UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES
Centre for Innovation and Leadership

Living with Psychosis as a Longer-term Health Condition: an Interpretative Phenomenological Analysis (IPA) study

by

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Thesis for the degree of Doctor of Clinical Practice

February 2015

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

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LIVING WITH PSYCHOSIS AS A LONGER-TERM HEALTH CONDITION: AN IPA STUDY

Wendy Jane Turton

This thesis details a phenomenological research study into the lived experience of living with psychosis as a longer-term health condition in Southern England between 2012 and 2013. Ten people living with psychosis and supported by NHS Community Adult Mental Health Services participated in in-depth interviews about their lived experience, which were analysed through the application of IPA. Five super-ordinate themes emerged: *The Awfulness, Psychosis as a Volitional 'Other', What is Real?, The Distressing Tyranny of Voices,* and *Liberation*. The degree of experiential convergence within themes was high and determined by the level of explicitly or implicitly expressed separation from the psychosis.

The study reveals an underestimated on-going awfulness, specifically compounded by voice hearing. A heightened sense of vulnerability and threat is experienced and a loss of confidence in being able to keep the 'self' safe from the psychosis, which is perceived as a malevolent 'other'. This is accompanied by a loss of confidence about what is real and what is not. Subjective realities suggest strongly that recovery-supporting 'liberating' interventions need to go beyond anti-psychotic medication. Findings resonate with the extant phenomenological literature and reawaken the debate about reconceptualising longer-term psychosis as a trauma response to extraordinary and self- altering experiences.

The thesis highlights that phenomenological research findings into the lived experience of living with psychosis as a longer –term health condition show a congruency and appear robustly salient with the subjective realities of living with psychosis yet remain under-represented in informing both people who are living with psychosis and mental health practice. The discussion focuses on the relevance of findings for clinical practice with people living with psychosis and on issues of using phenomenological methodologies such as IPA to explore the lived experience of psychosis.

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DECLARATION OF AUTHORSHIP

I, Wendy Jane Turton, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Living with Psychosis as a Longer-term Health Condition: an IPA study

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before.

Signed: ....

Date:...

Acknowledgements

Always my most loved family who have given me support, admiration, and enthusiasm when my own was waning.

Thanks to my Academic Supervisors, Dr Jo Brown (University of Southampton) and Professor Steve Tee (King's College, London) for the generosity of their unstinting academic support – I have learned so much through our time spent together.

Southern Health NHS Trust and Wessex Deanery who supported me to pursue my studies whilst in their employ and to the Faculty of Health Sciences at the University of Southampton who continued to support this pursuit once I had joined their family.

To Lisa and Susan for invaluable and fun peer support.

Thanks to Hans Zimmer and Lis Gerrard for composing the music for Gladiator which, for reasons that remain unclear, spurred me to 'write on' when all else failed.

Leslie, Phil, Chris, Marina, Gill, Viv, Bridget, Mandy, Alex, Terry, who live with and beyond psychosis, I hope I have meaningfully expressed the essence of your lives, thank you.

And to Sarah, my friend, who couldn't live with psychosis – remembered with love.

> *'May I be a guard for those who need protection*
> *A guide for those on the path*
> *A boat, a raft, a bridge for those who wish to cross the flood*
> *May I be a lamp in the darkness*
> *Enduring like the earth and the sky*
> *Until all beings are free from sorrow*
> *And all are awakened.'*
>
> Daily Meditation, His Holiness the 14th Dalai Lama, Tenzin Gyatso

Chapter 1: Introduction: Living with Psychosis as a Longer-term Health Condition: an IPA study

'Let that which shows itself be seen from itself in the very way in which it shows itself from itself.' (Heidegger 1962, p 58)

Living with a misunderstood and potentially devastating mental health condition, which impinges on every aspect of yourself and your life, where there is no consensus on best treatment, and where instead of social support there is stigma and exclusion, is undeniably something that no one would consider acceptable in our modern world. For people living with psychosis as a longer-term health condition, this is their likely lifeworld: a world of fear, distress, alienation, stigma, misunderstandings, loss, and poor treatment options. Psychosis is a recoverable condition for nearly half of people who develop it (Thornicroft et al. 2007), but for those people who move into only partial or unstable recovery, the ongoing experience makes life challenging, and both prioritising and support offered by health services is inconsistent (Prytys et al. 2011) and often lacking in effective recovery-promoting interventions (SANE et al. 2014).

It is my conjecture, from my many years of working in NHS mental health services, that the understanding of psychosis has become conceptually-relative and fragmented, and is frequently distanced from the lived experience. A consequence of understandings which lack consensus and adequacy is that treatment for psychosis is not necessarily targeted at the parts of the experience which may best facilitate recovery. Whilst there is much laudable and compassionate practice in UK mental health services and clear national guidance, interventions appear to have become ad hoc and practitioner dependent, and tend to be decided more by prevailing resource structures, ideologies, and professional power structures rather than the needs of the person living with the psychosis. Understandings and interventions remain based in competing theories, sometimes based more in assumption, extrapolation, and tradition, and dependent on service culture. Further, within the mental health field some evidence seems to influence practice yet some equally valid evidence does not. I have also come to wonder if mental health nurses have become disenfranchised from promoting best practice and having an equally weighed professional influence on practice change.

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I suggest that if we were able, in this currently highly pressured mental health environment, to take a breath and step back from our practice for a moment, the unsatisfactory nature of how we, as mental health practitioners, are currently attempting to help people living with psychosis to recover and the demoralising impact that this has upon mental health professionals would become clear, and lead to the asking of better questions to the right people in order to improve understandings of and interventions for psychosis.

This thesis critically addresses these reflections in its journey towards and beyond its primary inquiry into the lived experience of psychosis as a longer-term health condition through the application of Interpretative Phenomenological Analysis (IPA) (Smith et al. 2009). Through eliciting the lived experience and sharing the information, the thesis aims to offer an emically-based understanding of that lived experience which can influence understanding and interventions for the experience.

1.1 The Journey

> *'Even the longest journey must begin where you stand.' Lao-tzu (604 BC-531 BC)*

The research focuses on those people for whom psychosis has developed into a severe and enduring mental health condition or longer-term health condition, and who are in receipt of mental health care from adult mental health services, mostly through involvement with community mental health teams.

The experience studied in this research is persistent 'psychosis' (British Psychological Society (BPS) 2000). The research harmonises the two terms 'persistent psychosis' and 'schizophrenia', viewing them as synonymous because in either state the continued experience is multi-dimensional and not solely rooted in primary symptoms such as anomalous sensory perceptions and delusional beliefs. The experience of psychosis by participants is required to be one that has not reduced after one or two discrete episodes, and continues through its primary or secondary 'symptoms' to impact on, or to define, in the participant's opinion, their life. This continuing experience is defined in the study as 'living with psychosis'.

There are three exciting facets of this research, firstly that it uses the 'emic' knowledge base of the experience of living with psychosis in the UK today aiming to *'go back to this thing itself'* (Heidegger 1962). Secondly, that it takes an open and expansive approach to the experience of living with psychosis rather than focusing on one domain, which is a more common practice. It does this through the application of systematic and rigorous qualitative analysis, IPA, to the data and uses the generated information to develop understanding of the experience and so inform mental health practice. Finally, in its synthesising of its findings within the existing phenomenological knowledge about the phenomenon of living with psychosis, it aims to promote an evidence-based phenomenological perspective of longer-term psychosis in nursing practice.

The journey of the thesis begins in Chapter 1 by reflecting on why this particular mental health experience and phenomenological methodology were chosen, preceded by an explanation of why such reflexivity is important. Phenomenological writings can appear unusual in academic terms because the use of reflection positions the researcher as an active participant in the work, but there is an auspicious precedence for this (Davidson et al. 2004): Plato had Socrates looking over his shoulder, Socrates had his Daemon, and I shall have my reflective self looking over my shoulder.

The thesis moves forward into Chapter 2 by considering how psychosis is present, understood and misunderstood in England at this time, how it is served by mental health services, and our current knowledge and guidelines on intervention. Chapter 3 continues the journey with a consideration of historical and current conceptualisations of psychosis and the conceptual uncertainty that plagues our understanding of psychosis, before, in Chapter 4, discussing the research methodology chosen for the exploration. Chapter 5 presents the research study itself with Chapter 6 presenting the findings from the data.

In Chapters 7 and 8, the thesis offers a critical and detailed discussion of the findings along with a consideration of the implications for practice in terms of developing both understanding and recovery-promoting interventions for people who live with psychosis. A critical analysis of the study brings the journey to its end along with a concluding section drawing together the threads of the new knowledge gained through this research and recommendations for future research.

1.1.1 The Interpretative Phenomenological Analysis Study

‘There is music in words, and it can be heard you know, by thinking.’ (Doctorow 2009, p9)

Using IPA as a research methodology has implications not only for the method, but also for the way the thesis is presented. As IPA is an iterative and idiographic methodology, the Findings

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Chapter is of paramount importance for the study's validity and is presented as a long and expansive section. Equally, as IPA is data-driven rather than theory driven, findings will be discussed in the Discussion section in line with existing theories and literature which may not have been noted in the introductory chapters.

Phenomenological study strives to study phenomena from a position that is outside of theoretical commitments (Gallagher & Zahavi 2012), seeking to be critical and avoiding theoretical prejudices. It also seeks to be guided by what is actually experienced rather then what is expected to be found given potential fore-knowledge of theoretical constructs, and to allow such experiences to subsequently critically inform such theoretical commitments. In line with phenomenological and specifically IPA methodology (Smith et al. 2009), the use of and analysis of the literature was performed differently to that expected within quantitative analysis. The method utilised here, adherent with the principles of IPA, has been initially, to immerse myself in etic and emic writings and undertake a broad exploration of the multifaceted experience of living with psychosis, how it was understood within and outside of western psychiatry, and its historic and current socio-political contexts; this I have termed a 'scoping' review of the literature. The research base was then appraised to ascertain what research methodology had been used previously to inquire into the experience of living with psychosis, specifically how IPA had been utilised. These two activities supported the rationale for the meaningfulness of exploring such an experience from a phenomenological perspective and the refining of my research questions. The in-depth critical analysis of IPA research into living with psychosis was completed after the analysis in line with the principles of IPA and Heideggerian phenomenological philosophy (Heidegger 1962; Etherington 2004; Spinelli 2005; Mapp 2008) to avoid the enhancing of fore-knowledge and pre-conceptions about the findings. There are similar methodological arguments made for placing this type of in-depth critical analysis of existing research in the post-findings section of the text (Smith et al. 2009; Shinebourne 2011) but, having completed the critical analysis post hoc of the findings to avoid potential contamination of this study's idiographic method and its findings, an informed choice has been made to follow a standard academic template for presenting this research.

I have found this a very useful approach as not only do I have years of experience of being vicariously immersed in the experience of psychosis, but over that time I have developed theoretical and practice biases which I was able to accommodate to through the rigorous application of IPA methodology.

Phenomenological research requires us to be cognisant of the socio-political and cultural context of the research area (Yardley 2000) and the thesis sets this context by discussing the conceptual history of psychosis, its modern day context, and the socio-political, cultural, and health context for people who currently living with psychosis in England. This criterion is one of four that Yardley delineates as significant for rigour and validity in qualitative enquiry in health research. The first noted above, is ‘sensitivity to context’ and also incorporates an explicit and sound grasp of any study’s underpinning philosophy which for this study is Heideggarian Phenomenology (Heidegger 1962). The other three, ‘commitment and rigour, transparency and coherence, and impact and epistemological considerations’ (Yardley 2000) are addressed throughout.

1.1.2 Reflexivity

> *‘[Reflexivity] permeates every aspect of the research process, challenging us to be more fully conscious of the ideology, culture, politics of those we study and those we select as our audience.’ (Hertz 1997, p.viii)*

Reflexivity in IPA is defined as *‘deliberate controlled reflection’* (Smith et al. 2009, p. 189) and, in phenomenological research methodology such as IPA, is a key method of enhancing the rigour and validity of the research (Finlay 2014). This phenomenological reflexive process needs to be applied throughout the entire research process from early design and setting out the rationale, through information gathering, the study procedure and analysis (sense making), and within the discussion of findings (formal connecting with theory) (Smith et al. 2009). With IPA, the research process must remain true to the IPA methodology and its theoretical underpinnings, and so reflexivity becomes more than a means of checking for subjective biases and is a primary methodological vehicle that supports the rigour and validity of this relativist approach and, importantly, tempers the possibility of:

> *‘ navel gazing, solipsism, self-indulgence or narcissism’(Etherington 2004, p 31).*

In IPA, the inclusion of the self of the researcher in the research is intentional and not to be avoided; Etherington (2004) however, cautions that the inclusion of ourselves through such omnipresent reflexivity needs to be

> *‘a means to an end, not an end on itself’ (p.31)*

She highlights this with a quote from Behar (1996 cited in Etherington 2004 p31) that conveys articulately the essence of appropriate and meaningful reflexivity:

> *'exposure of the self should not be a decorative flourish or exposure for its own sake, but rather to help take us somewhere that we wouldn't otherwise get.'*

Through reflexivity, the researcher deliberately and self-consciously engages with their own experiences and contexts which they are aware are pertinent to the research topic, and this engagement, because it is shared within the research presentation, informs the process of enquiry and its outcome. Of course, it is unlikely we will be aware of all our pertinent experiences and knowledge fore-structures (Heidegger 1962) prior to the research process, and continued reflexivity supports our awareness of research-activated self-experiences which are equally pertinent in the enquiry.

Transparent reflexivity affords the audience the opportunity to better understand and contextualise the research because they are informed about the position the researcher has adopted in relation to the study. The inclusion of transparent reflexivity denotes that there will indeed be a good amount of myself in this thesis, woven throughout in addition to discrete sections of researcher reflection in the text. If done well, I should be present for the entire thesis without the research becoming about me and my experiences.

The thesis journey proper begins with a reflexive piece offering self-contextualisation for my choice of research topic, *the lived experience of living with psychosis as a longer-term health condition*.

1.1.3 Self-contextualising

> *'Make it thy business to know thyself, which is the most difficult lesson in the world.'*
> *(Miguel de Cervantes 1547-1616)*

The essential question when positioning myself to the topic for this research is *'How does my Doctoral research topic, living with psychosis, connect to myself ?'* (Etherington 2004). Psychosis has been of interest to me for many years and on many levels. My interest in the experience of psychosis was fuelled during the early years of my training in the 1980s, thanks to a charge nurse on my first psychiatric acute admission ward (John B) who is probably unaware of how influential his guidance was to me. John encouraged me to sit and talk with the patients on the ward, to talk with them as people, not to view them as clinical presentations of an illness. I learned so much from the patients who sat with me and told me about their lives with and beyond their experience of psychosis, and this experience defined my career and, importantly, my approach to mental health nursing and people living with mental health problems. I have subsequently focused my mental health career to become a British Association of Behavioural and Cognitive Psychotherapists (BABCP) accredited Cognitive Behavioural Nurse Therapist, specialising in working with people living with psychosis.

Between April 2004 and January 2013 I was privileged to be the Clinical Lead and Manager of PSIPS – the Psychosocial Interventions for Psychosis Service – a small NHS mental health team which specifically worked with people who were living with psychosis, offering evidence-based psychosocial interventions aimed at reducing the distress and life disruption engendered by an experience of psychosis. My contact with people who were living with psychosis was both therapeutically formal and socially informal. From 2006- 2011 I was very closely involved in the creation of two psycho-educational publications in partnership with adult mental health service users who were living with psychosis (Turton et al. 2009; Turton et al. 2010). During the project, people have shared their personal experiences of living with psychosis as a long-term health problem and detailed the breadth and depth of the impact it has had on themselves and their lives, their accounts emphasising that living with psychosis is not solely about its symptoms.

On another level, a personal level, I have experienced hypnopompic and hypnogogic (going into and coming out of sleep) (Kompanje 2008) visual, auditory, and tactile hallucinatory experiences since I was in my mid-teens. They are rarer experiences now but were frequent during these early years. These experiences, innocuous relative to those shared with me by people living with distressing hallucinatory experiences and diagnosed with psychosis, were accompanied by a sense of unbearableness and uncontrollability, with the world, my world, becoming this ‘other’ place, an unwanted experience. More recently, a very close blood-relative spontaneously shared with me his own visual hallucinatory experiences of his wife following her death. He actively welcomed the experience and was not unsettled in the slightest by her presence *‘she never hurt me in life, why would she do so in death?’*. He did not associate his experiences with fear or madness but as a natural part of bereavement. These experiences confirmed to me that hallucinatory experiences occur outside of a western psychiatric diagnosis of psychosis or indeed a disease process, and there is much evidence in the literature to support this (Romme & Escher 1993; Leudar & Thomas 2000; Teeple R et al. 2009; McCarthy-Jones S 2012). It aroused in me a curiosity about what causes one person to have such experiences and not become overwhelmed by them, and another to have their sense of themselves and their lives subsumed and determined by the experiences and this to be associated, in the majority, by high distress.

Finally, I offer a connection to my research topic of living with psychosis that is rooted in my personal values. I abhor unfair treatment of people in our world, and, as part of this, I remain appalled by the continued stigmatisation of people who live with psychosis by our Society and, sadly, within our mental health profession (McLeod et al. 2002). This stigmatisation is fuelled both by the media and by under-developed understandings of psychosis within our Society and within our profession of mental health nursing. I do not believe it is too grandiose an aspiration to want to make a difference through offering an emically informed contribution to the knowledge base of psychosis.

The Thesis journey is intended to captivate, stimulate, and inform, and I acknowledge the contribution of the ten people who shared their realities with me to give creation and meaning to this journey.

Chapter 2: Background: Psychosis

2.1 The Experience of Psychosis

> *'I felt there was something terribly wrong with me. I was swimming in confusion, misunderstanding and fear……I didn't know what was happening.' (David J. Fekete, p 33 in McNamara 2009)*

In the UK, the term 'psychosis' is used to cover a set of related conditions including schizophrenia, schizo-affective disorder, schizophreniform disorder, delusional disorder, non-affective psychoses, and affective psychoses (National Collaborating Centre for Mental Health 2014). Psychosis is a potentially serious and enduring mental health condition because its characteristic perceptual hallucinations can cause significant distress or drive unusual behaviours, and because conviction in extraordinary and culturally abnormal beliefs can fuel distress and also drive unusual and potentially risky behaviours (Kirkbride et al. 2011). These perceptual anomalies and paranoid, persecutory, and other forms of 'delusional' thinking are considered the 'primary' symptoms of psychosis in Western Psychiatry (American Psychiatric Association (APA) 2000).

> *'I have always felt very hurt and saddened by the things the voices have said, but actually began to believe them more and more as time went by. I was frightened of the voices because they encouraged me to commit suicide…..I felt I had no control over the voices whatsoever.'(Johnny Sparvang, p 222 in Romme et al. 2009)*

Someone who is experiencing psychosis may well hear voices that no one else can hear, see things that others cannot, may experience a sense of threat (paranoia or persecution) from known or unknown others, may perceive personal messages and reference from the media, and may struggle to order their thoughts or speech, or comprehend others motives, words or actions. They may find themselves feeling different from other people, losing a sense of belonging or connection, isolation and falling out of social and vocational roles may ensue. Behaviours change in line with the understanding of the world that is created by the experience and for most emotionality is high with distress, fear, and agitation; for others there is a malaise and a slowing down cognitively and behaviourally. Focus becomes very much on the internally created world and on internal experience.

People can experience ‘psychotic symptoms’ for a brief period or life long, they can be triggered by an evident stressor or can insidiously appear, they can detrimentally transform a life or be a one-off episode without major consequences. Such heterogeneity indicates that the experience of psychosis exists along multidimensional continuum from a severe disturbance in the self associated with frightening anomalous perceptions engendering high distress and interfering markedly with the ability for normative functioning, daily life, and prognosis:

> *‘Once arriving in the menacing empires and kingdoms of Psychosis I learned to cope with the agonising pain of my days which were long, terrible and full of internal and external noise: I could not concentrate or even begin the processes of thoughts, words that I had always trusted were scrambled and half formed, screaming and weeping and goading and on their edges with razor sharp teeth.’(Knight 2013, p 94)*

to experiences which are extraordinary but do not cause high distress and so allow life to continue normally with little interference or even possibly a benefit to the person (Romme & Escher 1993; Nixon et al. 2010a).

2.2 The Complexity of Psychosis

> *‘Exploring, studying and living within and through the phenomena known as madness has made me painfully aware of how little we know about the complexity of being fully human.’(Bassman 2012, p 269)*

Whilst diagnostically in Western Psychiatry the focus is on the ‘primary’ symptoms of the experience of psychosis, or those which are externally expressed or observed, there are additional characteristics of the experience: disturbance of Ipseity (the experience of the self), limited awareness of others, constant sense of threat and associated high arousal or emotional numbing, limited awareness of thoughts and emotions, poorer metacognitive awareness, and lack of goal directed behaviour (Fuller 2013). The disturbance in the self and the extraordinary beliefs can also be grandiose in nature, ascribing a special mission or status to the person, however, this creates its own stresses and functional interference.

> *'A lot of my delusions were grandiose, when you're thinking that you've got this special power or this special purpose on planet earth- the sense of responsibility that gives you! (Anonymous, in Turton et al. 2009)*

There is observable social impairment which is understandable given the distress, perception of threat, and/or extraordinary nature of the experience. There is also a turning inwards of focus because of the intensity of the experience and its associated emotional arousal.

> *'I have lived with [psychosis] for over half my life. The world was a threatening place, and I felt like a writhing snake with its skin torn off……it was so unbearably painful that I retreated within myself.' (Victoria E Molta, p57 in McNamara 2009)*

Cognitive deficits, rather than cognitive deterioration, are also a part of the experience of psychosis (Nuechterlein et al. 2009) pre-existing onset and persisting independently of symptomatic experience. Eight cognitive domains of impairment have been identified (Nuechterlein et al. 2004); processing speed, attentional processes, working memory capacity, verbal learning and memory, visual learning and memory, reasoning, problem solving, and social cognition, although, as with much of the understanding of psychosis, causation is unclear although possibly linked to neurological maturational changes during adolescence (Nuechterlein et al. 2004; Beck et al. 2009). These deficits are not solely biological in original, rather they are neuropsychological (Beck et al. 2009), arising from an interplay of potential neurophysiological insufficiencies with psychological factors such as reasoning and attribution styles, sense of self, and understanding of the world. If the ability to make sense of the actions of other people, or of anomalous perceptions, is challenged through a working memory deficit and an active cognitive distortion, perhaps an externalising attributional bias, then the sense made of a situation will be disadvantaged and the ability to experience a socio-culturally 'normal' life becomes impaired. This idiosyncratic sense-making may lead to stress and distress, and such cognitive deficits and resultant stress are argued to create the pathway for transition into psychosis (Beck et al. 2009).

For those who transition into enduring psychosis, there are often consequential secondary problems due to the devastation the episode of psychosis can wreak on the person themselves, their relationships, roles, and their futures. Cognitive deficits, because they are present and persistent, predict ongoing challenges in returning to normal functioning, social relationships, and independent living (Nuechterlein et al. 2009). Self-neglect and disenfranchisement from the opportunities of the social world frequently occur, self-stigma and societal stigma compound the experience and are deleterious to recovery (Time for a Change 2008). Harmful behaviour towards the self, and occasionally towards other people (Large & Neilssen 2011; Challis et al. 2013), may be part of the experience and this is an additionally distressing part of the experience for the person, friends and families, the mental health services, and for the wider society.

Secondary problems also include significant comorbid mental health problems (Naylor et al. 2012), in particular anxiety and depression, and life limiting physical health problems, some associated with anti-psychotic medication (Jones et al. 2006). Physical health problems seem to occur disproportionately for people living with longer term psychosis, particularly metabolic disorders associated with central obesity, and cardio-vascular and respiratory disorders. Physical deconditioning frequently occurs due to the psychosocial impact of the disorder and there is an excess mortality of ten to 20 years compared to the general population (Brown et al. 2010).

2.3 Epidemiology and Diagnosis in England

The Adult Psychiatric Morbidity Survey (APMS) (National Centre for Social Research & Department of Health Sciences University of Leicester 2009) gathers information on the Adult population of England every seven years, including the prevalence and incidence of mental health disorders and providing additional data on income and household characteristics. The latest Adult Psychiatric Morbidity Survey in 2007 reports a prevalence rate for psychosis in England, 2006 – 2007, of 0.4%, slightly higher for women than men (National Centre for Social Research & Department of Health Sciences University of Leicester 2009), and this rate has been shown to be stable since 1993 (Jenkins et al. 2009). The highest prevalence age for both women and men was between 35 and 44 years of age. The survey also showed its incidence to be about 1%, highest in early adulthood, with schizophrenia being the most common diagnosis. The current NICE guideline (National Collaborating Centre for Mental Health 2014) notes too that currently schizophrenia is the commonest form of psychosis but whether this is due to its actual incidence or, because it can be a persisting condition, its prevalence, is not clear. It could equally be because of the two diagnostic classification systems used in the UK are out of step with the clinical guideline by giving primary categorisation through the term 'Schizophrenia'. These systems are the ICD-10 Version 10 (World Health Organisation 2010) and the DSM-V (American Psychiatric Association 2013). There was a significantly higher prevalence of psychosis in 'black men' *[sic]* at 3.1% (National Centre for Social Research &

Department of Health Sciences University of Leicester 2009) but no ethnicity variance in women. Prevalence of psychosis correlated negatively with household income, the lowest income households having a higher prevalence, whether through cause or effect was not noted. Half of people living with psychosis were receiving some form of psychotherapeutic support, 65% were currently using mental health services, and over half had experience of being admitted to a psychiatric inpatient unit at some point during their life. Medication use was ten times higher than for people living with a non-psychotic mental health disorder, the majority of people living with psychosis are on a multi-pharmacological regime (Lochmann van Bennekom et al. 2013).

Psychosis has a disproportionate usage of mental health services, being less prevalent than other mental disorders but requiring more intensive mental health service involvement due to its seriousness (The NHS Information Centre 2011).

2.4 The Cultural Phenomena of Psychosis

> *'No society or culture anywhere in the world has been found free from schizophrenia.' (Barbato 1996, p1)*

Social and clinical historians note that people experiencing psychosis have not always been viewed as ill and yet their presentation and experiences have always had common defining elements (Berrios 1987) suggesting that it is temporal factors such as scientific knowledge and culture which determine our understanding of psychosis and so our treatment of people living with it. Socrates (Greek philosopher 470 – 399 BCE) self-reported being guided by an inner voice, his Daemon or Daimonion, which he allowed to inform his beliefs and to influence his actions (Leudar & Thomas 2000). Plato (Greek philosopher and student of Socrates 423-347 BCE) described Socrates' understanding of his daemon in his dialogue 'Theages' (Plato & Jowlett 2013)

> *'The favour of the gods has given me a marvellous gift, which has never left me since my childhood. It is a voice which, when it makes itself heard, deters me from what I am about to do and never urges me on.'*

Unfortunately for Socrates, disclosing about his perceived divine gift in his socio-cultural era led to his sentence of execution for blasphemy, which fortunately in the UK is no longer a response to hearing voices!

Chapter 2: Psychosis

The renown French philosopher Foucault (1926-1984) wrote that psychosis was taken to mean 'not real' (Foucault 1965 in Davidson 2003) once it was first conceptualised as a disease in Europe in the 17th century, prior to this such experiences were indeed seen to be intrusions from other realms. This reconceptualising of psychosis as an illness whose outward expression was without meaning coincided with the emergence of a medical profession and the field of science, where alternate realities were not entertained. Leudar and Thomas (2000) note that Socrates' daemon was re-considered a hallucination by 19th century psychiatrists and so Socrates, one of history's great philosophers, was subsequently diagnosed insane. As Nietzsche noted

> *'The Socrates' [daemon] which he explains in accordance with his prevailing moral thinking, but other than how it would be explained today.' (Nietzsche et al. 1878/1994, p126)*

Arguably then, it is our combined knowledge and cultural beliefs about psychosis that have played a significant role in how we detail our understanding of the experience at any particular point. Culture is of significance to psychiatry because culture defines normality and deviance, and attitudes towards emotional distress (Kalra et al. 2012).

There is evidence of differences in the course and the prognosis of the disorder across cultures (Jablensky 2007) and, frighteningly, robust evidence is building since a seminal research study in 1992 (Jablensky et al. 1992) that people experiencing psychosis in developing rather than developed countries (including the UK) have a significantly improved outcome (Bhurga 2006). This improved outcome includes complete remission rates (63.7% v 36.8%) and impaired social functioning (15.7% v 41.6%). More, only 15.9% of people in the original ten country study were on anti-psychotic medication in developing countries against 60.8% of people in the developed countries (Stompe 2009). Jablensky (2007) argues that it is cultural bio-psycho-social factors which influence these differences, from which can be inferred that it is also the reciprocal psychosocial factors of Society. Evidence that culture impacts on the experience of psychosis highlights the importance of the influence of the mental health care culture that operates in England on the outcomes and experiences of people living with psychosis; cultural knowledge and sensitivity being arguably essential qualities of mental health professionals (Stompe 2009).

2.5 Recovery from Psychosis

> *'The idea of illness, of illness that can never go away, is not a dynamic, liberating force. Illness creates victims' (Campbell in Read & Reynolds 1996, p 58)*

With mental health, recovery does not necessarily mean a 'cure', an extinguishing of anomalous experiences, or a return to the former non-psychosis self. Recovery is a personal rather than a clinical recovery, and is defined as the lived or real life experience of people as they accept and overcome the challenges of the disability (Deegan 1988); with psychosis such disability ranges from none to severe. People can and do recover from psychosis, both clinically and personally (Harrison et al. 2001; Thornicroft & Tansella 2003; Hopper et al. 2007; Romme et al. 2009), although there appears to remain for many living with and working therapeutically with psychosis a reticence to accept such findings. Williams (2012), a phenomenological clinician/researcher of the lived experience of psychosis, clearly articulated the observation that, whereas there is a

> *'widespread belief in [Western] society that people diagnosed with [psychosis] generally do not recover, the actual research tells a different story' (Williams 2012, p39).*

Williams (2012) defines recovery from psychosis as *'the abatement of the distressing aspects of anomalous experiences' (p 1),* aligning with the broader Recovery literature which gives primacy to personal recovery over clinical recovery (Deegan 1988; Romme & Escher 1993; Leudar & Thomas 2000; Romme & Escher 2012). Using this definition of the abatement of distress *from* anomalous perceptions rather than the *extinguishing* of them, Williams (2012) presents findings from 12 longitudinal studies into recovery from schizophrenia from 1974 to 2007 to support the concept of such recovery in psychosis. The research studies are culturally and methodologically heterogeneous: ten had between 105 and 502 participants, the other two having less than 100, and follow-up periods ranged from 15 to 37 years and all studies noted 'recovery'. Such methodological inconsistencies mean that results have to be approached with caution in terms of a meta-review; however, 'improved and recovery' rates ranged from 36% to 77% of people over the varying time periods. The largest longitudinal study, a WHO study with over 1000 participants from 18 global sites (Hopper et al. 2007), included a detailed 13 year longitudinal study of people (N=86) living with psychosis in Nottingham, England. Over these 13 years, only 24% experienced continuous psychotic symptoms, 69% had an episodic pattern, and this was in alignment with findings from the other studies which informed the WHO Report. This study revealed that the rates of hospitalisation reduced for most participants over time, employment was attained by 45%, 58% of the cohort continued to use anti-psychotic medication, and only 53% of the cohorts were still involved with mental health services.

Epidemiology studies concur (Thornicroft & Tansella 2003); for about 45% of people who develop psychosis there will be one or more florid episode but it will not become an enduring condition. For about 20% there are unremitting symptoms and increasing disability, and about 35% will show a mixed pattern with varying degrees of remission and exacerbations of different length having recurrences precipitated by stress, social adversity and isolation. The needs of people living with psychosis as a long term health condition, episodic or continuous, and attempting to sustain stability and wellness may require ongoing health or social care support. For example, an episodic, or relapsing and remitting, pattern of psychosis increases the risk of suicide and self-neglect (Wolfson et al. 2009) and opportunities and outcomes in terms of employment, income and social relationships are very much worse than in the general population.

2.6 Mental Health Practice and Policy in England

The clinical guideline in England for psychosis and schizophrenia (National Collaborating Centre for Mental Health 2014) is a fulsome document of 685 pages detailing the management and treatment of the condition based on *'careful consideration of the best available evidence' (p 8)* aiming to inform about service provision of high quality care for people living with psychosis and for their carers. The guideline aims through its clinical recommendations to improve engagement with treatment and services for people living with psychosis and makes specific recommendations for early intervention, crisis, and recovery. However, the clinical guideline, even in its two earlier forms (2002 and 2009), continues to suffer challenges in its implementation at both practitioner and service levels, so that whilst detailed evidence-based advice for the best treatment of psychosis and schizophrenia has been available for a number of years, the consistent provision of such care has not been (Prytys et al. 2011).

The current UK Government's mental health strategy was revealed in the cross party policy document 'No Health without Mental Health' (Her Majesty's Government & Department of Health 2011). This strategy places responsibility for our own and other peoples' mental health on each other, and proposes that we should all challenge stigma and discrimination towards people living with mental health problems; the strategy slogan being that ‘mental health is everyone’s business’. The latest mental health policy is the Closing the Gap report (Department of Health 2014) which identifies 25 priority actions to be undertaken by the NHS, charities, carers, individuals living with mental health problems, employers, social care organisations, and other agencies to promote sustainable mental well-being. In spite of policy and clinical guidelines, a favourable impact on the standard and ethos of care for people living with psychosis has not occurred and the current climate is one of drastic disinvestment in mental health services (http://www.bbc.co.uk/news/health-27980677).

‘The Abandoned Illness’ report (The Schizophrenia Commission 2012) identified ten areas of unsatisfactory outcome for people living with psychosis in England today including excess mortality, very poor access to psychological therapies even though it is recommended in the NICE Guideline, and very limited employment opportunities. The ‘Investing in Recovery’ report (Rethink 2014) noted a skewed provision of resources towards inpatient units rather than on the numerous effective community-based psychosocial interventions which offer beneficial outcomes in terms of relapse prevention and recovery. SANE et al. (2014) found further criticisms of current mental health provision for people living with psychosis; nearly 60% of people were not given any information at the diagnosis stage, and the information source reported to be the most reliable was a mental health charity, five times more so than mental health nurses and psychiatrists. Additionally, in spite of NICE guideline recommendations, a treatment choice of psychological therapies was discussed half as often as medication options, and only a fifth of respondents were in receipt of psychological therapy for which many had experienced significant delay, with 40% reporting that this limited access to psychological therapy was a reason for relapse.

Reports and research continue to reveal that care and treatment for people living with psychosis is not based on their actual experience, on the actualities and possibilities of the disorder, nor consistently on evidence or best treatment guidelines. The question of why this state of play persists needs to be asked. Its continuance could indicate that there is something fundamentally wrong with how we have come to understand the experience of longer term psychosis or schizophrenia and so are misinformed about its true nature and therefore meaningful recovery promoting interventions.

Chapter 3: Conceptual Context: Psychosis: The Problem of Conceptualisation

3.1 Wrong from the outset? Eurocentric development of the concept of psychosis

> *'Insanity is relative. It depends on who has who locked in what cage.' (The Meadow, Bradbury 2012, p538)*

The Eurocentric conceptual history of psychosis occurred in the pre-confederation states of emerging Germany, Austria, and Switzerland (Bürgy 2008). Whilst contested, Karl Canstatt (1807-1850), a German physician, introduced the concept of psychosis into the psychiatric literature in 1841, defining it as a 'psychic manifestation of a disease of the brain' (Bürgy 2012 p133) and siting its aetiology clearly, although with no evidence, in a physical disease process. From the middle of the 19th century the term psychosis became lodged in the emerging profession of psychiatry as a term applied broadly to insanity, mental disorder, and mental illness. Conceptual development continued with Emil Kraepelin (1856 – 1926) who developed his understanding from the observation of institutionalised patients and defined psychosis as Dementia Praecox, a chronic, unremitting disorder progressing only through mental deterioration to early death. Psychosis was viewed as a 'death sentence' whereby the person experienced increasing incoherence and withdrawal from the self-world, and inevitably from the social world too; death was viewed as a release for a tortured soul (Davidson 2003). Bleuler introduced the term 'schizophrenia' in 1911 to replace Kraepelin's 'dementia praecox'.

Hornstein (2012), a psychiatric historian and psychologist, notes that in the midst of the European medicalization of psychiatry, there was a lone voice, Freida Fromm-Reichmann (1889-1957) who continued to promote an underlying psychological cause for psychosis, that of *'abject loneliness caused by early experiences of trauma'* (Hornstein 2012, p xvi) which was amenable to healing through a therapeutic relationship.

Karl Jaspers (1883-1969), Kurt Schneider (1887-1967), and Eugen Bleuler (1857-1939) continued to explore the phenomenon and could be argued to have acted to entrench psychosis in the biological domain and concur on a broad conception of schizophrenia, claiming it as a unitary disease process in spite of the heterogeneity of its presentation and dearth of evidence, arguably beginning the process of abbreviating and objectifying the understanding of psychosis.

Today the persistence of the diagnostic ‘catch all’ category for persistent psychosis of ‘schizophrenia’ raises vociferous critical debate (Szasz 1961; Boyle 1990; Mcgorry 1994; Bentall 2003; Kingdon & Turkington 2005; Geekie & Read 2009). Critics argue that the concept of schizophrenia be abandoned as it is not an empirically reliable or valid scientific construct (Boyle 1990; Bentall 2003). It is argued (Mcgorry 1994) that the very existence of the category of schizophrenia , with its inherent reductionism and stigma, is an obstacle to both scientific and clinical progress in the understanding of the experience of psychosis. Indeed, following a popular campaign, the Japanese Society of Psychiatry and Neurology rejected the term schizophrenia in 2002 in favour of ‘Integration Disorder’.

In 2011, 100 years after Bleuler’s introduction of the term, ‘Schizophrenia’ continues to be a primary diagnostic category for the experience of psychosis in Western psychiatry, whilst the Critical Psychiatry Network in the UK (http://www.criticalpsychiatry.co.uk/) continues to call for the consignment of the diagnosis to history, citing research evidence that supports the notion that it has no scientific basis, is harmful, and leads to stigma (Critical Psychiatry Network 2011).

Dutch social psychiatry has been highly influential in this conceptual rethink of psychosis. Romme and Escher are Dutch social psychiatrists who have had since the late 1980s (Romme & Escher 1993), and continue to have (Romme & Escher 2012), a global impact on the understanding of hearing voices and psychosis. Romme and Escher believe psychosis to be an emotional crisis and even the term ‘psychosis’, let alone schizophrenia, is argued to be a ‘mystification’ which is harmful to those who experience hallucinations and are positively influenced by them, and equally creates terror in someone who is hindered by them (Romme & Escher 2012 p1). Romme and Escher have always stated that hearing voices or unusual beliefs are not in themselves signs of pathology and are ever-present in the population without associated distress or dysfunction, and this assertion has robust empirical support (Van Os et al. 2000). Whilst their work has been influential to the treatment philosophy in some NHS adult mental health services in England, such as in Manchester, Sussex, and London, most commonly within psychological therapy teams rather than across professional disciplines, Romme and Esher’s approach remains a radical position for many other of today’s UK mental health establishments. This adds to the inconsistencies in understanding and treatment for people living with psychosis. Such an approach though, has resonated and gained favour with people who are living with such experiences and with those given a diagnosis of psychosis by the psychiatric 'establishment', and has been perceived as empowering (Romme et al. 2009).

3.2 Psychosis: A Conceptually Relative Experience

> *'Psychiatry promotes and delivers treatments derived from a diseased, broken brain theory of mental illness. Simplistic explanations to de-mystify madness prevent us from expanding our knowledge of what is helpful.'(Bassman 2012, p 273)*

Even today, over 100 years since the attempts of European physicians to capture the understanding of persistent and distressing psychosis, it has not revealed itself to have one predominant cause. Conceptually there are now many theories for psychosis, its origins and maintenance, each indicating a particular clinical intervention. Geekie and Read (2009, p 112-136) separate theories into 11 categories depending on their primary emphasis, see Table 1.

Table 1 Theories of Psychosis as delineated by Geekie and Read (2009)

Biological	Evolutionary
Neuro-psychological	Psychological
Life Event	Communication/Family
Philosophical/Existential	Sociological/Anthropological
Stress-vulnerability	Spiritual

Each conceptualisation sees primary aetiology as being centred in their particular domain; for example, biological theories suggest different biological factors including genetics, biochemical, and brain structure as being implicated in psychosis (Stefanis & Stefanis 2009), whilst neuropsychological theorists (e.g.Frith 1992) look to neuropsychological impairments causing deficits in cognitive functioning for causality. More recently longer-term psychosis or schizophrenia is being argued to be a neuro-developmental disorder (Gross & Huber 2008) and neuro-regressive rather than neuro-degenerative because although full remission cannot be guaranteed, the disorder progresses only over five to ten years and recovery remains a possibility even after years of symptomatic experience. Some renown academic researchers into psychosis such as Parnas et al. (2010) and Bentall (2003)set their cap firmly outside of biological causation. Parnas et al. in particular citing that *'Psychosis is a phenomenological concept and we have no robust biological marker of its presence'* (Parnas et al. 2010p32)

Striving in the absence of agreement and robust evidence for an understanding of this observable state of psychological extraordinariness and accompanying distress, psychosis appears to be the experiencing of a cluster of identifiable symptoms whose aetiology may include a combination of factors - genetics, obstetric complications, psychological vulnerabilities, early abusive experiences, and internal and external environmental stressors - interfacing with possible vulnerabilities from disrupted frontal , temporal, subcortical, and/or neurotransmitter systems (Beck et al. 2009). Beck et al. (2009) suggest that it is likely, given the empirical evidence base to date, that structural and biological vulnerability factors probably arise early in neuro-development, possibly in-utero, but do not show themselves until further neural maturation transpires in adolescence; more, that such atypical brain functions lead to an atypical interaction of the individual with society due to a *'constellation of symptoms and cognitive deficits' (p61).*

From this perspective Beck et al are aligning with a bio-psycho-social model of psychosis (Zubin & Spring 1977; Nuechterlein & Dawson 1984). The bio-psycho-social model of mental health, also known as the stress-diathesis or stress vulnerability model, perceives mental health problems, including psychosis, emerging as vulnerabilities and stresses converge and become too great a task for the individual to manage. Within this model both the impact of stress on the individual and their predisposing vulnerabilities are recognised determinants of health. In mental health, this model supports the understanding that everyone has particular biological and psychological vulnerabilities to developing mental health problems or illnesses when combined with a 'critical' amount of stress in our lives. Nuechterlein and Dawson (1984) proposed that enduring vulnerability plus stress leads to a transient intermediate state of a cognitive, interpersonal, and intrapersonal processing overload which leads to 'outcome behaviour', i.e. psychosis.

