MAKING THE THREAT REAL: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS EXPLORING THE EMOTIONAL WELL-BEING OF PEOPLE WITH PSYCHOSIS DURING THE COVID-19 PANDEMIC

by

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Thesis overview

This thesis has been submitted by Jasmin Gill in completion for the degree of Doctor of Clinical Psychology (ClinPsyD) at the University of Birmingham. The thesis contains three chapters comprising the research component of the degree.

Chapter one of this thesis is a meta-ethnography exploring the impact of psychosis on development in young people. Meta-ethnography is an approach used to review and synthesise qualitative findings by translating them into each other. The review indicated two superordinate themes showing (1) how development is interrupted and (2) how it may be re-started. The review illustrates a journey characterised by young people concealing their experiences of psychosis, before learning to incorporate these experiences into their lives and sense of self.

Chapter two of this thesis is an Interpretative Phenomenological Analysis (IPA) exploring the experience of emotional well-being of people with psychosis during the COVID-19 pandemic. IPA is a qualitative method of analysis seeking to understand people's experiences of the world. Eight people with psychosis were recruited from a local NHS Trust and interviewed online. Four themes suggested the experience of the pandemic was polarising, being a time of amplified loneliness, vulnerability, segregation, and threat but also an opportunity to enrich the recovery from psychosis. Despite this opportunity, moments of loneliness and segregation had often impaired existing recovery made by participants and amplified symptoms of psychosis.

Finally, the third chapter of this thesis comprises two press release papers seeking to disseminate and communicate the findings of the previous chapters.

Dedication

I'd like to dedicate my thesis to my family. To my Mum and Dad who have taught me to never give up and have faith. My Mum – my pillar of support and my best friend, I would have no idea what to do without you. My Dad – for 'strength and honour,' always and forever your 'little cookie.' To my brothers: Jessy and Ricky – the 'guardians of the galaxy'. Finally, my surviving grandparent, Bibi-ji, and my late grandparents: Grandad, Baba-ji and Mar-ji – for the legacy.

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Chapter 1 – Psychosis during development: A meta-ethnography of the impact psychosis has on young people

Abstract

Objectives: This meta-ethnography synthesises qualitative literature that explores the impact of psychosis on development, in young people. Most research has focused on a single domain of development resulting in a fragmented view of the impact of psychosis. This synthesis sought build an overview of research findings in this area. *Method:* A total of 15 papers were identified to explore "what is the impact of psychosis on development, in children, adolescents and young adults." A meta-ethnographic approach was used to translate these studies into each other. *Findings:* Two main themes identified the journey young people may take following psychosis. This included where: (1) *development is interrupted following psychosis,* but young people may learn ways of (2) *moving forward and becoming unstuck.* Development seemed interrupted through three ways. Firstly, by young people concealing their experiences, then withdrawing from others and finally the secondary losses associated to psychosis. Moving forward involved young people learning self-acceptance and having accepting experiences from others. *Conclusion:* Young people may initially cope with psychosis by attempting to return to normal and ignore their experiences of psychosis. This could be supportive immediately but leads to challenges later. These challenges seem navigated by developing self-acceptance. This synthesis informs the coping mechanisms used by young people following psychosis have differing effects on development. Being aware of these coping mechanisms may help support the recovery from psychosis in young people, to reduce developmental challenges.

1.1: Introduction

From the moment a human is born, they engage in a journey of progressive changes biologically, cognitively, socially, and psychologically (Lidz, 1983). These changes mainly occur simultaneously in the early years of human life (Vander Zanden, 1993). Development has been socially constructed as a process which prepares humans for adult life (Coles, 2005) but development also continues throughout the lifespan (Lidz, 1983).

'Development' in Western cultures, has a strong emphasis on the completion of developmental tasks, which drives people towards becoming independent adults (Coles, 2005). These tasks might involve selected milestones such as learning how to drive, finishing school, starting college, gaining a first job, or moving away from home and caregivers (Coles, 1995). Psychologically, the developing child acquires cognitive and emotional skills which enable them to complete these tasks (Lidz, 1983). Therefore, meeting developmental milestones is considered healthy and contributes towards biological and social survival (Vander Zanden, 1993).

Rogoff (2003) argued human development is characteristically difference across cultural practices. This means people develop as participants of communities, which are defined by the practices a specific culture that are considered normative (Rogoff, 2003). Coles (2005) argued development is most important from birth to the age of 35, within Western cultures. At the age of 35, Western society often expect the individual to be an independent adult (Coles, 2005). This could refer to living independently and involve financially looking after their own welfare (Coles, 2005).

Research has documented several factors which might facilitate or impair development (Britto et al., 2017), particularly during early childhood (Black et al., 2017). Findings have demonstrated healthy, progressive development occurs under the circumstances of a trusting supportive relationship (Daelmans et al., 2017; Johnson et al.,

1987). Bowlby's (1969) Attachment Theory indicated these trusting relationships formed in the early years of development become an internal working template for later relationships in adulthood.

Research has shown fewer trusting relationships in childhood are related to the onset and maintenance of mental health difficulties (Van der Vegt et al., 2009). Trauma in childhood is often interpersonal and interferes with development (Triesman, 2017). Research has understood traumatic experiences, particularly one characterised with interpersonal abuse or neglect, can lead to experiences which promote developing becoming limited to the growing child (Triesman, 2017).

There is a strong relationship between childhood traumatic experiences and the onset of psychosis (Schäfer & Fisher, 2022). Psychosis is a term applied to a set of mental health diagnoses characterised by a distortion and fragmentation of reality (Bentall, 2003). People with psychosis may experience delusions, hallucinations, flattened affect, thought confusion, paranoid thinking, and ideas of reference (Bentall, 2003). Usually, the onset of these symptoms occurs during adolescence (Medoro, 2005; Morrison et al., 2003). This early onset has been referred to as a First Episode of Psychosis (FEP) (Medoro, 2005).

Firmin and colleagues (2021) found adults (aged 26-59 years), who reflected on their experiences of developing psychosis during adolescence, had reported psychosis disrupted their lives. Psychosis during adolescence affected their sense of emerging identity and led to an internalised stigma (Firmin et al., 2021). Adults in the study noticed a struggle with their interpersonal relationships, resulting in losses to their social network (Firmin et al., 2021). Psychosis had interrupted development of social skills in this way (Firmin et al., 2021).

Cloutier et al. (2021) also identified early onset of psychosis had implications for adult life, as experiences of romantic attachment were significantly reduced. Adults with psychosis had experienced more difficulties within their romantic relationships than people

without psychosis (Cloutier et al., 2021). Participants blamed the breakdown in these relationships on the symptoms of psychosis impeding their close relationships (Cloutier et al., 2021). Higher substance misuse is also associated to these interpersonal difficulties and linked with psychosis (Pencer et al., 2008).

Vargas-Cáceres and colleagues (2021) supported a reduced social world following an earlier onset of psychosis delayed the biological onset of puberty. Wyatt and colleagues (2015) suggested it was not only romantic relationships which seemed impaired and found women with post-partum psychosis experienced strained relationships with their peers and colleagues. Steenkamp and colleagues (2021) also demonstrated young people with psychosis had lower performance at school compared to their peers. Despite this, Wyatt et al. (2021) identified young people had noticed developing stronger, more meaningful attachments after their psychosis.

These research findings have been useful for understanding what aspects of development could be impaired by psychosis. However, much research has focused on a single specific domain of development, such as relationships (Wyatt et al., 2015) physical development (Vargas-Cáceres et al., 2021) or education (Steenkamp et al., 2021). This has often resulted in a fragmented perspective that misses the inter-section of how these aspects can influence each other. For instance, recent advances in Polyvagal theory have discussed the impact of socialisation for the internal nervous system where experiences deficient in safety can lead to a nervous system chronically stuck in hyperarousal states (Siegel, 2012). This illustrates the benefits of understanding development holistically across the range of social, emotional, and physical domains.

Griffiths and colleagues (2019) conducted a meta-synthesis to explore thew sources of distress for people with a FEP. They showed psychosis had impacted on people through social, physical, and psychological ways (Griffiths et al., 2019). The findings were split

between intra-personal and inter-personal forms of distress (Griffiths et al., 2019). However, whilst this pointed to distressing internal and external experiences of psychosis, it was not explicitly identified how this distress may, in turn, affect development. This chapter explores the impact of psychosis across these areas of development in young people using a meta-synthesis approach.

Aims

Meta-synthesis is a developing research method that aims to review and integrate findings from different qualitative studies (Sattar et al., 2021). It is argued this approach would help understand what is known about the impact of psychosis on development by synthesising the different studies around the components of development to provide a more complete perspective. Currently, there is no known meta-synthesis which integrates the broad components of development to understand the impact of psychosis. Therefore, this meta-synthesis aims to generate an understanding of how psychosis impacts on development in children, adolescents, and young adults.

1.2: Method

Meta-ethnography

For this meta-synthesis, a meta-ethnographic approach was selected. Meta-ethnography is a method of synthesising large amounts of qualitative data with the purpose of gaining a better conceptual understanding of specific topics (France et al., 2019; Sattar et al., 2021). The process of meta-ethnography involves synthesising qualitative research in an active and engaged process where the reviewer is involved in a 're-interpretation' of the data and the perspective of the researchers across findings (Sattar et al., 2021). This re-interpretation of papers can be helpful for updating the literature and differs from other approaches of synthesis such as narrative and thematic syntheses. This is because the meta-ethnographic process is analytical and can be helpful for understanding broader theories and

models (Sattar et al., 2021). For the current research question, a re-interpretation of the papers felt needed to capture the conceptual understanding of how psychosis impacts on development, of the processes which may underpin this experience and how we think of psychosis impacting on development in younger people. A meta-ethnography provides a way of relating papers to one another to build this conceptual understanding.

Noblitt and Hare (1988) outlined a meta-ethnographic approach with seven steps that helps to guide translation and comparison across multiple qualitative studies. These steps are outlined in Table 1.

Table 1: *Noblitt & Hare's (1988) seven steps of meta-ethnography*

Phase 1 – Getting started	Identifying an area of interest and noticing why a synthesis may be needed of the literature. Thinking about whether a meta-ethnographic approach is suitable for this work.
Phase 2 – Deciding what is relevant	Defining the focus of the synthesis and setting inclusion criteria. Locating the relevant studies and being able to appraise the quality of these studies using relevant frameworks.
Phase 3 – Reading the studies	Becoming familiar with the literature and papers identified. Extrapolate study information that includes the details of each paper in the synthesis such as their sample, collection methods, outcomes, and conclusions. This phase may continue throughout the process. Being able to move between data in individual papers and the growing awareness of what these studies mean. Extracting raw data into first and second order layers of the synthesis.
Phase 4 – Determining how the studies are related	The relationships between key concepts are explored across different papers. This involves an iterative process of looking into the papers to see how they might relate to answering the overall question. Key patterns across the studies are noted. Context is taken into consideration whilst reviewing these patterns. This could be reviewed again at a later point.
Phase 5 – Translating the studies into one another	Each concept from every paper is compared to one another to look for similarities and differences. These are then organised into categories to create 'third order' constructs that incorporates the original raw data, the researchers' interpretations and the interpretations made during synthesis.
Phase 6 – Synthesising the translations	Studies and concepts are viewed as a whole and can be developed into a framework that makes sense. This could be presented as a narrative and/ or diagrammatical. Translations may be reciprocal, refutational or form a line of argument. Translated concepts should be cross-examined with the original raw data to maintain validity.
Phase 7 – Expressing the synthesis	Communicating the synthesis in an appropriate way to an appropriate audience. A summary of the main findings is found with the reflexivity and recommendations from the synthesis.

Following Noblitt and Hare's (1988) guide, this meta-ethnography started by locating an area of academic interest. As a trainee in Clinical Psychology with interests in acute mental health presentations such as psychosis and developmental processes, the author of this work had a growing interest in the field of psychosis and its impact on life. The author had also worked clinically with children and young people and, based on the awareness of how much development occurs during earlier years, recognised a need to understand the impact of psychosis in this group. In discussions with her supervisor, the author decided to focus on exploring the research around the trajectory of early development through to young adults.

Systematic literature search

Once this area of interest had been established, steps for completing the literature search were started. This involved clarifying the research question: how does psychosis impact on social, emotional, and physical development in children, adolescents, and young people? Next, steps were taken to search and obtain qualitative research to complete the synthesis and provide an answer to this research question.

Search strategy

Booth and colleagues (2016) argued that syntheses are useful for identifying and understanding underlying mechanisms in the literature to bring together qualitative findings. However, the methods used to catalogue qualitative research in databases often means different terms are used across papers (Shaw et al., 2004). There is a need for syntheses to be transparent with their search criteria so this can inform what the research implies for specific areas in the literature (Booth et al., 2016). Shaw and colleagues (2004) recommended using strategies of searching qualitative research that combined different versions of terms from free-text parameters and thesaurus terms. A list of the full terms used in searches of literature databases is outlined in Table 2. Truncations of terms such as *"Schizophrenia"* and

"Schizophrenic" were denoted using an asterisk (*) symbol, for example, creating *"Schizophren*."*

As mentioned previously, the interest for this synthesis is during a stage of life when psychosis may be experienced for the first time. FEP was noticed in the initial screenings of papers as a phrase used to describe specifically younger people experiencing psychosis. Terms such as Transient Psychotic Episode and Psychotic Episode were also used to describe retrospective experiences of psychosis in early life. Screenings also suggested psychosis being described in the literature through specific symptoms such as hallucinations, delusions and amotivation. However, these terms were also used interchangeably with phrases such as 'hearing voices' and 'paranoid thinking.' The screening also showed interchangeable use of the phrase 'making sense of' to describe qualitative studies. Therefore, these phrases were used in searches again to ensure papers which used these terms were also captured.

Table 2: *Free-text terms used for searching literature databases*

Key words	Search terms developed
Psychosis	Psychosis OR Psychotic OR Active* Psychosis OR Schizophren* OR Hallucination* OR Delusion* OR Hearing voices OR Paranoid thinking OR Amotivation OR Apathy OR Negative symptoms OR Transient Psychotic episode OR First Episode Psychosis OR FEP OR Psychotic Episode
Impact	Impact OR Effect* OR Consequence* OR Outcome* OR Result* OR Produc* OR Influen* OR Create OR Leads to
Development	Development OR Developmental OR Maturity OR Transition* OR Life* OR Child-development OR Long-term impact
Children, adolescents, and young adults	Children, adolescents and young adults OR Kids OR School children OR Pre-schoolers OR youngsters OR Youth* OR Teens OR Teenagers OR Teen-agers OR Young people OR Young person OR Young man OR Young men OR Young woman OR young women OR Young boy* OR Young girl*
Qualitative analysis	Qualitative analysis OR Qualitatively OR Qualitative* study OR Individual accounts OR Accounts OR First-hand accounts OR attitudes OR Explorat* OR Interview* OR Narrative account* OR Making sense

Selecting qualitative limiters and using database filters helped search for these terms. The electronic databases: PsychINFO, PsychARTICLES, SCOPUS, Web of Science and Medline were selected to search for papers for the synthesis. These databases often have much healthcare research and were selected as appropriate for the topic area. Only peer reviewed articles were sourced for this synthesis, to ensure a level of rigour. Papers which were found using the search terms in the five databases were exported to the reference managing programme, EndNote, where they were submitted to further screening using inclusion and exclusion criteria.

Inclusion and exclusion criteria

Firstly, when papers were exported to EndNote, duplicates were removed. Titles and abstracts of the remaining papers were then screened using criteria based on the synthesis question. A full list of this inclusion and exclusion criteria is outlined in Table 3 below. As discussed previously, a large amount of development takes place earlier and effects could be investigated across the lifespan (Coles, 2005). As such, samples with participants 35 years

old and younger were included to capture these effects. Papers which were considered ‘Big Q’ were also included as they were likely to use rigorous procedures to help maintain reflexivity and validity. Kidder and Fine (1987) defined these Big Q studies as using robust qualitative analytic methods such as Interpretative Phenomenological Analysis (IPA), Grounded Analysis and Reflexive Thematic Analysis.

Table 3: *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria	Rationale
Peer reviewed and published research articles reporting original data	Theses, dissertations, and other papers not published in a peer reviewed journal article that do not report original data e.g., reviews, service evaluations, audits, opinion articles, books, book chapters, discussion papers, letters and magazines	As a large field of study, this helped to sample articles which were already published and had undergone a review for academic integrity
Articles are published or available in English language	Papers which are not reported or available to be made into English language	Synthesis was completed in English and therefore any translations which may have been made could have resulted in a loss of meaning as different words across languages hold different meanings.
Papers that report qualitative analyses (‘Big Q’ studies)	Mixed method studies and papers reporting quantitative analyses	The nature of a meta-ethnographic approach lends itself to 'Big Q’ studies. This requires studies to have used rigorous procedures of reflexivity and being immersed in the data.
Articles published in Western individualistic cultures (UK, USA, Canada, Australia, New Zealand)	Articles that report findings from more collectivist cultures	Developmental trajectories may differ depending on aspects within society and society can be influenced by culture. The definition that development rests on a growing independence is mostly a Western perspective (Rogoff, 2003).
Researching experiences of psychosis before (included prodromal/ at risk stages), during or after episode(s) of acute distress	Papers which focus on the comorbid presentations with psychosis or where psychosis is not the subject of interest.	The research question is concerned with how psychosis specifically affects development. Papers which do not explore specific factors relating the presentation of psychoses would not provide suitable answers to this question.
A focus on accounts from children, adolescents and/or young adults (up to the age of 35)	Later onset psychosis or people who experience psychosis in adulthood and later adult life.	There is a specific focus on the impact on development. As noticed by Coles (2005); a large amount of development takes place earlier on and effects from these stages could be investigated across the lifespan.
Papers that have a focus on the long-term impact of psychosis	Interventional studies e.g. studying exploring qualitative outcomes during and after CBTp	Papers that have a focus on the effects of psychosis are required to answer the research question for this synthesis. Interventional studies do not have this focus and would not be appropriate.

Inclusion criteria	Exclusion criteria	Rationale
Papers that may have included accounts from others but the individual with psychosis is included	Papers that don't report accounts directly from people who had experienced psychosis (staff, family, carers)	A compromise was made to increase the availability of studies as researchers may not always have direct access to people with psychosis that are acutely unwell. However, the research question is interested in the individual impact and therefore papers which involve others as well as the person with psychosis in the collection of data were included.

Systematic screening process

Figure 1 illustrates the systematic selection process using the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) model (Moher et al., 2009).

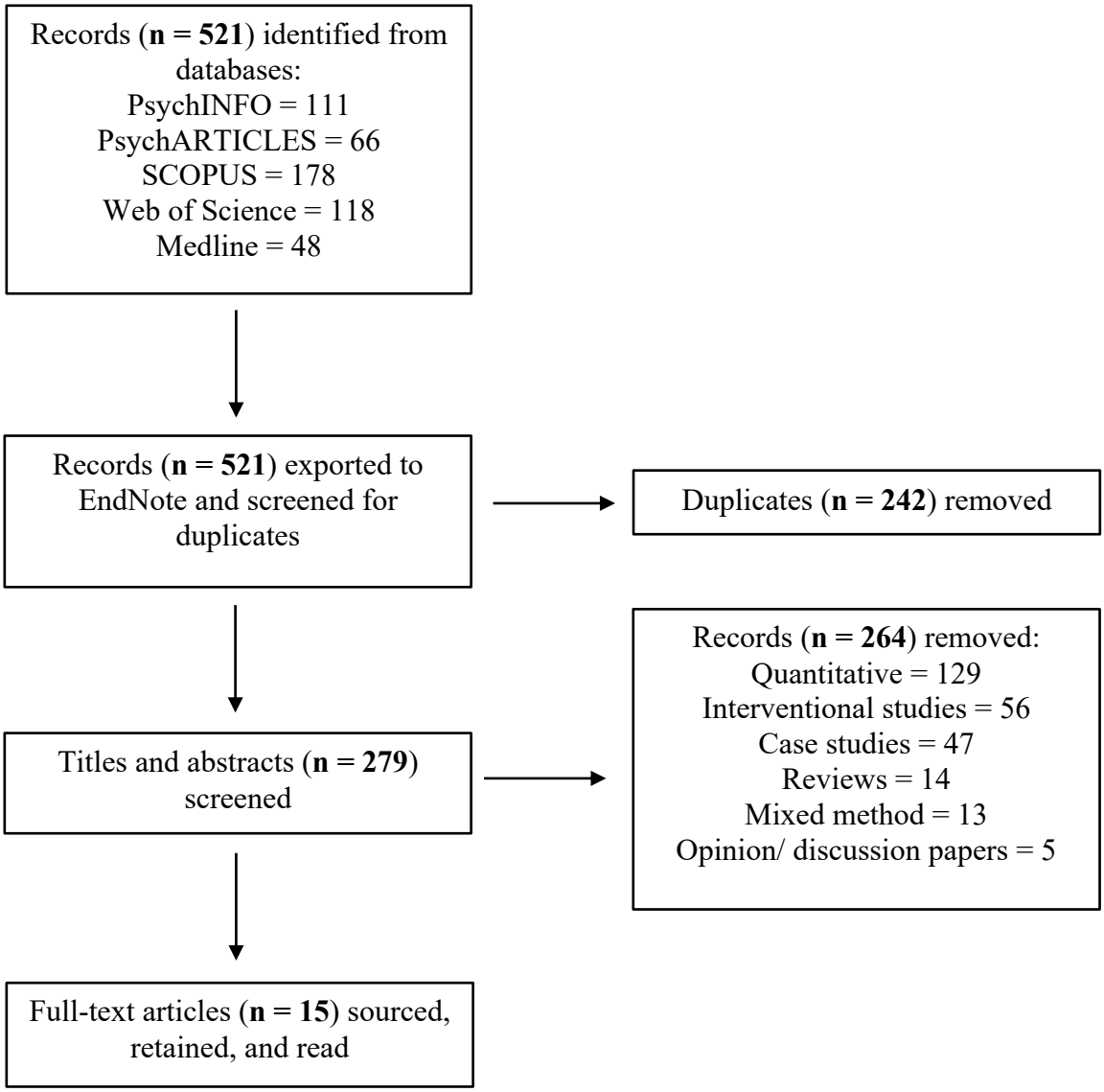


Figure 1: *PRISMA flowchart illustrating the number of papers included and excluded during the screening stages*

As illustrated by the PRISMA diagram, 15 papers were identified as meeting the inclusion and exclusion criteria and sampled for this synthesis. Table 4 outlined the study characteristics of the empirical papers included in the synthesis.

Table 4: *Characteristics of included empirical studies for the synthesis*

Research paper and author	Research question(s)	Rationale for study	Analysis	Participant demographics	Research/ study demographics
Huckle C., Lemmel F., Johnson S. (2021)	What are friendships like with young people who have psychosis?	Friendships are important for social development but could be hindered by psychosis. This paper wanted to explore the views of young people with psychosis around friendships.	Thematic analysis, semi-structured 1-1 interviews	14 participants, aged 19- 34 years old, 7 males, 7 females, 9 White British, 3 Black British, 2 Asian British	Researchers are psychologists in Surrey and London (United Kingdom)
Cogan N.A., Schwannauer M., Harper S. (2019)	How does living with early onset psychosis impact on self-identity for adolescents in recovery?	Typical onset of psychosis is during a crucial time of development that involves transitioning from the dependency of childhood to independent adulthood. This paper wanted to explore how psychosis impacts this transition and young people's emerging self-identity.	Thematic analysis, semi-structured 1-1 interviews	10 participants recruited from an Early Intervention Service, aged 16-18 years old, 5 females, 5 males, ethnicity not recorded (participants with co-occurring alcohol and drug addictions were excluded)	Researchers are psychologists based in Glasgow and Edinburgh (United Kingdom)
Cadario E., Stanton J., Nicholls P., Crengle S., Wouldes T., Gillard M., Merry S.N. (2011)	What is like to seek help for psychosis in adolescence from the perspective of service users and their primary caregivers?	Research has not yet explored how the under 18s seek for help. This paper wanted to explore perspectives of seeking help from people with psychosis aged 18 and below alongside their caregivers.	General Inductive Approach, young person and their caregivers are interviewed separately. Two parts of the interview involve (unstructured interview) inviting the participant to tell their story of seeking help and then (structured interview) are asked guided questions by the researcher	12 participants, aged 15-18 years old with their caregivers, 7 males, 5 females (caregivers' gender not recorded)	Researchers are psychologists from Auckland (New Zealand)
Byrne R., Morrison A.P. (2010)	What are relationships and communication like for people who are	Early intervention service have begun to include groups at risk of psychosis (ARMS) to intervene during prodromal stages of psychosis. However, the	Thematic analysis, semi-structured 1-1 interviews	8 participants, aged 16-28 years old, 7 males, 1 female, ethnicity not recorded except "all	Researchers from the University of Manchester (United Kingdom) within the school of psychology

Research paper and author	Research question(s)	Rationale for study	Analysis	Participant demographics	Research/ study demographics
	at risk of psychosis?	perspectives of people at risk of psychosis had not been captured. This study wanted to explore perspectives of how the prodromal stage of psychosis was impacting on relationships and social communication.		were British" (Clinical Psychologists in the EIP service assessed for at risk state identified through active attenuated active psychotic symptoms over the past week using the Comprehensive Assessment of At Risk Mental States)	and links to the early intervention mental health service.
Barker S., Lavender T., Morant N. (2009)	What is the dominant narrative during the development of schizophrenia, how does this impact on a client's sense of self and social relationships over time and how does the narratives used by mental health professionals contribute towards this sense making process?	Research has not yet explored perspectives of how psychosis has impacted on the person which considers how they position themselves in their own narratives. This study aimed to use a narrative approach to build a picture of what narratives are more dominant in the lives of people with psychosis and these stories are experienced by others and influence the young person's life.	Narrative analysis (Adopted from grounded analysis and constant comparative analysis), semi-structured interviews with both person with psychosis and their family member(s)	8 participants, with family, 6 males, 2 females, ethnicity and age not recorded, recruited from south London	Researchers were psychologists from Kent and Cambridge (United Kingdom)
Sandhu A., Ives J., Birchwood M., Upthegrove R. (2013)	What is the subjective experience of low mood following First Episode Psychosis?	There has been less focus in the research about the impact following a first episode of psychosis can have on motivation for life, mood, and processing of trauma. This study explored the impact these factors following FEP.	Framework analysis, using Photo-Elicitation methods and 1-1 interviews where participants were invited to discuss the photographs they have taken prior to the interview.	8 participants, aged 18-35 years old, recruited from early intervention mental health service in Birmingham	Researchers were from the school of psychology at the University of Birmingham

Research paper and author	Research question(s)	Rationale for study	Analysis	Participant demographics	Research/ study demographics
Brown J.A. (2011)	How does early psychosis effect life factors such as occupational performance?	How psychosis impacts on occupational factors (and therefore social factors) have not been explicitly identified from the perspective of a young adult population. This study aimed to explore these perspectives.	Life narrative approach, 3 unstructured interviews over 2 weeks	5 participants, aged 24-29 years old, 3 females, one male, ethnicity not recorded but 3 participants were reported as working/studying full time	Researcher is an assistant professor in occupational therapy at Dalhousie University (Canada)
Mackrell L., Lavender T. (2004)	What is the interaction between peer relationships and psychosis during adolescence?	Adolescence has been defined as moving away from a dependency on parents and becoming more independent. Peer relationships is an important feature of generating independence and exploring the world. Based on the theory of 'blocked adolescence' this usual transition is interfered with by early psychosis. This study aimed to explore how psychosis may impact on relational development.	Grounded theory, 1-1 semi-structured interviews	12 participants, aged 16- 30 years old, 7 males, 5 females, (selected based on developmental tasks described by Coles, 1995, not completed), 6 participants were within an inpatient unit, "all participants previously had one hospital admission for psychosis" 2 White, 2 Black-Caribbean, 2 Black-African, 1 Japanese, 1 White-Irish, 4 mixed/other	Researchers are psychologists in London (United Kingdom)
Macdonald E., Sauer K., Howie L., Albiston D. (2005)	What happens to social relationships in early psychosis?	There is a need to explore the experiences of social relationships during and after psychosis to help aid recovery. Many relationships could be impaired but the impact and mechanisms for why this occurs is less understood. This paper aimed to explore how social relationships are impaired.	Interpretative phenomenological analysis, semi-structured 1-1 interviews with a follow up interview 2-10 days later to clarify information	6 participants, aged 19-25 years old, 5 males, 1 female, "all were Caucasian," participants were known to researcher from a clinical recovery group in an early intervention	Researchers were academic researchers from the school of occupational therapy at La Trobe University, Brisbane (Australia)

Research paper and author	Research question(s)	Rationale for study	Analysis	Participant demographics	Research/ study demographics
				service (researcher continued kept a reflective diary and checked in with an independent researcher)	
Redmond C., Larkin M., Harrop C. (2010)	How do people experience romantic relationships alongside psychosis?	Romantic relationships often play a significant role in the transition from adolescence to adulthood. An onset of psychosis during this period of transition may disrupt the development of romantic relationships. This paper aimed to explore how people with psychosis experience these relationships.	Interpretative phenomenological analysis, semi-structured 1-1 interviews	8 participants, aged 21-31 years old, "with the exception of one participant they had all been brought up in this country," 3 females, 5 males, recruited from early intervention services across three sites (Birmingham and Wolverhampton) experienced at least one episode of psychosis in the past three years, ethnicity not recorded	Researchers are clinical psychologists in Redditch and Birmingham (United Kingdom)
Hirschfeld R., Smith J., Trower P., Griffin C. (2005)	How do young men with psychosis create meaning out of their experiences?	Historically use of arbitrary diagnoses and differentiation of schizophrenia and 'normal functioning' means a loss of understanding the personal perspective of psychosis. This paper aimed to explore the way in which young men made sense of their experiences of psychosis.	Grounded theory, semi-structured 1-1 interviews (data collected in two interviews 3-5 years after their first episode of psychosis)	6 male participants, aged 19-29 years old, unmarried, "the young men all had their education or employment interrupted by their psychotic experiences," ethnicity not recorded	Researchers are clinical psychologists, psychoanalytically trained at the school of psychology in the University of Birmingham (United Kingdom)

Research paper and author	Research question(s)	Rationale for study	Analysis	Participant demographics	Research/ study demographics
Grealish A., Tai S., Hunter A., Morrison A. (2013)	How do young people with psychosis experience 'empowerment'?	There have been little studies which show the understanding and conceptualising of 'empowerment' from the perspective of young people with psychosis, despite wide term use of the word 'empowerment.' This paper aimed to explore experiences of empowerment from the lens of younger people with psychosis.	Interpretative phenomenological analysis, semi-structured interviews with their parents present (all participants chose to have their parents present despite this being optional)	9 participants, aged 14-18 years old with an average 5-year duration of psychotic symptoms, all participants had experienced at least one admission to an inpatient unit, 5 males, 4 females, 8 White British, 1 Asian	Researchers are a collection of academics from nursing, midwifery and psychological sciences in Manchester and Ireland across University of Salford, University of Manchester, and National University of Ireland Galway (United Kingdom)
Perry D.M., Taylor D., Shaw S.K. (2007)	What do people experience after first episode psychosis and what influences their sense of hope?	Hope can influence recovery, but it has not been directly explored how hope is instilled in people who have experienced early psychosis. This paper aimed to explore these lived experiences.	Interpretative phenomenological analysis, semi-structured 1-1 interviews	5 male participants, 19-25 years old, (interviewed 6-8 months after first episode), White British	Researchers included a clinical psychologist from Southmead Hospital and academic psychology tutors from the University of Bristol (United Kingdom)
Dunkley J.E., Bates G.W., Findlay B.M. (2015)	How do people understand the experience of first episode psychosis and the negative impact it has? How does this understanding relate to trauma?	There is a strong connection between trauma and psychosis but there is a need to understand specifics of how trauma is experienced after first episode of psychosis. This paper aimed to explore the negative impact of psychosis through a lens of trauma.	Interpretative phenomenological analysis, semi-structured 1-1 interviews with significant other person present, if possible, (triangulated using 10 other clinicians to review data)	10 participants, aged 22-28 years old, 7 males, 3 females, 8 participants had their caregivers/family members or significant others present (including partners), two participants did not have a significant other who could be interviewed	Researchers are academics from the faculty of life sciences in Swinburne University, Victoria (Australia)
Dunkley J.E., Bates G.W. (2014)	What is the role of post-traumatic	Whilst there is a connection between trauma and psychosis, how people	Interpretative phenomenological	10 participants, aged 22-28 years old, 7	Researchers are academics from the

Research paper and author	Research question(s)	Rationale for study	Analysis	Participant demographics	Research/ study demographics
	growth following recovery from first episode psychosis?	recover and use their experiences of psychosis for further development has yet to be explored. This paper aimed to explore experiences of post-traumatic growth.	analysis, semi structured 1-1 interviews 3-6 months after acute episode and then again 3-4 months after their episode.	males, 3 females, 8 participants had their caregivers/family members or significant others present (including partners), two participants did not have a significant other who could be interviewed	faculty of life sciences in Swinburne University, Victoria (Australia)

All fifteen papers were published in the last 21 years. The most recent study was published in 2021 (Huckle et al., 2021) and the oldest paper was in 2004 (Mackrell & Lavender, 2004). The largest sample size was 14 participants (Huckle et al., 2021) whilst the smallest samples had five participants (Brown, 2011; Perry et al., 2004). In total 131 participants with direct experience of psychosis were included in this synthesis across the papers. This includes two papers (Dunkley & Bates, 2014; Dunkley et al., 2015) that used the same study sample for two separate empirical papers. Without this addition, 121 participants were the total, with a mean average of 8 participants in each paper synthesised.

Across the papers, the youngest participant was 14 (Grealish et al, 2013) whilst the eldest participant was 35 years old (Sandhu et al., 2013). This age range supported Coles' (2005) description of development where 'independence' is a milestone signifying 'adulthood.' Three papers (Barker et al., 2009; Cadario et al., 2011; Grealish et al., 2013) had included family and caregivers in the interviews, although only one of these (Cadario et al., 2013) had separately interviewed family and caregivers to the person with direct experiences of psychosis. The method of analysis across the papers were broadly in three categories: Interpretative Phenomenological Analysis (IPA) (6 studies), Thematic Analysis (3 studies) and Grounded Theory (2 studies). An additional four studies used narrative, framework, and general inductive approaches to analysis.

A large amount of the studies (Barker et al, 2009; Byrne & Morrison, 2010; Macdonald et al., 2005; Mackrell et al., 2004; Redmond et al., 2010) appeared to explore the impact of psychosis on relationships and attachments. However, due to the broad research question for this synthesis, papers were also found to focus on psychosis and self-identity (Cogan et al., 2019), help-seeking (Cadario et al., 2011), emotional well-being during recovery (Dunkley et al., 2015; Hirschfeld et al., 2005; Sandhu et al., 2013), occupational

functioning (Brown, 2011) and experiences of empowerment (Dunkley & Bates, 2014; Grealish et al., 2013; Perry et al., 2007).

Quality appraisal

Mays and Pope (2000) outlined and discussed two opposing views of quality appraising for synthesis research. These views are underpinned by epistemological positions of realism and relativism (Mays & Pope, 2000). A relativist position holds that all research has a unique perspective and cannot be compared to one another because there is a subjectivity which makes qualitative methods different to quantitative methods (Lincoln & Guba, 1985; Mays & Pope, 2000).

On the other hand, a realist position holds there is an underlying reality to all research which can be captured (Kirk & Miller, 1986). In this position, research can be compared to one another for comparisons of quality (Mays & Pope, 2000) similarly to quantitative methods. Hammersley (1992) rejected both these views and argued that ethnographic research should hold a *critical realism* perspective (also referred to as *subtle realism* or *naive realism*). This view holds that there are multiple realities, but it is the attempt of how particular realities are understood that can be of high methodological rigour rather than whether absolute 'truth' had been captured (Hammersley, 1992; Mays & Pope, 2000).

This critical realist approach to understanding quality fits well with a meta-ethnography approach (Hammersley, 1992; Noblitt & Hare, 1988) and is the chosen stance taken for this meta-synthesis. A quality review of the papers for the synthesis was undertaken to help identify possible research that may have methodological issues. Campbell and colleagues (2011) argued quality reviews can illustrate the overall quality of research of a specific topic and this can create an understanding of the limitations and patterns of methodological issues to address. A quality appraisal was used to help qualify the interpretations made within this review.

To determine the quality of the papers in this review, they were compared against The National Institute for Health and Care Excellence (NICE; 2012; Appendix 1A) quality appraisal checklist for qualitative research. This pre-existing standardised tool was adapted and merged with the JARS-Qual framework (APA, 2018; Appendix 1B), to create a new framework (Appendix 1C) for a holistic tool that shows what should be reported in high quality qualitative research.

All fifteen papers were read and were scored on whether the quality criterion was each met (3), partly met (2) or not met (1). These scores were colour coded accordingly (1= red, 2 = yellow and 3 = green) before then summed to give an overall score and percentage of how much of the quality criteria each individual paper had met. Table 5 illustrated the quality appraisal across 17 categories.

Table 5: *Quality review of studies included in synthesis*

Author/paper	Research area: inclusion criteria met?	Was the paper peer reviewed?	Was the study method (qualitative)	Clarity: was the purpose clear?	Defensibility: was there a rationale?	Systematic data collection	Trustworthiness: study is framed within context	Reflexivity: openness to context	Analytical procedure is clear	Fidelity to analytical procedure	Utility: coherence to literature	Richness: alternative views/ depth to analysis	Reliability: researchers stance considered	Convincing: findings evidenced and coherent	Relevancy: answers RQ	Implications to topic area and literature	Ethical	Comments	Total score (out of 51)	Percentage
Huckle et al. (2013)	3	3	3	3	3	3	2	1	2	1	2	3	2	1	3	2	3	Multiple weakness identified. Analysis did not appear supported by evidence from participants and reflexivity not reported. However, alternative meanings for conclusions were explored.	40	78%
Cogan et al. (2019)	3	3	3	3	3	3	3	2	3	3	3	3	2	3	3	3	3	Paper had good quality but there was limited discussion about the researcher's own position and the impact on analysis. Tools for reflexivity not reported/used.	49	96%
Cadario et al. (2011)	3	3	3	3	3	2	1	1	2	2	2	1	2	2	3	2	3	Does not explicitly mention what type of qualitative analysis but it is gathered from the results this is a thematic analysis. Quotes do not seem extensive and are not complete at times e.g., not referenced from which text or participant they may belong to.	38	75%
Byrne & Morrison (2010)	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	Very good quality. Followed a logical procedure, quotes for themes are evidenced. Researcher's stance clearly described and discussed.	51	100%

Author/paper	Research area: inclusion criteria met?	Was the paper peer reviewed?	Was the study method (qualitative)	Clarity: was the purpose clear?	Defensibility: was there a rationale?	Systematic data collection	Trustworthiness: study is framed within context	Reflexivity: openness to context	Analytical procedure is clear	Fidelity to analytical procedure	Utility: coherence to literature	Richness: alternative views/ depth to analysis	Reliability: researchers stance considered	Convincing: findings evidenced and coherent	Relevancy: answers RQ	Implications to topic area and literature	Ethical	Comments	Total score (out of 51)	Percentage
Barker et al. (2009)	3	3	3	3	3	3	3	3	3	1	3	3	3	3	3	3	3	A dyadic approach was used to identify ways carers and SU narrative differ. Method is defensible for this reason. Fidelity to analytical approach appeared inconsistent, at times inductive and other deductive. E.g., grounded theory was incorporated at times to allow for cross-comparisons and complexities of psychosis. Researchers highlighted this in their reflexivity and discussed influence in the results.	49	96%
Sandhu et al. (2013)	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	Very good quality. Reflexivity a particular strength of the paper. Used a journal and described researcher's stance. Used triangulation methods by sharing codes with research member who had no interest in the field and developed codes together, indicating good trustworthiness and reliability.	51	100%
Brown (2011)	3	3	3	3	3	3	2	2	3	2	3	2	2	2	2	3	3	Several weaknesses identified. Although use of multiple coders, reflexivity isn't reported of how this helped analysis. Analysis lacks depth at times and quotes are poorly illustrated. This seems to be affecting how reliable and convincing the findings are.	44	86%

Author/paper	Research area: inclusion criteria met?	Was the paper peer reviewed?	Was the study method (qualitative)	Clarity: was the purpose clear?	Defensibility: was there a rationale?	Systematic data collection	Trustworthiness: study is framed within context	Reflexivity: openness to context	Analytical procedure is clear	Fidelity to analytical procedure	Utility: coherence to literature	Richness: alternative views/ depth to analysis	Reliability: researchers stance considered	Convincing: findings evidenced and coherent	Relevancy: answers RQ	Implications to topic area and literature	Ethical	Comments	Total score (out of 51)	Percentage
Mackrell & Lavender (2004)	3	3	3	3	3	3	2	2	3	3	3	2	2	1	3	3	3	Alternative ideas are compared in the analysis of data. Triangulation measures used with researchers outside of the study, however, these researchers still had an interest in the field, it is not stated how differences resolved. Results seem a little unconvincing at times as quotes are not laid out directly and seemed to follow the researcher's own ideas.	45	88%
Macdonald et al. (2005)	3	3	3	3	3	3	2	2	3	3	3	3	3	3	3	3	3	Some weaknesses noticed. The study uses a journal for field notes and involvement of independent researcher to cross check codes and themes. However, alternative views and context is not discussed/ reported for how it influences data collection and analysis.	49	96%
Redmond et al. (2010)	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	Very good quality. Paper explains relationship of the researchers in relation to the subject area and participants in the study. Study also uses reflexivity and results can clearly be seen how derived from the data. Discussion and analysis are relevant, and implications are fully explored.	51	100%
Hirschfeld et al. (2005)	3	3	3	3	3	3	3	3	3	2	3	3	3	3	3	3	3	Good quality. Use of cross checkers for the codes and themes in the transcriptions. Use of a reflexive journal. However, data seemed more	50	98%

Author/paper	Research area: inclusion criteria met?	Was the paper peer reviewed?	Was the study method (qualitative)	Clarity: was the purpose clear?	Defensibility: was there a rationale?	Systematic data collection	Trustworthiness: study is framed within context	Reflexivity: openness to context	Analytical procedure is clear	Fidelity to analytical procedure	Utility: coherence to literature	Richness: alternative views/ depth to analysis	Reliability: researchers stance considered	Convincing: findings evidenced and coherent	Relevancy: answers RQ	Implications to topic area and literature	Ethical	Comments	Total score (out of 51)	Percentage
																		'experiential' in nature rather than building theoretical links.		
Grealish et al. (2013)	3	3	3	3	3	3	2	2	3	2	3	2	2	3	3	2	3	Researcher's stance is not adequately described. There is a lack of clarity to how analysis was performed and there is limited discussion around how the context of the study may have influenced interpretation.	45	88%
Perry et al. (2007)	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	Very good quality of research. Clear analytical procedure. Discussion of reflexivity and methods of managing researcher's stance are considered. Depth to analysis that answers RQ.	51	100%
Dunkley et al. (2015)	3	3	3	3	3	2	2	2	2	3	3	2	2	3	3	3	3	Some weaknesses identified. Researchers have used a sample from another study they had conducted. Despite triangulation methods, researcher's stance is not discussed and how this might influence the analysis.	45	88%
Dunkley & Bates (2014)	3	3	3	3	3	2	2	2	2	3	3	2	2	3	3	3	3	Paper does not clearly outline data collection process. Analysis is not reported in a clear way and at times feels lacking in depth. Although triangulated data, alternative views and the impact of researcher's stance is not directly linked to analysis.	45	88%

Several papers were identified to have differed from standard analytical procedures, which reduces confidence in the validity of the data analysis. In some cases, the researcher's stance and perspective was not considered or reported in depth (Brown, 2011; Grealish et al., 2013; Mackrell & Lavender, 2004). Although some papers had used triangulation methods, this had not been linked to other contrasting perspectives of the data they had analysed and instead appeared guided by the researcher (Dunkley et al., 2015). Reflexivity in some cases had not been reported (Huckle et al., 2021; Cadario et al., 2011) and it was noted this could be based on publication restrictions. However, limited use of quotes and examples from the data to support conclusions and illustrate arguments resulted in some analyses being more vulnerable to influence from the researchers' perspectives (Cadario et al., 2011; Huckle et al., 2021; Mackrell & Lavender, 2004).

