A qualitative study of people's experiences of sleep and paranoia

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Declaration

This work has not been submitted for any other degree or to any other institution

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Contents

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Abstract

This thesis comprises of a literature review and a research report. The literature review utilised meta-methodology and meta-synthesis to generate a contextualised account of the subjective experience of psychosis from Interpretative Phenomenological Analyses (IPA) research. In the meta-methodology, 25 papers were systematically reviewed for methodological and contextual data. In the meta-synthesis, 23 accounts pertaining to the experience of psychosis were synthesised. The review generated four themes relating to the experience of psychosis: 1. shattered reality, 2. being labelled with psychosis, 3. regaining control, and 4. understanding and rebuilding. The meta-synthesis themes indicated cognitive processes, explanatory models and recovery processes in psychosis. In addition two methodological points, reflexivity and diversity were highlighted. These findings have implications for research and clinical practice, particularly pertaining to empowering approaches in recovery. The second part of this thesis was an IPA study exploring the experience of psychosis and sleep problems in eight people who self-identify as experiencing these phenomena. Three superordinate themes emerged from the analysis: 1. a mind which won't switch off, 2. the impact of living with a mind which won't switch off, and 3. trying to getting relief. These themes indicated that people who experience paranoia and sleep problems described lifelong experiences of sleep and paranoia. Insomnia, nightmares, worry and vigilance to threat were pervasive and exhausting experiences for participants. These experiences had a wide ranging impact on daily functioning, relationships and wellbeing. Strategies, such as meditation, were helpful to 'calm the mind'. Currently, it was felt that there is inadequate understanding or support for people with these experiences, particularly concerning sleep. The clinical implications of using interventions to target specific difficult experiences, such as nightmares, and identifying individuals 'at-risk' were discussed.

Part 1. ‘The experience of psychosis’: a meta-methodology and meta-synthesis of Interpretive Phenomenological Analysis research

Abstract

Objective: This review used meta-methodology and meta-synthesis to produce a contextualised, synthesised account of the subjective experience of psychosis from Interpretative Phenomenological Analysis (IPA) research.

Method: A literature search was undertaken for IPA literature researching the experience of psychosis. Papers were screened for eligibility and assessed for quality. Twenty-five papers were included in the meta-methodology and 23 papers were selected for the meta-synthesis. Paterson and Canam's (2001) meta-methodology approach was used to guide a critical analysis of the contextual and methodological background to the experience of psychosis portrayed in IPA studies. Walsh and Downe's (2005) procedure for meta-synthesis was used to generate a synthesised narrative of the subjective experience of psychosis from the IPA literature.

Results: The meta-methodology analysis indicated that IPA is predominantly used by psychologists in the United Kingdom in the study of psychosis in White British participants from in an adult mental health setting. The meta-synthesis generated four themes relating to the experience of psychosis: 1. shattered reality, 2. being labelled with psychosis, 3. regaining control, and 4. understanding and rebuilding.

Conclusion: Two key methodological limitations, lack of diversity and reflexivity, were considered. The meta-synthesis themes were discussed in the context of literature, in particular relating to cognitive processes, explanatory models and recovery in psychosis. A number of clinical implications and future research directions were discussed.

Introduction

Psychosis is a psychiatric term used to describe a condition characterised by perceptual and thought disturbances (McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2009). Experiences commonly conceptualised as psychosis include hearing voices, seeing or feeling things others cannot see, suspicious or paranoid thoughts and beliefs which others do not share (BPS, 2014). These experiences may lead to the feeling of losing contact with consensus reality.

Psychotic experiences are distributed across a continuum in the population from mild to severe (Johns & van Os, 2001; Verdoux & van Os, 2002). At the mild end of the continuum, experiences are common, for example, suspiciousness and perceptual disturbances (Freeman, 2007; Nuevo et al., 2012). At the severe end, experiences are less common, such as persecutory delusions and hearing voices (Bebbington, McBride, & Steel, 2013; Ohayon, 2000). The diversity of psychotic experiences has led to much debate about the validity of psychosis and psychotic disorders (e.g., schizophrenia) as coherent disease constructs (Bentall, 2004). In clinical practice, a symptom-focussed approach has been increasingly adopted in understanding and working with psychosis (Hagen, Turkington, Berge, & Gråwe, 2010). This approach recognises the diversity in individual experiences of psychosis, and targets theoretically-driven interventions at specific experiences (e.g., delusions; Foster, Startup, Potts, & Freeman, 2010). Recently published guidelines for psychological practice with people who experience psychosis and schizophrenia highlighted the importance of recognising individual experiences and the meaning of those experiences for the person (BPS, 2014).

Qualitative research and ‘lived experience’

Reflecting the trend in clinical practice, research has focussed on understanding the diverse, individual differences in the experience of psychosis (Birchwood, 2003). Qualitative approaches are particularly suited to exploring the rich heterogeneity of psychotic experiences and capturing what these experiences mean to people (Smith, 2007). In recent years, a large corpus of qualitative research has attended to the subjective experience of psychotic phenomena (see McCarthy-Jones, Marriott, Knowles, Rowse, & Thompson, 2013, for a recent review). The first-person perspective provides insight to 'what it is like' to experience psychosis. This valuable perspective has potential to deepen conceptual knowledge and contribute to the development of theoretical models and clinical practice.

Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) is a qualitative approach commonly utilised to investigate lived experience. The epistemological background of IPA makes it a salient methodology for studying the first-person experience of psychosis. IPA is strongly grounded in the principles of phenomenology, the philosophy of lived experience (Smith et al., 2009). In IPA methodology, phenomenology is reflected in the focus on subjective experience. IPA research often aims to investigate 'what it is like' to experience a phenomenon. In addition to phenomenology, IPA is based on hermeneutics, the theory and practice of interpretation. In IPA, to access the meaning of lived experience, it is necessary to engage in a process of interpreting the experience of the participant. The process of interpretation in IPA is described as a 'double hermeneutic'; the researcher making sense of how the individual makes sense of an experience (Smith, 2011). The final principle of IPA is that it is idiographic, reflected in the detailed investigation of each case (Smith et al., 2009). This idiographic approach aims to 'give voice' to the individual; producing a detailed and nuanced account of each participant's experience of the phenomena in question (Larkin, Watts, & Clifton, 2006).

Literature review of IPA research about the experience of psychosis

IPA research possesses a valuable insight to the experience of psychosis. Moreover, there is a growing body of research utilising IPA to study the experience of psychosis. Currently, the generalisability and impact of IPA-psychosis research on policy and clinical practice is limited, due to the small number of participants, and specific populations and setting in each study (Finfgeld-Connett, 2010). This current review aimed to increase the generalisability of the IPA-psychosis literature through the use of meta-methodology paired with meta-synthesis. As the IPA-psychosis research had not been reviewed before, a meta-methodology approach was used to critically evaluate how IPA is applied in this field and to explore how it shaped knowledge about the experience of psychosis. Meta-methodology, developed by Paterson and Canam (2001), aims to systematically examine the application of qualitative research methodology in a body of literature. Contextual data was derived from the analysis, and was used to explore how the methodology influences the results. The process involved deconstructing the methodology; examining the participants, setting, researcher and other contextual variables. Meta-synthesis, based on Walsh and Downe's (2005) method, was used to review and synthesise the different narratives about the experience of psychosis in the IPA literature. This method produced the synthesised account of the first-person perspective of the experience of psychosis.

Aims

The aims of this literature review were to:

- Use meta- methodology to critically examine how IPA has been applied to the study of psychosis and how this shapes knowledge about the phenomenon.

- Perform meta-synthesis to produce a synthesised account of the experience of psychosis from the IPA literature.

- To discuss the clinical implications of the findings about the experience of psychosis.

Method

The literature review had 4 stages: 1. the literature search, 2. selection of papers, 3. meta-methodology based on Paterson and Canam's (2001) procedure for meta-study, 4. meta-synthesis based on Walsh and Downe's (2005) procedure for synthesising qualitative literature.

Literature search

Literature searches were conducted using the databases Scopus, PsycINFO and Medline Pubmed between November 2014 and March 2015. Papers published between 1996 and 2015 were included in the search, based on the publication year of the first IPA paper (Smith, 2011).

Keyword searches were conducted using combinations of two categories of search terms: (a) psychosis, (b) IPA (Table 1). Papers were only included if they contained at least one keyword from each category (e.g. “hearing voices” AND “IPA”). The databases were searched for relevant terms in the title, abstract or keywords. Papers were also sourced from forward citation searches and reference lists of the retrieved papers.

Table 1.

Search terms

Psychosis searches	IPA searches
abnormal experiences	interpretative
abnormal belief	interpretive phenomenological analysis
anomalous experiences	interpretative phenomenological analysis.
auditory hallucinations	IPA
bipolar disorder	phenomenology
brief psychotic disorder	phenomenological
delusions	
drug induced psychosis	
drug-induced psychosis	
grandiose delusions	
hallucinations	
hearing voices	
mania	
manic	
manic depression	
paranoid schizophrenia	
persecutory delusions	
psychosis	
psychotic	
psychotic depression	
substance induced psychosis	
substance-induced psychosis	
schizoaffective disorder	
schizophrenia	
spiritual crisis	
thought disorder	
visual hallucinations	
visions	
voice hearing	
voice-hearing	

Inclusion/exclusion criteria. Papers were included in the review if: (a) the study used IPA to explore the experience of psychosis, (b) it was published in a peer-reviewed journal. Papers were excluded from the review if: (a) the paper was a conference report, abstract, review article or discussion paper, (b) the paper was not available in English.

Selection of papers.

Through keyword searches of the databases and other sources 1034 papers were identified. The title and abstract of these papers were screened for the exclusion and inclusion criteria, and duplicates were removed. The majority of papers removed at this used the abbreviation 'IPA' to mean something other than Interpretative Phenomenological Analysis. Based on the screening process, 994 papers were excluded. The remaining 40 papers were read in full to determine eligibility for inclusion in the review. Any papers which did not meet the criteria for the review were removed, 15 papers were excluded at this stage. Most of the papers removed at this stage did not primarily focus on the experience of psychosis. The final number of IPA papers included in the meta-methodology was 25. Based on quality appraisals, performed in the meta-methodology analysis, two papers (de Wet et al., 2014; Johnstone et al., 2009) were excluded from the meta-synthesis, leaving 23 papers in the final synthesis. The literature search and selection process is depicted in the PRISMA flow diagram (Liberati et al., 2009) below (Figure1).

