opinions they were aware of, and that exercising choice in this was paramount. They were all unified in expressing how overwhelming the embodied experience of psychosis was, in addition to how powerfully the experience of psychosis was experienced emotionally. Ownership of meaning, captured by the superordinate theme *choosing a narrative* in the *Agency* master theme, was something that was reiterated by all participants, irrespective of their chosen meaning. However, there was also a continuous commentary throughout their accounts, that referred to how powerfully mental health services stated their understanding of psychosis and how that interacted with the participants’ meaning-making process. That is to say, that the language used had a significant impact on their overall experience and consequently their meaning-making.

I have chosen to start the IPA analysis of each individual participant with Jo, continuing with Doreen, Maria, and finishing with Jacky. Given my research question, the types of meaning are of a central focus. The rationale for starting with Jo is based on the prevalence of a medicalised understanding in his account, progressing to less medicalised meanings in Doreen and Maria’s accounts, and finally an absence of a medicalised meaning in Jacky’s account. The different types of meaning seemed to be related to different forms of recovery from psychosis, with engaging in meaning-making being related to autonomy and a sense of wellbeing.

Jo

> *I was probably going to get it anyway even if I had lived a clean life… that’s my understanding of it [psychosis]… that’s how I like to understand it. (Jo 15/1-17)*

Jo – who had internalised a medicalised understanding of his experience of psychosis, and therefore had developed ‘insight’ as defined by psychiatry, i.e., agreeing with the diagnosis and treatment plan – reported living a restricted life due to his illness. Although he quoted some statistics about people with schizophrenia being able to live an ordinary life, “a third of people with schizophrenia live pretty much normal lives – normal jobs” (10/19-26), it was apparent that he felt unable to do so, and that he experienced himself as a psychiatric patient (Georgaca, 2004). However, Jo did express gaining a sense of agency from being involved in the Lived Experience Advisory Forum (LEAF) and arriving at what was, for him, a satisfactory understanding of his experience of psychosis.

Jo’s reference to lived experience was very much about developing his own meaning, exercising his choice of what to include or dismiss in making *his* meaning. This is illustrated when he said, “That’s my understanding of it… that’s how I like to understand it” (15/16,17).[2] In claiming his own understanding he was also reclaiming some power.

Jo has a background in science and his exploration of psychosis and schizophrenia has, in the main, relied on medical journals, which promote the mainstream understanding of psychosis. Jo accepted this medical meaning and used it to make sense of his experience. Agreement with medical professionals also meant that Jo avoided conflict in the patient-doctor relationship and retained a sense of personal agency and parity, thereby reducing the need to *fight others/cope with the system*[3]. Jo felt predestined to experience schizophrenia, irrespective of his life experiences. His account was populated with scientific, medical and technological explanations, including references to medical illnesses, treatments and statistics, which can be seen in the following quotations:

> … discussed this with various different psychiatrists… consensus is people with mental illness are genetically predisposed to it much like some people are predisposed to cancer or diabetes. (Jo 14/27-32)

> … affects 1 per cent of the population regardless of geographical location. (Jo 10/19-26)

For Jo, accepting the facts – the “consensus” – seemed a way of escaping a conflict in opinion with mental health professionals, including the restoration of a sense of certainty and

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[2] Captured in the master theme *Agency: experiencing oneself as the agent*, particularly within the superordinate theme *agency in personal meaning*.

[3] A superordinate theme within the *Fight* master theme, which was also present for the other three participants.

agency. However, he did describe experiencing conflict with regard to his identity, his understanding of himself at the time, and a need to defend his personhood[4]:

> R[5]: but at the time when I was under the influence of those drugs and psychotic to a certain extent
>
> I: uhmm
>
> R: umm I denied it, I thought I'm still the same person, I've got the same body (16/11-15)

The reference to "it" seemed to be related to the radical changes in subjective embodied experience and the denial an attempt to retain a sense of a former sense of self. The subjective, embodied phenomena experienced during psychosis~~,~~ created disruption in intersubjectivity and intrasubjectivity, resulting in a *lack of trust in self*[6] accompanied by fear as the taken for granted aspect of existence changed:

> R: things just started to get really scary umm and my ability to communicate effectively with other people completely vanished.
>
> I: Oh right=
>
> R: =My ability to look after myself properly deteriorated significantly umm and yeah it was like I was lost even though I knew where I was umm (Jo 4/29-32&5/1-3)

Jo was responding to questions designed to elicit information about the embodied experience of psychosis in the quote above. His response indicated a breakdown of *trust in the self* during psychosis. The breakdown in his ability to rely on himself, to communicate and "look

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[4] Evident in the superordinate theme 'fight for self', within the master theme *Fight*.

[5] 'R' and 'I' denote 'respondent' and 'interviewer', respectively.

[6] A superordinate theme in the master theme *Trust: experiential issues around trust*.

after" himself generated fear and a sense of disorientation to the world and others. A *loss of selfhood*[7] was evident as he described the embodied experience of psychosis. Additionally, the issue of disruption in embodied perception was described as overwhelming, chaotic and unpredictable[8]:

> R: I've had hallucinations of almost every sense (.2) so tactile hallucinations where you can feel, feel something that isn't there (.2) I've smelt things that aren't there I've tasted things that aren't there I've heard things that aren't there and also I've seen things that aren't there.
>
> I: So, on every sensory level= (2/27-33)

The disturbance in the perception of reality[9] was experienced as terrifying for Jo, creating fear about his existence in the mental, emotional and social world:

> First psychotic breakdown – terrifying – didn't know what was up – what was down. (Jo 4/23-25)

The feeling of powerlessness to alter the phenomena experienced during the acute phase of a psychotic episode was represented in the superordinate theme *powerlessness when experiencing psychosis*:

> R: umm I was shifting into a very negative world view ah in terms of the paranoia and the delusions and they kind of took over, so it wasn't necessarily a question of why am I not thinking properly because I didn't know I wasn't thinking properly

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[7] A superordinate theme in the fourth master theme *Loss*.

[8] Captured in the superordinate theme *loss of 'taken for granted' sensory perception*.

[9] Captured in the superordinate theme *loss of 'taken for granted' reality*.

> I: Right okay hmm
>
> R: But these paranoias and these delusions were quite strong and became quite deep rooted (Jo 5/32-34&6/1-4)

Jo also reported being *mistrusted by others*[10] when attending a mental health support group a few days before the interview:

> R: he also knew that I have a drug problem and when I made it clear that I had a diagnosis of Schizophrenia yeah his instant reaction was oh yeah but you’re a druggie aren’t you so it’s as if he, he thought he knew that my Schizophrenia was caused by drugs and he wouldn’t even give me a chance to explain my, my opinion about that which is that you know that I was predisposed to it through genetics anyway I would probably have got it whether I took drugs or not and the way he handled that I wasn’t too impressed with to be honest I thought that was quite judgemental
>
> I: uhmm
>
> R: umm the fact that he seemed to think he knew better without really hearing all the facts or, or my side of the story
>
> I: yeah, without listening to you (18/21-35)

Jo appeared to be hurt by this dismissive and “judgemental” comment, which potentially connected him with some emotional sensitivity around his current drug use, and unresolved feelings regarding his past drug use as a teenager, which he told me had been considered by mental health services as a possible contributory factor for the psychosis he experienced. Jo had expressed relief that the diagnosis of ‘drug-induced psychosis’ had been dropped in

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[10] Another superordinate theme within the master theme *Trust: experiential issues around trust.*

favour of a schizophrenia/schizoaffective disorder diagnosis, which he understood to be a biogenetic disease he was predisposed to and would have developed regardless of his behaviour. For Jo, it was clear he wanted to engage with the information he was given and respond in a way that bore his best interests in mind. Although outwardly he could be seen to be complying with the medical opinion he was given, he emphasised that he had considered and reflected on this, and was keen to present himself as an autonomous individual actively making an informed independent decision.

This medicalised explanation also seemed to provide some reassurance and protection for Jo, who expressed fear about being blamed for the problems both he, and his family trying to help him, had experienced, rather than anticipating compassion and understanding for his difficulties. Jo's fears are perhaps unsurprising given the current neoliberal political agenda, where competition and individualism are promoted as core components for living, rewarded by the emotional experience of 'happiness' arising from successful competition with others. The excerpt of the conversation Jo had with the individual – ironically when both attending a mental health support group – highlights the erosion of social bonds and compassion in our neoliberal society. This is in turn reflected in our 'evidenced based' mental health services, with efficiency and economics at their core. Sadly, the brief conversation when attending the mental health support group seemed to substantiate Jo's fears of being blamed by others.

Jo cited both family and friends as valuable support during his experience, which generated feelings of trust with them[11]:

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[11] Captured in the superordinate theme *trust others with knowledge of oneself.*

> R: Well when I was ill, when I was actually in the grip of it I was terrified that the end is very close there's no hope no light and everything just seemed negative .umm as I came to recovery, which did take a long time umm .hh I started to see things a bit differently perhaps umm took me a long time to .hh to think that the future could be anything good umm but it really (2) really brought home to me how important family and friends are and who my real friends were umm (5) yeah I was in the psychiatric ward for about three months .hh and aah (2) it didn't feel great at all (6) it was quite distressing. (8/15-24)

The distress experienced when accessing the mental health service, for Jo, included being dismissed and having his personhood threatened, therefore feeling regarded as being of less importance – "a patient":

> R: when the, the psychiatrist almost ignored my question to a certain extent shrugged me off .hh umm (3) if a patient asks a question try and give them a reasonable answer
> I: Right okay
> R: and not to be shrugging people off (24/20-24)

The lack of response from the psychiatrist to Jo's query left him feeling rejected and disregarded. However, the experience of *loss of personhood*[12], appeared transient and the use of 'my' and 'me' in his account suggests his sense of self was still apparent to him, even if this was not acknowledged by another.

Jo elaborated on this experience and described increased levels of paranoia:

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[12] A superordinate theme in the master theme *Loss*

> it [psychiatrist didn’t answer the question] made me feel more paranoid because it made me feel that he was holding something back from me – it [being sent for a brain scan – no results given] had been some sort of experiment. (Jo 25/17-20)

The lack of response Jo received seemed to trigger a search for what this could mean and resulted in suspicion. The generation of a hypothesis, that maybe he was part of a secret medical experiment, is maybe unsurprising given the absence of information.

Powerlessness was not only expressed in relation to the embodied experience of psychosis, but also with regard to accessing mental health services:

> R: I was admitted to a local psychiatric ward much to my dismay because I didn’t think there was anything wrong with me=
> I: =Okay
> R: =I tried to protest it and I almost tried to run away but .hh but I was in too low a place to be able to do that=
> I: =Right
> R: =’Cause again I thought they were going to lock me up or something and just forget about me then yeah slowly through the experience of being in the psychiatric ward, which wasn’t the best experience I’ve ever had .hh umm (.2) yeah they managed to explain to me and get me on the right medication=
> I: =Okay
> R: And I slowly got better from that umm (7/28-35&8/1-6)

Jo was thereafter committed to the life-long consumption of antipsychotic medications to manage what he perceived and understood to be evidence of his medical condition[13]:

> after my second period in hospital, I realised that I have to take medication now for the rest of my life if I want to stay healthy (12/16-20)

The superordinate theme *work to do* encapsulated the sheer amount of effort required to reclaim personal power and maintain some stability in a situation that felt threatening on all fronts. This can be seen in Jo's response to a question about the language used to speak about his experience and how that results in him having to manage other people's understandings:

> R: I mean the word itself [schizophrenia] yeah, it's quite, quite, a powerful word if you are branded with it umm but rather than change the word itself change people's knowledge of what that word actually means=
> I: =okay so a different understanding. (Jo 11/7-11)

Jo's reference to being "branded" is a powerful one. It can evoke the use of a branding iron to imprint ownership, the trademark of a manufacturer, as well as the mark of disgrace or stigma which is imposed on another by a greater power or authority – illustrating the potential imposition of power and meaning on the individual. It also brings to mind Timimi's observation that mental health difficulties have been subject to a process of commodification promulgated within a neoliberal agenda: '[o]nce we have categorised states of emotional and behavioural deviance and these categories enter the market, they become the equivalent of brands' (Timimi, 2011, p. 158).

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[13] This is illustrated in the quote from the *work to do* superordinate theme, within the master theme *Fight: managing the experience*.

Jo progressed through a process of considering the schizophrenia diagnosis in relation to his experience of psychosis and developed his own individual way of relating to the diagnosis, thereby claiming ownership of his position via a process of assimilation and accommodation. In developing a different, individualised understanding, which he accepted and owned for himself – his own ‘brand’, if you will – he could avoid the passive position of being ‘branded with it’. Jo used a metaphor from sales and marketing to express satisfaction with his preferred choice, emphasising his sense of agency as a consumer and *choosing his narrative*[14]:

> R: .’hh they’re trying to find other ways of describing the words without using those words, as you said, like psychosis they call it distressing experience or something
> I: yeah uhmm
> R: very very positive
> I: umm does that feel better?
> R: for me I don’t mind
> I: Oh, right okay
> R: I’m happy with the word psychosis
> I: Okay
> R: for me that is what it is, it does what it says on the tin. (20/1-12)

Jo, who appeared satisfied with the medical meaning, then shifted the focus onto issues of relationship equality within the patient-doctor interface:

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[14] A superordinate theme in the master theme *Agency: experiencing oneself as an agent.*

> I feel it is very important for the patient to be included and to be kept up to speed with what the clinicians and health professionals are thinking. (Jo 25/22-26)

The need to be included and to proceed within a collaborative approach,[15] it seemed, was experienced by participants as balancing the power differential in the patient-doctor relationship and increased both a sense of agency and power within the individual. Jo's reference to being "kept up to speed" suggests the need to not be left behind or excluded with regard to the professional medical opinion, thereby avoiding an epistemic injustice where information is knowingly withheld.

Jo had personalised his understanding of schizophrenia:

> R: for me schizophrenia is a very broad word because that in the same way that every human brain is unique every schizophrenic sufferer will have their own version of schizophrenia to a certain extent
> I: okay yeah
> R: because it's a group of a lot of different symptoms and you don't have to have all those symptoms to be classed as schizophrenic you just need a certain number of them
> I: uhmm
> R: so (.) it can look, there are different extremes of schizophrenia, it's a bit of a spectrum really, I think. (Jo 10/26-34&11/1,2)

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[15] As captured within the superordinate theme *collaborating valued*, within the master theme *Agency: experiencing oneself as the agent*.

Despite his reservations about how a schizophrenia diagnosis might be interpreted by others, Jo's agreement with his diagnosis and treatment meant that he, unlike the other participants, did not express the superordinate theme *lack of agency others decide,* thus maintaining a feeling of *Agency: experiencing oneself as the agent* (the master theme).

There was an implication throughout his interview that Jo was concerned about being blamed for his 'illness' and the subsequent stress experienced by loved ones trying to help. It appeared that the medical explanation, which confers some inevitability in the development of the illness, provided him with an understanding he was more comfortable with:

> R: umm so my understanding is that (3) although taking large amounts of cannabis as a teenager probably brought it on early rather than caused it outright (2) I was probably going to get it anyway even if I had lived a clean life
> I: Right okay
> R: But it happened to me in early adulthood rather than mid to late adulthood
> I: Oh okay
> R: That's my understanding of it
> I: when you say you were going to get <u>it</u> anyway?
> R: yeah, the bad symptoms the you know the paranoia the delusions
> I: Right
> R: Hallucinations
> I: Right okay, okay, does that fit for you when you think about that, does that make sense to you?
> R: That's how I like to understand it. (Jo 15/1-17)

This is interesting because although Jo presented his understanding as grounded in medical science, he had also rejected an earlier diagnosis of drug-induced psychosis. It could be surmised that the neoliberal culture of responsibilising individuals led him to fear blame for the experience of psychosis if it was associated with his earlier drug use, which could be an underlying motivation and contributory factor in adopting this position. Regardless, his declaration of “that’s how I like to understand it” asserts an agentive position. In this regard, therefore, adopting a mainstream narrative is not a passive act for Jo.

For all the participants, meaning-making and the ownership of meaning seemed to be associated with, and facilitative of, recovery. Being able to create a platform of stability by making meaning, in and amongst the chaos of experiencing psychosis, seemed to help reduce emotional distress and create a path back to a meaningful life. Crucially, it would seem that wellbeing was associated with participants’ making sense of these experiences and believing that they can be managed and lived with. The process of making meaning – making sense – seemed to be related to a way out, or a way through, psychosis, to a reconnection with the common reality in time and space.

Doreen

> *I won’t entertain the story that isn’t helpful to me. (30/23)*

Doreen referred to the notion of “stories” frequently as she relayed her experience of psychosis to me. There was a metaphysical quality in her account, as she explored the nature of existence, being in the world, her reflections on the uniqueness of the subjective phenomena and their relationship to both the material and spiritual worlds. It was evident that ownership of her story was of the utmost importance to her, and was prioritised above other stories that might exist in relation to her experience:

> this is my story. (30/19-22)

Doreen’s account was richly populated with metaphors, the organising metaphor referencing journeys and travel through different types of terrain and spaces in time:

> it’s [psychosis is] a liminal place. (6/14)

This reference to a liminal place suggests that the phenomenological experience of psychosis feels like a space between reality and unreality. This might otherwise be understood as the common reality and the reality that is unique to the individual, not shared with others. What was interesting to notice was a similar reference being made with regard to the language used to conceptualise psychosis. The following extract incorporates a metaphor involving water. The surface tension of the water seems to indicate a boundary between the depths, which are dense with other people’s meaning, and skimming across the top of the surface as an intact solid object, preserving personal meaning. This enables increased possibilities for living – not getting lost in the depths:

> I seem to have (3) umm skimming along a diagnosis, that if you plunge into what a diagnosis means and take your reference from other people (2) then it does incredible damage to your self-esteem and your ability to see yourself as somebody who can live in the material world in an ordinary way and as, and I managed to skim along the surface. So, umm (2) I haven’t plunged in to (2) other people’s ideas of what a mental

> health issue is. I've, I'm still fighting back and I've, I'm quite solid in how I view a mental health problem .hh and in many ways it hasn't changed from how I viewed it before I had a psychotic phenomena. (19/4-14)

There was also an indication of returning to oneself and retaining personal meaning.

Trust in self[16] arose in Doreen's account (as it did for all four participants) in her references to autonomous movement within the subjective embodied experience of psychosis. Doreen expressed a sense of agency throughout her interview:

> I can step outside. (2/35)

> it was only a matter of transposing some of that and learning some new skills to navigate psychosis. (9/28,29)

> R: I need to move into the material world. 20/30-33
>
> R: I just have to tell myself it's fine, you know (2) err I have to not sink into it because that would be like taking it on more as part of me. So again, it's a bit skimming across the top of it.
>
> I: Oh, okay umm
>
> R: Because I think it could become the story of me and I have to not let the psychosis become the story of me. I, the story of me is (1) I function in the world. (25/34,35 & 26/1-7)

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[16] The superordinate theme within the master theme *Trust: experiential issues around trust*

Doreen's references to her past experiences indicated feelings of trust, metaphors of travel evoking a sense of a journey through, and around, the issue, for which there was access to a mental and emotional map. In contrast to this sense of agency related to *trust in self*, the superordinate theme *lack of trust in self* was also relevant for Doreen, and another two of the four participants. Notably, Doreen again used metaphors pertaining to travel, in this instance involuntary travel, relating to loss and powerlessness:

> get catapulted by just a little bit into psychosis or a long way. (8/8,9)

> moving in and out of being present. (2/4)

> I couldn't be sure of anything… was so off the planet. (5/22-26)

The reference to being "off the planet" invokes a notion of a loss and lack of feeling grounded on earth, with a connection to the material world and shared reality. The idea of being 'grounded' is also something Doreen refers to in her account of psychosis, and a sense of being in time and space.

Doreen's account of her experience of psychosis indicated a sense of powerlessness not only in relation to the embodied experience of psychosis, but also with regard to accessing mental health services. All four participants expressed powerlessness with regard to the treatment they received, yet Doreen (and Jacky) moved beyond a mere description of experience towards a critical social analysis of power relations and dynamics in the mental health system:

> Patients are done to rather than worked with. (15/15,16)

Travel references were also made by Doreen when speaking about accessing mental health services and the impact of the variety of diagnoses considered for her by the mental health professionals. The *powerlessness when accessing mental health services*[17] was evident as she spoke of the "layers" created:

> R: Would I have been upset if I'd got a diagnosis of PTSD? (3) I think it would have been a really serious error on their part because I don't think I have got PTSD.
>
> I: Right OK that doesn't make sense to you.
>
> R: At the time I probably could have been persuaded in that direction which is really interesting. So, I think what happens is, when they, when a psychiatrist pronounces, you get persuaded. So, it re-orientates, how you are looking, and I was very fortunate that they'd diagnosed me with psych, psychosis, .hh made sense to me and it didn't add an extra layer of, of having to come to terms with anything? (17/24-34)

The reference to layers was expanded upon as Doreen considered the various diagnostic options and the potential repercussions. Her description of being buried and suffocated illustrated the escalation in *work to do*[18]:

> R: So, I think being given a diagnosis, is <u>incredibly powerful</u> .hh and very difficult to then (1) unpack, and I think that you don't unpack it, (2) you're basically left with what they've laid on you and then what your family lay on you.
>
> I: Right uhm

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[17] The superordinate theme within the *Loss* master theme

[18] The superordinate theme within the *Fight* master theme

> R: Then you’re almost buried right underneath it. Umm whereas a diagnosis of psychosis, there’s a bit of air attached to it.
>
> I: Okay, okay because it’s, for you when you think about it, it’s more of a description of particular phenomena.
>
> R: /Yeah/yes, yes it, it, is.
>
> I: Rather than
>
> R: Rather than a category that I’ve been put in to
>
> I: Okay
>
> R: Which has attached to it some very negative complicated consequences. (18/17-32)

Doreen was critical of diagnosis – a concern she raised which chimed with the opinions of two other participants and is captured in the superordinate theme *loss of a ‘taken for granted’ future* – when highlighting her opinion regarding the potential ramifications diagnoses entail in delimiting the recipient’s possibilities:

> psychosis is a dustbin diagnosis… where you go and there’s no way out. (7/23,24)

This strong metaphor suggests a place from which there is no return, where objects are thrown away, discarded and deemed no longer of utility.

The potential for ‘not being seen’ as a person due to a diagnosis of psychosis was feared by Doreen[19]:

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[19] As noted in the superordinate theme *loss of personhood*.

> you’re still a mm, a person who is having an experience whereas I think that I, I worry, and I haven’t experienced this myself, that for some people it is a write off diagnosis, it’s, oh they’ve gone into that category and that means they’re there forever and . ahh then you start to make decisions about who you are as a person (2) (9/10-15)

Although Doreen began by emphasising the separation between the ‘person’ and the ‘experience’, including the use of ‘they’ with a regard to *a loss of personhood*, she lapsed back to the use of ‘you’ as she concluded her point, suggesting that this was indeed feared by personally.

Doreen indicated a change in embodied perception (Merleau-Ponty, 1962) of herself during the experience of psychosis. The issue of disruption in embodied self-awareness, in the superordinate theme *loss of ‘taken for granted’ sensory perception,* was described as overwhelming, chaotic and unpredictable by all four participants. Doreen described how:

> I could literally see my face change from what I tho:ught it was to how it actually is… (2/29,30)

As well as perceptual distortions, Doreen also referred to the impingement on her ability to function and how the phenomena of psychosis disrupted the ability to act[20]:

> didn’t know what I was doing basically (2/2)

In addition to a lack of self-awareness in general:

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[20] Captured in the superordinate theme ‘loss of function’.

> wasn’t aware of what I was doing. (1/35)

A further indication of *Loss and powerlessness in relation to others and the experience*[21] was a *loss of a ‘taken for granted’ reality* – “moving in and out of being present” (2/4) – the superordinate theme which for Doreen, and all participants, seemed to be related to disorientation, creating fear about their existence in the mental, emotional and social world. Furthermore, the feeling of powerlessness to alter the phenomena experienced during the acute phase of a psychotic episode was universal for the participants and represented in the superordinate theme *powerlessness when experiencing psychosis.* As Doreen explained:

> R: there’s a point at which they [people experiencing psychosis] make an error of judgement and then get catapulted by just a little bit, into psychosis or a long way into psychosis.
>
> I: Okay
>
> R: ‘.hh and I, for me that, that process is really important to be able to (2) make decisions about how I live, because I wanted to live in the material world °I didn’t want to live in the psychosis world°. (8/6-13)

The catapult metaphor creates a notion of sudden unpredictable loss of power, with the catapult determining the level of psychosis Doreen could be thrown into if “an error of judgement” is made.

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[21] The master theme with the most superordinate themes

Doreen’s summation of the precarious position individuals experiencing psychosis – ‘they’ – are engaged in is evocative of walking a tightrope, in which one false step – ‘an error of judgement’ – can be catastrophic. However, Doreen’s switching to ‘me’, and repetition of ‘I’, claims an agentive position implying she had some confidence she could ‘navigate’ this precarious act:

> one of the most important words in all of this is navigation. (10/14-19)

> navigation is staying in the material world. (21/5,6)

Doreen also explained how navigation enabled her to notice aspects of her experience despite the turmoil and chaos in her embodied experience of psychosis:

> I could actually trace where I made errors of judgement about my beliefs. (8/2-4)

I have taken the use of the word ‘trace’ to mean tracing steps, again a reference to travel. Doreen expressed the need to be able to navigate her experience herself and have support to do so:

> R: she’s [Community Practitioner Nurse] been prepared .hh to listen to me trying to navigate (2) a story, navigate a, not navigate the psychosis, get a narrative .hh umm . and that has been invaluable
> I: Yeah yes
> R: So, she’s actually listened whilst I’ve sort of wandered around a bit of paranoia and speculated a bit and emm talked to her about whether I’m psychic or not and what that

> might mean, and she's brought something about other cultures and different perspectives on spirituality .hh umm and it's just been a very gentle process of trying to develop that narrative (31/2-12)

The collaboration involved in being listened to seemed to engender feelings of agency,[22] as opposed to the imposed meaning she felt she had experienced from a psychiatrist[23]:

> a psychiatrist pronounces, and you get persuaded. (28/8-14)

Given Doreen's Christianity, the use of the word 'pronounces' here to describe her experience of an encounter with a psychiatrist could be interpreted as suggestive of a religious context – e.g., where a priest says, 'I pronounce you man and wife'. Maybe parallels could be drawn here, between the powerful priest (as opposed to judge, politician or other authority figure) and the biomedical psychiatrist who may both experience their beliefs as definitive.

Doreen found strength from her Christian faith, which she felt had helped her cope with some of the existential repercussions of psychosis:

> Christian faith seemed to keep me grounded… I resorted to the core of my Christian faith… It wasn't a battle of faith it was a battle for sanity. (4/5-32)

It was evident that a *fight for personal meaning*[24] was understood by Doreen as pivotal to retaining her sanity. It was also evident that she had strong feelings about diagnostic labels

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[22] As captured in the superordinate theme *collaborating being valued*

[23] As captured in the superordinate theme *lack of agency – others decide*

and the consequences for living that may arise, especially with regard to the diagnosis of schizophrenia:

> schizophrenia… I would have struggled with the weight of history. (7/10-14)

> don’t label me with what that label means. (30/24-29)

Doreen referred to diagnoses as ‘stories’ and made references to psychiatrists ‘playing around with diagnoses’ (as did Jacky), perhaps in part to minimise the perceived threat to her sense of self and her future. In addition, ‘stories’ implies that there was something imprecise and elusive in the process of others trying to make sense of what was going on for her – to ‘diagnose’ the problem while the reference to ‘playing’ suggests a lack of reliability and seriousness from psychiatrists, from Doreen’s perspective, and an indication of her lack of confidence and trust in the professional opinion[25]. This awareness or perception also seemed to cast doubt and mistrust about the treatment plan offered. The lack of certainty in the medical opinion presented to her created both an anxiety and an opportunity to entertain other meanings of the experience of psychosis, with a decrease in trust of others and an increase of trust within herself to search for her own meaning[26]. It was clear from the detailed account Doreen gave that she found the prospect of being diagnosed with schizophrenia frightening and potentially life changing, especially in relation to others and how much extra work she would have to do to cope[27]:

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[24] The superordinate theme within the *Fight* master theme.

[25] As captured in the *lack of trust in others* within the *Trust* master theme.

[26] As evident in the *trust in self* superordinate theme.

[27] A superordinate theme in the *Fight* master theme.

> emm but it makes no sense to me emm, what I would, why I would be cross because I would be dealing with an extra layer, which I would consider to be the layers that I would have to deal with my family. So, if I had a diagnosis of Schizophrenia for example, what would I say to my family? I feel happy to say to my family I've had psychosis, they know I've had psychosis .hh if they (2) if I had to say to my family, 'I've got Schizophrenia', I think that they would then have a picture in their mind of that, which I don't think would do me any favours, at all. I think it would be again about, this is a emm not, not a hopeless diagnosis, but there's, you know this is very serious, this will last for a lifetime, can you live a normal life? Umm can you have a family, can you run, you know, so there'd be all sorts of questions in their minds which I'd then have to deal with, which would add an extra layer of trouble to actually what I'm experiencing. (11/21-35 & 12/1,2)

Concerns of this nature were also evident in Maria's account[28].

Doreen made references to historical associations with danger:

> R: I think it's that because, it's that, being added another layer, another layer added on again
>
> I: It's that, yes
>
> R: It's that extra work against the fact, I don't know if other people do, but your (1) the first thing that people probably think is Schizophrenia is dangerous (3) whereas with psychosis, you probably go umm psychosis, mad (2) (22/31-35 & 23/1,2)

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[28] Grouped under the superordinate theme *fight others/cope with the system*.

Doreen's metaphorical use of 'layers' being added on emphasises her sense of more to work through. Doreen was emphatic about her intention to resist a diagnosis of 'schizophrenia' should this possibility arise in the future[29]:

> I won't entertain the story that isn't helpful to me. (30/23)

Doreen felt that being *distrusted by others*[30] would be the inevitable outcome she would need to negotiate, should a change in her diagnosis occur. For Doreen, *experiential issues around trust*[31] was associated with the diagnosis of 'schizophrenia':

> but it doesn't feel like it's you know, for example if you, if you umm (2) wanted to apply for a job would you declare that you had a diagnosis of Schizophrenia? It's much more complicated to declare that than to say you've had depression, cause half the population's had depression. (23/9-13)

Doreen expressed the social acceptance of depression as compared with 'schizophrenia' for employment within the current culture. She also relayed her awareness that this diagnosis had been abandoned in other countries, which enabled her to retain her opinion:

> would be having to think really carefully about that. In fact, I would probably be, disowning it, on the basis that in Japan they've got rid of the diagnosis. So, I would, I would be actively working against what I think that means for people. (22/8-11)

Doreen had a preference for referring to her experience as illness:

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[29] A struggle which is emblematic of the superordinate theme *fight for personal meaning*.

[30] A superordinate theme within the *Trust* master theme shared by three of the participants.

[31] A master theme.

> that degree of disturbance… is… illness. (33/1-5)

For her, ‘illness’ implied optimism:

> everyone gets ill, then they get better. (24/31-32)

However, Doreen was aware that this was not necessarily without issue and others might have other opinions:

> it’s what we attach to the illness, word illness, that can become unhelpful. (13/1-4)

She also referred to disruptions in her daily routine, which included sleep disturbance and dehydration, as contributory factors in her experiencing psychosis:

> I think half the problem is dehydration (3/6,7)

> I can’t function properly because I’m so dehydrated (3/15-16)

A sense that the experience of psychosis was transient and could be resolved seemed to enable her to retain or stay connected with her sense of resource and agency:

> I believe the ability to be healed is within the person. (19/33-35)

> the resources are in me. (20/7-10)

Again, a journeying metaphor illustrated her connection with a sense of an inner resource:

> I know when I'm going down-hill. (32/17-22)

She also referred to the awareness that was still apparent, despite the severity of the powerful embodied experience of psychosis:

> I was well enough to know I was unwell. (13/21/22)

Doreen's meaning-making pivoted around the concept of illness and having support to journey through it and get better again. She emphatically expressed her sense of being present regularly during her experience and having a sense of choice, however fleeting that may have been at times, contrasted with being 'off the planet':

> I think psychosis is .hh (1) .ahh oh dear [sigh] what is it? (2) It's a massive world which (2) you could, <u>I could</u> have chosen to inhabit permanently. .hh There were times interestingly, where I .hh as I got better, where I was making choices, and all, actually, and actually what's the word? .mm(3) clear choices in my mind about umm whether I would hold on to certain beliefs, which were psychotic beliefs, so if the psychosis meant holding all sorts of beliefs about what had happened umm and as I got better, those beliefs, sort of represented themselves to me and I could go, 'yeah I could hang on to that, that sort of makes sense', or I could go, 'actually the evidence says that's not true, that's a psychotic belief' and move into a normal understanding. So, I could actually trace where I made errors of judgement about my beliefs. (7/24-35 & 8/1-3)

Again, the sense of agency, choice and possibility was apparent in addition to a sense of ownership and ‘mine-ness’:

> there’s a strong sense of me in this psychosis experience. (20/1-4)

Her meaning-making was central to her recovery:

> in that making sense of it, I’m enabled to live my ordinary life. (31/26-29)

Doreen, although still taking a minimal dose of medication, expressed a sense of wellbeing and felt that life had more or less resumed satisfactorily for her, including her return to work. This was by contrast with Jo while expressing a sense of wellbeing, also expressed that he had given up on the life he thought he was going to have as a scientist and was now accepting his new future in supported accommodation, attending support groups.

