

KEREN D. YEBOAH, BSc Hons., MSc

RECLAIMING THE NARRATIVE: EXPLORING PERSONAL  
RECOVERY IN PSYCHOSIS

Section A: Narrative Approaches in Psychosis: A Systematic Review and  
Meta-Ethnography of qualitative findings

Word Count: 7,898

Section B: Personal Recovery in Black Individuals with Psychosis: A  
Grounded Theory

Word Count: 7,993

Overall Word Count: 15,891

A thesis submitted in partial fulfilment of the requirements of  
Canterbury Christ Church University for the degree of  
Doctor of Clinical Psychology

September 2020\*

SALOMONS INSTITUTE FOR APPLIED PSYCHOLOGY  
CANTERBURY CHRIST CHURCH UNIVERSITY

## Acknowledgements

Thank you to the participants who made this project possible by sharing their incredible stories with me.

To my supervisor, Professor Tony Lavender, thank you for being so generous with your knowledge and time. Your ability to see something great in even the smallest idea is incomparable.

To my family, your encouragement and understanding has been like a steady wave, and it continues to push me on. Thank you.

My parents, for your irrational levels of pride and love, your unwavering belief, for your prayers, thank you.

To my friends, thank you for your patience and your genuine desire to see me win.

## Summary of the Major Research Project

### **Section A:**

Presented here, is a systematic literature review of the application of narrative interventions in psychosis. Using a meta-ethnographic approach, the qualitative elements of the 9 included studies were synthesized. Nine core themes emerged, relating to therapeutic processes found across narrative approaches in psychosis. These are; equal stories, equal humanity; making meaning; doing it together; alternative narratives; openness; family members as equal partners; strengthening personal narratives; positive impact on social networks and quality of life. A critical appraisal of the included studies is discussed and the implications for clinical practice and research are considered.

### **Section B:**

Presented here, is an empirical paper outlining the development of a grounded theory of personal recovery as it pertains to Black individuals with psychosis. The model presents 8 key experiences that were found to facilitate the development of a sense of personal recovery. These are: engaging and re-engaging in strategies to maintain wellbeing; risk and reward of reintegration, finding safe spaces, power experienced as safe, an empowered sense of self; joining with others & making change; stabilising and deepening relationships and in pursuit of a better life. Six themes emerged that were found to serve as disempowering experiences. These are: overwhelming circumstances; being criminalised; mental health wards; the wider mental health system; power experienced as abusive; the hidden self. The model is summarised by 3 overarching themes. These are: recovery as delicate, effortful and long. The theoretical, policy and clinical implications are discussed.

CONTENTS

**Narrative approaches in psychosis: A systematic review and meta-ethnography of qualitative findings.....8**

**ABSTRACT.....9**

**INTRODUCTION..... 10**

**Discourses around psychosis and Schizophrenia..... 10**

**A new way of understanding and working with psychosis ..... 13**

**Indications for narrative therapy in psychosis treatment ..... 14**

**Challenges in the empirical investigation of evidence for narrative therapy ..... 16**

**Aim of the current review..... 17**

**METHOD ..... 17**

**Scope of the review ..... 17**

**Definitions..... 18**

**Eligibility Criteria ..... 18**

**Search strategy and data sources ..... 19**

**Data Extraction..... 20**

**Structure of the Review ..... 25**

**RESULTS ..... 26**

**Description of the studies..... 26**

**Quality assessment tool ..... 27**

**Quality assessment ..... 28**

**The meta-ethnographic approach..... 33**

**AN EMERGING MODEL OF THE THERAPEUTIC PROCESSES IN NARRATIVE THERAPY FOR psychosis ..... 39**

**Individual processes..... 39**

        Equal stories, Equal humanity ..... 39

        Making meaning ..... 39

        Doing it together ..... 40

        Alternative narratives..... 40

        Openness..... 40

**System processes ..... 41**

        Family members as equal partners..... 41

        Strengthening personal narratives..... 41

        Positive impact on social networks..... 42

**Results of change ..... 42**

        Quality of life..... 42

**Technical processes of change..... 42**

**DISCUSSION ..... 43**

**Clinical implications ..... 48**

**Research implications ..... 49**

**Strengths and limitations of the review ..... 51**

**CONCLUSION ..... 52**

**REFERENCES..... 53**

<b>Personal Recovery in Black Individuals with psychosis: A Grounded Theory .....</b>	<b>72</b>
<b>ABSTRACT.....</b>	<b>73</b>
<b>INTRODUCTION.....</b>	<b>74</b>
<b>Personal recovery .....</b>	<b>74</b>
<b>Psychosis and personal recovery .....</b>	<b>74</b>
<b>The role of culture in defining personal recovery.....</b>	<b>75</b>
<b>Race and cultural differences in the experience of personal recovery.....</b>	<b>76</b>
<b>Within community factors.....</b>	<b>76</b>
<b>Between community factors.....</b>	<b>77</b>
<b>Existing research in Black communities and psychosis .....</b>	<b>78</b>
<b>Project aims:.....</b>	<b>79</b>
<b>METHODS .....</b>	<b>80</b>
<b>Design .....</b>	<b>80</b>
<b>Participant recruitment:.....</b>	<b>80</b>
<b>Eligibility criteria and screening .....</b>	<b>81</b>
<b>Sample size.....</b>	<b>82</b>
<b>Interview design .....</b>	<b>82</b>
<b>Data collection:.....</b>	<b>83</b>
<b>Ethical considerations and data protection .....</b>	<b>83</b>
<b>Data Analysis.....</b>	<b>84</b>
<b>Quality assurance checks.....</b>	<b>84</b>
<b>Participant demographics.....</b>	<b>85</b>
<b>Grounded theory model.....</b>	<b>87</b>
<b>Model summary.....</b>	<b>89</b>
<b>Disempowering experiences .....</b>	<b>91</b>
Overwhelming circumstances.....	91
Being criminalised .....	93
Mental health wards.....	94
Wider mental health system.....	96
Power experienced as abusive .....	97
The hidden self .....	97
<b>Experiences facilitating recovery .....</b>	<b>98</b>
Engaging and re-engaging in strategies to maintain wellbeing .....	99
Risk and reward of reintegration .....	100
Finding safe spaces .....	100
Power experienced as safe .....	102
An empowered sense of self.....	102
Joining with others & making change .....	103
Stabilising and deepening relationships.....	103
In pursuit of a better life .....	104
<b>Recovery as delicate, effortful and long .....</b>	<b>104</b>
<b>DISCUSSION .....</b>	<b>105</b>
<b>Limitations.....</b>	<b>109</b>
<b>Theoretical implications.....</b>	<b>110</b>
<b>Policy and Clinical implications .....</b>	<b>110</b>
<b>CONCLUSION .....</b>	<b>111</b>
<b>REFERENCES.....</b>	<b>113</b>
<b>APPENDICES .....</b>	<b>125</b>

LIST OF TABLES AND FIGURES

Table 1. Summary of inclusion and exclusion criteria. 18

Table 2. Generated string search items..... 19

Figure 1. PRISMA diagram illustrating the study selection process (Moher et al., 2009)..20

Table 3: Data extraction table..... 22

Figure 2: Yin’s (2003) matrix of tests to consider in the development and evaluation of test studies ..... 28

Table 4: The definitions used for each checklist response option. .... 28

Table 5: Critical appraisal of case studies using the CEBMa checklist (Centre for evidence based management, 2014, adapted from Crombie, 2009). .... 29

Table 6: Critical appraisal of mixed methods studies using Hong et al’s (2018) Mixed Methods Appraisal Tool (MMAT) ..... 30

Table 7: An outline of the process of developing the emergent meta-ethnographic synthesis ..... 35

Table 1: Eligibility criteria 81

Table 2: Participants broken down according to sources of recruitment..... 82

Table 3: A table of participant demographic characteristics ..... 86

Figure 1: A model of Personal Recovery in Black individuals with psychosis. .... 88

Table 4: A table of the groups, themes and sub-themes in the model of personal recovery in Black individuals with psychosis..... 90

APPENDICES

<b>A.</b>	<b>Reviewed studies and their titles .....</b>	<b>125</b>
<b>B.</b>	<b>Ethical approval lett .....</b>	<b>125</b>
<b>C.</b>	<b>A positioning statement .....</b>	<b>126</b>
<b>D.</b>	<b>A bracketing interview excerpt.....</b>	<b>127</b>
<b>E.</b>	<b>A reflexive diary excerpt .....</b>	<b>127</b>
<b>F.</b>	<b>Recruitment Poster .....</b>	<b>127</b>
<b>G.</b>	<b>Participant information Sheet .....</b>	<b>129</b>
<b>H.</b>	<b>Participant consent form.....</b>	<b>133</b>
<b>I.</b>	<b>Participant screening form.....</b>	<b>135</b>
<b>J.</b>	<b>Semi-structured interview questions.....</b>	<b>137</b>
<b>K.</b>	<b>Transcript excerpt with open code and memo:.....</b>	<b>137</b>
<b>L.</b>	<b>Open code excerpt with memo excerpt .....</b>	<b>137</b>
<b>M.</b>	<b>Open code to focused code excerpt.....</b>	<b>138</b>
<b>N.</b>	<b>Initial thematic diagramming – Grouping focused codes into sub themes.....</b>	<b>139</b>
<b>O.</b>	<b>Sub- theme development .....</b>	<b>140</b>
<b>P.</b>	<b>Thematic diagramming – Establishing links .....</b>	<b>141</b>

**SECTION A**

Narrative Approaches in Psychosis: A Systematic Review and Meta-Ethnography of qualitative findings

Word count: 7,898



## ABSTRACT

There is increasing recognition of the importance of considering the wider contexts and systemic issues that impact the recovery of people with psychosis. Narrative approaches are aptly positioned to do this however there is no existing review of narrative interventions in psychosis. This paper aimed to systematically review and critically evaluate the extant literature about the use of narrative interventions in psychosis and to present a meta-ethnographic synthesis of the emerging themes across studies. Systematic searches were carried out using the electronic databases Medline, PubMed, ASSIA and PsycINFO. A manual, “grey literature” search was also conducted. Seven qualitative papers and two mixed methods papers met the set eligibility criteria. Results suggest the existence of research evidence supporting the clinical use of narrative interventions in psychosis populations. Methodological issues limit evidence for the effectiveness of the narrative approach in psychosis. The meta-ethnographic synthesis identified nine core themes related to therapeutic processes. These were; equal stories, Equal humanity; making meaning; doing it together; alternative narratives; openness; family members as equal partners; strengthening personal narratives; positive impact on social networks and quality of life. These findings, along with a methodological evaluation of the research area, yielded recommendations for future research and practice that promote the amplification of the client’s narrative. The strengths and limitations of the review are also discussed.

. Keywords: recovery, narrative therapy, psychosis

## INTRODUCTION

This paper will review the evidence for the use of narrative interventions within populations that experience psychosis. In order to address this aim, this paper will outline the sociocultural context surrounding the experience and current treatments of psychosis in the UK. It will then discuss the existing evidence supporting the use of narrative approaches in psychosis. The review will critically evaluate the existing empirical research on narrative interventions in psychosis. Finally, this paper uses a meta-ethnographical approach to synthesise the findings of the review.

***Discourses around psychosis and Schizophrenia***

The term ‘Psychosis’ describes a varied set of experiences that can alter a person’s perception of their reality in relation to social norms (Gaebel and Zielasek, 2015). Its aetiology is the subject of much debate however there is evidence to suggest that psychotic experiences are associated with a variety of factors such as trauma, stress, substance misuse and physical illness (Hardy, 2017; Phillips et al., 2007; Maslin, 2002; Samele, 2007). Experiences of psychosis can be present at a subclinical level however it is also considered a symptom of mental illness (Verdoux & van Os, 2002). Psychosis is a primary feature of psychiatric diagnoses under the category of, “psychotic spectrum disorders”, such as schizophrenia (World Health Organization, 2016). More recently psychosis has been conceptualised as a continuous, transdiagnostic feature across a number of psychiatric and physical health diagnoses as well as in nonclinical populations (van Os, 2015; Biedermann & Fleischhacker, 2016; Wigman et al., 2017; Keshavan & Kaneko, 2013).

This more recent emphasis represents a significant shift from historically dominant narratives about psychosis. Psychosis has traditionally maintained a strong conceptual identity within psychiatry, specifically, alongside the diagnosis, schizophrenia (van Os, 2015). This history is complex and likely links back to the early 20<sup>th</sup> century conceptualisations of psychotic experiences as a symptom of a genetic, brain-based medical disorder (Bèurgy, 2008). Michel Foucault argues that sociocultural discourses are important in the development of a more robust understanding of experiences and this principle can be applied to the understanding of the experiences and treatment of people living with psychosis (Burr, 2015).

Asylums were opened in the 19<sup>th</sup> century as a way of managing people considered ‘mentally ill’ and would have been where many experiencing psychosis, would have been housed. It has been argued that the social and rural displacement caused by these institutions, added to misconceptions and stigma about those treated there, from the public (Lakritz, 2009). The legacy of which, may have persisted over time (Gilmore and Hughes, 2019).

More recent literature around stigma in mental health suggests that a label of schizophrenia predicts a larger degree of stigmatisation and othering, compared to depression (Gilmore & Hughes, 2019; Angermeyer and Matschinger, 2003). Common narratives around schizophrenia involve assumptions about a global lack of mental capacity, unpredictability, violence, dangerousness, and madness (Corrigan, Kerr & Knudsen, 2005; Cross, 2014, Owen, 2012; Abu-Akel and Abushua’leh, 2004; Hewitt, 2010). Corrigan, Kerr & Knudsen (2005) discuss how this can lead to negative emotional reactions in others such as fear and aggression, ultimately resulting in a desire for social distance.

The implications of this are wide reaching and interact with issues of social

power, filtering through to the intrapersonal as well as socioeconomic (Link & Phelan, 2001; Aristegui et al, 2006). González-Torres et al. (2007) found prejudice, infantilization, and discrimination were common experiences of people with psychosis. These are experiences that can result in avoidance, economic disadvantage and social isolation. People with schizophrenia were also found to be more likely to come into contact with the criminal justice system either as perpetrators, or more likely, as victims (The Schizophrenia Commission, 2013).

Research has demonstrated that mental health clinicians are not impervious to acting out stereotypes and stigmas towards their clients with schizophrenia (Morrison and Nevid, 1976; Shoham-Salomon, 1985; Jorm et al., 1999). This will have likely impacted on some client's confidence in asking for support and help. Stigma within institutions is described in research as, 'structural stigma' (Schomerus, & Angermeyer, 2008).

Negative discourses about psychosis have also been found to diminish a person with psychosis' perception of self (Corrigan, 2004). This is known as 'self-stigma' and it appears to be a particular issue for people who have been diagnosed with schizophrenia (Vrbova et al., 2016).

Self-stigma, along with perceived interpersonal or structural stigma within services have arisen as key factors in maintaining poor adherence and engagement within psychosis services (Sin et al, 2016; Kreyenbuhl, Dixon & Nossel, 2009; Doyle, et al., 2014; Tait, Birchwood & Trower, 2003). Poor engagement with services has in turn been found to have a consequential effect on the efficacy of treatments offered within mental health services (Doyle et al., 2014).

The literature calls for sensitivity to people's varying beliefs about psychosis and for attention to be paid to experiences of marginalisation and discrimination, recognising

the potentially traumatic and cascading impact of external and internal forms of stigma on recovery (Hoftman, 2016). There has been a mounting call for new ways of working and of conceptualising distress that draw on non-stigmatising approaches and considers the palpable and harmful effects of social discourses around psychosis (Thomas et al., 2018; Johnstone and Boyle, 2018).

***A new way of understanding and working with psychosis***

The service user movement has amplified the voices of clients through the sharing of stories about treatment and recovery (Goossen & Austin, 2017). These personal narratives have proven to be a powerful way to initiate systemic change. This movement has also been key in offering critical thought around the medical model, its limited view of wellbeing and its inadvertent contribution to the othering of people, particularly those diagnosed with psychosis (Thachuk, 2011). Researchers and clinicians are increasingly interested the ideas of clinical and personal recovery (Macpherson et al., 2016).

Clinical recovery fits in with the medical model approach and focuses on removing or reducing ‘symptoms’ and restoring social functioning. Personal recovery on the other hand, is a considered to be a way of living a satisfying, hopeful, and contributing life even within the perceived limitations of a diagnosis (Slade, 2009). It recognises that ‘normal’ will hold different meanings for people and that life beyond a psychosis diagnosis will involve a deeply personal, unique process. In this way, recovery could be considered as being closely associated with the story a person is able to tell about themselves in the context of other competing narratives.

Research is showing promising therapeutic effects of sharing and listening to personal narratives in promoting recovery in people with mental health difficulties

(Rennick-Egglestone et al., 2019). Other relationally oriented approaches such as talking therapies and peer-led community interventions are also indicated. In 2014, NICE guidelines were amended to recommend that individual CBT is offered to all clients presenting with psychosis and that family interventions be offered to all families of people with psychosis or schizophrenia (National Institute for Health and Care Evidence, 2014). However, these guidelines are underpinned by a positivist ontological position that situates recovery in terms of the clinical definition. As such the research informing it, often has a focus on numerical outcome data, rather than on a recovery narrative that would reflect an individual's personal understandings, experiences and values (McPherson et al. 2009). The social constructionist therapeutic approaches that are more in line with personal recovery ideas are markedly absent (Williams, 2015). There is, therefore, an argument for the development of approaches to treatment in psychosis that adopt an interpretative perspective on recovery and is more in definitions of personal recovery (Pooremamali et al., 2011).

### ***Indications for narrative therapy in psychosis treatment***

Narrative interventions hold a constructionist ontological position (Freedman & Combs, 1996). It considers that 'truth' is socially constructed and is therefore constructed between the client and therapist during therapy. The narrative approach situates problems within social frameworks, viewing them as arising from their social, cultural and political contexts (White and Epston, 1990). Narrative interventions use particular therapeutic tools to highlight alternative narratives with the aim of revealing subjugated stories that might highlight a person's strengths, skills and values. The idea is that these attributes become tools to help someone access, embrace and live their preferred narrative.

Narrative interventions have become very popular in therapeutic work with individuals and groups whose voices and identities have been suppressed by problem-saturated societal discourses. It has been applied with promising effect, in learning disability and physical health contexts as well as with people who have experienced geographical displacement (Smyly et al., 2008; McParland, 2015). A qualitative study with individuals with late onset psychosis (Quin et al., 2009) highlights the potential value of a narrative approach; however it is difficult to ascertain which dimensions of narrative therapy are most likely to be helpful in supporting recovery in psychosis.

As an individual moves through the processes of social interaction, the self-narrative is subject to constant changes in line with the stories that that individual must develop to make sense of their own and others' lives (Davies and Harré, 1990). By identifying where wider discourses might interact with personal narratives to maintain distress, narrative therapy holds the potential to transform medical pathology discourses, or 'problem focussed narratives' into strength-based discourses and to consequently support the reconstruction of a preferred identity (Roe and Davidson, 2005; Hewson, 2015). This may be particularly applicable to people with psychotic experiences as research demonstrates that stigmatizing discourses disproportionately impact them (Gilmore & Hughes, 2019; Angermeyer and Matschinger, 2003).

Another perceived strength of narrative therapy is its focus on the self-narrative. It allows space for a clinician to attend to any meaning attributed to the psychotic experience, in line with client's own interpretations and understanding. The idea is that a client's view of themselves, and their relationship to others, potentially including voices or visions, might shift as they are given the space to express an alternative story (Busch 2007). The advantages outlined here suggest that narrative interventions may hold the potential for impacting change. However, to date there has been no review exploring

how narrative-based therapies might impact outcomes in psychosis.

### ***Challenges in the empirical investigation of evidence for narrative therapy***

Busch (2007) argues that attempts to fit narrative therapy into research methodologies intended for positivist investigations, compromise the epistemological foundations of the narrative approach. Positivist models assume that mental health is formed of distinct psychopathologies that can be assessed through objective investigation. Narrative therapy holds a largely improvised, conversational approach to problem finding that is led by the client. This poses a challenge to idea of objective investigation and complicates the comparison of samples across studies. White's (2007) *Maps of Narrative Practice* offers some direction about what constitutes a narrative therapy intervention. However these act as guiding principles, rather than inflexible strategies, which causes additional challenges to the reliability of comparison based research.

Further, the operationalization of narrative therapy appears to be at odds with the idea that meaning making is a relational and constitutive production of individual lived experience. What might be considered as a positive outcome is expected to vary greatly from client to client. Whilst this fits with the concept of personal recovery, it does further complicate systematic measurement (Busch et al, 2011).

Case studies have been a common approach to the empirical investigation of narrative therapy. This is likely due to their ability to present a complex description of a phenomenon within its context (Yin, 2004). Case study research has a long history within the social and behavioural sciences and has been central to the development of knowledge in psychotherapy (McLeod, 2010; Salminen, Harra, & Lautamo, 2006; Salminen et al., 2006). Busch (2011) argues that case studies offer a way to reflexively



investigate narrative therapy interventions in a way that is consistent with its theoretical position.

### *Aim of the current review*

The current review aims to systematically review the extant literature about the use of narrative approaches in psychosis. A critical evaluation of the methodology will be used to explore and comment on the quality of existing research on narrative approaches in psychosis. The review will also employ a meta-ethnographical approach to present the themes identified as being associated with change processes in narrative approaches for psychosis.

These aims will be addressed as guided by the following research questions:

1. Is there quality research evidence to support clinical use of narrative approaches in psychosis populations?
2. What are the key therapeutic processes in narrative approaches in psychosis?
3. What are the research and clinical implications from the literature?

## METHOD

### *Scope of the review*

This review evaluated peer-reviewed, published journal articles. The systematic literature search was conducted between 29<sup>th</sup> December 2019 and 3<sup>rd</sup> January 2020. The database search included papers that were published between 1960 and 2020. Advanced publications were considered.

### *Definitions*

Psychosis, in this study, is used to describe people who experience psychotic symptoms (American Psychiatric Association, 2017; World Health Organisation, 1992). Any description that includes the key features of psychosis will be considered, such as audio, visual or tactile hallucinations or delusions (Arciniegas, 2015).

A narrative approach, in this study, refers to any psychotherapeutic intervention based on narrative therapy ideas and/or its model specific techniques (White and Epston (1990), demonstrating the predominant influence of narrative therapy. This may include; externalisation, thickening the narrative, looking for alternative narratives, identifying strengths or resources or recognising preferred identities.

### *Eligibility Criteria*

This review sought to identify primary research that demonstrated the feasibility of narrative therapy interventions in populations with psychosis. It was decided to include both qualitative and quantitative research. See table 1 for inclusion and exclusion criteria.

*Table 1. Summary of inclusion and exclusion criteria.*

---

Papers were eligible for inclusion in the review if they met the following criteria:

---

- Research participants were adults (above 18 years old).
  - Original studies that included qualitative or quantitative methodology.
  - Peer reviewed published articles.
  - Evidence of reported use of a narrative approach within psychosis population
  - Group studies were included in the study given that group narrative interventions often include similar components to individual work.
- 

Papers were excluded from the review on the basis of meeting any of the following criteria:

---

- 
- Studies with children (involving participants under 18 years old).
  - Studies where the main diagnosis wasn't psychosis.
  - Studies that did not use primarily, a narrative approach. That is if they reported on integrated therapeutic approaches.
  - Studies not reported in the English language.
  - Unpublished data of any form including conference proceedings, dissertations.
  - Conceptual papers.
- 

### *Search strategy and data sources*

The systematic review was conducted and reported according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (Moher et al., 2009). Systematic searches were completed using the electronic databases Medline, PubMed, ASSIA and PsycINFO. A 'grey literature' search was also conducted by checking the reference lists of relevant papers. The search process was completed in five stages. Firstly, the string search items were developed based on results of an initial search of "using narratives in therapy with psychosis" on Google Scholar.