Given the multiple conceptualisations of psychosis, it could be argued that psychosis remains a disorder where understanding is uncertain; its cause, manifestation, and even its maintenance or remittance remains ambiguous**.** Evidence bases are inconsistent (http://www.cochrane.org/) and the varying theoretical conceptualisations (Geekie & Read 2009) lead to remarkable differences in interventions and treatment consistency for individuals, and moreover they can obfuscate the reality of living with psychosis. Bentall (2003), a critic of current psychiatric orthodoxy, goes further:

> *'I suggest that we have been labouring under serious misunderstandings about the nature of madness for more than a century, and that many contemporary approaches to the problem, although cloaked with the appearance of scientific rigour, have more in common with astrology than rational science'. (2003, p8)*

In summary, current understandings are limited by clinical, aetiological, and psychopathological heterogeneity, and by competing theories, inconclusive research evidence, and the politics of psychiatry. This is compounded with persistence in attempts to push such a heterogeneous experience into a unitary diagnostic category of schizophrenia (Keshavan et al. 2011).

3.3 Psychological Theories of Psychosis

> *'My hearing voices was a perfectly natural response to the sadistic torture I experienced. Psychiatrists should stop asking, what's wrong with you? and start asking, what's happened to you?' (Dillon, in Hornstein 2012, p 20)*

The history of western psychiatry can be described as competing ideologies struggling for domination (Martindale, Chapter 2 in Romme & Escher 2012), with the biggest conflict between biological and psychological explanations for psychosis, a *'meaningless versus meaningful'* defining of psychosis. Psychological theories give emphasis to psychological processes in the aetiology and maintenance of psychosis and are the theories that support my own knowledge base through training and clinical practice (e.g. Chadwick et al. 1996; Morrison et al. 2004b; Chadwick 2006).

Studies in the 1980s finally showed that, in stark contrast to the Kraepelinesque position, people did recover from psychosis either to a significant degree or attaining full recovery, and that this recovery time ranged from a relatively quick recovery, to recovery after being overwhelmed by their psychosis for many, many years (Harding et al. 1987). These results were perhaps a little overlooked in psychiatry 1980s 'era of the brain' (Davidson 2003) and this was possibly due to the concurrent developments in psychotropic medication, particularly the phenothiazines, which acted to tranquilise the person and, so too, their response to their experience of ‘primary’ symptoms (see page 9).

This period arguably shows a divergence between the world of clinical practice and the world of clinical research. Research into the experience of psychosis continued yet its transfer into practice appears to have stalled. My own career in mental health nursing began in this era and my experience, because this was the very beginning of community care services, was of psychiatrist-determined care with an emphasising of medication and occupational interventions, and a near absence of psychological or psychosocial interventions. Care was very much about containment of symptoms and the prospect of recovery was not really embraced in the mental health services as care was institutional, bringing with it the challenges of institutionalisation and consequent obfuscation of recovery from the psychosis. However, outside of this era’s clinical treatments and mental health care, clinical research into psychosis continued and complex aetiological and maintenance models of a multidimensional and heterogeneous disorder emerged (e.g. Zubin & Spring 1977; Nuechterlein & Dawson 1984). These bio-psycho-social models, as noted earlier, were centred about the person with psychosis, allowing them to assume a role in managing and recovering from the disorder (Davidson 2003).

Particularly since the 1990s there have been significant developments in both psychological modelling of, and clinical interventions for, the experience of psychosis particularly in the development of cognitive modelling of psychosis and Cognitive Behavioural Therapy for Psychosis (CBT-p) (Chadwick et al. 1996; Morrison et al. 2004b; Kingdon & Turkington 2005; Chadwick 2006) and similar tentative moves have been made in the field of psychodynamic therapy too (Read et al. 2004).

Kingdon and Turkington (2005) align with all cognitive therapy theorists of psychosis in asserting that there is personal meaning in all anomalous experiences often termed ‘psychosis’, and that such experiences are on a continuum from ordinary to extraordinary, from unemotive to highly distressing, and from having positive impact on functioning to disrupted functioning. Without diminishing the intensity and impact of the experiences there is a normalising of them into meaningful self-experience. A bio-psycho-social framework underpins such cognitive models, and developing a shared understanding from the subjective perspective is key to collaborative, recovery-focused psychological interventions. CBT models for psychosis allow for the integration of internal and external factors which predispose someone to develop psychosis, i.e. distal and proximal vulnerability factors (Nuechterlein et al.

2009) such as neuropsychological factors (discussed on page 12). Such models further allow for the integration of precipitating, perpetuating, and protective factors (Kingdon & Turkington 2005) within the person and their life, significant to their experience of psychosis; this CBT framework is known as the 4Ps. Precipitating factors are those which cause the transition into psychosis, perpetuating factors are those which entrap people within their 'psychosis', and protective factors are eponymous, those factors which protect from descent into overwhelming psychosis and/or support recovery. For example, the experience of trauma in both childhood and adulthood is robustly shown to be a predisposing factor in voice hearing and to psychosis (Morrison et al. 2003; Larkin & Morrison 2006a; Beck et al. 2009; Freeman & Fowler 2009; Berry et al. 2014). Unresolved trauma incidents act further as precipitating and perpetuating factors for psychosis because of the neuropsychological and psychological impact of such events. In particular for psychosis, the actual experiencing of psychosis in all its distressing extraordinariness is a trauma in itself and this is sometimes further progressed through the treatments received in the care of mental health services (Larkin & Morrison 2006a; Berry et al. 2013). CBT models accommodate to such factors, and allow for a shared understanding of the interplay of these 4Ps to be developed, creating a bio-psychosocial overview of the experience, and identifying meaningful targets for recovery interventions and self-management.

So remarkable has this latter period been it might be considered a paradigm shift in the understanding of psychosis from a biological to a psychological perspective. Fuller (2013) a bio-psycho-social theorist of psychosis, concurs that there has been a welcome and radical shift from an *'oversimplified bifurcation'* (p1) of psychosis or not psychosis, towards, finally, a growing acceptance that psychosis is not solely a biological condition, and that it is aetiologically and experientially diverse; this shift offering an antidote to restrictive diagnosis categorisation that equally restrict proffered treatments. Aaron T Beck (1921-), the father of cognitive behavioural therapy, believes that the 21st century will herald a humanising trend towards psychosis:

> *'In contrast to the more mechanistic framing of schizophrenia in terms of abnormal brain chemistry or anatomical lesions, the new approach views the patient as a whole person troubled by apparently baffling problems, but also having the resources for ameliorating these problems.' (Beck foreword in Bentall 2003)*

The challenge, it seems, is how to embed these more relevant conceptualisations into today's everyday mental health care for people living with psychosis, and perhaps a turning towards the subjective realities of people living with psychosis is a meaningful starting point.

Chapter 4: Methodology and Literature Review:

Psychosis: Learning from Subjective Realities

4.1 The Subjective Experience

> *'Mental events do not occur in a vacuum; they are lived by someone.' (Thompson 2007 p21 in Gallagher & Zahavi 2012)*

Attempts at conceptualising psychosis in psychiatry appear, in the majority, to develop from 'etic' knowledge, that is knowledge coming from someone who does not experience for themselves the phenomenon, from an observer or theorist perspective (Davidson et al. 2004). In contrast, 'emic' knowledge comes from people experiencing the phenomenon and so is, in essence, subjective. The subjective experience of mental ill-health such as psychosis has much to offer understanding of the phenomena, and this is important because how psychosis is understood or conceptualized will be reflected in its treatment. Geekie and Read (2009) postulate:

> *'any understanding of madness which overlooks subjective experience will inevitably provide an incomplete and, ultimately, inadequate conceptualization of the experience'. (Geekie & Read 2009, p21)*

Subjective accounts of the experience of living with psychosis are increasingly available in the public domain. Hornstein (2012) amassed over 600 such first person narratives of people living in the UK and writing about their experiences of psychosis, she notes that these accounts talk not of chemical imbalances or scrambled electrical signals, but of *'captivity, insight, and resilience'* (p xvii). Of course, the subjective experience could be a result of bio-neurological changes, but Hornstein ponders, and I do too, that given this body of literature, why is this voice ignored in the shaping of our understanding of psychosis? Perhaps people living with psychosis are still deemed 'mad' by default and so their words dismissed as 'Jasperian meaningless'. Hornstein notes

> *'If we want to understand it, we need translators – native speakers, not just brain scans.' (Hornstein 2012, p xix)*

Subjective accounts talk not of experiencing primary 'diagnostic' symptoms, but of a recognition of being predisposed (vulnerable) through early trauma and abuse to developing psychosis, which is precipitated as current life events become too challenging to manage. Awful voices or powerful ideation are experienced, driving fear and distress, the very sense of the self become fragile, the outside world becoming threatening. Responses involve being plunged into negatively destructive emotional, cognitive, and behavioural experiences, some compounded by mental health care which is depowering, stigmatising, and 'not hearing'. These experiences and recoveries support conceptualisations of psychosis which are not solely rooted in biological aetiology, and are about more than primary symptoms. The positive message from such accounts is that even given the dreadful periods of active psychosis, all are in sustained recovery and able to reflect on the times when they were overwhelmed by their psychosis, and they do this to better inform the people who need to know.

If the subjective experience is to be ethically utilised in research, then skill and rigour need to be used to elicit and understand emic knowledge in order to do fair justice to the people who are willing to share their subjective experience and aid the development of an etic knowledge base which in turn, will support a developed understanding and more meaningful, person-centred, and effective interventions. Qualitative inquiry, particularly phenomenological methodology, aims to generate subjective knowledge (Davidson 2003) and so it is to this methodology that the research has turned.

4.2 Qualitative Methodology and Capturing Lived Experience

A meta-synthesis (McCarthy-Jones et al. 2013) of inductive qualitative analysis studies exploring the experience of psychosis between 2000 and 2010 written in the English language has recently been published; 97 studies were included, giving a sample of 1942 participants. The importance of this review for this thesis and for the field of qualitative research was that the inclusion criteria was of analyses of first person accounts of people living with psychosis, aiming to synthesise what was present in the research base and create new knowledge about the meaning of psychosis from an emic position. Four themes emerged: Losing; Identifying a need for, and seeking, help; Rebuilding and reforging; and Better than new: gifts from psychosis.

Losing was the loss of the self, of a consensual reality, and of hope. These losses engendered fear and confusion, disruption and loss of daily routines and basic needs, and led to financial, relational, and occupational losses. Stigma, medication, and involvement with the mental health services compounded these losses. Identifying a need for, and seeking, help concerned the recognition of problems and those factors impeding help-seeking such as waiting for the experience to recede on its own and denying there is a problem. It also illustrated that it appears people need to develop some sense of 'illness' before seeking help or accepting treatment and that this is not an easy repositioning. The third theme began once the fear and sense of fragmentation had passed and rebuilding and reforging the self and the world lost to the psychosis was accessible. This new life phase could be rebuilt in spite of continuing anomalous experiences because they are managed better. A sense of coherence returns or is reforged. This phase though brings with it heightened anxiety as the possibility of losing it all again is very present. The process of rebuilding involves finding hope, positive action, and reconnecting to people. The re-establishment of basic needs such as good sleep is part the process too. The fourth theme is self-explanatory with some people perceiving positives from going through the experience, although this is not expanded on in much detail and is presented as being a less prevalent part of the experience.

McCarthy-Jones et al. (2013) noted that the consistency of the quality of the included studies was variable, although all provided sufficient evidence that they were inductive, and that the meta-synthesis was restricted to Western Europe and North American so cross-cultural generalizability was compromised. The discussion provides information about the clinical implications of the findings, but as with many qualitative papers, the information has to be pulled from the narrative and it would be useful to have tabulated the information to enhance its accessibility. In spite of this minor criticism, it is important to reiterate the significance of the study in its attempt to systematically bring together the wealth of disparate qualitative inductive work that is currently available and offer a synthesised picture of the lived experience.

The findings from McCarthy-Jones et al. (2013) show that the lived experience of psychosis, in all of its extraordinariness, can be captured and understood through the application of appropriate qualitative research methodology. They conclude that those seeking to help people who are living with psychosis should be aware of the '*broad impact of psychosis on all areas of life and its multifaceted nature' (p11)* and they caution that unaware clinicians have the potential for a destructive impact on people living with psychosis. This is a powerful statement and concurs with the first-person literature. It raises questions about the weak influence on the understanding of and interventions for psychosis from the qualitative evidence base, and about what it is that current practice is basing itself on if not the realities of the people living with psychosis. Practice arguably needs to be looking towards the subjective to consolidate meaningful knowledge about the experience of living with psychosis.

4.3 The Phenomenological Paradigm

> *'The exploration and doctrine of the essence of that which manifests itself.'(Bürgy 2008 p1203)*

Drawing clinical knowledge from subjective realities though, is fraught with controversy, particularly for an experience as unknown, extraordinary, and potentially devastating as psychosis. Many influential figures in the field of psychiatry have had strong views about the understandability of psychosis. Kraepelin (1905) did not believe that understanding of the experience of psychosis could be gleaned from discourse with a sufferer. Jaspers (1963) espoused that psychosis engenders no empathy and so no understanding from people outside of the experience. R D Laing (1927-1989), an existential phenomenologist and psychiatrist influential in his writings on the nature of mental illness and particularly psychosis (Laing 1960), believed that Krapelin (1905) and Jaspers (1963) were mistaken. Laing noted that whilst we judge ourselves to be sane and the person living with psychosis insane, that comprehending the experience of psychosis from within the confines of *'sane'* life-world will create an inadequate understanding. By adopting a phenomenological philosophical position, Laing, and subsequently others (e.g. Gibson 2000; Davidson 2003; Geekie & Read 2009; Nixon et al. 2010b; Hornstein 2012; Romme & Escher 2012), were able to develop a coherent shared understanding of the lived experience of psychosis.

Phenomenology is the *'how is it to be'* of research and phenomenological research investigates objects of enquiry as they show themselves in themselves (Schmidt 2006) and is underpinned by Heideggerian phenomenological philosophy. Phenomenological methodology strives to elicit subjective experience through the subjective eyes of the researcher. In this phenomenological paradigm researchers actively focus on the subjective experience of the researched and, when interpreting elicited information rather than merely presenting description, they incorporate their own subjective experience into the research 'data'. Heidegger (Mapp 2008) believed that it is not possible to separate the observer from the observed and that the very 'being' (in the philosophical sense) of the observer impacts on the 'sense' made of what is being observed. This to me seems an antidote to reliance on a scientific method, when, in striving for objectivity and homogeneity, the richness of the data available is reduced and so, potentially, the reality of the phenomenon.

The role of this research in informing understanding and practice explicitly roots it in phenomenological psychology which is the application of phenomenological philosophy to psychology through a focus on the subjective world (Langdridge 2007). Mainstream psychology tends to subscribe to a positivist paradigm believing that there is a real world that can become known through the scientific method (i.e. that a phenomenon can be isolated, observed and measured) meaning that in epistemological terms, they are very different. Within such a scientific paradigm research, procedure requires the researcher to be objective, detached, and value-free in order to discover these waiting truths (or best approximations as the post-positivists say). The phenomenological paradigm, in contrast, holds that how the individual interprets their experience and, post-Husserlian, how an interpreter interprets its meaning *is* relative and subjective – but that this is realism; truth cannot be limited to that which is knowable through the scientific method, and a shared language is the essential way understanding emerges.

A concept of ill-health originating from a 'naturalistic' approach (Carel 2013) denotes that any ill-health experience can be exhaustively accounted for by the physical facts alone in the absence of first-person accounts. This is evidently not the case in psychosis, nor, I would argue, in a vast proportion of ill-health experiences, because the consequences of living with the condition go far beyond the physical 'facts' of the condition. Phenomenology privileges the subjective revealing the global disruption of life-worlds. Carel (2013) takes an Existential position in accepting the embodied and enworlded nature of human experience, leading to the view that to provide an account of a human experience that lacks the element of human experience will reveal a deficient account. A phenomenological understanding of the experience of living with psychosis is arguably then within our grasp through the courageous use of phenomenological research methodology.

4.4 Phenomenological modelling of Psychosis

> *'[R]each out across Karl Jaspers' abyss' to the person distressed, cut off, and isolated in their psychotic world of fear, bizarreness, and desolation.' (David, foreword in Laing 2010)*

Chapter : Subjective Realities

Whilst there a numerous research studies which have inquired into a single aspect of psychosis, there are fewer which have considered the broader experience of living with psychosis, and fewer still which have been developed phenomenologically. Two such are Davidson (2003) and Geekie and Read (2009). Davidson (2003) developed a phenomenologically driven model of persisting and severe psychosis (he uses the term schizophrenia) through analysing over 100 dialogues with people living with psychosis in the United States of America. The model identified two phases – living inside schizophrenia, and living outside of schizophrenia. ‘Living Inside’ reveals a potentially downward spiral into distressing experience and entrapment. Davidson describes this spiral as the experiencing of cognitive intrusions and disruptions that bring about a decline in a person’s functioning which are made sense of in a delusional or idiosyncratic way, leading to failure at normative life tasks and an increased possibility of rejection from others. This progresses to an experience of reduced self-agency and increased vulnerability which increase the need to withdraw, resulting in demoralisation and despair.

Geekie and Read (2009) completed a Grounded Theory (Glaser & Strauss 1967) study with 60 participants living with psychosis in New Zealand. Three theoretical constructs emerged: fragmentation-integration, invalidation-validation, and spirituality. Fragmentation-integration concerns the sense of the self becoming distressingly fragmented with loosened or lost connections to the previously known self and its world. Integration is the recovery end of the construct. Invalidation-Validation relates to the self and the world again, and concerns confidence in the accuracy and authorship of perceptions or interpretations of experience. The spirituality construct is a contextual construct referring to the tendency of the person to explain their experience in terms of their own sense of themselves in relationship to the universe, sense-making that was meta-physical (e.g. God versus the Devil) rather than in the material world.

No phenomenological work on psychosis can ignore the contribution of The Divided Self (Laing 1960), Laing’s existential study into sanity and madness. Laing held Kraepelin’s investigations and categorising of psychosis as dehumanising (David, foreword in Laing 2010). Laing himself, was criticised by the psychiatric establishment for adopting an anti-psychiatry and unscientific stance in his later works, whether justified or not though, his ‘Divided Self’ stands above criticism as a considered phenomenological and philosophical study of the experience of psychosis. This was a seminal text for me in the early stages of my mental health career, confirming that there was meaning in psychosis and that connections with people living with psychosis were both possible and therapeutic. Laing identified a loss of a primary ontologically secure position through the extraordinary nature of psychosis, engendering an insecure sense of being-in-the-world and so driving anxieties, fears, and separateness; the over-riding experience being a terror of losing oneself through engulfment, implosion, or depersonalisation.

Convergent then in phenomenological modelling of psychosis is a dynamic process of descent into a disrupted state of 'being' which entraps through its extraordinariness and awfulness, but that is escapable given a supported separation from 'it'. This is in contrast to biological modelling of psychosis which explains the disorder as being inescapable and deteriorating over time. Equally, a significant phenomenologically revealed facet is the importance and accessibility of sense-making and differential understandings of the experience which can aid recovery and this throws doubt on the 'non-understandability' of the experience accepted in more traditional psychiatric theories. Phenomenological models of living with psychosis appear inherently more congruent with the subjective voice because they come from the subjective voice and are shown capture the realities of the experience. Phenomenological methodology appears to be a valuable vehicle for learning more the subjective realities of people's experiences of living with psychosis.

4.5 Interpretative Phenomenological Analysis (IPA)

As noted, this study uses IPA (Smith et al. 2009). Within the research community, the qualitative, phenomenological methodology of Interpretative Analysis (IPA) has become increasingly utilised in health psychology research (Smith et al. 2009) to explore health phenomenon. Heideggerian phenomenological philosophy is the theoretical underpinning of IPA and the tenet of a Heideggerian phenomenological enquiry is that what we experience as real is inextricably linked to our mental processes and an intrinsic human capacity to seek out or construct meaning.

IPA was developed in the 1990s in the UK (Smith et al. 2009). This phenomenological methodology allows for an analytic process to be applied to subjective data and focuses on what an experience means for an individual in their context with the context of the researcher being recognised and incorporated. It believes in a chain of connection from the embodied experience, through talking about it, making sense of it, and the emotion, cognitive, and behavioural responses to the experience (Smith 2011). Being both phenomenological and interpretative, it explicitly recognises both veracity in the subjective account and the centrality of the researcher in the research process (Smith et al. 2009). A reflexive consideration is offered for the interested reader in appendix 1 summarising my personal epistemological position which led to the choice of research methodology.

IPA has three underpinning principles: phenomenology, hermeneutics, and idiography. It studies the phenomenon itself through individual accounts of the phenomenon, and is enriched by the sense-making of the transparently contextualised researcher. This incorporation of hermeneutics enables intersubjective understandings to be developed (Pringle et al. 2011). IPA affords the opportunity to develop an emic perspective on the topic under focus because the iterative and inductive methodology begins with hearing the person's story and continues with prioritising the person's life world at the core of the research. There is a balancing etic perspective as a 'double hermeneutic' process is embraced by the researcher, making sense of the sense-making of the person experiencing the phenomenon under exploration.

The scoping literature review for the earlier part of this thesis revealed an abundance of exciting etic and emically informed writings about the experience of living with psychosis, recovery from psychosis, its history, meaningful conceptual modelling in spite of inconsistent evidence of aetiology or treatment, and of first person accounts of living with psychosis, enabling a rich background to be developed from which to explore the lived experience of living with psychosis; there are, in contrast, few research studies into the experience. With this in mind, the thesis now offers a focused Literature Review on IPA and Psychosis, undertaken in July 2014 using two major electronic databases of peer-reviewed research.

4.6 Focused Literature Review: IPA and Psychosis

Search Strategy: (1) CINAHL PLUS, MEDLINE, PsycINFO, and PsycARTICLES, and (2) Web of Science. Keywords: 'IPA' AND 'psychosis OR schizophrenia' NOT 'early*'. Delimiters: All Adult 19+, England, Academic Journals, 2003-June 2014, English Language. Inclusion criteria: adults living with psychosis in England. Exclusion criteria: specific populations, specific psychoses of short term or organic origin, efficacy studies, early intervention and 'at risk' groups, families, and mental health practitioners.

The literature review has been dated from 2003 because prior to this date there were no IPA and Psychosis research studies published, Knight et al. (2003) being the first published IPA and psychosis study. This, of course, is due to the newness of the methodology (Smith et al. 2009).

Early Intervention in Psychosis (EIP) studies have been excluded as they study a specific population of people who experience only one overwhelming episode of psychosis or are in a protracted prodromal phase. This study focuses on people living with psychosis as a longer-term health condition and so not achieving the clinical or sustained personal recovery expected of many of the people supported by EIP services and therefore requiring the ongoing support from mental health services for their ongoing experience of psychosis. The personal impact and life consequences of people experiencing just one episode have differing trajectories to those experiencing persisting psychosis (Naylor et al. 2012).

From the Search (1) five from six articles were excluded, from Search (2) there were 16 articles, seven studies meeting the inclusion criteria and a manual search of these included papers' references led to an additional two articles.

The number of articles included in this literature review on IPA studies into the experience of psychosis is, then, ten; summary tables (Smith 2011; Coughlan M et al. 2013) are included in Appendix 2, supplemented by summaries of the articles. The specific aspects of the lived experience of living with psychosis focused on in these studies were: stigma (Knight et al. 2003), recovery (Pitt et al. 2007; Wood et al. 2010), voices (Chin et al. 2009; Mawson et al. 2011; Milligan et al. 2013), employment (Nithsdale et al. 2008), paranoia (Campbell & Morrison 2007), fathers with psychosis (Evenson et al. 2008), and cognitive impairment (Wood et al. 2013).

Attempting a critical literature review of the research evidence base for recent studies into the lived experience of living with psychosis proved challenging, and the reasons for this serve to illustrate the wider challenges of using qualitative research to influence understanding and so, mental health practice. Most qualitative studies focus on one aspect of the lived experience and so the corpus of research appears fragmented. This is almost inevitable because IPA generates a huge amount of data which is time-intensive to analyse, equally a wider scoped study may lose sight of its focus or lose depth of analysis in its extended scope.

4.6.1 The Included Studies

Knight et al. (2003) explored the experience of stigma in people living with psychosis. Their findings illustrated how stigma has an interpersonal and intrapersonal domain, being present in the person's social world but equally present in the self, internalised as self-stigma.

Nithsdale et al. (2008) explored employment experiences of people living with psychosis. Three themes were found in relation to the challenges of attaining and maintaining paid employment whilst living with psychosis: coping, interpersonal support and reactions, and personal significance. Nithsdale et al. notes that there was no consistent relationship between being employed and quality of life; some people in work managed well, others struggled, some not in employment felt their lives were productive, others perceived their lives as diminished.

Evenson et al. (2008) explored the experiences of fathers living with psychosis, believing this group to be an ignored population. Themes emerged highlighting that psychosis undermines the father-child relationship and the work of parenting through creating a self-driven emotional disengagement from the child. This emotional disengagement was due to the overwhelming emotional and psychological challenges and preoccupations that psychosis brings with it. Evenson et al. note that there are similarities and differences between being a mother and a father living with psychosis. Earlier research (Nicholson et al. 1998, in Evenson 2008) showed that Mothers feared losing custody of their children and often avoided treatment due to the responsibilities of parenting, fathers it appear do not.

Campbell and Morrison (2007) explored the subjective experience of paranoia, looking at whether the experiences of people living with psychosis were different from people who had no psychiatric history. A significant difference between the groups emerged in terms of control and origin of beliefs, people living with psychosis believed that their paranoia ideation was not self-created nor was it controllable.

Wood et al. (2013) explored cognitive impairment in people living with psychosis. Cognitive impairment was established through psychometric measures, and then semi-structured interviews were undertaken in to the life experiences of the individuals, focusing on the difficulties in cognitive functioning. Six themes emerged: impaired controlled thinking, physical sensations and impaired movement, explanations for the impairment and comparisons with the past, managing the impairment, how others saw the impairment, and anticipating the future. Overall, participants expressed a *‘sense of bleakness regarding the impairment and the future’ (p9)*.

Pitt et al. (2007) and Wood et al. (2010) explored the experience of recovery in psychosis. Three themes emerged from Pitt et al., rebuilding of the self, rebuilding life, hope for a better future, whereas four themes emerged from Wood et al., impacts on mental health, self-change and adaptation, social redefinition, and individualised coping mechanisms. Both suggest that recovery is difficult to define both in conceptual and personal terms and that it is a relative concept for each person making the recovery journey, and both noted the importance of addressing psychosis-linked withdrawal and maintaining social roles, value, and inclusion.

Chin et al. (2009), Mawson et al. (2011), and Milligan et al. (2013) focused on the experience of hearing voices. The Milligan et al. paper focused on how the experience of voice hearing changed over time. The Mawson et al. study revealed an enmeshment of the voice and the hearer, the voice hearer's sense of themselves was influenced by how the voice related to them, and the voices were often blamed for aspirational and social failures experienced by the hearer. Hearer and Voice appeared to engage in a battle of control, with a perceived powerful voice exerting influence over the behaviour of the hearer, *'participants seemed stuck in a tiresome battle' (p264)* with their voices, unable to ignore or be controlled. Chin et al. (2009) concurred with the Mawson et al. findings in revealing a sense of a battling for control and power within the life of the hearer for issues from the most mundane to more significant life choices. Milligan et al. (2013) found that most participants (5/6) described voices beginning after a negative life event which aligns with the existing literature on voices (Romme & Escher 2012). Voices, as noted in the other IPA studies caused emotional change, and in turn were influenced by that emotional change. Further along the journey the hearer began to discover more about their voices, adjust to them, and begin to manage them more effectively, ultimately to develop new understanding of the experience.

Such detailed and disparate findings are difficult to make sense of and this illustrates a drawback of qualitative inductive research; it is almost *'hoisted by its own petard'* through providing such detail rich data from small samples and having to focus down on one aspect of experience rather than the broader experience in itself.

It appears possible to create a fragmented understanding of the experience of living with psychosis from the body of IPA research into psychosis, although maybe not clear guidelines about the implications of the findings for practice, but in order to accept such findings it is initially important to verify that the sources of such findings are robust through evaluating the studies. Being guided by the evaluation criteria developed by Smith (2011), with additional criteria supported from wider reading (e.g. Elliot et al. 1999; Etherington 2004; Smith et al. 2009; Finlay 2011; Shinebourne 2011), these ten IPA and Psychosis studies have been evaluated against the following criteria:

- Commitment to the three principles of IPA (phenomenology, hermeneutics, and idiography)
- Coherence, plausibility and contextualising of findings

- Transparency of rigour
- Focused research
- Sampling
- Elaboration of themes and referencing from the corpus
- Self-reported limitations
- Clinical transferability

The studies commitment to the three principles of IPA was variable. All studies except one (Campbell & Morrison 2007) showed commitment to idiography using semi-structured interviewing as a vehicle to collect the life stories of their participants and using direct quotes from these stories (data) to support the emergent themes; this also enhanced transparency. An example of how this was used to good effect was the paper by Knight et al. (2003) on stigma, where direct excerpts flowed with the narrative in the findings section. The Campbell and Morrison (2007) did not include excerpts in the narrative of the findings and placed them in a separate table and this detracted from the idiographic commitment necessary to engage the reader with findings and develop a sense of the veracity of the presented themes. Moreover, this paper because it was a comparison study combined the voices of their participants in a unit which lost the idiographic commitment.

Seven of the studies exhibited a commitment to phenomenology and phenomenological research. This was most noticeable in their rationales for using IPA methodology. All of these seven gave good rationales for the use of IPA. Chin et al. (2009 p3) noted *'using a qualitative approach to explore voice hearers' perceptions of any 'relationship' they have with the voice'*, Mawson et al. (2011) specifically noted that the aim of their study was to elicit the complexity of the experience of voice hearing that could not be accessed through quantative research methodology and wanted to explore sense-making of the experience, and Wood et al. (2013) noted that qualitative methodology had been used in a meaningful way in related areas and yielded useful results informing on the gaps left by quantative research, in particular about the lived experience. Knight et al. (2003) again showed its quality by expressing a commitment to phenomenology throughout its background section by the inclusion of first person account of the phenomenon under study, and offered a developed and explicitly informed rationale for the use of IPA. This is contrasted with three studies which did not develop an acceptable rationale for the use of IPA as a methodology, nor showed a commitment to phenomenology on their background information. Evenson et al. (2008) and (Nithsdale et al. 2008) did not discuss phenomenology or methodology on their background information and made only brief mention of this in their analysis section, and the Campbell and Morrison (2007) gave a rationale for the use of IPA that could be argued to express something other than commitment to phenomenological research methodology involving a responsibility to balance out the contribution of qualitative and quantative research in clinical psychology. This poor commitment to the principles of the methodology can be argued to be evident throughout the paper in that the write up echoes more a quantative paper rather than a qualitative research study.

The principle that seems most challenging to commit to is hermeneutics. Chin et al. (2009), Evenson et al. (2008), and Knight et al. (2003) are examples of papers where a hermeneutic approach is explicitly evident in the findings section and researcher interpretation of the words of the participants is bravely included. In the other studies, some made attempts at hermeneutics but others not all and offered more a description of the findings (e.g. Nithsdale et al. 2008; Wood et al. 2010) which is not consistent with IPA methodology (Smith et al. 2009). Some papers put their interpretative content into the discussion away from the findings (Milligan et al. 2013) and this is perhaps an acceptable compromise although again not consistent with the methodology of IPA. Interestingly, Campbell and Morrison (2007) did commit initially to hermeneutics but then circulated their interpretations to their respondents and changed them in line with feedback received. Perhaps this action could have been included in a different way to strengthen commitment to the hermeneutic process; a discussion of the differences in interpretation would have showed more immersion into the IPA methodology rather than changing one person's interpretation because of a differing perspective.

All discussed the findings in line with the extant literature in the discussion, although again to varying degrees. Some studies gave a rather brief exegesis (e.g. Nithsdale et al. 2008) but eight of the studies developed a rich discussion which added coherence and plausibility to the findings (e.g. Evenson et al. 2008; Wood et al. 2013). The coherence and contextualising of the findings was lessened when discussions were abbreviated. The Nithsdale et al. (2008) and Pitt et al. (2007) papers did not offer a discussion of note although both did discuss broader clinical implications of the findings. This is not to say that if studies are not written up well that the findings are invalid, but in order to strengthen the acceptance of qualitative research into the mainstream and so its influence on understanding and practice, it has to have explicit validity and so there is a responsibility on those who write up such studies, and on those who accept such papers for publication, to adhere to principles of rigour.

Methods used to be transparent about rigour included the explicit use of reflexivity (Etherington 2004; Smith et al. 2009) through the keeping of a research journal and though supervisory discussions (Knight et al. 2003; Evenson et al. 2008; Mawson et al. 2011; Milligan et al. 2013). Credibility checks (Elliot et al. 1999) including audit and shared or mediated data analysis (Knight et al. 2003; Pitt et al. 2007; Evenson et al. 2008; Nithsdale et al. 2008; Chin et al. 2009; Wood et al. 2010; Milligan et al. 2013) were employed. Four papers worked collaboratively with service users in the design of the study and the Semi-structured Interview Schedule, and in the analysis (Campbell & Morrison 2007; Pitt et al. 2007; Mawson et al. 2011; Wood et al. 2013). Campbell and Morrison as noted earlier explicitly stated that they changed their analysis in line with feedback from participants indicating less of a collaborative relationship, although to their credit, no other study detailed the process of shared analysis with service users. The main methodological difference here is that Campbell and Morrison consulted with their participants which could have been done as a triangulation research activity whilst still being transparent about their own original interpretation, whereas the service user involvement in the other studies was independent of research participation and service users were involved in the design, piloting and shaping of the semi-structured interview schedule (SSI), analysis, and in one case the writing up (Pitt et al. 2007). In one study in this literature analysis (Milligan et al. 2013) the researchers undertook sessions with a Counselling Psychologist to elicit into awareness preconceptions and biases prior to the undertaking of the interviews.

All of the studies isolated an element of the lived experience of psychosis and explored this independently. Whilst in most a worthy and informed positioning of the new knowledge within the existent literature was made, the focus remained narrow and the findings relationship to the totality of the experience of living with psychosis or the relationship between the focus of study and other aspects of the experience were not made explicit.

It is challenging to meaningfully decontextualize one aspect of such a complex experience as living with psychosis. This is what quantative research methods attempt to do by controlling for extraneous variables but this is neither possible nor desirable in qualitative methodology. Whilst isolating an aspect of experience may be expedient in research terms it has to be re-contextualised at some point for the findings and implications to be meaningful and this is often done in the exegesis of the paper where IPA expects findings to be positioned within the extant literature but, as noted above, the focus of this contextualising in the majority is found to remain narrow. Another issue when isolating an aspect of experience is the necessity of operationally defining what it is that you are asking about and not asking about, and what it is that has emerged from the data. An example of this is found in the studies which focused on recovery (Pitt et al. 2007; Wood et al. 2010). Whilst both papers claim to be focussing on personal recovery within psychosis, their questions and findings are not aligned because their operational definition of what they are exploring is different yet the same ‘conceptually rooted’ term is being used. The Wood study for example explored more the lived experience of psychosis whereas the Pitt study did explicitly focus on recovery.

Sampling is a contentious issue for IPA studies (Smith 2011; Larkin 2014) and will be discussed in detail later in this thesis. The studies in this review all used purposive samples that were relatively homogenous except for the six participants in the Campbell and Morrison study. Relative homogeneity is important in smaller sample qualitative research and a homogeneous sample for which the research question is meaningful is usually sought, Smith et al. (2009) does caution against striving to find ‘identikit’ participants (2009: 49). An advantage of homogeneity in the sample is that experiential convergences and divergences among people sharing a context will be illuminated. Smaller sample sizes enable a detail-rich analysis to be completed; larger sample sizes seem to be detrimental to the research as it becomes more difficult to adhere to the theory or to the methodology. It is the depth of idiographic analysis that is the research signature of IPA ; the issue for IPA is quality not quantity (Smith et al. 2009). The studies in this review appeared to be undertaking the research with people to whom the research question was relevant and numbers ranged from six to ten participants which is an acceptable range for IPA (Smith et al. 2009). Sample demographical information was given in all papers to inform about the participants and transparency in homogeneity. All except one study gave the rationale for their choice of sample as being determined by other IPA studies in the field and from the Smith IPA book (2009); all sample numbers appeared set *a priori*. The sample decision seemed to be based on pragmatic reasons rather than on any methodological rationale, only one study Wood et al. (2010) set a minimum number of 6 but continued on until theme saturation was agreed by the analysis team – this was at 8 participants. These sample sizes though did appear to offer sufficient meaningful information for analysis.

It was in the elaboration of themes where significant variability was found in both the style of presentation, the use of excerpts, and the number of themes presented. Weighting and support from the corpus needs to be transparent and Smith (2011) has created detailed criteria about what constitutes sufficient referencing from the data. For samples between four to eight, extracts from at least three participants need to support each theme, and in samples over 8 there needs to be an additional transparent weighting of how many of the participants experienced what within each theme presented. This is a clear guide but challenging to use as an assessment tool. Chin et al. (2009) and (Mawson et al. 2011) had samples of ten and their themes were well supported by references from the corpus but no prevalence within themes was included. It became apparent that this criterion was significant in my evaluation of the validity of the findings, it was important to know how prevalent the theme or sub-theme was within the sample. Milligan et al. (2013) included prevalence inconsistently and it was useful when present, and this study was one of the few which included divergent experiences within a theme as well as convergence. Some studies did not elaborate themes sufficiently (e.g. Pitt et al. 2007). The number of themes presented varied too, with some presenting so many themes that meaningful elaboration within a journal article was not possible (e.g. Wood et al. 2013). Themes presented ranged from 3 to 6, some identified lower order themes as subheading (e.g. Evenson et al. 2008) and some referred to them as issues within the Superordinate Theme and discussed them in the narrative of the findings (e.g. Mawson et al. 2011). Neither is wrong; I found that issues presented within the narrative flow engaged me more in the lived experience the participants. Neither style appeared to impact on the evaluation of validity, although too much detail is challenging to process and Chin et al. (2009) chose to present three of the five emerged themes in their paper in order to do justice to the full findings. Four of the studies (Campbell & Morrison 2007; Pitt et al. 2007; Nithsdale et al. 2008; Chin et al. 2009) included a table of themes which was helpful, and two studies (Milligan et al. 2013; Wood et al. 2013) included a Gestalt of their findings (Smith et al. 2009), mapping and suggesting relationship between the emergent themes and these inclusions were illuminating and meaningful.

Eight of the studies self-reported on the limitations of their research; two did not (Knight et al. 2003; Milligan et al. 2013). Chin et al. (2009) and Mawson et al. (2011) noted that the focus of their research was on people who were distressed by their voice hearing and wanted not to negate the experience of voice hearers in the general population who are not distressed by their experience. This is perhaps an issue which could have been noted clearly in the introductions rather than it being perceived as a limitation. Two studies wondered whether their recruitment processes led to a self-selection bias of people who were having a better of experience of the phenomenon of the research (Evenson et al. 2008; Nithsdale et al. 2008). This is an interesting and valid issue to raise, but one which is prevalent across all forms of transparent and consensual studies.

Three studies (Evenson et al. 2008; Chin et al. 2009; Wood et al. 2013) do note though that there is no cultural diversity or general population representation in the study sample and this is an area for further research and Pitt et al. (2007) notes their sample size as a limitation of the study which they believe will hamper generalizability. Generalizability and representational samples are not aims of IPA and so should not be seen as limitations as this can create an 'apologist' culture for such methodology rather than emphasising the rationale for such methodological features. Chin et al. (2009) does address this briefly in their limitation section by clearly noting that their findings are not a definitive account of the experience but a contribution to an emerging picture from the group of people from whom they elicited the presented lived experience. It is useful to note the specific population that participated in the study though, so that research can be taken on other groups to build a more complete picture of the lived experience of a phenomenon. Wood et al. (2010) sets the methodology in context by explicitly noting that the themes presented should not be considered mutually inclusive, and that whilst this relationship has not been explicitly noted in the paper than one should be assumed to exist.

Chin et al. (2009) noted a lack of service user involvement in the research process and it is best research practice now to involve service users in the entirety of the research process (National Institute for Health Research et al. 2010). However, Wood et al. (2010) questioned whether the use of a service user researcher as the interviewer meant that the direction of the data gathering in the interviews was biased by the interviewer's personal experiences. This is a limitation which could have been addressed of the interviewer had been supported in becoming committed to the principles of IPA and supported in bringing preconceptions into awareness prior to the interview process, it ought too, to have been addressed in the hermeneutic and reflective findings section. Campbell and Morrison (2007) recognised that the lack of matching between his two groups meant that the use of IPA for a comparison study was perhaps not ideal.

All of the studies included a consideration of the clinical implications of their research but presentation, emphasis, direction, and content were inconsistent. The ontological question of 'what is the experience' is addressed in all studies to varying degrees of quality (Smith 2011) but the translation of the findings, often rich, in to practice was often narrowly focused or unclear. Campbell and Morrison (2007) did give clear guidance about the inclusion of particular interventions in the treatment of paranoia based on their findings, whereas Chin et al. (2009), Wood et al. (2010), Pitt et al. (2007), and Wood et al. (2013) evaluated the relevance of their findings to the clinical experience but did not offer clear guidelines of what this means and how to do it; this would be a rare criticism of the Knight et al. (2003) study. The Chin et al. study and Mawson et al. (2011) communicate clinical implications in a well-informed but possibility not widely accessible language, a developed understanding of interventions and theoretical understanding of voice hearing probably needs to be present to fully interpret their suggestions. Nithsdale et al. (2008) offer useful ideas about how people living with psychosis could be better supported in maintaining employment or being motivated to embrace meaningful voluntary work, and the suggestions in Evenson et al. (2008) are meaningful and accessible but somewhat lost in the writing.

In summary, there are many features of the IPA research process which contribute to validity and against which studies can be evaluated for quality. The current research base for IPA studies into psychosis is small and considers varying isolated aspects of the lived experience. Studies are presented in varying ways and adherence to the principles of IPA is inconsistent but there is much to be learned from reviewing them. The experience of immersion in these papers is that, as a body of emerging IPA research, they are mostly well executed and, with some reservations, acceptably methodologically rigorous, revealing findings which have validity and convey a ‘felt sense’ of the participants who supported the study by sharing their lived experience. The Findings section appeared to be a key section in the ability of a paper to exhibit that IPA can elucidate lived experience and longer analyses were evaluated as giving a better ‘felt sense’ of the lived experience of the participants, linked possibly to the increased detail able to be included in an extended article. The discussion section is important in contextualising the findings and needs not to be given short shrift, and the clinical implications need to be more directed at transferability of findings into practice. Knight et al. (2003) appears to be an exemplary paper by these evaluative criteria, showing commitment to phenomenology and idiography in the background information, exhibiting hermeneutic commitment, describing procedures in detail, having elaborated and supported emergent themes, and explicitly detailing processes for rigour. More when reading this paper, I *felt* the experience of the fathers living with psychosis. The Mawson et al. (2011) paper too deserves credit for methodological adherence and rigour.

The critical analysis of these ten IPA studies highlights both the usefulness and the challenges of using IPA to explore the lived experience of living with psychosis. It identifies gaps in the literature, noting that all studies have focused on a decontextualized element of the experience and none to date have explored the broader experience. The review offers both a clear rationale for this research, and guidance for undertaking and presenting a rigorous and meaningful IPA exploration into the broader experience of living with psychosis as a longer-term health condition.