<u>Maria</u>

> *I don’t think it’s a medical problem necessarily, can’t be given a label really (17/31-33)*

> *I have my reasons to why things have happened to me. (19/7,8)*

Like Doreen, Maria employed travelling metaphors such as ‘being in the driving seat’, which she used in one of her meetings with her care co-ordinator, to express a sense of emerging agency. However, the meaning was taken literally, and she reported being called into a risk assessment meeting with her psychiatrist:

> R: I had said something (2) to .err one of my care coordinators years ago .umm that I wanted, I just felt really good and I wanted, I sort of used this metaphor that I wanted to sort of drive the bus, I was feeling really excited .hh and by that I just meant that I wanted to take control of my life and she took me in to (3) see a psychiatrist and he said oh Maria you know it can be (2) <u>dangerous</u> (3) I heard you want to drive a bus and things like that, I know, so ever since then I've kind of, (4) felt like yeah I'm being (4) restricted in some way or erm .hh (3) ° I don't know°'
>
> I: sounds as if you felt misinterpreted=
>
> R: =/I felt misinterpreted .umm yeah definitely (14/27-34 & 15/1-4)

However amusing this seemed to be for Maria, who was laughing as she recalled this experience, her feeling at the time was a sense of *distrust by others*[32]. This theme included the sense of being powerless to change or influence how she was perceived by others. Rejection of her as a person seemed an inevitable consequence of being misinterpreted and misunderstood, a sense of connection to the others and the world being lost. Conversely, experiences that confirmed she was still a person of worth and value, such as being asked to help look after her nephews and nieces by her stepbrother, led to feelings of agency and personhood as she experienced herself being perceived as trustworthy and responsible:

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[32] A superordinate theme in the *Trust: experiential issues around trust* master theme

> R: he trusted me to look after his children which I thought was really .hh nice actually .hh not that I would have, you know, I am not going to do anything untoward but .erm yeah I just thought it was really trusting yeah
>
> I: yeah
>
> R: an honour really
>
> I: yeah, so how did that make you feel about yourself?
>
> R: I felt .umm a sense, sorry I have a tear coming [laughs]
>
> I: have a tissue
>
> R: sorry, thank you, .ahh I just felt a sense of accomplishment really (2) of being able to do that. (23/27-35 – 24/1-2)

Maria was emotional as she relayed this experience, which she felt brought her back into being and being seen. A collaborative process between herself and others, where she experienced a sense of equality in the relationship, whether with family, friends, or services, seemed in itself to increase a sense of agency and connection with a sense of self and others. This affirming experience resulted in feelings of hope and a motivation toward future horizons.

Maria's account included instances of the superordinate theme *loss of 'taken for granted' sensory perception*[33]:

> I thought I was turning to plastic (4/25)

And the superordinate theme *loss of function*:

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[33] Contained within the master theme *Loss: loss and powerlessness in relation to others and the experience*.

> I mean I was seriously not thinking (3) straight at all (26/33)

Other metaphors expressed by Maria in speaking about her experience of psychosis included feeling like an actor in a film, where reality is somewhat distanced and removed:

> R: I was .umm thinking bombs were going, dropping all over .hh .umm (3) yeah seeing, just seeing the world in a different like we were living in a different <u>time</u> (2)
>
> I: Okay so how did that <u>feel</u> for you?
>
> R: It quite, it felt at times, it felt quite frightening and it was like an action-packed movie, it's almost like being in an action-packed movie yeah (..) (4/31-34&5/1-4)

Again, a loss of a sense of selfhood and personhood were experienced in the derealisation experienced during psychosis, in addition to a disturbance in temporality, which created fear. The feeling of powerlessness to alter the phenomena experienced during the acute phase of a psychotic episode~~,~~ was universal for the participants, and is represented in the superordinate theme *powerlessness when experiencing psychosis.*

Maria's account featured concerns with other people's perceptions and opinions of what was happening for her:

> R: I guess it is what other people have said it is like they've described it as being .umm a mood disorder that also can be .err can cause me to have hallucinations of some sort or .hh extreme paranoia (2) it's sort of in between, people kind of say it's in between Schizophrenia and .err bipolar disorder, sort of something in between .hh .err

> I: Okay so how do you feel about all of that? I mean, what does all of that mean to you?
>
> R: [laughs] How do I feel .umm (4) I suppose I don't really (3) I mean at first it was good to have a kind of diagnosis (2) but now I'm just trying to overcome that diagnosis? .hh (3) I find it upsetting at times [laughs] having this sort of diagnosis (2) (14/3-15)

Maria also expressed certain preferences and dislikes concerning how people might refer to the experience of psychosis and the sense of loss that results:

> Calling it a condition does make it feel like it's out of my control… it sort of takes it away from me. (21/9,10)

Maria expressed some doubt with regards to medicalised opinions about psychosis in her meaning-making. She accessed other ideas (including psychosocial and existentialist) in attempting to understand her experience. However, it was also evident that she was considering whether underlying physiological causes might be relevant in understanding her experience, given the debilitating nature of psychosis. The medical team she had encountered, at the interface with mental health services, had shared their biomedical understanding of psychosis with her, which left her feeling somewhat torn about how to understand her experience. The assessment process left Maria feeling at the mercy of decisions made irrespective of her own opinions – the 'experts' decide[34]. Maria expressed feeling confused by the conflicting opinions and treatments being offered to her, which made it difficult to know what to believe and how to make sense of her experience:

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[34] Encapsulated in the superordinate theme *fight others/cope with the system*.

> they said I had bipolar… prior to that… psychotic depression… then I got diagnosed with schizoaffective disorder, then four years ago I was diagnosed with bipolar disorder… then reverted back… (13/9-19)

This adversely affected her trust of others[35], which made it harder to make sense of her experience:

> R: one doctor did say that I didn't need to be on medication the rest of my life, but the others are very .umm (2) the new doctor that I've been seeing has sort of (2) more or less saying he feels I will be have to be on medication for the rest of my life which makes me think he sees it as a permanent (3) part of my life
>
> I: Okay okay
>
> R: I don't know if that makes any sense really…
>
> I: has that been explained to you? What the medication, if you have a condition or an illness, what the medication is doing or
>
> R: it's never been explained to me by the doctors really no:o .umm (2) I know that the medication I'm on at the moment is supposed to be a better one than others but and it's not so sedative, sedative as some of the others .umm but there's been no sort of (3) .hh other information [laughs]
>
> I: oh okay
>
> R: much about it. I mean when I first got unwell, they just, they withheld the .ermm side effects sheets from me they said no we are not going to give you the side effects sheets because you'll start feeling [laughs] like you've got the side effects, but then I

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[35] Identified in the master theme *Trust: experiential issues around trust.*

> really did get the side effects because I ended up feeling quite suicidal from the anti-depressants that they gave me so .ermm (2) but it's never really been explained ever. (20/2-35 – 21/1-4)

For Maria, it seemed the inconsistency and unreliability of the medical opinion in the above example was experienced as destabilising and led to an erosion in her capacity to trust others[36]. It also seemed that she was engaged in a process of trying to make sense of the discrepancies as she spoke to me, with her checking if 'it made any sense'. Given that psychosis involves increased levels of paranoia when dealing with potential threat, the conflict in opinion from the psychiatrists seemed to exacerbate an already fragile position, fraught with paranoia about who can be trusted.

Concerns (shared by three participants) around certain diagnostic categories, in the main 'schizophrenia', seemed to be associated with a constitutional change or transformation within the individual, which altered reality, not only for them, but how they would be perceived by others. Indeed, Maria expressed a desire for a change in the narrative, finding the language currently used to be stigmatising:

> call it mental health, how long have you been suffering with your mental health. (11/1,2)

Accountability to others and questions of responsibility for what was happening for the participants were part of the consideration in how to manage relationships during a chaotic

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[36] Encapsulated in the superordinate theme *lack of trust in others*.

experience: an attempt to achieve some stability and avoid blame when feeling the threat of persecution whilst under the scrutiny of others.

Maria also reported an awareness of new perceptions of herself, as if permanently changed:

> I start to interpret it, that this is my job in the world, my occupation is to be this sick person (Maria 22/11-15)

For Maria, the role of sick person or patient was potentially life changing, being ascribed a new identity or, in Jo's words, being 'branded with it', resulting in *work to do*[37]. It can also be seen, in addition to a new 'occupation', that there is a sense of the loss of a past identity free from sickness.

The issue of psychosis as a chronic condition was present in Maria's account:

> I don't feel offended by the word psychotic, I just don't like it being used as a long-term diagnosis, I think every, anybody could experience that (psychosis). (Maria 8/27-29)

For Maria, her concern was about what happens *following* an experience of psychosis, and not wanting to be defined by the experience with a long-term pessimistic diagnosis and prognosis. Furthermore, Maria expressed a view that the experience of psychosis is on a

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[37] One of the superordinate themes of the master theme *Fight: managing the experience*.

continuum of human experience and not evidence of abnormality present in reductive binaries such as normal and abnormal.[38]

All participants were aware of having to deal with a powerful system in addition to overwhelming, disorientating, unusual perceptual experiences[39]. Both of these experiences were described as feeling overpowering and confusing. The ‘taken for granted’ aspect of existence was described as becoming elusive or disappearing altogether, in respect to perceptual and relational experiences within the self. This was evident for Maria (as for Jo) in the superordinate theme *fight for self*:

> yeah, it’s almost like me at the end it’s like me against the world. I mean the last time I went into hospital I thought there were, we had been invaded by aliens and things like that (5/31-34)

It can be seen that the disruption in perception and intersubjectivity creates a difficulty for living in the world. These struggles and fights were also present with regard to meaning-making. The superordinate theme *fight for personal meaning* was present for all four participants, who expressed their personal preferences about how they understood their experiences irrespective of the professional opinions they had received. When asked about her understanding of her experience and how she had made sense of it, Maria responded:

> R: .umm I mean I (3) I think there is a depression underneath each time I know it starts off with a depression (2) .umm (2) and I also think it has a lot to do with my identity and the struggle that I’ve had with that over the years (2) °so° **(2) yeah**

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[38] This chimes with the work of psychologist and academic Richard Bentall (2004).
[39] Both encapsulated in the superordinate theme *work to do*.

> I: Okay
>
> R: .umm (3) yeah and some sort of fear that I've lived with for a long time maybe of .hh I don't know losing, I guess losing my mother cause she was an older mother I used to worry about that as a child (2) yeah I think it sort of I've never really let go of that (2) somehow (7/20-32)

She later explicitly claimed her own personal pursuit of meaning and ownership:

> I have my reasons to why things have happened to me. (19/7,8)

Although recovered from psychosis, Maria still expressed feeling somewhat trapped by the legacy of the psychotic breakdown experienced. Consequently, she was concerned with whether she and others could experience and perceive her as the person she felt still existed somewhere within, or whether she had to give that 'self' up:

> I start to interpret it, that this is my job in the world, my occupation is to be this sick person. (22/11-15)

Maria described this crisis in identity as having far reaching implications for her future possibilities:

> R: I just suppose I have some hope really that things that opportunities will arise that's all I can really think at the moment I just don't want to see my life remaining .hh (3) you know the way it is I guess, or I don't want to be in receipt of benefits for the rest of my life. I've seen it happen to too many people (3) some people are just resigned to

> being unwell or having that label put on them and they're getting to an age where it's too late possibly for them to think about returning to work or .hh
>
> I: Okay so this is something you really want for yourself (11/26-35)

Maria expressed the superordinate theme *loss of a 'taken for granted' future* as a somewhat persistent concern:

> Ye:ah I mean I suppose each time it's been quite traumatic, and it's taken me a lot of time, I feel like I've lost time recovering from each (2) admission (2) into hospital .umm (3) but I feel, I've got a bit of hope, but I lose it very quickly (11/8-11)

Yet Maria also felt supported by the hope held for her by family:

> as for my family… don't think any of them have treated me differently… they hold out a lot of hope for me. (23/20-24)

This helped her to trust herself and therefore connect with hopeful feelings[40].

For Maria, although the intense subjective, embodied experience of psychosis had ceased, she felt her life remained somewhat restricted as a consequence, both in terms of what she could do occupationally, recreationally and the enduring side effects of antipsychotic medication. The different ways of making sense of her experience seemed to create a crisis in identity and doubts about how her life could be lived in the future.

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[40] Encapsulated in the superordinate theme *trust in self* within the master theme *Trust: experiential issues around trust.*

Maria expressed reservations regarding the medical interpretations of her experience of psychosis, emphasising her awareness of the existence of a variety of opinions outside of her own. However, the medical understanding has persisted for Maria. She questions this at times but, as yet, has not been able to settle on an alternative meaning with certainty, accessing a selection of meanings which, in places, conflict with each other. Finding personal meaning was however of central importance to her, providing a sense of agency[41]:

> I have my reasons to why things have happened to me. (19/7,8)

The use of 'my' and 'me' reclaims ownership of making meaning and it would seem, therefore, that the search for meaning in and of itself is beneficial.

Jacky

> *Desire for a future… gave me hope I could recover… I couldn't have got better without actually wanting to. (34/9-11)*

Jacky, still living with a diagnosis of 'schizophrenia', made many references to temporality – the past, present and future – with an emphasis on her experience of psychosis as being in the past. She presented her experience of psychosis in the form of a story about her journey, expressing an evolving relationship with her experience to the present day. She was keen to distinguish her past experience of psychosis when she was a teenager in the 1980s and indeed her past self from the present, refuting the prospect that the experience could impinge upon her future. Despite feeling a sense of wellbeing in the present – having fully recovered from

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[41] As encapsulated in the superordinate theme *agency in personal meaning* within the *Agency* master theme

psychosis, being antipsychotic medication free, married with a family and working full time – the fear she had experienced at that time remained accessible to her and was evident in the room as she relayed her experience:

> I couldn’t bear the terror… thinking that people were just in my head. (6/2,3)

> I wanted to create a helmet to stop it. (4/7)

There was a sense that the experience had been intensely frightening and needed to be consigned to the time frame of her distant history, irrespective of her explicit statements: “you can live with it… incorporate it into your life, it doesn’t have to be a defining experience” (18/11-15). Statements of distancing from the experience included:

> this was the late Eighties, it was an illness (23/11-13)

> in a funny way, I feel privileged to have seen that [Victorian psychiatric hospital]… it’s part of history now. (15/7-9)

The following extract is longer and illustrates the repetition of communicating to me the distinction between then, in the 1980s, when she had been unwell, and now that she understood herself to be well:

> R: … what I did a couple of years ago, you know you can get those online questionnaires for depression and anxiety?
>
> I: Yup

> R: I filled one out as I was then and it was quite funny, I mean the screen may as well have just started flashing red [laughs] saying see a doctor now, because it said I was seriously unwell.
>
> I: Wow
>
> R: I know, I was deeply, I mean this is filling it out as I was then, not as I am now. [10/13-16 & 11/7-11]

Jacky relayed to me the future-orientated perspective that she had historically adopted in a bid to come through the experience of psychosis, and the recommended treatment:

> desire for a future gave me hope, that I could recover (34/9-10)

Trust in herself therefore seemed to be formed from a forward-looking approach in thinking of a brighter, meaningful future, free from the experiences of psychosis and looking toward increased opportunities in living, which inspired hope. Trust, both in herself, others and the future, was intimately bound up with temporality – both within what Jacky discussed throughout the interview and from the vantage point from which she relayed her historical experiences to me in the interview, namely from her present-day self.

Jacky did not express a lack of trust in herself, which could be related to her sense of herself as fully recovered in the present. Any doubts about herself in this respect were associated with past events that she perceived herself as having moved on from and overcome.

Jacky also spoke at length about her affiliation with psychotherapy, moving in critical circles, and teaching on a psychotherapy training, which seemed to provide some reassurance from the distress of her past in comparison to her sense of wellbeing in the present. Her awareness that she was speaking to me in my capacity as a psychologist conducting research into this area may also have been a factor:

> I mix in circles where we’re all quite critical… these days I spend so much time with likeminded people that it’s just become the norm. (24/9-12)

There was, however, some recognition that a process of forgetting was in motion, potentially another form of distancing:

> I forget out there amongst everybody else, there is a great deal of misperception. (24/12,13)

Accompanying this was an enduring concealment of the ‘schizophrenia’ diagnosis, which she declared hiding within two years of being discharged from the psychiatric hospital, preferring the term psychosis initially and, latterly, despair, which she felt resonated with her experience. Arriving at her own description and conceptualisation seemed to create a sense of agency from her own meaning-making:

> I did term it [psychosis] as depression, I’ve only recently been calling it despair. (20/5,6)

Jacky also found a sense of agency from making connections with her experiences prior to psychosis[42], stating that issues around power imbalances within her family and friends were at the heart of the problem:

> that's what happened… it was bullying by my peers and also bullying within the family (5/9-11)

That said, Jacky reported feeling initially reassured by her diagnosis of 'schizophrenia', which she took to indicate that a professional – a doctor – knew how to make sense of her experience, thereby validating her distress:

> I liked it ['schizophrenia' diagnosis] because it made me special and where I felt so different from my peers… it kind of named the difference. (13/9-14)

However, she also reported that in due course the treatment regime of a life-long consumption of antipsychotics led her to begin a questioning of the 'schizophrenia' diagnosis and accompanying treatment. Despite initially accepting and welcoming the diagnosis, Jacky critically recalled the power imbalance between her and her psychiatrist:

> *he knew he was in a position of power; he knew what was wrong with me, he knew how to treat me, .hh erm, and there was no interest in listening to my experience. (31/13-16)*

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[42] As captured by the superordinate theme *agency and personal meaning* within the master theme *experiencing oneself as the agent*.

In contrast, Jacky described the later agentive position in which *she* chose to communicate her experiences to those who she felt could listen and understand her such as others with lived experience of psychosis[43]:

> she understood though, she got it… I told people who actually got the experience …would be able to communicate with me. (19/12-14)

Jacky had initially been enamoured with the certainty of the medical meaning:

> he made another appointment to see me and all he said was, "it's very clear you are a very sick girl" (7/1-3)

However, she went on to fight back and entered into a power struggle with the mental health system.[44] Jacky wore a victorious smile as she reported overriding what had previously felt to be an inescapable truth:

> told him [the psychiatrist] I'm off the medication, he was absolutely raging, he was really furious and just said, "well, you'll be back." (35/9-11*)*

Jacky felt that declaring her 'schizophrenia' diagnosis during a job interview led swiftly to *distrust by others*[45]:

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[43] As evidenced in the superordinate theme *collaborating valued* in the master theme *Agency: experiencing oneself as the agent*.

[44] This struggle is captured in the superordinate theme *fight others/cope with the system* within the master theme *Fight: managing the experience*.

[45] A superordinate theme in the master theme *Trust: experiential issues around trust*.

> I was sent to an office to do some temp work, they really liked me, and they wanted me to apply for a job at the company. .hh So they arranged for me to have a meeting with HR, went down to HR and in my innocence, .hh because this was only about two years after the diagnosis, .hh I said that I had been diagnosed with paranoid schizophrenia and the atmosphere in the room just changed, it had been lovely 'till then because obviously they'd heard good reports about me from the manager in the office I was working in, no causes for concern whatsoever, I then say "Oh yeah, yeah, a couple of years ago I was, you know, diagnosed with paranoid schizophrenia but I'm fine now". [laughs] Well, that was that they couldn't get me out quick enough and I didn't get a job there. So, from then I hid it. (28/17 – 29/1-14)

In Jacky's opinion, sharing her diagnosis during the interview resulted in the potential job offer being retracted. This experience is a consistent feature in the accounts I have heard from clients in my clinical practice, who report feeling stigmatised and discriminated against. Literature looking at the stigma affiliated with mental health diagnoses and campaigns to drop the 'language of disorder', highlight the complications individuals can experience as a consequence, and so recommend a change in language as well as a paradigm shift (Kinderman et al., 2013).

Participants in this study employed different levels of acceptance and resistance toward the professional psychiatric opinion that had been given, which in turn had implications for the degree to which the opinion was shared with others. After the negative experience during interview, Jacky decided to hide the 'schizophrenia' diagnosis from others in a bid to manage any negative implications:

> I hid it [the schizophrenia diagnosis] for a long, long time. (17/14-16)

And also rejected the ‘schizophrenia’ diagnosis, resulting in *work to do*[46]:

> I refused to give into it and refused to let it define me. (18/10-11)

So, from the passive position of concealment, Jacky described moving to managing the situation by actively rejecting the concept of ‘schizophrenia’ in order to preserve her identity.

Like Doreen, Jacky employed the metaphor of ‘play/toying’ with reference to the psychiatrists’ attempts to arrive at a diagnosis. Whereas for Doreen, one possible interpretation of the deployment of this metaphor was to minimise the perceived threat to her sense of self and her future, for Jacky it was arguably much more of a scrutinised focus on the process by which psychiatrists were arriving at their diagnosis, and maybe not taking this process seriously enough, leading to a *lack of trust in others*[47]:

> I can’t believe to this day that on the basis of some experiences that I’d had whilst I was you know, extremely groggy from having taken an overdose, they made a diagnosis. I mean yes .hh I’d also had some very [laughs] unusual experiences anyway, but being told I had paranoid schizophrenia, well that was a working diagnosis at the time, ‘cos they were also toying with psychotic depression which makes a bit more sense. (13/1-8)

Jacky also expressed the need for support from her parents to “fight the system” (34/12-14),

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[46] A superordinate theme in the master theme *Fight: managing the experience*.

[47] A superordinate theme within the master theme of *Trust: experiential issues around trust.*

due to the power imbalance she was experiencing in mental health services, which she felt was ironic given that she had identified the power imbalance between her and her parents as a contributory factor in her experiencing psychosis. Despite this, Jacky (like Maria) expressed the importance of support from her family. Moreover, Jacky expressed emphatically that the direct intervention offered by her parents to liaise with mental health services on her behalf helped her discontinue antipsychotic medication. This supportive position, based on ‘knowing her’[48], enabled trust to be re-established in family relationships, despite pre-existing difficulties:

> as soon as my parents realised what was happening to me, they said, “no, this is not happening to our daughter this is not her life”. (34/4-6)

In retrospect, Jacky expressed finding the diagnosis of ‘schizophrenia’ unhelpful due to the treatment regime that was consequently recommended and the fear that was engendered:

> personally, I feel their diagnosis [schizophrenia] was very, very, unhelpful. (26/4)

> fundamentally the whole thing [schizophrenia] terrifies people. (30/9)

For Jacky, this seemed to be related to fears about both a loss of selfhood and personhood, in addition to being feared by others, and no longer recognised as a person with equal standing. The *loss of selfhood* superordinate theme[49] featured strongly in Jacky’s subjective embodied experience of psychosis. Moreover, the sense that her mind was not her own, and that the

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[48] Captured in the master theme *experiential issues around trust*.

[49] Contained within the master theme *Loss: loss and powerlessness in relations to others and the experience*.

boundary between herself and others had been dissolved, was evidence to her of a change in her usual sensory perception:

> I loathed myself so much that I couldn't even touch myself so I would have to sit with my arms and legs out so no part of me touched another part, .hh Um, so yes, I, I got to a point where I couldn't bear the terror of thinking that people were just in my head all the time, that they could actually see what was happening in my head and what I was thinking. (5/16-17 – 6/1-4)

The embodied experience of psychosis entailed a change in the usual orientation to the world where intrusion into personal experience was possible. This idea of a disturbance in the perception of reality was shared amongst all participants in the superordinate theme *loss of 'taken for granted' reality*[50]:

> I was having trouble distinguishing between my dreams and my waking life... they were as real and unreal as each other. (Jacky 3/18, 4/1,2)

A further *loss of function*[51] referred to how the phenomena of psychosis disrupted her ability to act:

> I couldn't read, I couldn't take the words in, the words swam all over the page. Jacky (16/3-6)

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[50] Within the *Loss* master theme.

[51] A superordinate theme still within the master theme *Loss*.

Additionally, the feeling of powerlessness to alter the phenomena experienced during the acute phase of a psychotic episode was universal for the participants and represented in the superordinate theme *powerlessness when experiencing psychosis*. As Jacky stated:

> nothing would have stopped it [psychosis] (30/14,15)

Attempting to manage the power differential between themselves and professionals was evident for all participants and it could be seen that there was a variation amongst the participants' responses to an authoritative professional opinion. Whereas Jo accepted and assimilated his diagnosis, Jacky moved from initially accepting, welcoming even, the diagnosis (it "named the difference") to resisting and ultimate rejecting it ("I… refused to let it define me").

A departure from the originally welcoming response to a 'schizophrenia' diagnosis~~,~~ was expressed with agency, with a reclamation of power and meaning[52]. The following extract highlights some of the difficulties Jacky encounters in the present when trying to speak about her past experience of psychosis within her family. She describes how her parents avoid any conversation or reference to what happened, maybe to escape any reminder of distress. However, conversation is possible with her brother, aided by 'choosing a narrative', they can both be comfortable with:

> R: In the family we don't talk about it [past experience of psychosis] at all, (.) we skirt around it but because I'm better now and I'm living a successful life, my parents just don't want to talk about it. My brother and I talk about it a lot because it turns out,

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[52] As captured within the superordinate theme *choosing a narrative*, within the master theme *Agency: experiencing oneself as the agent*.

> ‘cos I was 18 when it happened and then at the time, he was 16 .hh he told me a couple of years ago that at that point he was actually hearing voices .hh umm and it really, was really undergoing his own breakdown. So, we talk about it in terms of what we experienced, we don’t give it a name, we don’t say you know, I was psychotic, he was psychotic, we talk about it in terms of what we were experiencing at the time
>
> I: Right, so the phenomena.
>
> R: The phenomena, <u>absolutely</u>, rather than the labels. (21/5-17)

For Jacky, speaking about her embodied experience in the past tense meant that the labels or diagnostic categories could be dispensed with altogether and treated as belonging to the past. Reducing the relevance of diagnostic labels in the present also seemed to reduce any perceived adverse effects in terms of her sense of self. Retaining her identity as separate from her past experience of psychosis enabled Jacky to reclaim a sense of personhood:

> I think it’s a life experience… you can live with it [past experience of psychosis]… incorporate it into your life, it doesn’t have to be a defining experience. (18/11-15)

Jacky’s use of ‘it doesn’t have to be a defining experience’ indicates her awareness that, for some people, it may indeed be definitive, as she witnessed in the secure ward of the psychiatric hospital she was retained in. Contained within this statement might also be a reference to how close she felt she herself came to being defined by her experience as a psychiatric patient.

To varying degrees, all the participants expressed a sense of powerlessness both in relation to the subjective experience of psychosis and in the interface with services. Nonetheless, an attempt is made by all participants to make sense of things in a way that is meaningful to them, thereby reclaiming their sense of agency and power. Jacky, in her pursuit of meaning, had settled on a psychosocial account, which she felt was something that gave greater potential for positive future outcomes. She also emphasised the role of motivation within her and the will to get better as a significant factor:

> hope that I could recover, that I could get better because I couldn’t have got better without actually wanting to. (34/9-11)

The agentive position, in Jacky’s statement above, can be seen in the repetition of ‘I’ in her statement, which reconnects her with, and to, herself. By contrast, during the experience of psychosis her sense of selfhood, personhood and ‘taken for granted’ reality were lost. The fear she experienced as a consequence was something she could still access when recalling the experience, and it can be seen throughout Jacky’s account that distancing references were frequently used, separating her former self in ‘despair’ from her present-day self.

Interaction of Themes

Exploring the master themes present in the participants' accounts revealed a dynamic interaction between the themes, outlined in the diagram below.

Master Themes

Fight - *managing the experience.*

Trust - *experiential issues around trust.*

Agency - *experiencing oneself as the agent.*

Loss - *loss and powerlessness in relation to others and the experience*

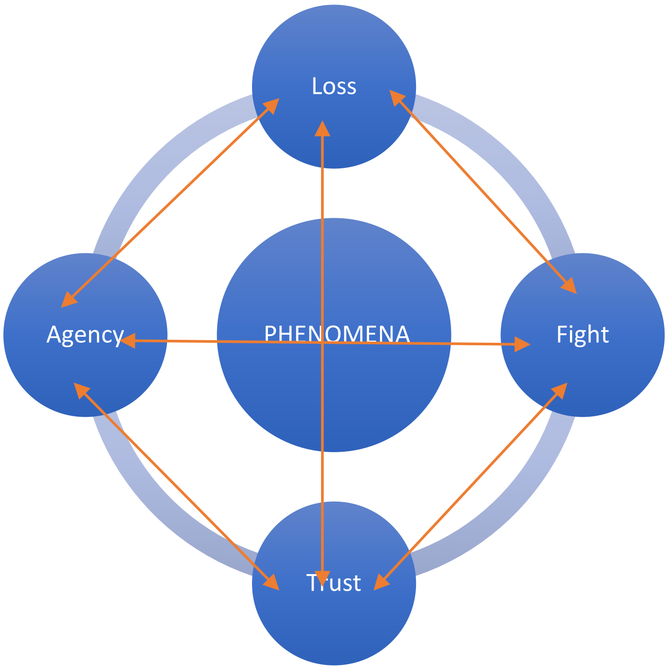


Diagram 2. Dynamic and Multidirectional Interaction of Themes.

The four master themes can be considered to be aspects of meaning-making in recovery from the experience of psychosis and are contained in the outer circles orbiting the inner circle containing the embodied phenomena i.e. lived experience of psychosis. The arrows indicate the direction of interaction, which can be seen as dynamic and multidirectional. Consequently, whatever is being experienced for a participant within one theme has repercussions for how and what is experienced within another. Therefore, feeling trusted increases a sense of agency, a sense of managing and a reduction in feelings of loss. Feeling mistrusted, by contrast, increases a sense of mistrust in others, the need to manage which now feels more of a struggle (a fight), and an increase in a sense of loss which also decreases a sense of agency. Agentive and managing themes have positive repercussions for trust in self and others, and a decrease in loss. The master theme of loss has negative consequences for agency, managing and trust. This resonates with Smith's (2019) proposition regarding meaning-making: 'Things only have meaning in a field, that is, in relation to the meanings of other things. This means that there is no such thing as a single, unrelated meaningful element; and it means changes in the other meanings in the field can involve changes in the given element...' (p. 169).

Summary of Meaning-Making as Related to Recovery

> '*To live is to suffer, to survive is to find some meaning in the suffering.*' (Nietzsche, 1908)

It could be concluded that the participants were on a continuum of recovery from the experience of psychosis and that meaning-making was fundamental in achieving some sense of stability, in what was expressed as an otherwise disorientating, distressing and chaotic lived experience. The type of meaning-making seemed to be related to and associated with various levels of recovery, from partial to full. Hasson-Ohayon et al.'s (2006) paper on 'Insight into psychosis and quality of life' concluded that 'insight' – a process of meaning-making defined by psychiatry as the patient accepting the biomedical understanding that they have a biological mental illness – was associated with poorer outcomes for 'emotional well-being, vocational status, and economic satisfaction' (p. 268). This is illustrated in Jo's account where he adheres to a medication regime, lives in supported housing and feels unable to work or pursue his interest in physics, his life now refocussed around support and interest groups for mental health patients. By contrast, Jacky, who felt she had also developed insight into her experience – not 'insight' as defined by psychiatry, but from a broader more diverse range of understandings including the context of her experience – had settled on a humanistic psychosocial understanding. She expressed that she was now, "moving in critical circles", away from the mainstream medical model of human distress, and welcomed innovation on the subject, such as the *Power Threat Meaning Framework* (Johnstone & Boyle, 2018), that she felt resonated with her experience and made sense to her. Both Jo and Jacky have received a diagnosis of 'schizophrenia' and live with that diagnosis to date. They both reported experiencing similar phenomena during the acute phase of psychosis but have arrived at very different meanings regarding their experience with direct implications for their lives in the present as a consequence.

Given the force exerted by language and the powerful nature of the experience of the language used to speak about psychosis, in addition to the subjective embodied experience I focussed on in the IPA, I will continue in the following section with an analysis of the discourses evident in the participants' accounts, using a Foucauldian Discourse Analysis (FDA).

This will be followed by a discussion containing an integration of the results from both analyses, in order to arrive at a comprehensive understanding of the lived experience of psychosis, given the direct influence that language has on constructing experience (Bhaskar, 2018), in addition to the phenomena experienced during a psychotic episode.

FDA Results

'Language is the house of being. In its home human beings dwell.' (Heidegger, 2011, p.147)

'Man acts as though he were the shaper and master of language, while in fact language remains the master of man.' (Heidegger, 2011, p.244)

It has been a somewhat difficult task to identify the distinct discourses at play in the participants' accounts due to the many overlaps that exist between some of the discourses and their histories. Any differences observed amongst discourses may be more to do with emphases from respective disciplines and conceptualisations, rather than the existence of an objective category. For example, between biopsychosocial and psychosocial, it could be concluded that the biopsychosocial model lies within a biomedical psychiatric discourse and psychosocial within psychological or sociological discourse. Read, Bentall and Fosse have criticised the overemphasis on biology in the medical model application of the biopsychosocial approach to psychosis, referring to it as the 'bio bio bio model of psychosis' (2009, p.299). They argue instead for an integration of biological, psychological and social factors. Furthermore, it has been suggested that psychosocial factors should not be regarded as secondary to biology in understanding how psychosocial factors such as child abuse have a causal role in the development of psychosis (Read et al., 2008). Within the discipline of psychology, the psychosocial model is regarded as a separate, different and valid consideration in the understanding of mental distress, as is evident in the British Psychological Society's (BPS) Clinical Psychology publication, *Understanding 'Schizophrenia' and Psychosis* (Rev. Ed. Jan 2017).

Rose's term 'psy disciplines' amalgamates psychiatry, psychology, and psychotherapy, to indicate the individualising focus inherent within those disciplines, with the associated practices of identifying problems with and within the individual. Mainstream psychology, 'psy' disciplines and mental health services as a whole, Rose argues, neglect the social, economic and political context in which human suffering evolves in preference for 'diagnosing increasing numbers of individuals with psychiatric disorders' (2019, p. 20).