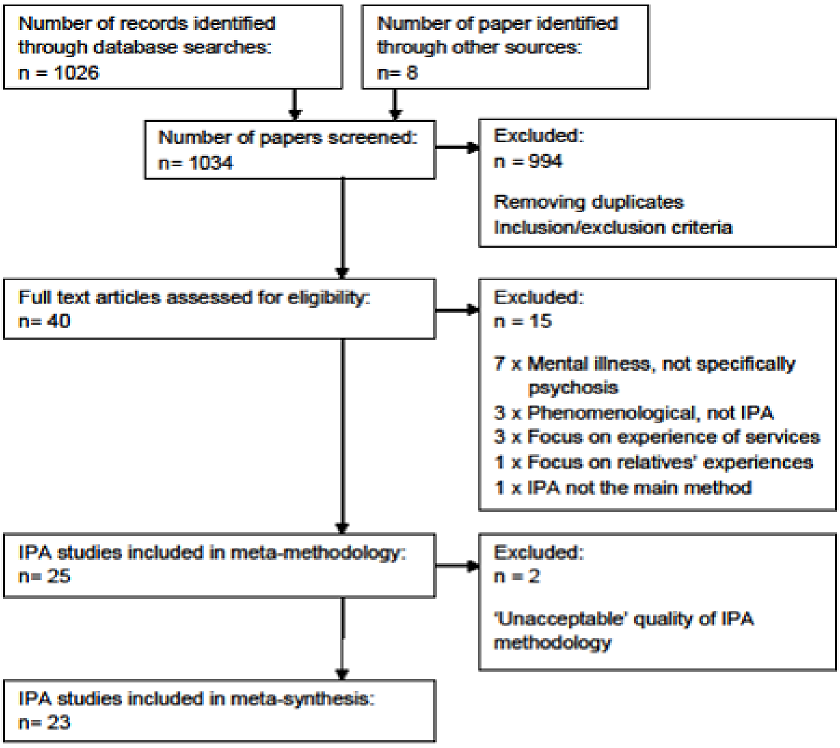

Figure. 1. **PRISMA flow diagram for the selection process of papers in the review**

Meta-methodology procedure

The 25 papers included in the meta-methodology were reviewed using a research appraisal tool based on Paterson and Canam's (2001) meta-study protocol. The appraisal tool guided a systematic review of the key methodological features (participants, setting, researcher, data collection, data analysis and quality) and the experience of psychosis in each study. The key features of the primary studies were collated into data extraction tables of the primary research features (see Appendix 2 for an example) and demographic information (see Table 2, page 12). The tables and the information from the research appraisal tools informed the analysis of the meta-methodology.

Quality appraisal. Quality was appraised using the qualitative research quality checklist from the Critical Appraisal Skills Programme (CASP; Public Health Resource

Unit, 2006; see Appendix 1) and a guide for assessing the quality of IPA (Smith, 2011; see Appendix 1). On the CASP checklist, papers were qualitatively assessed on ten areas related to quality in qualitative research. Using the guide for evaluating IPA, papers were either rated as good, acceptable, borderline-acceptable or unacceptable, based on the quality of the IPA methodology.

Five of the papers (25% of the total) were also reviewed and appraised by a peer-qualitative researcher to ensure validity of the analysis. Any disagreements about the quality were discussed and a decision was made by consensus about the quality of the paper.

Meta-Synthesis Procedure

The meta-synthesis was based on Walsh and Downe's (2005) method for synthesising qualitative research. The 23 papers were scrutinised for information about the subjective experience of psychosis. Information was taken from the primary reports and the research appraisal tools. Key metaphors, phrases or excerpts were extracted. These concepts were then collated and translated into broad clusters. The clusters were then arranged into more refined subthemes, representing different concepts in the experience of psychosis. This involved an iterative and interpretive process, engaging with the extracted content and translating the concepts into a structure for a narrative account to be based on. The subthemes were grouped into superordinate themes during this process. The superordinate themes were arranged to represent the journey through the experience of psychosis, the overarching theme of the synthesis.

Once the thematic analysis was complete, the themes were checked for validity by two people (an experienced qualitative researcher and a peer trainee psychologist). They each matched a random selection (25%) of the metaphors, phrases and excerpts from the primary studies to the subthemes and superordinate themes. Any difference in opinion was discussed and integrated into the analysis.

Results

Meta-methodology

Twenty–five papers were included in final analysis for the meta-methodology. The results of the analysis will be discussed in six sections: 1. participants, 2. researchers, 3. setting, 4. data collection, 5. data analysis, 6. quality. The data from the meta-methodology was summarised into a data extraction table (Table 2).

Table 2.

Meta methodology: Summary of participant demographics

Year	1st Author	N	Age		Gender		Ethnicity*	Place of recruitment
			Range	Mean	Male	Female		
2015	Mapplebeck	7	28-68	40	5	2	White British	National charity and support groups, England
2015	Solli	9	21-41	32	5	4	Norwegian	Closed inpatient intensive psychiatric unit, Norway
2014	De Wet	7	23-46	35.5	4	3	3 coloured & 1 white, Afrikaans 1st language; 3 coloured, English 1st language	Research unit, Cape Town, South Africa
2014	Pyle	9	19-54	23	4	5	8 White British 1 Asian	Health services, Manchester, England
2014	Solli	1	20s		1		Norwegian	Inpatient psychiatric intensive care unit, Norway
2014	Startup	8	20-54		5	3		NHS mental health teams, Oxford, England
2013	Allen	7	19-64	30	4	3	British Caucasian	Family Intervention Service, NHS mental health team, Somerset, England
2013	Kilbride	9	21-65	26	4	5	8 White British 1 Black British	8 from Early Intervention Service; 1 from CMHT, in Manchester, England
2013	Strand	12	25-63		7	5	8 Swedish 2 European 1 Middle Eastern 1 South American	Outpatient psychosis unit, in an urban area, south Sweden
2012	Harris	8	21-37		5	3	5 White British 2 White and Asian 1 White and Black Caribbean	Early Intervention Psychosis Service (NHS), covering both rural and urban areas, England
2012	Heriot-Maitland	12	C** 24-27; NC 20-63		6	6		C:2 psychosis teams in south eastern England; NC: Spirituality, medium and psychic organisations and networks, UK

Year	1st Author	N	Age		Gender		Ethnicity*	Place of recruitment
			Range	Mean	Male	Female		
2012	Taylor	6	37-59	48.5	2	4		Spiritualist National Union, England
2010	Cookson	11	19-44		7	4		Medium secure inpatient mental health unit, Liverpool, England
2010	Hayward	3	20-49		1	2	White British	Taken from a pilot trial for relating therapy, south England
2010	Redmond	8	21-31		5	3	Ethnically diverse population	3 NHS Mental Health Services in Birmingham and Wolverhampton, England
2010	Wood	8	24-35		6	2		6 from Early Intervention Service, 2 from CMHT, Manchester, England
2009	Chin	9	24-61		6	3	8 White British 1 White Scandinavian	3 CMHTs, south England
2009	Johnstone	27	27-64	43	16	11		4 CMHTs, Edinburgh, Scotland
2009	Pitt	8	18-65		6	2	6 White British 2 African Caribbean	NHS mental health groups and psychology services, West Manchester, England
2008	Evenson	10	34-67	51	10		White British	CMHTs in North and West London, England
2008	Nithsdale	8	35-56	42	4	4	White British	CMHTs in South Yorkshire, England
2007	Campbell	12	18-57	C 30.9 NC 37.5	6	5	White British	C: CMHTs in Manchester, England NC: University of Manchester student population
2007	Newton	8	17-18		3	5		Early Intervention Service, London, England
2007	Perry	5	19-25	21.8	5		White British	Mental health teams in large British city, England
2003	Knight	6	31-50	43	4	2		Recruited from a previous quantitative study on stigma, UK

Notes:
*Ethnicities are as reported in the original research papers
** C = Clinical group, NC = Non-clinical group

Participants. In the 25 studies included in the meta-methodology there were 225 participants in total. On average there were nine participants in each study (*M*= 9, *SD* = 4.44, range: 1- 27). This number is consistent with the principles of IPA, which is intended for idiographic study of a phenomenon in a small number of participants. Smith, Flowers, and Larkin (2009) state that between 3-10 participants are likely to be optimal for an IPA study, although the *n* is not prescriptive.

Interestingly, the study with one participant was an excellent example of IPA; it was a rich and nuanced account of the experience of music therapy for one man in a psychiatric intensive care unit (Solli, 2014). Conversely, the study with 27 participants was a weak analysis and a poor example of qualitative research in general (Johnstone, Nicol, Donaghy, & Lawrie, 2009). It was excluded from the meta-synthesis as it did not adhere to the principles of IPA; lacking in evidence of interpretation or hermeneutic inquiry it was more akin to thematic analysis.

All of the studies of psychosis reported some demographic information about the participants (Table 2). The extent of the demographic information and how it was used in the analysis varied widely across the literature.

All of the studies included the range of ages of participants; the overall range was 17-67. Mean age was reported in 13 studies; the overall mean age was 35.4 years. All studies reported gender mix, there was 90 women and 135 men overall, giving a gender ratio of 2:3 (women to men). Nine studies did not include information about the ethnicity of their participants. Of the remaining 16 studies (*n* = 122), the most prevalent ethnicity was White British (*n* = 87; 71%). The composition of ethnicities[1] in the UK-based studies are depicted on the graph below (Figure 2).

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[1] NB. The ethnicities are reported using the terms used in the original papers.

