PAUL RAINEY (BSc Hons., MSc)

EXPLORING THE LINK BETWEEN TRAUMA AND PSYCHOSIS FROM A POWER, THREAT, MEANING FRAMEWORK PERSPECTIVE

Section A: Representations of power, threat and meaning in individual accounts of psychosis: a meta-ethnography of psychosis narratives

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Section B: Exploring subjective experiences of EMDR for psychosis - a Power Threat Meaning Framework (PTMF) informed narrative inquiry

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Summary

Section A: This is a meta-ethnographical review exploring peoples' subjective experiences of psychosis. The review used the lens of the Power Threat Meaning Framework (PTMF) to explore the role of adversity in psychosis; to understand the extent that concepts of power, threat and meaning were represented in depictions of psychosis and to investigate what strengths and opportunities contributed to survival and recovery. A systematic literature search and synthesis of 15 narrative studies was undertaken. Six overarching constructs were identified and a conceptual diagram was developed. Implications for future research are discussed.

Section B: This is a narrative analysis study looking at subjective experiences of EMDR for psychosis. Informed by the PTMF, the aims of the study were to explore what focusing therapeutically on traumatic experiences in the context of psychosis might reveal about the link between adversity and psychosis, and; to explore what people depict as important when engaging with EMDR for psychosis. Participants who had experienced psychosis, had been known to a secondary care community mental health team and had subsequently engaged with EMDR were interviewed. A conceptual model is presented representing key findings within the research and a number of clinical implications are raised.

Contents

| Section A | |
|---|----|
| Note on terminology | 12 |
| Abstract | 13 |
| Introduction | 14 |
| Aims of the review | 16 |
| Methodology | 17 |
| Systematic literature search | 17 |
| Definitions | 17 |
| Inclusion criteria | 18 |
| Search strategy | 19 |
| Critical appraisal | 20 |
| Conceptual richness | 22 |
| Synthesis | 23 |
| Results | 25 |
| Description of the studies | 25 |
| Assessment of quality | 29 |
| Synthesis findings | 30 |
| Understanding psychosis as a consequence of adverse experiences | 35 |
| Making sense of psychosis phenomena | 39 |
| and strategies for survival | |
| Powerlessness, mistrust and the relationship with | 43 |
| mental health services | |
| Loss of self | 50 |
| Strengths and opportunities supporting recovery | 54 |
| The new self | 60 |
| Discussion | 64 |
| The role of adversity | 64 |
| Power, threat and meaning | 66 |
| Strengths and opportunities supporting recovery | 68 |
| Strengths and limitations of the review | 69 |
| Recommendations and conclusions | 69 |
| References | 70 |

| C 4. | D |
|---------|---|
| Section | к |
| SCCHOIL | D |

| Abstract | 79 |
|---|-----------|
| Introduction | 80 |
| The Power, Threat, Meaning Framework | 81 |
| Eye Movement Desensitisation Reprocessing (EMDR) | 81 |
| Research aims | 83 |
| Method | 84 |
| Theoretical framework | 84 |
| Design | 84 |
| Reflexivity | 85 |
| Participants | 85 |
| Ethics | 87 |
| Data collection | 87 |
| Analytical approach | 88 |
| Results | 90 |
| Research aim 1: What does focusing therapeutically on experiences of trauma that | 97 |
| commenced prior to the onset of psychosis reveal about the link between adversity | |
| and psychosis? | |
| Adversity, meaning making and unusual experiences | 97 |
| Emotionally detached coping mechanisms | 98 |
| The role of power in causing and maintaining adversity | 99 |
| Openness to a higher consciousness | 100 |
| Research aim 2: what peoples' experiences depict as important in undertaking | 103 |
| EMDR for psychosis? | |
| EMDR's role in change | 103 |
| The therapeutic relationship | 104 |
| EMDR and personal meaning making | 104 |
| Moving beyond dialogue | 105 |
| Reflexive positioning | 106 |
| Discussion | 106 |
| Research aim 1: What does focusing therapeutically on experiences of trauma that | 10′ |
| commenced prior to the onset of psychosis reveal about the link between | |

| adversity and psychosis? | |
|--|-----|
| Research aim 2: what peoples' experiences depict as important in undertaking | 109 |
| EMDR for psychosis? | |
| Strengths and Limitations | 112 |
| Clinical implications and recommendations | 113 |
| Conclusion | 114 |
| References | 114 |

Tables

| α | ection | |
|--------------|--------|-----|
| S-C | retion | ι Δ |
| \mathbf{v} | CUUL | |

| 1. | Six key questions of the Power Threat Meaning Framework | 15 |
|-----|---|----|
| | (Johnstone & Boyle, 2018) | |
| 2. | Initial study inclusion and exclusion criteria | 18 |
| 3. | Literature search terms | 19 |
| 4. | Scoring of quality and conceptual richness | 22 |
| 5. | Summary of analytical approach—based on Noblit and Hare's (1988) seven | 23 |
| | phase approach to meta-ethnography | |
| 6. | Overview of studies analysed (in order of assessed quality and conceptual richness) | 26 |
| 7. | Assessment of study quality and conceptual richness | 31 |
| 8. | Overview of study quality | 32 |
| 9. | Overview of third order constructs and underlying themes | |
| 10. | Understanding psychosis as a consequence of adverse experiences - | 37 |
| | example first and second-order constructs | |
| 11. | Making sense of psychosis phenomena and strategies for survival | 41 |
| | survival - example first and second-order constructs | |
| 12. | Powerlessness, mistrust and the relationship with mental health services - | 46 |
| | example first and second-order constructs | |
| 13. | Loss of self - example first and second-order constructs | 52 |
| 14. | Strengths and opportunities supporting recovery - example first and | 56 |
| | second-order constructs | |
| 15. | The new self - example first and second-order constructs | 61 |
| Sec | tion B | |
| 1. | Experiences commonly described as psychosis (Cooke, 2017) | 86 |
| 2. | Inclusion and Exclusion criteria | 86 |
| 3. | Participant demographics | 87 |
| 4. | Analytical procedure | 88 |
| 5. | Synopsis of narratives | 90 |

Figures

| Section A | |
|---|-----|
| 1. Systematic literature search process (PRISMA flow diagram) | 21 |
| 2. Diagrammatical representation of how meta-ethnography findings | 63 |
| integrated with the core concepts of the PTMF (Johnstone & Boyle, 2018) | |
| Section B | |
| 1. Conceptual model of participant themes – a pathway from adversity to unusual experiences | 102 |

Section C - Appendices

| Appendix A: Example first iteration data extraction table | 123 |
|--|-----|
| Appendix B: Example second iteration data extraction table | 124 |
| Appendix C: Full data extraction tables | 125 |
| Appendix D: Reflexive journal extracts | 159 |
| Appendix E: REC/HRA approval | 160 |
| Appendix F: Letters of access from NHS Trusts | 163 |
| Appendix G: Example Consent form | 171 |
| Appendix H: Interview protocol | 173 |
| Appendix I: Example completed narrative summary sheet | 175 |
| Appendix J: Thematic narrative analysis data synthesis | 185 |
| Appendix K: Coded transcript | 187 |
| Appendix L: Participant information sheet | 200 |
| Appendix M: Feedback to ethics panel | 204 |

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Note on terminology

Whilst the term 'psychosis' is acknowledged as a contested term and one that is conceptually problematic (Geekie & Read, 2009), it is employed in the current research not to imply illness or disorder, but as an overarching descriptor of unusual experiences such as; hearing voices or having visions; having racing thoughts and; having suspicious or grandiose beliefs that others find unusual ('hallucinations', 'thought disorder' and 'paranoid/grandiose delusions' in medicalised language). Where contested terms are employed within the research, this will be denoted by the use of quote marks on first use.

Abstract

Despite the wealth of evidence linking adverse experiences and 'psychosis', in psychiatric practice, biomedical explanations are often privileged over trauma-based explanations. The Power Threat Meaning Framework (PTMF, Johnstone & Boyle, 2018) offers a conceptual alternative to this position and, in doing so, considers the experience of emotional distress, and its associated behaviours, as a response to adverse life experiences. Whilst the application of the PTMF to experiences of psychosis appears to be both logical and insightful, the extent to which overarching PTMF concepts are represented in people's subjective experiences of psychosis is less clear. The aims of this review were to explore the role of adversity in psychosis, to understand the extent that concepts of power, threat and meaning were represented in depictions of psychosis and to investigate what strengths and opportunities contributed to individual survival and recovery. A systematic literature search and meta-ethnographic synthesis of narrative studies focussing on peoples' subjective experience of psychosis was undertaken. Six overarching constructs were developed (thirdorder constructs) from 35 underlying researcher-interpreted themes (second-order constructs) identified within the research. These were: Understanding psychosis as a consequence of adverse experiences; making sense of psychosis phenomena and strategies for survival; powerlessness, mistrust and the relationship with mental health services; loss of self; strengths and opportunities supporting recovery; and the new self. The findings provide further supporting evidence for the role of adversity in psychosis and the importance that meaning-making and re-storying one's experience plays in recovery.

Introduction

In the later part of the 20th century, 'psychosis' was predominantly viewed as a biologically determined 'illness' driven by genetics or brain pathology (Read et al., 2013), however, in more recent times, the association between adversity and psychosis has been well documented (Hardy, 2017). A wealth of evidence links trauma during childhood to an increased vulnerability to psychosis (Read et al., 2014, Varese, 2012), whilst later life adversities (Beards et al., 2013), social disadvantage (Kirkbride et al., 2014; Morgan et al., 2019) and discrimination (Pearce et al., 2019) have also been implicated in the cause of psychosis.

Despite the plethora of evidence linking adverse experiences and psychosis, within psychiatric practice, trauma-based explanations often remain secondary to biomedical ones (Harper et al., 2021). Criticisms of the psychiatric approach (often referred to as the 'illness', 'medical' or 'biomedical' model) include not only critiques of treatment practices (Kinderman, 2014), but also of the role dominant medicalised discourses play in an individual's ability to make sense of their experiences including, importantly, the psychological impact of adversity (Johnstone & Boyle, 2018).

In offering a conceptual alternative to the psychiatric paradigm, the Power Threat Meaning Framework (PTMF) positions the experience of emotional distress, and its associated behaviours, as "intelligible" responses to adverse life experiences (Johnstone & Boyle, 2018, p.25). The PTMF does not propose simple, direct cause and effect links between adversity and emotional distress, but rather offers a complex theoretical perspective that emphasises the exponential impact of multiple adversities and posits the meaning individuals make of their experiences shapes the myriad of automatic or consciously driven responses they may have to them (Ball et al., 2022).

Key to the PTMF is the understanding that the distress resulting from social and relational adversities are more common where social or economic inequalities exist and,

moreover, the greater number of adversities faced by an individual or group, the higher the risk of experiencing emotional distress. Underpinning this view is an acknowledgement of the substantial role power plays in peoples' lives and the resultant threats its misuse poses to them. The PTMF posits that power may be at an individual's disposal (power resources) or may be operating negatively on their lives. Types of power include observable forms such as coercive, economic and legal power and less visible types such as ideological power (control of language and meaning) and social or cultural capital (Johnstone & Boyle, 2018).

The framework's central focus on power has come under criticism, with some suggesting its role in emotional distress is "merely an assumption" and that the underpinning evidence is "selective" and "ideologically driven" (Salkovskis, 2018). Despite these misgivings, the theoretical application of the PTMF in the case of psychosis appears to be both logical and insightful. Ball et al. (2022) applied the six key questions of the PTMF (see table 1) to describe one person's experiences of psychosis. The resulting analysis provides a useful overview of how an individual's journey through emotional distress can be incorporated into a formulation that pays due diligence to the impact of adversity and social and economic inequalities.

Table 1
Six key questions of the PTMF (Johnstone, 2018, pp.190-191)

- "What has happened to you? (How is power operating in your life?)"
- "How did it affect you? (What kind of threats does this pose?)"
- "What sense did you make of it? (What is the meaning of these situations and experiences to you?)"
- "What did you have to do to survive? (What kinds of threat response are you using?)"
- What are your strengths? (What access to power resources do you have?)"

• "What is your story?"

Whilst the theoretical application of the PTMF to experiences of psychosis makes conceptual sense, what is less clear is the extent to which overarching PTMF concepts such as power, threat and meaning are represented in people's descriptions of their experiences of psychosis. Recent reviews of the literature looking into the lived experience of psychosis have focused on specific concepts, such as: 'delusions' (Ritunnano et al., 2022), identity (BenDavid & Kealy, 2020) and recovery (Wood & Alsawy, 2018). Broader focused qualitative reviews conducted in the last decade, such as those by McCarthy-Jones et al. (2013) and Walsh et al. (2016) do make reference to the role of adversity in psychosis, but this is predominantly orientated towards the difficulties individuals face after the first onset of distress and less so the causal role adverse experiences may play. Within these reviews, the negative operation of power (or threat) is identified in relation to societal stigma (McCarthy-Jones et al., 2013; Walsh et al., 2016) and to people's experiences of psychiatric treatment (Walsh et al., 2016), but not in relation to prior traumatic experiences or social or economic inequality. Within existing reviews 'meaning' or 'sense making' is acknowledged as an important part of coping with the experiences of psychosis (Holt and Tickle, 2014; McCarthy-Jones et al., 2013), however, research exploring the meaning of the content of psychosis experiences is limited (Moernaut et al., 2018).

Aims of the review

In this review the aims were threefold, firstly, to explore the role of adversity in psychosis; secondly, to understand the extent the PTMF concepts of power, threat and meaning are represented in depictions of psychosis; and thirdly, to understand what strengths and opportunities contribute to individual survival and recovery. In achieving these aims, the review will seek to synthesise qualitative research encompassing individual stories

of the experiences of psychosis. To understand more about people's journeys through these experiences, research will be prioritised that addressed the time before the onset of psychosis, the experiences of psychosis and stories of care and recovery. In doing so, the review will employ studies with a narrative methodology. With an emphasis on personal meaning-making, narrative methodology seeks to keeps stories intact and enables a deeper analysis of individual depictions of distress across time (Reissman, 2008). The approach also closely aligns with the PTMF's assertion that narrative represents a culturally informed "carrier of meaning" that can provide insights over time (Johnstone and Boyle, 2018, p. 89). It is hoped the research will contribute to the NHS value of 'Everyone counts' through a greater understanding of experiences of adversity in the context of social disadvantage.

Methodology

In attempting to answer the research questions posed, this review evaluated and appraised qualitative research in peer-reviewed journal articles and dissertations. There were three stages to the review; firstly, a systematic search of the literature; secondly, a critical appraisal and thirdly, synthesis using a meta-ethnographic methodology informed by the approach of Noblit and Hare (1988).

Systematic literature search

Definitions

The term 'psychosis' is not used to describe a discrete diagnosis, but as an overarching descriptor which, as described by Cooke (2017), encompasses the following experiences:

- Hearing voices and seeing, feeling, smelling or tasting things others do not.
- Holding strong beliefs others do not share such as suspicious beliefs or grandiose beliefs about the self.
- Having overwhelming and distracting thoughts and speaking in a way others find difficult to follow.

Inclusion and exclusion criteria for the review are outlined in table 2. The intention of the study was to review research exploring individual journeys through psychosis. The aim was not only to focus on accounts of psychosis, but on depictions of life before the onset of psychosis and on stories of care and recovery. To support this approach, only studies employing a narrative analysis methodology were included in the review. Although the term 'narrative analysis' is often used to describe a broad range of approaches to the qualitative analysis of data, there are several fundamental elements to narrative analysis that differentiate it from other research methodologies and make it suitable for this review. Firstly, in a process of personal meaning-making, individuals use stories to make sense of their experiences and to support the reconstruction of their identities after experiencing ill health (Frank, 1993). Secondly, narrative approaches aim to keep stories intact thus enabling greater interpretation of individual journeys as opposed to thematic concepts (Reissman, 2008). This enables a focus on how individual's construct the sequence of events within their narratives and the meanings they associate with their journey. Thirdly, narrative approaches enable analysis at multiple dialogical levels which can reveal a great deal about social inequalities and the use of power (Reissman, 2008). Murray (2000) has suggested narratives can be understood at the personal, interpersonal, positional and ideological levels. This enables a broadening of the frame of reference and a consideration of wider ecological factors. In operationalising the inclusion criteria, where the methodological approach of research articles only attended to partial extracts from the narratives and not the narratives as a whole, this was considered a departure from the fundamentals of the narrative methodology and therefore these studies were not included in the review.

 Table 2

 Initial study inclusion and exclusion criteria

Inclusion criteria:

- Studies that specifically focused on the experiences of psychosis (as previously defined).
- Studies that presented first person accounts
- Qualitative studies that used a narrative analysis methodology
- Studies in English language

Exclusion criteria:

- Studies where the focus was not on experiences of psychosis or where the focus was on mental health difficulties more broadly.
- Studies not describing first person accounts of psychosis
- Studies that did use not use, primarily, a narrative analysis methodology.
- Studies not reported in the English language.
- Conceptual papers.

Search strategy

The literature search was conducted in April 2022 and consisted of a search of four databases: ASSIA, Medline, PsycArticles and PsycInfo. Key terms (see table 3) were searched for in titles and abstracts. There were no limits placed on the date range of literature. Filters were added to return qualitative studies only and studies in English language. This search was supplemented by a separate search of literature referenced in associated studies and through a further search using google scholar.

Table 3

Literature search terms

| Search terms used (combined with AND) | Search of |
|--|----------------------|
| narrative* and (analysis or method* or approach) | Titles and abstracts |

*denotes wildcard search

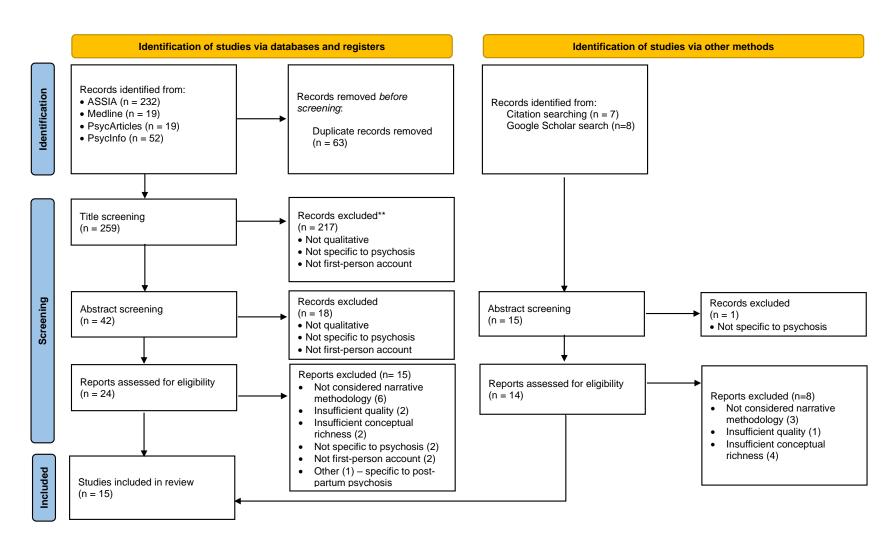
Figure 1 displays the literature search process. The literature search returned 337 records of which 63 were duplicates. The remaining 274 records were screened by title against the exclusion criteria (see table 1) and a further 217 excluded. The abstracts of the remaining 57 records were then screened and a further 18 excluded. Thirty-eight articles were read in full, 15 of these were included in the final review.

Critical appraisal

Quality of the studies was assessed using the Critical Appraisal Skills Programme tool (CASP, 2018). The tool, a 10-question quality checklist, is the most widely used method for assessing quality when synthesising qualitative health-related research (Long et al., 2020). It addresses aspects of research such as the clarity of research aims, the appropriateness of the research design, methodology, data collection, data analysis and the clarity of findings. It also covers ethical aspects of the research and how valuable the research is. Studies were screened out for quality on the basis of low CASP scores (<8) or where there were major omissions from the study (i.e. no description of analysis).

In seeking to understand more about the role of inequality in emotional distress, it was considered important to prioritise research with ethnically and culturally representative samples. The underrepresentation of minoritised ethnic groups within health research has been a longstanding issue (Redwood and Gill, 2013) and, as such, the first author took the decision to supplement the 10 CASP quality questions by a further question assessing the extent of ethnically diverse recruitment amongst the studies.

Figure 1
Systematic literature search process (PRISMA flow diagram)



Conceptual richness

To further determine eligibility and order the studies for analysis, the first author developed a measure of conceptual richness. Although using measures of conceptual richness is commonplace in meta-ethnography (Booth et al., 2013), no suitable existing measure was found. As such, a bespoke measure was calculated based on two factors, firstly, the timeline addressed within the study and, secondly, the frame of reference (see scoring in table 4). Research on mental health phenomena often focuses on specific periods in the individual journey of the service user, for example, transition from hospital (e.g. Hasson-Ohayon et al., 2016). The review prioritised research that incorporated narratives reflecting a broader timeframe in the service user's journey. Similarly, studies with a wider frame of reference that went beyond a purely medicalised 'symptom' focus and considered wider ecological perspectives (i.e. social, economic, material, environmental circumstances) were also prioritised. This can be further conceptualised as representing the PTMF question "what has happened to you?" as opposed to "what is wrong with you?". Where studies scored zero on both of these measures (six studies), they were screened out during the eligibility phase. Conceptual richness was rated independently by a supervisor and inter-rater reliability calculated (α =.77). Differences in scores were resolved by a consensus meeting.

Table 4Scoring of quality and conceptual richness

| Measure | Scoring system |
|--------------------------|---|
| 1. Quality | 0 point = did not meet criterion |
| | 1 point = partially met criterion |
| | 2 points = met criterion |
| 2. Conceptual richness - | 0 point = narratives address only specific time frame (i.e. |
| timeline | hospitalisation) |

| | 1 point = narratives address both onset of first episode and recovery |
|--------------------------|---|
| | period |
| | 2 points = narratives address period before first episode as well as |
| | treatment and recovery |
| 3. Conceptual richness - | 0 point = medical/dispositional/symptoms only |
| frame of reference | 1 point = reference to wider ecological perspectives (including |
| | individual social, economic, material and/or environmental |
| | circumstances) |
| | |

Synthesis

The meta-ethnographic approach employed within the present study is based on the seven-phase approach developed by Noblit and Hare (1988) and is summarised in table 5. Although the review was framed by the concepts within the PTMF (Johnstone and Boyle, 2018), the approach to synthesis was inductive and no priori concepts or themes were used to develop constructs.

Despite this, where overlap with the PTMF was apparent, this was identified within the analysis.

Table 5Summary of analytical approach—based on Noblit and Hare's (1988) seven phase approach to meta-ethnography

| Key tasks |
|---|
| Suitability of the approach assessed – The area of interest was identified, and the |
| suitability of a meta-ethnographic approach was assessed. |
| Decisions taken on what to include – The scope of the review was identified, inclusion |
| and exclusion criteria set and a systematic literature search undertaken. A quality |
| assessment of the studies was also undertaken. Based on the score of quality and |
| conceptual richness the studies were placed in the order of highest to lowest quality. |
| Reading the studies – The studies were read and re-read to increase familiarity. The |
| process of reading the studies proceeded from the highest scoring study (Lawrence et al., |
| 2021) through to the lowest (Gould et al., 2005). |
| |

- Phase 4 Determining relationships between studies Researcher interpretations of themes and concepts (second-order constructs) were extracted from each paper along with participant quotes supporting those interpretations (first-order constructs). Each of the constructs was added to a first iteration data extraction table (See example in appendix A).
- Phase 5 Translating one study into another Once all second-order constructs had been extracted from the studies they were then recorded, under each study, in a bullet point list. Second-order constructs were then translated across the 15 studies into one-another. To facilitate this, a second iteration data extraction table was created (see example in appendix B).
- Phase 6 Synthesising the studies Three stages of synthesis were undertaken. Firstly, a reciprocal synthesis where similarities across studies were attended to in the refining of second-order constructs and the development of third-order constructs. Secondly, a refutational synthesis that involved the identification of conflicting second-order constructs and the subsequent reordering of second-order constructs or renaming of third-order constructs to allow for differences within the findings. Thirdly, a line of argument synthesis was developed to contextualise third-order constructs in a way that offers new meaning or insight. Initially, second-order construct themes were further refined and were grouped together under emerging third-order constructs in third iteration data extraction tables (see appendix C). In many meta-ethnographic reviews, second-order constructs are identified only as themes or constructs and the authors verbatim interpretation is not retained. In order to increase the robustness of the current review, the decision was taken to retain verbatim interpretations to support second-order constructs.
- Phase 7 Reporting the findings Summarise the data, report on strengths and limitations and provide recommendations and conclusions.

Meta-ethnography not only aims to highlight similarities and differences across studies, but also seeks to bring an interpretive lens that offers a new level of conceptual or theoretical insight (Sattar et al., 2021). The perspective of the reviewer is considered central to the findings (Noblit and Hare, 1988) and, as a result, it is important to consider the first author's reflexive position. A perspective on societal inequalities that aligns with a "universal emancipatory"

approach (Haider, 2018) and often leads to a critical stance towards systemic factors that facilitate the oppression of marginalised groups is central to the first author's position. This includes a keen interest in the role social, economic and environmental inequalities play in emotional distress and in approaches to the amelioration of distress that consider both wider socio-political change and individual and community approaches to the healing of traumatic experiences.

Results

Description of the studies

After assessing eligibility, fifteen studies published between 2004 and 2021 were included (see table 6). Eleven of the studies were conducted in the UK with others conducted in Australia, Canada, Belgium and Finland. The reviewed studies included 212 participants aged between 13 and 70 (110 female, 94 male and 8 transgender and non-binary). Two studies included by Lawrence et al. (2020, 2021) utilised the same participants recruited from the wider AESOP10¹ study (Revier, 2015). Six studies did not provide the ethnic breakdown of participants. For the remainder of the studies the broad ethnic breakdown of participants was 68% white, 25% Black or black British and 7% Asian.

Five studies focused on the experiences of young people specifically, although only one study (Parry et al., 2020), included participants under the age of eighteen. Three studies focused specifically on the phenomena of hearing voices and one on 'paranoia'. The remaining eleven studies focussed on psychosis more broadly. Nine studies were sourced from peer-reviewed journals and six were unpublished theses. The included studies can be seen in table 6.

¹ AESOP-10 is a 10-year follow-up study conducted in the UK. The study followed 557 individuals with a first episode of psychosis looking at course and outcome in clinical, social and service use domains.

 Table 6

 Overview of studies analysed (in order of assessed quality and conceptual richness)

| Study no. | Author | demographic health information phenom | | Mental health phenomena researched | Research aims | Data collection | Approach to analysis | | |
|--------------|-----------------|---------------------------------------|----|---|--|--------------------|--|-----------|--|
| 1 | Lawrence et al. | 2021 | UK | Peer reviewed journal | 35 participants (18 female and 17 male) aged 18-65. 17 black Caribbean, 15 white British, and 3 non-British white | Psychosis | "To explore the journey through mental health services from the perspective of individuals from the black Caribbean and majority white British population to help understand variation in the use of mental health services" | Interview | Thematic narrative analysis |
| 2 | Lawrence et al. | 2020 | UK | Peer reviewed journal | 35 participants (18 female and 17 male) aged 18-65. 17 black Caribbean, 15 white British, and 3 non-British white. | Psychosis | "To investigate the long-term experience of living with psychosis and navigating mental health services within different ethnic groups" | Interview | Thematic narrative analysis |
| 3 | O'Brien | 2014 | UK | Unpublished thesis | 7 participants (3 female and 4 male), British, Pakistani, Indian, African and South-East Asian | Psychosis | "to explore the experience and meaning of recovery in early psychosis from the perspective of young people" | Interview | Narrative analysis |
| 4 | James | 2019 | UK | Unpublished thesis | 7 participants (4 female and 3 male) aged 17-50. 1 Black, 6 white. | "Paranoia" | "to explore an alternative perspective offered by John Cromby [2015], focussed on understanding how feelings and potentially feeling traps contribute to the experience of paranoia." | Interview | Critical Narrative Analysis (CNA) |
| 5 | Bluffield | 2006 | UK | Unpublished thesis | 7 participants (3 female and 4 male) aged 18-30. All white. | Psychosis | " to explore the experiences and meaning of recovery from the perspective of young people with early psychosis." | Interview | Narrative analysis |

| 6 | Anderson | 2010 | UK | Unpublished | 9 participants (4 | Psychosis | "to obtain personal narratives relating | Interview | Narrative |
|----|---------------------|------|---------|--------------------------|---|-------------------|---|---|-----------------------------------|
| O | Allucisoli | 2010 | UK | thesis | female and 5 male) aged 25-67. No ethnicity data. | r sychosis | to recovery from psychosis, and, based on these narratives, to develop a more nuanced and holistic understanding of recovery." | interview | analysis |
| 7 | Bergström et al. | 2019 | Finland | Peer reviewed journal | 20 participants (8 female and 12 male). No ethnicity data. | Psychosis | "to explore (i) how people themselves give meanings to experiences which, in the clinical context, are often interpreted as psychosis, and (ii) how these experiences are included in life stories." | Interview | Thematic narrative analysis |
| 8 | Thornhill et al. | 2004 | UK | Peer reviewed journal | 15 participants (9 female and 6 male) 30 - 70. 2 Asian, 13 white. | Psychosis | "to explore the narrative accounts of individuals who had experienced psychosis and who viewed themselves as recovered or recovering. The narratives were explored with respect to genre, tone and core narratives." | Interview | Narrative analysis |
| 9 | Parry et al. | 2020 | UK | Peer reviewed journal | 74 participants (45 female, 21 male and 8 transgender and non-binary) aged 13–18. No ethnicity data. | Hearing voices | "To advance phenomenological and aetiological insights into their experiences and interpretations into voice hearing in young people" | Via survey - 17 qualitative questions. | Narrative analysis |
| 10 | Harris | 2016 | UK | Unpublished thesis | 5 participants (3 female and 1 male) aged 18-35. 4 Black British, 1 British Asian | Psychosis | "to explore the culturally available narratives drawn upon by young people accessing EIP [Early Intervention for Psychosis] services and the consequences of these for service utilisation and subjectivity". | Interview | Narrative analysis |
| 11 | Colbert et al. | 2013 | UK | Peer reviewed journal | 12 participants (6 female and 6 male) aged between "late twenties to early sixties". 11 white British, 1 Middle Eastern heritage. (7 participants were service users others were staff) | Psychosis | "to provide an opportunity for individuals with a diagnosis of psychosis to explore the meaning of their life experiences through reflecting upon paintings in a public art-gallery along with National Health Service (NHS) mental health staff and gallery staff. " | Interview | Narrative analysis |

| 12 | De Jager et al. | 2016 | Australia | Peer reviewed journal | 11 participants (7 female and 4 male) aged 23-63. 10 White and 1 Asian participant. | Hearing voices | "To explore experiences of voice- hearing and recovery over time." | Interview | Narrative analysis |
|----|-----------------------|------|-----------|-----------------------|---|-------------------|---|--|---|
| 13 | Moernaut et al., 2018 | 2018 | Belgium | Peer reviewed journal | 10 participants (2 female and 8 male). No ethnicity data given. | Hearing voices | "To explore the content of voices through a Laconian framework (Lacan, 1955–1956, 1959)" | Interview | Narrative analysis and thematic analysis |
| 14 | Efthyvoulou | 2018 | UK | Unpublished thesis | 4 participants (2 female and 2 male). No ethnicity data given. | Psychosis | "[to gain] a deeper insight into the experiences of people with psychosis through first-person narratives" | Stories from published books | Narrative analysis |
| 15 | Gould et al. | 2005 | Canada | Peer reviewed journal | 4 participants (all male) aged 18- 30). No ethnicity data given. | Psychosis | "To explore the occupational needs and interests of young men, aged 18-30 years, who had been diagnosed with schizophrenia." | Focus group and follow- up meeting | Narrative analysis |

Assessment of quality

The fifteen studies were assessed for quality using the quality appraisal tool previously outlined. Full results of the assessment can be found in table 7 and an overview of study quality is provided in table 8. The highest scoring papers on quality were those of Lawrence et al. (2021, 2020) and the lowest Gould et al. (2005). All of the included studies provided a clear statement of the research aims and a justification of why the authors considered the research important. Likewise, a qualitative methodology was considered appropriate in all of the studies. The suitability of the study design by Efthyvoulou (2018) was contested in this review. In the study, first person accounts were accessed from four published stories. Aside from being a relatively small sample, it was judged that this placed limitations on the authors ability to fully explore the raw form of the narratives prior to them being submitted for publication. Despite these misgivings, the study was considered of high quality in other areas so was included in the review.

Recruitment was considered appropriate in all but three studies, however, information on participant ethnicity was not provided in six studies and, amongst those where information was provided, only three studies were considered to have sufficient representation of minoritised groups. Data collection was generally well described and considered adequate across all studies. Three studies used a data collection method other than interviewing. Efthyvoulou (2018) used published stories, Parry et al. (2020) used a qualitative survey and Gould et al. (2005) focus groups. The detail of these approaches, and any limitations, were discussed to varying degrees in the studies.