*Table 2. Generated string search items.*

---

Search items combined with "AND"

---

"narrative" or "narrative approach\*"

"Therapy" or "intervention" or "psychotherapy"

"psychosis" or "schizophrenia" or "voices or hallucination"

---

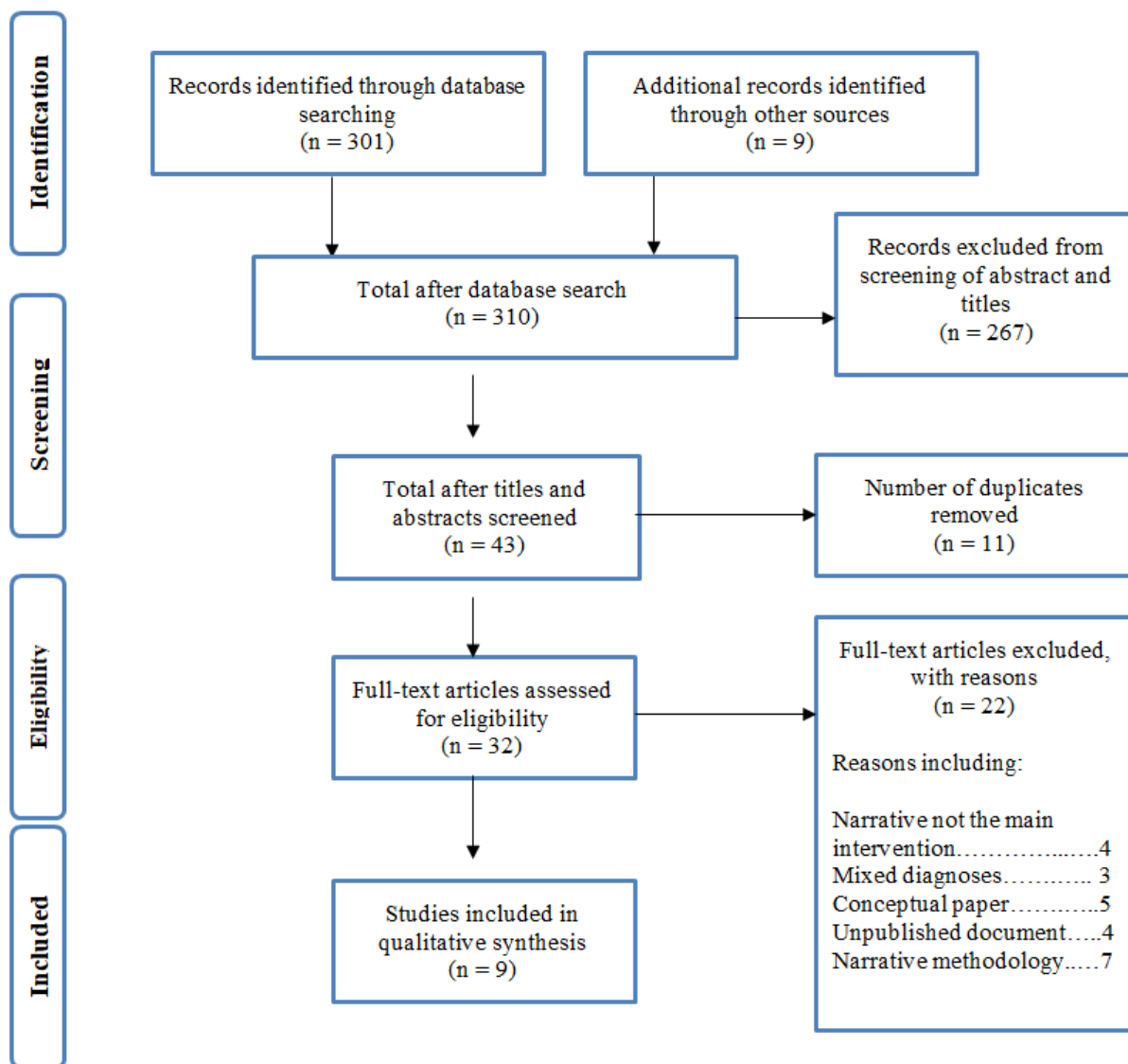
\*A decision was made to exclude the use of the single term "narrative" as results were too broad and included papers applying narrative methodologies.

\*\*Searched for in titles and abstracts only.

The search was then completed, using the string search terms outlined in table 2. The titles and abstracts of the identified studies were screened for eligibility against the

inclusion and exclusion criteria (table 1). Next, the full texts of the papers initially assessed as relevant for the review were retrieved and checked against the inclusion/exclusion criteria. Nine studies were identified and included in this review. Finally, included studies were marked against quality assessment criteria (Centre for Evidence Based Management, 2014; Hong et al, 2018).

The PRISMA diagram in Figure 1 summarizes the full search strategy and



process of selection.

Figure 1. PRISMA diagram, illustrating the study selection process (Moher et al., 2009).

### Data Extraction

The systematic search yielded 9 studies that met the criteria for inclusion in the

review. These studies are summarised in the extraction table 3 below. The ‘data extraction’ table is adapted, based on a checklist for data extraction in the Cochrane Handbook for Systematic Reviews of Interventions (Cochrane Collaboration, 2011). The data extraction table considered the following areas: source, country, design, participants, setting/context, data collection, analysis and results. Of the 9 studies included, 7 were qualitative studies and 2 had a mixed methods design. A list of studies and their included titles can be found in appendix A.

Table 3: Data extraction table

Author (Date)	Source	Country	Aims	Design	Setting/ Context	Participants	Data Collection	Data analysis	Results
Holma & Aalomen (1995).	Peer reviewed journal	Finland	To find out what differences exist between patients with collapsed and patients with non-collapsed self-narrative in creating a new narrative in the therapy meetings.	Multiple case studies.	First admission to a psychiatric hospital.	26 yr old male 42 yr old female 27 yr old female 19 yr old male  Diagnosed as having schizophrenia, delusional, or other psychotic disorder according to DSM-III-R (American Psychiatric Association, 1980).	The material was gathered in therapy meetings during the initial stage of treatment and in follow-ups. Constructed stories were recorded in writing immediately after each of the therapy meetings.	The objects of study are described, understood, and explained according to the theory in question.	These practices create a multiplicity of stories; they create multiple perspectives of self-narratives.
Holma & Aaltonen, (1997).	Peer reviewed journal	Finland	The aim was to describe how in psychosis a narrative and a sense of agency is achieved through therapy meetings.	Multiple case studies.	First admission to a psychiatric hospital.	22 yr old male 23 yr old female 24 yr old male  Diagnosed as having schizophrenia, delusional, or other psychotic disorder according to DSM-III-R (American Psychiatric Association, 1980).	The first author, immediately after every meeting, made a note of the oral accounts given of personal experience and the explanations of that experience and how the meetings had gone.	Observations, and recorded as thick description.  The second step in the analysis was to code this material according to the categories: sense of identity, narrative identity, and preparative quality of experience.	1) The stories available do not sufficiently capture the pre-narrative quality of personal experience.  2) The sense of agency is diminished when the stories surrounding the individual are only of the subjugating kind,  3) psychosis can also be an escape to maintain a sense of agency.
Vassallo, (1998).	Peer reviewed journal	UK	To demonstrate that it is appropriate, useful and very positive to do narrative group therapy with individuals affected by mental illness in a rehabilitation context	Case study.	Mental Health Rehabilitation Service  Group intervention	9 individuals A history of psychosis; No acute illness at the time of referral	A letter was used after each session to summarise the discoveries made by members.	Independent evaluators wrote a qualitative evaluation report	The outcome of the group was the alternative knowledge generated... “List of discoveries from the haven for active minds”
Ching, Smyth & Charlesworth (2019).	Peer reviewed journal	UK	To adapt and feasibility test the narrative component of Narrative enhancement and	Mixed methods multiple single-case	NHS secondary care services  Group	7 Individuals with Late Onset psychosis  40 yrs old and older	Qualitative field notes of sessions.  Quantitative outcome	Outcome scores were inputted and analysed using Statistical Analysis Software Package	Adaptations were made to the material and protocol.  Good on feasibility and

RECLAIMING THE NARRATIVE: EXPLORING PERSONAL RECOVERY IN PSYCHOSIS

			cognitive therapy (NECT)	design.	intervention		measures.	(SPSSv21)	acceptability of the intervention.
						Formal diagnosis of schizophrenia, schizophreniform, schizoaffective, delusional disorder, brief psychotic or psychotic disorder not otherwise specified.	Post-intervention qualitative interviews.	Three-step method was used to analyse multiple single-case studies: 1. Graphical display of change over time 2. Use of clinically significant change (CSC) and reliable change (RC) 3. Qualitative data from participant follow-up focus groups or individual interviews.	The adapted intervention may promote recovery
Mehl-Madrona, Jul & Mainguy (2014).	Peer reviewed journal	USA	To show the path through which the transpersonal narrative evolved.	Mixed methods Single case design.  (Including case studies)	Psychiatric outpatient service  Group interventions	51 patients over 20 years old who presented with psychosis and who remained in the service for at least six months.  Diagnoses included schizophrenia, bipolar disorder with psychotic features, psychosis not otherwise specified, and schizoaffective disorder.	Questionnaires were administered to all Participants.  Questionnaires were re-administered at quarterly intervals.	Descriptive statistics.  Case descriptions.	Most people who stick with the approach (for whatever reason) do largely improve on all baseline measures.
Holma, & Aaltonen, (1998a).	Peer reviewed journal	Finland	To study specific elements of the how meaning is developed from experiences via narrative construction in the therapy process.	Multiple case studies.	First admission to a psychiatric hospital.	34 yr old female 33 yr old male 22 yr old male  Diagnosed as having schizophrenia, delusional, or other psychotic disorder according to DSM-III-R (American Psychiatric Association, 1980)	The first author, immediately after every meeting, made a note of the oral accounts given of personal experience and the explanations of that experience and how the meetings had gone.	The method of analysis: the objects of study are found and describe, understood, and explained according to the theory in question.	Through the mutual knowledge constructed via dialogue with the patient and family members as equal partners the needs of the treatment as well the treatment modalities can be determined.
Holma & Aaltonen, (1998b).	Peer reviewed journal	Finland	To apply the narrative approach in therapy to investigate how time appears in the narrating activities of psychotic patients and their family members.	Multiple case studies.	First admission to a psychiatric hospital.	24 yr old male 32 yr old male 33 yr old female  Diagnosed as having schizophrenia, delusional, or other psychotic disorder according to DSM-III-R (American Psychiatric Association, 1980)	The material was gathered in therapy meetings during the initial stage of treatment and in follow-ups.	The method of analysis: the objects of study are found and described, understood, and explained according to the theory in question.	By becoming a competent narrator one also becomes an audience for his or her own narratives and gains reflexivity in relation to her or his experiences.

RECLAIMING THE NARRATIVE: EXPLORING PERSONAL RECOVERY IN PSYCHOSIS

Freedman & Combs (2009).	<i>Peer reviewed journal</i>	Australia	Record the learnings of a narrative approach in a community group	Case study	Community Mental Health Project.	Previous recipients of mainstream psychiatric services for varying lengths.  Unspecified number of people in the group intervention  Schizophrenia.  All hearing voices.	Facilitator kept a record of the conversation and asked questions to assist the group. After each meeting he would put together the group's ideas in a document	Themes are developed	The group produced several formal documents of their insider knowledge  Gave us some understanding of how narrative practices might be used in on-going community work.
Further information detailed in Brigitte, Sue, Mem, & Veronika. (1997)									
Bar-Am, (2016).	<i>Peer reviewed journal</i>	Australia	Using a magical realist listening stance to understand units of experience, units of meaning, and the fluidity of identity in psychosis, which is contextualised as a response to events in the client's story.	Case study	Private counselling service	Adult Female First episode psychosis	Process notes	Themes are developed	She remains well and has not been revisited by psychosis throughout her recovery; she also remains cautious while connected to her supports in a loving and non-pathologising manner.



### *Structure of the Review*

Each of the included studies is described in terms of its characteristics. The findings of the review are then presented with a critique of the study methodologies offered.

The synthesised findings are then presented using a meta-ethnographic approach (Noblit & Hare, 1988). In the discussion, the findings of the review are considered in the context of the wider literature. Clinical and research implications are discussed. The review concludes with comments on the strengths and limitations of the review.

## RESULTS

*Description of the studies*

The earliest published paper presented is by Holma and Aaltonen in 1995. They author four of the nine papers included in the review. These papers are derived from a wider research project within which Holma and Aaltonen (1995; 1997; 1998a; 1998b) describe the ways that narrative therapy concepts and techniques were applied in assessing and treating first-episode, non-affective psychosis. Treatment occurred in multiple conjoint therapy sessions, usually involving the patient, family members, and a treatment team. Each of the four studies presents three case studies and focuses on a specific hypothesis about how the client's narrative changes over the course of the intervention.

Vassallo (1998), Ching, Smyth & Charlesworth (2019) and Fredman and Combs (2009) all evaluated the application of narrative therapy approaches in a group setting. Vassallo (1998) worked with clients who were within rehabilitation services but not deemed to have what he described as 'acute' symptoms. Ching et al. (2019) worked with people who were diagnosed with late onset psychosis and were within statutory mental health community services. Finally, Fredman and Combs reported on an intervention in which members of the community, that had various experiences of statutory mental health services and had been diagnosed with schizophrenia, reached out to narrative therapists in order to co-develop a therapeutic space. Mehl-Madrona, Jul & Mainguy (2014) employed a mixed methods approach, using both qualitative and quantitative methods to explore the effectiveness of their intervention for people with psychosis who were being treated without the use of medication. Both Mehl-Madrona (2014) and Ching et al. (2014) used interventions that were guided by narrative ideas but that were not exclusively referred to

as narrative therapy. Both papers isolate the elements of the narrative intervention for discussion in their papers. Bar-Am, (2016) presented a single case study on young woman with first episode psychosis.

A total of 9 studies were extracted for the purpose of the review. Though this is relatively small sample for a systematic review, it is in line with the number of studies used in other reviews of narrative interventions (McParland, 2015; Etchison and Kleist, 2000).

### ***Quality assessment tool***

The quality assessment was conducted in accordance with the recommendations in the Cochrane Handbook for Systematic Reviews of Interventions (Cochrane Collaboration, 2011). The recommendations further advise checklists as a helpful way to approach quality assessments as they offer a degree of consistency and therefore, reliability to the process.

Eight out of the 9 studies used case study as part or all of the methodological approach. The Centre for Evidence Based Management's (CEBMa, 2014) checklist for the critical appraisal of a case study was selected to evaluate these. The construct validity of this checklist has not been tested empirically and there are no available guidelines regarding cut off scores. Previous studies reviewing narrative interventions have drawn on Yin's (2003) paper, which outlines descriptive strategies for evaluating case studies. Yin (2003) outlines four tests to consider in the evaluation of case studies; construct validity, reliability, internal validity and external validity (See figure 3). Upon review, these four tests were incorporated as part of the CEBMa (2014) checklist criteria. As such, it was decided to continue with the use of the more structured approach as recommended. Yin's (2003) matrix (figure 2) was used to support the clarification of the CEBMa (2014) checklist items. The two mixed methods studies were evaluated using Hong et al's (2018) Mixed Methods Appraisal Tool (MMAT). Again, no cut off information was available.

Tests	Case Study Tactic	Phase of research in which tactic occurs
<b>Construct validity</b>	● Use multiple sources of evidence	data collection
	● Establish chain of evidence	data collection
	● Have key informants review draft case study report	composition
<b>Internal validity</b>	● Do pattern-matching	data analysis
	● Do explanation-building	data analysis
	● Address rival explanations	data analysis
	● Use logic models	data analysis
<b>External validity</b>	● Use theory in single-case studies	research design
	● Use replication logic in multiple-case studies	research design
<b>Reliability</b>	● Use case study protocol	data collection
	● Develop case study database	data collection

Figure 2: Yin's (2003) matrix of tests to consider in the development and evaluation of test studies.

### **Quality assessment**

The critical appraisal checklists with data are summarised in tables 5 and 6. Both of the checklists use three options for response to each item. Each response option was defined for the purpose of this review as described in table 4.

Table 4: The definitions used for each checklist response option.

Response option	Definition
Yes	There is evidence for the presence of the criteria based on the published report
No	There is evidence for the absence of the criteria based on the published report
Can't Tell	There is no clear evidence for the presence or absence of the criteria based on the published report

Table 5: Critical appraisal of case studies using the CEBMa checklist (Centre for evidence based management, 2014, adapted from Crombie, 2009).

Appraisal questions	Holma & Aalonen (1995)	Holma & Aaltonen (1997)	Vassallo (1998)	Mehl-Madrona, Jul & Mainguy (2014.)	Holma& Aaltonen (1998a)	Holma& Aaltonen 1998b)	Freedman & Combs (2009).	Bar-Am, (2016)
1. Did the study address a clearly focused question / issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Is the research method (study design) appropriate for answering the research question?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Are both the setting and the subjects representative with regard to the population to which the findings will be referred?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Is the researcher's perspective clearly described and taken into account?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5. Are the methods for collecting data clearly described?	Yes	Yes	No	Yes	No	Can't tell	Yes	No
6. Are the methods for analysing the data likely to be valid and reliable? Are quality control measures used?	No	Yes	Can't tell	Can't tell	Can't tell	Can't tell	No	Can't tell
7. Was the analysis repeated by more than one researcher to ensure reliability?	No	No	Yes	Can't tell	Can't tell	Can't tell	Can't tell	No
8. Are the results credible, and if so, are they relevant for practice?	Can't tell	Can't tell	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell
9. Are the conclusions drawn justified by the results?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10. Are the findings of the study transferable to other settings?	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Can't tell
<b>Total score</b>	<b>7</b>	<b>7</b>	<b>8</b>	<b>7</b>	<b>7</b>	<b>7</b>	<b>7</b>	<b>5</b>

\*This is a mixed methods design however the case study element of this study was considered in the evaluation.

*Table 6: Critical appraisal of mixed methods studies using Hong et al's (2018) Mixed Methods Appraisal Tool (MMAT)*

Appraisal questions	Mehl-Madrona, Jul & Mainguy (2014)*.	Ching, Smyth & Charlesworth (2019).
1. Is there an adequate rationale for using a mixed methods design to address the research question?	Yes	Yes
2. Are the different components of the study effectively integrated to answer the research question?	Yes	Yes
3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Yes	Yes
4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	No	Yes
5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes	No
Total score	3	4

\*The case study component of this study has also been included in the CEBMa checklist in Table 5.

Out of the 8 studies included in the case study appraisal, 7 had checklist scores of 7 out of 10 or above. Six studies were given a score of 7 out of 10. One study received a score of 8 out of 10. Both studies included in the mixed methodology appraisal were given a score of 4 out of 5. Mehl-Madrona, Jul & Mainguy's (2014) study was assessed using both critical appraisal checklists. Cut offs were not available for any of the checklists, as such, researcher judgement was applied to assess and apply value to the checklist scores obtained.

The checklist scores indicate that the current literature for narrative interventions in psychosis consists of a number of good quality papers, with the exception of Bar-Am's (2016) study, which was allocated a score of 5. The following section will look at this more closely, offering a discursive approach to the critical evaluation of the methodologies as a way of augmenting the checklists.

The information in Tables 5 and 6 gives an overview of the quality assessments of the studies included in the review. They highlight that all of the studies presented a clear

research question, appropriate methodology and selected research subjects that appropriately reflected a wider population of people with clinical experiences of psychosis. This suggests that the studies in the review are well designed, offering some assurance of internal validity. All of the case studies were reported in such a way that made the authors positioning clear. This promotes reflexive considerations of the ways in which an author's views might impact the collection and interpretation of qualitative data and is an attempt to reduce the potential impact of researcher bias, thus improving the validity of a study.

There was wide variability in the ways that data collection was reported, with 4 of the 9 studies, all case studies, failing to report or vaguely reporting the strategy they used. Narrative interventions do vary greatly in how outcomes are collected and reported as is reflected in the findings of the review. Freedman & Combs (2009) reported on the co-creation of documents with group participants whilst Holma & Aaltonen (1995; 1997; 1998a; 1998b) tended to use a more interpretive approach based on the verbal accounts of participants. A lack of consistency in reporting of data collection strategies makes it more challenging for future studies to accurately replicate the methodology. In this way, the reliability of the case study literature evidencing the use of narrative interventions in psychosis is weakened.

Yin (2000) states that strong case study arguments reflect thoroughness in covering all relevant conditions combined with the explicit naming and entertaining of rival explanations. In the current review, such thoroughness does not appear to be demonstrated in the included case studies. The data yielded from the checklist (table 5) would suggest that poor reporting could be responsible for the lack of information about the methods of analysis used. It also suggests that over half of the studies did not include the use of multiple researchers to triangulate the findings in order to increase the reliability of the findings. The remaining half did not clearly report whether or not this strategy was used at

all.

The results reported across all the qualitative studies in the review appeared anchored in participant's narratives and the changes observed (e.g. Bar-Am, 2016; Vassallo, 1998). However, a failure to report on the methods the researcher used to analyse the data or a lack of a demonstrable systematic approach to analysis, at best, weakens the ability for the study to be replicated and thus its reliability. At worst, it can raise questions about the way in which associations between the intervention and the findings are described, namely its internal validity. The internal validity of the mixed methods design research studies was good. The clear reporting of study design and methodology supported this.

It was difficult to assess the credibility or the relevance of the results where the papers lacked a detailed enough discussion interpreting their findings in the context of the study aims and participant experiences (Holma & Aalonen 1995; Holma & Aaltonen, 1997; Holma & Aaltonen, 1998a; Freedman & Combs, 2009; Bar-Am, 2016; Mehl-Madrona, Jul & Mainguy, 2014). Nevertheless, the conclusions that were drawn across the studies did, in terms of face validity, appear to appropriately follow the presented findings, which were typically grounded in the verbal accounts reported. The confidence in these conclusions is strengthened in the studies where author reflexivity had been demonstrated.

All nine studies included in the review were assessed as being generalizable in that the study settings appeared representative of community and statutory therapeutic contexts involved in the support of individuals and the families of individuals experiencing psychosis.



### *The meta-ethnographic approach*

A meta-ethnographic approach to the synthesis of the review findings was chosen as it allows a researcher to examine commonalities across studies, particularly where there are qualitative components.

France et al. (2015) describe the seven phases of the meta-ethnography approach (figure 3). Phases 1 and 2 have been covered by the earlier stages of this review. The following section of the review will present the development of the synthesis outlined in phases 3 to 7 (figure 3).

*Phase 3:* In this phase, the papers were reviewed, and key concepts and themes were noted. As the data extracts included in the papers have already been selected from the full dataset by the study authors, the extracts and quotations do not reflect the totality of participant experiences.

*Phase 4:* This phase was used to determine how the studies are related. The previous list of concepts and themes were further developed and then juxtaposed to build a pattern of similarity across the studies, as suggested by Noblit and Hare (1988). This was a straightforward process and it became rapidly apparent that there were clear similarities across the studies, irrespective of variations in reporting style and methodologies.

*Phase 5:* The studies were sufficiently similar in their focus to allow reciprocal translation. Reciprocal translation is where the concepts from one study are translated on to those of the others. Reciprocal translation involved comparing the themes from paper 1 with paper 2, and the synthesis of these two papers with paper 3 etc. The themes created above in phase 4 were the starting point however an open stance was kept to notice emerging themes.

*Phase 6:* In this phase, the translated themes and subthemes were conflated to devise second and third order themes. A final overarching model was developed that linked

together the translations and authors' interpretations.

*Phase 7:* the emergent model is presented in the next section of the current review.

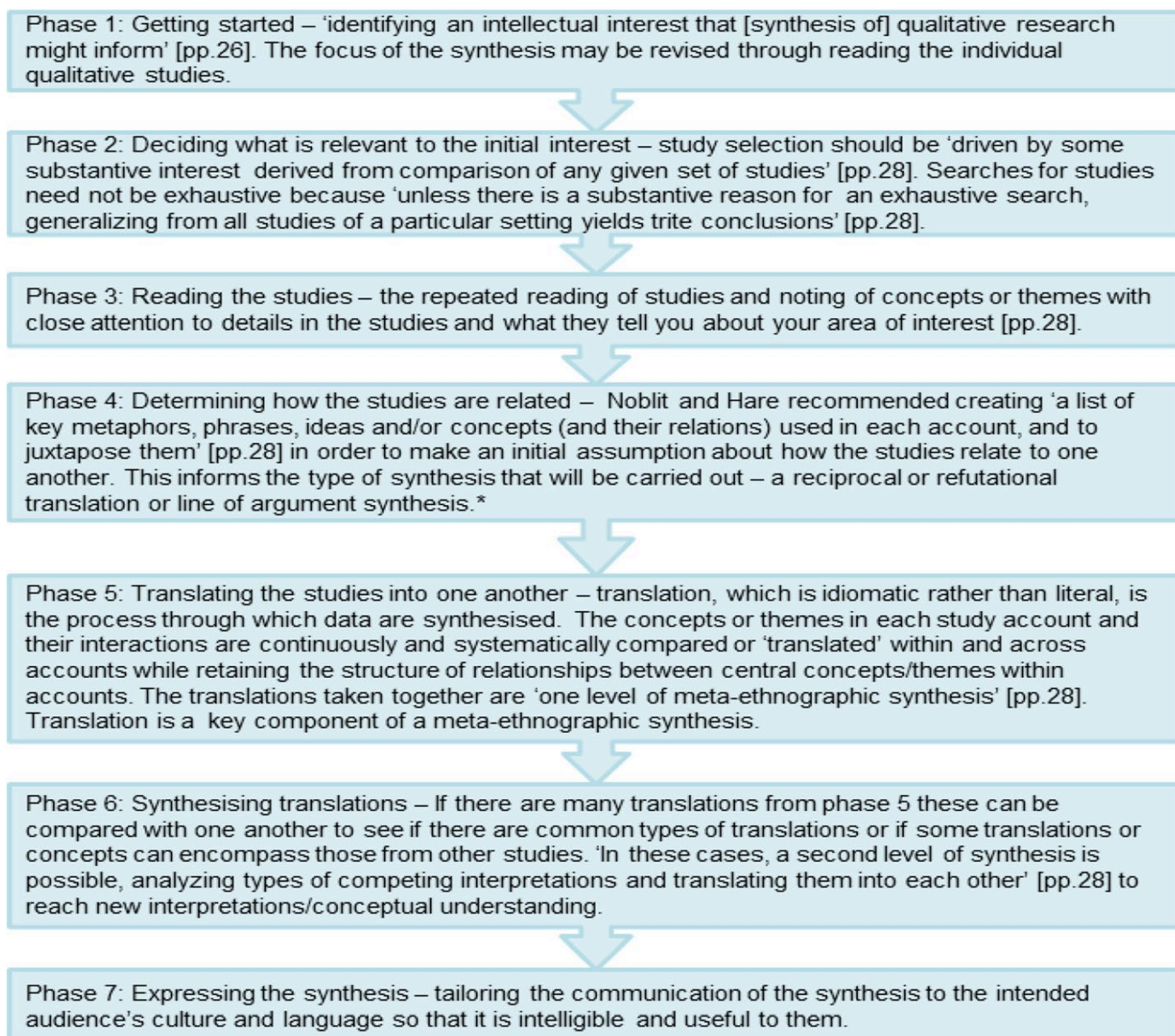


Figure 3: The seven phases of the meta-ethnography approach as outlined in Noblit and Hare France et al. (2015).