Out of the fifteen papers included in this synthesis, four were evaluated to be of very good quality (Byrne & Morrison, 2010; Perry et al., 2007; Redmond et al; 2010; Sandhu et al., 2013). The mean average quality score across the papers was 47 out of 51 (quality percentage of 92%). The two lowest quality scores (Cadario et al., 2011; Huckle et al., 2021) were noticed to contain several weaknesses in the papers. However, these papers still scored a quality percentage of 75% or above. As such, all papers were judged to be of acceptable quality and retained in the synthesis.

Data extraction

This synthesis started data extraction by reading the studies and becoming familiar with the literature. These steps follow phase three of Noblitt and Hare's (1988) procedure. A specific focus of this phase was the findings of each study such as the themes and sub-themes. Once each paper had been read, the themes and sub-themes from the study were placed into an 'extraction grid' (see Appendix 1D) where analysis of these findings could then begin.

Evidence of the initial theme from the paper such as direct participant quotes or a sample of the researcher's interpretation was copied into the extraction grid. The researcher's interpretation was considered a 'second' order of interpretation, whilst quotes from participants formed 'first' order. This is based on a double hermeneutic circle, where researchers are forming interpretations about the participant's interpretation and sense-making (Barker et al., 2016). The extrapolation of quotes from the papers helped maintain a contextual understanding of the themes across the papers and the layers of first order and second order interpretations.

Across the 15 papers, there were 106 core themes and sub-themes. These themes were listed in another extraction grid and the first and second order interpretations expanded (Appendix 1E). This expansion helped create third order interpretations from the perspective of the author of this synthesis (Appendix 1F). Sattar et al. (2021) argued third order interpretations help to understand a whole from a set of parts and expose hidden concepts within the literature.

Data analysis and synthesis

In following Noblitt and Hare's (1988) procedure, the findings of each study were then coded based on the first, second and third order interpretations made (Appendix 1G). These codes were then compared to one another for identifying similar patterns or contrasting concepts. This followed the fifth phase of Noblitt and Hare's (1988) procedure. Translations were indicated through combining codes together in the same colour. Codes were mapped to help draw connections across the papers and generate encompassing concepts and translations (Appendix 1H). Initially, 29 concepts were identified from this mapping process. Table 6 illustrates the 29 concepts and translations before they were further synthesised together.

Table 6: *List of concepts and translations after initial codes and mapping*

	Concepts and translations
1	loss of functioning
2	loss of friends
3	high emotional states of active psychosis
4	reliving traumatic experiences through symptoms
5	hospital treatment
6	feeling anxious to engage with others
7	inability to maintain contact
8	self-stigma
9	estranging self from others
10	uncertain identity
11	ambiguous sense of self
12	disintegration
13	losing purpose in life
14	goals and aspirations change
15	masking feelings
16	denying psychosis
17	bracketing/ separating psychosis from self
18	isolation results in fewer social situations
19	unable to hold old self and new self together
20	professional support
21	impaired relationship skills when milestones are not met
22	coming out experiences
23	acceptance from others helps create deeper trusting relationships
24	recognising psychosis throughout life
25	connecting to old self
26	confidence increased with acceptance from others
27	learning to trust
28	learning and becoming enlightened
29	The roles of others in building hope

During the fifth phase, third order interpretations were further developed. The third order interpretations and the concepts made across the studies were synthesised. During the sixth phase, checks with primary data in the first extraction grid were made to help maintain a contextual understanding of the themes being translated. Translations included: reciprocal (similar concepts), refutational (contrasting concepts) and line of argument (concepts that might build on each other) translations were created using the third order interpretations. Reflexive notes were added to the grid to contextualise translations and encourage thoughts of other interpretations which could be made of the data. These translations helped create

theoretically rich concepts which could then be placed into an interpretative order to express the synthesis (Appendix 1I).

Reflexivity

The author of this meta-ethnography is a Trainee Clinical Psychologist and conducted this synthesis in partial completion for a doctorate in Clinical Psychology. The author identifies as a female British Asian Indian and has been interested in complex mental health clinically and academically during pre-training experiences in an acute mental health hospital. The interpretations made during synthesis might be influenced by the clinical experiences the author has had before and during her clinical training, where she has had regular contact with people experiencing psychosis. For this reason, a reflexive diary (Appendix 1J) was kept throughout the process and reflections were shared during research supervision and peer support workshops. Notes were made around the author's feelings about reading the papers, as well as possible links that were identified. Discussions were held with the author's supervisor and peers to help make sense of these reflections. This helped assess the validity of the interpretations which could be applied to the papers. This helped to triangulate the findings and hold alternative interpretations in mind.

1.3: Results

Two superordinate themes were identified in the papers which described how development in children, adolescents and young adults with psychosis had been affected. The first superordinate theme describes how development had been stagnated following an episode of psychosis. In contrast, the second superordinate theme outlines how young people with psychosis also had the potential to recover and move forward with their development. This process of developmental recovery was hallmarked by empowerment and post-traumatic growth.

The synthesis overall expresses how psychosis can interrupt development in multiple ways, however, with support from family, friends and professionals, young people can develop positive life skills and engage in a transformative process where psychosis is a part of development. These stages appeared sequential in the papers, where early coping with psychosis impaired development in the long-term but could be protective initially. This seemed followed by later learning from experiences of psychosis. The synthesis followed this pattern identified across the papers in the organisation of the themes. Table 7 illustrates these themes.

Table 7: *Overall synthesised themes across the papers*

Superordinate theme	Subordinate theme	Description		Papers contributing to theme
1: Development is interrupted following psychosis	**1.1: Concealing psychosis to maintain normality**	Perceiving psychosis as pejorative resulted in young people attempting to conceal experiences of psychosis. This included avoiding discussions about their experiences and re-engaging with usual activities they would have previously engaged with before psychosis.	*"I wanted to prove to the world that I was back to normal […] I go out every weekend. And I work all week. That's it really. Just like normal people of my age"* (Perry et al., 2007, pp. 788).	Barker et al. (2009); Cadario et al. (2011); Cogan et al. (2019); Dunkley et al. (2015); Dunkley & Bates (2014); Hirschfeld et al. (2005); Perry et al. (2007); Redmond et al. (2010)
	1.2: Social isolation following psychosis	Isolation was used to manage psychosis but resulted in people feeling disconnected from their 'old' lives and stuck in a repetitive pattern which prevented them from acquiring new skills and experiences.	*"My friends are all going to college or University and I'm just here."* (Cogan et al., 2019).	Byrne & Morrison (2010); Cogan et al. (2019); Dunkley & Bates (2014); Grealish et al. (2013); Huckle et al. (2021); Hirschfeld et al. (2005); Mackrell & Lavender (2004); Perry et al. (2007); Redmond et al. (2010); Sandhu et al. (2013)

Superordinate theme	Subordinate theme	Description		Papers contributing to theme
	1.3: Loss and re-traumatisation associated with psychosis	Experiences of loss associated with the onset of psychosis resulted in ongoing trauma and feeling arrested in time and a feeling that people were held back by psychosis.	*"I would have been more similar to them if I hadn't been in hospital" (Huckle et al., 2021).*	Barker et al. (2009); Dunkley et al. (2015); Cogan et al. (2019); Huckle et al. (2021); Macdonald et al. (2005); Redmond et al. (2010); Sandhu et al. (2013)
2: Moving forward and becoming unstuck	**2.1: Self-acceptance**	Acceptance of psychosis experiences helped skills in understanding what was realistic and empowered people to be active members of a recovery journey characterised by integration.	*"*[…] *with time, it becomes something that forms only a part of their life experiences, and they continue to move forward and grow beyond psychosis"* (Brown, 2011)	Brown (2011); Byrne & Morrison (2010); Dunkley & Bates (2014); Hirschfeld et al. (2005); Huckle et al. (2021); Perry et al. (2007)
	2.2: Acceptance from others	Self-acceptance was a relational process and needed the presence of acceptance from other people to empower them. This helped restore aspects of life which had been considered lost through psychosis.	*"Throughout all the good and the bad* [my girlfriend] *stuck by me* [and] *gave me a real appreciation* [of] *the meaning of life* […]*"* (Dunkley & Bates, 2014)	Dunkley & Bates (2014); Grealish et al. 2013); Macdonald et al. (2005); Mackrell & Lavender (2004); Perry et al. (2007); Sandhu et al. (2013);

Theme 1: Development is interrupted following psychosis

Across the papers, perhaps unsurprisingly, development for children, adolescents, and young adults was identified as becoming impaired following the onset of psychosis. Usual development through the early years had either become arrested by the onset of psychosis or by the indirect consequences of treatment and stigmatisation. This theme was overarching but many papers had identified different ways in which development had become stagnated. This theme had three sub-themes which encompassed the ways in which development had been negatively affected.

Theme 1.1: Concealing psychosis to maintain normality.

Young people across the papers seemed aware of negative social connotations of psychosis and expressed a need to conceal their experiences to maintain a sense of normality.

> *All of the adolescents acknowledged that their larger cultural context holds pejorative viewpoints towards the[m] "being psychotic" (John) and reported experiences of stigma and social exclusion within social networks. They recognised that in telling other people about their psychosis they ran the risk of embracing an identity which, whatever it meant to themselves, was often seen as "mad" (Callum), "tainted" (Shona) and/or "dangerous" (John). For Alison, the fear surrounding psychosis was felt to have had a negative impact on how people perceived her:*
>
> > *'Stuff that I've been dealing with in my life so it's pretty normal to me (pauses) it's voices, I see things, it's hard for me to know what is and what isn't psychosis. I think if I say the word "psychosis" to someone it sounds really big and scary. It's quite a big part of me, em, it affects the ways [...] people perceive me, I think if people think that you've got this [psychosis] you're not allowed in public with them because you're weird (pauses). It's like being damaged in some way.'* (Cogan et al., 2019, pp.6)

Cogan et al. (2019) shows young people felt the negative perceptions about psychosis could affect their relationships with other people. Huckle and colleagues (2021) point out: "*Ten out of the fourteen participants indicated that social contacts had been reduced because of their anticipation of a negative reaction from others. […] 'I didn't want them to see any difference in me'"* (Participant 1, pp.7). Being perceived negatively placed an anxiety on young people. Young people concealed feelings associated with experiences of psychosis from people they were close to manage this anxiety.

When I am with people, I don't say what I feel. When I am with people I feel…Oh I am with people now, do you see what I mean. So I am on my own and I want to go and tell people how much I want to be with them, spend time with them, then I am with people and I relax, and think that now I am with people everything is alright, but I have not actually said how much. […] then when I hear he [participant's friend] is in I suddenly act as if 'oh hi Ken, how are you doing?' like acting normally, when what I mean is 'oh Ken you are in, wicked, wicked, I thought you might have been out' and like you are in and it is really good that you are in sort of thing. But there is some sort of I dunno…well it is something like that. (Hirschfeld et al., 2005, pp.259)

Hirschfeld and colleagues (2005) show an example of a young man avoiding discussions about how he valued the relationship he had with his friend. Instead of discussing with how he felt, the young man 'acts normally.' In Huckle et al. (2021) this resuming of 'normality' appeared protective: "*I don't like talking about it and when I do I get really upset and stuff like that so I don't like talking to people*, *even friends*, *about what happened*, *what I went through."* (Participant 11, pp.8). Concealing psychosis and resuming usual activities protected people from the feelings which psychosis had evoked. This concealment seemed helpful for defending against reminders of the traumatic experience psychosis had been for young people. Dunkley and Bates (2014) identified:

Conscious avoidance: The participants expressed a clear desire not to acknowledge the illness [psychosis] *in daily life. For instance, not wanting to talk or think about the psychotic episode, using substances, placing the illness experience in the past, and avoiding treatment.*

'I don't want to think about it at all ... I don't need to think about it anymore put it behind you.'" (Dunkley & Bates, 2014, pp. 133)

Across the papers, not acknowledging psychosis was noticeable in the early stages following psychosis. This avoidance seemed helpful for continuing as young people would have done prior to psychosis. Participant three in Perry et al. (2007) described, "*I wanted to prove to the world that I was back to normal […] I go out every weekend. And I work all week. That's it really. Just like normal people of my age"* (pp. 788). The Perry et al. (2007) study illustrates young people attempting to get back to their lives quickly after psychosis. This appeared to be a method to help feel as if they fit in with other people their age. One way this is discussed is to resume usual routines such as going to work. However, this is not without challenges. Barker et al. (2009) illustrated a participant who found: "*It's difficult because conversation is always two way and you can't really know when to take the information in and when to take it out"* (pp.207). Psychosis had appeared to influence the person's well-being, making the appearance of 'normality' unsustainable. Redmond et al. (2010) noted:

> *It seemed that there were struggles around interaction in general, specifically in negotiating the boundaries of proximity. Many of the participants advocated high levels of privacy in an attempt to keep other people out.*
>
> *'As soon as they [other residents] found out they'd be asking questions want to know about one's private things and I wouldn't really want that to happen. Just keep it separate, private from them, private from my family as well.'* (Nathan; Redmond et al., 2010, pp.10)

When attempts to return to normal may have failed, young people withdrew from others around them. There is an intensification of the anxiety felt from being negatively appraised. This seemed to perpetuate a need to maintain distance from others.

> *Stigma from others was externally focused and associated with being discredited by people and society in general because of one's mental illness.*

> *'Like people just don't understand at all and so, and people make judgements on your decisions . . . so I just don't discuss it* [psychosis] *with people like if anything I'll say it's depression . . . like on Law and Order the other day they said, someone said oh this person has psychosis and then the woman to me that means murder!. . . . And there's even this club that we were going to and it's called psychosis.'* (Dunkley et al., 2015, pp.261)

Young people seemed to disguise psychosis with other explanations to avoid stigmatising attitudes. This concealment is felt to protect the young person from judgmental opinions in the wider society, and so discussions about the effects of psychosis are not held. Overall, this sub-theme suggested young people attempted to avoid acknowledging the psychosis through returning to usual activities before onset. This became difficult to maintain, resulting in a withdrawal from other people around them.

Theme 1.2: Social isolation following psychosis

Self-isolation appeared to be a method for younger people to manage psychosis. Hirschfeld and colleagues (2013) showed the withdrawal from usual activities from young men following psychosis resulting in isolation:

> *Just stay in the house, don't watch the TV or listen to music. This is when it is really bad, it has not been like this for a while… I cannot listen to music or watch TV because of the voices and stuff, cannot play on my turntables, cannot do anything really, apart from sleep and try to get over it.* (Hirschfeld et al., 2005., pp.257)

Psychosis appeared to hinder people from taking part in their usual activities of daily living, such as hobbies. Hirschfeld et al. (2005) point out a withdrawal from living. Fearing psychosis might return had also led to increased worries about the future:

> *I felt really hopeless when I finally quit my job. I didn't know what to do. I just thought well that's it, I thought my condition's just going to get worse. And I'll end up*

going to hospital and then I'm never going to be able to get a job again. (Perry et al., 2007., pp.788)

Perry et al., (2007) shows withdrawal was expressed by a participant stopping their occupational activities. This appeared to contrast the sense of continuing to normal as discussed in the previous theme. Psychosis had appeared to interfere with people continuing these activities by generating fear. Social withdrawal appeared to be an initial coping mechanism to manage fears of relapsing:

Living in fear reinforced the devastating power that the illness had over these individuals and enhanced feelings of relative powerlessness and lack of control over their lives. This drove many participants to isolate themselves from social situations and they gradually became more withdrawn. (Sandhu et al., 2013., pp.168)

The Sandhu et al., (2013) study recognised how young people with psychosis had isolated themselves from social situations due to a fear of relapsing in public. This appeared to be a fear of the social costs to psychosis, such as being stigmatised or through having others around them witness their 'episode.'

I always think I'm gonna get unwell again and again, that's maybe another reason why I don't go out, I don't wanna talk to people 'cause I'm thinking last time, when I had an episode, it was in public y that kind of scared me y I'm thinking what if I get unwell again, what if that same thing happens again? (Sandhu et al., 2013., pp.168)

The anxiety of becoming 'unwell again' seemed to propel people with psychosis to avoid social interactions, becoming withdrawn from others. This social withdrawal appeared to impact on developing positive relationships.

Estrangement emerged in choices to disengage from relationships or interactions with others.

'I drifted away from them while I was crazy […] *you drift away so you don't hurt yourself or you don't hurt them* […] *there was a year that I here but I wasn't here at all.'* (Dunkley & Bates, 2014, pp.133)

The description of being 'here' but not being 'here' in Dunkley and Bates (2014) echoes the withdrawal highlighted by Sandhu et al. (2013). There is a sense of losing time when discussing a year where they had not engaged with others, or 'drifted away.' Although Dunkley and Bates (2014) suggest this 'emerged in choices,' it could be argued that participants felt they had little choice as they viewed their withdrawal from life as protecting others so '[they] don't hurt them.' This protection seemed to mirror the previous theme. Huckle et al. (2021) noted withdrawal from social relationships also protected young people from painful reminders of loss.

Talking to old friends seemed to make participants' lack of progress more painful as it highlighted this period of stagnation:

'I didn't want to talk to them because I knew it would be all about going back to uni . . .it would remind me of all the good times that I'm missing out on.' (Participant 7; Huckle et al., 2021, pp.9)

Withdrawal from relationships in younger people following psychosis appeared to help establish safety.

Difficulties with wider social relationships […] *were most commonly related to friendships and peer groups and included problems with attachments* […]

'Basically it was bullying at school […] *it's my instinct to run away and be alone instead of being with the group.'* (Participant 1; Bryne & Morrison, 2010, pp.165)

Bryne and Morrison's (2010) study highlights this pattern of coping may be ingrained from past negative relational experiences, such as bullying. This withdrawal appeared to

compound the problem, preventing people from moving past these earlier patterns of relating, unable to experience more adaptive or healthy attachments. Cogan and colleagues' (2019) study shows being stuck in these earlier patterns of relating undermines personal growth.

> *However, these comparisons were experienced as counterproductive as they made them worry about their own futures. This point was captured by John in describing his concerns about not being able to progress with his life through fear of being psychiatrically hospitalised again:*
>
> *'I can't really see me getting over it, like I worry about it all the time, I don't want to have to go back in [psychiatric] hospital again* […] *My friends are all going to college or University and I'm just here.'* (John; Cogan et al., 2019, pp.6)

The Cogan et al. (2019) study identifies comparisons made to other people had maintained anxiety about the future for people with psychosis. The extract above shows a young man with psychosis who had a sense of being different to his others around him, following psychosis. The threat of reliving the psychotic episode and experiencing hospitalisation undermines the ability to move beyond the psychotic episode itself.

Social isolation led to these unfavourable comparisons as there are a lack of skills and experiences to develop independence. Huckle and colleagues (2021) highlight isolation undermined people's interpersonal skills. Participant 10 describes: "*I think I lost them* [friends] *before I fell ill, or I was already ill but not diagnosed. I just...I was not nice or polite to them anymore, so we lost contact"* (Huckle et al., 2021, pp.9). Not being 'nice or polite' to their friends appears to have resulted in the loss of friends. This led to impoverished social experiences and consequent social skills.

> *Lack of experience* [in romantic relationships] *was identified as another huge hurdle by a number of the young people. The majority of participants, particularly males, had little or no experience. For instance as Phil said:*

'I've never actually gone out with anybody, so I wouldn't 'ave a clue how to start anything.' (Phil; Redmond et al., 2010, pp.13)

The Redmond et al. (2010) study shows a lack of experience in romantic relationships resulted in young males being underprepared for how to manage these romantic encounters. Anxiety created from this maintained young people seeking safety by avoiding the experience altogether. Mackrell and Lavender (2004) illustrate: *"I didn't have one boyfriend and Rachel didn't have one boyfriend. We were constantly dating different guys. That was one of the reasons why I had to leave"* (pp.474). This reduced social contact often led to a reliance on caregivers.

I can't make decisions at that time and sometimes I can't remember what happened so I rely on my parents to look out for me when I am ill and make the best decision for me. But it can also be important at that stage as well because I need help with what to do and how to cope when I'm feeling bad (Grealish et al., 2013., pp.144).

Young people with psychosis had an increased need for caregivers to support with decision-making following psychosis. This results in the person being unable to develop skills of problem-solving and decision-making. Overall, in the papers, there was identification that young people were being de-skilled through a lack of social interaction. These reduced social experiences led to the third sub-theme of loss.

Theme 1.3: Loss and re-traumatisation associated to psychosis

Psychosis itself appeared associated with indirect losses and young people subsequently felt their social network dwindle.

'When talking about relationships it's very traumatic for me. It's like, it's somebody has died yeah and I have to talk about that person.'

The metaphor emphasizes the depth of the loss suffered by this participant; it is experientially unbearable. (Ali; Redmond et al., 2010, pp.9)

In the Redmond et al. (2010) study, these losses appear traumatic, alike a bereavement. Young people seemed vulnerable to these unbearable losses, where a there is a sudden ending to relationships because of psychosis.

> *Before I was unwell I needed twenty hands to count all my friends. After being unwell I can use two, like people fade away, people drift away, they can't, they don't either want to deal with it or they don't understand or when you try to talk to them they don't listen.* (Dunkley et al., 2015, pp.216)

In Dunkley and colleagues' (2015) study, friendships are lost as psychosis creates a barrier for people. This created a sense of not being validated by others around them. This loss is blamed on feeling different because of psychosis.

> *It's just that they [former friends] view me differently now you know, because I've become psychotic they think that you are now a waste of life or something…They just think you're a loony or something like that which is not very good.* (Pat; Macdonald et al., 2005, pp.137)

The Macdonald et al. (2005) study identified young people felt other people would see them negatively after their psychosis. This new perception appeared internalised and contrasted how people had seen themselves previously in their relationships. This feeling of difference could be created from navigating different challenges to others. A participant from the Barker et al. (2009) study describes: *"My state of mind's not what it used to be - everyday is a struggle in the mind with thoughts and voices and all that"* (pp.206). The active symptoms of psychosis had resulted in a loss of cognitive functioning, further hindering young people in their lives. The Sandhu and colleagues (2013) paper describes feeling trapped by this loss of functioning.

> *Using strong imagery to convey his confusion, one participant photographed a jumbled array of alphabet letters and explained,*

'that's me describing my mind sometimes, it's kind of like confusion…because after I had a psychosis episode, that's how my mind was like, fully confused, and I couldn't break out of it.' (Sandhu et al., 2013, pp.168)

Changes which occurred because of psychosis, such as beginning treatment, hospitalisation, and active psychotic symptoms, appeared to undermine a sense of identity in younger people. This appeared both psychologically and physically. Dunkley et al. (2015) described:

The theme was present during the acute episode but was most evident in the recovery phase.

'It's changed me heaps cause now I'm a lot more timid. Not very outgoing. Very shy sort of person. Lost a lot of confidence. A lot of people have said I've changed physically as well because I've put on a lot of weight from the treatment.' (Dunkley et al., 2015, pp.216-217)

The Dunkley et al. (2015) paper illustrates changes occurring from the acute episode lasting into the person's recovery. Lasting effects of psychosis included how people perceived themselves. It is implied this is different to how they might have seen themselves prior to psychosis. These changes appeared to perpetuate a sense of on-going experiences of loss for people with psychosis, where loss in one domain leads to loss in another. This was specifically detrimental during a period when young people are exploring their sense of self.

Factors that served as referent points in the past (self, peer group, siblings, parents or school) no longer operated with the same force or clarity. While the majority of the adolescents placed importance on peer relationships, they all expressed their difficulties in developing and maintaining friendships. Michael described his sense of feeling socially isolated following a psychotic episode:

'I feared being alone and that I would lose all my friends, well my old friends just disappeared, I mean I told some of them (about psychosis) *but they just started going about with other people so* [pause]*, I just lost friends.'* (Michael; Cogan et al., 2019, pp.6)

Cogan and colleagues' (2019) paper identified losing the 'self-referent points in the past', suggesting the creation of a disconnection between the young persons 'old' self and their 'new' self. Like Dunkley et al. (2015) loss of friends results in losses in identity. Huckle and colleagues (2021) similarly found participant six: *"I would have been more similar to them if I hadn't been in hospital"* (pp.9). This implies psychosis undermined a sense of normality in people, as mandated treatments, such as hospitalisation, reduced their ability to be in similar environments to their peers. Sandhu and colleagues (2013) illustrate people with psychosis had made a clear distinction between their 'old self' and 'current self.'

"When I'm having a bad day, I can't even look in the mirror […] *because I feel so ugly and so, I am not the same as I used to be before the psychosis, I used to fix myself up, I used to do all these things, I used to be outgoing, it's like, I don't like the reflection I see staring back at me."* (Sandhu et al., 2013, pp.169).

The comparison between the two selves suggested an arbitrary boundary could be created before and after psychosis. This boundary could mark an interruption of young people's development. Huckle et al. (2021) shows young people's perceived differences to their old selves had been compounded by their social roles being changed in some way.

Participants described anxiety that their friends would notice changes in their personality or patterns of interacting. They described feeling different and had lower confidence in their ability to interact than they had before the onset of psychosis.

"If they wanted to go out I was worried that I wouldn't be the same person; I wouldn't be like the joker anymore." (Participant 7; Huckle et al., 2021, pp.7)

This was like Cogan and colleagues' (2019) discussion of diminishing self-referent points. Previous identity roles, such as being the 'joker' in a group, appeared altered following psychosis. For adolescents emerging an identity as a young adult, this could be damaging to their sense of self.

> *Adolescence itself was viewed as being a time when the certainties of the past (being cared for by parents, child status or having decisions made for you) gave way to a situation characterised by a greater level of ambiguity and scepticism. This point was captured by Jennifer who stated:*
>
> *'I mean being this age is hard enough, like, trying to work stuff out and deciding what to do next, like to go to college or whatever [pauses], I guess that's not gonna happen now, cos I'm in here [early intervention service], I don't see the point now.'* (Jennifer; Cogan et al., 2019, pp.6)

Cogan and colleagues (2019) demonstrated psychosis not only stagnated development but dismantled identity, with an impact on the transition from adolescence to young adult and associated identity formation. Psychosis may result in ambiguous life plans with people being in services rather than at college, suggesting a third implicit loss: a loss of their future aspirations. Huckle et al. (2021) notes the interruption of psychosis in developing interpersonal relationships.

> *There was also a sense that a romantic relationship might be important to moving on and progressing into adulthood, which might have been interrupted by psychotic illness:*
>
> *'You know like when you're young, like a teenager in school and you have a best friend you know, that best friend, do you know what I mean? But as you get older it gets replaced with a man, kind of thing. I haven't moved on to that bit yet.'* (Participant 9; Huckle et al., 2021, pp.10)

Transitions across different relationship patterns appeared disrupted by the onset of psychosis. Many young people across the papers had felt psychosis interfered with the usual progression from adolescence into adulthood, by there being an absence of characteristics which would have usually defined meeting these milestones. Overall, psychosis had resulted in a cycle of loss which drastically changed young people's lives, making it challenging for them to move forward.

Theme 2: Moving forward and becoming unstuck

The papers demonstrated participants can move forward and use their experiences of psychosis to make sense of themselves and develop important life skills. Theme two is influenced by the discussion of empowerment across the papers. Empowerment was noticed through experiencing acceptance from others. This appeared to encourage young people to accept their psychosis as a part of themselves. This theme captured how development might be 're-started' and 'un-stuck.' The theme contained two sub-themes which expresses how this transformation can take place through acceptance.

Theme 2.1: Self-acceptance

Young people, across the papers, discussed the need to accept their experiences to move forward with their lives. There is a sense of comparing their level of understanding psychosis at the time of the interview to when they were actively psychotic. Such reflections indicated the person had moved past their initial episode of psychosis and seem to be 'reality checking'.

> *Looking back, Shiloh believed she had been unrealistic, partially as a result of being "in denial" but, more important, because*
>
> *'If you're not doing anything, you don't know what is possible or not. I don't think I was aware at the time, until I tried to do things. I don't think I realized what was realistic.'* (Siloh; Brown, 2011, pp.160).

The self-reflections noticed in Brown (2011) demonstrated young people learning about themselves and their experiences of psychosis. Siloh in Brown (2011) develops a sense of being more realistic as she discovers what she can and cannot do. This appears to be contemplated and limitations become accepted rather than being concealed. The process of this 'reality checking' appears to empower people with knowledge about their psychosis. Such empowerment leads to re-gaining control over their lives and experiences. Hirschfeld and colleagues (2005) similarly report:

> *'Yeah, you could say, you know I have matured a lot more. You become more aware of what is around you, and you understand illnesses and all the ins and outs. So obviously, yah, you change a lot.'*
>
> *This participant is reflecting on the increase in his awareness and understanding. As a result, he feels he has also developed and become wiser as a person. The young men describe finding more meaning in existence through their individual experiences, and so their sense of handling the world around them and themselves matures. They come through the emotional challenges of their life stage, which appear magnified by their experience of psychosis and reflect on changes in their confidence and self- understanding.* (Participant 6; Hirschfeld et al., 2005, pp.260)

Hirschfeld et al. (2005) notices participants had used their reflections of psychosis to grow an awareness and understanding about their own lives. The challenges young people had faced appeared 'magnified' by psychosis but could later become a useful resource for self-understanding. Being able to have an anchor which young people could come back to was important for this self-awareness, as illustrated by Perry et al. (2007): *''You have to come back to some sort of normality so that you feel you belong here, no matter how different you are''* (pp.788). Reminders of belonging helped normalise participants. This contrasted with

theme 1.3 (loss and re-traumatisation) where a loss of self-referent points removed identity and belonging.

Despite feeling a difference, young people with psychosis may push through perceived social barriers by maintaining a sense they belong. This seemed to be fixed on the idea of accepting one's own 'normality,' such as what they can and cannot do.

> *I've been able to understand what is happening and why, why I feel such things in such a situation. Why I get certain images in my head, all sorts, and because of that I've now got a list of things that I need to work on, either to minimise them, or just accept there is nothing I can do about them* (Participant 1; Bryne & Morrison, 2010, pp.165-166)

The Byrne and Morrison (2010) study shows young people with psychosis were learning about themselves. Accepting the limitations which may be created by psychosis appeared a hallmark this self-learning. Developing self-acceptance of psychosis meant young people became more hopeful about their future.

> *05 [pseudonym chosen by participant] maintained a hopeful attitude and when asked if psychosis will affect his future, he replied:*
>
> *'I don't think so, because I think with whatever I do, um, right now, what I am feeling, what I find is that just time, what, the common saying: time heals. In that way, in a big way, is just putting things into perspective; time is still going; things are still happening.'* (05; Brown, 2011, pp.159)

Developing a positive attitude of 'time heals' generated hope that things could get better for young people. It is suggested, the passing of 'time' would heal the previous trauma and losses experienced through psychosis. This viewpoint contrasted with theme one, where young people's development is arrested following psychosis. Accepting things as they are appeared the first step to becoming unstuck in development.

Recognition of the illness is a changeable experience and part of the life course that cannot be completely controlled, as well as a desire to move forward.

'Trying to accept the way things are and not resisting […] *now if I feel crap I just get through it I don't try and fight it.* […] *I'm a little more determined to deal with it ...I see it more as a fixable problem than I did before.'* (Dunkley & Bates (2014), pp.134)

Dunkley and Bates (2014) identified young people were able to see psychosis as a journey and this appeared to contrast with 'fighting' against psychosis. Seeing the problem as 'fixable' led to psychosis being treated alike any other developmental challenge. That psychosis is malleable and changeable in this way, seemed conductive to empowering young people, compared to psychosis being unchangeable. Brown (2011) highlighted how psychosis experiences can be accepted as a relative normal:

'All my life there was certain things that always happened. Either like voices or hearing things that aren't there...I said, OK, you know, no big deal, this just must be normal.'

[For participants, psychosis] *becomes something that forms only a part of their life experiences'* (James; Brown, 2011, pp.158)

Identity development seemed 're-started' when people with psychosis were able to think of psychosis as an ever-present characteristic rather than a catastrophic event.

'Well, I can't really pinpoint 'a before' if there was 'a before' or if there was just 'leading up to it.' Even as a child I didn't really feel normal or like other kids, so not knowing if was just normally really withdrawn and then developed something else, or if, you know, I always had some sort of seed within me that just, kind of, unfurled naturally' […]

> *In essence, psychosis may start as "a seed that unfurls" within the participant, and has the effect of restricting the occupations in their lives, but, with time, it becomes something that forms only a part of their life experiences, and they continue to move forward and grow beyond psychosis.* (Siloh; Brown; 2011, pp. 158-160)

In a previous theme, 'loss and re-traumatisation,' psychosis interrupted a sense of identity and created an arbitrary boundary before and after the initial onset. Brown (2011) expresses how psychosis can become a normal part of identity once there was an awareness of early signs being present much sooner than active symptoms of psychosis. This supported self-acceptance was important to integrating psychosis into self-concepts, but the development of self-acceptance itself is also part of a learning journey. Self-acceptance may not necessarily occur immediately following the psychotic episode and instead happens when the person has been exposed to and learnt about the psychosis.

Across the papers, acceptance was typically discussed as an aspect occurring later. Papers with an older participant sample had more discussion of empowerment than papers with younger samples. This was marked by an awareness of recognising quality in relationships rather than a valuing of quantity in relationships.

> *Stronger and closer relationships* [developed] *because of the support they received from their friends during their illness and recovery. This was strongly related to a sense that friends who remained in contact proved that they could be relied upon even in the most difficult of circumstances.*
>
> *'We've become much closer since the breakdown* […] *She's just there all the time either to talk or if I felt I didn't want to stay on my own or something. No, she was like there for me but not in a way that was judgmental.'* (Participant 9; Huckle et al., 2021, pp.11)

Relationships that were sustained through and beyond the psychotic episode were of a different quality to other relationships. These relationships were stronger and more reliable. Supportive relationships were recognised by Huckle et al. (2021) as a resource which cultivated acceptance in the young person themselves. This formed the basis of the second sub-theme. Overall, the papers showed acceptance was an important step young people can make to promote development.

Theme 2.2: Acceptance from others

The second sub-theme suggested self-acceptance is created relationally and stemmed from experiences with others who had accepted them. There was a sense that young people needed to have their experiences accepted by others before they could accept themselves. Dunkley and Bates (2014) recognise a young person's existing support network was important for cultivating self-acceptance and empowerment: "*Throughout all the good and the bad [my girlfriend] stuck by me [and] gave me a real appreciation [of] the meaning of life and what love and […] life together [and] long living would be like"* (pp.134). Being able to identify the quality of specific relationships helped select a supportive social network.

> *Some participants felt accepted by peers but again this did not appear to prevent the isolation. The code ''not feeling judged'' was important for some participants;*
>
> *'When I came back the fact that my friends didn't judge me or anything was good.'''* (Mackrell & Lavender, 2004, pp.476)

Mackrell and Lavender (2004) notice acceptance from others did not always result in preventing isolation. However, relationships where young people did not feel judged were considered important and coded by the researchers. The paper showed acceptance from others may involve an openness from others to understand psychosis. Other papers illustrated the demonstration of this openness from other people was a significant supportive feature of ongoing development for the young person.

My mum, she has always stuck through me, all the trouble I have been in and that…they mean a lot to me, because some parents of friends, I know they kick their kids out when something happens to them. You know my family stuck by me and they have got confidence in me, more now than what they did. (Pat; Macdonald et al., 2005, pp.135)

It was not only friends or partners which facilitated this growth of empowerment but the positive relationships with professionals could also play this significant role. Grealish and colleagues (2013) noted:

The opportunity to talk to and discuss symptoms with clinicians was seen as empowering as this process enabled participants to increase their understanding of symptoms and facilitate their ability to seek help. They found this empowering because discussion of symptoms reduced anxiety and fear. Clinicians who discussed symptoms were valued not simply for their knowledge but for their willingness to engage with young people when required. (Grealish et al., 2013, pp.142)

The experience of conversations with professionals who showed a willingness and openness to understanding the experiences of psychosis young people had, was considered empowering. Young people held these experiences of acceptance to cultivate hope in a recovery from psychosis.

'He [the psychiatrist] told me not to worry he said he'd seen thousands of people the same age as me in the same situation and he said not one has not got over it.' […]

Participants described these messages as being hopeful and helpful.

(Participant 2; Perry et al.,2007, pp.789)

This implied the importance of others, such as family members and clinicians, in validating the psychotic experiences for young people. Being validated by others appeared to remove stigmatising attitudes, in turn helping them accept the psychosis. In this post-

psychotic growth, there was a recognition of growing confidence from being around other people who accepted them.

> *Get my confidence back,* […] *I need to get my life back and that would lead to getting jobs…I can just have some kind of hope and, you know, just try and do stuff. I have to have some kind of purpose. Some kind of reason for being here* […] *I'm grateful, you know, that I have people around me. They just support me, kind of know the situation and, you know, kind of just accept me* (Sandhu et al., 2013, pp. 170-171)

The Sandhu et al. (2013) study suggested young people had developed confidence through the acceptance of others. This led to an increase in social activities and supporting themselves independently.

> *They* [participants] *described this* [experiences of professional support] *as empowering as the fostering of new ways of coping allowed them to be less dependent on the health service and to recover. B* [pseudonym] *notes the value of practical input to help cope with voices.*
>
> *'They taught me different methods to use like m.. listening to my discs put the earphones into your ears so that it's right. And like getting an elastic band to pulling at it and stuff.'* (B; Grealish et al., 2013, pp.143)

The Grealish et al. (2013) study shows the development of coping mechanisms from experiences with professionals supporting them. Being able to support themselves was a step toward a positive transition and developmental growth.

> *The participants spoke about wanting to decrease dependency on families, to spend more time with friends, to work towards living independently, to go on holidays, and to get on with life. Cira spoke of the future saying:*
>
> *'Well I feel I need to back off a bit because like I am nearly twenty years old and I need to separate from my parents.... If I have enough money then I would like to*

live independently in a unit or something like that, or maybe if it's not possible maybe just live independently in my parents' house.' (Cira; Macdonald et al., 2005, pp.138)

The Macdonald et al. (2005) study shows young people with psychosis transitioning towards independent living. This seemed characterised by accepting this transition to independency would be in stages. Acceptance of the secondary effects of psychosis, such as the losses described theme 1.3, led to a greater appreciation of life. A potential reason for this was experiencing acceptance from others had returned what young people had 'lost.' This included relationships, social activities, identity, and future ambitions.

A desire to live life to the fullest was expressed as well as a greater recognition that life is precious, valuable, and fragile and is taken more seriously.

'I've never really realised how important life was till I started challenging my being […] *Going from thinking that life is just worthless I've gone to thinking that life's* […] *got a lot of things* […] *I've gotten to know myself a lot better and I tend to value my own life very well.'* (Dunkley & Bates, 2014, pp.136)

This appreciation for life was considered the ultimate goal for young people experiencing psychosis and appeared to represent a growth in their self-development. Overall, the acceptance experienced from other people was supportive of continuing development. This was characterised by creating a mindset for moving forward in small stages to achieve independent living.

1.4: Discussion

Summary of findings

This meta-ethnography has synthesised qualitative research exploring the impact of psychosis on the development of children, adolescents, and young adults. The papers included in this synthesis suggested development can be negatively impaired for young people following experiences of psychosis. A sequential pattern was found in the papers

where young people tended to experience an interruption in their development following psychosis. This was later succeeded by a re-start in development after learning about and embedding psychosis in their lives.

Firstly, young people may conceal their psychosis, and the associated feelings of psychosis. This seems in response to negative and pejorative attitudes towards psychosis made available from society. Young people become aware psychosis may hinder their relationships because of these stigmatising attitudes and seek to resume to normal life as they experienced it before the onset of psychosis. Whilst this seemed protective, it could be argued this avoids young people learning from their experiences of psychosis and accessing support in the form of validation from others. The papers showed maintaining the 'normality' was difficult as psychosis itself had created new challenges. The papers showed young people experienced increased anxiety of being 'found out.'

To manage this anxiety, young people isolated themselves, effectively arresting the development of social and interpersonal skills, as well as cognitive skills gained through social interactions. The synthesis suggested that people had turned to self-isolation to manage fears of relapsing, hurting other people and reliving traumatising experiences. Withdrawal led to impoverished social experiences and a sense they were underprepared for future stages of adulthood. For young people, this resulted in being trapped on a dependence on their caregivers or family.

The papers indicated that young people had experienced a series of losses brought on by their psychosis. This included loss of friends, previous identity, and life aspirations. Such losses resulted in people feeling further disconnected from their sense of self. In some cases, these losses trapped people in and even reversed phases of development, effectively re-traumatising young people to further trauma as a secondary effect of psychosis. These results

outlined the ways in which distress, as synthesised by Griffiths and colleagues (2019), may impact on development.

Theme two overall identified how young people may become 'unstuck' in their development through experiences of self-acceptance. Family, carers, and professionals may contribute towards empowering young people through facilitating experiences of acceptance. Such experiences appeared conductive to enabling younger people with psychosis to integrate their self-identity and accept psychosis as a part of themselves as opposed to a catastrophic event. Integral to these experiences was the presence of people around the young person who showed a willingness to be open and understand psychosis. Young people mirrored these experiences of openness for themselves, which in turn helped them set achievable stages to continue re-building their lives.

Sealing over vs integrated coping styles

The synthesis sought to reveal ways in which psychosis impacted on development. The way in which people coped with psychosis was the overall contributing factor impacting on development in children, adolescents, and young adults. Previous literature had identified two coping styles following an episode of psychosis (McGlashan & Levy, 2019; Modestin et al., 2004; Tait & Birchwood, 2004). In a 'sealing over' coping style, people separate psychotic experiences from themselves and repress them away from non-psychotic thoughts and feelings (McGlashan & Levy, 2019). People who do 'seal over' in this way may be reluctant to discuss their experiences of psychosis (McGlashan & Levy, 2019) and perceive their psychosis as a distinct event from their sense of identity (McGlashan et al., 1975). This coping style seemed apparent in the synthesis through young people suppressing the psychosis and wishing to return to 'normal.'

On the other hand, an integrating coping style refers to a process of developing continuity between the experiences of psychosis and a 'before' period of psychosis

(McGlashan & Levy, 2019). In this coping style, people may struggle early on in their recovery but gradually redefine the conflicts through a curiosity and learning about the psychosis (Tait and Birchwood, 2004). An integrated coping style has been associated to better long-term recovery and later life outcomes (Thompson et al., 2003). An integrated coping style was also echoed in the synthesis through young people's accounts of learning about the psychosis and being able to accept the new experiences to integrate their 'past selves' (pre-psychosis) and 'new selves' (post-psychosis).

A journey to manage the impact on development

This synthesis adds a further layer to understanding coping styles following psychotic episodes. Findings showed that initially young people's development had become stagnated as they struggled to come to terms with their psychosis, using self-isolation to protect themselves and others. It is argued that experiencing the associated loss to psychosis, such as loss of relationships, pre-morbid functioning, and life aspirations, resulted in a sense of re-traumatisation, which can be a reminder to some people with psychosis of past childhood trauma. To manage the emotional experiences of this loss, the synthesis suggested people can 'seal over,' drawing a line under their psychotic episode and suppressing the event to help them return to a 'normal.'