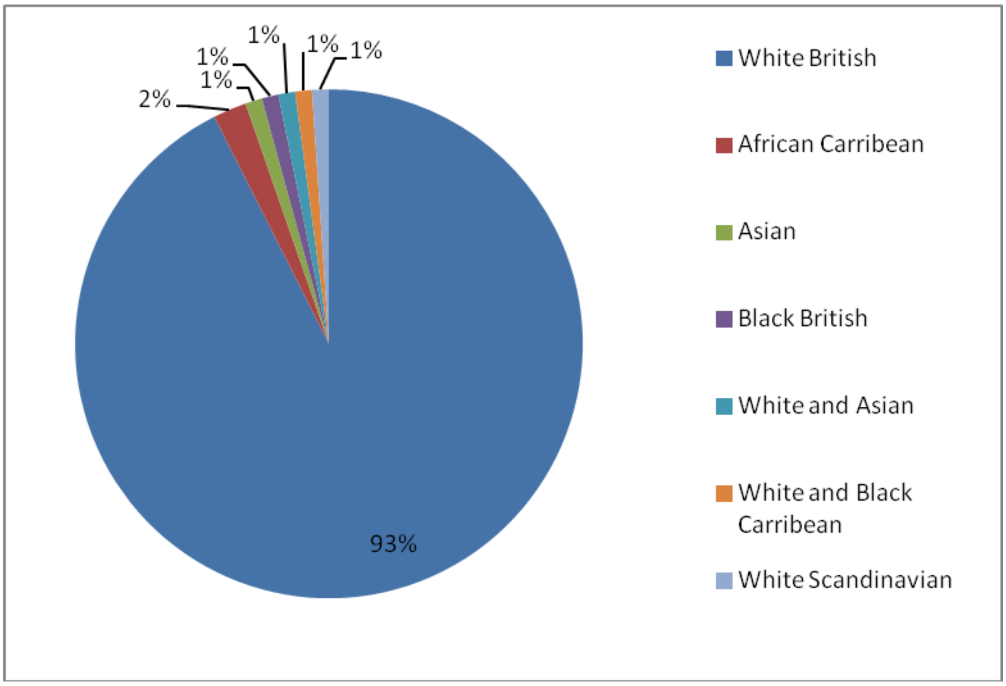

Figure 2. **Composition of ethnicities in the primary studies in the UK**

Thirteen studies included a detailed statement about participants' context and reflected on how the context may relate to the experience of psychosis (Campbell & Morrison, 2007; Cookson & Dickson, 2010; Evenson, Rhodes, Feigenbaum, & Solly, 2008; Heriot-Maitland, Knight, & Peters, 2012; Knight, Wykes, & Hayward, 2003; Mapplebeck, Joseph, & Sabin-Farrell, 2015; Newton, Larkin, Melhuish, & Wykes, 2007; Pyle & Morrison, 2013; Redmond, Larkin, & Harrop, 2010; Solli & Rolvsjord, 2015; Startup, Pugh, Cordwell, Kingdon, & Freeman, 2014). Redmond, Larkin, and Harrop's (2010) study was an excellent example. They included a section titled 'Context' where information about the participants' socio-economic and cultural environment was relayed; in this case a diverse urban setting with high unemployment. They reflect on how this may influence the results, namely that the participants are likely to be more developed and have different expectations in romantic relationships than peers in rural areas. Providing information about the context demonstrates the tenet of 'situating the sample', allowing the reader to make their own interpretations about the research findings

(Elliott, Fischer, & Rennie, 1999). This information is also valuable for applying the results of the study to specific populations in clinical practice or research or for service users themselves.

Researchers. Ten studies gave explicit contextual information about the researchers, such as their discipline or theoretical orientation (Allen, Burbach, & Reibstein, 2013; Campbell & Morrison, 2007; Harris, Collinson, & das Nair, 2012; Pitt, Kilbride, Welford, Nothard, & Morrison, 2009; Pyle & Morrison, 2013; Redmond et al., 2010; Solli, 2014; Solli & Rolvsjord, 2015; Startup et al., 2014). Three studies stated that they were led by service users or had service users in the research team (Kilbride et al., 2013; Pitt et al., 2009; Wood, Price, Morrison, & Haddock, 2010). There was generally a lack of reflexivity in the IPA literature. Eleven studies included a cursory statement to highlight their use of independent audits, supervision or a reflexive journal, to aid reflexivity (Allen et al., 2013; Harris et al., 2012; Heriot-Maitland et al., 2012; Mapplebeck et al., 2015; Nithsdale, Davies, & Croucher, 2008; Pitt et al., 2009; Pyle & Morrison, 2013; Redmond et al., 2010; Solli, 2014; Solli & Rolvsjord, 2015; Wood et al., 2010); however none of the studies gave examples or explicitly wove reflexive ideas into their discussion or analysis.

Although overall reflexivity was weak, there were exceptions. Five of the studies were explicit about researchers' contexts and beliefs. Pyle and Morrison, (2013) included a section titled 'Credibility' stating their clinical background and research interests. The service user-led studies all considered the advantages and disadvantages of a service user inclusive approach and were reflective about the impact on analysis (Kilbride et al., 2013; Pitt et al., 2009; Wood et al., 2010). Nithsdale, Davies, and Croucher (2008) stood out in their use of researcher reflexivity. The lead researcher declared her age, ethnicity and socioeconomic status, her dominant theoretical influences (critical psychiatry and person-centred) and her clinical background (Nithsdale et al., 2008).

Setting. Most of the papers originated from the United Kingdom (UK), 20 from England and one from Scotland, two papers were from Norway (both by the same author), one was from Sweden and one from South Africa. Most of the papers were from university psychology or psychiatry departments, or NHS mental health services in the UK.

The studies were published between 2003 and 2015, predominantly between 2007-2015 (Figure 3).

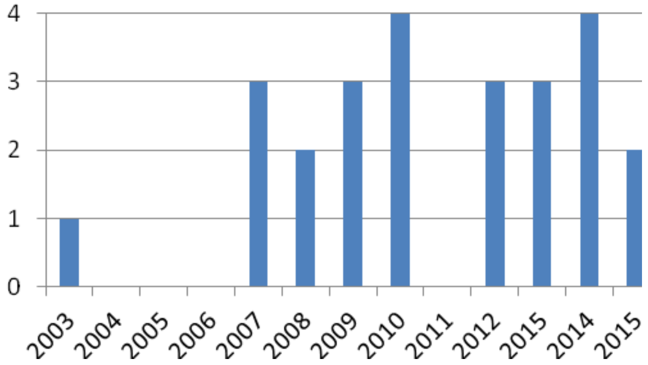

Figure 3. **Number of papers published by year**

Participants were recruited from a number of settings: nine recruited participants from community mental health teams, four from early intervention services, four from inpatient settings, three from psychology therapy services, three from charity/non-statutory sector, and one from university students. Three of the studies included ‘non-clinical’ participants. The non-clinical participants were people who experienced paranoia (Campbell & Morrison, 2007) and hear voices (Heriot-Maitland et al., 2012; Taylor & Murray, 2012).

Data collection. All the studies used semi-structured interviews for data collection. Solli's (2014) single-case study was the only example to use a variety of sources for data collection. The participant was not consistently able to communicate about his experiences. Consequently, the researcher creatively used 2 semi-structured interviews, observation, case notes, recordings from the music therapy sessions, and a log book of the sessions as material for the single-case analysis.

Across all the studies, the interviews were cited to be ‘flexible’ and using ‘open ended questions’, reflecting the principles of IPA (Smith et al., 2009). Two studies provided the full interview schedule or topic guide in the Appendix (Campbell & Morrison, 2007; Startup et al., 2014).

Five papers discussed difficulties they encountered in data collection and how they modified their approach (Newton et al., 2007; Perry, Taylor, & Shaw, 2007; Solli, 2014; Solli & Rolvsjord, 2015; Startup et al., 2014). Newton, Larkin, Melhuish, and Wykes, (2007) discussed difficulty obtaining rich accounts from young people with psychosis, and how they amended their approach. The studies led by service users reflected on the impact of having a service user interviewer; particularly the benefits of building rapport and openness (Kilbride et al., 2013; Pitt et al., 2009; Wood et al., 2010).

Data analysis. All of the studies, apart from one, included descriptive statements about their procedure for data analysis based on Smith (1996), Eatough and Smith (2008), or Smith et al., (2009). One paper did not cite an IPA reference, and did not adhere to the principles of IPA in their analysis (de Wet, Swartz, & Chiliza, 2014). Some papers excelled in analytic transparency. Taylor (2011) gave a demonstration of how they used interpretation by providing a worked example. Kilbride et al. (2013) were transparent about the ‘collective standpoint’ of their mixed research team (service users and professionals) and how they managed this in the process of analysis. All of the studies cited the use of credibility checks or audits in the data analysis process. No studies asked participants to validate the themes. Strand, Olin, and Tidefors (2013) was the only paper to state that they did not do this in their limitations.

Quality. Based on the guidelines for assessing the quality of IPA (Smith, 2011) six papers were ‘good’, eight papers were ‘acceptable’, nine papers were ‘borderline’ and two were ‘unacceptable’ (Table 3). The papers which were ‘good’ were well evidenced, had strong data interpretation and were good exemplars of IPA. The two papers which were deemed ‘unacceptable’ did not adhere to the principles of IPA and were insufficiently transparent in their analysis. The papers rated as ‘borderline-acceptable’ did not provide enough extracts to support their themes, or gave no indication of prevalence of themes.

Based on the CASP checklist (Public Health Resource Unit, 2006), six papers met all of the checklist criteria. Most of the papers were good examples of qualitative research, meeting most of the criteria. The area where most papers lacked, was in considering the relationship between the researcher and the participant; 15 papers provided insufficient or no detail about ‘critically examining’ the researchers’ role, or how they responded to events during the study.

Table 3.