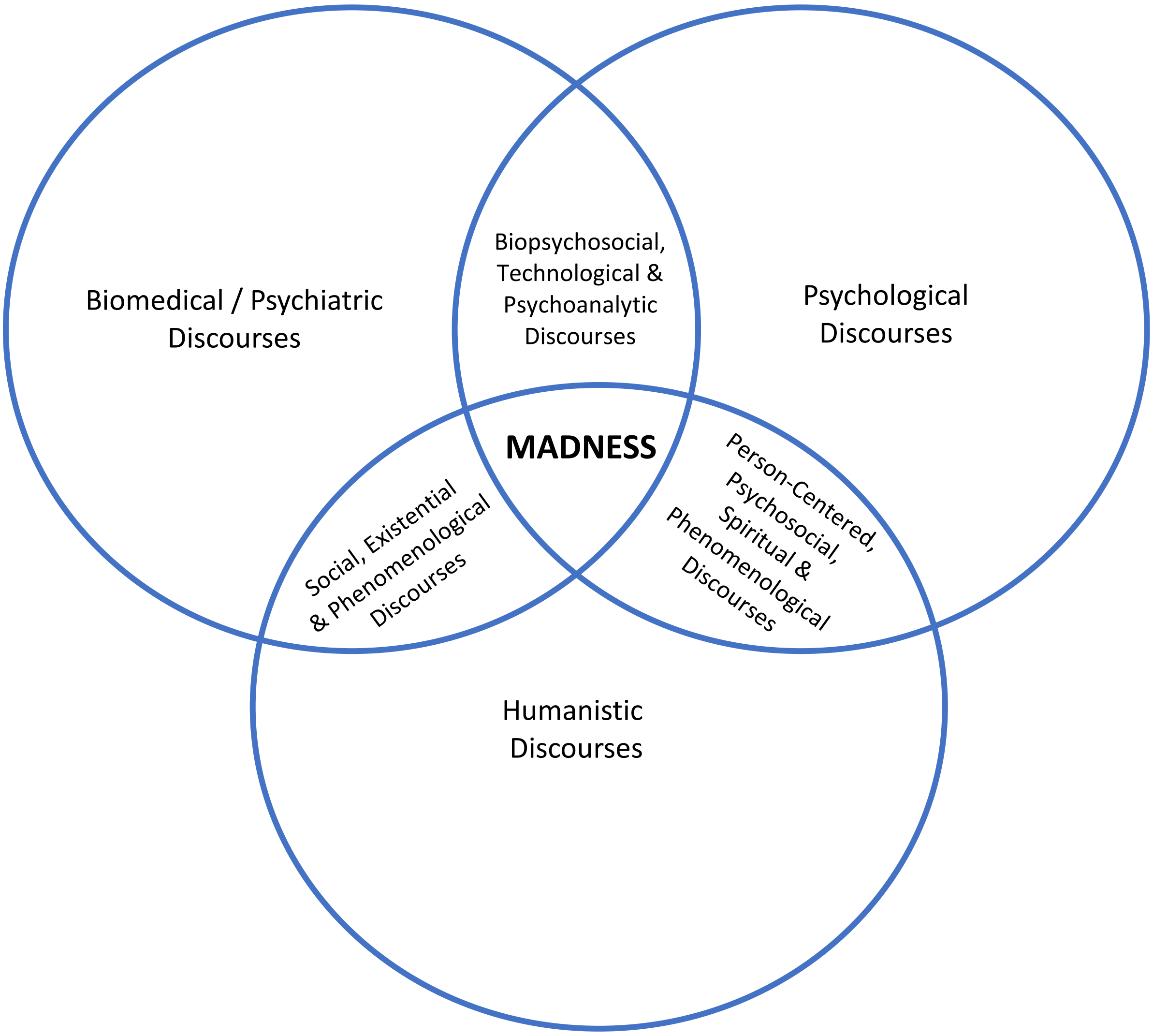
The potential to either amalgamate or, conversely, claim clear distinctions between the biological, psychological and social models of understanding human experience can be problematic in delineating discourses. However, in terms of the discourses identifiable in the participants' accounts, a difference between psychiatric discourse and psychological discourse was evident. This resulted in the identification of a psychological discourse as a separate category within the transcripts. Furthermore, in terms of my own cultural knowledge and clinical practice, though the professions of psychiatry and psychology are often regarded as distinct and different areas of expertise, overlaps are evident especially in mainstream services, which largely have a medical emphasis.

The dominant discourses identified in the participants' accounts relating to psychosis and 'schizophrenia' are: biomedical psychiatric, psychological, humanistic, madness, and discourse of dangerousness. It could have been possible to amalgamate madness and dangerousness discourse due to their historic coexistence, as is observed by Rose: '[m]aybe there is nothing new or surprising about this association of madness and risk. Has not madness always been associated with unpredictability, danger, hazard? Was not the mad person always thought to be a potentially dangerous individual? And reciprocally, from the mid-nineteenth century at least, was not the dangerous individual a person who was very likely, suffering from a form of madness?' (1998, p. 178). However, it was evident throughout the participants' accounts that discourses about madness and dangerousness were used separately, despite historic associations between dangerousness and madness (Foucault, 1978), in addition to discourses that contained implications of both.

The Discourses

Biomedical psychiatric discourse (being the dominant psychiatric discourse), humanistic and psychological discourses were evident in all the participants' accounts, with smaller units within each discourse present to varying degrees in the individual accounts. Participants shaped their interpretative repertoire by means of resistance or acceptance in meaning-making of their experience of psychosis.

Although there are distinctions between the available discourses, there are also overlaps that I have attempted to demonstrate in the following Venn diagram (diag. 3).



Diag. 3 Discourses Available in the UK 2020

Discourses within any given culture are intimately connected with the prevailing political landscape. As discussed in the introduction, neoliberal ideology and institutional practices create and produce a social reality where all aspects of human life pivot around economic concerns, which is in turn reflected in mental health policy, institutions and practices. This is evident in the dominant biomedical psychiatric discourse, where problems are located within individuals who are diagnosed and treated with medications associated with certain categories of diagnosis. The ‘branding’ of distress (Timimi, 2011) presumed to be ameliorated by consumption of the medications marketed to mental health professionals, complies with the neoliberal agenda of individualising distress. The complexity of the social context within which we live as a major contributory factor to distress is downplayed in preference for risk management and target driven interventions where both the clients and mental health professionals are measured for their performance. An important reminder at this point is the ‘Biomedical residualism’ referred to by Moth (2020), in explaining the impact of neoliberal policies on mental health institutions and practices. The biomedical psychiatric discourse, being the dominant discourse in current mainstream mental health services, illustrates the powerful impact of neoliberal politics on current statutory mental health service provision.

The Foucauldian informed discourse analysis, as outlined in Willig’s (2013) six stage model, suggests that the participants draw on a variety of dominant discourses which they deploy in their communication about their experience. These discourses contain constructions of psychosis within a variety of conceptual frameworks. This research aims to understand the potential implications of these constructions for individual subjectivity, the positioning of self and others, and consequently the implications for action (Willig, 2008).

I will present the constructions illustrated with quotes from the participants with a discussion of the implications for subjectivity, positioning and action, in addition to the differences between the participants in their use of these constructions.

The recurring constructions of psychosis for the participants in this research study are as follows:

1) Constructed as ‘an illness like any other’ – a medical problem diagnosable as ‘schizophrenia’ (originating from a biomedical psychiatric discourse).
2) Constructed as dangerous/risky/scary (related to biomedical psychiatric discourse).
3) Constructed as abnormal/other/madness (originating from a biomedical psychiatric discourse).
4) Constructed as an understandable part of the spectrum of human experience (arising from a humanistic psychosocial discourse).
5) Constructed as trauma related – response to adverse life events/threat (arising from a psychological psychosocial discourse).

Although it is customary to include fewer quotes in an FDA, I have adopted a liberal use of quotes in order to illustrate the analysis of my findings. I have considered this important in order to do justice to the participants’ sharing of their experience with me, the richness of the accounts and the time they allocated to this research study. I wanted to let the data speak and the participants’ voices to be heard in their original form, alongside my interpretation of their accounts.

1. Constructed as ‘an illness like any other’ – a medical problem diagnosable as ‘schizophrenia’

The recent ‘Time to Change’ (2007) campaign to reduce stigma in mental health has focussed on the premise that mental health problems are indistinguishable from physical health problems. The effectiveness of this campaign and others of a similar nature to reduce stigma has been criticised for an overemphasis on biogenetic causes accompanied by an exclusion of psychosocial factors (Read et al., 2013). Rose’s comments on the subject are worth noting: ‘[t]he ‘destigmatising’ strategies that seek to convince us that mental distress is, or arises from, diseases like any other, does not, in fact, seem to liberate individuals from responsibility, guilt and blame for their condition… [i]n our current climate, the narrative of ‘it’s a disease like any other’ almost always implies that this distress arises from an internal pathology, increasingly a brain pathology, that should be treated with medication, rather than by pinpointing the experiential roots of the distress in the current and past life of the individual…’ (2019, p. 189).

Read et al., found that the public preferred psychosocial explanations and that biogenetic explanations were ‘positively related to perceptions of dangerousness and unpredictability, and to fear and desire for social distance’ (2006, p. 33). I was interested to find that the participants used this construction in different ways and demonstrated both an acceptance and rejection of it, in attempting to understand their own experience and make meaning.

Jo, who used the terms psychosis and ‘schizophrenia’ interchangeably throughout his interview, embraced the biomedical psychiatric discourse and the constructions of genetic heritability and biological inevitability. In discussion with me about why he thought he had developed mental health problems, Jo said:

> predisposed to it through genetics anyway. (18/ 27,28)

> although taking large amounts of cannabis as a teenager probably brought it on early rather than caused it outright (2) I was probably going to get it anyway even if I had lived a clean life (15/1-4)

As Jo explained his understanding, his facial expression changed from frowning to being more relaxed and open. For Jo there seemed to be some reassurance and comfort in being positioned as a patient with a psychiatric illness originating from his physiology, which fully accounted for his experience of psychosis. Jo expressed acceptance of the psychiatric construction of his experience, whose legitimacy could not be questioned or doubted, creating a sense of certainty and security for him whilst also positioning him as a willing and cooperative recipient of psychiatric treatment to manage his illness.

For Maria, the biomedical psychiatric construction of her experience of psychosis was resisted due to the potential positioning of her as powerless to personally influence or change what was happening:

> I guess it, it's just not sort of saying that I'm yeah, that I've got an illness really – that I can't help it – that it's out of my control. (19/24-26)

The ‘out of control’ aspect of her experience, associated with the biomedical construction, is not accepted or welcomed by Maria, but perceived as highly problematic and anxiety inducing. The implied loss of agency in being able to influence or change her future, thereby being positioned as helpless, Maria rejected vehemently.

This was echoed by Doreen, who resisted the construction of inevitability and heritability in her response to a question about psychiatric language and constructions of psychosis:

> holding no hope whatsoever for the person who’s got the label of psychosis and also well it’s saying that psychosis is a dustbin diagnosis where you go and there’s no way out. (7/21-24).

The idea of permanence and chronicity was strongly communicated by Doreen with her ‘dustbin’ metaphor, which also indicated a sense of her lacking utility and therefore being dispensable.

For Jacky too, there was a rejection of this construction that “this was it for life.” (32/3) and she therefore refused to be a passive recipient of psychiatric treatment, which had included inpatient and long-term treatment with antipsychotic medication:

> I remember my last appointment with my psychiatrist. I went in and told him “I’m off the medication”, he was absolutely raging, he was really furious and just said, “well you’ll be back”. (35/10-13)

Jo however, who had accepted this construction evident in the psychiatrist's response to Jacky above, continues to take antipsychotic medication. He stated:

> I realised that I have to take medication for the rest of my life if I want to stay healthy. (12/18-19)

The construction of psychosis as biogenetic illness creates a 'vantage point' (Harre & Davies, 1990) from which certain options can be seen and others are occluded. For example, the conclusion from a recent research study (Hasson-Ohayon, 2019) that discontinuation of antipsychotic medication can be regarded as a reasonable life choice, is concealed from view.

For Jo, the construction of psychosis as presented to him by his psychiatrist – as being a hereditary biogenetic illness – also carried with it limitations for future aspirations as he located the problem within himself:

> that it would severely impair my future and write me off, I would never have any kind of success ever again and that it would be with me, you know it would be, I'd be ill for the rest of my life. (10/14-17)

The implication in Jo's statement is that he feels positioned as having to accept limitations in how his life can be lived, with adherence to long-term antipsychotic medication providing the only reasonable life choice 'to stay healthy', as stated in the quote above.

Despite mixed opinions about the relationship between psychiatric insight and wellbeing (Amador & David, eds. 1998), recent research is showing a negative relationship often characterised with internalised stigma in relation to the construction of psychosis as biogenetic illness (Hasson-Ohayon, 2018). A study examining quality of life and ‘insight’ as defined within psychiatry – i.e., accepting you have a mental illness, general lack of awareness of the mental disorder, lack of awareness of the significance of medication, and lack of awareness of specific symptoms – found that ‘general insight into mental disorder was negatively related to quality of life in the domains of emotional well-being, economic satisfaction, and vocational status’ (Hasson-Ohayon, 2006, p. 269). As is evident above, Jo’s acceptance of the psychiatric construction of psychosis and the consequent implications for living demonstrate insight, as defined within psychiatry.

The reference to ‘write off’ in Jo’s account also appeared in Doreen’s account. Doreen, unlike Jo, did not use the terms psychosis and ‘schizophrenia’ interchangeably and constructed these to refer to fundamentally different types of ‘illness’. Illness was a term she was comfortable with, as she constructed illness to include commonly experienced problems which resolved: “everyone gets ill and then they get better” (24/31). By contrast, ‘schizophrenia’ for her was associated with a long history focussed on a degenerative brain disease:

> it is a write off diagnosis, it’s,’ oh they’ve gone into that category and that means they’re there forever and . ahh then you start to make decisions about who you are as a person. (9/12-15)

For Doreen, a diagnosis of ‘schizophrenia’ was a ‘write off’ which not only limited possibilities for living, but also altered the person and sense of self. This was echoed by Maria, who expressed some resignation to this construction of her experience:

> My job in this world, my occupation is to be this sick person. (22/14,15)

The transformation from person to mental patient is present in the critical psychology literature regarding the diagnosis of mental disorders: ‘diagnosis is not a process of identification or recognition of disorder, but rather a process of active construction of disorder and of transforming the person to a mental patient’ (Georgaca 2004, p. 87).

However, Maria also expressed some resistance to this too:

> It just feels like it’s easier for them to give me this diagnosis because they can’t necessarily be bothered to look at my history at all! (19/10-13)

In this quote it can be seen that Maria is actively resisting the ‘construction of disorder’ via diagnostic means, by constructing the diagnosis as a lazy move by psychiatrists.

For Jo, having developed a biomedical understanding and acceptance of a construction of psychosis as a medical illness,[53] classification was both convincing and an assurance of an objective scientific explanation:

> My diagnosis is schizophrenia/schizoaffective disorder… to qualify or be diagnosed with that condition you must be experiencing so many of a range of symptoms (2/9-13)

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[53] “I’ve discussed this with various different psychiatrists and the consensus is that .umm people with mental illness are genetically disposed to it much like some people are predisposed to cancer or diabetes.” (14/28-32)

> it affects about one per cent of the population .hh regardless of geographical location 10/19-20

The use of the word ‘qualify’ is interesting as it alludes to achieving membership of a club or eligibility for a role (Foucault, 1982). Moreover, understanding that diagnostic categories are compiled by a consensus of professional psychiatric opinions (Davies, 2013), rather than scientific facts, evokes the idea of a club committee making decisions about who is eligible for membership. Despite the creation of diagnostic categories for mental health problems, via a consensual process, they are nevertheless widely accepted as medical facts derived from scientific evidence, obtained objectively and dispassionately. This assumption invokes measurements and scientific explanations which are rife in biomedical constructions, as evidenced in Doreen’s account:

> psychiatrist said, “you had an eighty per cent chance of relapse because you came off your medication” – eight out of ten chances of relapsing is too high for me. I mean I’m quite scientific. (14/7-12)

The statistics presented as evidence by her psychiatrist – that the odds are stacked against discontinuing medication (a prevalent construction within a biomedical psychiatric discourse) – occludes some of the most recent findings that discontinuation of antipsychotic medication can be a reasonable life choice (Hasson-Ohayon, 2019) and that a return of symptoms can be indicative of sudden withdrawal from medication (Breggin, 2010).

Maria expressed a loss of hope about her future, having been diagnosed with a range of diagnostic categories following an episode of psychosis, all of which were indicative of a long-term mental health problem:

> I guess it also says to me that I will never recover, that I will always have it, it’s permanent (19/27-29)

She also expressed some doubts about the validity of diagnosis, which is heralded as of utmost importance within a biomedical psychiatric discourse:

> I don’t think it’s a medical problem necessarily, can’t be given a label really (17/31-33)

Responding to questions about her experience of psychosis, Jacky recounted the process of intervention and treatment she received:

> sent to hospital and given the diagnosis (6/8-9)

> diagnosis… being told this is an illness for life (16/11-12)

She also related how this led to a biomedical discursive lens from which all of her experiences could be understood, which included constructions of psychosis as chronic and all thoughts, behaviours and emotions being related to the ‘medical’ illness. Jacky constructed herself as naïve in the past in accepting these constructions then, and having gone through a process of personal growth and change which enabled her to access other available discourses. At the same time, she emphasised the prevalence of the biomedical discourse from her past, “80s - was an illness.” (17/3*)*

However, she also acknowledged that she moves in critical circles professionally as a psychotherapist and lecturer, which was evident in her use of a critical discourse to reject psychiatric constructions of distress via diagnosis and emphasised by her repetition of the word ‘drop’:

> let’s drop, drop the label, let’s not think about it in terms of labels. (23/13-14)

The call to drop the language of disorder by Richard Bentall et al. (2017), in a paper criticising the use of diagnostic categories, advocated the need for a paradigm shift in order to focus on the nature of the difficulties experienced by an individual, rather than a treatment response focussed on symptoms and the psychiatric practice of diagnosis. This resonates with Jacky’s experience, in feeling that the context of her difficulties was overlooked in preference for the identification of an illness which therefore required medical treatment via long-term use of antipsychotic medication.

Psychosis constructed as thought disorder and therefore producing nonsensical speech (prevalent in biomedical psychiatric discourse), was another recurring construction evident in the participants’ accounts of their experience. Jo explained his understanding:

> psychosis is, you know it’s got a definition which is something which is contrary to the truth or something .hh that’s my definition of it (9/27-30)

This construction of psychosis resulted in Jo discounting any contextual information about his life, other than the drug use causing an earlier onset of psychosis due to his predisposition to ‘schizophrenia’/schizoaffective disorder illness. When asked whether his experience of psychosis may be related to any other factors such as being away from home at University, he replied vehemently:

> No, it was because I was becoming ILL (5/7)

Jo, unlike Jacky and Maria, did not attribute any relevance to his psychosocial history or the context of his experience, potentially and inadvertently positioning him in a reduced role to influence the course of his life and therefore, maybe also more reliant on adherence to medication to manage his distress. Foucauldian thinking on self-discipline suggests that individuals may internalise the understanding contained within discourses to make meaning and manage their experience, with responses ranging on a continuum from acceptance to resistance as an individual engages in self-management. This form of ‘self-empowerment’ creates the self-governing individual responsible for themselves, where a form of consumption, e.g. medication, is the rational choice in managing distress (Foucault, 1982).

It also seemed that any conflict in exploring family difficulties was averted, with the difficulty being located within Jo and originating from biogenetic illness.

By contrast, Jacky expressed frustration at not being listened to by the treating psychiatrists and an illness being diagnosed irrespective of the context she found herself in:

> can’t believe some experiences that I’d had… whilst I was extremely groggy… they made a diagnosis! (13/2-4)

Jacky constructed her family as problematic, resulting in her experiencing a psychotic breakdown, but also as beneficial in supporting her cessation of antipsychotic medication by enlisting a General Practitioner to prescribe a tapering course of medication. Jacky also referred to the bullying she experienced at school as a contributory factor in experiencing psychosis and being positioned by her peers as weird and an outsider. Doreen, who also found it important to refer to the context of her experience, described being positioned as not worthy of regard and what she wanted to speak about being dismissed as nonsensical.

Attempts by psychiatrists, notably Kraeplin and Bleuler, at the beginning of the Twentieth Century to understand differences in verbal communication between the general population and those experiencing psychosis led toward the inclusion of thought disorder and disorganised speech being amongst the criteria for a diagnosis of ‘schizophrenia’, since these were concluded to be evidence of deviance from the norm. However, social constructionists who have deconstructed this concept have posited that it is not the subjects that are psychotic, but the discourse. Furthermore, they argue that these psychotic discourses ‘make sense and have effects that are different from what is traditionally considered meaningful or intelligible’ (Parker, et al., 1995, p. 107). In Doreen’s account it can be seen that she is mobilising a critical discourse evident within critical psychology and social constructionist discourses, which in turn influenced her meaning-making process:

> We’re viewed as irresponsible and erm (2) making, not making any sense (14/23,24)

There was an indication that the discourses Doreen was accessing were in conflict, creating a dilemma over which discourse to accept or resist. Part of this dilemma was the concern that her understanding of her experiences could be constructed as ‘wild stories’ or myths:

> I’m probably still running some wild story about why it happened, so it’s like this world, whole world of emm myth, this myth that I created in both psychoses. (15/29-31)

This position limits what can be entertained as an explanation for the onset of psychosis and can facilitate further distrust and doubt within the self as a sense-making person that can create an understanding for themselves. A reduction in the expression of personal thoughts and feelings to others was also a consequence. This was apparent in Doreen’s explanation to me, where she fleetingly mentioned a relationship breakdown prior to the psychosis but disregarded this as a flawed hypothesis, whilst leaning towards theories she had been told by her psychiatrists and that she was also aware of from the public domain, e.g., ‘chemical imbalances’ and ‘relapse due to cessation of medication’.

It was evident during the interview that the contradictory discourses Doreen was accessing were creating a sense of conflict for her in how to interpret her experience. As Doreen endeavoured to express herself, it became apparent that she equated the deployment of a biomedical discourse with having the capacity to understand science, which she stated:

> I mean I’m quite scientific and you know (14/11,12.)

It was evident that being positioned as lacking in scientific acumen if she resisted a biomedical discourse was something that created a conflict in her meaning-making process, which was resolved by accepting the biomedical discourse, over a psychosocial discourse.
The implication being that the former ‘expert’ opinion was somehow superior. Being positioned as lacking the capacity to understand science left her feeling humiliated and put down, the antidote being that she too could elevate her understanding to a scientific level if the scientific information was shared with her by the psychiatrists. The lack of equality in the doctor / patient relationship is marked by the prioritisation of the scientific explanation, evident in biomedical discourse being regarded as closer to the true meaning, irrespective of the opinion of the patient.

The power differential experienced when accessing mental health services was something that was spoken about by all four participants and something that resulted in psychological distress, a loss of personhood and being constructed as other by the professionals within the mental health institution:

> It had been some sort of experiment or something and I wasn’t privy to the results [MRI scan of his brain] it made me feel .hh that I was outside of the circle to speak. (Jo 25/20-22)

For Maria, being constructed as a patient by others with the potential reassignment of her identity from person to patient was something she experienced when accessing mental health services, but also subsequently within some of her friendships:

> once you’re put into this role of patient – some people like her don’t ever see you (21/28,29)

The positioning as patient was something Maria resisted, despite the immense pressure she experienced to fulfil the patient role and position:

> you know it’s almost like an occupation… my job in this world, my occupation, is to be this sick person (22/8-15)

Being positioned ‘outside of the circle’ as a ‘sick person’ and a ‘patient’ entailed negative consequences in terms of identity and self-esteem. Even though these positions were resisted by Jo and Maria, they both still experienced a crisis in their identity, finding themselves, at times, both accepting the positioning of patient and resisting it when their personhood was overlooked in preference to being regarded as a patient.

Doreen also expressed a sense of being overlooked and being constructed in a different way by mental health professionals, as someone without agency:

> There’s this element of not being umm seen, as someone who is seen as still ehh a person who’s got agency (9/19,20*)*

And consequently, positioned as powerless to act autonomously:

> when a psychiatrist pronounces, you get persuaded (17/30,31)

Or to resist or manage a potential positioning of ‘schizophrenic patient’:

> thinking, gonna get a diagnosis of schizophrenia, don’t get a diagnosis of schizophrenia. So, I was really quite scared of that diagnosis (13/27-29)

Doreen’s facial expression and demeanour conveyed fear as she recounted the experience of waiting for the ‘pronouncement’, which she felt would adversely transform her life by being constructed in a different way by others and therefore positioned in a way that would create identity conflict:

> you’re basically left with what they’ve laid on you and then what your family lay on you (18/17-20)

The power of the expert psychiatric opinion to alter her experience and perception of herself and her relationships depending on which opinion was offered, was seen as life changing:

> if I had a diagnosis of schizophrenia for example, what would I say to my family? I feel happy to say to my family I’ve had psychosis, they know I’ve had psychosis .hh if they (2) if I said to my family, ‘I’ve got schizophrenia’, I think that they would then have a picture in their mind of that, which I don’t think would do me any favours at all… is very serious, this will last for a lifetime, can you live a normal life? (11/25-35)

Here it can be seen that psychosis is constructed by Doreen as transient, whereas ‘schizophrenia’ is constructed as a chronic condition, with life-long implications:

> I haven’t been labelled with something like schizophrenia, which I think I would have found fa:r more challenging because it adds an extra layer (6/28-30)

Doreen constructed not having received a diagnosis of ‘schizophrenia’ as a ‘lucky escape’, due to the mutually reinforcing practices she experienced as evident within the psychiatric institutions.[54] Awareness of this dynamic seemed to create a means of mitigating against some of the power experienced within the mental health system, but the threat of being overpowered still remained a fearful source of concern.

The experience of being overpowered was something that was also experienced by Jacky in her mental health treatment with a psychiatrist:

> He knew he was in a position of power, he knew what was wrong with me, he knew how to treat me… no interest in listening to my experience (33/1-3)

Jacky expressed contradictory feelings about this experience. On the one hand, she initially felt reassured that someone was able to make sense of her experience, but on the other her future seemed bleak and hopeless. She felt special that her difference had been recognised and named,[55] but also demoted to less important than other people, a mental patient, when she didn’t feel her experiences were being heard. Although she initially adopted the role of being positioned as a psychiatric patient, Jacky found herself wanting more than this position allowed, as was brought sharply into view by her visit to the locked ward:

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[54] “it’s like it’s a whole system run on the basis of the professional is here with their knowledge and the service user is here with their, their, lack of capacity, they’re vulnerable, they’re not able to be responsible for themselves and those, that’s, those stories run very strongly within the system” (15/5-10)

[55] “Umm, it, <u>I liked it</u>, because it made me special and where I felt <u>so different</u> from my peers, from all of those friends who (2) were living, phew, no teenager has a particularly <u>lovely</u> time of it, but they didn’t have a terrible time of it as I did. .hh Umm, it kind of named that difference.” (13/9-13)

> my fellow patient took me over on to one of the locked wards to visit her sister .hh and I suppose in a funny way, I feel quite privileged to have seen that because that really is (.) that just, it’s part of history now but it was also quite an eye opener and really shocking and I thought this (.) I don’t want this, I do not want this to be my future. (15/5-11)

The struggle for a reclamation of power and a meaningful future ensued. As Lupton explains, ‘[f]rom the Foucauldian perspective, power as it operates in the medical encounter is a disciplinary power that provides guidelines about how patients should understand, regulate and experience their bodies’ (1997, p.99) and this is evident in the participant accounts of their experience with mental health services.

2. Constructed as dangerous/risky/scary

The discourse of dangerousness with regard to mental health patients is prevalent within mental health services and the media, with dangerousness and risk being constructed as a legitimate concern. This is despite evidence to the contrary, that the risk of committing a dangerous crime posed by individuals accessing mental health services is not significantly higher than those in the general public (Pilgrim & Rogers, 2003). Risk assessments to manage individuals experiencing mental health concerns have become fundamental practice in mental health institutions. The potential for risk is considered in all areas of life for an individual experiencing a mental health issue, resulting in the scrutiny of all aspects of their existence. As Rose argues, in his critique of the pervasiveness of risk discourse, ‘[i]n practice, to put it crudely, all psychiatric patients can, and should be allocated to a level of risk, risk assessed, risk classified, risk managed: high risk, medium risk, low risk – but rarely no risk. And risk management is not confined to the question of whether or not a person should be detained in hospital or prison or to the mentally disordered offender: it extends over the everyday life of all patients and all psychiatric professionals' (1998, p. 179).

All four participants were aware of and expressed the 'importance' of risk and danger, when accessing a biomedical psychiatric discourse, which they also considered as applicable to themselves. However, this concept was rejected when speaking from within other discourses, which did not emphasise or focus on risk and danger. This led to contradictory opinions being expressed about the dangers posed. When I presented this finding at my annual progress review in 2017, one of the assessors commented that this could be evidence of thought disorder. However, my interpretation is that the discourses mobilised create certain forces which construct reality and affect the embodied experience. That is to say, that the socially available discourses used when expressing views about an experience, then shape the experience and form subjectivity. Additionally, all four participants had recovered[56] from their experience of psychosis and were not experiencing any unusual perceptual experiences or difficulties in communicating their thoughts, at the point of the research interviews.

I concluded that the contradictions and conflicts were mainly due to the 'vantage points' adopted in response to the type of question asked and the discourses that were being deployed. This is illustrated well in Maria's account of her experience, demonstrating the internal conflict produced by the discourses in action:

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[56] My use of the word 'recover' is intended from the lay meaning – i.e., getting better, returning to health etc. – rather than as evoking its more specific use as related to the Recovery paradigm (largely aimed at self-management) e.g., Recovery Colleges, Personal Recovery Framework (Slade (2009), Recovery Star (Mental Health Providers Forum 2013).

> I remember one of the doctors saying I could be dangerous .hh one of these psychiatrists and it was really (3) they just called me in and because I had said something (2) to .err one of my care coordinators years ago .umm that I wanted, I just felt really good and I wanted I sort of used this metaphor that I wanted to sort of drive the bus, I was feeling really excited .hh and by that I just meant that I wanted to take control of my life and she took me in to (3) see a psychiatrist and he said oh you know, can be (2) dangerous (3) I heard you want to drive a bus and things like that, I know, so ever since then I've kind of, (4) felt like yeah I'm being (4) restricted in some way or erm .hh (3) ° I don't know° **(**14/24-34 – 15/1,2)

This quote illustrates the internalised stigma made possible as a consequence of an interaction with mental health professionals, despite Maria's previously held belief that she did not pose a threat to others. She now alluded to experiencing doubts about herself highlighted by her comment~~s~~ towards the end of the quote, "so ever since then I've kind of, felt like yeah I'm being restricted in some way". This would appear to be a restriction created by the discourse of dangerousness, which altered her reality and created a new and different subjectivity. She was now positioned as a mental patient with the associated dangerousness and risk. Maria's comments above also highlight the mental health professionals' obscuring of her metaphor – being in the driving seat – taken instead as a literal statement denoting a potential risk. In this instance, the discourse of risk overrides the context of Maria's comments, which are instead interpreted as a statement of her 'risky' intentions and worthy of scrutiny.

For Doreen, violence and danger were used interchangeably and associated with a diagnosis of 'schizophrenia', but less so for psychosis:

> I think if I’d had a diagnosis of schizophrenia, that would have tapped into having a real fear attached to it because of how badly the idea of schizophrenia is described in the press… because you are associated with violence, you’re seen as dangerous (31/34,35 & 32/1-4)

When recounting her personal experience, doubts about her own evaluation of dangerousness were evident:

> I would have liked to have been in the 136 suite instead of the police station, ‘cause that was traumatising in itself, .hh I still don’t know why, I don’t, I don’t think I was violent? I was probably not very moveable because I wasn’t walking but I didn’t, I wasn’t actually violent as far as we know, so why wasn’t I in a 136 suite? (31/34,35 & 32/1-4)

The role played by professional discourses in clients’ experiences is discussed in Georgaca’s critical review of discourse analytic research in ‘the ways in which clients’ experiences are gradually shaped by professional discourses’ and the importance of exploring ‘the negotiation process taking place between the client and the professional’ (2014, p. 4). This can be seen in Doreen’s account, where the idea that she could be dangerous is accepted when accessing a psychiatric biomedical discourse:

> I was considered a danger to myself (2/1,2)

> totally immersed in that experience and, which is why I become a danger to myself (3/4,5)

Although Doreen refers to ‘total immersion’ in this quote, she later contradicted this when accessing a psychosocial discourse.

> I was well enough to know that I was very unwell, [laughs] if you see what I mean (13/21,22)

Jo, when discussing the language used in mental health services, expressed his approval, which was also evident in his deployment of a biomedical discourse. Jo was keen to state that although some patients might not like the language, it was acceptable to him and that patients’ lack of awareness and understanding of themselves and their illness constitutes a high risk:

> if they are ill at the time and they don’t really understand that they are ill (9/19,20)

His use of the pronoun ‘they’ suggests a distancing of himself from his experience of psychosis, and also could be interpreted as a consequence of the use of a biomedical discourse, which involves a positioning of ‘us’ and ‘them’. The issue of being othered, and othering, will be discussed in more detail in the next section. However, it would seem that by Jo incorporating the ‘them and us’ binary in his discursive interpretative repertoire, he is both exonerated from any responsibility when in the position of patient and also co-opting the power experienced within the system by a form of identification with the mental health institution, via the acquisition and utilisation of the biomedical discourse.

For Jacky, being accused of having violent intentions as part and parcel of her illness, was something she vehemently rejected:

> a staff member was coming down the ward and he [another patient] shoved the knife into my hand, so I was found with the knife and I protested that I, I you know, I'd just been given this, I didn't, you know, I didn't have the knife, it had just been put into my hands. I then, we were actually allowed to read our notes and it had been written up in the notes .hh as, how do you know, whatever, my protestations of innocence were interpreted as my illness, so this was a behaviour that (.) had happened as a result of my illness. I'm still furious about that, I was angry at the time and I did challenge them at the time, but they couldn't hear it (32/12-17 & 33/1-5)

Jacky constructed the professionals as unable to hear her and also subject to the discourse that associates madness/mental health issues with dangerousness. So, despite her attempts to correct the misinterpretation of events, she found she could not be heard, positioning her as helpless and powerless. This in turn limited what could be said and done, leading to resignation and repressed anger. This resonated with Maria's experience of being misinterpreted by the mental health professionals, who were making their evaluation from the position of risk assessors. It could be argued that the deafness she encountered was created by the prevalence and dominance of a biomedical discourse within the mental health inpatient facility, where practices of risk assessment and management are routinely utilised to mitigate against dangerousness.

The increase in the language of ‘risk’ in mental health services,–has been discussed by Nikolas Rose in a paper on ‘Governing Risky Individuals’, where he states that, ‘[i]ssues that previously had been the concern of a relatively small number of forensic psychiatrists who specialized in the assessment and treatment of mentally abnormal offenders have now become the concern of many, indeed of all, mental health professionals’ (1998, p.177).

Despite the turn to ‘risk’ as the organising principle for matters pertaining to the management of dangerousness, in order to reduce inappropriate detention in psychiatric hospitals and attain a more useful way of dealing with dangerousness, the meaning remains the same – although reframed and now generalised to everyone (Monahan, et. al.1993). It could be argued that this extension to all mental health patients increases a sense of risk and therefore a sense of fear, as expressed by Jacky:

> fundamentally the whole thing terrifies people (30/9)

Fear was acknowledged by all the participants, both in terms of the fear they experienced personally and the fear they encountered in others, thereby transforming their subjectivity, adversely affecting trust in interpersonal relationships and self-trust.