The process of developing the emergent synthesis is illustrated below in table 7

Table 7: An outline of the process of developing the emergent meta-ethnographic synthesis

Sources	First order theme <i>(Illustrative quotes from the published reports)</i>	Second order theme	Third order theme	Overarching theme
Holma and Aaltonen (1995)	<i>Produced stories about the patient in relation to others the patient began to create a cohesive self-narrative; the self-narrative was constructed socially.</i>	Stories about patient in relation to others	<b>Equal stories, Equal humanity</b>	Individual processes
Holma and Aaltonen (1998a)	<i>The patient's story was, however, on an equal level with the other stories.</i>			
Ching, Smyth & Charlesworth (2019)	<i>Knowing that they are not alone, being able to identify with other people</i>			
Freedman and Combs (2009)	<i>Meetings provide a forum for us to talk about many of our experiences of life. This includes our experiences of what others refer to as auditory or visual hallucinations.</i>	Experiences were acknowledged		
Mehl-Madrona, Jul & Mainguy (2014)	<i>Each [voice] was allowed to speak...and for those bearing witness to her story to accept her interpretation.</i>			
Holma and Aaltonen (1998a)	<i>At that particular meeting the family members respected the patient as an equal partner in dialogue.</i>	Giving client a voice. Their perspective was allowed		
Bar-Am (2016)	<i>On we talked. I recalled the writings of others who experience what the sane call Madness.</i>	Collective storytelling reduces stigma		
Vassallo (1998)	<i>It's a place where people living with a mental illness can be intimate... The so-called 'well' community have a double standard. They are often quick to judge</i>			
Mehl-Madrona, Jul & Mainguy (2014)	<i>Improvement came when God was allowed to speak and to declare what her experience had meant</i>	Symptoms having meaning	<b>Making meaning</b>	
Holma and Aaltonen (1995)	<i>She said that her life was richer when she had pictures. They had meaning...</i>			
Holma and Aaltonen (1998b)	<i>The psychosis had sped up the process of clarifying their relationship</i>			
Bar-Am (2016)	<i>And part of what was really painful for Eva, her own</i>	Lost meaning emerges		

RECLAIMING THE NARRATIVE: EXPLORING PERSONAL RECOVERY IN PSYCHOSIS

	<i>unresolvable dilemma, emerged from the conversation</i>		
Holma and Aaltonen (1995)	<i>The father's and the sister's self-narratives were connected to the accident and to the mother's death. During the next meeting the family members talked about life after the accident.</i>		
Mehl-Madrona, Jul & Mainguy (2014)	<i>The group generated discussions on the discrimination of mental health conditions in employment.</i>	Experiences validated	<b>Doing it together</b>
Vasallo (1998)	<i>The so-called 'well' community have a double standard. They are often quick to judge. In a group like this we can be ourselves.</i>		
Ching, Smyth & Charlesworth (2019)	<i>The environment allows validation of experiences</i>		
Ching, Smyth & Charlesworth (2019)	<i>They became encouraging, validating and supportive in the final three sessions. It is interesting to note that each participant played a unique role in the group.</i>	Group cohesiveness	
Vasallo (1998)	<i>They have developed friendships, laughter and fun and a sense of trust has been restored to them.</i>		
Freedman & Combs (2009)	<i>We are together in solidarity. We are secure in each other's company.</i>		
Ching, Smyth & Charlesworth (2019)	<i>They picked up other participants' ways of coping.....I got courage from the group...before, there was something blocking me.</i>	Learning from the group	
Vasallo (1998)	<i>The group members' enormous range of discoveries during the eight sessions constituted the written testimony to this</i>		
Bar-Am (2016)	<i>Her experiences are rich with meaning and sublime awe.</i>	Making thick, rich stories	<b>Alternative narratives</b>
Holma and Aaltonen (1998a)	<i>The possibilities for creating meanings and narratives had been widened.</i>		
Holma and Aaltonen (1995)	<i>The meanings of the event changed when the event was situated in alternative stories, first from the parapsychological story to the medical story and then from the medical story to the religious story.</i>	Change from problem to positive story	

## RECLAIMING THE NARRATIVE: EXPLORING PERSONAL RECOVERY IN PSYCHOSIS

Holma and Aaltonen (1998b)	<i>This story about the patient as an empathic person who had taken care of others and worried easily about others.</i>			
Ching, Smyth & Charlesworth (2019)	<i>The language participants used seem to reflect a shift in identity and narrative</i>	Discovering an alternative story		
Bar-Am (2016)	<i>e.g. 'I am normal', 'I am not alone', The storyline of the psychosis introduced several new embodied magical themes</i>			
Holma and Aaltonen (1998b)	<i>A story about lost love was constructed</i>			
Freedman and Combs (2009)	<i>It would be true to say that our work together has rekindled not just a love for life, but a love for justice and this sustains us in our new lives</i>	Acting in line with a new story		
Vasallo (1998)	<i>Communicate and look after your appearance and take charge of the practical aspects of your life. Through this you become a respectable person.</i>			
Freedman and Combs (2009)	<i>And now we are finding the opportunity to talk openly with friends and relatives about the pain they experienced.</i>	Discussing emotions and experiences openly	<b>Openness</b>	
Holma and Aaltonen (1998a)	<i>They now heard these events for the first time</i>			
Holma and Aaltonen (1998a)	<i>The mother recognized some anxiety in herself concerning the separation.</i>	Family also sharing their stories	<b>Family members as equal partners</b>	System transformations
Holma and Aaltonen (1998b)	<i>The parents and the ex-patient narrated many of the events that had happened during the psychosis and the subsequent hospitalization. They laughed at many things and said they somehow missed all the peculiar behaviour.</i>			
Holma and Aaltonen (1995)	<i>The children were worried about the father and his drinking, and his guilt feelings concerning the mother's death</i>			
Holma and Aaltonen (1997)	<i>But in the life of the family as a whole, a continuing process of a search for a narrative had emerged</i>	New family narratives		
Holma and Aaltonen (1995)	<i>The history of the family was re-storied</i>			
Holma and Aaltonen (1998b)	<i>His wife had found it very useful to undertake the process</i>			

RECLAIMING THE NARRATIVE: EXPLORING PERSONAL RECOVERY IN PSYCHOSIS

	<i>of finding a narrative form for her experiences, and they both were willing to search for a new narrative for their existing experiences</i>			
Bar-Am (2016)	<i>She also remains cautious while connected to her supports in a loving and non-pathologising manner.</i>	Families/ system shifting from a biomedical narrative		
Holma and Aaltonen (1995)	<i>The new story evolves in recognizing that the voices have an interactive role in patient's self-narrative and are useful to the patient.</i>			
Holma and Aaltonen (1997)	<i>the patient said she had learned to say "no" to her fellow patients in the ward. The mother said this also included her.</i>	Speaking back to the system as healing	<b>Strengthening personal narratives.</b>	
Freedman & Combs (2009)	<i>We do not have to put up with our lives being spoke about in ways that that reduce us, in pathologising and marginalizing ways</i>			
Holma an Aaltonen (1997)	<i>Her new found sense of agency and literally re-authoring reflected the generation of a new context of reflexivity in which she was simultaneously both performer (writer) and audience (the possible reader of her letter) of her own story.</i>	Separate story to client allowed and promoted		
Holma and Aaltonen (1998b)	<i>She was able to story her own story here and now,</i>			
Vasallo (1998)	<i>They thought their families were not as worried about them and they seem to be getting out more and not just sitting around.</i>	Others notice client's change	<b>Positive impact on social networks</b>	
Ching, Smyth & Charlesworth (2019)	<i>People in their social networks also observed these positive changes</i>			
Freedman and Combs (2009)	<i>We have a sense of living well. We have achieved a quality of life, a richness.</i>	Life has a new richness	<b>Quality of life</b>	Results of change
Vassallo (1998)	<i>The group had helped people to get the normal side of themselves going and this had developed further as they became more active.</i>			
Ching, Smyth & Charlesworth (2019)	<i>Reduced clinical symptoms across all participants.</i>	Reduced symptoms		
Bar-Am (2016)	<i>She remains well and has not been revisited by psychosis throughout her recovery.</i>			

AN EMERGING MODEL OF THE THERAPEUTIC PROCESSES IN  
NARRATIVE THERAPY FOR psychosis

*Individual processes*

*Equal stories, Equal humanity*

The review suggests that narrative interventions place value on amplifying the client's, narrative. This was illustrated by a number of examples where client's experiences were acknowledged, and their perspectives valued as key to developing a shared understanding of difficulties and solutions (table 7). In some studies, such as Holma and Aaltonen (1995), these perspectives were positioned next to the stories of others and thus another emergent theme was narrative sharing engendered a sense of connection with humanity.

*Making meaning*

The synthesis highlighted the role narrative interventions play in supporting reflection on meaning. Various studies spoke about exploring the meaning that clients might attribute to their psychotic experience (table 7). These studies suggest that this process helped to generate new understandings and shift from a problem-focused narrative (Mehl-Madrona, Jul & Mainguy, 2014). The studies also demonstrated that narrative interventions were able to help new meanings emerge. Many of these the new meanings had been previously hidden by the dominant stories of others. The emergence of new meanings helped clients develop a new perspective of themselves and psychosis (Holma and Aaltonen, 1998b).

### *Doing it together*

A sense of being in a supportive and validating environment was another theme from the synthesis (table 7). The studies took place in various settings ranging from inpatient psychiatric hospitals to community groups with no attachment to psychiatric services. Three of the studies applied a narrative approach in a group setting. Here, group cohesiveness emerged as a part of the narrative approach (Freedman & Combs, 2009). Clients within group, narrative interventions also found that they were able to learn from the experiences of others (Vasallo, 1998).

### *Alternative narratives*

The development of alternative narratives is a key feature of narrative interventions (White and Epston, 1990) and was found to be applicable in psychosis contexts. In some studies, the client's narrative was thickened by paying attention to the content of the voices and by adding new ideas and perspectives such as in Bar-Am (2016). The synthesis revealed that new stories often involved changing from a problem saturated to a new, strengths based narrative. Many studies spoke about this discovery of a new narrative as a key process and outcome of the intervention (Ching, Smyth & Charlesworth, 2019). People were encouraged to think about how new discoveries this might influence clients' actions and choices beyond the clinic room (Freedman & Combs, 2009).

### *Openness*

Another theme that emerged, highlighted the space narrative approaches in psychosis seem to hold for open discussion about emotions and experiences (Table 7). This was a particular feature of the studies that involved family or peers as part of the intervention such as in Holma (1995; 1997; 1998a; 1998b). In many studies, the



therapist's interest in the narratives of all parts of the system encouraged the open sharing of perspectives.

### *System processes*

#### *Family members as equal partners*

Various studies demonstrated ways in which family members were invited to join the therapeutic intervention. The studies of Holma & Aaltonen (1995; 1997; 1998a; 1998b) particularly influence this finding as studies were on the use of narrative approaches with families. They showed that narrative approaches facilitated the sharing of stories and emotions by family members as well as the client (Table 7). These case studies were also associated with families shifting from firm biomedical narratives around the aetiology and treatment of psychosis to being more open to client's often non-biomedical interpretations (Holma and Aaltonen, 1995). The findings also highlight the development new family narratives, suggesting that narrative approaches in psychosis can be focussed towards change at the family and not just the individual level (Holma and Aaltonen, 1997).

#### *Strengthening personal narratives*

The synthesis also revealed that narrative approaches in psychosis appear to impact a client's relationship to their wider systems (Table 7). Themes that emerged across studies indicated that interventions created a space where clients were able to develop and share their own narratives. People reported feeling more confident in communicating their perspectives and this was considered a therapeutic outcome in and of itself (Holma and Aaltonen, 1997).

### *Positive impact on social networks*

The personal impact of change as a result of narrative approaches in psychosis was commented on in a number of studies (Table 7). The emerging themes suggest that people in the client's social and care networks were able to notice positive change, as reported by the client. People also noticed that they felt increased confidence in interpersonal relationships (Vasallo, 1998; Holma and Aaltonen, 1998a).

### ***Results of change***

#### *Quality of life*

Fewer studies reported using standardised measures of change and seemed largely oriented towards the process of the intervention. This may explain the predominant use of case study methodology. The meta-ethnography however, found that reduced symptomology was reported in multiple studies, as was an increased sense of self-reported hope, joy and happiness. This was summarized as reflecting overall improved quality of life (Ching, Smyth & Charlesworth, 2019; Freedman & Combs, 2009).

### ***Technical processes of change***

The studies included in the meta-ethnography varied considerably in the way they reported the specific narrative techniques. Not enough similarity was found across the studies in relation to these described techniques to warrant their inclusion in the meta-ethnographic synthesis.

## DISCUSSION

The discussion will be structured in terms of the three research questions that were asked. The first research question was interested in understanding the quality of the existing research for narrative approaches in psychosis populations. A critical appraisal of the evidence demonstrating the application of narrative interventions in psychosis, suggests that there is a small body of quality, peer-reviewed research. Nine studies were included in the review. Eight of these studies were given a quality appraisal checklist score above a median range, which indicated a good level of quality in the absence of clear checklist guidelines. One study was found to have a reasonable level of quality. The strengths and limitations of the studies, in relation to the wider literature are also discussed.

One of the strengths identified across the research was that the studies generally demonstrated appropriate planning and design. Many of the studies included a case study as part of or all of their methodology and this methodology has been used in other studies investigating the application of narrative interventions in varying clinical populations, such as in McParland (2015). The popularity of case studies may relate to their ability to offer researchers a way to interact with data in a less structured, reflexive way, which facilitates complex description within context (Yin, 2003). Given the fact that narrative approaches have not been manualised, authors may appreciate the space case studies offer for the presentation of the enablers and outcomes of change in a more discursive way, however, this makes these studies more vulnerable to issues of researcher bias.

While the voice of service users was evident in the development of research questions and design of studies reporting group interventions, this was not so apparent in the studies presenting individual cases. The benefits of service user participation in

research are increasingly being attended to in the recovery literature (Schneider, 2012; Hutchinson and Lovell, 2013). Many of the studies included in the review were published before 2010 and as such, may have missed the more recent rise of participatory service user research.

The samples used across the extracted papers appeared generally representative of the population of people receiving clinical interventions for psychosis in western contexts. However, other potentially relevant demographic factors were not reported. Whilst participants may have shared the commonality of living with psychosis, being stigmatised or marginalised in society (Gerlinger et al., 2013; Thornicroft, 2009), other demographic factors may also lead to or compound experiences of marginalisation. There was limited evidence that this was considered in the included studies. This may be related to narrative therapists' tendency to forgo 'labels', which underpin demographic categories, in preference of being led by the client's language.

Although it cannot be certain that other marginalized experiences would necessarily have emerged as relevant in the application of narrative approaches in psychosis settings, however the omission of comprehensive demographic information means that the generalizability of the findings to people with intersectional, marginalized identities comes under question. Narrative interventions are considered aptly positioned to amplify oppressed and marginalised voices due to its particular emphasis on drawing on sociocultural discourses (Kahn and Monk, 2017). As such, focusing on mental health diagnosis as a single, marginalised identity presents as a missed opportunity and threatens to play out reductionist perspectives that have been criticized as part of other therapeutic approaches.

An additional strength of the reviewed studies was their fidelity to a social

constructionist framework, in the reporting of problem conceptualization and outcomes. There is much debate in the literature about whether using symptom-based outcomes as a form of evaluation compromises the theoretical underpinnings of the narrative approach (Busch, 2007). Simblett (2013) offers another perspective, introducing the idea of reflexive positioning in what he labels, 'narrative-informed psychiatric practice'. He argues that narrative approaches may in some contexts, need to work alongside more entrenched, realist discourses, before opportunities might be created for new discourses and ways of working to emerge. Both Busch (2007) and Yin (2009) describe ways that outcomes of narrative interventions might be more systematically evaluated though these have not been widely adopted in the literature.

Follow-up was not a feature in most of the studies, aside from by Holma and Aaltonen (1997), who provided a three-week follow-up. This is a drawback of the reviewed studies, limiting the potential for inferences about longer-term benefits of narrative approaches in psychosis.

The second research question was interested in the therapeutic processes occurring in the application of narrative approaches in psychosis. This review found 9 core themes relating to therapeutic processes described across the studies included in the review. These were; equal stories, equal humanity; making meaning; doing it together; alternative narratives; openness; family members as equal partners; strengthening personal narratives; positive impact on social networks and quality of life. These findings reflect that the components of narrative interventions used more broadly are also applicable in psychosis contexts. This review is important in that it has drawn together the key elements that are used specifically in psychosis contexts. Where thought to hold unique significance for psychosis contexts, themes are discussed in more detail below, with reference to the wider literature.

The current review found that the process of making meaning of psychotic experiences was a key part of the narrative approach (Mehl-Madrona, Jul & Mainguy, 2014). The process of telling stories, being heard and validated is key to reducing self-stigma (Prasko et al., 2010; White and Epston, 1990). In the included studies, it also helped individuals to find meaning from their experiences, which helped them move forward in their personal recovery.

Creating the space to share ideas openly and to strengthen these personal narratives also emerged as a feature of narrative interventions in psychosis (Freedman and Combs, 2009). The coherence of the narratives of people with psychosis has been thought to reflect the severity of distress and illness (Davidson and Strauss, 1992). The act of creating space for the strengthening of personal narratives may serve as a contribution to existing therapeutic techniques which aim to alleviate the perceived distress associated with the 'fractured' narrative in psychosis (Lysaker and Lysaker, 2006).

A sense of openness was extended beyond the context of the client-therapist relationship and was encouraged within families and wider systems as well (Holma & Aaltonen, 1995; 1997; 1998a; 1998b). Opportunities for these people to communicate and have their ideas and stories witnessed and affirmed by others, has been found to engender a sense of confidence and connectedness in the wider literature (White and Epston, 1990). This may be particularly important for people with psychosis, whose personal narratives and frameworks of meaning may not fit with commonly held narratives around wellness (Roe and Davidson 2008).

Research has suggested that narrative approaches may be aptly positioned to facilitate the thickening of stories and the amplifying of empowering, non-pathology

oriented perspectives (Besley, 2002). The current review also provides some support for this (Holma and Aaltonen, 1998b).

Some researchers have found that mutually sharing stories may create opportunities for change by allowing new, alternative and coherent narratives to emerge (Andrews, 2004; Fivush, 2010). The studies presented by Ching et al. (2019) and Freedman and Combs (2009) appeared to draw on these principles and used a collective approach to storytelling and knowledge production.

The literature suggests that when marginalized groups meet and share stories, they can begin to claim control and authority over their lives (Freedman and Combs, 2009; Kahn and Monk, 2017). A number of themes spoke to the role of narrative approaches in engendering a sense of community, support and togetherness (Vasallo, 1998; Freedman and Combs, 2009). This was not only a feature of the studies that used group interventions, but was also evident in some of the individual and family interventions presented (Holma and Aaltonen, 1998a). The potential for helping people with psychosis develop a sense of connection with others is important given the concerns about the impact of psychosis on social relationships and a person's sense of self, in relation to other (Duckworth, Nair, Patel & Goldfinger, 1997).

The theme of systemic transformation referred to the observation that changes were not just seen to occur on the individual level, but also in wider systems. Shifts in the family system are a reported feature of other narrative interventions (France and Uhlin, 2006), however the conscious facilitation of shifts in the wider system, and not just that of the client, may be a distinctive element of narrative work in psychosis contexts (Bar-Am, 2016; Freedman and Combs, 2009; Ching et al., 2019; Holma and Aaltonen, 1998a).

The final research question was interested in the research and clinical

implications from the literature.

### ***Clinical implications***

The review presents a number of ideas that hold potentially helpful implications for practice. Firstly, the narrative interventions were applied in several different contexts and with people with varied experiences of psychosis. This included people that were under compulsory hospitalization, people that were seeking therapy outside of statutory services as well as people that had been discharged from statutory services and were living in the community. The approach was applied in first episode psychosis and with people who had experienced multiple psychiatric admissions. As such, the use of narrative approaches in psychosis appeared feasible in a range of clinical contexts and with a range of difficulties across the psychotic spectrum.

The importance of listening to and valuing client's stories is not a new idea in psychotherapy (Chatoor & Kurpnick, 2001). This review highlights that narrative approaches shares this underpinning value with other psychotherapies. However, it also finds that the amplification of the personal narrative is a key element and that the sharing of multiple narratives with peers, family and carers can engender a common sense of humanity. This is an experience that might become lost as a consequence of internal and external stigma. The implication is that it may be worth considering how to promote the sharing of stories as routine in recovery practices. Rennick-Egglestone et al.'s (2019) research supports this, concluding that recovery narratives might be particularly useful for clients who are socially isolated.

This review found evidence to support the application of narrative approaches in 1:1 work. This may be a good fit with the current structure of mental health service provision, which is typically geared towards individual ways of working. The review further highlights that the inclusion of family in therapeutic sessions may also be



useful. Current NICE guidelines suggest family work as a distinct intervention in psychosis (National Institution for Health and Care Excellence, 2014), however this review presents emerging evidence to support a shift in focus that implicates change at a family system level as an explicit function of clinical interventions in psychosis.

The wider literature research already identifies the benefits of group-delivered interventions in psychosis (Saksa et al., 2009) and there is promising evidence suggesting the utility of group formats in narrative therapy (Khodayarifard and Sohrabpour, 2018; Laube, 1998). The current review found that narrative groups for psychosis have been possible. Services and community projects could consider developing and piloting narrative group interventions for psychosis that might further develop the evidence base for this approach.

This review presents tentative findings to suggest that narrative approaches could have the potential to affect change in line with both clinical *and* personal definitions of recovery. More robust evidence is needed to strengthen this finding, nevertheless, there are implications here, for the way psychosis services might be encouraged to define and engage with the concept of recovery in the future.

### ***Research implications***

Whilst the current review was able to demonstrate the existence of evidence to support the feasibility of narrative approaches in psychosis contexts, there are a number of ways the evidence base might be improved. Developing a robust evidence base could help improve the visibility and uptake of narrative interventions in clinical and community services (Barkham and Mellor-Clark, 2003). More robust research may also in the future, inform the development of services and policies that directly and indirectly impact on the experiences of people living with psychosis.

Only three of the studies included in the review were published within the last ten

years. Two of these, were published within the last 5 years. Furthermore, there is a 24-year gap between the earliest and most recent study published. There has been a low quantity of studies published over time though there appears to have been a slight increase over the last 5 years. Whilst this review has found emerging evidence to support the use of narrative interventions, more studies will be needed to further develop the evidence base.

The cause of the paucity of research in the area is unclear. While there has been an increase in the popularity of talking therapies for psychosis, there is a continued prevalence of symptom reduction discourses alongside a bias towards quantitative outcomes and research (Busch, 2007) of which narrative therapies and research do not easily fit. There is an argument for more experimental studies (such as randomised controlled trials) of narrative interventions. However, this might call for researchers to engage with the designing and application of standardised measures that fit with narrative principles and that can draw on client's strengths, as suggested by McParland (2015).

This review did find that case studies are an effective methodology for presenting the processes and outcomes of narrative interventions however the application of this methodology was weakened in the review as a result of unstructured and poorly reported methods of analysis. Future research should consider the inclusion of more structured and consistent reporting where using case studies, in order to improve the possibility of replication by future studies as well as more robust analysis. Yin (2003) & Busch (2007), both offer good models for this. Future research should also consider the inclusion of service users in the design and evaluation of studies.