Many of the papers with an older sample appeared to then discuss the movement from this 'sealing over' to integrating their experiences. It is argued people may progressively learn an integrative style, and that these coping patterns are not a stable trait but instead changeable (Thompson et al., 2003). The current synthesis supports this notion. The synthesis revealed people had felt a disconnection to themselves before psychosis and this may be telling of a sealing over coping style. It is thought this coping style is protective in the early recovery stages from psychosis (McGlashan & Levy, 2019). However, the synthesis also

suggested people, particularly from an older sample, were able to reflect on their experiences to integrate them together.

Tait and Birchwood (2004) found a sealing over coping style (also termed 'avoidance coping') was associated with reduced resources for personal resilience. For instance, people with sealing over styles may have experiences of insecure childhood attachment and negative self-evaluative beliefs (Tait and Birchwood, 2004). However, this synthesis suggested sealing over might be a protective early way of coping with psychosis before learning to integrate their experiences. This sealing over style helps to initially continue development, as shown by findings in this synthesis of continuing as 'normal' to attend work, school and maintain social contacts.

It was noted older participant samples appeared more reflective in nature, particularly about the immediate effects after psychosis. Many papers had used Interpretative Phenomenological Analysis, which lends itself to an approach to data analysis where experiences and sense-making is captured (Smith et al., 2022). Alongside this, there were papers which used a narrative approach to reveal reflective stories in the data (Barker et al., 2016). This could support the notion that most of the accounts from the papers were from participants reflecting on their experiences. Therefore, it could be argued participants were recruited during an integrative coping style and reflecting on times they had sealed over. As such the synthesis could reveal a way of coping that is a journey young people go through which can help to maintain development.

Support for cultivating acceptance

The synthesis identified self-acceptance was a mechanism for change and helped 're-start' development. It could be argued an integrated coping style developed through experiences of self-acceptance and the acceptance received from others. Jansen and colleagues (2020) identified Acceptance Commitment Therapy (ACT) for psychosis (also

referred to as ACTp) has built in momentum in recent years. ACT is a therapeutic treatment based on the understanding that mental pain is an experience of the human condition but could be offset by living life based on enriching values (Jansen et al., 2020).

In one meta-analysis of Randomised Controlled Trials (RCTs) investigating the impact of ACT on psychosis, acceptance had resulted in generally long-term alleviation of positive symptoms (Cramer et al., 2016). This did not extend to negative symptoms however (Cramer et al., 2016). Yet, White et al. (2011) indicated ACTp had improved depression following psychosis, suggesting ACTp targets the secondary effects of psychosis rather than the symptoms. This synthesis supports cultivating acceptance may benefit recovery following psychosis. There may need to be further work exploring this mechanism and the impact it has for young people's development following psychosis.

Limitations

The meta-ethnographic approach appeared useful to generating a broader understanding that connected the papers. The multiple layers of interpretations allowed for a critical perspective of the literature. Third order interpretations helped bring together a 'meta-awareness' of the research area and surrounding context. In following this practice, it is also important to reflect upon the context in which this synthesis took place.

Firstly, this synthesis took place following the Coronavirus pandemic on papers (apart from Huckle et al., 2021) which were published prior. It is plausible that the pandemic can also be understood to have influenced how psychosis may impact development and there may be additional factors produced through the pandemic which impair how people recover following a psychotic episode and how this affects their overall developmental trajectory. For example, the withdrawal from social contacts noted in, Huckle et al. (2021) could have been a by-product of national restrictions, particularly given the study's geographical location in the international City of London. Huckle et al. (2021) also noted young people had begun to

value the quality of relationships and not just the quantity. This too, could be influenced by the pandemic's widespread social restrictions.

The synthesis' research question, how psychosis impacts on development, is a larger and broader research question of the topic field. For this reason, the papers included in the synthesis cover a wide range of effects into psychosis and it is perhaps not surprising the work related to broader questions in the field about coping styles. Whilst there is a benefit to obtaining this overview of the literature, such as an awareness of the literature has focused on the impact of interpersonal factors, there could be a lack of depth of the mechanisms behind interpersonal effects from psychosis.

In addition, it is of note the synthesis expressed in this report is of papers published in Western, individualistic (Rogoff, 2003) cultures. Many of the papers therefore reflect a notion more concurrent with themes of developing independence. However, due to migration and inter-cultural communication, individualistic and collectivistic boundaries may no longer be so clear (Holliday, 2020).

Applying this understanding to the synthesis suggested individualistic ideas of independence and the impact of psychosis on this independence may be changeable. Therefore, the findings of this synthesis should be understood within the context and frame in which the papers were written, as well as the understanding of the current climate of cultural change. Future research could explore whether psychosis may have different developmental impacts across different cultures. For instance, an exploration of the qualitative differences cross-culturally of recovering from psychosis and a comparison with inter-cultural differences within the UK.

Reflexive factors in the synthesis

The author of this synthesis is aware that the findings can be influenced by her stance towards bringing together multiple elements of a narrative to create coherence and structure.

This formulation stance is part of the professional identity of a Clinical Psychologist (Head et al., 2020) and as an emerging Clinical Psychologist, the author is aware this growing potential to formulate, and sense-make could have influenced the integration of the findings into a coherent narrative.

The author held reflexive discussions with peers and her research supervisor, but as these individuals were also emerging and qualified Clinical Psychologists, alternative perspectives outside of psychology were not available. The author reflected during this process how there may have been a heavier focus on the psychological impact of psychosis on development compared to other factors. There were other papers which were included in the synthesis which were from professions such as Occupational Therapy (Brown, 2011) but arguably these may not have received as much attention. Furthermore, many studies included in this synthesis were from the same geographical location (Birmingham) and from the same profession as the author and her supervisor.

Recommendations

To improve on this synthesis, inviting other perspectives would have been helpful. Future syntheses may benefit from acknowledging the reflections of the author and attempting to bring other perspectives outside of the sphere of Clinical Psychology. Future research could enhance the present findings by developing meta-syntheses with the involvement of a wider range of stakeholders including service users, experts by experience, and from a wider range of cultures.

Another recommendation for future research would be to focus on other non-psychological impacts of psychosis. Many papers, if not all, were focused on the interpersonal and relational impact of psychosis. This could be because many of the authors of the papers were psychologists, a profession which seeks to understand relational and self-

processes (Head et al., 2020). Qualitative approaches also lend itself to understanding relational experiences rather than a biomedical frame of development.

Whilst some papers had other focuses (Brown, 2011), this was few. The literature around the impact of psychosis on cognitive development appeared lacking and there is a need to greater understand the possible mechanisms of how cognitive effects from psychosis contribute towards impaired relationships. As these factors, including biological and physical effects of psychosis, interact and relate to one another, the attempt of gaining a full perspective in this synthesis may not be realistic.

A quality appraisal of the research included in this area also suggested some studies had tended to move away from standardised analytical procedures and this made it harder to establish good methodological trustworthiness and reliability. It appeared this was a particular area which research exploring the impact of psychosis should be aware of. Finally, future research could focus on how the pandemic may have influenced the impact of psychosis on development based on the findings from this synthesis and findings following the pandemic.

Conclusions

Overall, this synthesis has explored papers investigating the impact of psychosis on young people's development. The synthesis revealed a general trend in the literature focused on the way in which young people may cope with psychosis, which has a lasting impact on whether development was interrupted. Psychosis appeared to interrupt development through young people concealing their experiences, socially withdrawing and the secondary losses associated with psychosis.

These factors may be self-protective and may be related to established ways of coping with life challenges. However, the synthesis also demonstrated the benefits for young people of acceptance and how this can support learning from the experiences of psychosis. This may

be a later method of coping, as suggested by older participant samples showing a trend of building self-acceptance. Further research can develop these findings by exploring the cultural relativity of the impacts of psychosis described here and by broadening the stakeholders involved in such research.

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Chapter 2 – Making the threat real: An Interpretative Phenomenological Analysis exploring the emotional well-being of people with psychosis during the COVID-19 pandemic

Abstract

Objectives: The secondary effects of the Coronavirus pandemic have included widespread mental health difficulties. A rise in psychosis following the pandemic has been well documented by the literature. However, what is less known is how people who had a psychotic disorder before the pandemic, experienced emotional well-being during this period. *Method:* Eight semi-structured interviews were carried out online with people who have psychosis. Timelines were used during interviews to help structure narrative accounts. Interpretative Phenomenological Analysis helped gain a perspective of the lived experience of the emotional well-being people who had a pre-existing psychosis had during the COVID-19 pandemic. *Findings:* Four main themes were found. This included: (1) *symptoms of psychosis are amplified,* (2) *the pandemic accentuated disadvantage in society,* (3) *the pandemic connected everyone to some of the experiences of psychosis, and* (4) *the pandemic as an opportunity to support recovery from psychosis. Conclusions:* The study helped identify challenges people with psychosis may have faced during the pandemic, some of which had the potential to unravel previous recovery. Intensification of symptoms and segregation in society led to feeling of unsafety and threat. Despite this, the pandemic also seemed to be an opportunity to support the recovery from psychosis. Implications of this work are discussed further.

2.1: Introduction

Mental health and Coronavirus

On the 11th March 2020, the World Health Organisation (WHO) (Evanson & Wilson, 2021) declared the global Coronavirus (COVID-19) as a world-wide pandemic. Nationally, in the United Kingdom (UK), people were exposed to high death rates, government enforced restrictions and isolation (Williams et al., 2020). These changes marked an unprecedented time and COVID became a shared experience (Bhugra et al., 2021; Hiscott et al., 2020). Ventriglio and colleagues (2020) developed a framework of the five stages faced during the COVID-19 pandemic globally. Figure 2 describes how people move through key stages in the model, of responding to the pandemic including fear, panic, anger, depression, and acceptance (Ventriglio et al., 2020). This framework was published before the end of the pandemic and is considered a loose understanding of psychosocial underpinnings of the Coronavirus pandemic (Ventriglio et al., 2020).

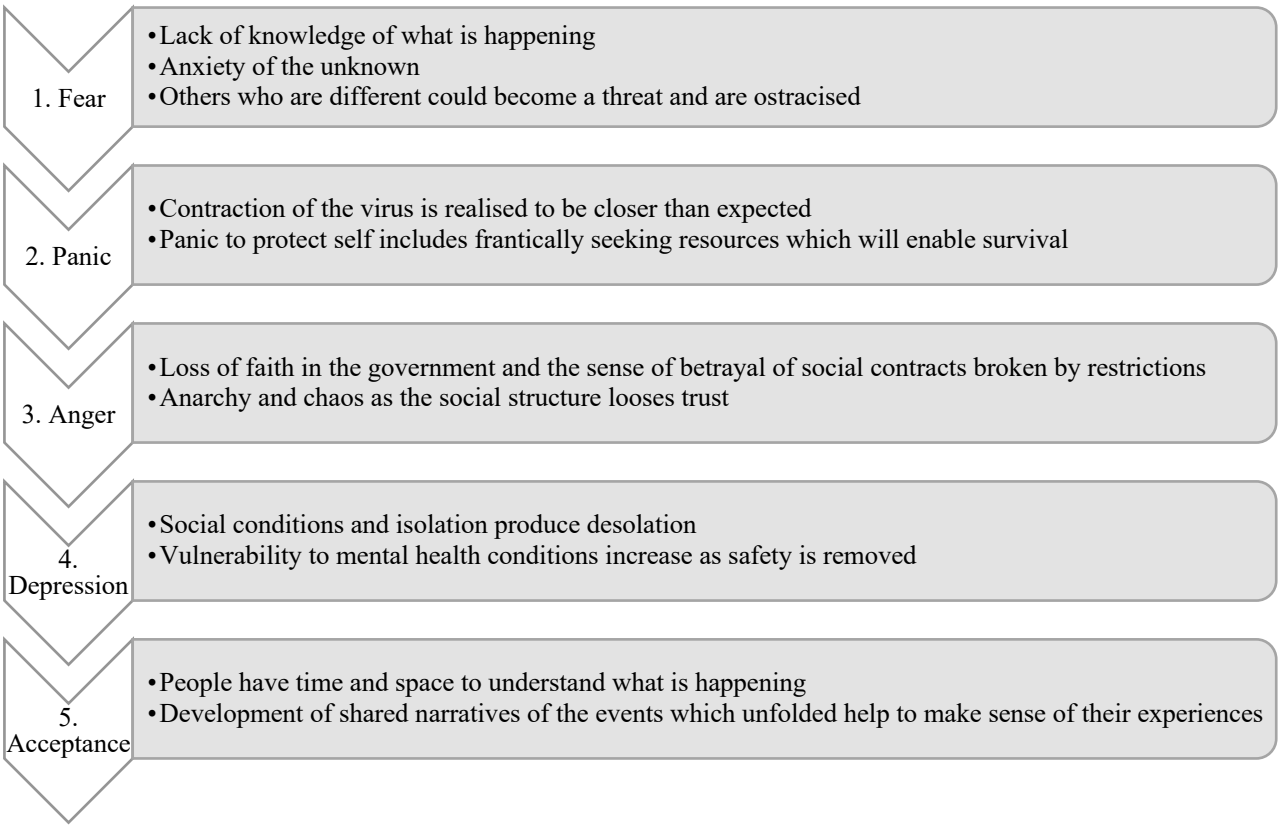


Figure 2: *Ventriglio and colleagues' (2020) Stages of Life of COVID-19 Pandemic*

As illustrated through this framework, it is argued that the secondary effects of the pandemic also included an increase of mental health difficulties (Bhugra et al., 2021). Widespread fear, panic, anger, and low mood could be building blocks of a public mental health crisis (Sidorov, 2015). O'Connor and colleagues (2021) surveyed 3077 adults in the UK during the first national lockdown from March 2020 – June 2020. During this three-month period, the survey found an increase in suicidal ideation over time, accompanied by anxiety and low mood (O'Connor et al., 2021). The study also found that people with pre-existing mental health difficulties and those from social disadvantaged backgrounds had worse mental health outcomes in comparison to the general population (O'Connor et al., 2021). The inter-section of mental health difficulties in those who may experience social disadvantage is documented in the literature (Cooper et al., 2008). These groups may already experience isolation and lockdown restrictions may have intensified loneliness. O'Connor's and colleague's (2021) findings supported the need to explore the impact of COVID within these groups to understand the mental health challenges encountered because of the pandemic.

Bhugra et al. (2021) explored the impact of previous epidemics and reported that there are higher levels of anxiety, depression, substance misuse, post-traumatic stress and survivors' guilt in people who had a pre-existing mental health condition. In their review, Bhugra and colleagues (2021) highlighted a need to understand the scale of the mental health challenge posed to the UK, particularly as the impact on those with pre-existing mental health conditions was unknown. Bhugra et al. (2021) also points out that research appeared focused on the physical needs of the population, along with a side-lining of mental health as a by-product of the pandemic. The current study aimed to support the development of a more complete understanding of the experiences of people with pre-existing mental health conditions.

Psychosis and COVID-19

Psychosis can be a debilitating and enduring mental health problem. Bentall (2003) defined psychosis as a term to describe a group of psychological problems which affect someone's reality. People with psychosis can face reduced social, cognitive, and occupational functioning and can require long-term support from mental health services (Bartholomeusz et al., 2013). It has been recognised that the COVID-19 pandemic may affect people who are vulnerable to psychotic experiences. McCormick (2020) conducted a discursive analysis on news articles during the first national lockdown and found 'war and battle metaphors' (such as 'world-ending' or 'fighting the virus') were used in the cultural construction of the pandemic in the media, government policies and anecdotal reports. There was a construction of pandemic 'heroes and villains' (such as 'NHS heroes' and 'antivaxxers') across narratives (McCormick, 2020) which have been associated with psychotic-like symptoms in the general population, particularly around perceptions of threat and persecution (Ferreira et al., 2022). The construction of vaccine conspiracy theories has also been associated with psychosis-like symptoms such as paranoia (Ferreira et al., 2022).

Lyons and colleagues (2021) explored the COVID pandemic through an analysis of online 'Reddit' posts that mentioned terms related to psychosis. The results included 65 posts that were thematically analysed (Lyons et al., 2021). The study found people who had posted about experiencing psychosis during the pandemic had experienced increased sleep problems, suicide ideation and auditory hallucinations (Lyons et al., 2021). Themes also suggested an increase in contamination-based fears and delusions as well as increased thoughts of responsibility for harmful effects of the pandemic (Lyons et al., 2021). The study also indicated that people who had experienced psychosis during the COVID pandemic had also experienced challenging beliefs which were 'disease-themed' (Lyons et al., 2021). For

example, people had reported hallucinations relating to masks used during the Bubonic plague (Lyons et al., 2021).

However, Lyons et al. (2021) does not explore the pandemic from an experiential perspective, and, due to the nature of the uncontrolled and open online forum, the validity of the claims in the posts remains unclear – including whether they were from people who had formal diagnoses of psychotic disorders. This points to a need for research exploring experiential accounts of the pandemic from people with known psychotic disorders to better understand the potential impacts of the pandemic on people with severe mental health issues.

There are few experiential UK-based studies exploring the impact of the COVID-19 pandemic on people with psychosis. One study conducted in Italy investigated the association of psychosis and COVID-19 infection. The study found referrals for First Episode Psychosis (FEP) had increased since the beginning of the pandemic (D'Agostino et al., 2021). Esposito and colleagues (2021) added to this work and recently found a positive correlation of increased psychosocial stressors in the first four months of the pandemic and a rise in First Episode Psychosis (FEP). These results indicated the Coronavirus pandemic had affected the emotional health of people producing higher incidences of psychosis.

This supports previous research that found an increased number of people with reported psychosis in Sierra Leona during the Ebola outbreak (Kamara et al., 2017). A case report series in published in the United States of America (USA) also found an increase in reported hallucinations and delusions following a positive COVID-19 test (Chaudhury et al., 2022). These symptoms were argued to be a product of the viral infection and should therefore be considered separately to psychosis (Chaudhury et al., 2022). Such arguments remain contested.

Tariku and Hajure (2020) completed a narrative review and found frequent reports of psychosis following COVID. They also concluded that the risk of psychosis appeared raised

following a positive COVID-19 infection (Tariku & Hajure, 2020). Ferrando and colleagues (2020) suggested that the neurological basis of the COVID infection could produce psychotic symptoms in people who had not experienced psychosis previously. However, these results do not progress our understanding of the difficulties faced by people with psychosis before the COVID-19 pandemic. Studies exploring pre-existing psychosis and the potential effects of COVID appear neglected. At the time of writing, the author is not aware of any other research exploring the experiences of people with pre-existing psychosis during the pandemic.

Social disadvantage from psychosis during COVID-19

It would be helpful to understand the experiences during the pandemic of people with pre-existing psychosis, as this is a group who are also disadvantaged through an intersection of their mental health and other personal characteristics (Cooper et al, 2008). Bhugra and colleagues (2021) drew attention to the intersection of these disadvantaged groups, the possible challenges they may have faced in the pandemic, and how these may differ from the general population. It is currently unknown how such groups experienced the pandemic and what different challenges, or facilitators, they might have faced compared to the general population. Research has documented the unequal effects of the pandemic on disadvantaged groups (Bottan et al., 2020; Proto & Quintana-Domeque, 2021) but there is limited knowledge of the experiences from people with psychosis.

For people with psychosis, the nature of their symptoms could lead to increased isolation and social withdrawal (Cooper et al., 2008). For instance, command hallucinations might become alarming, and the person could manage any potential risk to others through withdrawing from them. This can lead to a narrowing of social networks and connection to others. In some cases, this means stopping occupational activities and consequently having a lower financial stability than those not experiencing active psychotic symptoms.

Experiencing psychosis could therefore lead to a disadvantage. During the pandemic, closure of services and national restrictions could have intensified this disadvantage further. Yet, most research has focused on how the pandemic may have contributed towards experiencing psychosis. Less is understood about the impact of the pandemic in those who were already disadvantaged by their experience of psychotic symptoms.

Brown and colleagues (2020) conducted a systematic review of previous epidemic findings and found social distancing measures used for physical protection exacerbated isolation and social exclusion. For individuals who may benefit from more social support, it could be argued the effects of social distancing measures may have been greater. Wood and colleagues (2021) explored 14 family members and carers of people with psychosis who were admitted to an adult inpatient mental health hospital during the pandemic. Family members and carers who were interviewed discussed the experience as affecting their well-being, particularly around traumatic hospital admissions that were characterised by worries of not seeing their loved one again (Wood et al., 2021). Wood et al. (2021) did not explore the experience of the pandemic for those with psychosis and so the perspective of people with psychosis was not captured.

Aims

The limited understanding of the experience of the pandemic from people who have pre-existing psychosis before the start of the pandemic, suggests a need for further research. The aim of the present study is therefore to develop a greater understanding of the psychological impact of the COVID-19 pandemic on people with psychosis. The purpose of this current research study was to investigate the pandemic from the perspective of people with a pre-existing diagnosis of psychosis in the hope to develop better understanding of the possible effects of the COVID-19 pandemic on their mental health. This study explored how

people with psychosis experienced their emotional well-being during the COVID-19 pandemic.

2.2: Method

Theoretical background of 'phenomenology'

Phenomenological psychology is an approach seeking to explore how people make sense of their lived experiences (Smith et al., 2022). This approach is grounded in a critical realist perspective that implies knowledge about the world is developed through understanding experience (Barker et al., 2016). In this relativist stance, there is no 'one-truth,' but instead multiple versions of truth can be developed from different perspectives (Smith et al., 2022). In critical realism, an understanding of the truth may be captured through attempting to get as close to the person's lived experience (Pilgrim, 2019). As such, an interpretation is made of the person's experiences (Larkin et al., 2006).

Interpretative Phenomenological Analysis (IPA) is a method of acquiring knowledge of how people experience the world (Smith et al., 2022). IPA is grounded in the interpretations made of the specific and personal ways people make sense of their experiences (Smith et al., 2022). It is this aspect which makes the approach idiographic and attractive to psychologists seeking to understand phenomena experienced by people (Larkin et al., 2006). As the focus of this study is around the pandemic and how this experience is understood by people with psychosis, IPA was considered a suitable method of study.

In this study, IPA is used to explore the lived experience of the COVID-19 pandemic from the perspective of people with psychosis. Throughout this process, the researcher attempts to understand this experience. The attempt of understanding a lived experience comes from a secondary perspective and as such, is removed from the direct experience, involving a process referred to as the 'double hermeneutic' – the researcher makes interpretations of the participants' interpretations of their direct experience (Barker et al.,

2016; Smith et al., 2022). This study followed this process to explore how people with psychosis made sense of their own wellbeing during the Coronavirus pandemic.

Design

Participant recruitment

Based on the need to recruit participants who had psychosis before the start of the Coronavirus pandemic, purposive sampling methods were used. The research was conducted within a National Health Service (NHS) Mental Health Trust ('the Trust') where confirmation of diagnoses could be obtained to ensure participants had a diagnosis of psychosis during the pandemic. The study was available to all adult service users across the Trust with a diagnosis of psychosis; however, the researcher specifically contacted local Community Mental Health Teams (CMHTs) and Early Intervention Psychosis (EIP) teams in the Trust to inform them of the study's recruitment.

Ethical approval was sought and granted by the NHS Health Research Authority (HRA) (Appendix 2A) after careful consideration of ethical issues, including safeguarding, confidentiality, anonymity, risk, and informed consent. To help select participants with a diagnosis of psychosis, Table 8 outlined the included ICD-11 and care cluster codes which fall under the umbrella of psychosis.

Table 8: *ICD-11 and Care Cluster Codes used to identify people with a diagnosis of psychosis*

Diagnoses	Care Clusters
Schizophrenia Schizotypal (Personality Disorder) Delusional Disorder Acute and Transient Psychotic Disorder Schizoaffective Disorder Substance-induced Psychotic Disorder Secondary Psychotic Disorder	10: First Episode Psychosis (with/without manic features) 11: Ongoing Recurrent Psychosis (Low Symptoms) 12: Ongoing Recurrent Psychosis (High Disability) 13: Ongoing Recurrent Psychosis (High Symptom and Disability) 14: Psychotic Crisis 15: Severe Psychotic Depression 16: Psychosis and Affective Disorder (High Substance Misuse and Engagement) 17: Psychosis and Affective Disorder (Difficult to Engage)

Alongside these categories of psychosis, only people who were 18 years old or older were recruited from the service. Participants were also required to have access to technology to hold an online interview and engage with the researcher remotely. The first approach to potential participants came from members of the person's clinical team. Table 9 outlines the process for participants being recruited to the study through clinical teams in the Trust.

Table 9: *Process followed to recruit participants from clinical teams*

1. Researcher contacts clinical teams and passes information about the study using a clinical information sheet and posters. Further discussion is held at the request of clinical teams across the Trust. Participant information sheets and participant posters are distributed to clinical teams.
2. Clinicians discuss the option of participation with suitable service users and offer them the participant information sheet.
3. After verbal consent, the clinician passes the service users name and contact number to the researcher, including their diagnosis status
4. The researcher telephones participant to discuss the study further. After 48 hours, the potential participant is emailed a link to complete an e-consent form and email the researcher back to confirm they have signed this. The researcher sends back a copy of their signed consent form with a confirmation of the appointment time.
5. The participant is invited to an online interview using media platforms that enable 'share-screen' options to help create a virtual timeline of the pandemic. Participants are reminded of the two-week window they have should they wish to withdraw their information.

Materials

As per Table 9, clinical members of staff across the Trust were given separate information sheets (Appendix 2B) and posters (Appendix 2C) that detailed the requirements of the study. Staff teams were given separate participant information sheets (Appendix 2D) and participant posters (Appendix 2E) to share with interested service users in a way which removed clinical jargon. The participant information sheet also included details of where they could find emotional support following the interview should they need it.

Once a suitable participant was identified by the clinical team, they requested permission from the service user to be contacted by the researcher. After a discussion about the study was held with the researcher, the service user was sent an electronic consent form after 48 hours (Appendix 2F) through a mobile link. Participants were requested to contact the researcher on an internal NHS inbox to confirm it was themselves who had signed the form. The researcher would then download the completed form and send a copy back to the participant with a confirmation of their interview time.

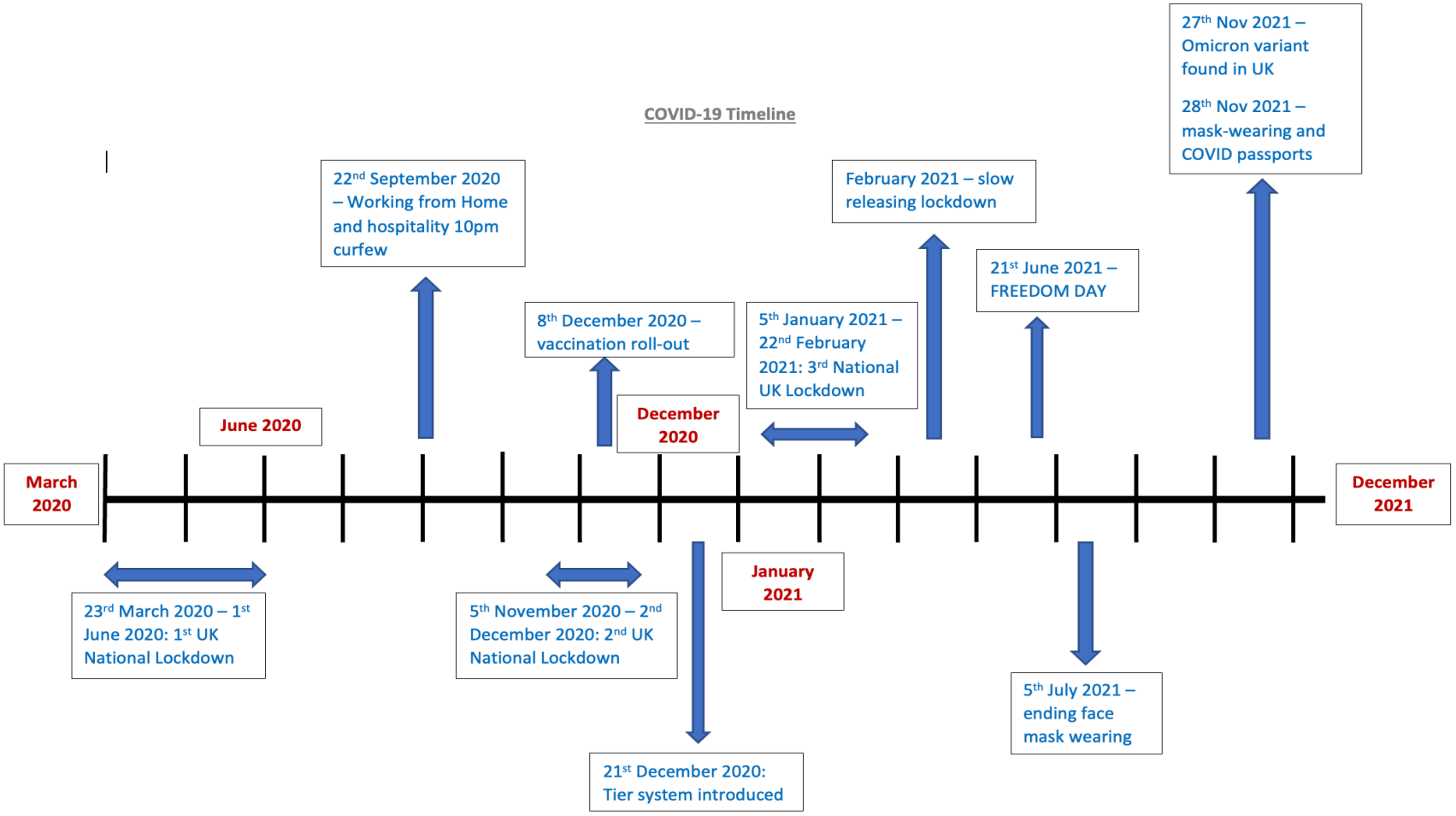
An interview schedule (Appendix 2G) was created to help guide semi-structured questions for the participant. Interviews were held online using a platform which would enable screen-sharing options. This was to help show a visual timeline which was completed as the interview progressed with participants. Figure 3 shows an example of the timeline completed with participants. This acted a template to visually show the COVID-19 pandemic and included key dates to help participants with their memory of the pandemic. People with psychosis may face cognitive difficulties which can sometimes impair abstract thinking, and that of times and dates (McCutcheon et al., 2023; Rund, 2018). Therefore, the timeline acted as a tool to enable participants to think about specific moments in the pandemic and order their narratives. The standard timeline was modified by the researcher, editing the template under direction of the participant. If they chose, participants were given a copy of their

timeline following the interview. Timelines were used to support participants engagement in the interview and did not form part of the analysis in this study.

At the end of the interview, participants completed a Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987) (Appendix 2H) to identify the characteristics of their psychosis for the purpose of homogeneity. The researcher informed participants they would be making observations based on the psychosis presentation during the consenting process. PANSS scores were based on the interview encounter. Scores from seven to 49 were given on positive and negative sub-sections of the scale. Higher sub-score for positive or negative suggested a higher incidence of psychosis characterised by that sub-category.

The PANSS has been granted permission for research use as outlined in Kay et al. (1987). Hamner et al. (1999) and Tarrier et al. (2007) both used the PANSS to categorise participants symptoms into positive and negative dimensions and to monitor the progression of these symptoms over time. The actuality of psychosis is that there is a cross over between negative and positive symptoms, but presentations could be dominated by specific features which makes the nature of the psychosis differ from person to person (Hamner et al., 1999). A discussion with the referring clinician was held to confirm whether the PANSS score appeared appropriate for the participant. These scores were not used for analysis but helped create a picture of the person's psychotic presentation to understand their experience of the pandemic.

Figure 3: *A Timeline of the COVID-19 Pandemic*



Sample

Eight participants were recruited to this study through the clinical teams in the Trust. This was considered an appropriate number of participants for a professional doctorate qualitative study based on the guidance from Smith et al. (2022) who recommended between six and ten individual interviews. Participants were aged between 19-51 years old (mean = 32 years) and comprised of 5 males and 3 females. Of the total eight participants, five identified as White British, one as British Asian Indian, one as British Asian Pakistani and one as Black British.

The PANSS indicated that six of the participants held a psychotic presentation characterised by positive symptoms (e.g., hallucinations and delusions) and the remaining two held a presentation characterised by negative symptoms (e.g., blunted affect, lack of motivation and interest). The names and details of participants were changed to protect their anonymity, including the names of other people and locations they mentioned in their accounts. Table 10 was used to capture some of contextual information around each participant. These details were important for grounding the analysis in the participant's context but all identifying information was anonymised or removed. Pseudonyms have been used for people, voices and places which may be important for understanding the participants' experiences.

Table 10: *Participant contextual information*

Participant Pseudonym	PANSS	Contextual description
Harry	Positive	After the death of his father, Harry had a transient psychotic episode where he believed the world would be chemically attacked by a Russian offense. He felt reminded of these beliefs when COVID-19 struck the world.
Amelia	Negative	Amelia had a heightened sensitivity to noises. Avoidance was Amelia's preference for coping with the distress that jarring noises made.
Jamie	Positive	Jamie reported being targeted by a gang who he owed £50,000 to. His hospital discharge coincided with the introduction of the first national lockdown.
Naomi	Positive	As a child, Naomi had been bullied, sometimes racially. She had heard the voice of 'Barry' since she was 12. He had usually helped her feel less alone but became threatening during the pandemic.
Carl	Negative	Before the pandemic, Carl described himself as isolated and withdrawn. He felt more connected to others during the pandemic.
Amir	Positive	In adolescence, Amir had experienced sexual abuse from his uncle. He had heard the voice of his uncle since. Going to the gym was a helpful coping mechanism but this removed during national restrictions. During the pandemic, Amir was outcasted by his family and community for being homosexual.
Nina	Positive	Nina feels psychosis implies she is an 'incompetent' mother. Nina's work identity was a large part of her recovery from psychosis where she felt valued and competent. Working from home removed this.
Scott	Positive	Scott's father passed away after contracting Coronavirus in the first lockdown. He had no other family and felt alone.

Data collection

Data for the study was collected through individual semi-structured interviews lasting between 60-95 minutes (mean = 77 minutes). Participants were interviewed once using online software. All participants held the interview online from their homes and in a private space. Interviews were audio recorded using an encrypted voice recorder. Audio recordings were then transcribed verbatim and by hand. Transcripts were anonymised through removing names of places and people, before being transferred outside of the NHS setting for analysis.

Analytical procedure

Analysis followed the procedure outlined by Smith et al. (2022) and is illustrated in Table 11. This approach considers recent adaptions made to IPA where there is a closer inspection of the individual accounts of participants to create 'experiential statements.' These statements later become coded into 'Personal Experiential Themes' (PETs) (Smith et al., 2022). Table 11 outlines the seven staged process developed by Smith et al. (2022) and followed in this study.

Table 11: *The process of IPA outlined by Smith et al. (2022)*

Stage	Description of process and actions within the stage
1. Reading and re-reading	Initially the interview is read during transcription and re-read to become familiar with the experiential account. In this study, interview transcripts were printed following transcription and read. Smith et al. (2022) argued a printed copy of the transcript can improve the engagement with the text and enable the researcher a different experience of engaging with the experiential account before them.
2. Exploratory noting	After an initial reading, the transcripts were then re-read whilst making exploratory notes (Appendix 2I). Notes, exploring the ways in which the participant describes, uses language and may be conveying a semantic message are made in the right-hand column of the transcript. These different levels of coding were applied line-by-line of the participant's account.
3. Constructing experiential statements	These notes were then developed into 'experiential statements' which referenced an understanding of what the participant was discussing with the interviewer (Appendix 2J). Text which illustrated the experiential statement was highlighted using different colours. These quotes from the transcript were then extrapolated with the experiential statement into a table.

Stage	Description of process and actions within the stage
4. Developing PETs	Smith et al. (2022) illustrates the benefit of having a physical copy of the experiential statements with their corresponding transcript quotes. These are printed, cut out and moved around to search for connections between experiential statements in the individual's account. These connections form PETs.
5. Organising PETs in a table	Once the connections have been established, each PET is placed into a table with the synthesised experiential statements underneath (Appendix 2K). In this study, the corresponding quotes were extrapolated with the experiential statements. This was to keep a proximity to the participants' accounts and enable an iterative process where PETs were continually checked with raw transcript data. This study also completed mind-maps for the individual PETs following each interview (Appendix 2L). This was to help illustrate the connection of PETs in the participant's account. This is additional to the steps and was a decision made by the research who found the participants had described their experiences in an inter-connected and 'story-like' way making it appear to have a structure. In part, this structure could have been introduced by the timelines. However, it was seemingly important for participants to structure their accounts in this way and important for understanding how they made sense of their experience during the pandemic.
6. Repetition of the process for each participant	This process was then repeated for each participant in the study. Smith et al. (2022) pointed out the order of participants early on could influence the interpretation of later accounts. To manage this, the order of participants was reversed from the order of which they had been read initially. Smith et al. (2022) also recommended managing these possible effects on later participant's accounts by coming to each participant account with a clearer mind. For this reason, the researcher ensured time between each participant's account of at least a day.
7. Developing Group Experiential Themes (GETs)	Once all participants had PET tables and mind maps developed, connections across PETs were explored. Mind-maps created for each participant were combined to visually notice patterns across the accounts (Appendix 2M). Colours and sticky notes were used to highlight shared connections and patterns. Once a set of common patterns were identified, this was typed into an Excel Spreadsheet (Appendix 2N), alongside the extrapolated transcript quotes. This helped generate a better understanding of the patterns and re-connect with the participants' raw experiential accounts. These commonalities were refined using the 'tab' function in excel to create a more synthesised understanding of different patterns. Commonalities were written up using the transcript data into separate groups which appeared most apparent to the researcher. These formed the first part of the Group Experiential Themes (GETs) across the whole group of participants. As discussed by Smith et al. (2022) the writing process can aid the organisation of GETs. This process helped

Stage	Description of process and actions within the stage
	synthesise and tighten the GETs to form a collective narrative of participant's experiences during the pandemic (Appendix 2O).

Using the process described in Table 4, four GETs were identified across the accounts of participants. One of these GETs included two smaller sub-themes.

Reflexivity

As discussed previously, IPA involves creating an interpretation of the accounts discussed by participants. To ensure these interpretations are grounded in the direct experiences being studied, and are therefore plausible, IPA researchers are encouraged to engage in triangulation and reflexivity processes (Smith et al., 2022). These processes require the researcher to be present. For this reason, this section of the report includes first-person discussion.

Firstly, throughout the process of data collection and analysis, I worked with and consulted my supervisor. Having discussions about the interview processes helped guide my thinking about my own perspective of what the participant had conveyed. These thoughts were written into a reflexive log to help contain and check my own positioning during analysis. I discussed these reflections with my supervisor and consulted with my peers completing similar doctorate projects during specific IPA workshops. Feedback received during these discussion helps modify and refine initial exploratory notes, experiential statements, PETs and finally GETs. As suggested by Smith and colleagues (2022), such conversations were helpful to the overall quality of the analysis by suggesting reliability of themes, including rigorous thought of plausible analytical themes.

As there is a double hermeneutic element to IPA, researchers are encouraged to reflect on themselves and how they may inadvertently influence the interpretations made of participant accounts (Smith et al., 2022). The discussions held with my supervisor

encouraged these reflections. I became interested in the experiences of people with complex mental health difficulties and the wider field of Clinical Psychology, because of a passion to help people experiencing distress and who could experience disadvantage. Whilst working within inpatient mental health settings, first as a Mental Healthcare Assistant, then as an Assistant Psychologist and currently now as a Trainee Clinical Psychologist, I have developed my curiosity in complex mental health.

My interest in the pandemic's influence on mental health came from an appreciation of the personal experience of the pandemic on myself and people I knew. This interest extended to a group of people with a diagnosis of psychosis who I had encountered during my first placement as Trainee Clinical Psychologist. I felt moved by the need to help these people and became enthusiastic about the prospect of a research study exploring the impact of the pandemic on emotional well-being of people with psychosis.

2.3: Results

During the interviews, participants shared their experiences of the COVID-19 pandemic. Participants described the pandemic using their timelines. This helped structure their narratives and showed how experiencing COVID interacted with people's pre-existing psychosis. This appeared to create a combination of challenging but equally empowering experiences which became useful for participants during their own recovery journey from psychosis. Analysis of the data identified three shared experiential themes.

The first theme suggested psychosis symptoms had become amplified during the pandemic, whilst the second theme identified segregation and disadvantage had become accentuated. Theme two included two smaller subthemes which clarified the ways in which COVID had been interpersonally challenging for people with psychosis. The third theme captured how COVID had helped become a means for other people without psychosis to connect with those with psychosis. Finally, the fourth theme built on this idea showing how

the pandemic had become an opportunity to support participants' recovery from psychosis.

Table 12 shows the structure of these themes in more detail with selected quotes.