Quality appraisal

Year	**1st Author**	**IPA quality**	**CASP quality ***
2015	Mapplebeck	Borderline	Relationship between researcher and participants Ethics approval Rigour in analysis
2015	Solli	Good	
2014	De Wet	Unacceptable	Relationship between participants and researcher Rigour in analysis
2014	Pyle	Acceptable	Rigour in analysis
2014	Solli	Acceptable	
2014	Startup	Good	
2013	Allen	Acceptable	Justification of methodology Information on data collection
2013	Kilbride	Acceptable	Information on data collection Ethics approval
2013	Strand	Borderline	Relationship between researcher and participants
2012	Harris	Good	
2012	Heriot-Maitland	Good	Relationship between researcher and participants
2012	Taylor	Acceptable	Information on data collection Ethics approval
2010	Cookson	Borderline	Relationship between researcher and participants
2010	Hayward	Borderline	Information on data collection Ethics approval Justification of methodology
2010	Redmond	Good	
2010	Wood	Borderline	Relationship between researcher and participants Information on data collection Ethics approval
2009	Chin	Acceptable	Relationship between researcher and participants
2009	Johnstone	Unacceptable	Research design is inappropriate Relationship between researcher and participants Ethics approval Rigour in analysis
2009	Pitt	Borderline	Ethics approval
2008	Evenson	Borderline	Relationship between researcher and participants
2008	Nithsdale	Borderline	
2007	Campbell	Borderline	Relationship between researcher and participants
2007	Newton	Good	Ethics approval
2007	Perry	Acceptable	Ethics approval
2003	Knight	Acceptable	Relationship between researcher and participants

Notes

*Insufficient evidence to support these categories

Meta-synthesis

The meta-synthesis analysis of the 23 IPA papers generated four superordinate themes relating to the experience of psychosis: 1. shattered reality, 2. being labelled with psychosis, 3. regaining control, and 4. understanding and rebuilding. The final table of themes are shown below (Table 4).

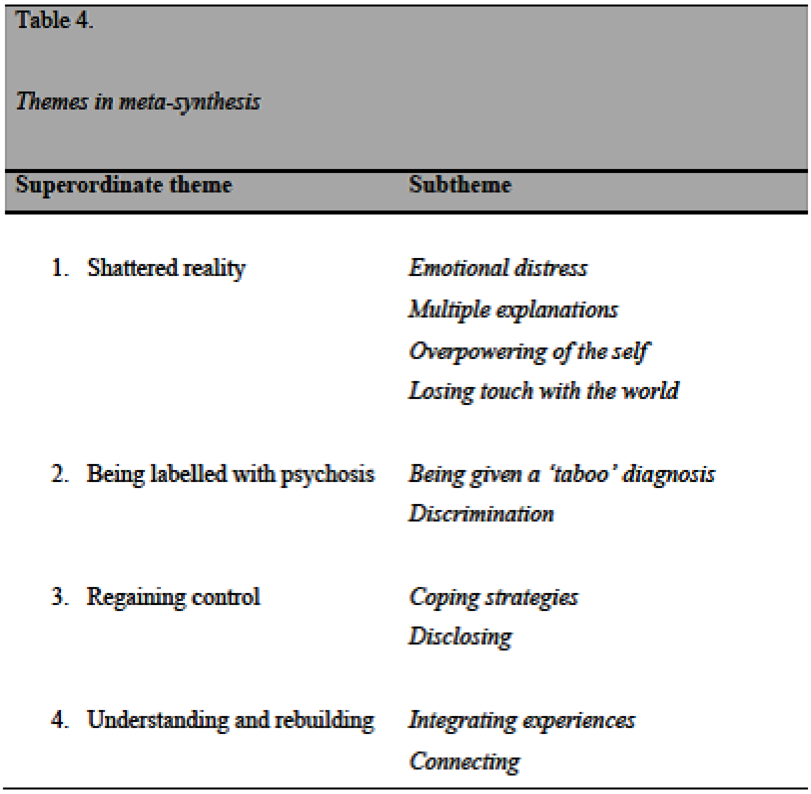

Table 4.

Themes in meta-synthesis

Superordinate theme	Subtheme
1. Shattered reality	*Emotional distress* *Multiple explanations* *Overpowering of the self* *Losing touch with the world*
2. Being labelled with psychosis	*Being given a 'taboo' diagnosis* *Discrimination*
3. Regaining control	*Coping strategies* *Disclosing*
4. Understanding and rebuilding	*Integrating experiences* *Connecting*

The themes were used to structure the narrative account of the meta-synthesis account of the experience of psychosis.

1. Shattered reality. This theme represents the shattering impact of psychosis on people's lives, sense of reality and integrity about sense of self. This process was described as a 'debilitating' (Heriot-Maitland et al., 2012) 'breakdown' (Cookson & Dickson, 2010; Newton et al., 2007) which was often the 'most difficult' time in someone's life (Wood et al., 2010). There was a constant 'battle' (Knight, Wykes, & Hayward, 2003; Solli, 2014) with psychotic symptoms and a 'struggle' to retain a grip on the consensus reality of the world (Mapplebeck et al., 2015; Perry et al., 2007).

Emotional self. Prior to the onset of psychosis-type experiences, a period of 'emotional suffering' occurred in clinical and non-clinical populations (Heriot-Maitland et al., 2012). Suffering may relate to childhood experiences, such as abuse or bullying, or more recent events, such as extreme stress or 'societal pressures'(Campbell & Morrison, 2007; Harris et al., 2012; Heriot-Maitland et al., 2012; Perry et al., 2007; Strand et al., 2013). Following the onset of psychosis or 'out of the ordinary experiences', the initial emotional response was distress for most people (Cookson & Dickson, 2010; Heriot-Maitland et al., 2012; Taylor & Murray, 2012). Worry and intense anxiety were pervasive emotions (Campbell & Morrison, 2007; Newton et al., 2007; Startup, Pugh, Cordwell, Kingdon, & Freeman, 2014; Wood et al., 2010). Some people felt threatened, unsafe and frightened, particularly if they experienced paranoia (Campbell & Morrison, 2007; Solli, 2014; Startup et al., 2014) or commanding or harassing voices (Cookson & Dickson, 2010; Newton et al., 2007; Strand et al., 2013). Some people experienced anger and frustration (Allen et al., 2013; Wood et al., 2010). It was common for people to feel cut off emotionally (Harris et al., 2012; Redmond et al., 2010; Startup et al., 2014) or 'numb' (Solli & Rolvsjord, 2015). Emotional distress or numbness led to self-harm and suicide for some (Campbell & Morrison, 2007).

Multiple explanations. This theme indicated the process of searching for an explanation for 'out of the ordinary' experiences. In the early stages of psychosis people considered multiple explanatory perspectives (Cookson & Dickson, 2010; Taylor & Murray, 2012). Explanations were often based on familiar conceptual frameworks, such as religion (Heriot-Maitland et al., 2012). There were numerous explanations for experiences, such as being controlled by jinn (Newton et al., 2007), magic (Heriot-Maitland et al., 2012), being spoken to by God (Perry et al., 2007), disease (Solli, 2014), a spirit (Solli & Rolvsjord, 2015), telepathy (Cookson & Dickson, 2010) and being 'mad'

(Newton et al., 2007). An illness explanation was generally supported by mental health professionals (Heriot-Maitland et al., 2012). In a family or social context, there may be conflicting explanatory models for conceptualising psychotic phenomena (Newton et al., 2007). Multiple perspectives were confusing and distressing, particularly when they are not concordant with each other (e.g., illness and a spiritual perspective; Heriot-Maitland et al., 2012).

Overpowering of the self. The feeling that the 'self' is controlled by external forces was common (Chin et al., 2009; Heriot-Maitland et al., 2012). The experience of 'self' being overpowered particularly related to experiences like intrusive thoughts (Solli & Rolvsjord, 2015), paranoia (Campbell & Morrison, 2007), and hearing voices (Strand et al., 2013). Psychotic experiences often led to a loss of integrity about the sense of self. This was characterised by a loss of boundaries between the mind, body and external sources. This dissolution of self-boundaries was apparent in phenomena like thought broadcasting (Heriot-Maitland et al., 2012), having thoughts projected into the mind (Cookson & Dickson, 2010), dissociation between the mind and body (Solli & Rolvsjord, 2015) and out of body experiences (Heriot-Maitland et al., 2012). Feeling out of control of experiences contributed to a lack of trust and insecurity about one's self (Allen et al., 2013; Campbell & Morrison, 2007; Chin et al., 2009). This was described by one person as "you can't rely on yourself, because it's not all that is there for real" (p80, Solli & Rolvsjord, 2015). For some people, giving up personal control to a guiding voice was a positive experience when decision-making was overwhelming (Strand et al., 2013). While for others, submission to overpowering voices contributed to risky behaviour (Cookson & Dickson, 2010).

Losing touch with the world. The experience of psychosis was often all-encompassing and overwhelming (Allen et al., 2013; Heriot-Maitland et al., 2012; Startup et al., 2014).

Due to unusual experiences, like hearing voices, the world could feel confusing and scary; withdrawal and ‘avoiding life’ were common coping strategies (Campbell & Morrison, 2007; Harris et al., 2012; Perry et al., 2007).

Psychotic experiences mean people perceived a different reality to the consensus reality and felt on a ‘different frequency’ (Cookson & Dickson, 2010; Harris et al., 2012; Newton et al., 2007). Experiencing things differently to ‘normal’ meant people felt ‘abnormal’, ‘mad’ and not understood by others (Mapplebeck et al., 2015; Newton et al., 2007; Startup et al., 2014). Losing touch was also a consequence of low motivation and some experiences (e.g., hearing voices or panic attacks; Evenson, Rhodes, Feigenbaum, & Solly, 2008; Nithsdale et al., 2008; Redmond et al., 2010).

Losing touch with the world was indicated by the prevalence of social isolation (Harris et al., 2012; Solli, 2014). Breakdowns in social networks, poorly developed social skills and a lack supportive relationships also contributed to losing touch with the world (Redmond et al., 2010; Wood et al., 2010). In addition, isolation was perpetuated by stigma and discrimination; people were avoided by others and felt judged and rejected by friends, family, colleagues and employers (Knight et al., 2003; Nithsdale et al., 2008; Wood et al., 2010).

2. Being labelled with psychosis. This theme represents the experience of being given a psychiatric diagnosis and the loss and discrimination people experience as a result of the diagnosis. These experiences were pervasive in the past present and future; people expressed long-held stigmatised beliefs about the diagnoses (Pitt et al., 2009), even after recovery the negative influence continued to be experienced (Knight et al., 2003) and there were fears that the stigma of diagnoses would continue to influence future generations (Evenson et al., 2008).