Wider sociocultural factors may impact the uptake and application of psychotherapy. These factors are also of relevance in narrative approaches, which

specifically aim to consider the impact of these issues on an individual (Semmler, 2000; Kahn and Monk, 2017). Post-modern philosophies have laid the groundwork for giving voice to the stories of women, ethnic minorities, sexual minorities, and other groups whose voices have often been subjugated under the authority of dominant discourses (Casey and Long, 2003). However, there is limited understanding about how demographic characteristics interact with sociocultural factors in the experience of psychosis. More richly described demographic information may help future researchers delineate the ways in which different groups of people experience narrative therapy in the recovery from psychosis.

### ***Strengths and limitations of the review***

This current review is one of very few outlining the evidence for the application of narrative interventions and is the first to draw together papers describing the use of narrative interventions with people who have had experiences of psychosis. The systematic approach involved following a structured protocol for data extraction, quality assessment and synthesis and therefore increases the robustness of the review.

This review can be critiqued for allowing the inclusion of a range of methodologies as this can make true comparison across studies more difficult to achieve. This decision was balanced against the benefit of increasing the sample size and fostering a broader discussion. This review should be updated once there are more studies published that might allow for the comparison of like methodologies.

The terms ‘narrative interventions’ and ‘narrative approaches’ have been loosely defined in the review. This is due to its broad definition in the literature. Many studies that describe the use of narrative interventions refer to being guided by its

principles and as such a specific definition of a narrative intervention is difficult to determine. The synthesis begins to address this potential heterogeneity by identifying the similarities in the therapeutic processes across studies and this is another strength of this review.

## CONCLUSION

This review has presented the extant empirical evidence for the application of narrative approaches within populations with experiences of psychosis. The research studies were largely found to be of good quality in terms of their reliability and validity however it is suggested that narrative interventions can be better and more systematically evaluated. The review has also discussed how an existing bias towards symptom-focussed interventions and outcome monitoring may have contributed to an observed paucity in the application of narrative based interventions in both research and practice in psychosis contexts.

The existing literature suggests that narrative approaches are aptly positioned to consider the wider contexts and systemic issues that impact the recovery of people with psychosis (Semmler, 2000; Kahn and Monk, 2017). This review has added to this evidence by presenting nine emerging themes that reflect the therapeutic processes observed across narrative approaches in psychosis. As such, this review presents tentative, but promising evidence for the application of narrative interventions in contexts with people reporting experiences of psychosis.

## REFERENCES

- Abu-Akel, A., & Abushua'leh, K. (2004). 'Theory of mind' in violent and nonviolent patients with paranoid schizophrenia. *Schizophrenia Research*, 69(1), 45-53.  
**[https://doi.org/10.1016/S0920-9964\(03\)00049-5](https://doi.org/10.1016/S0920-9964(03)00049-5)**
- American Psychiatric Association (2017). *Diagnostic and statistical manual of mental disorders: DSM-5*. American Psychiatric Association, Arlington, VA.
- American Psychiatric Association (1980). *Diagnostic and statistical manual of mental disorders DSM-III*. American Psychiatric Association, Washington, D.C.
- Andrews, M. (2004) Opening to the original contributions: Counter narratives and the power to impose. In Bamberg, M., & Andrews, M. (Eds.) *Considering counter narratives: Narrating, resisting and making sense*. (pp. 1–6). Philadelphia: John Benjamin Publishing Company.
- Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness: Effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica*, 108(4), 304-309. **<https://doi.org/10.1034/j.1600-0447.2003.00150.x>**
- Arciniegas, D. B. (January 01, 2015). psychosis. *Continuum*, 21, 3, 715-736. **<https://doi.org/10.1212/01.CON.0000466662.89908.e7>**

- Bar-Am, S. (2016). First episode psychosis: A magical realist guide through liminal terrain. *Australian and New Zealand Journal of Family Therapy*, 37(3), 381-396.  
**<https://doi.org/10.1002/anzf.1159>**
- Barkham, M., & Mellor-Clark, J. (2003). Bridging evidence-based practice and practice-based evidence: Developing a rigorous and relevant knowledge for the psychological therapies. *Clinical Psychology and Psychotherapy*, 10(6), 319-327.  
**<https://doi.org/10.1002/cpp.379>**
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*, 9(59), 1471-2288.  
**<https://doi.org/10.1186/1471-2288-9-59>**
- Bessley, A. C. (2002). Foucault and the turn to narrative therapy. *British Journal of Guidance & Counselling*, 30(2), 125-143. **<https://doi.org/10.1080/03069880220128010>**
- Bèurgy, M. (2008). The Concept of psychosis: Historical and Phenomenological Aspects. *Schizophrenia Bulletin*, 34(6), 1200-1210.  
**<https://doi.org/10.1093/schbul/sbm136>**
- Bhugra, D., Leff, J., Mallett, R., Der, G., Corridan, B. & Rudge, S. (1997). Incidence and outcome of schizophrenia in Whites, African-Caribbeans and Asians in London. *Psychological Medicine*, 27(4) 791- 798.  
**<https://doi.org/10.1017/s0033291797005369>**

- Biedermann, F., & Fleischhacker, W. W. (2016). Psychotic disorders in DSM-5 and ICD-11. *CNS Spectrums*, 21(4), 349-354. <https://doi.org/10.1017/S1092852916000316>
- Brigitte, Sue, Mem, & Veronika. (1997). Power to our journeys. In White, C., & Denborough, D.(Eds.), (1998), *Introducing narrative therapy: A collection of practice-based writings* (pp.203–215). Dulwich Centre Publications.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Burr, V. (2015) *Social Constructionism* (3rd ed.), New York: Routledge, Taylor.
- Busch, R. (2007). Transforming evidence: A discursive evaluation of narrative therapy case studies. *Australian Journal of Counselling Psychology*, 7(2), 8–15.  
<https://mro.massey.ac.nz/handle/10179/9737>
- Busch, R., Strong, T., & Lock, A. (2011). *Making Sense of Epistemological Conflict in the Evaluation of Narrative Therapy and Evidence-Based Psychotherapy*. [Conference Paper]. *Doing Psychology: Manawatu Doctoral Research Symposium 2011*.  
[https://researchonline.nd.edu.au/arts\\_conference/37/](https://researchonline.nd.edu.au/arts_conference/37/)
- Casey, B., & Long, A. (2003). Meanings of madness: a literature review. *Journal of Psychiatric and Mental Health Nursing*, 10 (1), 89-99.  
<https://doi.org/10.1046/j.1365-2850.2003.00562.x>

Centre for Evidence Based Management (July, 2014). *Critical Appraisal of a Case Study*.

CEBMA. <https://www.cebma.org/wp-content/uploads/Critical-Appraisal-Questions-for-a-Case-Study-july-2014.pdf>

Chatoor, I., & Kurpnick, J. (2001). The role of non-specific factors in treatment outcome of psychotherapy studies. *European Child & Adolescent Psychiatry*, 10(1), 19-25.

<https://doi.org/10.1007/s007870170004>

Ching, E. Y. N., Smyth, L., De, S. T., & Charlesworth, G. (2019). The Adaptation and Feasibility of Narrative Enhancement and Cognitive Therapy (NECT) for Late-Onset psychosis. *Community Mental Health Journal*, 56(2), 211-221.

<https://doi.org/10.1007/s10597-019-00495-5>

Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J., & Welch, V.A. (editors) *Cochrane handbook for systematic reviews of interventions*. (2019).

Cochrane, 2019. [www.training.cochrane.org/handbook](http://www.training.cochrane.org/handbook)

Corrigan, P., Kerr, A., & Knudsen, L. (2005). The stigma of mental illness: explanatory models and methods for change. *Applied and Preventive Psychology*, 11(3), 179-190.

<https://doi.org/10.1016/j.appsy.2005.07.001>

Critical Appraisal Skills Programme (2018). *CASP Qualitative Checklist*. CASP-UK.

<https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>



Crombie, I. K. (2008). *The pocket guide to critical appraisal: A handbook for health care professionals*. London: BMJ Publishing Group.

Cross, S. (2014) Mad and Bad Media: Populism and Pathology in the British Tabloids, *European Journal of Communication*. 29(2) 204-217.

**<https://doi.org/10.1177/0267323113516734>**

Davies, B., & Harré, R. (1990). Positioning: The Discursive Production of Selves. *Journal for the Theory of Social Behaviour*, 20(1), 43-63.

**<https://doi.org/10.1177/2158244016655584>**

Doyle, R., Turner, N., Fanning, F., Brennan, D., Renwick, L., Lawlor, E., & Clarke, M. (2014). First-episode psychosis and disengagement from treatment: A systematic review. *Psychiatric Services*, 65(5), 603-611.

**<https://doi.org/10.1176/appi.ps.201200570>**

Duckworth K, Nair V, Patel JK & Goldfinger (1997). Lost time, found hope and sorrow: The search for self, connection, and purpose during ‘awakenings’ on the new antipsychotics. *Harvard Res. Psychiatry* 199(5), 227–233.

**<https://doi.org.uk/10.3109/10673229709000305>**

Etchison, M., & Kleist, D. M. (2000). Review of Narrative Therapy: Research and Utility. *Family Journal: Counseling and Therapy for Couples and Families*, 8(1), 61-66. **<https://doi.org/10.1177/1066480700081009>**

Fivush, R. (2010). Speaking silence: The social construction of silence in autobiographical and cultural narratives. *Memory*, 18(2), 88–98.

<https://doi.org/10.1080/09658210903029404>

France, Ring, Noyes & Maxwell (2015). Protocol-developing meta-ethnography reporting guidelines (eMERGe). *BMC Medical Research Methodology*, 15(1), 103.

<https://doi.org/10.1186/s12874-015-0068-0>

France, C.M. & Uhlin, B.D. (2006). Narrative as an outcome domain in psychosis.

*Psychology and Psychotherapy: Theory, Research and Practice*, 79, 53-67.

<https://doi.org/10.1348/147608305X41001>

Freedman, J. M. S. W., & Combs, G. (1996). *Narrative therapy: The social construction of preferred realities*. New York: W.W.Norton & Company.

Freedman, J., & Combs, G. (2009). Ripples from the gatherings: Narrative ideas for consulting with communities. *Family Process*, 48(3):347-62.

<https://doi.org/10.1111/j.1545-5300.2009.01287.x>.

Gaebel W, Zielasek J. (2015). Focus on psychosis. *Dialogues in Clinical*

*Neuroscience*, 17(1), 9-18. <https://www.ncbi.nlm.nih.gov/pubmed/25987859>

Gerlinger, G., Hauser, M., Hert, M., Lacluyse, K., Wampers, M., & Correll, C. U. (2013).

Personal stigma in schizophrenia spectrum disorders: A systematic review of

prevalence rates, correlates, impact and interventions. *World Psychiatry*, 12(2), 155-164. <https://doi.org/10.1002/wps.20040>

Gilmore, L., & Hughes, B. (2019). Perceptions of schizophrenia in the Australian community: 2005–2017. *Journal of Mental Health*, 1-7.  
<https://doi.org/10.1080/09638237.2019.1630720>

González-Torres, M. A., Oraa, R., Arístegui, M., Fernández-Rivas, A., & Guimon, J. (2007). Stigma and discrimination towards people with schizophrenia and their family members: A qualitative study with focus groups. *Social Psychiatry and Psychiatric Epidemiology*, 42(1), 14-23. <https://doi.org/10.1007/s00127-006-0126-3>

Goossen, C., & Austin, M. J. (2017). Service User Involvement in UK Social Service Agencies and Social Work Education. *Journal of Social Work Education*, 53(1), 37-51. <https://doi.org/10.1080/10437797.2016.1246271>

Hamm, J. A., Buck, B., Leonhardt, B. L., Wasmuth, S., Lysaker, J. T., & Lysaker, P. H. (2017). Overcoming fragmentation in the treatment of persons with schizophrenia. *Journal of Theoretical and Philosophical Psychology*, 37(1), 21-33.  
<https://doi.org/10.1037/teo0000054>

Hardy, A. (2017). Pathways from trauma to psychotic experiences: A theoretically Informed model of posttraumatic stress in psychosis. *Frontiers in Psychology*, 8(697).  
<https://doi.org/10.3389/fpsyg.2017.00697>

- Harvey, A. G., & Gumport, N. B. (2015). Evidence-based psychological treatments for mental disorders: Modifiable barriers to access and possible solutions. *Behaviour Research and Therapy*, 68, 1-12. <https://doi.org/10.1016/j.brat.2015.02.004>
- Hatzenbuehler, M. L., & Link, B. G. (2014). Introduction to the special issue on structural stigma and health. *Social Science & Medicine* (1982), 103, 1–6. <https://doi.org/10.1016/j.socscimed.2013.12.017>
- Hewitt, J. (2010). Schizophrenia, mental capacity, and rational suicide. *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice*, 31(1), 63-77. <https://doi.org/10.1007/s11017-010-9137-x>.
- Hewson, H. (2015). Telling stories and re-authoring lives: A narrative approach to individuals with psychosis In Meaden, A., & Fox, A. (Eds.). *Innovations in psychosocial interventions for psychosis: Working with the hard to reach*. (pp.147-163). Routledge.
- Hinshaw, S. P., & Stier, A. (2008). Stigma as related to mental disorders. *Annual Review of Clinical Psychology*, 4, 367-393. <https://doi.org/0.1146/annurev.clinpsy.4.022007.141245>
- Hoftman, G. D. (2016). The burden of mental illness beyond clinical symptoms: Impact of stigma on the onset and course of schizophrenia spectrum disorders. *American Journal of Psychiatry Residents' Journal*, 11(4), 5-7. <https://doi.org/10.1176/appi.ajp-rj.2016.110404>

Holma, J., & Aalonen, J. (1995). The self-narrative and acute psychosis. *Contemporary Family Therapy*, 17, 3, 307-316. <https://doi.org/10.1007/BF02252668>

Holma, J., & Aaltonen, J. (1997). The Sense of Agency and the Search for a Narrative in Acute psychosis. *Contemporary Family Therapy*, 19, 4, 463-477.  
<https://doi.org/10.1023/A:1026174819842>

Holma, J., & Aaltonen, J. (1998)a. Narrative understanding in acute psychosis. *Contemporary Family Therapy*, 20(3), 253-263.  
<https://doi.org/10.1023/A:1022432810652>

Holma, J., & Aaltonen, J. (1998)b. The experience of time in acute psychosis and schizophrenia. *Contemporary Family Therapy*, 20(3), 265-276.  
<https://doi.org/10.1023/A:1022408727490>

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M., Griffiths, F., Nicolau, B., O’Cathain, A., Rousseau, M., Vedel, I., & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) Version 2018 for Information Professionals and Researchers. *Education for Information*, 34(4), 285-291.  
<https://doi.org/10.3233/EFI-180221>

Hutchinson, A., & Lovell, A. (2013). Participatory action research: moving beyond the mental health ‘service user’ identity. *Journal of Psychiatric and Mental Health Nursing*, 20, 7, 641-649. <https://doi.org/10.1111/jpm.12001>

Johnson, J., Horwath, E., & Weissman, M. M. (1991). The validity of major depression with psychotic features based on a community study. *Archives of General Psychiatry*, 48(12), 1075-81.  
**<https://doi.org/10.1001/archpsyc.1991.01810360039006>**

Johnstone, L., & Boyle, M. (2018). The Power Threat Meaning Framework: An Alternative Nondiagnostic Conceptual System. *Journal of Humanistic Psychology*.  
**<https://doi.org/10.1177/0022167818793289>**

Jorm A.F., Korten A.E., Jacomb P.A., Christensen H. & Henderson S. (1999). Attitudes towards people with a mental disorder: a survey of the Australian public and health professionals. *Australian and New Zealand Journal of Psychiatry*, 33(1), 77-83.  
**<https://doi.org/0.1046/j.1440-1614.1999.00513.x>**

Kahn, S. Z., & Monk, G. (2017). Narrative Supervision as a Social Justice Practice. *Journal of Systemic Therapies*, 36(1), 7-25. **<https://doi.org/10.1521/jsyt.2017.36.1.7>**

Keshavan, M. S., & Kaneko, Y. (2013). Secondary psychoses: an update. *World Psychiatry*, 12(1), 4-15. **<https://doi.org/10.1002/wps.20001>**

Khodayarifard , M., & Sohrabpour, G. (2018). Effectiveness of Narrative Therapy in Groups on Psychological Well-being and Distress of Iranian Women with Addicted Husbands. *Addiction & Health*, 10(1), 1-10. **<https://doi.org/10.22122/ahj.v10i1.550>**

- Kluge H., Becker T., Kallert T.W., Matschinger H. & Angermeyer M.C.(2007). Impact of structure and context on utilization of socio-psychiatric services in Saxony-A multi-level-analysis. *Psychiatrische Praxis*, 34, 20-25. <https://doi.org/10.1055/s-2005-866870>
- Lakritz, K. (2009). Michel Foucault's madness and civilization: A history of insanity in the age of reason. *Psychiatric Times*, 26(6), 45. <https://www.psychiatrictimes.com/schizophrenia/michel-foucaults-madness-and-civilization-history-insanity-age-reason>
- Laube, J. J. (1998). Therapist role in narrative group psychotherapy. *Group*, 22(4), 227-243. <https://doi.org/10.1023/A:1022107001720>
- Law, H., Morrison, A., Byrne, R., & Hodson, E. (2012). Recovery from psychosis: a user informed review of self-report instruments for measuring recovery. *Journal of Mental Health*, 21(2), 192-207. <https://doi.org/10.3109/09638237.2012.670885>.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385. <https://doi.org/10.1146/annurev.soc.27.1.363>
- Lysaker, P.H., Wickett, A.M., Campbell, K., & Buck, K.D. (2003). Movement toward coherence in the psychotherapy of schizophrenia: A method for assessing narrative transformation. *Journal of Nervous and Mental Disease*, 191, 538-541 <https://doi.org.uk/10.1097/01.nmd.0000082182.77891.89>

Maslin, J. (2002). *Substance Misuse in psychosis: Contextual Issues*. 3-23. John Wiley & Sons Ltd. <https://doi.org/10.1002/9780470713846>

McLeod, J. (2015). *Doing research in counselling and psychotherapy*. (3<sup>rd</sup> Eds). Sage Publications Ltd.

McParland, J. (2015). Narrative therapy in a learning disability context: A review. *Tizard Learning Disability Review*, 20(3), 121-129. <https://doi.org/10.1108/TLDR-08-2014-0028>

McPherson S., Evans C. & Richardson P. (2009) The NICE depression guidelines and the recovery model: is there an evidence base for IAPT? *Journal of Mental Health*, 18, 405–414. <https://doi.org/10.3109/09638230902968258>

Mehl-Madrone, Jul & Mainguy (2014). Results of a Transpersonal, Narrative, and Phenomenological Psychotherapy for psychosis. *International Journal of Transpersonal Studies*, 33(1), 57-76. <https://doi.org/10.24972/ijts.2014.33.1.57>

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Journal of Clinical Epidemiology*, 62(10), 1006-1012. <https://doi.org/10.1016/j.jclinepi.2009.06.005>

Morgan, C., Fearon, P., Lappin, J., Heslin, M., Donoghue, K., Lomas, B., Reininghaus, U., Onyejiaka, A., Croudace, T., Jones, P.B., Murray, R.M., Doody, G.A. & Dazzan, P.



(2017). Ethnicity and long-term course and outcome of psychotic disorders in a UK sample: The ÆSOP-10 study. *British Journal of Psychiatry*, 211(2), 88-94.

<https://doi.org/10.1192/bjp.bp.116.193342>

Morrison, J.K. & Nevid, J.S. (1976), Attitudes of mental patients and mental health professionals about mental illness, *Psychological Reports*, 38, 565-566.

<https://doi.org/10.2466/pr0.1976.38.2.565>

National Institute for Health and Care Evidence. (2014). *psychosis and schizophrenia in adults: Prevention and management*. London: NICE.

Noblit, G. W., & Hare, R. D. (1997). *Meta-Ethnography: Synthesizing qualitative studies*. California: Sage.

O'Keeffe, D., Sheridan, A., Kelly, A., Doyle, R., Madigan, K., Lawlor, E., & Clarke, M. (2018). 'Recovery' in the Real World: Service User Experiences of Mental Health Service Use and Recommendations for Change 20 Years on from a First Episode psychosis. *Administration and Policy in Mental Health*, 45(4), 635-648.

<https://doi.org/10.1007/s10488-018-0851-4>.

Owen, P. R. (2012) 'Portrayals of Schizophrenia by entertainment media: A content analysis of contemporary movies.' *Psychiatric Services*, 63(7), 655-659.

<https://doi.org/10.1176/appi.ps.201100371>

- Phillips, L. J., Francey, S. M., Edwards, J., & McMurray, N. (2007). Stress and psychosis: Towards the development of new models of investigation. *Clinical Psychology Review, 27*(3), 307. <https://doi.org/10.1016/j.cpr.2006.10.003>
- Pooremamali, P., Ostman, M., Persson, D., & Eklund, M. (2011). An occupational therapy approach to the support of a young immigrant female's mental health: A story of bicultural personal growth. *International Journal of Qualitative Studies on Health and Well-Being, 6*(3). <https://doi.org/10.3402/qhw.v6i3.7084>.
- Poreddi, V., Reddemma, K., Ramachandra, ., & Math, S. B. (2013). People with mental illness and human rights: A developing countries perspective. *Indian Journal of Psychiatry, 55*(2), 117. <https://doi.org/10.4103/0019-5545.111447>
- Quin, R. C., Clare, L., Ryan, P., & Jackson, M. (2009). 'Not of this world': The subjective experience of late-onset psychosis. *Aging & Mental Health, 13*(6), 779-787.
- Rennick-Egglestone, S., Morgan, K., Llewellyn-Beardsley, J., Ramsay, A., McGranahan, R., Gillard, S., Hui, A., ... Booth, S. (2019). Mental Health Recovery Narratives and Their Impact on Recipients: Systematic Review and Narrative Synthesis. *Canadian Journal of Psychiatry, 64*(10), 669-679. <https://doi.org/10.1080/13607860903046453>
- Roe, D., & Davidson, L. (2005). Self and narrative in schizophrenia: Time to author a new story. *Medical Humanities, 31*(2), 89. <https://doi.org/10.1136/jmh.2005.000214>
- Roe, D. & Davidson, L. (2008). *Recovery*. In K.T. Mueser (Ed.), *Clinical handbook of*

schizophrenia (pp 566-574). New York: Guilford Press.

Saksa, J. R., Cohen, S. J., Srihari, V. H., & Woods, S. W. (2009). Cognitive behavior therapy for early psychosis: a comprehensive review of individual vs. group treatment studies. *International Journal of Group Psychotherapy*, 59(3), 357-83.

**<https://doi.org/10.1521/ijgp.2009.59.3.357>**

Salminen, A.-L., Harra, T., & Lautamo, T. (2006). Conducting case study research in occupational therapy. *Australian Occupational Therapy Journal*, 53(1), 3-8.

**<https://doi.org/10.1111/j.1440-1630.2006.00540.x>**

Samele, C., Patel, M., Boydell, J., Leese, M., Wessely, S., & Murray, R. (2007). Physical illness and lifestyle risk factors in people with their first presentation of psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 42(2), 117-124.

**<https://doi.org/10.1007/s00127-006-0135-2>**

Schneider, B. (2012). Participatory action research, mental health service user research, and the hearing (our) voices projects. *International Journal of Qualitative Methods*, 11(2),

152-165. **<https://doi.org/10.1177/160940691201100203>**

Schomerus, G., & Angermeyer, M. C. (2008). Stigma and its impact on help-seeking for mental disorders: What do we know? *Epidemiologia E Psichiatria Sociale*, 17(1), 31-

37. **<https://doi.org/10.1017/s1121189x00002669>**

- Schwartz, R. C., & Blankenship, D. M. (2014). Racial disparities in psychotic disorder diagnosis: A review of empirical literature. *World Journal of Psychiatry, 4*(4), 133-40. <https://doi.org/10.5498/wjp.v4.i4.133>
- Semmler, W. (2000). Narrative therapy: A storied context for multicultural counseling. *Journal of Multicultural Counseling and Development, 21*(1), 51-62. <https://doi.org/10.1002/j.2161-1912.2000.tb00227.x>
- Shoham-Salomon, V. (1985), Are schizophrenics' behaviors schizophrenic? What medically versus psychosocially oriented therapists attribute to schizophrenic persons, *Journal of Abnormal Psychology, 94*, 443-53. <https://doi.org/10.1037/0021-843x.94.4.443>
- Simblett, G. (2013). Dancing with the DSM - The reflexive positioning of narrative informed psychiatric practice. *Australian and New Zealand Journal of Family Therapy, 34*(2), 114-128. <https://doi.org/10.1002/anzf.1007>
- Tait L, Birchwood M, Trower P. (2003). Predicting engagement with services for psychosis: Insight, symptoms and recovery style. *British Journal of Psychiatry 182*:123–128. <https://doi.org/10.1192/bjp.182.2.123>
- Thachuk, M. (2011). Stigma and the politics of biomedical models of mental illness. *International Journal of Feminist Approaches to Bioethics, 4*(1), 140-163. <https://doi.org/10.3138/ijfab.4.1.140>

The Schizophrenia Commission (November 2012) *The abandoned illness: A report from the Schizophrenia Commission*. Rethink Mental

Illness. <http://www.schizophreniacommission.org.uk/the-report/>

Thomas, F., Hansford, L., Ford, J., Wyatt, K., McCabe, R., & Byng, R. (2018). Moral narratives and mental health: Rethinking understandings of distress and healthcare support in contexts of austerity and welfare reform. *Palgrave Communications*, 4(1), 39. <https://doi.org/10.1057/s41599-018-0091-y>

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., & Leese, M. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: A cross-sectional survey. *The Lancet*, 373(9661), 408-415.

