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Institute of Health & Wellbeing

A meta-synthesis of service user perspectives of shared decision-making and a qualitative investigation of lived experiences of fear of recurrence in relation to psychosis

Lidia Brookmann, MA (Hons), MSc

Submitted in partial fulfilment of the requirements for the
degree of

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Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

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Chapter One: Systematic Review

Service user perspectives on shared decision-making in treatment of psychosis and other severe mental health problems: a systematic review and meta-synthesis

Chapter word count (including figures, tables, references): 8,655

Prepared in accordance with the guidelines for submission to the Journal of Mental Health (see Appendix 1.1, p.95)

Abstract

Background

Mental health legislation has been under review in England and Wales which highlighted the need for improving patient participation in treatment decisions. Review of the legislation is underway in Scotland and patient perspectives on their experiences of care and treatment are vital in informing this. This study aimed to synthesise service users' experiences of shared decision-making.

Method

A systematic search of PsycINFO, EMBASE, Medline and CINAHL databases was conducted for qualitative research on service user experiences of shared decision-making in the context of psychosis and other severe mental health problems. Consolidated Criteria for Reporting Qualitative Research was used to assess transparency of reporting of studies. The results of included studies were synthesised using Thematic Analysis.

Results

Twelve relevant articles were identified. Five major themes were constructed from the data which indicated that trusting therapeutic relationships, additional support and information-sharing could enhance participation in decision-making. Factors including disempowering interactions, unmet information needs, participants' poorer

mental health, and practical issues such as time constraints created barriers to participation.

Conclusion

Service users can experience barriers to inclusion in decision-making related to their care and treatment. Including service users in design of services, policy and research may embed their important perspectives and instil broader change.

Keywords: psychosis, mental health, shared decision-making, service user perspectives

Introduction

Psychosis is characterised by experiences of hallucinations (e.g. hearing voices) and delusional beliefs (e.g. paranoia). Individuals can also experience difficulties in thinking and concentration alongside feelings of apathy, withdrawal and lack of motivation (Cooke, 2017) which can significantly impact functioning and wellbeing. In the UK, prevalence varies according to age, gender, ethnicity, population density and social deprivation (Department of Health, 2016). The onset of psychosis occurs commonly in late adolescence and early adulthood and is more common in men, Black, Asian and Minority Ethnic (BAME) populations, and those living in densely populated or deprived areas (Department of Health, 2016).

Concerns related to legislation and compulsory treatment for people with severe mental health problems led to independent review of the Mental Health Act (2007) for England and Wales, and a review of the Mental Health Act (2015) for Scotland. The published review for England and Wales recommended legislative reform and the need for improved patient participation in decision-making to redress power imbalances (UK Government, 2018). In Scotland, the review is underway to embed the principles of the United Nations' Convention on the Rights of People with Disabilities (CRPD) in legislation, to better protect the rights of people with disabilities including mental health problems (Scottish Government, 2019).

Promotion of shared decision-making has been advocated in recent years (Coulter & Collins, 2011). Shared Decision Making (SDM), defined as a process occurring between a healthcare professional and service user involving collaboration,

information-exchange, and agreement on treatment decisions (Charles et al., 1997), sits between professional-led models of care and the informed-choice model. The former involves professionals' expertise to determine the most effective treatment, whilst the latter provides the service user with information so that they may make autonomous treatment decisions (Hamann et al., 2003). Research on SDM in the context of severe mental health problems has developed more recently (Patel et al., 2008; Duncan et al., 2010).

Severe mental health problems typically include psychosis (e.g. schizophrenia); bipolar disorder; and moderate to severe depression (WHO, 2017). SDM may be relevant for people experiencing such problems due to the nature of symptoms and treatment. Psychiatric treatment can be distressing, and service users may be vulnerable to coercion (Berry et al., 2013; Akther et al., 2019). Challenges to service user involvement have also been related to mental capacity (Chong et al., 2013). Research indicated that doubt on the decision-making capacity of service users affected health professionals' approach to service user involvement (Seale et al., 2006; Hamann et al., 2009). However, evidence has found that service users are capable and wish to be involved in decision-making (Hamann et al., 2005; Hamann et al., 2006; Adams et al., 2007).

Qualitative and mixed method reviews have evaluated literature regarding SDM in mental healthcare. Pedley et al. (2018) conducted a multi-perspective meta-synthesis of barriers and facilitators to patient participation in anti-psychotic prescribing. Key findings included the influence of service users' desire and expectation for involvement, service users' capability, and information-sharing on participation.

Clinicians emphasised organisational barriers whereas service users emphasised consultation factors. The importance of clinicians conveying positive regard for service users and facilitating a dialogue was indicated. Kaminskiy et al. (2017) explored stakeholder attitudes toward SDM related to general mental health including quantitative, qualitative and mixed method approaches. SDM was valued; however, a gap was reported between preferences and implementation. Health professionals endorsed SDM but had ambivalent attitudes towards user participation. Stakeholders, particularly clinicians, viewed SDM as context-dependent, influenced by service users' ability to participate. Service users desired information about treatments and highlighted the importance of positive relationships.

Lastly, Huang et al. (2019) investigated perspectives of SDM in relation to severe mental health problems, integrating data from stakeholders. Findings highlighted dynamic preferences for SDM; positive attitudes towards family involvement; need for inter-professional collaboration; importance of therapeutic relationships and issues in systems (e.g. time constraints). Barriers and facilitators included service user factors such as decision-making ability and motivation alongside health professional factors such as attitudes and interpersonal skills.

These reviews generated interesting findings, however, there are limitations.

Kaminskiy et al. (2017) investigated SDM related to general mental health which may be experienced differently to those with severe mental health problems given the challenges discussed. Additionally, Pedley et al. (2018) narrowed their review to experiences of anti-psychotic prescribing. Reviews included multiple stakeholder perspectives, and Huang et al. (2019) integrated these. Stakeholder perspectives can

differ and integration risks limiting the analysis of more nuanced perspectives. This is important given that people with severe mental health problems may be vulnerable to epistemic and testimonial injustice (Crichton et al., 2017; Kurs & Grinshpoon, 2018). Such injustices pertain to the discrediting of an individual's knowledge or testimony, often due to prejudices (Fricker, 2007). Therefore, it is vital to explore solely the perspectives of service users to provide a platform for such voices and it is a pertinent time to do so considering the current legislative context.

Review Aims

The aims of this meta-synthesis are:

- a) To understand the experiences and perspectives of service users with psychosis and other severe mental health problems in relation to SDM and the clinical implications.
- b) To critically appraise the included studies, highlighting the methodological strengths and weaknesses of the literature.

Method

Search strategy

Systematic searches of the literature were carried out on 10th September 2019.

Relevant studies were located within the electronic databases: PsycINFO, EMBASE, Medline and CINAHL. No time period was specified for the review.

Search terms

Scoping searches were completed to develop search terms which were informed by keywords of relevant articles (Stomski & Morrison, 2017; Stovell et al., 2016). A librarian from the University of Glasgow reviewed the search terms for sensitivity and specificity.

Databases were searched using the below terms with related synonyms:

1. “Psychosis” or “bipolar disorder” or “depression” or “severe mental illness”
2. “Decision-making”
3. “Qualitative methodology”

Search terms were combined within each case with the Boolean operator “OR” and all cases were combined with “AND.” Corresponding MeSH subject headings were applied where possible (see Appendix 1.2 for search strategy examples, p.97).

Inclusion and exclusion criteria

Articles were selected based on the following criteria: (i) studies related to service user experiences or perspectives on SDM, (ii) over 50% participants with diagnoses or symptoms related to psychosis or other severe mental health problems (depression and/or bipolar disorder), and (iii) participants were adults aged over 16. In studies that explored multiple perspectives, (iv) the findings from service users were clearly identified and were at least equally weighted with other perspectives. Studies were included if (v) qualitative methodology was utilised, (vi) quotes illustrated themes, and (vii) articles were written in English.

Studies were excluded based on the following: (i) studies that predominantly explored family or staff perspectives, (ii) studies that predominantly explored evaluations of SDM interventions, (iii) children and/or adolescent participants, (iv) quantitative or mixed method methodology, and (v) review articles or conference abstracts.

Critical appraisal

The Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al., 2007) is a 32-item checklist to assess transparency of reporting in qualitative studies which aided the critical appraisal of included studies (see Appendix 1.3, p.98). To reduce risk of bias, a subset of 3 articles were analysed by an independent rater. Cohen's kappa inter-rater reliability coefficient was calculated which indicated substantial agreement between raters ($k = 0.8$).

Method of synthesis

There is debate with regards to methods of qualitative synthesis. Barnett-Page and Thomas (2009) identified nine approaches to synthesis underpinned by various epistemological stances. Thematic analysis was selected which is an accessible approach which entails the identification of overarching themes within the data (Braun & Clarke, 2006). The analysis was informed by guidance from Braun and Clarke (2006) displayed in Table 1. An inductive approach was utilised to generate themes closely linked to the dataset. N-Vivo software was used to complete line-by-line coding of the results section of studies, completed independently (see Appendix 1.4 for coding example, p.100).

Table 1. Stages of thematic analysis, adapted from Braun & Clarke (2006)

Stage	Process
1. Familiarise self with the data	Read and re-read the data, note down initial ideas
2. Develop initial codes	Code aspects of the data in a systematic way, identifying data relevant to each code
3. Search for themes	Collate codes into potential themes
4. Review themes	Check that themes fit with coded extracts and entire data set
5. Name themes	Analysis to refine specifics of each theme
6. Produce the report	Final analysis and selection of extract examples

Results

Search outcome

A total of 9846 articles were identified through systematic searching. Following removal of duplicates, titles and abstracts of 5467 articles were screened and 37 full-text articles were reviewed for eligibility, resulting in 9 initial articles. Forward citation searches of included articles revealed no further articles. Reference lists of related reviews were searched (Huang et al., 2019; Kaminskiy et al., 2017; Pedley et al., 2018) resulting in 3 additional articles. The outcome of the selection process is displayed in Figure 1. Table 2 displays a summary of included articles.

Characteristics of included studies

This meta-synthesis included 12 studies with data from 222 participants (female=126, male=96). Ages ranged between 18-70 years (mean=41.5). Participants were diagnosed with psychosis/schizophrenia/schizoaffective disorder, bipolar disorder, depression, mood/affective disorder, personality disorder, substance misuse disorder and anxiety disorder. Recruitment settings included outpatient GP clinics, community mental health services, early intervention in psychosis services, clinical services specialising in mood and bipolar disorders, peer-organised club houses and drop-in centres, peer-run recovery-oriented community agencies, voluntary mental health organisations, and transitional care clinics. Inpatient settings included forensic and rehabilitation wards and psychiatric hospitals. Studies were conducted in USA (n=4), Germany (n=2), UK (n=3), Sweden (n=1), Norway (n=1) and Australia (n=1).

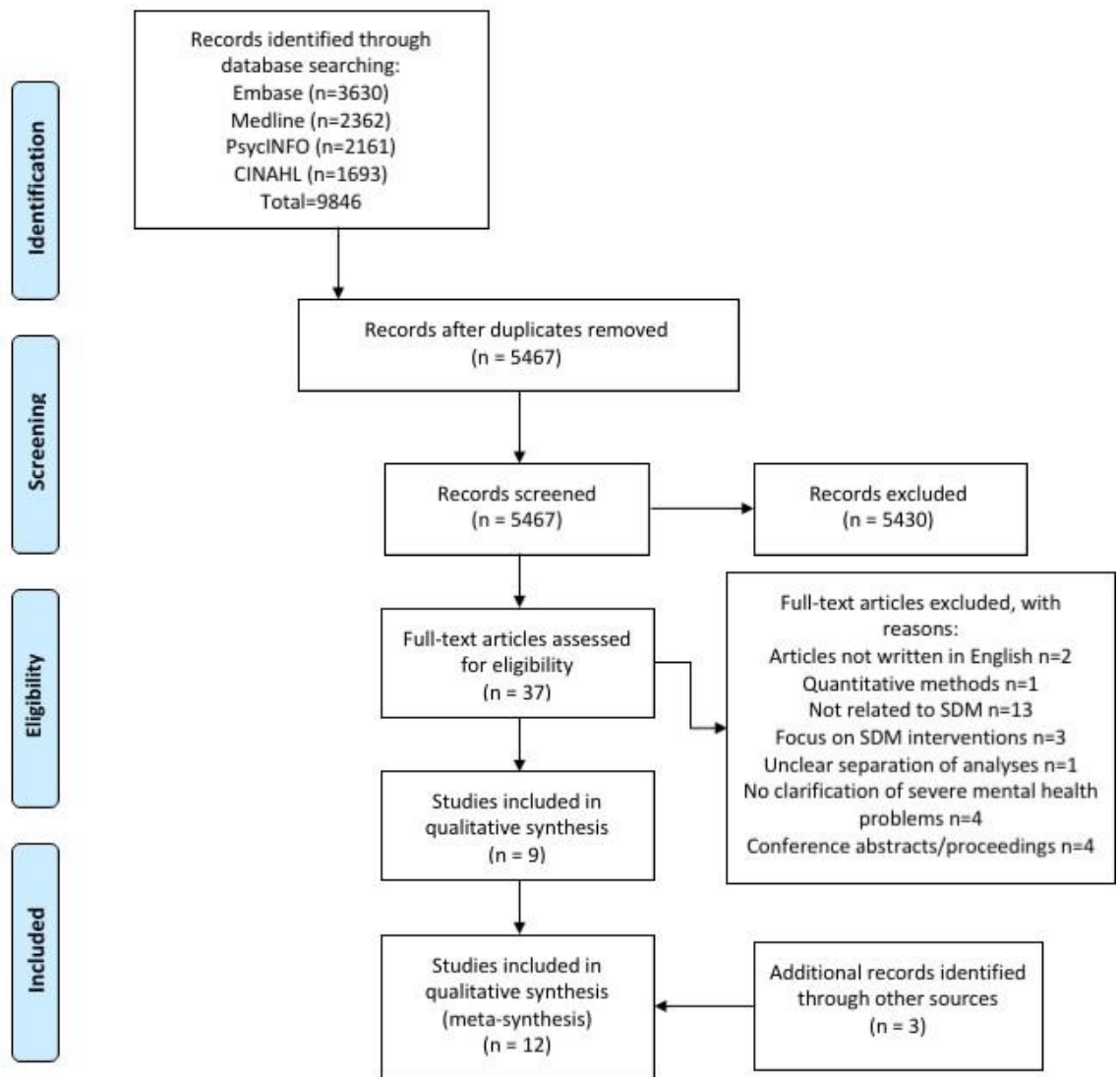


Figure 1. PRISMA Flow Diagram

Table 2. Summary of included studies

Author, Year, Country	Aims	Sample Characteristics	Data Collection and Method of Analysis	Summary of Themes and Subthemes
1. Dahlqvist-Jonsson et al. (2015). Sweden.	To explore service users' experiences of participation in decisions related to mental health services and the types of support that promote participation in decisions.	n=20 Age range=26-64 Mean=52 Female=14(70%), Male=6(30%) Ethnicity not reported Self-reported diagnoses: Psychosis/schizophrenia=3(15%) Bipolar disorder=4(20%) Depression=4(20%) Else or several (ADHD, chronic fatigue syndrome, eating disorder, personality disorder, PTSD)=6(30%) Missing data=3(15%)	Focus groups and individual interviews Constructivist grounded theory	Struggling to be seen as a competent and equal person <ul style="list-style-type: none"> - Being the underdog - Being controlled - Being omitted Internal conditions in the striving to promote SDM <ul style="list-style-type: none"> - Feeling respected as a person - Feeling confidence in one's ability External conditions in promoting SDM <ul style="list-style-type: none"> - Having personal support - Having access to knowledge - Having a dialogue - Having clarity about responsibilities
2. Delman et al. (2015). USA.	To explore the facilitators and barriers to the active participation of young adults in making	n=24 Age range=19-30 Mean=24 Female=16(67%), Male=8(33%) Sample primarily White	Interviews Inductive analytic approach	Facilitators: Psychiatrist openness/interest in client's perspective Support of mental health providers Personal growth Client self-confidence