Table 12: *Shared experiential themes across participants*

Shared Theme	*Sub-themes*	**Illustrating quotes**	**Participants contributing to theme**
Theme 1: Symptoms of psychosis were amplified during the pandemic		*"Like. I used do much shit to try and clear all that out of my head. It never left. […] But the pandemic. Well that put a stop to everything. […] and the voice. Ramesh just got louder and louder."* (Amir, Lines 115-121)	Amelia, Amir, Harry, Jamie, Naomi, Nina, Scott
Theme 2: The pandemic accentuated disadvantage in society			
	2.1: Segregation and difference is heightened	*"Society has like these type of rules. And I um always find. I'm on the outside like. […] just. Um maybe both actually. The rules are made for people like me to um listen to them. Like um follow the rules. The ones that make it don't have to."* (Naomi, Lines 292-297)	Amelia, Amir, Carl, Harry, Jamie, Naomi, Nina, Scott
	2.2: Loss is compounded by COVID	*"I haven't got shit. No friends except drinking pals that would just think it's ok to drink away the worries. Or laugh at me for being a pussy. I was alone with it. No one gave two fuckin' monkeys what was going for me."* (Jamie, Lines 319-322)	Amelia, Amir, Harry, Jamie, Naomi, Nina, Scott
Theme 3: The pandemic connected everyone to some of the experiences of psychosis		*"Like not just psychosis and not just normal people. But the whole damn world this affected. Covid affected. Like. We're all empty but we're empty together. They struggled and I struggled. There was no like. They're living their best life and I'm on my own."* (Carl, Lines 331-337)	Amelia, Carl, Harry, Jamie, Naomi
Theme 4: The pandemic as an opportunity to support recovery from psychosis		*"Knowing everyone else had something else to look forward to, I wanted to have the same. And finding my music again too. Maybe I could have this as being my way of having something of my own. […] hearing people talk about 'a new normal' made me think about 'yeah lets make a new normal' for me, my new normal. Helped me make that change."* (Amelia, Lines 427-438)	Amelia, Amir, Carl, Jamie, Naomi, Nina, Scott

Theme 1: Symptoms of psychosis are amplified

This theme summarises the experiences during the pandemic where psychosis symptoms had become exacerbated. Below is an example where Harry discusses how the Russian voices he heard became more powerful:

> *It's like I'm stuck in a sort of limbo, sometimes it's like I can tell myself, this isn't real and then other times, it's as real as anything. And then I can't shake it. I feel myself getting obsessed with it. The Russians in my ear get stronger too, it's like they sense it. And then I feel watched. The pandemic has just allowed it to take back over. You know?* (Harry, Lines 213-218)

Harry points out how the pandemic had given more power for the voice to 'take back over.' This is as if his previous recovery has been unravelled by the pandemic. Harry notices the blurring of the pandemic with the beliefs he held during an acute psychotic episode where he felt he was being targeted by the Russian government who he had understood to be attacking the world through a respiratory like disease. Naomi also had similarly experienced her voice becoming more threatening;

> *Just like um if I didn't pay attention to him* [the voice]*. He would tell me he's going to kill um like another five thousand people and I'll see it on the news.* […] *and I did like. Um I saw them on the news. And back then, um I knew I thought he means business. Um I know now like that they died because of the virus. But it felt like it was me.* (Naomi, Lines 194-200)

Naomi points out how the voice became more powerful by using the events she had witnessed on the news. The voice would take credit for the deaths from Coronavirus to command her. In this sense, the pandemic was proof for the voice's omnipotence. Naomi's symptoms and the events of the pandemic appeared to interact, resulting in her experience of

the pandemic being merged into one of threat, fear, and responsibility. Jamie also described how his past beliefs from psychosis had become intense:

> *The mind hacking. I literally thought to myself that I had been hijacked in some way. I remember thinking to myself it's you know the gang that were after me. I know they weren't but* […] *It just felt like they were. And it didn't matter how many times I told myself it wasn't like that and it's like this. It was in my head and there was no getting away from it.* (Jamie, Lines 119-126)

Jamie draws attention to the similarity of the media's portrayal of the virus and the beliefs Jamie held of being attacked, and how this left him feeling as if they had hacked into his mind. For Jamie, there is a sense of terror of not even his thoughts being safe. Nina also found:

> *It was really weird. I hear this. Sound. Low pitch. Just whispers down my ear about how awful the pandemic is going to be. If I take the vaccine I'll take it away from a child or expecting mother who really needs it. And it means I'm bad. Ruining another mother's life.* […] *when I got it. It was like. I don't have a choice here and it was really bad. I was really bad. My anxiety was so high. I kept thinking to myself. That's it I've killed an innocent child or something.* (Nina, Lines 367-376)

Nina describes her voice hearing and anxiety was also magnified by the events of the COVID pandemic. This raised Nina's anxiety and she highlights the difficulty she faced when she contracted the virus and felt there was no choice but to protect herself and take the vaccine. This amplified her long-standing difficulties with her own sense of motherhood. Amir also described:

> *Like. I used to do so much shit to try and clear all that out of my head. It never left.* […] *But the pandemic. Well, that put a stop to everything.* […] *and the voice. Ramesh* [pseudonym for uncle's voice] *just got louder and louder.* (Amir, Lines 115-121)

For Amir, the pandemic became another factor making it difficult for him to clear his mind. COVID seemed to halt his progress and the voice he heard of his uncle who had abused him during childhood seemed more intensified. Like Nina, Amir's past trauma appeared compounded. Scott described how the impact of some of the responses to the pandemic exacerbated his worries and difficulties:

> *Like when they* [the service] *did come it was like in was infected. They asked for windows and everything to be opened and then sat like no-where near me. Masks on and like these aprons and gloves.* […] *like you imagine my shock when I saw them come to the door like that.* […] *I was shocked like. I thought in- What are you gonna do to me. Why are you dressed like that for a conversation with me. It made no sense to me. I didn't trust them when they came to the door like that. (pause) I think that was a big barrier like to me getting any type of help. I couldn't trust them.* (Scott, Lines 159-170)

Scott highlights a distrust generated from mask-wearing and social distancing as it appeared to increase the emotional and human distance between them and the reasons for the visit to his home. Scott is shocked at the appearance of people coming to help him who had a physical barrier between themselves and him. Naomi likewise found measures during the pandemic unprecedented, *"With the government announcements. It was like we were going to war.* […] *it was scary. Being alone. My thoughts racing out of control um yeah that the world was going to end"* (Lines 103-108). The language used to describe this war, where the 'world was going to end,' creates a sense of fear that the COVID pandemic threatened human survival. Naomi's vulnerability appeared magnified by this sense of threat, and in this sense, COVID maintained the struggle Naomi experienced with controlling these thoughts.

Overall, this theme illustrates the pandemic magnified pre-existing symptoms of psychosis. Public health measures seemed to escalate beliefs of being attacked, persecuted, or

threatened. The nature of the Coronavirus itself lent it to being a weapon which attacked the world and reduced safety. This reduced safety formed the basis of theme two.

Theme 2: The pandemic accentuated disadvantage in society

The second theme encapsulated discussions from participants that the pandemic increased the existing disadvantage and separation that they had already experienced. This could be understood across two subthemes – 2.1: Segregation and difference is heightened and 2.2: Loss is compounded by COVID.

2.1: Segregation and difference is heightened

Participants described their experiences of being different from others. The pandemic processes seemed to create more separation and difference between them. Naomi describes feeling on the outside of society, as *"society has like these type of rules. And I um always find. I'm on the outside like.* […] *The rules are made for people like me to um listen to them. Like um follow the rules. The ones that make it don't have to"* (Lines 292-297). Naomi suggests a divide in society seemed more apparent between people who created the rules and people who had no choice but to follow them. She highlights the injustice that people who had made rules for society did not follow these rules themselves creating a sense of this divide being unfair. There is a sense that Naomi's experience of psychosis usually makes her feel 'on the outside' and this seems magnified through the pandemic as an example of political powers creating rules which are less inclusive for her. Scott describes his experiences following his father's death:

> *It was like a year later after dad's death. They* [college] *said I should have been over it by then. There was no point in dwelling in the past. And one of them* [college tutors] *said I should be over it because so many people have lost people during the pandemic. Like, it was 'get over it' and move on. They didn't understand. My dad was everything. He was my world. He literally did everything to help me. (pause)* […] *Just*

like expected to get over it. As if it didn't happen. (pause) that was hard. I think coronavirus brought this like 'get over it' type of vibe. I'm just supposed to accept death. (Scott, Lines 96-110)

Scott felt that there was a time frame which others believed he should have mourned and grieved for his loss of his father and moved on. He suggests the wider message from society and from the college was to 'get over it' which fails to recognise the personal significance of his loss. Like Naomi, there is a divide between Scott and others around him who he felt unfairly expected him to 'get over it.' For Scott, there is a sense his psychosis would have made it harder for him to 'get over' the loss of his father and his needs were not considered by those around him. This led to him feeling others were not understanding of his mental health and why his father, who was a main carer, may have been a significant loss to that affected how he lived his life. Scott discusses the difference between him and those without psychosis is then magnified through the pandemic. This form of separation ("normal" versus not normal) is described by Jamie:

That's the part that just really gets me, pisses me right off. When it came to the pandemic, I could just see there was a clear parallel. You know like similarity between what I saw on the news with the likes of teachers, doctors and the like coming on and telling the world their sob stories and then there was my own experiences. But because they're normal and I'm not. They got given the comfort and the attention and most of all people just understood them. People never understood me. It just fucks me right off. I've never been good enough and it's just a slap in the face. (Jamie, Lines 70-79)

Here, Jamie makes it clear the pandemic is continuing to enable people to treat him differently, and this leaves him angry. He discusses the similarities between the pandemic and psychosis but points out people with psychosis are less supported and understood. Jamie

is left feeling angry at the difference between himself and others which the pandemic had magnified. Carl points out a further aspect to this separation:

> *That's it! Exactly that. it was like. Erm hellllloooo. I'm here, I'm feeling it too. I'm not like just separate from the things you lot had. (pause) sorry. not like you, you but like norrr-mal (pronounced with emphasis) people* […] *yeah like it was just like. This is normal, for normal people. You ain't normal so you can't be a part of it.* (Carl, Lines 156-163)

Carl identifies how, like Jamie, people with psychosis were treated differently and shut out of a shared connection with others. Scott similarly discussed being isolated from others because of his psychosis:

> *Like because when you're psychotic and believe these things it means your not right. Like it's psychosis. For normal people. That don't have this label. They can believe whatever they want to like without people thinking they're becoming unwell. Some people believe all sorts of stuff and like it's just because they're stressed. I'm like. You don't think I was stressed?* […] *makes me mad.* (Scott, Lines 267-274)

Scott, like Jamie and Carl, has an anger at being separated. He draws attention to unfairness where 'normal' people can hold similar beliefs but instead of being ostracised, they are understood. Scott notices these people are considered as 'stressed' whereas for people with psychosis it is a sign of being 'unwell.'

Nina describes the existing disadvantage from an intersectionality of differences resulted in:

> [others] *treat me differently because of* […] *being all three. It doesn't feel like I have anywhere where it's mm ok to be in. like if I'm at home, it's the fact I'm um a woman. At work people don't get it can be different for me in a different like race. Mm and then being in both. Well neither get it that I'm different and hear things. I'm*

psychotic. Whatever that means. […] *The pandemic just um. Yeah. Brought all of that together. Nowhere to hide.* (Nina, Lines 242-252)

This includes an intersection of her culture, gender, and mental health status. Nina appears to identify segregation occurring based on these different characteristics and that this segregation is amplified by the pandemic where it occurs out in the open. Amir describes his view of how the pandemic was used as convenient way for his family to ostracise him and separate him from the family:

The pandemic gave him [his father] *that way out. Told everyone I had COVID and it changed me yeah m* […] *it made it easier for my family. You know yeah m to just cut me off. They didn't have to think about me then did they. Perfect excuse.* […] *I even heard from a cousin that my dad had told everyone I had actually died. (pause) he'd rather me dead than gay.* (Amir, Lines 331-329)

Amir suggests the pandemic allowed his family to kill him off. Amir describes the experience of homophobia from within his culture and community around his sexuality and there is a sense the pandemic was used to mask the discrimination shown towards him. In this way, COVID enabled Amir's family's discrimination and rejection of him and his sexuality. Naomi likewise discusses:

But things did happen um to me. Like racist things. You know. […] *Um. (pause) like a coughed once. And this man. It was at* [the supermarket] *and he said to like cover my mouth, even though um I had. Um. He was like cover your mouth. You people are killing people around here.* […] *um yeah. And he was like you're killing innocent people. Like um. I know what he meant. Like usual white people. We're always the um bad ones. Like.* […] *mm like I read between the lines. (pause) and it was like he was hostile with me um like.* (Naomi, Lines 260-276)

Naomi describes an experience of going to the supermarket during the pandemic and feeling segregated from White people as a Black female. For Naomi, who had experienced a sense of responsibility for the pandemic, this type of discrimination may have increased her vulnerability. The pandemic had enabled this segregation and for racial stereotypes to become more pronounced.

Overall, this sub-theme shows the pandemic heightened segregation within society. COVID seemed to enable micro-aggressions in society and difference is outcasted and un-acknowledged to maintain a status quo. This led to the second sub-theme where COVID differentiated people with psychosis by further accelerating loss.

2.2: Loss is compounded by the COVID pandemic

This sub-theme describes the experience of COVID for people with psychosis as one of loss that further narrowed their already limited world. These losses created a sense of loneliness. For example, Naomi explained

> *It came at a wrong time. I still wanted my family in my life um but they didn't want me. COVID just gave them the reason to lose contact with me.* […] *so I haven't got them anymore in my um life anymore.* […] *It made me feel like um anyone could be out to get me, the whole world was an enemy really* […] *It's not like anyone would miss me if I did go missing. There was no one on my side far as I could see. It was only me, um.* (Naomi, Lines 92-155)

Naomi points out her increased loneliness of having no-one who could support her. As Naomi lived alone and her family had stopped visiting her, there is a sense of her social world becoming even smaller. This effect of the pandemic has been long-term as her world is still altered and smaller than prior to COVID. Scott talks about the direct loss of his father from COVID:

I miss him. COVID wasn't something I was that much bothered about when it first happened. My world was like. Just me. And dad. Auntie. Uncle. College. That's it. Some friends. I wasn't that bothered. It wasn't that different to what I did before. I didn't really go out. I wasn't like a usual teenager. Or 16 year old. But yeah without him there. It just completely turned everything into a nightmare. That world. It just um changed. Like yeah. […] *yeah. It wasn't something on the radar before. But when it did happen. I just completely lost that world. I stopped studying at college. I got kicked out. I didn't see any of my mates. I didn't have many and I rarely saw them as it were there. so they weren't bothered like.* (Scott, Lines 75-89)

Scott discusses his life before the Coronavirus pandemic as being small and select. Through the loss of his father, the pandemic had narrowed this world further. Scott also describes his relationship with his friends and how this left him vulnerable to isolation, as they did not maintain contact. This was similar to Jamie:

I was scared, like real scared, Jasmin [interviewer], *that I might get it* [psychosis] *again and again. I haven't got family like yous that probably take care of yous. I haven't got shit. No friends except drinking pals that would just think it's ok to drink away the worries. Or laugh at me for being a pussy. I was alone with it. No one gave two fuckin' monkeys what was going for me.* (Jamie, Lines 317-322)

Jamie discusses feeling scared at being discharged from hospital in a changed world from the pandemic and without any genuine and caring support, like family. He holds a phantasy that this is different to how others would be cared for, like the interviewer. Jamie worries about what might happen if his psychosis returns whilst he is without support. He discusses feeling:

absolute fucking rage. I just managed to get someone and then they bloody leave! (laughs) I know it wasn't Sophie's [pseudonym for healthcare professional] *fault. She*

had to go because of the pandemic. […] *but like I couldn't get over it. Here again. Someone from high and mighty fucking land taking a decision that impacts on me without even looking at what I'd been through.* (Jamie, Line 218-226)

Jamie had developed a supportive relationship his nurse when the pandemic meant she was needed to leave and support acute inpatient wards. Jamie discusses his complete loss of support, and the scarcity of supportive figures in his life meant this loss was compounded. Nina also discusses the pandemic had compounded the loss of her sense of work identity:

Just being split between being the good worker, the good mom and the good wife. (pause) the funny thing is that I'm supposed to be 'good' (emphasised) at all of these but in reality I actually am not that good. I'm crap actually. […] *It's like the pandemic what's the word? Magnified. Things. I think I was only good at doing these things separately but not all together.* […] *it's like the walls between each role. Especially my home me and my work me were just taken down.* (Nina, Lines 188-202)

The pandemic had magnified the difficulty Nina had with swapping and changing in different roles. This seemed to dismantle her sense of being competent in the different roles she had as a mother, wife and a 'worker.' Amir also described a loss in his coping strategy:

The gym helped [with the voice-hearing]. *Then it was like trying everything I ever could. Trying to numb myself and then trying to feel something at the same time.* […] *The gym helped most of all. I didn't really come to like the self-medication until yeah the gyms all fucking closed didn't they.* (Amir, Lines 131-138)

Amir points out the gym was his most effective coping strategy for managing the distress caused through his voice hearing. When the national restrictions resulted in the gyms closing, Amir highlights his use of drugs to self-medicate. For Amelia, the loss of her usual lifestyle felt:

like being in a black hole, there was no light at the end. […] *my parents* […] *They weren't able to go out and do the same things so they were stuck at home with me too. Problem was it got really cramped in our house and I couldn't put up with that feeling of being overcrowded, if you get me?* […] *we're not very well off and there's not a lot of space at home. It was hard to have to share the TV, share the kitchen, share the lounge… twenty four seven, all day everyday* […] *I used to avoid going anywhere because I wanted to be rid of it* [the noise made by others] *but when the lockdowns happened, it just meant they'd do that in the house. I felt there wasn't any escape from it.* (Amelia, Lines 22-40)

For Amelia, she is encased in her home with her family who she feels is taking over the space she once had for herself. The lockdown measures, such as the working from home mandate, removed the physical boundaries she had to protect her from the sensitivity of noise. Amelia describes having no escape from these measures and the impact it had on her. Overall, this sub-theme identifies the pandemic had enhanced loss, resulting in a loneliness and separation from others.

Theme 3: The pandemic connected everyone to some of the experiences of psychosis

The third theme involved the way in which people had seen the pandemic as a way for others to connect to their experience of psychosis. Across the participants' accounts, they reflected on the pandemic as a shared experience with the rest of the world. For example, Harry said:

I knew others were the same as me. It felt better than being called crazy, not believed and ignored. Being alone this time was the same as everyone else. They were just as alone as me and I, just as much as them. Strange. Humanity coming together in their equal loneliness! (Harry, Lines 87-92)

Harry suggests that there is a shared isolation and loneliness during the pandemic which helps to make him feel like other people, and that others had an insight into the loneliness he felt from his psychosis. Carl echoed:

> *I feel a bit like. You know. A weirdo. For saying this. But like in a way the world became scary but in a way which everyone was scared of it together? You know? Like not just psychosis and not just normal people. But the whole damn world this affected. Covid affected. Like. We're all empty but we're empty together. They struggled and I struggled. There was no like. They're living their best life and I'm on my own.* (Carl, Lines 331-337)

Carl shows a shared sense of fear and struggle during the pandemic which removed the dividing line between psychosis and people who did not have psychosis. The indiscriminate way the pandemic affected everyone resulted in struggles becoming normalised. Amelia similarly conveyed:

> *I could get out of everything now and didn't need to say 'it's because I'm psychotic.' It sounded much better to say 'its because of covid.' And I knew people would get that, they experienced it too, it was normal to feel er anxious because of that because everyone understood and got it but psychosis was like it's just my problem.* (Amelia, Lines 167-172)

Amelia highlights how COVID enabled her to be understood by others who had no direct experience of psychosis but could understand her anxiety of being in public settings. The shared experience of the pandemic normalised this anxiety. Amelia suggests using the pandemic as an excuse for this anxiety. Jamie similarly expresses "*It was like the pandemic helped me feel normal again but also brought everyone to my level, sort of thing, in a way* […] *I was able to join in with that hype. And that doesn't happen very often like*" (Lines 545-

550). Jamie describes this as being unusual as he is usually less able to feel a togetherness with other people.

One way this is enabled by the pandemic is through the pandemic bringing people closer to Jamie's normality. Harry similarly identifies that *"the restrictions made us all the same. I've had to live with those restrictions since my dad died in 2018"* (Lines 95-96). Harry had already lived in a restricted world due to his psychosis and the pandemic had made people experience this in a similar way, reducing his sense of being different to people. Carl expanded:

> *Having other people who knew what that* [loneliness] *felt like. I know it was because of COVID but like yeah. Other people started to know what it felt like. Being alone. Just not having anyone else. It made me see that yeah like. I wasn't alone. Other people can feel threatened and that like you know cutting yourself if actually a way of protecting yourself like.* […] *I guess it kind of made me think that erm you know I'm not so alone anymore. That like other people also were isolating, and it were all out there like about people, like regular people feeling suicidal. (pause) I guess it did make me feel normal. I was just like them.* (Carl, Lines 70-107)

For Carl, the pandemic had normalised experiences of mental health difficulties. Witnessing other people having difficulties helped normalise his own struggles. However, Jamie points out this normalisation was temporary:

> *Welcome the world to psychosis. Psychosis meet world, world meet psychosis. It was like. This is what it is. You want to know the feeling of a mad person. Here you go. This is what it's like. Feeling threatened. Being away from people. Feeling isolated. Actually, being fucking isolated. They just experienced a little glimpse but this is actually what I have to live with. You know that bit there. The freedom day stuff?* [...]

that doesn't happen in psychosis land. There's no freedom here. (Jamie, Lines 397-406)

Jamie describes an abandonment when the pandemic comes to an end that draws attention to the main difference of the general population having a 'Freedom Day' from COVID. In contrast, Jamie feels there is no freedom from psychosis. He feels alienated from the freedom being experienced by the world. This related to previous themes of increased separation and difference. Overall, this theme suggested the pandemic helped normalise and connect people to the experience of psychosis through the national restrictions and the sensitivity to threat. This connection, however, was temporary.

Theme 4: The pandemic as an opportunity to support recovery from psychosis

This theme describes how the pandemic became an opportunity to help support recovery from pre-existing psychosis. This appeared to be a reflection shared by participants across their accounts. Amir explains:

I'm not yet there with everything yet. But um I'm going back to the gym and Paul [pseudonym for partner] *is making me eat healthy. That's a good thing. The pandemic did bring us closer. And (pause) maybe I needed that break away from my family. They weren't the best thing for me. And I'm much happier now. Even if I do miss them. And I do. Yeah m. I' just think it's better missing them from a far rather than being there and missing their love. Even though they're there. (pause) I miss my sister but I can't do anything now. It's just about moving forward.* […] *My therapist said it's like a bus. Everyone gets on and gets off but I'm driving it. It's my bus.* […] *I've stopped drugs now and haven't drank since. Urgh who knows when!* (Amir, Lines 381-396)

Amir describes the pandemic, in hindsight, helped him create changes to his life after his family had disowned him. This included ceasing substance misuse and building coping

strategies such as the gym, and Amir does highlight professional support had a role to play in adopting this new mindset. The pandemic also created distance from the opinions of his family. A similar use of the pandemic to strengthen relationships was discussed by Jamie:

> *Like the fact I was doing this normal thing, made me feel normal. And then being able to share with others, like asking 'why are you so angry' it meant I could talk about it. And it was ok. I talked about it to the other guys. Someone there, Brad who used to hold my bag for me and train me, he told me he had been diagnosed with depression and he had like really really erm bad messed up fucking thoughts like. and it made me see that like this anger maybe isn't so much like just psychotic. It's just helpful to know that there are others who felt like this too. (pause) Brad introduced me to some of the lads in the boxing classes like and er they too had felt some crap over the last year. You know. It's not my problem then. It's like it's society's shit problem, everyone has it its just some people like me get labelled and shoved around. It's good to just know that. I'm not against the world then.* (Jamie, Lines 446-562)

Through the gym, Jamie had become friends with Brad who had experiences of mental health and connected him to a group with similar difficulties. This formed a small community for Jamie to discuss his feelings. Jamie described feeling as if he was not so different to these people and they helped him question whether the challenges he faced were part of a wider society issue rather than being located in himself. Jamie seemed motivated to be part of 'normal' activities through the atmosphere created by the pandemic:

> J: *If I hadn't had that atmosphere then maybe when my mum and sister visited I would have gone back into feeling sorry for myself.*
>
> I: *mmm so that atmosphere helped you with finding the motivation to go to gym.*
>
> J: *Absolutely. Yeah. It was like this is the right fucking time for things. It just all fell into place.* (Jamie, Lines 536-542)

For Jamie, the atmosphere at the end of the pandemic helped him create changes like Amir. In this sense, the atmosphere of the pandemic's 'new normal' had become a means of making changes, which in turn supported a recovery from his psychosis. Similarly, Carl described:

> *People used to come out to see my in my flat and then like things changed and I was like I can come in to the hospital instead. That felt really good. Like such a change. Not being trapped. Being able to do like the basic type of things.* […] *just like that it produced something in me. Like I was doing things again. Things I ain't be able to do before. Like. You know?* […] *Like it* [the pandemic] *got me back to some sort of normality.* (Carl, Lines 195-209)

Carl, like Jamie, sees the pandemic as means which had produced changes in his life. These changes appeared to have enriched Carl's life which he had found being an entrapped cycle. He points out being able to use the pandemic to re-find the activities he had done previously. Amelia also described how:

> *Knowing everyone else had something else to look forward to, I wanted to have the same. And finding my music again too. Maybe I could have this as being my way of having something of my own.* […] *hearing people talk about 'a new normal' made me think about 'yeah lets make a new normal' for me, my new normal. Helped me make that change.* (Amelia, Lines 427-438)

Amelia discusses being included in this new normality and joining others around her. Amelia notices others getting back to how they were before the pandemic and feeling motivated to create her new normal based on rediscovering her music. This part of herself was lost during her psychosis episode but Amelia starts to make changes and feels motivated through the shared connection with others around her to use the pandemic as an event catalysing a recovery journey. Naomi also stated:

I carried it [new job] *on. The longest I've um ever been employed.* […] *I think it was because I didn't want to go back to how things were before um COVID and I didn't want it to be like um how it was during COVID. Me starting work was like um that I was making my own normal, as they say.* […] *yeah. I hated COVID but it gave me something like um that I've just clung to. like a new skill.* (Naomi, Lines 433-442)

Like Amelia, Naomi suggests utilising the pandemic's atmosphere of 'creating a new normal' to establish something protective in her life moving forward. Nina also found herself in forced changes from the pandemic:

But I think it brought me closer to my children. […] *I think being home with my children. I know it meant not being at work. But um with hindsight. It forced me to focus on being a good mom with them. I started cooking more with them. Especially my daughter. It was great. I actually really enjoyed that time with them.* […] *made me realise I didn't need to be frightened of spending time with them. I think just being able to know that it's not me, it's like the voice which isn't helping me being a good mom. Not that it's me an actual bad mom.* […] *it brought up that for me. Yeah like how my mum was with me. It just brought it all bad to me. Made me realise yeah I'm not quite so like that. I can actually be better than her.* […] *My mum. Mostly. She was awful. My dad was awful.* […] *Being able to spend time with my kids. It showed me. I'm not that. I'm not bad like they were.* […] *yeah. They were bad. But having that time at home. I could stop things from being like that for me with my kids.* (Nina, Lines 403-434)

Nina describes the pandemic unwittingly helped her strengthen relationships with her children, in particular her daughter. She does this through being more present and engaged in activities with them such as cooking. These experiences appeared powerful for challenging beliefs she had carried regarding being an incompetent mother. Overall, this theme suggests

the pandemic was a useful experience that could help challenge long-standing beliefs which perpetuate psychosis. The pandemic appeared to help re-set and create new opportunities to share in a recovery with other people. This transformed the experience of recovering from psychosis from being isolating, to an empowering one.

2.4: Discussion

The aim of this study was to explore how people with psychosis had experienced emotional well-being during the COVID-19 pandemic. An IPA of interviews from eight people with a known diagnosis of psychosis was used to develop an understanding of the ways in which people with psychosis experienced emotional and psychological health during COVID.

The amplification of psychosis

Overall, the analysis supported past findings that people with psychosis had experienced an exacerbation of their symptoms during a public health crisis (Lyons et al., 2021; Tariku & Hajure, 2020). However, this study extended this understanding to the phenomenology of why an exacerbation of symptoms appeared. Across participants' descriptions, there seemed to be a blurring of psychotic symptoms (especially positive symptoms of hallucinations and delusions) with the reality of the pandemic. A hallmark of this exacerbation was an interaction between the events of COVID creating a fear which perpetuated beliefs of being attacked, persecuted or being responsible for catastrophic death tolls. In this way, this study supported findings of a link between the pandemic and psychosis (D'Agostino et al., 2021; Epsposito et al., 2021; Ferrando et al., 2020).

The analysis also suggested people with psychosis experienced an intensification of previous paranoia and voice-hearing. Participants had noticed the role the media, face coverings and the involvement of the government were important features of the pandemic, that amplified their sense of panic and fear. Participants had felt fearful that their beliefs of

being attacked or persecuted were 'coming true.' Persecution appeared magnified for participants during this time which was felt to be catastrophic (for instance, the pandemic was likened to 'going to war' or the world ending). These findings supported McCormick (2020) who illustrated the public material surrounding the pandemic, including 'war' metaphors and conspiracy theories, had increased panic and fear in the general population.

For people with psychosis in this study, popular rhetoric during the pandemic is to some extent, held responsible for the exacerbation of symptoms by people with psychosis. Yet, this study mostly identified this was the exacerbation of positive psychotic symptoms. As only two participants in the study had been identified as having negative symptoms, it is unclear whether there are any qualitative differences between positive and negative symptoms becoming amplified. Although a starting point, it is suggested from this study that further research can explore potential differences. Developing this understanding may become applied to other complex mental health difficulties.

'Psychotic-threat'

This study also demonstrated participants living with real threat which mirrored their psychosis. Participants feared what other beliefs they held might be 'proven' by the pandemic. There was also a hypervigilance of events occurring during the pandemic, as participants worried an increase in cases of COVID-19 could lead to a re-emergence of their psychotic distress. With psychosis being uncontrollable and dependent on the events of the pandemic, participants described a type of 'threat inducing psychosis.' A key feature of this 'psychotic-threat' was a distrust of the systems around them and a subsequent feeling of lacking safety with a feeling of threat permeating everywhere.

This understanding may echo the stages of the pandemic outlined by Ventriglio et al (2020). The stages of fear, panic, anger, and depression appear more pronounced for people with psychosis during the pandemic. This is perhaps based on the finding from this study that

people with psychosis had experienced a further narrowing of an already narrowed and restricted world. This had resulted in people with psychosis becoming further disadvantaged through several losses they may have experienced such as routines, coping mechanisms, and supportive figures.

The pandemic and recovery from psychosis

Although there is an intensification of these initial stages, the final stage of acceptance from Ventrigilo and colleagues' (2020) model could also be more augmented for people with psychosis. The analysis showed the pandemic had become an experience which participants were able to reflect upon and use to promote changes in their lives. Participants described how these lifestyle changes had a positive effect on their recovery. An implication of this study is therefore the pandemic could become a retrospective event for people with psychosis to harness in supporting a recovery from psychosis, but the ways and means of doing this would need to be further elucidated through more detailed work with psychosis survivors of the pandemic.

The participants in the current study had noticed a connection between themselves and people without psychosis that helped to normalise experiences of psychosis. Life changes were aligned with the post-COVID atmosphere of 'creating a new normal.' The participants of this study suggested making changes that included seeking employment, being able to leave their house more regularly and enriching their lives through re-connecting with hobbies and activities. In this way, the pandemic magnified challenges but also offered an opportunity for growth and recovery.

It could be argued the traditional understanding of recovery from psychosis may be altered by the pandemic. Traditionally, it is understood people recovering from psychosis do so in a sealing-over or integrative way (McGlashan & Levy, 2019). Sealing-over refers to attempting to return to a 'normality' and perceiving the experience of psychosis as separate

from the self (McGlashan & Levy, 2019). Integrating this experience of psychosis into the self-identity has been associated to longer-term psychological well-being (McGlashan & Levy, 2019). Naqvi (2020) outlines adverse psychological reactions to facing life-threatening circumstances could lead to widespread mental health difficulties. Recovering from psychosis during this period of high-vigilance to threat of life where there was prolonged social withdrawal and economic strife (Naqvi, 2020) could mean 'sealing-over' and returning to a 'normal' might not be possible. This is because the world has changed for people and who are finding a 'new normality.' For people with psychosis who recover through 'sealing over,' this altering of the world and normality could be challenging. Explicit ways of recovering from psychosis could be potentially explored in future work post-pandemic. The current study suggests the pandemic has been challenging for recovery but also offers an opportunity. However, how the pandemic affects individual styles of recovering from psychosis and the mechanisms which facilitate or hinder this process could be examined further. This would aid clinical understanding and support those with psychosis with their recovery following the pandemic.

Segregation and division in society

The results from this study supported previous findings that people with power in society influenced the experience people with less power had (Bottan et al., 2020). A segregation within society was identified in this study, which directly had been experienced by people with psychosis who are likely to belong to disadvantaged minority groups (Bhugra et al., 2021). These experiences included overt displays of homophobia and racism which had become enabled and disguised by the pandemic. One clinical application of this finding could be the awareness that people with psychosis may have experienced increased discrimination based on an intersectionality of race, gender, ability, and social economic status.

Participants also described how the pandemic had removed their individuality. Analysis suggested there was an expectation of people to all experience the pandemic the same. Participants felt connected by this shared experience but equally dismissed by the lack of understanding their unique challenges. Based on this, the people in this study suggested the pandemic was used to benefit certain groups in society. It is wondered if this removal of individual difference was a wider defence against trauma. This may be of interest to Clinical Psychologists working with traumatised teams and organisations who witnessed large numbers of death and ill health during the pandemic (Billings et al., 2021).

A 'tyranny of sameness' and a message for future research

This study is the first known study exploring the experience of COVID in people with a pre-existing psychosis, within a UK NHS sample. A key message from this study for researchers investigating the Coronavirus pandemic, is not to forget the lives of people who had pre-existing mental health difficulties in the quest to explore the impact of the pandemic on public well-being. Many participants spoke about the interview being the first discussion about their emotional experiences in the pandemic. The findings demonstrated these individual discussions of the pandemic are supportive of participants recovery from psychosis.

Arguments from Chaudhury et al. (2022) suggested distinctions between psychosis occurring before and after COVID-19 help to avoid mistaking hallucinations and delusions as a product of psychosis rather than Coronavirus. These arguments may be considered one of classification, however the results of this study implied this segregation could be perceived to maintain 'normality' and separate the shared features of psychosis with the general population. This study found this type of segregation was unhelpful to people with pre-existing psychosis. Classifying symptoms of psychosis which occur after positive COVID-19

infection as a sub-set, may only further the divide to people who are already segregated. The current results are hoped to be helpful for informing this ongoing debate.

In addition, as discussed by participants in this study, the pandemic has created a 'tyranny of sameness' that removed individuality and subsequently led to the dismissal of their experience. This 'sameness' may be an implicit reason for why research in this area has been neglected. As the pandemic is a global event, there may be a sense of the experience being 'known.' Yet, this study shows there are qualitative differences based between people which could shape this experience. The idiographic approach of IPA has been helpful to give a voice to people with psychosis, who may belong to many disadvantaged minority groups. The findings of this study are hoped to inform a clinical understanding of the journey people with psychosis had during the pandemic, and how this might influence their recovery. Such findings will be useful for future public health crises to support people with psychosis.

Strengths and limitations

A challenge of this study is that the viral COVID-19 is still present and information regarding the events of the pandemic has been updated since interviews took place. This included information which about people in powerful government positions violating government legislation. This information may have influenced different reflections about the pandemic. Reflections particularly about unfairness around the restrictions may have been enhanced by the awareness of information which was not made available until after the initial stages of the pandemic.

There may be differences of advantage within the group of people with psychosis. This study sampled people from NHS settings that were able to take part in online interviews. This required having access to and an ability to engage with online software. It could be argued the study was not accessible for people with greater disadvantage and may have

experienced the pandemic differently. As such, this could be a direction for future research, particularly now that social distancing restrictions have been lifted.

Nizza and colleagues (2021) present four quality indicators for IPA research: constructing a compelling, unfolding narrative, developing a vigorous experiential account, close analytic reading of participants' words and attending to convergence and divergence. The present study was examined against each of these indicators as discussed by Nizza et al. (2021). A compelling narrative which unfolded throughout the analysis was considered within and across themes. This study appeared to illustrate a good narrative of how the pandemic had been experienced by people with psychosis and this was marked as a journey which participants had been through. Within themes there was a depth to the narrative, helped by a close reading of illustrative quotes.

However, there might be a disconnection between themes which identify the pandemic as negative and themes which identify this as empowering. These themes could be considered polarising, perhaps reflecting the polarisation of general attitudes in society discussed by participants. The researcher reflected on the polarisation noticed within and across participant accounts. This indicated the study had captured a range of experiences across a continuum of positive to negative experiences of the pandemic. Indeed, more empowering accounts of the pandemic came from participants who held a presentation of psychosis characterised by negative symptoms. Future research could explore this and study what creates this polarising experience of the pandemic for people with psychosis.

Conclusions

Overall, this study explored the experience of the COVID-19 pandemic for people with psychosis. Fear was induced not only through a viral threat of infection, but from the individual responses (e.g., symptom intensification) and interpersonal responses (e.g., restrictions and discrimination) experienced. It is noted the pandemic also offered an

opportunity of enhancing recovery for people with psychosis. However, such recovery appeared at odds with increased segregation in society and a dismissal of diversity in experience. This work has explored the experience of the pandemic from the perspective of people with a complex pre-existing mental health difficulty. Future research could explore *why* this group had experienced an amplification of symptoms, to understand the mechanisms supporting emotional health during public health crises. This may include understanding the individual factors buffering distress. It is concluded, this study is a useful starting point for beginning to understand the experiential impact of the pandemic on people with psychosis.

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Chapter 3 – Press releases

3.1: Meta-synthesis press release

University of Birmingham News Release

Embargo: For release after 22nd September 2023

Learning from our experiences: How psychosis impacts on development

A review took place of 15 research papers that studied life following a severe mental health condition, psychosis. Clinicians have been interested in how psychosis impacts on the development of young people, given the average onset usually occurs in adolescence. To explore the effect on development, papers which focused on the first-hand accounts of psychosis, by young people up to the age of 35 years old, were reviewed. The papers, published between 2004 – 2021, shared several similarities, building a picture of the journey young people may take following an episode of psychosis. Two themes split this journey: how psychosis interrupts development, followed by how they move forward.

Usual development in Western Countries involves moving through milestones such as finishing school, going to college, leaving home, starting employment and romantic relationships. This review found people who have a severe mental health problem, like psychosis, feel dependent on caregivers and unable to complete these milestones. This often resulted in young people feeling 'left behind' by their peers and stuck in a repetitive cycle. People reported to hide their experiences of psychosis, attempting to return to normal quickly after. This method of coping helped to maintain relationships and usual activities, minimising the loss associated to psychosis. Yet, ignoring psychosis meant young people did not learn from these experiences and resulted in feeling detached from themselves.

The review indicated young people slowly withdrew from others, resulting in missed opportunities to develop social skills. Withdrawal from others meant relationships became impaired and eventually dwindled. Young people reported they lost jobs, and in some cases, a

sense of independence as they relied more on caregivers. Identity was severely impacted by psychosis, particularly the stigma relating to psychosis that led to young people seeing themselves negatively.

Positive experiences of being accepted by other people, helped young people move forwards. These experiences reduced stigma and helped young people learn about themselves. In recent years, talking therapies have focused on new ideas of accepting mental pain as part of the human condition and so it seems better to focus on what can make life meaningful to offset this pain. Having supportive people around them, helped young people mirror the acceptance shown to them. These experiences were empowering and contrasted the earlier feelings of hopelessness during initial stages of psychosis.

This review may be helpful to mental health professionals working with young people who have experience psychosis. Further reviews may expand on this work to build insight into the cross-cultural effects of psychosis on development.

End.

3.2: Empirical press release

University of Birmingham News Release

Embargo: For release after 22nd September 2023

The lockdown continues: Psychosis during the COVID-19 pandemic

Eight adults, aged 19-51 years old, were interviewed to discuss their experience of well-being during the COVID-19 pandemic. Participants had a diagnosis of psychosis, a severe mental health condition, at the start of the pandemic. Psychosis is a term given to a group of mental health diagnoses characterised by a fragmentation of reality. In some cases, people may experience seeing, hearing, smelling, and feeling things which are not physically present. People may also experience bizarre beliefs or a lack of motivation. Participants in this study discussed their mental health seemed worsened by the pandemic, reporting that they felt unsafe. The unprecedented nature of the pandemic was described by people with psychosis as mirroring their worst fears, at times appearing as if their fears had come true. This left people feeling vulnerable and unravelled previous recovery. One man described he had been right in his belief the world would be attacked by a respiratory illness. This effectively awakened his beliefs of being persecuted. Challenging these beliefs seemed difficult during the pandemic, as there was evidence of a global threat.

Restrictions during the pandemic, such as working from home and social distancing measures, appeared to intensify loneliness. Many people found their lives became further narrowed during the pandemic. For instance, one man explained how his father had passed away from COVID and he was expected to move on from this because many others had too lost family members. The man's college did not consider his father was one of the only sources of support, in addition to being his only caregiver and companion. This was loss was greatly amplified for him, particularly when he was forced to leave college. All participants felt individual difference was ignored. Instead, there seemed an expectation to experience the

pandemic the same as others. Whilst the virus was not discriminatory, participants reported the restrictions affected people differently.

During the interviews, participants reported noticing a divide in society between those with power and without power. It was felt powerful groups had exploited the pandemic, further disadvantaging others. This included racism and homophobia. COVID was used to mask these overt displays of micro-aggressions in society. One young man reported his family had informed others he had died from Coronavirus to hide their disproval of his sexuality. Another woman in the study had experienced racism whilst going to the supermarket. These examples shed light on minority groups with mental health conditions had been particularly disempowered.

An important message of the research is that the pandemic enabled this disempowerment. It is important not to lose sight of individual differences we seek to understand the public's mental health. Those with mental conditions prior to the pandemic may have experienced a worsening of symptoms. Yet, this research also found the pandemic was an opportunity to aid recovery. For people with psychosis, shared experiences of loneliness during the pandemic helped feel connected to those without psychosis. Participants also spoke of using this shared connection to make changes to their lives and share in making a 'new normal.' For one young man this resulted in meeting new people. Another participant reported she had re-started activities she had done prior to her psychosis, helping her get back in touch with her sense of identity before the pandemic.

Overall, this research has identified people with psychosis may have faced many challenges during the COVID-19 pandemic. However, there could be an opportunity to use this historical event to support recovery from a severe mental health condition.

End.

Appendices – Chapter one

Appendix 1A – NICE Qualitative Checklist (NICE, 2012)

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		
3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure	Comments:
Data collection		
4. How well was the data collection carried out?	Appropriately	Comments:

For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Inappropriately Not sure/inadequately reported	
Trustworthiness		
5. Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		
8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:

9. Is the data 'rich'? For example: • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
10. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		

14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Appendix 1B – JARS-Qual Framework (APA, 2018)

Paper element	Guidance for inclusion
1. Title page	• Identify key issues/topic under consideration • Acknowledge funding sources or contributors • Acknowledge any conflicts of interest if any
2. Abstract	• State the problem/question/objectives under investigation. • Indicate the study design, including types of participants or data sources, analytic strategy, main results/findings, and main implications/significance. • Identify five keywords. *Guidance for Authors* – Consider including at least one keyword that describes the method and one that describes the types of participants or phenomena under investigation. – Consider describing your approach to inquiry when it will facilitate the review process and intelligibility of your paper. If your work is not grounded in a specific approach to inquiry or your approach would be too complicated to explain in the allotted word count, however, it would not be advisable to provide explication on this point in the abstract.
3. Introduction	**<u>Description of research problem or question</u>** • Frame the problem or question and its context. • Review, critique, and synthesize the applicable literature to identify key issues/debates/ theoretical frameworks in the relevant literature to clarify barriers, knowledge gaps, or practical needs. *Guidance for Reviewers* – The introduction may include case examples, personal narratives, vignettes, or other illustrative material.
	<u>Study objectives/ aims/ research goals</u> • State the purpose(s)/goal(s)/aim(s) of the study. • State the target audience, if specific. • Provide the rationale for fit of design used to investigate this purpose/goal (e.g., theory building, explanatory, developing understanding, social action, description, highlighting social practices). • Describe the approach to inquiry, if it illuminates the objectives and research rationale (e.g., descriptive, interpretive, feminist, psychoanalytic, postpositivist, critical, postmodern, constructivist, or pragmatic approaches). *Guidance for Authors* – If relevant to objectives, explain the relation of the current analysis to prior articles/ publications. *Guidance for Reviewers* – Qualitative studies often legitimately need to be divided into multiple manuscripts because of journal article page limitations, but each manuscript should have a separate focus. – Qualitative studies tend not to identify hypotheses, but rather research questions and goals.
4. Method	**<u>Research design overview</u>** • Summarize the research design, including data-collection strategies, data-analytic strategies, and, if illuminating, approaches to inquiry (e.g.,

Paper element	Guidance for inclusion
	descriptive, interpretive, feminist, psychoanalytic, postpositivist, critical, postmodern, constructivist, or pragmatic approaches). • Provide the rationale for the design selected. *Guidance for Reviewers* – Method sections can be written in a chronological or narrative format. – Although authors provide a method description that other investigators should be able to follow, it is not required that other investigators arrive at the same conclusions but rather that the method description leads other investigators to conclusions with a similar degree of methodological integrity. – At times, elements may be relevant to multiple sections and authors need to organize what belongs in each subsection in order to describe the method coherently and reduce redundancy. For instance, the overview and the objectives statement may be presented in one section. – Processes of qualitative research are often iterative versus linear, may evolve through the inquiry process, and may move between data collection and analysis in multiple formats. As a result, data collection and analysis sections might be combined. – For the reasons above and because qualitative methods often are adapted and combined creatively, requiring detailed description and rationale, an average qualitative Method section typically is longer than an average quantitative Method section.
	Study participants or data sources Researcher Description • Describe the researchers' backgrounds in approaching the study, emphasizing their prior understandings of the phenomena under study (e.g., interviewers, analysts, or research team). • Describe how prior understandings of the phenomena under study were managed and/or influenced the research (e.g., enhancing, limiting, or structuring data collection and analysis). *Guidance for Authors* – Prior understandings relevant to the analysis could include, but are not limited to, descriptions of researchers' demographic/cultural characteristics, credentials, experience with phenomena, training, values, and/or decisions in selecting archives or material to analyze. Guidance for Reviewers – Researchers differ in the extensiveness of reflexive self-description in reports. It may not be possible for authors to estimate the depth of description desired by reviewers without guidance. Participants or Other Data Sources • Provide the numbers of participants/documents/events analyzed. • Describe the demographics/cultural information, perspectives of participants, or characteristics of data sources that might influence the data collected. • Describe existing data sources, if relevant (e.g., newspapers, internet, archive). • Provide data repository information for openly shared data, if applicable. • Describe archival searches or process of locating data for analyses, if applicable. Researcher–Participant Relationship • Describe the relationships and interactions between researchers and participants relevant to the research process and any impact on the research process (e.g., was there a relationship prior to research, are there any ethical considerations relevant to prior relationships).