4.7 Living with Psychosis: the research questions

Embracing epistemological reflexivity (Pietkiewicz & Smith 2014) in defining initially the research questions and then the research design and interview schedule (see Chapter 5), the following considerations were taken into account:

- This study aims to elicit the lived experience of a phenomenon, not a theoretical understanding nor causal relationship, associations, or explanation
- It aims to use emic knowledge and embed itself in phenomenology
- I have a great extent of fore-conceptions from knowledge and experience of people living with psychosis
- The study aims to investigate the broad experience not an isolated domain of experience

This process led to a broad primary research question, *'What is the lived experience of living with psychosis as a longer-term health condition?'*, and it has been deliberately worded such to retain a clarity of the field of study and to distinguish it from previous research which has focused on 'the lived experience of psychosis' meaning the phenomenology of the experiences people have when they are overwhelmed by florid psychosis (Laing 1960; Gibson 2000). The broad research question indicates that this study is about the person living with psychosis as a longer-term health condition and their experience of just that rather than a study of their 'disorder' and so more in line with the inquiry of Davidson (2003). Its wording will hopefully elicit a deepening of the understanding of what it is to live with psychosis and this research focus will be more amenable to informing practice that better supports people in living with psychosis as a long-term health condition and improving that experience.

There are two subsidiary research questions concerning the usefulness of the methodology, IPA, and importantly a consideration of how the elicited experience of living with psychosis from this IPA study could be useful in terms of enhancing mental health practice. These subsidiary questions are pertinent to the Doctorate in Clinical Practice award for which this research has been undertaken, in that they specifically enquire into the relevance of the research methodology for a given clinical population, and allow a focus on subsequent implementation of clinical research outcomes into the clinical practice arena.

4.7.1 The Research Questions

1. What is the lived experience of living with psychosis as a longer-term health condition?

2. Is IPA an appropriate research methodology for eliciting this information?
3. How can the emergent picture from an IPA study be useful in enhancing mental health practice with people living with psychosis?

Chapter 5: Method and Procedure: The Research Study: Exploring Psychosis through IPA

5.1 Research Design

Phenomenological research aims to reveal the 'lived world' (Van Manen 1990) and this study intends to re-examine assumed knowledge by eliciting the 'living' experience of the individual. Using epistemological reflexivity (see chapter 4.8) to guide the choice of methodology, this study adopted a qualitative, phenomenological, hermeneutic, and idiographic design, specifically the application of IPA (Smith et al. 2009) to explore the subjective realities of the lived experience of living with psychosis not accessible through quantative methodology. IPA is concerned with the 'sense-making' process of people living with a phenomenon, immersing it in subjectivity and accommodating to multiple realities through its eliciting of convergences and divergences within the emergent themes of experience (Smith et al. 2009). IPA has also been shown to be a meaningful methodology for the exploration of the lived experience of psychosis (see Chapter 4.6).

5.2 Procedure

NHS ethical approval was granted prior to conducting this research alongside research site and university approval (appendix 3). Key to recruitment was the use of Gatekeepers who were mental health staff working directly with service users who met the inclusion criteria of the study appendix 4. Research Awareness presentations were made to mental health teams across southern England to inform and socialise potential research Gatekeepers into the research process, and Gatekeeper information was given in written form (appendix 5). At the same time advertisements and leaflets about the research were placed in the waiting rooms of the recruitment site allowing interested participants to refer themselves to the study through bringing it to the attention of their mental health practitioner acting as a research Gatekeeper.

The Gatekeeper role was independent of the research and served to protect the interests of the service users, Gatekeepers having the power to deny research access to the participant population and so protect vulnerable people from research. As the researcher, I had no direct contact with any service user until they had been approached by, or had approached, a Gatekeeper and, on being informed about the study through the Participant Information Sheet (appendix 6), had signed an ‘opt-in’ form allowing an approach to be made by the researcher (appendix 7). The participant was then telephoned by me to discuss the study and consent in more depth and an interview appointment arranged at a venue acceptable to the participant and risk assessed for research purposes. The Gatekeeper was notified of the Interview appointment in order to provide a post-interview ‘check-in’ with the participant and offer post-interview support if required. Had I, as the researcher, become concerned about the mental state of any participant during the interview I was to rely on my considerable experience in clinical care to manage the situation appropriately and ensure support was put in place for the participant.

Details of any contacts were recorded in the Research File; agreement to participation was confirmed to the GP (along with an information sheet about the study) and copied to the participant’s care co-ordinator and the participant. Informed consent was obtained by the researcher at the interview meeting and the interview then undertaken. Meetings lasted for one to one and a half hours but were to be terminated at any point if the participant requested this. Participants were told this explicitly and assured that their existing care package from the mental health Services will not be affected by either participation or withdrawal.

Each interview was audio-recorded for post- interview transcribing and an initial analysis was undertaken on each transcript. This study followed a concurrent data collection and analysis process to allow for the use of reflexivity to further inform the procedure (Smith et al. 2009).

5.3 Participants

The study used a purposive sample of ten mental health service users living with psychosis to allow for a level of homogeneity that enabled idiographic analysis (Smith et al. 2009). Participants were eligible for the study if they had experienced ‘positive’ symptoms indicative of persistent psychosis or schizophrenia according to the DSMIV – R (American Psychiatric Association (APA) 1994) or the ICD-10 (World Health Organisation 1994) for a minimum of five years, perceived themselves to be ‘living with psychosis’, and had current stability in their life as assessed by the research gatekeepers who were mental health practitioners known to potential participants (appendix 4). The five year cut-off was to preclude people who had been working with local Early Intervention in Psychosis Services and in their first episode of psychosis. Participants similarly had to be assessed as low risk to themselves or to others at the time of the study.

Participants had to be able to give informed consent to participation and have expressed a willingness to participate in a semi-structured interview process, to be audio-taped, for their interview data to be used for research purposes specified on the consent sheet (appendix 8), and for their GP to be informed of their participation. Inclusion was regardless of gender, religion, race, ethnicity, sexual orientation or disability however, proficiency in spoken English was required as the researcher is not conversationally fluent in other languages and IPA methodology does not fit well with an additional layer of hermeneutics from the use of translators.

If a participant who had given informed consent lost capacity during the study, the participant would be withdrawn from the study and data already collected with consent would be retained and used in the study. However, no further data would be collected or any other research procedures carried out on or in relation to the participant.

Participants were allocated an anonymising number and a pseudonym to be used for verbatim excerpts known only to the Researcher. Ethical information governance procedures were applied.

5.3.1 Participant Demographics

Table 2 overleaf, shows participant demographic information. IPA samples strive for some point of homogeneity within small samples, the main point of homogeneity in this purposive sample is that all participants perceived themselves to be living with psychosis and were being supported by mental health services. All participants were ethnically White British which is not a culturally diverse sample although perhaps more typically representative of the area in Southern England, where the study was undertaken. There were four men and six women, with ages ranging from 24 years to 58 years with a mean age of 44.4 years, Gillian at 24 years and Bridgette at 58 were at the extremes of the age range. Eight of the participants fell in the age range 38 to 53 years. Participants had been living with psychosis between eight 35 years, again a wide range of experience. Only two participants lived alone (Terry and Leslie), four woman participants lived with long-term partners/husband, two participants (Chris and Viv) lived as parents with their children, Phil lived with his parents, and Bridgette with her long-term lodger. Eight participants were currently hearing voices, Terry had heard voices in the past, and Leslie was not a voice hearer. Terry was the only participant who perceived himself to be beyond his psychosis, all of the others perceived themselves to be living with a distressing and enduring mental health condition.

Table 2 Participant Demographics (N=10)

Pseudonym and Diagnosis	Age	Ethnicity	Years living with psychosis	Gender	Living Situation	Voice Hearer
Terry Schizophrenia	41	White British	25	Male	Lives alone	Not at this time
Leslie Schizophrenia	48	White British	22	Male	Lives alone	No
Marina Schizophrenia	43	White British	10	Female	Lives with husband	Yes
Amanda (Mandy) Schizophrenia	53	White British	Unsure but voice hearing since she was 5 years old	Female	Lives with long-term partner	Yes
Bridgette Schizophrenia	58	White British	19	Female	Lives with a lodger	Yes
Alexander (Alex) Psychosis	46	White British	16	Female	Lives with long-term partner	Yes
Gillian (Gill) Schizophrenia	24	White British	8	Female	Lives with long-term partner	Yes
Vivian (Viv) Schizophrenia	40	White British	10	Female	Lives with her two teenage children	Yes
Phillip (Phil) Schizophrenia	38	White British	20	Male	Lives with parents	Yes
Christopher (Chris) Schizophrenia	53	White British	35	Male	Lives with adult son	Yes

5.4 Ethical Issues

In accommodating to the ethical issues pertinent to the research, a broad ethics framework (Beauchamp & Childress 2001) was utilised along with a consideration of peer-reviewed journal articles concerned with ethical research with people living with psychosis (Carpenter & Conley 1999; Dunn et al. 2006; Anderson & Mukherjee 2007; Jeste et al. 2007; Dunn & Misra

2009; Allison et al. 2011) and those concerning ethical application of methodology and method (Etherington 2004; Langdridge 2007; Smith et al. 2009). Issues which arose from this preparatory reading included:

- Likely distress in participants from the Interview process
- Decisional capacity in people living with psychosis
- Adherence to the Researcher role whilst being a Nurse Therapist
- Intrusion of fore-structures onto the data
- Data confidentiality and Information Governance procedures

These issues are discussed here in terms of participant protective procedures and discussed in more depth in Chapter 7, the discussion.

The use of research Gatekeepers was a key supporting process for some of these concerns. Gatekeepers were independent of the research process and bridged access between the research and the potentially vulnerable research population. Gatekeepers were mental health practitioners, known to the potential participant. They were socialised into the research through presentations supplemented with written information and through direct access to myself as the researcher. Their role was to support recruitment to the study and also to offer the post-interview ‘check-in’ to the participant and any support required following the interview. These Gatekeepers also enabled an informal risk and decisional capacity assessment to be undertaken. Issues of decisional capacity were discussed with the NRES Ethics Committee and it was decided that no formal measure needed to be taken due to the clinical experience of the Gatekeepers and myself as the Researcher, although this issue is addressed in Chapter 8 as too is the issue of undertaking research with people living with psychosis.

My clinical experience supported the protection of professional boundaries between the participant and the research in that no clinical work would be undertaken in the interview session but, if clinical need was identified, appropriate signposting was done. Participants were aware that the researcher was an experienced and specialist clinician so transparency about the role of the researcher was important to dispel any misperceptions. This process, and issues of potential data interference from my fore-conceptions, was supported through regular research supervision and the rigorous use of reflexivity.

Data confidentiality was ensured through coding participants and this coding being only known to myself. Pseudonyms, again only known to myself, have been used for all quotations. No participant identifiable data is accessible to anyone except myself. All data has been protected and stored in line with required information governance procedures for the NHS Trust involved in the research and the University of Southampton, and in line with the Data Protection Act 1998.

5.5 Data Collection

Informed by phenomenological method the interview schedule began with a *'Grand Tour'* question followed by open questions to elicit the phenomenology of the experience. The aim of the interview schedule was to maintain a broad focus on the overall experience of living with psychosis rather than to narrow it down to one domain of experience. Areas of the focus were the experience of living with psychosis, biographic phenomenology, and well-being facilitators. The interview schedule utilized open and expansive questions with prompts for encouraging dialogue, and was not designed around an existing theoretical framework (appendix 9).

The methodological flexibility of IPA allows emergent themes to be followed in subsequent interviews dependent on developments from the concurrent data analysis. The interview schedule was tweaked twice during the process in response to reflections on the usefulness of the questions in answering the primary Research Question.

No pilot study was judged necessary due to the flexibility of the methodology and the interview experience of the researcher.

5.6 Data Analysis

All IPA analysis must adhere to the principles of IPA, as noted in chapter 4.5, and so must be phenomenological, idiographic, and hermeneutic. The analytic focus of IPA is the sense-making of experience and in that respect the analysis works not with description but ideographically with the phenomenological data. As IPA is underpinned by Heideggerian phenomenological philosophy, it offers a hermeneutic variant (Finlay 2014), whereby the sense-making of the researcher is present and transparent in the analysis alongside the sense-making of the participant; this is the double hermeneutic process of IPA (Smith et al. 2009).

The analysis on the interview data in this study follow the accepted conventions of IPA (Smith et al. 2009; Frost 2011; Shinebourne 2011) and was further informed by Gee (2011) (appendix 10). The analysis adhered to the principles of IPA, data from each interview (the subjective experience) being worked with initially in isolation, to transparently reveal the sense making of the participant and the researcher, without the latter overshadowing the former. As IPA is iterative and inductive, a close line-by-line analysis of each separate dialogue was undertaken as detailed below, followed by the identification of patterns and themes within single cases and then across multiple cases (Smith et al. 2009). Once emergent themes across the data were revealed, Smith notes that the analyst should then apply psychological knowledge about what it may mean for the participants to have noted such issues or factors, and in this way the double hermeneutic process is supported, developing a more interpretative account, which is the goal of the methodology. This was done and explicitly included in the Findings chapter.

Following the Smith et al. (2009) IPA analysis process, each audio-taped interview was transcribed following the interview and then analysed by the researcher. The interview tape was listened to as each transcript was read through to attest to transcription accuracy and to re-enliven the interview experience; transcripts were read and re-read. The method described by Gee (2011) was then followed. Each full transcript was pasted into an A3 sketch pad, see appendix 10, allowing for the idiographic and hermeneutic process to be undertaken. Each page of the transcript was analysed through a process which began with a scan of the text and a highlighting of interesting features of the dialogue, then a free textual commentary was performed by the researcher. Following this the text was analysed for its linguistic and descriptive components, emergent themes were recorded, and, because this study is sited within phenomenological psychology, emergent psychological theoretical constructs were also noted at this point. Different coloured inks were used to delineate each component of the analysis with each emergent item of analysis linked by a drawn line to the relevant text within the data. A reflective journal was kept to note reflections that arose during the process to inform the double hermeneutic process and ensure adherence to the principles of idiography and hermeneutics. As the analysis progressed from finalised single case analyses to multiple cases, emergent themes were grouped and higher order themes identified; convergence and divergence in participant experience was noted. Finally, superordinate themes were identified and further analysis done at this stage to identify related themes under the overarching theme. The analysis was shared with academic supervisors to interrogate the interpretation through reflective discussions.

IPA analysis is a linear process, themes emerge from analysis of the first interview and these are carried forward into analysis of subsequent interviews. However, each interview was approached on its own merits and no attempt to push the experience of subsequent participants into an existing framework of themes was made.

5.7 Reflexivity

For rigour and validity, reflexivity was utilised throughout the research process (Etherington 2004) through the keeping of a reflective process journal and the use of these reflections to modify the research questions through the process of immersion in the theoretical underpinnings, the interview schedule and interviewer behaviour following reflections on the interview experience (Weiss 1994; Finlay 2011), and the interpretative analytic process through engagement with and reflections on the data and on its analysis (Smith et al. 2009). The interpretation was opened out to interrogation by two academic supervisors. I have contextualised myself explicitly and continuously, and transparently noted significant fore-structures (Mapp 2008) which exist in my awareness whilst using reflection and supervisory discussion to bring into awareness other fore-structures which were operating, and then explored their impact on the interpretative process (Spinelli 2005).

Chapter 6: Findings: The lived experience of living with psychosis

6.1 Emergent Themes

From the ten in-depth and detailed interviews, five super-ordinate themes (SOT) emerged. Two initially were lower order which were promoted to super-ordinate themes through subsumption (Smith et al. 2009) due to their significance within the lived experience. The other three were higher order themes bringing together several lower order themes. The table of themes (see Table 3 overleaf) shows an overview of emergent themes.

Following the IPA quality evaluation guide (Smith 2011) each emergent theme is presented adherent to the three principles of IPA, in that they will be explicitly idiographic and phenomenological, and will include my own hermeneutic commentary.

Smith (2011) further guides that for research studies with more than eight participants extracts from at least three participants for each theme are included plus a measure of prevalence within the sample. This guidance has been followed for the Findings section and informs the rationale for offering such an extended Findings section.

Participant synopses are included in appendix 11, with all identifiable details have been changed without losing the context of participants' lives and experience of living with psychosis.

Following the presentation of the emergent themes a brief summary is offered at the beginning of the Discussion in Chapter 7.

Chapter 6: The Findings

Table 3 Table of Themes

Super-ordinate Theme	Lower Order Themes
The Awfulness *'Episode of terror upon episode of terror….'*	• The Relentless, Inescapable Awfulness • Anxiety • Continuing Anomalous Experiences • Consequences and Losses • The Paradox of Medication • Vulnerability • Stigma
Psychosis as a Volitional Other *'I've got you now. You're mine.'*	• None as promoted through Subsumption
What is Real? *'I know that it ain't real……but it don't stop it happening.'*	• None as promoted through Subsumption
The Tormenting Tyranny of Distressing Voices *'I've heard some people can get positive voices - I don't get those'*	• Inescapability • Voice Content • Voice Determined Life • Relationship with the Voice • Separateness of the Voice • Beliefs about the Voice
Liberation *'Easier said than done, but I suggest get up, put some music on.'*	• Seeking Support • Know it for What it is • Reconnect and Don't give in • Seen Beyond the Psychosis

6.2 SOT 1 The Awfulness '*Episode of terror upon episode of terror….'*

> *'If I weren't living with psychosis I could get up and go to work, I could be happy all the time I suppose, um but with it you know you can wake up and think "oh no not another day".' (Phil)*

This superordinate theme was strongly supported by the analysis of participant data, all participants revealing this aspect of the phenomenon. This theme encompassed many lower order themes which are presented in Table 4 below.

Table 4 Lower Order Themes within SOT 1 The Awfulness 'Episode of terror upon episode of terror….'

The Awfulness *'Episode of terror upon episode of terror….'*
The Relentless, Inescapable Awfulness
Anxiety
Continuing Anomalous Experiences
Consequences and Losses
The Paradox of Medication
Vulnerability
Stigma

6.2.1 The Relentless, Inescapable Awfulness

With only one exception

> *'It's not the end of the world and there is light at the end of the tunnel.' (Terry)*

no participant (9)[1] had any positive comments to share about their lived experience of living with psychosis, see Table 5 overleaf. Descriptors shared included, *'torment', 'hell', 'isolation', 'conflict 24/7', 'not very nice', 'depressing', 'wanting to hide', 'wishing it would all go away'*, and *'believing it had stacked life's odds against them'*. Living with psychosis clearly created an environment of awfulness. A convergent (9) sense was conveyed of a tortuous existence, fighting the experience, wanting to hide from its relentlessness yet expending energy on survival despite pessimism about it ever letting up, leading to an emotional oscillation between anxiety and depression, and resulting in social withdrawal and ensuing isolation.

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[1] Numbers in brackets, where included in text, indicate the number of participants who described the particular theme under discussion Smith J (2011) Evaluating the contribution of IPA. *Health Psychology Review* 5(1): 9-27

Table 5 Excerpts from each participant describing their experience of living with psychosis

Excerpts	Excerpts
Mandy: 'Very depressed and alone, isolated.'	*Marina: 'A living hell really, it stops me doing a lot of things.'*
Phil: 'I would just say hectic, depressing.'	*Terry: 'I was in torment.'*
Chris: 'It wears me out….. I live in conflict 24/7.'	*Alex: 'It's not very nice, no.'*
Viv: 'Wish it would all go away- total isolation really.'	*Gill: 'I think that my odds are stacked against me.'*
Leslie: 'I don't like it, it's not very nice, it's not very pleasant.'	*Bridget: 'I just want to go away and just hide.'*

And even for Terry who claimed a currently divergent experience of being beyond his psychosis, memories of the awfulness were easily recalled:

> *'[Life] was chaotic, I just wanted out, every day I wished I committed suicide, I was really, really ill.'(Terry)*

Extreme ideas about escaping the psychosis by suicide or self harm were expressed (7):

> *'Well, like I said very depressed and alone, yeah, isolated. No, I mean in the past I've always tried to take tablets…..to try and kill- commit suicide.' (Mandy)*

There was an equally convergent sense of oscillation between fighting and defeat, of psychosis exhausting energy resources because it called for continual vigilance and argument (8).

> *'Life for me, living with Psychosis, wears me out.' (Chris)*

Words that came to my mind were *'victimised', 'entrapped'*. Indeed any synonym of the word *'entrapment'* appeared to capture the essence of the lived experience of living with psychosis, even for Terry, who appeared to be trapped in a desperate struggle to stay well.

6.2.2 Anxiety

The primary emotion evident for participants (9) was anxiety, experienced whether alone or in the social domain. Anxiety could be driven by ordinary events and thoughts, or extraordinary perceptions such as paranoid ideation:

> *'Well, when I'm on me own I sort of like get anxious, that sort of thing, looking at the clock and that. I don't like going out, no, I'd always, always be trying to escape and I'd be anxious about that'. (Alex)*

> *'I'd be right scared about something and something else would come along as well, and things would just keep coming along and I'd be frightened about so many different things all in one go.' (Gillian)*

There was a perception (8) of a psychological and emotional component determining the intensity of the psychosis experience. As illustration, when Marina felt explicitly 'loved' her experience of voices for example was less distressing, equally, when she found herself in stressful and distress-provoking situations her experiences became more unpleasantly intense, and this worsening of this experience drove fears that stress/distress were ultimately precipitants of a return to overwhelming experiences of psychosis and relapse.

> *'I think I need somebody to tell me that I - that they love me. I feel sure if <my husband> told me he loved me in the morning before he went to work, sometimes I think the voices wouldn't be as loud as they are.' (Marina)*

There was a sense of vulnerability and of fear within this and a sense of inadequacy of the self in relation to 'surviving' the psychosis. This also illustrated a curious convergent interpersonal component (6) in that it appeared that actions of 'others' towards the individual influenced the intrapersonal dynamics of the psychosis and the self. This seemed to suggest that the experience of living with psychosis was an intrapersonal conflict between the self and the psychosis. It appeared to give the psychosis the status of 'entity, of a separate and volitional being inhabiting the 'self-space' and creating continual challenge and fear (linking here with SOT2) interfering even with the most basic of functions (e.g. writing signatures) and abilities (e.g. to concentration).

> *'I can't concentrate, my concentration is very low. I mean, like telly, I can be watching it, perhaps not taking it in, it's too hard. I don't read, I mean pick up a book and try and read it, but….'.(Mandy)*

> *'I find it very difficult to concentrate. But I, I tend to give up very easily, I'll spend five minutes doing 'something' and then I think, 'Oh, I must have a rest' and I find I haven't got the patience and the concentration to do it on a longer level.' (Bridget)*

6.2.3 Continuing Anomalous Experiences

All participants (10) described experiencing anomalous experiences (Terry's were descriptions of his memories of the time he was overwhelmed by his psychosis), for some these were voices, noises, or visual perceptions, for others these experiences were cognitive or physiological in nature. Such experiences were accompanied by an emotional response, reduction in concentration, and by behaviour in line with the beliefs about the anomalous experience. These excerpts are illustrative of this:

> *'Um, sometimes it can be er, noisy even though it's sort of not the noisiest place in the world, but you hear like, odd noises and it can make you angry. So I would just say hectic, depressing…….um, and then the next minute you're happy. But when the night comes that's when it's worse, you hear – hear the voices louder and stuff.' (Phil)*

> *'I know that people read my mind an' that, yeah, it's like, I try not to think for a while. I hear whispering as well. It does distract me, yeah, it does.'(Alex)*

> *'Yeah, a problem I do have is a - when I'm having a thought, I will often think the opposite in words um, I know, I know that I like something or someone or what I'm doing and I know that I like it, but the words in my head will be saying I hate this or like horrible things and just being really insulting, and I can't get those words out of my head, and they make me feel really uncomfortable.'(Gillian)*

Gill was the only one to experience visual perceptual anomalies (hallucinations) and her excerpt illustrates the emotional and behavioural response to such experiences:

> *'Last night I um I had this thing there's always something in an enclosed space um that stands behind me that makes me jump. Um, in the bathroom it's a zombie, a very tall zombie and in the kitchen it's a clown, I end up spinning round chasing my tail trying to find it, to catch it out.(Gillian)*

Mandy was one of two participants (Viv also) to describe her 'psychosis' as a physical sensation as well as an invasion of her 'self', her head, by people and that this had been her experience since she had mumps and subsequent hearing loss at a very young age.

> *'Psychosis is my head being pulled around, um, people in my head, um I hear voices, um, feel my head being pulled apart, and locked.' (Mandy)*

So living with psychosis is also living with continuous 'other' experiences, whether voices or visions, there is no let up. Emotional, psychological, personal, and social stability and normality are persistently compromised by this, and the daily experience of life becomes fraught with potentially insurmountable experiences. If you cannot 'shut down' emotionally to this ongoing experience then managing it and moving beyond it must become incredibly difficult. Images of living each day on shifting sands, battered by external and internal insult, fill my mind.

6.2.4 Consequences and Losses

Consequences and losses from developing and then living with psychosis as a longer term condition were shared. There was convergence of the loss of the pre-psychosis self (6) suggesting that for most the pre-psychosis self was remembered and experienced poignantly as a 'lost self':

> *'I was very much the person in charge. But now I don't feel as if I'm in charge of myself, let alone other people. I see myself as a different person, yes.' (Bridget)*
>
> *'I would like to get better – back to what I used to be like. - want to get better to how I was.' (Leslie)*

The issue of psychosis impacting negatively on the family was shared (7), like the lost self, this issue was shared with sadness and guilt and a sense of wishing there was a way of 'atoning' for the detrimental impact of distress to still loved families. Terry's and Viv's words were illustrative of this.

> *'When I was ill, it took ten years off, my Mum's> life, yeah, ten years she reckons yeah. Yeah, it made me feel guilty, she said that ages ago. I do blame myself some of the time because I thought the Parkinson's was bought on because of the stress levels I given her.'(Terry)*
>
> *'When I got really bad, goin' back what say ten years ago, um I thought peop – I see people watching me, an' tape recording me in the house, an', I can't really remember to tell truth but it was like they [my kids] were seeing it as well and it wasn't fair on them, 'cos they was getting upset and saying 'Mum, I don't like seeing you like it', an' you know.' (Viv)*

Shared too was the issue of dangerousness (3). Chris felt awful about the impact his psychosis had had on members of his own family, guilt and shame at not being in control of his behaviour, and ultimately physically hurting all of them. This was echoed by other participants (2) who lived with a burden of guilt and shame brought about by their abusive or violent actions towards family members.

> *'[I used to] mm…er…..fighting, attacking people, I'm not really like that, my medication helps me, I used to hit my Dad but you are alright.'(Leslie)*

> *'If I get unwell, my family really suffers, it's them I aim it at - I've attacked 'em all.' (Chris)*

There was an expressed loss of friendships because of the psychosis (7) arousing a sense of the totality of loss for people who develop psychosis, that loss is personal and relational, compounding the challenges of recovering a meaningful and ordinary life.

> *'We was friends and had an argument and I thought myself it's easier if I stay on me own and then I haven't got the paranoia of things going on in my mind.' (Viv)*

> *'I lost my friends when my illness started, all of them. I was doing silly things, or had a mental illness, problems with the mind and most of them didn't stay around, none stayed around, can't think of one that stayed, all went.' (Leslie)*

A final convergent consequence (7) was the creation of a very negative sense of self from the very fact of being someone who developed psychosis as a longer-term condition, a sense of failing at life because they had become mentally unwell and lost the life opportunities which may have been available to them accompanied with a sense of it being their fault in some way. This was expressed in an absolute manner *'I **have** failed'*.

> *'Um, I feel very much the failure. I failed in life. I was going on ever so well and everything was hunky dory and then suddenly, there was a cut off - and um, I just feel, I just feel a failure.' (Bridget)*

6.2.5 The Paradox of Medication

Anti-psychotic medication was a convergent and contentious issue. All participants (10) were on long-term anti-psychotic psycho-pharmacological regimes and most had been prescribed a variety of such medications over the years. Medication did not for most participants (9) extinguish the unpleasant experiences of psychosis, rather it appeared to calm the experiences sufficiently for the persistent hypervigilance and anxiety to be moderated to a degree which enabled sleep, relaxation, or supported normal functioning.

> *'Takin' me medication at night [helps] an' when it's kicked in, you know and I'll think right, I can ignore it for a little bit, even though it's still there, and then I go to sleep. When the voices are active that's when I go on my medication. It doesn't stop them but it relaxes me, so I'm not on edge.'(Viv*

> *'I'm on a lot of medication but for the last seven, eight years since I've been taking this stuff, they've never been able to calm my voices down.' (Chris)*

Considered and regular use of medication was viewed as important for staying well:

> *'If I actually didn't get any <anti-psychotic medication>, after about two weeks I've gone completely. Lost it. I'd be – I'd start talking to myself and um, not loudly, but you do begin to go barmy and sort of find yourself gone away. Lost it.' (Phil)*

but there appeared to be a harsh trade-off between reduced emotional distress or relapse and deleterious side effects – *'a rock and a hard place'*. Participants noted physical effects of medication and sedation leading to feeling like a *'zombie'*; this sedating effect appeared to be significant in terms of reducing the ability to function in an ordinary way which is a paradox given that the medication is advertised as supporting a return to normal functioning.

> *'Side effects of medication, muscular effects, arms get stiff, feel like a robot, but [without it] I'd be staring at the sky all the time, it sedates me slightly…sedates me, can't work or drive now. Can't do a lot, can't work, can't drive, can't do a lot, been told I'm on too much medication.' (Leslie)*

> *'It <the medication> lessens them <the voices> , it gives me a chance to manage them without me being zombified. 'Cos that's the other side of it, if they give me more medication, with the side effects ….. I wouldn't function as a human being, I'd function as a mental health patient.' (Chris)*

Participants (7) were not enamoured by the way they perceived medications to be prescribed nor the perceived care involved in the decisions given the ramifications they have for allowing acceptable functioning as a person.

> *'An' some doctors have tried to trick me, they think I'm born yesterday, an' they say "you won't get any side effects on these – this one then Mr Smith"' (Phil)*

> *'People come to mental 'ealth, they get prescribed, 'well, this will calm you down' ((Slapping hand)), 'this will do this' ((Slapping hand)), 'take that', an' they're sent away, 'come back in three months an' we'll look at you again'. I think I've been medicated to the sense that I didn't function.' (Chris)*

However, in spite of the ambivalence about taking anti-psychotic medication, all participants (10) seemed to have accommodated albeit reluctantly to the prospect of taking medication for the long term.

> *'That's why I keep taking the medication so I don't get ill again.' (Terry)*

> *'My medication helps me, settles the mind, calms me down, always take my meds I think I'd be in hospital without medication.' (Leslie)*

> *'It's not about coming off your medication, medication is part of life, you know.' (Chris)*

6.2.6 Vulnerability

A convergence in experience concerned participants' views about what had caused them to be vulnerable to developing psychosis. Without exception (10) a common experience was childhood trauma/abuse and/or peer bullying: Terry, Alex (and in Care), Bridget, Gillian (and drugs), Chris (violence and alcohol), Leslie, Marina, Mandy (mumps and deafness at 5 years with voices since this time), Phil (drugs and family history of psychosis), Viv (violence and drugs).

These combinations of childhood abuse or life trauma, attachment problems with parents, and/or peer bullying, were not perceived by any participant to have been managed well or resolved. Such events were associated with emotional and behavioural responses by all participants and all were able to distinguish clearly between being distressed by early events and challenging behaviours in response to them, and their subsequent psychosis. Alex's early life was troubled by being in 'Care' and through peer- bullying but she distinguished these troubles from her later experience of psychosis which began when she was in her late teens. Marina and Viv recalled many episodes of depression preceding the development of psychosis and were very clear that these earlier mental health problems were very different. Chris recalled anger *in extremis* and heavy alcohol use prior to the development of voices and psychosis. Mandy talked about hearing voices since she was five following going deaf through contracting Mumps, but although distressed by her voices, was able to live alongside them until her mid-thirties, which she pinpointed as the beginning of her experience of psychosis although was unable to identify a trigger for this change in experience.

External negative events experienced by participants were consistently associated with internalised shame, guilt, or a negative sense of self; shame and a negative sense of self if the event was abuse from others or parental rejection/abandonment, and guilt if the event was self-determined, even if reactionary behaviours were in response to negative events.

> *'I was playing truancy from school when I was 7, I had a horrible teacher. I didn't tell anyone I was getting bullied. I was ashamed to think I was getting bullied. I was ashamed to admit to a teacher or to my mum.' (Terry)*

All participants, implicitly or explicitly, perceived the brain or self to be malleable, open to damage or change through particular characteristics of the self or by external events.

> *'My illness got really bad from '93 onwards, when I lost my son in a car accident. I say I went insane with gr- grief. You know and er, I had to find someone to blame, I couldn't – it was the voices just got out of control and I acted it <the psychosis> out.'(Chris)*

> *'I let things get to me and I've ended up how I am.'(Viv)*

> *I used to bottle it all up and that's why I went bang.'(Terry)*

Gillian believed that it was her response to her experience of peer and parental bullying that caused her to develop persecutory voices:

> *'I felt very persecuted growing up because I was bullied. My mum was horrible to me and I had fears of persecution pretty much all the time and I just felt very persecuted all the time, which is what the voices like to do, um, so I think I just grew up into the way of thinking that I feel persecuted, which taught my brain to make voices that then made it worse.'(Gillian)*

Gillian shared her sense that her way of interpreting the world became flawed, that she has developed a sense of herself in the world as being persecuted, and that this has fundamentally changed the way her thinking processes operate and even impacted in some way on her brain's functioning so that it generates persecutory voices.

There was partial convergence on abusive or unwise events, self-facilitated or imposed by others causing damage to the self or the brain and causing psychosis to develop – a detrimental impact of an external agent(s) (5). However, others (5) perceived causality as being intrinsic to themselves, originating from a 'flawed' self, irrespective of later external events, and saw the 'blame' for the development of psychosis as coming absolutely from within:

> *'Am I a bad person? I'm weak.' (Mandy)*

> *'I'm very weak, I was gonna say that's because I've allowed myself to have voices, but I don't know if that's the right way to put it.' (Marina)*

> *'I was extremely violent and everything I did you know, from playing with toys at a young age, they was always extreme, you know, pushing it to that limit. An' I was under the psychia – psychiatrist child – children services you know from the age of six with medication……me Dad was extremely violent, the man should 'ave been in prison.' (Chris)*

> *'I was always the bad one, not as much I suppose not the bad one, but Mum had her favourites. I was just feeling 'what have I done that's wrong?', I mean I wasn't good enough.' (Viv)*

Rather than attributing 'blame' or cause to external events they saw themselves as fundamentally flawed at the outset *'I'm very weak' 'I was extremely violent' 'I wasn't good enough'* and not requiring any external factor to precipitate the development of the psychosis. Chris, Marina, and Viv believed that they were ever likely to develop something or do something awful because of their flawed self.

Phil believed that he had always been predisposed to developing schizophrenia because his Mum lives with the same condition. Having this idea of inevitability in mind he felt had made him more reckless than he otherwise would have been and embrace a 'fait accompli':

> *'She's < Mum> had breakdowns in the past and I thought if I'm gonna follow suit like the experts say and end up with a mental illness, let's do drugs anyway, but um, I wasn't ill until I had my first joint……then I went in to Speed and loads of alcohol, but I've given it all up now and I would say since the year 2003 from then on I've got a lot better so it was the drugs that made me worse.'(Phil)*

Psychosis-preceding substance misuse was a factor for four of the participants:

> *'I smoked too much Cannabis when I was young, probably, um which is a big factor.'(Gillian)*

> *'I can remember certain things what I was like and what I was doin', it's silly things, like when I – 'cos my partner was violent to me as well, and he got me in to taking speed, 'cos I was a size 14 and I weighed 13 stone and he kept saying I was fat and I went down to nine stone, then I stopped taking it, cos I knew it was making it [the psychosis] worse. I went on the bridge and chucked it off the bridge and never touched it again.' (Viv)*

There was compassion and sadness engendered by this lower order theme in that this internalising of 'blame' or causality existed despite challenging childhoods with identifiable parental attachment issues and, for Chris, the experiencing of extreme emotional and physical abuse from his violent father. It appears that self-blame becomes a feature of the sense-making of the phenomenon of living with psychosis, self-forgiveness or repositioning ‘blame’ is not.

6.2.7 Stigma

> *‘It’s the way people treat us isn’t it? It does matter when you get someone like that, it’s rude. It does matter, it’s not very nice.’(Leslie)*

Stigma, both societal and self stigma, arose as a powerful feature of the lived experience of living with psychosis from eight (8/10) of the participants.. Leslie’s excerpt is illustrative of living with a condition vulnerable to societal stigma:

> *‘[People should] understand it better, be a bit nicer, understand them, understand psychosis, the police are beginning to know about psychosis. There’s still a stigma though isn’t there, people cross over the road you know. It’s not nice..’(Leslie)*

The sense emerged of people living with psychosis being judged *a priori* by others, of not being seen as themselves rather just as *‘mad and potentially dangerous’*, an ‘other’, someone who was different, odd, not normal, not belonging to the same society, perhaps not worthy of belonging to the same society. Bridget and Gill spoke about the damaging effect that being ‘prejudged’ by others on your sense of self and how it changed others’ behaviour.

> *‘If you just say you have a mental health problem ………then people tend to - to put you in a box and say, ‘well, this is what’s happening, with your life, and so we’ll say this or that or the other’, and then I guess treat you accordingly, so treat you as according to their um, beliefs that they hold or just the information that they have.’ (Bridget)*

> *‘I think the people don’t understand like it’s quite – it’s a very complicated subject to understand um, and I think that people think Schizophrenia is synonymous with ‘psycho’ and that I might, they like think that if I’m schizophrenic, if I tell them I’m schizophrenic, they think I’m out of control and I might just suddenly break their nose one day and um, which I won’t, I certainly won’t, but they think I’m telling them that when I tell them I’m schizophrenic.’ (Gillian)*

There was a sense of people living with psychosis being invisible and visible at the same time, invisible as themselves yet visible as 'alien', and this separateness making stigma, rudeness, exclusion, and judgement admissible.

> *'I could go to a training club and maybe the general public could see you and think 'Well, what's wrong with him? He's - he's not in a wheelchair, they don't see - see it, you see.' (Phil)*

This process can but be seen as devaluing and extinguishing which cannot fail to impact on the sense of self of the person living with psychosis. Two participants mentioned a popular UK television show that is notorious for interviewing people who have behaved in morally indefensible ways to their loved ones and they noted that people such as these were lauded on television, yet to be seen to be living with psychosis held more stigma than that. Leslie again articulated this expressively:

> *'Some people think I'm a nice chap, nice person really. I 100% want to be a nice person; going off the subject, but I watch the Jeremy Kyle show and I realise I'm nothing like that – the things you see are extraordinary, I like to be a nice person. No, I'd like people think I'm nice chap really.' (Leslie)*

It seems extraordinary that our society tolerates and exhibits people who publically confess to anti-social lifestyles yet remain intolerant of genuine mental distress.

> *'I think my friends left me, when I became first mentally unwell, thinking I had mind trouble, 'don't what to know him'.' (Leslie)*

Several participants (6) commented that part of the problem stemmed from psychosis being a difficult condition to explain and very difficult for people who have never been touched by it to understand and empathise with. There was also a convergent sense of psychosis being challenging to reveal given the perception that such revelation might lead to negative responses from people because of lack of understanding.

> *'It's not a well-documented disease or – or anything like that. Um, it's very wishy washy -* mental health*. People, can't understand it, there's no set 'you have this and then that happens, and then the other happens'. In a normal illness, you get your different degrees of what's going on, whereas with* mental health*, you don't get that option. It's like a bad dream really in that um, if you reveal yourself you come under*

> *more attack than you will understanding from people, which puts you in a worse position.' (Bridget)*

This convergence included an awareness that the manner in which the psychosis could cause anyone with psychosis to act could lead to understandable fear and prejudice from others.

> *'Obviously my closest friends and obviously me family know, but after that I don't really tell people, 'cos you tell people you're a schizophrenic and they think "Oh my God", you know, 'cos they'll think I'm a complete loon ((laughing)). They'll probably think 'don't trust her, don't be around her'.' (Viv)*

Yet equally there was a convergent sense that psychosis is visible externally in some way, that experiences cannot be contained, that it 'leaks out' into the social domain in spite of best efforts to keep experiences private and unseen. A common response to this was to 'hide away' (8) or to put on a front to disguise how much the psychosis is troubling you (7).

> *'I – I don't tell people that I've got schizophrenia unless I really know them very well, in which case it doesn't seem to bother them because they know me so well by then they're like <shrugs> whatever. Outwardly my main effort is to try and appear as if I don't have an illness, because that's how I'd like to be, so that's how I act or try to. I try to be quite sane ((brief laughing))!'(Gillian)*

There appeared to be a difficulty in articulating the experiences to themselves and consequently to others *'Um, what shall I say ((quietly))?' (Mandy)*, of maybe not having an explanatory framework for such unusual experiences, and also an awareness of the impact that disclosing such strangeness to others would have.

> *Um, I can't – it's difficult to explain to people the way my head feels. Feelings, an' voices, um aliens, the devil, yeah all of that, yeah. Mmmm, I feel I've been back in the past, of being reincarnated, that I was married to Kennedy [US former President], and um, like the um, rocket space, aliens…….' (Mandy)*

The experiences attributed to psychosis were so extraordinary and bizarre that they were difficult to articulate and to share because of their strangeness:

> *'How do I put it? Um…….. you know I don't know how to word it.' (Bridget)*

All participants made admirable attempts to really explain the strangeness of their experiences through the research interview and this felt like a privilege that they worked so hard and fearlessly to convey such extraordinariness.

Whilst most participants (8) talked about societal and self stigma, Phil vociferously expressed anxieties about the level of misunderstanding that people in positions of authority have about the reality of living with long term mental illness. He articulated the faults that he perceived within the system as it currently stands.

> *'Sometimes you get more paranoid about that <not being able to work> that the agency are gonna stop your benefits………there is a difference between refusing to work and actually not being able to but the way Mr Cameron and politicians look at it, is they think that all people with a mental illness have refused to work, but that's not the case, we actually can't. And so that – that means that we're actually not refusing you know, so there is a difference.' (Phil)*

It was refreshing to engage with the energy of Phil's narrative but paradoxically enlivened issues of frustration. It must be challenging to reside in a society where you are at the whim of absurdities and misunderstandings prevalent in those structures which are meant to be supportive; an example of continuing institutionalised stigma.

Chris and Terry did not view themselves as lost to a devalued societal sub-culture of 'psychotic', others (8) did perceive themselves as disenfranchised from ordinary society. None, however, actively embraced being pushed by their mental health into a societal sub-group of 'the mad' and expressed a paradoxical position of resisting being identified with a group of people they themselves held stigmatised views about. This was an experience of awakening to the knowledge that you are not a 'normal member of society', that you have become mad, damaged, lost.