Author, Year, Country	Aims	Sample Characteristics	Data Collection and Method of Analysis	Summary of Themes and Subthemes
	medication decisions with their psychiatrists.	<p>All participants were hospitalised at least twice during the past 10 years. All participants diagnosed with severe mental illness.</p> <p>Diagnoses: Schizophrenia=2(8%) Schizoaffective disorder=8(33%) Bipolar=9(38%) Depression=3(13%) Personality disorder=2(8%)</p>		<p>Psychiatrist availability</p> <p>Barriers: Psychiatrist resistance Lack of time for meetings Limited client self-efficacy</p>
3. Fisher et al. (2018). Australia.	To explore service user and family perspectives on decision-making in treatment of bipolar disorder-II, unmet need about information and decision-support, and barriers and facilitators to decision-making.	<p>n=28 service users Age range not reported Mean age=42 years Female=19(67.9%), Male=9(32.1%) Ethnicity not reported</p> <p>All participants were diagnosed with bipolar disorder-II.</p>	<p>Interviews</p> <p>Thematic analysis</p>	<p>Attitudes and response to diagnosis and treatment</p> <p>Influences on decision-making</p> <p>The nature and flow of decision-making</p> <p>Decision support and challenges</p>
4. Giacco et al. (2018). UK.	To investigate the barriers and facilitators to involvement in shared decision-making with service users under	<p>n=24 service users</p> <p>Focus groups: n=18 Age range not reported</p>	<p>Focus groups and individual interviews (with non-English-</p>	<p>Barriers: Communication difficulties Noisy and busy ward environment</p> <p>Facilitators:</p>

Author, Year, Country	Aims	Sample Characteristics	Data Collection and Method of Analysis	Summary of Themes and Subthemes
	involuntary psychiatric hospital treatment.	<p>Mean age=38.5 Female=10(55.6%) Male=8(44.4%) Ethnicity not reported</p> <p>Diagnoses: Psychotic disorder=9(50%) Mood disorder=7(38.9%) Substance misuse disorder=2(11.1%)</p> <p>Interviews: n=6 Age range not reported Mean age=37.7 Female=4(66.7%) Male=2(33.3%) Ethnicity not reported</p> <p>Diagnoses: Psychotic disorder=3(50%) Mood disorder=2(33.4%) Substance misuse disorder=1(16.7%)</p>	<p>speaking participants)</p> <p>Thematic analysis</p>	<p>Involvement in decision-making as early as possible Involving carers Positive relationships with staff</p>

Author, Year, Country	Aims	Sample Characteristics	Data Collection and Method of Analysis	Summary of Themes and Subthemes
5. Hamann et al. (2016). Germany.	To explore service users' and psychiatrists' perspectives on how service users may facilitate shared decision-making in acute mental health settings.	n=16 service users Age range not reported Mean age=41.8 Female=8(50%) Male=8(50%) Ethnicity not reported Diagnoses: Schizophrenia=7(43.8%) Bipolar disorder=3(18.8%) Major depression=6(37.5%)	Focus groups Content analysis	Honesty and openness Trust and patience Respect and politeness Informing the doctor, giving feedback Engagement and active participation during the consultation Gathering information and preparing for the consultation Implementation and transfer
6. Lacasse et al. (2016). USA.	To explore experiences of psychiatric medication from the perspective of clients diagnosed with severe mental illnesses, who have reached functional recovery.	n=16 Age not reported Female=12(75%), Male=4(25%) Sample primarily European American=11(69%) Participants diagnosed with severe mental illnesses who had reached functional recovery. All participants had a history of mood disorder. Other diagnoses: Anxiety disorders=8(50%) Psychotic disorders=7(44%)	Interviews Thematic analysis	Primacy of medication Informed consent Self-determination Clinical engagement

Author, Year, Country	Aims	Sample Characteristics	Data Collection and Method of Analysis	Summary of Themes and Subthemes
7. Lorem et al. (2014). Norway.	To explore mental health service users' perspectives on medication and user involvement.	<p>Personality disorders=8(50%)</p> <p>n=9 Age range=20s to 50s Female=4(44.4%), Male=5(55.6%) Ethnicity not reported</p> <p>All participants diagnosed with a psychotic disorder. All participants had a hospital admission within the previous 8 months.</p>	<p>Interviews</p> <p>Narrative thematic analysis</p>	<p>Information and advice</p> <p>Patient perspectives of drug treatment</p> <p>Need for dialogue</p>
8. Simon et al. (2006). Germany.	To investigate depressed patients' perceptions of the treatment decision-making process with GPs, to inform shared decision-making interventions.	<p>n=40 Age range=18-70 Mean=43.2 Female=24(60%) Male=16(40%) Ethnicity not reported</p> <p>All participants were diagnosed with depression. Depression severity: Non-clinical=4 (10%) Mild=9 (22.5%) Moderate=9 (22.5%)</p>	<p>Interviews</p> <p>Binary content coding analysis</p>	<p>First contact for mental health concerns</p> <p>Sources of information about illness and treatment options</p> <p>Topics of recent treatment decisions</p> <p>Attributes of the decision-making process</p> <p>Future expectations</p>

Author, Year, Country	Aims	Sample Characteristics	Data Collection and Method of Analysis	Summary of Themes and Subthemes
		Severe=18 (45%)		
9. Stewart, Anthony & Chesson (2010). UK.	To investigate the feasibility of undertaking qualitative research regarding views and experiences of medication management in inpatient settings.	n=12 service users Age range=27-70 Male=12 Ethnicity not reported All participants were diagnosed with schizophrenia in forensic and rehabilitation inpatient settings.	Interviews Grounded theory	Patient knowledge and awareness of medications Patient choice and responsibility for medication management
10. Stovell et al. (2016). UK.	To explore service users' experiences of decision-making regarding treatment for psychosis.	n=7 Age range=38-58 Mean=49 Female=3(42.9%), Male=4(57.1%) All participants were White British All participants had experienced psychosis.	Interviews Interpretative phenomenological analysis	A need to feel listened to Psychotic experiences, treatment and stigma Communication and support Differing conceptions of recovery
11. Velligan et al. (2016). USA.	To investigate the perspectives of service users transitioning from hospital to community	n=10 Age not reported. Female=5(50%), Male=5(50%) Ethnicity:	Focus groups Qualitative	Attitudes of treatment providers towards patients Access to mental health treatment Decision-making in mental health care

Author, Year, Country	Aims	Sample Characteristics	Data Collection and Method of Analysis	Summary of Themes and Subthemes
	settings on their role in treatment decisions.	White Hispanic=5 White non-Hispanic=3 African-American=2 Diagnoses: Schizophrenia/schizoaffective disorders=3(30%) Affective disorders=5(50%) Anxiety disorders=2(20%)		Experiences with psychosocial treatments
12. Woltmann & Whitley (2010). USA.	To investigate service user decision-making preferences and understanding of construction of decisions in community mental health.	n=16 Age range=33-58 Mean=45 Female=7(43.8%), Male=9(56.2%) Ethnicity: White=6 African-American=7 Non-African-American Latino=3 Diagnoses: Schizophrenia spectrum=8(50%) Bipolar disorder=4 (25%) Depression=2 (12.5%) Other (PTSD or other anxiety disorders) =2 (12.5%)	Interviews Cross-case thematic analysis	Consumer decision making preferences Participants' views of the case manager role in decision making

Transparency of studies

A summary of the transparency of reporting of included studies can be found in Appendix 1.5 (p.101). Areas of strength included: sampling; sample size; clarity of major themes; consistency between the data and findings; the number of data coders; and derivation of themes. Weaknesses in reporting included: participant knowledge of the interviewer; evidence of interviewer characteristics and bias; clarity of minor themes; transcripts being returned for review and comment by participants; and member checking.

The transparency of reporting aided the analysis of included studies in this meta-synthesis. Coding commenced with articles of the strongest transparency.

Meta-synthesis

The thematic analysis led to the construction of five major themes related to participants' experiences and perspectives of shared decision-making.

Major themes

1. Communication and support
2. Attitudes and approaches to shared decision-making
3. Being informed
4. Clinical factors
5. Practical and systemic factors

The coverage of themes across included studies can be found in Appendix 1.6 (p.102). The themes are discussed in detail below alongside extracts from studies for illustration.

Quotations with the symbols // denote a two-second-long pause.

1. Communication and support

This theme comprised two subthemes: a) The therapeutic relationship and b) The role of other supports.

The therapeutic relationship

Most studies referenced the importance of the patient-clinician relationship. Participants valued a trusting relationship based on understanding, listening, respect, empathy and hope, laying the foundations for SDM.

...what a difference, what a difference. He used to consult about me medication ...ask me how I'd found it, and he, he seemed as though he genuinely cared and was interested...(Stovell et al., 2016, Participant, p.315).

These qualities were associated with greater satisfaction, confidence and better communication (Fisher et al., 2018). Participants attributed agreement in decision-making to having trust and respect within long-standing clinical relationships (Woltmann & Whitley, 2010). Lack of trust could lead to participants withholding information which limited collaborative decision-making (Lacasse et al., 2016; Woltmann & Whitley, 2010).

A mutual understanding of participants' needs was viewed as a pre-requisite to SDM (Hamann et al., 2016; Dahlqvist-Jonsson et al., 2015). However, some participants believed that more thorough assessments were required so clinicians were better attuned to their needs (Velligan et al., 2016; Fisher et al., 2018). Participants highlighted their own role in facilitating SDM including being polite, respectful and speaking openly about their experiences (Hamann et al., 2016).

Participants also described experiences of feeling judged, being disrespected and not being listened to (Dahlqvist-Jonsson et al., 2015; Velligan et al., 2016; Giacco et al., 2018; Delman et al., 2015; Fisher et al., 2018; Lacasse et al., 2016; Lorem et al., 2014; Stovell et al., 2016) creating a barrier to SDM. These interactions had a disempowering and disruptive impact on care, potentially reinforcing negative stereotypes and stigma, as seen below.

“This medicine—I gained eighty pounds—I am enormous!” And he said, “Do you want to be fat, or do you want to be crazy?” . . . And I thought, “I need a different doctor.” You know, I don’t know. What I do think is that a lot of doctors don’t listen (Lacasse et al., 2016, Participant, p.75).

Alternatively, a strengths-based approach in which clinicians recognised participants' skills and abilities could foster motivation and confidence in decision-making (Dahlqvist-Jonsson et al., 2015). Participants spoke positively of clinicians instilling hope (Stovell et al., 2016) which was protective for participants in their recovery. The effects of an absence of this quality were apparent and acute leading to distress and hopelessness (Lacasse et al., 2016; Stovell et al., 2016).

...when you're crumbling //...you don't need to receive the message that it's always going to be the status quo, where you are now...everybody's got the ability to get better, really, and it would be nice to be told that...(Stovell et al., 2016, Participant, p.320).

The role of other supports

Studies explored the influence of other supports on SDM (Simon et al., 2006; Delman et al., 2015; Dahlqvist-Jonsson et al., 2015; Giacco et al., 2018; Fisher et al., 2018; Hamann et al., 2016). Supportive others included partners, relatives, friends and those involved in care, such as therapists, case managers and mental health support staff. Support facilitated SDM (Hamann et al., 2016) which was more common when family attended appointments (Fisher et al., 2018). The benefits of involving others included: increased carer understanding of mental health problems; comfort and reassurance; and accurate information-sharing at times when this was challenging, for example, hospital admission (Simon et al., 2006; Fisher et al., 2018; Giacco et al., 2018).

They know you inside and out, they know how to answer those questions when you are unwell (Giacco et al., 2018, Participant, p.116).

Involvement of others could support conversations outwith consultations as part of the ongoing decision-making process (Fisher et al., 2018; Simon et al., 2006). In situations where decision-making lasted considerable length of time, family and friends often provided a pivotal role in making a final decision (Simon et al., 2006). However, barriers to family involvement could occur due to insufficient knowledge and the participants' perceived

burden and worry of involvement for family members (Fisher et al., 2018; Giacco et al., 2018).

In a study of young adults, most received support services and had contact with case managers and/or support staff (Delman et al., 2015). They provided encouragement, guidance in preparing for consultations and took on an advocacy role where required, supporting participants' confidence and ability to participate in decision-making.

The [group home staff] encouraged me to write down what I wanted to say, or the questions I had. That way I didn't have to verbalize it. Having that paper in front of me, I was able to bring up medication problems right when we first sat down.
(Delman et al., 2015, Participant, p.246).

This could be particularly beneficial when participants had difficulty expressing their opinions to professionals due to prior experiences of feeling dismissed. Some participants expressed unmet needs for the involvement of a “supportive person” (Dahlqvist-Jonsson et al., 2015, p.693) or advocate, who could facilitate communication, provide guidance and safeguard their rights.

...we who have our disabilities...you can get caught up in a thought or not hear what is being said when you are at the meeting and you can perceive things differently. So therefore it is always good to have someone with you, because then it's four ears and four eyes that have both seen and heard what they talked about (Dahlqvist-Jonsson et al., 2015, Participant, p.694).

2. Attitudes and approaches to shared decision-making

Attitudes and approaches towards patient participation in SDM varied, for both participants' and their treating clinicians' styles of decision-making. Regarding decision-making preferences, participants desired some degree of autonomy (Stovell et al., 2016) or endorsed shared or autonomous decision-making styles (Woltmann & Whitley, 2010). Participants also saw themselves as the “*ultimate decision-maker*” (Fisher et al., 2018, p.72), informed by both their own and the clinicians' knowledge. When deferring decision-making when unwell, many participants still wished to be involved in some way (Fisher et al., 2018). However, in one hospital setting most participants were “*willing to leave it to the doctor*” (Stewart et al., 2010, p.215) viewing medication decisions as the doctor's role.

Preferences for involvement were not necessarily reflected in practice. On the one hand, those who were encouraged to participate, whose clinicians endorsed an SDM approach, were more engaged in decision-making (Delman et al., 2015). Indeed, clinicians' trust in participants' ability to participate, and their encouragement of a dialogue fostered confidence, self-efficacy and enabled participation (Dahlqvist-Jonsson et al., 2015; Delman et al., 2015). Even when opinions differed, when clinicians respected and promoted participants' preferences and goals, this was empowering (Delman et al., 2015; Dahlqvist-Jonsson et al., 2015).

When I get to be involved in discussions and . . . we may have different opinions but we always come to a decision if there is something that needs to be done or if

something needs to be fixed . . . then we will agree together which is good (Dahlqvist-Jonsson et al., 2015, Participant, p.694).

On the other hand, resistance, disinterest and exclusion of participants' perspectives could lead to feelings of incompetence and lowered confidence (Delman et al., 2015; Dahlqvist-Jonsson et al., 2015). During hospital admission, some participants reported that their opinions had little value or were ignored (Lorem et al., 2014).

The first thing he did was change my drugs. I hadn't even spoken to him before he changed my drugs. And it felt like I was . . . that the decisions were being made over my head. [...] that I felt that nobody was taking any notice of me (Lorem et al., 2014, Participant, p.353).

For some participants there was a “struggle to be seen as a competent and equal person” (Dahlqvist-Jonsson et al., 2015, p.692). Other participants described clinicians making negative judgments about their choices and capacity to engage in decision-making (Stovell et al., 2016), with one participant implying that the clinician had assumed incapacity due to psychosis.

I think on first meeting someone, erm, a more thorough investigation should be done into what their belief system is and whether or not they // they are coherent. I was coherent, I was just, erm, psychotic at the same time as well (Stovell et al., 2016, Participant, p.317).

Fisher et al. (2018) reported that treatment discussions involved clinicians' limited discussion of participants' preferences, particularly when they were experiencing symptoms. Service users' taking responsibility for expressing their preferences could facilitate SDM (Hamann et al., 2016). However, this may be more challenging for people with severe mental health problems who have had disempowering experiences of services. Disregard for participants' opinions included forms of coercion, on a background of inherent power imbalances in treatment settings.

The message is implicit—Don't ask. Don't be non-compliant. Don't show evidence that you're not gonna take the meds that they're telling you to take, because there could be consequences (Lacasse et al., 2016, Participant, p.73).

Participants described lacking influence, being “overridden”, “completely at your [psychiatrists'] mercy” and being “dictated to” (Stovell et al., 2016, p.318) and some described feeling too anxious or fearful to raise questions about treatments (Lorem et al., 2014; Stovell et al., 2016; Lacasse et al., 2016). Participants described difficulties in expressing preferences inconsistent to clinicians in fear of being dismissed (Delman et al., 2015) or regarded as non-compliant (Lacasse et al., 2016), sometimes leading to compliance and passivity.

3. Being informed

Most studies discussed the accessibility of information related to treatment decision-making. There was variation across participants' experiences, for example, some reported feeling

content with the information received and others did not wish for further information (Stewart et al., 2010) highlighting the importance of understanding individual preferences.

I feel very comfortable with the medication I'm taking, I feel very educated about the medication I'm taking, I'm very aware of the side effects there are, and should I have any, I would do something about it (Lacasse et al, 2016, Participant, p.71).

Many participants described receiving incomplete information regarding diagnoses, treatment options, care plans and medical information (e.g. treatment side effects) limiting participants' ability to make an informed decision (Lacasse et al., 2016; Fisher et al., 2018; Simon et al., 2006; Lorem et al., 2014; Dahlqvist-Jonsson et al., 2015; Velligan et al., 2016; Stewart et al., 2010).

...what I can sense when talking medicine is that you may only know what the idea is and how it should work, but then nothing is said about side effects (Dahlqvist-Jonsson et al., 2015, Participant, p.692).