[https://doi.org/10.1016/S0140-6736\(08\)61817-6](https://doi.org/10.1016/S0140-6736(08)61817-6)

van Os, J. (2015). The transdiagnostic dimension of psychosis: Implications for psychiatric nosology and research. *Shanghai Archives of Psychiatry*, 27(2), 82-6.

<https://doi.org/10.11919/j.issn.1002-0829.215041>

Vassallo, T. (1998). Narrative group therapy with the seriously mentally ill: A case study. *The Australian and New Zealand Journal of Family Therapy*, 19(1), 15.

<https://doi.org/10.1111/j.0814-723X.1998.00046.x>

Verdoux, H., & van Os, J. (2002). Psychotic symptoms in non-clinical populations and the continuum of psychosis. *Schizophrenia Research*, 54(1-2), 59-65.

[https://doi.org/10.1016/s0920-9964\(01\)00352-8](https://doi.org/10.1016/s0920-9964(01)00352-8)

Vrbova K, Prasko J, Holubova M, Kamaradova D, Ociskova M, Marackova M, Latalova K, Grambal, A., Slepecky, M., & Zatkova M. (2016). Self-stigma and schizophrenia: a cross-sectional study. *Neuropsychiatric Disease and Treatment*, 12, 3011-3020.  
**<https://doi.org/10.2147/NDT.S120298>**

White, M. (2007). *Maps of narrative practice*. New York: W.W. Norton & Company.

White, M. and Epston, D. (1990) *Narrative Means to Therapeutic Ends*. New York: W. W. Norton.

World Health Organisation (June 2, 2012). *Mental health, human rights and legislation: A global human rights emergency in mental health*.  
**[www.who.int/mental\\_health/policy/legislation/en/index.html](http://www.who.int/mental_health/policy/legislation/en/index.html)**

Wigman, J. T. W., de, V. S., Wichers, M., van Os, J., & Bartels-Velthuis, A. A. (2017). A transdiagnostic network approach to psychosis. *Schizophrenia Bulletin*, 43(1), 122-132. **<https://doi.org/10.1093/schbul/sbw095>**

Williams, C. H. J. (2015). Improving Access to Psychological Therapies (IAPT) and treatment outcomes: Epistemological Assumptions and Controversies. *Journal of Psychiatric and Mental Health Nursing*, 22(5), 344-351.  
**<https://doi.org/10.1111/jpm.12181>**

World Health Organization (1992). *ICD-10: International statistical classification of diseases and related health problems*. Geneva: World Health Organization.

Yin, R. K. (2003). *Case study research: Design and methods*. Thousand Oaks: Sage.

**SECTION B**

**Personal Recovery in Black Individuals with Psychosis: A Grounded  
Theory**

Word Count: 7,993

For submission to British Journal of Clinical Psychology



## ABSTRACT

**Objectives:** The main objective of this study was to develop a grounded theory of personal recovery in Black individuals with psychosis.

**Design:** This study employed a non-experimental, qualitative design and is guided by a Constructivist Grounded Theory (CGT) approach.

**Methodology:** Black individuals with experiences of psychosis, who further self-identified as having a sense of personal recovery were recruited through convenience sampling. 1:1 semi-structured, narrative interviews were completed with 11 participants, using a theoretical sampling approach.

**Results:** Eight themes emerge as facilitating the experience of personal recovery in Black individuals with psychosis. These are: engaging and re-engaging with strategies to maintain wellbeing, balancing the risk and rewards of reintegration into the community, finding safe spaces, power experienced as safe, developing an empowered sense of self, deepening and stabilising relationships, joining others and responding to injustice and a pursuit towards a better life. Six additional contextual experiences are included in the model under the theme, 'disempowering experiences'.

**Conclusions:** The findings reinforce the importance of exploring contextual barriers as well as enablers of recovery. The emergent model presents a number of testable hypotheses regarding the development of personal recovery in Black individuals with psychosis.

Key words: personal recovery, BME, Black communities, psychosis.

## INTRODUCTION

### *Personal recovery*

The service user movement has highlighted the limitations of biomedical conceptualisations of distress and of psychiatric institutionalisation. This has resulted in the critical examination of ideas around wellness and recovery in mental health (Rissmiller and Rissmiller, 2006). The concept of personal recovery has been presented as a subjectively oriented alternative to more objectivist, biomedical interpretations of wellness, which promote symptom reduction as the key objective of therapeutic intervention (Deegan, 1988; Chaimberlin, 1978; Slade, 2009).

In 1993, Anthony defined personal recovery as, “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles”. Slade (2009) has since emphasised the potential value of personal recovery as a concept, offering that clinical recovery, may offer a limited picture of what people consider to be wellbeing (Slade et al., 2014).

Macpherson et al (2016) found support for the idea of clinical and personal recovery as distinct concepts. However, the findings should be interpreted with caution given that the internal validity of existing measures of personal recovery is highly debated in the literature. Nevertheless, the results of this study are promising and suggest that personal recovery may be an important outcome to consider in clinical contexts.

### *Psychosis and personal recovery*

Recovery in psychosis is further complicated by the disproportionately negative perception it attracts in wider society (Angermeyer and Matschinger, 2004). Connotations of dangerousness and unpredictability often accompany stereotypical assumptions around lower cognitive and functional ability (Corrigan, Kerr, &

Knudsen, 2005). These perceptions can manifest in stigmatising practices that further contribute to the socioeconomic disadvantage and poorer mental health outcomes associated with this diagnosis (Killaspy, 2014).

It is important to recognise that experiencing ‘hallucinations’ and ‘delusions’ can be extremely distressing for some people; however others describe these experiences as a helpful and valued part of their lives (Fenekou and Georgaca, 2010). Applying a symptom reduction approach to recovery in psychosis may not always fit for those whose hallucinations serve a positive personal function. This has particular human rights implications in cases where recovery is linked to compulsory treatment under the mental health act (Spandler and Calton, 2009).

As such, the need for a more comprehensive and holistic conceptualisation of recovery that considers meanings, social contexts, personal values and goals is thought to be especially pertinent for people who experience psychosis.

### ***The role of culture in defining personal recovery***

Systemic theories would posit that factors such as race and culture are highly influential in the development of some of the elements considered central to a person’s world lens (Burnham, 2008). What might be considered as a highly useful or valued part of recovery in one culture might be seen as less valued, or even counterproductive, in another. There is a risk that existing definitions of personal recovery may lack adequate cultural nuance (Trivedi, 2010; Fernando, 2010).

Social theories suggest that individualist and collectivist cultures hold different values and practices that influence personal experiences and beliefs. While individualist cultures place the responsibility for attaining and safeguarding wellbeing on the individual, collectivist cultures view interdependence as an essential component of wellbeing (Papadopoulos, Foster & Caldwell, 2013). These differences

have not been explored in relation to the conceptualisation of personal recovery. This issue is even more complex where communities holding collectivist values are embedded within individualist cultures, an idea that might be particularly relevant when exploring the personal recovery experiences of migrant and ethnic minority communities living in the UK.

### ***Race and cultural differences in the experience of personal recovery***

The experiences of Black individuals with psychosis has been of concern because of their over representation within western mental health systems (Bhui, 2001). Various factors occurring within Black communities as well as between Black communities and more distal systems have been explored in an attempt to explain this overrepresentation.

#### *Within community factors*

Some research concludes that stigma towards mental illness in Black communities contributes to the minimising of difficulties and consequent delayed help seeking (Memon et al, 2016; Mantovani, Pizzolati & Edge, 2017). Black communities are also reported as experiencing high levels of uncertainty, distrust and shame around engaging with mental health services, also considered as leading to delays in seeking help. The consequence of delayed help seeking is thought to be more severe presentations at the point of entry to the mental health system, which is in turn, associated with longer hospital stays and poorer outcomes (Keating & Robertson, 2004).

Black service users were reported to identify spirituality and religion as valuable to their recovery (Leamy et al., 2011). Research has further concluded that service users and their families using religious and spiritual frameworks to make

meaning of psychotic symptoms, can also contribute to delays in seeking help from statutory services and also hinder medication adherence (Rabiee & Smith, 2014).

Littlewood's (1998) research highlighted a common belief amongst Caribbean communities, that cannabis use causes psychosis. This idea has been used to explain the overrepresentation of Black, Caribbean men in UK psychiatric hospitals however empirical evidence for a causal link between psychosis and cannabis consumption is inconsistent (Gage, 2019; Hamilton and Monaghan, 2019). With no current evidence to support the assertion that cannabis use in mental service users is any higher in those of African or Caribbean heritage (McGuire et al., 1995; Selten & Sijben, 1994; Selten et al., 1997).

### ***Between community factors***

Interestingly, researchers have highlighted that irrespective of routes into services, there is evidence demonstrating that Black men are more likely to be diagnosed with psychosis than their White counterparts presenting with the same symptoms (Schwartz, 2014). Furthermore, Black people are also less likely to be offered talking therapies than their White counterparts (Sainsbury Centre for Mental Health, 2008). This suggests that a systematic bias might be occurring.

Curiously, these findings appear to reflect the experiences of Black service users from various countries of origin, which suggests that these experiences of inequality may be underlined by the commonality of race. Within-community factors do not occur in a vacuum and failing to adequately examine the influencing role of social contexts and systems of power on the inequalities described, paints an incomplete picture and means these issues will be extremely difficult to address (Keating & Robertson, 2004; Fernando, 2008; Bowl, 2007). Of particular salience here, are the discourses around distrust and shame in relation to seeking help from

services. Situating the problem of access within marginalised communities serves to understate the historical and arguably on-going mistreatment of Black people at the hands of statutory services (Gee and Ford, 2011).

There is also a growing literature exploring the idea that experiences occurring as a result of having a psychosis diagnosis within wider society might also be experienced as traumatic. Reported experiences include, an increased likelihood of being targeted whilst in a vulnerable mental state (Carr et al., 2017), the impact of being sectioned and forcefully medicated under the Mental Health Act (Paksarian et al., 2014), and difficulty in being able to secure employment opportunities (Bouwman et al., 2015).

There is a limited understanding of how Black individuals with psychosis might navigate social traumas, such as discrimination, stigma, and coercive treatment, after diagnosis.

### ***Existing research in Black communities and psychosis***

There is importantly, ample evidence regarding the racial inequalities in the mental health system (Department of Health, 2005). There has however, been comparably less research exploring how these racial inequalities might be responded to. Tentative data suggests that spirituality; third sector organisations; advocacy and culturally sensitive clinicians can be helpful for Black Service Users' recovery (McLean, Campbell and Cornish, 2003; Leamy et al., 2011; Keating, 2002). However, without a developed understanding of the mechanisms by which these factors influence change, attempts to integrate these findings into practice risk being incongruous.

The spirit of personal recovery is one that critically examines the pedagogy from which mainstream ideas of wellness and recovery stem. It privileges the voices

of the service user in determining what is considered wellness and recovery. By privileging the voices of Black people who report experiencing personal recovery in psychosis, we might develop a better understanding of what this process looks like in this group. In line with a Positive Psychology framework (Schrank et al., 2014), it is hoped that exploring enabling factors and mechanisms have potential to inform recovery-oriented practice. It could also make a difference to how service development in Black communities is approached.

***Project aims:***

This project aims to contribute to the literature by developing a grounded theory of personal recovery in Black individuals with psychosis. This project explores the following research questions:

1. What do Black people who have been diagnosed with psychosis, find helpful in developing a sense of personal recovery?
2. What are perceived to be the contextual (culture and community) barriers and enablers that might impact personal recovery?

## METHODS

### *Design*

This project is a non-experimental, qualitative design and is guided by a Constructivist Grounded Theory (CGT) approach (Charmaz, 2000). Qualitative methodology was deemed appropriate as it supports an exploratory approach in areas of research where little knowledge currently exists.

The social constructivist, ontological underpinnings of Charmaz's (1995) CGT posits that an individual's perception of reality is constructed by their experiences. As such, it seeks to understand phenomena through the analysis of the social processes that led to its construction. It is an inductive approach and considers that theories are developed from data; that knowledge should be led by experience (Glaser & Holton, 2004). CGT has been used in other peer reviewed research exploring personal recovery in psychosis (Dilks, Tasker & Wren, 2010).

### *Participant recruitment:*

Participants were recruited using convenience sampling within peer-led and third sector organisations that hosted events and services for the population under investigation. The study was also advertised across various social media networks (Appendix F).

A theoretical sampling approach was employed, as is consistent with CGT methodology. Theoretical sampling is a "cumulative" approach in which iterative analysis of the collected interviews allows the researcher to visualize the emerging patterns, categories and dimensions (Kwortnik, 2003; Corbin & Strauss, 1998), in order to guide the on-going data collection in line with the emerging theory.



### ***Eligibility criteria and screening***

The eligibility criteria are outlined in table 1.

A screening form was used prior to the completion of research interviews to assess eligibility and to collect demographic information (appendix I).

*Table 1: Eligibility criteria*

<b>Inclusion criteria:</b>	<b>Clarifying definitions</b>
a) Participants identifying as being from a Black minority ethnic background	Black, in this study, refers to people with African or Caribbean heritage. This includes people of African or Caribbean descent who would identify as being of ‘Mixed heritage’.
b) Have had a primary diagnosis of psychosis	Psychiatric diagnoses under the category, “psychotic spectrum disorders”, such as schizophrenia (World Health Organization, 2016).
c) No longer under mental health services.	Participants may have been taking psychotropic medication under the review of a GP but were not presently under the care of statutory mental health services (NHS).
a) Willing to talk about race and culture	The nature of the interview can be considered sensitive and some individuals may not wish to reflect on race or cultural elements of their identity. As such willingness to do so was established prior to interview.
a) On a personal recovery journey	Terms describing personal recovery were developed in conjunction with service user researchers (ResearchNet). Participants were able to indicate positive identification with these phrases (Appendix I).
<b>Exclusion Criteria</b>	
a) People experiencing a crisis involving risk to self or others.	Participants who indicate distress in the form of thoughts of harm to self or others during the screening stage (which is prior to interview) were deemed unsuitable for the study.

### ***Sample size***

Theoretical sufficiency refers to a stage in data analysis where categories are deemed able to cope adequately with new data without requiring extensions or changes and no new themes are emerging (Dey, 1999). This is the point at which no further data is collected. Between eight and sixteen participants are usually required to reach theoretical sufficiency (Dey, 1999).

The first set of 1:1 interviews were completed with four participants. A further four participants were then interviewed. Finally, three more participants were interviewed. At this point, the data was deemed to have met theoretical sufficiency. The sources from which each participant was recruited can be found in Table 2.

*Table 2: Participants broken down according to sources of recruitment*

Social media respondents	4
Community centre respondents	6
Hearing voices groups	1
Total participants	11

### ***Interview design***

1:1 semi-structured, narrative interviews were used for data collection, informed by a similar methodological approach described in Brown, Kandirikirira, & Scottish Recovery Network (2008). Narrative interviews were designed to facilitate the telling of personal ‘stories of recovery’ in a manner that allowed space for the participant’s beliefs and ideas to emerge with minimal leading from the interviewer. The interview schedule was developed in consultation with service-user researchers within the participatory research group, “ResearchNet” (Appendix J).

### ***Data collection:***

Each 1:1 semi structured interview lasted between 25 and 65 minutes. The interviews were audio recorded and then transcribed. Earlier interviews closely followed the interview schedule, while later interviews were guided more actively, by the themes generated as the theory developed, in line with a theoretical sampling approach (Charmaz, 2016).

### ***Ethical considerations and data protection***

Ethical approval was granted by Salomons Centre for Applied Psychology Ethics Panel (Appendix C).

*Informed consent:* The study's nature, purpose, activities, voluntary nature, potential risks and benefits and data management, were shared with participants verbally and through an information sheet (Appendix G). Following this, agreeing participants were asked to provide written informed consent (Appendix H).

*Confidentiality and data protection:* The limits of confidentiality were discussed before beginning each interview and were also stated on the participant information sheet. Only the chief researcher had access to non-anonymised recordings, which were deleted once transcribed.

Identifying information was anonymised in the transcripts through the use of participant identification numbers. Data was stored securely according to GDPR, governance and data protection requirements.

*Managing potential harm to participants:* Participants were offered debrief following each interview and were provided with local sources of support to access if needed following the interviews. No participants stated that this would be needed following the interviews.

*Feedback to stakeholders:* Participants were able to indicate whether they would like to receive a copy of the final study report. An illustrated animation is being developed to outline the findings and will be shared with stakeholders where indicated.

### ***Data Analysis***

The process-driven stages of CGT analysis (Charmaz (1995) give it its methodological rigour as it offers a transparent description of how the theory emerges from raw data. As guided by CGT, the transcripts were read through several times.

Line by line open coding was used to code transcribed interviews.

Facilitated by the process of ‘memo writing’, focussed codes that seemed to be describing similar ideas or processes were brought together to form “sub-themes”.

A narrative of the emergent themes was then further developed in an attempt, to provide an explanatory model of personal recovery in Black communities.

In a process of constant comparison, all of the codes and themes were checked to ensure they accurately reflected what the research participants had said.

### ***Quality assurance checks***

A constructivist philosophy of meaning making suggests that data is constructed within social interactions. Therefore, a researcher’s pre-existing knowledge, ideas and beliefs are considered to inevitably interact with the collection and interpretation of data (Cutcliffe, 2000; Charmaz, 2016). Complete neutrality in CGT is considered impossible. Nevertheless, a number of strategies were used to account for the ways in which an author’s perception of reality might impact the collection and interpretation of data and to encourage a good standard of reliability and validity in this qualitative research.

'Independent audit' involved the academic supervisor checking how the researcher has analysed the data at each stage of the analysis process and agreeing whether changes should be made in order to reinforce or balance the perspective of the researcher.

'Respondent Validity': Due to the time constraints of the study, this was unable to be included in the current report. It is envisaged that respondent validity will be completed at some point and that participant feedback will be incorporated into the theory.

In the context of this study, 'reflexivity' involved distinguishing the researcher's pre-existing knowledge, ideas and beliefs and acknowledging how this might influence data collection and analysis. Reflexivity was demonstrated in the following ways.

- 1) A positioning statement (appendix B), in which the researcher's positions and assumptions were explicitly outlined.
- 2) A facilitated bracketing interview (appendix D) where the lead researcher's potentially hidden, values, assumptions and beliefs were brought to the fore.
- 3) Memo-writing, mapping and documentation of the coding process as evidenced in Appendices K-P.
- 4) A reflexive diary (appendix E) which logs the researcher's thoughts and experiences as they relate to the interview and wider research process.

### ***Participant demographics***

A total of 11 participants took part in narrative style interviews. A summary of the participant's demographic characteristics is illustrated below in table 3.

*Table 3: A table of self-described participant demographic characteristics*

Demographic characteristic	Number of participants
Gender	
Male	6
Female	5
Country of birth	
Jamaica	3
Nigeria	2
Barbados	1
UK	4
Ghana	1
Length of UK residency	
<10 years	0
11-20 years	1
21-30 years	1
30 +	9
Ethnic identity	
Black British – African	3
Black British – Caribbean	5
Black – Caribbean	2
Mixed – White & Black Caribbean	1
Age	
18 – 30	1
31-50	2
51 – 65	8
Years since discharge from mental health services	
<1	4
1-2	4
3-4	0
4-5	1
6-10	0
10+	2

## RESULTS

### *Grounded theory model*

The model presented in this section, is a theoretical representation of the process of achieving a sense of personal recovery for Black individuals who have experienced psychosis. This model is based on a grounded theory analysis of the stories shared by 11 participants. The model is illustrated below, in Figure 1, and is followed by a summary, a comprehensive description of each theme, as well as a commentary on how they are hypothesised to relate.

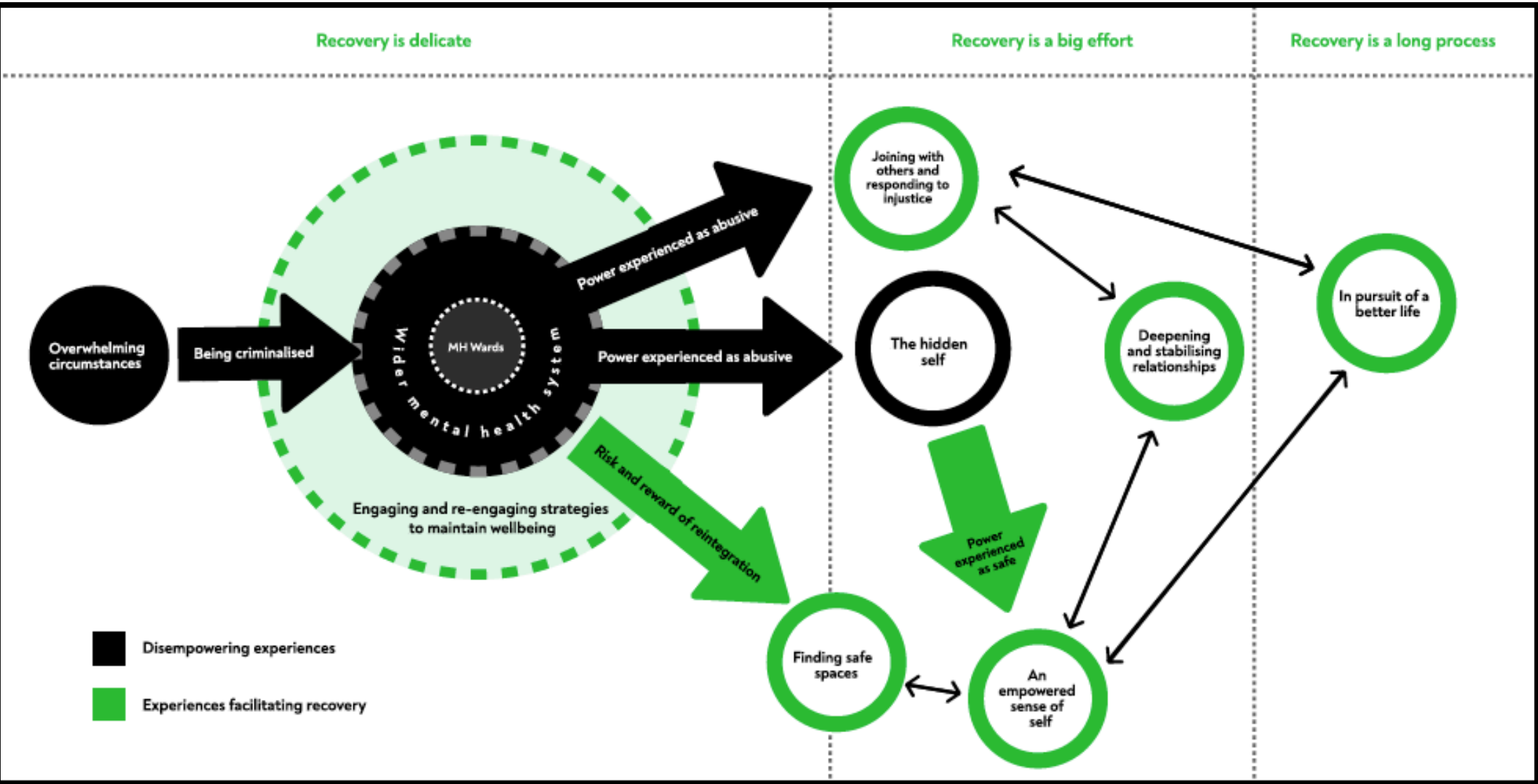


Figure 1: A model of Personal Recovery in Black individuals with Psychosis.



### ***Model summary***

The model (figure 1) highlights 8 themes representing the facilitating experiences encountered as Black individuals navigate the development of personal recovery. These are: engaging and re engaging with strategies to maintain wellbeing, balancing the risk and rewards of reintegration into the community, finding safe spaces, power experienced as safe, developing an empowered sense of self, deepening and stabilising relationships, joining others and responding to injustice and beginning a pursuit towards a better life. ‘Risk and rewards of reintegration’ and ‘power experienced as safe’ are represented by arrows, reflecting the ways they help people transition from disempowered positions. ‘Engaging and re engaging with strategies to maintain wellbeing’ surrounds the ‘mental health system’ with a permeable line. This is to illustrate that while engaging with wellbeing strategies is part of the experience of personal recovery, it also appears to gate-keep more clinical parameters of recovery in a way that does not necessarily detract from an individual’s overarching sense of personal recovery. In this way, the model allows for a dynamic conceptualisation of personal recovery, acknowledging it might involve periods of increased or decreased use of mental health services.