A relative weakness was found in researcher reflexivity with the researchers of four studies not examining their own role in shaping findings. Where reflexivity was partially addressed (Parry et al., 2020; Thornhill et al., 2004) authors referred to the influence of researcher assumptions but did not provide great detail on the actions taken to address this.

Information on ethical issues such as ethical approval, participant confidentiality and the process of explaining the research to participants was fully addressed in six studies. Where it was partially addressed (nine studies), this was often limited to a statement that ethical approval had been obtained.

Data analysis was rigorous and well described in nine of the studies and partially described in a further six. A range of analytical approaches were used, all considered to be under the banner of narrative analysis (see table 6). There was a clear statement of findings in the majority of studies. This was both in respect to the applicability of findings to the aims of the research and the credibility of the findings. Finally, ten studies fully addressed the value of the research and five partially addressed this.

Synthesis findings

Overall, there were 35 second-order constructs identified conceptualised under six third-order constructs. Third-order constructs were *Understanding psychosis as a consequence of adverse experiences*; making sense of psychosis phenomena and strategies for survival; powerlessness, mistrust and the relationship with mental health services; loss of self; strengths and opportunities supporting recovery; and the new self.

Table 9 provides an overview of the third-order constructs and their underlying themes. It also provides information on which studies contributed towards third-order constructs.

 Table 7

 Assessment of study quality and conceptual richness

| | Lawrence | Lawrence | | | | | Bergström | Thornhil | | | Colbert | De Jager | Moernaut | | |
|--|----------|----------|---------|--------|--------|----------|-----------|----------|--------|--------|---------|----------|----------|--------|------------|
| | et al. | et al. | O'Brien | James | | Anderso | et al. | l et al. | al. | Harris | et al. | et al. | at al. | voulou | Gould et |
| Author | (2021) | (2020) | (2014) | (2019) | (2006) | n (2010) | (2019) | (2004) | (2020) | (2016) | (2013) | (2016) | (2018) | (2018) | al. (2005) |
| Aims | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Methods | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Design | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 1 | 2 | 0 | 2 |
| Recruitment Ethnically and | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 2 | 2 | 2 | 0 | 1 |
| culturally diverse | | | | | | | | | | | | | | | |
| recruitment | 2 | 2 | 2 | 1 | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 1 | 0 | 1 | 0 |
| Data collection | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Reflexivity | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 0 | 0 | 0 | 2 | 0 |
| Ethical issues | 2 | 2 | 1 | 1 | 2 | 1 | 2 | 1 | 1 | 2 | 1 | 1 | 1 | 2 | 1 |
| Data analysis | 2 | 2 | 2 | 1 | 2 | 2 | 1 | 1 | 1 | 2 | 2 | 2 | 1 | 2 | 1 |
| Findings | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 1 | 1 | 2 | 1 |
| Value | 2 | 2 | 2 | 1 | 2 | 1 | 1 | 2 | 2 | 1 | 2 | 2 | 2 | 1 | 2 |
| Quality score | 22 | 22 | 21 | 18 | 20 | 18 | 17 | 18 | 17 | 17 | 18 | 16 | 15 | 16 | 14 |
| Conceptual richness - Timeline Conceptual richness - Frame | 2 | 1 | 2 | 2 | 1 | 2 | 2 | 1 | 2 | 2 | 0 | 2 | 2 | 2 | 2 |
| of reference | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 0 | 1 |
| Conceptual richness score | 3 | 2 | 3 | 3 | 1 | 3 | 3 | 2 | 3 | 2 | 1 | 3 | 3 | 2 | 3 |
| Quality and conceptual richness combined score | 25 | 24 | 24 | 21 | 21 | 21 | 20 | 20 | 20 | 19 | 19 | 19 | 18 | 18 | 17 |

Table 8Overview of study quality

| | Aims | Methods | Design | Recruitment | Diversity | Data collection | Reflexivity | Ethical issues | Data analysis | Findings | Value |
|---------------------|------|---------|--------|-------------|-----------|-----------------|-------------|----------------|------------------|----------|-------|
| Total met | 15 | 15 | 12 | 12 | 3 | 15 | 9 | 6 | 9 | 11 | 10 |
| Total partially met | 0 | 0 | 2 | 1 | 6 | 0 | 2 | 9 | 6 | 4 | 5 |
| Total not met | 0 | 0 | 1 | 2 | 6 | 0 | 4 | 0 | 0 | 0 | 0 |

 Table 9

 Overview of third order constructs and underlying themes

| | Lawrenc | e Lawrenc | e O'Brien | James | Bluffield | Anderson | Bergströr | n Thornhill | Parry | Harris | Colbert | De Jager | Moernaut | Efthy- | Gould et | No. | No. first |
|--|------------------|------------------|-----------|--------|-----------|----------|------------------|------------------|--------|--------|---------------|------------------|------------------|------------------|------------|-----------------|---------------|
| | et al. (2021) | et al. (2020) | (2014) | (2019) | (2006) | (2010) | et al. (2019) | et al. (2004) | (2020) | (2016) | et al. (2013) | et al. (2016) | et al. (2018) | voulou (2018) | al. (2005) | second order | order only |
| Understanding psychosis as a consequence of adverse experiences | | | | | | | | | | | | | | | | | |
| Interpersonal traumatic experiences | | X | | X | FO | X | X | X | FO | X | | | | X | | 7 | 2 |
| Build-up of stressors and breaking points | | | | x | x | | X | | x | FO | | x | | | | 5 | 1 |
| The role of social and economic inequality | X | X | FO | | | | | | | FO | | | | FO | | 2 | 3 |
| Unsupportive attachment figures | | | | X | | | | | X | | | | | FO | | 2 | 1 |
| Making sense of psychosis phenomena and strategies for survival | | | | | | | | | | | | | | | | | |
| Direct link between psychosis phenomena and past adverse | | | | | | | X | FO | X | X | | | FO | | | 3 | 2 |
| Threatening nature of experiences | | | | | | X | X | | X | FO | | | | | | 3 | 1 |
| Protective nature of psychosis experiences | | | | | | | | | X | FO | | | | | | 1 | 1 |
| Changing relationships with voices | | | | | FO | | | | X | | | | | | | 1 | 1 |
| Unable to make sense of experiences | | | | X | X | | X | | | | | | | FO | | 3 | 1 |
| Avoidance and escape | | | | | | X | | | | | | X | | FO | | 2 | 1 |
| Substance use as an explanation for psychosis phenomena | х | | | FO | FO | FO | | FO | | FO | | | | FO | | 1 | 6 |

Table 9 continued

| | Lawrence et al. (2021) | e Lawrence et al. (2020) | O'Brien (2014) | James (2019) | Bluffield (2006) | Anderson (2010) | Bergström et al. (2019) | Thornhill et al. (2004) | Parry (2020) | Harris (2016) | Colbert et al. (2013) | De Jager et al. (2016) | Moernaut et al. (2018) | Efthy- voulou (2018) | Gould et al. (2005) | No. second order | No. first order only |
|---|------------------------------|--------------------------------|-------------------|--------------|------------------|-----------------|-------------------------------|-------------------------|--------------|---------------|-----------------------|------------------------------|------------------------------|----------------------------|---------------------|------------------------|----------------------------|
| Powerlessness, mistrust and the relationship with the medical model | | | | | | | | | | | | | | | | | |
| Powerlessness | x | X | | | | | | | | X | | | | FO | | 3 | 1 |
| Mistrust of professionals | | x | | | | | | | | FO | | X | | FO | | 2 | 2 |
| Traumatised through psychiatric support | X | X | | | X | | | FO | | | | | | FO | | 3 | 2 |
| Lack of diversity and cultural awareness | FO | X | FO | | | | | | | | | | | FO | | 1 | 3 |
| Negative experiences of medication | | X | | | FO | | | | | x | | x | | FO | | 3 | 2 |
| Positive experiences of medication | X | | | x | X | | | | | | | X | | FO | | 4 | 1 |
| Acceptance of a medical explanation | X | | | X | X | | | X | | X | | | | | | 5 | 0 |
| Questioning of medical explanation | X | | | | X | | X | X | | X | | | | | | 5 | 0 |
| Loss of self | | | | | | | | | | | | | | | | | |
| Loss of identity | X | | | | | X | X | X | | X | X | X | | FO | X | 8 | 1 |
| Impact of stigma | | | X | | X | | | | X | FO | | X | | | | 4 | 1 |
| Isolation and feeling alone as barriers to healing | | | | x | x | X | | | X | | | x | | FO | | 5 | 1 |
| Struggle to get back to normal life | | | FO | | X | X | | | | | | | | | X | 3 | 1 |

Table 9 continued

| | Lawrence et al. (2021) | et al. (2020) | O'Brien (2014) | James (2019) | Bluffield (2006) | Anderson (2010) | Bergström et al. (2019) | Thornhill et al. (2004) | Parry (2020) | Harris (2016) | Colbert et al. (2013) | De Jager et al. (2016) | Moernaut et al. (2018) | Efthy- voulou (2018) | Gould et al. (2005) | No. second order | No. first order only |
|---|------------------------------|---------------|----------------|-----------------|------------------|--------------------|-------------------------------|-------------------------|--------------|------------------|-----------------------------|------------------------------|------------------------------|----------------------------|---------------------|------------------------|----------------------------|
| Strengths and opportunities supporting | | | | | | | | | | | | | | | | | |
| recovery | | | | | | | | | | | | | | | | | |
| Inner strength | X | | | FO | | X | | | | | | X | | | | 3 | 1 |
| Retaining balance and restoring confidence | X | | | | X | | | | | | | x | | | | 3 | 0 |
| Spiritual resources | | | FO | | | | | | | X | | | | X | | 2 | 1 |
| Embracing creativity | FO | | X | | FO | | | | X | | X | | | FO | | 3 | 3 |
| Regaining occupations and meaningful activities | | | | | x | | | | | | | x | | | X | 3 | 0 |
| Supportive relationships as key to recovery | X | | X | | X | X | X | | | | | X | | | FO | 6 | 1 |
| Restorying as central to recovery | X | | X | X | FO | | | | | X | | | | X | | 5 | 1 |
| Lack of opportunity for psychological support | X | | | | | | | | | | | x | | FO | | 2 | 1 |
| Community based support | | | X | X | | | | FO | | FO | | | | | | 2 | 2 |
| The new self | | | | | | | | | | | | | | | | | |
| Adverse views of self | | | | X | X | X | x | | | FO | | | | | | 4 | 1 |
| Post traumatic growth | | | | | X | X | | X | | FO | | X | | | | 4 | 1 |
| Renegotiating life | | | | | | x | X | | | | | | | FO | x | 3 | 1 |

^{*} x denotes appearance as second order construct, FO denotes appearance as first order consruct only (i.e. participant quote or author interpretation about one or two participants)

Understanding psychosis as a consequence of adverse experiences

This third-order construct describes how individuals made sense of their journey and how they attributed psychosis to adverse life experiences. Eleven studies identified themes of prior adversity being viewed as fundamental to the onset of psychosis. Interpersonal traumatic experiences were identified as a theme in seven studies (Anderson, 2010; Bergström et al., 2019; De Jager et al., 2016; Harris, 2016; James, 2019; Efthyvoulou, 2018; Thornhill et al., 2004). These experiences included early childhood adversity (Bergström et al., 2019; Thornhill et al., 2004) and physical and psychological abuse within intimate relationships (Anderson, 2010; Bergström et al., 2019).

The overwhelming build-up of stress resulting in breaking point was identified as a theme in five studies (Bergström et al., 2019; Bluffield, 2006; De Jager et al., 2016; James, 2019; Parry et al., 2020) as demonstrated by James (2019, p.50): "it's just small things that build that sort of build a bigger picture of sorts". The nature of stress was often not specified, however, occupational and educational stresses featured in several studies (Bergström et al., 2019; Bluffield, 2006).

A theme of social and economic inequality contributing to the onset of psychosis was highlighted in two studies (Lawrence et al., 2020; Lawrence et al., 2021) and cited by participants in a further three (Efthyvoulou, 2018; Harris, 2016; O'Brien, 2014). More specifically, poverty and deprivation, and the impact of discrimination, were highlighted as having a fundamental role and, as noted by Lawrence et al. (2020, p.6), as being intersecting in nature: "Many participants, particularly black Caribbean, considered their problems to be a consequence of exposure over time to several negative life experiences and adversities, ranging from poor housing and inadequate income to discrimination and trauma".

Two studies highlighted a theme of unsupportive attachment figures being central in the onset of distress (James, 2019; Parry et al., 2020). Narratives focused on the role of parenting in failing to acknowledge distress and encourage emotional expression.

In addition to meaning-making this construct reflects the concepts of threat and the negative operation of power presented within the PTMF (Johnstone & Boyle, 2018). Most commonly, the impact of coercive and interpersonal power was evident across the studies, with narratives also addressing, to a lesser extent, economic and material power. These forms of power appeared to underpin a range of threats to both safety and wellbeing; not least the emotional and physical impact of previous adverse experiences and a sense past experiences had depleted their resources for coping: "I've been through a lot and I feel like this is my body reacting to it." (Parry et al., 2020, p.5).

Table 10 provides examples of first and second-order constructs used in the development of this third-order construct (see appendix C for the full extraction table). The key contributing studies were Lawrence et al. (2020), which was considered to be of high quality and James (2019), Bergström et al. (2019) and Parry et al., (2020) which were considered moderate quality.

Table 10

Understanding psychosis as a consequence of adverse experiences - example first and second-order constructs

| Author | Example first-order constructs (illustrative quotes) | Example second-order constructs (researcher interpretations) | Second-order theme | Third-order construct |
|---------------------------|--|---|---|---|
| Thornhill et al., 2004 | "I was experiencing being raped and being sexually abused [] but there wasn't anybody there to sayThey just said, 'paranoid schizophrenia' which means, I was imagining it. But there wasn't anybody there who said to me 'Well, have you in your childhood ever experienced these things?" (p.190) | "Coming to understand the psychosis as a response to previously experienced psychological or physical trauma such as childhood sexual abuse is a recurring theme in some of these enlightenment narratives" (p.190) | Interpersonal traumatic experiences | Understanding psychosis as a consequence of adverse experiences |
| Lawrence et al., 2020 | "It was my Mum, I was upset at her for what she had done to me, abused me, hit me you know, violently, I just didn't like it and I just blew up because she had hurt me, I just blew up and I took my anger out on her, you know." (p.3) | "This reflected a deep-seated and pervasive belief among participants that harmful interpersonal experiences and social circumstances were at the root of their problems." (p.5) | | |
| James, 2019 | "it was kind of like a snowball effect that turns to an avalanche, so if I had noticed there was a snowball earlier on I would've been able to say stop and there would have been less to stop" "it's just small things that build that sort of build a bigger picture of sorts" (p.50) | "The narratives revealed that participants felt that they had experienced a build-up of feelings, in response to different social and environmental factors that became unbearable. Common feelings immediately prior to and during the most intense period of paranoia were fear, vulnerability and a feeling of unsafety." (p.59) | Build-up of stressors and breaking points | |
| Bergström et al., 2019 | "It was as if the house of cards that we had carefully built suddenly collapsed." (p.109) | "The crisis was often viewed as a consequence of multiple distressing life events, cumulative setbacks, or of significant changes in central life areas, breaking into the desirable life course" (p.109) | | |

| Author | Example first-order constructs (illustrative quotes) | Example second-order constructs (researcher interpretations) | Second-order theme | Third-order construct | 38 |
|-----------------------|--|--|--|-----------------------|----|
| Lawrence et al., 2021 | "Sometimes like you say, it's only hours before the Post Office opens for me to change the cheque, I'd get up from the bed and I couldn't go in because I was so hungry and that, and I was shaking, and I couldn't go out." (p.4) | "We found that participants often attributed their distress to social and environmental experiences, rooting it in precarious living situations, poverty, and fraught relationships, which in turn perpetuated the cycle of service | The role of social and economic inequality | | |
| O Brien, 2014 | "As soon as we're born our life's mapped out and we've got to deal with our lives no matter how crap they are, some lives are rubbish." (p.21) | use." (p.7) "Frank's narrative reflected feeling persecuted in relation to not feeling in control of his life, and the societal inequalities which have acted as constraints" (p.21) | | | |
| James, 2019 | "growing up as a child it was kind of strong emotions were always seen as a negative erm, and something to just kind of shy away from or kind of stop rather than understanding or exploring why there are those feelings" (p.58) | "Participants referred to parental relationships/roles (for instance, reporting feeling ill-equipped to deal with adverse circumstances) and spoke about the potential role of family scripts on understanding and managing feelings" (p.58) | Unsupportive attachment figures | | |
| Parry et al., 2020 | "parents said I was lying and have never helped me with any mental/ emotional problems I've had, so I don't trust them or anyone else they are related to". (p.7) | "Other barriers involved being disbelieved or misunderstood, which could deter the young person from seeking further help" (p.7) | | | |

Making sense of psychosis phenomena and strategies for survival

This third-order construct describes how participants made sense of psychosis phenomena (e.g. hearing voices and having beliefs that others find unusual) and the strategies they employed to survive (e.g. avoidance or escape). Eight studies addressed the nature of psychosis related experiences and the emotional tone and content of them. Drawing direct links between psychosis phenomena and past adverse experiences was a theme in three studies (Bergström et al., 2019; Harris, 2016; Parry et al., 2020) and as first-order constructs only in a further two (Moernaut et al., 2018; Thornhill et al., 2004). The threatening nature of voices was a theme in three studies (Anderson, 2010; Bergström et al., 2019; Parry et al., 2020) and participants often cited hearing the voice of the perpetrator of abuse: "In elementary school I was bullied constantly...I started to hear their voices and I often saw those figures in the forest near our house, but when I got closer there was no one there" (Bergström et al., 2019, p.110). The protective nature of psychosis experiences featured as a theme in one study (Parry et al., 2020) and was evident as a first-order construct only in a further study (Harris, 2016, p.55): "They want to protect me so because no one ever did anything, for me that much. I think they are looking out.... over me". Several studies also drew attention to the changing relationship that people can have with their voices, however, this was only a second-order construct within one study (Parry et al., 2020).

Although for many participants, sense making had been possible, in three studies there was a theme that this was not always the case (Bluffield, 2006; Bergström et al., 2019; James, 2019). For these people, moving beyond overwhelming emotions and putting this into words had been difficult: "fear, vulnerability and a feeling of unsafety were common amongst the narratives, with some participants stating that it was not easy to explain but 'you could feel it'" (James, 2019, p.52).

Avoidance and escape as survival strategies were a theme in two studies and substance use as an explanation for psychosis in one. These themes were closely linked. Substance use

was presented in two studies as an avoidant coping strategy that exacerbated psychosis:

"Because I was smoking weed to try and chill myself out, but it didn't really work" (Bluffield, 2006, p.92) and understood as partially or wholly causing difficulties in five studies: "[drugs] facilitated the paranoia" (James, 2019, p. 54). It was notable that the role of substance use featured in participant quotes in seven studies, however, was identified as a theme in only one study.

Table 11 provides examples of first and second-order constructs used in the development of this third-order construct. The key contributing studies were Bergström et al. (2019) and Parry et al. (2020), both of which were considered to be of moderate quality.

Table 11Making sense of psychosis phenomena and strategies for survival - example first and second-order constructs

| Author | Example first-order constructs (illustrative quotes) | Example second-order constructs (researcher interpretations) | Second-order theme | Third-order construct |
|---------------------------|--|---|--|---|
| Bergström et al., 2019 | "In elementary school I was bullied constantly. So much that I wanted to kill myself. I think my psychosis started then, though nobody realized it. I started to hear their voices and I often saw those figures in the forest near our house, but when I got closer there was no one there." (p110) | "beliefs interpretable as psychosis were often linked to actual life events" (p.109) | Direct link between psychosis phenomena and past adverse experiences | Making sense of psychosis phenomena and strategies for survival |
| Harris, 2016 | "So I think I could probably hear her voice and certain things like that and I met up with her recently and she explained her side of the story, I explained mine and we came to some mutual ground." (p.49) | "Three of the five participants described hearing malevolent voices associated with difficult interpersonal relationships or abuse" (p.86) | | |
| Parry et al., 2020 | "Sometimes if I am doing something like making a gift for someone, it would say that I am a bad friend and they wouldn't like it in a mean angry voice". (p.5) | "For instance, some participants described a paralleling of their critical thoughts or those of others in their voices". (p.5) | Threatening nature of experiences | |
| Bergström et al., 2019 | "Of course it's scary when you constantly see those characters flying around you and hear those voices. But on the other hand it was a constant fight with my parents about what was real and what was not, as they attempted to wake me up to the real world, even though the real world was precisely what I was afraid of." (p.111) | "As described in the sample, such mental states were characterized by terror, though some participants viewed this as in some sense a relieving state of mind, warding off an even more horrifying reality" (p.111) | | |
| Parry et al., 2020 | "the only other voice I heard said only the words 'your safe now' and I didn't hear from the other one for the at-least the next few months" (p.6) "I was excited. It felt like I had a bunch of friends that I could talk to and get help" (p.6) | "An emerging theme within some narratives was that voices could have a soothing influence upon other voices and the young person". (p.6) | Protective nature of psychosis experiences | |
| | "I miss my old voices, they feel like my closest friends who I can't talk to anymore" (p.6) | | | |

| Parry et al., 2020 | "I didn't realize it wasn't real until other people/their reactions told me." (p.6) "Before I was glad now I have mixed emotions about them" (p.7) | "For many, their voices changed over time as their awareness grew and they established more relationships, which often altered the participants' perceptions of their voices." (p.6) | Changing relationships with voices |
|---------------------------|--|--|---|
| Bergström et al., 2019 | "That psychosis was like you were sinking into some kind of a darkness where you couldn't find your way out. Like someone was pulling you down. I don't know what it really was." (p.111) | "These stories were characterized by a distorted sense of reality, and some participants indicated that they were still not certain as to what was real and what was not." (p.111) | Unable to make sense of experiences |
| James, 2019 | "my psychosis sort of spiralled into, it went from being emotions that I could quickly, that I could explain to you really easily and then it turned into kind of like a deluge of probably so many emotions and being in such, like a deprived state sort of physically and mentally" (p.53) | "Fear, vulnerability and a feeling of unsafety were common amongst the narratives, with some participants stating that it was not easy to explain but 'you could feel it'" (p.52) | |
| Anderson, 2010 | "I smoke a lot of grass (uh huh) and I have done for a long time (yeah) But whenever I do kind of stop, or do kind of cut down or whatever (yeah), it leaves me feeling quite vulnerable, because I find that with it, it kind of helps me to block out a lot of kind of (right) emotional stuff that is sort of, really builds up over time" (p.65) | "Types of coping were linked to the 'genre' of the individual's narrative: for example, attempts to avoid thinking about or talking about experiences were associated with 'escape' narratives" (p.60) | Avoidance and escape |
| De Jager et al., 2016 | First-order construct not available | "Overall, strategies initially trialled for dealing with voices including resisting them, avoiding feared situations and people related to voices, were ineffective." (p.1412) | |
| Lawrence et al., 2021 | "I'm over and done you know, it was something, was an episode something that happened, it was induced, drug induced, it was not so it shouldn't have any bearing for future things". (p.5) | "Some put the experiences of mental illness firmly in the past, for example Oliver (WB) and Richard (WB), and Beth (WB) and Lydia (WB), who felt that their psychotic episodes had been precipitated by illicit substances and prescription drugs, respectively, and had subsequently been treated." (p.5) | Substance use as an explanation for psychosis phenomena |

Powerlessness, mistrust and the relationship with mental health services

This third-order construct focusses on participant reflections on their relationship with psychiatric services at the point of onset of psychosis. It represents the most clear and explicit references to the negative use of power of any of the third-order constructs presented. Most notable are the allusions to ideological power (in relation to discourses used by mental health services to describe service-user difficulties) and coercive power (in relation to treatment practices viewed as oppressive). This underpinned a range of threats to individuals, such as the emotional impact of feeling unsafe and/or powerless and the reduced opportunity to make meaning of one's experiences. The construct also addressed perceived threats from, and the individual's relationship with, medication and the medical model.

Reflections on participants' relationship with psychiatric services featured in ten studies. A sense of powerlessness (Harris, 2016; Lawrence et al., 2020; Lawrence et al., 2021) and the mistrust of professionals (De Jager et al., 2016; Lawrence et al., 2020) were themes within the studies. The term 'powerlessness' was often invoked by researchers to describe participants' sense they could not influence psychiatric decisions made about them. This theme overlaps with the mistrust of professionals, which is presented across the studies as a response to threat. Mistrust often coincided with participants' experiences of withholding information from professionals for fear of being labelled or being subjected to oppressive practices. The two studies in this review by Lawrence et al. (2020, 2021) suggest this is especially the case for those of Black ethnicity. Three studies described a theme of participants' sense of being traumatised through hospitalisation, something that was present in other studies as first-order constructs only (Efthyvoulou, 2018; Thornhill et al., 2004). This was depicted in both physical terms, for example, being medicated against their will (Thornhill et al., 2004) and psychologically; by invoking guilt and shame though the language used by professionals, as demonstrated by Efthyvoulou (2018, p.120): "I could hear a nurse saying what a shame it was, how I was pretty, intelligent (seemingly) and had let it go to waste. 'She's from a good home,' said one. I felt guilty, as if I had committed a crime. Even here, I wouldn't fit in — I wasn't even mad in the right way." The lack of cultural sensitivity amongst support services was a theme in one study (Lawrence et al., 2020) and featured as first order constructs in several other studies (Efthyvoulou, 2018, O'Brien, 2014). The need for greater representation of cultural diversity amongst staff groups was highlighted along with the impact of silencing alternative perspectives because of one's own cultural viewpoint: "every Black Caribbean woman commented upon the absence of Black doctors in the health system who, it was felt, would be more likely to understand their perspective and concerns." (Lawrence et al., 2020, p.4).

The use of medication was a theme that ran through six studies. Positive experiences of medication was highlighted in four studies (Bluffield, 2006; De Jager et al., 2016; James, 2019; Lawrence et al., 2021) and negative experiences of medication in three (De Jager et al., 2016; Harris, 2016; Lawrence et al., 2020). Positive experiences included gaining more control and being able to think and communicate more clearly. These experiences, were however, often prefaced with the notion that the side effects of medication (particularly weight gain) were a major drawback.

The extent to which participants accepted a medical understanding of their difficulties, (i.e. diagnosis and biological explanations of distress) was addressed in five studies. Both an acceptance of a medical understanding (five studies) and a questioning of it (five studies) were represented. Acceptance was interpreted by several researchers as having a role in absolving feelings of shame by removing self-blame (James, 2019; Lawrence et al., 2021) and in several studies was seen as strongly influenced by the power of professional knowledge (ideological power) and the impact of being repeatedly given a medical explanation (Bluffield, 2006; Lawrence et al., 2021). Questioning of the model was linked to the search for meaning in one's experiences, although did not always represent a complete rejection of a medical understanding, but rather an integration of it with other explanations (Bergström et al., 2019).

Table 12 provides examples of first and second-order constructs used in the development of this third-order construct. The key contributing studies were Lawrence et al. (2020, 2021) which were considered high quality studies and Harris (2016) and De Jager et al. (2016) both of which were considered moderate quality.

 Table 12

 Powerlessness, mistrust and the relationship with mental health services - example first and second-order constructs

| Author | Example first-order constructs (illustrative quotes) | Example second-order constructs (researcher interpretations) | Second-order theme | Third-order construct |
|--------------------------|---|---|---|--|
| Lawrence et al., 2020 | "I just felt that I wasn't being listened to even though I was genuinely expressing what was going on, it's kind of not being believed" (p.4) | "Participants often felt powerless, forced to take medication against their will and unable to make their concerns heard." (p.4) | Powerlessness | Powerlessness, mistrust and the relationship with mental health services |
| Harris, 2016 | "I felt kind of vulnerable (2) and I felt like, no one was trying to, I felt alone, yeah, I felt isolated that I didn't have a say in anything of my life. I just thought I was a muppet, I was controlled." (p.51) | "Moreover, the young people described their fears of being misunderstood by professionals with the risk of being readmitted to hospital hanging over them. This was associated with a pervasive sense of powerlessness, perhaps leading to the self-censoring of some of their more critical views." (p.85) | | |
| Lawrence et al., 2020 | "From then I couldn't talk to anyone, I didn't feel I could trust anyone there, to be treated like that I just lost so much trust." (p.3) | "Our qualitative data suggests that mistrust of mental health services not only contributes to a reluctance to seek help among people of black ethnicity (Islam et al., 2015), but also exacerbates individuals' sense of vulnerability when services are accessed." (p.5) | Mistrust of professionals | |
| De Jager et al., 2016 | "As soon as you mention voices—and you pick it up really early—is they want to fill you up with medication. So it became quite secretive for me I never told people about them". (p.1412) | "They were acutely aware of the risk involved in disclosing that they were hearing voices to mental health professionals, fearing that disclosure may result in invasive treatments or involuntary admission to a psychiatric hospital" (p.1412) | | |
| Bluffield, 2006 | "I've never been treated like that before in my entire life. They were grabbing onto my arms so tightly, lifting me up by my arms, and I just started kicking and screaming, saying like 'I deserve my own space, my own time, my own freedom,' and stuff | "The young people conveyed how the traumatic quality of experiences of psychosis and hospitalisation had an impact on their sense of themselves and their world, such as becoming more fearful of people, | Traumatised through psychiatric support | |

| Lawrence et al., 2020 | like that, and they were like 'Not now you don't' kind of thing." (p.87) "This whole experience feels like complete rape, a complete psychological, mental rape". (p.3) | feeling ashamed and losing confidence and pride." (p.139) "This contributed to a sense of disempowerment that could have a profound and enduring effect on participants." (p.3) | |
|--------------------------|---|---|--|
| Lawrence et al., 2020 | 'It's interesting that there aren't that many, but yesAfricans, bring in the Africans. I'm serious, I think it would be very, very different, because unless they're completely taken in by this whole system business, which they probably wouldn't be because they were born somewhere else, but they'd just have a completely different way of hearing you when you were saying things." (p.4) | "Though not directly asked, every black Caribbean woman commented upon the absence of black doctors in the health system who, it was felt, would be more likely to understand their perspective and concerns." (p.4) | Lack of diversity and cultural awareness |
| Efthyvoulou, 2018 | "No attention was paid at any stage in my journey by any of my caregivers, therapists, psychiatrists or colleagues to addressing my spiritual history or my need to explore my cultural and spiritual heritage." (p.101) | "This belief also demonstrated her views that spiritual and cultural elements are crucial to a person's well-being and in a form of protest towards her caregivers, therapists and psychiatrists, she said that these elements were not cultivated during her early years and were missing from her therapy." (p.101) | |
| Harris, 2016 | "Woah, no one wants to go on medication really, you know, any, any human they feel like, you know, they feel (1) it's sort of like to know that you depend on something to keep you, you know, you don't feel human." (p.77) | "the young people in this study raised a range of side effects from their medication that at times hindered recovery." (p.104) | Negative experiences of medication |
| De Jager et al., 2016 | "They gave me some medicine and told me it would get rid of it, but they only just kept getting worse and worse and worseuntil a week or two later, it was virtually nonstop, these two guys talking to each other about me." (p.1412) | "Of the participants who had used medication, two reported that it was ineffective for them and led to significant negative side effects. Three reported that medication was helpful in calming them down or dampening emotional | |

| | | responsiveness. It is of note that it did not eliminate their voices. Those who had used medication emphasized negative side effects, describing lethargy, weight gain, fatigue, and lack of emotional responsiveness and spontaneity." (p.1419) | |
|---------------------------|--|---|-------------------------------------|
| Bluffield, 2006 | "I wasn't so freaked out about things, I wasn't so unsure and I was sort of back to normal thinking in perspective the medication, it sort of worked really quickly". (p.106) | "Although many of the young people took medication reluctantly due to unwanted side effects, particularly weight gain, they often talked about how it had enabled them to gain control of the most disabling symptoms." (p.106) | Positive experiences of medication |
| James, 2019 | "I've never felt this well balanced and I think it's got to do with the medications". (p.56) | "Participants drew on medicalised language and practice, widely referring to their experiences as an illness and speaking of the key role of medication" (p.56) | |
| Lawrence et al., 2021 | "If you're told enough times you believe it." (p.6) | "A recurring theme within this group was the narrative that doctors know best, and diagnoses had been made and accepted on this basis." (p.4) | Acceptance of a medical explanation |
| Bluffield, 2006 | "Something to do with too much dopamine in your brain or serotonin or something like that, it sort of mixes your head up and you start psychotic things, because I've been told that about 8000 times and I actually agree with it, it does actually do things like that." (p.106) | "Most of the young people held a medical explanation". (p.92) | |
| Bergström et al., 2019 | "Of course some people might benefit from treatment, I mean medication and stuff like that, but for me the most important thing was my friends and my family. It's just that someone listens to you, is interested in you, and is present." (p.110) | "Overall, in this study, people who had experienced a crisis diagnosable as psychosis commonly attempted to create meaning for their experiences by integrating the crisis with other life-course experiences; thus, they did not view it merely as a | Questioning of medical explanation |

| | | representation or symptom of a disorder." (p.112) | |
|--------------|---|--|--|
| Harris, 2016 | "but in the hospital they didn't tell me I'd got any diagnosis, they just kept pumping me with meds and injecting me, you know? So erm, they said I'd got bipolar and said it was triggered from breast feeding my child which I didn't know I just thought it was a pile of poo [laughing] because how can you go from being normal to having a total psychotic mental health issue from having a baby? A permanent one as well?" (p.68) | "The majority of service users did not narrate understanding their experiences within a medical framework." (p.82) | |

Loss of self

This third-order construct describes the loss of identity that accompanied participants' experiences of psychosis. The construct aligns with the "identity" core threat presented within the PTMF which describes a "loss of social, cultural or spiritual identity [and] the adoption or imposition of devalued, subordinate or shameful identities..." (Johnstone & Boyle, 2018, p. 207). The impact of isolation (loss of connection) and the impact of stigma (loss of dignity) are included under this construct due to their inherent link with identity. The loss of identity featured regularly as a theme within the studies (eight studies). It was associated with a sense individuals had become defined by psychosis (Colbert et al., 2013; De Jager et al., 2016). Participants talked about the good things in their life being "erased" (Gould et al., 2005, p.470) and of feeling "condemned" (Efthyvoulou, 2018, p.128). In being forced to adopt white, western conceptualisations of distress that may not be culturally aligned, minority ethnic groups were seen as being especially susceptible to the loss of identity (Lawrence et al., 2021).