Being given a 'taboo' diagnosis. The experience of being diagnosed with psychosis or schizophrenia-spectrum diagnoses was often scary, upsetting and distressing (Cookson & Dickson, 2010). There was an 'implied hierarchy' in mental health diagnoses (Harris et al., 2012), psychosis-like diagnoses were perceived as worse than others and 'taboo' (Pyle & Morrison, 2013). Negative preconceptions related to the implication of being 'labelled' as 'mad' (Cookson & Dickson, 2010; Perry et al., 2007; Solli & Rolvsjord, 2015). Negative beliefs about psychosis were often driven by media portrayals; as one man said "schizophrenics go round murdering and raping people" (Pitt et al., 2009, p.421). Stigmatised preconceptions related to difficulty accepting diagnoses, shame and secrecy (Harris et al., 2012; Pitt et al., 2009; Pyle & Morrison, 2013). Although there were negative connotations of these diagnoses for some people, others found their diagnosis helpful. Being given a diagnosis was a relief for some people; validating their distressing experiences and opening doors to support and understanding (Pitt et al., 2009). The benefit of the diagnosis purportedly related to how the diagnosis was given. If the diagnosis was given without an explanation at a level the person comprehended or they did not feel involved in the process, it was invariably a disempowering and confusing process (Cookson & Dickson, 2010; Perry et al., 2007).

Discrimination. Discrimination was common for people who experience psychosis. Hospital admissions were a particular source of discrimination and loss. In hospital, personal identity and freedom was lost; people felt 'locked up', 'de-humanised' and depersonalised (Perry et al., 2007; Solli & Rolvsjord, 2015). Discrimination was also prevalent in employment. Work was jeopardised by diagnoses (Cookson & Dickson, 2010) and often people did not feel supported by employers (Nithsdale et al., 2008). For those without work, it was hard to attain employment (Wood et al., 2010).

3. Regaining control. Regaining control was an important step in adjusting to life with psychosis and recovery. Regaining control was often initiated by a realisation that ‘something has to change’ and a decision to take responsibility for one’s own recovery (Allen et al., 2013; Nithsdale et al., 2008). Regaining control was not necessarily characterised by remission of psychotic symptoms, but symptoms often became less intense (Wood et al., 2010) and more controllable (Chin et al., 2009), with a reduction in distress and confusion (Heriot-Maitland et al., 2012; Kilbride et al., 2013).

Coping strategies. Many of the coping strategies related to the idea of ‘being in control’ of experiences (Chin et al., 2009; Newton et al., 2007; Wood et al., 2010). Strategies included distraction (Solli & Rolvsjord, 2015; Startup et al., 2014), visualisation (Taylor & Murray, 2012), reality testing (Campbell & Morrison, 2007; Startup et al., 2014), challenging voices (Hayward & Fuller, 2010), and setting boundaries about when to engage with psychotic experiences (Chin et al., 2009; Taylor & Murray, 2012). Hobbies, a routine and self-care were also important for coping with psychosis (Harris et al., 2012; Perry et al., 2007; Wood et al., 2010).

Medication helped to gain control over experiences by reducing the intensity of thoughts and voices, or removing them all together (Chin et al., 2009; Cookson & Dickson, 2010; Newton et al., 2007). Although medication is beneficial for some people, it does not help everyone. The detrimental side effects of medication, such as tremor and dulling of emotions, outweighed the benefits for many people (Evenson et al., 2008; Pitt et al., 2009). Furthermore, medication was not effective alone, and was most effective paired with positive life changes; consequently it was frustrating when medication was the only intervention offered (Nithsdale et al., 2008; Pitt et al., 2009).

Disclosing. After ‘losing touch with the world’ it was important for people to disclose to others about their experiences as an initial step to build relationships, get support and gain self-confidence (Redmond et al., 2010; Wood et al., 2010). Disclosing about psychosis was commonly challenging; psychosis was described as a ‘strange’ experience which is hard to explain to others (Pyle & Morrison, 2013; Solli & Rolvsjord, 2015). People were fearful that others might judge them or not understand; as one lady stated about her fear of disclosing to peers at college “people take the mickey around my area, ... other people find it weird” (Newton et al., 2007, p134). Some people chose to keep their experiences a secret (Knight et al., 2003), while others chose to use less stigmatising terms, such as illness or depression (Pyle & Morrison, 2013; Redmond et al., 2010).

Following disclosure, acceptance from others was a gradual process; people need to ‘get used to’ the idea of psychosis (Cookson & Dickson, 2010). During the process of acceptance, others could be avoidant (Nithsdale et al., 2008) or not supportive (Cookson & Dickson, 2010). Despite these initial reactions, following disclosure most people ‘end up’ being supportive and ‘sharing the load’ of psychosis (Allen et al., 2013; Nithsdale et al., 2008).

4) Understanding and rebuilding. This theme represents taking the shattered self and assimilating new understanding to ‘build up again’ after the breakdown of psychosis (Harris et al., 2012). Connecting with others and getting support were integral parts of this process.

Integrating experiences. Integrating and understanding psychotic experiences was an important part of recovery (Mapplebeck et al., 2015). Developing a personally-relevant understanding of psychotic experiences was often valuable and validating (Kilbride et al., 2013; Strand et al., 2013). Understanding psychosis could involve thinking about the past, and factors preceding the onset of psychosis, and exploring the content and meaning of psychotic experiences (Harris et al., 2012; Perry et al., 2007). Integration of emotional experiences was also important. People learnt to tolerate or manage emotions which were previously overwhelming or unbearable (Allen et al., 2013). Understanding precipitants to emotional disturbance, such as stress, repressed emotions or past trauma, was also key in the integration of emotional experience (Perry et al., 2007).

Understanding and integrating experiences was framed as a life changing process of personal development (Heriot-Maitland et al., 2012; Mapplebeck et al., 2015). Integration of experiences led to increased self-awareness and self-acceptance (Mapplebeck et al., 2015). Acceptance of experiences - as ‘part of you’ – was a pivotal to integration (Chin et al., 2009). Acceptance of experiences relieved distress and lessened the exhausting ‘battle’ with symptoms (Knight et al., 2003).

Connecting with others and rebuilding relationships. Supportive relationships were important for those who experience psychosis (Allen et al., 2013; Redmond et al., 2010). A close friend or family member who understands about mental health problems was a valuable source of support (Newton et al., 2007; Nithsdale et al., 2008). In addition, it was important to have relationships where ‘illness’ was not the focus (Solli & Rolvsjord, 2015). Relationships with mental health professional were an important source of support, and for some, were their main human contact when they were isolated by psychosis (Harris et al., 2012; Nithsdale et al., 2008). Relationships with professionals were valued when individuals felt listened to and working is in ‘partnership’ (Harris et al., 2012; Nithsdale et al., 2008). Conversely, these relationships were perceived as unhelpful when people were not given choices and felt passive recipients of treatment (Solli & Rolvsjord, 2015).

Connecting with peers who had similar experiences, often in support groups, was very powerful and valued (Pitt et al., 2009; Pyle & Morrison, 2013). Connecting with peers facilitated normalisation about unusual experiences and contributed to self-acceptance (Newton et al., 2007). One man spoke about the self-acceptance he experienced because of peer support, saying “this is who I am and I am proud of who I am. Whereas before I wouldn’t have discussed it with anyone” (Pitt et al., 2009, p422).

Discussion

This is the first systematic review of the published, peer reviewed IPA research on the experience of psychosis. The aims of this literature review were to critically examine how IPA methodology is applied to the study of the first-person experience of psychosis, and to produce a synthesised narrative of the first-person experience of psychosis. These aims were achieved through meta-methodological analysis and meta-synthesis of the experience of psychosis IPA research. The final aim was to discuss the clinical implications of these findings, which will be addressed in the following discussion.

Meta-methodology

The meta-methodology analysis indicated that IPA is an increasingly popular approach for investigating psychosis in clinical and non-clinical populations, used predominantly by psychologists in the UK. Although there were two papers of poor methodological quality, generally the quality of the methodology was a good standard and consistently reflected the main principles of IPA. The meta-methodology highlighted two areas of methodological weakness across the IPA corpus: diversity and reflexivity. These methodological issues have implications for the generalisability and transferability of the findings to a wider population, clinical practice and policy. Discussion of these points is intended to contribute to development of the methodology in future research, as IPA is a relatively new and evolving research method

There was a lack of ethnic diversity in IPA-psychosis research. In the 16 IPA studies that cited the ethnicity of their participants, in the studies based in the UK, 93% were White British. The bias towards White British participants is not representative of the prevalence of psychosis in the UK population. The Psychiatric Morbidity Survey in the UK found that 1.4% of black adults, rising to 3.4% in black men, experience psychosis in their lifetime, compared to 0.4% of white adults (McManus et al., 2009). Furthermore, people from BME backgrounds are more likely to be compulsory detained under the Mental Health Act or enter hospital through the criminal justice system than people of white background (Moffat, Sass, Mckenzie, & Bhui, 2009).

It is important for research investigating the experience of psychosis to be inclusive of people in different socio-cultural contexts. Socio-cultural factors are closely tied to the experience of psychosis. The biopsychosocial model (Engel, 1980), prevalently used in the conceptualisation of psychosis in clinical practice, recognises the importance of social factors, such as religious beliefs and discrimination, in the experience of psychosis (BPS, 2000). Moreover, explanatory models for the experience of psychosis are often influenced by culture (Bhui & Bhuhra, 2002). This idea was evident in the meta-synthesis; the belief that voices are caused by 'jinn' reflects the influence of Islamic culture of the participant in Newton et al. (2007). In the IPA literature, Pitt, Kilbride, Welford, Nothard, & Morrison (2009) were the only study which considered issues specific to BME participants. In this study, about the experience of being given a diagnosis of psychosis, BME participants felt that their culture was not understood or considered in their treatment (Pitt et al., 2009).

The bias towards White British participants in the IPA literature has implications for how the IPA-psychosis literature contributes to conceptual knowledge about the experience of psychosis. Currently, the lack of participant diversity narrows the research focus to a specific population, as the literature is largely representative of the experience of psychosis in White British people. This lack of diversity in the IPA literature delimits the opportunity to generalise the experience of psychosis from these studies to a wider population, even after the results from multiple studies are synthesised.

Secondly, the area where most IPA studies failed to meet the CASP checklist criteria was ‘considering the relationship between the researcher and participant’. This indicates the lack of reflexivity which was evident throughout the IPA corpus. In IPA, researchers are encouraged to openly reflect on how their own context and interpretative frameworks influence the study. Suggested mechanisms for reflexivity are reflexive journals (Biggerstaff & Thompson, 2008) and reporting the context of the research (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2012). Some IPA-psychosis papers did adhere to these principles, reporting researcher characteristics and their interpretative frameworks, although it was not common practice.