Paper element	Guidance for inclusion
	Participant recruitment Recruitment process • Describe the recruitment process (e.g., face-to-face, telephone, mail, email) and any recruitment protocols. • Describe any incentives or compensation and provide assurance of relevant ethical processes of data collection and consent process as relevant (may include institutional review board approval, particular adaptations for vulnerable populations, safety monitoring). • Describe the process by which the number of participants was determined in relation to the study design. • Provide any changes in numbers through attrition and final number of participants/sources (if relevant, refusal rates or reasons for dropout). • Describe the rationale for decision to halt data collection (e.g., saturation). • Convey the study purpose as portrayed to participants, if different from the purpose stated. *Guidance for Authors/Reviewers* – The order of the recruitment process and the selection process and their contents may be determined in relation to the authors' methodological approach. Some authors will determine a selection process and then develop a recruitment method based on those criteria. Other authors will develop a recruitment process and then select participants responsively in relation to evolving findings. *Guidance for Reviewers* – There is no agreed-upon minimum number of participants for a qualitative study. Rather, the author should provide a rationale for the number of participants chosen. Participant selection • Describe the participants/data source selection process (e.g., purposive sampling methods, such as maximum variation; convenience sampling methods, such as snowball selection; theoretical sampling; diversity sampling) and inclusion/exclusion criteria. • Provide the general context for the study (when data were collected, sites of data collection). • If your participant selection is from an archived data set, describe the recruitment and selection process from that data set as well as any decisions in selecting sets of participants from that data set. *Guidance for Authors* – A statement can clarify how the number of participants fits with practices in the design at hand, recognizing that transferability of findings in qualitative research to other contexts is based in developing deep and contextualized understandings that can be applied by readers rather than quantitative estimates of error and generalizations to populations. *Guidance for Authors/Reviewers* – The order of the recruitment process and the selection process and their contents may be determined in relation to the authors' methodological approach. Some authors will determine a selection process and then develop a recruitment method based on those criteria. Other authors will develop a recruitment process and then select participants responsively in relation to evolving findings.
	Data collection Data collection/identification procedures • State the form of data collected (e.g., interviews, questionnaires, media, observation).

Paper element	Guidance for inclusion
	• Describe the origins or evolution of the data-collection protocol. • Describe any alterations of data-collection strategy in response to the evolving findings or the study rationale. • Describe the data-selection or data-collection process (e.g., were others present when data were collected, number of times data were collected, duration of collection, context). • Convey the extensiveness of engagement (e.g., depth of engagement, time intensiveness of data collection). • For interview and written studies, indicate the mean and range of the time duration in the data-collection process (e.g., interviews were held for 75 to 110 min, with an average interview time of 90 min). • Describe the management or use of reflexivity in the data-collection process, as it illuminates the study. • Describe questions asked in data collection: content of central questions, form of questions (e.g., open vs. closed). *Guidance for Reviewers* – Researchers may use terms for data collection that are coherent within their research approach and process, such as "data identification," "data collection," or "data selection." Descriptions should be provided, however, in accessible terms in relation to the readership. – It may not be useful for researchers to reproduce all of the questions they asked in an interview, especially in the case of unstructured or semi-structured interviews as questions are adapted to the content of each interview. <u>Recording and data transformation</u> • Identify data audio/visual recording methods, field notes, or transcription processes used.
	<u>Analysis</u> <u>Data-analytic strategies</u> • Describe the methods and procedures used and for what purpose/goal. • Explicate in detail the process of analysis, including some discussion of the procedures (e.g., coding, thematic analysis) following a principle of transparency. • Describe coders or analysts and their training, if not already described in the researcher description section (e.g., coder selection, collaboration groups). • Identify whether coding categories emerged from the analyses or were developed a priori. • Identify units of analysis (e.g., entire transcript, unit, text) and how units were formed, if applicable. • Describe the process of arriving at an analytic scheme, if applicable (e.g., if one was developed before or during the analysis or was emergent throughout). • Provide illustrations and descriptions of the analytic scheme development, if relevant. • Indicate software, if used. *Guidance for Authors* -Provide rationales to illuminate analytic choices in relation to the study goals. *Guidance for Reviewers* -Researchers may use terms for data analysis that are coherent within their research approach and process (e.g., "interpretation," "unitization," "eidetic analysis," "coding"). Descriptions should be provided, however, in accessible terms in relation to the readership.

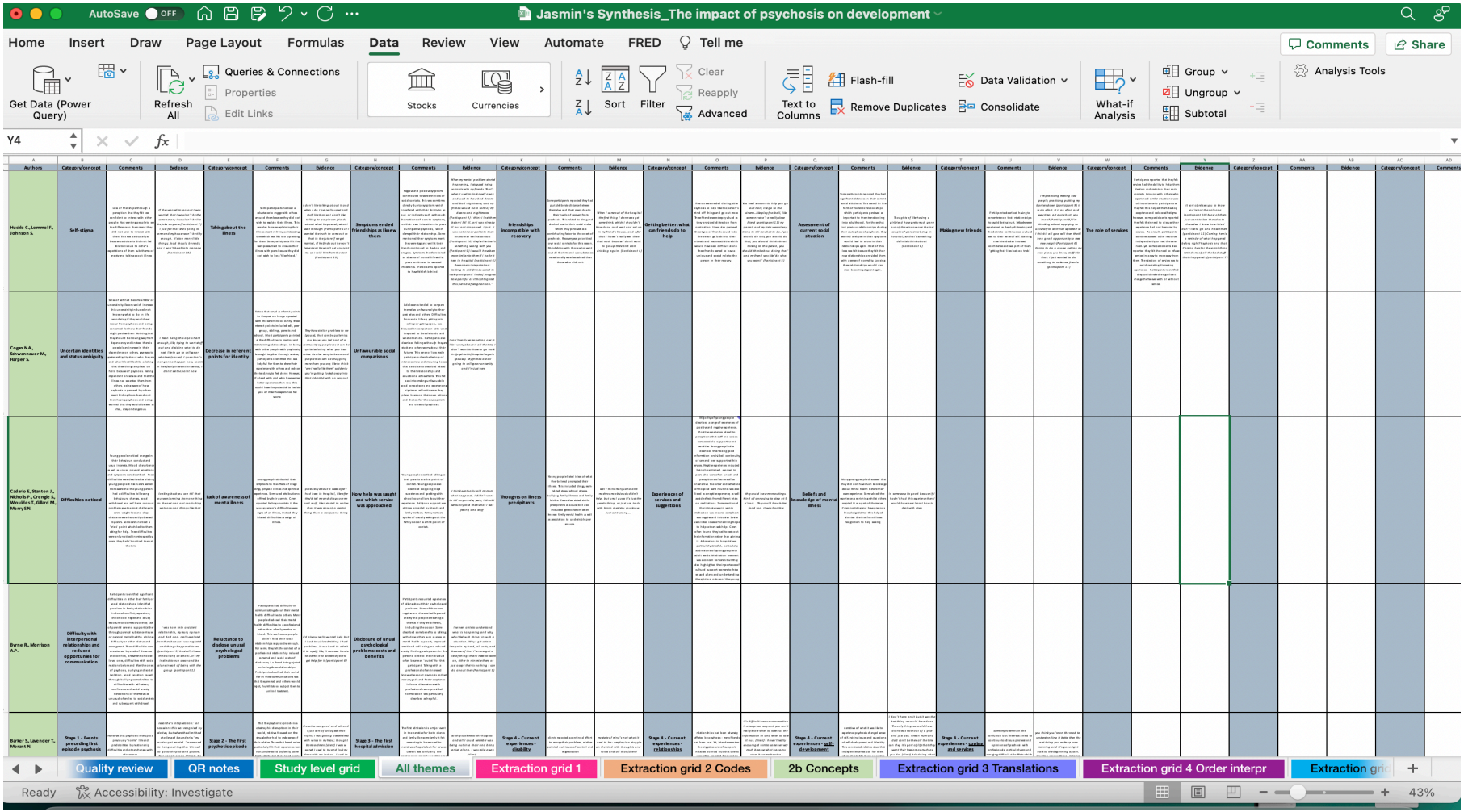
Paper element	Guidance for inclusion
	Methodological integrity • Demonstrate that the claims made from the analysis are warranted and have produced findings with methodological integrity. The procedures that support methodological integrity (i.e., fidelity and utility) typically are described across the relevant sections of a paper, but they could be addressed in a separate section when elaboration or emphasis would be helpful. Issues of methodological integrity include the following: - Assess the adequacy of the data in terms of its ability to capture forms of diversity most relevant to the question, research goals, and inquiry approach. - Describe how the researchers' perspectives were managed in both the data collection and analysis (e.g., to limit their effect on the data collection, to structure the analysis) - Demonstrate that findings are grounded in the evidence (e.g., using quotes, excerpts, or descriptions of researchers' engagement in data collection). - Demonstrate that the contributions are insightful and meaningful (e.g., in relation to the current literature and the study goal). - Provide relevant contextual information for findings (e.g., setting of study, information about participants, interview question asked is presented before excerpt as needed). - Present findings in a coherent manner that makes sense of contradictions or disconfirming evidence in the data (e.g., reconcile discrepancies, describe why a conflict might exist in the findings). • Demonstrate consistency with regard to the analytic processes (e.g., analysts may use demonstrations of analyses to support consistency, describe their development of a stable perspective, interrater reliability, consensus) or describe responses to inconsistencies, as relevant (e.g., coders switching midway through analysis, an interruption in the analytic process). If alterations in methodological integrity were made for ethical reasons, explicate those reasons and the adjustments made. • Describe how support for claims was supplemented by any checks added to the qualitative analysis. Examples of supplemental checks that can strengthen the research may include: • transcripts/data collected returned to participants for feedback • triangulation across multiple sources of information, findings, or investigators • checks on the interview thoroughness or interviewer demands • consensus or auditing process • member checks or participant feedback on findings • data displays/matrices • in-depth thick description, case examples, or illustrations • structured methods of researcher reflexivity (e.g., sending memos, field notes, diary, logbooks, journals, bracketing) – checks on the utility of findings in responding to the study problem (e.g., an evaluation of whether a solution worked). *Guidance for Reviewers* – Research does not need to use all or any of the checks (as rigor is centrally based in the iterative process of qualitative analyses, which inherently includes checks within the evolving, self-correcting iterative analyses), but their use can augment a study's methodological integrity. Approaches to inquiry have different traditions in terms of using checks and which checks are most valued.

Paper element	Guidance for inclusion
5. Findings/ results	• Describe research findings (e.g., themes, categories, narratives) and the meaning and understandings that the researcher has derived from the data analysis. • Demonstrate the analytic process of reaching findings (e.g., quotes, excerpts of data). • Present research findings in a way that is compatible with the study design. • Present synthesizing illustrations (e.g., diagrams, tables, models), if useful in organizing and conveying findings. Photographs or links to videos can be used. *Guidance for Authors* – Findings presented in an artistic manner (e.g., a link to a dramatic presentation of findings) should also include information in the reporting standards to support the research presentation. – Use quotes or excerpts to augment data description (e.g., thick, evocative description, field notes, text excerpts), but these should not replace the description of the findings of the analysis. *Guidance for Reviewers* – The findings section tends to be longer than in quantitative papers because of the demonstrative rhetoric needed to permit the evaluation of the analytic procedure. – Depending on the approach to inquiry, findings and discussion may be combined or a personalized discursive style might be used to portray the researchers' involvement in the analysis. – Findings may or may not include quantified information, depending upon the study's goals, approach to inquiry, and study characteristics.
6. Discussion	• Describe the central contributions and their significance in advancing disciplinary understandings. • Describe the types of contributions made by findings (e.g., challenging, elaborating on, and supporting prior research or theory in the literature describing the relevance) and how findings can be best utilized. • Identify similarities and differences from prior theories and research findings. • Reflect on any alternative explanations of the findings. • Identify the study's strengths and limitations (e.g., consider how the quality, source, or types of the data or the analytic processes might support or weaken its methodological integrity). • Describe the limits of the scope of transferability (e.g., what should readers bear in mind when using findings across contexts). • Revisit any ethical dilemmas or challenges that were encountered, and provide related suggestions for future researchers. • Consider the implications for future research, policy, or practice. *Guidance for Reviewers* – Accounts could lead to multiple solutions rather than a single one. Many qualitative approaches hold that there may be more than one valid and useful set of findings from a given data set.

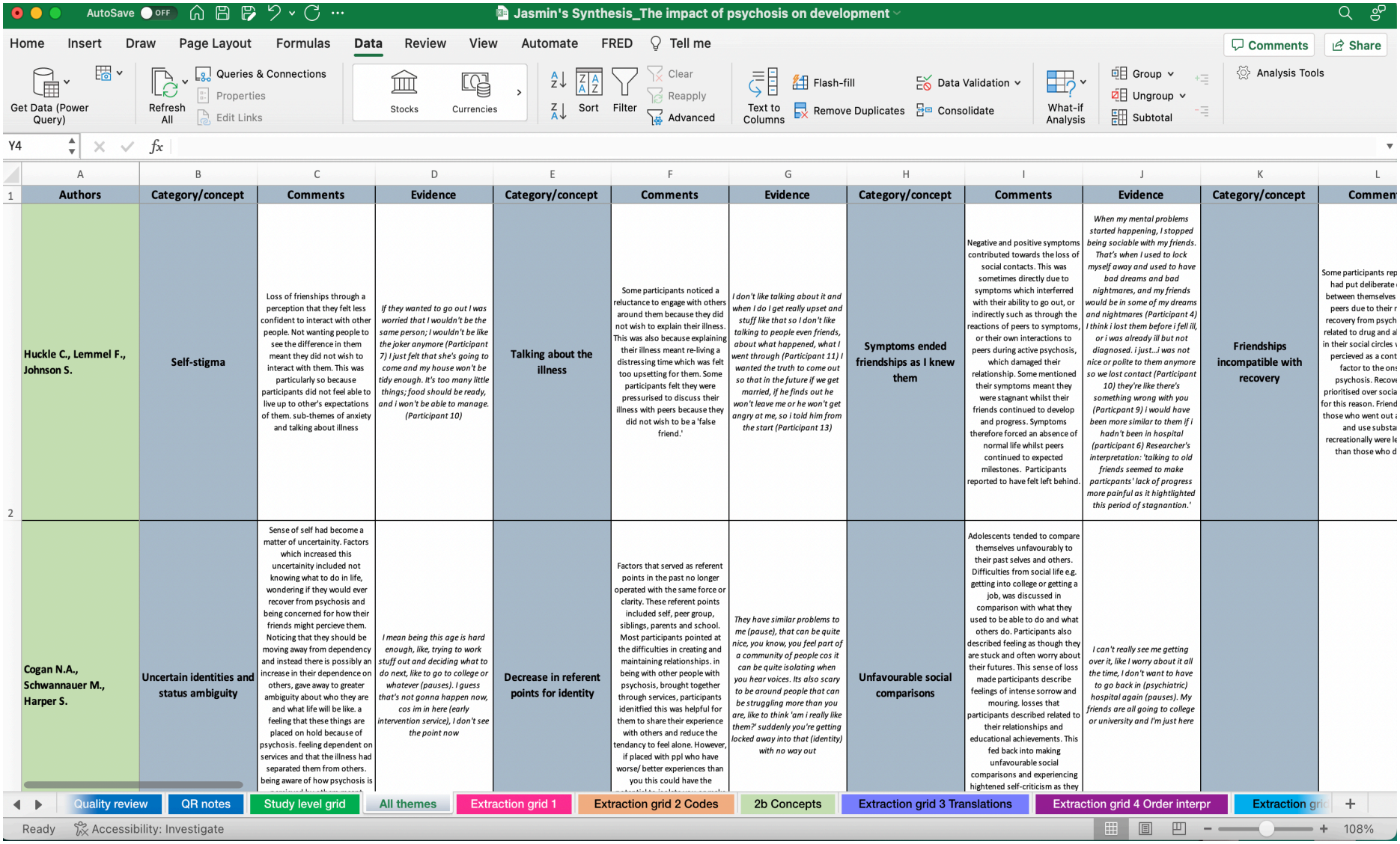
Appendix 1C – Combined Quality Appraisal Framework

(redacted to protect confidentiality)

Appendix 1D – Example of Initial Extraction Grid



Note. This is a screenshot of the initial extraction grid, showing a sample of the outlay, as it is too large. This picture illustrates the extraction grid.



Note. This is a screenshot of the initial extraction grid, showing a sample of the outlay. This screenshot is a magnified version, for illustration.

Appendix 1E – First Order and Second Order Interpretations

Themes	1st order interpretation	2nd order interpretation
<u>Self-stigma:</u> loss of friends through perceptions that they weren't able to interact and function with others. Not wanting others to notice a difference in them so avoiding others.	*If they wanted to go out I was worried that I wouldn't be the same person; I wouldn't be like the joker anymore (Participant 7) I just felt that she's going to come and my house won't be tidy enough. It's too many little things; food should be ready, and i won't be able to manage. (Participant 10)*	Researchers interpreted this theme as affecting how people perceived themselves and their own interactions with other people. They felt participants were anxious about the expectations of other people and avoid them to reduce this anxiety.
<u>Talking about the illness:</u> reluctance to engage with others around them because they did not wish to discuss and re-live their experiences.	*I don't like talking about it and when I do I get really upset and stuff like that so I don't like talking to people even friends, about what happened, what I went through (Participant 11) I wanted the truth to come out so that in the future if we get married, if he finds out he won't leave me or he won't get angry at me, so i told him from the start (Participant 13)*	Researcher's felt that participants would avoid discussions about their experiences of psychosis with significant others because they did not want to re-live the distress it created. However, they also felt there was some pressure on participants to disclose their experiences to avoid 'lying' to their close others.
<u>Symptoms ended friendships as I knew them:</u> both negative and positive symptoms of psychosis affected the level of social contact with peers	*When my mental problems started happening, I stopped being sociable with my friends. That's when I used to lock myself away and used to have bad dreams and bad nightmares, and my friends would be in some of my dreams and nightmares (Participant 4) I think i lost them before i fell ill, or i was already ill but not diagnosed. i just...i was not nice or polite to them anymore so we lost contact (Participant 10) they're like there's something wrong with you (Particpant 9) i would have been more similar to them if i hadn't been in hospital (participant 6) Researcher's interpretation: 'talking to old friends seemed to make particpants' lack of progress more painful as it hightlighted this period of stagnantion.'*	It was felt by the researcher's that participant's symptoms sometimes directly and indirectly led to ending friendships and altering their relationships to their peers. Some symptoms directly affected how well people felt to go out. The researcher's also interpretated the participant's accounts of their symptoms resulted in an 'absence of normal life' which impaired them reaching developmental milestones at the same time as their peers. Participants were felt to be 'left behind.'

Themes	1st order interpretation	2nd order interpretation
<u>Friendships incompatible with recovery:</u> Placing distance between themselves and people who they considered where incompatible to their recovery for example, people who accessed and used drugs and alcohol with them before they became unwell.	*When I came out of the hospital the first thing I done was get some drink, which I shouldn't have done, and went and sat up in my friend's house… and after that I haven't really seen them that much because I don't want to go up there and start drinking again. (Participant 4)*	Friendships with people who used drugs and alcohol recreationally were less valued that friends who did not. This was interpretated as recovery being more important than social contacts to participants.
<u>Getting better: what can friends do to help:</u> acknowledging that friends were needed to help take their mind off difficulties and instil a sense of belonging.	*You need someone to help you go out more, like go to the cinema…like play football, like someone who's a really close friend (participant 11) my parents and my sister were always trying to tell me what to do…'you should do this, you should do that, you should think about talking to this person, you should think about doing that' and my friend was like 'do what you want!' (Participant 5)*	The researcher's interpretation was that there were specific types of friends who could enable and be important to the person's recovery. These friends helped the person regain interests and hobbies which they had previously had before.
<u>Assessment of current social situation:</u> participants reported feeling deficiencies in their relationships, particularly romantic relationships.	*Thoughts of like having a girlfriend have pretty much gone out of the window over the last couple of years since being in hospital, so that's something I definitely think about (Participant 6)*	Romantic relationships were seen as an important transition to adulthood. Lacking in these relationships for participants led to interpretations by the researchers that they perceived themselves as socially deficient in some way. Interpretations also included perceived anxiety that people would lose friendships again if they became unwell. It was interpretated that loosing friendships in this way would mean becoming 'stagnant' again.
<u>Making new friends:</u> gaining new friends increased confidence whilst setbacks in relationships was distressing.	*I'm practicing meeting new people, practicing putting my barriers down (participant 9) it is an effort, it is an effort and every time I get quite hurt, you know? (Participant 8) I'm thinking about applying to university to start next September so I think it all goes well then that'll be a good opportunity to meet new people (Participant 6) Going to do a course, getting my own place, you know, stuff like that. i just wanted to do something to make new friends. (Participant 11)*	Loss of friendships was considered as related to perceptions of their treatment and illness trajectories. Participants were interpretated as seeing friendships as a marker of how well they were. More friends were considered a good indicator of wellness whilst set-backs was distressing.

Themes	1st order interpretation	2nd order interpretation
<u>The role of services:</u> participants hope that services could help them maintain social contact.	*it sort of relaxes you to know you're not the only one (participant 10) Most of them just want to keep themselves to themselves. I know how it is…I don't like to go and hassle them. (Participant 11) Coming here is a reminder of what happened before, right? Psychosis and that. Coming here for the social thing reminds me of all the bad stuff that's happened. (Participant 7)*	The researcher's interpretated the participant's experiences as wanting services to help support them to maintain social contacts. Groups were very important to this, by providing space for like-minded people to establish that they were not alone. This helped with acceptance and self-stigma. However, some participants reported they needed to move away from services to be more independent. Some people reported that they needed to move away from services as it had the potential to re-traumatise them through perceived rejections.
<u>Uncertain identities and status ambiguity:</u> Participants developing an uncertain and ambiguous sense of self.	*I mean being this age is hard enough, like, trying to work stuff out and deciding what to do next, like to go to college or whatever (pauses). I guess that's not gonna happen now, cos im in here (early intervention service), I don't see the point now*	The researcher's interpretated participants' experiences as being centred on uncertain sense of self and ambiguous self-identity. Participants were unsure of themselves, and this was increased by not knowing what to do in life, wondering if they would ever recover from psychosis and worrying about how their friends perceived them. Interpretation from the researchers about the accounts that participants noticed they were at a stage of life where they would normally be moving away from dependence and instead it was increasing. A feeling that 'working out' who they are is being placed on hold for participants because of psychosis. Interpretations of hiding psychosis diagnosis from others to avoid being perceived as 'crazy' 'mad' and 'dangerous.' Feeling in some way that psychosis had separated them from their peers.
<u>Decrease in referent points for identity:</u> factors which served as referent points in the past no longer operated with the same force or clarity.	*They have similar problems to me (pause), that can be quite nice, you know, you feel part of a community of people cos it can be quite isolating when you hear voices. It's also scary to be around people that can be struggling more than you are, like to think 'am i really like them?' suddenly you're getting locked away into that (identity) with no way out*	These referent points included self, peer group, siblings, parents, and school. Most participants pointed at the difficulties in creating and maintaining relationships. In being with other people with psychosis, brought together through services, participants identified this was helpful for them to share their experience with others and reduce the tendency to feel alone. However, if placed with ppl who have worse/ better experiences than you this

Themes	1st order interpretation	2nd order interpretation
		could have the potential to isolate you or make the experiences feel worse.
<u>Unfavourable social comparisons:</u> participants tended to compare themselves unfavourably to their past selves and others.	*I can't really see me getting over it, like I worry about it all the time, I don't want to have to go back in (psychiatric) hospital again (pauses). My friends are all going to college or university and I'm just here*	Difficulties in social life were discussed in relation to what participants perceived they were capable of before getting unwell. This was also compared with what peers were doing around them. The researcher's interpretated those participants had a sense of being stuck and worried about their futures. Feelings of loss about the future led to a sense that participants were experiencing intense sorrow and were mourning. Participants discussed losses in relationships and education. They blamed themselves for these losses and were interpretated to have high self-criticism as they were holding their own actions accountable for the development of psychosis.
<u>Difficulties noticed:</u> young people and their carers both noticed changes in their behaviour and mood.	*looking back you can tell that you were jumping from one thing to the next and not concluding sentences and things like that*	Carers of the young people, mostly parents, reported they had noticed social changes and changes to their ability to converse and interact. The researcher's interpretated this as a retrospective reflection from carers. They were often unaware at the time but recognised a 'crisis' point, usually where everything had built up, and they would seek help.
<u>Lack of awareness of mental illness:</u> looking for reasons for why they developed psychosis. Placing blame for psychosis on drugs, illnesses, and spiritual experiences.	*probably about 3 weeks after I had been in hospital, like after they'd tell me and diagnose me and stuff, like I started to realise that it was more of a mental thing than a marijuana thing*	Participants were looking for reasons to blame their psychosis on. They recognised having a lack of awareness about mental health and had to discover it through discussions with others. Adopting their carers' perceptions of why they might have developed psychosis.

Themes	1st order interpretation	2nd order interpretation
<u>How help was sought and which service was approached:</u> caregivers/ parents were the ones who mostly sought support for the participant. Caregivers were the first source of support for participants.	*I think eventually told my mum what happened. I didn't want to tell anyone else, yeah, I think I eventually told them what I was feeling and stuff*	The researcher's interpretated the participant's accounts as approaching their caregivers first. Caregivers then considered approaching their family doctor as a first point of contact. School and religious support was also accessed. These were familiar and comfortable for the caregiver and participant.
<u>Thoughts on illness precipitants:</u> participants had a sense of the things they did which contributed towards the development of psychosis, caregivers were more focused on the genetic determinants.	*well, I think marijuana and mushrooms obviously didn't help, but um, I guess it's just the genetic thing, or just um, to do with brain chemistry, you know, just went wrong….*	Young people listed ideas of what they believed prompted their illness. This included drugs, exam-related stress/ school stresses, bullying, family illnesses and family births. Carers also stated similar precipitants as a cause but also included genetic factors when known family mental health as well as association to undesirable peer groups.
<u>Experiences of services and suggestions:</u> both positive andnegative experiences of the service.	*they could have more outings. Kind of annoying to sleep at 9 o'clock…. They could have better food too, it was horrible*	Positive experiences related to perceptions that staff and services were accessible, supportive, and sensitive. Young people also described their being good information provided, continuity of care and peer support within services. Negative experiences included being hospitalised, exposed to peers who were often unwell and perceptions of some staff as insensitive. The order and schedule of hospital ward routines was also listed as a negative experience, as well as side effects from different trials on medications. Some mentioned the intrusive way in which medication was ensured compliant was negative and intrusive. Service users listed ideas of instilling hope to help others seek help. Carers often found they had to seek out the information rather than gaining it. Admissions to hospital was particularly stressful, particularly admissions of young people to adult wards. Medication treatment was a concern for carers, but they also highlighted the importance of cultural support workers to help set goal plans and understanding the spiritual nature of the young person's experience. carers suggested the use of self-help parent groups and reducing the threshold for seeking help.

Themes	1st order interpretation	2nd order interpretation
<u>Beliefs and knowledge of mental illness:</u> participants began to develop more adaptive beliefs about their illness and their recovery.	*in some ways its good because if I hadn't had this experience then I would have never learnt how to deal with stress*	Researchers interpreted that participants did not have much knowledge of psychosis prior to their experience and therefore had enriched knowledge about the diagnosis afterwards. Carer's knowledge about psychosis helped reduce the time spent between identification and treatment.
<u>Difficulty with interpersonal relationships and reduced opportunities for communication:</u> participants identified they had experiences interpersonal difficulties with peers or family.	*I was born into a violent relationship, my mum, my mum and dad and, really escalated from there because I was neglected, and things happened to me (participant 5) basically it was the bullying at school…it's my instinct to run away and be alone instead of being with the group (participant 1)*	Identified problems in family relationships included conflict, separation, childhood neglect and abuse, exposure to domestic violence, lack of parental care and support (either through parental substance misuse or parental mental health), siblings' difficulty or other relatives and estrangement. These difficulties were characterised by a lack of closeness and conflict, bereavement of close loved ones, difficulties with social relations before and after the onset of psychosis, bullying and social isolation. social isolation caused through bullying seemed related to difficulties with self-esteem, confidence, and social anxiety. Perceptions of themselves as unusual often led to social anxiety and subsequent withdrawal.
<u>Reluctance to disclose unusual psychological problems:</u> challenges in disclosing experiences to close others	*I'd always really wanted help but I had trouble admitting I had problems….it was hard to admit it to myself, like, it was even harder to admit it to somebody else to get help for it (participant 6)*	The researcher's noticed participants seemed to have difficulty in disclosing their experiences to people they were close with such as friends and family. It might have been due to people not perceiving their social support network as being supportive enough and instead preferred to contact a mental health professional. The researcher's also interpretated a fear towards losing relationships or being rejected. Central fear identified that participants worried they would receive unkind treatment, humiliation, and rejection from others once they disclosed their experiences.

Themes	1st order interpretation	2nd order interpretation
<u>Disclosure of unusual psychological problems:</u> costs and benefits: experiences of disclosure that was difficult but also had some benefits.	*I've been able to understand what is happening and why, why I feel such things in such a situation. Why I get certain images in my head, all sorts, and because of that I've now got a list of things that I need to work on, either to minimise them, or just accept there is nothing i can do about them (Participant 1)*	Negative experiences of disclosure were characterised by participants having social anxiety, e.g., thinking people were staring at them. Participants also described being stared at in this way by the doctors. However, there were also benefits to disclosing their experiences. Benefits included access to mental health support, improved emotional well-being and reduced anxiety. Finding a safe person in the personal circle to the individual often became an 'outlet' for that participant. Talking with a professional often increased knowledge about psychosis and set recovery goals and foster acceptance. Informal discussions with professionals who provided normalisation was particularly described as helpful.
Stage 1 - Events preceding first episode psychosis: participants noticed precipitating factors before the psychosis. For carers this was highlighted by breaking boundaries.	*my cousins got married. 'cos we used to hang out together. We used to go to the pub and pictures. So I was all alone. (Client) he was beginning to stay out later than he was allowed to (family)*	The researcher's noticed that participants tended to break boundaries prior to psychosis but that this was identified by their relatives more than themselves.
<u>Stage 2 - The first psychotic episode:</u> episode is a catastrophic disruption to the person's world.	*the voices were good and evil and I just sort of collapsed that night. I was getting overwhelmed with voices in my head; thought bombardment (client) I was so scared I used to try and lock my door with no lock on. I used to wedge it. I was so scared he would come in. (family)*	The researcher's interpretation included that carers were struggling to make sense of the experience for their loved one whilst participants felt they had a major disruption to their lives. Participants who had heard voices did not feel understood by family. Some family members attributed their loved one's behaviours and symptoms to teenage behaviours and this dismissal was interpretated as making them feel guilty.
<u>Stage 3 - The first hospital admission:</u> first admission to hospital was considered a major event in the narrative for clients and family.	*so they took me to the hospital and all I could remember was being out in a chair and being carried along. I was miles away. (client)*	Researchers noticed a difference in how the first admission to hospital was considered by service users and their caregivers. For carers it was considered reassuring but for service users it was considered confusing. The first admission was noticed and interpretated by researcher's as being an important landmark. This experience was deeply distressing and emotive.

Themes	1st order interpretation	2nd order interpretation
Stage 4 - Current experiences - <u>disability</u>: issues with control and ability to manage their problems.	*my state of mind's not what it used to be - every day is a stuggle in the mind with thoughts and voices and all that (client)*	The researchers identified that it is difficult to concentrate and manage problems. Relatives appeared to lay blame for this on the person's stigmatisation.
Stage 4 - Current experiences - <u>relationships</u>: relationships were the biggest source of support but also had been impacted negatively in many ways through psychosis.	*it's difficult because conversation is always two way, and you can't really know when to take out the information in and when to take it out. (client) I haven't really encouraged him to come here very much because what happens when he comes here the neighbours usually open the door just to question him. (relative)*	Relatives noticed their loved ones were often separated from society. Researchers interpreted the service user's experience had led to altered relationships, relationship break downs and changes in how to interact with others. Yet, it was noticed that service users social circle was a source of support.
Stage 4 - Current experiences - <u>self-development</u>: changes in self-identity and development of self. Concerns about whether independence is a good thing for service users.	*I don't harp on it but it was the best thing we could have done. The only thing we could have done was move out of a place and just visit. I mean mum and dad can't be there all the time can they. It's part of life that they want their freedom as much as you do. (client) he's doing what he want to do and he's not at home with his mother. he's becoming an entity of his own. (relatives)*	Researcher's noticed relatives were concerned and pre-occupied with whether independence was a good thing for service users, being worried they were becoming too independent and changing their sense of self. Service users often found that they needed to change and adapt to adjust. Wanting to place distance and encourage themselves to be independent.
Stage 4 - Current experiences - <u>coping and services</u>: road to recovery being bumpy and wobbly, needing professional guidance to help monitor and keep on track as well as supporting difficult side effects.	*you think your're on the road to understanding it better then the next thing you wake up one morning and it's gone right back to the beginning again. It's like a see-saw thing. (relative)*	Going back and forth with service users in their recovery journey. That this is not a straight process. Eventual improvement in confusion was noted by the researchers.
<u>Coming to terms:</u> having to accept a new reality after living in a 'delusional world' was difficult.	*one participant had taken a picture of jumbled fridge magnets and described 'that's me describing my mind sometimes, it's kind of like confusion…because after I had a psychosis episode, that's how my mind was like, fully confused, and I couldn't break out of it.(participant) in another: it's really hard for me to even deal with the fact that i had an episode... i mean i'm starting to come to terms with it now but for a while i couldn't even, i couldn't believe it... it's more the way i behaved when i had an episode and i kind of like look back and question like what was i doing?*	Researchers noticed that participants needed a period of deliberation to reflect but sometimes the remembering of difficult experiences brought confusion and shame.

Themes	1st order interpretation	2nd order interpretation
	what was that about? that makes me feel so, sometimes makes me feel embarassed about myself (participant)	
<u>Fear of relapse:</u> fearful of the psychosis coming back.	*I always think I'm gonna get unwell again and again, that's maybe another reason why I don't go out, I don't wanna talk to oeople 'cause I'm thinking last time, when I had an episode, it was in public…that kind of scared me…I'm thinking what if I get unwell again, what if the same thing happens again? (participant)*	Researchers identified that participants had a permeant fear of becoming unwell again and relapsing. Fearing public places and avoiding them because of a possible relapse. Worries that the destruction of their lives would be worse this time and isolating themselves to protect themselves.
<u>Blaming the medication:</u> reflecting on their experiences of altered mood after psychosis sparked a need to assign blame.	*participant took a picture of medications: it gets me down that I'm gonna have to take them [medications] for such a long time… and then I attribute all the problems since to them obviously, the cognitive problems anyway… it [medication] flattens you out and it also puts iike a mental straight jacket where you have a thought but you can't hold the thought...you can just feel the difference when you take the drugs*	The researcher's felt participants felt some need to assign blame for their experiences of low mood following psychosis after reflecting on their feelings. Blame was laid on medication for weight gain and flattened affect which participants indicated was contributing towards how they felt about themselves and life after psychosis.
<u>Losing purpose in life:</u> psychotic episode had destroyed sense of personality and left them feeling empty.	*participant that took photo of an empty mirror: when I'm having a bad day, I can't even look in the mirror… because i feel so ugly and so, I am not the same as I used to be before the psychosis, I used to fix myself yp, I used to do all these things, I used to be outgoing, it's like, i don't like the reflection i see staring back at me. another participant took a picture of a knife to describe suicide ideation.*	Researcher's suggested that participants viewed themselves as 'impaired' as they 'no longer operated as they did before their illness.' Difficulty in completing previous tasks led to job loss in some cases. Relationships were strained and in some cases, participants described a sense of identity crisis. This crisis led to participants feeling unmotivated, pessimistic, and devoid of energy. Researchers implied that there was a sense of losing control and independence leading to hopelessness.

Themes	1st order interpretation	2nd order interpretation
<u>Feeling misundertood and ignored:</u> a change in functioning led to a change in how people interacted and treated them.	*they kind of ignored the depression and went onto the psychosis, so the low mood was still there and even when I said about it not much happened…the doctors and everything, they're trying to control whats happening, feels like they're trying to control everything.*	Participants noticed people started to develop significant irritation at them, lack of understanding, feeling as though they should be now 'recovered.' Many people described they were ignored and 'swept under the rug' by healthcare providers.
<u>Social withdrawal:</u> a decline in social functioning led to decline in social life.	*I want to be alone and no matter what people say to me or anything like that, they can't cheer me up… I don't wanna communicate with anyone, I just wanna be in my bed sleeping because that's the best place for me I feel.*	The researchers implied participants had been struggling to keep up with college and work. Eventually being unable to keep up with activities and therefore dropping out - intensified sense of loss. Researcher's interpretated that participant appeared to 'isolate from the shame of psychosis.'
<u>Being depressed:</u> a sense of hopelessness, low self-esteem, and personality changes after the psychosis experiences and during recovery.	*sometimes it is very low mood, sometimes it is flat mood…when it's low mood, I am still able to get up and do things and just, you know, do things around the house…when it's flat mood, I don't want to do anything I jst stay in bed all day*	Researcher's interpretated that participants seemed unable to place a time on when depressed feelings occurred. The flat mood brought with it the inability to concentrate, hold or focus thoughts, amotivation and apathy.
<u>Wanting to get better:</u> participants were highly desireous to get better.	*I need to get my confidence back, I need help mentally…I've got a mental disability but I'm not fully gone, I need to get my life back and that would lead to getting jobs…I can just have some kind of hope and, you know, just try and do stuff. I have to have some kind of purpose. some kind of reason for being here. (participant) i'm grateful, you know, that i have people around me. they just support me, kind of know the situation and, you know, kind of just accept me because i'm just like that (participant)*	The researchers suggested that participants wanted to get out of the cycle of psychosis and recover fully to their lives. Regaining control of themselves and lives was important, wanting some sort of purpose. Wanting to connect and have support network near to them. Thinking about aspirations for the future.
<u>A seed unfolding:</u> the emergence of psychosis was akin to a seedling being expanded and developed.	*well, I can't really pinpoint 'a before' if there was 'a before' or if there was just 'leading up to it.' even as a child I didn't really feel normal or like other kids, so not knowing if was just normally really withdrawn and then developed something else, or if, you know, i always had some sort of seed within me that just, kind of, unfurled naturally. (Shiloh) all my life there was certain things that always happened. Either like voices or hearing things that aren't there...i said, OK, you*	Pervasive effect of psychosis in lives around relationships, occupation, interfering with learning and enjoyment in life. Believing that psychosis developed whilst in 'normal' stages and then gradually became disruptive. The researchers interpretated that psychosis as being considered normal at the beginning.

Themes	1st order interpretation	2nd order interpretation
	know, no big deal, this just must be normal. (Kasandra)	
<u>Psychosis in full bloom:</u> active psychosis led to an increasingly narrow life.	*Researcher's interpretation: 'Living with their parents was rarely mentioned by participants, seemingly it was taken for granted or necessary.'*	By not speaking about their parents, the researcher's interpretated that participants seemed to take them for granted. Unable to continue relationships and occupations in the same way.
<u>Growing beyond psychosis</u>: reconstructing life after psychosis, feeling grateful for understanding themselves better and accepting experiences might have produced a better version of themselves.	*I'm sort of glad that I had my illness. I can start to look at, sort of, other avenues that I might not have considered had I not been diverted from something else. If you're blocked from doing other things, then it's good to look at what you can do, and - i don't know. it's like if you're walking on a path, and suddenly, you know, you can't go a certain way, or there's lot of barriers, but you wander around lost for a while, and then you find another road...maybe you'd end up somewhere better (shiloh).*	Researcher's interpretated that participants had to reconstruct their lives. There was often a continuity between participants previous lives (before psychosis) and their lives after psychosis. Feeling grateful for being able to learn about themselves and set realistic goals. not disclosing the extent of their psychosis led to help not being received in the right areas.
<u>Childhood (5-11 years) Inequity in peer relationships:</u> perceived bias in their peer social groups. Difference, deprivation, and experiences of separation set them apart from their peers.	*it was upheaval really, my stepdad. My mum had an affair and my dad was upset' & 'we didn't have the money so I stayed home' & 'I went through this thing, I thought to myself 'oh' 'cause in Zimbabwe it was like 'ooh, black skin.' Where as here it wasn't. it was in my face and i thought 'what is this?'*	Early experiences of racism and separation, discrimination and difference created a barrier for connection in peer relationships. The researcher's interpretated that there seemed to be a sense from their accounts that participants had felt unequal to others.
<u>Early adolescence (11 - 15 years) Instability in peer relationships:</u> being considered unequal in relationships led to strain and instability in relationships.	*when I was about fifteen years my mother had ovarian cancer.' & '...well sort of pressure of people being nasty to me and erm teasing me and saying 'you chink' or whatever. Whatever I am it doesn' t matter I just felt negativity towards me.'*	It was interpretated that participants had felt bereavements consolidated their sense of difference to others and that experiences of bullying was a product of being considered separated/different to peers. To manage this, people spoke of putting up a shield.
<u>Late adolescence (16-30 years) Becoming isolated and increasing isolation - being isolated:</u> movement meant further isolation and a descended into ways of trying to manage this isolation through external methods.	*The problem was that I became dependent on it (cannabis) and it became a tool.*	The researcher's implied that geographical and physical movement meant increased isolation and a need to cope in ways which provided a 'quick fix.'