The impact of stigma was a theme within four studies. It was depicted both in terms of direct discrimination: "because some people who sometimes came out with us were like, 'that blokes a fucking freak'" (Bluffield, 2006, p.100) and in terms of perceived stigma: "yeah, it's like if you're mentally ill people look at you different don't they?" (O Brien, 2014, p.21). Six studies described a theme of the increased isolation that came with experiences of psychosis (Anderson, 2010; Bluffield, 2006; De Jager et al., 2016; James, 2019; Parry et al., 2020). This was often driven by social withdrawal instigated by the individuals themselves or in response to perceived rejection by others.

A struggle to move from what Gould et al. (2005) describes as the 'coasting' phase of psychosis and get back to everyday life featured as a theme in three studies (Anderson, 2010; Bluffield, 2006; Gould et al., 2005). Participants across the studies described a loss of routine: "the days are empty, there's nothing to do but sleep" (Gould et al., 2005, p.470) and of not being able to engage in education or employment: "It's just sort of what I wanted to do but I can't be

bothered these days [laughs]. Yeah. [sniffs] it's not laziness it's like I've given up" (O Brien, 2014, p.28). Table 13 provides examples of first and second-order constructs used in the development of this third-order construct. The key contributing studies were Bluffield (2006) which was considered of high quality and Anderson (2010) and De Jager et al. (2016) which were considered moderate quality.

 Table 13

 Loss of self - example first and second-order constructs

| Author | Example first-order constructs (illustrative quotes) | Example second-order constructs (researcher interpretations) | Second-order theme | Third-order construct |
|-------------------------|--|---|--|-----------------------|
| Colbert et al., 2013 | "The problem and you are the one, are the same thing" (p.252) | "Psychosis was depicted as defining the self" (p.252) | Loss of identity | Loss of self |
| Gould et al., 2005 | "all the good things I knew about me got erased'. It's kinda like all the good stuff gets erased and the negative stuff takes hold of your mind." (p.470) | "Before illness, the participants had perceived themselves to be competent: 'things were happening' in their lives and there were 'dreams, goals, normal things'." (p.469) | | |
| O'Brien, 2014 | "Yeah, it's like if you're mentally ill people look at you different don't they? [] Hmm, they see you as a stranger weirdo or something" (p.21) | "The majority of participants expressed stigmatised narratives regarding perceptions of the limitations and lack of agency of people with psychosis" (p.21) | Impact of stigma | |
| Bluffield, 2006 | "Because some people who sometimes came out with us were like, 'that blokes a fucking freak." (p.100) | "More generally, the young people received mixed reactions from their friends. In speaking about this they all related an awareness of being approached differently by others as a result of psychosis." (p.100) | | |
| Parry et al., 2020 | "I felt as if I was completely alone in my experience". (p.6) | "For most, voices ultimately enhanced feelings of isolation, especially for young people who did not feel they could talk to others about their experiences" (p.6) | Isolation and feeling alone as barriers to healing | |
| James, 2019 | "I can take a lot but obviously, some things have just been too much for me recently, and erm, I've just thought to hell with it and I've reacted to it. You know, and a lot of, a lot of it's been to my own demise. You know, cutting myself off from people" (p.54) | "There was a sense of feeling alone that permeated many of the narratives in nuanced ways. Many of the participants spoke about coping with difficult feelings and circumstances alone, prior to and during | | |

| | | their experiences. The reasons for this varied. Some participants spoke about feeling that they had to cope with it on their own, as a sign of strength or because they felt there was nobody available to turn to" (p.53) | |
|--------------------|--|---|-------------------------------------|
| Gould et al., 2005 | "The days are empty, there's nothing to do but sleep' and 'I just want to go to sleep and never wake up". (p. 470) | "Essentially, each portrayed this period of time as retrospective (looking back) or introspective (looking within), but never prospective (looking ahead). The coasting period was consumed with coping on a daily basis and often on a moment-to-moment basis. For some, the coasting lasted up to 8 years and, as time passed, it became increasingly difficult to engage in life and occupation and to break away from coasting" (p.470) | Struggle to get back to normal life |
| Anderson, 2010 | "My head was just, ehm, in a terrible mess, basically (uh huh). Um, so uhm, yeah, I had to quit the job." (p.58) | "Psychosis also changed participants' everyday lives and routines. A number talked about ways they had been prevented from normal function, from getting enough sleep and feeling able to go about one's business, to engaging in education or employment." (p.58) | |

Strengths and opportunities supporting recovery

This third-order construct addressed the personal strengths cited as the most supportive of recovery and aligns with the concepts of "strengths" and "power resources" as highlighted within the PTMF (Johnstone & Boyle, 2018). More specifically, it addressed the interpersonal, occupational and therapeutic opportunities that were central to recovery across the studies.

Inner strength was described as a theme within two studies (Anderson, 2010; Lawrence et al., 2021) and highlighted how, despite all difficulties, participants maintained a sense of agency throughout their difficulties. A theme of retaining balance and restoring confidence was present in three studies (Bluffied, 2006; De Jager et al., 2016; Lawrence et al., 2021) participants described a sense of agency in managing ongoing distressing experiences. Spiritual resources were cited as themes in two studies (Efthyvoulou, 2018; Harris, 2016). Links between spirituality and ethnicity were cited in several studies, as illustrated by Harris (2016, p.104): "The young people from Black and Minority Ethnic backgrounds in this research often constructed their experience within a spiritual framework".

The role of embracing creativity was the focus of two studies in the review (Colbert et al., 2013; O'Brien, 2014) and was a theme in three overall. The cathartic nature of creative pursuits, the distraction they provide and the sense of achievement they can bring were seen as important. The importance of regaining occupations and meaningful activities in recovery was a theme in three studies (Bluffield, 2006; De Jager et al., 2016; Gould et al., 2005) and the role of supportive relationships in recovery was a theme in six studies: "...developing supportive, non-judgmental relationships with others was invariably associated with recovery" (De Jager et al., 2016, p.1416).

The importance of re-storying and making sense of experiences was a theme in five studies (Efthyvoulou, 2018; Harris, 2016; James, 2019; Lawrence et al. 2021; O'Brien, 2014). There were many references to the role of talking therapies across the studies; more specifically in relation to their role in enabling participants to address difficult emotions attached to past

adversity: "It's [perceived recovery] particularly to do with the counselling, particularly unearthing one or two key incidents in my past and starting to deal with the emotions that are attached to them..." (Lawrence et al., 2021, p.5). Not having the opportunity to make meaning or re-story experiences was a theme in two studies (De Jager et al., 2016; Lawrence et al., 2021). Finally, two studies described a theme of the central role of community based mental health services in recovery. Table 14 provides examples of first and second-order constructs used in the development of this third-order construct. The key contributing studies were Lawrence et al. (2021), O'Brien (2014) and Bluffield (2006) which were considered of high quality and De Jager et al. (2010) which was considered moderate quality.

 Table 14

 Strengths and opportunities supporting recovery - example first and second-order constructs

| | | | | mi. i |
|-----------------------|---|--|--|---|
| Author | Example first-order constructs (illustrative quotes) | Example second-order constructs (researcher interpretations) | Second-order theme | Third-order construct |
| Lawrence et al., 2021 | "There was always a little candle in there still burning, it's never blown out you know, it definitely inspired me to really make something of myself." (p.5) | "Often contained within this narrative arc were references to a residual inner strength or 'survival mechanism' that had given individuals the confidence they could recover." (p.5) | Inner strength | Strengths and opportunities supporting recovery |
| Anderson, 2010 | "I made my own recoveryThrough my own determination and strength of will (right, uh huh) I'm in recovery (yeah). And now life is tolerable, tolerable. Not easy, but tolerable." (p.59) | "While due regard was given to the importance of social relationships, participants made it clear that they perceived themselves - regardless of their sense of control, confidence or wellbeing - as the main characters in their stories of adapting to psychosis." (p.61) | | |
| Lawrence et al., 2021 | "I woke up at four in the morning, for me that's a sign I've got too many problems, I'm worrying. So the first thing I did was meditation, 20 min, which is really simple meditation I'm not really advanced on this, I do a breathing meditation or a counting meditation, and the idea of that is to try to still my mind, to stop it from thinking too much, which can happen to everyone early in the morning." (p.6) | "Participants described how nurturing oneself through rest, diet, exercise, acupuncture, putting one's own needs before others, and keeping an eye on their wellbeing helped to retain balance." (p.6) | Retaining balance and restoring confidence | |
| Bluffield, 2006 | "You learn coping strategiesI went to the Young People's Group we listen to people talking to us and explaining stuff, you learn a lot of information as well. I know what I can do if I feel the symptoms starting again, I know what I have to do." (p.111) | "For most of the young people, learning to understand, anticipate and manage relapse restored their sense of control and confidence"(p.111) | | |
| Harris, 2016 | "I've been brought up in a church from birth, so I just thought it was spiritual thing, a godly thing. What I went through was real for me and no one can ever take that away from me and I pray and I, I still believe it's a spiritual thing." | "The young people from Black Minority Ethnic backgrounds in this research often constructed their experience within a spiritual framework." (p.104) | Spiritual resources | |

| Efthyvoulou, 2018 | "I am loved unconditionally by a Divine Father with my many vulnerabilities and failings. Once I discovered the trustworthiness of a loving Divine Father, I gradually learned to acknowledge my own vulnerability and to grieve my many losses. I slowly developed a resilient sense of my own worth, value, purpose, meaning and vocation." (p.103) | "All of the stories, in their own unique way, revealed a meaningful transformation from the narrator's distressful experience towards a sense of growth and 'spiritual awareness'." (p.149) | |
|---------------------------|---|---|---|
| O'Brien, 2014 | "you concentrate on and then not thinking so much about your own thoughts." (p.28) | "Art-making was also viewed as offering a distraction from being focused on thoughts and experiences, such as voice hearing" (p.28) | Embracing creativity |
| Colbert et al., 2013 | "one more step in a big long journey". (p.254) | "The processes that were depicted as enhancing recovery and wellbeing were: achievement, the physical process of artmaking and distraction." (p.254) | |
| Bluffield, 2006 | "I've just been off of work for too long, and it's just been really difficult, trying to get back out and doing things again. It's been really hard but I've been able to do it through [early intervention team] and [CPN] told me the name of somebody that will be able to help with finding a job, and I went in a few times to talk about the training course, try and get something sorted out."(p.112) | "The young people related processes of taking responsibility, coming to different perspectives on themselves or their beliefs, regaining control and confidence in managing illness, and re-establishing occupational or social activities as important in their recoveries." (p.122) | Regaining occupations and meaningful activities |
| De Jager et al., 2016 | "I had a structure in the day and I used to do mum's house work and cook dinner for the family. I enjoyed all my activitiesthat really got me activated and out of all that sedation. I felt I could do things and enjoy themMy life was good." (p.1416) | " engaging in meaningful activities, connecting with others and (re)developing a positive sense of self were key recovery processes common to both typologies. These processes were centered around meeting needs to feel competent, valued, purposeful, and connected to others." (p.1416) | |
| Bergström et al., 2019 | "Of course some people might benefit from treatment, I mean medication and stuff like that, but for me the most important thing was my friends and my family." (p.110) | "Other factors that brought relief were also often found outside the actual mental health treatment, especially in relationships with significant others" (p.109) | Supportive relationships as key to recovery |

| De Jager et al., 2016 | "We've got a lot in common and help each other she's a good friend to meIt's very comforting that she can be a friend, whereas my family is quite cold." (p.1416) | "developing supportive, nonjudgmental relationships with others was invariably associated with recovery" (p.1416) | |
|--|---|---|-------------------------------------|
| Lawrence et al., 2021 | "It's [perceived recovery] particularly to do with the counselling, particularly unearthing one or two key incidents in my past and starting to deal with the emotions that are attached to them that were quite traumatic in their own right, and it took me that long to get to what they were and start dealing with the emotions around them". (p.5) | "Therapists and counsellors had played an important role in helping individuals in this group to talk about painful emotions and experiences. Conversely, psychiatry was strongly criticised for neglecting these important aspects of individual's lives." (p.6) | Re-storying as central to recovery |
| Efthyvoulou, 2018 | "I am effectively 'cured' of schizo-affective psychosis, but this would never have come about if all I'd aimed to do was think about 'how to get out of it' — which is the usual focus of professionals. I had to delve into causes, not only genetic (my brother George also was schizophrenic) but also cognitive, motivational, familial, interpersonal, socioeconomic, political and spiritual." (p.90) | "Overall, the authors expressed their distressing experiences of psychosis but also their growth being part of their meaning making process and indicated that increased self-awareness was necessary for progress in recovery" (p.150) | |
| Lawrence et al., 2021 De Jager et al., 2016 | First-order construct not available First-order construct not available | "After years of close contact with CPNs and four repeat admissions, she felt that her symptoms were now bearable, but that mental health services had let her down by failing to address the traumatic events in her childhood. Like others in this group, she had not accessed talking therapy and appeared to have little hope that she would receive support for these issues in the future." (p.5) "It is important to emphasize that not one single participant reported receiving psychological intervention that was specifically aimed at dealing with voices. Those who engaged in behavioral experiments and other cognitive behavioral therapy (CBT) strategies did so without the | Lack of opportunity for re-storying |
| O'Brien, 2014 | "And I also I also wouldn't have to feel more, um, like an outsider and alone at home". (p.29) | help of a psychologist." (p.1419) "Most participants viewed the community-based setting as beneficial in overcoming | Community based support |

| James, 2019 | "I mean it wasn't like I woke up and it was gone, it | barriers to access and extending further into their communities." (p.29) "It was also noticed that EIP teams were |
|-------------|---|---|
| | did taper off slowly with the help of you know, it was really the help of the EIP team, you know their support". (p.56) | often positioned within saviour roles within narratives." (p.56) |

The new self

This third-order construct describes how individuals' sense of themselves had changed because of their experiences of psychosis. Four studies highlighted themes of the adverse view of themselves, and their place in the world, participants had been left with. This included reduced confidence (Bluffield, 2006; James, 2019), feelings of shame and fear (Bluffield, 2006), a view of the self as more vulnerable (Bergström et al., 2019; Bluffield, 2006) and a sense of loss and regret (Anderson, 2010; Bergström et al., 2019, Bluffield, 2006). The studies demonstrated that participants felt they were moving forward in the world from a disadvantaged position. Conversely, post-traumatic growth was a theme in four studies. This describes the perceptions of positive transformation amongst participants: "I'm not as angry, I'm not as, immature, I'm not as argumentative over stupid things" (Bluffield, 2006, p.104) and for some, a sense the experiences of psychosis promoted reflection: "I think it was the psychosis that really sort of made me look at things [...] And having looked at them I feel a lot more ... calmer about myself." (Thornhill et al., 2004, p.190). Three studies presented the 'new self' as being neither positive or negative, but representing a renegotiation of life (Anderson, 2010; Bergström et al., 2019; Gould et al., 2005). This involved integrating the experiences of psychosis into one's life, adjusting expectations with respect to life goals and aspirations and re-evaluating friendships. See table 15 for examples of first and second-order constructs used in the development of this third-order construct. The key contributing studies were Bluffield (2006) which was considered of high quality and Anderson (2010) and Bergström et al. (2019) which were considered moderate quality.

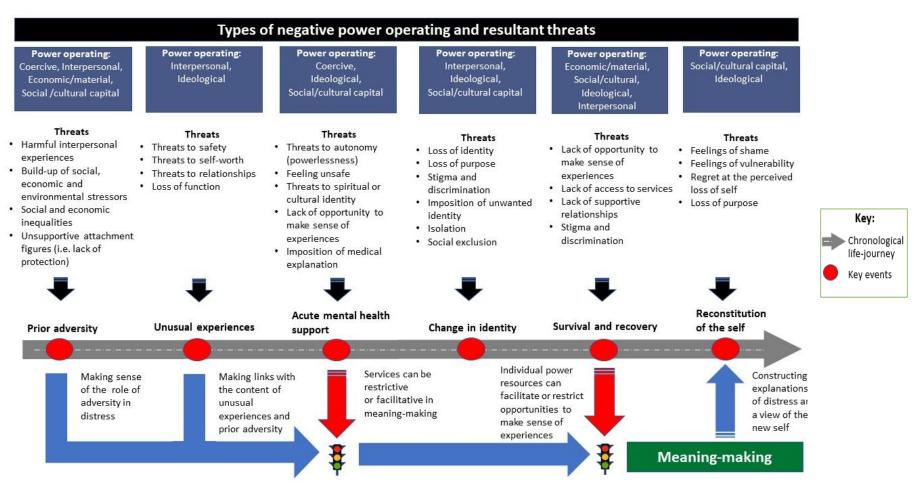
Table 15The new self - example first and second-order constructs

| Author | Example first-order constructs (illustrative quotes) | Example second-order constructs (researcher interpretations) | Second-order theme | Third-order construct |
|---------------------------|--|---|-----------------------|-----------------------|
| Bluffield, 2006 | "when I look back at that whole episode I feel, you know, shame, I feel, you know, it was a disgrace I did behave abnormally, I did behave disgracefully". (p.102) | "The young people conveyed how the traumatic quality of experiences of psychosis and hospitalisation had an impact on their sense of themselves and their world, such as becoming more fearful of people, feeling ashamed and losing confidence and pride." (p.102) | Adverse views of self | The new self |
| James, 2019 | "I just feel half the person I was" (p.49) | "All the participants reported that they were no longer experiencing significant paranoia. However, the majority of them reported that they had been left with difficult feelings" (p.55) | | |
| Thornhill et al., 2004 | "I feel like I've got the control back. And possibly the psychosis helped me to get that control back. [] I think it was the psychosis that really sort of made me look at things [] And having looked at them I feel a lot more calmer about myself." (p.190) | "Enlightenment narratives also sometimes reflect a different experience of psychosis to that described in some escape narratives. That is, the experience of psychosis itself is viewed as having positive as well as negative aspects." (p189) | Post traumatic growth | |
| De Jager et al., 2016 | "In a way it's been good that I got sick because I'm a lot less angryIt gives me heaps of empathy for other people too." (p.1415) | "Participants moved beyond developing a positive sense of self to describe an essential transformation in identity as a result of becoming unwell and hearing voices. They reported becoming less angry and more empathic toward others, becoming more communicative about their emotions rather than keeping their feelings to themselves, and having a stronger sense of self as a result of their voice-hearing experience" (p.1415) | | |
| Gould et al., 2005 | "It's like rewriting the programmes or getting into the habits like you did before and building healthier | "The participants did not initially perceive themselves to have engaged in a process of | Renegotiating life | |

| | habits to facilitate recovery'remaking' in the sense that you are rebuilding a new life reconfiguring or writing a new programme one that is more suitable to living with schizophrenia". (p.470) | trying to remake their lives. They did, however, speak of a negotiation and renegotiation of self, goals, dreams and abilities." (p.471) |
|---------------------------|---|--|
| Bergström et al., 2019 | "with earlier onset seemed to build their identities more specifically around their mental health crisis. Even though this might reflect symptom severity, and thus a higher need for treatment, it might also be consequence of the earlier onset itself." (p.112) | "Maybe without it (the psychosis) I wouldn't have those friends that are so important for me, but on the other hand, there are those negative things; I don't have a job, no education and, well, the coin always has two sides, right?" (p.111) |

Figure 2

Conceptual representation of meta-ethnography findings integrated with the core concepts of the PTMF (Johnstone & Boyle, 2018)



Note. The diagram above offers a conceptual representation of how the findings of the meta-ethnography may integrate with the core concepts of the PTMF (Johnstone & Boyle, 2018). Reading from left to right, the grey line depicts a chronological life-journey encompassing early adversity, the experiences of psychosis, and survival and recovery. The journey is punctuated by key events (red circles) that are informed by, but not intended to replicate, the third-order constructs found in the meta-ethnography. The types of power operating on each event is represented by the aligning blue box at the top of the page with the resultant threats identified below. The blue arrows identify how early experiences of adversity and the content of unusual experiences may inform the sense that people make of their journey and to what extent they may hold a trauma-informed explanation for their experiences of psychosis. The red downward arrows represent how mental health services and/or individual power resources may restrict or facilitate this. The sense made of one's journey is depicted as influencing new identities and the reconstitution of the self. The diagram is not intended as a definitive representation of the life course of psychosis experiences and, inevitably, the key events identified at times may interact, overlap and appear at temporally different stages during an individual's journey.

Discussion

The aims of the review were threefold: to explore the role of adversity in psychosis, to understand the extent that PTMF concepts of power, threat and meaning were represented in depictions of psychosis and to investigate what strengths and opportunities contributed to individual survival and recovery. In achieving these aims, fifteen qualitative research studies exploring individual stories of psychosis using narrative analysis were reviewed. A systematic literature search, critical appraisal and meta-ethnographic synthesis were then conducted. Six overarching constructs were developed (third-order constructs) from 35 underlying researcher-interpreted themes (second-order constructs) identified within the research. These were:

Understanding psychosis as a consequence of adverse experiences; making sense of psychosis phenomena and strategies for survival; powerlessness, mistrust and the relationship with mental health services; loss of self; strengths and opportunities supporting recovery; and the new self. The themes of powerlessness, mistrust and the relationship with mental health services; and strengths and opportunities supporting recovery were the most widely supported themes within the reviewed literature. In each case, the themes were well supported by several high quality and/or moderate quality studies.

The role of adversity

Several findings were consistent with those of previous research. Of the third-order constructs presented in this review: loss of self; strengths and opportunities supporting recovery; and the new self, aligned most clearly with the findings of previous qualitative reviews addressing lived experience of psychosis (McCarthy-Jones et al., 2013; Walsh et al., 2016). But despite the wealth of evidence linking experiences of trauma with psychosis (e.g. Read et al., 2014; Bailey et al., 2018), previous qualitative reviews did not find that people consistently made links between previous adversity and their experiences of psychosis (McCarthy-Jones et al., 2013). In the present review, stories of adversity were frequent throughout the reviewed literature, with all but four studies highlighting themes of adversity playing a fundamental role in

their experiences of psychosis. The most referenced adversities in the present studies were harmful interpersonal experiences; a build-up of social and environmental stressors that had reached breaking point; social and economic inequality; and unsupportive attachment figures. It was notable that whilst there were often references to adverse childhood experiences (such as abuse and neglect) throughout the reviewed studies, this was described as a theme in only two studies (Bergström et al., 2019; Thornhill et al., 2004). Difficulties within intimate relationships were regularly cited across the studies as a key contributing factor in the experiences of psychosis. This was often in conjunction with adversities such as psychological or physical abuse, especially for women (Bergström et al., 2019).

Experiences of psychosis were often seen as a response to cumulative life adversities that reached breaking point (Bergström et al., 2019; Bluffied, 2006; James, 2019) and included events such as occupational setbacks and academic pressures and, as Lawrence et al. (2020) found for Black Caribbean participants, economic inequality and discrimination. These findings have implications for the way trauma is conceptualised. There has been strong evidence linking psychosis and major traumas (i.e. bullying or sexual assault) in recent years (e.g. Bailey et al., 2018) but arguably receiving less attention has been the influence of ongoing life setbacks that, whilst perceived by others as less traumatic, may still result in feelings such as humiliation or powerlessness. Shapiro (2018, p. 51) defines events such as these as 'small t traumas' and emphasises the significance they may play in emotional distress and the importance of attending to them.

Consistent with literature linking insecure attachment to the experiences of psychosis (Gumley et al., 2014; Lavin et al., 2020), unsupportive attachment figures were cited as instrumental in relation to help seeking and dealing with adversity (James, 2019; Parry et al., 2020). Most notably, this was in regard to acknowledging experiences of adversity and distress and encouraging the discussion of emotions.

Power, threat and meaning

Figure 2 provides a conceptual representation of how the findings of this meta-ethnography may integrate with the core concepts of the PTMF (Johnstone & Boyle, 2018). This is not intended as a definitive representation of the life course of psychosis experiences however represents the common patterns observed within the meta-ethnography. Adversity was commonly viewed as leading to the onset of psychosis experiences. This was often followed by traumatic experiences at the hands of mental health services and a subsequent change in identity. Individual strengths and resources then dictated the course of recovery or survival and the shape new identities took.

Consistent with previous reviews, references to the concept of power were largely implicit (Walsh et al., 2016). The use of coercive power was evident in stories of adversity prior to the onset of psychosis and in relation to treatment practices viewed as oppressive. In line with the views of the PTMF (Johnstone & Boyle, 2018), the impact of ideological power was also implied. This was specifically the case in relation to the limits dominant psychiatric discourses place on peoples' ability to make meaning of their experiences and, furthermore, how a societal wide medical understanding of psychosis results in stigma and discrimination. Economic and material power featured in the reviewed studies, but to a limited extent. Where it did appear, it was largely set within a context of cumulative adversities including other factors such as the role of racial discrimination (Lawrence et al., 2020). The most direct references to power were made in relation to individual's experiences of mental health services and, more specifically, coercive treatment practices and a lack of participation in decision making related to their care. A theme of feeling powerless was explicitly noted in several of the reviewed studies (Lawrence et al., 2002, Harris, 2016).

The effects of the negative operation of power were, at times, conceptualised as 'threats' and at other times not so. For example, the threats to safety evident within early traumatic experiences, experiences of psychosis phenomena (such as hearing voices) and of treatment

practices viewed as oppressive were clearly emphasised. Also clear was the threat of isolation and social exclusion due to stigma and discrimination. Less clear, but implied, were threats to the opportunity to make sense of one's experience due to a lack of supportive personal relationships or therapeutic input. Although a theme in several of the studies (Lawrence et al., 2020, 2021), racial discrimination was not consistently emphasised as a threat. This was not surprising based on the relative lack of ethnic diversity of participants across the studies. The need for greater representation of cultural diversity in mental health services was emphasised as important. This echoes a wider problem regarding the underrepresentation of ethnicities across the mental health workforce and one which has become a focus of service improvement (NHS England, 2023).

Consistent with previous research (Johnstone and Boyle, 2018; Myers & Ziv, 2016; Romme et al., 2009), making meaning of, or 're-storying', one's experiences was not only seen by many as an important part of recovery, but also as empowering. The findings of the review suggested meaning-making was most often applied to three areas. These were: firstly, explanations of the cause of psychological distress; secondly, interpretations of the meaning held within experiences such as hearing voices and having beliefs that others find unusual; and thirdly, in conceptualising newly found identities. What was also clear within the findings of the review was that the opportunity and capacity to make sense of, or re-story, one's experience is not universal and is likely influenced by levels of social capital and access to services. The implications of this appear to be that those with few supportive relationships and a lack of access to therapeutic support may have less opportunity to develop an understanding of their difficulties that moves beyond medical interpretations. It should also be noted that, whilst an acceptance of a medical interpretation was common within individual narratives, this was often alongside an explanation that considered adversity as causal in their distress.

Strengths and opportunities supporting recovery

A third aim of this review was to explore what strengths and opportunities contributed to individual survival and recovery. Whilst arguably deserving of a full review in its own right,

some notable observations are worthy of brief discussion. Consistent with previous reviews on the facilitators of recovery (Wood & Alsawy, 2018), regaining a sense of purpose in life was seen as central to recovery. This meant regaining activities viewed as meaningful, such as occupational activities, social connection or embracing new creative pursuits. Perhaps surprising is that the strength found in spiritual resources and its impact on recovery was a theme in only two studies (Efthyvoulou, 2018; Harris, 2016). As found by Wood and Alsawy (2018), spirituality featured as both a way of making sense of one's experiences and as a means of finding solace (Efthyvoulou, 2018; Harris, 2016). A further theme was that spiritual resources were often not embraced and nurtured by mental health services (Efthyvoulou, 2018; O'Brien, 2014). Also consistent with previous reviews (McCarthy Jones et al., 2013) was that medication was viewed as effective for many, but not for all. Furthermore, the negative side-effects of medication (most notably weight gain) were consistently referenced throughout the literature and seen as a problematic.

The use of recreational drugs was a theme commonly referenced within the reviewed studies. Often cited as the explanation of distress or as a major contributor to it, the use of recreational drugs was seen in several studies as a coping strategy for existing distress that subsequently hastened the experiences of psychosis (Harris, 2016; Lawrence et al., 2021). Consequently, reducing drug intake was seen as facilitative of recovery.

Strengths and limitations of the review

There are several key strengths and limitations with this review. Firstly, in seeking to address all aspects of the journey through the experiences defined as psychosis, it inevitably means depth of analysis has, at times, been sacrificed for breadth. Secondly, although the narrative approach is well suited to the aims of the review, it is possible broadening the scope to include other qualitative research methodology would have provided further insight. Moreover, due to its intensive analytical approach, narrative analysis is not considered a useful methodical

approach for studies of large sample sizes (Reisman, 1993). As such, several reviewed studies had relatively small sample sizes.

Thirdly, the synthesis of qualitative information is subjective and, in the case of metaethnography, where new insights are sought, this is particularly the case. Noblit and Hare (1988, p.35) describe this as "interpretations on interpretations on interpretations". In this review, I have sought to counter any potential bias through an approach to meta-ethnography that retained much of the original language of the reviewed studies in the findings. It is hoped this will enable the reader to follow the thread of interpretations and take their own view on the findings.

Recommendations and conclusions

Through a meta-ethnographic approach to qualitative synthesis this review built on the existing literature linking earlier life adversity to the onset of psychosis phenomena. It provides further supporting evidence for the importance that meaning-making and re-storying one's experience plays in recovery. The review offered new conceptual insights into the journey through the experiences of psychosis, including the key stages when meaning-making was applied and the role power relations played within that journey. There are implications both for clinical work and future research. The review highlighted the importance that multiple 'small t' traumas may play in psychosis phenomena. Participants' experiences of what helped recovery varied significantly, suggesting that a pluralistic approach to mental health support that considers factors such as cultural and spiritual beliefs, creativity, connection and the regaining of meaningful activities is important in recovery. Within the narratives, there was a less than expected focus on the role social, environmental and economic inequalities may play in the development of psychosis phenomena and factors such as racial discrimination, income inequality and poverty and deprivation were rarely addressed within the studies. Researchers may seek to address this gap.

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PAUL RAINEY (BSc Hons., MSc)

EXPLORING THE LINK BETWEEN TRAUMA AND PSYCHOSIS FROM A POWER, THREAT, MEANING FRAMEWORK PERSPECTIVE

Section B: Exploring subjective experiences of EMDR for psychosis - a Power Threat Meaning Framework (PTMF) informed narrative inquiry

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Abstract

An extensive body of evidence supports the association between life adversity and experiences such as hearing voices and holding beliefs that others may find unusual. Emerging evidence suggests Eye Movement Desensitisation Reprocessing (EMDR) may be an effective intervention for lessening the emotional impact of trauma memories in the context of psychosis. Despite this, there has been limited research into clients' subjective experiences of EMDR for psychosis. The aims of the present study were to explore what focusing therapeutically on traumatic experiences in the context of psychosis might reveal about the link between adversity and psychosis, and; to explore what clients' depict as important when engaging with EMDR for psychosis. Participants recruited from community mental health teams were interviewed and a qualitative narrative analysis methodology employed. Within the narratives, trauma-derived personal meanings were common and could be linked to the content of unusual experiences. Participants consistently positioned themselves as advocates of EMDR for psychosis, citing improved relationships and feeling calmer amongst positive changes. In reflecting on their experiences of EMDR, participants more commonly cited the importance of a trusting therapeutic relationship than specific EMDR techniques. A number of clinical implications are raised, including recommendations for care resourcing and planning.