The stories shared indicate that these 8 facilitating experiences occur in the context of, and in some cases, in direct response to disempowering experiences that take place during recovery. As such, 6 other experiences are also included in the model under the theme, ‘disempowering experiences’. These themes are: ‘overwhelming circumstances’, ‘being criminalised’, ‘mental health wards’ and the ‘wider mental health system’, ‘power experienced as abusive’ and the ‘hidden self’.

The ‘hidden self’ is a product of being disempowered and is therefore positioned slightly differently and represented by a different circle. The model is intended to demonstrate how experiences might relate to each other and inferences about a temporal

component to recovery are not made. The themes in this model are grouped according to the three overarching themes that emerged. These are: “Recovery is delicate”, “Recovery is a big effort” and “Recovery is a long process”.

As would have been expected, race and cultural factors are interwoven in each of the themes that emerged rather than as a standalone component of recovery. The model presents theoretical hypotheses of how issues of race can, in some cases, negatively impact the experience of Black individuals with psychosis and it further demonstrates how this has been responded to by participants who managed to achieve a sense of personal recovery despite this. Table 4 further outlines the themes and subthemes represented in the model.

*Table 4: A table of the groups, themes and sub-themes in the model of personal recovery in Black individuals with psychosis.*

Themes	Sub-themes	Group
Disempowering experiences	Overwhelming circumstances	<i>Recovery can be delicate</i>
	Being criminalised	
	Mental health wards	
	Wider mental health system	
	The hidden self	<i>Recovery is a big effort</i>
Experiences facilitating recovery	Engaging and re engaging with strategies to maintain wellbeing	
	Risk and reward of reintegration	
	Finding safe spaces	
	Joining with others and responding to injustice	
	Power experienced as safe	

Developed sense of self

Deepening and stabilising

Relationships

*Recovery as a long process*

In pursuit of a better life

### ***Disempowering experiences***

Disempowering experiences were found to occur prior to the onset of mental health difficulties, at the point of entry into the mental health system as well as within it. The first 4 sub-themes were found to interact, at times in a cumulative manner, and left some participants with a hidden self (the fifth sub-theme).

### ***Overwhelming circumstances***

Many participants had experienced adversity in life, in their families, or more personally. This was described as having been particularly overwhelming at the point that mental health difficulties had become unmanageable.

*He [manager] was really racist. And he was sexist...he was a horrible man*

*(Participant 11)*

*Look after the house, look after my son hold down a full time job, still come home wash, cook, clean, you know erm.... prepare myself for work, look after my son. It just became all too much for me....and erm, one day I just,-I just snapped. You know. (Participant 9)*

*They [the Police] used to pick on me didn't they, people like me. (Participant 5)*

A culture of presenting as 'OK' and getting on with things appeared to make these experiences much more challenging to process. There was some indication that a culture of

coping was learned in the family and is part of a wider cultural discourse. One participant highlighted how this might intersect with her female identity.

*It was unexpected. I'm like... you know, one of these strong black women that just get on with life. (Participant 10)*

Most participants considered their experience of adversity to have contributed to the development of their mental health difficulties in some way.

*- I had my breakdown- after, I had my breakdown. I was in the Royal Artillery, I went there in a- t - I- the errr... in the army. You know, I had all the racism in there as well. (Participant 3)*

An awareness of racism was held in mind by participants and seemed to influence how they navigated the world. There was a sense that this made them acutely conscious of how they are represented in the mind others. This awareness became very live to participants who spoke about how this impacted their sense of self.

*See ... groups of black men, young black person,-man. You might react in a certain way or behave in a certain way, [but] he's only Jamaican, he don't mean any harm (Participant 5)*

*And went to school... I had to deal with racism and was a very lonely child (Participant 4)*

Struggling with psychosis made things even more difficult. Particularly as people had an awareness of how negatively mental illness, and psychosis in particular, is stigmatised within wider society.

*People don't want to see you as schizophrenic (Participant 3)*

*nah... I don't get to express this side. Cos people don't understand ....I don't get to do this... the voices, I can't. They totally scared of me I can't... I can't speak like this to anyone. (Participant 6)*

### *Being criminalised*

Prior to the onset of their mental health difficulties, some participants had experienced being perceived through the lens of existing negative stereotypes about Black people. This included biased misconceptions around drugs, violence and criminal activity. One participant spoke of how being viewed as violent placed him in situations, at an early age, where he then had to use violence to defend himself. Being violent and strong seemed to have become part of his identity and way of defending against racism.

*Racism you mean and all that stuff? I'm too big, I've always been big. I've always been a fighter I've al- everyone knows I'm a fighter. all- in the ends, everyone knows me as a fighter..... [Interviewer: did that- did that protect you?] Yeah, it did, it was just -don't f\*\*k with me. (Participant 7)*

For other participants there was a striking dissonance between the way they were viewed by others and their view of themselves as upstanding people. This came across as being particularly distressing for participants who had experienced being falsely accused and falsely arrested by the Police for serious crimes. The emotions and details of these experiences were acutely remembered and communicated in the interviews even if decades later.

*Yeah. So they say, when you go there to buy food, you buy drugs.... But I don't even smoke or drink, cause they do the swab with me... Strip search, ahhhh. Me had a good head of hair and the ting gone and they pulled my hair. Yeah! Looking for drugs. Yeah. But I didn't order. (Participant 2)*

*I was living in a halfway house....you know, the police took me away because they said I tried to burn a bit of paper and put it through a letterbox - pipe.....and they drum it in my head, the police people, the prison people that I'd done it, you know, and in the end, I never said I'd do it- I never said I'd did it but in the end I said I don't know if I might have got ill and done it. I had done nothing, you know [participant began to cry]. (Participant 5)*

Participants also spoke about what it was like to encounter the Police while in a state of vulnerability and acute distress. Police involved entry to the mental health system was experienced as extremely frightening. One participant was left wondering if his vulnerability may have been more thought about if he had been a young White female.

*Because if you wrapped up the same behaviour that I had, and you put it into a white woman, would it lead to the same things? Would they spend time in the police cell...Or would they interpret them... 'Okay, you can sleep in the car whilst we wait. Or you can just sit in the station,' you know? So these things I don't have the answers to, I can only speak on my experience. And that's why I'm asking.... I don't know. (Participant 1)*

### *Mental health wards*

Reflecting on their experiences of the wards, participants spoke about feeling that clinicians adopted a stance of superficial curiosity about them. Interest in their experiences was often limited to questions concerned about symptoms. Some participants were on wards where the majority of the decision-making staff held White ethnicities. With a knowledge and experience of racism and bias before hospital, many described feeling acutely aware that some of the ideas about who they were may have been filled with

assumptions and misunderstandings. Particularly where clinicians may not have the same cultural references and had further not taken the time to get to understand them.

*I think if I had, - I tell you what helps me; having people relate to me as me, as a Black woman, to share it. They didn't understand. Although I wasn't a Christian, they know when they're being...- So I started to talk about God! I know they associate that with erm... with mental illness!*

*(Participant 11)*

Behaviours some participants thought were normal and justified, were sometimes seen as a symptom of illness or dangerousness, even by staff members with the same cultural background. This was understood by participants as relating to a pathologising of culturally normative behaviours, at a system rather than at a personal level. Without cultural and social context given to their behaviour, participants were left feeling unsafe and unheard on the ward.

*And now they deem meet to be hostile, aggressive, unmanageable. So those three terms is up for interpretation. Right? Because the way I'm speaking, some people speak with a resonance, and they gesture a lot, and they get excited and furthermore.... You've taken me away from my house, you've taken my freedom. How would you like me to react in this situation, you know, so they deem that hostile and unmanageable. (Participant 1)*

Being misunderstood or misinterpreted was felt to have a consequent impact on care. Participants reported being treated in ways that didn't feel proportionate or fair. Participants spoke about their voices not being heard in decisions about their care, coercive and restrictive measures were opted for more easily and some felt like they were viewed with less empathy.

Back in *my days*, they were giving out ermm... medication, like Smarties.  
So there's a lot of ermm... and if you're Jamaican, don't tell me you're Jamaican, because you're getting.... [Interviewer: You're getting the medication? Do you think that's what happened to you?] Almost, definitely, almost definitely. Y-y,- those days I mean most of those... the most of those ermm,, doctors who was in charge of you in those mental institution, they were from White, middle class background, and they never had no association with Black people. So generally you know what I mean... if you're Black, you know, you are.. You're told.. well... If you're White, you was alright, If you were Brown stay down, If you're Black you get back. That's how it was in those days. (Participant 3)

#### *Wider mental health system*

Many participants had sought advice from their GPs when their mental health deteriorated. Some had been able to avoid an admission and instead were offered care through NHS community services. Community care was thought to be “alternative” by participants and seemed to be a preferred approach.

*And because he [GP] knew me well enough, he just thought well, this you know, this is the alternative outlet..... you go to the therapist.*

*(Participant 10)*

Interestingly, this participant still held in mind, a narrative about the mental health system treating Black people differently. Even where care was talked about favourably, this was considered good fortune in the context of a flawed, biased system.

*I've not met anybody that's had as much intervention therapy that I had....most of them will just get like the six sessions and then that's it. But for me to have been able to have all of that and not have to pay for*



*any of it, like I got it all on the NHS as well?... They were just saying to me that, 'you know what someone really was looking after you because that is not the norm'. (Participant 10)*

### *Power experienced as abusive*

Whether within the mental health system or within larger society, all the Black individuals interviewed shared stories touching on ways in which people and systems of power had encroached on their sense of freedom and wellbeing.

### *The hidden self*

Where power as abusive held particular resonance, some participants responded by keeping things in to survive in the world. Many participants gave examples of learning to dampen their own voices, to assimilate in order to fit in with others' expectations of what wellness looked like and to avoid coercive and restrictive treatment.

*The medics, the psychologists, they would come with their book theory.*

*And anything I said will be seen as failing, (Participant 11)*

*What I'm thinking [is], how are they going to perceive me? Are they going to, are they going to put this, are they going to tell the doctor? Is this going to inform what happens to me next? And so even though I was open, there were some things that I was still filtering. (Participant*

*1)*

In some stories, this practice was pervasive and lasted even after they were no longer under the care of mental health services. Hiding parts of the self that were deemed undesirable or unacceptable to the family and wider community was a way to avoid painful scrutiny.

*[Interviewer: So you couldn't talk about that with your friends and family?] No, not really, because I didn't think that people would understand. (Participant 1)*

The hidden self also reflected some participant's grief about the loss of a life and identity that may have been.

*That's quite a powerful one because I thought that if this never happened, I maybe would have been so successful but ermmm I had to deal with all of this..... It stripped me from, yeah it stripped me from actually being ermm... a person that I maybe could have been.*

*I don't know how powerful I could have ever been. (Participant 4)*

### ***Experiences facilitating recovery***

All the stories shared, conveyed various elements that participants felt contributed to their current sense of personal recovery. These themes are positioned away from the mental health system to represent that they seemed to serve as a response to experiences had within the mental health system as well as in wider society. This should not be mistaken as suggesting that recovery-facilitating experiences only took place outside the context of the mental health system.

Five of the recovery-facilitating experiences in the model are connected by double-headed arrows. This is intended to highlight that having even one of these experiences seemed to hold the potential for a cascading, positive effect on an individual's sense of personal recovery. Where interpersonal experiences may have left some participants especially cautious of others, a further two recovery-facilitating experiences emerged as particularly useful in helping people overcome this. These are therefore represented as green arrows.

### *Engaging and re-engaging in strategies to maintain wellbeing*

Some participants spoke about the practical strategies they used to keep themselves feeling well. For many participants this included adhering to medication. Some spoke strongly about the negative impact of medication side effects, however, the majority of participants who were taking medication at the time of interview, found its “numbing”, “stabilising” effect useful.

*Basically calms me down. When I'm not on medication, my mind races, I see things, I get aggressive, I concentrate more erm- on- Medication stops me from concentrating on bad things, it slows me down, sedation and it keeps me calm. When people say I look tired, m- most of the time I am tired but sometimes I just get \*exhales\* that's how it can get with some types of medication. (Participant 7)*

Engaging in passion projects was important for some participants. Participant 10 had written several books, and Participant 7 was training in boxing at a professional level. While filling time and keeping busy emerged as key, having an interest or passion about their chosen activities felt particularly useful.

Many participants warned of the risk of doing too much and shared about learning to intentionally make room for regular rest and recovery. Engaging with positive and encouraging people had kept many participants going. These ‘encouragers’ were found in churches, old friendship groups and other service users. Having positive people around was described particularly important at times when more vulnerable to relapse.

*She would always encourage me to come and do the programme. And at that time I wasn't 100% well, ....through her encouraging me, always encouraging me to come, you know, let's go and get this talk, let's do this workshop, Let's erm, you know, let's, you know, do you want to set up the, do you want to help with the programme? ..... And at the time I said yes,*

*because I thought I was ready and everything like that. But there were times when I couldn't cope, you know, I felt overwhelmed. (Participant 9)*

### *Risk and reward of reintegration*

The model aims to demonstrate how some participant's disempowering experiences seemed to be more tangibly attributed to specific people and systems they encountered (power as abusive) whereas for other participants, there seemed to be a more generalised sense that people can act in harmful ways. For this latter group of participants, deciding whether to reintegrate back into society seemed to be a balance of risk and reward. Where people were able to take this risk, it facilitated a shift towards recovery-facilitating experiences.

*Trust is a big word. But erm... I mean, just Just-Just being friends, friendly with people you know cos I was very conservative... I always keep myself to myself ... 20 years ago, I wouldn't say words and all. I wouldn't say words at all. But now I, I.- I try in my own way to let people know you don't have to be inside. Being outside is okay. (Participant 6)*

### *Finding safe spaces*

Attending groups, churches, events and mental health community centres appeared to help participants begin to feel connected and safe in the community again. Despite the variations in the format of these spaces, they had common attributes. Participants described the importance of having a shared history with the people facilitating and attending the group.

*Because no one- everyone, we're all the same. No one looks at me that I'm different.... people accept me here. (Participant 4)*

For many, feeling safe had involved self-isolation and avoidance of close relationships, however, safe spaces were described as an opportunity to build pressure-free,

causal friendships and as a good way to test and increase the safety and comfort of social interaction.

*People here were very welcoming. So we tended to meet halfway, which was perfect. (Participant 8)*

One participant highlighted that for people who have spent a large proportion of their lives under the care of services, discharge may feel highly disorienting. She spoke about how useful it had been for her to have access to familiar, supportive people when she was feeling vulnerable. She and many other participants spoke about the role of safe spaces in protecting from readmission to mental health wards.

*It feels like I'm at home, I've always been institutionalised. So yeah, I don't like to be out on my own. I don't like to be in a room on my own, I don't like to be in my house on my own.... I was always brought up around noise loads of other people ....So this makes me feel quite safe. (Participant 4)*

For spaces to be experienced as safe, they had to be predictably present. Some participants had attended churches, 3<sup>rd</sup> sector groups and community centres for decades. The closing down of known safe spaces had left some participants feeling lost and hurt. For one participant, the closure of her safe space connected her with feelings of being silenced and disregarded by authority.

*If you are not unwell, you don't understand people that is not well, when they fit into a place and you're coming like a family....because it's going on quite a while. And they're used to each other and now it's, as according to them, on pause! ..... So then you start to shout, why did you do that?.... and then they're going to say oh... we can't take the meeting any further.....-because 'somebody is aggressive and abusive here'. (Participant*

2)

### *Power experienced as safe*

Being advocated for and meeting genuine professionals who wanted to listen and understand, was reported as powerful for participants. The stories highlighted the simple value of a gentle, informal and relaxed approach, either as part of therapy, or not. This helped shift participants from a position of being unheard, to one of feeling understood. As a result, people learned that it is safe and important to speak up about their needs, experiences and injustices faced.

The model illustrates the way in which being heard and encouraged to speak up by people who hold power, can serve to diffuse some of the effects of having learned to keep parts of self, hidden.

*I think one of the things maybe was that I had someone who I felt was listening.*

*I think I had someone who I felt could relate to me.... I had someone sitting in front of me who I don't -I didn't know her. I was not distrusting of her. I didn't find myself distrusting, whereas on the ward, it was kinda like, didn't really trust the staff... maybe it's just the way she practised what she did with me ...she practiced very well. (Participant 11)*

### *An empowered sense of self*

The finding of safe space and experience of being supported by powerful others appeared to nurture a newly developing sense of self. Many participants held non-judgemental, compassionate, non-blaming stories about themselves. Participants spoke about understanding their needs as multifaceted and that true wellbeing, for them involved balancing a holistic integration of the social, spiritual and personal. Many participants were able to demonstrate awareness of how things had deteriorated in the past and expressed an on-going commitment to noticing and avoiding things that might make them more

vulnerable. Having a level of understanding and commitment to self, left participants feeling more confident and driven in their capacity to care for and help others.

... and looking after me as well,...yeah, I do a lot of affirmation. I affirm myself I, I don't wait for other people to have to affirm me. I know how to do that for myself. So that you know, so all of that, you know, that's a whole journey. So when I look back now, I'm a different person. (Participant 10)

### *Joining with others & making change*

Experiencing power as abusive left some people with a desire to action change and to ensure that others are not affected in the same way. Participants seemed to hold some awareness of the stories of other Black individuals with experiences of being disempowered. Many participants spoke about comparing stories with others and this sometimes led to participants being involved in connecting stories across communities. Some participants had mobilised change upwards, towards those with power. For some participants, change was focussed internally and this theme was associated with a sense of taking back their personal sense of power and autonomy.

*Instead of being a victim... I became the victor. (Participant 10)*

### *Stabilising and deepening relationships*

The model places relationships between an, 'empowered sense of self' and 'joining with others & making change'. This is to demonstrate the ways in which these themes led to some participants deepening and developing relationships with others. The double-headed arrow helps to illustrate the ways in which having valued; stable relationships also helped some participants feel more able to engage with these recovery-facilitating experiences. Many participants spoke about having a friend, family member or even GP,

who stuck by them. A live and intimate relationship with God was described by a number of participants and was also included in this theme.

*Having a good having a good doctor ... having someone to listen to me and believe me....and my doctors believe me, it was in her notes. She was the inspiration of me carrying on fighting and fighting and she would keep writing letters and keep sending the paperwork and saying this is what's happened. And yeah, my doctor is my rock. (Participant 4)*

#### *In pursuit of a better life*

The experience of psychosis changed participants' perspectives of themselves, others and the world in many ways. Some spoke about a strengthened spirituality. Others spoke about the importance of believing in the possibility of recovery and having a motivation to live a life that defies the limiting stereotypes that come with a diagnosis of psychosis.

*Realise that you are a person. I am [name] before. I am.. Schizophrenic  
(Participant 3)*

Self-development was of particular interest to some participants. Reflecting on the events of their lives seemed to enthuse participants with a sense that their difficulties had led to a greater purpose and a new zeal for life.

*Where do I want to be in a year's time? Alright ... understanding how fear was holding me back and actually committing myself to improvement,  
(Participant 1)*

#### ***Recovery as delicate, effortful and long***

Overall, participants summarised recovery as delicate, a big effort and a long process. Trying to recover when in close proximity to disempowering experiences could make one's personal sense of recovery feel extremely delicate, particularly where



disempowering experiences might act as a barrier to accessing recovery-facilitating experiences.

A process of shift towards self-development seemed associated with thinking about their lives in the future and the potential for living beyond perceptions of the limits that come with a diagnosis of psychosis. This pursuit presented as a long-term endeavour and participants did not seem to orient this around a fixed endpoint. In this sense working towards a better life as a wider goal might be what led participants to conceptualise personal recovery as a long, limitless process.

Many participants spoke about how others coming alongside them in their recovery, helped them to in some ways share the effortful load of recovery. In this way, personal recovery in this study is described as an effort requiring the support of others.

## DISCUSSION

The aim of this study was to develop a grounded theory of personal recovery in Black individuals with psychosis. The emergent model presents 8 key experiences thought to facilitate the development of a sense of personal recovery. These are: engaging and re-engaging with strategies to maintain wellbeing, balancing the risk and rewards of reintegration, finding safe spaces, power experienced as safe, developing an empowered sense of self, deepening and stabilising relationships, joining others and responding to injustice and pursuit towards a better life. Six contextual experiences to personal recovery also emerged. These were: overwhelming circumstances, being criminalised, mental health wards, the wider mental health system, power experienced as abusive and the hidden self. The themes can be summarised into three overarching themes: “recovery is delicate”, “recovery is a big effort” and “recovery is a long process” (figure 1).

The next section will outline how the key findings of study answer the research questions outlined at the start of the study, and will explore how this relates to the existing literature in this area.

The first research question asked about what Black individuals with psychosis find helpful in developing a sense of personal recovery. The findings suggest that what Black individuals find helpful is in line with the existing literature about recovery more generally (Wilken, 2007; Slade, 2009; Leamy et al., 2011). While issues of race and culture did not form a distinct theme, emergent themes were underlined by participants' cultural experiences and their Black identity.

In multiple studies, hope and belief in recovery as possible, have been identified as enhancing the recovery process (Wilken, 2007; Leamy et al., 2011; Copic, 2011). This study found that a belief in recovery was part of a wider drive towards a better life. This involved for many participants, the strengthening and sometimes, initiation of a spiritual faith. The wider literature highlights the importance of spirituality in BME communities, often reduced to descriptions of how it impacts a person's 'explanatory models of illness' or the role of the faith community in wellbeing (Sainsbury Centre for Mental Health, 2002; Islam, Rabiee & Singh, 2015). However, this model adds that a personal relationship with God was experienced as live and intimate for some participants and often engendered a wider sense of purpose in them.

Social relationships have been thought of as integral to recovery in psychosis (Breier and Strauss, 1984; Topor et al., 2006). The results of the current study also suggest that having someone who remained alongside them throughout recovery had a stabilising effect on participants. However, a common view was that deeper sharing of emotions and experiences did not occur unless participants felt vulnerable to relapse. This may speak to a wider cultural style of communication that should be further explored. 'Stabilising

relationships' served as a safe base from which people could explore other recovery facilitating experiences, and develop deepening relationships with peers.

Participants seemed to talk more about their experiences, with peers who had also used mental health services. Sharing and witnessing stories with others in the development of a sense of personal recovery appeared associated with the development of a sense of autonomy and control over their recovery. This adds to building evidence in the literature about the benefits of sharing narratives of recovery (Rennick-Egglestone et al., 2019). In Black individuals, sharing stories appears associated with a desire to raise awareness about experiences of injustice and in some cases, to mobilise to action. This has not been highlighted as central to recovery in other groups.

The role of peer support and community groups is already richly evidenced and has received wide-ranging support amongst mental health professionals and service users (Longden, Read & Dillon, 2017; Castelein et al., 2015). This study adds to the established benefits of these spaces as safe and healing for people with psychosis. It further highlights the importance of identity and a sense of shared experience, adding some weight to the voices of those who continue to call for the creation of spaces for people who need places where both their mental health and cultural identities feel understood (Keating, 2002).

In the wider personal recovery literature, empowerment involves supporting a service user to take personal responsibility and control over their lives (Leamy et al., 2011). Empowerment, in this model, takes a similarly personal approach but is presented as an ability to connect with an integrated, compassionate sense of self, developed confidence and desire to meet the needs of others. This may reflect a more interdependent approach to the view of self and wellbeing in Black individuals with psychosis.

In this study, the factors appearing to safeguard re-entry into the mental health system were the most connected to ideas around symptom management and clinical

recovery (Macpherson, 2016). Interestingly, for Black individuals with psychosis, medication was only a small part of what was felt to be useful. A more holistic approach to clinical recovery also included ample rest and staying busy.

For participants who had become more withdrawn and cautious of others, achieving a sense of personal recovery was associated having more opportunities to experience others as safe. Taking the risk of re-integrating socially, and having safe experiences of power were integral to this; however, only occurred when facilitated by professionals who used their power and resources to listen to, advocate for and provide safe spaces for them. While advocacy has been deemed as important for all mental health service users, it is particularly recognised as valuable for BME service users (Joint Commissioning Panel for Mental Health, 2014).

The second research question asked what some of the race and culture-specific barriers to personal recovery are in Black individuals with psychosis. The findings replicate other conclusions in the literature highlighting that BME groups often see themselves as recovering from the trauma of stigma, racial discrimination, and violence as well as mental health difficulties (Leamy et al., 2011; Trivedi, 2015).

The concerns about systematic bias and institutional racism in the mental health system raised in this study, have existed for decades (Bhugra & Bahl, 1999; Bhui et al., 2003). This study presents some lived and described harmful experiences that Black individuals with psychosis have had. As is found to be the case for many people with psychosis (Varese et al., 2012), Black individuals in this study had all had adverse life experiences prior to the onset of their mental health difficulties. Many of these experiences were underlined by influences of racism and other overwhelming socio-relational experiences. For Black individuals with psychosis, services that are meant to be experienced as sources of support and healing, have in some case, been experienced as re-

producing the harm and sense of powerlessness that precipitated their presenting distress (Sashidharan, 2001; Shooter, 2003).