In qualitative research it is considered good practice for researchers to demonstrate ‘owning one’s perspective’ by providing information about themselves, their theoretical orientation and values (Elliott et al., 1999). Elliot et al (1999) state that the researcher can never be truly objective in their analysis, subsequently the reader should be able to discern how the researchers’ beliefs may influence the results. In the IPA studies, the lack of reflexivity and transparency about the researcher characteristics prevents the reader from making their own critical interpretations of the research findings. This limits how trustworthy the IPA research findings are as examples of the participants’ experiences of psychosis. Furthermore, the presentation of the findings about the experience of psychosis as ‘truth’, without the use of reflexivity, moves away from the principles of IPA and is more analogous to positivist research approaches.

Meta-synthesis

The meta-synthesis generated four super-ordinate themes related to the experience of psychosis in the IPA literature: 1. shattered reality, 2. being labelled with psychosis, 3. regaining control, and 4. understanding and rebuilding. The synthesised account portrayed the experience of psychosis from the distressing and fragmenting onset of experiences, to processes in recovery, where integration and connectedness were key. The influence of stigma and discrimination were also prevalent throughout the synthesis, particularly pertaining to diagnostic labelling. The experience of psychosis in IPA research mirrors findings in the wider research literature and has implications for clinical practice.

Firstly, the concept of 'control' was prevalent in the synthesised account. In 'shattered reality' psychotic symptoms were experienced as controlling external forces, which overpowered the 'self' and contributed to 'losing touch with the world'. These finding are supported by research demonstrating appraisals of psychotic experiences as powerful and controlling are associated with negative affect and the use of avoidance strategies, such as self-isolation (Birchwood, Mason, MacMillan, & Healy, 2009; Birchwood, 2003; Freeman, Garety, & Kuipers, 2001). Furthermore, processes such as jumping to conclusions, 'external locus of control' and 'self-monitoring deficits' contribute to the attribution of power and control to psychotic experiences (Freeman et al., 2004; Harrow, Hansford, & Astrachan-Fletcher, 2009; Johns et al., 2001). In the theme 'regaining control', coping skills and medication were used to 'gain control' over symptoms. In practice-based literature from the service user perspective, interventions to increase self-esteem and coping skills, without challenging existing appraisals and beliefs about experiences, are effective to reduce the power and control of psychotic experiences (May, 2004).

The importance of individual conceptual frameworks or explanatory models to understand psychotic experiences was highlighted both at the onset of experiences, in ‘multiple explanations’, and in recovery, in ‘integrating experiences’. Explanatory models for psychosis are often culturally-bound and may not concur with a medical model explanation for psychosis (Bhikha, Chaudhry, & Hussain, 2008; Bhui & Bhuhra, 2002). In clinical practice, understanding and respecting how individuals conceptualise psychotic experiences improves engagement with services and is related to positive treatment experiences (Bhikha et al., 2008; BPS, 2014; Callan & Littlewood, 1998). Socio-cultural context should be considered when working with personal explanatory models of psychosis; avoiding the pathologising of experiences (Bassett & Baker, 2015). Developing personally-relevant understanding of psychotic experiences is valued from the service user perspective. It can be a validating experience, and an empowering step in recovery, increasing self-awareness and individual coping skills (Chadwick & Chadwick, 2008).

The experience of overwhelming distressing emotions was pervasive, particularly in early stages of psychosis in ‘shattered reality’. Birchwood (2003) stated that emotional problems are ‘intrinsic’ to psychosis. This concept is reflected in the prominent stress-vulnerability model of psychosis. In this model, emotional distress is related to the onset and maintenance of psychosis (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). In recovery, understanding and learning to cope with emotional experiences is important, as demonstrated in ‘integrating experiences’. This finding has implications for clinical practice to support people in coping with emotional distress. Research and practice evidence endorses Cognitive Behavioural Therapy (CBT) to manage distressing affect in psychosis (Birchwood & Trower, 2006; Foster, Startup, Potts, & Freeman, 2010; Kuipers et al., 2006). In addition, practice-based evidence has indicated that Dialectical Behavioural Therapy (DBT; an evidence-based approach commonly used in treatment of

Borderline Personality Disorder [Stoffers et al., 2012]), is an effective intervention to increase emotional coping skills in people who experience psychosis (Clarke & Wilson, 2009).

The theme 'being labelled with psychosis' highlighted the impact of schizophrenia-spectrum diagnoses. For some, these diagnoses were detrimental and for others they were beneficial. The perception that schizophrenia-spectrum disorders are more stigmatised in comparison to other diagnoses, such as depression, is supported by research of public attitudes towards psychiatric diagnoses (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). In the synthesis, stigmatised labels led to shame and secrecy about diagnoses, perpetuating isolation. This suggests that people who have received a diagnosis may benefit from support focussing on their experience of being given the diagnosis. Professionals may also have a role in assisting and support individuals in disclosing their diagnosis to others.

The themes 'regaining control' and 'understanding and rebuilding' both reflect the principles of 'personal recovery', a concept derived from the service user-led recovery movement (Slade, Amering, & Oades, 2008). In the synthesis, developing coping skills and interests, connecting with others and working in partnership with professionals were prominent processes in recovery. These ideas mirror the findings in research that social factors, such as empowerment, connectedness and social inclusion, are central to personal recovery (Tew et al., 2011). These findings have implications for clinical practice. Tew et al., (2011) highlight the need for services to reflect these recovery principles; they suggest the use of self-directed support, and family and community-based approaches. These approaches, particularly community care, are also vital strategies to prevent hospital admissions, which were a significant source of discrimination in the synthesis. In considering how to develop clinical practice and services which reflect the principles of ‘personal recovery’, the synthesis highlighted the power of peer support. Self-management and self-help groups, often led by experts by experience, are valued by services users with psychosis (Davidson, 2009). There are a number of well established self-help groups in the UK, for example the Hearing Voices Network groups. People who experience psychosis should be offered autonomy and choice to self-manage their recovery, and self-management options should include access to peer support.

In addition to the implications for clinical practice previously discussed, the importance of relationships with professionals was highlighted. Working in partnership with professionals was valued, promoting equality and negating disempowerment. There was also the need for information about diagnoses to be presented at an accessible level.

Future Research

In considering directions for future research, there was a wealth of information about the experience of recovery in this literature, it was not possible to explore these experiences in depth in this review. These experiences provide valuable insight to recovery process and potentially could inform theory, clinical practice and policy. It may be a valuable direction for future research to focus on synthesising the experience of recovery from psychosis in this literature and from qualitative accounts in general.

A second point to consider in future research concerns the development of Smith's (2011) IPA quality appraisal checklist. Based on the results of the IPA quality checklist, nine papers were rated ‘borderline-acceptable’ quality IPA, due to insufficient supporting excerpts for each theme. It is possible that reflects the issue of word-limits in published research, rather than poor quality research. Redmond, Larkin, & Harrop (2010) discuss this issue explicitly, stating the article length limited their use of excerpts. Smith’s (2011) checklist is a novel and untested tool; it is possible that it has unrealistic parameters considering the reality of word limits in published research. A direction in future research may be to test the validity and develop this tool.

Limitations

The studies in the review spanned from 2003 to 2015. It is possible that the experience of psychosis has changed over the time following developments in the conceptualisation of psychosis, new approaches in clinical practice and public anti-stigma campaigns for mental health. It was not in the capacity of this review to examine any change in the experience of psychosis over time.

A further limitation was the brevity of the meta-synthesis. It was not possible to portray the richness of the individual narratives relating to the experience of psychosis in the review. This was in part due to the large number of studies included in the synthesis, in addition, a significant proportion of the review focussed on the meta-methodology.

Conclusion

The review indicated that the IPA-psychosis research contains rich and valuable accounts of the subjective experience of psychosis. Currently the generalisability of IPA findings are limited by the lack of participant diversity, and it may be worthwhile to address this in future research. The synthesis presented the experience of psychosis as shattering to the self, emotions and sense of reality. Stigma and discrimination were pervasive for people who experience psychosis, leading the shame and secrecy about diagnoses. A number of experiences related to recovery; in particular coping skills, integration of experiences and connecting with others. These findings reflect the principles of the service user-led recovery movement; highlighting the need to respect individual explanatory frameworks and use an empowering approach in clinical work supporting people who experience psychosis.

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Part 2. People’s Experience of Sleep and Paranoia: An IPA Study

Abstract

Objective: There is growing quantitative research investigating paranoia and sleep dysfunctions. This literature indicates a central role for sleep in paranoia. However, there is a paucity of literature exploring lived experience of these phenomena. This study aimed to use qualitative methodology to explore the subjective experience of paranoia and sleep problems, and to elucidate what these experiences mean to people.

Method: The qualitative methodology Interpretative Phenomenological Analysis (IPA) was used to analyse semi-structured interviews from eight participants who self-identified as experiencing paranoia and sleep problems.

Results: Three superordinate themes emerged from the analysis: 1. a mind which won't switch off, 2. the impact of living with a mind which won't switch off, and 3. trying to getting relief.

Conclusion: People who experience paranoia and sleep problems described lifelong difficulties, particularly insomnia, nightmares, worry and feeling unsafe. These experiences had a wide ranging impact on daily functioning, relationships and wellbeing. Substance use was common to relieve experiences. Some positive strategies, such as meditation, were helpful to 'calm the mind'. Currently, it is felt that there is inadequate support for people with these experiences, particularly concerning sleep. The potential benefit of targeted interventions for nightmares and worry in people who experience paranoia was discussed. In addition, the potential benefit of identifying children 'at-risk' was considered.