Key words: psychosis, EMDR, narrative, trauma, adversity

Introduction

The association between experiences of adversity and the phenomena referred to as 'psychosis' is now widely acknowledged amongst researchers. Forms of adversity such as childhood abuse and neglect (Bentall et al., 2014, Varese et al., 2012; Bailey, 2018), bullying (Cunningham et al., 2016; van Dam et al., 2012), poverty and deprivation (Kirkbride et al., 2014; Morgan et al., 2019), discrimination (Pearce et al., 2019) and parental loss (Morgan et al., 2007) have all been implicated in the cause of experiences such as hearing voices and having beliefs that others find unusual. The link between childhood trauma and psychosis is a consistent finding within the literature. A review by Varese et al. (2012) found that survivors of childhood adversity were nearly three times as likely to experience psychosis than those who had not. Moreover, research indicates that people who have experienced childhood adversity are more likely to be admitted to a psychiatric hospital and more likely to be prescribed antipsychotics (Bailey et al., 2018; Read et al., 2009).

Whilst the link between later life adversities and psychosis has been less of a focus of research (Beards et al., 2013), associations between social and economic inequality and psychosis have been observed (Read et al., 2013). Urban living is commonly linked to an increased risk of experiencing psychosis, with a more in-depth analysis suggesting that stressful life events, overcrowded accommodation and poverty are amongst the main factors explaining this association (van Os et al., 2009). Stilo et al. (2016) found that people with a first-episode of psychosis were 12 times as likely to be unemployed and nine times as likely to be living below the poverty line than those who had not experienced psychosis. Moreover, they found a cumulative effect of adversity, which supports previous findings of a dose response-relationship between adversity and psychosis (Shevlin et al., 2008). Extensive research has found rates of psychosis to be higher for racially and ethnically minoritised groups (e.g. Radua et al., 2018) and experiences of discrimination have been commonly cited as a causal factor. Evidence supports the understanding that experiences of discrimination make people more vulnerable to psychosis

(Pearce, 2019) and that the greater the extent of discrimination experienced the more likely the individual is to later experience psychosis (Stowkowy et al., 2016).

The Power, Threat, Meaning Framework

Whilst ongoing research continues to strengthen the understanding that adverse experiences underpin psychosis-related distress, greater emphasis has, more recently, been placed on the complexity of the relationship between adversity and mental health difficulties. The Power Threat Meaning Framework (PTMF, Johnstone & Boyle, 2018), offers a traumainformed, theoretical perspective on the exponential impact of multiple adversities on an individual or group. It draws attention to the interplay between social and economic inequalities and adversity and suggests where inequality exists, adverse life experiences are more likely. A core tenet of the PTMF is the pivotal role power plays in the lives of groups and individuals. Power is understood as operating negatively on the group or individual (i.e. coercive power) or positively through the resources an individual or group have at their disposal (i.e. economic, social or cultural capital). The meaning individuals place on their experiences is also central to the PTMF and considered fundamental in how emotional distress is expressed. Personal meaning is said to be represented in both feelings and beliefs about oneself (Cromby, 2015) and, in this way, forms a culturally shaped, embodied understanding of one's experience.

In conceptualising 'trauma', the PTMF highlights how the term can often be restrictive and predominantly focussed on isolated and extreme events (often referred to as capital-T traumas) which risks neglecting the role of ongoing adverse experiences that, whilst perhaps not universally considered as 'major' traumas, may have a high emotional impact. This may be particularly pertinent in relation to adversities resulting from social or economic inequality which, whilst having the potential to be highly traumatic, may often be overlooked. Such experiences may be perceived as "small-t" traumas, but nonetheless may have a lasting impact on an individual's sense of self (Shapiro, 2018, p.51).

Eye Movement Desensitisation Reprocessing (EMDR)

Alongside the ever-growing research base linking adversity with psychosis, emerging evidence suggests trauma focused therapies (TFT) may be an effective intervention for reducing the emotional impact of trauma in the context of psychosis (Swan et al., 2017, van den Berg et al., 2018). Eye Movement Desensitisation Reprocessing (EMDR) is one form of TFT that has shown encouraging potential in this area (Adams et al., 2020) and there is growing literature on its adaptation for these purposes (e.g. Miller, 2015). Initial research on the use of EMDR in the context of psychosis has predominantly focussed on its ability to resolve what are viewed as 'comorbid symptoms' of Post-Traumatic Stress Disorder (PTSD) such as nightmares and flashbacks (e.g. van den Berg et al., 2018). Less of a focus has, as yet, been placed on the use of EMDR for the experiences of psychosis where the main objective is targeting the traumatic memories associated with psychosis related phenomena such as hearing voices and holding unusual beliefs (Hardwick, 2023b). This is reflected in National Institute for Health and Care Excellence (NICE) guidelines for the prevention and management of psychosis (NICE, 2014) which recommend individualised Cognitive Behavioural Therapy (CBT) as a therapeutic intervention but do not, currently, specify a trauma-focused aspect to CBT or recommend other trauma-focused therapies such as EMDR. When an individual is re-experiencing a traumatic memory in the context of psychosis, NICE guidelines for post-traumatic stress disorder (NICE, 2018), which recommend both trauma-focused CBT and EMDR as suitable therapeutic interventions, are considered applicable.

Whilst there is increasing research into the subjective experiences of EMDR for PTSD (e.g. Whitehouse, 2021) research on peoples' experiences of EMDR in the context of psychosis is limited. Interpretative Phenomenological Analysis (IPA) by Hardwick (2023a) explored clients' experiences of EMDR for psychosis and found EMDR transformative for some, but for others it was difficult to engage with and trauma was not considered relevant to their difficulties. For participants who had found it effective, the ability to connect with trauma memories on a physical and emotional level set it apart from other therapies they had experienced. A key

transformative element cited was EMDR's role in supporting the development of new meanings that absolved self-blame from previous trauma. The ability to make meaning of one's experiences is commonly cited as supportive of recovery from psychosis (e.g. Romme et al., 2009) and it may be an important factor in the applicability of EMDR in this context. In safely exposing people to traumatic memories, EMDR can help individuals develop associations between fragmented trauma memories and other episodic memories thus integrating the traumatic material with the rest of their knowledge and experiences. The process of integration enables people to develop new meanings and helpful understandings of their experiences (Shapiro, 2018). With this in mind, understanding people's subjective experience of the meaning-making processes in the context of EMDR for psychosis was a focus of the current research.

Of further interest was the role EMDR may play in helping individuals address the distress associated with adversity in the broader sense, such as 'small-t' traumas and those arising from social or economic inequality. The idea that TFT could be used as an intervention to help individuals manage the impact of experiences such as poverty or discrimination may be seen as a, potentially problematic, attempt to individualise systemic failings (Kinderman, 2019). But whilst individual therapeutic work may not address systemic inequality, it does provide the opportunity for the empowerment of individuals in the face of adversity (Herman, 1992). This may be through challenging harmful ideologies, raising awareness of how to oppose oppression, or by supporting individuals to overcome internalised oppression (Nadal, 2017). As such, the breadth and depth of adversity addressed within EMDR for psychosis was also an area of interest for the study.

Research aims

There were two main aims of the investigation. Firstly, to explore what focusing therapeutically on experiences of trauma that commenced prior to the onset of psychosis might reveal about the link between adversity and psychosis and; secondly, to explore what people

depict as important when engaging with EMDR for psychosis. In achieving these aims, two further objectives were set:

- To explore what peoples' narratives reveal, in the context of EMDR, about the meanings they have placed on their experiences.
- To explore what peoples' narratives reveal about how EMDR may reduce the distress associated with adversity in the broader sense (i.e. 'small-t' traumas or those rooted in social or economic inequality).

With an interest in individual journeys through the experiences of psychosis, a narrative analysis methodology is employed in the study. Narrative approaches enable in-depth exploration of how individuals' construct the sequence of events within their lives and the meanings they derive from their experiences (Reissman, 2008). It is hoped, through the development of psychological interventions for psychosis, the study will contribute to the 'Improving lives' NHS value.

Method

Theoretical framework

The philosophical stance of the study draws upon a social constructionist epistemology (Gergen, 1997) and a critical realist ontology (Bhaskar, 1978). From a social constructionist perspective, people construct reality in cultural contexts that are inherently linked with, and shaped by, their personal, social and political realms (Gergen, 1997). In this way, knowledge is maintained by social processes and the influence of power embedded within them. Critical realism rejects the positivist notion that there are scientifically discoverable universal relationships but considers that statements about what is real (ontology) cannot be reduced to statements about knowledge of the world (epistemology). In taking a middle ground between radical constructionism and positivism, critical realism espouses that whilst there is a reality, it is one that is ever-changing and not free from the influence of the observer (Johnstone and Boyle, 2018).

Design

A qualitative, narrative inquiry approach to analysis was used within the study. Narrative analysis enables an emphasis on personal meaning-making through the reconstruction of identity (Frank, 1993) and, by keeping stories intact, provides the opportunity to interpret how people construct their journey through adversity. Narrative analysis also has the potential to recognise the multiple voices that make up an individual's story (Frank, 2012) such as the reproduction of the words of professionals or through the echoing of family members attitudes towards mental health difficulties. In this way, it can provide the opportunity to explore how people position themselves in relation to dominant discourses. In allowing for a focus upon both personal experiences and stories, and their relationship with wider societal discourses, narrative analysis was deemed the most appropriate methodology for the study.

The present research was one of two, separately conducted, studies using qualitative data from a series of interviews addressing people's experiences of TFTs for psychosis. Whilst the studies differed in focus, it was possible to collaborate on obtaining ethical approval, recruiting participants and in designing an interview protocol that addressed the research questions of both studies. The author undertook five of the eight interviews used in the present study.

Reflexivity

Interviews were conducted by two trainee clinical psychologists, one female and one male (author), both White British. A reflexive journal was used throughout the process to reflect on how the authors personal characteristics, circumstances and values may have influenced the research process (see extracts in Appendix D). A brief summary of the author's reflexive position can be seen in section A (Synthesis, pp.24-25). An audit of coding and analysis was conducted by a supervisor to further improve the quality of the research.

Participants

A purposive sampling method was employed in the study. Purposive sampling involves the intentional selection of participants based on those that are most likely to have experienced the

phenomena in question (Robinson, 2014). As such, people who had experienced psychosis as described by Cooke (2017, see table 1), had been known to a secondary care community mental health team and had engaged with EMDR were included. Participants were jointly recruited by therapists delivering EMDR for psychosis across three NHS trusts in the Southeast of England. Inclusion and exclusion criteria are outlined in table 2 and a breakdown of participant demographics in table 3. There were initially eight participants recruited, however, one participant withdrew from the study immediately prior to submission. Although outside of the agreed time for withdrawal of information, it was felt most ethical to remove what was possible of the data - including the narrative synopsis and any quotes. Despite this, data from the interview still informs the themes outlined.

Table 1Experiences commonly described as psychosis (Cooke, 2017)

- Hearing voices and seeing, feeling, smelling or tasting things that others do not.
- Holding strong beliefs that others do not share such as suspicious beliefs or grandiose beliefs about the self.
- Having overwhelming and distracting thoughts and speaking in a way that others find difficult to follow.

 Table 2

 Inclusion and Exclusion criteria

Inclusion criteria

- Aged 18 or over
- Assessed by client and EMDR therapist to have experienced psychosis as defined by Cooke et al. (2017)
- Currently or previously known to a community mental health team

• Completed at least 8 sessions of EMDR for psychosis

Exclusion criteria

- under the age of 18
- no experiences of psychosis as defined by Cooke et al. (2017)

Table 3Participant demographics

| Gender | Age range | Ethnicity |
|--------|---|---|
| Female | 35-44 | White British |
| Female | 25-34 | White British |
| Female | 55-64 | White British |
| Female | 25-34 | Black British |
| Female | 45-54 | Black African |
| Female | 25-34 | Black Caribbean |
| Male | 25-34 | White British |
| | Female Female Female Female Female Female | Female 35-44 Female 25-34 Female 55-64 Female 25-34 Female 45-54 Female 25-34 |

^{*} Names changed to protect anonymity

Ethics

Participant facing information was reviewed by Experts by Experience prior to submitting the project for ethical approval. The study was reviewed by the Research Ethics Committee (REC) and granted approval on 7/4/22 (see Appendix E). Further capacity and capability approval was given by three independent NHS trust research and development teams prior to recruiting (See Appendix F). Written consent was obtained from all participants prior to interview using a consent form (see Appendix G). Basic transcripts were extracted from audio recordings using transcription software and then manually adjusted for inaccuracies. Transcripts and audio recordings were anonymised and stored in an encrypted format prior to archiving at the end of the analysis phase.

Data collection

A shared interview protocol was developed for the purpose of the two studies (see Appendix H). In line with the approach used by Thornhill (2004), participants were asked a single interview question after which they were invited to tell their story without interruption:

"As mentioned the conversation we are about to have is to help us understand about therapy for psychosis that addresses traumatic memories. Perhaps you could start by telling me the story of your experiences of what you now understand to be psychosis."

Follow up questions were asked to further explore topic areas associated with the research questions. Interviews were conducted in person (n=7) and online (n=1). All interviews were audio recorded. The length of interviews ranged from 53min to 1hr 40min (M = 1hr 14min, SD = 16 min). Demographic information was completed by participants prior to interviews.

Analytical approach

Narrative analysis represents a range of methods (Reissman, 2008). In the present study, the methodology incorporated a combination of structural (Labov & Waletsky, 1967), thematic (Reissman, 2008) and dialogical (Frank, 2012) narrative analysis approaches. Whilst both structural and thematic narrative analysis place an emphasis on the insights deriving from content ('what' is said), structural analysis enables a deeper look at the embedded aspects of a story, such as variation in the personal meaning of experiences and the moral standpoints taken (Reissman, 2008). Furthermore, the process of structural coding (Labov & Waletsky, 1967) facilitates total immersion into the data enhancing other forms of analysis. Dialogical or positional analysis (Frank, 2012) seeks to move beyond 'what' and 'how' dialogue has been expressed to consider why it has been communicated (purpose) and to whom. This provides greater opportunity for exploring the influence of societal discourses and the role of power in the construction of narratives. In line with the work of Murray (2000), the present study incorporated analysis at the personal, interpersonal, positional and ideological levels. The analytical approach

taken in the study is summarised in table 4. Although presented in a linear format, analysis was undertaken iteratively, going back and forth between steps as the analysis progressed.

Table 4 *Analytical procedure*

- Step 1 Each transcript was read and structural elements were identified and coded using Labov's framework of narrative structure (Labov & Waletsky, 1967).
- Step 2 The content of each story was explored using the identified structural elements and findings entered into the narrative summary sheet (see completed example in Appendix I). Key questions asked of the data were:
 - Where do people's narratives begin?
 - How do people summarise their journeys?
 - What metaphors do they use?
 - What do narratives reveal about the meanings the individual has made of their experiences?
 - How were stories resolved and returned to the present?
- Step 3 Each transcript was re-read and themes within each narrative were extracted and findings entered into the narrative summary sheet. A synopsis of the narrative was also created to include:
 - Timeline of events
 - Characters
 - Settings
 - Outcomes
 - Key assumptions and key themes
- Step 4 Each transcript was re-read and a dialogical/positional analysis was undertaken based on the work of Murray (2000) and informed by

Thornhill (2004). This involved commenting on each narrative using the following lines of inquiry:

Personal

- What were the key narratives within the story?
- What function did the narrative serve for the interviewee?

Interpersonal

- What messages were people trying to convey?
- What gaps or omissions were there in the narrative?
- What was noticeable from the interviewer's use of language?
- How did people position themselves socially?
- Who else could be heard in peoples' stories?

Positional

- What aspects of peoples' identity may have impacted the construction of the narrative?
- What power relations are at play between interviewer and interviewee?

Ideological

- What dominant or counter narratives could be identified within the story?
- How did people draw upon or reject dominant narratives?

Once complete, findings were entered into the narrative summary sheet.

Step 5 Narratives were compared and contrasted to identify unifying themes (see Appendix J)

- **Step 6** Units of speech were extracted in order to demonstrate findings
- Step 7 Participants were provided with a synopsis of their narrative in order to give feedback on accuracy.

Results

The following results are displayed thematically with insights offered from structural, thematic and dialogical narrative analysis approaches reflected within each theme. A synopsis of each narrative is provided in table 5.

Table 5Synopsis of narratives

| Participant | Synopsis |
|-------------|--|
| Hayley | Hayley's narrative began at the point immediately prior to the onset of |
| | psychosis. She pinpointed a stressful divorce from an abusive partner as the |
| | trigger for her difficulties. In her narrative, she depicted an initial sense of |
| | euphoria following the divorce accompanied by a period of spiritual |
| | exploration where she described "searching for the meaning of life" and |
| | "wanting to release everything that no longer serves me right". Her narrative |
| | described the day, around six months after the divorce, where she began to |
| | experience voices and visions. She was subsequently hospitalised for the first |
| | time. As her narrative progressed, she told of several further episodes of |
| | psychosis. After her first episode, voices and feelings of euphoria were |
| | replaced by racing thoughts and suspicious beliefs. Hayley's story went on to |
| | depict experiences of adversity as a child, describing the impact of neglect |
| | and having to care for her sister as a result of her mother's mental health |
| | difficulties. She described how looking after her own son triggered memories |
| | of caring for her sister and how witnessing poverty in her role as a support |
| | worker reminded her of her childhood. Hayley had undertaken a number of |

years of counselling prior to the onset of psychosis but had not experienced EMDR until after her second episode. She cited the therapeutic relationship

as the most important part of her therapy. A key theme of the narrative is the

role psychosis played in re-evaluating what is important in life.

Amy Amy's story was one of terror, tragedy and survival. In her narrative, she

told of how she suffered a physically and psychologically abusive

relationship at the hands of a partner she met whilst travelling. Amy

managed to escape the relationship and return home, but soon after her

return, her ex-partner, the perpetrator of the abuse, ended his own life. Upon

returning to the UK, Amy had rekindled a relationship with a former

boyfriend who she described as "very dark". In her narrative, she recounted

how his influence led her to an understanding of the world as full of "evil"

forces, something that she believed was instrumental in her experiences of

psychosis. Alongside a sense of self-blame for her ex-partner's suicide, this

outlook on the world featured heavily in her unusual experiences, which

manifested in racing thoughts and visual and auditory intrusions. Amy told

of how, initially, her experiences of psychosis were "exciting" but as time

went by, the role of religious ideology featured more heavily, convincing her

that the only way to avoid a "lifetime in hell", was to take her own life. After

her first hospitalisation, Amy engaged in EMDR for around six months

focussing on the experiences of abuse she suffered from her ex-partner.

During this time, Amy was advised by professionals to stop taking her

medication, which Amy viewed as central in the onset of a second episode of

psychosis. Following a second hospitalisation, Amy undertook further

EMDR that focussed to a greater extent on the trauma associated with her

unusual experiences. Towards the end of her narrative, Amy told of previous adversities including a traumatic abortion at age 16 and of a sexually motivated assault in her twenties.

Nina

Nina's narrative began at the point of the onset of psychosis and then moved onto the impact of traumatic childhood experiences on her difficulties. A key turning point was the deterioration of her relationship with her parents from secondary school onwards. Her narrative depicted psychological and physical abuse by her father, and a mother who became increasingly critical of her as she became a young woman. During university, Nina found a passion in jazz and focussed her efforts on developing a career in music, something wholly rejected by her parents, which resulted in Nina breaking off contact with them. Nina described the break-up of a long-term relationship with a fellow musician some years later as the trigger for her psychosis, at which point her parents came back into her life. Her story told of experiencing "telepathic" connections with childhood musical heroes and people from another planet. She also described "delusions" that got "darker and darker" and more "paranoid". Nina was initially supported by a community mental health team and later hospitalised as her difficulties became more pronounced. Nina subsequently spent almost three decades trying to find the "right kind of therapy". Nina's mother died in 2003 and her father in 2005. Nina undertook 18 months of EMDR, which she described having helped her to cope with traumatic memories and in shifting beliefs that she was an "unlovable" and "despicable" child. In her narrative, Nina viewed "grandiose" beliefs she experienced as "compensatory for feeling low power" and "low self-esteem".

Danielle

Danielle's narrative began with her describing the onset of psychosis, which she considered at the time to be a religious punishment. She depicted a traumatic time in her childhood, which involved a period of separation from her family when she was put into foster care and denied contact with her biological family. Her story told of mental health difficulties that began at university after the break-up of a relationship with an abusive partner and the loss of contact with a close friend. Initially, Danielle experienced a deep depression and was forced to abandon her studies and return to her hometown. Upon returning, she began to experience visions, a sense of grandiosity and "borderline voices", which she described as "negative" thought patterns and "powerful" self-talk. Her narrative weaves through the lengths she initially went to in order to hide her distress from her family. She described a series of hospitalisations depicting psychiatric treatment as "dehumanising and demoralising". In particular, Danielle described how the use of a particular anti-psychotic medication against her will resulted in serious complications and ultimately, total kidney failure. Key themes in her narrative included how she felt ill-equipped to deal with her emotions in her younger years and used socialising as a means of distracting herself from them. She also described how not meeting her own aspirations and measuring up with others had a profound effect on her low self-esteem, which she saw as inherently linked to the sense of grandeur that came with her early experiences. Danielle emphasised that her two periods of undertaking EMDR had helped her to heal traumatic memories, to make sense of her journey and, as a result, to develop closer and more meaningful relationships with her family.

Mimi

Mimi's story described her experiences as a long-term victim of intimate partner violence perpetrated by her late husband that began when she first became pregnant. After decades of abuse, Mimi took the decision to leave her husband and become homeless. Mimi and her children were housed in temporary accommodation until being permanently housed after two years. Around a year later she began to hear voices and to have unusual experiences such as feeling like she was being pressed onto her bed (reminiscent of her experiences of abuse). In her narrative, Mimi repeatedly referenced feelings of shame in relation to the experiences of psychosis, financial hardship and racism. Her narrative told of how, through EMDR and a trusting relationship with her therapist, she was able to rebuild her confidence and restore her dignity. Mimi took up the role of educator and advocate in her narrative (particularly for single black mothers) and emphasised how she viewed it as a miracle that she had escaped the abuse alive. Mimi made a number of references to the role of societal, community and religious ideologies in oppression and gave an example of feeling unable to leave an abusive partner due to the view of a community 'elder'.

Lucia

Lucia's narrative told of how witnessing intimate partner violence from an early age and experiencing a series of family bereavements between the ages of 14 and 17 resulted in the onset of grandiose and suspicious beliefs that led to her first and only admission to hospital. Following the death of her grandmother, who was a central figure in her life, Lucia began having problems sleeping and experienced rapid weight loss and feelings of elation and unbridled energy. She describes her "psychotic episode" as lasting for several months. After being discharged from hospital shortly before turning

18, Lucia undertook several different therapies before engaging with EMDR. Her narrative described how early life experiences led to her blocking out difficult emotions and developing coping strategies based on high levels of activity. She told of how EMDR supported her in understanding the role that this played in her difficulties and enabled her to make meaning of her experiences. She compared EMDR favourably to her experiences of other therapies which she described as too short-term and leaving her with emotions that she didn't "know what to do with". Lucia's narrative is one of fighting stereotypes in relation to what it means to have mental health difficulties. In her narrative, she protested against societal and professional discourses that place limits on the life expectations and ambitions of those that have survived mental health difficulties and make assumptions about their lifestyles and occupations.

Robert

Robert's story told of how several months after a neighbour threatened to kill him with a hammer, he began to experience visions, voices and smells. After a psychiatric hospital stay, Robert undertook EMDR therapy, which helped him to move from feeling "weary" and "hypervigilant" to feeling "confident" and "more relaxed" despite still living close to the perpetrator of the threatening behaviour and awaiting a court case regarding the incident. In his narrative, he drew parallels with his own life and the depiction of 'the Joker' in the film 'A dark knight'. Robert described how he viewed the isolation felt by the Joker as reminiscent of his own life. Along with other cultural figures and the perpetrator of the threatened assault, the Joker featured heavily in both the voices and visions that Robert experienced during psychosis. Robert did not go into detail about early life experiences in his narrative but referred

to the loss of his mother 10 years ago and abusive behaviour by his father and brother towards him in his early years. Robert's story also told of early spiritual experiences alongside the rejection of his parents' religion, which subsequently distanced him from his family. Despite some highly distressing experiences, Robert described some positive aspects of his experiences in his story. His narrative also drew attention to long term difficulties with depression due to being out of work and being unable to get a job.

Research aim 1: What does focusing therapeutically on experiences of trauma that commenced prior to the onset of psychosis reveal about the link between adversity and psychosis?

Key themes and assumptions were identified and synthesised into four broad headings.

These were: adversity, meaning-making and unusual experiences; emotionally detached coping mechanisms; the role of power in causing and maintaining adversity; and, openness to a higher consciousness.

Adversity, meaning-making and unusual experiences

All participants had experienced multiple adversities in their life and expressed the belief that trauma and adversity underpinned their experiences of psychosis. Aside from Mimi - who began her narrative by expressing her wish not to talk about early experiences - childhood adversity featured in all of the narratives. Forms of early adversity were often disclosed later in the narratives and included physical and psychological abuse (Nina, Lucia, Robert), neglect (Hayley), traumatic abortion (Amy), witnessing of intimate partner violence (Lucia) and separation from family (Danielle). For most participants, trauma-based explanations of psychosis were linked to multiple adversities: "another layer of trauma is what sort of kicked it off, in my opinion" (Hayley). Later life adversities depicted in the narratives (often seen as the 'trigger' for psychosis) included intimate partner violence (Hayley, Amy, Mimi, Danielle), threatened assault

(Robert), relationship breakdown (Nina) and familial loss (Lucia). Every participant disclosed traumatic experiences that were interpersonal in nature.

For some participants, adverse experiences were directly relatable to their unusual experiences (Amy, Mimi). An example of this came from Mimi who described a sensory experience reminiscent of abusive acts perpetrated by her ex-husband: "it's like somebody's pressing me on my bed". For others, links were apparent between the personal meanings derived from traumatic experiences (e.g. feeling unsafe) and the content of psychosis phenomena. Themes of personal meaning were common and included guilt and self-blame (Nina, Amy, Danielle, Mimi), self-defectiveness (Nina, Robert, Hayley), shame (Mimi, Danielle), feeling unsafe (Hayley, Amy, Mimi, Robert) and powerlessness (Amy, Mimi, Danielle). A theme of self-blame in the content of unusual experiences was demonstrated by Amy: "I assumed I was going to hell because I was instrumental to [ex-partner] dying. So I was constantly preparing myself to go to hell, and they told me in hell you have to breathe backwards". This is further demonstrated by Danielle: "I thought it was um, a religious kind of thing like, I'd done something wrong in my life and it was just my punishment". Feeling unsafe was apparent in Robert's unusual experiences: "I've heard like a crowd of people like cheering to kill me for no apparent reason".

In the case of Mimi and Robert, the impact of social and economic inequality was linked with personal meanings of self-defectiveness. For Mimi, the shame associated with financial difficulties was deepened by an experience of racist abuse from a dentist: "it gives me a flashback like, I don't want to live again. I can't take this anymore. I have never been so ashamed of myself". For Nina, although she had experienced physical abuse perpetrated by her father, it was her parents' ongoing criticism that she cited as having the most impact: "It was mainly the memories of being criticised and feeling as if I'd never be good enough to do music". In her narrative she demonstrates this in action: "my specific memories of coming fifth out of my

whole year at school at secondary school, and being really pleased about it, my mother just saying sneeringly, well, why weren't you top?"

Emotionally detached coping mechanisms

In describing their experiences, four participants (Amy, Nina, Danielle, Lucia) highlighted a long-term difficulty in managing emotions and, more specifically detachment from them, as central to their difficulties: "I felt like from childhood, I had a very, I had a, I didn't, I didn't know how to deal with all my emotions, so I bottled them up" (Danielle). Lucia also made connections between early adversity, avoidant coping strategies and the onset of psychosis: "So that meant that I like didn't want to upset my mum because what she was going through and that meant that I would suppress my emotions as a child. And that's how I got to the state where I was as I grew older". In Nina's narrative, she also describes the avoidance of emotions: "I'm not dissociative, but I certainly use avoidance". In his narrative, Robert stated that avoidance was not an issue for him, however, the speed he moved on from an emotional subject in one exchange, suggested it may play a role for him. This was depicted when the interviewer offered condolences regarding the loss of his mother: Interviewer: "I'm sorry to hear that". Robert: "That's fine. So hopefully I'll get a part time job soon, which I keep going on about".

The role of power in causing and maintaining adversity

The negative use of power was evident throughout the narratives. Forms of coercive, economic and ideological power acted to cause or maintain adversity and the subsequent personal meanings made from it. For participants who had been a victim of intimate partner abuse (Hayley, Amy, Mimi, Danielle), the combination of coercive and ideological power served to maintain oppression and feelings of powerlessness. Mimi highlights this when describing the response of a community elder to her experiences of intimate partner violence perpetrated by her ex-husband: "Our elder told us you have to be patient. You can't just leave your marriage. Just, it's like, in our communities, like it's normal is [sic] known. If they abuse you that is normal".

tell me about like witchcraft and demonization and things like that. So as soon as like, I got ill, I realised I had internalised all of that". In Amy's narrative she reflects how dominant narratives around mental health had been used interpersonally to manipulate her: "I saw his [browsing] history on his things about dead bodies and different things. But like to the surface, everyone thought he was a prince-charming and I thought I was going insane. And he gaslighted me and made me believe that I was going insane".

The underlying voice of capitalist ideology and the drive to achieve economic success could be found within participants' stories. For Danielle, this drive had led to feelings of defectiveness, which had been a long-standing issue for her, and could be linked to her experiences of psychosis: "I was really insecure about like, had I measured up to like what I'm supposed to achieve or what everyone else is doing?" Robert's ongoing quest for employment to overcome feelings of isolation was central to his unusual experiences, and for Nina, her resistance to an ideology that values economic success over creative expression led to a long-lasting conflict with her parents, which underpinned her difficulties. In rejecting a "corporate lifestyle", Hayley's story depicts a resistance to this narrative, describing herself as "more connected to living now". It was notable that resistance to an ideology where success is judged economically was more accessible for those who had previously considered themselves to be economically successful (Hayley, Mimi).

Openness to a higher consciousness

A common thread running through the narratives was an openness to a higher consciousness prior to the onset of psychosis (Hayley, Amy, Danielle, Mimi, Robert). This predominantly came in the form of non-religious spiritual beliefs (Hayley, Amy, Robert) or religious beliefs (Danielle and Mimi). In her narrative, Hayley described how spiritual exploration led to her reassessing the boundaries of reality: "I've read quite a lot of spiritual stuff as well. So I think the lines between reality and you know, were becoming blurred anyway...".

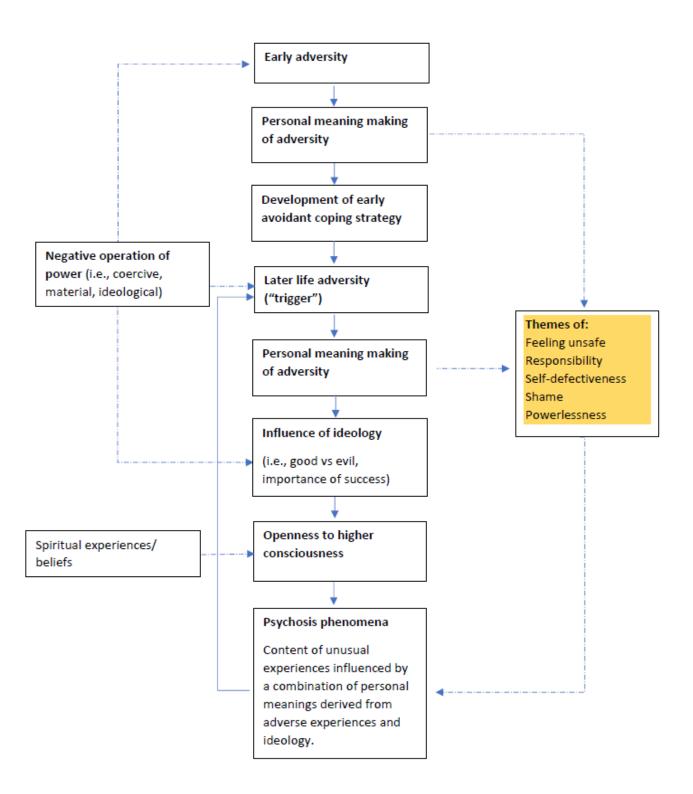
Robert's narrative also depicted a strong sense of spirituality: "But yeah, apparently I'm

connected to like spiritual like sort of things but not like as good as a medium." For Danielle, there was a clear link between religious beliefs and the experiences of psychosis: "I don't want to associate [anymore] with any religion, because I feel like soon as I put religion in that um, it makes me it just makes me a bit more paranoid". Neither Nina or Lucia's narrative made reference to religious or spiritual beliefs and they were not prompted by the interviewer.