This could provoke anxiety and ambivalence due to not being informed about costs and benefits of treatment (Simon et al., 2006) with some describing that costs were minimised, and benefits emphasised (Lacasse et al., 2016). Lorem et al. (2014) explored experiences of recent hospital admission and found that many participants had minimal information eliciting frustration.

I think it's a lot better [...] that they explain things exactly the way they are. I believe that things aren't explained to spare or protect me (Lorem et al., 2014, Participant,

p.351).

Participants entering adult mental health services, who did not have decision-making input as adolescents, described not having the knowledge that they could have an active role in SDM (Delman et al., 2015). Insufficient information and knowledge could be disempowering, sometimes leading to compliance with clinicians' decisions (Dahlqvist-Jonsson et al., 2015).

Information preferences included both verbal and written information (Dahlqvist-Jonsson et al., 2015; Fisher et al., 2018) presented in accessible ways (Velligan et al., 2016) as some participants reported difficulty understanding complex information leaflets (Stewart et al., 2010; Lacasse et al., 2016). Some participants reported "*being an expert on one's disease and symptoms*" (Hamann et al., 2016, Participant, p.620) facilitated SDM. Some participants took responsibility to gather information including discussions with patients, using the internet or books, and learning from others' lived experiences (Stewart et al., 2010; Simon et al., 2006; Delman et al., 2015; Fisher et al., 2018) which empowered individuals to be active in decision-making (Delman et al., 2015; Fisher et al., 2018).

4. Clinical factors

Studies referenced the impact of clinical factors affecting participation in SDM including mental health and its effects. Severity of symptoms, insight, distress, and medication side effects influenced participants' ability to engage in SDM (Simon et al., 2006; Stovell et al., 2016; Stewart et al., 2010; Dahlqvist-Jonsson et al., 2015; Hamann et al., 2016; Fisher et al., 2018).

But it can tranquilise you too much. And, // that made me feel vulnerable because I was heavily tranquilised ... (Stovell et al., 2016, Participant, p.316).

The effects of depression reduced participant interest and desire to make decisions sometimes leading to passivity in decision-making (Fisher et al., 2018; Hamann et al., 2016; Simon et al., 2006) and deferring decisional responsibility to others (Fisher et al., 2018). For participants with bipolar disorder participation in decision-making could be facilitated by doing so when participants were experiencing euthymia (Fisher et al., 2018).

when you're depressed or even when you're hypomanic, sometimes I experience a high level of confusion and an inability to think logically...when you're presented with options...it's not possible to think through the solutions (Fisher et al., 2018, Participant, p.71).

Sometimes individuals desired a directive approach and wanted clinicians to take responsibility when they were “*too consumed by their symptoms*” (Simon et al., 2006, p.70) in which a trusting therapeutic relationship was important. One participant who was particularly distressed described feeling relieved when her GP took control.

I went to see my GP and said: I can't go on anymore. I don't know what to do. Please help me and do something (Simon et al., 2006, Participant, p.69).

5. Practical and systemic factors

Participants reported several practical and systemic factors related to participation in SDM (Dahlqvist-Jonsson et al., 2015; Delman et al., 2015; Velligan et al., 2016; Fisher et al., 2018; Lacasse et al., 2016, Stovell et al., 2016; Simon et al., 2006; Giacco et al., 2018). Time constraints were frequently reported which restricted opportunities for discussion leading to “*prescriptive*” treatment decision-making (Fisher et al., 2018, p.75).

There really is not enough time for me to give my opinion on the medications. I just kind of go with what she says since she’s very knowledgeable (Delman et al., 2015, Participant, p.248).

Continuity of care and follow-up appointments were valued by participants (Stovell et al., 2016; Lacasse et al., 2016) in supporting them to better consider treatment options (Fisher et al., 2018). Conversely, poor continuity of care could disrupt the development of trusting relationships and participants’ management of their mental health (Fisher et al., 2018; Lacasse et al., 2016).

...there’s never been any ongoing ‘are you taking it, how are you going with it.’ So there’s probably something missing there...if a GP has prescribed you some medication there should be some sort of follow up (Fisher et al., 2018, Participant, p.73).

Infrequent meetings were reported (Delman et al., 2015) and participants wanted greater accessibility of clinicians outwith appointments (Dahlqvist-Jonsson et al., 2015; Simon et al.,

2006). Participants whose psychiatrists had increased availability between appointments were more actively engaged in SDM (Delman et al., 2015). Within inpatient settings, staff availability and accessibility were important for facilitating discussions. However, some participants wanted earlier conversations about treatment, as contact with psychiatrists could be delayed following admission (Giacco et al., 2018). Additionally, the practicalities of hospital settings described as “*constantly noisy, crowdie, screamy...*” (Giacco et al., 2018, Participant, p.115) posed challenges.

Discussion

Findings

This meta-synthesis explored service user experiences of SDM for mental health treatment. Findings highlighted that service users valued trusting therapeutic relationships, being listened to and being perceived as capable. The involvement of supportive others, access to information, continuity of care, time, and accessibility of clinicians could facilitate service user involvement in SDM. Service users' mental health and its effects could influence their ability to engage in decision-making. Despite this, the analysis suggested that many service users preferred some level of involvement in treatment decision-making. Unfortunately, this was not always reflected in accounts, with some experiencing disempowerment, being disregarded, perceived lack of influence and at times coercion in decisions on their care. Indeed, asymmetries of knowledge and power could inhibit meaningful service user participation. Where these asymmetries were absent, user empowerment was more evident.

The findings corroborate evidence from similar reviews and the wider literature, particularly discrepancies between preferences for involvement and routine service user inclusion (Kaminskiy et al., 2017; Huang et al., 2019). It is widely recognised that trusting therapeutic relationships are central to service user engagement in treatment decisions where service users are respected and supported to feel heard (Kaminskiy et al., 2017; Pedley et al., 2018; Huang et al., 2019). However, service users can face disempowerment in their interactions with mental health professionals, which can engender feelings of mistrust (Farrelly et al., 2015; Kaminskiy et al., 2017; Pedley et al., 2018). Service users have reported feeling unheard and undervalued in their perspectives (Kaminskiy et al., 2017), being denied the

opportunity to exercise their influence in decision-making (Stomski & Morrison, 2017) and position themselves as being outside of decision-making (Stacey et al., 2016).

The findings suggested that disempowering interactions could affect service users' confidence sometimes leading to compliance and passivity. Similarly, a review of stakeholder perspectives on anti-psychotic prescribing by Pedley et al. (2018) found that some service users did not desire or expect involvement. They suggested passivity could be influenced by service users' being unaware of their rights to involvement, experiences of involvement being denied and power imbalances, which professionals may construe as lack of desire for involvement. Indeed, a barrier to SDM implementation includes healthcare professionals' beliefs that service users do not want to be involved (Farrelly et al., 2015; Joseph-Williams et al., 2017). Other consistent findings included unmet information needs (Stomski & Morrison, 2017; Pedley et al., 2018) and time constraints (Pedley et al., 2018) providing further challenges to involvement. Conversely, it is consistently shown that additional support can facilitate SDM (Huang et al., 2019; Pedley et al., 2018) and findings suggested that some service users may desire more formal support.

These findings, particularly issues of disempowerment, have been replicated consistently in the literature signifying a need to address the fundamental issues they may raise related to potential broader issues of systemic discrimination. Elevated levels of disempowerment, stigma and coercion in mental health services may amplify barriers to SDM over and above that of general healthcare (Morant et al., 2016). It is argued that specific challenges faced by service users with mental health problems are ambivalent attitudes towards the legitimacy and value of their experiential knowledge in the form of epistemic injustices (Fricker, 2007; Morant et al., 2016; Grim et al., 2019). Grim et al. (2019) explored stakeholder perspectives

to identify barriers to legitimising service user knowledge in decision-making which highlighted that service users can feel devalued, disregarded as collaborators, perceive communication with clinicians as a ‘struggle’ and may edit information due to power imbalances. Clinicians described disinclination to involve service users, in part due to perceptions of safeguarding against insufficient decision-making ability (Grim et al., 2019). A meta-synthesis of stakeholder perspectives on service user participation in mental healthcare illustrated that when participation was realised, it was often ‘tokenistic’ by including service users in discussions when their views aligned with professionals (Stomski & Morrison, 2017).

It has also been conceptualised that epistemic injustices may be extended to circumstances in which service users are denied the opportunity to articulate their views and experiential knowledge due to organisational barriers (Carel & Kidd, 2014; Grim et al., 2019). Several factors evidenced in the current findings such as service users’ preferences not being elicited, time constraints and lack of continuity of care reflected this (Grim et al., 2019).

These findings shed light on the complexity of SDM in mental health settings and the structural issues that may be involved in difficulties with implementation. Realising SDM in practice can be challenging (Joseph-Williams et al., 2017) and may require a multifactorial approach with significant “*organisational and cultural shifts*” (Morant et al., 2016, p.1012). The challenge will be legitimising service user perspectives and generating a system in which service users are empowered and routinely involved in decision-making, in line with their individual preferences and rights.

Clinical, policy and research implications

The findings suggest that service users can face barriers to inclusion in SDM. Such findings contravene the principles set out in the United Nations' CRPD which seeks to protect the rights of people with mental health problems, including involvement in decision-making. Given the review of the Mental Health Act (2015) for Scotland is to ensure the United Nations' CRPD principles are reflected in legislation, the current findings should have significance.

Based on the findings, service users should be empowered to exercise their autonomy and self-determination and made aware of their rights to participation in decision-making on initial contact with services. Developing service users' confidence should be prioritised. Trusting therapeutic relationships will be central to facilitating service user involvement. Additional support may be beneficial and the importance of working with carers to increase their contribution to treatment decisions and care planning has been evidenced in recent years (Giacco et al., 2017) however current research suggests that carers may not routinely be involved (Dirik et al., 2020). Clinicians should routinely enquire about service user preferences for such involvement. Additionally, offering alternatives such as peer support within services may overcome challenges reported in these findings, for example, the effects of adverse treatment experiences and power imbalances on participation, to enhance service users' confidence and empowerment (Repper & Carter, 2011; Gillard & Holley, 2014). Recent research indicated that peer support can play an important role in fostering meaningful relationships, promoting rights and facilitating decision-making (Cleary et al., 2018).

Given the fluctuating nature of service users' mental health and its impact on involvement in SDM, clinicians should endeavour to utilise advance decision-making, for example, Advance Statements, to promote the rights and preferences of service users (Jankovic et al., 2020). Recent research indicated that there was a discrepancy between service users' desires for advance decision-making and implementation (Hindley et al., 2019). However, benefits have been found in implementing interventions, such as Joint Crisis Planning, including improvements in service users' appraisals of the therapeutic relationship, increased empowerment, feeling heard and respected, and increased sense of control (Farrelly et al., 2015).

Fundamentally, addressing wider structural barriers requires legitimising the perspectives of service users. One approach may be ensuring service user inclusion in the development of mental health care services and policy design, which may reconfigure and make more equitable the power relations between health professionals and service users. Routinely involving service users as co-producers in future research would offer a more embedded approach to inclusion of the perspectives of those with lived experience.

Strengths and limitations

There are some limitations of this review. It is possible that relevant articles were missed. However, care was taken to ensure sensitivity and specificity of the search terms by consulting a librarian and forward citation searches to ensure a rigorous approach to identifying articles. Non-English articles were excluded, and the grey literature was not

identified possibly leading to bias. The researcher coded articles independently and development of themes may have been influenced by the researcher's preconceptions despite efforts made to bracket these. Analysis began with coding articles with the strongest transparency of reporting which could have potentially biased analysis. A careful line-by-line coding approach was taken to counter this. To the researcher's knowledge people with lived experience did not co-produce the research included in the review, or the current meta-synthesis, which is a limitation on the knowledge gained. Furthermore, there were limitations of the sample demography of studies. It was unclear how SDM is experienced by people of specific populations. For example, age, particularly people of younger and older adult populations, ethnicity including people of BAME populations, and those with a forensic history, whose experiences may differ and therefore may engender specific challenges.

Strengths included the sole focus on service user insights as compared to similar reviews in this field which integrated service users' perspectives with other stakeholders. This allowed for a more in-depth analysis of important perspectives of service users.

Conclusion

The review sought to explore experiences of service users with psychosis and other severe mental health problems in relation to SDM. Findings highlighted that service users can face barriers to participation in decisions about their care which may reflect broader structural issues. These may begin to be addressed through routine inclusion of service users' experiential knowledge in the co-production and design of mental health services, policy and research to offer a more informed approach to improving service users' experiences of treatment decision-making and to redress systemic imbalances of power.

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Chapter Two: Major Research Project

How do individuals experience and make sense of psychosis recurrence: an interpretative phenomenological analysis

Chapter word count (including figures, tables, references): 8,217

Prepared in accordance with the guidelines for submission to the Journal of Mental Health
(see Appendix 1.1, p.95)

Plain English Summary

Title: A qualitative study exploring how people experience and describe fears about relapse of psychosis

Background

Psychosis involves having unusual experiences like hearing voices when there is no-one there. People may also see or feel things that others do not. People can hold beliefs that are not shared by others such as paranoia. Many people who experience psychosis will get better. However, some people can relapse which means their psychosis will return. Relapse can be frightening and can cause great distress. Some people may need to go to hospital for treatment to help them recover. Research has shown that people who have had psychosis who are worried or fearful about becoming unwell again might be more likely to have a relapse or become unwell again in the future (Gumley et al., 2015). By listening to peoples' worries or fears about becoming unwell it may help us to better understand how to help people.

Aims

This study explored peoples' experiences of psychosis and their worries about relapse. The researcher asked people to describe their worries or fears about relapse. They were asked to talk about what it was like to worry about becoming unwell.

Method

Four adults who were worried about relapse took part in the study. Participants were invited to take part from Community Mental Health Teams in NHS Ayrshire & Arran. The researcher completed the interviews which were audio-recorded and typed word-for-word. The interviews were analysed using a research method called Interpretative Phenomenological Analysis (IPA). It involves carefully looking for similarities or themes from the interviews.

Findings

Two main themes were found. They were labelled using the participants' own words. The first theme was called "I think my worry would be going back to the worst period." It described the participants' worries about having a relapse. The second theme was called "I think a lot of it's just about feeling in control of it." This theme showed how participants had tried to feel more in control of how they were feeling. It also described how they tried to recover from their psychosis.

Conclusion

Participants talked in detail about their worries about relapse. The themes that were developed may help us to better understand how to help people who are worried about relapsing. We hope this will support them to stay well.

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Abstract

Background

Evidence has shown that people who fear psychosis relapse may experience a shorter duration to actual relapse. Therefore, fear of relapse may be an important clinical construct in understanding the transition to relapse. However, relatively little is known about its phenomenology and how individuals make sense of their fears and worries. This study sought to explore the lived experiences of fear of relapse.

Method

Four individuals who self-reported as being worried about relapse were recruited from Community Mental Health Teams in NHS Ayrshire & Arran. Semi-structured interviews were conducted. Data were analysed using Interpretative Phenomenological Analysis.

Results

Analysis identified two superordinate themes: “I think my worry would be going back to the worst period” which reflected participants’ fears and experiences of worry and “I think a lot of it’s just about feeling in control of it” reflecting participants’ efforts to assert control of their experiences and limit recurrence.

Conclusion

Findings provided a rich insight into the diverse and multi-dimensional nature of participants' experiences of fear of relapse which has implications for both clinical practice and future research.

Keywords: psychosis, fear of recurrence, experiences, Interpretative Phenomenological Analysis

Introduction

Psychosis is characterised by experiences of hallucinations (e.g. hearing voices) and delusional beliefs (e.g. paranoia). Individuals can also experience difficulties in thinking and concentration alongside feelings of apathy, withdrawal and lack of motivation (Cooke, 2017). Psychosis can lead to significant social and vocational disruption (Bucci & Tarrier, 2016) and can be debilitating. Mortality risk is two to three times that of the general population (Brown et al., 2010) and individuals are at increased risk of suicide (Taylor et al., 2015). Prevalence varies according to age, gender, ethnicity, population density and social deprivation (Department of Health, 2016). The onset of psychosis commonly occurs in late adolescence and early adulthood and is more common in men, Black, Asian and Minority Ethnic (BAME) populations, and those living in densely populated or deprived areas (Department of Health, 2016). Vulnerability to psychosis has also been associated with adverse life events and trauma (Cooke, 2017).

In relation to psychosis, relapse has been conceptualised as the recurrence or exacerbation of positive symptoms, typically including hallucinations and delusional beliefs, impacting functioning and behaviour (Burns et al., 2000). Relapse occurs in approximately 82% of people with first-episode psychosis 5 years after remission (Robinson et al., 1999). Each relapse can result in further residual symptoms (Takeuchi et al., 2019) and increased risk of relapse (Alvarez-Jimenez et al., 2012).