3. Constructed as abnormal/other/madness

The construction of psychosis as abnormality, madness and *other* (prevalent within biomedical psychiatric discourse), featured strongly in all the participants’ accounts. For Jo there was a sense that he viewed himself as both abnormal and insane, wishing for an alternative view, but feeling this could only be possible within the realms of ‘magic’:

> R: When I was diagnosed with that [schizophrenia], it gave me something to work with I guess, cause then I had an answer. It might not be the answer I wanted but it was an answer.
>
> I: Okay well what was the answer you wanted?
>
> R: A magic wand that could just say take it all away and make me normal again I think was what I wanted but that’s not how it always works umm yeah it gave me something to work with and (2) I wouldn’t say (2) it helped me deal with the symptoms or anything (2), but I guess it gave me some sort of .hh (2) some sort of closure in a way so I actually have a diagnosis .hh umm. (11/28-34&12/1-5)

There is certainly a sense here that Jo feels positioned outside of the socially constructed category of normality and is fundamentally transformed. The construction of fundamental difference also occludes the possibility of entertaining other constructions and understandings of his experience and acceptance of a restricted life.

In ‘Clinical psychology in psychiatric services: The magician’s assistant?’, the authors reference to magic pertains to how ‘biomedical concepts perform conjuring tricks that obscure the social and historical causes of distress’ (Coles et al., 2009, p. 5), thus making them vanish. It would seem that Jo’s experience includes a ‘vanishing’ of the context of his experience, firmly locating the problem within his biology and genes. Therefore, the sense of permanence of his condition is reinforced, thus leading to an entrapped position where only magic could reverse his fortune. However, from a critical perspective, it would seem that the ‘magic’ performed via a biomedical discourse could indeed have conjured up this position. If so, breaking the discursive spell and dispelling the illusion could be a possibility via access to a psychosocial discursive ‘magic’ wand or an alternative discursive resource, which offered other positions for what can be thought, felt and done.

For Maria, the experience of being othered when diagnosed was defended against and resisted by evaluating the mental health system as reductionist and failing to take into account the context:

> It just feels like it’s easier for them to give me this diagnosis because they can’t necessarily be bothered to look at my history at all! (19/10-13)

Maria’s constructing of the mental health professionals as lazy yet also humans with flaws reduces their status from all knowing and powerful. This construction positioned Maria in an agentive position whereby she could reject the ‘othering’ and understand her experience in a way that made sense to her by drawing on the context of her experience:

> It starts off with depression and I think it has a lot to do with my identity (7/25-28)

Furthermore, she retained her opinion that:

> I don’t think it’s a medical problem necessarily, can’t be given a label really (17/31-33)

It is also evident in this statement that she feels the phenomena are being labelled, not her, thereby keeping her identity separate and maintaining the subject/object split. She went on to express her belief that psychosis was part of what was possible in the spectrum of human experience:

> I think anybody could experience that (8/29)

Rejecting the medical discourse and therefore the medicalisation of her experience enabled her to position herself as experiencing a range of phenomena that are possible for ‘anybody’. This active distancing between herself and her problems, rather than her *being the problem*, seemed to provide an agentive position from which to reflect on her troubling experiences and also critically evaluate the mental health system.

Doreen’s account contained many references to psychosis constructed as abnormality, madness and alien/other. Contradictions were apparent as she fluctuated from utilising different discourses, in response to questions about her experience of psychosis.

From:

> I couldn’t be sure of anything that I’d experienced, in the psychosis cause, I was so off the planet. (5/24-26)

To:

> I could go, ‘actually the evidence says that’s not true, that’s a psychotic belief’, and move into a normal understanding (7/35 & 8/1,2)

Here we can see the contrast of abnormal, as described by ‘off the planet’ and identification of an abnormal ‘psychotic belief’, with the ability to acquire a ‘normal understanding’.

The wider discourses arising from the contemporary view of madness, as being related to irrationality as suggested by Foucault (1967) and abnormality which is socially constructed when appraising what constitutes normality, can be seen in action in Doreen’s account.

The quotes above illustrate the struggle to defend herself, as she attempts to retain the desirable normative position, having also been positioned in the abnormal space, which is ‘off the planet’.

For Doreen, there were implications of varying degrees of abnormality associated with different diagnostic categories:

> It’s much more complicated to declare that [a diagnosis of schizophrenia] than to say you’ve had depression, cause half the population’s had depression (23/11-13)

Doreen’s opinion regarding depression was that it was accepted as being a normal part of human experience, thus making it easier to deal with in society.[57]

Doreen went on to say that, “depression is socially acceptable” (24/20,21), thus explicitly acknowledging the normal status within society that depression has attained. Conversely, Doreen expressed that ‘schizophrenia’ was constructed as abnormal, othering and therefore something her family would not be able to accept.[58] Again, the diagnostic categories

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[57] The term ‘normalising’ is commonplace within psychological therapy, whereby a reframing of an individual’s experience as a normal response to adversity is used to avoid the pathologisation of their responses and distress.

[58] “if I had a diagnosis of schizophrenia for example, what would I say to my family? I feel happy to say to my family I’ve had psychosis, they know I’ve had psychosis .hh if they (2) if I had to say to my family, I’ve got schizophrenia, I think that they would have a picture in their mind of that, which I don’t think would do me any favours at all” (11/25-31)

psychosis and ‘schizophrenia’ are constructed in different ways by Doreen, which leads to different positionings and consequences for subjectivity. Doreen speaks of psychosis as a transient experience from her past (‘I’ve had psychosis’) and ‘schizophrenia’ as something that she would still have if diagnosed as such, despite the phenomena abating. This is indicated by the use of the present tense, ‘I’ve got schizophrenia’. This reflects the permanence of the ‘schizophrenia’ diagnosis whereby, once diagnosed, individuals remain labelled, but said to be ‘in remission once symptom free’.

For Doreen, depression, psychosis and ‘schizophrenia’ seemed to be organised on a spectrum of normal to abnormal, incurring a variety of feelings about herself in the social world and within herself. From acceptance of herself having a transient experience, to a chronic condition that would have negative consequences for living:

> schizophrenia is very serious, this will last for a lifetime, can you live a normal life? (11/34,35)

> adding something on which is socially so stigmatised and umm understood in a certain way .hh is just compounding the problem multiple times (12/10-15)

The reference here to ‘adding something on’ suggests that Doreen is aware of the socially constructed nature of experience and fears the impact that a change in diagnosis – from depression with psychosis to ‘schizophrenia’ – would have for her sense of self, personhood, relationships and the negative consequences for living her life.

Jacky, who was diagnosed with ‘schizophrenia’, recounted the experience once out of hospital, of being pointed at by others whilst they said, “that’s her she’s mad” (28/13). Whilst she was in agreement that there was indeed something wrong, she rejected the construction of her experience as madness:

> But I would say I was mentally ill, unsound mind, unstable, unbalanced (2/14)

> I’ve only recently been calling it [psychosis] despair and that’s a result of my psychotherapy training (20/5-8)

> I said I experienced psychosis (20/10,11)

> I had some unusual experiences, which is how I refer to it [psychosis] now (29/16,17)

In the first quote – “mentally ill, unsound mind, unstable, unbalanced” – from the beginning of the interview, Jacky accesses a biomedical discourse and its association with irrationality as suggested by Foucault (1967). However, as the interview progresses it can be seen that other discourses are being deployed from a professional psychotherapy discourse, lived experience and a humanistic psychosocial discourse, which is discussed in the next section.

4. Constructed as an understandable part of the spectrum of human experience arising from a humanistic psychosocial discourse[59]

The humanistic discourse emphasises the nature and rights of human beings, which was evident in all of the participants' accounts. I wondered how different the interviews would have been in the middle of the last century, when the divide between the 'mentally ill' and medical professionals was established as the standard expectation: an unchallengeable division between the *sane* and *insane*, and who has the right to speak or have an opinion.

However, even to date we still have Community Treatment Orders (CTOs), which override individuals' rights to decline psychiatric treatment and medication – this despite criticism (Moncrieff, 1999) highlighting the extent of control individuals subject to CTOs face, thereby increasing stigma and maintaining the divide between mental health patients and medical professionals.

Groups such as Mind and Survivors Speak Out, who aim to support the needs of service users, oppose CTOs as an infringement of civil and human rights, but despite the controversy from within and outside mainstream mental health services the use of CTOs continues to rise. A study conducted by DeRidder et al., (2016) found that the opinions of psychiatrists in the UK had not changed with regard to use of CTOs, since their survey in 2010, despite evidence challenging the effectiveness of CTOs, the lack of improvement in outcomes and the negative consequences for patients.

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[59] I am referring to psychosocial within a humanistic framework and discourse, to distinguish the psychosocial which is often marginalised when part of the biopsychosocial discourse in which the psychosocial is secondary to the biomedical.

Despite this, wider mental health institutional discourses have been shifting towards collaborative approaches which include patients in a bid to improve mental health treatments, e.g., experts by experience, service user research forums, and lived experience advocacy forums.

Movements such as Mad Pride and mad-positive activism, evolving in the late Twentieth Century from earlier waves of activism in the 1970s, reclaim the word ‘mad’ and reject the language of mental ‘illness’ and ‘disorder’, seeking alternative discourses and different understandings of madness to those widely accepted in society and prevalent within psychiatric discourses.

Pressure groups have formed calling for specialist support services tailored to their particular needs. But the question remains, how much are individuals being heard by mainstream mental health services, given the dominant psychiatric discourses which are pervasive within the mental health institutions? The existence of contradictory ideological positions expressed in the various discourses persists and is evident in the participants’ accounts.

Although Jo referred to his lived experience, and was part of a lived experience forum within mainstream services, the discourses he deployed were primarily biomedical psychiatric: he spoke at length about ‘schizophrenia’ involving a difference in brain structure; a genetic predisposition to ‘schizophrenia’; the importance of a biomedical psychiatric understanding of ‘schizophrenia’; long-term adherence to antipsychotic medication; and the development of insight as it is understood within biomedical psychiatry[60].

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[60] As noted earlier, accepting you have a mental illness, general lack of awareness of the mental disorder, lack of awareness of the significance of medication, and lack of awareness of specific symptoms

Jo referred to himself:

> I'm an old timer so I'm used to it (21/2)

And although Jo did not think that the 'language of disorder' (Bentall et al., 2013) needed to change, he acknowledged the power of being diagnosed with "schizophrenia stroke schizoaffective disorder." 2/9-13

> I mean the word itself yeah it's quite a powerful word if you're branded with it [schizophrenia], but rather than change the word itself change people's knowledge of what that word actually means (11/7-10)

Jo had utilised biomedical psychiatric discourses that constructed psychosis as a medical illness. He appeared to have limited awareness of other discourses, but had rejected the drug-induced psychosis explanation, which potentially was a challenge to his firmly held view. He saw himself as a mental health patient for life, who would be able to sustain a somewhat restricted life as long as he adhered to his psychiatric treatment and medication. Interestingly, the one time he deployed a humanistic psychosocial discourse was when he spoke about the fallibility of mental health staff, when he relayed some of the errors he experienced whilst in a psychiatric hospital:

> we are all human, the staff are human (24/28)

Although he included himself in 'being human' along with the staff, the main emphasis throughout his interview was that his subjective experience of himself was as a mental patient with a mental illness and that his experiences were not part of the spectrum of human experience, but a mental illness.

Jo rejected a psychosocial discourse, in preference for a biomedical psychiatric discourse conferring inevitability and certainty about the biogenetic origins of his experience. By contrast, Jacky's account was rich with humanistic psychosocial discourse:

> a lot of my experiences came from my upbringing and a very, very repressive home environment (34/9,10)

Jacky perceived not only a correlation but a causation for her experience of psychosis, which she felt had been a response to difficulties she had experienced. Psychosis being constructed in this way seemed to open up opportunities for her to envisage a life beyond:

> It was the desire for a future that gave me hope that I could recover, that I could get better (34/2,3)

> the whole idea of meaning-making and hope (33/17)

Furthermore, when accessing a psychosocial discourse, Jacky expressed strong opinions about the role of diagnosis and what it does:

> What fuels my anger? What the diagnosis does to people (27/16-17)

The action component of the discourse is evident here, as Jacky suggests that diagnosis creates experience. When accessing a psychosocial discourse, psychosis was constructed by her as a transient part of human experience:

> it’s a life experience… you can live with it… it doesn’t have to be a defining experience (18/11-15)

Jacky expressed a form of awareness that other opinions and discourses existed, beyond those she was exposed to while accessing mental health services:

> Let’s start deconstructing this, let’s start looking at what is really going on for the person in front of you, rather than the lens you’re looking through (25/10-13)

The reference to ‘lens’ is akin to the ‘vantage point’ referred to by Willig (2013), indicating how discourses influence how things can be perceived, understood, and the implications for behaviour and subjectivity. Jacky had an awareness that some people held different views, which she disagreed with from her ‘vantage point:

> Amongst everyone else there is a great deal of misperception (24/12,13)

For her it was a ‘misperception’, rather than a different opinion. The rejection of a different opinion as misperception enabled her to retain her hope of recovery and a meaningful future. However, it was also interesting for her to notice that despite her awareness that others may have a ‘misperception’ regarding psychosis, and that other discourses existed, she noticed herself lapsing briefly into a biomedical psychiatric discourse:

> The fact that a lot of the illness, ‘illness!’ see even I use those words (34/1,2)

Given Jacky's declaration of moving in 'critical circles' and, in the main, accessing critical discourse with an emphasis on humanistic discourse, it seemed surprising to her that she used a word she associated with stigma. This suggests that the biomedical psychiatric discourse is not only pervasive within mental health services, but prevalent in the public domain, where it has achieved a 'taken for granted' status.

For Maria, accessing a psychosocial discourse created possibilities for reclaiming her life prior to the experience of psychosis and retaining her sense of identity:

> I think anybody could experience that (8/29)

This is in accord with Bentall's (2004) argument that psychosis is on the spectrum of human experience. Maria went on to reject notions of the validity of psychiatric diagnosis:

> I don't think it's a medical problem necessarily, can't be given a label really (17/31-33)

Maria proceeded to access a psychosocial discourse whereby what was happening emotionally was regarded as relevant to her experience:

> It was like a bomb going off inside me… I couldn't contain what I was feeling anymore (8/10-18)

> I think it's a way of shutting out that I'm feeling low (3/29)

She referred to her experience with the word ‘it’, potentially indicating discomfort with the available discourses she was aware of so far, to describe her experience.

As a woman of dual heritage, born to an English mother and Nigerian father who had separated, and being brought up singlehandedly by her mother who she recognised as being an ‘older mother’, Maria experienced conflict in her identity, a fear of loss and cultural confusion. Accessing a psychosocial discourse gave space for her to pay attention to these difficulties and acknowledge them as relevant to her experience. Paying attention to her individual experience, as prioritised in a humanistic psychosocial discourse, further reinforced her opinion:

> psychosis experience can be named in general terms but doesn’t take into account the individual (17/31-33)

She also reflected on why the prevalence of diagnosis was maintained:

> It just feels like it’s easier for them to give me this diagnosis because they can’t be bothered to look at my history at all! (19/10-13)

Maria’s deployment of a psychosocial discourse, and construction of psychosis as related to her personal history, seemed to enable her to adopt a critical stance towards the mental health system she encountered, thus enabling her to retain the meaning-making that made sense to her.

For Doreen, being a human being and deploying a humanistic discourse made the extraordinary, ordinary:

> I think half the problem is that both times I've been completely dehydrated… I was given a lot of water… I actually started to feel much better… (3/6-15)

Psychosis constructed as part of the spectrum of human experience (as in humanistic discourse as contrasted with biomedical psychiatric below) also provided some reassurance for her personhood and sense of identity:

> you're not written off (2) you're still a mm, a person who is having an experience (9/11,12)

Doreen was also aware of other discourses beyond the biomedical, from her place of work in a psychology training centre:

> There's a (2) notion of psychosis, a difference of, there's a very strong and different story about psychosis there (9/6-8)

This quote suggests awareness of a different discourse, in which there are other possibilities for what can be felt, said and done.

Doreen was accessing a psychosocial discourse, which she elaborated on:

> I actually do believe that… the ability to be healed is within the person… a strong sense of ME in this psychosis experience (19/34,35 & 20/3,4)

Doreen expressed feeling empowered as she spoke about her experience deploying a psychosocial discourse:

> I have a very strong sense of agency (3) so (2) I'm aware of all of (2) these different perspectives in talking about psychosis (30/15-17)

She also referred to a continuum of experience for human beings, which is a common construction of psychosis within a psychosocial discourse with an emphasis on human nature:

> It's almost as if the world of psychosis sort of exists here and the material world exists here, and I need to move into the material world (20/31-33)

She explained:

> I did recover my sto:ry, .my material story, the ordinary living story… because I've learnt very much to be aware when I'm, my experiences are changing, my sensory inputs are changing. So, I can, I can identify something that's beginning to look a little bit like psychosis and pull back (10/9-35 & 11/1)

Again, her switching from 'I'm' to 'my', when speaking about her experience, suggests she is resisting the psychiatric in preference for a psychosocial discourse, wherein she can acquire the position of experiencing a problem, rather than being the problem. This position is an agentive one, which leaves her feeling she can be part of the solution by drawing on her own resources:

> because you think you're in a reality that is so:o different and is actually very coherent (4/33,34)

> stories that I had around it were very coherent. I umm (2) I think it (3) it, eh it draws back the boundaries that we normally have round our (1) our material world (6/1-3)

Here it can be seen that Doreen is trying to make sense of her experience of psychosis and she went on to explain that the experience, far from being disabling and evidence of deficit, was an enriching one for her:

> If you haven't got (1) much that emm (1) offers you something different in your material world the psychosis world is much more fascinating and full and interesting… you could call it an escape… it is an alternative way of living (8/25-32)

Doreen constructed her experience as spiritual, spirituality being something that is appreciated as part of human nature:

> very strong spiritual elements in it for me (4/5)

Doreen also stressed the importance of retaining her own sense of faith and spirituality:

> to manage the threat… I resorted to the core of my Christian faith… it wasn't a battle of faith, it was, it was more emm a battle for sanity (4/21-32)

Doreen did not perceive her experience to be a spiritual crisis, as she felt her faith had been a resource for her. She also had strong views about her meaning-making and the value of the language of illness, as something that is a transient human experience but acknowledges the severity of the experience:

> I've thought about it and I call it depression .hh and I call it being ill… that degree of disturbance to my normal way of living is… illness in my mind (3/30-35)

This demonstrates Wittgenstein's (1953) philosophical point about looking at the use of a word to understand it's meaning. Doreen's use of the word 'illness' is not from an illness narrative (Frank, 1995) wherein she occupies the 'sick role', or where her illness is the totality of her existence and identity, but a transient aspect of her experience. Doreen's use of the word 'illness' was not from a biomedical psychiatric discourse, but a humanistic psychosocial discourse:

> its [the word 'illness'] preferable, it's preferable to umm to saying it's a genetic problem (12/31-32)

Her repetition of 'it's preferable' emphasises her position on the matter, as she rejects a biomedical construction of psychosis. She also added her rejection of the term 'disorder', which is widely used within psychiatric discourse, as evident in the various editions of the *Diagnostic and Statistical Manual of Mental Disorders*:

> Whereas disorder is something about not functioning correctly and that sounds quite serious, it sounds more serious than illness (25/1-3)

> I can just about tolerate psychotic disorder but I'm, I'm very uncomfortable with it cause it says something, it feels, it feels like it's trying to get to the heart of a person (2) there's something wrong (4) for me it has something, has something about umm, a more permanent thing than an illness. Because everyone gets ill and then they get better (24/26-31)

From a psychological perspective, Doreen's comments indicated that she had insight into her experience. Her acceptance of 'illness' was from a construction of psychosis as transient, affording her a position of hope for a future, rather than the construction of an 'illness' as an 'illness like any other' from the wider institutional mental health and psychiatric discourses.

Doreen summed up her understanding of the mental health system:

> R: It's like it's a whole system's run on the basis of the professional is here with their knowledge and the service user is here with their, their, lack of capacity, they're vulnerable, they're not able to be responsible for themselves and those, that's, those stories run very strongly within the system.
> I: uhm uhm
> R: And yes (2), I, I could be very vulnerable at times but I'm still also able to be very responsible at times and I need the information to reduce my vulnerability .hhh so it

> just goes along with the entire view of patients within this country, which is that patients are ‘done to’ rather than worked with
>
> I: | Right, like a collaboration
>
> R: | Yeah, enable people to self-care and self-manage. (15/5-18)

She added:

> I think that mental health services find it very difficult to get, keep somebody on a diagnosis of depression all their lives with a bit of psychosis going on occasionally. (2) I don’t think that’s where they go (29/34,35 & 30/1,2)

It is evident in her summary of making sense of her experience when accessing mental health services that Doreen has experienced an imbalance of power, between herself and the mental health institutions and practices. Her involvement in peer support groups and experts by experience enables her to not only be aware of other discourses but also to deploy them.
This, for Doreen, has been part of the process by which she reclaims a sense of power and agency to self-care, self-determine and retain her identity.

5. Constructed as trauma related response to adverse life events/threat

Psychosis constructed as trauma related has emerged within psychological discourse and in recent years has resulted in the proliferation of trauma focussed services within psychological assessment and treatment provision in mental health services. Trauma is increasingly recognised as a major contributory factor in adults experiencing psychosis, particularly childhood trauma, emotional, physical, and sexual abuse, bullying by peers, loss of parent/s and institutional care (Bentall et al., 2008). Furthermore, certain specific categories of trauma have been found to correspond with particular symptoms in psychosis, e.g., child sexual abuse is positively correlated with hallucinations (Bentall. et. al., 2007). The phenomena of auditory hallucinations have been elaborated on by prominent individuals from the lived experience movement who have shared their personal accounts of hearing the voices of their abusers e.g., Jacqui Dillon and Peter Beresford from the national Hearing Voices Network (HVN). Dillon (2012), chair of HVN, also explained that her voice experience was interpreted by one psychiatrist as indicative of the onset of 'schizophrenia'.

Within psychology and mental health services, the trauma model has become widely acknowledged as a useful way of including the context of human experience in making sense of mental distress, thus giving rise to a discourse of trauma. However, there has also been criticism (Miller, et al., 2006) emphasising the need to move beyond an exclusive focus on trauma, by utilising a social-constructivist framework that can integrate the sociocultural perspectives present within any given social context and how individuals might understand psychological wellbeing and mental distress.

In January 2018, the Power Threat Meaning Framework (BPS, Clinical Psychology Division) was launched as an important tool for helping individuals make their own sense of their experience, with a focus not only on trauma, but a broader appreciation of the adverse effects of power overwhelming an individual, the perceived threat and the resultant response, e.g., anxiety, depression, psychosis etc.

Psychosis constructed as a response to trauma and threat, was referred to by Jacky, who suggested that this resonated strongly with her experience:

> something in the PTM [Power Threat Meaning Framework] about bullying leading to paranoia and I just thought Wow, you know yes, that’s happened (5/7-9)

The use of this construction for Jacky seemed to lend itself to the formulation of a meaning that was perceived as hopeful for her, “this whole idea of meaning-making and hope” (33/17).

By contrast, Doreen feared the possibility of her experience being constructed as a response to trauma (within psychological discourse), as she did not want to reflect on any trauma in her past and preferred the construction of ‘psychotic ramblings’ (prevalent in biomedical psychiatric discourse). This suggests she wanted to avoid thinking about difficulties she had encountered in the breakdown of an intimate relationship, which she mentioned briefly during the interview. She also had some awareness of the wider institutional discourses on mental health that emphasise the association with childhood trauma and mental distress in adulthood. Doreen further defended her position by stating that she had not experienced any significant trauma in her childhood, and that her relationship difficulty had occurred in adulthood.

For Doreen, her experiences could not be constructed as responses to trauma, as her experiences did not constitute a valid traumatic experience for exploration, as constructed within the wider mental health discourses. However, she was aware that if the mental health team had decided to change her diagnosis from depression with psychosis to Post Traumatic Stress Disorder (PTSD), she would have felt under pressure to address the difficulties she was choosing to avoid:

> Yeah, yes, so it made, I think it made, erm (2) re-diagnose me with PTSD, I think it would have been, I was going to say catastrophic, because I think I would have

> confirmed some of my paranoid psychotic ramblings and beliefs in my head as, as real, whereas I don't think they were. So, I was emm talking about (2) err or I was verging on, I was wondering what traumas I had experienced through these psychoses .hh and the more I have pondered on that the less I've believed that I've experienced really serious trauma. I have experienced some serious traumas, .hh but I didn't experience serious trauma in my childhood, and I think that they could've made me, that, having that diagnosis could've made me linger on those, that pondering about that. (17/22-34 & 18/1-15)

Maria and Jo did not speak of psychosis as a response to trauma or threat, however prior to the experience of psychosis both mentioned experiencing an identity crisis, difficulties with peers and, for Jo, the involvement in a 'drug culture'. Although threat was not explicitly acknowledged by them as a precipitating factor, the experiences identified prior to psychosis could be interpreted as threats and contributing factors in their experience of psychosis when considered through the lens of the Power Threat Meaning Framework.

What was universally experienced and communicated explicitly by all four participants was the threat and trauma experienced when accessing mental health services. The power differential between mental health professionals and the participants was constructed as a threat to the self and sense of agency as an equal human being:

> He knew he was in a position of power, he knew what was wrong with me, he knew how to treat me… no interest in listening to my experience (Jacky 31/13-16)

Jacky's experience with her psychiatrist was one in which she felt marginalised and powerless, which resonated with her experience of being bullied by her peers. Accessing a psychosocial discourse opened up other ways to make sense of her experience as compared to the options and constructions available within a psychiatric discourse.

Having completed the FDA, I will attempt to offer an integration of the findings and the dynamic interaction between the discourses and the subjective embodied experience of psychosis in the next section.

Discussion of the Integration of IPA & FDA Findings – The Implications of Language on Experience

Before integrating the findings, it is worth restating the research title: ‘Meaning-making of the subjective experience of psychosis when subject to a dominant psychiatric discourse: a dynamic phenomenological and discursive analysis.’

The aim of this study was to learn more about psychosis from a lived experience perspective. I wanted to understand both the phenomena of the embodied experience of psychosis and the discourses regarding psychosis, and how these aspects of experience interact with each other to influence the process of meaning-making when accessing mental health services. The experiences reported are from specific individuals in a particular context, which means their meaning-making contains both idiosyncrasies and universalities across the shared themes. As Smith summarises with regard to IPA, ‘[i]nherent to this model is the notion of a person as intrinsically a self-reflexive, sense-making agent who is interpreting his or her engagement with the world’ (2019, p. 167). Inevitably, this includes both the pre-reflective, embodied experience and the reflective experience, the latter involving cognitive and emotional considerations generated in thinking and feeling with a turn to language to articulate the meaning. The language available via discourses present in a particular culture and time in history play their part in influencing meaning-making. It would seem we live and experience ourselves in the world not only through our embodied experience but also in the world of communication, language and discourse. As Merleau-Ponty puts it, ‘[w]e may speak several languages but one of them always remains the one in which we live’ (1962 / 2003, p. 218) although focusing on the status of one particular language over another, this quote emphasises living within language which is implicated in experience and the construction of ourselves, our relationships and the wider context.

I have narrowed my focus to those who have accessed mental health services due to the second part of my research question. Of course, not all individuals experiencing psychosis present for psychiatric treatment.

The object under examination was psychosis, for both the embodied, lived experience and discourse. Firstly, it is worth clarifying that I am using the term psychosis because this term is still widely acknowledged and understood to refer to unusual perceptual experiences, thoughts and beliefs, when experiencing severe emotional distress. I prefer the terms mental or emotional distress, increasingly used in critical psychology texts such as the undergraduate psychology textbook *Psychology, Mental Health and Distress* (Cromby et al., 2013), which would have previously been categorised as a textbook on Abnormal Psychology. The change is also evident in other areas where descriptive terms are being substituted in place of medicalised language. Examples include an emphasis on psychological formulation, as opposed to diagnosis of human distress (Johnstone, 2018), and movements such as the Hearing Voices Network[61], Spiritual Crisis Network[62], Mind[63] and The Soteria Network[64]. The re-appropriation of lay terms such as ‘mad’ have been taken up by the Mad Pride movement, thereby reframing the experience as part of the diversity of human existence in addition to offering positive narratives about madness. Mad pride discourse posits that madness should be recognised as grounds for identity and culture, in addition to providing counter narratives to remove madness from psychopathology (Rashed, 2019). Support

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[61] https://www.hearing-voices.org
[62] https://spiritualcrisisnetwork.uk/
[63] http://www.mind.org.uk
[64] http://soterianetwork.org.uk

networks such as the Icarus Project[65] speak instead of the phenomena experienced as ‘dangerous gifts’. Mainstream disability movements and mental health anti-stigma campaigns prefer a medicalised conceptualisation of severe mental distress, regarding it as ‘an illness like any other’[66]. The survivor, service user, consumer, ex-patient involvement has also sought to provide alternative discourses and conceptualisations of the experience of psychosis with mixed responses to the notion of ‘recovery’. Critics claim the initial aspirations of a return to wellbeing and social justice have been co-opted to influence ‘workfare’ (over welfare) policies and reductions in welfare and social care provision, central to a neoliberal agenda (Harper & Speed, 2012; Friedli & Stearn, 2019).

Scepticism about the reification of rationality as fundamental to knowledge is evident in the field of mad studies, which seeks to emphasise the importance of paying attention to experiential first-person accounts that include imaginative, less orthodox or challenging to understand passages. It would seem that psychiatric research, which does not take into account experiential knowledge in its entirety, is more likely to produce knowledge that is underpinned by existing assumptions and a restricted focus that excludes the whole human being in their social and cultural context, in preference for the physiological components that constitute a human. It is apparent, from working in and researching this area, that the experience of mental distress can be framed and spoken about in many different ways and that these are constantly evolving as individuals attempt to be heard and understood from their perspective. This discursive field is indeed a crowded one with its roots deep in history – as discussed in the introduction.

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[65] https://theicarusproject.net

[66] See for example https://www.rethink.org

I was interested to note that, despite the re-appropriation of the word ‘mad’ in activist and survivor groups, to reconceptualise the meaning of their experience in empowering ways, the word ‘mad’ was markedly absent in the participant accounts. Two accounts (Jo and Maria) were completely devoid of a mention, whilst Jacky and Doreen only used the word either to indicate derogatory or dismissive attitudes by others towards themselves – “I heard her announce to the entire umm room, ‘Oh, that’s Jacky she’s mad’” (28/12,13) – or in referring to others experiencing psychosis – “mad psychotic people who do harm to other people, you know I, I, I just, I suppose I think the distance between what they are describing in the press and me is so (1) large it sort of doesn’t have an impact on me” (Doreen 22/15-18). In Doreen’s statement, the repetition of ‘I’ suggests the need to emphasise the difference between herself as an ‘I’ who is not associated with harm to others or indeed being ‘mad’ or experiencing ‘madness’. My mother persistently rejected the term ‘mad’, preferring to use it in reference to the psychiatric treatment received and aggressive behaviour perpetrated by my father.

The terms ‘schizophrenia’, psychosis and madness, all refer to similar experiences, but from different origins. The former two originate from the medical tradition, where experiences are interpreted as symptoms of mental illness. Dictionary and discipline specific definitions for all three terms indicate some form of permanence and chronicity, which contrast with lived experience and first-person accounts of the experience as well as qualitative research in recent decades (Robertson 2012; Geekie et al., 2012; Larsen 2004). What became clear in this research study is that the participants also had their preferences of terminology, with their associated meanings: from Jo’s account retaining ‘schizophrenia’ but expressing a desire to change knowledge and understanding of the term, to Jacky preferring ‘despair’.

So, moving from the micro detailed analysis of IPA and FDA to the macro level of integrating both analyses to develop an overview, what does it all mean? What follows is a discussion on the integration of findings including considerations from previous dual focussed research utilising IPA and FDA, and recommendations from other academics and researchers for using this methodological approach. A summary of the main findings from the IPA and FDA will then be presented alongside findings from other research on mental health focussing predominantly on experiential phenomena, or the discourses and socially constructed nature of experience. I will conclude with an integration of the findings emanating from this research, the organising principle involving questions of central concern for sense-making human beings in relation to their experiences.

Phenomenological Consequences of the Subjective Embodied Experience of Psychosis and Implications of the Discursive Constructions Deployed in Meaning-Making

'[A]n important part of the phenomenological work is to understand the transition between our pre-reflective and pre-conceptual grasp of the world and our subsequent conceptualization of and judgement about it.' (Zahavi 2018, p. 5)

It would seem from my findings that the various constructions of psychosis emanating from different discourses produce a variety of meaning-making possibilities of the experience of psychosis, as identified in the IPA themes. Furthermore, although all participants were symptom free and reported a sense of wellbeing at the point of interview, it could be argued that having engaged in meaning-making there were positive consequences for a sense of self and a future. There also seemed to be implications for the level of recovery, meaning in this instance a sense of wellbeing, associated with the different meanings inherent in the various constructions of psychosis. It is worth reiterating that although the analysis was conducted on the same data set, the semi-structured interviews were designed to elicit responses about both the lived experience of psychosis and the language used to speak about the experience when accessing mental health services. I had hoped I would be able to find a clear, structured way to blend the two analyses such as the dual IPA to FDA linear method proposed by Black & Riley (2018) whereby the IPA themes become the object for the FDA. The innovative approach developed by Black and Riley worked well for their analysis of the experience and construction of tattoos as therapy. Regrettably however, this method could not be utilised since the object for both the IPA and FDA analyses in this study is psychosis, rather than a generation of an object emanating from IPA which subsequently becomes the focus for the FDA, so another method was required.

Before I continue, the diagram below illustrates the relationship between the IPA themes and the discourses concerning the experiential phenomena of psychosis.