Figure 1 displays a conceptual model representing how themes from the narratives may link together to form a pathway between adversity and unusual experiences. The model is not intended as generalisable to all experiences of psychosis, but represents patterns emerging from the present study. The diagram highlights the presence of both early and later life adversities in the narratives and depicts how early adversity may lead to the development of avoidant coping strategies and personal meanings such as self-blame (responsibility), self-defectiveness, shame, powerlessness and a lack of safety. Later life adversity (experienced as a 'trigger' for psychosis) is depicted as leading to further personal meaning-making which, in turn, influences the content of unusual experiences. The diagram also depicts the role of the negative operation of power in causing and maintaining adversity and in shaping ideological beliefs that feature in unusual experiences. An openness to a higher consciousness is also depicted as a potential factor shaping unusual experiences.

Figure 1

Conceptual model of participant themes – a pathway from adversity to unusual experiences



Research aim 2: what do peoples' experiences depict as important when engaging with EMDR for psychosis?

Key themes and assumptions were synthesised into four broad headings. These were:

EMDR's role in change; the therapeutic relationship; EMDR and personal meaning-making; and,
moving beyond dialogue.

EMDR's role in change

Participants consistently took up the role of advocates of EMDR in their stories, often emphasising how EMDR had been more effective than other therapies: "I'm able to process it differently. Whereas I think the other therapies just left me with that feeling" (Lucia). Each participant addressed their experiences of EMDR towards the end of their stories and in doing so often used words such as "now" or "anymore" in resolving their stories: "I don't feel triggered by my son anymore" (Hayley). As was the case for a number of participants, Danielle's resolution depicted improved relationships: "I think to this day, I think my mum, me and my mum's relationship has benefited the most from the reprocessing...". Participants often resolved narratives by describing how EMDR had helped them to feel calmer (Robert, Lucia, Mimi, Danielle, Nina), as demonstrated by Mimi: "But now I'm more calmer. Little things don't stress [sic], before little things will stress me out". Although not prompted specifically, the majority of participants did not describe any further unusual experiences after undertaking EMDR. The exceptions to this were Amy, who experienced a second episode, was hospitalised, and then had further EMDR; and Mimi, who described still hearing voices from time to time but described them as less intrusive and more manageable: "I don't listen to them. It's not as distinct like before".

There were several examples of the interviewer prompting for specific insights into the therapeutic process, on these occasions responses were often related to the therapeutic relationship and the meaning-making process rather than specific techniques. Despite this, there

were a number of references to the usefulness of the safe/calm place exercise (Hayley, Amy, Danielle, Nina, Lucia) and to varying extents references to reprocessing memories. In Nina's narrative, she explained how processing traumatic memories became quicker as therapy progressed: "the first trauma thought that we focused on which was my father hitting me was um... took about half a dozen sessions to resolve itself. But as the as the therapy progressed, then the time for processing the trauma thoughts decreased".

The therapeutic relationship

For a number of participants, a trusting therapeutic relationship was emphasised as the most important element of their EMDR therapy. This was especially the case for participants who had experienced intimate partner abuse (Hayley, Amy, Danielle, Mimi), as emphasised by Hayley: "Just having a woman that I've trusted, and I could talk to and you know, that unconditional regard... those type of things really made a difference to me". This is further demonstrated by Mimi: "You can have help there and then, but the person, the connection with the someone that is helping you". In Amy's narrative, she positions her therapist as a 'saviour': "Tve always said that she kind of has single-handedly saved me". For others (Nina, Danielle, Lucia), time was a factor in building that relationship: "I think with the challenges is knowing that, like an understanding, that I have maybe issues with trust in general. So short term therapies wouldn't have worked, because it takes me a long time to actually trust the therapist" (Lucia). The length of therapy was also cited as important by Nina: "...the first CBT I had in 2000, I think it was, that was only three months...I felt as if I needed more than that, but couldn't, couldn't get more. And so it was very helpful to...go through things in my own time".

EMDR and personal meaning-making

A common theme across the narratives was how EMDR had helped participants to address personal meanings emanating from adverse experiences. Hayley demonstrated this in relation to self-defectiveness: "But we, we managed to come to a theme of feeling not capable. And that's kind of where we started our work...And so we did a lot of work around that. And it was really,

really useful...". In Nina's narrative, she suggested that it was therapist input that helped her to relinquish self-blame "A lot of it was [therapist] assuring me that it wasn't my fault that that I wasn't unlovable, and despicable...". For Mimi's story she emphasised how EMDR empowered her to act against a dentist who had racially abused her: "I told her, you know what? I'm not going to allow anybody to bring me down anymore...I'm going to take it on this doctor. So what I did, I wrote a letter of complaint... It empowered me yes. It empowered me a lot". In her narrative she also referred to a changing attitude towards patriarchal control: "That is the man power. But not anymore". She continued: "Before I used to blame myself well yes, 'you have the right to beat me up'. Well, no, it's not my fault".

Personal meaning-making through EMDR also seemed to address participants', aforementioned, emotionally detached coping strategies and how they linked with adversity: "But the EMDR really helped me pinpoint that because it helped me understand, like, when things get too overwhelming, emotionally, I switch off from it..." (Lucia). This is further demonstrated by Amy: "And I buried that. I've suffered for a while after that, and all that kind of stuff but very much buried it and moved on. And that came out a lot in EMDR".

For some participants (Hayley, Lucia, Nina), EMDR appeared to play a role in developing a view that their difficulties may be also, in part, related to less pronounced experiences of adversity: "so it helped me understand that I guess a lot of it I used to blame on like the domestic [sic] but actually was just down to like, sibling rivalry and feeling almost like I had to support the whole family rather than be a child" (Lucia).

Moving beyond dialogue

There were several references to EMDR's ability to process traumatic memories on a physical and emotional level, as well as cognitive level (Lucia, Hayley, Amy, Robert): "It was almost like, all the feelings came up in me. And, you know, I needed to be sick, it was a very physical reaction. And that was a real turning point. Like after that I felt a lot better" (Hayley). In Robert's narrative, he noted how processing memories led to a delayed physical reaction: "At the

end she was like 'did you get any symptoms or nothing?', I was like 'no', and then about five to 10 minutes later I got a massive shock through my head like where he held the hammer.", he continued: "I had a red spot on my forehead where he held the hammer". For Lucia, this set EMDR apart from other therapies that she had undertaken: "EMDR, like, continuously going over it and then thinking about the words that would come up and then where I was feeling it... I'm able to process it differently. Whereas I think the other therapies just left me with that feeling". Several participants noted how physical and emotional reactions made the process of therapy difficult at times: "And there'd be times where I'd be absolutely like streaming with tears, but she's like, 'No, don't stop, we're gonna keep going through this' and like, push me through it sort of thing. And after every session, I would leave there and just be like, god I feel like I can breathe" (Amy). This is further emphasised by Robert: "It was quite painful, but it was worth it".

Reflexive positioning

Reflection on the personal characteristics of interviewers offered further insights into the data. Both interviewers were White trainee clinical psychologists, one male and one female. This appears relevant in how participants constructed their stories around social and economic inequality, specifically, in relation to racism. Of the three Black participants, Mimi's narrative was the only one to explore the emotional impact of racism and this followed prompting from the interviewer. Danielle and Lucia's narratives focussed on stigmatised views around mental health and in the instance of Danielle, she was clear that oppressive treatment practices were not linked to racial injustice. To what extent these findings may have been shaped by the identity of the interviewer is not clear, however, this context should be considered when making inferences from the data.

Discussion

There were two overarching aims of the investigation. Firstly, to explore what focusing therapeutically on experiences of trauma that commenced prior to the onset of psychosis might reveal about the link between adversity and psychosis, and secondly, to explore what clients'

experiences depict as important when engaging with EMDR for psychosis. Further objectives pertained to exploring the meanings people had placed on their experiences and the extent to which EMDR may lessen the distress associated with adversity in the broader sense (i.e. 'small-t' traumas or those rooted in social or economic inequality). An interpretation of the findings, study limitations and clinical implications of the research are presented below.

Research aim 1: What does focusing therapeutically on experiences of trauma that commenced prior to the onset of psychosis reveal about the link between adversity and psychosis?

Four areas emerged from the narratives linking adversity and psychosis, these were: adversity, meaning-making and unusual experiences; emotionally detached coping mechanisms; the role of power in causing and maintaining adversity, and; openness to a higher consciousness. Figure 1 represents a conceptual model of how, for participants in this study, these themes may link together to form a pathway between adversity and unusual experiences.

Whilst all participants had experienced multiple adversities throughout their lives, and all but one shared experiences of childhood adversity, for the majority of participants, it was a later life adversity that had preceded the onset of psychosis. In line with the findings of previous research (Morrison et al., 2003), some participants were able to make direct links between experiences of adversity and the content of psychosis phenomena. For others, trauma-derived personal meanings were represented within the content of unusual experiences (see figure 1). Themes of self-blame, shame, self-defectiveness, feeling unsafe and powerlessness were common in the narratives and were reflected in the content of psychosis phenomena. This aligns with the PTMF's premise that the meaning individuals make of their experiences shapes the response they have to them (Johnstone and Boyle, 2018). Within the current study, there were some, albeit tentative, emerging patterns linking the types of personal meanings and the nature of unusual experiences. For example, a combination of self-blame and a lack of safety seemed to leave participants feeling highly suspicious and vulnerable during their unusual experiences

(Amy, Hayley, Mimi). Where unusual experiences were dominated by grandiose beliefs (Nina, Danielle, Lucia), personal meanings appeared to centre around self-defectiveness. This finding aligns with the perspective of the 'paranoia-as-defence' literature (Murphy et al., 2018) which views the external attributions for negative events inherent in persecutory delusions as serving a function in reducing awareness of low self-esteem. The link between grandiose delusions and low self-esteem has also been proposed within the literature, however, there appears to be mixed evidence that they serve a similar function in defending against low self-esteem (Knowles et al., 2011).

It was notable that participants' experiences of adversity were predominantly interpersonal in nature. Research by Thomas et al. (2021) suggests that interpersonal trauma leads to more severe post-traumatic stress experiences than non-interpersonal trauma (e.g. road traffic accidents or natural disasters) and it is possible that due to interpersonal trauma shattering personal meanings of safety, it may underpin experiences of psychosis to a greater extent than non-interpersonal experiences of adversity.

In making links to early adversity, four participants referred to the development of detached emotion regulation strategies. Within the literature, emotion regulation strategies have often been seen as a potential link between adversity and psychosis (see Hardy, 2017, for review) and in a study looking at associations between childhood trauma and psychosis, Powers (2016) found that the avoidance of emotions was strongly associated with the onset of psychosis. For Danielle and Lucia, there was a clear sense that detaching from their emotions had led to a build-up of unprocessed emotions that contributed to the onset of psychosis.

A theoretical perspective underpinning the research was the PTMF (Johnstone and Boyle, 2018), a key element of which is the role that the negative operation of power plays in the creation and maintenance of distress. The impact of coercive, economic and ideological power on adversity was evident across the narratives and, as a result, forms part of the conceptual model presented in figure 1. For those participants who had suffered intimate partner violence it

was the combination of coercive power, and ideological power wielded interpersonally, that appeared to be the most damaging. Alongside physical violence, there was evidence of the use of religious ideology, patriarchal messages around the sacredness of marriage, and societal stigma around mental health difficulties, in maintaining adversity (e.g. gaslighting). As suggested in the PTMF (Johnstone and Boyle, 2018), this appeared to emphasise a sense of feeling trapped and powerless. The negative operation of power was also evident in relation to social and economic inequality and featured in personal meanings of self-defectiveness and shame, which were linked to experiences of racism, unemployment and financial difficulties.

A further theme throughout the narratives was an openness to a higher consciousness prior to the onset of psychosis in the form of religious or non-religious spiritual experiences or beliefs. Unusual experiences are often conceptualised as a spiritual experience (Phillips et al., 2009) and the role that spiritual practices and religious or spiritual beliefs play in the onset of psychosis has been the subject of research (Lucchetti et al., 2021; Sharma et al., 2022). Although there is little evidence to suggest that religiosity or spirituality leads to psychosis (Huguelet & Mohr, 2009), there is some evidence of an association (Brito et al., 2021) and it is possible that, for the current participants, a greater openness to spirituality may have played a role in the onset of unusual experiences. This resonates with the concept of 'transliminality' which is described as hypersensitivity to ideational and affective psychological phenomena originating in the unconscious or external environment (Thalbourne and Delin, 1994). Highly transliminal people have been found to report more unusual experiences and are more likely to experience alterations in consciousness (Thalbourne and Houran, 2000).

Research aim 2: what do peoples' experiences depict as important in undertaking EMDR for psychosis?

In exploring peoples' depictions of EMDR for psychosis, four broad headings emerged.

These were: EMDR's role in change; the therapeutic relationship; EMDR and personal meaning-making; and, moving beyond dialogue.

Participants consistently reported positive experiences of EMDR and positioned themselves as advocates of EMDR for psychosis. This is perhaps unsurprising as participants were jointly recruited by EMDR therapists. Positive effects included improved relationships, feeling calmer and having a better understanding of how adversity had impacted their ability to cope with emotions. In line with previous research into the effectiveness of EMDR for psychosis (Adams et al., 2020), there were no safety concerns highlighted. Two participants described further unusual experiences after having EMDR. For Amy, this seemed to have been influenced by an abrupt stop to medication. For Mimi, she continued to hear voices, but found them less intense, more benign and manageable. No other participants reported further unusual experiences. It is possible this finding was also influenced by the recruitment strategy, as therapists may have been less likely to put forward participants who had reexperienced psychosis.

In line with previous findings on psychological therapy (Lambert & Barley, 2001), the therapeutic relationship was often cited as the most important factor in participants experiences of EMDR and it was notable how participants spoke less about the specific processes of EMDR and more about the relationship they had with their therapist. This was strongly emphasised by participants who had experienced intimate partner abuse. For these participants, a trusting therapeutic relationship appeared to be both healing and empowering. For these participants, they had not only been subject to coercive power, but also to ideological power used on an interpersonal level as a control strategy. It follows that whilst clinicians may not be able to change the use of coercive power, they have a key role in combating the harmful use of ideology.

A central feature of the narratives was how participants depicted change through the healing of personal meanings associated with adverse experiences. Participants seemed able to make reappraisals of trauma-derived personal meanings and move to more helpful positions in relation to their adverse experiences. Previous research on the subjective experiences of EMDR for psychosis (Hardwick, 2023a) found a key transformative element to be EMDR's role in

reducing peoples' sense of responsibility and self-blame in relation to experiences of adversity. That finding was echoed in the current research along with EMDR's ability to lessen feelings of self-defectiveness, shame and powerlessness. What was less clear from the research was to what extent participants reached more adaptive personal meanings spontaneously through reprocessing, with the support of therapeutic interweaves (therapist suggestions) during reprocessing, or outside of reprocessing sessions (i.e. client history taking).

Of interest to the current study was EMDR's role in lessening the distress associated with 'small-t' traumas or those rooted in social or economic inequality. There were several examples of memories that, whilst the scale of the trauma might not be universally considered as major, the impact on the internal self as a result of what happened was significant. For example, in Nina's narrative, a memory depicting her mother's response to her school results appeared to have been central to feelings of self-defectiveness. For some participants, EMDR had played a role in helping them to acknowledge the impact of these types of experiences.

There was also some evidence EMDR can play a role in healing trauma-derived personal meanings linked to inequality, such as self-defectiveness and shame. In Mimi's narrative she tells of the shame she felt as a result of financial difficulties and racism, and how EMDR helped to restore her dignity and empower her to act against her oppressor. Elsewhere in her narrative, she referred to a changing attitude to patriarchal oppression, which suggested her experience of EMDR may have played a role in raising her consciousness to these issues. The appropriateness of one-to-one psychological therapy in the face of oppression has often been critiqued (e.g. Crossley, 1999) and, historically, liberation psychologists have favoured systemic and narrative approaches, as opposed to trauma focused therapies (e.g. Afuape, 2012). Despite this, there has been some recognition that individual psychological therapy can play an emancipatory role (Comes-Diaz, 2020) and the findings from the present study suggest EMDR may, under the right conditions, offer such opportunities. Such conditions might include EMDR therapists

understanding the role of power in individual distress and having a firm commitment to social justice.

A further finding of previous research (Hardwick, 2023a) was EMDR's ability to move beyond the realm of cognition and to engage emotions at the physical level. This was also a finding within the present study and one which participants cited as a key difference from other therapies they had experienced. Existing research has emphasised the role of the body in both manifestations of traumatic experiences (Van der Kolk, 2014) and in meaning-making (Cromby, 2015) and the ability to move beyond cognitive reappraisals of trauma-derived personal meanings was depicted as important for participants.

Strengths and Limitations

There were several notable strengths and limitations with the study. An open approach to interviewing gave participants greater freedom in narrating their stories than might have been afforded with a more structured interview approach. A potential downside of this approach was the extent to which participants reflected on the process of EMDR itself. Interviewer prompts were used to encourage further reflection in this area, however, participants' views were less focused on specific aspects of EMDR. There were also limitations with the sample size and gender diversity of participants. Being a mainly female sample limited insight into the experiences of men and subsequently, how gender roles, and expectations in relation to them, may influence experiences of adversity and personal meaning-making. Furthermore, a sample size of eight may be considered low when compared to other qualitative methodologies, however, as emphasised by Reissman (1993), in narrative analysis, the emphasis is on the depth of analysis rather than breadth and is therefore suited to smaller sample sizes. In the present study, a methodical, in-depth approach to analysis that included a combination of structural, thematic and dialogical narrative approaches offered extensive insights into the data.

A key limitation of the study was the use of EMDR therapists to jointly recruit participants.

This is likely to have influenced findings in relation to people's experiences of EMDR. Not only

is it possible participants may have felt the need to be positive about their experiences of EMDR for fear of it reflecting badly on their therapist, it is also possible therapists would not have identified them as potential participants were they not advocates for its use. The inclusion of participants who had not benefitted from EMDR is likely to have provided further insights. A further limitation of the study, due to space limitations, was the lack of focus on strengths and social capital. An example of this relates to faith. For several participants, even though they had turned away from organised religion following their experiences of psychosis, faith and a belief in god had played a key role in helping them to survive their difficulties.

Clinical and research implications and recommendations

For clinicians and policymakers, a number of considerations emanate from the research. Firstly, in line with previous findings (Read & Fraser, 1998), participants did not immediately reveal experiences of early adversity and disclosures often came later in the interview. In research focusing on the disclosure of traumatic events in the context of psychosis, Campodonico et al. (2021) found participants viewed talking about traumatic experiences as beneficial, and furthermore, that a lack of opportunities to discuss traumatic events contributed to negative feelings of self-blame, shame and guilt. As such, questions about experiences of adversity (including 'small-t' traumas and those arising from economic and social inequality) should be central to assessments. Secondly, several participants emphasised the benefit of having a longer period of therapy compared to what they had undertaken previously. Due to the extent and multiplicity of the adversity that may underpin the experiences of psychosis (including any trauma associated with the experience of psychosis and hospitalisation), this may indicate a more extensive period of therapy may be required. Thirdly, in order to support meaning-making for the client and inform care planning, clinicians may wish to pay specific attention to the personal meanings situated within the content of unusual experiences and forge links with any personal meanings arising from adversity. Finally, EMDR clinicians may wish to consider their role as therapists in promoting resistance to oppression.

As reflected in current clinical guidelines for the prevention and management of psychosis (NICE, 2014), researchers have largely viewed the re-experiencing of traumatic memories in the context of psychosis as evidence of 'comorbid' PTSD which is distinct from the unusual experiences associated with psychosis. Future research may seek to explore the role of EMDR in addressing the direct impact of trauma memories on unusual experiences. In doing so, researchers may wish to consider the usefulness of the conceptual model presented within the research and to investigate, in more detail, experiences of the specific elements of EMDR therapy for psychosis.

Conclusion

Through a narrative analytic approach, the study built on existing literature exploring the subjective experiences of people who have lived through adversity, have experienced psychosis and have subsequently engaged with EMDR therapy. All participants had experienced multiple adversities and took the view that trauma and adversity underpinned their experiences of psychosis. Participants consistently positioned themselves as advocates of EMDR for psychosis and cited positive effects such as improved relationships, feeling calmer and having a better understanding of how adversity had impacted them. Personal meanings derived from traumatic experiences such as self-blame, shame, self-defectiveness, feeling unsafe and powerlessness were common within the narratives. In summarising the participants' experiences, the study offered a tentative, conceptualisation of a potential pathway between adversity and unusual experiences. Several clinical implications were raised, including recommendations for assessment and care planning that place an emphasis on links between trauma derived personal meanings and the content of unusual experiences. Future researchers may wish to further explore the role of EMDR in addressing the direct impact of trauma memories on psychosis.

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Appendices

Appendix A: Example first iteration data extraction table

| Author | Second-order construct/author | First-order construct |
|-------------------------|---|---|
| | interpretation | |
| Bergström et al. (2019) | "Another frequent subtheme included adversities faced within intimate relationships. In women's stories, in particular, this was experienced as a threat, involving both physiological and psychological abuse"(p.109) | "Back then my husband's nerves were constantly on edge and I and my children had to be afraid when he started yelling at us. I couldn't say anything or express my own thoughts. It was like a continuous stalemate situation, where we couldn't communicate. Finally I collapsed. I couldn't sleep and I started to feel that everybody wanted something bad for me."(p.109) |
| Efthyvoulou (2018) | "Again, without expressing any kind of emotion, she described her mother's dismissal when she revealed her sexual abuse. Her mother did not validate it, but denied Patte's traumatic experience, and she also excused him 'if he did it', because he was an artist:" (p.109) | "my mother saying, 'that couldn't have happened or if it did, it's because he's an artist', and dismissing my attempts to tell her of my confusion." (p.109) |
| O Brien (2014) | "His experiences were in the context of a family-breakdown, resulting in him becoming homeless:" (p.18) | "it seemed like in the family I could not fit in to the way that they were to be, which was quite sad" (p.18) |
| James (2019) | "There was also a critical element to her narrative, as she felt she had not been equipped by her parents to deal with the situations that arose in her life."(p.47) | "growing up as a child it was kind of strong emotions were always seen as a negative erm, and something to just kind of shy away from or kind of stop rather than understanding or exploring why there are those feelings" (p.58) |
| Parry (2020) | "Emotional mirroring within voice—child and child—parent relationships was described across the majority of accounts. For some, this was a mirroring of mutual feelings in the voice—child relationship" (p.5) | "he hates me and I hate him" (p.5) |
| Moernaut (2018) | "Matts was adopted as a child and despite having a rather good relation with his adoption family, he feels what he calls "bottomless." In search for solid ground, he immerses himself in philosophy and religion, which eventually resulted in psychosis." (p.4) | |

Appendix B: Example second iteration data extraction table

| Author | Second-order construct | First-order construct | Second order construct theme |
|-------------------------|--|---|---------------------------------|
| Bergström et al. (2019) | "Another frequent subtheme included adversities faced within intimate relationships. In women's stories, in particular, this was experienced as a threat, involving both physiological and psychological abuse"(p.109) | "Back then my husband's nerves were constantly on edge and I and my children had to be afraid when he started yelling at us. I couldn't say anything or express my own thoughts. It was like a continuous stalemate situation, where we couldn't communicate. Finally I collapsed. I couldn't sleep and I started to feel that everybody wanted something bad for me."(p.109) | Abusive intimate relationships |
| James (2019) | "Participants referred to parental relationships/roles (for instance, reporting feeling ill-equipped to deal with adverse circumstances) and spoke about the potential role of family scripts on understanding and managing feelings" (p.58) | "growing up as a child it was kind of strong emotions were always seen as a negative erm, and something to just kind of shy away from or kind of stop rather than understanding or exploring why there are those feelings" (p.58) | Unsupportive attachment figures |
| Parry (2020) | "Other barriers involved being disbelieved or misunderstood, which could deter the young person from seeking further help" (p.7) | "parents said I was lying and have never helped me with any mental/ emotional problems I've had, so I don't trust them or anyone else they are related to". (p.7) | Unsupportive attachment figures |
| Thornhill (2004) | "Coming to understand the psychosis as a response to previously experienced psychological or physical trauma such as childhood sexual abuse is a recurring theme in some of these enlightenment narratives" (p.190) | "I was experiencing being raped and being sexually abused [] but there wasn't anybody there to say They just said, 'paranoid schizophrenia' which means, I was imagining it. But there wasn't anybody there who said to me 'Well, have you in your childhood ever experienced these things?" (p.190) | Childhood abuse |

Appendix C: Full data extraction tables

| | | s a consequence of adverse experien | |
|---|---|--|--------------------|
| Second order construct themes | Example second order constructs (researcher interpretations) | Example first order constructs (illustrative quotes) | Author |
| Interpersonal traumatic experiences | "This reflected a deep-seated and pervasive belief among participants that harmful interpersonal experiences and social circumstances were at the root of their problems." (p.5) | "It was my Mum, I was upset at her for what she had done to me, abused me, hit me you know, violently, I just didn't like it and I just blew up because she had hurt me, I just blew up and I took my anger out on her, you know." (p.3) | Lawrence, 2020 |
| | "Three of the five participants described hearing malevolent voices associated with difficult interpersonal relationships or abuse, and all of the participants described 'paranoia' or suspicion of others in the context of tangible threats of harm, surveillance or deceit." (p.86) | "I had a lot of anger inside me that I had been holding from when people mistreated me and I hadn't said anything, I've let things slide and like I've just brushed it off, like it was still there" (p.48) | Harris, 2016 |
| | "The stories in this category ['Crises as a response to adversity n=7/20'] were characterized by significant life adversities occurring from early childhood." (p.110) | "I was bullied quite severely, and I think my mind somehow got stuck in the school premises. Eventually that led to a feeling that everything was a kind of a theatre, and everybody was just faking and hiding some secrets from me." (p.110) | Bergström, 2019 |
| | "Descriptions of intense experiences were evident in all four stories and psychosis sense making was found to be related to previous adverse experiences." (p.145) | "But then memories began to surface, memories which had been buried for years, partly banished by the numbing, sweaty nubs of sulphur-yellow pills. Memories of being pillaged then discarded, bruised and dripping please don't hurt me, please, please. No wonder I was mad." (p.119) | Efthyvoulou, 2018 |
| | | "I had had a baby and when he was seven months old I had been deserted by my husband" (p.108) | |
| | "Coming to understand the psychosis as a response to previously experienced psychological or physical trauma such as childhood sexual abuse is a recurring theme in some of these enlightenment narratives" (p.190) | "I was experiencing being raped and being sexually abused [] but there wasn't anybody there to say They just said, 'paranoid schizophrenia' which means, I was imagining it. But there wasn't anybody there who said to me 'Well, have you in your childhood ever experienced these things?" (p.190) | Thornhill, 2004 |

| "Many of the participants indicated that the circumstances around the onset of their difficulties involved strong, difficult feelings that reminded them of prior negative experiences that had not been dealt with, such as times where they had felt vulnerable or fearful." (p.51) | "I was reliving it because this other individual, it's happened, erm, about X years ago with this in this job. Erm, but this individual at the office, by him, sort of putting his hand on my shoulder, it sort of brought it all back and I thought no I'm not going to be a victim again so that's when I reacted" (p.51) "probably, I've been through so much, so much trauma, I think it's massive post-traumatic stress | James, 2019 |
|---|---|--------------------|
| "The participants' explanations for their voices varied from commonly accepted doctrines, such as 'Trauma/Mental Illness' (Milo, 17), to more socially constructed accounts, 'I think they're here to protect me and my friends' (James, 14)" (p.5) | disorder" (p.49) "Because I lost my sister and lots of other relatives and I've been through a lot and I feel like this is my body reacting to it." (p.5) | Parry, 2020 |
| "In contextualising the emergence of psychosis, participants appeared more readily able to access negative interpersonal experiences, such as rejection, loss, threat, negative self-other comparisons, conflict, neglect and isolation, than of positive support." (p.56) | "Basically, eh, I fell out with my partner, so I did (mm) and she taken away my kid, and stuff like that. It was maybe, like, four weeks later, you know (right), I started hearing these voices, you know?" (p.56) | Anderson, 2010 |
| "Most but not all had embraced a medical understanding but this did not preclude them from also having personal explanations, such as increasing stress, relationship breakdown, teenage life struggles, or smoking cannabis as also contributing." (p.95) | It was very much connected with that relationship and the fact that he was controlling my life, or that I thought he was controlling my and having all these people talking and leaving, kind of leaving clues for me and things like that I was deeply in love and I had built this fantasy around him, around the idea of him, you know, and I was feeding that fantasy. (p.93) | Bluffield, 2006 |
| "Another frequent subtheme included adversities faced within intimate relationships. In women's stories, in particular, this was experienced as a threat, involving both physiological and psychological abuse"(p.109) | "Back then my husband's nerves were constantly on edge and I and my children had to be afraid when he started yelling at us. I couldn't say anything or express my own thoughts. It was like a continuous stalemate situation, where we couldn't communicate. Finally I collapsed. I couldn't sleep and I started to feel that everybody wanted something bad for me."(p.109) | Bergström, 2019 |

| Build-up of stressors and breaking points | "The narratives revealed that participants felt that they had experienced a build-up of feelings, in response to different social and environmental factors that became unbearable. Common feelings immediately prior to and during the most intense period of paranoia were fear, vulnerability and a feeling of unsafety." (p.59) | "it's just small things that build that sort of build a bigger picture of sorts" (p.5) "it was kind of like a snowball effect that turns to an avalanche, so if I had noticed there was a snowball earlier on I would've been able to say stop and there would have been less to stop" "it's just small things that build that sort of build a bigger picture of sorts" (p.50) "it's been my guard through all my life. So just to keep things inside, piling up nice and quietly, just ready for a you know, one complex on top of a complex, you know, it's going on and on and on. Something had to give, and it was my mental health" (p.50) | James, 2019 |
|---|--|---|--------------------|
| | "The crisis was often viewed as a consequence of multiple distressing life events, cumulative setbacks, or of significant changes in central life areas, breaking into the desirable life course" (p.109) | "It was as if the house of cards that we had carefully built suddenly collapsed." (p.109) "Prior my collapse, I worked so hard and I was sure that I'd get that promotion. However, they decided to hire another guy for that position, going right past me. It was horrible. I felt that they had mistreated me, and I started to think it was all just some kind of strange game." (p.109) | Bergström, 2019 |
| | "Leo narrated the experiences that led her to being admitted to an acute in-patient mental health ward as a build-up of stress and unexpressed anger." (p.47) | "The doctor said, because it is building up so much pressure inside you and it has to bust one time, one day." (p.55) "sometimes you will just hold things in and it's builds up into some big thing and then you just blow up and they're like 'where did that come'" (p.75) | Harris, 2016 |
| | "The young people made associations between their explanatory models and consequences of their behaviour, often attributing difficulties to lifestyle, stress or stopping medication abruptly." (p.130) | "I came to the conclusion that I can't really handle any kind of exam stress or anything like that. Because I was smoking weed to try and chill myself out, but it didn't really work." (p.92) | Bluffield, 2006 |

| | "Additionally, when participants experienced further relational or environmental stress or stigma, this could have an aggravating effect on the voices, perhaps signifying that these reactions to voices could also be, to a degree, traumatic." (p.6) "Most participants described poor general mental health, distal and proximal stressors, and disconnection from others prior to voice onset." (p.1412) | I wish I knew the answer to this but the doctor has told me it is because I went through a really difficult time with other mental health problems that it probably came from stress" (p.5) | Parry, 2020 De Jager, 2016 |
|---|--|---|-----------------------------|
| The role of social and economic inequality | "We found that participants often attributed their distress to social and environmental experiences, rooting it in precarious living situations, poverty, and fraught relationships, which in turn perpetuated the cycle of service use." (p.7) | "Sometimes like you say, it's only hours before the Post Office opens for me to change the cheque, I'd get up from the bed and I couldn't go in because I was so hungry and that, and I was shaking, and I couldn't go out." (p.4) | Lawrence, 2021 |
| | "Finally, Joseph appeared to draw upon counter narratives to highlight the role of social factors and an oppressive context in his 'unusual experiences'." (p.78) | "It was like very violent where I live (1) and the violence is just so erm (1) you knowevery time I fall asleep I just (1) something would just boom, or there would be loud music (1) and then I wouldn't be able to sleepand then there was the noise pollution the er, the woman downstairs shewas in an abusive relationshipso all that was coming up and then you had people upstairs as well who were making noise, so it was just a lot of tension as well at the same time." (p.78) | Harris, 2016 |
| | "Frank's narrative reflected feeling persecuted in relation to not feeling in control of his life, and the societal inequalities which have acted as constraints" (p.21) | "As soon as we're born our life's mapped out and we've got to deal with our lives no matter how crap they are, some lives are rubbish." (p.21) | O Brien, 2014 |
| | "In his story, he claimed that his family and his social environment rejected his sexuality and feminine nature, and this led to his descriptions about the culture in his hometown, which was a constant reminder of his feelings of rejection, sadness, anger, and disappointment." (p.83) | "I was, in turn, a victim of sex and gender fascists. [Line 106-108] My life has very much been characterised by the fighting spirit of the underdog. I was stigmatised for supposed homosexuality in the 1960s and for transvestism — my real orientation — in the 1970s. Scandal and gossip followed me and clung to me like a cloud of magnetic gas." (p.83) | Efthyvoulou, 2018 |