The fundamental structure of the mental health system means that many people are likely to have experienced a loss autonomy and power (Wang et al., 2018). Cultural variations in this are difficult to disentangle based on a study of this design. What is evident, is that the experience of being a Black individual with psychosis left many participants in this study, vulnerable to disempowering experiences both prior to and then after encountering the mental health system. Personal recovery emerged as an action to counter the impact of this on a person's sense of self.

### ***Limitations***

The non-experimental design of this study means that it is not possible to draw conclusions about the causal relationships hypothesised between the components in the model. The model is considered to be theoretical, based on an understanding of a small group of participants. Further research is needed to test the hypotheses generated by the model.

While theoretical sufficiency was met with the existing sample, there is the potential that having a larger proportion of younger participants may have revealed specific enablers and barriers to personal recovery that might be generational. The experiences shared and included in the model were evident across participants and there was no suggestion that having had a more recent admission, gender, or age at the point of entry to the mental health system, led to any noticeable changes in the way that the themes emerged. Nevertheless, future research may want to focus on these elements in more depth.

The inclusion criteria for this study allowed for a range of psychotic-spectrum disorders. This significantly improved the recruitment numbers however it did increase the

heterogeneity of the sample. It is not clear whether some psychotic-spectrum disorders lead to engaging with recovery in a different way.

### ***Theoretical implications***

The congruency of this model with existing research, adds a level of validation to the presented model of personal recovery. Models of recovery have been criticised as being reductionist with concerns that they may marginalise some service users who do not identify with service-defined interpretations of personal recovery (Trivedi, 2015; Fernando, 2008). Indeed, this study highlights the importance of context. While many existing recovery principles were replicated, they were found to be experienced in very different ways and for very specific reasons in Black individuals with psychosis.

Promoting recovery without personal and social context, has the potential to place the onus back on the often, less powerful service user to change while inadvertently, overlooking the responsibilities of those with more power to implement systemic transformation (Masterson and Owen, 2009). Bringing a focus back to the person in context may create space for thinking about how it might be possible for policy makers, services and clinicians to promote effective outreach, equal access and restorative justice for Black individuals with psychosis.

This project offers another step towards the meaningful exploration of race and culture in relation to mental health experience and recovery. More research should be encouraged, that explores the development of personal recovery in other minority communities in the UK.

### ***Policy and Clinical implications***

It can be argued that efforts to promote recovery for Black individuals with psychosis can occur by dismantling disempowering practices at policy and service level. Addressing the inequalities in BME mental health has been on the government agenda for

several years (Department of health, 2003) however the measures taken to implement and review change are unclear. The findings of this study would support that this remain on the agenda and be engaged with in meaningful ways.

The model suggests there is potent opportunity for personal empowerment and distress alleviation when professionals are able come alongside, listen to and advocate for Black individuals with psychosis. There may be a role for community and NHS based professionals to intervene here, and to gently encourage the potential rewards of attending ‘safe spaces’ that contain the elements outlined in this study. This may also need to be coupled with the development of sustainable safe spaces in the community.

Overall, the findings would suggest that clinicians encountering a Black individual in distress, or one that might be stuck in the ‘hidden self’, could best intervene by considering and or exploring the wider contexts and systematic factors that might also be fuelling and maintaining this distress. Working to become more acutely aware of the ways in which personal and systemic bias might be influencing practice is also important.

## CONCLUSION

The factors that have been found to be useful in promoting a sense of personal recovery from mental health more broadly are demonstrated in this study as also relevant for Black individuals who have experienced psychosis. Beyond this, the current study has explored and presented some of the ways in which race and culture influences the definition and experience of these factors by Black individuals with psychosis. The facilitating experiences brought about psychological, emotional and behavioural shifts that helped participants feel that they had achieved a sense of personal recovery as defined by themselves.

The findings reinforce the importance of exploring contextual barriers and enablers of recovery. Black individuals with psychosis appear to face a number of disempowering experiences underlined by racism and other forms of discrimination. This means that personal recovery, for this group, might often involve overcoming the impact of stigma and injustice in addition to clinical indicators of distress.

There are implications for theory, policy and practice which all involve the consideration of wider systemic and contextual issues that impact the development of personal recovery in Black individuals with psychosis.



## REFERENCES

Angermeyer, M. C., & Matschinger, H. (2004). The Stereotype of Schizophrenia and Its Impact on Discrimination Against People With Schizophrenia: Results From a Representative Survey in Germany. *Schizophrenia Bulletin*, 30(4), 1049-1061.

<https://doi.org/10.1093/oxfordjournals.schbul.a007120>

Anthony, W.A. (1993) Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. *Psychosocial Rehabilitation Journal*, 16, 11-23.

<https://doi.org/10.1037/h0095655>

Bhugra, D., & Bahl, V. (1999). *Ethnicity - An Agenda for Mental Health*. London: Royal College of Psychiatrists.

Bhui, K. (2001). Over-representation of Black people in secure psychiatric facilities. *The British Journal of Psychiatry : the Journal of Mental Science*, 178.

<https://doi.org/10.1192/bjp.178.6.575>

Bhui, K., Stansfeld, S., Hull, S., Priebe, S., Mole, F., & Feder, G. (2003). Ethnic variations in pathways to and use of specialist mental health services in the UK. Systematic review. *The British Journal of Psychiatry*, 182, 105-116. <https://doi.org.uk/10.1192/bjp.182.2.105>

Bouwman C, De Sonnevile C, Mulder C. L, & Hakkaart-van Roijen, L. (2015). Employment and the associated impact on quality of life in people diagnosed with schizophrenia. *Neuropsychiatric Disease and Treatment*, 2015, 2125-2142.

**[https://doi.org.uk/ 10.2147/NDT.S83546](https://doi.org.uk/10.2147/NDT.S83546)**

Bowl, R. (2007). Responding to ethnic diversity: black service users' views of mental health services in the UK. *Diversity in Health and Social Care*, 4(3), 201-210.

Breier, A., & Strauss, J. S. (1984). The role of social relationships in the recovery from psychotic disorders. *The American Journal of Psychiatry*, 141(8), 949-55.

**<https://doi.org/10.1176/ajp.141.8.949>**

Brown, W., Kandirikirira, N., & Scottish Recovery Network. (2008). *Recovering mental health in Scotland: Report on narrative investigation of mental health recovery*. Glasgow: Scottish Recovery Network

Carr, S., Holley, J., Hafford-Letchfield, T., Faulkner, A., Gould, D., Khisa, C., & Megele, C. (2017). Mental health service user experiences of targeted violence and hostility and help-seeking in the UK: a scoping review. *Policy and Systems, Interpersonal Violence and Mental Health, Review*, 4(25). **[https://doi.org.uk/ 10.1017/gmh.2017.22](https://doi.org.uk/10.1017/gmh.2017.22)**

Castelein, S., Bruggeman, R., Davidson, L., & van, G. M. (2015). Creating a Supportive Environment: Peer Support Groups for Psychotic Disorders. *Schizophrenia Bulletin*, 41(6), 1211-1213. **<https://doi.org.uk/10.1093/schbul/sbv113>**

Caqueo-Urizar, A., Rus-Calafell, M., Urzúa, A., Escudero, J., & Gutiérrez-Maldonado, J. (2015).

The role of family therapy in the management of schizophrenia: challenges and solutions. *Neuropsychiatric Disease and Treatment*, *11*, 145-51.

**<https://doi.org.uk/10.2147/NDT.S51331>**

Charmaz, K. (1995). Grounded theory. In J.A. Smith, R. Harré, & L. Van Langenhove (Ed.),

Rethinking methods in psychology (pp.27–49). London: Sage.

Charmaz, K. (2000). *Grounded theory: Objectivist and constructivist methods*. Handbook of qualitative research. Thousand Oaks, California: Sage.

Charmaz, K. (2016). The Power of Constructivist Grounded Theory for Critical

Inquiry. *Qualitative Inquiry*, *23*(1), 34-45. **<https://doi.org/10.1177/1077800416657105>**

Chamberlin, J. (1978). *On our own: Patient-controlled alternatives to the mental health system*.

New York: Hawthorne books

Copic, V., Deane, F. P., Crowe, T. P., & Oades, L. G. (2011). Hope, Meaning and Responsibility

across Stages of Recovery for Individuals Living With an Enduring Mental Illness. *The Australian Journal of Rehabilitation Counselling*, *17*(2), 61-73.

**<http://dx.doi.org/10.1375/jrc.17.2.61>**

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks: Sage.

Corrigan, P., Kerr, A., & Knudsen, L. (2005). The stigma of mental illness: explanatory models and methods for change. *Applied and Preventive Psychology, 11*(3), 179-190.

<https://doi.org/10.1016/j.appsy.2005.07.001>

Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing, 31*(6), 1476-84. <https://doi.org.uk/10.1046/j.1365-2648.2000.01430.x>

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 11*(4), 11–19. <https://doi.org/10.1037/h0099565>

Department of Health (2003). *Delivering race equality: A framework for action. Mental health services consultation document*. London: Great Britain.

Dey, I. (2008). *Grounding grounded theory: Guidelines for qualitative inquiry*. Bingley: Emerald.

Dilks, S., Tasker, F., & Wren, B. (2010). Managing the impact of psychosis: A grounded theory exploration of recovery processes in psychosis. *British Journal of Clinical Psychology, 49*(1), 87-107. <https://doi.org.uk/10.1348/014466509X439658>.

Fenekou, V., & Georgaca, E. (2010). Exploring the experience of hearing voices: A qualitative study. *psychosis, 2*(2), 134-143. <https://doi.org/10.1080/17522430903191783>

Fernando, S. (2010). *Mental health, race and culture*. Basingstoke, Hampshire: Palgrave Macmillan.

- Gage, S. H. (2019). Cannabis and psychosis: triangulating the evidence. *The Lancet Psychiatry*, 6(5), 364-365. [https://doi.org/10.1016/S2215-0366\(19\)30086-0](https://doi.org/10.1016/S2215-0366(19)30086-0)
- Gee, G. C., & Ford, C. L. (2011). Structural racism and health inequities: Old Issues, New Directions. *Du Bois Review: Social Science Research on Race*, 8(1), 115-132. <https://doi.org.uk/10.1017/S1742058X11000130>
- Glaser, B.G. & Holton, J.A. (2004). Remodeling grounded theory. *Forum: Qualitative Social Research*, 5(2), 1–22. <http://dx.doi.org/10.17169/fqs-5.2.607>
- Hamilton, I., & Monaghan, M. (2019). Cannabis and psychosis: Are We any Closer to Understanding the Relationship? *Current Psychiatry Reports*, 21(7), 48. <https://doi.org/10.1007/s11920-019-1044-x>
- Islam, Z., Rabiee, F., & Singh, S. P. (2015). Black and Minority Ethnic Groups' Perception and Experience of Early Intervention in psychosis Services in the United Kingdom. *Journal of Cross-Cultural Psychology*, 46(5), 737-753. <https://doi.org/10.1177/0022022115575737>
- Joint Commissioning Panel for Mental Health (2014). Guidance for commissioners of mental health services for people from black and minority ethnic communities [PDF file]. Retrieved from <https://www.jcpmh.info/wp-content/uploads/jcpmh-bme-guide.pdf>
- Keating, F. (2002). Black-Led Initiatives in Mental Health: An Overview. *Research, Policy and Planning: the Journal of the Social Services Research Group*, 20, 9-20

Keating, F., & Robertson, D. (2004). Fear, black people and mental illness: A vicious circle? *Health and Social Care in the Community*, 12(5), 439-447.

<https://doi.org.uk/10.1111/j.1365-2524.2004.00506.x>

. Killaspy, H., White, S, Lalvani, N., Berg, R., Thachil, A., Kallumpuram, S., Nasiruddin, O., Wright, C., & Mezey, Gill. (2014). The impact of psychosis on social inclusion and associated factors. *The International Journal of Social Psychiatry*, 60(2), 148–154.

<https://doi.org.uk/10.1177/0020764012471918>

Kwortnik, R. J. (2003). Clarifying “fuzzy” hospitality-management problems with depth interviews and qualitative analysis. *Cornell Hotel and Restaurant Administration Quarterly*, 44(2), 8-8. [https://doi.org/10.1016/S0010-8804\(03\)90025-5](https://doi.org/10.1016/S0010-8804(03)90025-5)

Leamy, M., Bird, V., Boutillier, C. L., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *British Journal of Psychiatry*, 199(6), 445-452. <https://doi.org/10.1192/bjp.bp.110.083733>

[10.1192/bjp.bp.110.083733](https://doi.org/10.1192/bjp.bp.110.083733)

Lewis-Beck, M. S., & Bryman, A. (2004). *The Sage encyclopedia of social science research methods: Vol. 1*. Thousand Oaks, CA:Sage Publications.

Littlewood, R. (1988). Community-initiated research: a study of psychiatrists' conceptualisations of ‘cannabis psychosis’. *Psychiatric Bulletin*, 12(11), 486-488. <https://doi.org/10.1192/pb.12.11.486>

- Longden, E., Read, J., & Dillon, J. (2018). Assessing the Impact and Effectiveness of Hearing Voices Network Self-Help Groups. *Community Mental Health Journal*, 54(2), 184-188. <https://doi.org.uk/10.1007/s10597-017-0148-1>
- Macpherson, R., Pesola, F., Leamy, M., Bird, V., Le, B. C., Williams, J., & Slade, M. (2016). The relationship between clinical and recovery dimensions of outcome in mental health. *Schizophrenia Research*, 175(1), 142-147. <https://doi.org.uk/10.1016/j.schres.2015.10.031>
- Mantovani, N., Pizzolati, M., & Edge, D. (2017). Exploring the relationship between stigma and help-seeking for mental illness in African-descended faith communities in the UK. *Health Expectations*, 20(3), 373-384. <https://doi.org.uk/10.1111/hex.12464>
- Masterson, S., & Owen, S. (2009). Mental health service user's social and individual empowerment: Using theories of power to elucidate far-reaching strategies. *Journal of Mental Health Abingdon-*, 15(1), 19-34. <https://doi.org/10.1080/09638230500512714>
- McLean C, Campbell C and Cornish F (2003) African-Caribbean interactions with mental health services in the UK: experiences and expectations of exclusion as (re)productive of health inequalities. *Social Science and Medicine* 56:657–69. [https://doi.org/10.1016/S0277-9536\(02\)00063-1](https://doi.org/10.1016/S0277-9536(02)00063-1)
- McGuire, P. K., Jones, P., Harvey, I., Williams, M., McGuffin, P., & Murray, R. M. (1995). Morbid risk of schizophrenia for relatives of patients with cannabis-associated

psychosis. *Schizophrenia Research*, 15(3), 277. [https://doi.org.uk/ 10.1016/0920-9964\(94\)00053-b](https://doi.org.uk/10.1016/0920-9964(94)00053-b)

Memon, A., Taylor, K., Mohebati, L. M., Sundin, J., Cooper, M., Scanlon, T., & De Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: A qualitative study in Southeast England. *Bmj Open*, 6(11). <https://doi.org/10.1136/bmjopen-2016-012337>

O'Donnell, A. T., Corrigan, F., & Gallagher, S. (2015). The impact of anticipated stigma on psychological and physical health problems in the unemployed group. *Frontiers in Psychology*, 6. <https://doi.org.uk/10.3389/fpsyg.2015.01263>

Paksarian, D., Mojtabai, R., Kotov, R., Cullen, B., Nugent, K. L., & Bromet, E. J. (2014). Perceived trauma during hospitalization and treatment participation among individuals with psychotic disorders. *Psychiatric Services*, 65(2), 266-9. <https://doi.org.uk/10.1176/appi.ps.201200556>.

Papadopoulos, C., Foster, J., & Caldwell, K. (2013). 'Individualism-Collectivism' as an Explanatory Device for Mental Illness Stigma. *Community Mental Health Journal*, 49(3), 270-280. [https://doi.org/ 10.1007/s10597-012-9534-x](https://doi.org/10.1007/s10597-012-9534-x).

Rabiee, F., & Smith, P. (2014). Understanding mental health and experience of accessing services among African and African Caribbean Service users and carers in Birmingham, UK. *Diversity and Equality in Health and Care*, 11(2), 125-134.



Read, J., van Os, J., Morrison, A. P., & Ross, C. A. (2005). *Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications*. Wiley-Blackwell Publishing, Inc.

Rennick-Egglestone, S., Morgan, K., Llewellyn-Beardsley, J., Ramsay A., McGranahan R., Gillard S., Hui, A., Ng, F., Schneider J., Booth S., Pinfold V., Davidson L., Franklin D., Bradstreet S., Arbour, S. & Slade, M. (2019). Mental Health Recovery Narratives and Their Impact on Recipients: Systematic Review and Narrative Synthesis. *Canadian Journal of Psychiatry*. 64(10), 669-679. <https://doi.org/10.1177/0706743719846108>

Rodrigues, R., & Anderson, K. (2017). The traumatic experience of first-episode psychosis: A systematic review and meta-analysis. *Schizophrenia Research*, 189, 27-36. <https://doi.org.uk/10.1016/j.schres.2017.01.045>.

Rissemiller, D. J., & Rissemiller, J. H. (2006). Open Forum: Evolution of the Antipsychiatry Movement Into Mental Health Consumerism. *Psychiatric Services*, 57(6), 863-866. <https://doi.org/10.1176/appi.ps.57.6.863>

Roosenschoon, B.J., Kamperman, A. M., Deen, M. L., van, W. J., & Mulder, C. L. (2019). Determinants of clinical, functional and personal recovery for people with schizophrenia and other severe mental illnesses: A cross-sectional analysis. *Plos One*, 14(9). <https://doi.org/10.1371/journal.pone.0222378>

- Sainsbury Centre for Mental Health (2002). *Breaking the circles of fear: A Review of the Relationship Between Mental Health Services and African and Caribbean Communities*. London: Sainsbury Centre for Mental Health.
- Sashidharan, S. P. (2001). Institutional racism in British psychiatry. *Psychiatric Bulletin*, 25(7), 244-247. <https://doi.org/10.1192/pb.25.7.244>
- Schwartz, R. C. (2014). Racial disparities in psychotic disorder diagnosis: A review of empirical literature. *World Journal of Psychiatry*, 4, 4, 133. <https://doi.org.uk/10.5498/wjp.v4.i4.133>
- Schrank, B., Brownell, T., Tylee, A., & Slade, M. (2014). Positive Psychology: An Approach to Supporting Recovery in Mental Illness. *East Asian Archives of Psychiatry*, 24(3), 95-103.
- Selten, J. P., & Sijben, N. (1994). First admission rates for schizophrenia in immigrants to the Netherlands: The Dutch national register. *Social Psychiatry and Psychiatric Epidemiology*, 29(2), 71-77. [https://doi.org.uk/ 10.1007/BF00805625](https://doi.org.uk/10.1007/BF00805625)
- Selten, J. P., Slaets, J. P. J., & Kahn, R. S. (1997). Schizophrenia in Surinamese and Dutch Antillean immigrants to The Netherlands: Evidence of an increased incidence. *Psychological Medicine : a Journal for Research in Psychiatry and the Allied Sciences*, 27(4), 807-812. [https://doi.org.uk/ 10.1017/s0033291797005199](https://doi.org.uk/10.1017/s0033291797005199)
- Shooter, M. (2003). Reply to Ian Bronks' letter for the Bulletin : Mike Shooter. *Psychiatric Bulletin*, 27(4), 155. <https://doi.org/10.1192/pb.27.4.155-a>

- Slade, M. (2011). *Personal recovery and mental illness: A guide for mental health professionals*. Vancouver, B.C: Langara College.
- Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., Perkins, R., Shepherd, G., Tse, S, Whitley, R. (2014). Uses and abuses of recovery: Implementing recovery-oriented practices in mental health systems. *World Psychiatry, 13*(1), 12-20. <https://doi.org/10.1002/wps.20084>.
- Spandler & Calton (2009). *psychosis and Human Rights: Conflicts in Mental Health Policy and Practice*. Cambridge: Cambridge University Press.
- Thomas, N., Farhall, J., Foley, F., Leitan, N. D., Villagonzalo, K. A., Ladd, E., Nunan, C., Farnan, S., Frankish, R., Smark, T., Rossell, S.L., Sterling, L., Murray, G., Catle, D. J. & Kyrios, M. (2016). Promoting Personal Recovery in People with Persisting Psychotic Disorders: Development and Pilot Study of a Novel Digital Intervention. *Frontiers in Psychiatry, 7*(196). <https://doi.org/10.3389/fpsy.2016.00196>
- Topor, A., Borg, M., Mezzina, R., Sells, D., Marin, I., & Davidson, L. (2006). Others: The Role of Family, Friends, and Professionals in the Recovery Process. *American Journal of Psychiatric Rehabilitation, 9*(1), 17-37. <https://doi.org/10.1080/15487760500339410>
- Trivedi, P. (2010). A Recovery Approach in Mental Health Services: Transformation, Tokenism or Tyranny? Bassett and Stickley (Ed.), In *Voices of experience: Narratives of mental health survivors* (pp. 152-164). Chichester: Wiley-Blackwell.

Van Eck, R. M., Burger, T. J., Vellinga, A., Schirmbeck, F., & de, H. L. (2018). The Relationship Between Clinical and Personal Recovery in Patients With Schizophrenia Spectrum Disorders: A Systematic Review and Meta-analysis. *Schizophrenia Bulletin*, 44(3), 631-642. <https://doi.org/10.1093/schbul/sbx088>.

Varese, F., Bentall, R. P., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., .Van, O. S. & Read, J. (2012). Childhood adversities increase the risk of psychosis: A meta-analysis of patient-control, prospective-and cross-sectional cohort studies. *Schizophrenia Bulletin*, 38, 4, 661-671. <https://doi.org.uk/10.1093/schbul/sbs050>.

Wang, K., Link, B. G., Corrigan, P. W., Davidson, L., & Flanagan, E. (2018). Perceived provider stigma as a predictor of mental health service users' internalized stigma and disempowerment. *Psychiatry Research*, 259, 526-531. <https://doi.org.uk/10.1016/j.psychres.2017.11.036>

Wilken, J. P. (2007). Understanding Recovery from psychosis: A Growing Body of Knowledge. *Journal of the Norwegian Psychological Association*, 44(5), 658-666.