Relapse is frequently associated with emotional distress and disruption to social, vocational and interpersonal functioning (Gumley & Schwannauer, 2006). Experiences of psychosis and

treatment can be traumatic (Dunkley et al., 2015; Rodrigues & Anderson, 2017) potentially involving involuntary hospitalisation and treatment (Berry et al., 2013). Psychosis can lead to additional difficulties including post-psychotic post-traumatic stress disorder (Rodrigues & Anderson, 2017), social anxiety and depression (Tarrier, 2005). Post-psychotic depression is associated with appraisals of being unable to control or prevent a relapse and fear of relapse (Birchwood et al., 1993). Additional difficulties can increase the probability of earlier relapse (Birchwood, 2003; Gumley & Schwannauer, 2006).

Subtle changes in thoughts, emotions, physiology and behaviour precede the recurrence of psychosis (Herz & Melville, 1980; Birchwood et al., 1989). These ‘early warning signs’ can include anxiety, low mood, withdrawal, insomnia and incipient psychosis (Birchwood et al., 1989; Birchwood et al., 2000). These changes are sensitive to but not specific to relapse: they may be considered an “at risk mental state” with cognitive, behavioural and interpersonal coping responses moderating further emotional distress (Gumley, 2007, p.2).

Indeed, psychological conceptualisations have outlined that cognitive appraisals in response to cognitive or emotional changes, or low-level attenuated psychosis can accelerate or decelerate relapse (Thurm & Haefner, 1987; Birchwood, 1995; Gumley et al., 1999). Gumley and colleagues (1999) proposed that activation of beliefs about psychosis (e.g. loss of control) related to emerging symptoms associated with psychosis can lead to fear of impending relapse. Fear, depression, hopelessness and shame can be a common response to such changes (Gumley, 2007). Birchwood (1995) proposed that anxiety and depression are a response to either fear of an impending relapse or the inability to explain subtle changes. Fear of relapse has been reported in the weeks preceding relapse (Herz & Melville, 1980) and research exploring the detection of early signs of relapse in individuals diagnosed with

schizophrenia found that fears of relapsing prompted self-monitoring for early signs (Baker, 1995).

Gumley and MacBeth (2006) proposed a trauma-based model to understand the transition to relapse in which catastrophic appraisals of the content or nature of thinking is combined with autobiographical memories of psychosis and reliving of these traumatic events, influencing emotional distress. The threat of relapse can lead to disorganisation including fear, hypervigilance and worry alongside emotional, cognitive and behavioural avoidance, and postponed help-seeking (Gumley and MacBeth, 2006; Gumley, 2007). Indeed, some individuals avoid help-seeking due to fear of hospitalisation (Gumley et al., 2003).

Individuals who fear relapse are more likely to have had traumatic or distressing experiences of psychosis and hospitalisation and are more fearful of symptoms (White & Gumley, 2009). Fear of relapse has been associated with elevated depression, entrapment, self-blame and shame (Gumley et al., 2015). A qualitative study investigating post-psychotic depression identified that ‘fear of relapse’ was linked to fear of shame, feeling powerless, social withdrawal and isolation (Sandhu et al., 2013). In a randomised controlled trial, monitoring fear of relapse was as sensitive to the detection of relapse in psychosis as monitoring early warning signs (Gumley et al., 2015) and individuals who were more fearful experienced a shorter duration to actual relapse.

Therefore, fear of relapse could be an important clinical construct in understanding the transition to relapse. In light of the literature highlighting the importance of fear of relapse and its impact on people with psychosis (White & Gumley, 2009; Gumley et al., 2015) and given that, to our knowledge, there have been no qualitative studies explicitly exploring fear

of relapse in psychosis, this study sought to understand the lived experience and phenomenology of fear of relapse. Interpretative Phenomenological Analysis (IPA) was employed which explores how individuals make sense of their personal and social world to understand the meanings attached to particular experiences or phenomena (Smith & Osborn, 2007) in this case, the phenomenology of fear of psychosis relapse.

Research Aims

This study explored how individuals who have experienced psychosis described and made sense of worry or fear related to relapse.

Method

Ethical approval

Ethical approval was obtained from the West of Scotland Research Ethics Committee (19/WS/0106; Appendix 2.1, p.103) and NHS Ayrshire and Arran Research and Development Department (2019AA033; Appendix 2.2, p.106).

Design

This study utilised a qualitative design to collect interview data analysed using Interpretative Phenomenological Analysis (IPA). IPA has its theoretical foundations in phenomenology, hermeneutics and idiography (Smith et al., 2009) and involves “*the detailed examination of personal lived experience*” (Eatough & Smith, 2017, p.193) in which the researcher plays an active role in the research. Idiography focuses on an individual's personal meaning-making regarding a phenomenon; it is concerned with rich details of experience as opposed to making generalisations across populations (Smith et al., 2009). This methodology was selected as being amenable to gaining an in-depth exploration of how people described and made sense of fear or worry related to psychosis relapse.

Sampling and recruitment

Participants were recruited from Community Mental Health Teams across NHS Ayrshire and Arran between November 2019 and February 2020. The study aimed to recruit a homogenous sample of people over the age of 16, with a diagnosis related to psychosis (e.g. schizophrenia)

and who self-reported as having been worried about relapsing. Participants were not required to have experienced a relapse for inclusion in the study. Those who had a level of English that did not require an interpreter were considered for inclusion. Those deemed not to have capacity and who were experiencing acute psychosis were not considered for participation. The researcher liaised with consultant psychiatrists, consultant clinical psychologists and team leaders of services and attended key multi-disciplinary team meetings to provide information on the study and eligibility criteria.

Potential participants were approached by their care team through routine clinical contact. Staff provided information and a leaflet with details about the study and how to participate. Potential participants either contacted the researcher directly to express their interest or gave their agreement to keyworkers for the researcher to make contact by telephone or e-mail. Following contact with the researcher, a participant information sheet (see Appendix 2.3, p.108) was sent to all individuals interested in participating and they were given at least 24 hours to decide whether they wished to take part. Interviews were subsequently scheduled with those who wished to take part. Participants were not previously known to the researcher.

A sample of four participants agreed to take part in the study. Three additional potential participants agreed to be contacted and sent information but did not participate in the study for reasons unknown. The characteristics of the recruited sample can be found in Table 1 with pseudonyms used throughout to protect participants' confidentiality.

Table 1. Sample characteristics

Participant	Gender	Age
Michael	Male	45
Blair	Male	29
Catherine	Female	51
Jane	Female	47

Interview procedure

Informed consent

Participants provided fully informed and written consent (see Appendix 2.4, p.112) to participate. During the process of obtaining informed consent, the participant information sheet was discussed. Participants were informed of the researcher's interests in the study and were encouraged to ask questions about the research. Participants were informed that their participation was confidential and voluntary, and they had the right to withdraw. Participants provided consent for fully anonymised quotations to be used in the write-up of the research.

Interview schedule

The interview schedule (see Appendix 2.5, p.113) was developed by the researcher following guidance (Smith et al., 2009) and reading relevant literature. The interview guide was discussed and refined in collaboration with the research supervisor who had expertise in both the topic of interest and IPA.

Interview protocol

Interviews took place on NHS Ayrshire and Arran premises, in clinic settings where participants attended for treatment or as near to their home as possible, to increase familiarity and comfort. The researcher conducted semi-structured interviews guided by the interview schedule which was used flexibly in line with IPA methodology (Smith et al., 2009).

Interviews lasted between 53 and 69 minutes. No other individuals were present during the interviews and no repeat interviews were carried out. All participants provided consent for the interviews to be audio-recorded, which were transcribed verbatim. All potentially identifiable information was anonymised.

Data analysis

Data were analysed by the researcher using Interpretative Phenomenological Analysis based on guidance by Smith et al. (2009). Interviews were transcribed verbatim and read repeatedly to become immersed in the data. The next stage involved noting linguistic comments on the transcript paying attention to the language used and overall structure of the interview. A key example of this was Michael's transcript which highlighted frequent pausing, trailing off at the end of sentences and redirection of certain topics. When these linguistic features were explored in the broader context of the transcript, it was noted that they occurred in relation to describing painful memories of relapse which led to initial ideas about the meaning of Michael's language. The researcher then re-listened to the audio recording to remain close to the participant's original account including nuances in tone and language. Descriptive comments were made by noting the content of the transcript including key experiences and events which appeared important to the participant. Next, conceptual comments were

developed focusing on the interpretative aspect of analysis, informed by linguistic and conceptual comments (see Appendix 2.6 for coding example, p.116). During each stage, the researcher's initial thoughts were bracketed in order not to bias the analysis. Based on exploratory comments, initial themes were constructed for each transcript and clustered to produce superordinate themes. At this stage, the researcher re-read the transcript to ascertain whether themes reflected the entirety of the transcript and themes were revised as necessary to ensure there was an idiographic representation of the data, in line with IPA methodology. A written case study was produced for each participant. Case-by-case analysis was completed following this structure for each case and superordinate themes were derived from identifying patterns and connections across cases. The superordinate and emergent themes were listed in a table (see Appendix 2.7, p.118 for example) with reference to transcript evidence. The researcher took an iterative approach, continually re-checking case studies and original transcripts, revising the analysis as appropriate to ensure data was saturated. Themes were devised using the participants' own words to ensure that the researcher's own interpretations of the data remained close to the original transcripts.

Researcher reflexivity

Reflexivity and bracketing of the researcher's own preconceptions are important in IPA (Smith et al., 2009). As such, the researcher was mindful of her motivations for conducting the study. The researcher is a female, trainee clinical psychologist, who has worked in the field of mental health for seven years and is experienced in delivering psychological therapies for adults with mental health problems, but not psychosis specifically. The researcher had no prior experience of use of qualitative methods and was particularly interested in using this approach as a method for gaining an in-depth exploration of the phenomenology of fear of

relapse. The researcher was acutely aware of her influence on data collection and analysis and took steps to ensure a reflexive position throughout by writing personal reflections after each interview and note-keeping during data analysis to bracket preconceptions.

Results

From the data collected, two superordinate themes were constructed with seven emergent themes. Superordinate themes identified were: *“I think my worry would be going back to the worst period”* and *“I think a lot of it’s just about feeling in control of it.”* Themes are discussed in detail below with participant quotations for illustration.

“I think my worry would be going back to the worst period” (Catherine, p.1, 12)

Participants described the nature of their experiences of psychosis and fears about relapse, which highlighted the meanings attached to experiences. This theme also encapsulated the varying levels of threat associated with relapse and participants’ experiences of worry as a response. Four emergent themes were identified: *“I think that’s my worry is getting to the stage of being out of control again”*, *“I feel like I’ve a lot more to lose”*, *“I was entirely engulfed by horrible feelings”* and *“It is a real worry at times.”*

“I think that’s my worry is getting to the stage of being out of control again” (Catherine, p.1, 14-15)

Participants’ experiences of psychosis were characterised by feelings of loss of control and agency. All participants described concerns about the consequences of losing control of their thoughts and behaviour. Blair was particularly concerned due to having self-harmed without awareness of his actions, leading to a sense of mistrust of his mind, fears of potential self-harm or suicide, and letting others down.

I think my mind was quite serious about attempting to harm myself, you know, eh, I didn't realise until I got better that I tried multiple times and came surprisingly close so, I think a large part of how I feel is that I understand that there's a part of my mind that is willing to face an ultimatum such as that (p.1, 16-19).

Catherine's account had similarities; she feared becoming suicidal and the devastating consequences for those around her. Jane feared being unable to control her own mind due to hearing voices. Similarly, Michael feared being controlled by his thoughts and feelings. A sense of powerlessness was expressed in Michael's account, particularly through his language. Michael compared his experiences to being in a "battle" and eventually being "defeated" by his own thoughts. The phrase "dictated to" below reinforced a sense of being at the mercy of his thoughts.

The worst thing would be a sense that, em, (pause) I've not got very much control, that I'm kind of being dictated to by anxious thoughts, depression, depressive thoughts, paranoid thoughts (p.10, 211-213).

Additionally, Catherine feared loss of control in public which may have reflected an underlying fear of the embarrassment or shame that this could incur. Catherine's concerns appeared tied to her awareness of stigma which she raised throughout the interview. Earlier in her recovery fears of losing control in public led to her staying at home in case something was to happen.

I would worry that, I don't know, just losing control in public and things as well (p.13, 314-315)....I actually, I stopped going out so much, sort of thing, so I did stay at home more. I kept myself to myself more eh.. at that stage (p.14, 326-327).

"I feel like I've a lot more to lose" (Blair, p.1, 21)

All participants expressed fears about the disruption and losses that they perceived would be encountered as a result of relapse including loss of employment, higher education, day-to-day functioning and relationships. Catherine had experienced paranoia which adversely impacted her relationships and she feared the loss of her ability to maintain social connections.

When I was at my worst, there was paranoia there as well, sort of thing, just because of all what I was getting told all the time, so it was like being negative with me, towards my friends and things like that, so it was quite difficult to disassociate the psychosis from the real stuff, sort of thing, so it did affect friendships (p.11, 262-265).

For some participants, it appeared that fears of loss were heightened by the gains made in their recovery. Michael had been recovering from a period of relapse and hospitalisation and described experiencing "stability" which was comforting and reassuring. The thought of losing the progress he made was concerning.

I feel as though there's been quite a bit of progress made, em, and, due to that, if I was to relapse, I'd be disappointed because that progress has, has been lost (p.16, 333-335).

Fear of loss was felt acutely by Blair who had been involved in new social and educational opportunities during his recovery providing significant value and meaning in his life. He was fearful of relapse having recently recognised the onset of feelings, thoughts and physical sensations associated with experiences of psychosis. Blair described a sense of anticipatory grief for what he imagined himself losing and the heightened emotional distress which accompanied this was evident.

*I've spent the past six years building a life since. I feel like I've a lot more to lose now, so, if it was ever to get as bad as it was **now**, I think it would hit me a lot harder than it did before (p.1, 20-22).*

"I was entirely engulfed by horrible feelings" (Blair, p.6, 139)

Michael, Jane and Blair spoke of the distressing nature of psychosis. In their own ways, they all collectively described the intensity of their experiences highlighting the suffering they had endured and the unrelenting nature of their experiences. Jane's experience of psychosis was captured in her emotive language use, having described it as "*an absolute living nightmare*" (p.5, 114) and "*absolute torture*" (p.28, 673). This reflected the emotional pain of psychosis itself; however, she also described the distress of treatment. She described: "*being sectioned was an absolutely terrible experience*" (p.4, 95) and she reflected on being forced medication: "*I didn't want to take medication, but, and I got forced to take that medication*" (p.11, 254-255). Jane described "*I don't want to relive it too much*" (p.28, 673-674), which

highlighted how distressing that period of her life had been which she wanted to distance herself from.

Michael described symptoms as “*suffocating*” suggesting the overpowering nature of his experiences. Blair’s experiences were so intense that he described reaching a point of “*breaking*” and feeling numb due to feeling as though he did not have the capacity to cope with his experiences.

I feel like one of the things that happened when I broke as well was, yeah it was horrible feelings all the time but, you became kinda, felt quite muted after a while [...] maybe you’d felt that bad for that long and it was that much strain on your mind, that you just stopped feeling like it anymore (p.6, 145-150).

Participants also conveyed a sense of lack of escape and entrapment from such intense experiences which in some cases led to suicidal thoughts.

The thought was there that I’ll maybe not get out of this alive because I don’t know how I’m going to get this to stop (Jane, p.28, 677-678).

“It is a real worry at times” (Catherine, p.22, 542)

Participants expressed fear and worry related to relapse, which included examples of when and how this was experienced. Relapse posed varying degrees of threat to participants and the

nature in which worry was perceived as problematic varied. Worrying appeared to occur in response to the perceived threat of relapse, providing a protective strategy in the face of uncertainty which Blair captured most explicitly. In response to his perception that he was losing control of his thoughts and feelings, worry became a way of reducing complacency and minimising the risk of relapse.

...I wish I wouldn't worry as intensely as I do but it feels like, I feel like if I don't worry then I'm becoming complacent. And if I become complacent, then I, then I better fucking watch because I'm in trouble (Blair, p.11, 268-272).

Relapse had been experienced as less threatening for Catherine and Jane recently, who were feeling more in control of their experiences. Catherine described that worry was heightened when she experienced hearing voices or changes in physical sensations related to her experiences of psychosis. For Jane, worry increased at times where she perceived herself to be more vulnerable to relapse, such as being faced with stressors.

Well, I don't sit about all the time worrying about relapse. It's just when I think I go to make big steps in my life, like when I went to go back to jobs, or, do you know, when I, maybe... or at times when I think I'm going to put myself under too much stress (p.22, 535-538).

Their experiences differed to Michael's whose recovery had encompassed a sense of stability on the one hand, and feelings of vulnerability and fear on the other, including ongoing anxiety and worry related to relapse. It appeared that Michael's painful memories of relapse gave rise to a sense of continued threat.