Introduction

Paranoia

Paranoia is a common feature of mental health presentations such as psychosis, bipolar disorder and schizophrenia (Freeman & Garety, 2006). Paranoia is also a common experience in the general population. In the Adult Psychiatric Morbidity Survey in the UK, 18.6% of the 7281 respondents positively reported items indicating paranoid thinking (Freeman et al., 2011). The experience of paranoia occurs along a spectrum, ranging from mild to severe. This spectrum manifests in traits like mistrust and suspiciousness at the mild end. At the more severe end of the spectrum, paranoia manifests as persecutory delusions with beliefs about severe threat of harm or persecution (Startup, Freeman, & Garety, 2007). Freeman (2007) proposes a hierarchy of paranoia which demonstrates how the phenomenon of paranoid experiences is distributed across a spectrum (Figure 1)

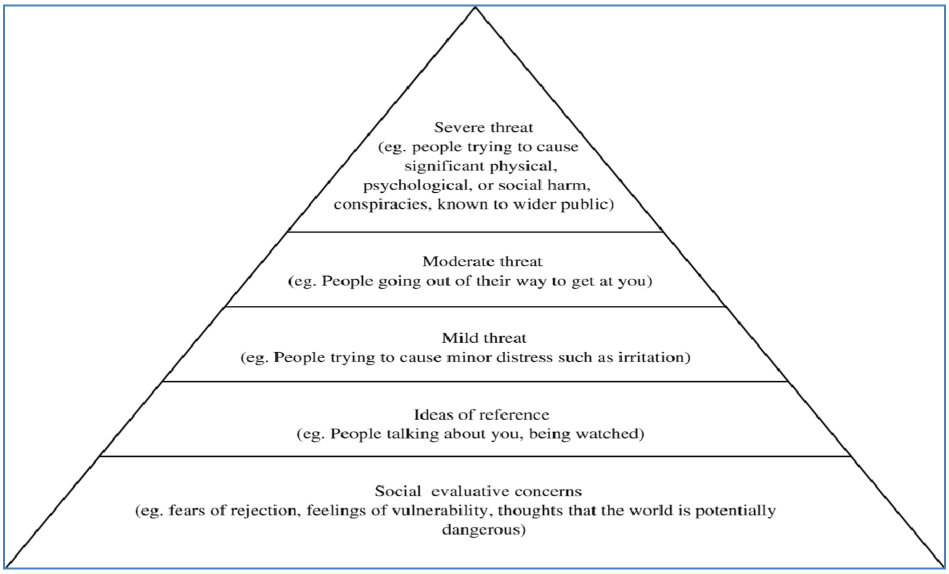

Figure 1. Hierarchy of paranoia. Reprinted from “Suspicious minds: The psychology of persecutory delusions”, by Freeman, 2007, in *Clinical Psychology Review*, *27*, 425–457.

The hierarchy of paranoia has been established across the general population in a factor analysis performed on survey responses from a sample of 8576 British people (Bebbington et al., 2013). In this study, a larger proportion of the population (20-30%) experienced the low grade, social evaluative concerns and a smaller proportion of the population (2%) experienced the high grade, concerns about severe threat.

Paranoia, even at the milder end of the spectrum, can impact on people's functioning and wellbeing (Combs & Penn, 2004). At the more severe end of the paranoia spectrum, persecutory delusions are associated with poor psychological wellbeing, including increased depression and anxiety (Freeman et al., 2014)

A cognitive model for the development of persecutory delusions has been suggested by Freeman, Garety, Kuipers, Fowler, and Bebbington (2002). The model proposes anomalous experiences are interpreted as threatening, and are maintained by safety behaviours and disregarding evidence against the delusion. These beliefs are distressing and consuming, impacting on functioning.

It is evident that paranoia is a common human experience, which can lead to distress for the individual and difficulties with relationships, social functioning and wellbeing (Freeman & Garety, 2014). Research at the mild end of the paranoia spectrum, in the general population, has contributed to knowledge about paranoia processes across the spectrum (Bebbington et al., 2013). Moreover, investigating paranoia over the spectrum gives insight into how milder forms of paranoia predict and develop into more severe experiences and clinical presentations (Kaymaz et al., 2012). Understanding paranoia across the spectrum is also valuable for developing interventions for clinical practice.

Sleep

Sleep disorders are a common experience, with up to 20% of adults experiencing sleep problems requiring clinical intervention at some point in their lives (Wilson & Nutt, 2007). Sleep disorders cover a range of presentations, such as hypersomnia (sleepiness and sleeping during the day), insomnia (inability to fall asleep or stay asleep) and parasomnias (experiences such as sleepwalking, nightmares and night terrors). The spectrum of sleep problems also includes less common experiences such as narcolepsy and restless leg syndrome and common experiences such as difficulty falling asleep, difficulty staying asleep and disturbed sleeping patterns (Wilson & Nutt, 2004).

A relationship between sleep and mental health has been well established in research and clinical practice. This includes a wealth of research of insomnia in common mental health problems, such as anxiety and depression (Ohayon & Roth, 2003), alcohol dependence (Brower, 2003), obsessive compulsive disorder (Paterson, Reynolds, Ferguson, & Dawson, 2013) and suicidality (Carli et al., 2011). The causal direction of the sleep-mental health relationship has also been explored in research, remaining inconclusive and debated. Although some research suggests that sleep problems precede and predict the development of mental health problems. For example, in an epidemiological longitudinal study of young adults, insomnia was found to be predictive of the development of depression (Breslau, Roth, Rosenthal, & Andreski, 1996).

Sleep and paranoia

Psychological research and practice has moved towards a more symptom focused, trans-diagnostic approach to mental illness. This approach is based on the premise that targeting specific symptoms of mental illness is an effective way to treat mental health problems (Bentall, 2003). For example, treatments for psychosis are likely to be improved by targeting single symptoms, such as hearing voices or persecutory delusions, using theoretically-driven interventions (Foster, Startup, Potts, & Freeman, 2010; Hagen, Turkington, Berge, & Gråwe, 2010). In clinical practice, a symptom-focused approach, attending to the personal meaning of psychotic experiences, is recommended for psychological interventions for psychosis and schizophrenia in the recent British Psychological Society (BPS) guidelines (BPS, 2014).

Reflecting the trend in wider research and clinical practice, sleep and psychosis research has also focused on specific symptoms of psychosis such as hallucinations and delusions (Reeve, Sheaves, & Freeman, 2015). Paranoia has also received attention in sleep research. The first study looking at sleep and paranoia was a quantitative, cross sectional, survey study (Freeman, Pugh, Vorontsova, & Southgate, 2009). The study found that in individuals with a clinical diagnosis of paranoid delusions, only 17% did not have any sleep problems. It also found that in a general population group, there was a correlation between paranoid thinking and insomnia. Epidemiological studies have found an association between insomnia and paranoia, and inferred that worry, negative affect and insomnia predict the onset and persistence of paranoid thinking in the general population (Freeman et al., 2011; Freeman et al., 2010, Freeman et al., 2012). A limitation of these studies is that they are all based on survey responses, so do not indicate causality or infer how this association impacts wellbeing and functioning. Moreover, they are focussed on insomnia, neglecting other sleep dysfunctions.

An intervention for insomnia for people experiencing persecutory delusions and hallucinations has been developed by Myers, Startup, and Freeman (2012). The cognitive behavioural therapy for insomnia (CBT-I) intervention has been effective in reducing insomnia in a pilot (*n*=15*),* and in a pilot prospective, randomised controlled trial, the 'Better Sleep Trial' (BEST; Freeman, Startup, Myers, & Harvey, 2013; Myers, Startup, & Freeman, 2011). The BEST found by week 12, 41% of participants in the CBT group (*n*= 24) no longer experienced insomnia and had improved sleep compared to the control group (*n*= 26). Mixed effects were reported to the delusions and hallucinations, with both increases and decreases of these symptoms. The results from the BEST research indicate a promising direction for treatment of insomnia in people who experience paranoid thinking.

Qualitative research into sleep and mental health

Quantitative research has demonstrated a strong link between the experience of paranoia and sleep dysfunction, particularly insomnia. Due to the quantitative nature of the studies, little is known about what it is like to experience sleep dysfunction and paranoia or what these experiences mean to people.

There has been one recent qualitative study using the methodology Interpretative Phenomenological Analysis (IPA) to explore the experience of sleep and the experience of the CBT-I in the BEST participants (Waite et al., 2015). Participants in this study (*n*= 10) experienced clinical levels of persecutory delusions and hallucinations. The findings of this study reported a number of sleep disturbances, including insomnia and frustration about not being able to sleep, which had an impact on daytime functioning. Poor sleep impacted participants' sense of coping with psychotic experiences. Participants spoke about positive change following the CBT-I and valued learning skills to manage their sleep. Waite et al.'s (2015) IPA study focused on the experience of sleep problems and their treatment following CBT-I in a clinical population. To date, there have been no qualitative studies exploring the understanding people have of their experiences of sleep and paranoia, and investigating what these experiences mean to them, regardless of treatment-context or clinical diagnoses.

This leads to the research area of the current study. It is apparent from the paucity of studies of this area, that a qualitative investigation of how people experience sleep problems and paranoia would be a salient contribution to the field at this time. A literature search yielded no qualitative studies of sleep and paranoia that did not focus on the experience of an intervention. Freeman and Garety (2006) suggested that there is a need for research of paranoia in the wider population, rather than focussed at the clinical end of the spectrum, due to the pervasiveness of the phenomenon throughout the population. The need for research about sleep across the paranoia spectrum has also been indicated in a recent review of sleep and psychosis research (Reeve, Sheaves, & Freeman, 2015). In addition, most previous research focused on specific sleep dysfunctions (either insomnia or nightmares), highlighting the need for further research to explore sleep dysfunction more broadly (Reeve et al., 2015)

Johnston (1998) discusses the importance in developing qualitative research in the field of adult mental health, to help practitioners understand how people experience mental health problems. A deeper understanding of people's experiences leads to the development of more appropriate treatments and focuses research on relevant areas. Consequently, there is a need for research focusing on the experience of sleep problems and paranoia across the spectrum. As reflected by the gap in current literature, this study will not focus on specific sleep disorders, but will enquire about sleep in general. Similarly, by recruiting people who self-identify as experiencing paranoia from the general population, paranoia will be explored across the paranoia spectrum.

Aims

- To explore 'what it is like' to experience paranoia and problems with sleep.
- To examine how people make sense of their experiences of paranoia and sleep.
- To consider what the experiences of sleep and paranoia mean to the participants, in the context of their lives.