## SECTION C

### APPENDICIES

#### A. Reviewed studies and their titles

##### *Reviewed studies and their titles*

Study Author(s)	Study Title
Holma & Aalomen (1995).	The self-narrative and acute psychosis
Holma & Aaltonen, (1997).	The Sense of Agency and the Search for a Narrative in Acute psychosis.
Vassallo, (1998).	Narrative group therapy with the seriously mentally ill: A case study.
Ching, Smyth & Charlesworth (2019).	The Adaptation and Feasibility of Narrative Enhancement and Cognitive Therapy (NECT) for Late-Onset psychosis.
Mehl-Madrona, Jul & Mainguy (2014).	Results of a Transpersonal, Narrative, and Phenomenological Psychotherapy for psychosis
Holma, & Aaltonen, (1998a).	Narrative understanding in acute psychosis
Holma & Aaltonen, (1998b).	The experience of time in acute psychosis and schizophrenia.
Freedman & Combs (2009).	Ripples from the gatherings: Narrative ideas for consulting with communities.
Bar-Am, (2016).	First episode psychosis: A magical realist guide through liminal terrain

#### B. Ethical approval letter

*This has been removed from the electronic copy*

C. A positioning statement

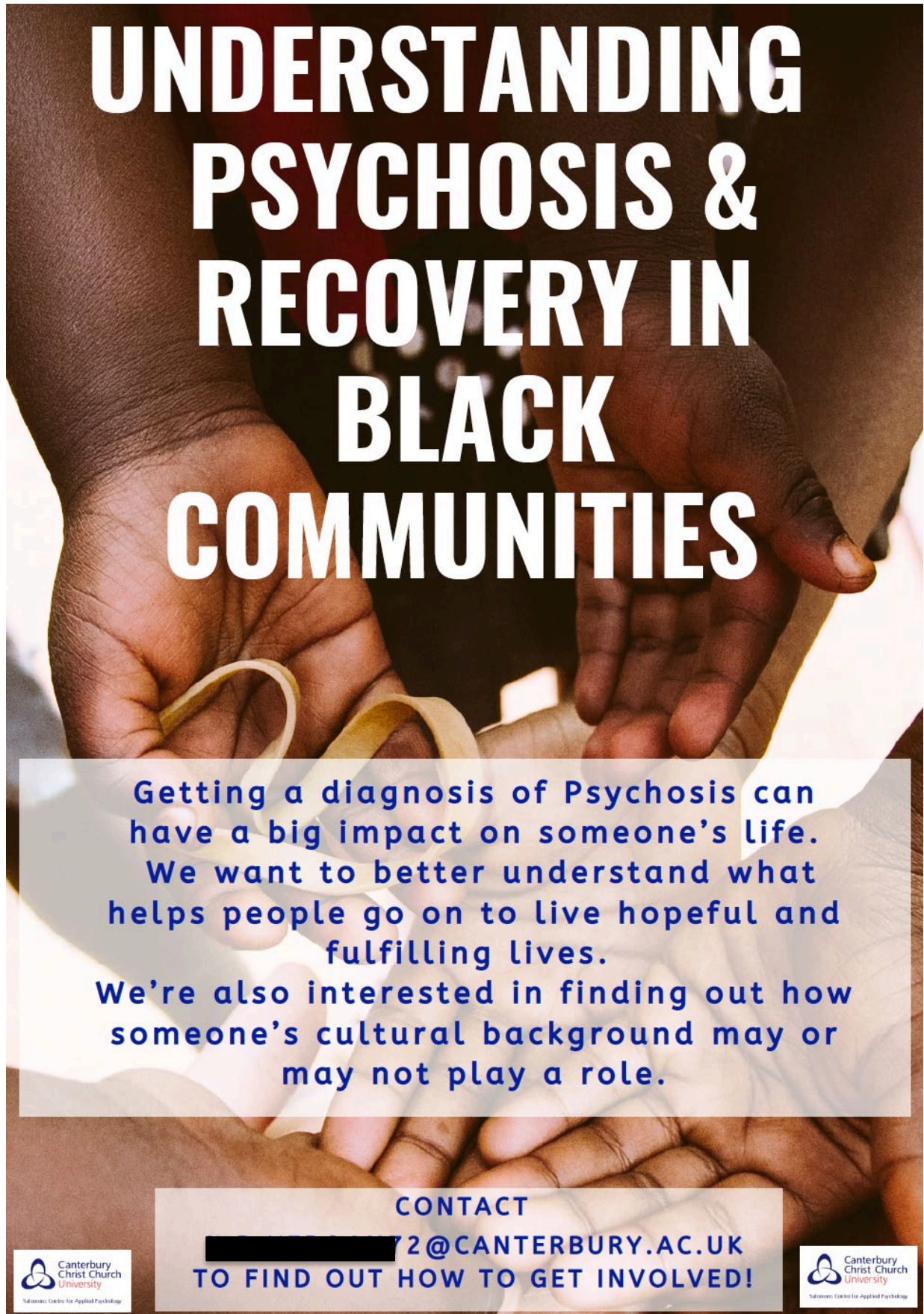
*This has been removed from the electronic copy*

D. A bracketing interview excerpt

*This has been removed from the electronic copy*

E. A reflexive diary excerpt



- *This has been removed from the electronic copy*



# UNDERSTANDING PSYCHOSIS & RECOVERY IN BLACK COMMUNITIES

Getting a diagnosis of Psychosis can have a big impact on someone's life. We want to better understand what helps people go on to live hopeful and fulfilling lives. We're also interested in finding out how someone's cultural background may or may not play a role.

**CONTACT**  
██████████72@CANTERBURY.AC.UK  
**TO FIND OUT HOW TO GET INVOLVED!**





F. Participant information Sheet

**Chief research investigator:**

[REDACTED]

[REDACTED]

[REDACTED]

[xxxxx@canterbury.ac.uk](mailto:xxxxx@canterbury.ac.uk)

[REDACTED]



Salomons Centre for Applied Psychology

**INFORMATION SHEET:**

***Exploring personal recovery in Black individuals with psychosis***

Dear participant,

You are being invited 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. Please read the information below:

**1. What is the purpose of this project?**

Getting a diagnosis of psychosis can have a big impact on someone's life. We want to better understand what helps people live hopeful and fulfilling lives even if they continue to face difficulties or on-going 'symptoms'. We're also interested in finding out how someone's cultural background may or may not play a role.

**2. Why have I been invited to take part?**

You may have indicated that you feel that your life is in a good place, or maybe that things are better for you now than when you were first diagnosed with psychosis.

We would like to speak to adults who have had a diagnosis of Schizophrenia or psychosis *but are no longer under mental health services*.

We particularly want to speak to people of African or Caribbean decent who are happy to talk about race / cultural issues.

**3. Do I have to take part?**

It is up to you to decide whether to join the study. If you agree to take part, you are still free to withdraw at any time, without giving a reason. This would not affect any care you might be currently receiving. If you decide at a later date that you would prefer us not to use the information you have shared, you can let us know and we will withdraw your data from the study.

#### **4. 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 then be asked to complete a screening form to see if you are eligible to take part in the study. - The form will ask you to tell us more about yourself, your ethnic identity, mental health and diagnosis and your GP details. We will only contact your GP if we become concerned about your safety, or the safety of someone else.
- c) If you are not eligible to take part in the study, we will let you know.
- d) If you are eligible for the study, you will be invited to have a 60-90 minute interview with me where we will talk about your experiences since entering mental health services.  
-I will send you the interview questions in advance, so you will have time to think about what you want to share.
- e) The interview will need to be recorded so that I can listen back to it for the research analysis.
- f) You will be offered the opportunity to comment on the findings of the project.

#### **5. Expenses and payments**

Everyone who is interviewed will be offered a £10 reimbursement for his or her time and travel.

#### **6. What are the possible disadvantages and risks of taking part?**

Some people might find it distressing to talk about their experiences and views of mental illness and mental health services. If you were to become too upset at any point during the interview, you could stop and would only continue the interview if you wanted to.

If you feel that talking about your experiences will make you feel too distressed, we would advise that do not take part in this study at this time.

#### **7. What are the possible benefits of taking part?**

It is not possible for us to claim any direct benefit for participants however some people find that sharing their stories can be a highly meaningful experience.

This research also hopes to improve the experiences and support of Black people in mental health services and in the community, by finding out what helps them.

#### **8. 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 taken seriously.

*If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me 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 me, Keren Yeboah, and I 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 [fergal.jones@canterbury.ac.uk](mailto:fergal.jones@canterbury.ac.uk)*

### **9. Compliance with General Data Protection Regulation (GDPR)**

Canterbury Christ Church University is the sponsor for this study based in the United Kingdom. We will be using the information you share with us in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Canterbury Christ Church University will keep identifiable information about you for 1 year after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Deborah Chadwick who is the named data custodian for Salomons Institute for Applied Psychology, Canterbury Christ Church University on 01227 927074 or by emailing [deborah.chadwick@canterbury.ac.uk](mailto:deborah.chadwick@canterbury.ac.uk).

Individuals from Canterbury Christ Church University and regulatory organisations may look at the research records to check the accuracy of the research study. The only people in Canterbury Christ Church University who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, contact details. Canterbury Christ Church University will keep identifiable information about you from this study for 1 year after the study has finished.

### **10. Will my taking part in the study be kept confidential?**

We will follow ethical and legal practice and all information about you will be kept strictly confidential.

- a) Our audio-recorded conversation will be temporarily stored on an encrypted, password-protected computer.
- b) After our recorded conversation has been typed up and made anonymous, the audio-recorded version will be deleted.
- c) All results of this study will be anonymous, so your name will not appear on any report of the study and you will not be identifiable.
- d) The research team will be the only people who have access to the information you share.
- e) All personal identifiable data (e.g. consent and screening form) will be deleted one year after we finish the study.
- f) We will delete all data that was made anonymous, after 10 years.
- g) The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become

concerned about your safety or the safety of someone else. In this case, I would share information with your GP or emergency services.

**11. Who is on the research team?**

Keren Yeboah is the main researcher and the person who will interview you should you decide to take part in the study. Keren is a trainee clinical psychologist at Christ Church Canterbury University and she is conducting this study as part of her doctoral training in clinical psychology.

Professor Tony Lavender and Dr Mary Leamy make up the rest of the research team and are supervising Keren.

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

You are still free to withdraw at any time, without giving a reason. This would not affect any care you might be currently receiving. If you decide at a later date that you would prefer us not to use the information you have given us, let us know and we will withdraw your data from the study.

**13. What will happen to the results of the research?**

The results of this project will be written up as a Doctoral thesis with the possibility of being published in a relevant scientific journal.

We will also summarise the findings in a short interactive video so that more people will get a better understanding of what our participants have told us helps Black people diagnosed with psychosis. If you would like to receive a copy of this video, please let us know.

**14. Who is sponsoring and funding the research?**

Canterbury Christ Church University is the sponsor and will be funding and supporting the organisation of the research.

**15. Who has reviewed the study?**

The research has been reviewed by the Health Research Authority and The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

**16. Can I keep this form?**

You can keep this form and will also be given a signed copy of your consent form should you wish to take part.

**17. If I have questions or problems about the study, whom should I contact?**

Lead researcher – xx xxx : [xxxxx@canterbury.ac.uk](mailto:xxxxx@canterbury.ac.uk)

Research Supervisor – xxx xxx [xxxx@canterbury.ac.uk](mailto:xxxx@canterbury.ac.uk)

**if you do feel you need more support, or are in crisis, please contact one of the following:**

- Your G.P.
- The Samaritans: 116 123 (24 hour helpline)
- SLaM crisis line: 0800 731 2864 (24 hour helpline)
- Your current Clinical Care Team



Salomons Centre for Applied Psychology

Thank you,

G. Participant consent form

**PARTICIPANT CONSENT FORM:**  
*Experiences of Black people with psychosis*

**Important** – Please initial the boxes below and sign this consent form to confirm you would like to take part in this study.

1. I confirm that I have read and understand the information sheet dated 10/7/19 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that I will be asked to complete a screening form to establish my eligibility for the study.

3. I understand that the researchers will need to share information with my GP and or emergency services if I share information about myself or others being at risk of harm.

4. I consent for my interview to be audio recorded.

5. I understand that my participation is voluntary and that I may withdraw from the research at any time, without giving a reason. This would not affect any care I might be currently receiving.

6. I understand that data collected during the study will be looked at by Keren Yeboah and her research supervisor, Tony Lavender, I give permission for these individuals to have access to my data.

7. My anonymised data will be kept on an encrypted, password-protected computer or in a locked filing cabinet and kept for a period of 10 years after the appearance of any associated publication.

8. Some of my personal identifiable data (such as this consent form) will be kept for records in a locked filing cabinet, for one year after the appearance of any associated publication

9. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings

10. I would like to receive a summary of the results

11. I agree for my anonymous data to be used in further research studies.

12. I give my consent to participate in the above study:

Participant Name.....  
.....



Salomons Centre for Applied Psychology

Participant Signature:.....  
.....

Date:.....

Researcher Name:.....

Researcher Signature.....

Date:.....

#### H. Participant screening form

##### **SCREENING FORM:**

##### ***Experiences of Black people with psychosis***

This questionnaire should take about 5-10 minutes to complete.

Thank you for your interest in taking part in this study about your experience of life after a diagnosis of psychosis.

This screening form will help us understand a little more about who is interested in taking part. After you have completed this form, you may be invited to take part in a one to one interview with the lead researcher, Keren Yeboah.

##### **Section A: Please provide your name and contact details:**

1. Full name \_\_\_\_\_
2. Date of Birth: \_\_\_\_\_
3. Contact number: \_\_\_\_\_
4. Contact email: \_\_\_\_\_
5. GP name: \_\_\_\_\_
6. GP address: \_\_\_\_\_

\*Please note that we will not be contacting your GP unless there is concern about your safety or the safety of someone else.

**Section B: Please tick which statements you think apply to your life right now:**

My life is better than it used to be  I am doing well at the moment

I am on my personal recovery journey

I am learning to manage my mental health

I am enjoying my life

None of these statements apply to my life

**Section B: Please tell us a little bit about who you are and your ethnic identities:**

1. *What is your gender?* Male  Female  non binary  prefer not to say

2. *Which country were you born in?*

---

3. *How long have you lived in the United Kingdom?*

---

4. Which ethnic group best describes you? (please tick one)

Black British-African  Black British-Caribbean  Afro

Latino-British

Black African  Black Caribbean  Afro Latino

Mixed- White &Black- African  Mixed- White &Black- Caribbean  Mixed-

Other

5. Which countries would you and your parents/carers say you were from?

---

**Section C: Please tell us a little bit about your mental health experience:**

1. *Do you have a mental health diagnosis?* Yes  No

If yes, please specify \_\_\_\_\_



2. Do you agree with this diagnosis? Yes  No
3. Were you given any other diagnoses in the past? Yes  No   
 If yes, please specify \_\_\_\_\_
4. Are you currently under a mental health community team? Yes  No   
 If no, how long has it been since you were discharged? \_\_\_\_\_

**Section D: Please us know if you are having any difficult thoughts at the moment:**

1. Have you recently been having thoughts of harming yourself? Yes  No
2. Have you recently been having thoughts of harming someone else? Yes  No

**Important** – If you have ticked “yes” to any of these questions, we will be required to inform your GP.

If you are worried about your ability to keep yourself or others safe, please consider taking any of the actions recommended below:

- ▶ Contact and inform your G.P.
- ▶ You can attend your local A & E department
- ▶ **Phone the Samaritans (a confidential phone based service):** 116 123 (24 hour helpline)
- ▶ **SLaM crisis line (Your local NHS crisis phone based service):** 0800 731 2864 (24 hour helpline)

I. Semi-structured interview questions

*This has been removed from the electronic copy*

J. Transcript excerpt with open code and memo:

*This has been removed from the electronic copy*

K. Code excerpt with memo excerpt

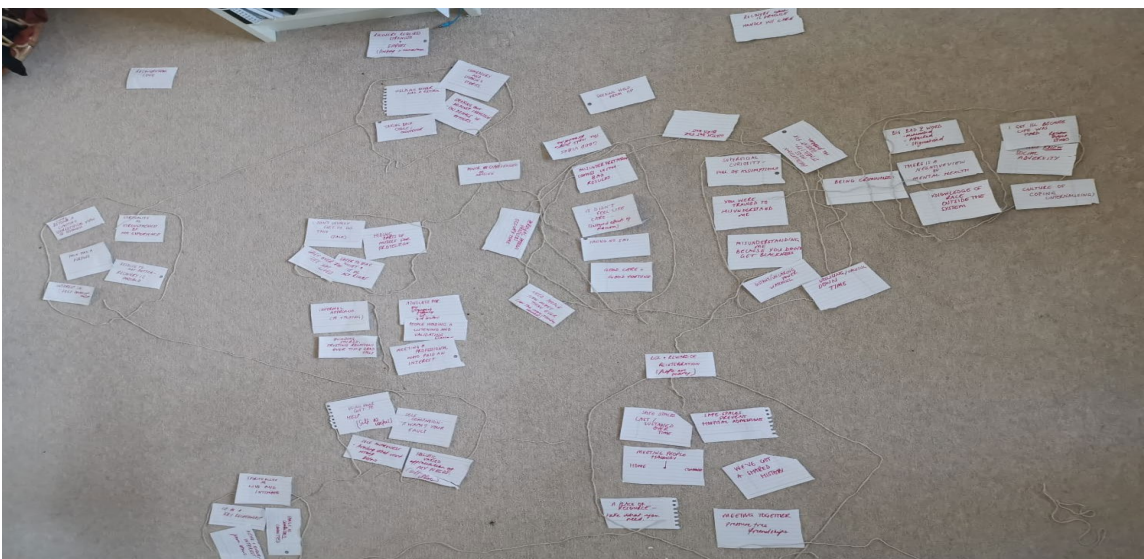
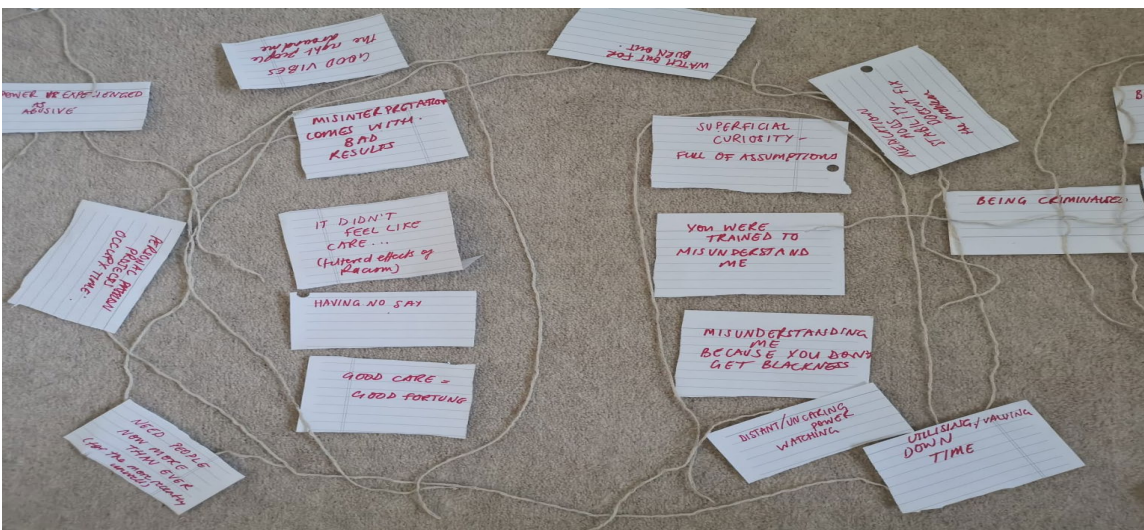
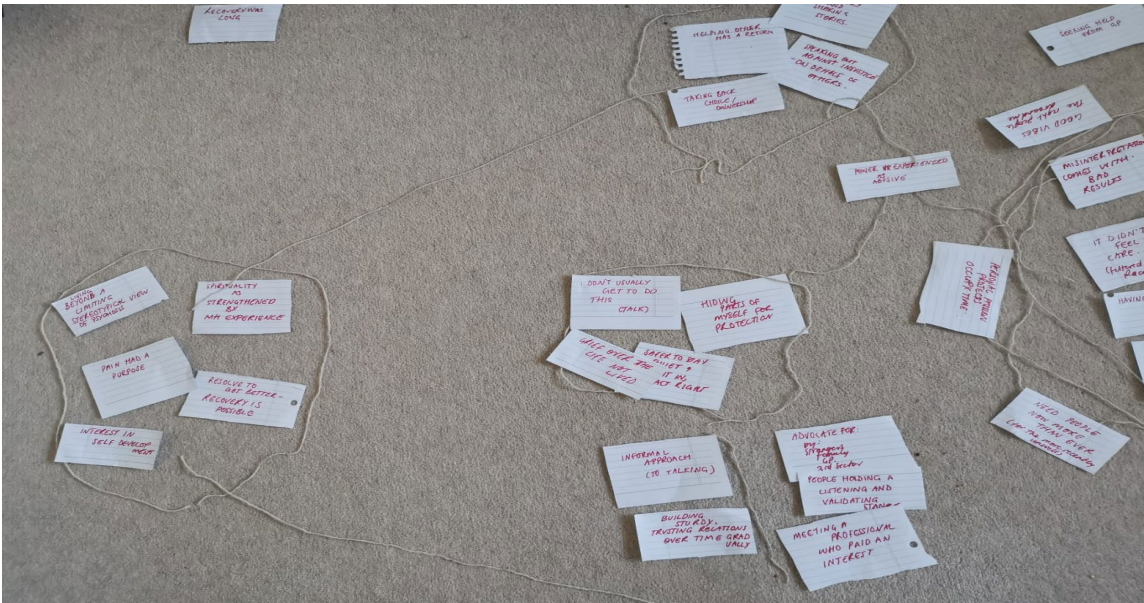
Transcript x	
Open Code	Memo
'It's not nice'	Previous 'not caring' stance as a cover up for

	hurt...?
Makes me want to fight for myself and what I've been though'	Hurt leading to angry motivation to win-transcripts x & x?
I'm not going to bow down to them because they've got degrees. – they haven't had to struggle with being unwell	Self-compassion
Even if I did nothing... I was strong... for 20 years	What a powerful comment
If he had given in to drugs he might understand why they look down on him	
But he has been struggling through for 20 years	

### L. Open code to focused code excerpt

AB												Being misinterpreted comes with risk of rehospitalisation											
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P							
1																							
2	Professionals Label service users for their own peace of mind.	Label service users for their own peace of mind.	Learning difficulty was missed and be	Police and psychic	People who don't understand think its			MH services are v	doctors and psychol	Professionals sho	Started talking about	God though she was aware they associate that with mental illness											
3		Being aggressive in	Doctors in charge of mental institutio					Just listening to your dr for 2 minutes			Singing associated with high												
4	Had to study for himself	Aggressive is to talk loud and ask, 'why are you doing that?'			Dominant idea in healthcare - They say smoking marjua				There is common	Held things in and didn't share as she felt they would not understand her	Get help to decide	Quiet associated with depressed											
5	first interaction with doctor when being assessed to leave hospital	This behaviour will be called abusive			Maybe other black doctors and social workers are not in			Stay close to the	Another black person would understand and would have similar experiences to you			Trusted her though she was a stranger											
6	Fear of being misinterpreted by professionals	Has been labelled abusive for talking loud sometimes.			In hospital, if a black patient was being disagreeable abo			Being over confid	Less people being critical, judgements			Did not trust staff on the ward											
7	Uncertain what is safe to say	Not visiting experienced as not caring			Thinks that black mental health staff were/are? Used like			You eventually lie	Judging what is speaking too much o			Maybe its just the way she practiced											
8	Being misinterpreted comes with risk of rehospitalisation				Doctors and psychiatrists use it to this end against black			They will always find out if they are taking your medicat				Nurse didn't believe that she had experienced the above. She called me a liar											
9	Openness came with a filter							They will not take you off if you are prone to relapse				the medics, the psychologists, they would come with their book theory.											
10	behaviour interpretations are subjective							Professionals are at a vantage				Everything she did would have been seen as failing											
11	In his day they gave out medication like smarties							Obey the obey your doctor's early instructions you know.				if they had sectioned her they would have finished her because they didn't understand											
12												if very unwell in an externalised way, they are involved. Otherwise, they not interested.											
13												Same way they treated her mother. Said no one can save you – mother lived for another 10 years											
14																							

# M. Initial thematic diagramming – Grouping focused codes into sub themes



## N. Sub- theme development

C78 Speaking about issues and injustices faced by self and others				
A	B	C	D	E
1	Grouped focussed codes	Corresponding tab	Description	
2	<b>OVERWHELMING CIRCUMSTANCES</b>			
3	<b>Personal context</b>			
4	Got ill because life was hard	Making sense	People made sense of their MH difficulties as a response to life difficulties	
5	Already experienced social adversity	Life as hard	People faced extremely difficult life circumstances prior to onset of MH difficulties	
6	Culture of coping (internalising)	Culture of coping	Managing and coping with all life's challenges is a culture within Black families and wider communities	
7				
8	<b>Social discourses</b>			
9	Negative view of mental health	others' perceptions	Noticed others stereotypical negative expectations of mental health	
10	Racism exists	societal injustice	Knowledge and awareness of historic, current and experienced examples of racism	
11	Psychosis as bad	diagnosis relationship/ ot	People received direct and indirect messages that psychosis was bad through	
12				
13	<b>Being criminalised</b>	societal injustice	Experienced as systemic criminalisation of Black individuals by the Police in the community as well as upon entry to the MH system	
14				
15	<b>MENTAL HEALTH WARDS</b>			
16	<b>Attitudes to care within hospital</b>			
17	Superficial curiosity	really heard?	Assumption, rather than genuine curiosity led assessment	
18	You were trained to misinterpret me	Trust of professionals	Idea that certain behaviours and responses have been pathologised at a system level	
19	Cultural difference contributes to misinterpretation	Trust of professionals	A lack of exposure to and/or understanding of Black culture can also lead to pathologising normal responses	
20	A distant /uncaring power		An experience of omniscient, distant power, rather than warm, interested care	
21				
22	<b>Care experience within hospital</b>			
23	Misinterpretation impacts care	trust of professionals	Being misunderstood has led to more coercive and restrictive care	
24	It didn't feel like care	societal injustice	Dissonance between personal definition and experience of care	
25	Having no say	power battles	Decision making and autonomy was suspended	
26				
27	<b>Wider mental health system</b>			
28	Sign posting from GP	help seeking	Many participants accessed the mental health system via their GP. Not everyone went to hospital.	
29	Good care as good fortune		Where people reported good experiences of care, this was believed to be good fortune in the context of an flawed system	
30				
31	<b>Engaging and re engaging strategies to maintain of wellbeing</b>			
32	Utilising down time	practical learning	Taking intentional, planned periods of rest and downtime	
33	Medication adds stability	relationship with drugs	Medication was experienced as a key stabilising factor for many. It was considered but a part of what it takes to be well	
34	Needing people now more than ever	relationships	Social interaction and/or support was felt to be particularly necessary at time when more vulnerable to relapse	
35	Personal passion project to fill time	helping others	Engaging , time limited projects was helped people occupy their time in meaningful ways	
36	Watch out for burn out	helping others	Doing too much led to relapse for some participants. Others highlighted the importance of coping and vigilance to manage this	

Theme development power battles ward experience identity communication culture internalising help seeking stories of others transferr

O. Thematic diagramming – Establishing links