It [stability] gives you a wee bit of security it gives you emm, (pause) and you feel good that it's not the way it was before in terms of crisis (pause) and just also anxious that it continues to be stable. There's always in the background of your mind emm, memories that are quite distressing about what it's like to relapse (p.3, 52-55).

This was also portrayed linguistically throughout the interview. When potentially distressing memories appeared to arise, the conversation shifted to more uplifting topics, as though such memories were too painful to linger on. It appeared that distressing feelings, thoughts and memories were continually present for Michael; his use of the word “carry” below highlighted the weight of this and a sense of his feelings of vulnerability to relapse.

Em, it feels like you carry (pause) anxiety, depression and paranoia, emm, with you, eh, (pause – 6 secs) so in that sense it's always there to a greater or lesser extent (p.7, 131-132).

“I think a lot of it's just about feeling in control of it” (Blair, p.27, 670-671)

Given the disruptive impact of their experiences of psychosis, participants highlighted how they had managed their recovery and coping with experiences including the possibility of relapse. Participants described ways in which they had attempted to regain a sense of control exemplified by three emergent themes: “*I've kinda made sense of what, em, I've went through*”, “*That's just the way I've dealt with it*” and “*I know it's the best thing to do, is to go and seek help.*”

“I’ve kinda made sense of what, em, I’ve went through” (Jane, p.23, 550)

This theme encompassed the way participants talked about and made sense of their experiences. There was variation in the degree to which participants had reflected on and developed an understanding of their experiences, which may have influenced their adaptation and recovery. Jane talked about how she had come to understand her experiences as spiritual and continued to see these spiritual aspects as important.

But, what happened was, this amazing experience that I was going through, albeit very stressful, em, turned into an absolute living nightmare, em, when I did go psychotic, so I believe my experience has actually been both. I believe it is been both spiritual and the stress of that spiritual experience led to a period of psychosis (p.1, 18-23).

Jane was diagnosed with schizophrenia and spoke about the damage of this diagnosis, leading to a period of depression. Jane’s need for “closure” (p.23, 551) led to development of an alternative perspective which aided her recovery; her spiritual beliefs had lifted low mood, supported her autonomy in treatment decision-making and had given her “courage” (p.2, 50) to return to employment.

Conversely, Michael, Blair and Catherine described their experiences as related to problems with their mental health and wellbeing. Catherine appeared somewhat accepting of a diagnosis and referred to having a “psychosis label” (p.21, 515) to reframe her experiences

which was perceived as helpful. However, her diagnosis entailed an acute awareness of stigma.

...I was actually just reading on my news app about, it was about Van Gogh, and it was actually psychosis he had, sort of thing, and everyone thinks he was mad, you know, totally mad and out his head sort of thing, so, so I think well, if that's the perception so... (p.19, 470-473).

The linguistic features of Catherine's and Blair's accounts highlighted their reflective approach in attempting to make sense of their experiences. For Michael, it appeared that the pain of his experiences and memories of relapse made it hard to think about and reflect on. This was highlighted in linguistic features when potentially distressing thoughts or memories appeared to arise for Michael during the interview there were extended pauses followed by shifts in the direction of the conversation to more reassuring topics, such as his stability. This was seen below in Michael's response when asked about his experiences of relapse.

Just really paranoid, really anxious, emm, and depressed, emm, I felt as though I was in a tunnel with no end in sight and it was a very dark place. Emm, (pause-6 seconds). Fortunately, in most recent times, ehh, since I left the hospital I haven't had a relapse - I left the hospital last December and in that time my mental health in comparison to the times that I've just mentioned, emm, has been a bit better (p.2-3, 41-45).

Whilst distancing from difficult memories and feelings may have been protective for Michael, it may have potentially impacted his recovery as it may have been more challenging for Michael to process and make sense of what he had experienced. This may have

contributed to the sense of continued threat of relapse, heightened by distressing relapse memories. Taken together, participants' experiences indicated that a reflective approach in which participants developed a narrative or understanding of their experiences could support them to regain a sense of control and adjustment.

"That's just the way I've dealt with it" (Jane, p.28, 692)

Whilst accounts varied, all participants described how they had learned to manage their experiences of thoughts and feelings related to relapse. This included strategies for gaining and maintaining control of their inner experiences and attempts to prevent or limit the risk of relapse and its consequences. Michael described his ongoing struggle to gain control.

...the thoughts and the feelings, they have control, and you kind of feel a real struggle to try and regain control of them, kind of thing. Particularly during a stage of relapse, but also to a lesser extent just everyday life (p.10, 236-239).

This struggle highlighted the effort Michael exerted in efforts to prevent relapse. Michael attributed his "willpower" (p.1, 12) or control of thoughts and feelings to having achieved this, by using strategies like positive coping statements, thought-challenging and mindfulness. Such strategies involved increased awareness of his thoughts combined with attempts to "get away" (p.4, 74) from thoughts and feelings through avoidance of distressing thoughts or memories related to relapse, providing a sense of control. Michael also described distraction and withdrawing from others at times, to protect himself from negative thoughts and feelings. Michael's struggle for control was reflected linguistically as it appeared that

when exploring potentially painful thoughts or memories the conversation shifted to more uplifting topics, perhaps providing distance. This may have reflected Michael's strategy for managing the continued threat of relapse.

Blair reflected on the challenge of coping with heightened intensity of emotions and had learned that focusing his attention on tasks such as work or studying alleviated distress.

Usually, when I, when I'm trying not to think about stuff I try and read or study (mm-hm). Like I says, I've found out that being intensely focussed on something alleviates a lot of my symptoms (p.23 570-572).

Feeling in control was important to Catherine. In response to the occurrence of thoughts, feelings and sensations related to psychosis, she attempted to ignore or reframe her experiences as "psychosis", think of different thoughts and practiced breathing exercises. It appeared that Catherine's behaviour reflected her fears about the social consequences of relapse. She described not socialising to the extent she once did and limited her alcohol intake to prevent loss of control amongst others.

I do go out now with friends and things but as I say I'm still, you know, limit myself, with the likes of on Friday night there I had a pint of cider and that was it [...] I don't know, just scared that things are going to start happening again when I'm out so... (p.25, 608-611).

Jane's ability to manage how she was feeling was partly attributed to the positive outcomes of her spiritual experiences which included learning reiki and mindfulness. Jane also

appeared to cope by not thinking about thoughts associated with that period of her life.

Reflecting on this she commented:

I try not to talk about it, I tend not to talk about it, do you know what I mean. And I've just kinda, I've accepted it's illness and I just try and not to think about it or analyse it or anything like that (p.28, 686-688).

Jane also made efforts to ensure she had enough sleep and limited stress to reduce the possibility of relapse.

"I know it's the best thing to do, is to go and seek help" (Catherine, p.23, 555)

All participants described the need for support and the importance of help-seeking in the face of potential relapse. Participants valued support networks which included family, friends and mental health services, in aiding their recovery. Having an awareness of supports provided reassurance and alleviated the impact of fear about relapse.

There's also the knowledge that the crisis team is there, emm, and that, there's in effect, a safety, emm, net, so that provides a kind of feeling of reassurance, to know that they're there if there's ever any problems (Michael, p.4-5, 85-87).

Knowing that I've got somewhere to go to and speak to, you know, if anything did get bad then that does help, certainly (Catherine, p.22, 543-547).

Despite the value placed on supports, participants described challenging aspects of help-seeking and disclosure of their experiences, indicating the complexities of navigating support. Michael's concerns about burdening his friends and family could lead to delayed help-seeking perhaps postponing opportunities to lessen the risk of relapse.

I'm conscious of the fact that, emm, friends and family and their needs, so it's only really when things get to an advanced stage that I would get in touch with them (mm-hm). I think my first port of call was always going to be the crisis team (p.7, 139-141).

Blair described that typically he tried not to speak with others about his concerns due to fears of annoying people, but a recent recurrence of distressing thoughts and feelings prompted Blair to seek support. However, he described initially not feeling believed or being taken seriously as he appeared to be coping well from an outsider's perspective, which was emotive for Blair to reflect on.

I realise I enjoy having people in my life but I feel like I've been speaking to people that I'm quite close to for a couple of months and trying to like warn people, maybe my family too, but everyone sees that I'm coping really well [...] I feel like no-one believes me (tearful) (p.9-10, 220-227).

Jane spoke of the challenges of having a different conceptualisation of her experiences in comparison to her psychiatrist. She spoke of being misunderstood and misdiagnosed as Jane believed her experiences were partly spiritual which differed from her psychiatrist's approach.

...so I feel like I've been faced with psychiatry not understanding my experience, em, and, seeing it as illness when it's not necessarily an illness (p.3, 60-62).

The disempowering effect of these interactions and having initially felt perceived as “*mad*” (p.24, 573) affected Jane’s initial willingness to share her experiences. Additionally, Catherine illustrated the impact of stigma in influencing her decisions to disclose her experiences with friends and employers. The fear of being perceived unfavourably contributed to her refraining from disclosure.

Discussion

This study sought to make sense of participants' accounts of the phenomenology of fear of psychosis relapse. Four interviews were conducted and analysed using IPA which resulted in two superordinate themes: "I think my worry would be going back to the worst period" and "I think a lot of it's just about feeling in control of it."

Participants' accounts were rich and diverse. In describing their experiences of psychosis, a wide range of meanings were observed related to fears of losing control, fears of self-harm, fears of hospitalisation, anticipated losses and disruption, fears of embarrassment and stigma, fears of letting others down, and fears of the emotional impact of experiences and entrapment. Participants made efforts to assert control over their experiences, to reduce the risk of relapse, and to recover. This was reflected in varied efforts by participants including reflecting on and making sense of their experiences, reducing uncertainty and feeling prepared through worrying, distancing from distressing memories, thoughts and feelings, social withdrawal, reframing experiences, thought-challenging, practicing mindfulness and reducing stress. Another aspect of gaining control related to social support and help-seeking. There was complexity in participants' decision-making to seek support based on individuals' experiences and appraisals. Challenges to help-seeking could arise due to participants' fears of burdening others, stigma and not feeling validated or believed in their disclosures.

This phenomenology contributes towards a more nuanced and multi-dimensional understanding of fear of relapse than previously understood and may have implications for measuring fear of relapse. The Fear of Recurrence Scale (Gumley & Schwannauer, 2006), which was originally developed based on the cognitive content of early signs of relapse,

encompasses cognitive appraisals related to intrusiveness of thoughts, awareness of cognitive perceptual changes, and fear of relapse itself. Current findings suggest that additional domains may also be important including a broader range of meanings linked to fear of relapse (e.g. fear of loss) and their implications for seeking support. Research investigating perspectives on early warning signs of relapse highlighted that service users may be fearful of help-seeking due to the potential consequences of disclosure, for instance, fear of hospitalisation (Allan et al., 2020). Service users' help-seeking responses to early warning signs may be related to risk appraisals, based on previous experiences and meanings of relapse (Allan et al., 2020).

The phenomenology may also be explored in comparison to well-established literature on fear of cancer recurrence (FCR; Simard et al., 2013). FCR is a multi-dimensional and complex experience (Fardell et al., 2016; Almeida et al., 2019). Similar to current findings, varied meanings and fears are found in relation to FCR, including fears of treatment, dying and loss (Almeida et al., 2019). A qualitative meta-synthesis highlighted a range of emotions implicated with FCR including fear and anxiety related to vulnerability and uncertainty, and sadness, loss and grief (Almeida et al., 2019). FCR was described in a trauma-like manner, including re-experiencing, arousal related to cancer-related triggers or memories, and avoidance. FCR is linked to varied coping responses including efforts to gain control of experiences through attempts to reduce recurrence (e.g. paying attention to bodily changes) and experiential avoidance including distancing or distracting from distress related to FCR and avoiding cancer-related stimuli (Almeida et al., 2019). The literature highlights potential overlaps of FCR with the phenomenology of fear of psychosis recurrence suggesting the potential complexities of this experience and need for further recognition and research.

The current findings may also be considered with regards to the related concept of ‘fear of madness’ (Bassett et al., 2009). In a group of individuals with persecutory delusions, ‘fear of madness’ was associated with higher levels of anxiety, worry and persecutory delusion distress. Fear of madness may be a form of worry that contributes to paranoia distress (Bassett et al., 2009) and has recently been shown to be elevated in people with persecutory delusions (Collett et al., 2016). Current findings highlighted that worrying was a feature of participants’ experiences and recoveries. This may be important given research by Freeman and colleagues (2015) has shown that worry may be a causative factor of persecutory delusions. It was shown that intervention targeting the process of worry (e.g. meta-cognitive beliefs about worry) significantly reduced delusions and worry (Freeman et al., 2015). Therefore, it may be suggested that worry could be a potential target in psychological therapy for reducing fear of relapse.

Finally, the findings may be interpreted in relation to cognitive-behavioural models of anxiety disorders which outline the role of catastrophic cognitive appraisals in influencing anxious and fearful emotional responses (Wells et al., 2011). Cognitive and behavioural coping strategies or ‘safety behaviours’ are utilised to avoid feared outcomes, however, they prevent disconfirmation of fearful appraisals thus maintaining anxiety or fear (Salkovskis et al., 1999). Cognitive models of trauma place emphasis on the meanings attached to traumatic events, and cognitive and behavioural avoidance (e.g. thought suppression) which maintain anxiety and a sense of current threat through limited cognitive processing of experiences (Ehlers & Clark, 2000). The current findings highlighted the varied meanings and threats associated with relapse which may shape efforts to assert control and reduce the threat of relapse through cognitive and behavioural strategies. It may be suggested that such

observations may reflect potential mechanisms maintaining fear of relapse in people with psychosis.

Strengths and limitations

Fewer participants were recruited to the study than proposed due to challenges in recruitment resulting in a small sample. Discussions with recruiting clinicians highlighted challenges in identifying service users who had expressed fears of relapse which indicated broader issues of the under recognition of this phenomenon in mental health services. Given this, steps were taken to ensure rigour in data analysis which included case-by-case analysis. The careful and systematic approach to constructing themes ensured adherence to the iterative and idiographic nature of IPA methodology.

The small, homogenous sample limits generalisability of these findings. However, this is not the intended purpose of IPA which seeks to uncover an in-depth understanding of experiences. The small sample creates further limitations due to important perspectives not being represented. For example, those of younger or older adult populations and people of BAME populations. In addition, individuals who were not currently engaged with services were not recruited to the study, whose experiences may have importance in appraisals of fear of recurrence.

A strength of this research was the informational power of the data (Malterud et al., 2016). Given the study was supported by established theory, the interview data were rich, and in-depth case-by-case analysis was conducted, it could be suggested that the study achieved informational power with the sample size (Malterud et al., 2016). A strength was the

production of a rich, descriptive phenomenology of fear of psychosis relapse, which can inform future practice and research.

Clinical and research implications

These findings have important implications. Experiences or memories of psychosis can be distressing therefore it is advisable to work within trauma-informed frameworks (Sweeney et al., 2016) due to the potentially triggering nature of contact with services. The findings suggested that varied meanings or appraisals associated with psychosis, and cognitive, behavioural and interpersonal coping responses may be potential mechanisms implicated in the maintenance of fear of relapse. This may highlight the importance of thorough assessment and individualised formulation to ascertain possible maintenance processes as targets for psychological intervention. The associations between fear of relapse and coping strategies, such as worrying, merit further quantitative research.

Regaining a sense of control was important for service users who employed varied coping strategies. Clinicians should utilise a strengths-based approach to support the use of adaptive strategies to gain a sense of control, to promote service users' recovery. Service users can experience dilemmas in decision-making related to help-seeking and disclosure, which clinicians should be sensitive to. This may be aided by assessment of service users' experiences and appraisals associated with help-seeking, to identify potential blocks and aid intervention.

The current findings, including the identification of varied meanings of psychosis relapse, for instance, appraisals of control and anticipated loss, can potentially expand aspects of the

phenomenology of fear of relapse as measured by the Fear of Recurrence Scale (Gumley & Schwannauer, 2006). However, further research utilising larger, more diverse and representative samples could build on the current research by offering an increased understanding of the phenomenology and measurement of fear of relapse.

Conclusion

This study sought to explore experiences of fear of relapse in relation to psychosis. Findings highlighted the diverse and multi-dimensional nature of this experience which may impact recovery, meriting further research. The findings signal the need for recognition of service users who may be fearful of relapse, and the provision of individualised support to improve wellbeing and facilitate recovery.

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Appendices

Appendix 1.1 Author Guidelines for Submission to the Journal of Mental Health

Extract of author guidelines (Full guidelines available at:

<https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=ijmh20>)

Aims and Scope

The *Journal of Mental Health* is an international forum for the latest research in the mental health field. Reaching over 65 countries, the journal reports on the best in evidence-based practice around the world and provides a channel of communication between the many disciplines involved in mental health research and practice. The journal encourages multi-disciplinary research and welcomes contributions that have involved the users of mental health services.