> *''Cos I look at them <her peer psychosis support group members> and think, 'am I like that ((loud whisper))?' - not that there is anything wrong with being like they are.'(Marina)*

> *'I only know two other people who have been in hospital, but I don't get on with them ferociously because um, one of them's been in a very long time and just behaves in a way that I can't stand.' (Gillian)*

6.3 SOT 2: Psychosis as a Volitional Other *'I've got you now. You're mine.'*

Psychosis appeared to be perceived by all participants as a separate entity, as if it was a cognisant being. People do personalise 'illness experiences', depression for example is known colloquially as 'the black dog'. Psychosis emerged from the data as a malevolent, controlling, blanket-like entity, aiming to subsume the person and acting from its own volition. This perception makes for unimaginable torment because the psychosis entity is viewed as targeting the individual, being more powerful, and attempting to inhabit the 'self-space' yet being beyond the control of the individual. This phenomenon is captured in Chris' narrative, expressing the experience of having his self-space taken over by an 'other' or 'others':

> *'Cos sometimes it's like I got two 'eads, you know what I mean? Something can come in and I think 'that's really inappropriate, where did that come from?', but it came from the back of me 'ead. It's like having two brains, I'm – it's the only way I can think about it. An' both of 'em got a function in everything I do. It's like Cowboys and Indians; one's good, one's bad, you know, and they're always in conflict. An' er, when the good side (me) is having a bad day, the bad side (psychosis) gets on top.'(Chris)*

Chris very clearly had an intact sense of himself and knew his personal values, that he was the good guy and the psychosis, the bad guy. As well as giving a sense of the separateness of the psychosis and himself, his words included in them a sense of the psychosis and his own mind having separate strands, of thoughts coming from his own mind, and of thoughts coming from the psychosis.

There was a fear of the loss of the self to psychosis, a subsumption one cannot return from, and so living with psychosis brings about hypervigilance to the psychosis and fear of its ability to harm you. At the end of the above quote, Chris reiterated the sense of separateness of functioning and existence by his description of the struggle to keep the 'good side' in control and for it not to be subsumed by the 'bad side'. A convergent finding (6), there was a sense of two parts of the self, of the mind, involved in an enduring struggle for dominance. This struggle must be exhausting and would make the hypervigilance and anxiety described by many of the participants understandable. Chris shared an example of what happens when his personal resources are reduced, he used sleep disruption as an example.

> *‘Cos what happens when I get tired, I can’t manage ‘em. He’ll <the voice> says “I’ve got you now”, “You’re mine”. And I have to really struggle to pull it back. (Chris)*

This illustrated a convergent (6) sense of the psychosis drawing somebody in, attempting to take them over, as if the person has no ability to protect themselves and retain an autonomous sense of self. The boundaries between the psychosis and the self were experienced as seamless, with a weaker ‘self’ being at the mercy of the psychosis. This suggested that the psychosis is experienced as a cognisant entity, which acts on its own volition, having motive – malevolent usually, and an ability to act independently of the wishes of the person within whose psyche it exists within.

> *Nothing I could do about it I couldn’t control it….and it just took over my life.’(Mandy)*

Because the psychosis is viewed as a volitional other there is a significant impact on self agency in staying well and having control over the experience. This phenomenon is illustrated well through Viv’s and Mandy’s quotes. They clearly talk about being out of control of their own minds, that something else has control that is not ‘you’, and that once it gains control that it is viewed as inescapable.

> *‘Psychosis is not knowing your own mind, not being able to control it, I don’t know, I don’t know how to explain it. Um, just not being in control.’ (Viv)*

The sense of the psychosis being an ‘other’ was emphasised through participants’ use of personal pronouns and descriptions of interpersonal dynamics with the psychosis. Mandy’s excerpt illustrates this, she described the type of dialogue she heard from her voice, hearing a voice that was speaking directly and appropriately to her about her fears at that time, and it was easy to imagine how one might welcome into your life an empowering other at a time you felt depowered and scared.

> *‘Um beliefs, um I was against, um, a lot of ah, foreigners coming over and overtaking us and that’s why I had in my head “I’ll give you real power”, “believe in me” and things like that. Yeah, “believe in me”, “I’ll give you power”.’(Mandy)*

Because the psychosis was seen as a volitional other there was a definite sense of one’s life being at the whim of the psychosis, of a loss of autonomy and self-determination.

> *It's weird though because it takes me away from what I'm doing so it's got a hold on me, "gotcha!".'(Chris)*

This brought with it a sense of loss of self-agency against the ravages of the psychosis and was a recovery interfering experience. If we consider Terry's recovery: in his interview he constantly repeated phrases about being 'lucky', he believed it was luck and medication that delivered him recovery from psychosis.

> *'I mean it's lucky that I got a total recovery y'know.'(Terry)*

As such Terry saw no role for himself in managing the experience of psychosis which might not auger well should the psychosis return, as his beliefs about managing psychosis do not include a role for self agency, rather that when the psychosis was active, that he was at the whim of it. Other participants shared Terry's beliefs that they were at the whim of the psychosis.

> *'I suppose it's living on the edge really wondering when it's going to happen. Even when you've felt really good, it's always in the back of your mind, is this going to last?' (Bridget)*

> *'As I said, one day you are in paradise, the next day you're literally in that – in a depressed, agitated, angry, confused state.'(Phil)*

Both Phil and Bridget described the uncertainty that living with psychosis brought, that your emotional state could be changed at any time by the psychosis, that your well-being was out of your hands, that the psychosis determined your life at its will and that you were merely its prey, waiting to be overtaken by it.

The sense of the self having little control over the psychosis and the psychosis having its own volition meant that to prevent subsumption one had to be hypervigilant to its activity and fight to retain the self.

> *' 'Cos some days you are waiting for it to happen, you are waiting for the voices start an' all of it really………on edge waiting for it to 'appen. I feel just on edge all the time, yeah, you never seem to relax.' (Viv)*

It was understandable that this phenomenon would lead to heightened anxiety – bringing a state of constant physiological arousal as you could never be certain when it was going to begin/invade again, and if you took your eye of the psychosis, it could rear its head again in moments of unpreparedness with potential catastrophic consequences.

So the participants living with psychosis appeared to exist with a constant sense of threat to their psychological and physical integrity. Living with constant anxiety appears to extract a cost both physically and psychologically on the person. It certainly does nothing to moderate the belief that you have no control over the psychosis, nor that the psychosis has its own volition, and that it is a separate entity. There was no sense of integration between the psychosis and the self – it was seen as a separate and uncontrollable other. This once more drove anxiety and behaviours which supported the 'saving of the self' from the psychosis. Survival, though, could not be guaranteed despite the person's best efforts.

> *'But, no matter what it says, it always wins in the end by me doing something. You can't, you can't get away from it. It will always win in the end.' (Bridget)*

The use here of the term 'it' is very illustrative of this SOT as Bridget clearly delineated the psychosis as an entity with volition and power over which Bridget believed herself to be powerless. This excerpt emphasised the self-oppression that experiencing psychosis exerts and the entrapment. It further depicted the reduced ability to determine your own actions and life course, and a sense of the uncontrollability of your own self and your life.

The phenomenon of psychosis is experienced as acting on its own volition with a purpose, and being outside of the person's control, and if you cannot escape or predict its presence, then drawing yourself out from under its shadow and reclaiming a sense of a strong, autonomous self could be experienced as unreachable.

6.4 SOT 3: What is Real? *'I know that it ain't real……but it don't stop it happening.'*

This theme emerged to be a significant phenomenon of living with psychosis experienced by all participants. Polarisation emerged within this theme, divergence within the phenomena becoming evident. Two participants (Mandy and Alex) were subsumed by their psychosis and believed that what they were experiencing was reality despite its oddness or extreme nature; because they believed in the reality of their psychosis, they lived a life that was defined by the psychosis. They did not engage in a meta-dialogue or a challenging dialogue with their 'psychosis defined reality', questioning what the voices said or reflecting on the extraordinary beliefs that developed even though they were out of alignment with their culture. For them, there was an acceptance, a certainty and security that no matter how odd or frightening, how they experienced their world whilst living with psychosis was how the world was.

> *'I'm just paranoid about people, um, I think they are all terrorists and things like that and they are after me and things like that. It's what I believe. I think they're having a go at me, the law and all that.'(Alex)*

The other participants (8) were in a state of ontological dichotomy, being uncertain about what was real and not. It is as if once you have experienced something as real, it gains a reality no matter how extraordinary, and on repeated meetings with this phenomenon the ability to reject it as unreal, however extraordinary, is compromised. Psychosis, with all its extraordinary perceptual symptoms, appears to challenge ontological security and a new epistemological framework is created to accommodate to this new 'knowledge', experiences and perceived certainties. There are 'knowns' about the shared world but there are also things that become 'knowns' about the idiosyncratic world entered into when what is termed 'psychosis' develops. These 'knowns' are different, often antithetic to understandings of the shared world but held with conviction and based on epistemological developments to account for a shift in ontological security. As such, voices experienced phenomenologically as 'real' become 'known' as real, as certainties in our new world *'Yeah , but it's sometimes it's like whatever goes on in my head is real'(Viv)*. This leads to a struggle to re-establish pre-psychosis ontological security and it emerges that people living with psychosis inhabit a world of ontological dichotomy – where people are uncertain about whether what they are experiencing is real or not, and it emerged that people living with this state engaged in a dialogue with their psychosis.

Gillian's shared experience was detailed and illustrative of this phenomenon.

> *'An insult will come out of nowhere and I'll think that it's real, 'cos it sounds real and I'll have to look around and I've been taught to look around and make sure there is no one there, and then just disregard it and relax again. I - I guess I've always known that I should look around like if I think someone's there and I can't see them, I probably should look around as I've been told, but there have been times when I'm too frightened too.'(Gillian)*

Gillian first noted that her perception 'sounds real' so she responded to it as if it were real by turning towards it. Indeed, a coping strategy she had been taught was to do exactly that, confirm that it was not real and so disregard it. However, there are times when Gillian was just too frightened to look around and check. Gillian was then experiencing ontological dichotomy wherein she entertained the two possibilities at the same time, *'it is real, it is not real'*. The frightening prospect that it was real prevented her from discarding the 'new' knowledge about her experience of psychosis and feeling confident in her pre-psychosis or post-psychosis ontological security.

Participants (5) described not being able to discriminate between 'real' and 'not real' sounds until a 'real' noise occurs.

> *'I realise it's not real after I hear another noise to compare it to, but it's sounds like, it's sort of like this second hearing of like hearing at a distance, or perceiving that I might be psychic or something picking up on these things, and then a real voice will – will cancel it out 'cos I'll realise that I'm listening to something ((brief laughing)) that doesn't exist.' (Gillian)*

This is a strange phenomenon as the 'real' sound is recognised as real, but voices in this example are not recognised as 'not real'. Thus the person exists in an ontological dichotomous state, wherein two pieces of contradictory knowledge are held concurrently, i.e. that people can read minds and that people cannot read minds, that an 'other' can inhabit our psychological space and that this cannot happen.

This ontological dichotomy, to be in a world where the frightening things are possible as well as impossible, resonated with participants (7). Bridget's brief quote captured the essence of this ontological dichotomy as she described knowing that her voice was not real and yet still engaging with it as if it were a real interpersonal entity.

> *'[I hear] one voice and think that it's not real. Or should I say in a way I think it's not real and I have arguments with it.' (Bridget)*

Likewise, Chris' narrative also exposed an ongoing ontological dilemma, not just in being able to determine what is real and what is not real, but in the behaviour that ensued even if a sense of a perception or experience being 'unreal' is present.

> *'See I feel a presence when I get unwell. I- it comes on my left shoulder and he's just out of sight but it's there. An' I've heard the telly talk to me when it's been on, you know but I've told myself that ain't real, I know that it ain't real, you know I can make that distinction, but it don't stop it happening.'(Chris)*

Chris asserted that he has knowledge that it is not real yet the phenomenon was believable – *it feels real.* Leslie had similar experiences, he was still troubled by active extraordinary beliefs about the world and people's motives towards him; like other participants, he noted his ontological dichotomous position. Sometimes Leslie, like the others, knew what was not real and sometimes he did not. Knowing some of the time that these beliefs were not real did not appear to extinguish those times when he believed them as his reality.

> *'Still see planes, still rubbish, go out for miles with my support worker – even now I get troubled by helicopters and planes – sometimes I think some of it is rubbish but other times I take it seriously. You talk yourself out of thinking it sometimes.' (Leslie)*

Like the other participants, Leslie used other people as reference points for reassurance and ontological repositioning. It seems sometimes that this repositioning can be done by a person themselves but at other time it cannot.

> *'Sometimes I say 'There's no one there watching you, you know just ignore it, turn the telly up louder or whatever', and then other times it's like I say to myself 'Was that real?' (Viv)*

This leaves a person with a life experience that is inconstant and can be understood to maintain hypervigilance and anxiety.

Overall this ontological dichotomy appears to lead to an experience of confusion and continuing uncertainty about what is real and what is not, what is possible and what is not, leading to persisting anxiety and hyperarousal, a persisting sense of threat and vulnerability, and a seeking of reassurance from others. Imagine living in a world where the rules and possibilities are not clear and may change at any moment, where you might be under threat, or actually you might be quite safe. Maintaining wellbeing at such uncertain times will be challenging.

Reality, it emerges, cannot be taken for granted and once ontological security is rocked reality becomes something that has to be checked out because ontological dichotomy allows idiosyncratic 'knowns' to be assimilated into your ontological position.

> *'I don't know I'll either put the music on, or as I say the tellies are on and I try and concentrate on, could be a son- you know a song and start singing to meself, or then*

> *it's trying to ignore it and think what's reality and what's not. I just tell myself it's not real.' (Viv)*

6.5 SOT 4: The Tormenting Tyranny of Distressing Voices '*I've heard some people can get positive voices - I don't get those'*

6.5.1 Overview

This SOT brought together six LOT regarding the experience of hearing voices within the experience of psychosis. Seven of the participants (Viv, Bridget, Marina, Chris, Phil, Gillian, and Alex) were living with voices which caused distress. Leslie had never heard voices as part of his psychosis, an experience he described as

> *'…trouble with helicopters, planes, radio and telly; I think there are people in there that know me. And I've had trouble with the people on the radio referring to me, DJs referring to me like I have no personal life'.*

Leslie did not perceive hearing any of this 'interference' as a voice or voices.

Terry had heard terrible voices in the past but was not hearing them at the time of our interview:

> *'I used to wear headphones, before I went into hospital, headphones, all day long, I was just blocking it all out, I was walking past the houses, I was paranoid, I thought people were talking about me'.*

Mandy lived with voices but experienced her voices differently *'Yeah, the voices believe in me, give me power'*. Mandy shared little further information about her voices during the interview and confirmed my shared reflection that she perceived her voices as special and private to her, certainly not an experience that was for public scrutiny and certainly not for sharing with a researcher at an initial meeting. She did describe a Western culturally contradictory belief about the identity of the voices given that she did not perceive them as malevolent *'It's psychosis, the devil, um, aliens'.*

The dialogue with Mandy also indicated that she did not believe that the voices she heard were audible to or accessible by anyone else. Indeed, when talking about their voice hearing experiences, no participant expressed a sense of their voices being audible to others, rather that the voice hearing was a personally focused struggle they were engaged in, whether or not they perceived their voices as emanating from external sources. Across the discourses there was a clear sense of personal persecution.

Of the seven hearing distressing voices, only Gillian had completed a course of psychological therapy for her experience of psychosis (CBT-p) and expressed a different yet still dichotomous and complex relationship with her voices:

> *'The voices haven't got their teeth in me anymore, I sort of shrug them off a bit, they can be discarded, dismissed, although sometimes they do feel very real, so I have to ask for reassurance.' (Gillian)*

From these seven voice hearers there was a significant convergence of experience, and distress was aroused by a complexity of interrelated facets of the experience drawn out as lower order themes and listed in Table 6.

Table 6 Lower Order Themes within 'The Tormenting Tyranny of Distressing Voices'

The Tormenting Tyranny of Distressing Voices *'I've heard some people can get positive voices - I don't get those'*
Inescapability
Voice Content
Voice Determined Life
Relationship with the Voice
Separateness of the Voice
Beliefs about the Voices

6.5.2 Inescapability

There was a sense of the inescapability from the voice hearing experience. The voice hearing for some (Chris, Alex, Viv) was relentlessness, voices described as being present constantly, having omnipresence:

> *'They never go away' (Chris)*

> *'They're always there, right from when I wake up, a few seconds into the morning. And it's like 'bang' it's there. It's just talking about me 24/7.' (Viv)*

Similarly Alex described a sense of inescapable immersion in the voice hearing experience, an encapsulation by the experience, which she clearly linked to changes in her emotional state

> *'I'm surrounded by it, the voices, and I just get depressed. The anxiety starts an' then my mood does down, and always the voices.' (Alex)*

Others, Gill, Phil, Bridget, and Marina, experienced more of a variance in their voice hearing pattern. It was not a relentless experience but one which had periods where the voices were less intense or intrusive, or were absent for a time. Even in this reduced phase, though, the voices were not far from hearers' awareness, Phil's account is typically illustrative:

> *'It <the voice> comes and goes now, where it used to be all, all the hour of the time, now it comes and goes, as I say mainly night-time's the worst. Through the day you can hear, if it goes quiet you can hear bits and pieces an' it's – you sort of hear um, whispering, so you can't understand what they are saying, then you'd hear a word clearly like "you're an' f'ing t****r[2]" or whatever, then it will go back to muttering.' (Phil)*

There was a marked hypervigilance for the voice and its absence generated worries about their imminent return.

> *'I'm worried that they'll always come back you know, ten to five minutes later they are back again and saying exactly the same things. Oh, just to get rid of them!' (Marina)*

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[2] The language used in the interviews was frank and candidly expressive and included, for some, the use of culturally defined offensive language. For the purposes of this document some letters in such words have been replaced with asterisks to avoid detracting from the significance of the content through potential offence to the reader. However, this courtesy is not intended to depower or invalidate the awfulness of the subjective experience nor the cultural identity of the person using such language to describe their experience.

6.5.3 Voice Content

Voice content was perceived as overwhelmingly negative (8:1 voice-hearing participants). Voices were experienced or interpreted as critical, demeaning, hostile and undermining,

> *'…they're always telling me about I'm not good enough, can't do this, can't do that.' (Chris)*

> *'It's weird. I hear voices, yeah, a voice, a woman laughing, that as well, yeah, cruel things, it's a cruel voice, it's horrible.' (Alex)*

> *'Um – 90% of the time it's name-calling like "W"- the "W****r" word, "You're a pathetic idiot" or "you're an a***hole" or sort of names like that.' (Phil)*

The negative content was delivered in two distinct forms; in the second person as illustrated by the quotes of personally directed statements above, and also as a third person commentary:

> *'It's like if you've gone for a walk that day and you think of that walk that you went on that day a voice will come in and say "Did you see that T**t walking down the road?"'(Phil)*

> *'Sort of "oh, she's up now" and "she's getting in the bath" an' I don't know, I can't describe it really, it's like a running commentary.'(Viv)*

6.5.4 **Voice Determined Life**

Distressing voices convergently appeared to be a definer of the emotional life of the hearer and of the behaviours they felt driven to do, whether through coercion and fear of consequences:

> *'They start to talk about me and they see things that I do. I can go on the toilet…..and they count. If I haven't gone when it's an even number they say it'll be bad…..an' then other things like, I can't explain it, um, silly things, that I'll hear like 'She's [my daughter] going to college', an' it can be things like, 'Well, if her room isn't done by this time' like when she walks over the bridge, 'she's gonna fall off the bridge'.' (Viv)*

-through command:

> *'They just tell me , the voice is just telling me to do things, I don't have to do it, but it's the voices and I find I have to really, really fight to cope with even going to the One Stop shop because all the time the voices want me to hurt myself. They want me to walk in front of the traffic. Um, luckily the footbridge is now gone, at the bottom of <xx> Road, 'cos ….every time I walked up that way, the voices told me to throw myself off.' (Marina)*

- or in a desire to 'shut the voice up':

> *'Because of the struggle I've had with them and I find it very um, exhausting and so to – to end them going at me, 'cos it doesn't erm, stop them, but to calm them down I invariably do something to myself.' (Bridget)*

Because the voice hearing experience defined the hearers' lives there was a psychological, emotional and social cost to voice hearing when voices are distressing. Participants disclosed emotional states of anxiety and depression linked to the voice hearing experience:

> *'The paranoia usually comes with voices. I get very intense voices, very intense. The voices do seem to come out of nowhere, quite loud, every so often I'll get really frightened 'cos it seems so real, an experience of just an incredibly inappropriate voice shouting at me. If - if I'm worried I'm much more likely to have voices.' (Gillian)*

> *'I get depressed, I was depressed yesterday. I just get depressed. The anxiety starts an' then my mood does down, and always the voices.' (Alex)*

All the hearers of distressing voices described a psychological, emotional, and behavioural response to the voice, a battle which was internal mental anguish and struggle, and belief or distress based behavioural responses, and in addition two participants (Alex and Viv) described experiencing the voice physically:

> *'When I go out] it's like everything's spinning round really fast and I walk like I'm drunk, 'cos where everything is spinning round, you know it's, I can't explain it. The 'spinning' is the voices, it's like someone's pressed fast forward and it's going through my mind really, really quick and I can't focus on that and I think that's what makes*

> *me walk like I'm drunk, yeah 'cos it's my mind's, just going overtime. It's the worry, it's the voices getting louder and they get faster, so some of the time you can't make out what they are saying, like I say someone's pressed fast forward.' (Viv)*

6.5.5 Relationship with the Voice

There was a relational quality to all shared distressing voice/hearer dialogues (7). Voices were consistently engaged with in a resistant manner, in a recognisable interactional format. Voices were listened to, argued with, and either resisted through intense mental wrangling, complied with, or an alternative 'placating' behaviour performed. Behaviours elicited were either in accordance with the voice content or beliefs about what was needed to contain or reduce the voice activity, preserve the self, or protect others.

Voices were not consistently experienced as internal or external. At times voices were heard from particular locations external to the person and at other times as an internal experience, equally sometimes the discourse was internal and at other times external with the hearer speaking out loud to the voice. It did not seem to appear to matter whether the voices were heard from within the head or from the external environment, hearer response and voice influence was the same.

> *'But it's s - sort of um, you think to yourself it's sort of coming round – round the walls or sort of outside, from Space. It's coming from the clouds or something. Yeah, when I used to think it was someone doing it to me, you wanna find them and think you can stop it you know. You don't know who it is but you actually look out the window sometimes and you see, I used to shout "Who is it?" and "Why don't you show your face" "Who are you?" you know, "I wanna know who you are".' (Phil)*

> *'But it's normally in the kitchen above the cooker, it feels there's someone watching me through the floorboards, they talk about me what I'm doing all the time, and 'scuse my language and I tells them to f**k off!' (Viv)*

All participants experienced their voice(s) as existing within themselves or having an intrinsic connection to themselves, the struggle was seen as themselves against the voice(s), that even if the voice was perceived as an external other, that its modus operandi was to share the hearer's 'self', to inculcate its way into inhabiting the person's essential space and dominating the person.

Chris' words were typical of the sort of dialogue that hearers had with their voice(s). He talked about hearing negative voices which conferred through their words a sense of control and power from which he struggled to maintain a sense of autonomy. Chris also described the process which happens when he is interacting with someone socially during which the voices are continually active, becoming a contradictory third party to all conversations, throwing doubt on the choices of topics, the information shared.

> *'I'm always having a running battle, even talking to you, "Why you telling her this?", "What you doing this for?" "What about your family?" "Keep it quiet", you know, "Keep it within", "You shouldn't have told her that" "She''ll judge yer" All that's been going on and I have to stop and think before I say the next word.' (Chris)*

This social and relational cost is a daily struggle for some:

> *'It's hard to get up 'cos usually by the time I'm wide awake, the voices kick in, um, I sometimes have to have lots of reassurance before <my husband> goes to work that I'm going to be alright during the day.' (Marina)*

-which for others leads to social withdrawal:

> *''It's awful. Living with voices and the paranoia an' not bein' able to go out because I think everybody's watching me. It's things spinning around really fast, and every time I go out it's – if my daughter takes me to the shop quickly which is round the corner or, if I go, I don't know, to the doctors, that's it. I used to go down and visit my Mum, my Nan, and I used to get on a train, on me own, go an' see 'em an', see my friends, now I don't see anyone.' (Viv)*

There was a sense of struggle or conflict to maintain a sense of self-determination and some semblance of self-control. The dynamics of the discourse were very much about trying not to be subsumed by the will of the voice(s), this was extremely effortful yet frequently led to the acceptance of ideas or the undertaking of actions proposed by the voice(s), even if these actions and beliefs were unhelpful or harmful to the psychological and physical integrity of the individual. It was evident just how much time was spent in dialogue with the voice and in the struggle to survive or beat its oppression.

> *'But, no matter what it says it always wins in the end by me doing something. You can't, you can't get away from it. It will always win in the end, whether it's a very*

> *minor win or, or um, when it's told me to hurt other people or do things to other people as I have done it in the past.' (Bridget)*

There was a sense of malevolent reciprocity in that the hearer believed they were obliged to do what the voice was commanding because if they did not then dire consequences would occur. Hearers appeared to be in the thrall of an oppressor, a bully, in a relationship with a marked power imbalance.

> *'I think I should be able to sort of like block them out… and they'd go, but I just can't, they are always there.' (Marina)*

6.5.6 Separateness of the Voice

A sense of separateness of the voice(s) and the self could be interpreted from the narrative discourse. This very much related to SOT2, of the 'psychosis' being perceived as a separate volitional entity and questions arose for me about whether participants were seeing their voices as the 'voice of the psychosis' or whether living with psychosis was synonymous with 'living with distressing voices'.

Personal pronouns were used to identify the voice which strengthened the perception of separateness, and were used in dialogue with the voice.

> *'It's weird though because it takes me away from what I'm doing so it's got a hold on me, "Gotcha!". (Chris)*

> *'Sometimes it can be "Oh s**t, he can hear us" -   I don't know what that one's all about.' (Phil)*

> *'She <the voice> is mean, yeah.' (Alex)*

The voice activity was perceived to be beyond the control of the person and compromised the ability of the hearer to determine their own actions:

> *'It's like um, it's like um, I can't do nothing when the voice tells me to do things. I do have wobbles when that happens to me, that sort of thing.' (Mandy)*

This was accompanied by beliefs about the voices beginning on its own whim, and strengthened the perception that the voice is an ‘other’ which has taken up residence in or is choosing to focus on the ‘self-space’.

> *‘Ah well, like I say, it’s just people in my head and I’ve met up with them and they are [the] people that I saw in my head; I see them outside my head and then also it felt like I had them in my head, and Jesus…..’.(Mandy)*

This ‘other’ drove behaviours that the hearer did not want to engage in, and gave rise to a sense that their voice(s) determined the hearers’ lives and behaviours rather than being able to have a self-determined existence.

> *‘I wish I knew what the trigger was, because people say “What is the trigger?” and I say “Well, if I knew that I wouldn’t have the problems!” Um, it can be anything at all. It can be watching the telly, Um ‘cos I normally watch TV, I’m a big TV viewer, um, what happens is the voices interrupt by saying “if this happens on the television……..then you must hurt yourself”. And then it might change its mind, but you still end up hurting yourself at some point.’ (Bridget)*

There was a distinct sense that the voice was acting to ruin the hearer’s life, to entirely subsume the person, and this aroused a fear of the loss of the self. There were descriptions of effortful and frightening struggles to prevent the voice from winning.

> *‘If I get too overtired an’ I can’t sleep I’m in trouble, pacing an’ when I start to pace I start to think – you know what I mean an’ um, I haven’t got the energy to do it. My reality gets screwed up, I don’t know what’s right, what’s wrong, I start to believe what they say about me. (Chris)*

> *‘The voice is just telling me to do things, I don’t have to do it, but it’s the voices and I find I have to really, really fight to cope.’ (Marina)*

> *‘The voices have to win sometimes.’(Bridget)*

6.5.7 Beliefs about the Voices

Beliefs people held about their voices appeared to be that they were omnipresent, omnipotent, and malevolent and bullying, wanting to overwhelm and defeat or subsume them. It is the language of battle, of oppression, the voice(s) were viewed as powerful, malevolent, inescapable, and invasive.

Viv’s account was typical. Her life seemed to be controlled by the words of the voice and Viv’s belief that she needs to operate by their rules in order for things to be okay.

> *‘and so you go out there an’ you could be peeling something stupid – the potatoes and then it will be like “well, I wouldn’t do it that way, I’d do it this way’ so you end up doing it the way they say. Because they make you feel like you are doing things wrong an’ you should be doing what they say otherwise [they say] bad things can happen.’ (Viv)*

As illustrated by earlier quotes from other participants, this belief about operating by the voices ‘rules’ in order to avoid harmful consequences was a convergent finding. This belief infers that a power is attributed to the voice(s), that the voice can directly influence events in the physical world. This belief about the voice arouses understandable anxiety or fear, comparable to living with a relentless bully driving you to act in ways that you ordinarily would not and into behaviours which are perceived as not self-initiated and are self-harming or dangerous.

6.6 SOT 5: Liberation *‘Easier said than done, but I suggest get up, put some music on.’*

Liberation emerged from participants’ descriptions of how they moved beyond merely surviving the experience of living with psychosis. It encapsulated experiences shared about being freed from the fear of or experience of the loss of the self to the psychosis. It was the sense of no longer being subsumed by the psychosis and have a greater sense of control, agency, self-determination, and self outside of the psychosis.

Liberation did not come easily and maintaining it required commitment to a life that was effortfully and self-determinedly steering oneself away from the pull of the psychosis.

Liberation was about having a life that was beyond living in the moment with the impact of distressing and extraordinary psychosis, and reclaiming the self. Most participants were on this journey (7) but two lived predominantly a psychosis-determined life.

Terry's experience was divergent from the other participants in being the only one to perceive himself to be 'recovered' and beyond his psychosis. A long excerpt has been included here from Terry to illustrate what he means by recovery. Whilst he does put his recovery down to luck, Terry's excerpt contains implicit and explicit optimism about the future and about himself, describing a 'rebirth' of someone very different from his 'psychosis self'. He notes the importance of good medication, and how the difficulties he experienced whilst living with psychosis, such as paranoia, are no longer a feature of his life. Terry also notes the importance of being accepted and valued by other people, and about reconnecting with the non-psychosis world.

> *'I've turned into a new person. I mean the medications got right at last and the lithium and the Clozapine …… and I've got so much to live for now. Before when I was at home, when I was ill for all of the years, I lived one day at a time; now I can live, look forward to the future and think well, everything's alright now. I'm lucky; they got the medication right at the right time . . . . and getting the flat and everything yeah, I'm lucky I mean ….I talk to people in the shops, I'm popular, people are always talking to me, I'm erm, intelligent, some people say I'm intelligent and all this. Erm yeah, before erm, I was shy and introvert but now I'm extravert and I've turned my whole world round now yeah. Like when I was young, I could never go out, I mean only with my mum and dad ……….erm, but now I can go out and talk to anyone, I don't feel paranoid, I don't feel like people are talking about me, I don't think people are staring at me or things, I mean its lucky that I got a total recovery y'know.' (Terry)*

Whilst a divergent experience, the factors which Terry draws together in his description of what recovery from psychosis means are echoed as 'liberation factors' by the other participants and emerged as LOTs. There are four LOTs under the umbrella of the SOT Liberation and these are presented in Table 7 overleaf.

On the Liberation journey, rather than being lost in the negative and incontrollable internal environment, something different develops, some new insight leads to a changed understanding and a changed sense of control, and so a change in response and level of distress. This turnaround in understanding appears to lead to a remarkable shift from feeling abused and enslaved by a tormenter (the psychosis) who has its own volition, to an understanding that the experience is within and not separate, and so is controllable or at least if not controllable, then within the self and so accessible to self-will. There appears to be an integration of the experience with an outcome of strengthening autonomy, and a journey from torment to laughable for some (6) and from separation to integration (3).

Table 7 Lower Order Themes within Liberation 'Easier said than done, but I suggest get up, put some music on.'

Liberation *'Easier said than done, but I suggest get up, put some music on.'*
Seeking support
Know it for what it is
Reconnect and don't give in
Seen beyond the psychosis

6.6.1 Seeking Support

Eight participants discussed the usefulness of having available different kinds of supportive opportunities and of choosing to access them. Two noted the usefulness of inpatient care for times when the psychosis became overwhelming, as a place of safety from the outside world despite the psychosis being 'carried in' to the sanctuary by the person and a sense of universality with the other patients.

> *'A sanctuary, that's what you need is a sanctuary when you're ill you know, I think there should be more places like that, it's very important, yeah, away from the outside world.'(Terry)*
>
> *'Ah well, I suppose being there where other people are ill - you find that a comfort in a way.' (Mandy)*

Opportunities to talk were perceived as important (8) and that the topic of discussion ranged beyond the psychosis. This appeared to be associated with remaining connected to the non-psychosis world. Viv distinguished between talking with family and with professionals, perceiving that she burdens her family with her experience of living with psychosis and not feeling that she has to protect the professionals from the details of her experiences. Mental health practitioners were seen as providing a focused opportunity to talk about the challenges of living with psychosis and supporting the recovery journey.

> *'Someone to talk to …. like what me an' you been talking about, I don't know, just to share it with someone so that it's not a burden, you know all on me, if that makes sense.' (Viv)*

> *'Talking to staff you know, makes a difference, not being treated like being on the scrap heap, people with the same condition, just more people like us, people smoking, being allowed to go back in, meeting people and talking to people. It gives me confidence to talk and in expressing myself. I go out every day and go shopping, I do it all myself now. No, no, before I bottled it all up, I was ashamed of it.' (Terry)*

The importance of being accepted and understood given the extraordinary and frightening nature of the experience of psychosis was clear in all the narratives (10), so too was the importance of positive peer identification.

Being involved with mental health services appeared to be a route to creating an alternative peer group, with most participants having lost their original peer group due to their psychosis (7). There emerged a comfort from universality in a similar way to the community on inpatient units, and from this could be drawn a more positive sense of identity and an accepting understanding space to inhabit as opposed to the sense of separation from the non-psychosis world that emerged earlier as pervasive; this is in contrast to the earlier described (Chapter 6.2.7) fear of belonging to a stigmatised group.

> *'I have made new friends that come to the mental health Centre, and groups and go swimming once a week. People like myself - in the homes, so the people that have also experienced mental health difficulties. I've made some new friends due to supposedly having a troubled mind.'(Leslie)*

Bridget noted that she could 'hide' less from her 'psychosis peer group' because they were more inclined to ask questions based on an empathetic understanding of the experience. There was also a sense that such peer groups gave permission for you to be yourself and admit to difficulties without the interaction being defined by it (5).

> *'Peer groups, to a degree, give you a certain amount of understanding, although I think you can still put your face on and go through it. But I find it harder to hide how I'm feeling when I am with that group because they'll say "Oh, you sure you're alright? You've done this, that and the other", um I'll go "Yeah, I'm fine, I'm alright"*

> *and then they'll say something and you say "Well, actually I'm not feeling great at the moment but you know, I'll get through it".' (Bridget)*

Four participants were attending a Hearing Voices Support Group and found this a forum that allowed for a different quality of discussion about their experiences of living with psychosis. This again appeared to be due to the shared nature of experience.

> *'Being able to talk about it for the first time in years.'(Mandy)*

> *'I – I like the support group, I think it's good. I think everybody should do it.'(Marina)*

> *'I can see them or know them, they're not 100% well (and I am not being rude), so I know I'm not the only one. Yeah, it's good – to get with people like myself.' (Leslie)*

6.6.2 Know it for what it is

Five of the ten participants expressed an understanding of their experience of psychosis which allowed them to step back from the experience and know it differently. There was more of a meta-perspective, standing on the outside looking at the psychosis and its action rather than being subsumed by it. A divergent view was from Mandy who perceived her experience as having a supernatural cause and was living a life defined by this belief:

> *'It's psychosis, the devil, um, aliens.' (Mandy)*

Terry and Leslie were very clear that their psychosis was an illness, treatable by medication:

> *'I know I'm suffering, got an illness, I'm suffering and people are trying to help me.'(Leslie)*

For three participants, their view was that the psychosis operated outside of their control and this had an impact on beliefs about self-agency in regard to liberation, in that believing in an illness explanation alone determined a reliance on administered medications to alleviate the illness. Chris, Bridget and Gillian saw the usefulness of medication in treating their experiences but also described a psychological understanding of psychosis. This psychological perspective appeared to increase a sense of agency in regard to the psychosis, that whilst medication helped there was something tangible that each could do psychologically to moderate the impact of their psychosis:

> *'Things have changed; I've got better on the medication that I've been on and I- I used to spend an awful lot of time in hospital when I first, um, became ill, but I haven't been in hospital for about four or five years now. And that's, I suppose, that's me becoming more aware of what is happening to me and what I can do to stop it.'(Bridget)*

> *'Psychosis turned into an episode of terror upon episode of terror ((laughing)) which was finally sorted out with the medication and I got CBT and um, the terror has subsided.' (Gillian)*

Gillian was the sole participant who had completed a course of psychological therapy (CBT-p) for her experience of psychosis and she did express a more psychological interpretation of her experience of living with psychosis. Her understanding was that her emotional state brought on her voices, and that if she was able to manage that more effectively, then her experience of psychosis would be minimised. This explanation put Gillian in a position of power against her psychosis and fed self-agency and control.

> *'CBT has promoted my self-worth, um, it – it was a really worthwhile experience, because like - it's just made me feel a lot safer um, having practiced and tried - I tried the mindfulness, but it didn't work, but like to look around and to seek reassurance and to just realise that it's how I'm feeling that's just causing the voices and to just remember to just stay happy for the sake of not getting into trouble with my mind and also letting things go and not panicking and all sorts of stuff. Just loads of little tricks.' (Gillian)*

Phil also described very clearly how he had come to 'know his psychosis' and how this helped him to re-evaluate his experience and gain a sense of control over it. He was able to delineate a process that linked his daily activities to his voice activity and content. Indeed, he was able to 'play' with his voices by using his thoughts to elicit a voice response to confirm the psychological explanation he had naturally developed. The emotional response he reported is one of laughter at the stupidity of his voices. This is a hugely significant repositioning of the self in regard to the psychosis in terms of power and control and cannot but support Liberation from the psychosis.

> *'I was having fun with it the other day because when I began to remember what we were doing through the day, I knew what voice was gonna come in and I thought 'I*

> *caught you out now, I know that there is no voices there, this is just in me 'ead'', so I just went to sleep afterwards laughing ((laughing)).' (Phil)*

6.6.3 Reconnect and don't give in

Eight of the participants discussed how they strived to keep themselves as far ahead of overwhelming psychosis as they can. Strategies ranged from regular medication use, reasserting oneself against the psychosis, staying busy, and staying connected to the non-psychosis world. Terry was a proponent of medication and talking to someone when times felt tough as well as living in line with values that supported a positive sense of oneself in spite of living with psychosis:

> *'Keep taking medication, don't cut yourself off from the outside world, keep on your medication, take medication and keep well. If you're feeling down, don't bottle it all up, tell your doctor. I'm sure there's the right medication out there for everybody. A friend said I was the nicest person she'd ever met; I try and be a better person.' (Terry)*

Phil's thoughts resonated with Terry's, and he went further to offer a comprehensive overview of living with psychosis that indicated a position of 'knowing' his psychosis and its impact. His strategy also expressed a sense of continual battle to stay well and ahead of the psychosis, linking back to 'effortfulness' of living with psychosis:

> *'The worst thing you could do is lay there and give in to that… get up out of bed, put the radio on and smoke a cigarette, watch the Jeremy Kyle show and see that a lot of people have more problems than you. But if you are going to lay there in bed it's beaten yer, you gonna just go down hill …. 'cos the more you lay there in bed and feel sorry for yourself the worse it's gonna get. You see easier said than done, but I suggest get up, put some music on.' (Phil)*

Phil was clear that the worst approach was to give yourself up to the psychosis, which echoes SOT2, although he acknowledged that this was not easy to achieve, and that sometimes the psychosis won – this was a highly resonant experience with other participants (Chris, Marine, Bridgette, Viv, Terry). Phil echoed a determination expressed by others (8) that this is a battle that you want to win, that you are worth more than giving in to it. This seems to be a call to 'get out of your psychosis' and to connect with the non-psychosis world.

Viv was able to goad her voice in a similar way to Phil, by telling them that she had survived their worse so *'bring it on'*. There is a strength and defiance within these words again resonant with other participants (Chris, Marina, and Bridgette). There was a definite sense of needing to reposition yourself in relation to the psychosis in order to gain power and control, and that to do this you needed to be 'stepped away' from immersion in the psychosis.

> *'Like, say now, I'd shouts out 'F**k off' when I goes in the kitchen, but if the kids are there I'll sort of do that at- at the ceiling an' say to 'em [the voices] "Carry on 'cos there's nothing you can do that's any worse than what it is now".' (Viv)*

Bridget too noted how she had developed an awareness of how her voices have driven her behaviour in past times and how she now had the determination to behave more in a more self determined way.

> *'Probably 'cos I know I'm gonna end up doing something that I <u>know</u> I shouldn't do so I'm trying to stop it and not do the things that I used to do a long time back.' (Bridget)*

This repositioning seemed achievable only if an awareness of the psychosis had developed and stepped back from. For two participants (Mandy and Alex) however, this journey towards Liberation had not really begun and both were immersed in their experience of psychosis. Mandy however, clearly noted the importance of a missing understanding; without understanding and separation no assertion of the self emerged in terms of managing the experience of psychosis, and life descended into its thrall.

> *'How do I escape from this, how do I get out of this? I don't understand.' (Mandy)*

Having a routine and staying busy and engaged with life outside of the psychosis was convergently viewed as an important Liberation strategy. Activities included having a recovery programme to focus life around (Chris), staying busy (Viv, Phil, Marina, Bridget), and staying socially connected (8 participants). Alex and Mandy again, shared a divergent experience within this theme. They were very socially isolated and passed the days subsumed on their psychosis. Viewing the composite summary of Alex's experience of living with psychosis at the time of the interview, Table 8, a sense of her lived experience can be gained, one of a high level of immersion in and enormous impact on her life with psychosis. Such an overwhelmed experience does not allow the space other participants appeared to have developed that allows for a reconsideration of the experience and development of understanding or strategies to reposition oneself in regard to the experience of psychosis, and so develop a better quality of life and a lower level of distress and interference.

Table 8 Composite of excerpts summarising Alex's experience of living with psychosis

I didn't have any school friends at school, I don't want them now. It all comes back to school an' bullyin' an' that, I'm worried that if I get friends they'll think like that.	*I'm just paranoid about people, um, I think they are all terrorists and things like that and they are after me and things like that. It's what I believe. I think they're having a go at me, the law and all that. They're not really, [but] when it happens it's like it's real, sort of thing. If I do go out I just look down all the time. I won't stare at the people and that sort of thing.*
I know that people read my mind an' that, yeah, it's like, I try not to think for a while. I hear whispering as well. It does distract me, yeah, it does.	*: I've got family but they not around. I've got mum she's lovely, she moved on to the edges of Weston, but I won't go out on me own there, I won't go out on me own.*
I don't like going out, no, I'd always, always be trying to escape and I'd be anxious about that.	*I don't do a lot, mmm, I dunno, just pass the time.*

In contrast, Chris' words illustrate striving to live beyond the psychosis, with increased separateness from it, a stronger sense of self relative to the psychosis.