| | "Many participants, particularly black Caribbean, considered their problems to be a consequence of exposure over time to several negative life experiences and adversities, ranging from poor housing and inadequate income to discrimination and trauma." (p.6) | | Lawrence, 2020 |
|---------------------------------|--|---|-------------------------|
| Unsupportive attachment figures | "Participants referred to parental relationships/roles (for instance, reporting feeling ill-equipped to deal with adverse circumstances) and spoke about the potential role of family scripts on understanding and managing feelings" (p.58) "Other barriers involved being disbelieved or misunderstood, which could deter the young person from seeking further help" (p.7) | "growing up as a child it was kind of strong emotions were always seen as a negative erm, and something to just kind of shy away from or kind of stop rather than understanding or exploring why there are those feelings" (p.58) "parents said I was lying and have never helped me with any mental/emotional problems I've had, so I don't trust them or anyone else they are related to". (p.7) | James, 2019 Parry, 2020 |
| | "Patte's story illustrated a young girl who grew up with insecure parental attachment style, invalidation, and childhood sexual trauma; events that may have contributed to a complex trauma and the development of psychosis at a later stage in her life". (p.162) | "I was brought up in, where meaning was found solely in intellectual and educational achievement, and vulnerability was to be avoided at all costs". (p.103) | Efthyvoulou, 2018 |

| making sense of | making sense of psychosis phenomena | | | |
|-----------------|-------------------------------------|--------------------------------------|--------------|--|
| Second order | Example second order | Example first order constructs | Author | |
| construct | constructs (researcher | (illustrative quotes) | | |
| themes | interpretations) | | | |
| Direct link | "Three of the five participants | "So I think I could probably hear | Harris, 2016 | |
| between | described hearing malevolent | her voice and certain things like | | |
| psychosis | voices associated with difficult | that and I met up with her | | |
| phenomena and | interpersonal relationships or | recently and she explained her | | |
| past adverse | abuse" (p.86) | side of the story, I explained mine | | |
| experiences | _ | and we came to some mutual | | |
| _ | | ground." (p.49) | | |
| | | | | |
| | "beliefs interpretable as | "In elementary school I was | Bergström, | |
| | psychosis were often linked to | bullied constantly. So much that I | 2019 | |
| | actual life events" (p.109) | wanted to kill myself. I think my | | |
| | - | psychosis started then, though | | |
| | | nobody realized it. I started to | | |
| | | hear their voices and I often saw | | |
| | | those figures in the forest near our | | |
| | | house, but when I got closer there | | |
| | | was no one there." (p110) | | |
| | "Donald describes a crucial step | "Well, I suppose what it was, was | Thornhill, | |
| | on his journey of recovery was | in my psychotic episodes the | 2004 | |
| | realizing that his voices were | really the one theme was about | | |
| | meaningful within his life | my own child abuse when I was | | |
| | experience, for example, that he | younger and in my psychosis I | | |

| priest who sexually abused him as a boy, of his dead father, and of his girlfriend who committed suicide." (p.190) detective trying to work out the riddles, the clues as to what happened." (p.190) | | heard the voice of the catholic | alwaya want baala lilaa a [] | |
|--|-------------|----------------------------------|-----------------------------------|---------------|
| as a boy, of his dead father, and of his girlfriend who committed suicide." (p.190) "Howard has been abused as a child and crossed the line himself as an adult with a 16-year-old. He hears voices which condemn him for his deeds. Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | | always went back like a [] | |
| of his girlfriend who committed suicide." (p.190) "Howard has been abused as a child and crossed the line himself as an adult with a 16-year-old. He hears voices which condemn him for his deeds. Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | | | |
| suicide." (p.190) "Howard has been abused as a child and crossed the line himself as an adult with a 16-year-old. He hears voices which condemn him for his deeds. Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | | · · | |
| "Howard has been abused as a child and crossed the line himself as an adult with a 16-year-old. He hears voices which condemn him for his deeds. Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | _ | TT TT | |
| himself as an adult with a 16- year-old. He hears voices which condemn him for his deeds. Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | | | Moernaut, |
| year-old. He hears voices which condemn him for his deeds. Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | | | 2018 |
| condemn him for his deeds. Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | | | |
| Furthermore, he also has telepathic contact with two notorious child abusers and murderers, with whom he | | I = | | |
| telepathic contact with two notorious child abusers and murderers, with whom he | | | | |
| notorious child abusers and murderers, with whom he | | | | |
| murderers, with whom he | | | | |
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| | | · · | | |
| | | | "I will be able to smell my dad's | Parry, 2020 |
| discussed associating "smells with the voices". (p.7) | | discussed associating "smells | | 1 4113, 2020 |
| "They get really loud when I see | | (p./) | "They get really loud when I see | |
| something that reminds me of my | | | | |
| experiences such as growing out | | | | |
| my hair, my scared self voice | | | my hair, my scared self voice | |
| starts telling me he is gonna come | | | | |
| back" (p.7) | mi . | 100 | | |
| Threatening nature of "Participants used a range of words to describe experiences," "I could hear something (yeah) speaking tae me, but I couldnae 2010 | | | | Anderson, |
| experiences including 'terrifying', speaking tae me, but I containe 2010 hear it, you know? And it was if it | - | _ | | 2010 |
| 'frightening' intense', was trying tae make me say (yup) | experiences | | • | |
| 'confusing', 'comforting', 'a buzz' stupid things, you know? Like I | | | | |
| and 'exhilarating'." (p.58) was always watching what I was | | | | |
| saying, and I became worried | | | | |
| about going out of the house | | | | |
| (right) and stuff like that." (p.58) | | | | |
| | | | | Bergström, |
| such mental states were characterized by terror, though flying around you and hear those | | | | 2019 |
| some participants viewed this as voices. But on the other hand it | | | | |
| in some sense a relieving state was a constant fight with my | | | | |
| of mind, warding off an even parents about what was real and | | | | |
| more horrifying reality" what was not, as they attempted | | | | |
| (p.111) to wake me up to the real world, | | (p.111) | | |
| even though the real world was | | | | |
| precisely what I was afraid of." | | | | |
| (p.111) "For instance, some participants" "Sometimes if I am doing Parry, 202 | | "For instance, some participants | | Parry, 2020 |
| described a paralleling of their something like making a gift for | | | | 1 411 y, 2020 |
| critical thoughts or those of someone, it would say that I am a | | | | |
| others in their voices". (p.5) bad friend and they wouldn't like | | | | |
| it in a mean angry voice". (p.5) | | * ' | | |
| "I started seeing two people and Harris, 20 | | _ | "I started seeing two people and | Harris, 2016 |
| also erm (1) the voices I heard | | | | ĺ |
| most of the time, there's two | | | | |
| people I can hear them (1) clearly | | | | |
| (1) they say that I'm not worth in | | | | |
| this world, I shouldn't live in this | | | | |
| world, I should do something to myself (1) I should, I should | | | | |
| | | | | |
| | | | die" (p.54) | |

| Protective nature of psychosis experiences | "An emerging theme within some narratives was that voices could have a soothing influence upon other voices and the young person". (p.6) | "the only other voice I heard said only the words 'your safe now' and I didn't hear from the other one for the at-least the next few months" (p.6) "I was excited. It felt like I had a bunch of friends that I could talk to and get help" (p.6) "I miss my old voices, they feel like my closest friends who I can't talk to anymore" (p.6) | Parry, 2020 |
|---|---|---|--------------------------|
| Changing relationships with voices | "For many, their voices changed over time as their awareness grew and they established more relationships, which often altered the participants' perceptions of their voices." (p.6) | "They want to protect me (1) so because no one ever did anything, for me that much. I think they are looking out over me." (p.55) "I didn't realize it wasn't real until other people/their reactions told me." (p.6) "Before I was glad now I have mixed emotions about them" (p.7) | Harris, 2016 Parry, 2020 |
| | "Gareth also describes a similar change in his thinking when he realised that the voices he had been hearing were not real" (p.110) | "Maybe it was the fact that I'd been told, 'look, something's been going seriously wrong in your mind, ok, you've got to stop' when I went on a holiday with my parents to Sicily obviously everyone around me was speaking Italian and I was still hearing these voices so it was then that it really kicked in, 'I am not really hearing these things'." (p.110) | Bluffield, 2006 |
| Unable to make sense of experiences | "These stories were characterized by a distorted sense of reality, and some participants indicated that they were still not certain as to what was real and what was not." (p.111) | "That psychosis was like you were sinking into some kind of a darkness where you couldn't find your way out. Like someone was pulling you down. I don't know what it really was." (p.111) | Bergström, 2019 |
| | "Although this was not always depicted as a crisis, the stories of developing psychosis and being hospitalised were all characterised by confusion." (p.91) | "It was very, very strange. It was very strange how my brain just completely () started making strange associations and building ideas. I still don't know which part is true actually." (p.91) "I went nuts, well I sort of no I, I don't know I just didn't feel the same I didn't know what was going on. I used to get really screwed up ideas, I used to go on walks trying to find people just weird Its sort of, a lot of problems with psychosis, you don't know what's real and what's not any more." (p.91) | Bluffield, 2006 |

| | "Fear, vulnerability and a feeling of unsafety were common amongst the narratives, with some participants stating that it was not easy to explain but 'you could feel it'" (p.52) | "my psychosis sort of spiralled into, it went from being emotions that I could quickly, that I could explain to you really easily and then it turned into kind of like a deluge of probably so many emotions and being in such, like a deprived state sort of physically and mentally" (p.53) | James, 2019 |
|---|---|--|----------------------|
| | "She stressed repeatedly that psychiatric professionals failed to interpret her emotions accurately, as they could not see that the difficulty was only in the articulation of her feelings, not in the feelings themselves." (p.115) | "I remember a helpless sense of 'How do I express the inexpressible? How do I talk about my fear, when to articulate that I'm afraid is, in itself, frightening?" (p.115) | Efthyvoulou, 2018 |
| Avoidance and escape | "Types of coping were linked to the 'genre' of the individual's narrative: for example, attempts to avoid thinking about or talking about experiences were associated with 'escape' narratives" (p.60) | "I smoke a lot of grass (uh huh) and I have done for a long time (yeah) But whenever I do kind of stop, or do kind of cut down or whatever (yeah), it leaves me feeling quite vulnerable, because I find that with it, it kind of helps me to block out a lot of kind of (right) emotional stuff that is sort of, really builds up over time" (p.65) | Anderson, 2010 |
| | "The fear and horror of psychosis and extreme emotions such as fear, despair and fragmentation revealed Eleanor's need to disconnect from the world physically, as a preventative coping strategy, such as by stopping herself from moving" (p.115) | "My own experience of this reflected a fundamental need to disconnect from a world with which I had ceased to identify or desire to know. Or, at other times, it protected me from the shocking, unsettling impact of voices or flashbacks." (p.115) | Efthyvoulou, 2018 |
| | "Overall, strategies initially trialled for dealing with voices including resisting them, avoiding feared situations and people related to voices, were ineffective." (p.1412) | First-order construct not available | De Jager, 2016 |
| Substance use as an explanation for psychosis phenomena | "Some put the experiences of mental illness firmly in the past, for example Oliver (WB) and Richard (WB), and Beth (WB) and Lydia (WB), who felt that their psychotic episodes had been precipitated by illicit substances and prescription drugs, respectively, and had subsequently been treated." (p.5) | "I'm over and done you know, it was something, was an episode something that happened, it was induced, drug induced, it was not so it shouldn't have any bearing for future things". (p.5) | Lawrence, 2021 |
| | "Most but not all had embraced a medical understanding but this did not preclude them from also | "Because I was smoking weed to try and chill myself out, but it didn't really work. And I just | Bluffield, 2006 |

| having personal explanations, such as increasing stress, relationship breakdown, teenage life struggles, or smoking cannabis as also contributing." (p.95) "Patte frequently referred to different ways of coping with life's difficulties and her overall 'confusion'. She initially | started smoking on my own which was probably what done my head in. I mean, the weed probably didn't actually do it completely, like 'it was all because of me smoking cannabis'. I reckon it was just other things which I was having trouble handling at the time as well." (p.92) "In the maelstrom of emotional confusion, denial and avoidance of my repeatedly broken heart, I had a puff of marijuana, | Efthyvoulou, 2018 |
|--|---|----------------------|
| mentioned the use of marijuana, which seemed to have intensified her experiences into an alternated state of bliss, ecstasy but also terror about her 'non-existence'." (p.105) | andtime stopped. I could hear the same sound over and over, and let out a terrified, choking scream." (p.106) | |
| "Frank emphasised that he accessed the EIP service as a result of excessive drug use." (p.60) | "Basically (1) I used to binge on drugs. On a cocktail of drugs and then (1) like you hear about the celebrities just freaking out on the drugs, I just got too high, erm, and just freaked out." (p.60) | Harris, 2016 |
| "Following a series of difficult experiences, use of LSD, and involvement in a 'New Age' style weekend, which he says drove him 'completely mad', Simon was admitted to hospital." (p.189) | "It was like serendipityit was like a moment of, you know religious language would be kind of 'grace' or something, you know. It would be like something changed. And I was aware that something changed and I let go of something." (p.189) | Thornhill, 2004 |
| "Michael and Dane alluded to the potential for the use of substances contributing to their experiences, which could be understood as a biological or social factor Dane was sceptical about the role of substances in his experience but felt his family and the team largely attributed his difficulties to drug use." (p.54) | "[drugs] facilitated the paranoia" (p.54) | James, 2019 |
| The state of the s | "I stopped taking acid and ecstasy because people seemed to be betraying me, and - my, in my thoughts - seemed to be betraying me worse when I was on these kind of drugs (right, okay). So I just smoked hash, and people didn't seem to be as bad" (p.60) | Anderson, 2010 |

| Psychiatric treatment: Powerlessness, mistrust and the relationship with the medical model | | | | |
|--|--|--|--------|--|
| Second order construct themes | Example second order constructs (researcher interpretations) | Example first order constructs (illustrative quotes) | Author | |

| Powerlessness | "Participants often felt powerless, forced to take medication against their will and unable to make their concerns heard." (p.4) | "I just felt that I wasn't being listened to even though I was genuinely expressing what was going on, it's kind of not being believed" (p.4) | Lawrence, 2020 |
|---------------------------|---|---|-------------------|
| | "In this context, psychiatric services may not be experienced as therapeutic, but as a form of oppression that initially provokes resistance, and over time, acquiescence, and resignation to the identity of psychiatric patient." (p.7) | "I don't know what madness is but I wouldn't say anything, I'd let them [CPN] do the talking but I won't contradict or say what I think if you know what I'm trying to say because whatever I say is not right but what they say is right so that's why I don't say anything." (p.4) "I didn't want to say that I was hearing voices in case I got put into hospital and I was confirmed mad". (p.5) | Lawrence, 2021 |
| | "Moreover, the young people described their fears of being misunderstood by professionals with the risk of being readmitted to hospital hanging over them. This was associated with a pervasive sense of powerlessness, perhaps leading to the self-censoring of some of their more critical views." (p.85) | "I felt kind of vulnerable and I felt like, no one was trying to, I felt alone, yeah, I felt isolated that I didn't have a say in anything of my life. I just thought I was a muppet, I was controlled." (p.51) "I got put into the hospital (1) which was the worst move to this day I'll say they ever made, because they didn't even tell me it was a mental health hospital, they just kind of threw me in the hospital and left me there". (p.68) "They didn't explain it's for my mental health and they (1) all I got told was just take your medication and if you don't we're going to inject you." (p.68) | Harris, 2016 |
| | "Eleanor emphasised repeatedly how she was overwhelmed by her emotions because of her schizophrenia experiences, however she quite frequently mentioned emotional distress and punishing approaches occurring during her hospitalisation. One specific example of this was revealed when she was detained because she refused to take medication" (p.119) | "In the end the surliness and stillness which led me to resist the doctors' probing and refuse medication earned me a place in 'The Annexe'. This chamber was little more than a padded cell, and I was aware of being watched through the grille in the door." (p.119) | Efthyvoulou, 2018 |
| Mistrust of professionals | "Our qualitative data suggests that mistrust of mental health services not only contributes to a reluctance to seek help among people of black ethnicity (Islam et al., 2015), but also exacerbates individuals' sense of | "From then I couldn't talk to anyone, I didn't feel I could trust anyone there, to be treated like that I just lost so much trust." (p.3) "I know from, you know, my brother that works for an | Lawrence, 2020 |

| | vulnerability when services are | organisation and he, beforehe | |
|--|---|--|----------------------|
| | accessed." (p.5) | worked for somebody who dealt with mental health and that's what they dealt with was you know people of colour being put into mental health, being wrongly diagnosed, totally drugged up. I was just, I was terrified". (p.3) | Do Iozar |
| | "They were acutely aware of the risk involved in disclosing that they were hearing voices to mental health professionals, fearing that disclosure may result in invasive treatments or involuntary admission to a psychiatric hospital" (p.1412) | "As soon as you mention voices- and you pick it up really early-is they want to fill you up with medication. So it became quite secretive for meI never told people about them" (p.1412) | De Jager, 2016 |
| | "As such, Frank appeared acutely aware of the potential for diagnostic overshadowing and the power of the medical narrative to subjugate any views that challenges its legitimacy"(p.65) | "They use words like drug induced thing and you're not really understanding it, they don't use literal words if you get what I mean, they use coded words, so if there was just, if the wording was more upfront and formal it would register more personally I think."(p.65) | Harris, 2016 |
| | "Eleanor's fearfulness, silence and withdrawal was due to the doctor's disinterest and scientific approach" (p.121) | "The doctors were polite but sceptical and disinterested — and intent, it seemed, to sacrifice me on an eerie altar of science. This left me fearful and wordless, burning in obliterating, outraged silence, and after that I resolved to tell them nothing more." (p.122) | Efthyvoulou, 2018 |
| Traumatised through psychiatric support | "This contributed to a sense of disempowerment that could have a profound and enduring effect on participants." (p.3) | "It was awful, there was very few people who actually cared in there, I mean to be in such an environment where people don't care, and they hold all the cards, and you have absolutely no rights and you have, you know, there's no respect, I mean it wasa nightmare." (p.3) "This whole experience feels like complete rape, a complete psychological, mental rape." (p.3) | Lawrence, 2020 |
| | "The young people conveyed how the traumatic quality of experiences of psychosis and hospitalisation had an impact on their sense of themselves and their world, such as becoming more fearful of people, feeling ashamed and losing confidence and pride." (p.139) | "I've never been treated like that before in my entire life. They were grabbing onto my arms so tightly, lifting me up by my arms, and I just started kicking and screaming, saying like 'I deserve my own space, my own time, my own freedom,' and stuff like that, and they were like 'Not now you don't' kind of thing." (p.87) | Bluffield, 2006 |
| | | "They started saying 'Oh don't you have any pride?' and all this. Iwas like 'Oh my God'. You just, you know, this actual process of | |

| | | hospitalisation strips you of your | |
|---|--|---|----------------------|
| | | own pride, you don't have anything left because you don't have any choices or any freedom at all, you're in kind of captivity. You're being watched all the time, where can you find the pride in that?" (p.87) | |
| | "Mary talked about 'being convicted of' five psychotic episodes. She experienced hospital as 'a prison' in which there was a continual danger of attack." (p.188) | "And I walked to the door. You know, goon squad jump on me they actually showed me the needle they held it in front of my eyes said, 'Here it is. This is what you'll get if you don't take your tablets'." (p.188) | Thornhill, 2004 |
| | "When Eleanor overheard the nurses' conversation she described feeling shame, which caused her to think that she 'wasn't even mad in the right way'; as a result, she felt guilty about what she was experiencing. She was also mistreated by medical staff." (p.120) | "I could hear a nurse saying what a shame it was, how I was pretty, intelligent (seemingly) and had let it go to waste. 'She's from a good home,' said one. I felt guilty, as if I had committed a crime. Even here, I wouldn't fit in — I wasn't even mad in the right way." (p.120) | Efthyvoulou, 2018 |
| Lack of diversity and cultural awareness | "Though not directly asked, every black Caribbean woman commented upon the absence of black doctors in the health system who, it was felt, would be more likely to understand their perspective and concerns." (p.4) | "It's interesting that there aren't that many, but yesAfricans, bring in the Africans. I'm serious, I think it would be very, very different, because unless they're completely taken in by this whole system business, which they probably wouldn't be because they were born somewhere else, but they'd just have a completely different way of hearing you when you were saying things." (p.4) | Lawrence, 2020 |
| | "This belief also demonstrated her views that spiritual and cultural elements are crucial to a person's well-being and in a form of protest towards her caregivers, therapists and psychiatrists, she said that these elements were not cultivated during her early years and were missing from her therapy." (p.101) | "No attention was paid at any stage in my journey by any of my caregivers, therapists, psychiatrists or colleagues to addressing my spiritual history or my need to explore my cultural and spiritual heritage." (p.101) | Efthyvoulou, 2018 |
| | "There was a resounding sense among many of the black Caribbean participants that medication and their diagnosis were imposed on them, the latter often incongruent with their own social model of their condition (see below), | | Lawrence, 2020 |

| | confirming negative expectations and exacerbating feelings of powerlessness." (p.6) "These accounts also brought certain characteristics to the fore, as individuals explained their experiences in the context of being deeply sensitive, artistic, imaginative, deep thinking, or spiritual. Together these narratives asserted the importance of the social, psychological, and spiritual aspects of their illness and lives." (p.6) "Frank also noted that spiritual explanations were less-recognised by services" (p.23) | "For me it was a spiritual journey, it was a massive spiritual journey, and yes you do need help on the way and you do occasionally need something to help you sleep or you do need protection, but there's a lot of other things in the medical system that you don't need it's [psychiatry] very sterile, a lot of it is very sterile and it is very clinical, and it's a narrow perspective of life" (p.6) "Yeah but the mental health people don't see the spiritual side of it". (p.23) | Lawrence, 2021 O Brien, 2014 |
|--|--|---|-------------------------------|
| Negative experiences of medication | "Participants typically depicted their first experience of medication as something that they had been done to them. Side effects of the medication were discussed at length with participants using metaphors of 'zombie' and 'vegetable' that conveyed a diminished sense of self." (p.4) | "I told them that I didn't think it [taking lithium] was a good idea. I was quite clear in my mind what I was doing, why I was there and what I was trying to do, what I was trying to do was get the Prozac out of my system, to calm down, restock and get back on with my life really." (p.4) "But the medication, I don't know, I don't know what it was for."(p.3) | Lawrence, 2020 |
| | "Of the participants who had used medication, two reported that it was ineffective for them and led to significant negative side effects. Three reported that medication was helpful in calming them down or dampening emotional responsiveness. It is of note that it did not eliminate their voices. Those who had used medication emphasized negative side effects, describing lethargy, weight gain, fatigue, and lack of emotional responsiveness and spontaneity." (p.1419) | "They gave me some medicine and told me it would get rid of it, but they only just kept getting worse and worse and worseuntil a week or two later, it was virtually nonstop, these two guys talking to each other about me." (p.1412) | De Jager, 2016 |
| | "She narrated her recovery as not only an escape from psychiatric oppression but escape from the stigma of having a psychiatric illness." (p.88) | "I've got a bit of a silence policy on it all, I'm waiting until I come off the lithium What does it mean to you, coming off the lithium? "Just cutting loose another of those chains really"(p.88) | Bluffield, 2006 |
| | "Ed spoke about how, despite changes in medication, he continued to hear voices. He | "Ed also differed in that he 'still got [voices] and they still can be really bad at points' | Bluffield, 2006 |

| withdrew and often drank to cope with this and felt apart from the rest of the world" (p.97) "the young people in this | despite his being on medication. He therefore made less of a distinction between getting well by getting rid of symptoms and the ongoing recovery." (p.107) "GP used to take me seriously | Harris , 2016 |
|--|---|----------------------|
| study raised a range of side effects from their medication that at times hindered recovery." (p.104) | but since the mental health started when I say to them something, they don't take it seriously (1) they always say, oh because you are taking the er, mental health medication." (p.59) | |
| | "Woah, no one wants to go on medication really, you know, any, any human they feel like, you know, they feel (1) it's sort of like to know that you depend on something to keep you, you know, you don't feel human." (p.77) | |
| | "I actually thought yeah that they made [risperidone] deliberately gave it to people who were criminals just to zone you out. That's actually, that's not me being paranoid it's literally made to zone you out and not do any criminal activities." (p.65) | |
| "Even though Patte's mental distress seemed unmanageable, she refused to take more medication due to the side effects. She mentioned that side effects of the chlorpromazine, including suffering from jaundice, made her feel dreadful. She chose to engage in long term therapy instead, in order to manage her extreme states and psychosis experiences." (p.106) | "I began to take regular antipsychotic medication which eventually resulted in very rare form of tardive dystonia leaving me unable to speak without great effort." (p.106) | Efthyvoulou, 2018 |
| "Furthermore, at the initial stages of his story, Richard also referred to the 'appalling time' he had because of his medication." (p.133) | "The medicine I was put on, as I was diagnosed as suffering from paranoid schizophrenia, gave me an appalling time. In terms of thinking I could neither remember nor articulate any." (p.133) | Efthyvoulou, 2018 |
| "This view seemed to leave him hopeless in managing his difficulties in any other way, therefore, he explained submitting to the psychiatric treatment even with the drawbacks of his medication" (p.134) | "Physically, I was like an old man, even though I was only 24 years old at the time. This experience led me to an initial, but deeply felt hatred of psychiatric drugs." (p.134) | Efthyvoulou, 2018 |
| | "I also don't want people to tell on me to mental health professionals because I have heard that | Parry, 2020 |

| | | antipsychotic medicine sucks a lot" (p.5) | |
|------------------------------------|---|---|----------------------|
| Positive experiences of medication | "Although many of the young people took medication reluctantly due to unwanted side effects, particularly weight gain, they often talked about how it had enabled them to gain control of the most disabling symptoms." (p.106) | "recovery from being acutely ill was kind of easy in that I just took the tablets and then got myself a job and a house". (p.106) "I wasn't so freaked out about things, I wasn't so unsure and I was sort of back to normal thinking in perspective the medication, it sort of worked really quickly". (p.106) "Well, I keep to my meds now because a lot of it was that I didn't stay on my meds when I was at college."(p.109) | Bluffield, 2006 |
| | "Medication contributed to recovery by enabling them to function better, communicate with others, engage in activities, and think more clearly" (p.1414) "Medication also eliminated voices in some cases or allowed participants to change their response to their voices, enabling them to hold a more comfortable distance from them." (p.1414) | "I can function better and I can think better and I've been able to pass my courses." (p.1414) "I started to see the light at the end of the tunnel more and more it was not a train coming from the other way but a light outside." (p.1414) | De Jager, 2016 |
| | "Participants drew on medicalised language and practice, widely referring to their experiences as an illness and speaking of the key role of medication" (p.56) | "the combination of the medication and team has really pulled me through" (1130-1131), "I've never felt this well balanced and I think it's got to do with the medications". (p.56) | James, 2019 |
| | "Even though Richard mentioned having had negative side-effects from the medication, he continued to use the established psychiatric medications, implying that previous attempts at stopping had not been helpful." (p.133) | "In that time I have learnt about many alternative treatments, but despite using these as complementary, my experience has taught me to stick to the established medicines, even though their effects are not always helpful." (p.133) | Efthyvoulou, 2018 |
| | "Though flawed: medication helped alleviate symptoms; inpatient admissions kept them safe; diagnoses described their problems; and mental health professionals could help to keep them on an even keel." (p.5) | "I would put it [perceived recovery] down to five things possibly, my Mum, my close friends, medication, the professionals and of course me, I have played a big part in me getting better". (p.5) | Lawrence, 2021 |

| Acceptance of a medical explanation | "A recurring theme within this group was the narrative that doctors know best, and diagnoses had been made and accepted on this basis." (p.4) "These accounts seem to illustrate how medical frames of reference could be used to create a 'self-protective narrative', alleviating feelings of self-blame and shame". (p.7) | "They say it's schizophrenia but appeared unsure of what that meant or what contributed to his relapses" (p.4) "If you're told enough times you believe it."(p.6) | Lawrence, 2021 |
|--|---|---|--------------------|
| | "Most of the young people held a medical explanation"(p.92) | "Something to do with too much dopamine in your brain or serotonin or something like that, it sort of mixes your head up and you start psychotic things, because I've been told that about 8000 times and I actually agree with it, it does actually do things like that." (p.92) | Bluffield, 2006 |
| | "There was also an indication that the medicalisation of distress was supportive for some participants, in that it absolved them of feelings of shame." (p.59) | "the way my brain works" (p.55) | James, 2019 |
| | "The master medical narrative of psychosis was present in all of the young people's constructions. For some participants, this was adopted and appeared to offer a way to legitimise their distress and access support that they had been previously denied." (p.85) | "[EIP] diagnosed me with bipolar, so I knew what that was, so I understood it a bit better" (p.68) | Harris, 2016 |
| | "A stance of endurance, and even acceptance of a diagnosis of 'schizophrenia', did not necessarily preclude a definition of oneself as recovered, however." (p.191) | "recovery is 'a process [] rather than an 'end thing'" (p.191) | Thornhill, 2004 |
| Questioning of biomedical explanations | "Participants recognised the utility of medication for managing symptoms but were unequivocal that their experience could not be reduced to psychopathology and biological treatments." (p.7) | "I wouldn't put it in a doctor's I wouldn't use the same language you would use for it For me it was a spiritual journey, it was a massive spiritual journey, and yes you do need help on the way and you do occasionally need something to help you sleep or you do need protection, but there's a lot of other things in the medical system that you don't need " (p.6) | Lawrence, 2021 |
| | "Overall, in this study, people who had experienced a crisis diagnosable as psychosis commonly attempted to create meaning for their experiences by integrating the crisis with other life-course experiences; thus, they did not view it merely | "Of course some people might benefit from treatment, I mean medication and stuff like that, but for me the most important thing was my friends and my family. It's just that someone listens to you, is interested in you, and is present." (p.110) | Bergström, 2019 |

| as a representation or symptom | | |
|--|---|--------------------|
| of a disorder." (p.112) | "I was bullied quite severely, and I think my mind somehow got stuck in the school premises" (p.110) | |
| | "In elementary school I was bullied constantly. So much that I wanted to kill myself. I think my psychosis started then, though nobody realized it." (p.110) | |
| "However, in these studies hope was often found from somewhere other than psychiatric services, which were often associated with diminishing hope." (p.130) | "I don't think you can recover totally so suddenly you just turn around and go click no voices, no depression, no pills, sortedBut it's just like working out what you're going to do with your life." (p.121) | Bluffield, 2006 |
| | "by next summer, I will be trying to leave my medicationif everything goes well, if it works then I think I will be recovered. Only if I leave my medication really" (p.120) | |
| "The majority of service users did not narrate understanding their experiences within a medical framework." (p.82) | "but in the hospital they didn't tell me I'd got any diagnosis, they just kept pumping me with meds and injecting me, you know? So erm, they said I'd got bipolar and said it was triggered from breast feeding my child which I didn't know I just thought it was a pile of poo [laughing] because how can you go from being normal to having a total psychotic mental health issue from having a baby? A permanent one as well?" (p.68) | Harris, 2016 |
| "Thus the tellers of some escape narratives would contend that they had to escape form a false and limiting notion of 'mental illness' in order to recover meaningful lives. Interestingly, all of those who told escape narratives had been diagnosed with either schizophrenia or schizo-affective disorder, arguably the most stigmatizing of diagnoses, and escaping from the identity this commonly represents was a crucial part of all these narratives." (p.193) | "support all the way roundmoney, partners [] health professionals You need positive people in your profession. You don't need people who say, 'She'll never recover. She's for the scrapheap, she'll never work again, she's on medication for the rest of her life'."(p.191) | Thornhill, 2004 |