The international editorial team are committed to seeking out excellent work from a range of sources and theoretical perspectives. The journal not only reflects current good practice but also aims to influence policy by reporting on innovations that challenge traditional ways of working. We are committed to publishing high-quality, thought-provoking work that will have a direct impact on service provision and clinical practice.

The *Journal of Mental Health* features original research papers on important developments in the treatment and care in the field of mental health. Theoretical papers, reviews and commentaries are also accepted if they contribute substantially to current knowledge.

About the Journal

Journal of Mental Health is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Journal of Mental Health accepts the following types of article:

- Original, research or evaluation article
- Review article
- Book reviews

Peer Review and Ethics

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. Find out more about [what to expect during peer review](#) and read our guidance on [publishing ethics](#).

Preparing your paper

Original, research or evaluation article:

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 4000 words, inclusive of the abstract, footnotes.
- Should contain a structured abstract of 200 words.
- Should contain between 3 and 7 **keywords**. Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.
- When submitting an Original Article or Research and Evaluation, please include a sentence to confirm that ethical approval has been granted (with the name of the committee and the reference number) and that participants have given consent for their data to be used in the research. Original, research or evaluation articles should have a total of 4000 words. Manuscripts are limited to a maximum of 4 tables and 2 figures.

Review article:

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should contain a structured abstract of 200 words.
- Should contain between 3 and 7 **keywords**. Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.
- When submitting a Review, please confirm that your manuscript is a systematic review and include a statement that researchers have followed the PRISMA guidance. Please also confirm whether the review protocol has been published on Prospero and provide a date of registration.
- Manuscripts are limited to a maximum of 4 tables and 2 figures.

Style Guidelines

Please refer to these [quick style guidelines](#) when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use double quotation marks, except where “a quotation is ‘within’ a quotation”.

Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

[Word templates](#) are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact us [here](#).

References

Please use this [reference guide](#) when preparing your paper.

An [EndNote output style](#) is also available to assist you.

Appendix 1.2 Search Strategy Examples

Database: CINAHL - EBSCO (n=1693)

Sample	(MH "Psychotic Disorders") OR (MH "Affective Disorders, Psychotic") OR (MH "Schizoaffective Disorder") OR TI psychosis OR AB psychosis OR TI psychiatric OR AB psychiatric OR (MH "Schizophrenia") OR TI schizophre* OR AB schizophre* OR (MH "Depression") OR TI depression OR AB depression OR (MH "Bipolar Disorder") OR TI bipolar OR AB bipolar OR TI (((mental* n1 ill*) or (serious* n1 mental*) or (severe* n1 mental*) or (chronic n1 mental*)) OR AB (((mental* n1 ill*) or (serious* n1 mental*) or (severe* n1 mental*) or (chronic n1 mental*)))
Phenomenon of Interest	(MH "Decision Making, Patient") OR (MH "Decision Making, Shared") OR (MH "Decision Making") OR TI decision-making OR AB decision-making OR (MH "Advance Directives" OR TI advance directive* OR AB advance directive* OR (MH "Advance Care Planning") OR TI advance care plan* OR AB advance care plan* OR TI advance statement* OR AB advance statement* OR TI crisis plan* OR AB crisis plan* OR (MH "Consumer Participation") OR TI (((patient* or service user* or client* or consumer*) n5 (participat* or involve*))) OR AB (((patient* or service user* or client* or consumer*) n5 (participat* or involve*)))
Research Design	(MH "Qualitative Studies+") OR TI (interview* or qualitative or focus group* or phenomenolog* or grounded theory or content analys* or thematic analys* or narrative* or discourse) OR AB (interview* or qualitative or focus group* or phenomenolog* or grounded theory or content analys* or thematic analys* or narrative* or discourse)

Database: EMBASE - OVID (n=3630)

Sample	psychosis/ or psychosis.tw. or psychiatric.tw. or exp schizophrenia/ or schizophre*.tw. or exp depression/ or depression.tw. or exp bipolar disorder/ or bipolar.tw. or ((mental* adj1 ill*) or (serious* adj1 mental*) or (severe* adj1 mental*) or (chronic adj1 mental*)).tw
Phenomenon of Interest	exp patient decision making/ or exp shared decision making/ or decision-making.tw. or patient participation/ or ((patient* or service user* or client* or consumer*) adj5 (participat* or involve*)).tw. or advance care planning/ or advance statement*.tw. or advance care plan*.tw. or crisis plan*.tw. or advance directive*.tw.
Research Design	exp qualitative research/ or (interview* or qualitative or focus group* or phenomenolog* or grounded theory or content analys* or thematic analys* or narrative* or discourse).tw.

Appendix 1.3 Consolidated Criteria for Reporting Qualitative Research

COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 1.4 Coding Example

Being the underdog

The category 'being the underdog' describes experiences of not being listened to or taken seriously when decisions are made in mental health care and support. With regard to decision making, the respondents felt that the professional made decisions based on what they considered was in the best interest of the person in need of care. Decisions were often made without taking the person's own view and knowledge into consideration. Exclusion of their point of view made them feel incompetent and unappreciated, and they became more passive in situations of decision making.

... It was just to do what they said, for they were always right, even if you felt that this can't be correct, that this is not right for me, they were right in all cases and that was not good at all. (Respondent 1, female, focus group 1)

Experiences of not being listened to

Clinician as expert/ professional

Clinicians not considering service users' views in SDM

Experiences influencing service users' feelings of competence and confidence leading to passivity

Being controlled

The category 'being controlled' refers to actions and situations within psychiatric services that limited the respondents' ability to make own choices. This included experiences of receiving incomplete information about medications or interventions, but lack of information about choices and experiences of being steered by professionals in their decisions. The respondents expressed how professionals sometimes avoided informing them about alternatives to treatments or interventions that the professional considered the most relevant. The consequence of the lack of information was that the respondents were unable to make informed choices.

... what I can sense when talking medicine / is / that you may only know what the idea is and how it should work, but then nothing is said about side effects. (Respondent 2, female, focus group 2)

The respondents felt themselves being controlled and without influence when no options were considered for their treatment and support beyond those presented by the professional. As they lacked knowledge as to alternatives and were in need of help, they felt that they had to go along with the professionals' proposal. Furthermore, they expressed feeling controlled because of the limited time and space that was given for them to reflect or prepare for decisions.

Lack of information and not fully informed about treatments

Lack of information to assert oneself or make informed decisions

Lack of options offered limits involvement

Time pressures – unable to reflect

Appendix 1.5 Outcome of COREQ Appraisal

COREQ Items	Study Number											
	1	2	3	4	5	6	7	8	9	10	11	12
Interviewer identified												
Researcher credentials												
Researcher occupation												
Researcher gender												
Experience and training												
Relationship established												
Participant knowledge of interviewer												
Interviewer characteristics												
Methodological orientation and theory												
Sampling												
Method of approach												
Sample size												
Non-participation												
Data collection setting												
Presence of non-participants												
Sample description												
Interview guide												
Repeat interviews												
Audio/visual recording												
Field notes												
Duration of interview												
Data saturation												
Transcripts returned												
Number of data coders												
Description of coding tree												
Derivation of themes												
Software												
Participant checking												
Quotations presented												
Data and findings consistent												
Clarity of major themes												
Clarity of minor themes												
Total number of COREQ items	20	22	23	19	17	15	12	18	16	22	14	13

Appendix 1.6 Coverage of Themes Across Included Studies

Theme	Study Number											
	1	2	3	4	5	6	7	8	9	10	11	12
Communication and support	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓
Attitudes and approaches to shared decision-making	✓	✓	✓		✓	✓	✓		✓	✓	✓	✓
Being informed	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	
Clinical factors	✓		✓		✓			✓	✓	✓		
Practical and systemic factors	✓	✓	✓	✓	✓	✓		✓			✓	

Appendix 2.1 Ethical Approval from West of Scotland Research Ethics Committee

WoSRES
West of Scotland Research Ethics Service

Miss Lidia Brookmann



West of Scotland REC 3
Research Ethics
Clinical Research and Development
Dykebar Hospital
Grahamston Road
Paisley PA2 7DE

Date 07 August 2019
Direct line 0141 314 0211
E-mail WoSREC3@ggc.scot.nhs.uk

Dear Miss Brookmann

Study title: How do individuals experience and make sense of psychosis recurrence: an interpretative phenomenological analysis.
REC reference: 19/WS/0106
IRAS project ID: 259043

Thank you for your letter of 06 August 2019. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 31 July 2019

Documents received

The documents received were as follows:

Document	Version	Date
Covering letter on headed paper [Covering Letter]	1.0	06 August 2019
Participant consent form [Participant Consent Form]	2.0	05 August 2019
Participant information sheet (PIS) [Participant Information Sheet]	2.0	05 August 2019
Research protocol or project proposal [Major Research Project Protocol]	2.0	06 August 2019

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	1.0	07 June 2019
Copies of advertisement materials for research participants [Study Leaflet]	1.0	07 June 2019
Covering letter on headed paper [Covering Letter]	1.0	06 August 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]		06 August 2018
GP/consultant information sheets or letters [GP Letter]	1.0	07 June 2019

Interview schedules or topic guides for participants [Interview Schedule]	1.0	07 June 2019
IRAS Application Form [IRAS_Form_01072019]		01 July 2019
Other [University Proceed to Ethics Confirmation Letter]		26 February 2019
Other [Study Debriefing Information]	1.0	07 June 2019
Other [Information for Staff]	1.0	07 June 2019
Other [Notice of Interest Form]	1.0	07 June 2019
Participant consent form [Participant Consent Form]	2.0	05 August 2019
Participant information sheet (PIS) [Participant Information Sheet]	2.0	05 August 2019
Research protocol or project proposal [Major Research Project Protocol]	2.0	06 August 2019
Summary CV for Chief Investigator (CI) [Chief Investigator Summary CV]		
Summary CV for student [Student Summary CV]		07 June 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

19/WS/0106	Please quote this number on all correspondence
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Yours sincerely

Moyra Evans
REC Manager

Copy to: *Prof Andrew Gumley*
Emma-Jane Gault
Dr Karen Bell, NHS Ayrshire and Arran
nhsq.NRSPCC@nhs.net

Miss Lidia Brookmann

West of Scotland REC 3
Research Ethics
Clinical Research and Development
Dykebar Hospital
Grahamston Road
Paisley PA2 7DE

Date 19 December 2019
Direct line 0141 314 0211
E-mail WoSREC3@ggc.scot.nhs.uk

Dear Miss Brookmann

Study title: How do individuals experience and make sense of psychosis recurrence: an interpretative phenomenological analysis.
REC reference: 19/WS/0106
Amendment number: REC Ref AM02
Amendment date: 11 December 2019
IRAS project ID: 259043

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	V2.0	21 November 2019
Copies of advertisement materials for research participants [Study Leaflet]	V2.0	21 November 2019
Copies of advertisement materials for research participants [Study Leaflet]	V3.0	19 December 2019
Copies of advertisement materials for research participants [Poster]	V3.0	19 December 2019
GP/consultant information sheets or letters [GP Letter]	V2.0	21 November 2019
Notice of Substantial Amendment (non-CTIMP) [Notice of Substantial Amendment]	REC Ref AM02	11 December 2019
Other [Information for Staff]	V2.0	21 November 2019
Other [Staff Information]	v3.0	19 December 2019
Participant consent form [Consent Form]	V3.0	21 November 2019
Participant information sheet (PIS) [PIS]	V3.0	21 November 2019
Research protocol or project proposal [Major Research Project Protocol]	V3.0	21 November 2019

Membership of the Committee

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

Appendix 2.2 Approval from NHS Ayrshire and Arran Research and Development Department



Research & Development
56a Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Prof Andrew Gumley
Professor of Psychological Therapy
University of Glasgow
Institute of Mental Health and Wellbeing
University of Glasgow
Gartnavel Royal Hospital, 1055 Great
Western Road
G12 0XH

Date 20 September 2019
Your Ref
Our Ref CM/KLB/CI 2019AA033
Enquiries to Karen Bell
Extension 25850
Direct line 01563 825850
Fax 01563 825806
Email Karen.Bell2@nhs.uk

Dear Prof Gumley

How do individuals experience and make sense of psychosis recurrence: an interpretative phenomenological analysis.

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

Documents received:

Document	Version	Date
IRAS Form	5.12	01/07/2019
Localised Organisational Information Document	1.0	09/06/2019
Protocol	2.0	06/08/2019
Schedule of Events	1.0	09/06/2019
Participant Information Sheet	2.0	05/08/2019
Participant Consent Form	2.1	13/08/2019
MakingSense Poster	1.0	07/06/2019
Study Leaflet	1.0	07/06/2019
GP Letter	1.0	07/06/2019
Interview Schedule	1.0	07/06/2019
Study Debriefing Information	1.0	07/06/2019
Staff Information	1.0	07/06/2019
Notice of Interest	1.0	07/06/2019

Research & Development Office
56a Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Miss Lidia Brookmann

Date 24 December 2019

Your Ref

Our Ref

CM/KLB/CI 2019AA033

Enquiries to

Karen Bell

Extension

25850

Direct line

01563 825850

Fax

01563 825806

Email

Karen.bell2@nhs.uk

Dear Lidia

Title: How do individuals experience and make sense of psychosis recurrence: an interpretative phenomenological analysis

IRAS ref: 259043

Amendment ref: AM02 11.12.19

R&D ref: 2019AA033

I have received the undernoted documentation, relating to proposed changes to the above study:

- Notification of Substantial Amendment
- GP Letter V2.0 21.11.19
- Major Research Project Protocol V3.0 21.11.19
- Participant Consent Form V3.0 21.11.19
- Participant Information Sheet V3.0 21.11.19
- Poster V3.0 19.12.19
- Staff Information V3.0 19.12.19
- Study Leaflet V3.0 19.12.19
- 19-WS-0106 259043 Fav Op_SA AM02 19 Dec 19

I can confirm that the above amendment has been approved.

Please contact the R&D Office if you have any queries. On behalf of the department, I wish you every success with the project.

www.nhs.uk



Appendix 2.3 Participant Information Sheet



Institute of Health
& Wellbeing



Participant Information Sheet – Version 3.0, 21.11.19 IRAS Project ID: 259043

Contact:

Lidia Brookmann, Trainee Clinical Psychologist
University of Glasgow
Gartnavel Royal Hospital,
1st Floor, Admin Building,
1055 Great Western Road, Glasgow,
G12 0XH
E-mail: MakingSenseStudy@glasgow.ac.uk

Making Sense of Psychosis Relapse

You are being invited to take part in a study looking at experiences of psychosis and relapse. This research is being carried out by Lidia Brookmann, Trainee Clinical Psychologist from the University of Glasgow. The supervisors are Professor Andrew Gumley, University of Glasgow, Institute of Health & Wellbeing and Dr Cindy Shiels, Consultant Clinical Forensic Psychologist.

There is information about the study below for you to read. This information explains why the research is being carried out and what it would involve for you. Please read the following information and feel free to ask us any questions you may have. It is important that you understand what is being asked of you before deciding whether to take part.

What is the research about?

We would like to speak to people who worry about having a relapse of their psychosis. Psychosis involves having unusual experiences which may include hearing voices when there is no-one there or seeing and feeling things that other people do not. Individuals may also hold strong beliefs that are not shared by others including feelings of paranoia.

We are interested in learning about peoples' experiences of psychosis and worries about relapse. We understand that many people recover from psychosis and that some individuals may experience relapses. Relapse involves a return of unusual experiences or strong beliefs. We are very interested in finding out about your own personal experiences of psychosis and worries about relapse, and the impact this has on your day to day life.

We think this study may be important to gain a much better understanding of worry about relapse and the impact this has on individuals. We hope that the information gained in this study can contribute towards improving and developing services for people experiencing psychosis to help people recover.

Why am I being invited to take part?

We are looking for adults (over 16 years) who have experienced an episode of psychosis, who are worried or fearful about relapse and are also currently under the care of a Community Mental Health Team, mental health inpatient services, community addictions services or the forensic community mental health team in NHS Ayrshire & Arran.

If you would like to take part in the study, the researcher may speak with a team member of the service that you attend to check that you are eligible for the study.

Do I have to take part?

No, you can choose whether you wish to take part or not. If you do choose to take part you can withdraw from the study at any time, and you do not need to provide a reason for doing so. If you choose to withdraw, the care you currently receive will not be affected. If you decide to take part, you will be asked to sign a consent form.

What does taking part involve?

If you decide to take part a suitable appointment time will be arranged. The interview will be held in an NHS setting that is familiar to you. You will be provided with travel expenses of up to £10. The interview will last approximately 1 hour and will involve talking about your experiences of psychosis and worries about relapse. There are no right or wrong answers as it is your own unique experiences that are most important. You can have a break during the interview if you would like and you do not need to answer any questions that you don't want to.