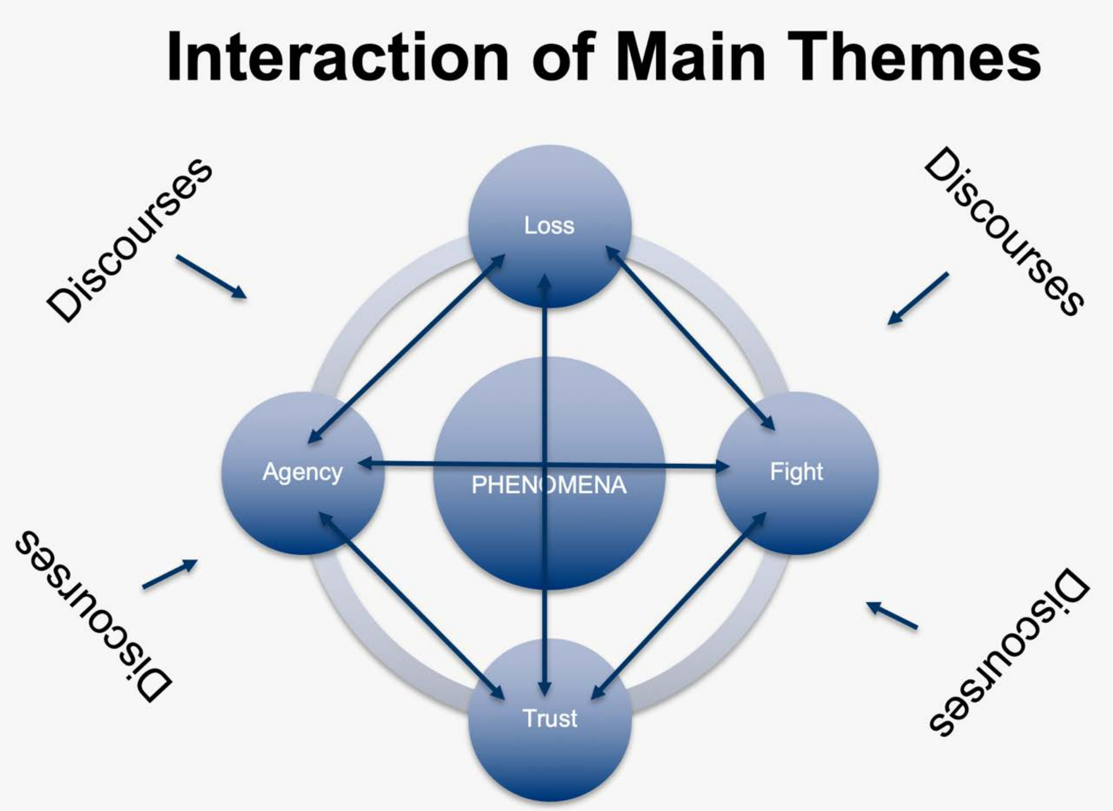

Figure 1 Impact of discourses on lived experience and meaning-making.

From investigating both the experiential phenomena of psychosis and the discourses used to speak about it, it was evident that both the lived, embodied experience of psychosis and the impact of the discourses mobilised had a profound effect on emotions, beliefs, behaviour and overall subjectivity. My conceptualisation of the relationship between discourse and experience presupposes that experience pre-exists discourse, but that discourse both constrains how experience can be talked about *and* shapes the experience by providing a context for it. Central to my consideration is the phenomenological, embodied, subjective experience of psychosis. Furthermore, because I theorise a dynamic interaction between discourse and experience, this analysis initially involves an experiential focus which progresses to a consideration of the dynamic interplay between language and experience, and how language mediates and shapes the experience of psychosis.

As Willig clarifies, ‘the researcher’s conceptualisation of the relationship between discourse and experience’ informs the interpretation process. Conceptualisations include language-dominant, proposing that discourse constructs experience, or in this case a combination of a phenomenological emphasis proposing that experience pre-exists discourse but that discourse constrains how experience can be talked about, in addition to discourse shaping the experience by providing a context for it – ‘a bottom-up story (of how experience is distorted, denied or silenced through discourses), or something in between (of how experience is transformed into accounts of experience through the use of available discursive resources)’ (2017, p. 285).

The discourses deployed, with their inherent constructions, result in subject positions from which to view and understand experience. These positions, in turn, constrain what can be thought, said and done, leading to consequences for meaning-making of the experience of psychosis. I argue that discourse *both* constrains how experience can be spoken about and also shapes the experience by contextualising the experience in a particular way. There are implications for subjectivity in both instances. This is why a binocular approach (Willig, 2017) has been essential in this research study, in order to gain a more complete understanding of the phenomena within the sociocultural context. I hope it will be evident that the findings from a dual focussed methodology, paying equal attention to both language and lived experience, show how these inform and dynamically interact with each other. This combined focus is pertinent in recommendations for practice within the field of mental health, where language and communication are central to the provision of intervention and support. This is apparent in the wide range of talking therapies available from Psychodynamic, Person-centred, Existentialist, Cognitive Analytic Therapy (CAT), the ever-popular Mindfulness Based Cognitive Therapy (MBCT) and Mentalisation Based Therapy

(MBT), to the Cognitive Behavioural Therapy (CBT) often associated with the government funded initiative to Improve Access to Psychological Therapy (IAPT) as proposed by economist Lord Layard (2008).

It seemed appropriate to focus on the IPA superordinate themes/subthemes and explore how constructions of psychosis affected the meaning-making of the lived experience: how meaning might be reinforced, altered, or dismissed through the available discourses that are deployed by an individual and how that, in turn, can affect the lived experience. That is to say, the sense-making individual accesses language to retrospectively make meaning of the pre-reflective experience. Hence the importance of considering the available discourses that are deployed in the pursuit of meaning.

I am aware that the discourse of phenomenology and the discourse of discourse, in other words the language of analysis, in each case is quite different, as are the theoretical assumptions underpinning them (discussed in the methodology chapter). However, I will attempt to deliver my findings in a way that respects both, as it is evident from my clinical work and confirmed in this study that both provide vital information when making meaning of anything. Furthermore, these processes are not mutually exclusive but inform and interact with each other.

A hypothetical example to consider would be a research study on the lived experience of intimacy in a homosexual relationship in the UK. The findings would be completely different in the middle of the last century, when homosexuality was pathologised and criminalised, as compared to now, where neither is the case and same sex marriage is legal. The meaning-making of the lived experience would be informed by both the subjective embodied experience *and* the available discourses pertaining to homosexuality. Discourses available at each respective time would not only shape the experience but also constrain how it can be spoken about and therefore understood. As Eatough and Smith argued, when summing up their IPA research on meaning-making and anger, ‘personal meaning-making is an irreducible part of psychological life. The meaning-making person cannot be reduced to the internal cognitive activity of hypothesised causal relationships, even if we can demonstrate that this is what people do at least some of the time. Likewise, meaning-making is always more than the prevailing discourses and conventions of a culture, although these form an inevitable part of it’ (2006, p. 132).

Although I have not analysed the direct interactions between clients and mental health professionals involved in their care – a direction for outstanding research highlighted by Georgaca (2014) – I have included the impact of psychiatric professional opinion via clients’ experience at the interface of accessing mental health services. All four participants recounted conversations they had with health professionals and commented on this experience. The outcomes have confirmed that scrutinising, problematising and deconstructing psychiatric discourse to allow space for alternative perspectives can be transformative and empowering for meaning-making.

Despite IPA and FDA research into subjective experience being conducted separately in previous research, it would seem that there is much to be gained by a dual focussed approach that considers both the impact of embodied lived experience and discourse on meaning-making. Furthermore, as Eatough and Smith acknowledge, ‘IPA shares some common ground with Foucauldian discourse analysis, which examines how people’s worlds are discursively constructed and how these are implicated in the experiences of the individual’

(2006, p. 118-119). However, lived experience is the central focus in an IPA study and in order to explore the subjective experience of psychosis I wanted to include both language and experience equally, hence my utilising IPA and FDA on the same data. A dual-focussed methodology integrating IPA and FDA has been a rarity in qualitative research with just a few notable examples whereby the intention to inform the research from a dual perspective is explicitly acknowledged e.g. Colahan 2014, Cosgrove 2000, Willig 2011, Johnson et al., 2004, Black & Riley, 2018. Although some (Eatough & Smith, 2006) claim that this dual focus has been undertaken in research, as noted by Colahan (2014), it is not explicitly stated. Langridge (2004) and Del Busso & Reavey (2013) could be considered examples of such research, encapsulating a diversity of interests including lived experience and the constitutive role of language, emanating from a pluralist tradition.

Smith (1996) has spoken of a connection between these approaches and how they are not only compatible but complementary in terms of achieving a richer understanding of the experience being investigated. Despite the conflict in the philosophical underpinnings with ontology and epistemology, both IPA and FDA focus on language. Although some (Johnson et al., 2004) have negotiated the theoretical conflict by adopting a pragmatic position, I have adopted a critical realist position, with a realist ontology and relativist epistemology. This is discussed in detail in the methodology chapter.

I felt it was necessary to conduct both analyses equally and simultaneously to gain knowledge of both, including the dynamic interaction between them. I hope that my attempt to integrate both analyses will demonstrate the beneficial nature of this approach and the richer knowledge that can be gained as a consequence.

So, what did I find?

There was considerable compatibility between my findings and those of previous research, which found that making sense of the experience of psychosis was an active process of fundamental importance to individuals' wellbeing (Geekie & Read, 2009, Larsen, 2004). Indeed, my findings indicated that the meaning-making process itself was integral to the acquisition of a sense of stability and security in relationship to self, other, and the world. Furthermore, the subjective experience of psychosis was described as affecting one's whole being in the world (Walton, 1999). This featured strongly in the subjective experience of the participants in my study, who spoke of the loss of the 'taken for granted' aspect of experience. The experience of psychosis was described as immersive, revealing brief moments of connecting with the common reality. However, whilst immersed, the meaning-making was focussed on the reality they were immersed within. The process of meaning-making when connected with the shared reality was made within the social context the individual found themselves. For example, at the interface with mental health services, mental health professionals, family, friends or indeed any interactive process with the material and social world in general.

Participants used metaphors and analogies when relaying their experiences, which echoed findings in previous personal accounts of the subjective experience of psychosis, and ill health in general, e.g., for the former, feeling 'written off' (Geekie & Read, 2009) and the latter, the sense of being on a 'journey' (Frank, 1995). It would seem from this research that a broader contextual meaning of the experience of psychosis is made retrospectively, once a connection with the common reality is somewhat restored. My findings suggest that it is at this point the available discourses become utilised to make sense of the experience. For example, Maria recounted her sense of being in an action-packed movie whilst experiencing psychosis, which provided a sense of excitement and feeling special. This contrasted with her subsequent existential concerns about her identity and feeling lost in the world. Once reconnected with the shared reality, the process of meaning-making of the experience of psychosis involved drawing on the available discourses present within her sociocultural context. These included a psychosocial discourse, when speaking about her family and identity, and a humanistic discourse pertaining to existential concerns about her place in the world and the acquisition of a meaningful life. She rejected the biomedical discourse and resisted any positionings of herself as a ‘mental health patient’, feeling that this contributed to a loss of selfhood, which was already part of the disorientating experience during psychosis. For Maria, the process of recovery involved reclaiming her sense of self, identity and personhood.

The following tables contain a summary of the main themes and constructions resulting from the IPA and FDA discussed in this chapter.

Summary Tables of IPA Master Themes and FDA Main Constructions of Psychosis

Master Themes and Subthemes of the Subjective Experience of Psychosis	
Managing the experience: *Fighting for personal meaning and the self, coping with the system, 'work to do'.*	Experiential issues around trust: *Lack of trust in others/self, distrusted by others.* *Trust in self, trust others with a knowledge of oneself and psychosis.*
Experiencing oneself as the agent: *Agency in personal meaning, collaboration, ownership of narrative, own knowledge and experience.* *Lack of agency others decide.*	Loss & powerlessness in relation to others and the experience: *Powerlessness when experiencing psychosis.* *Loss of personhood, selfhood, the 'taken for granted' reality, future, sensory perception and loss of function.* *Powerlessness when accessing mental health services.*

Table 1: Master themes and Subthemes

Discursive Constructions of Psychosis and the Corresponding Meanings	
Constructed as trauma: *Response to adverse life events / traumatic events.*	Constructed as abnormal, mad, other: *Fundamental difference in human nature, disordered, damaged, flawed.*
Constructed as an illness like any other: *A medical problem that can be diagnosed and treated with medication.*	Constructed as dangerous: *Risky, scary, unpredictable and a risk to self and other.*
Constructed as an understandable part of the spectrum of human experience: *Part of human nature and embodied subjective experience.*	

Table 2: Discursive Constructions of Psychosis

Looking at table 2 suggests that the ‘lens’ created by the constructions from which to understand the experience of psychosis created a variety of different meanings, which in turn impact and shape experience, including how it can be spoken about.

I found five dominant discursive constructions regarding psychosis in the interviews with the participants, which is also a reflection of the discourses available in the current sociocultural context in westernised society. The available constructions, it could be argued, are organised on a spectrum from a medicalised biogenetic understanding of psychosis to one that accepts that human nature includes a variety of experiences including psychosis as an understandable response to adversity, and not an indicator of disease.

Larsen (2004), in his research on meaning-making in first episode psychosis, found that how participants relate to their experience depends on the context and question. Again, it is worth reiterating that the questions in the semi-structured interview were created to elicit answers regarding the language used and embodied experience. Therefore, responses to both types of question are contained in the summary tables.

In making meaning of any experience, we are searching for answers to questions, hence the production of an interview schedule (appendix 4) for the semi-structured interview. It was evident that the participants had drawn information from both discourse and embodied experience in their responses to my questions. What occurred to me in thinking about how to blend the analyses was a consideration of the questions the participants may have entertained thus far, as ‘sense-making agents’ about their experience of psychosis in the pursuit of meaning. Smith (2019) in his paper, ‘Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis’, suggests a typology for levels of meaning associated with certain questions. The five levels of meaning spanned from the first and more basic – the *literal*, concerned with linguistic definitions – to more complex concerns in the fifth category, the *existential,* concerning the meaning of life. The second level of meaning, the *pragmatic*, considered what something means as a whole in addition to reflections about who said what and why. The third level, referred to as the *experiential* and regarded as the 'centre of gravity' for an IPA study, focusses on the significance of a major event happening and what it means to the individual. The fourth level, also *existential*, pertains to implications for identity.

When considering the examples of convergence for discourse and experience in this study, it became apparent that the levels of meaning were not only related to certain questions regarding experiencing psychosis and how to understand that experience, but also broader questions related to life in general, existential concerns and consequences for living. These core concerns are also reflected in the body of literature on madness, by academics, mental health professionals and those with lived experience. It therefore seemed appropriate to use the questions participants may have considered as part of their meaning-making as the organising principle in the discussion of the dynamic interaction between language and experience utilising data from both the FDA and IPA.

The questions I identified as central to this study were orientated on *being* and what it is to be a human being having the specific experience of psychosis – this is the *experiential* focus as identified by Smith in his typology of meaning and regarded as of central importance in an IPA study. Additionally, questions focussing on existential concerns regarding identity, meaning and purpose of life were included in relation to the experience of psychosis, as well as the linguistic and relational considerations. Furthermore, as this is a dual focussed study, all questions contained a focus on discourses and experience constructed in a particular way which shapes experience, in addition to how it can be spoken about and understood. What follows is not necessarily an exhaustive range of questions. Rather, these questions seemed to capture what was of central importance to the participants in this study and occurred to me in somewhat of an ‘aha’ moment, when reflecting on the results from both the IPA and FDA, which I hastily jotted down (appendix 8).

Intersection of Language and Experience

How dangerous am I?

The discourse of dangerousness and risk has long been associated with madness and mental health institutions, and is also reflected in the participants’ accounts. What was of interest was the difference in opinion offered depending on the orientation of the question. For example, when asked about her subjective, embodied experience of psychosis and her preferences for care, Doreen’s own evaluation of the risk she posed to self and others was negligible when she was accessing a humanistic psychosocial discourse:

> I would have liked to have been in the 136 suite instead of the police station, ‘cause that was traumatising in itself, .hh I still don’t know why, I don’t, I don’t think I was violent? I was probably not very moveable because I wasn’t walking but I didn’t, I wasn’t actually violent (31/34,35 – 32/1-4)

However, when asked a question aimed at the experience of accessing mental health services and the language used, Doreen responded from within a biomedical discourse, where she offered a contrasting opinion that she might be dangerous:

> It’s been life-saving (2) really. Probably literally because you know I have been quite dangerous when I’ve been unwell. Erm because I don’t know what I’m doing. .hh umm and I could harm myself (2) (33/14-17)

This also seemed to be informed from the discourse of dangerousness she was aware of in the media:

> R: I think there would be <u>fear</u> attached to it because of how badly the idea of Schizophrenia is described in the press .hh so umm
>
> I: Could you say a little bit about? what you mean, what
>
> / / you’re referring to?
>
> R: / because you’re associated with violence, you’re seen as dangerous.
>
> I: Okay
>
> R: .hh (1) umm dangerous and people are wary of you and I think that, that is a very difficult thing to… live with .umm it’s got implications if you have children, it’s got implications if you want to work, it’s got implications in all sorts of ways and aa I’m quite out about my mental health issues most of the time, having said that, I think yesterday that I wasn’t. (21/28-35 & 22/1-6)

This passage conveyed her fear of being perceived as dangerous by others were she to have received a diagnosis of ‘schizophrenia’. But it was also evident that she had reservations about how open she wanted to or could be about her ‘mental health issues’, depending on the context of her situation. She went on to explain her thoughts about how others might perceive her and how that perception might be affected by the understandings or meanings attached to different labels and the relationship with danger:

> It’s that extra work against the fact, I don’t know if other people do, but you’re (1) the first thing that people probably think is Schizophrenia is dangerous (3) whereas with psychosis, you probably go umm psychosis, mad. ((2) 22/34,35 &23/1,2)

Doreen was aware of the constructions others were utilising in their perception of her, thereby creating *work to do* in managing her own sense of self and understanding of her experience. This concern was shared amongst all the participants who did not consider themselves dangerous or risky when relaying their embodied experience of psychosis. However, their meaning-making and positioning with respect to danger and risk seemed to fluctuate in relation to the discourses mobilised, emphasising the interaction of discourse and experience, which not only changes what is said but also the experience itself.

The participants had been informed that the research interview was conducted by a psychologist, which inevitably affected their responses, influenced by their previous experiences with psychologists and their assumptions about ‘them’. Meeting at an independent psychology practice was also noted by the participants. It was evident that fluctuations in their positionings in relation to me occurred throughout the interviews, from presenting themselves as expert, deferring to me as expert, wanting to please or help me, identifying with me, disagreeing or reaching an agreement with me. It was also evident that participants were drawing on a variety of discourses in response to my questions.

It would seem from the findings in this study that the embodied experience of psychosis, as explored in the IPA, is not in itself as dangerous or as risk laden as its reputation amongst mental health professionals, institutions and the public at large would suggest, as evidenced in the FDA. The conflict in opinions informed from embodiment (IPA) and discourse (FDA) thereby creates complications for meaning-making and subjectivity.

Is psychosis a consequence of trauma?

Trauma, and specifically childhood trauma, are increasingly recognised as contributory factors in the experience of psychosis, as is evident from examining the personal histories of individuals experiencing psychosis (Read et al., 2005; Bentall, 2012). The centrality of a meaning-making process for human beings is also evident in first-person accounts of psychosis, both during psychosis and in recovery from psychosis. Jacqui Dillon, Chair of the Hearing Voices Network UK, relayed her meaning-making of her experience of psychosis:

> 'There is inherent meaning in madness, which is inextricably bound up in unresolved, traumatic experiences. These meanings may be communicated in a number of highly symbolic, metaphorical and literal ways and need to be untangled, teased out and examined within the context of the person's life history' (Dillon, 2012, p. 21).

It can be seen in Dillon's reflection of her experience, that meaning-making was a continuous process, from psychosis to recovery. The reference to 'unresolved, traumatic experiences' as being causal was echoed in Jacky's account of bullying by peers and her family:

> that's what happened… it was bullying by my peers and also bullying within my family. (5/9-11)

> a lot of my experiences came from my upbringing and a very, very repressive home environment. (34/9,10)

For Jacky, this understanding was welcomed in terms of making sense of her experience and created a sense that the position of 'mental patient' was temporary. However, for Doreen, the potential for a traumatic history to be at the core of her experience was one that created fear and instability in her sense of self and capacity to make meaning of her experience:

> R: Yeah, yes, so it made, I think it made, erm (2) re-diagnose me with PTSD, I think it would have been, I was going to say catastrophic, because I think I would have confirmed some of my paranoid psychotic ramblings and beliefs in my head as, as real, whereas I don't think they were. So, I was emm talking about (2) err or I was verging on, I was wondering what traumas I had experienced through these psychoses .hh and the more I have pondered on that the less I've believed that I've experienced really serious trauma. I have experienced some serious traumas, .hh but I didn't experience serious trauma in my childhood, and I think that they could've made me, that, having that diagnosis could've made me linger on those, that pondering about that. (17/22-34 & 18/1-15)

Doreen, although rejecting the construction of psychosis as trauma related, accessed a range of alternative constructions emanating from humanistic discourses to make sense of her experience. These included her embodied physiological experience of being 'dehydrated' and behaviour in 'overdoing it'. Biomedical discourses were also evident, with references to changes in her 'chemicals', 'stopping her medication' and her interpretation of her own thoughts as 'paranoid psychotic ramblings'. Contradictions were evident in her struggle to make sense of her experience as she accessed a variety of available discourses at different time frames in her experience:

> I was hallucinating and that I couldn’t be sure of anything that I’d experienced, in the psychosis cause I was so off the planet (5/24-26)

The otherworldliness of psychosis, was transformed to ‘boundary’ changes, as she moved from a construction of psychosis as ‘abnormal, mad, other’, to ‘part of the spectrum of human experience’, which resulted in an agentive position of being able to make sense of her experience in a way that was understandable for her:

> reality I was in, was a very coherent reality .hh umm and the stories that I had around it were very coherent. I umm (2) I think it (3) it, eh it draws back the boundaries that we normally have round our (1) our material world (5/35 & 6/1-3)

Again, the interaction of discourse and experience is apparent as the struggle for meaning ensues. For some, the construction of psychosis as a consequence of trauma is embraced and facilitates meaning-making. However, for others it creates inner conflict and a hurdle to overcome in order to make meaning of the experience.

Who am I? Experiential consequences of loss

The previous two questions have been focussed on the ‘what is it?’ and have been more concerned with available discourses from which to understand the experience of psychosis.

However, questions with regard to identity following an experience of psychosis seemed to be related to the experience of change and loss. The master theme of *Loss: loss and powerlessness in relation to others and the experience* was the most prevalent and contained the most subthemes. The human experience of 'being in the world' was described as being completely transformed during psychosis, where the 'taken for granted' aspect of human experience was fundamentally altered. Participants described a range of corporeal, spatial, temporal, self and social disturbances, where every facet of their experience had changed. This was congruent with Blankenburg and Mishara's (2001) phenomenological conceptualisation that individuals diagnosed with 'schizophrenia' experienced a 'loss of natural self-evidence', which refers to a loss of the usual common-sense orientation to the world. The reference to common sense equates with the 'taken for granted' categories denoted in the master theme *Loss,* including the reference to corporeal disturbances:

> I thought I was turning into plastic. (Maria 4/25)

> I was looking in the mirror and I could literally see my face change from what I tho:ught it was to how it actually is. (Doreen 28/30-32)

The lack of 'mine-ness', which is associated with embodied self-awareness, is illustrated in the above quotes. The temporal and spatial disruption was evident in the subtheme *loss of the taken for granted reality*:

> I was having trouble distinguishing between my dreams and my waking life… they were as real or unreal as each other (Jacky 3/18 &4/1-2)

> first psychotic breakdown – terrifying – didn’t know what was up – what was down (4/23-25)

The disturbance in a sense of self was also articulated by the participants:

> I was lost even though I knew where I was (Jo 5/2-3)

> They could see what was happening in my head, what I was thinking. (Jacky 6/3-4)

The loss of a sense of self and the demarcation between self and other, illustrates the disturbance in ipseity, totally transforming subjectivity. Sass and Parnas (2003) conceptualised that ‘schizophrenia’ is characterised by a heightened self-consciousness and diminished self-affection. This reference is not to psychiatric ‘signs and symptoms’, which are associated with possible biological causes, but ‘the embodied consciousness of a person embedded in the realm of meaning’ (Parnas, Sass & Zahavi, 2013).

In addition to a loss of a sense of self, which was in the main attributed to the subjective, embodied experience of psychosis, participants also expressed a loss of personhood. However, this was mainly in relation to the experience of accessing mental health services and feeling perceived as ‘other’, which entailed consequences in other relational spheres, e.g., family, friends, including within the self:

> there’s this element of not being seen (Doreen 9/19)

> then you start to make decisions about who you are as a person. (Doreen 9/15,16)

> once you’re put in this role of patient… people like her don’t ever see you. (Maria 21/27-32)

An overwhelming sense of powerlessness was experienced by all the participants, both when accessing mental health services and when experiencing psychosis. The struggle for meaning ensued, amidst the confusion caused by subjective, embodied disturbances in perception and awareness of the perception and opinion of others expressed in the discourses, which both entail consequences for subjectivity:

> he knew he was in a position of power… he knew what was wrong with me… he knew how to treat me. (Jacky 31/13-15)

Here, the sense of power is linked to ‘knowledge, competence and qualification’, ‘which categorises the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognise, and which others have to recognise in him. It is a form of power which makes individuals subjects’ (Foucault, 1982, p. 781). This power is exerted via discourses and the extra discursive materiality of institutions with their inherent practices. It is important to acknowledge at this point that although Foucault emphasised the potential for transformation when power is exercised over another, he conceived the ‘other’ to be in a dynamic relationship to power, where a variety of responses were possible on a spectrum from acceptance to resistance. This is evident in the participant accounts. Although they speak in similar terms about their experience of mental health services, all demonstrate a variety of responses, from acceptance of the biomedical discourse (Jo), to resistance (Jacky) and sceptical in between positions for Maria and Doreen, who deploy alternative discourses to make sense of their experience whilst retaining elements of a biomedical discourse.

Given the overwhelmingly powerful and debilitating nature of the psychosis phenomena described unanimously by the participants – e.g., “I was shifting into a negative world view – paranoia and the delusions – they kind of took over” (Jo 5/32-34); “nothing would have stopped it [the psychosis]” (Jacky 30/14,15) – some gravitation towards a medical understanding seemed inevitable in the current socio-political climate, which privileges scientific knowledge and medicine, reflected in the discursive field. The powerlessness they spoke of related to the phenomena of psychosis, the experience of accessing mental health services, and consequences arising from constructions of psychosis implying chronicity, biogenetic causation, and the requirement for medication as first line treatment with psychosocial therapies as complementary.

The positioning resulting from acceptance of a biomedical discourse was for Jo a voluntary position, accepting the experts know best with adherence to a medication regime essential for alleviation and management of symptoms. Supported living, with occasional part-time voluntary work and attendance at mental health centres, was accepted as the only lifestyle option, given his experience of disabling and debilitating phenomena believed by him to be evidence of his ‘schizophrenia’, as conceptualised within a biomedical psychiatric discourse. Becoming part of the experts by experience group gave Jo a sense of agency and power within the discursive field he had accepted. Part of this positioning involved ‘toughening up’, evident in his expression ‘you can’t sugar coat it’ when asked about language used within mental health services to speak about psychosis. He referred to himself as being an ‘old timer’, who was now used to the concepts and language used, although he could see how this could be ‘tough’ for newcomers. Jo may have been part of a peer support group, but it seemed he was now very much part of the medical system. As Howell and Voronka argue, groups aimed at recovery within the medical system encourage members to be, ‘responsible for their own adherence to prescribed ways of governing their interior lives, while at the same time leaving medical authority intact’ (2012, p. 2). Jo accepted his position as a mental health patient and perceived the mental health staff as both professional medical experts trying their best, and human beings who could be fallible. Although he included himself by adding ‘we are all human beings’, the overriding sense of his statement, and the interview as a whole, was that he was somehow othered by his mental health status and experience.

Jacky, by contrast, rejected the biomedical discourse, having experienced powerlessness when accessing mental health services. For her, a meaningful future involved the deployment of alternative discourses. The humanistic psychosocial discourse, which constructed psychosis as a relational and systemic consequence of life, was deployed positioning her as a human being with agency and resources to recover her life. A visit to the acute locked ward in the psychiatric hospital, with padded cells and physical restraints in the form of straight-jackets, created a resistance to the biomedical discourse and motivation to reject her position as a mental patient and reclaim her identity and personhood. Jacky had glimpsed a potential future within the medical system, which she rejected for herself. This created some psychological conflicts, as the reassurance she initially experienced at being given a medical explanation was relinquished as she began the challenge of confronting the family issues and bullying, which had originally resulted in feelings of powerlessness in relation to others. The reclamation of power within her family and within the services was aided by support from her family and GP, which she perceived as fundamental in reclaiming her future outside the confines of mental health institutions and practices.

As can be seen so far, there are a variety of potential positionings depending on the interaction and responses by the participants to the available discourses. These positionings have far-reaching implications for subjectivity, as explained by Willig: ‘positionings constitute ways of being through placing the subject within a network of meanings and social relations which facilitate as well as constrain what can be thought, said and done by someone so positioned’ (2000, p. 557).

For both Doreen and Maria, ambivalence was evident in their relationship to the available discourses, with a preference for alternatives to the biomedical discourse but a sense that a failure to resume health could be indicative of an underlying biogenetic predisposition. Resistance and hesitant resignation were being grappled with as they considered their current positions by saying: ‘ok for now’, their preferred position of ‘permanently well’, and the ‘write off’ position of ‘chronically unwell’. Their sense of powerlessness increased as they moved towards the ‘chronically unwell’ position informed by biomedical discourses that locate the problem within the individual, who is positioned as a mental patient requiring medical treatment from the professional experts.

Other research into health and illness has considered the impact of meaning on the experience of illness, and concluded that the type of meaning made has a significant effect on the experience itself. For example, IPA research exploring the personal experience of chronic benign lower back pain by Osborn and Smith (1998) concluded that, ‘participants would be helped by gaining access to an explanation that allowed them to establish a basis for taking therapeutic action, to retain a sense of control over their pain and to gain a sense of legitimacy in relation to their suffering and disability’ (p.75). The emphasis on the importance of developing a meaning that enables an agentive position, whereby the individual can ‘take therapeutic action’ to self-manage, is seen as a key factor in managing the pain experienced, thereby directly transforming the experience of pain itself. Although the Osborn and Smith (1998) research did not incorporate an analysis of the available discourses for the health concern they were examining, e.g., as Willig (2011) has done, it can be appreciated that the meaning an individual can make in such circumstances is fundamentally influenced by the available discourses and positionings.

The *‘constructed as, an illness like any other’* component was evident in all participant accounts and was understood to mean a severe and enduring biogenetic medical problem which requires diagnosis and treatment by medical professionals. Potentially, the position on offer here is that of a recipient of care as a patient, where the professional experts know best and take control of the situation. Adherence to medication regimes and acceptance of the imposition of the expert understanding can be part of the trajectory of experience. Resistance to the ‘patient’ position can lead to negative consequences, such as being identified as ‘non-compliant’, ‘lacking insight’ into their condition and being identified as a ‘difficult patient’ due to ‘nonadherence’ to medication. By contrast, acceptance of the position of patient, (or ‘passenger’ in the driving analogy mentioned by Maria) can lead to a reduction in social and psychological expectations, less personal responsibility or blame for health concerns, and an absence of interpersonal conflict with the medical professionals who are positioned in the ‘driving seat’. However, living a more restricted life, with less choice, control and a sense of agency, can be a consequence, with regard to relationships, employment and independent living. This does not necessarily make life less or more meaningful though, as what constitutes a meaningful life is a personal matter for the individual to consider.

As has been observed, positionings can be ‘ephemeral’ (Harre et al., 2009, p. 10) and liable to change as individuals seek meaning and answers to the existential questions they may have about themselves, their lives and the world. Disturbances in a sense of self and identity are affected by positionings as individuals move from a subject/object split, e.g. ‘*I am experiencing psychosis…*’, to an existential identification with the experience, e.g. ‘*I am schizophrenic*’, starting their ‘careers as mental health patients’ when they are diagnosed (Georgaca, 2014) and ‘cast into a discursive field’ (Willig, 2017) within which to try and understand their experience and new identity.

The construction of ‘*psychosis as part of an understandable aspect of human experience*’ was less evident in the *loss and powerlessness* theme, and appeared to be associated with agentive positions, a sense of self and trust in others. However, Simblett (2013) warned against the tempting notion that humanistic discourse can provide an antidote to a biomedical construction of abnormality. In drawing from Foucault’s work, he concluded that rather than regarding discourses as simply ‘good’ or ‘bad’, the level of uncertainty present within a discourse influences the available positions that can be accepted or resisted. It thereby becomes understandable how the findings from this research imply that the certainty associated with a biomedical discourse can serve to constrain the parameters of what can be felt, thought, said and done, by contrast to a humanistic discourse which, it could be argued, allows a wider range of perspectives to be considered in developing an understanding.

Meaning in madness or meaningless ‘psychotic ramblings’?

When examining and reflecting on the participants’ accounts, it can be seen that the process of meaning-making involves an element of individual choice and ownership. For Jacky, her experience of psychosis was directly related to the power differential she experienced in her relationships, both within her family and her peers at school who bullied her. The voice experience and sense of threat experienced during psychosis seemed to mirror her prior experience in the common reality. Making meaningful connections related to the traumatic nature of her relationships and drawing on discourses related to trauma and threat, facilitated a meaning that seemed to reconnect her to her sense of self and the shared reality with hope of a meaningful future.

By contrast, Doreen seemed to find reassurance in the notion of her utterances during her experience of psychosis being ‘psychotic ramblings’. Although she had made fleeting references to trauma during her account, her preferred position was to dismiss or discount what she had been talking about during her episode of psychosis, thereby avoiding any exploration of any emotionally painful traumatic experiences. She rejected the construction of psychosis as a consequence of trauma, preferring the deployment of a biomedical discourse to understand her verbal communication during psychosis, thereby minimising any salience.

Within his examination of madness in individuals diagnosed with ‘schizophrenia’, psychiatrist R. D. Laing (1960) observed the dissolution of boundaries between self and other, consequent of the disintegration of the *real self* with the associated breakdown in the ability to experience the self or society as real. He was keen to stress that the utterances made by individuals experiencing psychosis were intelligible and had meaning pertaining to their experiences, which needed understanding. He also criticised the psychiatric classification of such patients as a denigration of their experience, which was dehumanising and therefore unhelpful. By contrast, while discussing the clinical depression he had experienced in his fifties during a BBC radio interview with psychiatrist Anthony Clare (1985), Laing expressed his opinion that depression was potentially genetic and intergenerational. He did not perceive any meaning in his episodes of depression and declared he would take medication to alleviate depressive symptoms: “it’s not so much things that depress me, but a completely senseless – and that’s one of the depressing things about it – a completely senseless and inexplicable and opaque and infinitely boring state of sort of down-ness.” What is surprising here is the lack of meaning he attributed to his emotional state, given his interest in finding meaning in madness that was intelligible and relatable to personal experience. This seems to highlight the element of personal choice and ownership involved in meaning-making, whereby different positions as a consequence of meaning-making can be desired or unwanted, thereby impacting the choice of meaning. Whether consciously or unconsciously, for Laing, adopting a position whereby his depressive symptoms were related to his genes and biology negated the attribution of significance to past difficulties in childhood or relationships in general, thereby averting the need to revisit painful experiences. Doreen’s account resonated with this position: she expressed relief that a diagnosis of PTSD was retracted, thereby removing the need to explore past difficulties that she preferred to identify as ‘psychotic ramblings’.