Themes	1st order interpretation	2nd order interpretation
<u>Late adolescence (16-30 years) Becoming isolated and increasing isolation - increasing isolation:</u> actively attempting to not rely on friends and trying to rely on self meant further isolating from previous support network.	*since I went to hospital and got help they always said like, if I walk inside a pub and they just say 'oh madman' so I don't keep them as a my friends' & 'when I came back the fact that my friends didn't judge me or anything was good'*	Not wanting to rely on others and turning inwardly to self. Positive relationships were characterised by not being judged.
<u>Hanging out with people I like and who understand me:</u> wanting to surround self with people who they were able to trust.	*probably play a game of soccer [or] get to gether and have a drink or something,' (courtney) & 'because people have got problems here, and so habe I, it's just easier because I know people have got problems here, and it makes me feel I don't, I feel safe here.' (Jay) & 'Like he was talking about a personal problem he had and i was telling him about one i had a few weeks back and still do. we talk about personal stuff.' (Gabe)*	Wanting to spend time and be around people their own age group. People who might understand them, their own peers and also others who had experienced psychosis. Trust was integral to people with psychosis maintaining or establishing contact with people.
<u>Valuing families and other supports:</u> reliance on family supports and others involved in their care.	*my mum, she has always stuck through me, all the trouble I have been in and that…they mean a lot to me, because some parents of friends, I know they kick their kids out when something happens to them. You know my family stuck by me and they have got confidence in me, more now than what they did.' (pat)*	Participants seemed reliant on the support they received from people in their family. People who were important to supporting them and being there because they were related to them.
<u>Spending less time with old friends:</u> psychosis led to feeling misunderstood by old friends therefore needing to spend time with people who were able to understand what it was like for them.	*This guy [previous friend] wouldn't understand it you know. Maybe he doesn't know that I'm going through another psychosis, I don't know. But if he just put himself in my position he might understand but he's so arrogant he can't.' (Jess) & 'once I get my drivers licence i will drive to her [relative] house and talk to her sometimes. stuff like that. go to my friends house and talk to them.' (Circa) & 'I am not the type of person that says hey let's go to a nightclub, let's go to this or that. maybe i prefer that person to say it to me. because i don't like to be leader, you know what i mean?' (Circa) & 'i am angry about it, because i thought they were good friends. I don't know...but through experiences you learn who your good friends are, you learn the one's who are going to stick by you no matter what, no matter what you are doing at the time.' (Jess)*	Feeling unable to spend time with friends who echoed loss and also were not able to relate to their experiences. Learning about having quality over quality.

Themes	1st order interpretation	2nd order interpretation
<u>Something happened to me:</u> being different now: being perceived as different from their peers.	*it's just that they [former friends] view me differently now you know, because I've become psychotic they think that you are now a waste of life or something…They just think you're a loony or something like that which is not very good' (Pat)*	Researchers identified that participants seemed to acknowledge there was a stigma to psychosis and that people avoided them because of this. Participants seemed to desire to be involved in group and wanting to be re-establish contact.
<u>Building new relationships:</u> worrying about new relationships and re-evaluating how they make these and basing them on quality not quantity.	*he's very overpowering, he's is like… when I was friends with him I was like a 'puppy dog' to him. Now I couldn't do that, I couldn't be a 'suck' anymore. I have learnt from my past experiences .' (Jess) & 'I want to see my old friends again, I want to start up a band with them, i want it to be like the old days, youi know. I don't know if I...I don't know what will happen now, I don't know if they are users pr if they really like me as a person or they think i'm a "dickhead" or you know, just want to use me. i don't know.' (Jess) & 'well i feel i need to back off a bit because like i'm nearly twenty years old and i need to separate from my parents...if i have enough money then i woukld like to live independently in a unit or something like that, or maybe if it's not possible maybe just live independently at my parent's home.' (Circa)*	Re-evaluating lifestyles, social interactions, and personal beliefs. Made participants wonder about whether their past relationships were 'true' and considered they had learnt lessons about themselves, others, and the world around them. Thinking about the future and the need to separate, have independence away from relatives/ parental figures.
<u>Illness as incompatible (to romantic relationships):</u> psychosis was considered as being incompatible and conversely affecting the ability to have romantic relationships.	*erm, because at the moment I'm having blackouts, I'm not too…I'm not very trusting in myself to do anything else.' (Phil) & 'they might be scared or shocked.' (Leanne) & 'if I didn't think the family liked me then that'd be a barrier, one of the main barriers you see. if there was part they weren't interested in or they didn't think i was good enough for her, or that i was worthwhile, that'd be a barrier for me' (Nathan)*	Incompatibility seemed to stem from being considered different to other people and feeling disconnected. Participants also questioned their abilities to have these relationships and referred to symptoms which may impair their socialising. A lack of trust in self was confounded by not trusting others to understand or accept them. Worries of other dynamics in the relationship such as how their potential partner's friends or family would perceive them. Some participants discussed possibly with-holding true information about their psychosis or watering it down with 'mental health' rather than 'psychosis.'

Themes	1st order interpretation	2nd order interpretation
<u>Relationships as normalising</u>: wanting relationships to be considered as having a usual 'normal life.'	*I think they'd be pleased for me 'cos I found someone…I'm not just hiding behind my mental health problems…I'm getting on with life and doing things just like any other young woman.' (Leanne) & 'it might make me a more rounded person. Might not be so, so jagged' (Jay)*	Researchers identified that participants seemed to explain romantic relationships were considered usual for 'normal' lives and therefore if they had one they could be seen as 'normal.'
<u>Relationships as high risk:</u> endings to relationships were incredibly traumatic.	*when talking about relationships it's very traumatic for me. It's like, it's somebody has died yeah and I have to talk about that person.' (Ali) & 'oh my family aren't supportive…they've got too many problems…they never, I mean all the relationships I've been in, my mum and dad never supported me, they never liked them. My mum used to say that they're not good enough for you....and used...and used to try...to try and put me off relationships' (Leanne)*	Participants found the endings to these relationships incredibly difficult. Researchers noticed participants struggled to talk about the relationship especially if there was a traumatic ending. Learning to be ambivalent about the relationship especially if they had previous experiences/ witnessed others.
<u>Risk reduction:</u> trust was considered a way in which risk in developing romantic relationships was reduced.	*I think trust is really important, if you can't trust them then you have o basis for anything because nothing can build up from that' (Isobel) & 'hopefully they'll be a bit understanding and yeah…understanding mostly…and know that it was probably not in my control or anything.' (Phil)*	The researcher's wondered whether needing trusting romantic relationships in their lives was a way of compensating for previous abuses of their trust. Participants seemed to want either a stable founded relationship or nothing at all.
<u>lack of experiences and resources:</u> participants faced challenged to romantic relationships was that they lacked psychological, social and physical resources which would enable them.	*for me, when I first start getting to know someone male I always think I can't get close to them 'cos there's always that barrier of you sort of think 'well I might fancy them, it's stupid,' or you know, you get too close, they think 'why's she flirting with me?'...and your're like, well no i'm not.'*	Young people described a deprivation in psychological resources (confidence, energy and robustness) and social resources (peer group and support network). All described a lack of money to go out dating (physical resources).
<u>1. Experience of psychosis: Uniquely psychotic phenomena:</u> altered interactions with the world.	*he said 'would you like something to eat? I went, 'mmm,' like that, I did not answer him really. And he come in and he went to give me some toast, and I went to bite it, and I went, I was so paranoid I said, 'you poisoned this, I am not going to eat it.' he is like tearing his hair out, he could not understand it.'*	No longer able to take for granted feeling safe. Researcher's identified participants had a different relationship with the world around them from these experiences. Relationships with others also being undermined by the suspiciousness and paranoia they felt.

Themes	1st order interpretation	2nd order interpretation
<u>1. Experience of Psychosis: Experiencing emotions:</u> extreme emotional states.	*Researcher's interpretation: 'he did not want to hurt anyone despite commands to the contrary; instead he stabbed a wall in cathartic expression of anger that accompanied his experience of these voices.'*	Extreme emotional states were interpretated from client's narratives about their psychotic experiences.
<u>1. Experiences of Psychosis: Thinking about dying:</u> extreme emotional states produced thoughts of dying and desires to commit suicide.	*I was just feeling stressed, angry, and unhappy…I tried to take an overdose once…of sleeping tablets… I vomited back up… that's how bad it was really.'*	Descriptions of being hated by others was interpretated by researcher's as not having another way out and thinking of death as an escape. It was implied by researchers that the accounts felt the thoughts about death and suicide were worse than the psychosis.
<u>2. Immediate expression of psychotic experiences: avoidance of experience:</u> staying away from anything that might trigger emotional psychotic experience.	*erm… just stay in the house, don't watch the TV or listen to music. This is when it is really bad, it has not been like this for a while… I cannot listen to music or watch TV because of the voices and stuff, cannot play on my turntables, cannot do anything really, apart from sleep and try to get over it.*	Researcher's noticed participants attempting to block out and prevent thinking about the psychotic experience. Avoiding activities usually would prevent the stimulation of psychotic experiences.
<u>2. Immediate expression of psychotic experiences: Expression of experience:</u> engaging with the experiences to make sense of it.	*yeah I should have brought it with me actually, some weird, some really weird pictures I drew from some tissue. There was like this alien, this alien's head with the horns, and I drew it and I told my nan, 'I just blew my noise on the bus and when I was home i drew a picture from it' she's like 'you drew that, that is quite disturbing like'*	Participants engaged with their previous experiences of psychosis by communicating it directly or indirectly. This was interpretated as a way of trying to make sense of their experiences.
<u>3. personal and interpersonal changes:</u> changes affected age-related goals.	*yeah it is like it is easy, if anything college is like easier for me in a way, I dunno why but it seems… before, I mean I went to college before and I could not deal with it before and I left and then my mum wrote a letter. But I really wanted to give it ago but my motivation went then, you got to have motivation all the time.*	Loneliness alienation produced from the changes made by psychosis experiences created anxiety when in social groups. The researcher's interpretated that this created a challenge for people to remain focused on achievements and educational goals. Some anxiety around how they may be received.
<u>4. personal explanations:</u> psychosis becoming the explanation for why developmental milestones were not met.	*well I mean, it is one thing sort of standing around looking at nice girls, thinking, god I would like to pull her and it is another thing… doing something about it*	Differences to others were described in relation to be a product of psychosis. Participants held this accountable for why they had not got to certain milestones expected in society.

Themes	1st order interpretation	2nd order interpretation
1. Treatment: empowerment was increased when participants were able to control and have a say in the treatment.	*they would just shove you on a medication and there were it, take it*	Control and choice around treatment increased empowerment. Having a sense of personal involvement in all aspects of the treatment process and being able to express their positive and negative personal opinions about their treatment.
1. Managing personal well-being: good emotional health came from being supported to look after self.	*because I had the freedom to go anywhere I like when I was hearing the voices and stuff I had the freedom to use my ways of coping*	Having the freedom to take charge of their own personal care, such as utilising their own coping mechanisms was empowering. Having flexibility to employ their personal coping strategies.
1. living within institutions: lifestyle choices influences how empowered people were, this was affected by being institutionalised.	*when I was at X they wouldn't let me out for walks that annoyed me and me worse no freedom it was terrible… you need to free to do your own things and not treated like a little kid…you need power and if you don't have that you can't do anything*	Having their own lifestyle choices influenced how empowered they felt. When staff enforced rule restrictions, this felt inflexible and patronising.
1. symptoms: being empowered helped to manage symptoms.	*it [empowerment] helps to stay in control and just not do it not do what the voices say*	Responding to symptoms that are recognised in oneself and using empowerment - ability to be in control - to manage this.
2. being listened to and understood: by clinicians/ professionals.	*yes that's it, they were always reassuring me and talked in a nice manner, that helps a lot when your feeling ill. I think when someone listens to you you get better and more better they understand me more and what I am trying to say.*	When clinicians spoke in a way which was jargon free, participants reported that they felt more empowered as they felt listened to and understood.
2. validation from service and professionals involved in care: having validation felt as if professionals were understanding but also believed them.	*when people ask what do I think, when they listen to me and explain things so that I understand them. When I went on ram felt like an achievement.*	The researcher's interpretated that there was something important for participants to be believed by professionals.
3. the quality of information: knowledge as power	*they were so good at explaining things, they'd keep explaining things until I understood them and they didn't use big words*	The more knowledge participants had of psychosis and themselves meant better understanding and therefore ability to manage.

Themes	1st order interpretation	2nd order interpretation
<u>3. information about treatment</u>	*you know what is going on and you know how to get help eh*	Participants discussed they were rarely involved and informed about decisions about their treatment. When participants were this made a difference to their treatment and understanding.
<u>3. talking about symptoms:</u> discussions can be enabling but getting into discussions is hard.	*I feel comfy asking them for help I would just go up to them and say can I have help like other places I don't go up to them about it I end being silent*	Discussions about symptoms have the potential to help someone during recovery but getting into these conversations are difficult.
<u>4. recognition of need:</u> professional support was needed and recognised by participants.	*the gp just did nothing, myself and mum pleaded with him begged him to help us, he just didn't understand my illness*	Some experiences of staff members and professionals was that they were not doing enough to support them. Researcher's interpreted this as participants recognising, they needed professional support.
<u>5. coping mechanisms:</u> strategies learnt with professionals most helpful when looking at when and where to use them.	*they taught me different methods to use like m… listening to my discs put the earphones into your ears so that it's right. And like getting and elastic band to pulling at it and stuff.*	Difference noticed between coping mechanisms developed with professional's support, and their own coping mechanisms. Learning when and where to use these strategies and why was important.
<u>5. structuring time and planning for the future:</u> having a daily structure helped to reduce boredom and reduce stress.	*sometimes they haven't done anything with me about how to cope with the symptoms but at the unit the nuse she was doing things with me about how to recognise the early warning signs and she did stuff on anger management with me.*	Boredom was a big factor causing stress for participants. The researcher's interpretated that having a daily structure was important to mitigate this.
<u>6. relationship to clinician:</u> Importance of creating a relationship to professionals.	*they didn't spent time with me they just sat in the office all day… just sit in a office and just sit on their bums all day*	The researcher's made interpretations that participants had a need to create relationships with clinicians, especially when hospitalised.

Themes	1st order interpretation	2nd order interpretation
<u>6. emotional support from clinicians:</u> relationships to clinicians provided emotional support.	*they had a laugh with me… and that helped me to relax and I felt I could open up to them they were so caring friendly and always listened to me talk to me and stuff and they tried to understand me as well and I had fun with them as well*	Relationships with clinicians was also needed for emotional support. Better relationships were with staff who came across to participants as more approachable and friendly.
<u>6. practical support from clinicians:</u> family members involvement in their recovery journey to enable development.	*I can't make decisions at that time and sometimes I can't remember what happened so I rely on my parents to look out for me when I am ill and make the best decision for me. But it can also be important at that stage as well because I need help with what to do and how to cope when i'm feeling bad*	Empowerment through parents being consulted by clinicians was important for participants. This empowerment improved recovery for participants following psychosis.
<u>1. "what's it all about":</u> the researcher's had difficulty in trying to find meaning within the participant's narrative	*I think that, erm, I was being guided by God throughout this time. There was too many things that went right for me at the right time, during when it got really bad, for me not to have an explanation like that. Just little things that I got help with during that time.*	Participants spoke about it being difficult to make sense of their experiences. The researcher's identified their own difficulty in trying to make sense of the participant's accounts and themed there seemed to be a general confusion like 'mist' over the accounts. Sometimes this confusion led to participants not wanting to discuss what had happened to them. Some participants blamed god for what happened to them.
<u>2. ‘‘I just felt like an animal, being locked up all of the time’’:</u> participants' feelings of being trapped and helpless towards being admitted to hospital and receiving treatment.	*When I first got there I didn’t like it cos I was locked in a room. There was just like a bed you know. And people used to walk past all the time and lift up like a little wooden panel and look through a glass window at me.*	A feeling of being admitted without any choice or control. Being treated without any respect. Language used was interpretated by the researcher's as being imprisoned, segregated and punished in some way.
<u>2. ‘‘I didn’t have a clue what was going on’’:</u> participants did not feel aware about what was happening to them.	*‘‘I was out of touch with reality. I needed someone to sit down who I trusted and explain what was going on. But no one really said anything"*	The researcher's interpretated the lack of awareness participants had in their experiences was related to how much information they were given. Less information/ education about their experiences resulted in the participants feeling confused about what happened to them.

Themes	1st order interpretation	2nd order interpretation
<u>3. ‘‘Some kind of normal’’:</u> participants desire to be seen by themselves and others as normal.	*‘‘You have to come back to some sort of normality so that you feel you belong here, no matter how different you are’’ ‘I wanted to prove to the world that I was back to normal’’ (Participant 4, Pg 16, Ln 7). ‘‘I go out every weekend. And I work all week. That’s it really. Just like normal people of my age’’*	Researcher's suggested that the need to get on with a normal life seemed closely related to participants wanting to belong. Researcher's noticed participants had a strong desire to be seen as normal and to prove to others around them they were 'back to normal.' Participants expressed a strong desire to pursue and do things which were expected for their age group.
<u>3. ‘‘When you’ve got your friends around (. . .) you feel a lot more hopeful’’:</u> the importance of belonging in social groups and the need for social acceptance.	*‘‘My best mate (. . .) has been supportive as well. (. . .) has been with me throughout it trying to level me’’ (Participant 3, Pg 4, Ln 35). Feeling understood was an important part of being accepted. For example, one participant described the need to talk to friends with similar belief systems: ‘‘I often think of my contact with the Buddhist people and stuff and yeah, maybe like contact with them, more contact with them would be a good idea’’ (Participant 5, Pg10, Ln 6). In contrast, one of the participants reported that, although his friends were important to him, he did not want to share his experiences, feeling, ‘‘worried that people will think that I’m crazy’’ (Participant 2, Pg 6, Ln 37). It appeared that for this participant sharing his experiences might have highlighted his difference and resulted in him being rejected. All of the participants highlighted the importance of having social relationships in terms of their feelings of hope: ‘‘When you are alone you feel more hopeless’’*	The need to discuss and share experiences was debated by participants. Some preferring to share experiences and others not wanting to for fear it might impede social belonging and relationships to their peers.
<u>3. ‘‘If you don’t work, staying at home, it just drives you insane’’:</u> employment and occupation as being necessary to stay well.	*I felt really hopeless when I finally quit my job. I didn’t know what to do. I just thought well that’s it, I thought my condition’s just going to get worse. And I’ll end up going to hospital and then I’m never going to be able to get a job again.*	Participants described the importance of having work or some kind of occupation to prevent isolation and segregation from others. One participant highlighted the importance of having things to do to drive him forwards.

Themes	1st order interpretation	2nd order interpretation
<u>3. ‘‘Not alone’’:</u> importance of hearing that other people have experienced psychosis.	*He [the psychiatrist] told me not to worry he said he’d seen thousands of people the same age as me in the same situation and he said not one has not got over it.*	The researcher's interpretated that participants felt hearing stories about others experiences helped them identify with others and know they were not the only ones. These shared stories were very powerful and could offer narratives of empowerment but also narratives of never being able to get well.
1. Perceived enforced treatment: anger at being forced and having their freedom taken away from them.	*I’m my own person. You can’t do this. . . . I was angry at the doctors for locking me up. . . . I’m not angry because I have a chemical imbalance. I’m angry because strangers who don’t know me have locked me up and taken my freedom . . . I’d gotten locked up and had my freedom taken away for being me*	This theme was defined as being subject to outside intrusive and impersonal discipline, enforced treatment, and monitoring. This could lead to feeling angry, fearful, unheard, and disempowered
<u>2. Disintegration:</u> a fragmented sense of self in the acute stage of FEP.	*I’m feeling totally different like I’m not myself and that freaks me out . . . Like the thoughts that I’m thinking and the way that I talk to other people like sometimes it surprise me. . . . I have no idea what I just said and what was you know my face expression . . . freak me out and my thoughts start going why you know why, why is that.' & ‘I was doing things that I couldn’t control. . . . when you’re aware of something you’re doing but you can’t stop it, it burns you’.*	A perceived lack of control over oneself and one’s interaction with others due to psychotic symptoms was clearly evident and central to distress during the acute phase of FEP. The person’s sense of self appeared fragmented and could be associated with ambiguity, disbelief, uncontrollability, and feeling surreal and disconnected from one’s identity, others and the world. This disintegration continued in the person's acute and recovery stages.
<u>3. self-stigma:</u> negative views of themselves and their treatment	*I never used to think that I was crazy (laugh) until I actually had people coming around to the house everyday to make sure I wasn’t dead (laugh) . . . Frightening to be honest, it’s not fun. I hate to think that I’ll end one day up in a padded cell with a straight jacket on not knowing my name, that’s a bit scary.*	The researcher's identified participants seemed to negatively perceive themselves compared to others. They also had a negative view of their treatment as well as their mental health difficulties. This was sometimes adopted from a media and social perspective.
<u>3. stigma from others:</u> stigma was associated to media portrayals external in society around the person.	*Like people just don’t understand at all and so, and people make judgements on your decisions . . . so I just don’t discuss it with people like if anything I’ll say it’s depression . . . like on Law and Order the other day they said, someone said oh this person has psychosis and then the woman to me that means murder! . . . . And there’s even this club that we were going to and it’s called psychosis.*	Media portrayal of psychosis played into how people believed others perceived them as.

Themes	1st order interpretation	2nd order interpretation
4. Estrangement: people continued to feel estranged from their loved ones and peers following the acute psychotic episode	*Before I was unwell I needed twenty hands to count all my friends. After being unwell I can use two, like people fade away, people drift away, they can't, they don't either want to deal with it or they don't understand or when you try to talk to them they don't listen.*	Although evident during the acute illness, estrangement was predominant in the recovery phase. It was associated with feelings that people did not understand or relate to the illness experience and were unable to provide support. This could be the person's perception or indicative of actual behaviour. Communicating about the illness was difficult, the person could feel different due to the illness, and treatment and/or symptoms could produce isolation and disconnection
5. Sense of loss and deficit: a range of losses experienced in participants' lives and identities.	*It's changed me heaps cause now I'm a lot more timid. Not very outgoing. Very shy sort of person. Lost a lot of confidence. A lot of people have said I've changed physically as well because I've put on a lot of weight from the treatment*	Losses and deficits were specific or general and were associated with different aspects of life or sense of self. The theme was present during the acute episode but was most evident in the recovery phase.
6. Recognizing the illness as an ongoing problem: viewing the psychosis as a recurrent difficulty and challenges of having to accept it.	*At the moment I have no control over anything. The voices have affected me so much. The depression's affected me so much and I just feel so powerless to change it. Cause everything's happening so slowly like being treated . . . I feel so powerless like I wish I could change it all in an instant.*	Mental health issues and/or secondary consequences were identified as an ongoing and enduring difficulty. The illness was viewed as a struggle which required ongoing management. Progress was regarded as slow and produced a sense of disempowerment and hopelessness.
Perception of treatment as restricting treatment methods as being restrictive and not conductive to supporting independence and freedom.	*I'm a bit controlled by the medication ... I'll probably always have to go see a psychiatrist and get scripts filled and take my pills."*	Treatment could be disempowering, burdening, and/or inconvenient contributing to disengagement, resignation or a desire for self-control.
Estrangement: making conscious decisions to stay away from significant people to 'protect' them.	*"I drifted away from them while I was crazy ... you drift away so you don't hurt yourself or you don't hurt them ... there was a year that I here but I wasn't here at all."*	choices to disengage from relationships or interactions with others.

Themes	1st order interpretation	2nd order interpretation
<u>Conscious avoidance:</u> not wanting to acknowledge the presence of psychosis in their daily lives.	*I don't want to think about it at all ... I don't need to think about it anymore put it behind you."*	Preferring to avoid talking or touching the subject of psychosis. Placing illness in the past. Using distraction methods and numbing through substances. Sometimes avoiding treatment as want to be distanced from psychosis.
<u>Awareness of one's vulnerability:</u> researcher's interpretation that avoidance was because participants felt vulnerable.	*I'm always going to have to be really careful about overwhelming myself ... I would have the same dreams ... but I just don't think it's going to happen ... that's the price I'm prepared to pay to stay well ... it's ... disappointing.*	Worries, fears, cautiousness, and concerns about becoming unwell again and active attempts to avoid relapse reflected a sense of vulnerability. This led to withdrawal from past activities and taking things slowly
<u>Developing acceptance and moving forward:</u> dual process.	*"Tying to accept the way things are and not resist- ing ... now if I feel crap I just get through it I don't try and fight it."*	Recognition of the illness is a changeable experience and part of the life course that cannot be completely controlled, as well as a desire to move forward.
<u>Viewing recovery as a journey:</u> not always straight and linear journey but one marked by different variation.	*"It's ... like a roller coaster it goes up and down ... some days are good some days are bad."*	Recovery was ongoing and gradual, characterised by fluctuating difficulties and parallel improvement. This involved identifying problems and considering what recovery might be like once achieved.
<u>Self-directed recovery:</u> individuals being able to lead their own recovery journey.	*I'm a little more determined to deal with it ...I see it more as a fixable problem than I did before."*	A desire to actively achieve change and overcome and/or manage the impact of FEP. Treatment strategies or non-treatment related coping strategies were important. There was also realisation and reflective examination of what went wrong.
<u>The interpersonal environment facilitates recovery:</u> social belonging supported recovery.	*Just talking about what I go through ... talking about the nitty gritty of it ...every time I repeat what I've been through that tends to make me get better cause I realise that it's not true. Sort of grounds me as well.*	Interactions with others facilitated recovery. Improvement could be facilitated through the company of others, talking through the experience, emotional and practical support or teaching new skills.

Themes	1st order interpretation	2nd order interpretation
<u>Functional recovery:</u> a return to previous levels of functioning or engagement in tasks previously done was a sign of recovery.	*"A lot of things kind of slowly dropped off and now they're slowly coming back ... Getting to go back to school. I'm going travelling ... I feel like a productive member of society."*	A return to prior functioning or re-engagement in prior activities. Areas of improvement involved: symptom resolution, increased self-worth and confidence, general health and wellbeing, regaining a positive outlook, and contributing to society. Treatment changing was also a sign of recovery.
<u>Social recovery:</u> being able to do further activities meant increased social contact and therefore learning new interpersonal skills. This was helping young people develop.	*I'm a better listener now ...I try to listen to them ... and learn from whatever they're saying as opposed to listening to it kind of half in one ear, shrugging it off, and think- ing something in my head at the same time.*	Captured the renewal of relationships and re-establishment of social skills as core elements of the recovery process.
<u>Development of deeper and closer relationships:</u> idenitfying with quality over quantity.	*"Throughout all the good and the bad ... (girlfriend) stuck by me gave me a real appreciation ... the meaning of life and what love and ... life together long living would be like."*	(a) seek- ing, receiving, and accepting support and/or spending increased time with others; (b) recognition of the difficulties the relationship has endured; (c) more open and intimate communication; (d) sharing similar problems to significant others.
<u>Increased desire to interact with others and improve the relationship:</u> a modelling of relationships, wanting to make sure their relationships were ok and investing more time into this.	*I'm less snappy, more patient ...I'm more understanding now ... Especially when it comes to my family ... watch out to see if they're ok or if they're feeling ok ... making sure that everybody's happy not just myself ... I was suddenly wanting to know how they (parents) were.*	The new purpose for engaging with people was not previously evident and was a new realisation of the importance of relationships. This was accompanied by an enhanced motivation to improve and put more effort into relationships. There was also a new recognition that people can provide valuable support and an acceptance of the need for others.
<u>Enhanced perspective taking and sense of unity:</u> researcher interpretation that participants seemed able and wanting to take in different perspectives and that they had learnt about what it is like to have a mental health diagnosis.	*I wasn't as compassionate towards people who had mental illnesses ... I can understand what people go through when they have mental illnesses which has made a huge differences in my life ... I've got a bit more understanding.*	An awareness of difficulties coupled with compassion and empathy for others and increased consideration of others in general was present.
<u>Confirmation of character of others and quality of relationships:</u> trusting in others due to the support being shown before.	*My mum ... helped me with my medication ... I just realised how lucky I was you know to have someone like that ... it just made me sit, stand back a bit and like see what I had and realise ... I was sort of destroying it in a way.*	a realisation of genuine relationships and support; the positive qualities of others; and the value of relationships.

Themes	1st order interpretation	2nd order interpretation
<u>Greater appreciation of life:</u> experiences led to a re-evaluation of life and seeing it as valuable, fragile, and therefore needing to take better appreciation of it.	*I've never really realised how important life was till I started challenging my being ... Going from thinking that life is just worthless I've gone to thinking that life's ... got a lot of things ... I've gotten to know myself a lot better and I tend to value my own life very well.*	The psychotic experience was reframed as an opportunity to reassess life and as facilitating a greater appreciation for life. A desire to live life to the fullest was expressed as well as a greater recognition that life is precious, valuable, and fragile and is taken more seriously.
<u>New possibilities and direction:</u> re-assessment of life goals and direction	*My dreams are a lot different cause I no longer want things I used to want ...Well I used be heavily into drinking. I used to love it and now I don't and never wanted to get fit and now I do and so it's changed a lot.*	A perceived qualitative change in life-direction was apparent. This involved re-assessing and thinking about goals, interests, priorities, and life-path expressed as a desire for change or actual change.
<u>Deepening of self-knowledge:</u> a shift in attitude and behaviour following a development of self-awareness.	*"It's made me less selfish ... it's made me more harmonious around my family and ... I've matured a bit and don't look at things the same way."*	this theme captured development of the self, which explicitly or indirectly implied increased self-awareness. A shift in attitude and behaviour due to these changes was also expressed.
<u>Development of a sense of mastery and personal strength:</u> researcher's interpretation.	*desire for increased self-reliance and strong-mindedness. This involved increased control over one's situation and a determination to deal with residual and future difficulties. These perceptions promoted increased confidence and acceptance of one-self.*	The researcher's interpretated that participants had developed a sense of them becoming self-reliant and were able to focus on dealing with future difficulties. This increased their self-confidence.