Prior to the interview, Lidia will meet with you to ensure that you have understood this information sheet and would like to participate. A written consent form will be provided for you to sign.

What happens to my information?

The interviews will be recorded using a digital voice recorder. This is to ensure that interviews will be transcribed word for word. This is necessary for this kind of research. The interviews will be typed up and the audio recording will be retained until the study is complete, after which it will be destroyed. Lidia will show you the digital audio recording device and explain how this works before commencing the interview. Your information will be stored on a password-protected university computer. Your information will be anonymous. Any information that would identify you will not be included in any resources related to the research.

The written project will include reporting common themes across peoples' experiences and fully anonymised quotes will be used to illustrate these themes. Your quotes may be used, and whilst you may recognise these, no-one else will be able to identify you from the study.

Will my taking part be kept confidential?

We will inform your GP, Key Worker and Psychiatrist that you have taken part in the study. The information you provide will be treated confidentially and will not be shared with others. If you share information that makes us concerned about your safety or the safety of other people, we may be required to share this information with others involved in your care (e.g. your key worker or psychiatrist). We will always notify you beforehand if we are going to do this and explain why.

Representatives of the study sponsor, University of Glasgow may look at your information to make sure the study is being conducted correctly.

What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research. However, some people find it helpful to have an opportunity to talk about and make sense of their experiences and to be listened to. The study may also contribute towards improving services and treatments for people who experience psychosis.

Are there any downsides to taking part?

We recognise that discussing personal experiences of psychosis and relapse may be potentially distressing or upsetting. If you do feel stressed or upset by the content of the interview you can take a break or end the interview depending on your own preferences. Additionally, you can end your involvement with the research at any time.

What will happen to the results of the study?

A summary of the results of the study can be sent to you if you wish when the study has been completed. The results will be written up as a completed project. It will be available to the public on The University of Glasgow's thesis website. The study may also be published in a research journal.

Who has reviewed the study?

This study has been reviewed by University of Glasgow, NHS Ayrshire and Arran, and by the West of Scotland Research Ethics Committee.

What can I do if I have a problem with the study?

If you have a problem with the study or would like to make a complaint you can contact the researcher in the first instance, but the standard NHS complaint procedure is also available to you. You can call the Complaints Team on 0800 169 1441.

GDPR Statement

University of Glasgow is the sponsor for this study based in the United Kingdom. We will be using information from you 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. University of Glasgow will keep identifiable information about you for ten years 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. If you withdraw from the study, we will keep the information about you that we have already

obtained. 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 Data Protection and Freedom of Information Office, Tay House, University of Glasgow, Glasgow, G12 8QQ or you can make a data protection enquiry by telephone on 0141 330 3111.

If you have any questions or would like to take part:

If you wish to take part in the study or would like further information, please contact Lidia Brookmann by telephone on 07956012229 or by email MakingSenseStudy@glasgow.ac.uk.

If you would like to speak to someone who is not closely involved in the study you can contact Dr Hamish MacLeod, Programme Director for Doctorate in Clinical Psychology. You can contact him by e-mail: Hamish.McLeod@glasgow.ac.uk or by telephone: 0141 211 3922.

Thank you for taking your time to read this information.

Appendix 2.4 Participant Consent Form



Institute of Health
& Wellbeing



University of Glasgow
Gartnavel Royal Hospital,
1st Floor, Admin Building,
1055 Great Western Road, Glasgow,
G12 0XH
MakingSenseStudy@glasgow.ac.uk

Participant Consent Form – Version 3.0, 21.11.19 IRAS Project ID: 259043

Identification number for this study:

Title of project: Making Sense of Psychosis Relapse

Name of researcher: Lidia Brookmann, Trainee Clinical Psychologist

Please initial each box if you agree with the statement:

I confirm that I have read and understood the participant information sheet (Version 3.0, 21/11/19). I have had time to think about the information provided and I have had the opportunity to ask questions and I am satisfied with the answers I received.

☐

I understand that my participation is voluntary, and I can withdraw at any time. If I decide to withdraw, I understand that I can do so without specifying a reason and without my medical care or legal rights being affected.

☐

I agree to the interview being audio recorded.

☐

I agree that fully anonymised quotations may be used in the write-up of the research, in future publication and in other materials arising from the study.

☐

I understand that my data collected during the study may be looked at by individuals from the research team and regulatory authorities where it is relevant to my taking part in this research.

☐

I agree that you may inform my general practitioner, key worker and psychiatrist of my involvement in the study.

☐

I would like to receive a copy of the study results.

☐

I agree to take part in this study.

☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1 copy for participant; 1 copy for researcher; 1 copy for notes

Appendix 2.5 Interview Schedule

Interview Schedule - V2.0 23.01.20

IRAS Project ID: 259043

‘Making Sense of Psychosis Relapse’

Thank you for meeting me today and for your interest in our study. My name is Lidia and I'm a trainee clinical psychologist. I'm carrying out research on people's experiences of psychosis and relapse, particularly any worries people may have about relapse to help us understand how we can best support people and improve services.

The last time we met we talked through the participant information sheet and consent form that you were provided. I wondered if you had any questions about these since we last met? Is there anything you would like to ask me about the study or about the information you've been provided before we get started?

I'll be asking you some questions today about your experiences of worrying about psychosis relapse, but I might say very little and will spend most time listening to and understanding what you have to say. There are no right or wrong answers, what I'm really interested in is finding out about you and your experiences. We have approximately one hour, but we can use as much or as little of that time as feels comfortable for you.

I understand that some of the things you discuss today might be sensitive and may bring up different feelings for you. If you would like to take a break at any point during the interview, please let me know. Also, you don't need to answer any questions that you don't want to.

I'll be using this digital recorder to record the interview today to make sure I've heard everything correctly. You are welcome to have a look and play around with this (hand digital recorder to participant).

Before we get started, do you have any other questions?

Are you ready to begin?

(see next page)

Topic Areas	Function	Key Questions	Prompts
Describing worries or fears about relapse	<p>To develop a shared understanding of the range of worries or fears related to relapsing.</p> <p>To develop descriptions of worries.</p>	<p>Can you tell me a bit about worries you have about relapsing?</p> <p>What most concerns you about that?</p> <p>What's the worst thing about that?</p> <p>Is there anything else that worries you about a relapse of psychosis?</p>	<p>Tell me more about that.</p> <p>Can you describe your worries?</p> <p>Tell me about past worries.</p>
Reviewing specific episodes of worrying about relapse	To develop the cognitive, emotional, physiological and behavioural aspects of worrying or fear about relapse.	<p>Can you tell me about a time when you were particularly worried about relapsing?</p> <p>Can you talk me through a particularly intense example of worrying?</p> <p>What do you do to manage these worries? Is there anything you do to cope when you're worrying?</p> <p>Does worrying about relapse ever stop you from doing things?</p> <p>How typical is this example?</p>	<p>Tell me more about that.</p> <p>Can you describe that?</p> <p>Where were you?</p> <p>Who was there?</p> <p>What was happening?</p> <p>How were you feeling?</p> <p>How did that feel in your body?</p> <p>What went through your mind?</p> <p>Were there any pictures/images/memories?</p> <p>What did you do?</p>
Interpersonal support and help-seeking	To explore and understand experiences of support for	When you worry about relapse, do you seek help?	<p>Tell me more about that.</p> <p>What do you do?</p>

Topic Areas	Function	Key Questions	Prompts
	worrying and help-seeking behaviours.	<p>Have you had any help for worrying about relapse?</p> <p>Who do you have around for support?</p> <p>If you had worries about relapse, who would you talk to?</p> <p>If there was help for worries or fears about relapse, is that something that would appeal to you?</p>	<p>How do you feel about seeking help?</p> <p>What is/was that experience like?</p> <p>How would you describe that support/relationship?</p>

Appendix 2.6 Transcript Coding Example

Emergent Themes	Transcript Excerpt	Exploratory Comments: <i>Linguistic – italics</i> , Descriptive, <u>Conceptual – underlined</u>
<p>Recurrence of ‘symptoms’ is worrying</p> <p>‘Symptoms’ reminder of past distress</p> <p>Disconnection/loss</p> <p>Negative feelings/thoughts unrelenting/constant</p> <p>Worry as response to threat of relapse</p>	<p>I: So, you mentioned that your, one of your worries is some of these symptoms coming back.</p> <p>P: I mean they <i>have</i> come back. My leg’s been shaking a <i>lot</i> over the past two weeks (<i>yeah</i>). Em, I’ve been pacing in my house again, that’s concerning because I’ve not done that for years (<i>mm-hm</i>). And that was, like I said, I feel like that was involuntary. It just feels nice when I do it, because I think my mind’s not coping and my body wants to for me (<i>yeah</i>), is kinda what it feels like.</p> <p>I: And you mentioned that your body’s having these physical reactions, and you mentioned the pacing, and what concerns you most about these sorts of symptoms returning?</p> <p>P: Because it highlights what happened to me before I broke (<i>mm-hm</i>). I feel like I broke before, that’s all I was (tearful). I feel like there was a tipping point, where like, I went from feeling ok to feeling like I wasn’t in the same room as anyone else (tearful), or the same space or the same anything, like I said, I couldn’t connect with people for a long time. All I could think about was hurting myself or speaking negatively about myself or, I just felt more dreadful than I’ve ever felt in my entire life, and I felt like that all day every day, and it’s things like that are starting to come back (<i>yeah</i>). So, I <i>should</i> be worried, I don’t, I don’t think I shouldn’t be.</p>	<p><i>Have/lot – emphasis</i></p> <p>Recent recurrence of symptoms is concerning</p> <p><u>Pacing is a sign that his mind isn’t coping</u></p> <p><i>Broke – fell apart</i> <i>Tearful – reminder of distress</i></p> <p>Felt disconnected from others, isolated – <u>loss of connection</u></p> <p>Constant negative thinking and thoughts about self-harm – <u>emotional burden</u> <u>Unrelenting nature of experiences – feeling trapped?</u> <u>Should – emphasis. Worry in response to perceived threat of relapse. Worry has a protective function?</u></p>

<p>Fear of disconnection, loss of relationships</p> <p>New relationships/socialising as positive outcome</p> <p>Experiences unrelenting</p> <p>Value of relationships</p>	<p>I: And you mentioned feeling it was hard to connect with people.</p> <p>P: Absolutely. I felt like, I know it's a kinda like silly analogy, but it felt like there was frosted glass between me and everyone else, but not physical glass, I just felt like I wasn't in the same place as anyone else (tearful – pause). I felt like I couldn't connect with anyone at all, it didn't matter if it was my family or my friends or anyone. I felt like I wasn't able to have a connection with anyone and I was never a lonely person, I've always been quite isolated, I'm actually quite social now, but back then I was quite isolated and that was fine, but when that happened and I realised that I couldn't feel like that with anyone then it felt terrible (tearful) and when it's happening you think it's never going to end (<i>mm-hm</i>), which makes it worse because then you're thinking what's the point, do you know what I mean, like you don't realise how much you value these things until you can't experience them anymore, so..</p>	<p><i>Frosted glass metaphor – barrier, detachment</i> <i>Tearful - this is upsetting to reflect on, sense of anticipated grief.</i> Disconnection from everyone around him</p> <p>He has become more social now</p> <p>Feelings never-ending, unrelenting – <u>entrapment?</u></p> <p>New sense of appreciation and value of relationships and connections – <u>intensifies the fear of loss, links back to having 'more to lose now'?</u></p>
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Appendix 2.7 Example of Themes with Transcript Evidence

Superordinate Theme 1: I think my worry would be going back to the worst period

	Michael	Blair	Catherine	Jane
<p>“I think that’s my worry is getting to the stage of being out of control again”</p>	<p>Michael’s fears about a recurrence of psychosis were centred around losing control of his inner experiences; being controlled by his thoughts and feelings. Michael’s use of the phrase ‘dictated to’ below reinforced a sense of powerlessness that he experienced in the face of relapse. As seen in the following quotation, Michael’s repetition of the word ‘thoughts’ highlighted the sense of threat that unhelpful thoughts could pose, as these were a sign of relapse and impending loss of control.</p> <p><i>“The worst thing would be a sense that, em, (pause) I’ve not got very much control, that I’m kind of being dictated to by anxious thoughts, depression, depressive thoughts, paranoid thoughts, em, so all of those kind of thoughts come to the fore during a period of relapse so I’m really anxious about experiencing those</i></p>	<p>Blair expressed worries about relapse which reflected his fear of ultimately having no control over his experiences and actions. This was particularly worrying for Blair because he had self-harmed in the past and had not been aware of how unwell he had felt at that time, indicating a sense of loss of agency. Throughout the interview, Blair described that he was aware of a negative part of his mind that could get ‘loud’ again, which could lead to a mistrust of himself and his decision-making.</p> <p><i>“I didn’t realise at the time but, I think my mind was quite serious about attempting to harm myself, you know, eh, I didn’t realise until I got better that I tried multiple times and came surprisingly close so, I think a large part of how I feel is that I understand that there’s a part of my mind that is willing to face an</i></p>	<p>Catherine felt most concerned about a loss of control, autonomy and agency.</p> <p><i>“I think my worry would be going back to the worst period, em, I mean at my worst I took myself to hospital, em, and I really didn’t know what was going on. I didn’t know right from wrong at that time, what was real and what wasn’t, em, so, I was out of control really, so I think that’s my worry is getting to the stage of being out of control again” (12-15, p.1).</i></p> <p><i>“Well, I think as I say, at the worst I was in no control at all, em, I had constant voices, constant physical sensations, eh, it was a very negative voice I was getting all the time so it was basically telling me what to do, even, you know, going for a shower, I couldn’t, I didn’t know how to shower properly because the voice was constantly, you know, telling me do this, do that, do this, do that, sort of thing</i></p>	<p>Jane described that the worst part of her previous experiences of psychosis was not being in control of her own mind due to hearing voices, which were highly distressing. Jane particularly feared not being in control of her own thoughts. Below, Jane commented on what she most feared about a recurrence of psychosis:</p> <p><i>“I think just that fear of (pause) losing your mind again” (111, p.5).</i></p> <p><i>“Just not being able to, being in control of your mind” (147, p.6).</i></p> <p><i>“Well, em (pause), just that feeling that you’re not able to control what’s going on. I wasn’t able to control the voices in my head, em, and when it was a spiritual experience it wasn’t like that. I felt, I’d always felt kinda guided. I felt kinda guided through that spiritual</i></p>

	Michael	Blair	Catherine	Jane
	<p><i>thoughts and feelings again because that would signify a relapse” (211-215, p.10).</i></p> <p>The quotations below suggested that Michael had appeared to externalise his thoughts and feelings, as though his thoughts and feelings were another entity that held power and control during a period of relapse. Michael’s use of the word ‘spiralling’ reinforced the uncontrollable nature of his thoughts at such times and the threatening nature of this.</p> <p><i>“The thoughts and the feelings, they have control” (237, p.11).</i></p> <p><i>“The thoughts are spiralling out of control and into very negative territory” (277, p.13).</i></p> <p>Michael’s language use in the following quotes, including ‘battle’ and ‘defeated’ conveyed that his experiences of relapse were comparable to a fight which highlighted the struggle that he had experienced in trying to gain control of his thoughts and feelings, eventually leading to feelings of defeat. His inability to</p>	<p><i>ultimatum such as that” (16-19, p.1).</i></p> <p><i>“I never realised how serious I was about, like, I’ve got really bad scars on my arm and I never realised I meant that (yeah), do you know what I mean, like, that worries me because when I was in that frame of mind I didn’t worry about things like that that much anymore, do you know what I mean. I worry about it a lot now (mm-hm) because, I guess maybe it’s knowing what you’re capable of. That’s quite scary, because I mean, I think a lot of people might think these things, but I don’t think as many of them would follow through” (541-546, p.22).</i></p> <p>Blair described that it may only take a ‘bad day’ for him to act on such thoughts and he reflected on the consequences that his actions would have on those around him as Blair particularly feared letting others down if he was to lose control in this manner.</p> <p><i>“And the thing that worries me about relapse is that, I mean, it’s</i></p>	<p><i>so, em (pause) so I was out of control in myself then, sort of thing, and I just couldn’t get any respite from it at all” (117-122, p.5).</i></p> <p><i>“I was even saying to my sister yesterday there, even like cleaning the house and things like that, I mean I’m not (laughs) a housewife but all of a sudden I was made to like scrub every little square inch of everything and throw out perfectly good kitchen utensils and everything like that” (214-219, p.9).</i></p> <p><i>“I was constantly being told what to do and what not to do and constantly getting a lot of negative criticism and everything sort of thing so, so it just, I mean it made it impossible to do anything” (214-216, p.9).</i></p> <p>The most concerning aspect of losing control for Catherine was the fear of becoming suicidal again and having had personal experience of the effects of suicide due to bereavements, she was aware of how that could affect those around her.</p>	<p><i>experience, but then when it turned into psychosis (pause) hearing voices and things like that happened all the time, and it’s just, aye, just a fear of going back to that and having to live with that again” (128-133, p.6).</i></p>