Frank (1995) describes how contextualising the experience of illness can lead to a reframing which can provide ‘sense to an otherwise senseless experience’, leading to the development of a more positive identity as distinct and separate from the illness experience. However, as can be seen from the participant meaning-making and indeed Laing’s, this is not always the desired outcome. The positions afforded by different meanings are in themselves a point for consideration, which can lead to a revision of the meaning.

Who can I trust? Power and threat?

Experiential issues of trust were evident in all aspects of the participants' experiences.
The issue of trust seemed to be at the heart of relational concerns both in terms of relationships with others and within oneself. Feeling able to trust others created a sense of connection and security in the relationships. Conversely, a sense of mistrust of others and feeling distrusted by others resulted in feelings of disconnection, isolation and feeling othered, compounding the embodied experience of psychosis. At the interface of mental health services, trust was cited as of central importance in terms of the capacity to accept the support being offered including the diagnosis and recommended treatment plan. Adherence to medication being offered was also determined by the level of trust the participants experienced in their relationship with the treating mental health professionals, as discussed by McCabe and Priebe in their paper on the importance of the therapeutic alliance in attaining good outcomes with patients in psychiatry (2004).

Issues of trust within the embodied self were also experienced with regard to the disorientating phenomena, which resulted in confusion and uncertainty about reality – what was real or unreal and how to distinguish between them. The chaos and unpredictability in their reality and perceptual experiences created a sense of disconnection, anxiety and fear, as the previously trusted and relied upon embodied sensory and perceptual experience appeared to be lost. However, what was also notable was that the participants disclosed moments of connection with the common reality, even during the acute phase of psychosis, with an awareness of some type of choice to reconnect or disconnect. For example, in Doreen's account, "I was well enough to know I was very unwell" (13/21,22). This is consistent with other historical accounts (Bentall, 2004) where psychiatric patients experiencing psychosis are reported to have become well enough to adopt roles as nurses when a typhoid epidemic broke out in the area of psychiatrist Eugen Bleuler's (1857-1939) hospital in the early 1900s. This capacity to connect with the common reality is harnessed in Soteria houses for individuals experiencing psychosis, where individuals are expected to take an active role in the running of the homes, including shopping, cooking and taking part in recreational activities. Bleuler's observation that 'the condition could retreat given a crisis', it would seem, could be extrapolated further by offering individuals invitations to engage in other pursuits.

For individuals who have experienced severe and enduring mental health problems, issues related to historical power differentials in life experiences have been put forward as being significant in the causation of severe emotional distress by the British Psychological Society's Division of Clinical Psychology in the *Power Threat Meaning Framework* (Johnstone & Boyle, 2018). Their model involves an intervention that focusses on power and the threat imposed by power on the individual, present in all forms of abuse. They promote helping clients to understand the threat response in the context of their experience and developing a narrative that includes the context. This model was cited by Jacky as helpful in making sense of her experience of being bullied at school and within her family.

How can I live? ‘Experiencing oneself as the agent’

This IPA theme could be considered to overlap with a subject position in FDA, thus creating a link between the two analyses. The agentive position was very much evident in descriptions of relationships where there was a sense of equality and being seen as a sense-making person with a valid opinion. My impression during the research interviews was that these individuals found the experience of their opinion being sought somehow therapeutic. The opportunity for their point of view to be heard, without their opinion being challenged or their version of events doubted, in addition to contributing to a body of knowledge about psychosis that has been exclusively dominated by the ‘psy’ professionals until the last few decades, seemed empowering for them. However, their awareness that they were being interviewed by a researcher working as a practising psychologist in this area was an inescapable fact of the situation, and I found myself wondering how their answers, even to the same semi-structured interview, might have been different had I been either a peer or a psychiatrist. That said, the participants knew from the beginning that the research was about meaning-making of the experience of psychosis and I was interested in *their* meaning-making.

The superordinate theme *agency in personal meaning* was applicable for all participants, who stated in an emphatic way that they had arrived at their *own* meaning, resulting in beneficial consequences for life after psychosis:

> in that making sense of it, I’m enabled to live my ordinary life. (Doreen 31/26-29)

For Doreen, a reconnection with the ordinary from the extraordinary seemed to have been made possible through the process of meaning-making. The construction of psychosis as part of human nature provided a defence against the idea that she was fundamentally different from other people, facilitating a return to her ordinary life.

For Jo, the converse seemed to be the case, where being positioned as fundamentally different biologically provided a potential defence against his fear of accusations that drug abuse had been a causal factor in him experiencing psychosis. It could be argued that, within the neoliberal culture of our time, he did not anticipate a compassionate response and wanted to defend against the feared attack, whether experienced externally from others or within himself. In this instance the biomedical discourse was mobilised to create a sense of agency in personal meaning. Furthermore, acceptance of the position of 'mental patient with medical insight' seemed to create an elevation in status of someone who understood their condition, such that adherence to medication would not pose a conflict, thus maintaining an agentive position and a positive self-concept. It is interesting to note that for Jo, the superordinate theme *lack of agency others decide* was less apparent, apart from the results of his brain MRI scan being withheld and questions about it being avoided by his psychiatrist and the mental health team.

Maria had not settled on a definitive understanding for her experience of psychosis, however she had rejected a medical explanation and was critical of being perceived as a passive recipient of psychiatric treatment and of being positioned as a mental patient. A sense that she had ownership of her meaning – "I have my reasons to why things have happened to me" (19/7,8) – seemed to create a sense of stability in her sense of self and feelings of agency.

For Jacky, a psychosocial discourse afforded an explanation that she could both incorporate and move on from, positioned as an active agent in her recovery from a severe but transient psychotic experience:

> That's what happened it was bullying by my peers and also bullying within my family (5/9-11)

Choice of language and meaning was also articulated by the participants as contributing to feelings of agency and identity, with unanimous agreement that identification with the difficulty was detrimental to a sense of personhood, and to be avoided in preference for being recognised primarily as a person. As Doreen explicitly stated:

> You're still a person having an experience (9/11,12)

Being regarded as a person was an important part of 'experiencing oneself as the agent' and collaboration with others was also experienced as validating, aiding the process of recovery from psychosis to a meaningful life. This was also the case for Jo who, although accepting the biomedical discourse and the position of patient, still wanted to be kept informed of the professional opinions held about him, something that he felt had been absent in response to information about his MRI brain scan:

> I feel it is very important for the patient to be included and to be kept up to speed with what the clinicians and the health professionals are thinking (25/22-26)

Being included and involved altered the passive mental patient position of ‘being done to’ by the professional experts to one where he could feel the expertise was shared with him, creating an ‘expert mental patient’ position, thereby opening up more possibilities for what he could think, feel and express. However, this position is still one which presupposes certain meanings over others and privileges a medical meaning.

How can I manage life? Is psychosis a life-long condition requiring medication for life?

The experience referred to here is both the embodied subjective experience of psychosis and the consequences of this experience, which include the interface with the mental health system, family and friends. Managing the experience can also be perceived as a subject position, one where all aspects of the experience require a *manager* to work through a number of tasks generated by the situation.

The superordinate theme *struggle for personal meaning* revealed the difficulties encountered by the participants in making meaning of their experience, and how the available discourses are utilised in an attempt to understand what has happened and how to live their lives subsequently. There were also repercussions in terms of their sense of self, which Maria expressed as a causal factor:

> I think there is a depression underneath each time, I know it starts off with a depression (2) .umm (2) and I also think it has a lot to do with my identity and the struggle that I’ve had with that over the years (2) °so° (2) **yeah**. (7/22-26)

The various constructions were associated with a variety of subject positions and consequences for living. For Jo, psychosis constructed as a biomedical illness increased his dependence on the mental health system and the medications prescribed for his condition. In fact, it seemed that he was unaware that there were alternative approaches or other meanings available. For Doreen, a different position resulted, which involved a determination to develop her ‘story’ and an agentive position – “I won’t entertain the story that isn’t helpful to me” (30/23) – which she implied was possible due to her awareness of other discourses available to her at the psychology training centre she worked at. Similarly, Jacky, who now worked as a psychotherapist, was aware of alternative discourses, including critical theories, which underpinned her current position emphasising ‘despair’ and the fallibility of human nature and existence.

Existential crises, with respect to the self, were evident for all participants who spoke of uncertainty with regards to their sense of self: “at the time I denied it, I thought I’m still the same person” (Jo 16/11-15). For Jo, holding on to his former sense of self was eventually relinquished as he accepted his new identity as a long-term patient within the mental health system. For Doreen, a struggle for the selfhood ensued: “don’t label ME with what that label means” (30/24-29), as it did for Jacky: “I refused to give into it, and I refused to let it define me” (18/10,11). For Maria the struggle continues: “it’s like me against the world” (5/33,34).

What was clear, was that there was *work to do* for all of them, not only in coping with the experience of psychosis, but subsequently in managing meaning both for themselves and in their relationships with others, which in turn shapes the experience. It would seem that the lived experience includes the lived experience of discourses – living through the discourses – which shapes our experience: “I start to interpret it, that this is my job in the world, my occupation is to be this sick person” (Maria 22/11-15). The potentially powerful impact of the words is illustrated here by Jo: “I mean the word itself [schizophrenia], it’s quite a powerful word if you are branded with it” (11/7-10). It is evident in Jo’s statement that how the word schizophrenia is used can have lasting implications, ‘branding’, that exceed its definition. As Wittgenstein (1953) proposed, the meaning of a word is much more than its definition and how it is used, and the context reveals more about the meaning. In Jo’s example, a redefining of the person as abnormal or other is implicated.

The question of whether antipsychotic medication is essential treatment for psychosis is currently being researched by Moncrieff et al., (2019) in the Reduction and Discontinuation of Antipsychotic medication study (RADAR). For meaning based on a medicalised interpretation medication is recommended for life, however meaning drawn from other discourses, conceptualisations and research suggests that antipsychotic medication may not be required at all and that long-term use is not of benefit (Whitaker 2010, Harrow & Jobe, 2014).

Given the lack of consensus amongst researchers, professionals and the public regarding what exactly ‘schizophrenia’ is, it is understandable that the participants can be seen to be struggling with making meaning of their embodied experience and the potential clash of meanings emanating from the variety of available discourses. Nevertheless, prior to attending the research interviews, all of the participants had engaged in meaning-making, seeking answers to their own questions, resulting in a sense of agency from the ownership of meaning and a reclamation of identity. This process in itself seemed to restore a connection with the common reality, a sense of self and a meaningful life.

Summary - Interaction of discourse and lived experience – a clash of meanings?

What was notable on reflection was the intensity of the emotional experience expressed by the participants, particularly the overwhelming level of anxiety and fear, in addition to the continuous thread of existential enquiry pertaining to identity. The interplay of discourse and embodied experience created a chaotic storm within which to attempt to glean a personal meaning of the experience, thus providing and thus identify a path to a future for a meaningful life. The desire for a life, coupled with the reported immersive experience of psychosis, created tension and conflict about how to live. Access to the available discourses provided a means to decipher the experience, the positionings with rights and responsibilities for action, and ultimately to the future beyond the acute phase of psychosis.

Conclusion

‘What is distinct in post-modern times is people feeling a need for a voice they can recognise as their own… post-modern times are when the capacity for telling one’s own story is reclaimed’ (Frank, 1995, p. 7).

I came to this research study motivated by my own personal history and professional experience working as a chartered counselling psychologist in the field of mental health, one of my main areas of interest being working therapeutically with individuals experiencing psychosis. My interest in critical perspectives and alternatives over the years, e.g., Soteria Network, Hearing Voices Movement, Spiritual Crisis Network, critical psychiatry and psychology, led me to question the taken-for-granted assumptions evident in the modernist paradigm regarding the nature of severe mental human distress and the pathways to healing and feeling better. Certain insights had arisen in my work as a practitioner that confirmed earlier ideas I had experienced personally with regard to mental distress and which informed my therapeutic approach. Prioritising the person and their story, developing a good therapeutic alliance based on collaboration, and supporting the development of personal meaning, have been central to my practice. Undertaking this research study provided an opportunity to explore in detail the phenomena experienced in psychosis and the dynamic interplay of language and experience. Insights resulting from this study include implications for therapeutic practice with individuals experiencing psychosis, in addition to advancing dual focus methodology in qualitative psychological research.

This research study has been illuminating with regard to meaning-making when subject to a psychiatric discourse and the implications for embodied subjectivity and selfhood. Additionally, employing a dual focus methodology has led to the development of what are hoped to be useful guidelines for integrating two qualitative analytic methods, namely IPA and FDA. The dual focus was achieved by initially identifying emergent themes in the transcripts of the interviews via IPA and subsequently, on the same data set, identifying discourses, psychosis 'constructed as' components and subject positions with implications for selfhood, subjectivity and what can be felt, thought, said and done (Willig, 2013). The transcripts were then analysed again simultaneously with a dual focus of IPA and FDA to identify the interplay between language and experience. A summary IPA grid table (appendix 7) was produced to illustrate the shared themes between participants, but also the differences. The IPA was then written up using a single case study approach to retain the uniqueness of experience and points of divergence, whilst noticing the shared themes. The FDA was written up separately before a blended analysis of IPA and FDA illuminating the socially constructed nature of reality and interplay between language and experience, which I concluded contributed to meaning-making of the experience of psychosis and the levels of recovery described by the participants. The guidelines for conducting a dual focus methodology incorporating IPA and FDA on the same data set will be outlined in a research paper to be published in the British Psychological Society (BPS) *Qualitative Methods in Psychology Bulletin* (QMiP) in due course.

Before I continue, I want to acknowledge the great courage the participants demonstrated in revisiting an extremely distressing point in their lives, without which this research would not have been possible. It was also evident that sharing their stories and being heard was important and of value to them, especially since they all relayed times during their experience of psychosis where they had felt dismissed and disregarded by others – a focus on what had happened to them, and their perspectives on their experiences, being largely ignored in mental health services, with their preferential focus on symptomatology, diagnosis and treatment with antipsychotic medications.

What was clear in both listening to participants’ accounts and subsequently reading the transcripts was how overwhelming, disorientating and powerful the embodied experience of psychosis was, in addition to a sense of disempowerment when accessing mental health services, with potential conflicts arising in meaning regarding their experience. Fears regarding the diagnostic possibilities being considered within the dominant biomedical psychiatric discourse, withheld information and a prescriptive approach to consultations, were cited as contributory factors in increasing paranoia, decreasing trust and exacerbating already distressing embodied phenomena associated with the experience of psychosis. The main themes emerging were loss, trust, agency and a fight for a meaningful existence, in both the embodied lived experience and socially constructed nature of reality, which is consistent with the findings of previous research in the field of psychosis – a core feature of the subjective experience of psychosis being the pursuit of personal meaning in understanding the experience whilst also having a sense of being the agent in authoring the experience. The interaction with others was described as potentially supportive, or undermining personal meaning-making. Doubts in understanding, what is happening and why, in addition to anxieties about being able to have a meaningful existence all creating an overwhelming embodied experience. Overall, I can conclude there is a considerable degree of congruence in my findings and those of other researchers in the field including, most importantly, from the voices of those with lived experience.

All four participants, at the point of interview, were ‘symptom’ free from psychosis, i.e., not having any distressing experiences associated with psychosis such as paranoia, hearing voices, or distressing unusual beliefs, and reported feeling well in themselves living meaningful lives to their satisfaction. It could therefore be concluded that they were in recovery from psychosis or had indeed recovered from the acute phase of psychosis. Making meaning in whatever way possible, made available via the variety of culturally available discourses, suggests that some stability was achieved in and amongst the chaos of an overwhelming, disorientating, embodied experience. Although the evaluation of discourses as good or bad has been warned against (Simblett, 2013), it could be concluded from the findings in my research that there are implications for the level or type of recovery possible related to the discourses accepted and utilised to make-meaning, which consequently provide a vantage point from which to understand the experience of psychosis, with implications for what type of life is possible subsequently.

Broadly speaking, two types of recovery have been identified in the literature (Jordan et al., 2020). Clinical recovery is most often associated, from the perspective of mental health service providers, with remission from symptoms of psychosis and resumption of social and occupational roles. Personal recovery relates rather to lived experience and focusses on reclaiming areas of life deemed important to the individuals themselves, as evident in alternative approaches and activist traditions.

It has been argued that one discourse cannot be regarded as better or worse than another due to the agency of an individual to exercise choice in how they respond, e.g., resisting or accepting a discourse, with the consequent subject positions and implications for action, thoughts and feelings. However, this relies on the individual having full access to a variety of up-to-date information. For instance a recent paper from August 2020, in the *Journal of the American Medical Association* (JAMA) advocates the tapering of antipsychotic medication in psychiatric practice and the need for guidelines in that regard (Horowitz et al., 2020). This is a new development, which is not currently reflected in the dominant biomedical psychiatric discourse. That discourse currently includes the necessity for long term use of antipsychotic medication, as was apparent in Jo's understanding expressed in his interview: "I realised that I have to take medication now for the rest of my life if I want to stay healthy .hh umm but that doesn't have to be a bad thing" (12/18-20).

Sir Robin Murray, professor of psychiatric research, in a paper titled '[s]hould psychiatrists be more cautious about the long-term prophylactic use of antipsychotics?' (Murray et al., 2016), emphasises the need for caution in the long-term prescription of antipsychotics for psychosis. This is not as yet reflected in the dominant psychiatric discourse, nor is the recent acknowledgement (Murray et al., 2020) that de-prescribing antipsychotic medication needs to become part of best psychiatric practice in psychiatry due to progress in understanding that long-term medication is, not - always - necessary, and is in fact associated with worse long-term outcomes and damaging physiological side effects, including a reduction in brain volume (Murray et al., 2020). It could therefore be argued that the dominant biomedical psychiatric discourse creates assumptions about the necessity of antipsychotic medication for the treatment of psychosis. This is potentially harmful for individuals experiencing psychosis, in addition to the construction of the person as a long-term psychiatric patient with associated limited levels of recovery due to the dependence on medication and therefore, mental health services.

This has led me to conclude that caution should not only be exercised in the prescription of antipsychotic medication for individuals experiencing psychosis but also in the deployment of a biomedical psychiatric discourse, which contains a particular understanding of the aetiology of psychosis, prevalent in psychology, mental health, and a variety of therapy trainings aimed at helping individuals experiencing mental distress. A recent study into emotional distress and beliefs concluded, ‘our findings are in line with accumulating evidence that some biogenetic beliefs, like the chemical imbalance belief, are linked with poorer expectations for improvement, especially among those with the most troubling symptoms’ (Schroder et al., 2020 p. 544). This finding also indicates the importance of a change in both the education of mental health professionals, and the way they communicate with individuals about their experience of psychosis. A broader understanding is required to incorporate the diversity in knowledge available from psychosocial and phenomenological perspectives, and the plethora of information emanating from survivor movements and first-person accounts from individuals with lived experience of psychosis. Embracing the wide range of culturally available discourses on the subject, rather than imposing meaning from a dominant biomedical psychiatric perspective, offers choice for individuals to make personal meaning of their experience. This enables both recovery from the experience of psychosis and also attainment of a meaningful and purposive existence. Although it is evident that the language used to speak about the experience of psychosis is undergoing some change, the diversification of discourses – such that alternative constructions on the subject of psychosis are readily available – still has some way to go.

Although objections have been raised within the positivist paradigm regarding the calls for a change of language and ‘dropping the language of disorder’ (Bentall, 2017) due to the further stigmatisation of individuals experiencing mental distress, the social constructionist contribution to knowledge has enabled an understanding of how discourse constructs realities. Discourse analytic work focussing on the deconstruction of ‘taken for granted’ categories challenges assumptions and the accepted practices, which opens up potential for change and liberation from what can be regarded as interest-driven opinions on reality (Willig, 1998). As Harper neatly summarises, ‘[t]here is a danger of service users’ experiences being colonised by professional categorisations and classifications rather than allowing users of services to theorize those experiences themselves in their own words. Some of these conceptualisations will, of course, reflect dominant professional conceptualisations, but others will be different. Those who use psychiatric services have argued that they have a right to understand their experiences in a way that makes sense to them and have set up self-help groups to support them to do just this – the UK Hearing Voices Network’ (2004, p. 60).

Furthermore, it has been argued by philosopher Mohammed Rashed (2019), in his work on madness and the demand for recognition, that the ‘othering’ of individuals experiencing psychosis and the dehumanising of their experience – via the biomedical psychiatric discourses prevalent in anti-stigma campaigns theorising unpredictability, riskiness and danger of ‘mental illness’ that necessitates the use of medication for safety – creates positions of powerlessness and helplessness, resulting in feelings of fear (2019). These concerns were evident for the participants in this study, who expressed fear about being othered, and the uncertainty they lived with, but also awareness of reclaiming some power by becoming experts by experience within the mental health system. The seeming difficulty for western communities to readily accept the diversity of human experience, including the variation in how people might like to speak about their experiences using imagination and metaphor is reflected in the culturally available discourses, where, although there have been shifts, with regard to psychosis the dominant psychiatric discourse prevails. This was certainly evident in the participants’ experiences, whereby, although they all referred to journeys and navigation, using travel metaphors to speak about their distressing experiences, they reported that the response from mental health professionals did not reflect this, preferring a medicalised response to distress. Individuals experiencing intense distress from unusual mental states do so in a social context, where everyone is involved in trying to make sense of what is happening, from the individual themselves to professionals, family and friends.

The dimension of meaning has been found to be fundamental in the experience of psychosis (Rashed, 2019) which is congruent with the findings in this research. Furthermore, Rashed has argued for reconciliation as opposed to alienation, fostering acceptance, transformation and integration in addition to the importance of the philosophical concept of recognition, enabling validation of social identity, dignity, respect and self-esteem (2019) which resonates with the findings in this study where participants expressed the importance of being seen as a person and supported in making-meaning of their experience.

If it is reasonable to conclude that making-meaning is fundamental to feeling better and individuals navigate the experience of psychosis via the culturally available discourses, it becomes clear that being transparent about the variety of discourses available is not only important but essential within any therapeutic setting aiming to offer help and support – especially given the role that dominant discourses play in shaping subjectivity and selfhood. Issues of power and empowerment are subject to change as discourses capture and represent the changing landscape of dominant understandings within any given culture. Meanings and definitions are transformed as we traverse the discourses emanating from a wide range of sources, from the neoliberal ideology reflected in mainstream mental health services, to phenomenological accounts of embodied lived experience speaking of the complexity, not only of human experience, but the diversity in meanings attributable.

So how are we to help and support intensely distressed individuals in making-meaning of their experience, given the conclusion from this study – which is in accord with a variety of research findings – that making-meaning is fundamental in ameliorating distress and feeling better? The dominance of biomedical psychiatric discourse with an emphasis on risk assessment and diagnosis, to the neglect of meaning-making and identity, can be seen as limiting the levels of recovery possible, so what are the alternatives?

It would seem that a move away from concerns with disorder, dysfunction, and abnormalities in body and mind, such as those prevalent in dominant psychiatric discourse, and towards broader concerns with social relationships in and to the world, would enable an approach with humanity at the core. A client-centered approach advocated by Rogers (1951), which provides an empathic space for the individual to express themselves choosing whichever narrative works for them, creates a liberatory therapeutic encounter that is particularly important for individuals experiencing psychotic phenomena. The opportunity to feel heard and seen, fundamental for a sense of personhood, selfhood and self-esteem, was universally important to the participants.

By contrast, a sole focus on symptoms and functioning, I would argue, obscures the potential to make personal meaning of the subjective experience of psychosis whilst prioritising institutional practices. For example, it could be argued that unusual beliefs are not necessarily in themselves problematic. While an absence of meaning, experiences of isolation and secrecy, coupled with not knowing how to manage and cope, can lead people to seek help, the beliefs themselves do not necessarily require modification in order for individuals to feel better. This was evident in Doreen’s account where she expressed still feeling she may have the capacity to predict events and felt this to be related to her spirituality. From within the Hearing Voices movement the emphasis has been on changing the conversation about voice hearing, and not reducing the experience to symptoms of illness, but finding a way to understand the experience and see it as part of the diversity of human experience. Experiential information from mad activists has suggested other ways of conceptualising the experience of psychosis, as 'dangerous gifts'. It could be argued that a psychosocial understanding as promoted by the BPS creates opportunities for meaning-making of the subjective experience of the individual in a social matrix of relationships and circumstances, increasing potential for recovery. Additionally, a focus on understanding trauma, and the threat response in relation to power inequalities in relationships, can be beneficial.

What this study, and others, show is that the uniqueness of a human being is not only evident in everyday life but also in the experience of psychosis – meaning that the propensity of individuals to author their own lives and experiences is also part of navigating distress in life. An appreciation of the interpreting aspect of all human beings is important for expansion in the field of meaning-making and incorporation of the myriad of culturally available understandings. An approach that embraces the need of all individuals to be 'at home' in the social world, including those experiencing mental distress, also creates the potential for uniting us in our humanity. A more hopeful approach with an emphasis on personal growth, liberation and meaning-making, in addition to an awareness of the language we use containing the available cultural discourses shaping our reality and identity, I would argue, increases the potential for a meaningful therapeutic encounter where a variety of discourses can be mobilised in making personal meaning.

It would seem that the complexity of mental health phenomena can defy straightforward understanding, as evidenced by the wide range and often contradictory nature of opinions and conceptualisations represented in the culturally available discourses. Incorporating the wealth of knowledge and perspectives-recognises the complexity of human experience and deepens our understanding of it still further, while for the individuals themselves, providing an opportunity to facilitate meaning-making resulting in reparation and restoring the potential of a meaningful existence and hope for the future.

In the episteme of our time (as conceptualised by Foucault, 1970), there is an unconscious bias toward meriting explanations for human experience based in science and medicine. This continues despite loud calls for reappraisals in how we understand human distress (see e.g. Bentall, 2015, ‘Time for a paradigm shift’). It would seem that individuals attempting to understand human mental and emotional distress go through a process of filtering theories depending on their sociocultural background, personal experience and professional training, just as I did. The communication between medical professionals and individuals with lived experience at psychiatry conferences, failing to reach a mutual understanding due to the seeming incomprehensibility of the other, demonstrates how completely different the opinions can be about the same topic. The power differential between medical professional and ‘mental patient’ plays a significant role in which ideas survive the conflict in opinion.

The conflict in meaning-making was also evident in the participants’ accounts as they deployed a range of discourses in their attempts to make-meaning of their experience of psychosis, the dominant psychiatric discourse being present in all of their accounts as a central feature in meaning-making whether it was mobilised to reinforce a particular type of meaning or reject it. An integration of other forms of knowledge in understanding the complexity of human experience, I would argue, enables a richer and more accurate understanding of mental distress, leading to a wider range of therapeutic interventions, whilst also avoiding the dominant reductionist medicalisation and pathologisation of human experience.

Yanchar argues, ‘[t]he conception of science privileged as the single foundation of knowledge has largely informed psychological methodology to the exclusion of other methods of enquiry’ (1997, p. 428), and this was certainly my experience as a psychology undergraduate. However, progress since then has seen qualitative research in psychology rise, advancing insights into human experience with new developments in methodology making it possible for me to undertake not only a qualitative piece of research but also a dual focus approach! A combined methodological approach enabled a comprehensive understanding of the dynamic interaction between language and the situatedness of embodied experience, coexisting dynamically within our personal and social realities. Making-meaning and participants’ developing their own personal meaning was found to be fundamental in experiencing life as meaningful, thereby creating hope for the future.

Recommendations for practice

The psychological significance of meaning-making in the experience of extreme mental states and distress experienced in psychosis seems to be related to efforts in negotiating and indeed attempting to survive the experience. The levels of fear and anxiety that accompany the unusual perceptual experiences, and mistrust of the taken-for-granted aspects of social and experiential life including the very notion of reality, create an urgent need to make sense of what is going on. This can then provide a sense of how it might be possible to cope, manage or even fight to survive, mitigate from any further loss and reclaim agency – all major areas of concern expressed and evident in the master themes emerging from the IPA. Meaningful understandings seem to provide a way forward, a path to a meaningful life and therefore the generation of hope in working towards real achievable possibilities in the future. It would seem there is no hope without meaning – hope being an attitude, a felt meaning state anchored in future possibilities of something arising from the process of meaning-making. This leads me to conclude that incorporating therapeutic strategies to include a focus on meaning-making of the experience of psychosis is not only beneficial but may be imperative in aiding recovery and a sense of wellbeing.

Furthermore, we can prioritise the subjective lived experience of psychosis *and* acknowledge the socially constructed nature of our reality by creating a therapeutic encounter in which personal meaning can be made by drawing on a variety of culturally available discourses, rather than imposing meaning associated with dominant psychiatric discourse. In fact, the imposition of any discourse goes against the importance of the co-construction of meaning and working collaboratively within the therapeutic relationship. My own position as a critical psychologist does at times create challenges for me when I hear accounts from individuals who have accepted medicalised explanations and I have to resist the temptation to enlighten them with my understanding. However, I fully accept that imposing meaning is unhelpful, and the priority is the wellbeing of the individual. The task in psychological therapy is therefore to neither collude nor vehemently disagree with an individual's perspective, but to share the diversity of culturally available understandings with openness and transparency as and when, or if appropriate, to enable individuals to claim and formulate their own meaning as they choose.

The diagnostic label of 'Schizophrenia' is one that produced strong emotional responses from all of the participants, from intense fear and anxiety, to the resignation of needing to 'toughen up' and cope with that meaning. Three out of the four participants rejected this diagnostic category, preferring terms such as psychosis, mental health issue and despair. Although Jo did not express the same opinion, his assertion of needing to ‘toughen up’ implies a level of discomfort or difficulty requiring some form of negotiation. He expressed the need to re-educate people about what ‘schizophrenia’ means and refers to, in order to reduce fear from others and for those diagnosed. Given the legacy of this out-dated term, imbued with ideas relating to faulty biology and genes that are not confirmed by any scientific evidence (Boyle, 1990), it would seem timely to reform the language around how we speak about intense mental distress accompanied by unusual perceptual disturbances. The results from this research confirm concerns raised by the Division of Clinical Psychology (2013) to ‘drop the language of disorder’ in preference of using language that describes phenomena and tailors responses to the complaints and difficulties people are experiencing, and grounded in what they have to say about their life experiences, avoiding the risk of ‘interpretative violence’ (Willig, 2012) whilst maintaining an ethical and compassionate stance.

Dasein therapy originating from Heidegger’s work, and Logotherapy developed by Frankyl, have an existential and phenomenological focus, which is important for making meaning. Given the urgency for individuals experiencing psychosis to make meaning, it would appear important to move away from an exclusive focus on the symptom management prevalent in mental health services. Evidence-based therapies that focus primarily on cognitions, behaviour and functionality, as apparent in cognitive-behavioural therapy (CBT), limit the breadth of conversation possible. Maybe it is now time to provide more choice, not only in the language used to speak about the experience of psychosis but also in the range of therapies available, so conversations about life, relationships and identity are included, all being core concepts for the pursuit of meaning.

Limitations and further research

Undertaking this research study as a sole researcher incurs limitations in the interpretation of the data, and my preference for any future research would be to collaborate with others in order for the data and analysis to be discussed in detail before drawing conclusions. I am aware that my critical stance may have obscured certain insights that could have been identified by a co-researcher from a different viewpoint, potentially resulting in some interesting debates, joint reflections and enhanced conclusions. Ultimately, qualitative research relies on interpretation by the researcher and it is inevitable that the researcher's opinions will influence the findings somewhat.

Furthermore, I acknowledge that adopting a social constructionist approach epistemologically means that the knowledge produced is only one of a variety of possible interpretations (Charmaz, 2006). This is at a contrast with my commitment to a realist ontology in terms of the embodied phenomena experienced during psychosis, where there seemed to be some universalities in subjective experience. Although a dual focus methodology seemed an obvious answer to explore the intersection of language and experience, the absence of previous research studies detailing how to successfully combine the two analyses was another limitation. However, I hope that insights from this research about how they can both be integrated will inspire others to adopt this approach in order to pay due attention to the impact of language on experience.

Although I did endeavour to recruit participants who had experienced one episode of psychosis in the previous five years, I am aware that the sample included participants who had experienced more than one episode dating back to 20 years. Although this is potentially informative regarding the changing landscape of culturally available discourses over time, it would have been illuminating to attain a snapshot of culturally available discourses within a certain time period. Additional limitations are the sample size of only four participants due to the dual focus that necessitated two analyses of the same data set. This study has been challenging methodologically in terms of the epistemological conflicts in integrating IPA and FDA. These were resolved by adopting a critical realist position. However, challenges remain for the researcher attempting such an integration, given the lack of precedent for this endeavour and appreciation of this perspective.

Further research into mental distress and the interplay between language and experience using a dual focus methodology will enable a richer understanding of the phenomena of mental distress, how it can be understood via a variety of culturally available discourses and consequently how it can be managed in order to produce better outcomes for the individual experiencing psychosis, including their families and friends. Given the growing diversity in how mental distress is spoken about and conceptualised beyond the parameters of the dominant psychiatric discourse, especially when we draw on the voices of lived experience, it would now appear essential for this knowledge to be integrated in the provision of mental health services in order for a wider variety of therapeutic interventions to be included for the benefit of individuals seeking help for their distress.

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Appendix 1

Application for Ethical Approval

CITY UNIVERSITY
LONDON

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

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

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

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

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

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

1. Name of applicant(s).

Constance Baboulene

2. Email(s).

Constance.baboulene@city.ac.uk
Katyb1963@gmail.com

3. Project title.

Constructing meaning of the experience of psychosis when subject to a psychiatric discourse: a dynamic phenomenological and discursive analysis.

4. Provide a lay summary of the background and aims of the research. (No more than 400 words.)

Hope has been shown to be an important factor in recovery from mental health problems such as depression, anxiety, post-traumatic stress disorder (PTSD) and more recently psychosis, in studies that have focussed on the correlation between hope and symptoms of psychosis, (Walder et al., 2011).

Meaning-making of the experience of psychosis has also been shown to be fundamental in the process of recovery in facilitating hope and maintaining wellbeing. An interpretative phenomenological analysis (IPA) of hope and first episode psychosis, (Perry et al., 2007), identified the importance of supporting individuals in their search for meaning as this enabled them to maintain hope and recovery.