> *'On an average day? Er, I've plans in place ((chuckles)). Every morning I get up I try and meditate, go have coffee with friends an' I come home I do somethink on the computer, Wednesdays an' Saturdays I talk to my friend online, you know, we go to an online meeting where we can converse and we have a chat afterwards and I sleep in the afternoon.' (Chris)*

Chris, a recovered alcoholic, applied the Alcoholics Anonymous 12 Step Recovery Programme to his recovery from psychosis:

> *'You know I work a 12 step programme an' what I've done over the years is adapted a 12 step philosophy to deal with my mental health because it tells me in step 12 we work these steps in all of our affairs. You know an' er an' - an' that taught me I –I like-*

> *look at my mental 'ealth side of it. An' I started to manage my illness on a different level. See I know I'm ill, I know I'm ill 24/7, but I don't let it get me down.'(Chris)*

The sense of determination gleaned from Chris' words resonated with other participants and their descriptions of how they stay beyond overwhelming psychosis.

Staying occupied and not giving time to introspection and rumination emerged as other key factors in liberating oneself (8).

> *'So I've been alright, when I'm out and focused.'(Gillian)*

> *'I think 'cos me minds kept busy talking an' laughing and joking, yeah it's, it goes to the back of my mind, if that makes sense.' (Viv)*

There were also positive emotional or psychological responses to the experience of living with psychosis that supported liberation.

> *'A sense of humour, I think, yeah, and being able to verbalise it. Just silly one off things that I say when something happens, um I find being light hearted brings me up a bit. And I s'pose in a way, I'm a bit of a fighter, I've got a sense of wrong, of right from wrong as well.' (Bridget)*

Of course this does not allow for the times when company and activity were not available, and striving to maintain well-being through these two factors alone did not alleviate the challenges living with psychosis brought when one is alone (8), as illustrated by Gillian's words:

> *'I've got it under control, it's manageable um, it's just sometimes where - it's mainly when I'm on my own, that's when it's at its worst.' (Gillian)*

6.6.4 Seen beyond the psychosis

All participants (10) shared how important it was to be explicitly valued by other people and how important this was to helping alleviate some of the distress that worsened their experience of living with psychosis. For some it was being valued explicitly through personal relationships. I had a sense that participants felt they were being viewed as more than just 'someone living with psychosis' and that this gave strength to their personal struggles with psychosis.

> *'I spoke to my sister a few weeks back and she said 'Terry, you sound really well, we're really pleased' and she said 'keep thinking positive, don't go back again, keep well'.' (Terry)*

> *'Um, and it- I suppose I – it takes my boyfriend to just like cheer me up and convince me to keep ploughing on – I know I've got to keep ploughing on because like you got to stand up really.' (Gillian)*

Even Alex, who described her partner as not being helpful, implicitly expressed receiving signs of caring from him which she valued:

> *'My partner, he don't really help, no, no, he don't really sit and talk to me. Um he'll bring me cups of tea, yeah, he's always doing that, he's always doing that. We've been together five years.' (Alex)*

For others (4) it was also being generally valued by other people:

> *'Yes, we want to show that we are happy and reasonable when we are in out-patients or out meeting people; happy meeting people. It does make me feel good when people say 'Hello, Good morning, Hello', yes. Makes you feel good about yourself, yes it does, I try to smile back.' (Leslie)*

And for Bridget it was acceptance and the opportunity to give back something from herself to her friends:

> *'I find it very satisfying helping people out, buying them things, I don't buy things for myself, but I buy things for other people and I enjoy doing that I get a lot of satisfaction out of it. Um, not so that somebody says 'oh, you bought me something' but……… I find it's the only way that I can give myself. I do paintings and I give them away, and they seem to go down quite well, but erm, I don't know, I just the way I've been brought up I suppose; respect.' (Bridget)*

Bridget's excerpt also echoes words from other participant narratives (7) about the importance of being given the opportunity to live in line with ones values again, and seen beyond the psychosis:

'Yeah, yeah, I wanna help people 'cos I think it's important these days for people with psychosis, I think the more aware we make people to become more aware, it's good, I want to help people that are in my situation.' (Terry)

Chapter 7: Discussion of Findings

The exegesis of this study begins with summarising the study's findings before discussing the findings' associations with extant phenomenological literature on living with psychosis. The early subsections of this chapter highlight the knowledge contribution from the study, accommodating to the epistemology of the methodology by positioning this study's idiographic analysis within the wider phenomenological and psychological knowledge of living with psychosis. It also offers a consideration of the wider implications of the knowledge contribution from the study.

7.1 Findings Summary

> *'The voices became louder and more frequent, sometimes screaming in the world outside and in the battered places of my psyche.'(Knight 2013, p94)*

When an overview of the subjective realities of the participants is taken, a detail-rich picture of experiential convergence appears. Within the experience of living with psychosis, emotionality is high, with primary emotions of fear and anxiety and secondary struggles with sadness and despair. Days are frequently troubled by the ongoing anomalous perceptual and cognitive experiences or fear of relapse, and the ensuing emotions interfere with personal, social, and relational functioning, and overall wellbeing. There is a sense of relentlessness in the experience, it never stops, and one is never free of it. The experience is viewed as unpredictable, that one day can be good and then, seemingly without reason, tomorrow will be dreadful. There is a sense of inescapability as the torment from living with psychosis occurs internally, inside the head or the self, and so one cannot remove oneself from it. On top of these experiences there is also a ruminative awareness of the consequences and losses of living with psychosis. People are very aware of the impact on families and loved ones, guilt and shame arise from this awareness along with a desire to atone. Lost life goals and futures are equally within this awareness, along with negative self-judgements of blame and self-stigma. Societal stigma is encountered regularly and adds detrimentally to the personal experience of living with psychosis.

The psychosis becomes perceived as an uncontrollable, volitional other, with mostly malevolent intent, taking residence within the 'self-space'; an entity which would subsume the self given any opportunity. This leads to a life of hypervigilance towards the psychosis so that the guard is never let down leaving an opportunity for the psychosis to take over. People believe themselves to be at the whim of the psychosis, which strengthens a sense that the psychosis is a volitional entity. This perception reduces self agency in terms of sustaining separateness and autonomy from the experience and confirms beliefs about the lack of controllability of mental health and of not being able to move beyond, and stay beyond, the psychosis.

The above experience is one of the ontological changes which appear to occur when living with psychosis; people move into a state of ontological insecurity as the life-world previously known, that familiar sense of 'being-in-the-world', their *Dasein* (Heidegger 1962), becomes inconstant and unknown or uncertain. Epistemological accommodations appear to occur to explain the ontological change and provide a framework of understanding which reduces the terror bought about through the ontological insecurity. Unfortunately, it emerges that once these ontological and epistemological changes have occurred, then rejecting the accommodations and reverting to previously known states of *being* does not automatically happen as overwhelming psychosis recedes. People are left in an ontological dichotomous state where more than one way of 'being-in –the-world' is possible and can be possible because of the epistemological accommodations. Thus, being certain of *'what is real and what is not'* is difficult to achieve; once the ontological boundaries have slipped and new idiosyncratic knowledge been created, remaining rooted in consensual epistemology is challenging and requires reassurance and external confirmation.

It appears that it is in the Hearing of Voices that the experience worsens to one of tortuous inescapability and daily assault. This is different yet similar to perceiving the psychosis as a volitional other. Voices are frequently given an identity and are more specific than the general 'other' of psychosis; they exist within the experience of psychosis. Is the psychosis the voices? Whilst there is an enmeshment, it seems not; more that 'psychosis' is what is experienced as invading the 'self space' whilst the voices causing mental distress are perceived either as coming from the 'psychosis' or not. Although challenging to clearly delineate, the psychosis was convergently perceived as a looming presence striving to subsume the self whereas distressing voices were elements of experience which were identifiable and accessible to argument. A relationship could be formed with the voices but not with the omnipotent and inaccessible entity of psychosis.

There are ways through and beyond living with the experience of psychosis, *Liberation* from it. This involves reaching a point where support seeking is a possibility, and that the support received needs to include a way of repositioning the understanding of what is being experienced. Sometimes this support is about providing appropriate and minimally harming medication, although there appears to be a tolerance of major side effects due to the relief some experience from taking the medication. Support needs to be broader than just a focus on the psychosis, and include valuing the person beyond the psychosis. Reconnecting to the consensual reality and social world appear to be powerful recovery facilitators, and the importance of peer groups and new friendships emerges as paramount.

Crucially, what also emerges from the data is a striving to survive in spite of this experience. Implicit in the subjective accounts from participants was a striving for a ‘taking back’ of the self despite the persisting awfulness, a constant revisiting of life each new day to test out how it would be for them today. For the eight who lived alongside their psychosis rather than within it, life opportunities however small were consistently grasped. These could be seeking reassurance, value, and love or friendship, an opportunity to laugh at their voices, or engaging in the social world. From these eight there was also a sense of wanting to ‘atone’, to ‘give back’ in some way, even whilst struggling to live with their own ongoing psychosis. Overall, there was a known sense of the enormity of the psychological burden they were living with, and a weighty sense of how challenging life was living with psychosis.

7.1.1 Contribution to the Knowledge Base

The contribution to the existing knowledge base and the implications for clinical practice from the participants’ shared life-worlds can be captured within these points:

1. Continuing Awfulness: There was a continuing awfulness of experience in living with psychosis as a longer-term health condition; the experience of hearing voices compounded the awfulness of the experience
2. The Centrality of the Self: The sense of self in relation to the psychosis and the sense of the ‘psychosis’ was a central component of the experience
3. Ontological Insecurity and Epistemological Accommodations: Ontological shifts and epistemological accommodations were implicitly and explicitly reported to have occurred during the experience and to persist beyond, leading to a lived experience of ontological dichotomy
4. Liberation, Escape, and Recovery: Recovery-supporting interventions need to go beyond, but do include the use of, medication. Interventions indicated in this research appear to include a finding of separation from the experience of psychosis – an

escape, a reconnection in the social world, and a suggestion that any intervention is couched within person-centred values (Rogers 1951)

5. Powerful resonance with the extant phenomenological literature on psychosis
6. A conceptual reconsideration of longer-term distressing psychosis as a trauma response

This knowledge contribution is considered in depth in the following subsections, positioning the first four contributions within the extant literature to illustrate the clarity of resonance, add credibility to the study's findings, and highlight practice implications. The question of reconceptualisation of the experience of living with psychosis as a longer term health condition as a complex trauma disorder is considered following this.

7.2 Resonance with Extant Phenomenological Understandings of Psychosis

7.2.1 The Awfulness of the Persisting Experience

> *Everything was wrong. Deep inside nothing seemed to mean anything. I went from deep despair to abject psychosis. Later in my illness I had terrible hallucinations that seemed to make a cesspool and a war zone of my mind.' (Anonymous in McNamara 2009, p13)*

The findings from this study clearly resonate with existing phenomenological knowledge of living with psychosis as a longer term health condition. Theme one in the McCarthy-Jones et al. (2013) meta-synthesis, 'Losing', details a loss of the self, consensual reality, and of hope. The theme is elaborated, noting the emotional response of fear, confusion, dysfunction, and the socio-cultural cost of such losses; this is echoed in this study's Theme 1 'The Awfulness *'Episode of terror upon episode of terror….'.* The experience of daily awfulness of experience appears robustly found through inductive research; people living with psychosis sharing a sense of a persistent intrusion of the psychosis into daily life, of significant amounts of life being intruded on by the experience of the psychosis or responses to it, and of the experience wreaking loss and detrimental consequence. Participants in this study used words including *'hectic, alone, isolated, conflict, depressed, torment, living hell'* to describe their experience. Such findings resonate with Davidson's earlier phenomenological enquiry into living with psychosis (Davidson 2003). Davidson elicited a picture of a 'downward spiral' into entrapment featuring cognitive intrusions and disruptions and negative emotional states. This itself resonates with later phenomenological work by Nixon et al. (2010b) describing a ‘descent’ into an intensely altered state. As with the McCarthy-Jones et al. (2013), Davidson and Nixon noted a decline in ordinary functioning on account of the distressing and entrapping downward spiral wrought by extraordinary mental experiences, accompanied by increased potential exclusion from the socio-cultural world and from personal relationships. This study did not look at the progressive deterioration potentially inflicted by transition into psychosis, but looking directly to the heart of the Davidson spiral and the Nixon et al. descent, resonance of experience is once again found in SOT 1 (Chapter 6.2) *‘The Awfulness’* and also in SOT 4 *‘The Tormenting Tyranny of Distressing Voices* ‘ (Chapter 6.5). SOT 4 illustrates more the extraordinary mental experiences precipitated and perpetuated through auditory intrusions, as noted by both Davidson (2003) and Nixon et al. (2010b), echoing their role in entrapment, enmeshment, relational loss, and social exclusion.

7.2.2 Self Disturbance and Psychosis as a Volitional Other

> *‘Unrelenting tirades, nasty comments poured into my inner ear. Any sense of self drifted out of my chest leaving me weak, empty, more crazed each day.’(Markwood in McNamara 2009, p 114)*

This study’s findings revealed that there is a disrupted and fragile sense of self as a core feature of the participants’ experience of living with psychosis and adds further support to the existing literature on psychosis as a disturbance in Ipseity (Laing 1960; Lysaker & Lysaker 2008; Parnas 2011). SOT 2 *‘Psychosis as a Volitional Other’* and the sense of self in relation to the psychosis, emerged as an entrapping and depowering perception driven by misperceptions and misunderstandings about the nature of the psychosis, and is arguably a primary and central feature of the experience of living with psychosis. This sense of psychosis as a more powerful volitional other inhabiting the ‘self-space’ with the potential to subsume the self creates anxiety, hypervigilance in the sense of persistent engagement with the ‘psychosis’ or watchfulness, and produces a sense of inescapable torment and enduring personal vulnerability; it fuels the ‘*Daily Awfulness* ‘described by participants.

Parnas (2011) described a disturbance in the self as being central to psychosis, including a diminished self-presence, porous self-boundaries, a diminished sense of self-identity, and an opaqueness of conscious as core clinical features. The McCarthy-Jones et al. (2013) meta-synthesis noted the loss of the self in their first theme. When the sense of self is diminished or unstable (Parnas 2011) then what Parnas describes as '*the structure of subjectivity'* (2011; p7) is altered, diminished, and uncertain. Part of this experience is reduction in the sense of self-agency, that the belief in the ability to control one's own self is lessened.

A sense of self-agency is believed to depend on consciousness of agency (Gallagher & Zahavi 2012). If consciousness is impaired and we are not aware that we have either caused something to happen or that what is happening is from within ourselves is a feature of a mental health condition associated with a disrupted sense of self, then there is little or no experience of such agency. This is applicable to experiences of living with psychosis whether it is because voices are perceived as 'others' because there is no sense of them being generated from within, and to recovery, for example, if perceptions of the medication being taking is that it is the sole cause of staying well, then any sense of agency in recovery will be diminished and the belief that there is no control over the psychosis will not change. This diminished sense of self-agency was both explicitly and implicitly expressed by participants in terms of their sense of control over the psychosis, their voices, or their recovery.

A further consequence of a disturbed or disrupted sense of the self was expressed through participants' descriptions of the dysfunctional relationship between the self and the psychosis, and the self and the voices. Here a reduced sense of self-agency existed in relation to the experiences of the psychosis and also in terms of the self in acting beyond or 'against' the psychosis or the voices. This dysfunctional relationship was defined by descriptions of experiencing the psychosis as a volitional entity, acting independently of the self whilst inhabiting and subsequently influencing or hijacking the 'self-space'. Gibson (2000) earlier postulated that there was a mental space which was inhabited during the heightened experiencing of psychosis, 'a borderline space'. This study's findings suggest that rather than there being a mental place people inhabit when experiencing psychosis, it is more an experience of the self in conflict with an 'other' within the whole self; more a separate part of the self or a separate entity, which creates anxieties and terrors or extraordinary ideas or explanations for events, and which exists in a volitional state, is powerful, and can subsume the 'self-self' into this 'other'. It is as if something else is experienced as invading the self-space, frequently experienced as powerful and defining, as controlling and malevolent; something that requires compliance, obeisance and obedience, something that is able to cause horror, to impact on the world, something that has a malevolent purpose or something which gives you a special purpose, a mission, an imperative. Something that, however extraordinary, constructs a believable reality that is not perceived as being within your control.

Laing (1960) wrote that if a sense of an autonomous self is impaired then a person can neither experience his separateness from or relatedness to *'an other'* in the normal way yet feels bound to it. It is possible then that because of the impaired sense of autonomy and agency associated with psychosis, that the self can neither be immediately separated from or functionally related to the psychosis, and that whilst bringing terror of subsumption of the self into the psychosis and the loss of a self-determined life or indeed of the self, that there is a sense of being bound to the psychosis. It is possible too, that given the high association between early abusive experiences and psychosis (Bebbington et al. 2011) a history of dysfunctional social attachments could support the formation of dysfunctional relationships with internal experiences such as those experienced in psychosis. If there is a history of disrupted attachment then there may well be more of a vulnerability to becoming locked into this unhelpful relationship with the psychosis (Morrison et al. 2004b). Over the past decade, Attachment theory (Bowlby 1988) has been presented as a possible framework for understanding psychosis (Read & Gumley 2008). Attachment theory argues that each infant has a biological drive to seek protection and sustenance from an identifiable primary caregiver and it does this through a range of attachment behaviours undertaken to provoke a response from the caregiver. If early relationship experience is positive then a secure base for emotional, intellectual, and social development is created. If there are challenges to positive caregiving through neglect or abuse, then such a secure base is not available and development is compromised in all domains leading to struggles in future relational and social situations, disadvantaged intellectual development, and emotional dysregulation.

A significant concept from Attachment theory relevant to vulnerability to psychosis and a disrupted sense of self is that of Internal Working Models (Bowlby 1988). Bowlby defined these models as an understanding of the self, an understanding of others, and an understanding of the relationship between the self and others which develop based on early experiences. Such internal models retain plasticity and so are open to change over the life span; however, internal models which are influenced by abusive, neglectful, confusing, or invalidating experiences will inevitably drive disorganised and insecure negative beliefs and understandings about the self, others, and the relationship between the two. These negative internal models can be argued to provide the basis for the disrupted sense of self that occurs in psychosis and the developing of a negative and ineffectual relationship with the psychosis when it is perceived as a volitional other. It is worthwhile to reiterate here that all ten participants disclosed experiences of early abuse or personal invalidation.

Parnas (2011) argued that a firm sense of one's own autonomous identity is required so that one experiences a sense of being 'bounded', that is a sense of not be open to invasion or inhabitation by another. The findings from this study reveal that this sense of being 'bounded' is not present in people living with psychosis, so that the possibility of others 'taking over the self' is a marked anxiety. Laing (1960) described distinct forms of ontological anxiety experienced by someone living with psychosis, with the over-riding experience being a terror of losing oneself through engulfment, implosion, or depersonalisation. Taking a different relational perspective from Laing, it could be argued that rather than it be a fear of a loss of oneself 'in the world' that it is a loss of oneself to the psychosis, in terms of the psychosis being perceived as a volitional other inhabiting the self-space. This becomes experienced as an intra-self conflict between the self and the psychosis or the self and the voices. It is, of course, possible to isolate ourselves from external others, but when the source of threat is perceived as coming from within, for example as it presents itself to be from many people who hear distressing voices, then there is no physical escape and survival strategies have to be different. Fears of Laingian engulfment can be argued to lead to a hypervigilant engagement with the experience as a 'constant, strenuous and desperate' strategy to prevent engulfment, and isolation from others happens as there is a dread of 'taking your eye off the ball' and the occurring of the most feared consequence of allowing psychosis to gain the upper hand and subsume the self within – to lose the self to this malevolent invader. However, paradoxically, this anxiety-driven disengagement from the shared lifeworld acts to embed people in their ontologically insecure psychosis world and so the self does become lost within their psychosis.

This links to Laing's third anxiety, 'petrification and depersonalisation'. These responses to a sense of threat to the self are to turn oneself to stone, dehumanise oneself, or to depersonalise oneself, or indeed the threatening other. Interestingly, this latter response could be argued to be a route to liberation from the psychosis because it separates out the psychosis from the self. Laing, though, describes these responses as stemming from fearing that if one experiences another entity or person as a free agent, then one is open to experiencing the self as an objective part of the other's reality and so, if that 'other' is omnipotent or if you perceive yourself as vulnerable, potentially feeling one's own subjectivity perish. Put more clearly, on perceiving the psychosis as an objective 'other' taking up residence in your 'self-space', one cannot but entertain the concept that 'it', as an objective being, has the further power to subsume the totality of your very self. Laing surmised that there were two potential responses to this type of ipseic experience, on the one hand to perceive yourself enhanced by it, which some people experiencing psychosis do feel and is termed ‘grandiosity’. The alternative response is one of terror because of beliefs of the self being *‘deadened or impoverished (p47)* by becoming nothing but part of the ‘other’s reality. For many people living with psychosis and perceiving the psychosis as a free agent, a volitional other, then given the accompanying disturbance in the sense of themselves there is an understandable sense of threat of becoming no more than an entity in the psychosis’ lifeworld, without any life for oneself, without any being for oneself – a state of existential terror.

Ipseity is selfhood, a sense of oneself; it is possible that it is in the very nature of a disturbance in ipseity, such as psychosis, that there could be a sense of inhabitation by an ‘other’ and a loss of belief in the integrity of the self. Fuller (2013) notes that in the most severe psychosis people *‘lose the knowledge and reassurance of existence’ (p7).* Participants shared their fear of loss of the self to the psychosis, losing the battle for self-survival, a fear of extinction by the perceived entity of psychosis. Even where there was a better defined grasp of the self, there was a persisting sense of threat to psychological and physical integrity from the psychosis which manifested itself as fear of actual annihilation (through persecutory delusions) or existential engulfment from the volitional entity of psychosis or the voices which were inhabiting the self-space.

This fear of losing oneself is arguably the quintessential existential terror of annihilation, compounded by extraordinary fears that the physical body of the self will persist in existence but not be of the self to whom it belongs. This existentially present fear of the death of the self might be argued to be at the heart of this particular psychic suffering (Yalom 1980) even if this is not explicitly articulated by people living with psychosis, it appears to be implicit in their shared experiential descriptions. Indeed if an overview is taken of the study’s findings, it can be viewed that the four essential givens of existence as proposed by Yalom (1980): death, freedom, isolation, and meaningless:

> *‘the inevitability of death for each other and those we love; the freedom to make our lives as we will; our ultimate aloneness; and, finally, the absence of meaning or sense to life’ (p xiii Yalom 1989/2012):*

are implicated in the experience of suffering through living with psychosis, because psychosis appears to make one confront each one and drive inner conflict. Similarly moving towards Liberation involves the repositioning of the self in the battle and resolving the conflicts in a self-determined and self-benefitting manner.

Sass and Parnas (2003) argue that conceptualising psychosis as a fundamental disturbance of the self (Ipseity) accommodates for its heterogeneous 'psychiatric' presentation. Within their proposed phenomenological framework of understanding psychosis, a disturbance in our first-person perspective on the world develops, characterised by hyper-reflexivity (a heightened and intense self-consciousness) leading to self-alienation, and diminished self-affection which diminishes the intensity or vitality of one's own self-presence. This hyper-reflexivity allows for what is normally tacitly assumed about the self, the world, and one's being in the world, becoming intensified in our mental attending. Concurrently, the diminishing of one's subjective self-presence which is believed to occur, is driven by the hyper-reflexive process, *'the fact that what once was tacit is no longer being inhabited as a medium of taken-for-granted selfhood'* (p 430 in Sass & Parnas 2003). So within psychosis a person develops an exaggerated sense of self-consciousness, which can lead to elements of the self not being perceived as belonging to the self, concurrently with a sense of a diminished self in terms of will and agency.

Psychosis is essentially perceived by Sass and Parnas (2003) as an ipseic disturbance. This theory resonates with the subjective experiences of the participants in this study who fail to recognise psychosis as a psychological experience, instead perceiving it as a separate inhabiting entity with malevolent or omnipotent qualities, which the self is insufficiently strong to fight, resist, or self-determine one's course.

7.2.3 Ontological Insecurity and Epistemological Accommodation

> *'Once you reject consensual reality, when you step across the line into forbidden territory, when choice becomes compulsion, are you able to return? My innocence, lack of training and knowledge about alternative realities made all explanations equally plausible.' (Bassman 2012, p 270)*

This radical shift in the core sense of self is ontological, the study's findings and the extant literature reveal that when experiencing psychosis the very sense of one's 'being in this world' is challenged and what was once 'known' is no longer certain. This study does give strong support to the notion that the 'sense of self' within the world and the sense of self even within the self, becomes disturbed or insecure. In addition, the sense of the self in relation to experiences both internal and external becomes insecure, and the very sense of the world becomes disturbed. Ultimately in phenomenological language, the sense of 'being in the world' is insecure and the *Dasein* (Heidegger 1962) is unanchored. Laing (1960) described an ontologically secure person as having a centrally firm sense of oneself arising from their experience of being in the world. When there is a disturbance in the way one experiences the world or indeed themselves, as happens in psychosis, explanations and sense making are sought in an attempt to regain a sense of ontological security (Morrison et al. 2004a), a re-anchoring, because being ontologically unanchored, where we are no longer secure in our sense of being in the world, is disturbing and frightening. These explanations and sense-making attempts are epistemological; they are informed by our existing knowledge frameworks. Re-anchoring in an attempt to increase ontological security can, then, be argued to be achieved through epistemological accommodations which are, because of the extraordinary nature of psychosis, frequently out of alignment with a consensual reality. This process suggests that in striving to achieve an ontological re-anchoring and so feel more in control of one's life-world or previously experienced *Dasein* whilst living with psychosis can take one further away from consensual reality and entrap one in the psychosis life-world.

Phenomenological philosophy asserts that as human beings, attempts are made to sense of all experiences and to impose meaning on the world (Spinelli 2005). *'What is real?'* is regarded by Spinelli to be the most basic of all philosophical questions. Experiencing psychosis changes the epistemological framework because it shakes ontological security. The very essence of psychosis is so extraordinary with hallucinations and delusional ideation, that ontological experience is changed. Psychosis brings with it such extraordinary experiences that are outside of our previous experiences and so shake our 'knowns' about the givenness of our life world. Things previously believed not to be possibilities in our lifeworld become part of our changed reality. As ontological sureties become distanced there is a striving to make sense and meaning from experiences in this changed world and our epistemological framework assimilates and supports our sense-making. It seems that once this broadening of our epistemological framework has occurred it becomes embedded. Subsequently there is an ability to 'be' in an ontological dichotomous experience whereby there is a sense of ourselves in both the 'reality of psychosis' or 'reality of non-psychosis' at the same time, and rather than this supplemented epistemological framework benefitting us, it drives the ontological insecurity. Once the line is crossed into psychosis and epistemological adaptations made, it seems that they are difficult to ignore because all experiences become possible truths and we are plunged into a persisting *Ontological Dichotomous* state where uncertainties abound and sureties are few.

For those lost within their experience of psychosis, life is subsumed and the psychosis is lived, it is a life-world, their reality. Connections to the psychosis world are prioritised over the consensual reality and people become isolated within their idiosyncratic life-worlds; as previously discussed, McCarthy-Jones et al. (2013) note the loss of consensual reality in their first theme in their meta-synthesis of inductive findings about the experience of living with psychosis. For those living in their idiosyncratic life-worlds, dialogue comes from this other world and behaviours are synonymous with it, being determined by the psychosis and not the non-psychosis self. This study's participants noted this experience in their dialogues; those who were in the ontological dichotomous state were able to question their experience and had an awareness of the existence of the two realities. This drove uncertainty, questioning, frustration, internal conflict, and higher emotional arousal. Paradoxically those who were, at the time of the study lost in their psychosis world (Mandy and Alex), did not describe such conflict nor emotional distress from this recognition of dichotomy, rather, whilst they were undeniably living in torment, there was a 'giving over of the self' to their experience which limited the experience to a self-psychosis domain rather than a fight to free oneself from the psychosis and reassert the self. It was my experience that Mandy and Alex were not aware of the idiosyncracity of their life-worlds and how much it was out of alignment with consensual reality.

7.2.4 Liberation: Moving Beyond the Psychosis

> *'Some people who undergo my difficulties die. I'm still alive, still hoping. It's not the end of my life. I can still have wellbeing. I have hope for the future.'(Colbert & Peace 2014, p 188)*

Davidson (2003) uses the metaphor *'helping someone get out of their hole'* to describe the process of supporting someone into recovery. Davidson's journey towards recovery in psychosis is to support someone in moving from being stuck within their experience of psychosis with its isolation, despair, and subsumption, towards acceptance and belonging. From 'I am my psychosis' to the establishment of a secure self separate from the psychosis, and this resonates strongly with the subjective experiences of the participants, from Mandy and Alex who were 'living their psychosis', to Leslie, Phil, and Chris who were striving to live 'beyond it'. It is useful to consider recovery from psychosis on a continuum and each participant being at some point along it. Geekie and Read (2009) from their grounded theory study of psychosis developed three continuums of experiences of living with psychosis. Their first continuum, 'Fragmentation-Integration', polarised the sense of the self as distressingly fragmented with loosened or lost connections to the previously known self and its world, and

Integration as the recovery end of the construct. Such phenomenological literature describes a recovery process in which a separation of the self from the psychosis is crucial. Chris, Phil, and Leslie described very clearly the importance of the strength of the sense of self in the fight with psychosis. Fuller (2013) encapsulates this in noting that, in recovery from psychosis, the sense of self as a coherent and separate individual develops as the person 'reconstitutes'. It is in the reconstituting of a stronger sense of self that the dilemma arises, reconstituting a separate and strong self when the psychosis is powerfully active is a further challenge. The subjective accounts of this study's participants reveal the importance of finding an differential understanding of the psychosis and the experiences it drives, and the finding of someone who becomes 'a turning point' (Perry et al. 2007) or an 'anchor'. Such people begin to provide an acceptance and value which is further progressed by the finding of a peer group, of friendships, of an antidote to isolate and exclusion. This process begins to reduce the impact of the stigma experienced by people living with psychosis, both societal and self-stigma, benefitting further the coalescence of a stronger self.

The findings resonate with the albeit disparate findings from the focused literature review considered in this thesis, that moderating symptoms and distress is important for progressing recovery and attaining liberation from the psychosis, but so too are finding strategies to separate from the psychosis, reconnecting socially, and the finding of hope or a hope-keeper when all feels lost . Chin et al. (2009) concurred with the Mawson et al. findings in finding a sense of a battling for control and power within the life of the hearer for issues from the most mundane to more significant life choices, but for some there was also a sense of 'we-ness', a togetherness or interdependent joining of the voice and the hearer. Rejecting this we-ness emerged as an uncoupling strategy for the hearer from the power and influence of the voice and a move towards a separate or more bounded sense of self and recovery. This is not an easy endeavour given the extraordinary nature of psychosis and the challenges of both understanding the experience and articulating it to others found in this study.

7.3 Is Psychosis Really So Different?

Hope fights the fear, nurtures the courage and inspires the vision and the work required to resist giving up and accepting that your goals are unattainable.'(Bassman 2012, p 274)

As this study is positioned within phenomenological psychology, the process of analysis through IPA can identify pertinent psychological constructs from the data. Numerous complex psychological constructs emerged from the idiographic analysis. These constructs have been organised within the study's knowledge contribution framework in Table 9.

Table 9 Psychological Constructs Identified from the Study's Data

Knowledge Contribution	Psychological Constructs
The Awfulness of the Continuing Experience	• Living with continuing awfulness, persistence and intrusion, anxiety & depression, hopelessness & despair, torment &torture • Living with anomalous experiences • Consequences of long-term health conditions • Loss – personal, relational, social, vocational, educational, roles, future, financial • Stigma, Exclusion, & Isolation
The Centrality of the Self	• Disturbance in Ipseity • Self Agency • Entrapment in experience • Living with anomalous experiences
Ontological Insecurity and Epistemological Accommodation	• Living with anomalous experiences • Ontological Insecurity • Ontological Dichotomy • Epistemological Accommodations
Liberation, Escape, and Recovery	• Help seeking • Liberation, Escape, Freedom • Developing a meaningful explanatory framework • Repositioning the Self in relation to experience • Healing from traumatic experiences • Finding Personal, Relational, and Social Value • Living alongside a long-term health condition • Reconnecting
Significance of a Phenomenological Understanding	• The importance of the subjective voice • Conceptualisation of another's experience
Trauma	• Hypervigilance • Entrapment • Ontological Changes • Anxiety • Cognitive Intrusions

It is interesting to note that the emergent constructs are transdiagnostic experiences. Some of the experiences from living with psychosis are perhaps unique to the condition such as the extraordinary ideation which can occur, or the hearing of distressing voices, but other experiences have a commonality with other health/illness experiences. Rather than viewing psychosis as a unique experience with no resonance with other health conditions, perhaps there might be a usefulness in comparing living with psychosis to other long term health conditions and to reconsider understanding and approaches to it in a more normalising light.It is possible that if the perception of psychosis as being a matchless health condition, not understandable in the same way as other health conditions, is challenged then there may be much to extrapolate from approaches to other long-term health conditions. This is particularly possible in regard to learning to live alongside the psychosis rather than striving for a complete absence of symptoms. On viewing the emergent psychological constructs (see Table 9) from the study's findings, it can be seen that extrapolation from existing knowledge about psychosocial elements of recovery from health conditions can be done: how to develop a separateness from the ill-health experience, how to not define the whole self by the ill-health condition, and about the importance to well-being and personal recovery to reconnect with the consensual reality or our social world. These factors did indeed emerge from this research and were presented in SOT5 *'Liberation'.*

The other side of the coin though, is to ask whether it is appropriate to think about psychosis as we do about any other illness. Is psychosis a special case because the experience is one of an altered reality, an altered sense of self? In other long-term conditions, such as Chronic Pain, it is still known that one is living in the consensual reality, there is no fundamental ontological shift or a fear of losing the very self to 'it' as there is in psychosis or arguably in other mental health conditions such as PTSD. Maybe mental health conditions do necessitate a different experiential understanding because their lived experience has fundamental differences.

A generic cognitive understanding (e.g. Beck 1976) informs that emotional and behavioural responses to experience are determined by the beliefs held about that experience, and this holds true for response to health experiences. Is believing that you are living with an 'illness' as much use to people living with psychosis because of its extraordinary intra-psychic element as it is to people who have an identifiable physical disease process? A small (N=20) comparison study utilising thematic analysis of qualitative interviews with people experiencing overwhelming psychosis and those living beyond it (Kinderman et al. 2006) found that those in the thrall of psychosis did not identify their experience as 'illness', and those beyond appraised their experiences as abnormal for themselves but due to stress responses to life events, a state of altered psychological functioning. Explanations did not parallel physical health belief frameworks and Kinderman et al. (2006) question the usefulness of applying physical ill-health models to mental ill-health experiences. In addition, rather than concurring with the physical health body of knowledge that disease labels provide a basis for neutral communication, in mental health they are often perceived as moral assaults because of the stigma associated with them (Kinderman et al. 2006). These findings, albeit from a small sample, are supported by and offer support to the mental health stigma literature which reveal that labelling and stigma following from a medical model is a prejudicial to understanding, acceptance and recovery in psychosis (Beresford et al. 2010). In a meta-review by Read et al. (2006) bio-genetic causal beliefs and diagnostic labelling were found to be positively associated with prejudice and fear, and a preference for psychosocial explanations of mental ill-health and mental health treatments was found in the reviewed literature. It appears that psychosis is more acceptably understood outside of psychiatry as a stress response, with Read et al. (2006) revealing strong evidence that viewing psychiatric symptoms as understandable psychological responses to life-events reduces distance, fear, and discrimination.

Yet misunderstandings persist inside and outside of psychiatry. It is possible that psychosis is such an extraordinary condition that it is tenaciously perceived as uncontrollable and dangerous because there is a loss of the rational self, the self-controlling self who would act within normal expectations and social mores. Surely, the more we are open to and informed by the lived experience the sooner our understandings and practice will be representation of the actual experience of living with psychosis, and for mental health nurses this has to begin during pre-registration education.

7.4 Reconceptualising Long-term Psychosis as a Trauma Response

> *'Schizophrenia is a chronic terror syndrome'(Karon 2007)*

A question raised by this work is that of conceptualisation; is it appropriate to continue to conceptualise Psychosis as a discrete, inexplicable, devastating mental 'disease'? Karon (2007) in his critique of the conceptualisation of schizophrenia argued that the contentiously supported theory that schizophrenia is an incurable disease, as discussed in the Introductory chapters of this thesis, obfuscate the reality that *'all schizophrenics* [sic] *are the victims of lives filled with trauma, sometimes subtle but usually obvious'* (p127 Karon 2007). It is important to note that a link between early trauma and vulnerability to psychosis has been repeatedly shown (e.g. Morrison et al. 2003; Freeman & Fowler 2009), however, this study did not intend to explore the aetiology of psychosis, so trauma is considered here from the perspective of a potential definer of post-psychosis psychological states.

Finding from this study suggest that living with longer-term psychosis can be a life of surviving continuing and inescapable trauma, or being the victim of such, in particular from SOT1 'The Awfulness'. Gill noted that her experience of living with psychosis as a longer-term condition was just *'Episode of terror upon episode of terror'.* Other participants concurred (8), as noted in the Findings section, using the language of trauma victims, *'a living hell', 'in conflict 24/7', 'torment', 'I just wanted out', 'I could have died', 'try and commit suicide', 'so isolating'.* These words also convey a sense of wanting to escape from an experience which is perceived as inescapable and out of personal control.

There is growing support from the literature that the experience of psychosis itself is so traumatising that it creates a trauma response in the person, and that it is this psychophysiological condition which the person suffers (Larkin & Morrison 2006b; Karon 2007; Lu et al. 2011; Berry et al. 2013; Berry et al. 2014). Indeed the current NICE Guideline for Psychosis in Adults (National Collaborating Centre for Mental Health 2014) using meta-reviews of research evidence, notes that PTSD symptoms have been documented in approximately one-third of people with psychosis and that the absence of PTSD symptoms in this context predicts better mental health outcomes, lower service use and improved life satisfaction. Findings from this study, and from the extant phenomenological literature on the lived experience of psychosis (Laing 1960; Davidson 2003; McCarthy-Jones et al. 2013), appear to resonate with a conceptualisation of longer-term psychosis as a trauma response to the psychosis itself, with convergent subjective experience of the psychosis as one of persisting, inescapable, and continuous re-traumatising intra-psychic events from which the person has no easy escape nor perceived control over:

> *'you are waiting for the voices start an' all of it really………on edge waiting for it to 'appen. ' (Viv)*

The chapter by Bendall et al. (2006) in the seminal Trauma and Psychosis book published in 2006 (Larkin & Morrison 2006b) discusses how personal accounts from people experiencing psychosis *'attest to the traumatic nature of the experiences'* (e-book location 1624). They note that trauma may arise from the extraordinariness of the symptoms, from the sense of threat to the person's physical and psychical integrity, or from the coercive nature of treatment including hospitalisation. From the subjective accounts included in the chapter, Bendall et al. (2006) note experiences of being controlled by the psychosis, fear of annihilation because of the ideation developed from the psychosis experience, and the shattering of one's sense of self as a response to psychiatric treatment. They conclude that the subjective reality of psychosis is a trauma which can in itself lead to PTSD.

Symptoms of PTSD include repetitive intrusions from the triggering trauma, arousing high levels of distress and physiological reactions (National Institute for Health and Care Excellence (NICE) 2005). It is the re-traumatising effect of the involuntary intrusions that is a perpetuating factor in PTSD, along with a recurrence of the original trauma perceptions of helplessness and loss of control, and the emotional arousal of fear, horror, or terror. People living with PTSD will behave in ways to avoid focussing on the intrusions, or actively ruminate on them. There is a hyperarousal and a hypervigilance to threat, and sometimes dissociation becomes a frequent experience. The similarities in distressing experience for the participants in this study are evident in their accounts. All participants lived with heightened anxiety and described heightened physiological arousal and hypervigilance to the perceived threat from their 'psychosis', whether this was paranoid ideation, voices, or attributed to the 'entity of psychosis' itself. All were living with a perception of enormous threat, both physically and psychically. There was a dread in eight of the participants, that if they went 'off guard' and reduced their hypervigilance that they might lose themselves to the psychosis. This is again the fear of existential death, of subsumption by a malevolent, inescapable, and powerful other. This is the continuing threat to their psychological integrity. There is additionally the continuing threat to their physical integrity through the sense that the only escape is death.

Interestingly, in the two participants who were living within their psychosis, this experience of fearing for the preservation of the self was less evident. It was most prominent in the other participants who were striving to develop or maintain independence from the psychosis and exist beyond its thrall. This is a particularly salient observation in terms of supporting recovery because it suggests that in the immediate post-psychosis recovery period the fear of the psychosis and fear for the self, given that the self is likely to be vulnerable at such a time, is likely to be at a high level.

It may be appropriate then to reconceptualise longer-term psychosis as more of an anxiety-based trauma response such as PTSD. Mueser et al. (2011), from a small sample study of N=38, found that over 50% reported intense distress related to their experience of psychosis, 66% reaching symptom criteria for PTSD, and a 39% meeting full psychiatric diagnostic criteria for PTSD (American Psychiatric Association (APA) 1994). The diagnostic criteria in western psychiatry (American Psychiatric Association (APA) 1994) for Posttraumatic Stress Disorder (PTSD) at the date of this study was exposure to an extreme traumatic stressor involving actual threat of death or serious injury to oneself, or a threat to one's physical integrity. In psychosis, as the findings from this study reveal, there is a significant sense of continuing threat to one's psychical or psychological self. In terms of existence, this psychical self is of equal import to the physical self. This threat to psychological integrity was so named in the literature by (Shaw et al. 1997). Findings from this study reveal less an exposure to an 'actual' externally imposed threat (except the perception of one in people living with paranoid ideation such as Leslie) but there is a convergent perception of an intra-psychic threat of self extinction, a fear of losing oneself to this uncontrollable other taking up residence in the 'self-space'. Chris' quote illustrates this experience:

> *'He'll <the voice> says "I've got you now", "You're mine". And I have to really struggle to pull it back.'*

In addition to this perception of threat, diagnostic criteria for PTSD require that there are accompanying emotions of helplessness, intense fear, or horror in response to the trauma event. These two participant quotes are examples of this type of experience in people living with psychosis:

> *'You can't, you can't get away from it. It will always win in the end.'*
> *'Nothing I could do about it I couldn't control it….and it just took over my life.'*

And it is not only in the perception of threat and loss of agency experienced by people living with psychosis which are pertinent to this argument; it is also in the relentlessness of the intrusion from the psychosis. Trauma definitions guiding today's western psychiatry separate trauma into Type I and Type II trauma (Terr 1991), with Type I trauma being traumatic exposure of a singular and brief duration and Type II being trauma that is repeated and prolonged. Applying a trauma definition to living with psychosis, it can be argued that living with longer-term psychosis is a Type II trauma experience of persisting and inescapable trauma exposure. Illustrations of this from the participants include this from Bridget and Terry:

> *'[Life] was chaotic, I just wanted out, every day I wished I committed suicide, I was really, really ill.'*
> *I find it very um, exhausting and so to – to end them <the voices> going at me, 'cos it doesn't erm, stop them, but to calm them down I invariably do something to myself. (Bridget)*

Exploring the experiences of people who have had multiple episodes of psychosis, Lu et al. (2011) in an N=50 study, found that, similar to Mueser et al. (2011), intense levels of distress were reported by 66% in relation to the experiences of psychosis , with 69% reaching symptom criteria for PTSD, and 31 % meeting full psychiatric diagnostic criteria for PTSD (American Psychiatric Association (APA) 1994). However, a meta-review of 24 studies investigating the prevalence of PTSD as a result of the actual experiencing of psychosis and associated hospitalisation, published over 31 year period to 2011 (Berry et al. 2013), revealed a wide variation in prevalence rate of 11-67% due to methodological differences in the included studies, but noted that the median value for prevalence was 39%. This meta-review did note significant distress in participants living with psychosis who did not make full criteria for PTSD (American Psychiatric Association (APA) 1994) and, that this was present in both first and multiple episode experiences. Extrapolation from these findings would suggest that between one and two thirds of people living with psychosis as a longer-term condition are in fact living with PTSD in relation to the very living with that experience of psychosis, and that even for those who do not reach criteria for PTSD, there is an intense distress reaction to the experiencing of psychosis.