	Michael	Blair	Catherine	Jane
	<p>control his experiences was tied with a strong sense of helplessness due to feeling unable to effect any change to his circumstances, resulting in the belief that life was futile.</p> <p><i>"So you feel defeated by your thoughts and defeated by your physical reactions, kind of thing" (278-279, p.13).</i></p> <p><i>"Just a sense that everything that I'd tried hadn't worked and that that led to a feeling of things being futile because I felt as though the battle was too big, em, for me to win" (205-206, p.10).</i></p>	<p><i>fine to have loads of really good days, but if that's how you feel on a bad day then, you could end your life, you could do something stupid, you could hurt other people around you, do you know what I mean, things like that, that concerns me. It's not just about me. I've got loads of people that care about me as well" (485-489, p.20).</i></p>	<p><i>"At the point where I felt suicidal, I was told what to do, to kill myself, when I went through and did what I was told to do, sort of thing, em, sort of thing, so, so, losing control was very much, you know, like that" (227-229, p.10).</i></p> <p><i>"I think the worst part would, if it became like that, I might become suicidal again, I think that could be the worst. I don't think there's anything worse than that really, sort of thing" (235-236, p.10).</i></p> <p>Relapse was also associated with the potential for loss of control in public, which may have reflected Catherine's underlying fears of shame or embarrassment that this could incur. This also appeared to be tied with Catherine's awareness of stigma and potential negative attitudes towards people who had experienced psychosis. Earlier in her recovery, such fears had led to a prolonged period of avoidance.</p> <p><i>"I would worry that, I don't know, just losing control in public and things as well" (314-315, p.13).</i></p> <p><i>"I actually, I stopped going out so much, sort of thing, so I did stay at</i></p>	

	Michael	Blair	Catherine	Jane
			<i>home more. I kept myself to myself more eh.. at that stage" (326-327, p.14). "But em, it did stop me from socialising" (329-330, p.14).</i>	

Appendix 2.8 Research Proposal

How do individuals experience and make sense of psychosis recurrence: an interpretative phenomenological analysis

Introduction

There are varying definitions of relapse in psychosis, however, it has generally been accepted that relapse involves the recurrence or exacerbation of positive symptoms (Burns, Fiander & Audini, 2000) and is often associated with negative outcomes. For example, psychotic symptoms can be highly distressing and disorientating (Tan et al, 2014) and a common finding from the literature is the distressing nature of hospitalisation (Berry et al, 2013). Indeed, some people experience coercive treatments including involuntary hospitalisation, use of restraints and forced medication (Paksarian et al, 2014) and service users have described the negative impact of loss of freedom and privacy (Tan et al, 2014). Moreover, a survey of service users with schizophrenia indicated that approximately one third of individuals reported that fear of coercion was a barrier to future help-seeking (Swartz, Swanson & Hannon, 2003). Relapse can also result in social disadvantage, for instance, breakdown in social, vocational and interpersonal functioning (Gumley & Schwannauer, 2006; Tan et al, 2014).

It is also well recognised that family members or carers of individuals with psychosis experience significant distress, including symptoms of anxiety and depression (Martens & Addington 2001; Lobban & Barrowclough, 2009). In a sample of 60 relatives of individuals with schizophrenia, 55% experienced clinically significant distress (Barrowclough, Tarrier & Johnston, 1996). This can extend to healthcare professionals involved in service users' care, who may experience disappointment, self-criticism or frustration in response to relapse (Gumley & Schwannauer, 2006). Relapse also has wider implications including significant economic burden, particularly due to increased unplanned hospital admissions (Knapp, Mangalore & Simon, 1997; Almond et al, 2004; Hong et al, 2009).

Studies have highlighted that early signs of relapse can be identified within a period of a few weeks prior to full relapse of psychosis, as indicated by subtle changes in thought, emotion, physiology and behaviour (Herz & Melville, 1980, Birchwood et al, 1989). These changes may include anxiety, low mood, withdrawal, insomnia and low-level psychotic symptoms (Birchwood et al, 1989; Birchwood, Spencer & McGovern, 2000). A review of eleven prospective studies investigating the validity of these early warning signs in predicting relapse indicated modest predictive validity (Eisner, Drake & Barrowclough, 2013).

Psychological conceptualisations have prioritised the role of cognitive appraisals in understanding transition to relapse. Thurm and Haefner (1987) proposed that individuals face adaptational demands as a result of their illness and subsequent cognitive appraisals influence coping strategies, which may then impact the course of symptoms. For instance, appraisals of lack of control over symptoms can lead to decreased use of adaptive strategies resulting in acceleration of relapse. Birchwood (1995) similarly suggested that meanings or appraisals of early symptoms can either accelerate or decelerate the transition into relapse.

He suggested that fear and depression result from either impending relapse of psychosis, or the inability to explain unusual experiences or subtle changes, respectively. Moreover, Gumley, White and Power (1999) proposed that activation of implicational meanings (for example, schemata or beliefs about illness) related to symptoms associated with emerging psychosis can lead to fear of impending relapse. This may result in negative outcomes including anxiety, worry and hypervigilance which may hasten relapse.

Gumley and MacBeth (2006) have developed a trauma-based psychological model in understanding relapse. They suggested that catastrophic appraisals of low-level cognitive changes combined with autobiographical memories of distressing experiences of psychosis can influence emotional dysregulation. As a result, maladaptive strategies to cope with such distress can accelerate relapse. Based on this model, the Fear of Recurrence Scale (Gumley & Schwannauer, 2006) was developed which focuses on individuals' appraisals of relapse, as opposed to measuring symptoms only. The scale has three factors: 'Intrusiveness', 'Awareness', and 'Fear of Recurrence.' Research implementing this measure has shown that monitoring fear of relapse was as sensitive to the detection of relapse in psychosis as monitoring early warning signs (Gumley et al., 2015). Fear of relapse could therefore be considered a precursor to relapse perhaps due to individuals' catastrophic appraisals of low-level cognitive and emotional changes. It was suggested that an increase in awareness, fears about hospitalisation and intrusive thoughts or memories of psychosis could be associated with psychosis relapse.

Indeed, it has been suggested that individuals who fear relapse of psychosis are more likely to have had traumatic or distressing experiences of psychosis and hospitalisation, potentially resulting in symptoms of Post Psychotic Posttraumatic Stress Disorder (PP-PTSD; White & Gumley, 2009). A recent systematic review of the literature showed that 42% of individuals reported symptoms of PTSD and 30% of individuals met diagnostic criteria for PTSD within two years of a first episode of psychosis highlighting the long-lasting negative outcomes of psychosis (Rodrigues & Anderson, 2017). White and Gumley (2009) proposed that fear of relapse may be associated with increased avoidance of trauma-related stimuli, for example, memories or places that provoke the original trauma. This avoidance could possibly influence help-seeking behaviours. Indeed, as a result of past experience, some individuals might refrain from help-seeking or contacting services for fear of hospital admission (Gumley et al., 2003).

The findings outlined in the literature suggest that fear of relapse may be an important clinical construct in understanding the transition to relapse. However, relatively little is known about the phenomenology of fear of relapse in psychosis and whether this may be a discrete form of emotional dysfunction. Interestingly, a qualitative study exploring the experience of depression following first episode psychosis identified that during this period individuals reflected on the episode and the subtheme 'fear of relapse' was identified which the authors linked to fear of shame, feelings of powerlessness and social withdrawal or isolation (Sandhu et al, 2013). However, to date there has been no qualitative and in-depth exploration of fear of relapse. The current study therefore seeks to explore experiences of fear of relapse to understand its phenomenology.

Aims

The aim of the proposed research is to explore experiences of psychosis and fear of relapse amongst people who have experienced an episode of psychosis.

Research Question

How do individuals who have experienced psychosis describe and make sense of worry or fear of relapse?

Plan of Investigation

Participants

A purposive sample of between six and ten participants aged 16 and over will be recruited from NHS Ayrshire and Arran Community Mental Health Teams (CMHT) within three localities; North, South and East Ayrshire, within mental health inpatient services, community addictions services and forensic community mental health services

Recruitment Procedures

The proposed recruitment procedure will involve liaising with consultant psychiatrists, consultant clinical psychologists and the team leaders within services to inform them of the proposed research, and to enlist their support in recruitment within their service. We will also liaise with team leaders of inpatient services. At the outset, we plan to speak with teams to enquire about attending a multi-disciplinary team meeting within each locality to share information about the study. Attendance at the meeting would involve a presentation of the research and discussion about recruitment with the team members. Staff will be provided with further information to support their identification of potential eligible participants. Staff information sheets can be provided, and study leaflets can be provided to staff to give to potential participants who are interested in participating in the study. Permission will also be sought to display posters advertising the study in CMHT waiting areas, to publicise the study. If staff identify an individual as eligible and they are interested in participating in the study, they will be informed that they can contact the researcher directly and will be provided with the researcher's contact details. Alternatively, with the potential participant's permission, they can provide staff with their contact details to give to the researcher who will then make contact with the individual. Written confirmation of this permission to contact will also be obtained through use of a notice of interest form.

Inclusion Criteria

- Participants must be over 16 years of age.
- Participants will be recruited with a diagnosis related to symptoms of psychosis, e.g. Schizophrenia.
- Participants will have experienced a previous episode of psychosis and self-report as being worried about relapse.

Exclusion Criteria

- Individuals who do not have capacity to consent.
- Individuals experiencing acute psychosis.
- Individuals whose understanding of English would require use of an interpreter.

Design

The study will be qualitative in design, using Interpretative Phenomenological Analysis (IPA) to analyse the data. IPA has theoretical foundations in phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009). Phenomenology is concerned with a detailed account of an individual's experience as it is subjectively perceived. This involves bracketing preconceptions through a shift from the taken-for-granted *natural attitude* to the *phenomenological attitude* (Eatough & Smith, 2017). A phenomenological approach therefore is not influenced by predetermined hypotheses but wishes to understand as closely as possible, the lived experience of a phenomenon as it appears on its own terms (Smith & Osborn, 2015), in this case, experiences of psychosis and fear of relapse.

Hermeneutics involves the act of interpretation and in IPA it is recognised that the researcher and their personal attitudes or beliefs play an active role in this process. A double-hermeneutic is involved, as described by Smith and Osborn (2015; p.26) "The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world." Therefore, the process of 'epoche' or bracketing of the researcher's own preconceptions or assumptions is particularly important, alongside reflexivity and awareness of the impact of the researcher on the knowledge gained from the study (Langdridge, 2007).

Idiography focuses on an individual's personal meaning-making regarding a particular experience or phenomenon; it is concerned with rich detail as opposed to making broad generalisations across the population (Smith, Flowers & Larkin, 2009). Therefore, in line with the theoretical foundations of IPA, the current study seeks to investigate the phenomenology of psychosis and fear of relapse. It will investigate how individuals make sense of their experiences to understand how this phenomenon appears, and how it may be subsequently delineated.

Procedure

Data collection

Data collection will involve conducting in-depth, semi-structured interviews. This provides the participant with space for exploration and flexibility as an "experiential expert" to talk openly about their experiences (Smith & Osborn, 2015; p.31). Open questions will facilitate this approach with prompts used when necessary. An interview guide will be developed relating to participants' understandings and definitions of relapse, appraisals of experiences of psychosis and relapse, and the impact of these on affect, physiology, behaviour and interpersonal functioning.

The interviews will be recorded using a digital audio recorder. The interviews on the recorder will be retained during the study until its completion and will then subsequently be deleted. The interviews will be transcribed on a University of Glasgow password-protected server which only the researcher has access to. Documents with personally identifiable information will be stored in locked cabinets within the academic supervisor's office at Gartnavel Royal Hospital and will be transferred using a securely locked bag. Research data will be retained for 10 years, as per the policy of University of Glasgow.

Data analysis

The interviews will be recorded and transcribed verbatim. Following transcription, the data will be analysed using the principles of IPA as documented in Smith, Flowers and Larkin (2009). This involves closely reading and re-reading transcripts to identify emergent themes and possible connections across themes. Cases will be analysed one-by-one before exploring patterns to develop a structure of the relationship between themes.

Justification of sample size

Unlike quantitative research which relies on large representative samples, IPA is an idiographic approach, aimed at gaining rich detail of participants' experiences of a phenomenon. Therefore, a homogenous sample will be purposively selected with a suggested guide of between four and ten participants for a doctoral thesis (Smith, Flowers & Larkin, 2009).

Settings and equipment

Participants will be interviewed on NHS Ayrshire and Arran premises. A digital voice recorder will be required, which can be borrowed from The University of Glasgow to record interviews and an encrypted laptop with software for analysing qualitative data will be required.

Health and Safety Issues

Interviews will be conducted one-to-one in an NHS setting within work hours and with colleagues on site at the time of interviewing. The interviews will be conducted according to local health and safety procedures. Where possible, a mutually convenient time and location for the appointment will be arranged with the participant prior to sending out an appointment letter. If the participant does not have a key worker, the researcher will seek to arrange the interview in an appropriate clinical space, where the participant is usually seen for psychiatric review if possible. If this is not possible, an appointment will be arranged as close as possible to where the participant is usually seen. Prior to conducting the interviews, there will be discussion with the participant's care team and if there is any indication that a participant may benefit from having support at the interview (e.g. CPN or support worker), this can be arranged, particularly if the participant might feel uncomfortable attending alone, may require emotional support, or whether it is advised that they require 2:1 contact.

It is recognised that the study will involve participants' accounts of potentially traumatic or distressing experiences. As such, procedures will be in place if participants become distressed during interviewing such as offering breaks, informing the participant that they can opt out of answering questions should they experience distress and suspending the interview. Participants will be informed that they can withdraw at any point during the research.

Ethical Issues

Prior to conducting the interviews, service users will have the choice of participating if they wish to. Potential participants will be provided with written information about the study to enable them to provide fully informed and written consent. This information will summarise the study and inform individuals that they have the right to withdraw from the study at any point without providing a reason and withdrawal will not impact the care/treatment they

receive. Participants will also be informed that they can gain access to results of the study if so desired.

Confidentiality procedures will be adhered to, including limitations to this. For instance, if concerns regarding safety or risk are indicated there will be a duty of care to the participant to breach confidentiality. If this occurs there will be an open discussion with the participant about why this information is required to be shared and who they would want this information to be shared with, e.g. key worker or Psychiatrist. Prior to conducting the interviews there will be an opportunity to liaise with staff and any information that contributes towards risk assessment will be considered. The participants' clinical care team may also wish to document contact with the researcher in the participants' case notes.

Consent to digitally record the interviews will also be requested. Participant data will be anonymised, and participants will be given the choice of consenting for anonymised use of their data within the written thesis, including direct quotations.

Financial Issues

Printing and photocopying costs will be estimated for the development of resources required for the study. A digital audio recorder and transcription pedal will also be required.

Timetable

- Proposal (draft) – June 2018
- Systematic review outline – July 2018
- Proposal (final) – September 2018
- Ethics application and attendance at ethics committee – February-July 2019
- Recruitment and data collection – August-November 2019
- Data analysis – December-January/February 2019-2020
- Report submission – February 2020

Practical Applications

Having a clearer understanding of the phenomenology of fear of relapse could assist clinicians to systematically identify those at risk of relapse which could inform psychological intervention. The study will also provide important perspectives of service users which may act as a resource for informing future research or relapse prevention approaches. A detailed, descriptive account of fear of relapse could contribute towards developing a screening test or questionnaire for clinical practice. The current Fear of Recurrence Scale (Gumley & Schwannauer, 2006) is potentially limited in that it does not grasp specific emotions, physiology and safety-seeking behaviours; a further idea is that the study could provide a basis to develop a measure including these factors. Lastly, the research may form the basis of a study investigating the development of the phenomenology over time.

Dissemination

The research will be developed into a written thesis and will be made available to the public on the University of Glasgow's Enlighten website. The study may also be published in a scientific research journal and may be disseminated at conference presentations following its completion.

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Appendix 2.9 COREQ Checklist for this Study

COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	65
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	66
Gender	4	Was the researcher male or female?	66
Experience and training	5	What experience or training did the researcher have?	66
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	63
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	64
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	62/65
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	62-63
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	63
Sample size	12	How many participants were in the study?	63
Non-participation	13	How many people refused to participate or dropped out? Reasons?	63
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	65
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	65
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	113-115
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	65
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	65
Field notes	20	Were field notes made during and/or after the interview or focus group?	67
Duration	21	What was the duration of the interviews or focus group?	65
Data saturation	22	Was data saturation discussed?	66
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	65-66
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	65-66
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	68-81
Data and findings consistent	30	Was there consistency between the data presented and the findings?	68-81
Clarity of major themes	31	Were major themes clearly presented in the findings?	68-81
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.