| Second order construct | Example second order constructs (researcher | Example first order constructs (illustrative quotes) | Author |
|------------------------|---|---|----------------------|
| themes | interpretations) | , | |
| Loss of identity | "Many people experience an initial sense of their identity being subsumed by that of being a patient or voice-hearer and losing their sense of self because of the overwhelming nature of voice-hearing experiences" (p.1417) | "When I was in trouble with hearing voices, I didn't know myselfI lost my feeling, lost my self-knowledgeWith the voice telling me to do things I just lost my self-controlI behaved toward peoplejust aggressively." (p.1413) | De Jager, 2016 |
| | "Some of Eleanor's descriptions revealed loss of self." (p.122) | "And so I submitted to this version of events, submitted to what was happening to me, let go of my will and suffered the loss of myself." (p.122) | Efthyvoulou, 2018 |
| | "Before illness, the participants had perceived themselves to be competent: 'things were happening' in their lives and there were 'dreams, goals, normal things'." (p.469) | "I remember when I was normal it was so different so much nicer The life I had before wasn't that bad when I was younger I always felt popular the same as everyone else." (p.470) "all the good things I knew about me got erased'. It's kinda like all the good stuff gets erased and the negative stuff takes hold of your mind." (p.470) "Usually I liked to go for bike rides and skateboard and hang out with friends and stuff like that play games watch TV" (p.470) "(I'm) always dreaming about going back to my old life I just want to go back to them days the memories of being normal." (p.470) "Healthy might be a better term instead of 'normal' I think healthy reflects everything because there's physical, mental and emotional health. You can have diabetes and just not be healthy but you're still normal." (p.470) | Gould et al., 2005 |
| | The impact of psychosis appeared to be pervasive, affecting emotions, sense of identity and role, relationships with others, occupational activity, and thoughts and feelings about the world and | "I've never been a needy person, and it was very hard having to be needy when I first became ill. That was a (right) massive blow to me (uh huh)." (p.58) | Anderson, 2010 |

| expressed stigmatised narratives regarding perceptions of the limitations and lack of agency of people with psychosis" (p.21) "you know, mental health people, no job, no career, no progression after my studies and it's just, you know, all around all round disappointment really" (p.21). "More generally, the young people received mixed reactions "Because some people who sometimes came out with us were "Buffield, 2006 | | | | |
|---|-----------|---------------------------------|--------------------------------|---------------|
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| people received mixed reactions sometimes came out with us were 2006 | | "More generally, the young | "Because some people who | Bluffield, |
| from their friends. In speaking | | | | · |
| nom men mends, in speaking | | from their friends. In speaking | | |

| about this they all related an awareness of being approached differently by others as a result of psychosis." (p.100) | like, 'that blokes a fucking freak." (p.100) "People reacted with a lack of knowledge really. They don't know much about psychosis. If you say schizophrenia they understand better but then they started getting afraid a little bit. But most of the time they were surprised really because I am such a calm person". (p.100) "Some of my friends have been great, and some of them have dropped away completely." (p.100) "And then my friends were a bit taken aback () because they hadn't seen me all the time I was ill something kind of fundamentally changed in their perception of me" (p.101) | |
|--|--|-------------------|
| "Frank talked about accessing the EIP service in a way that suggested this posed a threat to his previous sense of self, one strongly associated with dominant narratives of masculinity and the non-expression of emotion." (p.63) | "I was embarrassed, I was, I felt like I don't need it, I felt embarrassed in a sense that people are degrading me because I'm a grown man and I've got to come see a lady and talk to her and everything." (p.63) | Harris, 2016 |
| "Participants of all ages were keenly aware of the stigma associated with voice hearing, even if their personal experience of voices was relatively positive" (p.5) "Overall, the impact of judgements from others was profound, leading to the internalization of stress and stigma, which influenced help-seeking, self-perception, relationships, and voice-related distress." (p.5) | "I don't feel comfortable talking about it to my siblings or anyone else since I'm scared they'll be full of stigma and they'll leave me out. Or call me insane or crazy" (p.5) "there's a stigma that people who hear voices have psychosis and think of serial killers and psychopaths but that's incorrect" (p.5) "people don't want to be singled out as weird or different especially teenagers, we are very self-conscious". (p.5) "Often, what makes people mentally ill is some other people's prejudice". (p.5) "I feel bothered by people for not being 'normal', which makes interacting with others hard". (p.5) | Parry, 2020 |
| "Participants feared the | "As soon as you mention voices—and you pick it up really | De Jager, 2016 |

| Isolation and feeling alone as barriers to healing | consequences of disclosing their experiences to others, expressing concern that they would be judged negatively because of stigma." (p.1412) "There was a sense of feeling alone that permeated many of the narratives in nuanced ways. Many of the participants spoke about coping with difficult feelings and circumstances alone, prior to and during their experiences. The reasons for this varied. Some participants spoke about feeling that they had to cope with it on their own, as a sign of strength or because they felt there was nobody available to turn to" (p.53) | early—is they want to fill you up with medication. So it became quite secretive for meI never told people about themit wasn't untilI went to a workshop withother voice-hearers that I actually—that I started to talk about them—because I was too embarrassed about telling people what was going on." (p.1412) "I can take a lot but obviously, some things have just been too much for me recently, and erm, I've just thought to hell with it and I've reacted to it. You know, and a lot of, a lot of it's been to my own demise. You know, cutting myself off from people" (p.54) | James, 2019 |
|---|--|--|--------------------|
| | "Many of the stories recounted a period of feeling isolated and disconnected, in which the young people spent a considerable amount of time on their own." (p.97) "Ongoing symptoms, losses, adjusted lifestyle and altered social networks left the young people feeling isolated, disconnected from others and distanced from their peer group." (p.104) | "And after that became quite isolating. I remember saying to my dad that reminded me of a toy town, it was like these people would do their little things every day and I felt as though I was removed from that () which depressed me even more because I thought 'how can I relate? I can't relate to anybody now, I'm in trouble here, I'm sort ofI'm seeing things that aren't there, or I am believing things that aren't real, and I'm not connected to this at all." (p.97) "I started to believe that my friend didn't really want to know me anymore because of the illness and because of the stuff I'd been thinking and saying to her and others." (p.99) | Bluffield, 2006 |
| | "For most, voices ultimately enhanced feelings of isolation, especially for young people who did not feel they could talk to others about their experiences" (p.6) | "I felt as if I was completely alone in my experience" (p.6) "It's a kind of loneliness thing because I didn't have a lot of friends being young and its kind of stayed". (p.6) "Because I don't usually have anyone else to talk to about things". (p.6) | Parry, 2020 |

| | "Eleanor's experiences of madness (flashbacks and voices), her extreme emotional states and her inability to articulate her inner subjectivity to others, led to her withdrawal and disconnection from her environment." (p.117) | "it makes you feel so alone and the voices get worse". (p.6) "Truly, though, it's hard to explain; descriptions of despair are only ever approximations. Sometimes you need to move away from the imprecision of words, to the silences hidden." (p.117) between speech. And so, slowly, unwittingly, I began to withdraw. [Lines 40-43] | Efthyvoulou, 2018 |
|---|--|---|-----------------------|
| | "For some, the emergence of psychosis was associated with loss of relationships, whether due to their own withdrawal, or perceived withdrawal by others." (p.58) | "everybody kinda, when I took no well, they all kinda back-seater (uh huh) and I never seen them again (right) for like months on end (uh huh), you know? And it was as if they just kinda gie'd up on me, you know?" (p.58) "I don't trust anyone" (p.58) | Anderson, 2010 |
| | "Although many had supportive friends or family members, participants felt disconnected from others, which was often encouraged by their voices." (p.1413) | | De Jager, 2016 |
| Struggle to get back to normal life | "Essentially, each portrayed this period of time as retrospective (looking back) or introspective (looking within), but never prospective (looking ahead). The coasting period was consumed with coping on a daily basis and often on a moment-to-moment basis. For some, the coasting lasted up to 8 years and, as time passed, it became increasingly difficult to engage in life and occupation and to break away from coasting | "The days are empty, there's nothing to do but sleep' and 'I just want to go to sleep and never wake up". (p. 470) "I sit there I just think about life." (p. 470) "Sometimes I feel like crap, so I won't do nothing just sit there or veg I'll just sit just laying down on the couch and just doing nothing." (p. 470) | Gould et al., 2005 |
| | "Psychosis also changed participants' everyday lives and routines. A number talked about ways they had been prevented from normal function, from getting enough sleep and feeling able to go about one's business, to engaging in education or employment." (p.58) | "My head was just, ehm, in a terrible mess, basically (uh huh). Um, so uhm, yeah, I had to quit the job." (p.58) | Anderson, 2010 |
| | "When reflecting on this image he appeared critical and overcome by a sense that things cannot change"(p.27) | "It's just sort of what I wanted to do but I can't be bothered these days [laughs]. Yeah. [sniffs] it's not laziness it's like I've given up". (p.28) | O Brien, 2014 |

| "In the period following the first episode the young people were concerned with 'getting back'." (p.96) | "When I came out of hospital I was just really stressed about finding a job, sort of getting back to normality really to get on where I was living independently and have a job and that was all I wanted." (p.96) | Bluffield, 2006 |
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|--|--|--------------------|

| | pportunities supporting recovery | | |
|----------------|--|--|-------------------|
| Second order | Example second order | Example first order constructs | Author |
| construct | constructs (researcher | (illustrative quotes) | |
| themes | interpretations) | | |
| Inner strength | "Often contained within this narrative arc were references to a residual inner strength or 'survival mechanism' that had given individuals the confidence they could recover." (p.5) | "There was always a little candle in there still burning, it's never blown out you know, it definitely inspired me to really make something of myself." (p.5) "I never lost my kids, I never stopped looking after them, I was always preserved, I was always sane, although the world would say you've lost the plot, you know". (p.5) "I think a lot of life's painful experiences are like that, it moulds us, it shapes us, separates the wheat from the chaff, you know, I think it addresses a lot of issues that maybe you wouldn't look at otherwise". (p.5) | Lawrence, 2021 |
| | "While due regard was given to the importance of social relationships, participants made it clear that they perceived themselves - regardless of their sense of control, confidence or wellbeing - as the main characters in their stories of adapting to psychosis." (p.61) | look at otherwise". (p.5) "I made my own recoveryThrough my own determination and strength of will (right, uh huh) I'm in recovery (yeah). And now life is tolerable, tolerable. Not easy, but tolerable." (p.59) | Anderson, 2010 |
| | "Rob inhabited an alternative position when speaking about having overcome childhood abuse and addiction, indicating that was a journey he actively managed alone. " (p.45) | [the experience of childhood abuse] "made me quite strong. (p.45) | James, 2019 |
| | "Experiences of despair and exhaustion gave rise to participants challenging their voices or testing their beliefs about them." (p.1415) | "Challenging the voicesthey might say the whole world will end and your mother will die or people will come round and kill you. But I actually learnt if I said no, no one would come round and kill me." (p.1415) | De Jager, 2016 |

| Retaining balance and restoring confidence | "Participants described how nurturing oneself through rest, diet, exercise, acupuncture, putting one's own needs before others, and keeping an eye on | "I woke up at four in the morning, for me that's a sign I've got too many problems, I'm worrying. So the first thing I did was meditation, 20 min, which is | Lawrence, 2021 |
|---|---|---|----------------------|
| | their wellbeing helped to retain balance." (p.6) | really simple meditation I'm not really advanced on this, I do a breathing meditation or a counting meditation, and the idea of that is to try to still my mind, to stop it from thinking too much, which can happen to everyone early in the morning." (p.6) | |
| | | "You can't avoid stress, but you can avoid being stressed unduly, taking on other people's burdens and stuff, that's something I majorly learnt". (p.6) | |
| | "For most of the young people, learning to understand, anticipate and manage relapse restored their sense of control and confidence". (p.111) | "You learn coping strategiesI went to the Young People's Group we listen to people talking to us and explaining stuff, you learn a lot of information as well. I know what I can do if I feel the symptoms starting again, I know what I have to do." (p.111) | Bluffield, 2006 |
| | "Many participants used mindfulness and distraction techniques to create some space between themselves and their voices" (p.1416) | "(Mindfulness) is really helpfuleven if I think I do hear someone swearing at me, I don't have to take it on board for myself." (p.1416) | De Jager, 2016 |
| Spiritual resources | "The young people from Black Minority Ethnic backgrounds in this research often constructed their experience within a spiritual framework." (p.104) | "I've been brought up in a church from birth, so I just thought it was spiritual thing, a godly thing."(p.48) "What I went through was real for me and no one can ever take that away from me and I pray and I, I still believe it's a spiritual thing." (p.52) | Harris, 2016 |
| | "Seeking spiritual, culturally relevant support offered her a more personal meaning, if not completely modifying her narrative of feeling cursed"(p.23) | "I talked to the holy guy, you know [] I don't know how long it took but I was okay after that little while" (p.23). | O Brien, 2014 |
| | "All of the stories, in their own unique way, revealed a meaningful transformation from the narrator's distressful experience towards a sense of growth and 'spiritual awareness'." (p.149) | "I am loved unconditionally by a Divine Father with my many vulnerabilities and failings. Once I discovered the trustworthiness of a loving Divine Father, I gradually learned to acknowledge my own vulnerability and to grieve my many losses. I slowly developed a resilient sense of my | Efthyvoulou, 2018 |

| | | own worth, value, purpose, meaning and vocation." (p.103) | |
|-------------------------|--|--|----------------------|
| Embracing creativity | "The coping strategies participants described were equally multisensory, with many of the participants discussing creative means such as writing, drawing, storying, listening to music, meditation, and colour breathing. Imagery was a powerful medium, especially for participants who experienced visions as well as voices" (p.8) | Turn it into an imaginary setting and talk to them if they're bothering you". (p.8) | Parry, 2020 |
| | "Art-making was also viewed as offering a distraction from being focused on thoughts and experiences, such as voice hearing"(p.28) | "you concentrate on and then not thinking so much about your own thoughts" (p.28). | O Brien, 2014 |
| | "He mentioned the significance of creativity, beauty, love and finding meaning and purpose in his life as factors that helped to overcome psychosis." (p.90) | "To overcome schizophrenia one must create, value beauty, seek love in one's heart and meaning and purpose in one's life. Reason and fact can help, but in the story of life they are the lesser good." (p.90) | Efthyvoulou, 2018 |
| | "Another prominent theme linking the project to recovery was distraction from distressing thoughts" (p.254) | you don't have to consistently and constantly be consumed with your own inner world, you can be distracted nicely, don't have to be a bad reflection all the time". (p.254) "it was a definite positive step" (p.254) "one more step in a big long journey". (p.254) "normal things can still be entertaining". (p.254) | Colbert, 2013 |
| | | "And then after that I'll write, either a poem if that's how I feel or I just write what my feelings are if they're angry feelings that really helps just to write what they're about, and immediately I feel phew, it's gone I'm not carrying it around anymore, the next thing I do I've got my incense on, I'll have a bowl of porridge, something like that something wholesome and nutritional with a banana, have a bath and go back to bed, something as simple as that and | Lawrence, 2021 |
| | | I'll feel much better." (p.6) "I learnt that there is a lot of things you can do with your life. | Bluffield, 2006 |

| | | You don't have to keep yourself limited to just one thing you can occupy your time with creative things and that actually those things are important to keep you going." (p.84) "I spent a lot of time listening to music and doing lots of artwork | Bluffield, 2006 |
|---|--|--|-----------------------|
| | | It just blocked out everything really, it just stopped me thinking, and it stopped me feeling depressed and alone and all the rest of it and just that made me feel as though there was some sort of purpose to actually getting up in the morning, which was good. And yeah just made me feel better really.! (p.111) | |
| Regaining occupations and meaningful activities | "The young people related processes of taking responsibility, coming to different perspectives on themselves or their beliefs, regaining control and confidence in managing illness, and re-establishing occupational or social activities as important in their recoveries." (p.122) | "I'm getting back in there, I've got a job and I'm at University." (p.112) "I've just been off of work for too long, and it's just been really difficult, trying to get back out and doing things again. It's been really hard but I've been able to do it through [early intervention team] and [CPN] told me the name of somebody that will be able to help with finding a job, and I went in a few times to talk about the training course, try and get something sorted out" (p.112) | Bluffield, 2006 |
| | " engaging in meaningful activities, connecting with others and (re)developing a positive sense of self were key recovery processes common to both typologies. These processes were centered around meeting needs to feel competent, valued, purposeful, and connected to others." (p.1416) | "I had a structure in the day and I used to do mum's house work and cook dinner for the family. I enjoyed all my activitiesthat really got me activated and out of all that sedation. I felt I could do things and enjoy themMy life was good." (p.1416) | De Jager, 2016 |
| | "Activities, intellectual activities, social activities, vocational activities, just anything you can get your hands on Just return to the normal things, like before you were ill, the things you did before you were ill and try to remake that life as best you can." (p.471) | Whether it's spiritual or intellectual or cognitive kinds of things that will integrate into a normal – integrate the person into normal things – so stuff like painting, art, stuff like surfing the net, doing, fixing computers, fixing bikes, writing, you know, all those things humans do because that's what makes us human. (p.473) | Gould et al., 2005 |

| Supportive relationships as key to recovery | "For example, the 'steadying self' narrative, evident among some white British participants, provided examples of positive social circumstances in which family, friends, and colleagues supported individuals to maintain careers and formal education, which in turn, helped nurture a belief that they could recover." (p.7) | "I would put it [perceived recovery] down to five things possibly, my Mum, my close friends, medication, the professionals and of course me, I have played a big part in me getting better". (p.5) | Lawrence, 2021 |
|---|---|--|--------------------|
| | "Participants discussed the ways in which relationships had helped them to cope with the impact of psychosis. Kinds of support described were instrumental and socioemotional." (p.61) | "taking me shopping and stuff like that, taking me down what I needed"(p.61) | Anderson, 2010 |
| | "The importance of connection to others was highlighted as being useful in feeling understood by people with similar experiences"(p.32) | "I think it's helpful if everyone in the group has had, um, a mental health experience at some point in their life [] Because then you don't feel like you're the only one who's been through that sort of thing" (p.29) | O Brien, 2014 |
| | "Many felt less confident, less able, more insecure and more sensitive to others. For some, these changes for the worse were moderated by having friends who had been accepting and supportive and by maintaining some continuity in their lives." (p.105) | "having good friends is probably the main part that helped me recover quicker your friends know what's going on, because a couple of them spent hours researching it. [friend] walked in one day with a fucking big pile like that, and went 'see all this, I've read all this.' I went 'what is it?' He went 'It's about psychosis and depression.' I went 'What have you read that for?' He went 'So I know what's going through your head. ' So they knew a hell of a lot about it, and they were there for me and they understood it all." (p.108) | Bluffield, 2006 |
| | "Of course some people might benefit from treatment, I mean medication and stuff like that, but for me the most important thing was my friends and my family." (p.110) | "Other factors that brought relief were also often found outside the actual mental health treatment, especially in relationships with significant others" (p.109) | Bergström, 2019 |
| | "developing supportive, nonjudgmental relationships with others was invariably associated with recovery" (p.1416) | "It's goodsometimes I say 'I don't feel like talking for five minutes or at the moment, just feeling a bit stressed." And she more than understands. (p.1416) | De Jager, 2016 |
| | | "We've got a lot in common and help each other she's a good friend to meIt's very comforting | |

| | | that she can be a friend, whereas | |
|---|---|--|-----------------------|
| | | my family is quite cold." (p.1416) | |
| | "Robert described that he would not have been able to regain control of his life without the support of family and friends" (p.471) | "If I didn't have my parents and my family and friends I wouldn't be going nowhereI'd be stuck." (p.471) | Gould et al., 2005 |
| Community based support | "Most participants viewed the community-based setting as beneficial in overcoming barriers to access and extending further into their communities." (p.29) | "And I also I also wouldn't have to feel more, um, like an outsider and alone at home". (p.29) | O Brien, 2014 |
| | "It was also noticed that EIP teams were often positioned within saviour roles within narratives." (p.56) | "I mean it wasn't like I woke up and it was gone, it did taper off slowly with the help of you know, it was really the help of the EIP team, you know their support". (p.56) | James, 2019 |
| | "Shoma described how the support offered by the EIP service had helped her to regain a sense of independence and pursue her goals such as going to university; her choice of course perhaps an insight into her belief in the medical narrative." (p.56) | "I don't think I would be able to do it, what I'm doing now without their help. I guess, because I'm planning, I thought I wouldn't be able to do anything, but now I plan to go to Uni, I've applied for it to do medicine" (p.56) | Harris, 2016 |
| Re-storying as central to recovey | "Participants expressed turning- points through the re-storying of experience, to offer them hope or a new perspective."(p.22) | "the broken pieces of my life, in the past [] I would try to bring the pieces back together again, like a puzzle." (p.22) | O Brien, 2014 |
| | "Some of the participants shared a view that it was only within their psychology sessions that they really had time to explore what they had been through, suggesting that their previous contact with the team had focussed on present factors." (p.57) | "You know, that was when it really brought it home to me when, as soon as the psychologist had left, I would sit down and think about things and think oh blimey, you know, you have been through the ring a bit" (p.57) | James, 2019 |
| | "Therapists and counsellors had played an important role in helping individuals in this group to talk about painful emotions and experiences. Conversely, psychiatry was strongly criticised for neglecting these important aspects of individual's lives." (p.6) | "It's [perceived recovery] particularly to do with the counselling, particularly unearthing one or two key incidents in my past and starting to deal with the emotions that are attached to them that were quite traumatic in their own right, and it took me that long to get to what they were and start dealing with the emotions around them". (p.5) | Lawrence, 2021 |
| | "In attending to the young people's constructions, those who had actively engaged in | " What I got from it was that everything that I've been through was a pattern from like something | Harris, 2016 |

| | more formal means of sense- making (e.g. through psychological therapy or support groups), appeared to construct more multi- dimensional understandings of their 'unusual experiences', drawing upon a wider range of narratives." (p.84) | I've held in from the past from people and [my psychologist] allowed me to reflect on certain experiences in my life that I held on, or certain traumas and stuff like that that made me understand a bit more." (p.48) | |
|---|--|---|--------------------|
| | "Overall, the authors expressed their distressing experiences of psychosis but also their growth being part of their meaning making process and indicated that increased self-awareness was necessary for progress in recovery" (p.150) | "I am effectively 'cured' of schizo-affective psychosis, but this would never have come about if all I'd aimed to do was think about 'how to get out of it' — which is the usual focus of professionals. I had to delve into causes, not only genetic (my brother George also was schizophrenic) but also cognitive, motivational, familial, interpersonal, socioeconomic, political and spiritual." (p.90) | Efthyvoulou, 2018 |
| | "Gareth identifies the opportunity to express the shame he had felt through talking with formal professionals and with informal supports as the most important thing in helping' him to move on" (p.108) | "And just thinking it through and talking about it with [psychologist] and with my mum. Basically those are the only things that have allowed me to get over it. Those were the main things." (p.108) | Bluffield, 2006 |
| | "On her second admission she was admitted onto a therapeutic ward, run along psychodynamic lines. Here she was offered the opportunity to talk and be listened to She felt that being listened to and taken seriously was a 'life and death issue'" (p.188) | "I had a very passionate feeling that I needed help with a great many human problems'." (p.188) | Thornhill, 2004 |
| Lack of opportunity for re-storying | "There were quite a few descriptions of emotional risks and punishing approaches that she encountered from the medical staff. Furthermore, the clinicians' assessments were ruled by misguided assumptions based on the diagnosis schizophrenia rather than from listening to Eleanor's subjective experiences." (p.120) | "This is an important issue, because a diverse and meaningful emotional life has traditionally been denied individuals designated 'schizophrenic', emotion is either dismissed as disturbed and disorganized, or else presumed to be entirely absent." (p.120) | Efthyvoulou, 2018 |
| | "It is important to emphasize that not one single participant reported receiving psychological intervention that was specifically aimed at dealing with voices. Those who engaged in behavioral experiments and other cognitive | First-order construct not available | De Jager, 2016 |

| behavioral therapy (CBT) strategies did so without the help of a psychologist." (p.1419) | | |
|--|-------------------------------------|-------------------|
| "After years of close contact with CPNs and four repeat admissions, she felt that her symptoms were now bearable, but that mental health services had let her down by failing to address the traumatic events in her childhood. Like others in this group, she had not accessed talking therapy and appeared to have little hope that she would receive support for these issues in the future." (p.5) | First-order construct not available | Lawrence, 2021 |

| The new self | | I was | I |
|--------------------------|---|--|--------------------|
| Third order constructs | Second order constructs (researcher global interpretations) | First order constructs (illustrative quotes) | Author |
| Adverse views of self | | | |
| | Reduced Confidence | | |
| | "These experiences had affected their view of themselves in terms of their confidence, activity levels, concentration, memory, vulnerability, social skills or body image." (p.102) | "I was always kind of brimming with confidence and even if my boss was there or something I would never have a problem with it and now I find it really stressful dealing with people in positions of authority" (p.103) "I guess I wish I'd stayed the same more than I have. I worry a lot about how much I think I might have changed because of being unwell. Whereas I quite liked my old self but a big part of me feels very different, and I think it's to do with insecurity." (p.103) | Bluffield, 2006 |
| | "All the participants reported that they were no longer experiencing significant paranoia. However, the majority of them reported that they had been left with difficult feelings" (p.55) | "I just feel half the person I was" (p.49) | James, 2019 |
| | Shame | | |
| | "The young people conveyed how the traumatic quality of experiences of psychosis and hospitalisation had an impact on their sense of themselves and their world, such as becoming more fearful of people, feeling | "That's the only negative side. It means that I cannot do itIt's living on benefits forever, not being productive, not being able to build something. Therefore not being able to actually build a family, you know, have children as well So it's the whole thing, not | Bluffield, 2006 |

| ashamed and losing confidence and pride." (p.102) | being able to have a life as everybody else has really." (p.106) "when I look back at that whole episode I feel, you know, shame, I feel, you know, it was a disgrace I did behave abnormally, I did behave disgracefully". (p.102) | |
|--|---|--------------------|
| Fear | | |
| "The young people conveyed how the traumatic quality of experiences of psychosis and hospitalisation had an impact on their sense of themselves and their world, such as becoming more fearful of people, feeling ashamed and losing confidence and pride." (p.139) | "I noticed so much stuff that I didn't used to notice 1'11always have an insight that I wouldn't have if! hadn't got ill .1became much more fearful of people that's something that started in hospital and it's really lasted". (p.102) | Bluffield, 2006 |
| "Overall, in these stories, life continued after the crisis. Most of the participants were able to continue with their jobs and to maintain other important life aspects. However, most of them also expressed regret, in that there was no going back to the time before the crisis, and that things had not worked out in their lives as they had expected" (p.110) | "I imagined my life was going to be good, or at least normal, or something like that. You get a job, you have friends, but for me things didn't work out that way. Of course you still wish you could be a herd animal like others, but for some reason I always had those difficulties." (p.110) | Bergström, 2019 |
| "Narratives [of entrapment] were distinguished by rumination and perseveration upon loss, dissatisfaction and negative emotional experiences. Conversely, positive experiences were minimised or diminished within the discourse. They compared themselves unfavourably with other people. It was notable that participants described few strategies for managing the impact of psychosis." (p.64) | "Michael compared himself with friends who were able to 'walk straight in to a job' and 'guaranteed a job for life" | Anderson, 2010 |
| "In considering who they had become, many of the young people compared themselves less favourably with their 'old selves'. The disruption to occupational activity and disconnection from peers as a result of lifestyle changes, negative reactions or withdrawal | "I don't think I'll ever be the same person. So I can't go back and recover to be this person that I was before but I can be an ok person, a functional person". (p.88) | Bluffield, 2006 |

| | meant that the foundation of their previous identity had often changed." (p.136) Perception of self as more vulnerable | | |
|--------------------------|--|--|--------------------|
| | "Most of the young people spoke about a new sense of fragility that came with having been ill or living with a risk of Relapse" (p.115) | "I'm just hoping it never crops again, I hope I never end up in that position again really because I forget a lot of the things that I was thinking at the time, but I still remember some of the feelings of dread and worry and distrust and all these other things that cropped up and, not knowing what to believe or if you can believe anything that anyone's saying. So that's something that I just don't want to happen again." (p.116) | Bluffield, 2006 |
| | "Jade described her aims for the future included maintaining the stability of her current wellbeing and adapting to her life with a permanent mental health problem. She described numerous losses due to the side effects of medication and the perceived limitations her diagnosis placed on her future aspirations. Her compliance in the face of these losses perhaps indicated how compelled she is by the biomedical argument and the ongoing threat of 'relapse' associated with this" (p.69) | "Do you think it's had an impact on anything else in your life? yeah my career (2) like I haven't actually been back to work since and I erm, the thought of working a full like week, a full like a full-time job like thirty-six to forty hours a week. I don't think I am capable of doing that (1) right now." (p.70) | Harris, 2016 |
| | "Many participants also felt that they had become more vulnerable to psychological distress, and this had made them more cautious, especially in stressful life situations." (p.110) | | Bergström, 2019 |
| Post traumatic growth | "In addition to perceiving themselves as having changed for the worse in some ways, many young people also spoke about how their experiences had made them more mature, compassionate or responsible people. Danny seemed to have developed a different perspective" (p.104) | "I'm not as angry, I'm not as, immature, I'm not as argumentative over stupid things". (p.104) | Bluffield, 2006 |
| | "Participants moved beyond developing a positive sense of self to describe an essential transformation in identity as a result of becoming unwell and hearing voices. They reported becoming less angry and more empathic toward others, becoming more communicative about their emotions rather than keeping their feelings to | "In a way it's been good that I got sick because I'm a lot less angryIt gives me heaps of empathy for other people too." (p.1415) | De Jager, 2016 |

| | themselves, and having a stronger sense of self as a result of their voice-hearing experience" (p.1415) "In general, narratives of exploration and discovery shared a stance of optimism and excitement. Participants talked about approaching the future with a sense of exploration and interest." (p.69) | "The last six weeks have been the most stimulating and interesting of my life. I've laughed more and I've cried more in the last six weeks than I have in my life (mm hmm). I've met more interesting people and more soul mates in the last six weeks than I have in the rest of my life (mm hmm) () And I'm happier now than I've ever been." (p.69) | Anderson, 2010 |
|-----------------------|--|--|-----------------------|
| | "Enlightenment narratives also sometimes reflect a different experience of psychosis to that described in some escape narratives. That is, the experience of psychosis itself is viewed as having positive as well as negative aspects." (p189) | "I feel like I've got the control back. And possibly the psychosis helped me to get that control back. [] I think it was the psychosis that really sort of made me look at things [] And having looked at them I feel a lot more calmer about myself." (p.190) | Thornhill, 2004 |
| | | "I just see my future like, it's going to be big and bright as ever before (1) because I don't know, I like, to me yeah I've faced death, I've seen death so I'm not scared of failing or dying anymore I just want to live my life" (p.49) | Harris, 2016 |
| Renegotiating life | "The participants did not initially perceive themselves to have engaged in a process of trying to remake their lives. They did, however, speak of a negotiation and renegotiation of self, goals, dreams and abilities." (p.471) | "It's like rewriting the programmes or getting into the habits like you did before and building healthier habits to facilitate recovery'remaking' in the sense that you are rebuilding a new life reconfiguring or writing a new programme one that is more suitable to living with schizophrenia". (p.470) | Gould et al., 2005 |
| | "As a form of resistance to conformity, he also referred to the radical changes inside with himself and his behaviour, and outside with his environment, as being important factors in his recovery." (p.90) | "To recover. I didn't only have to change what was inside my mind but also what my mind was inside of. I had to change my circle of friends, both male and female, my place of work, the kind of work I did, the town I lived in, and how I lived and expressed myself." (p.90) | Efthyvoulou , 2018 |
| | | "But that is not what madness is, for when you go mad you don't actually go anywhere, you remain exactly where you are. And a different person arrives instead." (p.118) | Efthyvoulou, 2018 |

| "with earlier onset seemed to build their identities more specifically around their mental health crisis. Even though this might reflect symptom severity, and thus a higher need for treatment, it might also be consequence of the earlier onset itself." (p.112) | "Maybe without it (the psychosis) I wouldn't have those friends that are so important for me, but on the other hand, there are those negative things; I don't have a job, no education and, well, the coin always has two sides, right?" (p.111) | Bergström, 2019 |
|--|--|--------------------|
| "In narratives of endurance and acceptance (James, Jean, Lindsay), the experience of psychosis was described and its various impacts acknowledged. Also described were attempts made by the individual to adapt self, relationships and circumstances in order to integrate the experience and move forward." (p.65) | "Jean: 'I feel optimistic for the future, and you know, instead of shying away from people because I'm, I've got a mental illness, I'm gonna, you know, just grab the bull, grab the - what's it?' Interviewer: 'Grab the bull by the horns?' Jean: 'The horns! And, and make friends when I, when I get my new house () That's what I want to do'". (p.66) | Anderson, 2010 |

Appendix D: Reflexive journal extracts

Appendix E: REC/HRA approval

Appendix F: Letters of access from NHS Trusts

Appendix G: Example consent form



Salomons Institute for Applied Psychology

One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number (IRAS): 304072 Version number: 2.3

Date: 11/3/22 Participant Identification number for this study:

CONSENT FORM

Title of Project: Experiences of therapy for psychosis

Name of Researchers: Alana Lovering and Paul Rainey

Name of Participant______ Date__

| Please initial box 1. I confirm that I have read and understand the information sheet dated 11/3/22 (version 3.3) for the above study. | |
|---|--|
| 2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| 3. I understand that my participation is voluntary and that I am free to withdraw my data up to 14 days after the interview (without my medical care or legal rights being affected). | |
| 4. I agree for the interview to recorded. | |
| 5. I understand that data collected during the study may be looked at by the lead supervisor Dr Susannah Colbert and researchers Alana Lovering and Paul Rainey. I give permission for these individuals to have access to my data. | |
| 6. I agree for the interview I undertake to be transcribed by an approved confidential transcription service. | |
| 7. I agree to my GP (or care coordinator where still registered with mental health services) being contacted with regard to my participation in this study. | |
| 8. I agree that quotes from my interview may be used in published reports of the study findings with names and places changed for anonymity. | |
| 9. I agree for my anonymous data to be used in further research studies | |
| 10. I agree to take part in the above study. | |
| 11. I agree that in the event that I lose capacity during the study, I will be withdrawn. | |
| 12. If I am withdrawn, I agree that my information can still be used (with names and places changed). | |
| 13. I would like to be contacted, at a later date, to be given the opportunity to comment on the findings of the research. | |
| | |

| Signature | |
|-------------------------------|------|
| Name of Person taking consent | Date |
| Signature | |

Appendix H: Interview protocol

Interview Schedule

Version 3.0 - 28.01.22

1. Opening and introduction:

- Hello. My name is xxxx/xxxxx and I'm a Trainee clinical psychologist at Canterbury Christ Church University.
- Thank you for agreeing to take part in my study about your experiences of therapy for psychosis.
- I will explain a bit more about what we'll be doing today, but before I do, do you have any initial questions?
- If you are still happy to continue may I ask you to complete this consent form?