The aim of this research will be to investigate the personal experiences of participants following a recent episode of psychosis and the meaning-making process of the subjective experience of psychosis when receiving psychiatric diagnosis and treatment. There will be a focus on the experiential component, beliefs, understanding and language used in relation to their experience.

Up to 8 participants will be interviewed, within 3 years of an episode of psychosis, using a semi-structured interview. These participants will be invited from the Service User Research Forum (SURF), which is a forum for service users who access Sussex Partnership NHS foundation trust Early Intervention in Psychosis services. The SURF group have an interest in consulting with and collaborating with researchers because the information learned is used to inform client care and improve service delivery. If there are not sufficient participants available from this group, other organisations in Sussex, including MIND and the Hearing Voices Network, (HVN) will be contacted.

One individual who has lived experience of psychosis, psychiatric diagnosis and treatment, has been consulted in the development of the semi-structured questionnaire that will be used for the interviews.

5. Provide a summary of the design and methodology.

Up to 8 individuals will be interviewed from the service user research forum, (SURF), who have experienced a psychotic episode in the preceding 3 years. Written consent will be required to take part in the study. Individuals who are still involved with mental health services, will be asked for permission to consult with their lead practitioner, if required, to ensure suitability to take part in the study and that a negative impact to well-being is not envisaged or a risk factor.

Interviews will be conducted in a confidential and private setting convenient for the individual. The 50 -90-minute interviews will be recorded and transcribed.
Confidentiality will be maintained by removing any information that identifies the individual. A copy of their transcript and final research project will be made available to the participants and the right to withdraw at any point will be offered.

A semi-structured interview will be developed, in consultation with my supervisor at City University London and an individual who has experience of living with a diagnosis of psychosis.
Questions will be aimed at facilitating discussion around the themes related to the subjective experience of psychosis and psychiatric treatment, specifically regarding the language used and the understanding, beliefs and conceptualization of psychosis.
The impact of their beliefs on the relationship to the self, sense of hope, internalized stigma and recovery will also be explored.

A qualitative design using a combined methodological approach will be utilised in order to explore the dynamic between experience and discourse, with regard to the experience of psychosis and diagnosis.
Both Foucauldian Discourse Analysis, (FDA) and Interpretative Phenomenological Analysis, (IPA) will be applied to the same data to gain an understanding of both the socially constructed nature of experience and the lived experience.
Although IPA and FDA emerge from different epistemological origins that are potentially contradictory, there are "in between" positions (Willig, 2008) that can be adopted within both; e.g., between relativist and realist, i.e., critical realist, and between constructed and experiential, i.e., phenomenological."

Adopting an integrative position that does not privilege language over experience, or vice versa, makes it possible to combine the FDA and IPA methods, as they are compatible with the methodological approach in this research which aims to explore the different forms of knowledge that are inherent in both phenomenological and discursive perspectives. This affords an opportunity to gain insight into the interplay between experience and language, which occurs naturally together in our everyday reality.

The proposed 'dynamic approach' will aim to explore the experiential aspect of psychosis and meaning-making when the individual is situated within a psychiatric construction of psychosis.

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

The data will be collected by the audio recording of a semi-structured interview, between the participant and myself in a confidential and private setting that is convenient for the participant. The interview will be subsequently transcribed and used for analysis.

The interview will be between 50 to 90 minutes in duration and conducted using a semi-structured interview style. My approach will be to adopt both an empathic and suspicious stance during the interview.

Listening empathically will enable the phenomena of the lived embodied experience of psychosis and diagnosis to be explored, as described by the participant. Whilst the suspicious stance involves adopting a curious position where interpretation of what is being communicated, looks to examine what might exist beyond the explicit content of the communication, that the participant may not be aware of themselves, including the meanings contained in the structure of language - the discourses which construct objects and subject positions.

My aim is to be mindful of maintaining a researcher position, whilst working sensitively and compassionately with the participant and the personal information they are disclosing. Additionally, I will aim to maintain a reflexive awareness of the context of the participant's involvement and my own personal contribution to the relationship dynamic and the research study.

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

As I will be asking questions about a distressing time, there is potential for issues of concern to be disclosed by the participant. I will acknowledge this possibility in the preliminary information sheet for participants and at the beginning of the interview, to ensure that the participants have given information pertaining to their support networks, so that a referral can be made, if required.

Participants will be asked to fill out a personal information form, to include name, address, contact details, emergency contact and GP as standard.

Additionally, details of any other mental health professionals involved will be requested e.g., care coordinators, key workers, lead practitioners, peer support, and facilitators of any support groups attended, will also be requested information, so that communication/referral can be made if required.

The decision to refer a participant for additional support following the interview will

be based on my clinical experience and my assessment about the level of emotional distress present at the end of the interview and indeed if they are explicitly expressing the desire to speak more about their experience of psychosis, psychiatric diagnosis and treatment.
Contact details of other individuals who provide support e.g., family or friends will also be requested.

8. Location of data collection. (If any part of your research takes place outside England/Wales please also describe how you have identified and complied with all local requirements concerning ethical approval and research governance.)

N/A

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

Participants will be aged 18 years and over who have recently recovered from an experience of psychosis and are interested in speaking about both their experience of psychosis and their understanding of that experience, but also eager to comment on the psychiatric diagnosis and treatment they received and the impact on meaning-making of their psychotic experience.

10. How will participants be selected and recruited? Who will select and recruit participants?

I will be recruiting the participants from the service user research forum (SURF) by contacting the group about the study with the advertisement information and selecting those that meet the criteria for interview. In the event of not being able to recruit enough participants from SURF, I will widen my search by contacting MIND and the Hearing Voices Network (HVN) in Sussex.

11. Provide details of any incentives participants will receive for taking part.

Participants will be paid £10per hour for their time, plus expenses. This is part of the agreement when recruiting from the service user research forum (SURF), as this is seen as a valuing of the participants time. This is especially important in a group who have been marginalised in society.
Participants will be free to offer their opinions and it will be made explicit in the participant information form, that whilst they are being paid for their time, they are indeed autonomous agents, whose opinion is being sought.

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

YES

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

Potential participants will be provided with an information sheet about the research study from the initial stages, in order to make an informed decision about taking part. Additionally, participants will be offered the opportunity at the beginning of the interview to ask any questions before proceeding with the interview.

Additionally, there will be an opportunity at the end of the interview to ask any questions and a debrief information sheet will be given, which will be discussed before ending the interview. Participants will also be asked if they require anyone to be contacted on completing the interview.

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

As the participants will be speaking about a time in which psychological and emotional distress reached an intense peak, there is potential for them to feel emotionally upset as they reconnect with and describe their experiences.

Even though they will be speaking about a time which has passed and that they have recovered from, events preceding the psychotic experience may still be emotionally painful and unresolved, e.g., trauma, difficult relationship dynamics etc. And indeed, the psychotic experience itself may still be painful to reconnect with.

As an experienced counselling psychologist, I feel confident that I will be able to maintain an appropriate level of careful empathic listening in order to provide a level of containment of distressing emotions, whilst also adopting a researcher position which aims to obtain data for the purposes of IPA and FDA.

Interviews will be conducted at my practice - Psychology Sussex, in Hove, which has both an insurance policy and a general health and safety policy.

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

The risk to myself will be managed by having appropriate levels of personal supervision and the writing of my reflexivity diary. I will be especially mindful of managing the interviews in such a way that distinguishes the research interview from a therapeutic intervention, when talking about sensitive material, to reduce the risk of additional involvement and the additional work that would entail. As the interviews will be conducted at my practice - Psychology Sussex - I will be protected by the practice’s public liability insurance and the health and safety policy.

16. What methods will you use to ensure participants' confidentiality and anonymity? (Please note that consent forms should always be kept in a separate folder to data and should NOT include participant numbers.)	
Please place an 'X' in all appropriate spaces	
Complete anonymity of participants (i.e., researchers will not meet, or know the identity of participants, as participants are a part of a random sample and are required to return responses with no form of personal identification.)	
Anonymised sample or data (i.e., an *irreversible* process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates.)	
De-identified samples or data (i.e., a *reversible* process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location.)	X
Participants being referred to by pseudonym in any publication arising from the research	X
Any other method of protecting the privacy of participants (e.g., use of direct quotes with specific permission only; use of real name with specific, written permission only.) ***Please provide further details below.***	

17. Which of the following methods of data storage will you employ?	
Please place an 'X' in all appropriate spaces	
Data will be kept in a locked filing cabinet	
Data and identifiers will be kept in separate, locked filing cabinets	x
Access to computer files will be available by password only	X
Hard data storage at City University London	
Hard data storage at another site. *Please provide further details below.*	x
Any hard data will be stored a Psychology Sussex, 6 The Drive, Hove BN3 3JA. **This is my independent healthcare practice, where I am the Clinical Director.**	

18. Who will have access to the data?	
Please place an 'X' in the appropriate space	
Only researchers named in this application form	x
People other than those named in this application form. *Please provide further details below of who will have access and for what purpose.*	

19. Attachments checklist. *Please ensure you have referred to the Psychology Department templates when producing these items. These can be found in the Research Ethics page on Moodle.

Please place an 'X' in all appropriate spaces

	Attached	Not applicable
***Text for study advertisement**	x	
***Participant information sheet**	X	
***Participant consent form**	x	
Questionnaires to be employed		x
Debrief	x	
Others topic guide for semi structured interview	x	

20. Information for insurance purposes.

(a) Please provide a brief abstract describing the project

This research will aim to explore the recovery from psychosis using a qualitative design with a combined methodological approach. There will be an emphasis on what individuals understand about their experience of psychosis when positioned within a psychiatric construction of their experience, via psychiatric discourse and diagnosis.

What has happened and why, the language used, the relationship to the self and others, including internalised stigma and hope will be explored.

A maximum of 8 individuals who have experienced psychosis will be interviewed in depth using a semi-structured interview, which will be audio recorded and subsequently transcribed.

Participant interviews will be analysed using Interpretative Phenomenological Analysis and subsequently with Foucauldian Discourse Analysis to gain an understanding of the experiential impact of psychiatric diagnosis and discourse, on meaning-making of the experience of psychosis, the self, and implications for recovery, when positioned within psychiatric constructions of psychosis.

Please place an 'X' in all appropriate spaces

(b) Does the research involve any of the following:	**Yes**	**No**
Children under the age of 5 years?		x
Pregnant women?		X
Clinical trials / intervention testing?		x
Over 5,000 participants?		x
(c) Is any part of the research taking place outside of the UK?		x

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

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

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

Name …………………………………………. Date……………………………

21. Information for reporting purposes.

Please place an 'X' in all appropriate spaces

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

22. Declarations by applicant(s)

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

I certify that to the best of my knowledge the information given above, together with accompanying information, is complete and correct.	x
I accept the responsibility for the conduct of the procedures set out in the attached application.	x
I have attempted to identify all risks related to the research that may arise in conducting the project.	X
I understand that **no** research work involving human participants or data can commence until ethical approval has been given.	x

	Signature (Please type name)	**Date**
Student(s)	**Katy Baboulene**	**6th July 2015**
Supervisor	**Carla Willig**	**6th July 2015**

Reviewer Feedback Form

Name of reviewer(s).

Email(s).

Does this application require any revisions or further information?

Please place an 'X' the appropriate space

No Reviewer(s) should sign the application and return to psychology.ethics@city.ac.uk, ccing to the supervisor.		**Yes** Reviewer(s) should provide further details below and email directly to the student and supervisor.	

Revisions / further information required
To be completed by the reviewer(s). PLEASE DO NOT DELETE ANY PREVIOUS COMMENTS.

Date:
Comments:

Applicant response to reviewer comments To be completed by the applicant. Please address the points raised above and explain how you have done this in the space below. You should then email the entire application (including attachments), with tracked changes directly back to the reviewer(s), ccing to your supervisor.
Date: Response:
Reviewer signature(s) To be completed upon FINAL approval of all materials.

	Signature (Please type name)	**Date**
Supervisor		
Second reviewer		

Appendix 2

Ethical Approval Letter

CITY UNIVERSITY
LONDON

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

24th September 2015

Dear Constance Baboulene
Reference: PSYETH (P/F) 15/16 07
Project title: Constructing meaning of the experience of psychosis when subject to a psychiatric discourse: a dynamic phenomenological and discursive analysis.

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

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

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

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

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

(a) Adverse events
(b) Breaches of confidentiality
(c) Safeguarding issues relating to children and vulnerable adults
(d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

[redacted] [redacted]

Appendix 3

Participant Study Information Sheet

CITY UNIVERSITY
LONDON

Research Study Information Sheet

Title of study

Psychosis : Experience, meaning-making and psychiatric diagnosis.

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

What is the purpose of the study?

Hope has been shown to be an important factor in recovery from mental health problems such as depression, anxiety, PTSD (post-traumatic stress disorder) and more recently psychosis. Meaning-making of the experience of psychosis has additionally been shown to be important in the process of recovery and maintaining wellbeing.
The aim of this research will be to investigate the personal experiences of individuals following a recent episode of psychosis and the meaning-making process of that experience, when receiving psychiatric diagnosis and treatment.
In recent years there has been much debate about the pros and cons of different approaches to psychosis. This study aims to add the voice of individuals who have experienced both psychosis and psychiatric diagnosis and treatment, to that debate.
Findings from this research may result in recommendations for improvements to current mainstream mental health services, by including the opinions of individuals who have experienced psychosis and accessed services.
This research study is part of a 3-year, part-time doctoral research programme at City University in London, which includes a literature review and case study submission.

Why have I been invited?

Eight adult individuals - *18yrs* old and over, who have experienced psychosis in the preceding 3 years and feel able to talk about it, have been invited for interview, with a focus on what it feels like to experience psychosis, psychiatric diagnosis and treatment.

Do I have to take part?

.

Participation in the project is voluntary and you can choose not to participate in part or all of the project. You can withdraw within one month of the interview without being penalised or disadvantaged in any way.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

You will be invited for one interview of 90 minutes duration with the researcher.

You will be asked some questions related to the topic, but as the interview is semi-structured there will be space to speak freely about your experience and express your opinion.

The interview will be audio recorded and subsequently converted into written text for analysis. The analysis will focus on both the lived experience of psychosis and the process of meaning-making, in addition to the impact of psychiatric diagnosis and treatment, especially the language used.

The research study will take approximately three years.

The research is being undertaken at City University in London, as part of a Doctoral program of study, however the individual interviews will be conducted at Psychology Sussex, 6 The Drive in Hove. This is an independent psychological health care practice, which will provide a confidential, private and safe setting to conduct the research interviews.

Expenses and Payments (if applicable)

Payment for your time will be £10 per hour.

On completion of the interview, you will receive your earnings in cash.

What do I have to do?

A mutually convenient appointment time will be arranged with you at Psychology Sussex, for the interview to take place. You will be expected to attend this interview and in your own words express your opinions in response to the semi-structured questions. You will also be able to ask any questions at the beginning and end of the interview.

What are the possible disadvantages and risks of taking part?

As the interview will be focusing on a distressing time from your past experience, you may feel distressed at times during the interview, as you remember and reconnect with this past experience. This distress is likely to be mild to moderate and a temporary response to focusing on painful past experiences. The distress is likely to reduce in a short space of time as you switch your focus to the present day and resume your daily activities.

What are the possible benefits of taking part?

Talking about difficult experiences, although potentially distressing, can also be useful and helpful. Having your say about your experience, being taken seriously and listened to can

feel liberating. This research aims to focus on the opinions of individuals with lived experience of psychosis in order that this vital information is included in the debate about what is and is not of benefit for persons experiencing psychosis.
Conclusions from research findings, could result in recommendations for improving services and policy regarding best practice for mental health well-being.

What will happen when the research study stops?

If for any reason this research had to stop all personal data will be shredded and disposed of securely.

Will my taking part in the study be kept confidential?

Only the researcher will have access to the information and data.
Only the researcher will have access to the audio recordings.
There will be no future use of the personal information.
All data will be stored securely in locked filing cabinets in the office at [redacted]
All information is confidential, the only exception being disclosure about intended or potential harm to yourself or others.

What will happen to the results of the research study?

Confidentiality and privacy will be maintained at all stages of the research including the interview, audio recordings, transcriptions of the recordings, research report and in relevant professional journals and publications, pertaining to this subject area.
Participants wanting to receive a copy of the research report or any future publication, which has arisen as a direct result of this study, can inform the researcher at the end of the interview and ensure their contact details are correct on the participant information form.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study within one month of the interview, without explanation or penalty.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Psychosis: Experience, meaning-making and psychiatric diagnosis.

You could also write to the Secretary at:
[redacted] [redacted]
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: [redacted]

City University London holds insurance policies, which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone’s negligence, then you may have grounds for legal action.

Who has reviewed the study?
This study has been approved by the Psychology Department Research Ethics Committee at City University London. [*PSYETH (P/F) 15/16 07*].

Further information and contact details

Researcher
Constance.Baboulene@city.ac.uk

Supervisor
C.Willig.@city.ac.uk

Thank you for taking the time to read this information sheet.

Participant Recruitment Poster

CITY UNIVERSITY
LONDON

Department of Psychology
City University London

PARTICIPANTS NEEDED FOR RESEARCH INTO THE LIVED EXPERIENCE OF psychosis, PSYCHIATRIC DIAGNOSIS AND TREATMENT

Have you experienced, psychosis? Did you receive a diagnosis? Did you receive psychiatric treatment?

Do you want to talk about it and be paid for your time?

We are looking for volunteers to take part in a study on the lived experience of psychosis who have received psychiatric diagnosis and treatment. You would be asked to attend one 90minute interview with a researcher to talk about your experience in your own words.

In appreciation for your time, you will receive £10 per hour for your time.

For more information about this study, or to take part, please contact: Katy Baboulene at Psychology Sussex [redacted] or email Constance.Baboulene@city.ac.uk

This study has been reviewed by and received ethics clearance through the Psychology Department Research Ethics Committee, City University London [*PSYETH (P/F) 15/16 07*].

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

Participant Consent Forms

CITY UNIVERSITY
LONDON

Consent Form

Title of Study:

Psychosis: Experience, meaning-making and psychiatric diagnosis.

Ethics approval code: [PSYETH (P/F) 15/16 07]. Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve • being interviewed by the researcher • allowing the interview to be audiotaped	
2.	This information will be held and processed for the following purposes: to explore the embodied, lived experience of psychosis, to explore the meaning-making process of the experience of psychosis, and explore the experience of psychiatric diagnosis and the impact on the meaning-making process. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. I understand that I will be given a transcript of data concerning me for my approval before it is included in the write-up of the research. I consent to the use of sections of the transcript of audiotapes in publications.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw within one month of the interview without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

____________________ ____________________________ _____________

Name of Participant Signature Date

____________________ ____________________________ _____________

Participant Debrief Forms

Title - Psychosis: Experience, meaning-making and psychiatric diagnosis.

DEBRIEF INFORMATION

Thank you for taking part in this study! Now that it’s finished we’d like to explain the rationale behind the work.

Hope has been shown to be an important factor in recovery from mental health problems such as depression, anxiety, PTSD (post-traumatic stress disorder) and more recently psychosis. Meaning-making of the experience of psychosis has also been shown to be important in the process of recovery and maintaining wellbeing.

The aim of this research was to investigate the personal experiences of participants following a recent episode of psychosis and the meaning-making process of their personal experience of psychosis, when receiving psychiatric diagnosis and treatment.

This research was aimed at asking the individuals themselves how it is for them and to explore their views, in order to contribute lived experience knowledge and information to the debate about what is helpful. Findings from the research will be used to contribute to recommendations for best practice in services for individual’s experiencing psychosis, especially with regards to supporting the meaning-making process, which has more recently been found to be important in sustained recovery.

If being involved in the interview today has raised any concerns for you, do not hesitate to contact your GP, key worker/care-coordinator or lead practitioner.

Useful references and support networks are also cited in the ‘Understanding Psychosis and Schizophrenia’, report which you can read online on the British Psychological Society website or contact them directly by email or telephone for a free copy. We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Katy Baboulene, Chartered Psychologist
[redacted]

Ethics approval code: *[PSYETH (P/F) 15/16 07.]*

Appendix 4

Interview Schedule

Semi-structured interview for research study[67]:

Constructing meaning of the experience of psychosis when subject to a psychiatric discourse: a dynamic phenomenological and discursive analysis.

I would like to ask you some questions about your experience, which may have included voice hearing, seeing visions and other unusual perceptions. These types of experiences are commonly referred to as ‘psychotic’ experiences, but you may have other words, which you would prefer us to use during the course of our meeting today and I would like you to tell me in your own words about your experience.

1. What did you think and feel about my flyer information – the language used - and how did you make your decision to consider taking part?

2. What was the experience of psychosis like and how were you affected?

3. What did you think the experience was about in terms of making sense of it?

4. How did it leave you feeling about yourself, others and the future?

5. How did you decide which words to use to speak about this?

6. How did this affect the meaning-making process – the making sense of what was happening?

7. How do you feel about the words used and the explanation you were given about your experience when accessing services?

8. What did you think this meant? (about you, the future, about them etc.)

9. How did this affect the meaning-making aspect of your experience?

10. How did you decide to talk about it here?

11. How do you feel about how other people talk about this subject? e.g. family, friends, health professionals, media etc.

12. How do you feel about those words/language?

13. How does this affect the meaning-making process of the experience of psychosis?

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14. What would you change or want to be different to improve the experience that you had?

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[1] This semi-structured questionnaire has been developed in consultation with an individual with lived experience of psychosis, in order to focus questions accurately on the research aims.

Appendix 5
Transcription notation

The form of notation used throughout the transcript was developed by Gail Jefferson. A more complete description is found in Atkinson and Heritage (1984).

Extended square brackets mark overlaps between utterances, e.g.:

A: Right [so you
B: [I'm not sure

An equals sign at the end of a speaker's utterance and at the start of the next utterance indicates the absence of a discernible gap, e.g.:

A: Anyway Brian =
B = Okay, okay

Numbers in brackets indicate pauses timed to the nearest tenth of a second. A full stop in brackets indicates a pause which is noticeable but too short to measure, e.g.:

A: I went (3.6) a lot further (.) than I intended

One or more colons indicate an extension of the preceding vowel sound, e.g.:

A: Yea::h, I see::

Underlining indicates that words are uttered with added emphasis; words in capitals are uttered louder than the surrounding talk, e.g.:

A: It's not <u>right</u>, not right AT ALL

A full stop before a word or sound indicates an audible intake of breath, e.g.:

A: I think .hh I need more

Round brackets indicate that material in the brackets is either inaudible or there is doubt about its accuracy, e.g.:

A: (I couldn't tell you) that

Square brackets indicate that some transcript has been deliberately omitted. Material in square brackets is clarificatory information, e.g.:

A: Brian [the speaker's brother] said [ ] it's okay

Appendix 6

Master Table of IPA Themes

MASTER TABLE OF THEMES		
Superordinate Themes	Page/Line	**Master Theme – Managing the experience**
Fight/struggle for personal meaning	15/1-7 7/27,28 30/23 34/9-11	1T: ‘my understanding –taking large amounts of cannabis as a teenager brought it on early, rather than caused it outright – probably going to get it – even if I lived a clean life’ 2A: ‘to do with my identity and the struggle’ 3L: ‘I won’t entertain the story that isn’t helpful to me’ 4LN: ‘desire for a future… gave me hope that I could recover…I couldn’t have got better without actually wanting to’
Fight for self	16/11-15 5/33,34 30/24-29 18/10-11	1T: ‘at the time – I denied it, I thought I’m still the same person’ 2A: ‘it’s like me against the world’ 3L: ‘don’t label ME with what this label means’ 4LN: ‘I refused to give in to it, and I refused to let it define me’

Fight others/cope with 'the system'	14/27-32 13/9-19 17/32-34 35/9-11	1T: 'suggested at first - drug induced because of my cannabis use – discussed this with various different psychiatrists – consensus is people with mental illness are genetically predisposed to it much like some people are predisposed to cancer or diabetes' 2A: 'they said I had bipolar…prior to that…psychotic depression…then I got diagnosed with schizoaffective disorder, then four years ago I was diagnosed with bipolar disorder…then reverted back…' 3L: 'fortunate they diagnosed me with psychosis…didn't add an extra layer' 4LN: 'told him (*psychiatrist) I'm off the medication, he was absolutely raging, he was really furious and just said, "well, you'll be back."'
'Work to do'	11/7-10 22/11-15 11/22-26 17/14-16	1T: 'I mean the word itself – it's quite a powerful word if you are branded with it…change people's knowledge of what the word actually means' 2A: 'I start to interpret it, that this is my job in the world, my occupation is to be this sick person' 3L: 'I would be dealing with an extra layer…if I had a diagnosis of Schizophrenia, what would I say to my family?' 4LN: 'I hid it (*schizophrenia diagnosis) for a long, long time'

Superordinate Themes	Page/Line	**Master Theme – Trust**
Lack of trust in others	25/17-20	1T: 'it (*psychiatrist didn't answer the question) made me feel more paranoid because it made me feel that he was holding something back from me – it (*being sent for a brain scan – no results given) had been some sort of experiment'

	20/3-11 7/16-19 13/6-8	2A: ‘one doctor did say I didn’t need to be on medication the rest of my life…new doctor…medication for the rest of my life…don’t know if that makes any sense’ 3L: ‘psychiatrist…play around with diagnosis’ 4LN: ‘being told I had paranoid schizophrenia…they were also toying with psychotic depression’
Lack of trust in self	4/29-32 11/22-24 5/22-26	1T: ‘started to get really scary – my ability to communicate – vanished’ 2A: ‘I question myself a lot…flashbacks to the hospital and the experience before’ 3L: ‘I couldn’t be sure of anything…I was so off the planet’
Distrusted by others	18/24 23/9-11 29/10-13	1T: ‘you’re a druggie aren’t you’ 3L: ‘doesn’t feel like…you declare a diagnosis of Schizophrenia’ 4LN: ‘I was…diagnosed with schizophrenia but I’m fine now…they couldn’t get me out quick enough’
Trust in self	4/26-29 11/30-31 9/24-26 34/9-10	1T: ‘knew what the routine was – knew my way around’ 2A: ‘I have some hope…that opportunities will arise’ 3L: ‘I had navigated depression before, so I already knew how to manage a mental health problem.’ 4LN: ‘desire for a future…gave me hope that I could recover’
Trust others with knowledge of the person	8/21-22 23/20-24	1T: ‘brought home to me how important family and friends are’ 2A: ‘as for my family…don’t think any of them have treated me differently…they hold out a lot of hope for me’

	28/8-14 34/4-6	3L: ‘knows an enormous amount about it [psychosis]… enormously helpful’ 4LN: ‘as soon as my parents realised what was happening to me, they said, ‘no’ this is not happening to my daughter, this is not her life’

Superordinate Themes	Page/Line	**Master Theme – Experiencing Oneself as The Agent**
Agency in personal meaning	15/1-17 19/7,8 31/26-29 5/9-11	1T: ‘so my understanding is that… although taking large amounts of cannabis as a teenager probably brought it on early rather than caused it outright… I was probably going to get it anyway even if I had lived a clean life… That’s my understanding of it… that’s how I like to understand it’ 2A: ‘I have my reasons to why things have happened to me’ 3L: ‘in that making sense of it, I’m enabled to live my ordinary life’ 4LN: ‘that’s what happened…it was bullying by my peers and also bullying within the family’
Collaborating Valued	25/22-26 23/29-34 31/1-5	1T: ‘I feel it is very important for the patient to be included and to be kept up to speed with what the clinicians and the health professionals are thinking’ 2A: ‘he trusted me to look after his children which I thought was… really trusting yeah, an honour really’ 3L: ‘listen to me navigate…that has been invaluable’

	31/7-14	3L: ‘she’s actually listened’
	19/12-14	4LN: ‘she understood though, she got it…I told people who got the experience…able to communicate with me’
Choosing a narrative	20/7-12	1T: ‘I’m happy with the word psychosis – for me that is what it is, it does what it says on the tin’
	11/1,2	2A: ‘call it mental health, how long have you been suffering with your health, your mental health’
	6/24-25	3L: ‘psychosis does me very well …as it describes the phenomena’
	21/14-17	4LN: ‘talk about it in terms of what we were experiencing at the time, the phenomena…rather than the labels’
Agency from knowledge and experience	10/26-33	1T: ‘for me schizophrenia is a broad word – own version of schizophrenia – it’s a group of a lot of different symptoms’
	8/27-29	2A: ‘I don’t feel offended by the word psychotic I just don’t like it being used as a long-term diagnosis, I think every, anybody could experience that [psychosis] at any time’
	9/11-12	3L: ‘you’re still a person having an experience’
	18/11-15	4LN: ‘I think it’s a life experience…you can live with it…incorporate it into your life, it doesn’t have to be a defining experience’
Lack of agency ‘others decide’	14/6-11	2A: ‘I guess ‘it’ is what other people have said’
	17/30-31	3L: ‘a psychiatrist pronounces, you get persuaded’
	7/1-3	4LN: ‘he made another apt to see me and all he said was ”it’s clear you are a very sick girl”.’

Superordinate Themes	Page/Line	**Master Theme – Loss**
Powerlessness when accessing mental health services	7/34,35	1T: ‘thought they were going to lock me up – forget about me’
	21/1-7	2A: ‘they said we’re not going to give you the side effects sheets because you’ll start feeling that you’ve got the side effects, but then I really did get the side-effects because I ended up feeling quite suicidal from the anti-depressants that they gave me… but it’s never really been explained ever.’
	15/15-16	3L: ‘patients are done to, rather than worked with’
	31/13-15	4LN: ‘he knew he was in a position of power…he knew what was wrong with me…he knew how to treat me’
Powerlessness when experiencing psychosis	5/32-34	1T: ‘I was shifting into a negative world view – paranoia and the delusions – they kind of took over’
	14/8-9	2A: ‘it [psychosis]… can cause me to have hallucinations of some sort or, err, extreme paranoia’
	8/8-9	3L: ‘get catapulted by just a little bit, into psychosis or a long way’
	30/14-15	4LN: ‘nothing would have stopped it (*psychosis)’
Loss of ‘taken for granted’ reality	4/23-25	1T: ‘first psychotic breakdown – terrifying – didn’t know what was up – what was down’
	4/32-34	2A: ‘it’s almost like being in an action-packed movie’
	2/4	3L: ‘moving in and out of being present’

	3/18 & 4/1-2	4LN: ‘I was having trouble distinguishing between my dreams and my waking life…they were as real or as unreal as each other’
Loss of ‘taken for granted’ future	8/17-20 11/15-16 & 27-29 7/23-24 32/3	1T: ‘took me a long time to think that the future could be anything good’ 2A: ‘I’ve got a bit of hope, but I lose it very quickly… my future…plans…they seem quite out of reach’ 3L: ‘psychosis is a dustbin diagnosis…where you go and there’s no way out’ 4LN: ‘this was it for life’
Loss of ‘taken for granted’ sensory perception	2/27-31 4/25 2/29-30 6/2-3	1T: ‘hallucinations of every sense – tactile – smelt things – tasted – heard – seen things that aren’t there’ 2A: ‘I thought I was turning to plastic’ 3L: ‘see my face change from what I tho:ught it was to how it actually is’ 4LN: ‘thinking that people were just in my head all the time’
Loss of function	6/1-2 26/35 1/35 2/2 16/3-6	1T: ‘I didn’t know I wasn’t thinking properly’ 2A: ‘I was seriously not thinking straight’ 3L:‘wasn’t aware of what I was doing’ ‘didn’t know what I was doing basically’ 4LN: ‘I couldn’t read, I couldn’t take the words in, the words swam all over the page’

Loss of personhood	24/20,21 21/27-32 9/19… 15,16 31/15-16	1T: ‘the psychiatrist almost ignored my question to a certain extent shrugged me off’ 2A: ‘once you’re put into this role of patient…people like her don’t ever see you’ 3L: ‘there’s this element of not being seen’ ‘then you start to make decisions about who you are as a person’ 4LN: ‘there was no interest in listening to my experience’
Loss of selfhood	5/2-3 8/22-23 19/7-9 6/3-4	1T: ‘I was lost even though I knew where I was’ 2A: ‘I became a completely different type of person’ 3L: ‘damage to your ability to see yourself as somebody who can live in the material world in an ordinary way’ 4LN: ‘they could see what was happening in my head, what I was thinking’

Appendix 7
Master Table of Themes

MASTER TABLE OF THEMES

MASTER THEME – MANAGING THE EXPERIENCE

Superordinate Theme	Pg. / Ln	Participant 1T	Pg. / Ln	Participant 2A	Pg. / Ln	Participant 3L	Pg. / Ln	Participant 4LN
Fight/struggle for personal meaning	15 / 1-7	‘my understanding –taking large amounts of cannabis as a teenager brought it on early, rather than caused it outright – probably going to get it – even if I lived a clean life’	7 / 27, 28	‘to do with my identity and the struggle’	30 / 23	‘I won’t entertain the story that isn’t helpful to me’	34 / 9-11	‘desire for a future… gave me hope that I could recover…I couldn’t have got better without actually wanting to’
Fight for self	16/ 11-15	‘at the time – I denied it, I thought I’m still the same person’	5 / 33, 34	‘it’s like me against the world’	30 / 24-29	‘don’t label ME with what this label means’	18 / 10-11	‘I refused to give in to it, and I refused to let it define me’
Fight others/cope with ‘the system’	14 / 27-32	‘suggested at first - drug induced because of my cannabis use – discussed this with various different psychiatrists – consensus is people with mental illness are genetically predisposed to it much like some people are predisposed to cancer or diabetes’	13 / 9-19	‘they said I had bipolar…prior to that…psychotic depression…then I got diagnosed with schizoaffective disorder, then four years ago I was diagnosed with bipolar disorder…then reverted back…’	17 / 32-34	‘fortunate they diagnosed me with psychosis…didn’t add an extra layer’	35 / 9-11	‘told him (*psychiatrist) I’m off the medication, he was absolutely raging, he was really furious and just said, “well, you’ll be back.”’
‘Work to do’	11 / 7-10	‘I mean the word itself – it’s quite a powerful word if you are branded with it’	22 / 11-15	‘I start to interpret it, that this is my job in the world, my occupation is to be this sick person’	11 / 22-26	‘I would be dealing with an extra layer…if I had a diagnosis of Schizophrenia, what would I say to my family?’	17 / 14-16	‘I hid it (*schizophrenia diagnosis) for a long, long time’

MASTER THEME - TRUST

Superordinate Theme	Pg. / Ln	Participant 1T	Pg. / Ln	Participant 2A	Pg. / Ln	Participant 3L	Pg. / Ln	Participant 4LN
Lack of trust in others	25 / 17-20	'it (*psychiatrist didn't answer the question) made me feel more paranoid because it made me feel that he was holding something back from me – it (*being sent for a brain scan – no results given) had been some sort of experiment'	20 / 3-11	'one doctor did say I didn't need to be on medication the rest of my life…new doctor…medication for the rest of my life…don't know if that makes any sense'	7 / 16-19	'psychiatrist…play around with diagnosis'	13 / 6-8	'being told I had paranoid schizophrenia…they were also toying with psychotic depression'
Lack of trust in self	4 / 29-32	'started to get really scary – my ability to communicate – vanished'	11 / 22-24	'I question myself a lot…flashbacks to the hospital and the experience before'	5 / 22-26	'I couldn't be sure of anything…I was so off the planet'		
Distrusted by others	18 / 24	'you're a druggie aren't you'			23 / 9-11	'doesn't feel like…you declare a diagnosis of Schizophrenia'	29 / 10-13	'I was…diagnosed with schizophrenia but I'm fine now…they couldn't get me out quick enough'
Trust in self	4 / 26-29	'knew what the routine was – knew my way around'	11 / 30-31	'I have some hope…that opportunities will arise'	9 / 24-26	'I had navigated depression before, so I already knew how to manage a mental health problem.'	34 / 9-10	'desire for a future…gave me hope that I could recover'
Trust others with knowledge of the person	8 / 21-22	'brought home to me how important family and friends are'	23 / 20-24	'as for my family…don't think any of them have treated me differently…they hold out a lot of hope for me'	28 / 8-14	'knows an enormous amount about it [psychosis]…enormously helpful'	34 / 4-6	'as soon as my parents realised what was happening to me, they said, 'no' this is not happening to my daughter, this is not her life'

MASTER THEME – EXPERIENCING ONESELF AS THE AGENT

Superordinate Theme	**Pg. / Ln**	**Participant 1T**	**Pg. / Ln**	**Participant 2A**	**Pg. / Ln**	**Participant 3L**	**Pg. / Ln**	**Participant 4LN**
Agency in personal meaning	15 / 1-17	'so, my understanding is that… although taking large amounts of cannabis as a teenager probably brought it on early rather than caused it outright… I was probably going to get it anyway even if I had lived a clean life… That's my understanding of it… that's how I like to understand it'	19 / 7, 8	'I have my reasons to why things have happened to me'	31 / 26-29	'in that making sense of it, I'm enabled to live my ordinary life'	5/9-11	'that's what happened…it was bullying by my peers and also bullying within the family'
Collaborating Valued	25 / 22-26	'I feel it is very important for the patient to be included and to be kept up to speed with what the clinicians and the health professionals are thinking'	23 / 29-34	'he trusted me to look after his children which I thought was… really trusting yeah, an honour really'	31 / 1-5 31 / 7-14	'listen to me navigate…that has been invaluable' 'she's actually listened'	19 / 12-14	'she understood though, she got it…I told people who got the experience…able to communicate with me'
Choosing a narrative	20 / 7-12	'I'm happy with the word psychosis – for me that is what it is, it does what it says on the tin'	11 / 1,2	'call it mental health, how long have you been suffering with your health, your mental health'	6 / 24-25	'psychosis does me very well …as it describes the phenomena'	21 / 14-17	'talk about it in terms of what we were experiencing at the time, the phenomena…rather than the labels'
Agency from knowledge and experience	10 / 26-33	'for me schizophrenia is a broad word – own version of schizophrenia – it's a group of a lot of different symptoms'	8 / 27-29	'I don't feel offended by the word psychotic I just don't like it being used as a long-term diagnosis, I think every, anybody could experience that [psychosis] at any time'	9 / 11-12	'you're still a person having an experience'	18 / 11-15	'I think it's a life experience…you can live with it…incorporate it into your life, it doesn't have to be a defining experience'
Lack of agency 'others decide'			17 / 30-31	'I guess 'it' is what other people have said'	28 / 8-14	'a psychiatrist pronounces, you get persuaded'	7 / 1-3	'he made another appointment to see me and all he said was "it's clear you are a very sick girl".'