Perhaps a trauma conceptualisation of post-psychosis PTSD makes more sense of the lived experience of living with and beyond psychosis; a very significant supposition in regard to the conceptualisation of longer-term psychosis and its treatment. Such a conceptualisation does not have to be formulated within a sophisticated psychological understanding of psychosis, although it could be; trauma experiences can easily be incorporated into cognitive models of psychosis (Morrison et al. 2004b; Kingdon & Turkington 2005; Chadwick 2006; Beck et al. 2009) where it can be acknowledged as a perpetuating factor of the experience allowing it to be addressed psychologically. Rather, a more immediately accessible approach is to look to the prevention of further trauma caused by overly coercive or disempowering treatments when people are acutely unwell (Berry et al. 2013). The reality is that, when people with psychosis are unable to effectively look after their own or other people’s safety, some form of responsibility-taking intervention is required of mental health services, but this type of action should be at the minimum required for everyone involved, with, wherever possible collaboration with the person. Another accessible intervention is the support to ‘reassemble’ and to make sense of the experience once the most acute phase has passed. Sense-making and psychological interventions following trauma (National Institute for Health and Care Excellence (NICE) 2005), and in psychosis (Gumley & MacBeth 2006), are shown to be a crucial recovery factors and time to talk following an overwhelming episode needs to be seen as a meaningful task for recovery and self-management. Finally, those people who live with psychosis as a longer-term condition must not be forgotten, as the very nature of continuing distressing voices and other anomalous experiences may not bring frequent crises, but act as Type 2 trauma for those living with such experiences. The impact of this type of experience and its bio-psycho-social consequences in terms of hyper-physiological arousal, distress, and compromised lives needs to be acknowledged as a key part of a person's experience and treated accordingly and appropriately.

It is open to question whether diagnostic reconceptualisation sits well within phenomenological enquiry. One has to be cautious of a '*pandering to the empiricist scientific community*' and a further negating of the voices from the subjective realities of living with psychosis as a longer term health condition. One would have to be careful of making the same evidential errors underpinning the current conceptualisations of psychosis. In beginning to answer these questions it is parsimonious to return to the rationale underpinning the use of a phenomenological methodology thereby using emic rather than etic experience. Rather than building assumption-based knowledge from external observation of another's experience, a reconceptualisation based on subjective experience is more likely to be compatible with the subjective realities, and possibly a *consensual subjective reality*, of those who live with the experience. Whilst there will always be divergence and difference within groups, beginning from someone's subjective experience may lead to a better understanding of that person's reality and so lead to more effective and meaningful treatment. Thus, if for a proportion of people living with psychosis as a longer-term condition there is a trauma response to the psychosis, the identification of this may lead to interventions which treat that as a primary mental health problem, rather than inappropriately dampening down emotional responses with psychotropic medication and leaving a treatable psychological condition untreated.

Chapter 8: Critical Analysis, Implications for Practice, and Conclusions

Whilst this study is arguably methodologically robust, this chapter continues the thesis journey by offering a critical analysis of the elements of IPA which are argued to limit its strength as a research methodology and its influence, and also considers the ethical dimension of undertaking research with people living with psychosis. The chapter proceeds by considering the clinical implications of the findings and the challenges of knowledge transferability from qualitative research to practice. The thesis closes with recommendations for further research and a concluding reflection.

8.1 Critical Analysis

It is crucial that any research study expose itself to critical analysis so that its findings are set within a context of validity, rigour, and ethical appropriateness, and this is done through an in-depth analysis of the varying facets of the research process. This section critically evaluates the study's application of IPA, asking whether the perceived limitations of IPA and qualitative research in terms of knowledge contribution have been addressed through the study. Ethical dimensions of the research are then considered, followed by a consideration of the dilemmas posed by undertaking clinical research whilst being a clinical therapist specialising in the clinical area explored in the study.

8.1.1 Study Limitations

Informed reflection and research supervision indicates that this research study has been completed in an ethical and methodologically rigorous manner by transparently utilising the methods suggested to enhance rigour and validity in IPA research (Heidegger 1962; Yardley 2000; Etherington 2004; Smith 2011). There are always potential areas of research limitation (Smith 2011) to consider, summarised overleaf in Table 10 and discussed in subsequent sub-sections.

Table 9 Areas of Potential Limitation of IPA Research

Areas of Potential Limitation	
IPA is challenging to do well and easy to compromise	Undertaking research with people living with psychosis
Issues of reflexivity, validity, and methodological rigour	Ethical issues of research with people living with psychosis
Sample Size	The dilemma of being a 'Therapist Researcher'

8.1.1.1 Doing Interpretative Phenomenological Analysis Well

It is not uncommon to find in the literature examples of IPA research which could be evaluated as lacking sufficient rigour and commitment and so presenting invalid findings (Paley 2005; Brocki & Wearden 2006; Smith 2011). In 2006, a critical evaluation of the use of IPA into health research (Brocki & Wearden 2006) found 52 such studies published between 1996 and 2004 showing a wide variation in adherence and commitment to IPA methodology and its underlying principles. Brocki and Wearden (2006) noted that in particular there was variability in the way studies approached the interpretative element of the research process, and recommended that, along with the inclusion of verbatim excerpts, acknowledgments of the researcher's fore-structures and greater inclusion of more detailed reflexivity would increase transparency.

Smith (2011) has set out a very clear guide for evaluating the quality of IPA. Good IPA adheres to its three theoretical principles of hermeneutics, phenomenology and Idiography, offers a coherent and plausible analysis, is supported through a defined sufficiency of excerpts from the sample, and is well focused and enlighteningly presented to the reader. Reflecting on this study, Smith's criteria for a sound study are transparently and soundly met. This study commits to the three underlying principles by exploring the lived experience of a phenomenon through inquiring into the subjective experiences of people who live with the phenomenon.

When using IPA, there is no predetermined research hypothesis rather a general question to explore. This meant a lengthy journey from the initially proposed research question to what the research questions (RQ) came to be. Paradoxically, this developmental process involved not tightening up the RQ but a process of widening it out to become the most open question it could be so that it could capture subjective accounts of the phenomenon under study, with no extraneous criteria.

The evaluation guide for good IPA set out by its founder Smith (2011), and also utilised in the Literature Review, see chapter 4.5, can be utilised to assess the methodological quality of this study. Smith notes the importance of adhering to the following criteria in IPA research in order to explicitly show methodological rigour:

- Subscribes to the theoretical principles of IPA (phenomenology, hermeneutics, idiography)
- Sufficiently transparent so that the reader can see what was done
- Coherent, plausible, and interesting analysis
- Sufficient sampling from the corpus to show density of evidence for each theme (Smith 2011 p17)

This study meticulously adhered to these criteria. Data collection and analysis were transparently idiographic (see appendix 10), working with the subjective experience of the participants revealed through an interview schedule designed from a phenomenological perspective aiming to capture the subjective experience. Within the presentation of the findings are examples of double hermeneutics through the transparent inclusion of sense-making from the researcher perspective, having previously acknowledged my fore-knowledge and context. Included in the presentation of findings were weightings of findings from the sample, accompanied by the required sufficiency of excerpts to support the analysis. The analysis has plausibility and coherence within in itself, and in terms of its resonance with extant phenomenological literature. The study explicitly set a self-context at the outset of this enquiry, acknowledging fore-knowledge and setting the agenda for reflexivity to be prominent throughout the research and this thesis. This study also used individual face-to-face semi-structured interviewing as its method, noted by Smith et al. (2009) as an exemplary method for IPA, enabling the study to commit to the principle of idiography through its linear process of transcript analysis, building from analysis of each individual's subjective experience to the combined findings, both convergent and divergent.

Finlay (2014) stresses that phenomenological writing needs to describe, and describe well, the creation of the findings and through this process achieve some degree of scientific credibility, express the phenomenon evocatively, and integrate phenomenological concepts into the writing. There was, in this study, a critical questioning of interview transcripts, asking, *'what is* *it that is being implicitly and explicitly expressed here?'.* This is known as 'questioning hermeneutics' (Smith and Osborn, Chapter 4 in Smith 2008) and in IPA this is combined with empathetic hermeneutics, which is to interpret another from authentically 'being' with that another *(Mitdasein)* (Heidegger 1962). In this study these different types of hermeneutics were progressed through a commitment to immersion and reflexivity during analysis. The narratives from the participants, and the participants themselves, were not subjected during the analysis or discussion to a critical review, rather the critique is, and should be (Smith 2011), of the researcher, the research process, and existing literature. Findings from this study have also been validated through the inclusion of weighting of theme from the participant corpus and well supported by excerpts from the interviews (Smith 2011).

Findings were situated within extant phenomenological literature to heighten scientific credibility, answer the issue of generalisation, and accommodate to epistemological consistency (Paley 2005). Mindful crafting from phenomenological language allowed the phenomenon of living with psychosis to emerge evocatively from the analysis. Some detail was given about how the analysis proceeded and this is an issue which could certainly be more meaningfully detailed given a dedicated paper about the process, and this would further support the study's credibility.

8.1.1.2 Sample Size

There are continuing debates about qualitative methodology and sample size. This study chose a sample size of ten participants but this was not an arbitrary number, it was based on information from the qualitative methodology literature. Are ten subjective accounts sufficient to reveal a resonant account of the lived experience, are they too few for convergence, or are they too much to analyse through idiographic methodology? Is ten too small for the findings to be taken seriously? The issue of sample size in qualitative research seems to be a constant source of criticism from the scientific paradigm and is used to diminish the influence of qualitative research, so it is useful to devote some time to the debate.

Samples for qualitative research are usually smaller than those required for statistical power in quantative research. Samples are purposive so that people are recruited from a closely defined group for whom the research question will be significant. Specifying sample size has been rather shied away from the literature for IPA and for other qualitative methodologies, and rationales and clear guidelines are scarce. There are suggested rationales based in the methodology used, for example idiographic research, there are reasons of pragmatism and resource restraints (Mason 2010), and there are reasons based on the data. Ritchie, Lewis, and Elam in Mason (2010) discuss the issue of 'diminishing returns' whereby more data from more participants does not necessarily lead to more information and strengthened findings. They also note that in qualitative research the frequency of findings is not of the same importance as in quantative research, and one incidence in the data may be as useful as ten. It is important to make explicit to that qualitative research is not about causality or theoretical falsification as in the case of quantative research and so does not aim for proof, but rather for understanding and meaning – and for that it needs to be as close as possible to the experiencee through the use idiographic methodology (Smith et al. 2009) rather than aggregating responses ad suggesting possibilities for a wide group of people. IPA privileges subjective accounts from small samples allowing for a richer depth of investigation which are likely to be inhibited by working with larger samples whereby maintaining a true idiographic approach would be challenging because of the amount of data elicited.

In IPA 'less is more', the methodology challenges the traditional linear relationship between the number of participants and the quality of the research (Reid et al. 2005). To maintain an idiographic focus, experts in the field recommend that ten participants should be the higher end of sample size (Reid et al. 2005). In his wide scoping meta-review into sample size in qualitative studies, Mason (2010) concluded that there seemed to be no logical nor theoretically driven rationale for numbers. He found that the most common sample size, particularly in Doctorate studies ended with a zero and were multiples of ten, and this would be unlikely if there was a rigorous determinant of sample size such as data saturation, and IPA does not rely on the concept of data saturation as other qualitative methodologies such as Grounded Theory (Glaser & Strauss 1967) do. So there has to be alternative criteria for sample size.

Indeed, its founder Jonathan Smith, noted that *'there is no right answer to the question of sample size'* in IPA (Smith and Osborn p56, Chapter 4 in Smith 2008). He argues that it depends on the commitment to idiography, the richness of the cases, and the constraints under which one is operating. Smith et al. (2009) contents that too large a sample size de-emphasises the idiographic commitment and suggests that sample sizes could increase in line with academic levels, three to six for a Master's level study, and four to ten for a Doctorate study. He notes a requirement for a sufficiently penetrating analysis to be presented and posits that it is the skill of the researcher which is key to creating an in-depth engagement with however many participants used and their subsequent analysis. Smith reminds us of the intensity of research activity that is required by each case and that sample sizes have to be small in order for the potential of IPA as a rich research methodology to be released. Where a smaller sample has its data collected and analysed with skill and methodological adherence, then numbers should not detract from a worthy and valuable contribution to the knowledge community.

Mason (2010) perceives a pragmatic approach to sample size, being dependent on resources such as available time because IPA is, and has to be in order to produce a good IPA study (Smith 2011), a highly labour intensive and time consuming methodology. It is possible then that sample size is set *a priori* for pragmatic reasons and perhaps in line with a sample size that it is assumed will have acceptable value by academic peers.

For this study, the purposive sample of ten appears to have revealed meaningful and convergent findings, whilst being possible to undertake idiographic analysis within the time constrictions of part-time doctorate study.

8.1.1.3 Undertaking Phenomenological Research with People Living with Psychosis

People who live with psychosis live with a disturbance in Ipseity (Parnas 2011), a disconnection from social mores, potential cognitive deficits and certain cognitive functioning challenges (Beck et al. 2009), extraordinary primary symptoms which give rise to emotional arousal and heightened internal focus, and a neuropsychological impact from prescribed psychotropic medication. Given this, it would not be surprising if there were challenges in articulating subjective experience. Questions indeed, are frequently asked about the usefulness and validity of prioritising first person accounts and qualitative methodology which involve working through some form of dialogue, for research with people living with psychosis. .

It could be perceived as counter-intuitive that people living with such interference in normal functioning and experience could construct and share their own life narrative. People living with psychosis can be so enmeshed with, and impacted on by, their experience that they can be narratively incoherent. Roe and Davidson (2005) argue that longer term psychosis involves a loss of the self at a most fundamental level of one's self-awareness, and if people lose this sense of themselves as people, as agents of their own life, how is it, then, that they can author their own story?

Frank (2013), a proponent of a narrative healing approach, notes that initial narratives can be disrupted or challenging due to the impact of the ill-health experience and emerge as a *'narrative wreck'* (Frank 2013 p91); people can then journey towards a restitutional narrative. However arguably, when the health experience is ontologically un-anchoring as in the case of psychosis, narrative description can lack coherence and emerge as a ‘chaos narrative’ (Frank 2013 p1617). Chaos narrative impacts on both the listener and the teller, the teller because it is not restitutional, and the listener because its extraordinary nature disrupts normal routes of communication and empathetic comprehension. This understandably brings challenges for people trying to explain and understand their experience, clinical practitioners striving to negotiated meaningful intervention and support, and for qualitative researchers into psychosis. Chaos narrative was evident in the dialogues shared with the participants, particularly from those living within their experience of psychosis, Mandy and Alex. Frank (2013) comments that even in chaos narrative there is an element of distance from the experience allowing for a reflective positioning by the story-teller and this suggests that narrative are available to people who are emerging from the thrall of their psychosis or moving beyond it, but not for those times when one is lost to the psychosis; at such times, creating a sense of safety and reducing distress appear a more appropriate intervention than struggling to work through healing narratives - *‘those who are truly living the chaos cannot tell in words’* (Frank 2013 p1633). Frank continues by cautioning that, in spite of its extraordinariness, the chaos narrative must be honoured as to deny the chaos story is to deny the person telling the story, and this has implications for practice as well as research.

The importance of SOT2 which revealed the felt-sense of psychosis as a more powerful volitional other inhabiting the ‘self-space’ with the potential to subsume the self is also supported by Frank’s (2013) writing on the availability of story-telling. Frank noted that a ‘*chaos narrative is lived when ‘it’* <the ill-health experience> *has hammered ‘me’ out of self recognition’* (p1701). Lysaker and Lysaker (2001 and 2005) found that there can be a disconnection between the various self-positions so no coherent self-narrative is easily available, and that narratives are further disrupted by meta-cognitive difficulties in the sense of not being cognisant of one’s own thoughts or in inferring motives to others. Saavedra et al. (2009) however, found that narratives were not disrupted by primary symptoms and that people living with psychosis were able to produce a coherent narrative, although difficulties were found because of not necessarily ascribing agency to themselves and having a rather vague conception of their psychological problems. Davidson et al. (1999) had earlier noted that stories from people living with psychosis can be socially and relationally barren. It is possible then, that narratives from people living with psychosis are impoverished and Saavedra et al. (2009) further cautions that this impoverished contextualisation of a narrative can have the effect of dehumanising a life story. This impoverishment and potential poor narrative could be perceived as a challenge for IPA in terms of its fundamental reliance on the eliciting of the life world of others, and also for its requirement for empathetic hermeneutics.

This potential outcome seems pessimistic and certainly it has not been my experience as a cognitive psychotherapist working with people living with psychosis that all people living with psychosis struggle to articulate their lived experience. Challenges have been evident when interacting with people who have a heightened internal focus or a sense of a loss of the self to the psychosis, just as others might find in me if I were lost to some internal preoccupation or distress. There is though, often an impoverishment of content perhaps attributable to the constraining of the life world by the very experience of living with psychosis in our current society in conjunction with the neuropsychological, cognitive, behavioural, and emotional impact of the psychosis. In spite of potential impoverishment of personal narratives, the recent meta-synthesis by McCarthy-Jones et al. (2013) offers robust evidence that inductive research based on first person accounts of people living with psychosis produces valid findings.

8.1.1.4 Research Ethics: Decisional Capacity and Informed Consent to Participation

An ethical issue highlighted in undertaking research with people living with psychosis over and above rigorous adherence to ethical guidelines and processes for health care research in the UK, is decisional capacity (Wilson & Stanlely 2006). The unique features of persistent psychosis, such as residual voices or unhelpful cognitive biases, do pose a dilemma for the process of informed consent as fluctuations in lucidity, reason, and capacity can, for some, happen relatively rapidly. Such psychological fluctuations can lead to difficulties in assessing the understanding of the research information and decisional capacity in the moment. It is this potential fluctuation which differentiates this group from people who do not have capacity per se; similar fluctuations in cognitive impairment might be seen for example, in people living with dementia. Decisional capacity of people living with psychosis was explored as part of the ethical approval process for this study.

The ethics of research into long-term psychosis has been a focus of study and review over the last ten years or so, mostly emanating from the United States of America (Carpenter & Conley 1999; Anderson & Mukherjee 2007; Jeste et al. 2007; Dunn & Misra 2009; Allison et al. 2011). Ethical concerns arise because psychosis is a disorder impacting on cognitive functioning and on emotionality. The argument is that if thinking is disrupted, then surely it must impact on decisional capacity, and where emotionality is heightened then the person is potentially more vulnerable to harm from research participation. Dunn et al. (2006) highlighted five areas of ethical research practice which need to be considered carefully when undertaking research with people living with psychosis. They are: the scientific design, informed consent and decisional capacity, understanding and perception of risks and benefit taking (including therapeutic misconception), influences on research participants, and participant safeguards. The framework within this paper offers useful guidance to researchers in the field of psychosis.

Given the personal and societal cost of long-term psychosis there is an ethical imperative to actively undertake research into the experience, to better inform knowledge, understanding, and meaningful therapeutic intervention. Carpenter and Conley (1999) argue that deliberation over the ethics of research into schizophrenia erroneously linking a diagnosis of psychosis and assumptions about global cognitive impairment with lack of decisional capacity. They further suggest that an element of stigma may be involved in the holding of such positions as that there are many other health conditions where capacity may be compromised yet psychosis seems to be singled out for special ethical consideration requiring additional safeguarding measures, such measures giving an unwieldy methodological or procedural complexity in research into psychosis. Whilst it is morally right and necessary to safeguard vulnerable people in the research process, in regard to people experiencing psychosis Anderson and Mukherjee (2007) suggest that overprotective ethical measures, unique to this particular population, serve to disenfranchise this already disadvantaged and stigmatised group from research processes, thereby disadvantaging the progression of understanding and knowledge. They comment further that opposition to participation is more often found in psychiatrists rather than in the potential participants themselves. In fact people living with psychosis are reported to value the research and want altruistically to aid development of understanding and to help others (Allison et al. 2011) and are shown to be able to participate meaningfully in the informed consent process. Palmer et al. (2013) found decisional capacity showed a general pattern of stability with positive symptoms not predicting such capacity, suggesting that a diagnosis of psychosis should not be an automatic indicator of inability to meet the requirements for informed consent, including decisional capacity.

For this research study, people could only become participants if they were experiencing stability in mental state and life circumstances, assessed by research Gatekeepers who had an established relationship with the potential participant and this served as an informed identification point for challenges to informed consent and decisional capacity. There was also a safety network of agreed support from the research gatekeeper should mental state change detrimentally during the research process. The Ethics Committee decided that the use of mental health practitioners who knew the potential participant as the research Gatekeepers was sufficient safeguard against recruiting someone into the study who did not have decisional capacity.

8.1.1.5 The Dilemma of Being a 'Therapist Researcher'

There are triggers met through the dialogue in research encounters that would ordinarily bring about a therapeutic response from a clinician-researcher and this issue was a challenge in this research study. Moving from a nurse-therapist to a nurse-researcher was a challenge and I found it difficult initially to 'know' my role as it was so unfamiliar. I struggled to decide whether I was a passive recipient of the information. I did not see how I could be that as my empathy and curiosity was aroused immediately. Was I offering to be an advocate for them through my research? I struggled to decide what I would do if a recognised that a participant might benefit from the psychological therapy that I delivered as a core part of my nurse-therapist role.

Warne and McAndrew (2010) distinguish between a therapeutic process whereby the therapist is there with the person as they navigate through their life-story, and a research encounter which does not offer such continuous support to engage in life-story enquiry as a process. In this study my usual role had to be put on the back burner and the researcher role brought consciously and initially quite effortfully to the fore ground. Of course, I utilised my therapeutic skills in alleviating distress, using guided discovery to bring into articulate awareness concepts and experiences participants were struggling to convey, and actively listening, validating, and encouraging dialogue.

Data collection in this study did adhere to the semi-structured interview schedule to ensure the information elicited was research appropriate rather than the beginning of a therapeutic process. There is a therapeutic effect or gain reported by participants involved in psychosis research (Taylor et al. 2010) and it could be argued that this occurs because of the interpersonal context of this particular research methodology, particularly when people living with psychosis are so frequently denied or excluded from this interpersonal context. This is unlikely to be avoidable, nor perhaps should it be, if the research is undertaken with skill. It is not possible in IPA methodology to control for whether participants experience the research interview process as therapeutic or not (Warne & McAndrew 2010), the dialogue I shared with Viv illustrates this. Viv and I were discussing what might be helpful in terms of her mental well-being and recovery:

> *'Someone to talk to …. like what me an' you been talking about, I don't know, just to share it with someone so that it's not a burden, you know all on me, if that makes sense.' (Viv)*

I was very aware that this plea for talking therapy pulled me into my nurse-therapist role and I had to consciously distinguish between the roles to respond appropriately as a researcher whilst bearing in mind the ethical responsibility I had to advocate for Viv as a mental health service user.

The initial few interviews were the most challenging in regard to this role dilemma, the first interview with Terry in particular where post-interview reflection highlighted a sense of *'the worst one-to-one interview I have completed in years'*. Fortunately, this sense of incompetence was not shared by Terry but on my part alone, I felt deskilled, unsure of what to say, and unclear about what I was aiming to achieve. Finlay (2011) notes that experienced therapists can often struggle with the role of researcher because the process of interviewing is likely to feel very comfortable and familiar and there is a *'play-acting the researcher' (p 201)* trap which can occur. This, perhaps, may be what caused my first research interview to be such a challenging experience. Finlay (2011) describes this experience to be where a more formal, more distanced approach is committed to by, along with reliance on pre-prepared questions. The antidote, Finlay suggests, is to relate to the participant in a 'natural, empathetic, and genuinely human way' (p 201) – good advice for the later research interviews in this study.

There are undeniable parallels between a research methodology which uses dialogue or the eliciting of a life-narrative as its vehicle for data collection and the therapeutic process, and this has its advantages and disadvantages and its own ethical dimension (Warne & McAndrew 2010). At times the qualitative research interviews can feel *'uncomfortably close'* (Weiss 1994 p 134) to a psychotherapy session. Warne and McAndrew (2010) note that mental health nurse- or psychotherapist-researchers need to particularly cognisant of the similarities between the two activities to avoid the roles blurring and inappropriate behaviour being used in clinical research. A useful, if now dated, guide from Weiss (1994) clarifies that in the therapy encounter the functioning of the patient is the centre of the session and the therapist's aim is to support the person through therapeutic processes. In research, the aim is to elicit information which is of import to the study, seemingly harsh, but clear.

However, equally undeniable is that qualitative research does depend on the interpersonal relationship which can be argued to be a necessary condition for generating rich data (Guillemin & Heggen 2009). A particular issue which I experienced was utilising the skill of therapeutic engagement (Turton 2014) with the research participants. This skill was used to socialise the participant into the research interview and perhaps progress the research dialogue at a quicker pace, eliciting potentially a more in-depth level of disclosure. This raised a concern about whether the use of such skills were ethically acceptable in such encounters, or manipulative for the benefit of the research rather than the participant. Using therapeutic engagement skills also served to develop in the participant a sense of safety and trust in myself as the researcher, but again this has its uses and abuses. Guillemin and Heggen (2009) argue that there is a balance required between establishing rapport and developing a rich research relationship whilst maintaining a distance which respects the role of the participant – being mindful that they are not in a patient role. My usual role of nurse-therapist was known to each participant and our encounter was transparently researcher to participant, but even with this information *a priori* it could not entirely control for expectations and subsequent behaviours within the research interview. Whilst I disciplined myself through research supervision and adherence to ethically approved processes to act ethically within the research process with benevolence, protection, and respect for the participant, it is easy to understand how this skill could be ill-used, even inadvertently, if the participant is not held at the centre of the interview process, and the research agenda of data-gathering takes precedence. Finlay (2011) notes that it is at this data gathering part of the process where the researcher faces ethical challenges regarding their use and misuse of power stemming from their professional authority and the way they choose to control the research. Remembering that Participants are our guides to their life-worlds, and that they share with us portraits of their experiences for the benefit of our research, is beneficially levelling.

8.2 Implications for Practice

Making global claims about practice implications from one small sample IPA study is fraught with challenges because not only is the empiricist principle of generalisation inappropriate to phenomenological research but important epistemological issues are raised by attempting to make subjective realities an objective truth. A compromise position is to recognize that there is both an objective and a subjective reality, but an objective reality which is different from the natural or scientifically objective world (Berger & Luckmann 1991) with such an objective reality being a social assimilation and consensus of subjective realities. IPA takes this Relativist position, aiming to produce *a* credible account, not *the* credible account (Smith et al. 2009). It allows for rigorous idiographic exploration of subjective experience and does not question its shared subjective accounts rather works with them from a position of acceptance of the veracity of the personal account, this fits with the ethos of mental health nursing and psychotherapy.

Yet frequently in IPA publications, non-caveated global clinical implications are suggested from the findings. Paley (2005) offered an unabashedly critical commentary on the epistemological errors he claims are often found in phenomenological studies. He notes that whilst researchers adopt the recommended procedures for phenomenological research, they proceed to make claims about reality, aspire to objectivity, and generalise findings. He notes that this is appropriating the *'prerogatives'* (p 107 Paley 2005) of scientific enquiry whilst disowning science in the search for subjective reality, and so commitment to phenomenology becomes merely *'rhetorical'* (p 107 Paley 2005). Nowhere is Paley more critical than in the exegesis of research studies where the clinical implication or conclusion section traditionally sits, but a worthy academic point is being made. In this section traditional scientific enquiry formatting requires knowledge from findings to be extrapolated to the wider world in order for the research to have merit and worth. In phenomenological research this is where the boundary between subjectivity and objectivity collapses, and assertions of objective reality are made.

To be cognisant of such epistemological challenges a consideration of the practice implications of the findings as they sit within the extant literature is offered. Many, many implications emerge from aligning the findings from this study with the existing phenomenological evidence and literature and each cannot be given due consideration within a word-limited thesis. Practice implications from this research and its salience to the extant literature can be divided into three dimensions: Conceptualisation, Understanding, and Intervention. Dimensions are inter-related as each informs the other. The multitude of practice implications across the three dimensions are presented in Table 11 but, as noted, cannot all be considered in detail in this document.

Table 11 Practice Implications from the Resonance of the Study's Findings with the Extant Phenomenological Literature on Psychosis

Conceptualisation

- Phenomenological modelling is robustly salient to experience and so must inform conceptualisation
- Inadequate or harming conceptualisations must be addressed across professional disciplines
- Informed psycho-education be available to all

Understanding

- There is much to learn from phenomenological evidence
- People can and do recover from psychosis or are able to achieve personal recoveries and live with psychosis
- There is an unpredictable pattern of experience across time
- Daily awfulness needs to be recognised and not underestimated
- Psychosis is much more than hearing voices/ delusional thoughts and treating to extinguish these alone is inadequate
- A disturbance of the self pervades the experience
- Self-agency is diminished
- Comorbid **mental health** problems occur
- People can become lost to their psychosis
- Fear of loss of the self or relapse is a significant fear
- Psychosis realities are salient to the person living it
- Reassurance can help in ontological dichotomous states
- People are aware of the impact of their extraordinary experiences on others
- Experiences are difficult to describe
- People effortfully strive to stay ahead of their experience
- Emotionality is high
- It's exhausting
- Sometimes it is easier to withdraw
- Listening and hearing is key to understanding and psychosis has an understandability
- Unresolved early experiences are significant
- Consequences and losses are distressing and common
- Stigma is a daily encounter if not actively avoided by withdrawal Self-stigma

Intervention

- Use of phenomenological conceptualisation to underpin interventions
- Use of developed understanding to underpin all interventions
- Broad scope of bio-psychosocial interventions
- Development of a meaningful explanatory framework
- Alleviation of distress
- Healing from the past and the current experience
- Different interventions are needed at different phases of experience
- Supported Recovery Phase
- Intervention should always go beyond medication
- Family Interventions
- Reconnection
- Redefining the Self
- Recapturing opportunity
- Peer Support
- Friendships
- The importance of being valued

8.2.1 Conceptualisation

> *'Hope is a key ingredient in successful recoveries. Traditionally this has been lacking in mental health services. Therefore stories of success are important ingredients in both*

> *information given to service users and training for mental health workers.'(May 2004, p3)*

Subjective realities of living with psychosis resonate clearly with the phenomenological literature and with emergent findings from this study. It appears that phenomenological modelling of living with psychosis is robustly salient to experience and so arguably has to begin to inform conceptualisations used in clinical practice. Traditional conceptualisations do not appear to align themselves with subjective accounts and this raises the question of how useful they are in informing about the lived experience of people with psychosis. If the basic conceptualisation is invalid because it is not based on reliable evidence, then at best it is not useful and at worse it is stigmatising and harmful to promoting recovery. Biological conceptualisations continue to be promoted in spite of inconclusive evidence for validity and with evidence of its unhelpfulness in supporting recovery (Bentall 2003; Kingdon & Turkington 2005; Read et al. 2006; Geekie & Read 2009; Critical Psychiatry Network 2011). More challenging too, given the hierarchical power structure which persists in UK mental health care, is that it is headed by professionals who align themselves with this narrow and uni-dimensional understanding of both the aetiology and maintenance of psychosis (Beresford et al. 2010). In an interesting and constructive spat recently between esteemed contributors to the psychosis literature (Bentall & Varese 2014; Murray et al. 2014) the issue of equating the acceptability benchmarks for biological and psychosocial research evidence into psychosis was debated, the argument noting that biological models of psychosis were rarely caveated whilst psychosocial theories were over-caveated because psychosocial theories are treated more sceptically in spite of the reliability and validity limitations of biological research evidence, which were deemed to be unethically poorly publicised. With the multiplicity of influential factors on the actuality of living with psychosis (Beck et al. 2009) and the convergence of subjective experiences (e.g. Hornstein 2012) the bio-psycho-social understanding of psychosis (Zubin & Spring 1977; Nuechterlein & Dawson 1984) appears more resonant with subjective realities of people living with psychosis. Whilst a conceptual parsimony is sought, and likely to be an extended process given the biological hegemony in psychiatry, the use of the bio-psycho-social model of mental health for psycho-education and treatment guidance for people living with psychosis is a credible choice (Beck et al. 2009).

Implications are then that in practice a phenomenological conceptualisation of the experience should underpin understanding and inform recovery-oriented interventions, with a focus on the psychological and social domains of the experience and with medication used as an adjunctive therapy to diminish the impact of the anomalous experiences, the high level of anxiety, and secondary depression. More, that this theoretical underpinning be used as a framework for information available in the public domain because of its robust saliency with the subjective experience, perhaps acting against continuing detrimental stigma by being transparent about the daily awfulness and torment that people living with psychosis can experience. Perhaps it would also aid social and personal recovery if it was more broadly known that re-inclusion promoted recovery, a recovery that was possible for the majority of people diagnosed with psychosis, contrary to popular beliefs and questionably valid evidence that schizophrenia defines a person as lost and dangerous for all time.

8.2.2 Understanding

'I found myself rebuilding one piece at a time. Sometimes it was a case of one step forward and eight steps back.'(Comans 2011, p 246)

The clinical implications from the siting of this study's findings in the existing phenomenological literature for understanding are manifold. Indications are that there is much of value to be gleaned from the phenomenological literature on psychosis, including this study's findings, because there is a resonance and convergence with and within subjective accounts. People can and do recover from psychosis, but the journey is unpredictable and often times has a daily awfulness of experience which is observably underestimated by many who offer mental health care. It is clear that living with psychosis is much more than living with anomalous perceptions and extraordinary thoughts and so treating merely to extinguish these, although welcomed and useful, is in itself insufficient to maintain recovery. There are also understandable comorbid mental health problems in the anxiety and depression arena which, if addressed, might further support recovery from the primary experience of psychosis.

Beyond overwhelming psychosis or crisis episodes, people living with psychosis can entertain two explanations of the world concurrently, a state of ontological dichotomy. It appears that reassurance is a useful method of supporting the repositioning of the person given this, of being accessible to giving respectful reassurance when requested. Such reassurance appears to reduce anxiety.

Associated with psychosis too, is a disturbance in the core self which reduces the sense of agency necessary for moving beyond the influence of the psychosis, and as in the hopelessness experienced by people living with psychosis, sometimes when people are unable to 'hold' recovery enabling beliefs themselves, the role of the mental health practitioner is to hold it for them until they are able to hold it themselves.

People can and do become lost in their psychosis, appearing inaccessible to intervention, but people move on from this into a frightening and inconstant world of uncertainty, fear, and isolation. Such experiences are challenging to articulate, yet listening and hearing appear to be of significant value in supporting someone forward onto sustaining a position beyond overwhelming psychosis.

Finally, it is important to note that stigma is a daily encounter if not actively avoided by withdrawal and is a huge issue in its own right because of its pervasive impact on people who are stigmatised. Stigmatising attitudes towards people experiencing severe mental health problems such as psychosis remain high in our society (The Schizophrenia Commission 2012). There is evidence that contact with mental health services can be perceived as a highly stigmatising experience for people experiencing mental health problems and for their families (Schulze 2007). There is an assumption that mental health professionals are somehow immune to such ideation and behavioural responses (McLeod et al. 2002) but this robustly appears not to be the case (Lauber et al. 2004; Lauber et al. 2006; Nordt et al. 2006; Rao et al. 2009).

Is *'something is rotten in the state of* mental health *services'?* Campbell, a UK mental health activist, notes

> *'There is no way that being known, or knowing yourself, as 'a schizophrenic' can be anything else than a heavy burden. After the cataclysm of entry into the mental health system, people with a mental illness diagnosis are trying to re-orientate themselves. Unfortunately professional interventions frequently confuse them even further and end up pointing them in the wrong direction.' (Campbell 2007, p299)*

Lower order findings from this study presented in SOT1, Stigma *'It does matter, it's not very nice'*, reinforce the detrimental impact of stigma on people living with psychosis. Such stigma drives social disenfranchisement, disconnection, and isolation which supplement the negative consequences and losses experienced by people living with psychosis, and fuelling distress and despair or hopelessness. There is a continuing reluctance to work with people experiencing psychosis and a low level of belief in the therapeutic efficacy of interventions despite research evidence to the contrary (McLeod et al. 2002). Staff attitudes correlate with their personal experiences of working with people with mental disorders and poorer experience correlated with more negative attitudes (McLeod et al. 2002). These negative attitudes lead to a more pessimistic view of potential recovery from serious mental health problems than that found in the general public, and not representative of recovery findings (Thornicroft et al. 2007).

The question, of course, is how such professional stigma is challenged. One route could be to explicitly engage students in stigma awareness developmental activities on clinical training courses and, through such an approach, change the attitudes of those people who will be in positions of influence over people living with psychosis (Pinto-Foltz & Logsdon 2009). Part of this teaching would necessarily have to encompass reappraising attitudes developed and powerfully reinforced by media:

> *‘information about mental illness learned from a lifetime of media use will be a source of stereotypes, impacting judgments people make in their everyday life when they encounter situations related to mental illness, mental health care, or persons with mental illness’. (Martin et al. 2008 p435)*

Reporting in the media is frequently stereotyping (Time for a Change 2008) and it is robustly shown that an impact of stereotyping is to dehumanise the subject (Hinshaw & Cicchetti 2000). A recent meta-synthesis into mental health stigma reduction interventions revealed that humanising interventions that included live or video interactions with or recording of people living with a mental health condition had a positive effect on stigma reduction, along with web-based learning activities, printed educational material, documentary and anti-stigma films (Seroalo et al. 2014). It may appear unnecessary, but informing trainee mental health professionals about mental health perhaps needs to be the key target of any mental health clinical training course. There is evidence suggesting that people with low mental health literacy have a heightened sensitivity to media images and information (Pescosolido et al. 2008) so strengthening the understanding of mental health in professionals is an imperative of training and post-qualification. Working with professionals both within and beyond training may also diminish the impact of stigmatising service culture on the perpetuation of stigmatising understandings, attitudes and treatments.

It is known that that being perceived as a member of a stigmatised group further strengthens self-stigma which compounds the impact of living with psychosis (Brohan et al. 2010). If people living with psychosis are not protected from stigma coming from within the services providing their care due to poorly developed understandings lacking in empathy, then this is a priority for practice; utilising emically-informed understandings could be a powerful agent of change. Taking a critical psychiatry perspective, Hornstein states that it is important to listen to more than just the medical profession if new understandings of psychosis are to be developed, to listen to shared experiences not solely disputed theories; first person accounts of mental distress, she states, serve to *'expose the limits of psychiatric explanations and treatments'* (Hornstein 2012, p xxii) and to offer potentially better alternatives. This could be strengthened through the use of rigorous qualitative research inquiring into the phenomenology of living with a mental health problem, the experience of being a family member or friend of someone living with a mental health problem, and the experience of being a mental health nurse. Information gleaned would illustrate, for example, how it is that mental health nurses remain entrenched in understandings which are evidently stigmatising and begin to guide ideas about approaches to attitudinal change. This supports a recommendation for further meaningful research into the experience of mental health nurses working with people living with psychosis; indeed such research into stigma has been noted as not merely a matter of curiosity, but a vital component (Martin et al. 2008) in supporting people with longer-term mental health conditions to lead the best life they can.

8.2.3 Intervention

> *'I was unhappy, trapped and fighting my descent into hopelessness'(Bassman 2012, p 270)*

Interventions that are meaningful to the experience of living with psychosis as a longer-term health condition need to be informed by just that, the phenomenology of the experience as noted in the previous two sections on conceptualisation and understanding. Such interventions are discussed briefly here, informed by this study and their resonance with the inductive findings of Geekie and Read (2009), Davidson (2003), McCarthy-Jones et al. (2013), and (Nixon et al. 2010b).

It is in the developing of a meaningful framework that recovery appears to take root. It appears to support the separation of the person from their overwhelming psychosis and support the self to re-emerge and be recognised as distinct from the psychosis, leading to enhanced self agency and beliefs about control. The use of clinical language and its inherent meaning has been argued to position people as victims of active pathology compounding fear and powerlessness, and so detrimental to recovery (May 2004). The extraordinariness of the experience of psychosis is challenging to articulate, so a new shared, meaningful, and accessible vocabulary may have to be developed.

Charon (2006) guides us to question whether people living with long term health conditions, such as psychosis, are being accompanied on their journey through the uncertainties and indignities of their experience by a trusted guide? This echoes the finding that developing a dialogue so that mutual understanding can emerge is a necessity, and being open to hearing and collaborative sense-making being paramount too within this; this cannot occur when practice is entrenched in erroneous or abbreviated assumption. Once again the importance of adopting a phenomenological perspective is highlighted by this and draws us towards utilising a narrative approach to intervention. Charon (2006) believes that a healing process begins with the commencement of a narrative, no matter with whom the narrative takes place. A narrative gives suffering a voice that acts to provide an escape from its *'dominion'* (p65 Charon 2006) which, given the findings from this study in SOT2 *'Psychosis as a Volitional Other'* , makes the use of a narrative approach highly appropriate. Much evidence and theorising points towards the need to increase meaningful dialogue with people living with psychosis about their subjective experience both within and outside of clinical practice, implying that we all have to open our minds to different understandings of peoples' experiences of living with psychosis. Like Charon (2006) and Carel (2013), Frank (2013) believes in the restorative power of storytelling and narrative approaches to living alongside ill health, indeed that becoming unwell is a '*call for stories'* (p966). Frank believes that stories begin to repair the damage that illness experiences do to our sense of ourselves, our lives and our futures, as well as developing an explanatory vehicle for those who need to know about such experiences. If this avenue is abruptly cut off through therapeutic nihilism or applying unsupported theories giving primacy to the meaninglessness of the experience of psychosis, then a disservice is done to people who live with psychosis.

Findings indicate too, that interventions need to be directed towards healing from past and current experiences and to the alleviation of immediate experiential distress through psychological techniques as well as medication. Reconnecting is paramount and the creation of a new peer-group is part of this, allowing new friendships to flourish and personal value to grow. Opportunities to 'give back' also emerge as recovery promoting and so need to be facilitated by services, but will be more likely pursued by staff who have moved beyond stigmatising beliefs about people who live with psychosis.