2. Initiation and orientation:

- I'll now just explain how we will go about the interview today.
- When we start, I will ask you a question and, in doing so, will invite you to tell me your story.
- My research is about finding out more about individual experiences of psychosis after having therapy that focusses on traumatic experiences.
- I am interested in your experiences of getting to this point and the sense you have made of it.
- Are you happy to begin?

3. Interview

The interview will begin with an open question adapted from Thornhill et al. (2004):

- As mentioned, the conversation we are about to have is to help us understand about therapy for psychosis that addresses traumatic memories. Perhaps you could start by telling me the story of your experiences of what you now understand to be psychosis.
- If the participant finds difficulty in starting, respond with, "Start wherever you feel comfortable. This might be the first time you felt distressed, or more recently such as when you were offered therapy".

Further prompts, if required: "I'm interested in what or who has influenced your journey.

What has made it harder and what has helped it?"

Could you tell me more about your experience of therapy?

Once the participant has finished telling their story, the researcher may prompt for further information in relation to topic areas identified below. This will be done by using questions such as:

[&]quot;What was it like for you when....?"

[&]quot;You mentioned...., so what happened next?"

[&]quot;What sense did you make of that?"

- Where topic areas have been touched upon, but not been covered the researcher will prompt for further information, using questions such as:
- "You mentioned you have changed the way you think about (insert the type of trauma/adversity here, if already known from the earlier narrative). Can you tell me more about what helped with that?"
- "You touched on the therapy, can you tell me a bit more detail about the sessions and how they played out?"
- "You mentioned (insert type of stressor here i.e. specific trauma, material/economic circumstances, marginalisation, discrimination, relationship difficulties, other stressors) to what extent do you think they contributed to you becoming unwell? how do you describe it? did it change through TfT? And how?

How have you been able to make those links?

You mentioned dissociation and avoidance experiences, how do you describe it? did it change through TfT? And how?

Example topic areas:

- a. Experiences of trauma focused therapy for psychosis
- b. Links between adversity and psychosis.
- c. Personal meanings of distress (within phenomena, now, explanations).

4. Where the participant appears distressed

In the event of a participant appearing distressed or where the narrative is beginning to focus on detailed accounts of traumatic experiences the safety of the participant will be explored:

"I just want to take a moment to check that you are feeling ok and that you are happy to continue or whether you would like to end to interview?"

Follow this up with:

"We can take a short break if it would be helpful for you."

Or: "There is no need for us to continue if you are not feeling comfortable." If the participant wishes to continue:

If you are happy to continue then please carry on telling me your story.

Appendix I: Example completed narrative summary sheet

| Participant: | Findings |
|---|--|
| Participant 5 – Mimi | |
| Structural/literary | |
| Where does the narrative start? | Starts with participant saying that she does not want to talk about childhood and then how intimate partner violence resulted in her |
| | 'losing her mind' |
| Do episodes appear in expected sequences? | Narrative moves from initially the cause of her distress into her story of survival and how she can use it to help other women |
| How do participants | On experiences of psychosis |
| sum up their journey? | "I can hear voices then I can see like, feel someone around me." (AB) |
| (AB) | Summarising a key turning point |
| | "so I decided to leave him and I become homeless with my six children in the UK" (AB). |
| | Summarising how she used to be |
| | "Why would before I used to be so hot tempered (AB), I don't have, yes. Yes, I don't have patience always I'm hungry" (AB). |
| | Summarising her experiences of EMDR "This program (EV) *right* I can as that's changed me. I can say changed me 110% (EV) *really*, Yes, and I can recommend it [EMDR] to the world" (AB). |
| | Summarising the view of medication "When I stopped I had the voice again (CA), then I start taking it. Okay. So then medication helps" (AB). |
| | Role of religion and other cultural influences "Likely, maybe. Religion and the community? Played a lot role. Yeah." (AB) |
| | "Yeah, in our community, when you get married, and you have children, you can only view, you cannot leave your husband" (AB). |
| | "Just, it's like, in our communities, like it's normal is known. If the abuse you that is normal" (AB). |
| | On her role as educator "I've never, you know, so I don't want other people to go through what I've been through" (AB) |
| | On stigma towards black single mothers "Yeah, I can say, with black women, the stigma is like it's 85% yeah (AB). With white, yes, there's a lot of white single mothers as well, but the stigma is more on black women. When you're single mother, your children will not come out good" (AB) |

"So we are trying to do something about it. Because we are here we have all like me, for example, I have six children, and I'm having more grandchildren I have four grandchildren. So I don't want this to continue" (AB).

"Because I've seen it, I've witnessed it. And also I say a lot need to be done in terms of more education, employment and empowerment to empower single mothers and the children."

"Because of the stigma of single black women, their children, because sometimes when they say a lot, putting down people, they have it in their mind, their mind said, 'Oh, I don't care'" (AB).

What metaphors are used to describe their journey?

Employs the phrase 'miracle' on many occasions to describe her survival

Use of the term 'lose my mind'

"I was domestically abused, physically, verbally everything (CA) so it's like I lose my mind" (AB).

How was meaning making applied within the narrative – what assumptions did this lead to? (EV)

On experience of racism

"I was so depressed" (EV).

"Because at that moment, if I lash out, I should have been like, maybe they should have arrested me" (EV).

"I've never been so ashamed of myself".

On experience of EMDR

"So [name of EMDR therapist], to be honest, this this um session with [name of EMDR therapist], it think can help a lot of people (EV)."

"But yes, not to go back to the emotional memories of what I've been through but she would encourage me that sometimes I don't want to say but she encouraged me to say it out (CA). And when I say that, I felt better. I felt like I'm free (EV)."

Therapist connection

"That is the main point with [name of EMDR therapist] (EV). I might have had other people to help me but maybe the connection will not be there. But with [name of EMDR therapist], she helped me a lot (EV)."

"I was so confident to say to her, I trusted her so much (CA). Yes. So she played a big role in in my healing (EV)."

Responsibility

"Yeah um ...that voice it lead me to do a lot of things I was not supposed to do to myself" (EV),

Turning point of telling doctor

"So I made the bold step to talk to my doctor (CA). And I think it was the good decision" (EV).

On empowerment

"I can't take this anymore. I have never been so ashamed of myself (EV). So I said I'm gonna stand for my rights (EV)."

"She help me, oh my goodness. She help me, she gave me my confidence, restore my dignity" (EV)

"I'm not ashamed to. Because if I say that it's going to help a lot of women, totally restore their dignity, respect (EV)."

"It empowered me yes. It empowered me a lot (EV)."

On abuse

"yeah it's only a miracle I survived (EV)."

"I was thinking even now the children always blamed me (EV). (for not leaving)"

"Just lack of confidence. I was afraid of him, I was so scared of him (EV)."

"I was depressed (EV) Yeah. When I was with him throughout I was depressed."

"Before I used to blame myself while yes, "you have the right to beat me up". Well, no, it's not my fault (EV)."

Meaning of psychosis phenomena

"like the placing on the bed is like when because he passed now (CA), he passed last year because like when he used to beat me up, like, place, on my neck or (EV)."

On identity change and losing status

"What I mean is it's not always rosie rosie, always have to be good, good, good (AB). Yeah. Sometimes you have to face challenges (EV)"

"Before it's like I was present, but it's like I'm not present (EV)"

Financial hardship

"Because I was still depressed that this is not the way I used to be (EV)."

loss of friends

"I think, because I'm such a giver, I like to give help (AB). So there was a time now I need help myself I can't help them anymore. So they left me (EV)."

"when challenges happen, you learn (EV). It's not like before I have friends there are friends, but they are not genuine (EV)." On being told she would need medication long term "Okay, and how did you feel about that? Yeah, a little bit sad (EV)." How were stories On recovery resolved and returned to "It's helped me a lot I can say (RE)." the present? (RE) "So when I started therapy, when I had voices, I used to put, I can hear voices but not as before (Coda)." "Yeah um. I do. Like I walk. I eat, I don't drink alcohol anymore (RE). I drink a lot of water, I eat veg, eat fruit (RE)." "Yeah because the community has helped me the community I have to give back I have to give back you know (laughs) (AB)." On thoughts of harming self "Yeah, but not anymore, I don't do that anymore (Coda)." Dialogical/positional analysis: **Psychological** /intrapersonal/ Responsibility Personal Telling the reader that her voices led her to do things that were against her belief system. "That voice it lead me to do a lot of things I was not supposed to do to myself (EV), you know self-harm (CA)." **Shame** The role of stigma (and perhaps even worries about what will happen to her children) makes her feel ashamed and want to hide it: "I was ashamed to say to anybody, but I was deteriorating (EV)." In relation to racism: "I have never been so ashamed of myself (EV)" In relation to financial hardship: "Yeah, yeah. Because I was still depressed that this is not the way I used to be (EV). I was not I was financially strong (EV), or now. I hate to claim benefits (EV). I have to wait every week for benefits (CA), sometimes not even enough..." **Powerlessness** "I thought I was, because you know like when you have this narcissistic partner, them pulling you down (CA)."

On Coping strategies

In relation to voices:

"I don't listen to them (CA). It's not as distinct like before. *right okay* And I find out that before, it's when I become too depressed thats when it's worse (EV). So now I try not to be anything that is stressing me out. I stay away from it (CA)."

"I do. Like I walk. I eat, I don't drink alcohol anymore (RE). I drink a lot of water, I eat veg, eat fruit (RE)."

Humanitarian and human rights work central to recovery:
"Yeah. I just celebrated 22 years on the 26th of November (OR).
Wow. Yeah. It was very big. I have friends because I travel a lot.
Okay yeah I have friends from America, Canada. Europe, they come and support me (OR)."

On religion

"Did it help you did having that belief help your recovery as well?" "Thank you. *Yes, it did*. Yes. Yes. (EV)"

Identity change

Emphasizing an identity change from wealthy and successful to a more fulfilling life:

"No, I used to live in a big six bedroom house everything on but unfortunately sometimes stuff happens for you to learn and grow."

A message to the reader that the change in identity also meant the loss of friends.

"I think, because I'm such a giver, I like to give help (AB). So there was a time now I need help myself I can't help them anymore. So they left me (EV)."

When talking about her old self - Is hunger a metaphor for a consumerist lifestyle ?

"I don't have, yes. Yes, I don't have patience always I'm hungry (AB)."

What are the common propositions and assumptions

- That she was lucky to survive
- Links mental health difficulties and ultimately psychosis directly to abuse
- She had to sacrifice financial wellbeing and status to save herself but this lead to personal growth
- Shame links many of her experiences discrimination, financial hardship, mental health difficulties.
- Community/religious ideology played a key role in maintaining abuse
- Abuse kept her in a state of powerlessness and fear in destroying self-worth
- Medication as helpful

| What are the key narratives? | The role of patriarchy and it's links with coercive and ideological power Links with abuse and mental health |
|--|---|
| What is the function of these narratives? (i.e. changing identity, removing guilt, self- expression) | To express a positive change in identity and to reevaluate what's important Educating others and protecting others from oppression |
| What is the core narrative? (i.e. "fighting for the right treatment") | Saving others |
| What is the genre? (i.e. "enlightenment") | Educating |
| What is the tone (i.e. "protesting") | Survival |
| Interpersonal | The voice of the therapist resonating: "What happened was not your fault is him that have the problem" (CA) In this, she highlights a function of the interview, to empower other women and to communicate the strength to fight. "that's why I founded my own organization. Never to keep quiet (AB). Some people will not be as lucky as I am to take their views (AB)." Whose voice is this? This community, the elder, patriarch? "Before I used to blame myself while yes, "you have the right to beat me up" The voice of the believer "So I said I have to become stronger. I have to seek help I have to accept I have to do something. And thank God" |
| What messages is the participant trying to convey? | Change in identity The power of patriarch in society (coercive and ideological) That EMDR, and a trusting therapeutic relationship was central to her recovery. Taking the decision to live (by leaving her husband) was a difficult decision and involved sacrifices, but a turning point in her life |
| What gaps or omissions were there from the narratives? | - Participant did not discuss childhood experiences and was clear from the start they didn't want to. |

| What was noticeable from the interviewers dialogue? | Tries to distinguish specific experiences of psychosis (i.e. unusual beliefs) and of EMDR. A focus on activism and empowerment and less the emotional | | | | |
|---|--|--|--|--|--|
| | impact of racism | | | | |
| How do individuals socially position themselves? | - Mimi positions herself as a lifelong victim of abuse, but also someone who has the power to influence change and educate people. | | | | |
| What multiple voices can be heard in any speakers voice? | Dominant narratives around stigma in relationship to financial hardship and the experience of psychosis Advocate for trauma informed therapy Human rights campaigner and advocate for women who have | | | | |
| | had the same experiences - Voice of the therapist | | | | |
| What were the interviewee's attempts to engage the audience? | On several occasions encouraged the interviewer to research her background and personal achievements. Use of an expressive "thank you" when an interviewer intervention resonated or depicted accurately her experience | | | | |
| Positional | | | | | |
| What aspects of the interviewers/participants identity may have impacted co-construction | Being both male and white is likely to have had an impact when discussing issues of racism. What wasn't said? Despite this, I believe she viewed me as someone with an understanding of trauma (like her therapist). This may have eased co-construction of narratives. | | | | |
| What power relations are at play between interviewee and participant? | The participant may possibly be impacted by the interviewers power to accurately represent her messages. This may be evident in her keenness for me to explore her achievements outside of the interview. | | | | |
| Ideological | | | | | |
| (concerned with a society's 'own ideologies, its own systems of beliefs and representations') | A concern of injustice perhaps influenced by narratives around black people and violence may have influenced her response to racism "Because at that moment, if I lash out, I should have been like, maybe they should have arrested me (EV)." | | | | |
| | Speaks to community narratives about successful people: "No. Instead they are just gossip, our community (AB). That's what they love is like before some people would think that oh, she thinks she is big. Now look at her (EV)." | | | | |
| | Links psychosis with being dominant narrative of being 'crazy' "I didn't know what the meaning (CA). I didn't know the meaning of that, you know. *Okay*, this letter they explained to myself. Oh, does that mean I'm crazy? They said "no" (CA)." | | | | |

Ideology of religious/culturally important figures:

"Yeah, in our community, when you get married, and you have children, you can only view, you cannot leave your husband (AB)."

"Just, it's like, in our communities, like it's normal is known. If the abuse you that is normal (AB)."

Dominant narrative about societal view of single mothers:

"You said something a moment ago about kind of the views of single mums. Do you think there is a stigmatized view?"

"A lot (EV) Even. You can't believe even my late husband...He told me 'Oh, you're a black single mother. Your children are not coming out good' (CA)."

"Because of the stigma of single black women, their children, because sometimes when they say a lot, putting down people, they have it in their mind, their mind said, "Oh, I don't care" (AB). We're not coming out good. So there are a lot of people with children going to prison, single mother children, they went to prison most of them doing the drugs"

Subject specific

Experiencing the phenomena

Voices and other unusual experiences

"I can hear voices then I can see like, feel someone around me. (AB) Is like I will be looking at you but I would thinking that its like someone is at my side but as soon as I turn they disappear then before it's like somebody's pressing me on my bed (AB)."

"Before...before when I heard voices, I used to respond, like if it counted, i dont know, like all this is danger. First it would tell me I would jump from the stairs down"

Depression prior to experience of psychosis

"And so when I look at that, the struggle, I become so depressed, I wanted to take my life"

"Yeah, yes. I was not going out (CA). Okay. I was not going out. There was time, I can't even get out of bed (CA). Like I'm not getting dressed properly, you know?"

Critiques of services

N/A

Socio economic

On racism

"It gives me like a flashback. Yes, Yes (CA)."

Note that present tense is used and it is unclear if this is a colloquialism or is an ongoing issue.

"I processed yes [processed experience of racist abuse with EMDR]. We processed it together (CA). That was like, it gives me a flashback

like, I don't want to live again (CA). I can't take this anymore. I have never been so ashamed of myself (EV). So I said I'm gonna stand for my rights (EV)."

Again talks in present tense, but this is likely colloquial use of grammar when actually she is talking about what she experienced in the past.

On having unstable accommodation for several years

"Yeah, yeah. Not very soon, or as well as we used to, because we are so many with six children and me (AB). So they will give me like a temporary accommodation few months, we'll move again to another temporary (CA). Before finally we have a permanent"

On financial hardship

"Yeah, yeah. Because I was still depressed that this is not the way I used to be (EV). I was not I was financially strong (EV), or now. I hate to claim benefits (EV). I have to wait every week for benefits (CA), sometimes not even enough, we have to charge."

EMDR specific

EMDR process encouraging clients to go where they feel most uncomfortable

"But yes, not to go back to the emotional memories of what I've been through but she would encourage me that sometimes I don't want to say but she encouraged me to say it out (CA)."

Empowerment

This is both emphasising the inner strength to tackle discrimination, but also the importance of having an advocate who is in a position of relative power.

"I told her, You know what? I'm not going to allow anybody to bring me down anymore (CA). I'm going to take it on on this doctor. So what I did, I wrote a letter of complaint (CA)."

"It empowered me yes. It empowered me a lot (EV)."

"I don't used to believe in myself, then [name of EMDR therapist] remind me that because I get together with him when I was like 16. So she's the one that told me that you were a child (CA)."

Leaves the reader wondering which part of EMDR this was, cognitive interweave or even participant reached these conclusions herself during processing.

Positive effects

"this this um session with [name of EMDR therapist], it think can help a lot of people (EV). "

"So when I started therapy, when I had voices, I used to put, I can hear voices but not as before (Coda)."

| | "What what what has changed? I can say is this. This program (EV) *right* I can as that's changed me. I can say changed me 110% (EV)" |
|--------------------|---|
| Important elements | Importance of strong therapeutic bond "You can have help there and then, but the person, the connection |
| | with the someone that is helping you." |
| | "I might have had other people to help me but maybe the connection will not be there." |
| | "I was so confident to say to her, I trusted her so much (CA)." |
| | "Whatever situation, bad or good, she was the first person I will want to tell (EV)" |
| Adaptations | |

Appendix J: Thematic narrative analysis data synthesis

| | | | EMDR and the therapeutic relationship o a higher consciousness Views of psychosis | | EMDR and meaning making Relationship with the medical model Coercive, economic and ideological power Relationship with the medical model | | | Detached |
|--------------------|--|--|---|---|--|--|---|--|
| Headline themes | Hayley 1) Psychosis directly linked to neglect she experienced as a child | Amy 1) Role of religious ideology in psychosis – Good/evil views | Nina 1) Understands delusions as being a response to low self esteem | Danielle 1) Understands grandiose delusions as defending against low self-esteem | Mimi 1) Mental health difficulties linked directly to abuse 2) Underlying feelings of | Lucia 1) Loss and early adversity directly triggered psychosis 2) Role of stigma | Robert 1) Psychosis "definitely" caused by trauma 2)Cultural figures play an | Andrea 1)Narrative of feeling unsafe and of Powerlessness in the face of |
| | and having to care for her sister as a result of her mother having mental health difficulties 2) Trusting relationship the most important aspect of therapy 3) Renegotiating life and rexyellyating what's important 4. Themes of feeling unsafe during psychosis experiences and needing to protect son 5) A misture of elation and spiritual awakening took place prior to psychosis talks of the lines between reality being "blurred" 5) EMDR supportive of the meaning making process | herself as responsible in her narrative 2) Personal meanings of terror, guilt/self-blame and powerlessness 3) Psychosis as an alternate reality that is ig, initially exciting and then terrifying 4) Clear meanings made of phenomena at the time it happened 5) EMDR successful, but lots of preparation was put in and you need to give yourself to if 6) Emotionally avoidant coping stratesy prior to becoming unwell 7) View of the world as a dark and dangerous place 8) New self as changed for the better 9) Views self as spiritual person prior to psychosis | 2) A sense that you are never safe from psychosis 3) Views parental controlling and abusive behaviour as underpinning psychosis 4) Underpinning theme of seeing self as unlovable and not good enough—linked to parents comments EMDR supportive of the meaning making process 5) Story of seeking validation in life | 2) Role of emotionally avoidant coping strategies 3) Role of religious ideology in psychosis — and link with coercive nower | shame link many of her experiences — discrimination, financial hardship, mental health difficulties. Community/religious ideology played a key role in maintaining abuse 4) Abuse kept her in a state of powerlessness and fear destroying self-worth SJEMDR considered life changing — but the narrative suggests that a trusting relationship and strong connection with the therapist was the most important aspect of this 5) EMDR as empowering 7) The power of patriarch in society (coercive and ideological) | 3)EMDR helping where other therapies hadn't 4) Suppression of emotions key to her difficulties 5) EMDR and facilitating of adaptive meaning making (including on emotional avoidance) | important role in coping strategies – but also featured heavily in psychosis phenomena 3)Isolation is a big factor in his difficulties (identifies with cultural figures on this basis) 4)Being unable to secure work also played a big factor in his difficulties 5) Not all psychosis phenomena experienced as bad 6) EMOR was really helpful 7) Being long term unemployed had significant impact on self-esteem 8) Previous spiritual experiences/beliefs | injustice 2)Psychosis as an alternate reality 3) makes a direct link between traumatic experiences and psychosis 4)EMDR and facilitating of adaptive meaning making Lots of preparatory work |
| Other themes | - Victim of psychological abuse from partner and neglect as a child - Psychosis was triggered by stress but underpinned by fears for her son and a sense of the lack of safety - Quite high and 'elated in the initial phases of psychosis Hospital viewed as helpful - Not keen on medication to start but position changed when dosage was adjusted and began to function well - Psychosis experiences moved from being a | - EMDR not just about major traumas - Describes psychosis as "alternate reality" - Psychosis experiences are real for the person - EMDR supportive of meaning making Impact of trauma on the body - Cannabis use /addiction part of narrative - Psychosis as initially exciting - Medication as useful in the short terms advised to come off abruptly caused her to become unwell again | - Grateful to have experienced therapy - Attitude changed on medication consideres self (anti medication.) - EMDR helped hearelationships - Delusions started as helpful and "nice", ended in being darker and frightening (in the end relieved to go into hospital) - Highlights avoidance as a way of dealing with emotions as a child (reading books) - EMDR stopped the thoughts from being so invasive | - Medication is helpful but can be extremely harmful - Health services treat physical and mental health patients differently - Religious ideology seen as a threat as it increases paranoia - Blocking out emotions by doing lots of stuff and staying busy has not been helpful in the long run - Feeling uneducated about mental health - Importance of being able to express emotions - Trying to hide psychosis from family - Taking an activist stance - Social comparison | -She had to sacrifice financial wellbeing and status to save herself but this led to personal growth -That she was lucky to survive | - Not all about big trauma - Her diagnosis doesn't entirely fit - low self-esteem a long term issue - Importance of care coordination and psycho social interventions - Did not experience hospital as bad except poor communication - Perfectionist tendencies Medication was helpful to a point, but the side-effect were not conducive with her life - Importance of trust and impact on short term therapies | -Voices encouraging him to kill himself outcast from family due to no believing in jehovahs, witness - physical side of processing trauma memory - (pain in head when processing) - Strength in new self - Audience features as part of psychosis phenomena – cheering to kill himself. Neglecting of physica health problems in hospital - Diabetes - Ketoacidosi causes hallucinations EMDR difficult | - Identity as a protector - Critique of services - Lespecially ECT - Describes psychosis as alternate reality - Links specific psychosis phenomena to experiences (shower incident) - EMDR not always successful - Working environment triggering – a social cause |

| | positive experience to | Positive experiences of | - suggests she did not | Psychosis as a | | |
|-----|--|---|---|---|--|--|
| 1 1 | being a frightening one | hospital | come to these | shield/protection "saved | | |
| | - Preparation phase | Role of gaslighting as | conclusions adaptively | and almost harmed me" | | |
| | important | form of power | her self during | -Psychosis as an escape or | | |
| | EMDR and support of | EMDR also worked on | processing so | even saviour from deep | | |
| | adaptive thinking | trauma arising from | interweaves likely used | depression | | |
| | reference to guilt of not | psychosis itself | often | -Support from family and | | |
| | protecting sister | - Psychosis impact on low | Example of the impact | professionals important | | |
| | - Personal - | self-esteem | of a small t trauma | part of recovery | | |
| | acknowledgment that it | - Fine line between | event | The new self as more | | |
| | wasn't trauma alone, but | flashbacks and | | positive and calm | | |
| | another layer of trauma | hallucination | | - Talks of borderline voices | | |
| | (metaphor) | Peer work supported | | (validation?) | | |
| | Left old corporate life | recovery | | Distraction as a coping | | |
| | behind – emergence of a | | | strategy | | |
| | new identity and | | | No reassurance in | | |
| | -EMDR theme of not being | | | psychiatric care | | |
| | capable (self- | | | - Importance of | | |
| | defectiveness) | | | occupational activities | | |
| | Triggered by experiences | | | | | |
| | of poverty and | | | | | |
| | deptivation in work as | | | | | |
| | support worker | | | | | |
| | Views intergenerational | | | | | |
| | trauma as important | | | | | |
| | -Reference to the physical | | | | | |
| | side of EMDR | | | | | |
| 1 1 | ! | | | | | |
| | | | | | | |

Appendix K: Coded transcript

Appendix L: Participant information sheet



Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number (IRAS): 304072

Version number: 3.3 Date: 11/3/22

Information about the research

Experiences of therapy for psychosis

Hello. We are representatives of Canterbury Christ Church University. We would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

This information sheet is for you to keep along with your signed consent form. The document is split into 2 parts. Part 1 tells you the purpose of this study and what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study.

This information sheet can be kept for future reference. Where your consent form has been signed and returned remotely you may also keep the hard copy for your reference. Where the consent form is returned in person, we will keep the hard copy.

Part 1

What is the purpose of the study?

Experiences of psychosis are often very challenging. We want to understand more about people's experiences of therapy for psychosis.

Why have I been invited?

We want to hear specifically from people who have taken part in psychological therapies for psychosis that focus on traumatic experiences. We are specifically interested in the story of your journey and the sense that you have made of it.

Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, We will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

- a) You will be asked to sign a consent form to confirm that you would like to take part in the study.
- b) You will be invited for a 60-90 minute interview to tell us your story. This will be conducted with one of the research team. Once you have told us your story, we may ask some further questions about what you have told us. You can choose to conduct the interview either online or in person. You will be able to take a break during the interview if required.

- c) The interview will need to be recorded so that we can listen back to it for the research analysis.
- d) After the interview you will be offered the opportunity to be invited for comment on the findings of the project at a later date. This is optional and at this stage you will only be agreeing to be contacted when the research is nearing completion. Should you then choose to review the findings, you will be provided with extracts from the research and given the opportunity to provide comments should you wish. You will be given the option to feedback via a 30-minute online meeting or to provide a written response via email. These online meetings will not be recorded.

Expenses and payments

Participants will be offered a £10 reimbursement for time and travel for attending interviews and will be entered into a prize draw to win a £30 voucher.

What will I be asked to do?

When we meet for the interview, we will give you the opportunity to ask any initial questions that you have and will explain how we will go about the interview. We will then ask you to tell us your story in relation to your experiences of therapy for psychosis. We will not interrupt you whilst you are telling your story. When you have finished, we may ask further questions based on what you have told us.

What are the possible disadvantages and risks of taking part?

Some people might find it distressing to talk about some experiences. If you were to become upset at any point during the interview, you could stop and only continue the interview if you wanted to. If you feel that talking about your experiences will make you feel too distressed, we advise that you do not take part in this study at this time.

We will check that you have adequate support prior to undertaking the interview. In the case where this cannot be provided by a clinical care team, we will ask you to provide contact details of a family member or friend that could be contacted in the event that you feel too distressed to contact them yourself. Contact details for friends or family members will only be kept for the duration of the interview and will be deleted once the interview is complete. In the event that you feel distressed by the interview, your GP, clinical care team or friends and family, will only be contacted with your consent.

What are the possible benefits of taking part?

Although we cannot promise any direct benefit from taking part, some people find that sharing their stories can be a highly meaningful experience. The research also hopes to contribute to the development of psychological therapy for psychosis.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details
- NHS number

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the research will be kept strictly confidential. Any information held about you will have your name and contact details removed so that you cannot be recognised. At any time, you will have the right to check the accuracy of data held about you and correct any errors.

There are some rare situations in which information would have to be shared with others. The only time when we would be obliged to do this would be if you told us something that made us concerned about your safety or the safety of someone else.

Further information:

- Audio recordings will be made of our conversations and will be stored temporarily on a password protected computer.
- Once our conversation has been transcribed all references to people or places will be changed (pseudonymised). Audio recordings will then be deleted.
- Audio recordings may be shared with an external company for transcription. Any such company used will be bound by a confidentiality agreement.
- Any other information which identifies you (e.g. contains personal data such as your name) will be deleted one year after the study has been completed.
- All pseudonymised data will be deleted after 10 years.

What will happen if I don't want to carry on with the study?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. If you decide that you would prefer us to not use the information you have given us we ask that you notify us within 14 days of the interview and we will withdraw your information from the study. After this time, it will not be possible to remove your data from the study as the data will have been pseudonymised and aggregated with other data so won't be identifiable. Withdrawal will not affect any current care you may be receiving.

Where can you find out more about how your information is used?

You can find out more about how we use your information at:

- NHS Health Research Authority: www.hra.nhs.uk/information-about-patients/
- Canterbury Christ Church University's approach to data protection (including the complaints procedure) please see: https://www.canterbury.ac.uk/university-solicitors-office/data-protection.aspx

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Concerns and Complaints

If you have a concern about any aspect of this study, please ask to speak to us and we will do our best

to address your concerns. You can contact us by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for one of the research team: xxxxx, xxxxx and xxxxx. We will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology via email at: fergal.jones@canterbury.ac.uk

Who are the research team?

The research team is made up of the following: Dr Susannah Colbert (academic tutor and research supervisor) and Alana Lovering and Paul Rainey (trainee clinical psychologists and researchers). You will be interviewed by either Alana or Paul should you decide to take part in the study.

What will happen to the results of the research study?

The findings of the study will be written up as a university project and may be published in a scientific journal. We will also summarise relevant findings for participants in a short information leaflet. If you would like to receive a copy, please let us know. We will use pseudonymised quotes as part of these documents.

Who is sponsoring and funding the research?

The research is funded and supported by Canterbury Christ Church University.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the London-Stanmore Research Ethics Committee.

Further information and contact details

If you would like to speak to us and find out more about the study, you can leave a message for us on a 24-hour voicemail phone line at 01227 927070. Please leave a contact number and say that the message is for one of the research team: Dr Susannah Colbert, Alana Lovering or Paul Rainey. We will get back to you as soon as possible. You can also contact the research team via email:

Researcher: xxxxx - xxxxx@canterbury.ac.uk
Researcher: xxxxx - xxxxx@canterbury.ac.uk
Research supervisor: xxxxx - xxxxx@canterbry.ac.uk

If you feel you need support, or are in crisis, please contact one of the following:

Your G.P. or current Clinical Care Team

Samaritans

Telephone: 08457 90 90 90

Available 24 hours a day, seven days a week

Confidential and non-judgemental emotional support whenever you need someone to talk to

Saneline

Telephone: 0845 767 8000

Available from 12.00 pm to 2.00 am

Out-of-hours telephone helpline offering practical information, crisis care and emotional support to anybody affected by mental health problems

Thank you

Appendix M: Feedback to ethics panel