Appendix 1F – Expanded Third Order Interpretations

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Self-stigma:</u> loss of friends through perceptions that they weren't able to interact and function with others. Not wanting others to notice a difference in them so avoiding others.	*If they wanted to go out I was worried that I wouldn't be the same person; I wouldn't be like the joker anymore (Participant 7) I just felt that she's going to come and my house won't be tidy enough. It's too many little things; food should be ready, and i won't be able to manage. (Participant 10)*	Researchers interpreted this theme as affecting how people perceived themselves and their own interactions with other people. They felt participants were anxious about the expectations of other people and avoid them to reduce this anxiety.	Interpretation of the data that participants may have felt developmentally behind and unable to manage tasks that are considered 'normal' so therefore avoid other people in their social sphere to reduce the anxiety. Creation of an internal world, by avoiding the outside 'real world,' that reduces feelings of being 'different' from others and manages the anxiety created through expectations placed on them.
<u>Talking about the illness:</u> reluctance to engage with others around them because they did not wish to discuss and re-live their experiences.	*I don't like talking about it and when I do I get really upset and stuff like that so I don't like talking to people even friends, about what happened, what I went through (Participant 11) I wanted the truth to come out so that in the future if we get married, if he finds out he won't leave me or he won't get angry at me, so i told him from the start (Participant 13)*	Researcher's felt that participants would avoid discussions about their experiences of psychosis with significant others because they did not want to re-live the distress it created. However, they also felt there was some pressure on participants to disclose their experiences to avoid 'lying' to their close others.	A sense of a dilemma for participants to disclose or not to disclose, depending on what was at stake for them. It felt as if the researcher's interpretation that there was some pressure for participants may have related to the participants perceiving they could suffer a social loss if they didn't disclose. It felt as if participants had to weigh up the costs of a potential social loss if they did disclose and a social loss if they didn't and it eventually came out to the other person. Perhaps this was a source of anxiety for people.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Symptoms ended friendships as I knew them:</u> both negative and positive symptoms of psychosis affected the level of social contact with peers	*When my mental problems started happening, I stopped being sociable with my friends. That's when I used to lock myself away and used to have bad dreams and bad nightmares, and my friends would be in some of my dreams and nightmares (Participant 4) I think i lost them before i fell ill, or i was already ill but not diagnosed. i just...i was not nice or polite to them anymore so we lost contact (Participant 10) they're like there's something wrong with you (Participant 9) i would have been more similar to them if I hadn't been in hospital (participant 6) Researcher's interpretation: 'talking to old friends seemed to make participants' lack of progress more painful as it highlighted this period of stagnation.'*	It was felt by the researcher's that participant's symptoms sometimes directly and indirectly led to ending friendships and altering their relationships to their peers. Some symptoms directly affected how well people felt to go out. The researcher's also interpretated the participant's accounts of their symptoms resulted in an 'absence of normal life' which impaired them reaching developmental milestones at the same time as their peers. Participants were felt to be 'left behind.'	Emphasis on being unable to reach developmental milestones <u>*at the same time*</u> as their peers. This led to a sense of the participants holding their symptoms of psychosis responsible for impacting their developmental trajectory with peers. This also created a sense that participants has social losses from this stagnation in development and that participants were therefore alone in trying to 'catch up.' This sense of loneliness also appeared at a time when development during adolescence and young adulthood value friendships. Having to catch up without these resources is a difficulty.
<u>Friendships incompatible with recovery:</u> Placing distance between themselves and people who they considered where incompatible to their recovery for example, people who accessed and used drugs and alcohol with them before they became unwell.	*When I came out of the hospital the first thing I done was get some drink, which I shouldn't have done, and went and sat up in my friend's house… and after that I haven't really seen them that much because I don't want to go up there and start drinking again. (Participant 4)*	Friendships with people who used drugs and alcohol recreationally were less valued that friends who did not. This was interpretated as recovery being more important than social contacts to participants.	A sense that it was either recovery or friendships with people before they were unwell. The chance to have both seem to be incompatible for participants. This might translate as black and white thinking for participants; either or, not both. There was a sense that participants could have done this to 'cut off' previous connections to their life before being unwell, in a bid to make changes and get well. Perhaps people cut off from friends they thought would deteriorate their recovery to prevent feeling they were becoming unwell.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Getting better: what can friends do to help:</u> acknowledging that friends were needed to help take their mind off difficulties and instil a sense of belonging.	*You need someone to help you go out more, like go to the cinema…like play football, like someone who's a really close friend (participant 11) my parents and my sister were always trying to tell me what to do…'you should do this, you should do that, you should think about talking to this person, you should think about doing that' and my friend was like 'do what you want!' (Participant 5)*	The researcher's interpretation was that there were specific types of friends who could enable and be important to the person's recovery. These friends helped the person regain interests and hobbies which they had previously had before.	There seemed to be an active need for friendships which supported the individual and participants could benefit from their friendships for their recovery.
<u>Assessment of current social situation:</u> participants reported feeling deficiencies in their relationships, particularly romantic relationships.	*Thoughts of like having a girlfriend have pretty much gone out of the window over the last couple of years since being in hospital, so that's something I definitely think about (Participant 6)*	Romantic relationships were seen as an important transition to adulthood. Lacking in these relationships for participants led to interpretations by the researchers that they perceived themselves as socially deficient in some way. Interpretations also included perceived anxiety that people would lose friendships again if they became unwell. It was interpretated that loosing friendships in this way would mean becoming 'stagnant' again.	Normalising that wanting a romantic relationship alongside peers is usual in teenage and young adult years. However, participants point out additional barriers to their ability to have these types of intimate relationships with psychosis. A sense that psychosis, particularly being in hospital impair the ability to keep these types of relationships. Interpretation of these usual challenges encountered in adolescence being magnified by psychosis.
<u>Making new friends:</u> gaining new friends increased confidence whilst setbacks in relationships was distressing.	*I'm practicing meeting new people, practicing putting my barriers down (participant 9) it is an effort, it is an effort and every time I get quite hurt, you know? (Participant 8) I'm thinking about applying to university to start next September so I think it all goes well then that'll be a good opportunity to meet new people (Participant 6) Going to do a course, getting my own place, you know, stuff like that. I just wanted to do something to make new friends. (Participant 11)*	Loss of friendships was considered as related to perceptions of their treatment and illness trajectories. Participants were interpretated as seeing friendships as a marker of how well they were. More friends were considered a good indicator of wellness whilst set-backs was distressing.	Emphasis on the loss of friendships mirroring previous losses. This echoed sense of loss compounded stagnation and difficulty/ loss/ grief. Interpretation that friendships have a different meaning to people with psychosis at this stage.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>The role of services:</u> participants hope that services could help them maintain social contact.	*it sort of relaxes you to know you're not the only one (participant 10) Most of them just want to keep themselves to themselves. I know how it is…I don't like to go and hassle them. (Participant 11) Coming here is a reminder of what happened before, right? Psychosis and that. Coming here for the social thing reminds me of all the bad stuff thats happened. (Participant 7)*	The researcher's interpretated the participant's experiences as wanting services to help support them to maintain social contacts. Groups were very important to this, by providing space for like-minded people to establish that they were not alone. This helped with acceptance and self-stigma. However, some participants reported they needed to move away from services to be more independent. Some people reported that they needed to move away from services as it had the potential to re-traumatise them through perceived rejections.	It might be a grandiose idea from services to play this role and instead it was wondered if participants should be supported to have independence and develop/ maintain social contact for themselves. A critical lens of the data and the researcher's interpretation could be that participants wanted this independence and there is a need to 'create' services as being the only important thing for people with psychosis. It might instead be that services are providing a function, that of social contact with people who have psychosis, not that it is the service per se that is important.
<u>Uncertain identities and status ambiguity:</u> Participants developing an uncertain and ambiguous sense of self.	*I mean being this age is hard enough, like, trying to work stuff out and deciding what to do next, like to go to college or whatever (pauses). I guess that's not gonna happen now, cos im in here (early intervention service), I don't see the point now*	The researcher's interpretated participants' experiences as being centred on uncertain sense of self and ambiguous self-identity. Participants were unsure of themselves, and this was increased by not knowing what to do in life, wondering if they would ever recover from psychosis and worrying about how their friends perceived them. Interpretation from the researchers about the accounts that participants noticed they were at a stage of life where they would normally be moving away from dependence and instead it was increasing. A feeling that 'working out' who they are is being placed on hold for participants because of psychosis. Interpretations of hiding psychosis diagnosis from others to avoid being perceived as 'crazy' 'mad' and 'dangerous.' Feeling in some way that psychosis had separated them from their peers.	A sense that participants perhaps did not want to be defined by their diagnosis of psychosis. Trying to find out who they are and psychosis creates stagnation and confusion. Plans for life being postponed or even these life plans/ hopes are lost for participants. Motivation for development is therefore undermined and replaced by a hopelessness sense of loss and ambiguity.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Decrease in referent points for identity:</u> factors which served as referent points in the past no longer operated with the same force or clarity.	*They have similar problems to me (pause), that can be quite nice, you know, you feel part of a community of people cos it can be quite isolating when you hear voices. Its also scary to be around people that can be struggling more than you are, like to think 'am i really like them?' suddenly you're getting locked away into that (identity) with no way out*	These referent points included self, peer group, siblings, parents, and school. Most participants pointed at the difficulties in creating and maintaining relationships. In being with other people with psychosis, brought together through services, participants identified this was helpful for them to share their experience with others and reduce the tendency to feel alone. However, if placed with ppl who have worse/ better experiences than you this could have the potential to isolate you or make the experiences feel worse.	A sense of danger in providing participants with a space to connect with others who have psychosis, and a need to manage and monitor these spaces to ensure maximum benefits. A sense that participants struggle to retain a connection to identity before the psychosis. This seemed to produce an image of people with psychosis having to re-start or 'jump start' development again, re-form identity and begin the process of self-discovery anew.
<u>Unfavourable social comparisons:</u> participants tended to compare themselves unfavourably to their past selves and others.	*I can't really see me getting over it, like I worry about it all the time, I don't want to have to go back in (psychiatric) hospital again (pauses). My friends are all going to college or university and I'm just here*	Difficulties in social life were discussed in relation to what participants perceived they were capable of before getting unwell. This was also compared with what peers were doing around them. The researcher's interpretated that participants had a sense of being stuck and worried about their futures. Feelings of loss about the future led to a sense that participants were experiencing intense sorrow and were mourning. Participants discussed losses in relationships and education. They blamed themselves for these losses and were interpretated to have high self-criticism as they were holding their own actions accountable for the development of psychosis.	Interpretation that participants seemed to hold themselves responsible in some way could be questioned whether this was just due to the comparisons they made or because of the involvement/ unspoken messages from services. That the researcher's did not highlight this or make this connection could question whether the very role of services being involved in the person's care is affecting the person's developmental trajectory.
<u>Difficulties noticed:</u> young people and their carers both noticed changes in their behaviour and mood.	*looking back you can tell that you were jumping from one thing to the next and not concluding sentences and things like that*	Carers of the young people, mostly parents, reported they had noticed social changes and changes to their ability to converse and interact. The researcher's interpretated this as a retrospective reflection from carers. They were often unaware at the time but recognised a	Whether retrospective reflections made participants and their carers question what could have happened if they had noticed the signs earlier.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
		'crisis' point, usually where everything had built up, and they would seek help.	
<u>Lack of awareness of mental illness:</u> looking for reasons for why they developed psychosis. Placing blame for psychosis on drugs, illnesses and spiritual experiences.	*probably about 3 weeks after I had been in hospital, like after they'd tell me and diagnose me and stuff, like I started to realise that it was more of a mental thing than a marijuana thing*	Participants were looking for reasons to blame their psychosis on. They recognised having a lack of awareness about mental health and had to discover it through discussions with others. Adopting their carers' perceptions of why they might have developed psychosis.	Readily accepting carer's perceptions as their own was noticed. This was interpretated as perhaps evidence of a dependency from participants on their carers. Carer's perceptions of why they became unwell was therefore powerful and could affect the person's sense of self, their sef-esteem and self-stigma.
<u>How help was sought and which service was approached:</u> caregivers/ parents were the ones who mostly sought support for the participant. Caregivers were the first source of support for participants.	*I think eventually told my mum what happened. I didn't want to tell anyone else, yeah, I think I eventually told them what I was feeling and stuff*	The researcher's interpretated the participant's accounts as approaching their caregivers first. Caregivers then considered approaching their family doctor as a first point of contact. School and religious support was also accessed. These were familiar and comfortable for the caregiver and participant.	Comfortable and familiar sources of support were sought after by caregivers and participants. It was interpretated that this could be anxiety provoking as participants held back at times, perhaps because they were concerned about losing their regular social support.
<u>Thoughts on illness precipitants:</u> participants had a sense of the things they did which contributed towards the development of psychosis, caregivers were more focused on the genetic determinants.	*well I think marijuana and mushrooms obviously didn't help, but um, I guess it's just the genetic thing, or just um, to do with brain chemistry, you know, just went wrong….*	Young people listed ideas of what they believed prompted their illness. This included drugs, exam-related stress/ school stresses, bullying, family illnesses and family births. Carers also stated similar precipitants as a cause but also included genetic factors when known family mental health as well as association to undesirable peer groups.	Blaming genetics may have been a way of externalising precipitants of psychosis, away from the self.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Experiences of services and suggestions:</u> both positive and negative experiences of the service.	*they could have more outings. Kind of annoying to sleep at 9 o'clock…. They could have better food too, it was horrible*	Positive experiences related to perceptions that staff and services were accessible, supportive and sensitive. Young people also described their being good information provided, continuity of care and peer support within services. Negative experiences included being hospitalised, exposed to peers who were often unwell and perceptions of some staff as insensitive. The order and schedule of hospital ward routines was also listed as a negative experience, as well as side effects from different trials on medications. Some mentioned the intrusive way in which medication was ensured compliant was negative and intrusive. Service users listed ideas of instilling hope to help others seek help. Carers often found they had to seek out the information rather than gaining it. Admissions to hospital was particularly stressful, particularly admissions of young people to adult wards. Medication treatment was a concern for carers, but they also highlighted the importance of cultural support workers to help set goal plans and understanding the spiritual nature of the young person's experience. carers suggested the use of self-help parent groups and reducing the threshold for seeking help.	More negative restrictive practices than positive. A need for cultural understanding from services. There was a sense of disengagement from services if participants were not being understood well.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Beliefs and knowledge of mental illness:</u> participants began to develop more adaptive beliefs about their illness and their recovery.	*in some ways its good because if I hadn't had this experience then I would have never learnt how to deal with stress*	Researchers interpreted that participants did not have much knowledge of psychosis prior to their experience and therefore had enriched knowledge about the diagnosis afterwards. Carer's knowledge about psychosis helped reduce the time spent between identification and treatment.	Researcher's interpretation might be influenced by an EIP stance where early detection is imperative. This paper scored quite low on the quality criteria (they scored the lowest, 38 out of 51). Reflexivity was lacking in the paper, and it might be that researchers had been influenced by their EIP backgrounds. In addition, it could be argued that participants perhaps only valued this experience retrospectively when they had time to reflect on what it had left them with. This perception seems more conductive to well-being and the participant's development moving forward and could be argued as a target goal for interventions to aim towards.
<u>Difficulty with interpersonal relationships and reduced opportunities for communication:</u> participants identified they had experiences interpersonal difficulties with peers or family.	*I was born into a violent relationship, my mum, my mum and dad and, really escalated from there because I was neglected and things happened to me (participant 5) basically it was the bullying at school…it's my instinct to run away and be alone insead of being with the group (participant 1)*	Identified problems in family relationships included conflict, separation, childhood neglect and abuse, exposure to domestic violence, lack of parental care and support (either through parental substance misuse or parental mental health), siblings' difficulty or other relatives and estrangement. These difficulties were characterised by a lack of closeness and conflict, bereavement of close loved ones, difficulties with social relations before and after the onset of psychosis, bullying and social isolation. social isolation caused through bullying seemed related to difficulties with self-esteem, confidence, and social anxiety. Perceptions of themselves as unusual often led to social anxiety and subsequent withdrawal.	Interpretation that psychosis was a reaction to the traumatic experiences the participant had. This seemed to be a useful way of making sense of the experiences for participants.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Reluctance to disclose unusual psychological problems:</u> challenges in disclosing experiences to close others	*I'd always really wanted help but I had trouble admitting I had problems….it was hard to admit it to myself, like, it was even harder to admit it to somebody else to get help for it (participant 6)*	The researcher's noticed participants seemed to have difficulty in disclosing their experiences to people they were close with such as friends and family. It might have been due to people not perceiving their social support network as being supportive enough and instead preferred to contact a mental health professional. The researcher's also interpretated a fear towards losing relationships or being rejected. Central fear identified that participants worried they would receive unkind treatment, humiliation, and rejection from others once they disclosed their experiences.	Easier nature in disclosing experiences to mental health professionals, suggesting there is a difficulty in the disclosure of experiences to significant others. Social contact is important to people with psychosis and there is a large fear of losing further relationships. It is interpretated from the data that perhaps participants are motivated to retain their social relationships because of this fear of rejection and loss.
<u>Disclosure of unual psychological problems:</u> costs and benefits: experiences of disclosure that was difficult but also had some benefits.	*I've been able to understand what is happening and why, why I feel such things in such a situation. Why I get certain images in my head, all sorts, and because of that I've now got a list of things that I need to work on, either to minimise them, or just accept there is nothing i can do about them (Participant 1)*	Negative experiences of disclosure were characterised by participants having social anxiety, e.g., thinking people were staring at them. Participants also described being stared at in this way by the doctors. However, there were also benefits to disclosing their experiences. Benefits included access to mental health support, improved emotional well-being and reduced anxiety. Finding a safe person in the personal circle to the individual often became an 'outlet' for that participant. Talking with a professional often increased knowledge about psychosis and set recovery goals and foster acceptance. Informal discussions with professionals who provided normalisation was particularly described as helpful.	The researcher's interpretations appeared to be a cost-benefit analysis but there seemed to be a lack of understanding of why participants might lead to eventually disclosing experiences particularly if there had been previous bad experiences of disclosure. This might relate to other idea that participants get to this point after other factors occur to help recover them.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
Stage 1 - Events preceding first episode psychosis: participants noticed precipitating factors before the psychosis. For carers this was highlighted by breaking boundaries.	*my cousins got married. 'cos we used to hang out together. We used to go to the pub and pictures. So, I was all alone. (Client) he was beginning to stay out later than he was allowed to (family)*	The researcher's noticed that participants tended to break boundaries prior to psychosis but that this was identified by their relatives more than themselves.	There seemed to be an interpretation made about the differences between carers and participants. However, it could be that carers hadn't noticed the changes and life events which participants had, and which anticipated the 'break and challenges in boundaries.' It could be argued this break in boundaries were a communication to carers that they were distressed.
<u>Stage 2 - The first psychotic episode:</u> episode is a catastrophic disruption to the person's world.	*the voices were good and evil and I just sort of collapsed that night. I was getting overwhelmed with voices in my head; thought bombardment (client) I was so scared I used to try and lock my door with no lock on. I used to wedge it. I was so scared he would come in. (family)*	The researcher's interpretation included that carers were struggling to make sense of the experience for their loved one whilst participants felt they had a major disruption to their lives. Participants who had heard voices did not feel understood by family. Some family members attributed their loved one's behaviours and symptoms to teenage behaviours and this dismissal was interpretated as making them feel guilty.	That people who was hearing voices did not feel understood by their parents could have interacted with their ability to seek help. Guilt experienced by caregivers could play an interpersonal role in the mirroring of participants when they felt self-stigma, self-blame and shame.
<u>Stage 3 - The first hospital admission:</u> first admission to hospital was considered a major event in the narrative for clients and family.	*so they took me to the hospital and all I could remember was being out in a chair and being carried along. I was miles away. (client)*	Researchers noticed a difference in how the first admission to hospital was considered by service users and their caregivers. For carers it was considered reassuring but for service users it was considered confusing. The first admission was noticed and interpretated by researcher's as being an important landmark. This experience was deeply distressing and emotive.	A sense of trauma from the first hospital admission for both service users and caregivers involved. Responses of feeling depersonalisation and de realisation in service users' experiences. Admission feeling as if 'reality' has hit in, denial and other defences against accepting a psychosis diagnosis is restricted.
Stage 4 - Current experiences - <u>disability</u>: issues with control and ability to manage their problems.	*my state of mind's not what it used to be - every day is a struggle in the mind with thoughts and voices and all that (client)*	The researchers identified that it is difficult to concentrate and manage problems. Relatives appeared to lay blame for this on the person's stigmatisation.	Management of thoughts appeared to be minimised by the relatives in favour of things they could perhaps 'see' and hold which are more tangible than the person's thoughts.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
Stage 4 - Current experiences - <u>relationships</u>: relationships were the biggest source of support but also had been impacted negatively in many ways through psychosis.	*it's difficult because conversation is always two way and you can't really know when to take out the information in and when to take it out. (client) I haven't really encouraged him to come here very much because what happens when he comes here the neighbours usually open the door just to question him. (relative)*	Relatives noticed their loved ones were often separated from society. Researcher's interpreted the service user's experience had led to altered relationships, relationship break downs and changes in how to interact with others. Yet, it was noticed that service users social circle was a source of support.	Loss of social contact but perhaps an increased desire to establish connection.
Stage 4 - Current experiences - <u>self-development</u>: changes in self-identity and development of self. Concerns about whether independence is a good thing for service users.	*I don't harp on it but it was the best thing we could have done. The only thing we could have done was move out of a place and just visit. I mean mum and dad can't be there all the time can they. It's part of life that they want their freedom as much as you do. (client) he's doing what he wants to do and he's not at home with his mother. he's becoming an entity of his own. (relatives)*	Researcher's noticed relatives were concerned and pre-occupied with whether independence was a good thing for service users, being worried they were becoming too independent and changing their sense of self. Service users often found that they needed to change and adapt to adjust. Wanting to place distance and encourage themselves to be independent.	Questions of whether participants placing distance between themselves, and their parents/ caregivers is being undermined by carers who are needing to hold on to their child so they can feel containment and safety.
Stage 4 - Current experiences - <u>coping and services</u>: road to recovery being bumpy and wobbly, needing professional guidance to help monitor and keep on track as well as supporting difficult side effects.	*you think your're on the road to understanding it better than the next thing you wake up one morning and it's gone right back to the beginning again. It's like a see-saw thing. (relative)*	Going back and forth with service users in their recovery journey. That this is not a straight process. Eventual improvement in confusion was noted by the researchers.	Sometimes the treatment of psychosis can also be a challenge for service users, and this can undermine recovery progress. Side effects from medications and needing professionals to help support are some of the challenges needing to navigate in the recovery journey. This has the potential to be traumatising for service users.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Coming to terms:</u> having to accept a new reality after living in a 'delusional world' was difficult.	*one participant had taken a picture of jumbled fridge magnets and described 'that's me describing my mind sometimes, it's kind of like confusion…because after I had a psychosis episode, that's how my mind was like, fully confused, and I couldn't break out of it.(participant) in another: it's really hard for me to even deal with the fact that I had an episode... I mean I'm starting to come to terms with it now but for a while i couldn't even, I couldn't believe it... it's more the way I behaved when I had an episode and I kind of like look back and question like what was I doing? what was that about? that makes me feel so, sometimes makes me feel embarrassed about myself (participant)*	Researchers noticed that participants needed a period of deliberation to reflect but sometimes the remembering of difficult experiences brought confusion and shame.	Acceptance of the experience even when not able to understand and comprehend what might have occurred. Feeling the experience was in some way real but having no logical sequence for what had occurred. Learning to take on board the feeing's which came along. A sense of social losses/ face being lost and having to adapt and accept this change of social role. Even the researcher's 'coming to terms' label for the theme reflected a sense of grief and needing to mourn a loss. Loss of social role, status, and contacts?
<u>Fear of relapse:</u> fearful of the psychosis coming back.	*I always think I'm gonna get unwell again and again, that's maybe another reason why I don't go out, I don't wanna talk to people 'cause I'm thinking last time, when I had an episode, it was in public…that kind of scared me…I'm thinking what if I get unwell again, what if the same thing happens again? (participant)*	Researchers identified that participants had a permeant fear of becoming unwell again and relapsing. Fearing public places and avoiding them because of a possible relapse. Worries that the destruction of their lives would be worse this time and isolating themselves to protect themselves.	Isolation as a defence against intense fear that they could relapse and become unwell again. Worries that what they had in life could be affected again.
<u>Blaming the medication:</u> reflecting on their experiences of altered mood after psychosis sparked a need to assign blame.	*participant took a picture of medications: it gets me down that I'm gonna have to take them [medications] for such a long time… and then I attribute all the problems since to them obviously, the cognitive problems anyway… it [medication] flattens you out and it also puts like a mental straight jacket where you have a thought but you can't hold the thought...you can just feel the difference when you take the drugs*	The researcher's felt participants felt some need to assign blame for their experiences of low mood following psychosis after reflecting on their feelings. Blame was laid on medication for weight gain and flattened affect which participants indicated was contributing towards how they felt about themselves and life after psychosis.	Participants could be referring to being chemically restrained by medication. There seemed to be a poor relationship between participants and their medication because of the effect it had on other aspects of self. Medication side effects could add to the trauma of psychosis treatment which understandably left people with a further sense of loss and being removed from their former selves.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Losing purpose in life:</u> psychotic episode had destroyed sense of personality and left them feeling empty.	*participant that took photo of an empty mirror: when I'm having a bad day, I can't even look in the mirror… because i feel so ugly and so, I am not the same as I used to be before the psychosis, I used to fix myself up, I used to do all these things, I used to be outgoing, it's like, I don't like the reflection I see staring back at me. another participant took a picture of a knife to describe suicide ideation.*	Researcher's suggested that participants viewed themselves as 'impaired' as they 'no longer operated as they did before their illness.' Difficulty in completing previous tasks led to job loss in some cases. Relationships were strained and, in some cases, participants described a sense of identity crisis. This crisis led to participants feeling unmotivated, pessimistic, and devoid of energy. Researchers implied that there was a sense of losing control and independence leading to hopelessness.	Description from researchers and participants indicates a sense of depression after psychosis. Participants may have felt disconnected from their previous lives.
<u>Feeling misunderstood and ignored:</u> a change in functioning led to a change in how people interacted and treated them.	*they kind of ignored the depression and went onto the psychosis, so the low mood was still there and even when I said about it not much happened…the doctors and everything, they're trying to control what's happening, feels like they're trying to control everything.*	Participants noticed people started to develop significant irritation at them, lack of understanding, feeling as though they should be now 'recovered.' Many people described they were ignored and 'swept under the rug' by healthcare providers.	Lack of understanding led to possibilities of being discriminated against because of their level of functioning and ability by friends and family, as well as healthcare providers who seemed patronizing and pathologizing.
<u>Social withdrawal:</u> a decline in social functioning led to decline in social life.	*I want to be alone and no matter what people say to me or anything like that, they can't cheer me up… I don't wanna communicate with anyone, I just wanna be in my bed sleeping because that's the best place for me I feel.*	The researchers implied participants had been struggling to keep up with college and work. Eventually being unable to keep up with activities and therefore dropping out - intensified sense of loss. Researcher's interpretated that participant appeared to 'isolate from the shame of psychosis.'	Parallels between the isolation from psychosis and the isolation with covid.
<u>Being depressed:</u> a sense of hopelessness, low self-esteem and personality changes after the psychosis experiences and during recovery.	*sometimes it is very low mood, sometimes it is flat mood…when it's low mood, I am still able to get up and do things and just, you know, do things around the house…when it's flat mood, I don't want to do anything I jst stay in bed all day*	Researcher's interpretated that participants seemed unable to place a time on when depressed feelings occurred. The flat mood brought with it the inability to concentrate, hold or focus thoughts, amotivation and apathy.	Depression as a reaction from the loss and trauma around the experiences. There was a sense that this produced a different challenge for participants to navigate after the psychosis experiences.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Wanting to get better:</u> participants were highly desirous to get better.	*I need to get my confidence back, I need help mentally…I've got a mental disability, but I'm not fully gone, I need to get my life back and that would lead to getting jobs…I can just have some kind of hope and, you know, just try and do stuff. I have to have some kind of purpose. some kind of reason for being here. (participant) i'm grateful, you know, that i have people around me. they just support me, kind of know the situation and, you know, kind of just accept me because i'm just like that (participant)*	The researchers suggested that participants wanted to get out of the cycle of psychosis and recover fully to their lives. Regaining control of themselves and lives was important, wanting some sort of purpose. Wanting to connect and have support network near to them. Thinking about aspirations for the future.	A sense that alleviating loneliness helps create meaning and purpose.
<u>A seed unfolding:</u> the emergence of psychosis was akin to a seedling being expanded and developed.	*well, I can't really pinpoint 'a before' if there was 'a before' or if there was just 'leading up to it.' even as a child I didn't really feel normal or like other kids, so not knowing if was just normally really withdrawn and then developed something else, or if, you know, i always had some sort of seed within me that just, kind of, unfurled naturally. (Shiloh) all my life there was certain things that always happened. Either like voices or hearing things that aren't there...i said, OK, you know, no big deal, this just must be normal. (Kasandra)*	Pervasive effect of psychosis in lives around relationships, occupation, interfering with learning and enjoyment in life. Believing that psychosis developed whilst in 'normal' stages and then gradually became disruptive. The researchers interpretated that psychosis as being considered normal at the beginning.	Bizarre experiences being the threshold between what was considered normal and usual for participants and what wasn't. Idea that disruption to lives, self-identity and functioning meant 'abnormal' consideration of psychosis.
<u>Psychosis in full bloom:</u> active psychosis led to an increasingly narrow life.	*Researcher's interpretation: 'Living with their parents was rarely mentioned by participants, seemingly it was taken for granted or necessary.'*	By not speaking about their parents, the researcher's interpretated that participants seemed to take them for granted. Unable to continue relationships and occupations in the same way.	Whether participants didn't speak about their parents because they were unable to notice their input during active psychosis stages or whether they felt ashamed for depending on them.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Growing beyond psychosis</u>: reconstructing life after psychosis, feeling grateful for understanding themselves better and accepting experiences might have produced a better version of themselves.	*I'm sort of glad that I had my illness. I can start to look at, sort of, other avenues that I might not have considered had I not been diverted from something else. If you're blocked from doing other things, then it's good to look at what you can do, and - i don't know. it's like if you're walking on a path, and suddenly, you know, you can't go a certain way, or there's lot of barriers, but you wander around lost for a while, and then you find another road...maybe you'd end up somewhere better (shiloh).*	Researcher's interpretated that participants had to reconstruct their lives. There was often a continuity between participants previous lives (before psychosis) and their lives after psychosis. Feeling grateful for being able to learn about themselves and set realistic goals. not disclosing the extent of their psychosis led to help not being received in the right areas.	Post-traumatic growth, development as a person seemed apparent. Continuity as a way of supporting the participant's narrative. This continuity of narrative before psychosis might be a hallmark of post traumatic growth and helps reduce a sense of loss for people with psychosis.
<u>Childhood (5-11 years) Inequity in peer relationships:</u> perceived bias in their peer social groups. Difference, deprivation and experiences of separation set them apart from their peers.	*it was upheaval really, my stepdad. My mum had an affair and my dad was upset' & 'we didn't have the money so I stayed home' & 'I went through this thing, I thought to myself 'oh' 'cause in Zimbabwe it was like 'ooh, black skin.' Where as here it wasn't. it was in my face and i thought 'what is this?'*	Early experiences of racism and separation, discrimination and difference created a barrier for connection in peer relationships. The researcher's interpretated that there seemed to be a sense from their accounts that participants had felt unequal to others.	This sense of inequality may had produced feelings of being vulnerable to threat. Damaged connection in relationships may have meant the relationships they had prior to psychosis were important and had required work to get. Losses in these relationships may be traumatic and have grief reaction.
<u>Early adolescence (11 - 15 years) Instability in peer relationships:</u> being considered unequal in relationships led to strain and instability in relationships.	*when I was about fifteen years my mother had ovarian cancer.' & '...well sort of pressure of people being nasty to me and erm teasing me and saying 'you chink' or whatever. Whatever I am it doesn' t matter I just felt negativity towards me.'*	It was interpretated participants had felt bereavements consolidated their sense of difference to others and that experiences of bullying was a product of being considered separated/different to peers. To manage this, people spoke of putting up a shield.	Placing a shield up as a safety behaviour against threat might have followed through to more of the negative presentations of psychosis.
<u>Late adolescence (16-30 years) Becoming isolated and increasing isolation - being isolated:</u> movement meant further isolation and a descended into ways of trying to manage this isolation through external methods.	*The problem was that I became dependent on it (cannabis) and it became a tool.*	The researcher's implied that geographical and physical movement meant increased isolation and a need to cope in ways which provided a 'quick fix.'	a sense of downward spiralling, psychosis symptoms lead to geographical movement perhaps from hospitalisation and this produces loneliness. Coping through substances also maintains this isolation because it does enable contact, stigmatising and perhaps increases sense of threat. This downward spiral leads to people feeling further isolated.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Late adolescence (16-30 years) Becoming isolated and increasing isolation - increasing isolation:</u> actively attempting to not rely on friends and trying to rely on self, meant further isolating from previous support network.	*since I went to hospital and got help they always said like, if I walk inside a pub and they just say 'oh madman' so I don't keep them as a my friends' & 'when I came back the fact that my friends didn't judge me or anything was good'*	Not wanting to rely on others and turning inwardly to self. Positive relationships were characterised by not being judged.	Relationships which were 'let go' had an element of judgement. Perhaps not wanting to rely on other people because they struggled to trust them. This could come from experiences when their trust had been betrayed.
<u>Hanging out with people I like and who understand me:</u> wanting to surround self with people who they were able to trust.	*probably play a game of soccer [or] get together and have a drink or something,' (Courtney) & 'because people have got problems here, and so have I, it's just easier because I know people have got problems here, and it makes me feel I don't, I feel safe here.' (Jay) & 'Like he was talking about a personal problem he had and i was telling him about one i had a few weeks back and still do. we talk about personal stuff.' (Gabe)*	Wanting to spend time and be around people their own age group. People who might understand them, their own peers and others who had experienced psychosis. Trust was integral to people with psychosis maintaining or establishing contact with people.	Trust seeming integral to socially connecting with others around them. Wanting to feel safe in the relationships they had to develop security. Relational security as an important part to recovery in psychosis.
<u>Valuing families and other supports:</u> reliance on family supports and others involved in their care.	*my mum, she has always stuck through me, all the trouble I have been in and that…they mean a lot to me, because some parents of friends, I know they kick their kids out when something happens to them. You know my family stuck by me and they have got confidence in me, more now than what they did.' (pat)*	Participants seemed reliant on the support they received from people in their family. People who were important to supporting them and being there because they were related to them.	Reliance on family might be a factor which is involved in the developmental stagnation, especially as development is characterised by the movement away from family supports.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Spending less time with old friends:</u> psychosis led to feeling misunderstood by old friends therefore needing to spend time with people who were able to understand what it was like for them.	*This guy [previous friend] wouldn't understand it you know. Maybe he doesn't know that I'm going through another psychosis, I don't know. But if he just put himself in my position he might understand but he's so arrogant he can't.' (Jess) & 'once I get my drivers licence i will drive to her [relative] house and talk to her sometimes. stuff like that. go to my friends house and talk to them.' (Circa) & 'I am not the type of person that says hey let's go to a nightclub, let's go to this or that. maybe i prefer that person to say it to me. because i don't like to be leader, you know what i mean?' (Circa) & 'i am angry about it, because i thought they were good friends. I don't know...but through experiences you learn who your good friends are, you learn the one's who are going to stick by you no matter what, no matter what you are doing at the time.' (Jess)*	Feeling unable to spend time with friends who echoed loss and were not able to relate to their experiences. Learning about having quality over quality.	Quality over quantity feeds into idea that people needed trusting relationships not a large social circle. Not being able to go to people's houses or have a driver's licence could also be affected by people's ability after psychosis: psychosis affects functioning and this feeds into isolation
<u>Something happened to me:</u> being different now: being perceived as different from their peers.	*it's just that they [former friends] view me differently now you know, because I've become psychotic they think that you are now a waste of life or something…They just think you're a loony or something like that which is not very good' (Pat)*	Researchers identified that participants seemed to acknowledge there was a stigma to psychosis and that people avoided them because of this. Participants seemed to desire to be involved in group and wanting to be re-establish contact.	Whether the desire to re-establish contact mirrored the desire people had to connect back to their old lives. There is something about implicit loss which is being noticed but not explicitly identified in research e.g., loss of friends but less talk about the loss of previous life, intended dreams, hopes and aspirations. Is this because this loss is intangible and cannot be remedied?

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Building new relationships:</u> worrying about new relationships and re-evaluating how they make these and basing them on quality not quantity.	*he's very overpowering, he's is like… when I was friends with him I was like a 'puppy dog' to him. Now I couldn't do that, I couldn't be a 'suck' anymore. I have learnt from my past experiences.' (Jess) & 'I want to see my old friends again, I want to start up a band with them, I want it to be like the old days, you know. I don't know if I... I don't know what will happen now, I don't know if they are users pr if they really like me as a person or they think I'm a "dickhead" or you know, just want to use me. I don't know.' (Jess) & 'well I feel I need to back off a bit because like I'm nearly twenty years old and I need to separate from my parents...if I have enough money then I would like to live independently in a unit or something like that, or maybe if it's not possible maybe just live independently at my parent's home.' (Circa)*	Re-evaluating lifestyles, social interactions, and personal beliefs. Made participants wonder about whether their past relationships were 'true' and considered they had learnt lessons about themselves, others, and the world around them. Thinking about the future and the need to separate, have independence away from relatives/ parental figures.	Worrying about what other people thought of them and acknowledging they needed quality over quantity in relationships and lifestyle.
<u>Illness as incompatible (to romantic relationships):</u> psychosis was considered as being incompatible and conversely affecting the ability to have romantic relationships.	*erm, because at the moment I'm having blackouts, I'm not too…I'm not very trusting in myself to do anything else.' (Phil) & 'they might be scared or shocked.' (Leanne) & 'if I didn't think the family liked me then that'd be a barrier, one of the main barriers you see. if there was part they weren't interested in or they didn't think i was good enough for her, or that i was worthwhile, that'd be a barrier for me' (Nathan)*	Incompatibility seemed to stem from being considered different to other people and feeling disconnected. Participants also questioned their abilities to have these relationships and referred to symptoms which may impair their socialising. A lack of trust in self was confounded by not trusting others to understand or accept them. Worries of other dynamics in the relationship such as how their potential partner's friends or family would perceive them. Some participants discussed possibly with-holding true information about their psychosis or watering it down with 'mental health' rather than 'psychosis.'	Not being able to trust other people seemed to undermine the ability to have romantic relationships. Whether development could be seen as therefore being undermined as this is sometimes an important developmental milestone. Anxiety provoking to enter into relationships and wonder about other factors such as family member's perceptions and whether to disclose information. Self-stigma seemed to be a factor mediating this.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Relationships as normalising</u>: wanting relationships to be considered as having a usual 'normal life.'	*I think they'd be pleased for me 'cos I found someone…I'm not just hiding behind my mental health problems…I'm getting on with life and doing things just like any other young woman.' (Leanne) & 'it might make me a more rounded person. Might not be so, so jagged' (Jay)*	Researchers identified that participants seemed to explain romantic relationships were considered usual for 'normal' lives and therefore if they had one they could be seen as 'normal.'	Pushing to have romantic relationships to be considered as normal may not be a healthy way of recovering. Seemed to be a lack of awareness of how much these relationships might require investment and whether participants had enough emotional resources to manage them.
<u>Relationships as high risk:</u> endings to relationships were incredibly traumatic.	*when talking about relationships it's very traumatic for me. It's like, it's somebody has died yeah and I have to talk about that person.' (Ali) & 'oh my family aren't supportive…they've got too many problems…they never, I mean all the relationships I've been in, my mum and dad never supported me, they never liked them. My mum used to say that they're not good enough for you....and used...and used to try...to try and put me off relationships' (Leanne)*	Participants found the endings to these relationships incredibly difficult. Researchers noticed participants struggled to talk about the relationship especially if there was a traumatic ending. Learning to be ambivalent about the relationship especially if they had previous experiences/ witnessed others.	Possibility of romantic relationships having the ability to mirror painful rejections, separations, abuses.
<u>Risk reduction:</u> trust was considered a way in which risk in developing romantic relationships was reduced.	*I think trust is really important, if you can't trust them then you have o basis for anything because nothing can build up from that' (Isobel) & 'hopefully they'll be a bit understanding and yeah…understanding mostly…and know that it was probably not in my control or anything.' (Phil)*	The researcher's wondered whether needing trusting romantic relationships in their lives was a way of compensating for previous abuses of their trust. Participants seemed to want either a stable founded relationship or nothing at all.	All or nothing thinking. Was considered that perhaps participants wanted a relationship which was 'proper' and if not would prefer to be alone. There was no in between for participants. This may not be realistic as sometimes not all relationships work out and 'proper' partners can be identified from the beginning.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>lack of experiences and resources:</u> participants faced challenged to romantic relationships was that they lacked psychological, social, and physical resources which would enable them.	*for me, when I first start getting to know someone male I always think I can't get close to them 'cos there's always that barrier of you sort of think 'well I might fancy them, it's stupid,' or you know, you get too close, they think 'why's she flirting with me?'...and your're like, well no i'm not.'*	Young people described a deprivation in psychological resources (confidence, energy, and robustness) and social resources (peer group and support network). All described a lack of money to go out dating (physical resources).	Feeling worried about committing to a relationship such as this, and being worried when it might happen, as unable to support it psychologically, socially and physically. This could be anxiety provoking. Avoiding situations which could potentially lead to a risk of a romantic relationship e.g., even talking to someone who they feel they would become attracted to. This has the potential to be a vicious cycle as these people who they are attracted could reject them if they are 'acting indifferent' and therefore participants could feel they are not able to get into these relationships.
<u>1. Experience of psychosis: Uniquely psychotic phenomena:</u> altered interactions with the world.	*he said 'would you like something to eat? I went, 'mmm,' like that, I did not answer him really. And he come in and he went to give me some toast, and I went to bite it, and I went, I was so paranoid I said, 'you poisoned this, I am not going to eat it.' he is like tearing his hair out, he could not understand it.'*	No longer able to take for granted feeling safe. Researcher's identified participants had a different relationship with the world around them from these experiences. Relationships with others also being undermined by the suspiciousness and paranoia they felt.	Interactions with others and the world around them led to isolation perhaps?
<u>1. Experience of Psychosis: Experiencing emotions:</u> extreme emotional states.	*Researcher's interpretation: 'he did not want to hurt anyone despite commands to the contrary; instead he stabbed a wall in cathartic expression of anger that accompanied his experience of these voices.'*	Extreme emotional states were interpretated from client's narratives about their psychotic experiences.	Reactions to emotional experiences seeming to be violent or of intense sorrow shook participants. These emotional states were a hallmark of experiences being traumatising.
<u>1. Experiences of Psychosis: Thinking about dying:</u> extreme emotional states produced thoughts of dying and desires to commit suicide.	*I was just feeling stressed, angry, and unhappy…I tried to take an overdose once…of sleeping tablets… I vomited back up… that's how bad it was really.'*	Descriptions of being hated by others was interpretated by researcher's as not having another way out and thinking of death as an escape. It was implied by researchers that the accounts felt the thoughts about death and suicide were worse than the psychosis.	Feeling distressed by a wish to die was worse than the unusual experiences encountered by participants.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
2. Immediate expression of psychotic experiences: avoidance of experience: staying away from anything that might trigger emotional psychotic experience.	*erm… just stay in the house, don't watch the TV or listen to music. This is when it is really bad, it has not been like this for a while… I cannot listen to mysic or watch TV because of the voices and stuff, cannot play on my turntables, cannot do anything really, apart from sleep and try to get over it.*	Researcher's noticed participants attempting to block out and prevent thinking about the psychotic experience. Avoiding activities usually would prevent the stimulation of psychotic experiences.	Avoidance of life could be considered a self-isolation method of protection. Feeling anxiety perhaps around relapse.
2. Immediate expression of psychotic experiences: Expression of experience: engaging with the experiences to make sense of it.	*yeah I should have brought it with me actually, some weird, some really weird pictures I drew from some tissue. There was like this alien, this alien's head with the horns, and I drew it and I told my nan, 'I just blew my noise on the bus and when I was home i drew a picture from it' she's like 'you drew that, that is quite disturbing like'*	Participants engaged with their previous experiences of psychosis by communicating it directly or indirectly. This was interpretated as a way of trying to make sense of their experiences.	Making sense of their experiences seemed to help with organising and understanding them but could also leave some sense of how alarming the experience was.
3. personal and interpersonal changes: changes affected age-related goals.	*yeah it is like it is easy, if any thing college is like easier for me in a way, I dunno why but it seems… before, I mean I went to college before and I could not deal with it before and I left and then my mum wrote a letter. But I really wanted to give it ago but my motivation went then, you got to have motivation all the time.*	Loneliness and alienation produced from the changes made by psychosis experiences created anxiety when in social groups. The researcher's interpretated that this created a challenge for people to remain focused on achievements and educational goals. Some anxiety around how they may be received.	Social anxiety being a factor involved in hindering developmental milestones.
4. personal explanations: psychosis becoming the explanation for why developmental milestones were not met.	*well I mean, it is one thing sort of standing around looking at nice girls, thinking, god I would like to pull her and it is another thing… doing something about it*	Differences to others were described in relation to be a product of psychosis. Participants held this accountable for why they had not got to certain milestones expected in society.	Milestones seemed socially determined and might link in with the social anxiety described in other themes from the paper. That participants' anxieties were affecting how well they were able to continue development.
1. Treatment: empowerment was increased when participants were able to control and have a say in the treatment.	*they would just shove you on a medication and there were it, take it*	Control and choice around treatment increased empowerment. Having a sense of personal involvement in all aspects of the treatment process and being able to express their positive and negative personal opinions about their treatment.	Having a say in treatment choices as it was important to empower the individual so they can have a good recovery.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
1. Managing personal well-being: good emotional health came from being supported to look after self.	*because I had the freedom to go anywhere I like when I was hearing the voices and stuff I had the freedom to use my ways of coping*	Having the freedom to take charge of their own personal care, such as utilising their own coping mechanisms was empowering. Having flexibility to employ their personal coping strategies.	Good psychological well-being comes from being able to support self and learn new skills how to do this. Role of professionals in this support was apparent.
1. living within institutions: lifestyle choices influence how empowered people were, this was affected by being institutionalised.	*when I was at X they wouldn't let me out for walks that annoyed me and me worse no freedom it was terrible… you need to free to do your own things and not treated like a little kid…you need power and if you don't have that you can't do anything*	Having their own lifestyle choices influenced how empowered they felt. When staff enforced rule restrictions, this felt inflexible and patronising.	Experiences of institutionalisation gave a sense of dependency on these environments after a while which further removed people from their sense of selves.
1. symptoms: being empowered helped to manage symptoms.	*it [empowerment] helps to stay in control and just not do it not do what the voices say*	Responding to symptoms that are recognised in oneself and using empowerment - ability to be in control - to manage this.	Empowerment as a management strategy requires and relies on others. This might not be available if other steps are not in place such as trusting relationships characterised by understanding.
2. being listened to and understood: by clinicians/ professionals.	*yes that's it, they were always reassuring me and talked in a nice manner, that helps a lot when your feeling ill. I think when someone listens to you get better and more better they understand me more and what I am trying to say.*	When clinicians spoke in a way which was jargon free, participants reported that they felt more empowered as they felt listened to and understood.	A sense that using own language to describe their distress produced a more empowered recovery.
2. validation from service and professionals involved in care: having validation felt as if professionals were understanding but also believed them.	*when people ask what do I think, when they listen to me and explain things so that I understand them. When I went on ram felt like an achievement.*	The researcher's interpretated that there was something important for participants to be believed by professionals.	Being believed was important to recovery. Perhaps it feels as if they are not so 'alone' and cut off.
3. the quality of information: knowledge as power	*they were so good at explaining things, they'd keep explaining things until I understood them and they didn't use big words*	The more knowledge participants had of psychosis and themselves meant better understanding and therefore ability to manage.	Self-management was important to being independent and this could only be achieved if participants had been able to learn about themselves, psychosis and what happened to them. Knowledge was therefore power.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
3. information about treatment	*you know what is going on and you know how to get help eh*	Participants discussed they were rarely involved and informed about decisions about their treatment. When participants were this made a difference to their treatment and understanding.	Having information could make a difference to how people see themselves and therefore be able to recover and live without service input.
3. talking about symptoms: discussions can be enabling but getting into discussions is hard.	*I feel comfy asking them for help I would just go up to them and say can I have help like other places I don't go up to them about it I end being silent*	Discussions about symptoms have the potential to help someone during recovery but getting into these conversations are difficult.	Conversations may be difficult because of symptoms themselves, or because of the anxiety, or because of self-stigma and needing to anticipate if someone could reject them.
4. recognition of need: professional support was needed and recognised by participants.	*the gp just did nothing, myself and mum pleaded with him begged him to help us, he just didn't understand my illness*	Some experiences of staff members and professionals was that they were not doing enough to support them. Researcher's interpretated this as participants recognising, they needed professional support.	That the researcher's noticed that participants were stipulating staff were not helping them enough meant they had recognised a need for professional support, may have resulted in the fact that there is a professional - client re-enactment of abuse/ trauma. Perhaps this type of wanting support and feeling as if there is withdrawal from professionals mirrored times when there had been withdrawal/ rejection from caregivers?
5. coping mechanisms: strategies learnt with professionals most helpful when looking at when and where to use them.	*they taught me different methods to use like m… listening to my discs put the earphones into your ears so that it's right. And like getting and elastic band to pulling at it and stuff.*	Difference noticed between coping mechanisms developed with professional's support, and their own coping mechanisms. Learning when and where to use these strategies and why was important.	Professionals' strategies were noticed by the researchers perhaps because of awareness of these strategies.
5. structuring time and planning for the future: having a daily structure helped to reduce boredom and reduce stress.	*sometimes they haven't done anything with me about how to cope with the symptoms but at the unit the nurse she was doing things with me about how to recognise the early warning signs and she did stuff on anger management with me.*	Boredom was a big factor causing stress for participants. The researcher's interpretated that having a daily structure was important to mitigate this.	Planning and having time to structure activities may set participants up to have the best ability to have recovery.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>6. relationship to clinician:</u> Importance of creating a relationship to professionals.	*they didn't spent time with me they just sat in the office all day… just sit in a office and just sit on their bums all day*	The researcher's made interpretations that participants had a need to create relationships with clinicians, especially when hospitalised.	Possibility of participants having to create these relationships with clinicians to maintain or even develop better interpersonal skills, especially if avoiding others, facing relationship break down or preferring to isolate from peer and social groups.
<u>6. emotional support from clinicians:</u> relationships to clinicians provided emotional support.	*they had a laugh with me… and that helped me to relax and I felt I could open up to them they were so caring friendly and always listened to me talk to me and stuff and they tried to understand me as well and I had fun with them as well*	Relationships with clinicians was also needed for emotional support. Better relationships were with staff who came across to participants as more approachable and friendly.	Significance of developing professional relationship to help guide interpersonal skills but also to support emotional well-being and help foster a sense of belonging, comfort and safety when interacting with others. As staff are in powerful positions with participants, this provides an opportunity for corrective emotional experience.
<u>6. practical support from clinicians:</u> family members involvement in their recovery journey to enable development.	*I can't make decisions at that time and sometimes I can't remember what happened so I rely on my parents to look out for me when I am ill and make the best decision for me. But it can also be important at that stage as well because I need help with what to do and how to cope when i'm feeling bad*	Empowerment through parents being consulted by clinicians was important for participants. This empowerment improved recovery for participants following psychosis.	Could it be that participants and their caregivers were brought closer to their parents/family circle by having clinicians in a role where they could mediate and bring them together in their recovery journey. Importance of systemic working with people with psychosis that can enable their interpersonal and social development.
<u>1. "what's it all about":</u> the researcher's had diffiuclty in trying to find meaning within the participant's narrative	*I think that, erm, I was being guided by God throughout this time. There was too many things that went right for me at the right time, during when it got really bad, for me not to have an explanation like that. Just little things that I got help with during that time.*	Participants spoke about it being difficult to make sense of their experiences. The researcher's identified their own difficulty in trying to make sense of the participant's accounts and themed there seemed to be a general confusion like 'mist' over the accounts. Sometimes this confusion led to participants not wanting to discuss what had happened to them. Some participants blamed god for what happened to them.	Ideas about whether there is an ability to make sense of their accounts if participants can't. Also, not wanting to talk about what happened because of feeling confused, could there be an element of anxiety, could there be a need for people to avoid others to avoid 'not knowing.'