8.3 Conclusion

'The most important part of my journey has been hope. When I have not held it for myself, others have held it for me.' (Comans 2011, p 247)

This study intended to capture the lived experience of living with psychosis through the use of IPA methodology, and aimed to answer the research question about whether IPA is an appropriate methodology through which to complete the primary research enquiry. Finally, given the challenges associated with the transferring of qualitative research knowledge into clinical practice, the study included a subsidiary research question asking *'How can the emergent picture from an IPA study be useful in enhancing* mental health *Practice with people living with psychosis?'*

Findings from this study have revealed interesting insights into understanding the lived experience. There is a continuing awfulness of daily life, with anxiety, loss, and stigma, into which voices add inescapable intra-psychic conflict. The relationship to the experience based on the personal understanding of the experience dictates how one lives with the experience, and this is accompanied by a sense of the self being violated and fear of it being subsumed and lost. The extraordinariness of the experience drives an ontological un-anchoring, which is accommodated to through epistemological changes in attempts to reduce fear, uncertainty, and increase a sense of safety. These changes persist and create an ontological dichotomous state so certainty is compromised. Liberation is possible once a separateness of the self from the psychosis is recognised and the journey towards understanding proceeds. In addition, finding value and purpose, freedom from stigma, and reconnecting with the consensual reality and social world support continued recovery.

From the detail-rich and in-depth experiential picture emerging from the idiographic analysis of the subjective experiences of the participants it can be argued that the phenomenon of living with psychosis for the people interviewed for this study has been captured evocatively through the use of IPA. This assertion is strengthened by the resonance this study's findings have with the extant phenomenological evidence on psychosis. It appears that in agreement with the conclusions of McCarthy-Jones et al. (2013) inductive research methodology can be a viable vehicle for capturing the lived experience of psychosis.

Geekie and Read (2009) argue that those who have the lived experience of 'madness' (2009, p19) are able to offer a unique commentary and make a significant contribution to understanding and I would support this strongly given the findings from this research study. Qualitative research applied to people living with psychosis is not only possible but yields important insights by bridging the gap between *'remote 'objective' methods and first hand lived experience'* (Geekie & Read 2009 p91) and produce findings that must begin to challenge the professional presumptions which continue to mental health practice of psychosis. Excitingly, this thesis has been able to detail how its findings and their resonance with the extant literature could beneficially inform practice.

This research study appears to have offered valid information that addresses all of the research questions it asked. The enquiry aimed to capture the totality of the experience of living with psychosis as a long-term health condition for the people contributing to this study as participants, and it can be argued that it has indeed done this and more, that it has allowed for such experiences to become part of a journey of potential reconceptualisation and understanding which will lead towards meaningful and effective interventions for those who live with psychosis.

8.3.1 Further Research Recommendations

The major research recommendation from this study concerns working to promote the use of qualitative research findings in education, practice and policy, and not just for psychosis but for all mental health experiences because the case for its inclusion, as presented in this thesis, is robust. A route to this would be through strengthening the rigour in the developing qualitative knowledge-base. This study has attempted to be strongly rigorous and transparently discussed issues of validity and methodology throughout, but when qualitative research is distilled into shortened research articles then transparency is often lost within restricted word limits, so accountability for rigour falls on the researcher.

Taking IPA as an example, it appears to be a valuable research methodology for exploring the lived experience of psychosis, enhancing empathetic understanding, and revealing implications for practice. However, the review of the evidence base aroused a number of concerns. Firstly, that the translation of the research into practice-transferable form does not seem to happen well, and perhaps this is why the influence of good qualitative findings appears only weakly to influence policy and practice. There is a huge amount of qualitative research evidence available yet lost, perhaps because there is little synthesis or a bringing together of the disparate findings. Secondly, that the presentation of qualitative research is inconsistent and not necessarily rigorous in its adherence to its methodology, so knowing the methodology and being immersed in it as part of the researcher journey is important to its outcome. Thirdly, that qualitative research into psychosis reviewed to date fragments the experience into discrete research targets. This is almost inevitable because methodologies such as IPA generate a huge amount of data which is time-intensive to analyse, but equally a wider scoped study may lose sight of its focus, lose commitment to idiography, or lose depth of analysis in its extended scope. However, what is missing in this fragmented literature is a sense of the totality of the experience, clarity of the relationships between the uncovered dimensions of the lived experience, and clear guidelines for meaningful intervention. Whilst pragmatically narrowing the research focus to a specific domain within the experience of psychosis, are we attempting to explore the parts before we have elicited an understanding of the whole? It's rather like the Indian parable 'The Blind Men and the Elephant' in that our understanding of what we know will depend on which part of the whole we are close to.

This indicates that a rigorous and coherent programme of research into particular lived experiences is required, having a longer-term view of knowledge creation rather than a short-term one-off investigation.

Certainly there is much to follow up from this study in terms of further research into the subjective experience of psychosis, and more studies on the broader experience of living with psychosis would be useful to strengthen the extant literature before then isolating a domain and enquiring with more focus. Research too, would be useful in exploring attitudinal change and practice effectiveness for mental health nurses taught a phenomenological model of psychosis rather than a medical model, although there would be ethical and professional ramifications to consider in such a study's design.

8.3.2 Final Reflection

To close, a final personal reflection is offered.

Psychosis emerged as an unwanted, inescapable state which led to emotional distress, despair, withdrawal, and an impoverished life in the thrall of the psychosis rather than a self-determined existence. This information was elicited at the beginning of all my interviews and caused me to feel saddened and shocked by the sense of distressing entrapment shared by participants, even from Terry who described himself as in recovery; he appeared to be equally trapped in staying ahead of his psychosis, as if it were chasing him to reclaim him, as if it was stalking him with malevolent intent. I had expected the findings to be disturbing but I found them profoundly poignant because many experiences were heart-rendingly sad and shared in such an honest way; some were big experiences, some were small, but all equally poignant. This sadness was accompanied by admiration that, given the awfulness of the continuing experience, people were struggling to live a life, albeit two of the participants doing so subsumed within the ‘altered state’ of psychosis. I did not meet personal anger or bitterness, I met stoic acceptance *‘this is how it is, it’s awful but we just have to live with it’* was more the attitude voiced. Hornstein (2012 p27) writes that in mental health there is no neutral ground and every framing is political. This is, I believe, true. My stance identifies me as a critic of current psychiatry and an advocate for change on behalf of people living with psychosis; I find it ethically untenable to be otherwise.

Phenomenologically informed understandings of psychosis are observably under-represented in informing nursing or wider clinical practice. Rigorous research is a cornerstone of today’s evidence-based health care, but the *‘quantative hegemony’* (Biggerstaff & Thompson 2008, p214) continues to hold sway in spite of potentially rigorous phenomenological methodologies such as IPA (Smith et al. 2009). It could be argued that such methodologies are easy to apply without rigour or commitment and so deliver findings which can be easily dismissed in scientific circles (Paley 2005). Whilst not condoning poorly applied phenomenological methodology, it is an interesting paradox that the understanding of psychosis which is espoused in mental health practice today does not itself stand on rigorous or consistent quantitative evidence and appears to be promoting treatment based in assumption rather than conclusive knowledge (Bentall & Varese 2014).

I have struggled throughout this research process to rationalise why practice is not informed by what is known but rather from that which we are not sure about, and this frustration emerged as anger in my reflections, aroused by a felt-sense of *‘surely this isn’t how we should be leaving people living with psychosis, surely we can do better; it’s not okay, it’s not enough’.*

Appendix 1: Ontology, Me, and Epistemology

'Everything we hear is an opinion, not a fact. Everything we see is a perspective, not the truth.'
(Marcus Aurelius 121-180 AD)

When I wrestle with my ontological and epistemological orientation from my position of awareness of the unsophisticated nature my knowledge, my initial musing bring me to:

> *'there is an objective world which exists independently of me, providing a shared platform of natural world reality for all';*
>
> *'within this shared natural world reality, my personal reality, the reality I live, is my subjective interpretation of such a world'.*

I believe my subjective reality is mutually developed through my experience of the world and of the others who inhabit it, with my experiences being interpreted through cognitive processes which are informed by my personality traits and my previous experiences, and further guided by socially defined and scientifically identified declarative and procedural knowledge, which I assimilate to further interpret my future experiences of myself in the shared world.

I believe that what we do to others and what we experience from them influences our sense of ourselves in our shared world, and that whilst our subjective realities sit on a shared platform affording the possibility of similar experiences of the reality, the personal and social element of our species ensures that each of us develops an potentially unique reality based in subjectivity.

My sense then, of myself within our shared world, is that my subjective reality is informed by the natural, personal, and social world, within which I believe that both myself and others exist, and that through interaction and our sense-making (cognitive processing) we influence each other's subjective realities and create a shared lifeworld.

I further believe that the vehicle through which we come to know others' subjective realities is through interaction and more, that we are not meeting others' subjective realities 'cleanly'; it is one subjective reality meeting another. I do not believe that we can deny our own subjective reality when we meet with others, and so knowledge acquisition will be contaminated by ourselves. If however, we engage reflexively and acknowledge our subjectivity and its influence on understanding others' subjectivities, then it is possible to developed shared understandings acknowledging our starting points in terms of knowledge and experience, and being open to another’s world. This I offer, contentiously to the Positivists amongst my readers, is the cleanest and most ‘real’ that encounters can be.

Epistemologically, where does this leave me? I would make claim to adopt a soft social constructivist stance (Searle 1996) and an acceptance of a relativist position (Baghramian 2004), which I accommodate to through Critical Realism (Bunge 1993). I believe that we live on a shared scientifically *and* socially defined world platform, living in which we construct our subjective reality through a combination of top-down (cognition and shared world knowledge) and bottom-up (experiential) processes. I embrace phenomenological philosophy and phenomenological method in research as I perceive this to be a vehicle which brings us closest to understanding the subjective realities of others and so affords us the best opportunity to beneficially re-influence the life experiences of those living with deleterious subjective realities through illness, through misinterpretation, and sometimes cruel and excluding social worlds. I am aware that I live this position through my current clinical role as a psychological therapist.

Appendix 2 Literature Review Summary Tables and Summaries of Included Literature Search Articles

Two tables are presented and are slightly changed from accepted summary tables for literature reviews (e.g. Coughlan M et al. 2013) because this study is evaluating the literature guided by Smith (2011) and Etherington (2004) as detailed in chapter 4.5.

Author(s)	Year	Full Reference	Sample	Aspect of Experience
Knight, M Wykes, T Hayward, P	2003	'People don't understand': An investigation of stigma in schizophrenia using Interpretative Phenomenological Analysis (IPA). Journal of Mental Health, 12(3),209-222	6 Purposive	Stigma
Campbell, M Morrison, A	2007	The subjective experience of paranoia: Comparing the experiences of patients with psychosis and individuals with no psychiatric history. Clinical Psychology & Psychotherapy, 14(1), 63-77	12 Purposive	Paranoia
Pitt, L Kilbride, M Nothard, S Welford, M Morrison, A	2007	Researching recovery from psychosis: A user-led project. Psychiatric Bulletin, 31(2), 55-60	7 Purposive	Recovery
Nithsdale, V Davies, J Croucher, P	2008	Psychosis and the experience of employment. Journal of Occupational Rehabilitation, 18(2), 175-182	8 Purposive	Employment
Evenson, E Rhodes, J Feigenbaum, J Solly, A	2008	The experiences of fathers with psychosis. Journal of Mental Health, 17(6) 629-642	10 Purposive	Fathers with psychosis
Chin, J Hayward, M Drinnan, A	2009	'Relating' to voices: Exploring the relevance of this concept to people who hear voices. Psychology & Psychotherapy: Theory, Research & Practice, 82(1), 1-17	10 Purposive	Voices
Wood, L Morrison, A Haddock, G	2010	Conceptualisation of recovery from psychosis: a service user perspective. The Psychiatrist Online, 34, 465-470	8 Purposive	Recovery
Mawson, A Berry, K Murray, C Hayward, M	2011	Voice hearing within the context of hearers' social worlds: An interpretative phenomenological analysis. Psychology and Psychotherapy-Theory Research and Practice, 84(3), 256-272	10 Purposive	Voices
Wood, H Cupitt, C Lavender, T	2013	The Experience of Cognitive Impairment in People with Psychosis. Clinical Psychology & Psychotherapy, wileyonlinelibrary.com	8 Purposive	Cognitive Impairment
Milligan, D McCarthy-Jones, S Winthrop, A Dudley, R	2013	Time changes everything? A qualitative investigation of the experience of auditory verbal hallucinations over time. Psychosis-Psychological Social and Integrative Approaches, 5(2), 107-118	6 Purposive	Voices

Appendices

Author(s)	Year	Phenomenological	Hermeneutic	Idiographic	Sample rationale given?	Transparent	Reflection	Excerpts	Rigorous	Elaborated themes	Convergence and divergence	Well-wrought, sustained narrative
Knight, M Wykes, T Hayward, P	2003	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Campbell, M Morrison, A	2007	N	N	N	N	Y	N	P	P	N	N	N
Pitt, L Kilbride, M Nothard, S Welford, M Morrison, A	2007	Y	N	Y	N	Y	N	P	Y	N	P	N
Nithsdale, V Davies, J Croucher, P	2008	P	N	Y	N	Y	Y	Y	Y	Y	Y	N
Evenson, E Rhodes, J Feigenbaum, J Solly, A	2008	Y	Y	Y	N	Y	N	Y	Y	Y	P	Y
Chin, J Hayward, M Drinnan, A	2009	Y	Y	Y	N	Y	P	Y	Y	P	P	Y
Wood, L Morrison, A Haddock, G	2010	Y	N	Y	P	Y	N	P	Y	N	N	N
Mawson, A Berry, K Murray, C Hayward, M	2011	Y	P	Y	N	Y	Y	Y	Y	P	P	Y
Wood, H Cupitt, C Lavender, T	2013	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N
Milligan, D McCarthy-Jones, S Winthrop, A Dudley, R	2013	Y	P	P	Y	Y	Y	Y	Y	Y	Y	P

Knight et al. (2003) explored the experience of stigma in people living with psychosis. Their findings illustrated how stigma has an interpersonal and intrapersonal domain, being present in the person's social world but equally present in the self, internalised as self-stigma. Three themes emerged: judgement, comparison, and personal understanding. Judgement was the *'anticipated and actualised reactions' (p214)* from any person in the social world, including family and friends as well as strangers and authority figures. This was particularly informed by a perceived lack of understanding in others and in perceived erroneous assumption-led responses from others. Prejudicial attitudes and discrimination were frequently encountered at support providers. This constant meeting of stigmatised responses impacted on self-concept through feeling labelled by others, but significantly there was a perception of being responsible for the prejudicial responses as well as a victim of them, thus equally creating a self-stigmatising process detrimental to the sense of self. The second theme, Comparison, depicted a sense of a qualitative shift in life due to the emergence and persistence of psychosis, which was, in the majority, perceived as negative and irreversible. Coupled with this was a struggle of wanting a sense of cultural belonging yet not wanting to be part of a sub-culture that does not have a positive social identity, i.e. the 'mentally ill'. The final theme was about the personal understanding of the issue of stigma, and by this Knight et al. mean how the specific psychosis life experience is conceptualised. The use of the concept of 'illness' appeared to lead to a passivity and acceptance of a diminished 'sick role' or 'sick persona'; more, that the use of the term 'ill' did not seem to capture the full breadth of the experience; one participant noted *'The nature of this illness is that it takes over if you let it' (Joan, 26, p217)*. Within this theme, sub-themes of coping with stigma arose; the elicited methods were avoidance and withdrawal, education, and secrecy, a 'to tell or not to tell' dilemma. Knight et al. believes these factors present an *'almost insurmountable barrier to recovery' (p219)* and noted that this stigmatising process began at the beginning of their involvement with mental health services when they were given a diagnosis of schizophrenia without sufficient and appropriately informed explanations of the condition and so were initially self-informed by myths and assumptions about psychosis which drive societal and self stigma.

Nithsdale et al. (2008) explore employment experiences of people living with psychosis. Three themes were found in relation to the challenges of attaining and maintaining paid employment whilst living with psychosis: coping, interpersonal support and reactions, and personal significance. Building coping strategies for the experiences of psychosis within the workplace was significant, managing voices or paranoia were key to avoid the symptoms becoming so severe that remaining at work became impossible. Using Supportive Services to sustain the ability to remain in work was beneficial, and remaining in work was beneficial overall as it supplemented the perceived benefit of undertaking meaningful activity outside of paid work. Even if remaining in paid employment became untenable, participating in unpaid, voluntary meaningful activity was deemed significant in sustaining a more positive sense of self. Psychological support and understanding from people outside of the employer was important in enabling a successful embrace of the challenges of remaining in paid employment and had some influence on disclosing to work colleagues and employers. Lack of support from the employer in the work place was unhelpful and was perceived to contribute to increased challenges with coping with symptoms whilst at work. Such lack of support was perceived as stemming from ignorance on the part of the employer. The third theme illustrated how important paid employment is to the person living with psychosis in terms of social contact and value, however, Nithsdale et al. notes that there was no consistent relationship between being employed and quality of life; some people in work managed well, others struggled, some not in employment felt their lives were productive, others perceived their lives as diminished.

Evenson et al. (2008)explored the experiences of fathers living with psychosis, believing this group to be an ignored population. Themes emerged highlighting that psychosis undermines the father-child relationship and the work of parenting through creating a self-driven emotional disengagement from the child. This emotional disengagement was due to the overwhelming emotional and psychological challenges and preoccupations that psychosis brings with it. Acute episodes were also seen as a disruption to the father-child relationship, removing him from the family, but also through reluctance to be visited whilst in a psychiatric hospital due to a perception of shame about their own mental distress and because of a desire to protect the child from witnessing their own and others' mental distress and consequential behaviour. The impact of medication on psychosocial functioning was a further detrimental experience to the father-child relationship. There was also a sense of loss of the kind of father and father experience that they wanted their child to experience, particularly where these aspirations were driven by the father's own abusive parental experiences. There were fears too, for the child in terms of their futures because of the psychosis in the parent. Parenting however, emerged to deliver a sense of pride in the father in spite of the challenges of living with psychosis and was a motivating factor to staying well and maintaining recovery, more, that the support and empathy shown by the child helped the parent to manage their psychosis better. In their discussion, Evenson et al. note that there are similarities and differences between being a mother and a father living with psychosis; earlier research (Nicholson et al. 1998, in Evenson 2008) showed that Mothers feared losing custody of their children and often avoided treatment due to the responsibilities of parenting, fathers it appear do not. Both parents though do report that the impact of medication prevents then engaging fully as a parent due to its detrimental psychosocial impact. Evenson et al. also note that previous research (Johnson, Cohen, Kasen, Smailes, and Brook 2001, in Evenson et al. 2008) has demonstrated that parents living with psychosis are indeed likely to demonstrate parenting deficits that can be associated with mental health problems in their children, and fear of this was alluded to from their study's participants.

Campbell and Morrison (2007) explored the subjective experience of paranoia, looking at whether the experiences of people living with psychosis were different from people who had no psychiatric history. Four themes emerged from the data, the phenomena, and beliefs about paranoia, factors which influence paranoia, and consequences of paranoia, with five issues emerging from the themes: the self, life experiences, emotion, cultural acceptability, meta-cognitive beliefs. The experience of people living with psychosis and experiencing paranoid ideation was that they felt powerless and viewed themselves negatively because of their paranoia. People living with psychosis expressed higher levels of anger and anxiety about their experience of paranoia than people who were not living with psychosis, indeed they were overwhelmed by anger and their anxiety was longer lasting and more intense. In addition there appeared to be a tendency to '*over-involve' (p73)* the self by making extreme internal explanatory attributions of the experience and a belief that negative life experiences contributed to the experiencing of paranoia. The main difference between paranoia in people living with psychosis and those not, was that the explanations created for the paranoid ideation was not within cultural acceptability. The content of the paranoia was important, people living with psychosis envisaged physical or psychological harm compared to the social harm feared by non-psychosis people, and people living with psychosis talked more about malicious intent from their experiences of paranoia. Experiencing paranoia led to confusion as people tried to make sense of it and derive meaning, this process was usually unsuccessful and so the confusion remained, and they was a tendency to talk more about the strangeness of the paranoid ideation than about its possible inaccuracy. A significant difference between the groups emerged in terms of control and origin of beliefs, people living with psychosis believed that their paranoia ideation was not self-created nor was it controllable.

Wood et al. (2013) explored cognitive impairment in people living with psychosis. Cognitive Impairment was established through psychometric measures, and then semi-structured interviews were undertaken in to the life experiences of the individual's focusing on the difficulties in cognitive functioning. Six themes emerged: impaired controlled thinking, physical sensations and impaired movement, explanations for the impairment and comparisons with the past, managing the impairment, how others saw the impairment, and anticipating the future. In terms of impaired controlled thinking, people described blanking and forgetting, with recall being effortful. There was a reduced ability to focus and concentrate, with dedicated concentration often being used for *'unusual purposes' (p6),* i.e. to ruminate on extraordinary ideation. There was also an expressed inability to initiate action or anticipate events. This reduced attentional experience was experienced physically to with control of bodily movements being experienced as impaired. Explanations for this experience of cognitive impairment emerged as a shift in quality, a loss from before, yet was challenging for participants to describe as if until it was brought to their attention they had simply become used to living with it without question or thought. When questioned though, all participants (8/8) associated their cognitive loss with hospitalisation and psychotropic medication, and some also attributed it to a negative trait in themselves, i.e. laziness. Managing this impairment included avoidance and withdrawal, and the use of humour when in social situations because there was an expressed sense that others' didn't understand. It did appear to create a dependency on other people, on deliberate mental prompts, or on substance use, cannabis, coffee, alcohol, etc.. Overall, as with other studies in to other aspects of living with psychosis, participants expressed a *'sense of bleakness regarding the impairment and the future' (p9)*.

Pitt et al. (2007) and (Wood et al. 2010) explored the experience of recovery in psychosis. Three themes emerged from Pitt et al., rebuilding of the self, rebuilding life, hope for a better future, whereas four themes emerged from Wood et al., impacts on mental health, self-change and adaptation, social redefinition, and individualised coping mechanisms. Both suggest that recovery is difficult to define both in conceptual and personal terms and that it is a relative concept for each person making the recovery journey. Pitt et al. found that rebuilding of a self diminished by the disempowering and distressing experience of psychosis is key to the recovery process. Developing an understanding of the self, both the' pre-psychosis self' and the current self, and '*being able to make sense of the experience of mental distress on their own terms' (p58)* was significant for people. Part of this process was to seek empowerment though engaging in activities which enhanced self-esteem and enables them to assert their needs more effectively. Rebuilding life involved the reconnecting with social support and reducing withdrawal through moving towards an active participation in life. The third theme, 'Hope', appeared to involve a desire for and process of transformational change, involving challenging one's beliefs about recovery and challenging others' beliefs about psychosis to move from social exclusion to inclusion. This, as in the Knight paper, involves challenging discrimination and stigma. The study does not however say how the desire to change is developed. The Wood et al. study stated that it was about recovery, but presented results that were more in line with detailing the lived experience of psychosis. It initially noted that all participants (8/8) expressed that the alleviation of their primary symptoms of hallucinatory experiences and delusional ideation was key to recovery because such relief improved their emotional state. However, further themes detailed more the challenges of living with psychosis rather than eliciting the process of recovery. 'Self-change and adaptation' illuminated that the experience of psychosis had caused a negative shift in their sense of self and in their behaviour, e.g. self-care, and 'Social redefinition' noted that it became a struggle to maintain social, relational and occupational roles. Recovery is said to emerge from the study as a *'multi-dimensional' (p468)* process which includes a role for symptom change, although recovery may be achieved in the continued presence of such experiences. Managing consequential and deleterious emotional states are important in this process of recovery. Both studies note the importance of addressing psychosis-linked withdrawal and maintaining social roles, value, and inclusion.

Three IPA studies focused on the experience of hearing voices, Chin et al. (2009), Mawson et al. (2011), and Milligan et al. (2013). Two of the studies are sited within a particular Psychosis Research Group in the South of England, Chin et al. and Mawson et al., and their focus is the relationship between the voice hearer and their voice(s) and both worked with purposive samples of 10 participants from mental health services. The Milligan et al. paper focuses on how the experience of voice hearing changes over time and used a purposive sample of 6 mental health service users. Five themes emerged from the Mawson et al. study: 'the person and the voice', 'voices changing and confirming relationship with the self', 'a battle for control', 'friendships facilitating the ability to cope', and 'voices creating distance in social relationships'. Voices were frequently assigned an identity and referred to as if interpersonal others; some had a congruence with people from the hearer's social world. Some people heard one voice, others heard many. Most hearers heard a range of positive and negative voices evoking an emotional response dependent on the meaning ascribed to the experience, and for some the quality of the hearer-voice relationship mirrored particular social relationships they had experienced. Some voice content was extreme and abusive. There appears to be an enmeshment of the voice and the hearer, the voice hearer's sense of themselves was influenced by how the voice related to them, and the voices were often blamed for aspirational and social failures experienced by the hearer. Hearer and Voice appeared to engage in a battle of control, with a perceived powerful voice exerting influence over the behaviour of the hearer. Whilst some hearers perceived a positive relationship with their voice, there was still a fear of disapproval by the voice, *'participants seemed stuck in a tiresome battle' (p264)* with their voices, unable to ignore or be controlled. Social relationships emerged as important in managing the relationship with the voices better, which is an unfortunate finding given the level of social isolation and withdrawal in people living with psychosis. Mawson et al.'s participants believed that voice hearing was associated with social isolation and great value was subsequently placed on social relationships that provided a sense of normalcy. Finally it emerged that the voice hearing experience created a boundary between the hearer and their social world. This appeared to be created from two directions, the hearer not wanting to burden others with their voice hearing experiences and the voices suggesting that connection with others was perilous in some way.

Chin et al. (2009) used IPA to explore the understanding of how voice hearers understand their voices in relation to themselves. Five themes emerged of which three are discussed in the paper which detail how the voice was defined and the relational hearer-voice power dynamic. Most voices were heard as identifiably 'real voices' which could explain the Mawson et al. (2011) findings of an 'other' or social identity being ascribed to the voice, and attempts to personify the voice were undertaken, or in other cases actively yet unsuccessfully resisted. The personification of the voice whether willingly or unwillingly, was a detailed experience with personalities, abilities, and motives ascribed – the voice appeared to become 'known' as a person. Again concurring with the Mawson et al. findings, there was a sense of a battling for control and power within the life of the hearer for issues from the most mundane to more significant life choices, but for some there was also a sense of 'we-ness', a togetherness or interdependent joining of the voice and the hearer. Rejecting this we-ness emerged as an uncoupling strategy for the hearer from the power and influence of the voice and a move towards a separate or more bounded sense of self and recovery.

Milligan et al. (2013) explored voice hearing over time with six long term voice hearers living with psychosis. Six themes emerged detailing a potential phased experience of voice hearing moving from a 'negative trigger' onset, through 'rejection' and 'crisis-induced change', to 'discovering, adjusting, and trying to cope' and 'new understanding'. Most participants (5/6) described voices beginning after a negative life event which aligns with the existing literature on voices. Voices, as noted in the previous IPA studies caused emotional change, and in turn were influenced by that emotional change. Initially on hearing voices all participants described a rejecting of the experience and a seeking for causes which were not about themselves but were extraordinary, i.e. a brain implant. For each participant their difficulties came to a head, a crisis, and the response to that crisis influenced both the beliefs about the voice hearing, and the voice hearing itself, either positively or negatively, this might suggest that there remains some plasticity in the voice hearing experience which can be mediated at time of post-crisis to good effect. Further along the journey the hearer begins to discover more about their voices, adjust to them, and begin to manage them more effectively, ultimately to develop new understanding of the experience although this final theme was not an absolute phase, nor one where struggling with older understandings or less than helpful new understandings is minimised. Milligan et al. again highlight the importance of social relationships for promoting beneficial change, and the helpfulness of opening up about the voice hearing experience to a 'truly' external other.

Appendix 3 Ethical Approval

UNIVERSITY OF
Southampton

Ms Wendy Turton

RGO REF - 7737

09 May 2011

Dear Ms Turton

Professional Indemnity and Clinical Trials Insurance

Project Title 'Living with Psychosis: Using Qualitative Analysis to Re-awaken Understanding and Inform Meaningful Intervention'; also known by the lay title of 'Living with Psychosis: What Can we Learn about the Experience by Asking People who are Living with Psychosis?'

Participant Type:	No Of Participants:	Participant Age Group:	Notes:
Patients	18	Adults	

Thank you for forwarding the completed questionnaire and attached papers.

Having taken note of the information provided, I can confirm that this project will be covered under the terms and conditions of the above policy, subject to written informed consent being obtained from the participating volunteers.

Insurance will only be activated when we have received a copy of the Ethics Committee approval and you must not begin your project prior to this. Please forward a copy of the Ethics Committee approval letter as soon as it is to hand to complete the insurance placement.

If there are any changes to the above details, please advise us as failure to do so may invalidate the insurance.

Yours sincerely

Mrs Ruth McFadyen
Insurance Services Manager

Tel: 023 8059 2417
email: hrm@soton.ac.uk

cc: File

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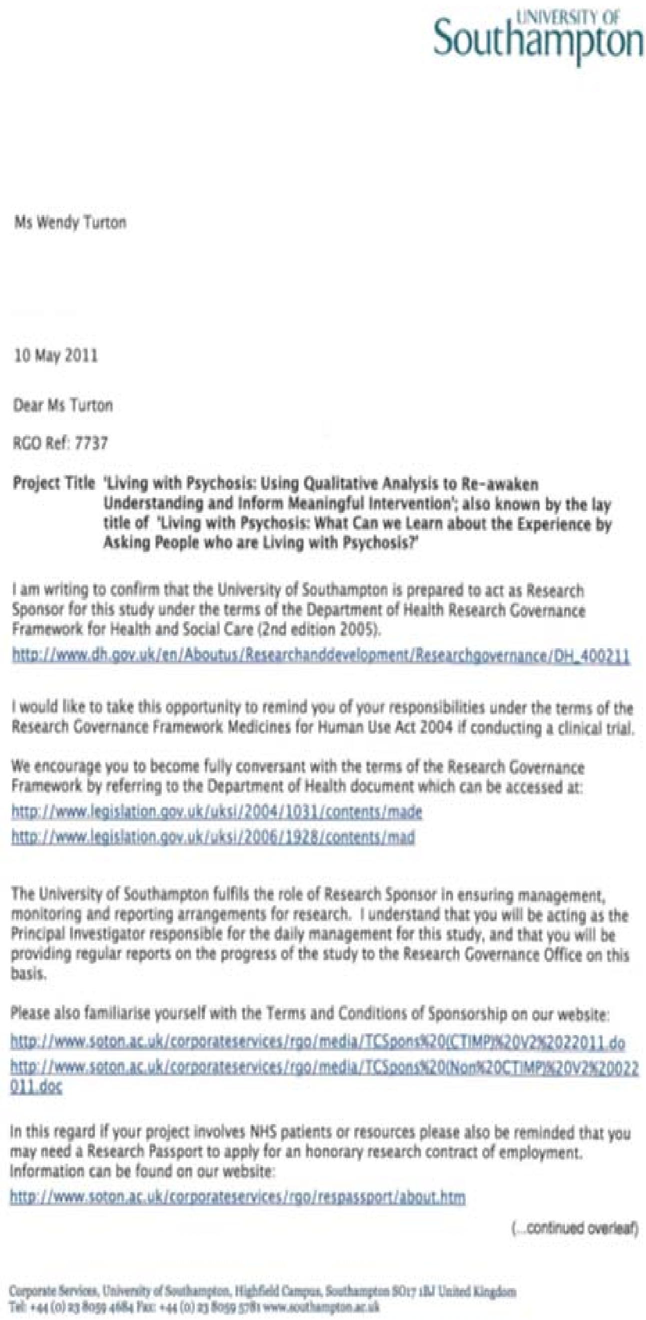


UNIVERSITY OF
Southampton

Ms Wendy Turton

10 May 2011

Dear Ms Turton

RGO Ref: 7737

Project Title 'Living with Psychosis: Using Qualitative Analysis to Re-awaken Understanding and Inform Meaningful Intervention'; also known by the lay title of 'Living with Psychosis: What Can we Learn about the Experience by Asking People who are Living with Psychosis?'

I am writing to confirm that the University of Southampton is prepared to act as Research Sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005).

http://www.dh.gov.uk/en/Aboutus/Researchanddevelopment/Researchgovernance/DH_400211

I would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework Medicines for Human Use Act 2004 if conducting a clinical trial.

We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

http://www.legislation.gov.uk/uksi/2004/1031/contents/made
http://www.legislation.gov.uk/uksi/2006/1928/contents/mad

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

Please also familiarise yourself with the Terms and Conditions of Sponsorship on our website:

http://www.soton.ac.uk/corporateservices/rgo/media/TCSpons%20(CTIMP)%20V2%2022011.do
http://www.soton.ac.uk/corporateservices/rgo/media/TCSpons%20(Non%20CTIMP)%20V2%20022011.doc

In this regard if your project involves NHS patients or resources please also be reminded that you may need a Research Passport to apply for an honorary research contract of employment. Information can be found on our website:

http://www.soton.ac.uk/corporateservices/rgo/respassport/about.htm

(...continued overleaf)

Corporate Services, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
Tel: +44 (0) 23 8059 4684 Fax: +44 (0) 23 8059 5781 www.southampton.ac.uk

UNIVERSITY OF
Southampton

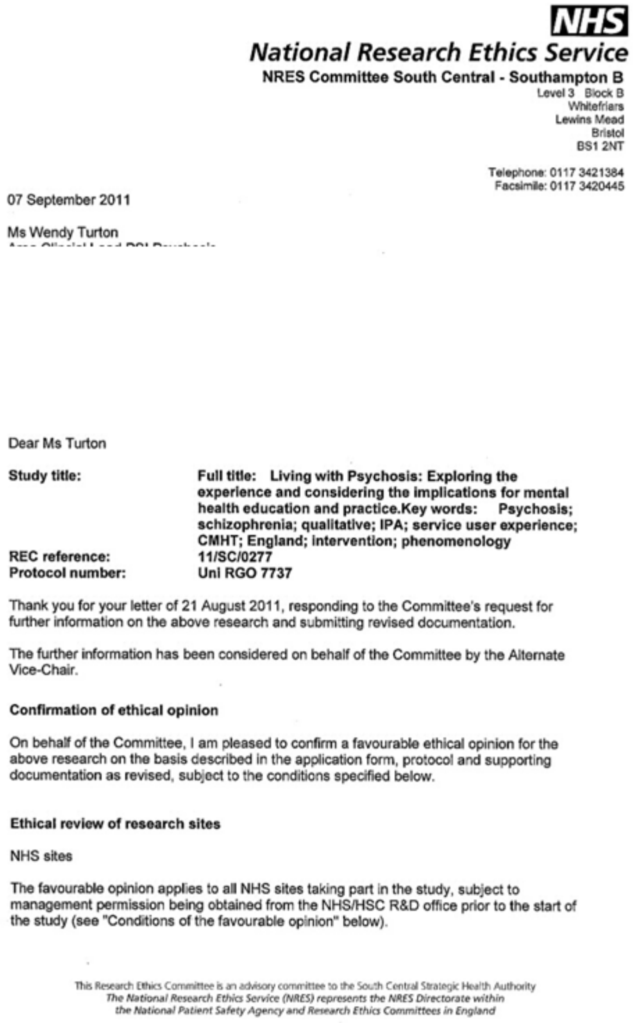
Please send us a copy of your NHS REC and Trust approval letters when available.

Please do not hesitate to contact me should you require any additional information or support.
May I also take this opportunity to wish you every success with your research.

Yours sincerely

Dr Martina Prude
Head of Research Governance
Tel: 023 8059 5058
email: rgoinfo@soton.ac.uk

Corporate Services, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
Tel: +44 (0) 23 8059 4684 Fax: +44 (0) 23 8059 5781 www.southampton.ac.uk



NHS
National Research Ethics Service
NRES Committee South Central - Southampton B
Level 3 Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 3421384
Facsimile: 0117 3420445

07 September 2011

Ms Wendy Turton

Dear Ms Turton

Study title:	**Full title: Living with Psychosis: Exploring the experience and considering the implications for mental health education and practice.Key words: Psychosis; schizophrenia; qualitative; IPA; service user experience; CMHT; England; intervention; phenomenology**
REC reference:	**11/SC/0277**
Protocol number:	**Uni RGO 7737**

Thank you for your letter of 21 August 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

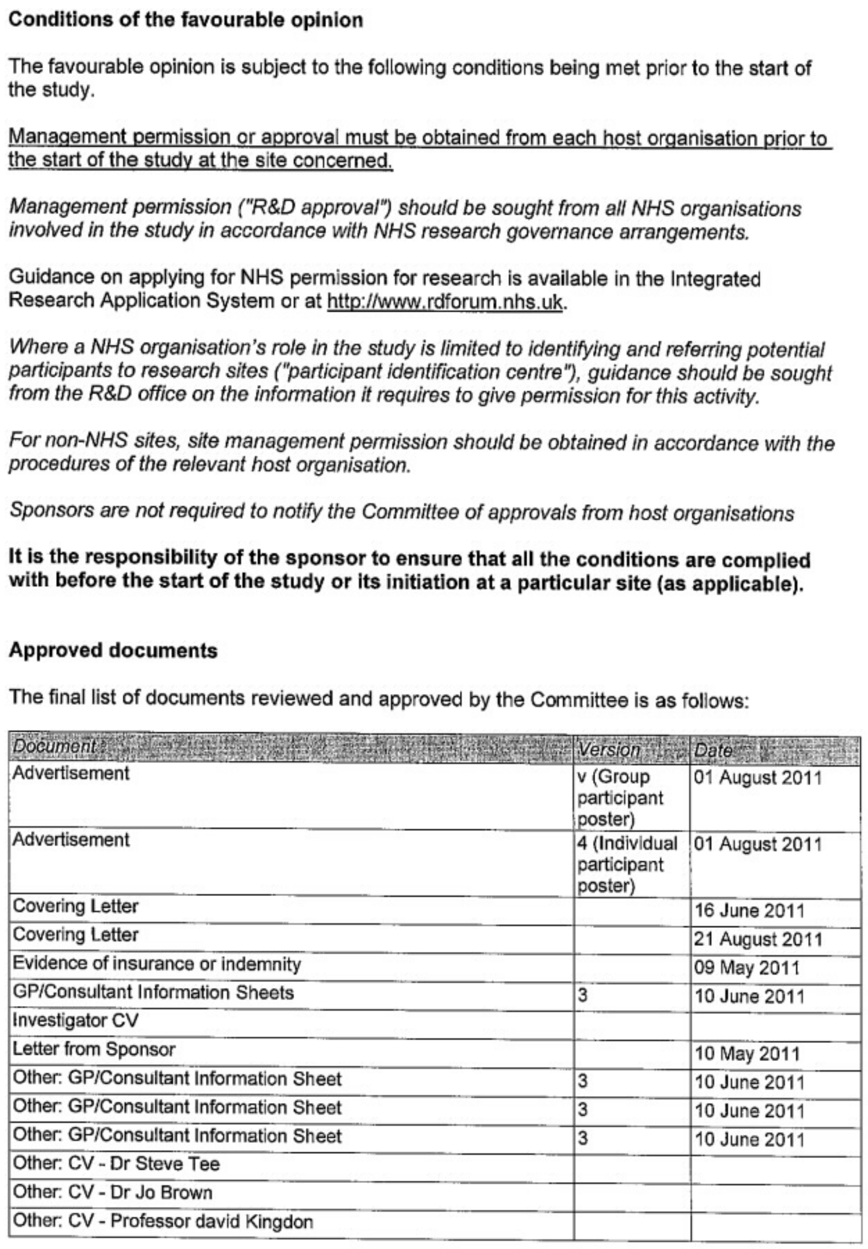
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

This Research Ethics Committee is an advisory committee to the South Central Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

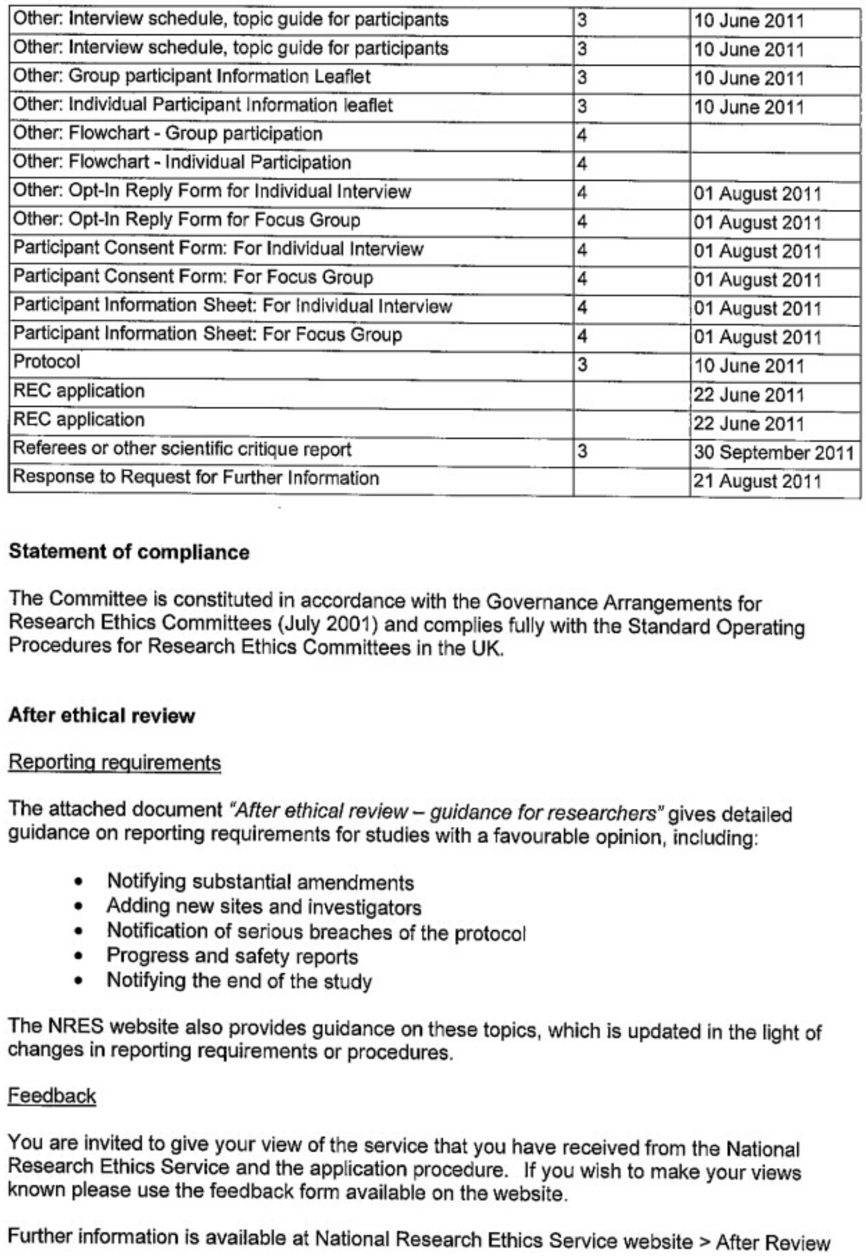
Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Advertisement	v (Group participant poster)	01 August 2011
Advertisement	4 (Individual participant poster)	01 August 2011
Covering Letter		16 June 2011
Covering Letter		21 August 2011
Evidence of insurance or indemnity		09 May 2011
GP/Consultant Information Sheets	3	10 June 2011
Investigator CV		
Letter from Sponsor		10 May 2011
Other: GP/Consultant Information Sheet	3	10 June 2011
Other: GP/Consultant Information Sheet	3	10 June 2011
Other: GP/Consultant Information Sheet	3	10 June 2011
Other: CV - Dr Steve Tee		
Other: CV - Dr Jo Brown		
Other: CV - Professor david Kingdon		



Other: Interview schedule, topic guide for participants	3	10 June 2011
Other: Interview schedule, topic guide for participants	3	10 June 2011
Other: Group participant Information Leaflet	3	10 June 2011
Other: Individual Participant Information leaflet	3	10 June 2011
Other: Flowchart - Group participation	4	
Other: Flowchart - Individual Participation	4	
Other: Opt-In Reply Form for Individual Interview	4	01 August 2011
Other: Opt-In Reply Form for Focus Group	4	01 August 2011
Participant Consent Form: For Individual Interview	4	01 August 2011
Participant Consent Form: For Focus Group	4	01 August 2011
Participant Information Sheet: For Individual Interview	4	01 August 2011
Participant Information Sheet: For Focus Group	4	01 August 2011
Protocol	3	10 June 2011
REC application		22 June 2011
REC application		22 June 2011
Referees or other scientific critique report	3	30 September 2011
Response to Request for Further Information		21 August 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

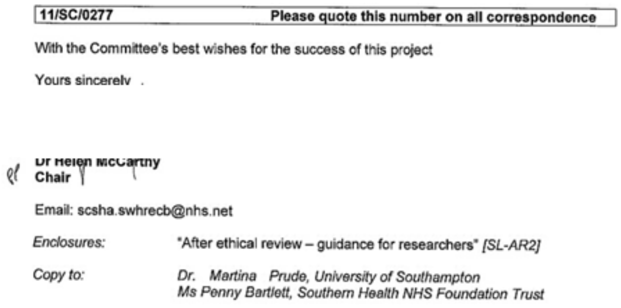
- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review



11/SC/0277	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely .

Dr Helen McCarthy
Chair

Email: scsha.swhrecb@nhs.net

Enclosures:	"After ethical review – guidance for researchers" *[SL-AR2]*
Copy to:	*Dr. Martina Prude, University of Southampton* *Ms Penny Bartlett, Southern Health NHS Foundation Trust*

NHS
Health Research Authority
NRES Committee South Central - Southampton B
Bristol REC Centre
Level 3, Block D
Whitefriars
Lewins Mead
Bristol
BS1 2NT
Tel: 01173 421384
Fax: 01173 420445

21 March 2012

Ms Wendy Turton

Dear Ms Turton

Study title: **Full title: Living with Psychosis: Exploring the experience and considering the implications for mental health education and practice.Key words: Psychosis; schizophrenia; qualitative; IPA; service user experience; CMHT; England; intervention; phenomenology**
REC reference: **11/SC/0277**
Protocol number: **Uni RGO 7737**
Amendment number: **1**
Amendment date: **28 February 2012**

The above amendment was reviewed at the meeting of the Sub-Committee held on 14 March 2012 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		28 February 2012
Notice of Substantial Amendment (non-CTIMPs)		28 February 2012
Protocol	4 (clean)	28 February 2012
Protocol	4 (tracked changes)	28 February 2012
Participant Information Sheet: Individual Gatekeeper Information Sheet	4 (clean)	28 February 2012
Participant Information Sheet: Individual Gatekeeper Information Sheet	4 (tracked changes)	28 February 2012
Participant Information Sheet: Group Gatekeeper Information Sheet	4 (clean)	28 February 2012

A Research Ethics Committee established by the Health Research Authority

Participant Information Sheet: Group Gatekeeper Information Sheet	4 (tracked changes)	28 February 2012
Confirmation email from Sponsor		28 February 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/SC/0277:	**Please quote this number on all correspondence**

Yours sincerely

[illegible]
Alternate Vice-Chair

E-mail: scsha.swhrecb@nhs.net

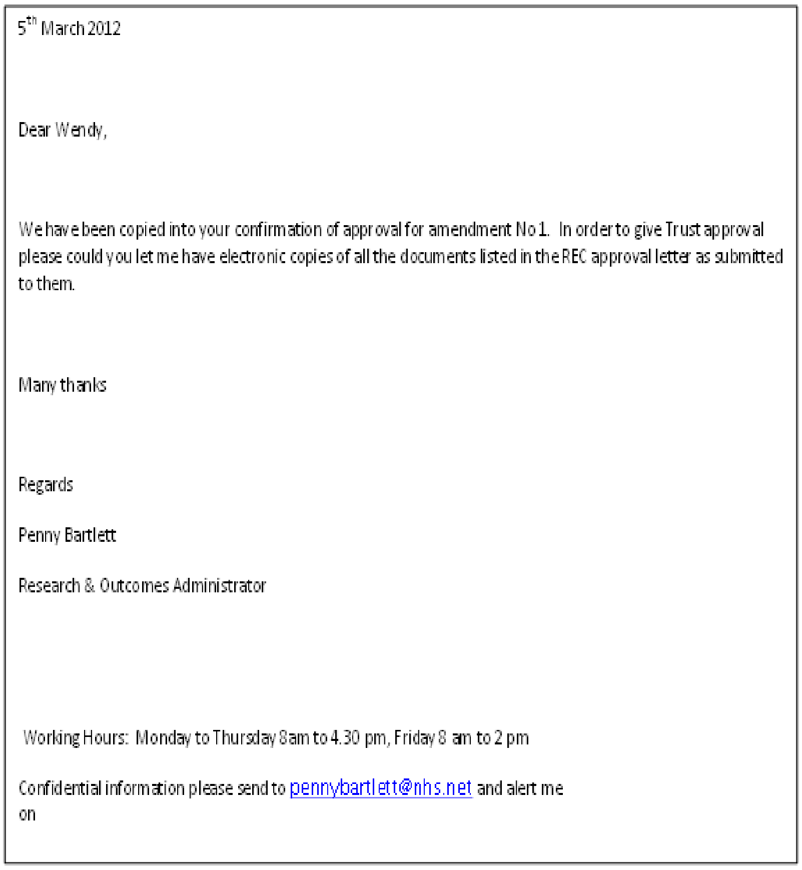
Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Mrs Penny Bartlett, [illegible]*
Martina Prude, University of Southampton

NRES Committee South Central - Southampton B

Attendance at Sub-Committee of the REC meeting on 14 March 2012

Name	*Profession*	*Capacity*
Dr Karl Nunkoosing	Principal Psychology Lecturer	Lay
Dr Giles Tan	Consultant Psychiatrist	Expert



5th March 2012

Dear Wendy,

We have been copied into your confirmation of approval for amendment No 1. In order to give Trust approval please could you let me have electronic copies of all the documents listed in the REC approval letter as submitted to them.

Many thanks

Regards

Penny Bartlett

Research & Outcomes Administrator

Working Hours: Monday to Thursday 8am to 4.30 pm, Friday 8 am to 2 pm

Confidential information please send to pennybartlett@nhs.net and alert me on

---

Substantial Amendment: RGO 7737 REC 11/SC/0277

Prude M.A.

Actions

In response to the message from turton w.j. (wjt104), Tue 28/02

To: turton w.j. (wjt104)

]scsha.swhrecb@nhs.net[;Rgoinfo

28 February 2012 23:58

Dear Wendy
I have reviewed and am happy with the proposed amendment.
Best Wishes

Martina Prude

Appendix 4 Inclusion Criteria for the Research Study

Inclusion Criteria
People who have experienced 'positive' symptoms indicative of persistent psychosis or schizophrenia according to the DSMIV – R or the ICD10 for a minimum of five years
Stability in life circumstances and existing treatment of the psychosis.
Actively involved with the Secondary Mental healthMental health Service with a supportive relationship with a care co-ordinator.
Assessed low level of risk to self or others.
Able to give Informed consent to participation.
Willing to participate in a semi-structured interview process, to be audio-taped, for their interview data to be useful for research purposes specified on the consent sheet, and willing for their GP to be informed of their participation.
Inclusion is regardless of gender, religion, race, ethnicity, sexual orientation or disability. However, proficiency in spoken English is required.

Appendix 5 Written Information for the Research Gatekeepers

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Health
Sciences

(IGIS) Individual Gatekeeper Information Sheet: 'Living with Psychosis' Research Study.

This short document will tell you a little about the proposed research, about your important role in the study, and about me. The research is evidenced based but I have excluded the references from this information sheet to enhance its readability. If you would like to discuss the evidence base simply contact me. The term 'service user' is used throughout with apologies to those who prefer a different term.

The study is entitled ***'Living with Psychosis: Exploring the experience and considering the implications for mental health education and practice'***, also known as ***'Living with Psychosis: Exploring the experience'.***

Background

'Psychosis' can be used as an umbrella term for experiences such as unusual sensory perceptions and/or holding extraordinary beliefs about one, or several, aspects of life. The incidence of psychotic disorders in the UK is about one percent, schizophrenia being the most common diagnosis.

Psychosis remains a disorder poorly understood; its cause, manifestation, and even its very concept remain unclear, and factors involved in recovery are equally unclear. Psychosis has its primary symptoms but also can lead to secondary problems due to the devastation an episode of psychosis wreaks on the person themselves, their relationships, roles, and their futures. Stigma and discrimination are key issues in this secondary arena.

Varying theoretical conceptualisations of psychosis lead to remarkable differences in interventions and treatment consistency for individuals, and they obfuscate the reality of living with psychosis.

The subjective experience of mental ill-health such as psychosis has much to offer understanding of the phenomena, and how psychosis is understood or conceptualised will be reflected in its treatment.

Personal accounts of living with psychosis are becoming more widely available and also a strengthening service user movement is developing within secondary mental health Services asserting that the validity of their experience be heard and respected when treatment options are considered. There are too, policy documents and reports which utilize the expert experience from someone living with the phenomenon in the creation of its guidance for best practice. As yet though, there is little systematic organization of this growing knowledge base for its voice to impact sufficiently on practice, and personal journeys, whilst invaluable in progressing understanding, tend to offer qualitative or narrative accounts rather than qualitative analysis. This lack of systematic analysis could be argued to support the persistence of more traditional knowledge underpinning understanding, defining interventions, and influencing practitioner education.

This study proposes to develop the subjective knowledge base of the experience of living with psychosis in the UK today and to apply systematic qualitative analysis to the generated data. The primary Research Question is **‘What is the experience of living with psychosis?’,** which it asks of people living with psychosis. A subsidiary research question is **‘What can this knowledge offer in terms of mental health practice and practitioner education?’**

Proposed Time Line

- Jan-May 2011 Presentation to CMHTs.
- Oct 2011 Recruitment through Gatekeepers begins and interviews are undertaken.

Role of Gatekeepers

Key to recruitment is the use of Gatekeepers – and that is where you come into the picture. The role of the Gatekeeper is to protect the interests of the service users. Gatekeepers have the power to deny access to the participant population, so protecting vulnerable people from ungoverned research. It is a role that is crucial to the protection of service users from inappropriate inclusion in the research process.

You are invited to be a Gatekeeper for this research. Your Gatekeeper role is to identify Service Users who could be potential participants and determine whether their participation is appropriate. You will need to check out the inclusion criteria for the study and then use the Gatekeeper Checklist to guide you through the role.

You are invited to act as Gatekeeper for as many service users as you feel are appropriate to the study, although the study sample will be small at around 10 – 12 people. Simply make sure you photocopy the required paperwork. If you run out of forms though, please do e—mail me and I will send you e-copies to print off.

You will need to meet up with the service user and discuss the study and read through the participant Information Sheet with them. Then, if the service user is interested, take down their details on the Service User Details form in your Gatekeeper pack, and, crucially, gain signed 'informed' consent for me to contact them by completing the consent form together.

Once you have done this, you simply need to post all the forms to me in the envelope provided; I will acknowledge receipt of the service user's details with you and take it forward from there. I will telephone the service user and discuss the study in more depth, seek consent for participation and arrange an interview appointment at a venue acceptable to the participant and risk assessed for the researcher. The venue is intended to be an adult mental health service venue familiar to the participant and I will let you know the date of the interview. The interview will then be undertaken.

Most people find it positive to talk about their experiences, but sometimes talking about issues that are or were frightening or strange can cause a sense of vulnerability, as if it is being 'stirred up' again. The interview is designed not to cause deliberate distress and participants will be able to stop the interview anytime they feel uneasy. As a further safeguard for participants, it is required that the care co-ordinator contact the service user within 72 hours of the interview and check out whether additional care co-ordinator support is needed. I will let you know when the interview will take place so you can undertake this last bit of Gatekeeper input.

The care co-ordinator/lead practitioner, GP, Psychiatrist and client will receive confirmation of both participation and closure of participation in the study.

A presentation of findings will be arranged for each participating site team.

Thank you for your support.

Who am I?

My name is Wendy Turton. I am currently the Clinical Lead for <service name>. The service offers evidence-based psychosocial interventions aimed at reducing the distress and disability associated with the experience of psychosis, and has a service objective to promote best practice in psychosis. I am undertaking this research as part of my Doctoral programme of study and so, whilst a <Trust name> NHS Foundation Trust employee, as a researcher I come under joint governance with the University of Southampton Faculty of Health Sciences, who are the sponsors for this research.

If you have a concern or a complaint about this study you should contact Susan Rogers, Head of Research & Enterprise Services, at the Faculty of Health Sciences. If you remain unhappy and wish to complain formally Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.(Address: University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7942; Email: S.J.S.Rogers@soton.ac.uk).

My contact details: wendy.turton@nhs.net

Appendix 6 Participant Information Sheet

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Health Sciences

Participant Information Sheet for Individual Interview.

‘Living with Psychosis: Exploring the experience and considering the implications for mental health education and practice’

Researcher: **Wendy Turton**

RMN RNMH BSc. MSc. BABCP Accredited.

‘I would like to invite you to take part in this research study. The research is about trying to understand more clearly what the experience of living with ongoing psychosis is like for people, and from this information it is hoped that a better understanding of psychosis and more helpful clinical interventions can be developed. You have been asked to consider participating because you are currently living with psychosis and so may have many useful insights to offer the study.’

This research is being completed as part of my Doctoral Studies at the University of Southampton. My main job is with <Trust name> NHS Foundation Trust where I am the Area Clinical Lead for [redacted]<service name>..

Before you decide about participating I would like you to understand why the research is being done and what it would involve for you. The person giving you this information sheet will go through it with you and answer any questions you have. This should take less than 10 minutes. Following this (usually within a week), if you ‘opt-in’, I will make telephone contact with you to discuss participation. This telephone call will also be an opportunity for me to answer any further questions you may have about the research.

Part 1 of this sheet tells you the purpose of this study and what you can expect if you agree to participate and Part 2 gives you more detailed information about the conduct of the study. Please do ask if there is anything that is not clear.”

Websites:

University of Southampton Faculty of Health Sciences:
http://www.southampton.ac.uk/healthsciences

<Trust name> NHS Foundation Trust: http://www. <Trust name>.nhs.uk

Part 1.

Q: What will I have to do?

A: The research involves meeting with me for a face-to-face interview and answering some questions in depth about your experience of living with psychosis. Questions will cover your current life experience and also some details about how things have developed for you since you first developed psychosis. The interview will be held at a Community Mental healthMental health Centre familiar to you and will last between 1 and 1.5 hours. I will ask you for your consent to participate and we'll both sign a consent sheet of which you, me, and your notes will have a copy. I will also ask for your permission to audiotape the interview; the interview cannot go ahead if you decline to be audio-recorded. This is less daunting than it sounds; the audio recorder is about the size of a mobile phone and has its own microphone, so it will just record in the background. The reason for recording the interviews is that every participant's words need to be transcribed so I can examine your experiences in depth – something I can't rely on my memory to achieve alone! It may be that I feel it useful for us to meet again and I will ask for your permission to do this, you may, of course, decline. The study will run for 12 months from September 2011 to September 2012. The following year there will be some information prepared from the interviews and you will be offered the opportunity to receive this information.

Q: What are the possible benefits of taking part?

A: There may be no immediate benefit to yourself from taking part in this research, but the information you kindly share should help to develop a deeper and more realistic understanding of the experience of living with psychosis in the UK today and as such improve treatment and support.

Q: What are the possible disadvantages and risks of taking part?

A: Most people find it positive to talk about their experiences, but sometimes talking about issues that are, or were, frightening or strange can cause you to feel vulnerable, as if it is being 'stirred up' again The interview is designed not to cause deliberate distress and you will be able to stop the interview at any time you feel uneasy. Occasionally, and understandably, people do find that when they talk about distressing events, they become distressed; some safeguards are in place to look after you if this happens. Your care co-ordinator has agreed to take responsibility for supporting you after the interview and this is who you should contact if you do experience distress due to the interview. Your care co-ordinator will also ring you within 72 hours of our interview and check that you are doing okay. Remember that the Duty Service will also be available for you should you need additional post-interview support.

Part 2.

Q: What if there is a problem or I have a complaint?

A: If you have a concern or a complaint about this study you should contact Susan Rogers, Head of Research & Enterprise Services, at the Faculty of Health Sciences. If you remain unhappy and wish to complain formally Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.(Address: University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7942; Email: S.J.S.Rogers@soton.ac.uk). You can also contact PALS, the Patient Advisory Service, on 023 8087 4065.

Q: Will my taking part in the study be kept confidential?

A: Details that you share with me in the interview will remain confidential. Audio-recording and Transcripts will be stored within the requirements of the Data Protection Act and under NHS and University of Southampton Policies. That means that all information will be 'anonymised' by the use of numbers known only to me and information will be stored within secure premises. Transcribers used in the study have a confidentiality clause in their contracts with the University of Southampton. I will also agree a pseudonym with you at our interview so that if you words are useful in illustrating the deepened picture of living with psychosis it will not be traceable back to you.

I have a duty of confidentiality and I also have a duty of care which means that if you do disclose information to me that either indicates potential harm to yourself or another, or suggests some form of criminality, then I am bound to share this information with, in the first instant your care co-ordinator. I'm sure this is understandable. If you lose the capacity to consent during the study you will obviously be withdrawn from the study . Information given to the study up until the loss of capacity will be used but you will not be further obliged to participate.

Q: Who else can I speak to about the research?

A: If you would like to discuss the research further you can contact Dr Steve Tee at the Faculty of Health Sciences or Professor David Kingdon at the School of Medicine, both at the University of Southampton via 023 8059 5000. Dr Tee and Professor Kingdon are Supervisors of this research.

Q: Involvement of the General Practitioner/Family doctor (GP)

A: When you agree to meet with me, I will send a letter confirming participation and information about the study to your GP, your care co-ordinator, and your psychiatrist. I will not divulge the contents of our interview with them.

Q: What will happen to the results of the research study?

A: Findings from this research trial will be presented as part of my Doctoral Award. Often findings appear in scientific journals and this would be an aim of this study and sometimes presented at conferences too. All information included in any of these formats will remain anonymised and so you will not be identifiable as a participant.

Q: Who has reviewed the study?

A: All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by a local Research Ethics Committee.

Thank you for taking the time to consider participating in my research.

Appendix 7 Participant Opt-in Document

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UNIVERSITY OF
Southampton
Health Sciences

‘OPT-IN’ FORM FOR INDIVIDUAL INTERVIEW

Study title: **‘Living with Psychosis: Exploring the experience and considering the implications for mental health education and practice’**

Researcher name: **Wendy Turton**

Thank you for considering taking part in this research study. I hope the person who has talked with you about the study has been able to answer your questions and that you found the Information Sheet useful. You have been invited to take part in the research because you are living with psychosis or symptoms indicative of psychosis. All research has to run with the highest of ethical standards to protect participants and as part of these safeguards I would like to ask you to complete this ’opt-in’ form so that I can make contact with you.

Thank you

Please **initial** the box(es) if you agree with the statement(s):

I have been given the Participant Information Sheet (IPIS Aug 2011/version 4). ☐

I am ‘opting in’ and will expect contact from the researcher ☐

Please note the following two points:

(i) Your GP will be informed that you are participating in the study although no details of the information you share will be divulged to your GP unless deemed clinically or criminally relevant..

(ii) If you are involved in any criminal proceeding you will need to discuss participation with your lawyer to check that participation will not prejudice your case.

My contact telephone number is…………………………………………………….

Name of Service User (print name)…………………………………………….

Signature of Service User…………………………………………………….

Name of Gatekeeper (print name) …………………………………………….

Contact number ………………………………………………………………….

Signature of Gatekeeper …………………………………………………………..

Date…………………………………………………………………………….

Appendix 8 Consent for Interview Document

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CONFIDENTIALITY PURPOSES

UNIVERSITY OF
Southampton
School of Health Sciences

CONSENT FORM

Study title: ***'Living with Psychosis: Exploring the experience and considering the implications for mental health education and practice'***, also known as ***'Living with Psychosis: Exploring the experience'.***

Researcher name: **Wendy Turton**

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (Aug 11/v4) and have had the opportunity to ask questions about the study ☐

I consent to this interview being recorded and understand it will be transcribed for the purposes of analysis. ☐

I agree to take part in this research project and agree for my data* to be used for the purpose of this study and the further use of this research. I understand that this may include the use of anonymised quotes from the interview. ☐

I understand my participation is voluntary and I may withdraw at any time without any impact on my usual care. ☐

I consent to the researcher making contact with me and inviting me to a further interview although I understand I am under no obligation to do so. ☐

Name of participant (print name)…………………………………………………

Signature of participant……………………………………………………………..

Name of Researcher (print name) …………………………………………………

Signature of Researcher……………………………………………………………..

Date…………………………………………………………………………………

cc Participant

Research File

NHS Casenotes

* data refers to the information shared in the interview.

Appendix 9 Interview Schedule

Interview Schedule

Do my questions provide an opportunity to capture the lived experience of 'living with psychosis'?

GTQ alternative questions:

- *What is your experience of living with psychosis?*
- *There have probably been times when your experience of psychosis has been overwhelming, would you describe yourself as being in a more stable period at the moment? What is that like for you? How would you describe this 'post-psychosis' life? Would you describe it as 'post-psychosis'?*
- *Can you help me to understand how life is for you now?*
- *How has having psychosis made your life different to that of those who haven't experienced it?*
- *Can you describe for me what it is like living with psychosis?*
- *Please can you tell me about living with psychosis?*
- *As someone who has experienced overwhelming psychosis in the past, what difficulties has it left you with?*
- *How does psychosis impact on your daily life?*

  Prompts are allowed following this question to orientate the participant to issues described in literature about the experience of living with psychosis or to the essence of the phenomenon.

Secondary: Biographical Phenomenology.

- *When did you first begin to experience psychosis?*
- *When did things start to feel difficult for you?*
- *Were there things about you that made you more vulnerable than other people you know to developing psychosis?*
- *In retrospect, do you think there was anything others could have done for you at that early time?*

Tertiary: Phenomenology.

(What facilitates recovery/ What hinders it/ What can I learn for MH Practice?)

- *How do you keep well?*
- *What helps you manage your life post-psychosis?*
- *What helps and what hinders living with psychosis?*
- *Can you give me a recent example of……..how it impacts on your life, something that has helped, something that has hindered?'*

- *How have mental health professionals helped or hindered your experience of living with psychosis? Can you give me a recent example………*

- *Do you need different things for different phases of your psychosis?*

- *What do you want from professionals?*

Quaternary: Identity.

- *How do you feel about having psychosis?*

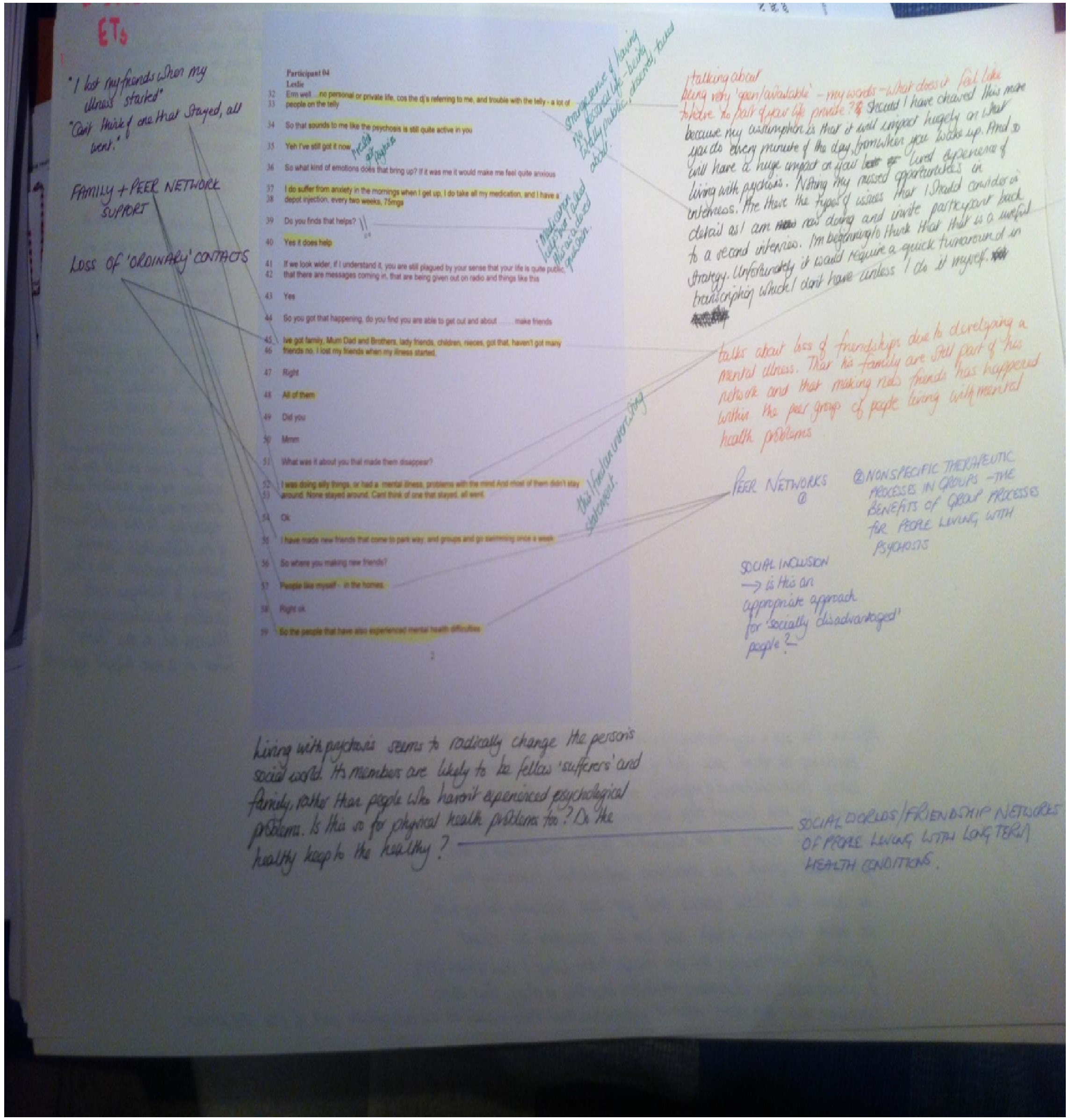
- *How has psychosis changed the way you view yourself?*

- *What sense do you have of yourself in this world, as someone who lives with psychosis (using an analogy of people living with long term health conditions to normalise and attempt to reduce a 'suggested' sense of stigma/prejudicial attitude)?*

Closing Question:

- *Is there anything else you would like to tell me about your experience of living with psychosis?*

Appendix 10 Snapshot of the IPA Data Analysis Process



"I lost my friends when my illness started"
"Can't think of one that stayed, all went."

FAMILY + PEER NETWORK SUPPORT

LOSS OF 'ORDINARY' CONTACTS

Participant 04
Leslie

Erm well….no personal or private life, cos the dj's referring to me, and trouble with the telly - a lot of people on the telly

So that sounds to me like the psychosis is still quite active in you

Yeh I've still got it now

So what kind of emotions does that bring up? If it was me it would make me feel quite anxious

I do suffer from anxiety in the mornings when I get up, I do take all my medication, and I have a depot injection, every two weeks, 75mgs

Do you finds that helps?

Yes it does help

If we look wider, if I understand it, you are still plagued by your sense that your life is quite public, that there are messages coming in, that are being given out on radio and things like this

Yes

So you got that happening, do you find you are able to get out and about …… make friends

Ive got family, Mum Dad and Brothers, lady friends, children, nieces, got that, haven't got many friends no. I lost my friends when my illness started

Right

All of them

Did you

Mmm

What was it about you that made them disappear?

I was doing silly things, or had a mental illness, problems with the mind And most of them didn't stay around. None stayed around. Cant think of one that stayed, all went

Ok

I have made new friends that come to park way, and groups and go swimming once a week

So where you making new friends?

People like myself - in the homes

Right ok

So the people that have also experienced mental health difficulties

2

[illegible]

strange sense of having no personal life - being totally public, discussed, talked about.

medication helps but I asked this as a closed question.

this I feel an understanding statement.

talking about being very 'open/available' - my words - what does it feel like to have no part of your life private? Should I have chased this more because my assumption is that it will impact hugely on what you do every minute of the day, from when you wake up. And so will have a huge impact on your lived experience of living with psychosis. Noting my missed opportunities in interviews. Are these the types of issues that I should consider in detail as I am now doing and invite participant back to a second interview. I'm beginning to think that that is a useful strategy. Unfortunately it would require a quick turnaround in transcription which I don't have unless I do it myself.

talks about loss of friendships due to developing a mental illness. That his family are still part of his network and that making new friends has happened within the peer group of people living with mental health problems

PEER NETWORKS ①

② NONSPECIFIC THERAPEUTIC PROCESSES IN GROUPS - THE BENEFITS OF GROUP PROCESSES FOR PEOPLE LIVING WITH PSYCHOSIS

SOCIAL INCLUSION
→ is this an appropriate approach for 'socially disadvantaged' people?

Living with psychosis seems to radically change the person's social world. Its members are likely to be fellow 'sufferers' and family, rather than people who haven't experienced psychological problems. Is this so for physical health problems too? Do the healthy keep to the healthy?

SOCIAL WORLDS/FRIENDSHIP NETWORKS OF PEOPLE LIVING WITH LONG TERM HEALTH CONDITIONS.

Appendix 11 Participant Synopses

All identifying and identifiable details have been amended to prevent identification and respect confidentiality.

Alex ***'I don't do a lot, mmm, I dunno, just pass the time.'***

(Alex Line 204)

Alex described a very isolated life where she does not go out of she can avoid it and does not have any friends to invite in either. Alex believes she lives with psychosis but not schizophrenia, although she has been given a diagnosis of paranoid schizophrenia; she takes long-term anti-psychotic medication but continues to experience distressing anomalous perceptions (a voice), anxiety, paranoia, and depression. Alex found temporal recall difficult so was unclear about when she had begun to experience psychosis (possibly when she was about 16 years of age). It was clear that her early life was troubled by being in 'Care' and through peer- bullying but she distinguished these troubles from her later experience of psychosis. She lives a solitary life even though she lives with a partner; her partner seems to have his own separate life and Alex did not appear to know what it was he did or who it was he saw. She told me that they didn't talk much but she gained a sense of companionship from the relationship. So Alex spends her days alone, rising late, spending her time watching the television and smoking, sometimes painting watercolours and listening to music. Going out is extremely anxiety provoking for her so she avoids this – her mental health team come to her home and her shopping is done for her. Sitting at home does not extinguish her experience of hearing voices, nor diminish her sense of paranoia. The voice she hears is female, critical and nasty, derogatory and demanding. It is not always active but once it begins it can go on the whole day. Alex struggled to describe details of her lived experience or even to engage in a more discursive manner yet evidently wanted to remain engaged in the process despite it causing her voice hearing to intensify and some paranoia to surface. I felt that I was able to support her in this by using a more question and answer yet gentle and accepting style of interview and still come to know and share that lived experience. Alex appeared genuinely pleased to have completed the interview with me despite the difficulties that arose.

Bridget ***'I feel as if I'm fighting with myself so that the voices don't take over me.'***

(Bridget Lines 155-159)

Bridget is in her fifties and lives alone in a flat; she is not able to undertake paid employment. Bridget had previously held a high rank in military service and served in many foreign deployments, including a conflict posting during which she encountered the terrifying horrors of such conflict; the development of psychosis, with which she still lives, was precipitated by a specific experience during this posting. Bridget has an aging Mother living locally with whom she spends time each day; she also has one sibling. With neither does she share her lived experience of living with psychosis. Bridget hears one voice which, although she 'some of the time' knows it comes from her, she believes she has to comply with in some way and this compliance is often in the form of self-harm to avoid harm to other people. Bridget describes herself as having a strong sense of right and wrong in addition to a good sense of humour; these traits she believes keep her as well as she can now be. Bridget does have friends but seems not to feel equal to them because they make allowances for her experiences and take a 'caring role'. She feels as if her previous self is unrecoverable and tries not to think about her future. Bridget claims not to be suicidal, she does not actively seek to end her life but should her death be imminent she believes that she would welcome it. Her description of her life appears to be an acceptance of a reality that is at the same time untenable and unchangeable. In contrast, I experienced Bridget as a strong, warm, funny, and intelligently insightful person. My experience of her was so incongruent with the pain she shared with me that I felt that the need to share my experience of her with Bridget during our discussions. The interview was deeply moving. It aroused in me profound sadness, helplessness, and admiration; admiration for surviving the sheer tortuous weight of the persisting experience of psychosis. It aroused in me also frustration because I wanted 'us', mental health professions, to 'do better'.

Chris '*When the good side is having a bad day, the bad side gets on top.*'

(Chris Lines 2049 – 2051)

Chris describes himself as a Schizophrenic with a secondary illness of addiction; he works closely with local and national third sector addiction services. Chris is in his early fifties and has been experiencing psychosis since the age of 18. Currently Chris lives in a Housing Association flat in which, when his brother isn't lodging there, he lives in alone. He perceives himself to be in recovery, and to have been in recovery, from both his schizophrenia and his addiction for a long time. Chris has found the addiction recovery programme has helped him enormously with his schizophrenia too, and volunteers frequently for opportunities to share this with other people living with psychosis. Talking with Chris about his lived experience was a powerful experience for me as he shared much distressing personal trauma and on-going challenges from the psychosis, yet was so evidently invested in staying ahead of his psychosis and maintaining his recovery; the amount of effort and commitment this took was humbling, as too was his continuing provision of support for others in mental distress.

Gillian '*Outwardly, my main effort is to try and appear as if I don't have an illness, because that's how I'd like to be.*'

(Gillian Lines 890 – 892)

Gillian is in her early twenties, living with her boyfriend and currently studying at a Further Education College having left University before attaining her degree because of the impact of the psychosis. She first experienced what she now describes as psychosis at about 17 years of age. For Gillian, this experience includes visual and auditory perceptual anomalies, she continues to see things which frighten her, hears 'intense' voices which are derogatory and also drive her experience of paranoia, and she has frequent periods of intrusive thoughts which she feels are highly inappropriate or contradictory to what she actually thinks, and so are confusing and disorganising. Gillian's Mum lives locally; although they do not have a supportive relationship, she and Gillian's Grandma are significant people in Gillian's life. Gillian was somewhat different from the other participants in that she was in her twenties and had only been living with psychosis for seven years. She was more socially engaged with a peer group who did not live with psychosis and her psychosis was less immediately visible than some participants through her interpersonal behaviour. However she had been living with her experience for seven years which aligned with two of the other older women participants. Gillian was also one of only two participants who had undertaken some formal CBT-psychosis psychotherapy. In spite of these differences Gillian's lived experience showed convergence with the participant group. Gillian was an articulate participant who shared her experience openly and gave a sense of striving to maintain her sense of herself beyond the psychosis whilst living with its terrors and challenges. We both enjoyed the interview.

Closing dialogue:

G: Yeah, I should be alright <after the interview> and I think I'm tough enough; I'll be okay.
R: I've really enjoyed talking with you.
G: Thank you.
R: I'm really pleased you were able to come in today.
G: Well, thanks for this opportunity ((laughing)).

Leslie ***'I don't like it, it's not very nice, it's not very pleasant.'***

(Leslie Lines 4 – 5)

Leslie is just into his forties, he lives alone in a flat, and has been living with psychosis for about 20 years although has managed to avoid going into a mental health hospital for many years. Leslie does not do any paid work at present and he feels he is unlikely ever to be able to do so. He described losing most of his friends when he developed psychosis, his 'troubled mind' but has over recent years found a new peer group with whom he now spends time and shares leisure activities. Leslie describes his psychosis as the ideas of reference that he gets from many things – the television, the radio, traffic as it passes by, and for Leslie, these ideas persist, indeed Leslie shared with me that his lived experience of living with psychosis is an on-going challenge of not being able to really 'know', even now, if such experiences were real or not; I was aware that occasionally during our discussions Leslie would talk about these more extraordinary ideas as if they were alive to him in that moment and defining his immediate reality. Like Alex and some of the others, Leslie's sense of entrapment in living his psychosis was palpable during our discussion yet he was able to step outside of this experience to share with me his thoughts ***on*** his experience. Like other participants I was grateful to Leslie for choosing to remain in the interview in spite of the intensifying of his experience through recounting it.

Mandy ***'Strange feelings and strange thoughts.'***

(Mandy Lines 406)

Mandy explained that she had heard voices from around the age of five when she had mumps and went deaf. She described hearing voices for her whole life and her 'whole life' being ruined because of it although Mandy did not become significantly unwell until her mid-thirties and she was given a diagnosis of schizophrenia at this point. Mandy is now in her late forties, lives with her partner who also has mental health problems, and finds her life is extremely restricted because of her lived experience. Mandy has three adult children, a couple of friends and does go out; most of her days are plagued by the voices, whether one voice or multiple, these voices are both strangers to her, *'people I has never met'* and are people she knows *'stored in my head'*. Mandy was the only participant to describe experiencing her psychosis as a physical sensation, embodied in and around her head. Psychosis for her was now *'everyday life for me; I can't shift it'* echoing the entrapment shared by other participants. Mandy showed similar temporal recall and contradictions in her account as the other participants, describing to me a difficulty in articulating such extraordinary experiences that other participants had also shared. Being involved in such interviews I was very aware of the effort and tenacity participants like Mandy had generously shown in attempting to share clearly with me their unusual and often odd experiences in spite of evident challenges on doing so. I was equally aware of having successfully created an interpersonal environment in which participants, including Mandy, felt able and willing to struggle with articulating their lived experience to me.

Marina ***'Sometimes it's like a bit of a living hell really.'***

(Line 518)

Marina is in her 40s, married for over 25 years and has one daughter who now lives and works away from home. Marina described a challenging childhood during which she was aware that her reactions to situations were always 'over-the-top' resulting in somewhat strange paybacks to people who she had had a run in with. Marina did not feel loved or accepted by her parents, believing that her Mum preferred her friend to her, leading to jealously and upset. Marina left home at an early age and married young. She described experiencing depression from her late teens but felt disregarded by her GP. It was not until after the birth of her daughter that her husband demanded services take Marina's mental state seriously. The depression lasted on and off for many years until her experience worsened several years ago and Marina began hearing voices which distressed her. Her voices are derogatory and anxiety-provoking; they criticise her, cause her to doubt other people's motives, and encourage her to behave in ways she does not want to. Since this occurrence Marina described becoming much more anxious and often overwhelmed by her experiences, she has, however, during this time raised her child, maintained her marriage and household, and stayed in contact with some of her friends. She has recently survived a serious physical illness whilst living with her experience of distressing psychosis. Such a strong woman, who fights through each day to maintain a resemblance of normality and hold tight to herself beyond her psychosis.

Phil ***'You can be fine; <but> one day it's alright and the next day is horrible.'***

(Phil Line 115 – 118)

Phil is a man in his thirties, settled in his parental home, living in the community in which he grew up. His Dad is in good health but his Mum has recently been experiencing some significant health problems and this is a cause of stress for them all. Phil has been living with paranoid schizophrenia and depression for about 17 years, although shared that he had experienced 'anger' problems all of his life which was particularly disruptive to his early and teenage years. He is not currently in paid employment and described himself as *'…just sitting around doing nothing at the moment'*. Phil was a remarkably political young man with many strong and informed opinions about Society's treatment of people living with a mental illness and these he generously shared with me during our interview; in a sense they shape his lived experience. I perceived Phil as an untapped asset for mental health advocacy, able to articulate clearly the unfairness of support systems and public misunderstandings prevalent against people living with longer term mental health difficulties in our society; unbowed and fighting!

Terry ***'I've turned into a new person'***

(Terry Line 27)

Terry is in his late thirties, currently living alone and not in paid employment. Terry met with me when he was welcoming in a 'marvellous' new phase in his life so his current lived experience showed divergence from other participants. His discourse oscillated between the horror of the past (very clear memories of being lost in his psychosis) and the relief and optimism of the present experienced as beyond psychosis. He was feeling extremely happy and positive about his recovery from the psychosis that had plagued him for so many years. He felt well supported and loved by his family and friends, and confident about his ability to stay well. His one point of sadness was that after living a life tormented by his psychosis and driving some truly dreadful consequences on his closest relationships, his Mum had become seriously unwell and was unable to share in his ‘new life’. Terry expressed a burning desire to give back in some way to others who were living the torment he had just escaped from. Following our interview Terry sent me a message to tell me that he had ‘*really enjoyed meeting and telling his story*’, and saying ‘*how it felt good to give something back*’. He found our meeting ‘*valuable and rewarding*’. I felt rather privileged to have been the catalyst for such a positive and valuing experience for Leslie.

Viv - *‘I just wish it would all go away’.*

(Viv Line 982)

Vivyan, or Viv, as she prefers to be called, is in her early forties and described experiencing psychosis since she was about 30. She described having four episodes of depression, including puerperal depression, before developing psychosis and subsequently being given a diagnosis of Schizophrenia. Viv lives with two of her children, one of whom is finishing school and another who is now out at work; she supports herself and her youngest child on Disability Living Allowance and other welfare benefits. Viv has two other children who live locally and visit frequently, her teenage son living with her Mum. She has recently become a Grandmother, a role she has embraced. Viv has no partner at the moment, nor any plans to find one, neither though, does she have any friends of her own at this time. Viv never goes out on her own these days as the prospect makes her anxious, paranoid, and sets off dreadful derogatory voices. Her voices plague during her days in the house right from awakening and she manages them as best she can. Viv struggles to put on a front for her family so as not to burden them with her problems, but in the solitude of the day Viv becomes low and tearful. Like many others, Viv has experienced abuse in her past but blames herself for becoming a victim of this and making poor life choices; the voices echo this negative sense of herself. Viv is also aware of all she has lost in her life through her continuing experience of psychosis and wants the psychosis to ‘just go away’, she does not feel in control of it, or of her mind, and struggles to identify what is real and what is not during her day. Viv shared with me that this was the first time that she had been able to talk with someone in depth about her lived experience of psychosis, commenting that she would like:

> *‘Someone to talk to …. like what me an’ you been talking about, I don’t know, just to share it with someone so that it’s not a burden, you know all on me, if that makes sense.’*
>
> (Viv Lines 2097-2102)

This made me feel that I wanted to give her more time and I felt constrained and conflicted in my role as the Researcher.

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