MASTER THEME – LOSS

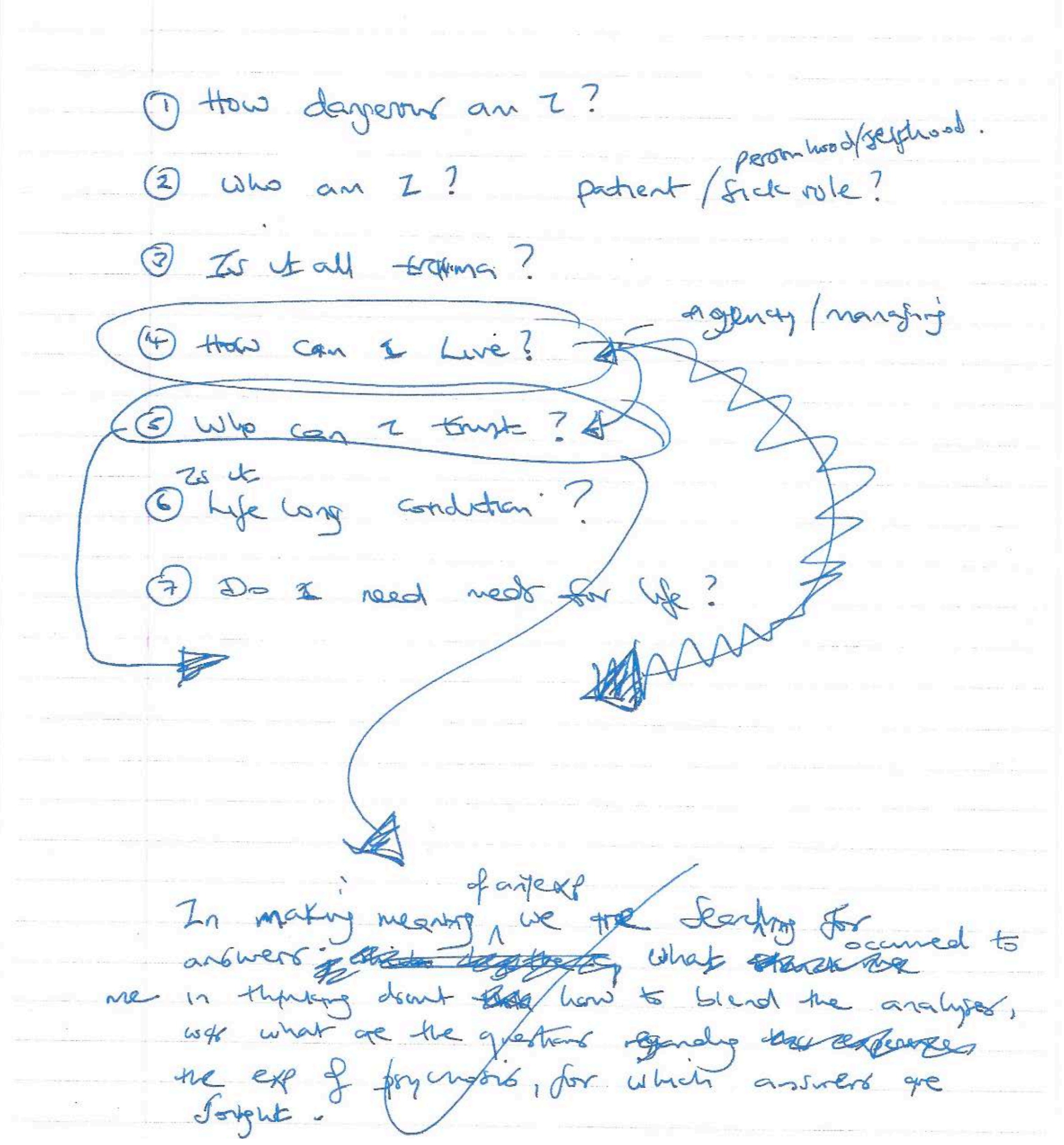
Superordinate Theme	**Pg. / Ln**	**Participant 1T**	**Pg. / Ln**	**Participant 2A**	**Pg. / Ln**	**Participant 3L**	**Pg. / Ln**	**Participant 4LN**
Powerlessness when accessing mental health services	7 / 34, 35	‘thought they were going to lock me up – forget about me’	21 / 1-7	‘they said we’re not going to give you the side effects sheets because you’ll start feeling that you’ve got the side effects, but then I really did get the side-effects because I ended up feeling quite suicidal from the anti-depressants that they gave me… but it’s never really been explained ever.’	15 / 15-16	‘patients are done to, rather than worked with’	31 / 13-15	‘he knew he was in a position of power…he knew what was wrong with me…he knew how to treat me’
Powerlessness when experiencing psychosis	5 / 32-34	‘I was shifting into a negative world view – paranoia and the delusions – they kind of took over’	14/8-9	‘it [psychosis]… can cause me to have hallucinations of some sort or, err, extreme paranoia’	8 / 8-9	‘get catapulted by just a little bit, into psychosis or a long way’	30 / 14-15	‘nothing would have stopped it (*psychosis)’
Loss of ‘taken for granted’ reality	4 / 23-25	‘first psychotic breakdown – terrifying – didn’t know what was up – what was down’	4 / 32-34	‘it’s almost like being in an action-packed movie’	2/4	‘moving in and out of being present’	3 / 18 & 4 / 1-2	‘I was having trouble distinguishing between my dreams and my waking life…they were as real or as unreal as each other’
Loss of ‘taken for granted’ future	8 / 17-20	‘took me a long time to think that the future could be anything good’	11 / 15-16 & 27-29	‘I’ve got a bit of hope, but I lose it very quickly… my future…plans…they seem quite out of reach’	7 / 23-24	‘psychosis is a dustbin diagnosis…where you go and there’s no way out’	32/3	‘this was it for life’
Loss of ‘taken for granted’ sensory perception	2 / 27-31	‘hallucinations of every sense – tactile – smelt things – tasted – heard – seen things that aren’t there’	4 / 25	‘I thought I was turning to plastic’	2 / 29-30	‘see my face change from what I tho:ught it was to how it actually is’	6 / 2-3	‘thinking that people were just in my head all the time’

LOSS (Cont.)

Superordinate Theme	**Pg. / Ln**	**Participant 1T**	**Pg. / Ln**	**Participant 2A**	**Pg. / Ln**	**Participant 3L**	**Pg. / Ln**	**Participant 4LN**
Loss of function	6 / 1-2	‘I didn’t know I wasn’t thinking properly’	26 / 35	‘I was seriously not thinking straight’	1/35 2/2	‘wasn’t aware of what I was doing’ ‘didn’t know what I was doing basically’	16 / 3-6	‘I couldn’t read, I couldn’t take the words in, the words swam all over the page’
Loss of personhood	24 / 20, 21	‘the psychiatrist almost ignored my question to a certain extent shrugged me off’	21 / 27-32	‘once you’re put into this role of patient…people like her don’t ever see you’	9 / 19…15, 16	‘there’s this element of not being seen’ ‘then you start to make decisions about who you are as a person’	31 / 15-16	‘there was no interest in listening to my experience’
Loss of selfhood	5 / 2-3	‘I was lost even though I knew where I was’	8 / 22-23	‘I became a completely different type of person’	19 / 7-9	‘damage to your ability to see yourself as somebody who can live in the material world in an ordinary way’	6/3-4	‘they could see what was happening in my head, what I was thinking’

Appendix 8

The Questions in Pursuit of Meaning



① How dangerous am I?

② Who am I? patient / sick role? personhood/selfhood.

③ Is it all trauma?

④ How can I Live? — agency / managing

⑤ Who can I trust?

⑥ Is it Life long condition?

⑦ Do I need meds for life?

In making meaning of any exp, we ~~are~~ searching for answers ~~[illegible]~~, what ~~[illegible]~~ occurred to me in thinking about ~~[illegible]~~ how to blend the analyses, was what are the questions ~~regarding the experiences~~ the exp of psychosis, for which answers are sought.

Appendix 9

Participant Table of Superordinate Themes and Themes

TABLE OF SUPERORDINATE THEMES AND THEMES FROM PARTICIPANT 1T (*master theme – 'manage & cope/fight & struggle'*)

Themes	Page/ Line	Key words/extracts
Fight/struggle for personal meaning	4/17-19 15/1-7 18/26-29	'didn't know it was psychosis - 'my understanding –taking large amounts of cannabis as a teenager brought it on early, rather than caused it outright – probably going to get it – even if I lived a clean life' 'my opinion – was predisposed to it (schizophrenia) through genetics anyway – whether I took drugs or not'
Fight and struggle for sense making/understanding	3/17-23 8/25-30 9/23-28 11/28-31 12/1-5 13/19-23 14/27-32	'don't know how it works – you'll be thinking something – might be delusional or psychotic or it might not – then hear the words – it's a real word - always seems significant' 'I understand in the old days manic patients and psychotic patients used to be separated – don't do that anymore – perhaps they should' 'if explain to someone they are ill – gentle in terms of language – but can't sugar coat it so much that it loses, it's meaning' 'when I was diagnosed, it gave me something to work with – an answer' 'I wouldn't say it (i.e., diagnosis of schizophrenia) helped me deal with symptoms or anything – it gave me some sort of closure – I actually have a diagnosis' 'Over the years I've kind of pieced together my understanding of what happened and perhaps why – a lot of things about the illness as well – it's taken years' 'suggested at first - drug induced because of my cannabis use – discussed this with various different psychiatrists – consensus is people with mental illness are genetically predisposed to it much like some people are predisposed to cancer or diabetes'

Managing personal meaning	3/2-8	'I'll be thinking something, then I will hear on the radio, or someone talking – say a word at exactly the same time as I think it – sense of significance about the event'
Coping with self	4/20-22	'paranoia – hearing voices in my head'
	12/16-20	'after my 2nd period in hospital I realised that I have to take medication now for the rest of my life if I want to stay healthy – but that doesn't have to be a bad thing.'
Manage to retain own beliefs/opinion	12/14,16	'not to say what other people might think – but what I think myself is that it's not such a bad thing anymore'
	12/27-33	'given me a different outlook on life to a lot of normal people, if there is such a word as normal - because everyone has their own little quirks – don't find that very helpful myself.'
	19/16-20	'it does grind my gears a bit when someone will wash their hands once and someone goes you've got OCD and like no, empathise with people with proper OCD – crippling illness – in media – anecdotes – experienced it, in my family'
Managing experience	8/22-25	'in the psychiatric ward for about 3 months – quite distressing at times'
	12/22-25	'positive about it these days - it's (psychosis) largely under control with the meds'
	23/22-29	'anything I hear be it someone else or some music or a voice in my head – everything has a slant on it which is against me'
Fight for self	6/35 & 7/1-4	'I was trying to escape a drug culture – using a lot of cannabis – it completely backfired on me'
Fight for sanity		
Fight for identity	16/11-15	'at the time – I denied it, I thought I'm still the same person'
Fight for support/understanding	9/1-3	'they don't seem to understand'
	23/7-19	'if it would be possible to have a different ward for people suffering from paranoid delusional psychotic type symptoms – I don't think it helped my recovery at all to be exposed to manic people'

Fight Others		
Cope/fight mental health services	8/29-33	‘perhaps they should – if you’re in depths of despair – last thing you need – bouncy bipolar people in your face’
	24/21-24	‘try and give them (*patient) a reasonable answer and not be shrugging people off’
Fight/struggle to resist power of diagnosis	10/10-17	‘when I first got the diagnosis – shocked – understood schizophrenia to be severe mental illness – impair future – ‘write me off’ –ill for the rest of my life – as more educated about the word – more hope’
	11/7-10	‘powerful word (schizophrenia) if you’re branded with it – change people’s knowledge of what that word actually means’
Resist acceptance of diagnosis: drug induced psychosis	14/27,28	‘it was suggested at first it was all drug induced because of my cannabis use’
Managing (inconsistent) information	10/19-26	‘affects 1% of population regardless of geographical location – 1/3 people with schizophrenia live pretty much normal lives – normal jobs’
	14/27-32	‘suggested at first - drug induced because of my cannabis use – discussed this with various different psychiatrists – consensus is people with mental illness are genetically predisposed to it much like some people are predisposed to cancer or diabetes’
‘Work to do’		
weight of history	10/10-17	‘when I first got the diagnosis – shocked – understood schizophrenia to be severe mental illness – impair future – ‘write me off’ –ill for the rest of my life – as more educated about the word – more hope’
Manage/cope with other’s/families’ beliefs	11/4-10	‘a lot of people don’t really understand – what would help me – not change the word schizophrenia – change people’s understanding’
Manage feelings	4/2	‘really exaggerated paranoia’

Manage other’s fear and own fear	3/11-15	‘quite unnerving and unsettling – my friends who have schizophrenia say it’s happened to them’
Managing other and family relationships	7/22-27	‘my parents had to pick both of us up – it wasn’t great for them’
Managing consequences of stigma of a mental health diagnosis e.g., schizophrenia	11/7-10	‘I mean the word itself – it’s quite a powerful word if you are branded with it’
	12/8-10	‘as time progressed from then until now – less of an impact on me (i.e., schizophrenia diagnosis)
	20/30-32	‘when they hear the word psychosis from a health professional - it can be scary – big thing if first time’
Cope with media/drama representations of psychosis		
Managing friendships	18/13-18	‘I guess I could call the guys who go to the group friends’
Managing/coping with other’s knowledge: language/labelling/diagnosis	18/21-23	‘he also knew I had a drug problem – made it clear to him I had a diagnosis of schizophrenia – his instant reaction was oh yeah but you’re a druggie’
	16/32-34	‘I’ve suffered with depression – Churchill called his depression his big black dog and that’s how my Mum refers to depression’
	19/7-10	‘they use stereotype words for mental illness – completely inaccurate like the word ‘schizo’ – sometimes people use the word out of context and that annoys me’
	19/25	‘when people trivialise it – really upsets me’
	20/14-19	‘it’s when it’s used out of context - used in a frivolous way – that’s what can get annoying – or inaccurately’
	22/15-21	‘it becomes offensive talking about mental illness – people don’t know all the facts and get something wrong – obvious one schizophrenia is a split personality’

TABLE OF SUPERORDINATE THEMES AND THEMES FROM PARTICIPANT 2A
(*master theme – ‘manage & cope/fight & struggle’*)

Themes	Page/ Line	Key words/extracts
Fight/struggle for personal meaning	7/33,34	‘losing my mother…she was an older mother…I’ve never really let go’
Fight and struggle for sense making/understanding	6/1-13	‘thought…invaded by aliens…conspiracy theories…not all the time…it changes’
	8/17,18	‘maybe I couldn’t contain what I was feeling anymore’
	9/6-9	‘it’s an alternative state of mind maybe?’
	7/7-9	‘it was partly to do with reducing my medication which brought on the psychosis’
Managing personal meaning	7/17-18	‘my therapist thinks…underlying depression’
	8/10-12	‘like a bomb was about to go off in me’
	7/27,28	‘to do with my identity and the struggle’
Coping with self	12/27-29	‘don’t know how I’m gonna really manage unless I get some sort of support network, for myself really’
	13/31-33	‘I don’t’ want to know too much about it’
	15/2-4	‘since then…felt like…restricted in some way’
Manage to retain own beliefs/opinion	7/25-27	‘I know it starts off with a depression’
	10/17-19	‘I suppose ill isn’t as bad as disabled’
	17/16-20	‘Maybe if I’d been able to talk it through, that would have helped, but they just gave me pills basically.’
Managing experience	6/25-30	‘I’ve just felt so good that I want to keep it going’
	11/32-34	‘don’t want to see my life remaining…the way it is…in receipt of benefits for the rest of my life’
	12/5-7	‘I’d love to come off benefits and find a job’
	13/28-30	‘I had just nearly died…just happy to be alive’
	15/2-4	‘ever since…felt like …I’m being restricted in some kind of way…I don’t know’
	24/18-24	‘I have my ups and downs…need somewhere safe’
Fight for self	5/33,34	‘it’s like me against the world’

Fight for sanity	24/18-26	‘not saying I don’t have my ups and downs’
Fight for identity	21/24-29	‘ignorant towards it…put into this role of patient…don’t ever see you’
Fight for support	24/23-29	‘need somewhere safe…didn’t feel safe in hospital’
	25/2,3	‘I needed to be somewhere’
	25/25-32	‘it was difficult…home treatment team to come around when I needed them’
	26/1,2	‘what else would help…a place of safety’
Fight/cope with ‘the system’	16/22-24	‘it’s hard to say how I feel about the diagnosis…sometimes it’s been helpful and sometimes it just hasn’t and it’s difficult’
	22/1-3	‘other people that are in the services…think like that, that once you’re in the services that’s where you remain’
Fight others	21/22-25	‘they’re a bit ignorant towards it…I get quite annoyed’
Cope/fight mental health services	16/5-11	‘difference in services…jumping on my every word…taking things so seriously’
Fight to resist power of diagnosis	14/16	‘now I’m just trying to overcome that diagnosis’
	19/28-32	‘says to me I’ll never recover…I don’t want to look at it like that’
	22/8,9	‘it’s kind of almost like a job…almost like an occupation’
Resist acceptance of diagnosis	14/17,18	‘upsetting at times having this sort of diagnosis’
	17/31-33	‘don’t think it’s medical…or given a label’
	19/22-26	‘it’s* (*condition) saying, I can’t help it’
Managing inconsistent information	13/9-19	‘they said I had bipolar…prior to that…psychotic depression…then I got diagnosed with schizoaffective disorder, then four years ago I was diagnosed with bipolar disorder…then reverted back…’
‘Work to do’		
weight of history	22/30-34 & 23/1,2	‘a guy…psychotic state…pushed somebody into the lion’s den, back in the 80’s or 70’s? ... didn’t give a good perception of people with mental health conditions’
Manage/cope with other’s/families’ beliefs	9/12-16	‘psychotic…to me it’s not offensive…but to others it’s what they think’

		‘sometimes I feel offended…how people write…about mental health’
Manage feelings	2/16-20	‘I just wanted to contribute…I’ve been wanting to get away from it as well’
	2/22-29	‘I was quite pleased, I wasn’t upset by it’
	23/9-19	‘one of the students said I looked like I’d come out of an asylum…suddenly felt really upset’
Manage other’s fear and own fear	2/13,14	‘it felt quite frightening’
	5/4-8	‘fear I’ve lived with for a long time’
	7/31,34	‘I guess losing my mother…I used to worry about that as a child’
Managing other and family relationships	23/20-22	‘my family…some…don’t understand at all’
Managing consequences of stigma of a mental health diagnosis e.g., schizophrenia	22/11-15	‘I start to interpret it, that this is my job in the world, my occupation is to be this sick person’
Cope with media/drama representations of psychosis	22/33,34 &23/1,2	‘he was very unwell…didn’t give a good perception of people suffering with their mental health’
Managing friendships	12/13-16	‘I wrote her a letter recently…she felt I was somehow draining her’
	23/17-19	‘people make little jokes…they don’t realise how it affects people that have actually suffered with this’
Managing/coping with other’s knowledge: labelling/diagnosis	9/20-22	‘people say she’s ill or disabled, I find that more offensive…than psychotic’
	9/28-33	‘housing form…referring to mental health as an illness or disability…easier for them’
	10/3,4	‘I guess it works for others, for you know, the general public’
	10/23-28	‘maybe they could call it mental health…I don’t even like the word condition’
	14/15	‘at first it was good to have a kind of diagnosis’
	17/1-9	‘I just see it as the clinical way of making sense of my experience…don’t think there is a diagnosis that… I could put on my life experience’

TABLE OF SUPERORDINATE THEMES AND THEMES FROM PARTICIPANT 3L
(*master theme – 'manage & cope/fight & struggle'*)

Themes	Page/ Line	Key words/extracts
Fight for personal meaning	4/7,8 4/33-35	'weird saying you're grounded when you're completely psychotic, but there we go' ''psychic element within psychosis'
Fight for sense making/understanding	5/18-21	'struggle I've had…make more sense out of it'
Managing personal meaning	4/10	'I hear voices from my friends'
Coping with self	16/23-27	'I still think I'm unravelling that'
Manage to retain own beliefs	10/9-11 30/23 30/27-29	'I did recover my sto:ry, my material story, the ordinary living story' 'I won't entertain the story that isn't helpful to me' 'developing a narrative about my life'
Managing experience	4/8,9	'it was a way of managing what had become disturbing voices'
Fight for self	22/34-36 24/10-13 30/24-29	'extra work against the fact…the first thing that people think is schizophrenia is dangerous' 'BPD…stigmatising…whole being is disordered' 'don't label ME with what this label means'
Fight for sanity	4/31,32	'it wasn't a battle of faith…battle for sanity'
Fight for identity	9/22,23 22/31-35 24/26-30 25/34,35 26/1-7	'all of those things were really important to keeping my confidence.' 'being added another layer…extra work to do' 'trying to get to the heart of a person' 'have to tell myself it's fine…I have to not sink into it' 'skimming across the top of it…could become the story of me'

Fight ‘the system’	29/34-35 to 30/1,2	‘mental health services find it very difficult, to get, keep somebody on a diagnosis of depression, all their lives with a bit of psychosis going on occasionally’
Fight mental health services	11/13,14	‘I would be really cross if, if, they changed my diagnosis now’
Fight to resist power of diagnosis	22/8-12	‘I would be actively working against what I think that means for people’
Resist acceptance of diagnosis	19/21-23	I’ve worked against the diagnosis’
	22/8-11	‘I would probably be disowning it (schizophrenia)’
‘Lucky escape’	17/32-34	‘fortunate they diagnosed me with psychosis…didn’t add an extra layer’
Managing inconsistent information	7/18-20	‘you can’t have had psychosis…infuriates me’
‘Avoid being buried’	19/3,4	I seem to have… skimming across a diagnosis’
Work to do	31/24	‘it’s a big task making sense of it’
	12/1,2	‘add extra layer, trouble to actually what I’m experiencing’
	26/32-33	‘travels with me all the time’
	29/16-19	‘little snippets, it’s never a big discussion’
‘weight of history’	7/10-14	‘schizophrenia…I would have struggled with the weight of history’
Manage other’s/families’ beliefs	11/22-26	I would be dealing with an extra layer…if I had a diagnosis of Schizophrenia, what would I say to my family?’
	25/18-22	‘a relative…prejudiced about my ability to remain sane…difficult to cope with’
Manage other’s fear and own fear	11/34,35	‘can you have a family? … questions in their minds’
	12/9,10	‘difficult for family’
	25/23-30	‘I’m in that state…they get worried…distressed’
	31/14-21	‘it still holds quite a lot of fear’
Managing other and family relationships	12/6-8	‘big problem is keeping your family relationships’
	26/24-26	‘she can’t cope with it’
	29/16-19	‘I sometimes have short chats’

Managing consequences of stigmatising label of ‘schizophrenia’	12/12-15	‘compounding the problem multiple times’
	22/7-12	‘if I’d had a diagnosis of Schizophrenia…I’d probably be disowning it’
	21/22-25	‘depression…been there done that’
Cope with media/drama representations of psychosis	22/13-16	tolerate… the dramas about…mad psychotic people that do harm to others’
	22/16-19	‘distance between what they are describing in the press and me…tolerate…live with’
	23/15	‘in that sense, I feel I can navigate’
Managing friendships	23/12,13	‘say you’ve had depression…cause half the population’s had depression’
	28/22-27	‘she knows it means……..’
Managing other’s knowledge -labelling	28/19-20	‘don’t want to educate her’
	28/29,30	‘I don’t talk to other people about it’
	29/18-22	‘we’re all experiencing the same phenomena in a weird way, which makes it even weirder, because they’ve probably got a different diagnosis to me’
	29/26-31	‘person I spoke to...age at which they started to have their phenomena…might even be paranoid schizophrenia?’

TABLE OF SUPERORDINATE THEMES AND THEMES FROM PARTICIPANT 4N (*master theme – ‘manage & cope/fight & struggle’*)

Themes	Page/ Line	Key words/extracts
Fight/struggle for personal meaning	34/9-11	‘desire for a future… gave me hope that I could recover…I couldn’t have got better without actually wanting to’
Fight and struggle for sense making/understanding	4/12-18	‘so, on multiples of 7 (*mins) had to think really, really good things…multiples of 13 had to keep my brain empty for a whole minute’
Managing personal meaning	10/7-12	‘read an article…this is actually what I am going through’
Coping with self	11/15-17	‘it was this odd juxtaposition kind of…romance, fantasy and utter debilitating despair’
	28/15,16	‘really painful…art college for a bit…then I left’
Manage to retain own beliefs/opinion	24/12,13	‘I forget out there amongst everybody else, there is a great deal of misperception’
Managing experience	4/12-18	‘obsessed with time and numbers…this was happening all the time’
	6/7,8	‘that was it, I just had to kill myself’
	7/14,15	‘I just said I was already seeing one (*psychiatrist)’
	14/8-10	‘in the hospital for a while seen people… in and out…the chronic hospital’
	18/1,2	‘episodes of depression that I have never sought treatment for’
	31/4,5	‘that was worse than the complete experience itself’
Fight for self		
Fight for sanity	2/8,9	‘I just knew that I had to do something to myself, to feel better’
	4/6,7	‘I actually used to fantasize, I never made it, but I wanted to create a helmet to stop it’
	5/2,3	‘every day, every hour…because otherwise disaster would happen’
	15/9-11	‘I do not want this (*inpatient) to be my future)

Fight for identity	15/9-11 18/10,11 23/8,9 28/13-15	‘I do not want this (*inpatient) to be my future’ I refused to give in to it, and I refused to let it define me’ ‘it’s a way of saying please help’ ‘she’s mad…really painful’
Fight for support	23/8,9 35/7-9	‘it’s a way of saying please help’ ‘lucky to have GP’s support because without him, I actually don’t know how we’d have done it’
Fight/cope with ‘the system’	34/12-14	‘I needed the support of my parents…to fight the system’
Fight others	26/13-16	‘initially wanted to… just tear strips off him (*judgemental mental health worker)…I get very angry’
Cope/fight mental health services	35/9-11	‘told him (*psychiatrist) I’m off the medication, he was absolutely raging, he was really furious and just said, “well, you’ll be back.”’
Fight to resist power of diagnosis	26/4 27/15-17 28/4-8	‘personally, I feel they’re (*diagnosis of schizophrenia) very, very unhelpful’ ‘started to feel shame…that is what fuels my anger now, it’s what the diagnosis does to people’ ‘scape goat…paints every single person with that diagnosis in the same light’
Resist acceptance of diagnosis	20/13-17	‘I was questioning whether it was paranoid schizophrenia…but I don’t think it was’
Managing (inconsistent) information	10/4,5 33/5-7	‘a lot of it (*psychosis) is intermingled with the way I think about it now’ ‘I don’t know why we were allowed to read the notes…I do think those nursing stall quite rebellious’
‘Work to do’	5/12-14 17/14-16 18/17 26/13 31/2,3	‘I’m going to do my ‘A’ levels for everybody then that’s it’ ‘been a long journey…I hid it for a long, long time’ ‘after having hid it for years, I told 2 friends’ ‘I will challenge him’ ‘it (*meds) made the recovery a lot harder’

weight of history	2/7,8	‘in those days it wasn’t in the cultural lexicon’
	8/9-11	‘paranoid schizophrenia’
	15/7-9	‘in a funny way, I feel privileged to have seen that (*Victorian psychiatric hospital)…it’s part of history now’
	17/3	‘No this was the late 80’s it was an illness’
	23/11-13	‘I don’t think they’re (*media) interested in …reframing this experience…let’s drop the label’
	35/9-11	‘told him (*psychiatrist) I’m off the medication, he was absolutely raging, he was really furious and just said, “well, you’ll be back.”’
Manage/cope with other’s/families’ beliefs	20/9,10	‘when I told them about my experiences as an 18yr old it was more…this is in my past’
	29/16-18&30/1	‘I don’t know…had I gone in and said, ‘I had some unusual perceptual experiences’, which is how I refer to it now – don’t think it would have made much difference’
	30/4-7	‘difficult to find a way to talk about this…I think it (*schizophrenia) scares people’
Manage emotions/feelings	26/12-14	‘really angered me, had to sit with that (*judgemental opinion individuals with emotional instability), I will challenge him’
	33/3,4	‘I was furious about that, I was angry at the time’
Manage other’s fear and own fear	2/11,12	‘parents saw the cuts once and their response was of utter horror…so I kept them hidden’
	6/2,3	‘I couldn’t bear the terror… thinking that people were just in my head’
	11/6,7	‘filling it (*questionnaire) out as I was then not as I am now’
	15/9,10	‘it (* seeing psychiatric hospital) was an eye opener and really shocking’
	30/6,7	‘whether you use the label or just the descriptions of the phenomena, I think it scares people’
	30/9	‘fundamentally, the whole thing (*schizophrenia) terrifies people’
	35/11-13	‘told him (*psychiatrist) I’m off the medication, he was absolutely raging, he was really furious and just said, “well, you’ll be back.”’

Managing other and family relationships	2/11,12	‘parents saw the cuts once and their response was of utter horror…so I kept them hidden’
	5/13,14	‘so, I did my A levels for everybody else’
	21/5-7	‘we skirt around it(*paranoia/unusual perceptual experiences)…my parents just don’t want to talk about it’
Managing consequences of stigma of a mental health diagnosis e.g., schizophrenia	17/14-16	‘I hid it (*schizophrenia diagnosis) for a long, long time’
	22/5-9	‘I was in a group of fellow trainees…I disclosed I had been diagnosed with schizophrenia’
	27/13-15	‘I also experienced a great deal of discrimination and stigma and that’s when I started to feel shame around the diagnosis’
	28/1,2	‘role in society…not a fulfilling one’
	28/9-13	‘I personally experienced discrimination…I heard her announce to the room…she’s mad’
Cope with media/drama representations of psychosis	23/10-16	‘the way the media talk about it…media needs things they can hang stories on, sensationalise’
Managing friendships	22/2-4	‘friends – don’t really talk about it…recently…I started disclosing it’
	27/12-14	‘I had some very nice friends that spent time with me but what I also experienced was a great deal of discrimination and stigma’
Managing/coping with other’s knowledge: labelling/diagnosis/info	20/4,5	‘I did term it (*schizophrenia) as depression’
	24/16,17&	‘I’ve only recently been calling it despair’
	25/1,2	‘I have to park the analysis…and focus on person centred approaches’
	26/8-12	‘one of my students…mental health supporter…judgemental and unpleasant about people with emotional unstable personality disorder’
	29/14,15	‘my experience of it (*schizophrenia) using those words is incredibly unhelpful’
	35/10-13	‘told him (*psychiatrist) I’m off the medication, he was absolutely raging, he was really furious and just said, “well, you’ll be back.”’

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