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
2. ‘‘I just felt like an animal, being locked up all of the time’’: participants' feelings of being trapped and helpless towards being admitted to hospital and receiving treatment.	*When I first got there I didn’t like it cos I was locked in a room. There was just like a bed you know. And people used to walk past all the time and lift up like a little wooden panel and look through a glass window at me.*	A feeling of being admitted without any choice or control. Being treated without any respect. Language used was interpretated by the researcher's as being imprisoned, segregated, and punished in some way.	A sense that participants valued empowerment and when this was not in place, they did not trust the service, carers or professionals. Treatment from service and others had the potential to dehumanise and undermine recovery.
2. ‘‘I didn’t have a clue what was going on’’: participants did not feel aware about what was happening to them.	*‘‘I was out of touch with reality. I needed someone to sit down who I trusted and explain what was going on. But no one really said anything"*	The researcher's interpretated the lack of awareness participants had in their experiences was related to how much information they were given. Less information/ education about their experiences resulted in the participants feeling confused about what happened to them.	Confusion from lack of information / education seemed to be a re-traumatising experience, feeling further confused by the treatment process as they are by their actual psychosis experiences. Does this re-traumatisation prolong the distress and disruption caused by psychosis?
3. ‘‘Some kind of normal’’: participants desire to be seen by themselves and others as normal.	*‘‘You have to come back to some sort of normality so that you feel you belong here, no matter how different you are’’ ‘I wanted to prove to the world that I was back to normal’’ (Participant 4, Pg 16, Ln 7). ‘‘I go out every weekend. And I work all week. That’s it really. Just like normal people of my age’’*	Researcher's suggested that the need to get on with a normal life seemed closely related to participants wanting to belong. Researcher's noticed participants had a strong desire to be seen as normal and to prove to others around them they were 'back to normal.' Participants expressed a strong desire to pursue and do things which were expected for their age group.	A sense that participants were trying so hard to be considered 'normal' that they are actually not accepting that they could need to make some changes to support and adjust. Trying to do the things which are normally expected of them could also 'set them up to fail' as they are not holding in mind that there are certain things which have happened to them which makes it tricky. In addition, wanting to stay the same as before the psychosis could mean participants are placing themselves in 'stagnation.' Not wanting to accept what has happened and instead trying to get back to pre-morbid state could potentially get in the way of post-traumatic growth for participants, they are not learning about themselves or from experiences.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
3. ‘‘When you’ve got your friends around (. . .) you feel a lot more hopeful’’: the importance of belonging in social groups and the need for social acceptance.	*‘‘My best mate (. . .) has been supportive as well. (. . .) has been with me throughout it trying to level me’’ (Participant 3, Pg 4, Ln 35). Feeling understood was an important part of being accepted. For example, one participant described the need to talk to friends with similar belief systems: ‘‘I often think of my contact with the Buddhist people and stuff and yeah, maybe like contact with them, more contact with them would be a good idea’’ (Participant 5, Pg10, Ln 6). In contrast, one of the participants reported that, although his friends were important to him, he did not want to share his experiences, feeling, ‘‘worried that people will think that I’m crazy’’ (Participant 2, Pg 6, Ln 37). It appeared that for this participant sharing his experiences might have highlighted his difference and resulted in him being rejected. All of the participants highlighted the importance of having social relationships in terms of their feelings of hope: ‘‘When you are alone you feel more hopeless’’*	The need to discuss and share experiences was debated by participants. Some preferring to share experiences and others not wanting to for fear it might impede social belonging and relationships to their peers.	Adolescence is characterised by a period of dilemma and needing to find an identity and belong with others. For people with psychosis there seemed an added dynamic of whether to disclose their experiences or not.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>3. ‘‘If you don’t work, staying at home, it just drives you insane’’:</u> employment and occupation as being necessary to stay well.	*I felt really hopeless when I finally quit my job. I didn’t know what to do. I just thought well that’s it, I thought my condition’s just going to get worse. And I’ll end up going to hospital and then I’m never going to be able to get a job again.*	Participants described the importance of having work or some kind of occupation to prevent isolation and segregation from others. One participant highlighted the importance of having things to do to drive him forwards.	Employment and occupation to stay well, not just to become independent for many young people. Psychosis seemed to add another dynamic to wanting to work/ be employed. The cycle here is that actually being unwell might hinder work and then the individual could feel hopeless about their recovery, and this further prevents occupation. There is also the issue of stigma that people with psychosis could face when in looking for employment that prevents them being successful and therefore increases beliefs of going to be unwell (this anxiety could inadvertently produce the state of being unwell). Also, other themes where wanting to be seen as 'well' often aligns to having a relationship, doing things 'normal' people would do. This could produce a need and anxiety about getting employment.
<u>3. ‘‘Not alone’’:</u> importance of hearing that other people have experienced psychosis.	*He [the psychiatrist] told me not to worry he said he’d seen thousands of people the same age as me in the same situation and he said not one has not got over it.*	The researcher's interpretated that participants felt hearing stories about others experiences helped them identify with others and know they were not the only ones. These shared stories were very powerful and could offer narratives of empowerment but also narratives of never being able to get well.	The need for participants to feel hopeful from these stories and the sensitivity required to support them in this empowerment. E.g., hearing from a psychiatrist who the participant felt had better knowledge of psychosis, had never seen anyone get better actually compounded their sense of hopelessness in recovering. this could produce a further sense of loss, distance from others and their 'previous life' and therefore impede their sense of recovery and development.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
1. Perceived enforced treatment: anger at being forced and having their freedom taken away from them.	*I'm my own person. You can't do this. . .. I was angry at the doctors for locking me up. . .. I'm not angry because I have a chemical imbalance. I'm angry because strangers who don't know me have locked me up and taken my freedom . . . I'd gotten locked up and had my freedom taken away for being me*	This theme was defined as being subject to outside intrusive and impersonal discipline, enforced treatment, and monitoring. This could lead to feeling angry, fearful, unheard, and disempowered	Feelings of anger and frustration were interpretated from being forced against their will and having their freedom taken away from them. These experiences could have mirrored previous experiences they had and denies them an opportunity for corrective emotional experience. Therefore, core beliefs have the potential to be consolidated through these harrowing experiences. In addition, participant's sense of injustice seemed triggered by these experiences. This sense of injustice has the capability of affecting their emotional wellbeing throughout life. Feelings of anger might also indirectly mean relationships deteriorate as the feelings of anger can be taken out and experienced by those closest to the individual.
2. Disintegration: a fragmented sense of self in the acute stage of FEP.	*I'm feeling totally different like I'm not myself and that freaks me out . . . Like the thoughts that I'm thinking and the way that I talk to other people like sometimes it surprises me. . .. I have no idea what I just said and what was you know my face expression . . . freak me out and my thoughts start going why you know why, why is that.' & 'I was doing things that I couldn't control. . .. when you're aware of something you're doing but you can't stop it, it burns you'.*	A perceived lack of control over oneself and one's interaction with others due to psychotic symptoms was clearly evident and central to distress during the acute phase of FEP. The person's sense of self appeared fragmented and could be associated with ambiguity, disbelief, uncontrollability, and feeling surreal and disconnected from one's identity, others, and the world. This disintegration continued in the person's acute and recovery stages.	An unravelling of someone's sense of self and their identity. Not being able to piece together experiences. That the psychosis experience itself is traumatic and therefore develops a level of complexity.
3. self-stigma: negative views of themselves and their treatment	*I never used to think that I was crazy (laugh) until I had people coming around to the house every day to make sure I wasn't dead (laugh) . . . Frightening to be honest, it's not fun. I hate to think that I'll end one day up in*	The researcher's identified participants seemed to negatively perceive themselves compared to others. They also had a negative view of their treatment as well as their mental health difficulties. This was	Participants seemed to catastrophised their mental health difficulties once they were giving credit to a more socially determined trajectory of their illness. There was a degree of hopelessness that

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
	a padded cell with a straight jacket on not knowing my name, that's a bit scary.	sometimes adopted from a media and social perspective.	these types of dominant negative narratives created.
<u>3. stigma from others:</u> stigma was associated to media portrayals external in society around the person.	*Like people just don't understand at all and so, and people make judgements on your decisions . . . so I just don't discuss it with people like if anything I'll say it's depression . . . like on Law and Order the other day they said, someone said oh this person has psychosis and then the woman to me that means murder! . . . . And there's even this club that we were going to and it's called psychosis.*	Media portrayal of psychosis played into how people believed others perceived them as.	The importance of culture around the person e.g., through media portrayal was important.
<u>4. Estrangement:</u> people continued to feel estranged from their loved ones and peers following the acute psychotic episode	*Before I was unwell I needed twenty hands to count all my friends. After being unwell I can use two, like people fade away, people drift away, they can't, they don't either want to deal with it or they don't understand or when you try to talk to them they don't listen.*	Although evident during the acute illness, estrangement was predominant in the recovery phase. It was associated with feelings that people did not understand or relate to the illness experience and were unable to provide support. This could be the person's perception or indicative of actual behaviour. Communicating about the illness was difficult, the person could feel different due to the illness, and treatment and/or symptoms could produce isolation and disconnection	Perceptions that other people did not understand them or did not want to understand them when seeking support meant a change to those relationships.
<u>5. Sense of loss and deficit:</u> a range of losses experienced in participants' lives and identities.	*It's changed me heaps cause now I'm a lot more timid. Not very outgoing. Very shy sort of person. Lost a lot of confidence. A lot of people have said I've changed physically as well because I've put on a lot of weight from the treatment*	Losses and deficits were specific or general and were associated with different aspects of life or sense of self. The theme was present during the acute episode but was most evident in the recovery phase.	Treatment of psychosis also led to significant changes in them, and participants seemed distanced from their 'previous selves.' A sense that participants were considering themselves altered or different to who they were before. This created a narrative of being not the same person or having a previous self.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>6. Recognizing the illness as an ongoing problem:</u> viewing the psychosis as a recurrent difficulty and challenges of having to accept it.	*At the moment I have no control over anything. The voices have affected me so much. The depression's affected me so much and I just feel so powerless to change it. Cause everything's happening so slowly like being treated . . . I feel so powerless like I wish I could change it all in an instant.*	Mental health issues and/or secondary consequences were identified as an ongoing and enduring difficulty. The illness was viewed as a struggle which required ongoing management. Progress was regarded as slow and produced a sense of disempowerment and hopelessness.	Sense of hopelessness that things were going to revert to 'normal.' Feeling as though there was no end to psychosis and therefore being pushed to accept the effects it continued to have on their lives.
<u>Perception of treatment as restricting</u> treatment methods as being restrictive and not conductive to supporting independence and freedom.	*I'm a bit controlled by the medication ... I'll probably always have to go see a psychiatrist and get scripts filled and take my pills."*	Treatment could be disempowering, burdening, and/or inconvenient contributing to disengagement, resignation, or a desire for self-control.	A sense of being trapped in a dependency loop.
<u>Estrangement:</u> making conscious decisions to stay away from significant people to 'protect' them.	*"I drifted away from them while I was crazy ... you drift away so you don't hurt yourself or you don't hurt them ... there was a year that I here but I wasn't here at all."*	choices to disengage from relationships or interactions with others.	Being physically present but mentally/ psychologically elsewhere meant people also were psychologically removed from the people around them. Wanting to place distance between self and others and fearful of hurting them or being hurt in return e.g, rejection, it is far easier to reject than to wait to be the rejected.
<u>Conscious avoidance:</u> not wanting to acknowledge the presence of psychosis in their daily lives.	*I don't want to think about it at all ... I don't need to think about it anymore put it behind you."*	Preferring to avoid talking or touching the subject of psychosis. Placing illness in the past. Using distraction methods and numbing through substances. Sometimes avoiding treatment as want to be distanced from psychosis.	Wanting to be considered 'normal' might result in attempting to avoid acknowledgement of what happened to them. This included avoiding treatment options and avoiding thinking about what they could learn about their experiences to progress and continue with development. This is a potential block to post-traumatic growth.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Awareness of one's vulnerability:</u> researcher's interpretation that avoidance was because participants felt vulnerable.	*I'm always going to have to be really careful about overwhelming myself ... I would have the same dreams ... but I just don't think it's going to happen ... that's the price I'm prepared to pay to stay well ... it's ... disappointing.*	Worries, fears, cautiousness, and concerns about becoming unwell again and active attempts to avoid relapse reflected a sense of vulnerability. This led to withdrawal from past activities and taking things slowly	Heightened awareness of vulnerability not clearly named by participants suggesting that perhaps they were not aware of this, and the researcher's had picked up on an unconscious feeling of vulnerability motivating participants to avoid psychosis, estrange and isolate themselves. However, this could be 'othering' as people with psychosis might have a rather extreme sense of vulnerability from moments when they were hurt when younger. This also locates the problem inside the person; 'they are doing these things purposely because...' however, it is that they didn't have control over the events which have encouraged them to feel vulnerable and at threat. In addition, participants are responding to their experiences, and this feeling of vulnerability is a product/ outcome of x, y and z.
<u>Developing acceptance and moving forward:</u> dual process.	*"Tying to accept the way things are and not resisting ... now if I feel crap I just get through it I don't try and fight it."*	Recognition of the illness is a changeable experience and part of the life course that cannot be completely controlled, as well as a desire to move forward.	Dual process of acceptance but also having a desire to move forward and develop greater understanding about self, life, and the world.
<u>Viewing recovery as a journey:</u> not always straight and linear journey but one marked by different variation.	*"It's ... like a roller coaster it goes up and down ... some days are good some days are bad."*	Recovery was ongoing and gradual, characterised by fluctuating difficulties and parallel improvement. This involved identifying problems and considering what recovery might be like once achieved.	A gradual recovery was interpretated by researchers as being positive but there was a sense that participant's describing it as a 'roller coaster' was that it felt exhausting, draining, and difficult to manage the twists and turns not knowing when they might occur. Being able to think and hold both good and bad days together is a big part of the recovery journey.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Self-directed recovery:</u> individuals being able to lead their own recovery journey.	*I'm a little more determined to deal with it ...I see it more as a fixable problem than I did before."*	A desire to actively achieve change and overcome and/or manage the impact of FEP. Treatment strategies or non-treatment related coping strategies were important. There was also realisation and reflective examination of what went wrong.	Like ideas of needing empowerment to motivate and create desire in patients with psychosis.
<u>The interpersonal environment facilitates recovery:</u> social belonging supported recovery.	*Just talking about what I go through ... talking about the nitty gritty of it ...every time I repeat what I've been through that tends to make me get better cause I realise that it's not true. Sort of grounds me as well.*	Interactions with others facilitated recovery. Improvement could be facilitated through the company of others, talking through the experience, emotional and practical support or teaching new skills.	The importance of other people in the person's social network. This can be vicious cycle as the person also isolates self from others yet needs this to support their recovery.
<u>Functional recovery:</u> a return to previous levels of functioning or engagement in tasks previously done was a sign of recovery.	*"A lot of things kind of slowly dropped off and now they're slowly coming back ... Getting to go back to school. I'm going travelling ... I feel like a productive member of society."*	A return to prior functioning or re-engagement in prior activities. Areas of improvement involved: symptom resolution, increased self-worth and confidence, general health, and wellbeing, regaining a positive outlook, and contributing to society. Treatment changing was also a sign of recovery.	A sense that this engagement in previous activities encouraged others to be able to see a change in their psychosis and therefore prompted ideas of the person being 'well' again - although social and interpersonal factors may not have been necessarily addressed. This could be a means in which to mediate how people with psychosis are able to receive further contact from peers e.g., supporting them to return pre-levels and then allowing the person to gain increased social contact.
<u>Social recovery:</u> being able to do further activities meant increased social contact and therefore learning new interpersonal skills. This was helping young people develop.	*I'm a better listener now ...I try to listen to them ... and learn from whatever they're saying as opposed to listening to it kind of half in one ear, shrugging it off, and thinking something in my head at the same time.*	Captured the renewal of relationships and re-establishment of social skills as core elements of the recovery process.	Being 'less in their heads' and more in contact with the reality around them. This is a good sign of recovery for participants but also matches society expectations.
<u>Development of deeper and closer relationships:</u> identifying with quality over quantity.	*"Throughout all the good and the bad ... (girlfriend) stuck by me gave me a real appreciation ... the meaning of life and what love and ... life together long living would be like."*	(a) seeking, receiving, and accepting support and/or spending increased time with others; (b) recognition of the difficulties the relationship has endured; (c) more open and intimate	Participants seemed to identify with having learnt more interpersonal skills and having improved relationships following psychosis, although sad about having lost other relationships.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
		communication; (d) sharing similar problems to significant others.	
<u>Increased desire to interact with others and improve the relationship:</u> a modelling of relationships, wanting to make sure their relationships were ok and investing more time into this.	*I'm less snappy, more patient ...I'm more understanding now ... Especially when it comes to my family ... watch out to see if they're ok or if they're feeling ok ... making sure that everybody's happy not just myself ... I was suddenly wanting to know how they (parents) were.*	The new purpose for engaging with people was not previously evident and was a new realisation of the importance of relationships. This was accompanied by an enhanced motivation to improve and put more effort into relationships. There was also a new recognition that people can provide valuable support and an acceptance of the need for others.	Participants seemed keen to invest their time and effort into their relationships. They also seemed to model the behaviours shown to them to build their interpersonal skills. Participants were motivated to get relationships. There was a sense from reading the researcher's interpretations that participants perhaps wanted their relationships to be seen more equal and were investing in having a two-way relationship. This seemed on par with participants wanting to have independence and seeking to be distanced from a dependency on others.
<u>Enhanced perspective taking and sense of unity:</u> researcher interpretation that participants seemed able and wanting to take in different perspectives and that they had learnt about what it is like to have a mental health diagnosis.	*I wasn't as compassionate towards people who had mental illnesses ... I can understand what people go through when they have mental illnesses which has made a huge differences in my life ... I've got a bit more understanding.*	An awareness of difficulties coupled with compassion and empathy for others and increased consideration of others in general was present.	Being able to relate to others with the same or similar mental health difficulties.
<u>Confirmation of character of others and quality of relationships:</u> trusting in others due to the support being shown before.	*My mum ... helped me with my medication ... I just realised how lucky I was you know to have someone like that ... it just made me sit, stand back a bit and like see what I had and realise ... I was sort of destroying it in a way.*	a realisation of genuine relationships and support; the positive qualities of others; and the value of relationships.	Developed a sense that participants considered their experiences as a trial which demonstrated to them who was most important, who had supported them. Being able to use this mindset to support that these people cared about them, and this was a positive strength. This helped with resilience and developing a mindset that it was quality over quantity.

Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Greater appreciation of life:</u> experiences led to a re-evaluation of life and seeing it as valuable, fragile, and therefore needing to take better appreciation of it.	*I've never really realised how important life was till I started challenging my being ... Going from thinking that life is just worthless I've gone to thinking that life's ... got a lot of things ... I've gotten to know myself a lot better and I tend to value my own life very well.*	The psychotic experience was reframed as an opportunity to reassess life and as facilitating a greater appreciation for life. A desire to live life to the fullest was expressed as well as a greater recognition that life is precious, valuable, and fragile and is taken more seriously.	Seeing life after psychosis as a 'second chance?' In addition, there are elements of post-traumatic growth.
<u>New possibilities and direction:</u> re-assessment of life goals and direction	*My dreams are a lot different cause I no longer want things I used to want ...Well I used be heavily into drinking. I used to love it and now I don't and never wanted to get fit and now I do and so it's changed a lot.*	A perceived qualitative change in life-direction was apparent. This involved re-assessing and thinking about goals, interests, priorities, and life-path expressed as a desire for change or actual change.	Re-evaluation of 'life goals' seemed a big jump in the researcher's interpretation. The participants seem to be discussing and describing changes to their lifestyle habits and goal directed 'behaviour' rather than larger life aspirations. This feels as if perhaps the researchers were drawn into the narrative that people with psychosis who show 'normal' behaviours must be getting better and therefore being healthy is aligned to making these changes to lifestyle. Whilst this is important and does have knock on effects on a person's emotional well-being it seemed to minimise that something has been done, usually, to these people and isn't being addressed in treatment. It's usually about treating the person and not the things around them which influenced their reaction. Developing some sense of injustice from this treatment on a more unconscious level?

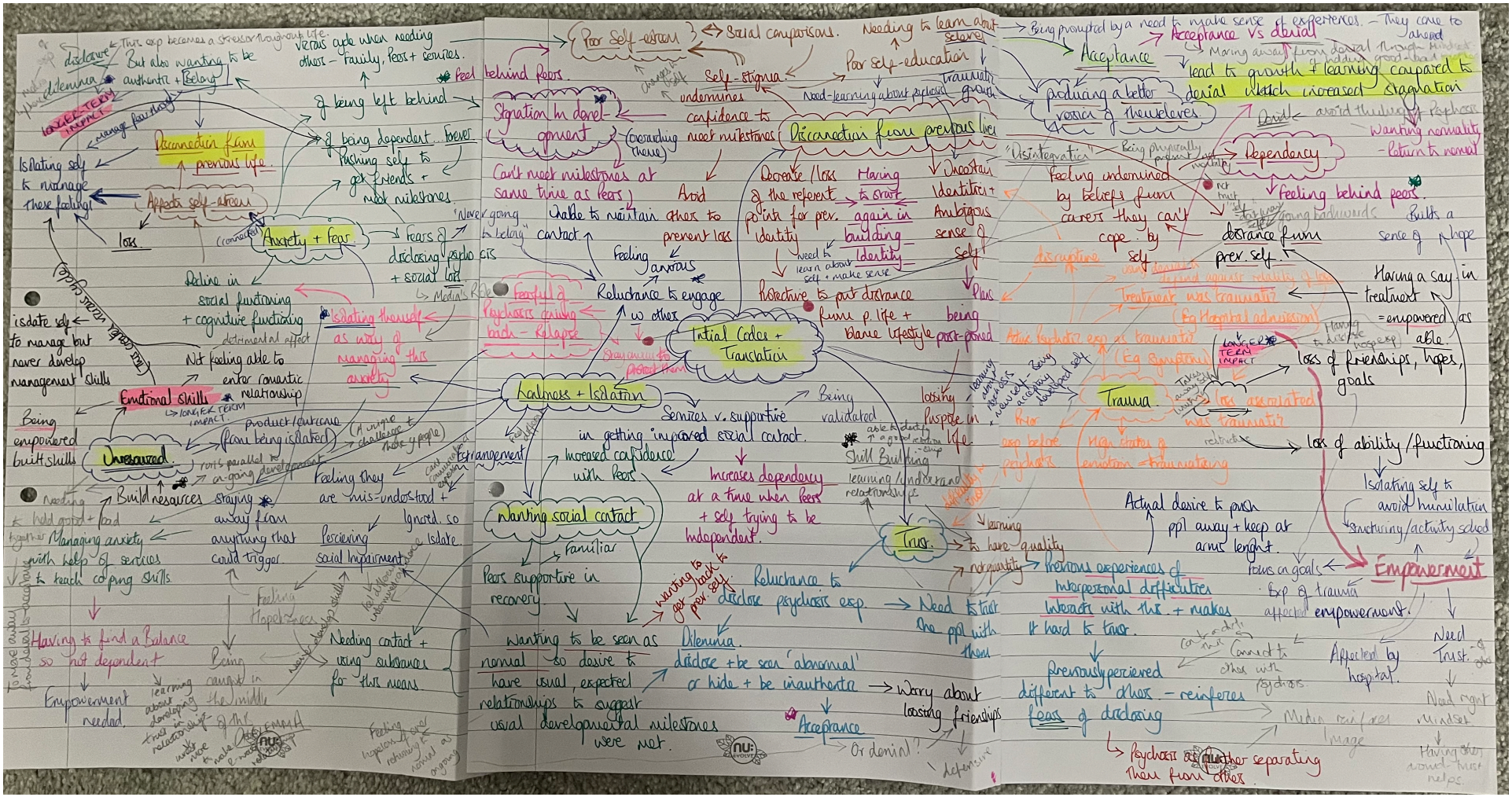
Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
<u>Deepening of self-knowledge:</u> a shift in attitude and behaviour following a development of self-awareness.	*"It's made me less selfish ... it's made me more harmonious around my family and ... I've matured a bit and don't look at things the same way."*	this theme captured development of the self, which explicitly or indirectly implied increased self-awareness. A shift in attitude and behaviour due to these changes was also expressed.	Increased self-awareness was interpreted by the researchers and from people around them when they exhibited behaviours in accordance to this. However, this does not necessarily mean that participants didn't have some sort of self-awareness before, they just hadn't been able to communicate it through their behaviours. Interpretating this as participants needing to communicate their level of distress, recovery, and development through their behaviour so others can make an interpretation about it: rather than participants being able to stipulate themselves. Not able to trust their voices and therefore don't trust themselves?
<u>Development of a sense of mastery and personal strength:</u> researcher's interpretation.	*desire for increased self-reliance and strong-mindedness. This involved increased control over one's situation and a determination to deal with residual and future difficulties. These perceptions promoted increased confidence and acceptance of one- self.*	The researcher's interpretated that participants had developed a sense of them becoming self-reliant and were able to focus on dealing with future difficulties. This increased their self-confidence.	Being able to control emotions and thoughts and cope well with future difficulties was a sign that participants were recovering well. This can be difficult as most young people are not always capable of doing this. It leads to a question of whether young people with psychosis are often at a disadvantage for a quick recovery - because they need to be able to develop these skills. yet, very likely they didn't have them before and were in the process of developing them when they had psychosis. Having to navigate the most difficult part of life, adolescence with these experiences = adds to confusion and difficulties with stress management.

Appendix 1G – Codes of First, Second and Third Order Interpretations

Note. Column labelled as 'themes' are the initial themes across papers coded in different colours which appear like each other. The first column 'initial codes and translation' aims to discuss the similarities and differences noted between themes. This is a sample of the added column to avoid replicating the whole table.

Initial Codes and Translation	Themes	1st order interpretation	2nd order interpretation	3rd order interpretation
Dis-connection from previous lives - being perceived as different to peers impacts developmental milestones by undermining confidence.	**Self-stigma: loss of friends through perceptions that they couldn't interact and function with others. Not wanting others to notice a difference in them so avoiding others.**	*If they wanted to go out I was worried that I wouldn't be the same person; I wouldn't be like the joker anymore (Participant 7) I just felt that she's going to come and my house won't be tidy enough. It's too many little things; food should be ready, and i won't be able to manage. (Participant 10)*	Researchers interpreted this theme as affecting how people perceived themselves and their own interactions with other people. They felt participants were anxious about the expectations of other people and avoid them to reduce this anxiety.	Interpretation of the data that participants may have felt developmentally behind and unable to manage tasks that are considered 'normal' so therefore avoid other people in their social sphere to reduce the anxiety. Creation of an internal world, by avoiding the outside 'real world,' that reduces feelings of being 'different' from others and manages the anxiety created through expectations placed on them.
Loneliness and isolation - creating an internal world and staying away from others to avoid further social loss. ***Feeling fearful and anxious*** about social loss if they have to speak to others about psychosis.	**Talking about the illness: reluctance to engage with others around them because they did not wish to discuss and re-live their experiences.**	*I don't like talking about it and when I do I get really upset and stuff like that so I don't like talking to people even friends, about what happened, what I went through (Participant 11) I wanted the truth to come out so that in the future if we get married, if he finds out he won't leave me or he won't get angry at me, so i told him from the start (Participant 13)*	Researcher's felt that participants would avoid discussions about their experiences of psychosis with significant others because they did not want to re-live the distress it created. However, they also felt there was some pressure on participants to disclose their experiences to avoid 'lying' to their close others.	A sense of a dilemma for participants to disclose or not to disclose, depending on what was at stake for them. It felt as if the researcher's interpretation that there was some pressure for participants may have related to the participants perceiving they could suffer a social loss if they didn't disclose. It felt as if participants had to weigh up the costs of a potential social loss if they did disclose and a social loss if they didn't and it eventually came out to the other person. Perhaps this was a source of anxiety for people.

Appendix 1H – Mind Map of Codes and Translations



Appendix 1I – Grid showing the Development of Thematic Structure

Translation/theme	Comments	Subthemes	Further break down of codes and translations	Comments/ discussion	Reflexivity comments
			interpersonal relations.		
	Cycle: loss of referent points from the isolation to manage psychosis leads to increased sense of loss of previous identity.	**Loss of functioning**	Reduced distance to previous self before the psychosis and created a dis-connection. Fewer referent points for previous sense of self. Loss of these referent points = loss of identity.	**Related to 'disconnection from previous lives'**	*This loss leads to further worries of future loss - a worry of everything happening all over again.*
		›› **Loss of friendships**			
		High states of emotion during active psychosis			

Note. This is a sample of the table created in Excel to help develop the thematic structure

Appendix 1J –Reflexive Diary Extract

Below are photographs illustrating an extract taken from the literature review reflexive diary. This diary was held during analysis and includes the researcher's thoughts around the papers, particularly after conversations held with peers and supervisors.

(redacted picture to protect confidentiality)

Appendix 2A – Health Research Authority (HRA) NHS Letter of Ethical Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Jasmin Gill
Trainee Clinical Psychologist
Birmingham and Solihull Mental Health Foundation NHS Trust
University of Birmingham, School of Psychology
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Email: approvals@hra.nhs.uk
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07 April 2022

Dear Miss Gill

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring emotional well-being of people with psychosis during the COVID-19 pandemic: An interpretative phenomenological analysis.**
IRAS project ID:	**307481**
Protocol number:	**1.0**
REC reference:	**22/SW/0038**
Sponsor	**University of Birmingham**

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **307481**. Please quote this on all correspondence.

Yours sincerely,
Sharon Northey

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Dr Birgit Whitman*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Participant poster]	version 1	04 February 2022
Copies of materials calling attention of potential participants to the research [Clinician Poster]	version 1	04 February 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter]	version 1	14 February 2022
GP/consultant information sheets or letters [Clinician information sheet]	version 1	04 February 2022
Interview schedules or topic guides for participants [Interview Schedule]	version 1	04 February 2022
Interview schedules or topic guides for participants [Timeline]	version 1	04 February 2022
IRAS Application Form [IRAS_Form_22022022]		22 February 2022
Letter from sponsor [Confirmation of sponsorship]	version 1	14 February 2022
Organisation Information Document [Organisation Information Document]	version 1	14 February 2022
Other [Letter confirming withdrawn data]	version 1	04 February 2022
Other [Data management plan]	version 2	01 April 2022
Participant consent form [E-Consent Form]	version 2	01 April 2022
Participant information sheet (PIS) [Participant information sheet]	version 2	01 April 2022
Research protocol or project proposal [Research Protocol]	version 1	04 February 2022
Schedule of Events or SoECAT [Schedule of Events]	version 1	04 February 2022
Summary CV for Chief Investigator (CI) [CV for Jasmin Gill]	version 1	22 December 2021
Summary CV for student [CV for Jasmin Gill]	version 1	22 December 2021
Summary CV for supervisor (student research) [CV for Andy Fox]	version 1	07 January 2022
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance letters]	version 1	01 August 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance letters]	version 1	01 August 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance letters]	version 1	01 August 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance letters]	version 1	01 August 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance letters]	version 1	01 August 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance letters]	version 1	01 August 2021
Validated questionnaire [PANSS]	version 1	04 February 2022

IRAS project ID	307481

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is one NHS participating organisation; therefore there is one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No study funding will be provided to sites as per the Organisational Information Document	This is a single site study and the study Chief Investigator will, in addition, act as Principal Investigator (PI). Therefore, no additional PI or Local Collaborator (LC) is required.	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
• The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio. • The CI is an employee of the one NHS organisation taking part in the study.

Appendix 2B – Clinician Information Sheet

(redacted to protect confidentiality)

Appendix 2C – Clinician Recruitment Poster

(redacted to protect confidentiality)

Appendix 2D – Participant Information Sheet

(redacted to protect confidentiality)

Appendix 2E – Participant Recruitment Poster

(redacted to protect confidentiality)

Appendix 2F – Electronic Participant Consent Form

(redacted to protect confidentiality)

Appendix 2G – Interview Schedule

A) <u>Introduction of interview –</u>

- **<u>Environmental checks: (prior to audio recording starting)</u>**
    - Time: (we have 60-90 minutes today and we can break at any time, just let CI know when)
    - Structure: Timeline creating and questions (PANSS questionnaire at the end)
    - Location: (somewhere private – comfortable?) Using the video calling platform; mute/video button for breaks, pausing audio recording during this time on dictaphone.
    - Trouble shooting internet issues: what to do if one of us gets 'kicked out' of the online meet (wait for the other person to come back in 15 minutes, if either CI or participant is not back in the meeting after 15 minutes then CI to make telephone contact with participant, confirm happy to continue and if necessary, re-send link or re-schedule).
- **<u>Timeline:</u>**

Show the timeline using share screen, explain to participant that they can have a copy of the timeline we make together today after the interview should they wish to.
Briefly explain how the timeline will be completed together as this is on the CI's computer, the participant should be able to see the timeline using share screen. Encourage participant that if at any time they can't see the timeline, let the CI know. Breaks can be offered at any point. After each break, the researcher checks in with the participant and asks whether they are happy to proceed with the interview.
(Inform participant that interview will now start with audio recording, start audio recording)

B) <u>Questions whilst filling in timeline:</u>

1. What did you think of the national restrictions? What do you remember of when the restrictions were first introduced? *What were you doing? With whom? Where?*
2. How did the lockdowns affect you? If possible, do you have an example you could share? *Was there anything bad about this time? Did you access services? How did that affect you? Anything good?*
3. Did anything change in the next few Lockdowns? Is so, what? *Did anything change for the better? Did anything change for the worse? How did this affect you?*
4. What was it like during the vaccine roll-out? *How did you feel? Were there challenges? Were there positives?*
5. What challenges did the pandemic present for you? Where do you want to put these on the timeline? *Are these challenges connected to other events that are on the timeline?*
6. What helped during the pandemic? What didn't help? *What did it help you with? Can you think of things people/or yourself did that were helpful or unhelpful?*
7. What was the releasing of restrictions like for you? How did 'Freedom Day' affect you? *Are there any changes in the way you think about the pandemic now compared to when it first started?*

(Offer break)

C) <u>PANSS – Positive and Negative Syndrome Scale (completed by CI/Researcher with participant and based on observations during the interview)</u>

Appendix 2H – Positive and Negative Syndrome Scale (PANSS; Kay, 1987)

(redacted to protect confidentiality)

Appendix 2I – Exploratory IPA Notes

Note. This illustration is a sample taken from 'Nina's' transcript

(redacted to protect confidentiality)

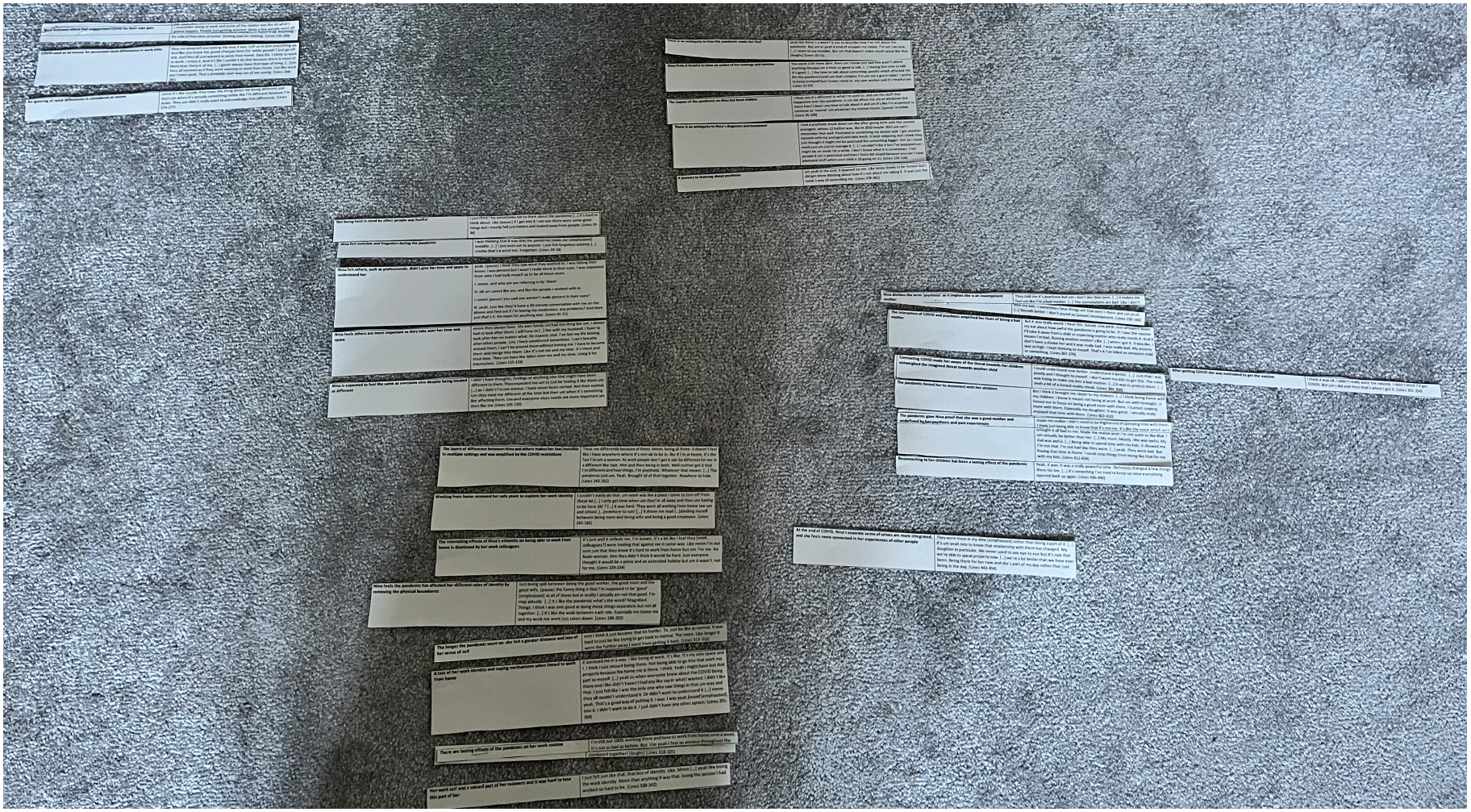
Appendix 2J – Experiential IPA Statements

Note. This illustration is a sample taken from 'Nina's' transcript

(redacted to protect confidentiality)

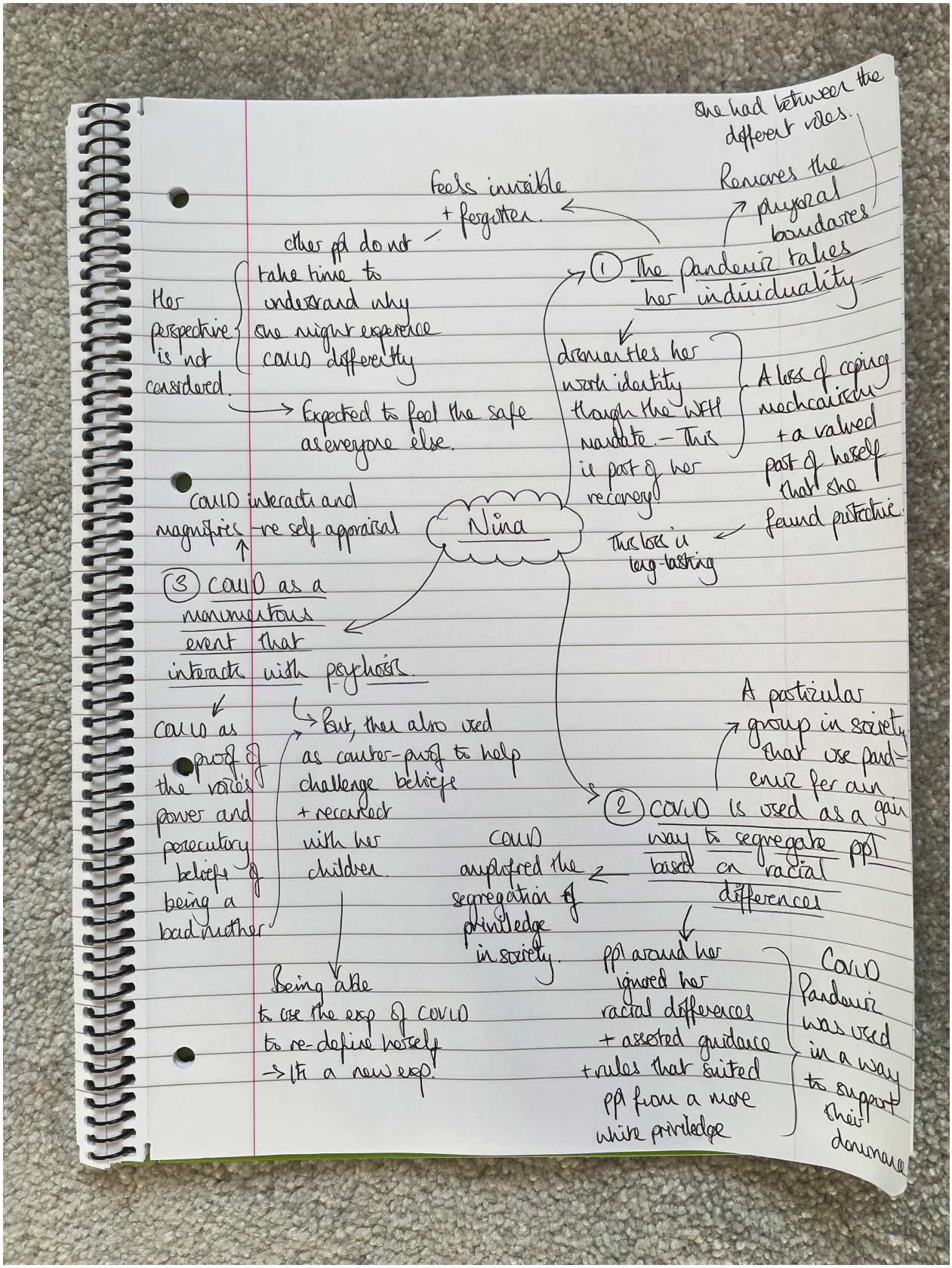
Appendix 2K – Developing Personal Experiential Themes (PETs)

Note. This illustration was taken from Nina's Experiential Statements



Appendix 2L – Individual Mind map of PETs

Note. This illustration was taken from 'Nina's' PETs

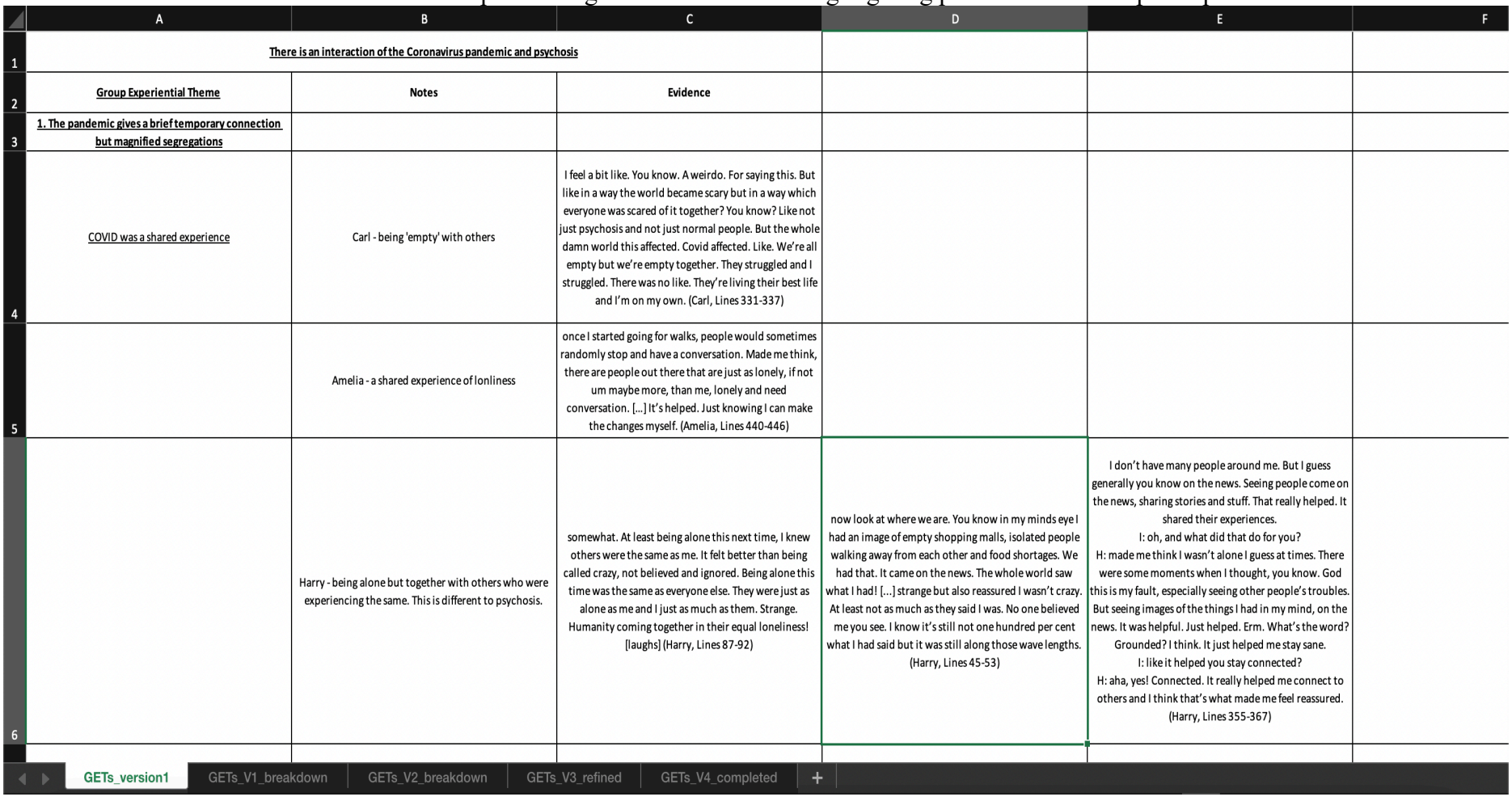


Appendix 2M – Combined Mind Maps across Participants

(redacted to protect confidentiality)

Appendix 2N – Common Patterns and Developing Grouped Experiential Themes (GETs)

Note. This illustration is a screenshot and sample of the grid created in Excel highlighting patterns across the participants



	A	B	C	D	E	F
1	**There is an interaction of the Coronavirus pandemic and psychosis**					
2	**Group Experiential Theme**	**Notes**	**Evidence**			
3	**1. The pandemic gives a brief temporary connection but magnified segregations**					
4	COVID was a shared experience	Carl - being 'empty' with others	I feel a bit like. You know. A weirdo. For saying this. But like in a way the world became scary but in a way which everyone was scared of it together? You know? Like not just psychosis and not just normal people. But the whole damn world this affected. Covid affected. Like. We're all empty but we're empty together. They struggled and I struggled. There was no like. They're living their best life and I'm on my own. (Carl, Lines 331-337)			
5		Amelia - a shared experience of lonliness	once I started going for walks, people would sometimes randomly stop and have a conversation. Made me think, there are people out there that are just as lonely, if not um maybe more, than me, lonely and need conversation. [...] It's helped. Just knowing I can make the changes myself. (Amelia, Lines 440-446)			
6		Harry - being alone but together with others who were experiencing the same. This is different to psychosis.	somewhat. At least being alone this next time, I knew others were the same as me. It felt better than being called crazy, not believed and ignored. Being alone this time was the same as everyone else. They were just as alone as me and I just as much as them. Strange. Humanity coming together in their equal loneliness! [laughs] (Harry, Lines 87-92)	now look at where we are. You know in my minds eye I had an image of empty shopping malls, isolated people walking away from each other and food shortages. We had that. It came on the news. The whole world saw what I had! [...] strange but also reassured I wasn't crazy. At least not as much as they said I was. No one believed me you see. I know it's still not one hundred per cent what I had said but it was still along those wave lengths. (Harry, Lines 45-53)	I don't have many people around me. But I guess generally you know on the news. Seeing people come on the news, sharing stories and stuff. That really helped. It shared their experiences. I: oh, and what did that do for you? H: made me think I wasn't alone I guess at times. There were some moments when I thought, you know. God this is my fault, especially seeing other people's troubles. But seeing images of the things I had in my mind, on the news. It was helpful. Just helped. Erm. What's the word? Grounded? I think. It just helped me stay sane. I: like it helped you stay connected? H: aha, yes! Connected. It really helped me connect to others and I think that's what made me feel reassured. (Harry, Lines 355-367)	

GETs_version1 | GETs_V1_breakdown | GETs_V2_breakdown | GETs_V3_refined | GETs_V4_completed | +

Appendix 2O – Developing the Written Structure of GETs

(redacted to protect confidentiality)