Method

Design

A qualitative design using Interpretative Phenomenological Analysis (IPA) was selected for the study. IPA is concerned with lived experience; what it is 'like' to experience a particular phenomenon and how people understand and make sense of their experiences (Eatough & Smith, 2008). One of the main philosophical frameworks informing IPA is phenomenology – the study of lived experience (Manen, 1997). In IPA phenomenological enquiry is interpretive, the method of interpretation in IPA is a 'double hermeneutic'. The double hermeneutic is the participant interpreting and making sense of their experience, and the researcher interpreting and making sense of the participant's experience. The researcher is actively involved in the process of meaning making, by applying their own theoretical perspective to the process of interpretation (Larkin et al., 2006). IPA is also idiographic, it examines the phenomenon case by case; attending to the nuances in individual accounts and making comparisons between participants' accounts of the phenomenon (Eatough & Smith, 2008). The theoretical principles which underpin IPA make it an appropriate method to use to explore the experience of sleep and paranoia. The method also enables the researcher to make interpretations about what experiences mean in the context of psychological theory and practice.

Researcher characteristics

In IPA, the researcher applies their own experiences and knowledge to interpret and understand the participant's experience (Biggerstaff & Thompson, 2008). The analysis process requires the researcher to reflect and remain transparent about the subjectivity of their analysis. Transparency is a central tenet of good quality qualitative research (Yardley, 2000). As part of the process of reflexivity, transparency and 'owning one's perspective' it is important to consider the researcher characteristics and context (Elliott et al., 1999).

I am a 33 year old White British female. I was born and raised in rural southern England, however I have lived for most of my adult life in cities in both the south and the north of England. I am currently a Trainee Clinical Psychologist in my final year of training. I have worked for 10 years in adult mental health, predominantly in inpatient settings with people experiencing acute mental health crises. In this setting and in my training, I have spent a lot of time working with people experiencing paranoia and sleep difficulties. I have an interest in psychosis, both in clinical practice and in research.

The perspectives which contribute to my interpretative frameworks relate to my clinical practice, beliefs and experiences. In my clinical work with people in crisis, I use a symptom- and emotion-focussed approach, to empower people in their recovery, influenced by the work of Isabel Clarke (Clarke & Wilson, 2009). I am also interested in the wider conceptualisation of psychosis, stigma and critical psychology; my main influences are proponents of critical discourse about mental health, such as Mary Boyle and Richard Bentall, and service user movements, like Asylum Magazine.

I anticipated that my experience and beliefs would influence my interpretation of the experiences of the participants. I used reflexive writing throughout the research process. In my reflexive writing, I used the systemic-constructionist model 'Coordinated Management of Meaning' (Barnett Pearce, 2005) as a tool to aid reflection and explore the intersubjective dynamics between myself and the participant. I applied bracketing of my ideas during the research process, particularly during the interviews and in the initial stages of analysis when I was analysing at an exploratory level. Bracketing was used to ensure that the analysis remained focussed on the experience of the participant. I also used supervision with my research supervisor and with peers to perform audits of the research process and reflect on how my interpretative frameworks were applied to the analysis.

Recruitment

A purposive sampling strategy was used to recruit people who self-identified as experiencing paranoia and sleep problems. The aim was to recruit a sample homogenous by their self-identification as experiencing paranoia and sleep difficulties. Ethical approval was gained from the University of Sheffield (Appendix 3). People were recruited using posters advertising the project at locations holding mental health self-help groups, in the local area to the research project. People were also recruited online using adverts on internet forums and social networking pages for people who experience paranoia, mental health problems and sleep disorders. Online adverts used a link to the study webpage. The webpage and poster stated the inclusion criteria for participation: experiencing paranoia and problems with sleep, being over 18 years old and speaking fluent English. Participants also had to give informed consent to participate. In addition, the webpage stated that online video interviews could be used if people were not in the local area and included an anonymous email form to contact the researcher.

When people contacted the researcher they were provided with the information sheet (Appendix 4) and consent form (Appendix 5) for the study in their preferred format (email or post). They were invited to contact the researcher for a further discussion or to arrange an interview if they were interested in participating.

Participants

Six people expressed interest in response to the poster advertisements and 26 people expressed interest via the webpage. In total eight participants went on to complete the interview. Two were respondents to the posters and the remaining six were via the study webpage. Demographics and quantitative information about paranoia and sleep problems were collected in the interview from the demographic questionnaire and the two standardised questionnaires; one sleep (Sleep-50, Spoormaker & Verbeek, 2005, see Appendix 6) and one paranoia (Green et al. Paranoid Thought Scales; Green et al., 2008, see Appendix 6).

The Sleep-50 (Spoormaker & Verbeek, 2005) is a 50-item questionnaire used to screen for common sleep disorders (sleep apnea, insomnia, restless legs, circadian rhythm sleep disorder, sleepwalking, nightmares). A validation study in the general population found high reliability (50 items; α = .85) and agreement between the sleep-50 sleep disorder categories and clinical diagnoses (κ = .77). On the scale, participants rated their experience in the past month on each item from 1 (not at all) to 4 (very much). Clinical diagnoses were indicated by scores above the cut-off value for each sleep disorder subsection, in addition to meeting the cut-off value on an impact of sleep subscale. Overall scores ranged from 50-200.

The Green et al. Paranoid Thought Scales (GTPS; Green et al., 2008) are two a 16 item self-rated scales. The first scale assesses for thoughts related to social reference, and the second for persecution. The scales have good reliability in clinical (32 items; α = .90) and non-clinical populations (32 items; α = .95). Participants rate their experience of paranoid thoughts in the past month on a scale of 1 (not at all) to 5 (totally). Scores on each scale range from 16-80, with higher scores indicating higher levels of paranoid thinking.

The data from the questionnaires is displayed below (Table 1).

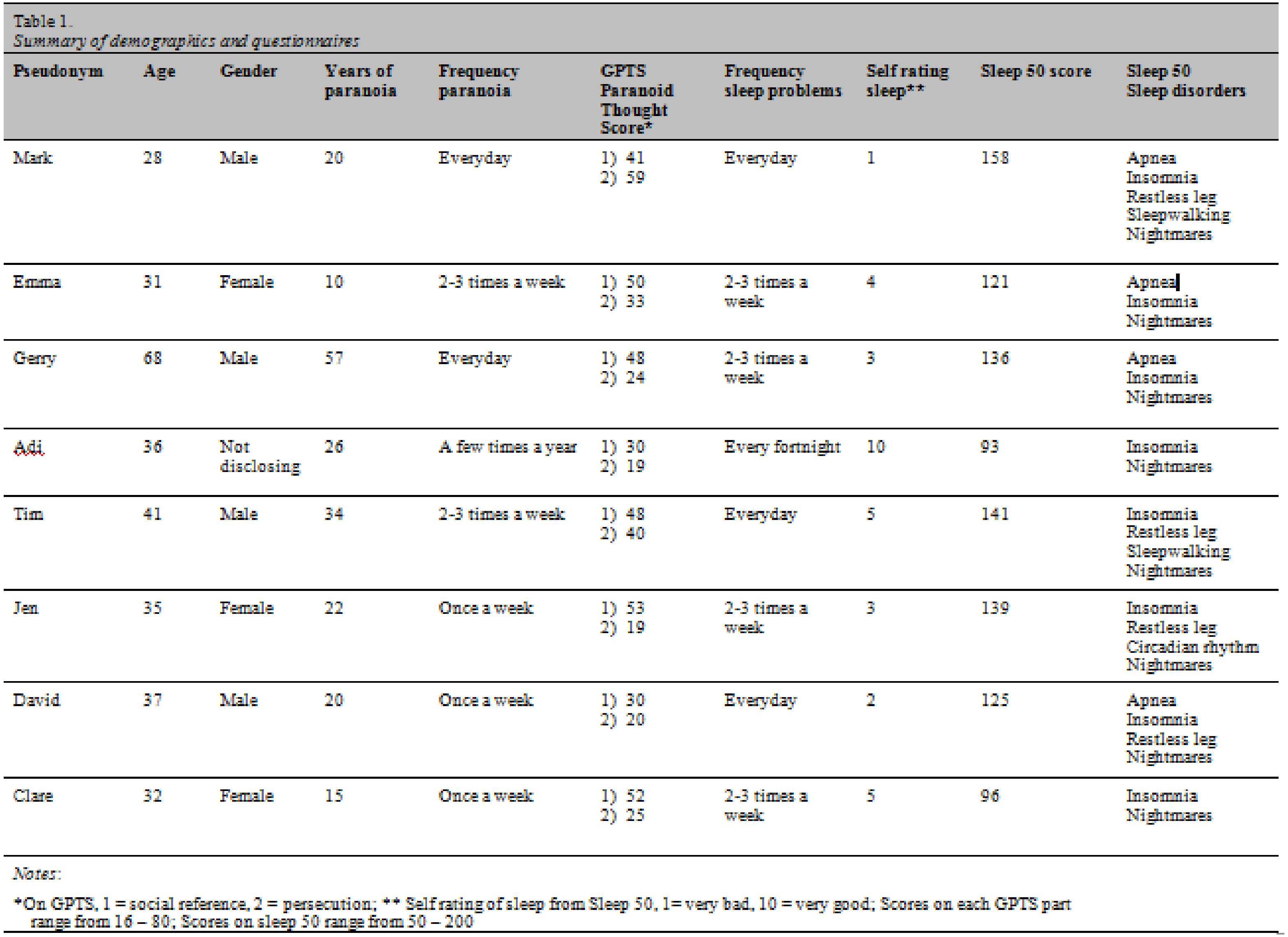

Table 1.

Summary of demographics and questionnaires

Pseudonym	**Age**	**Gender**	**Years of paranoia**	**Frequency paranoia**	**GPTS Paranoid Thought Score***	**Frequency sleep problems**	**Self rating sleep****	**Sleep 50 score**	**Sleep 50 Sleep disorders**
Mark	28	Male	20	Everyday	1) 41 2) 59	Everyday	1	158	Apnea Insomnia Restless leg Sleepwalking Nightmares
Emma	31	Female	10	2-3 times a week	1) 50 2) 33	2-3 times a week	4	121	Apnea Insomnia Nightmares
Gerry	68	Male	57	Everyday	1) 48 2) 24	2-3 times a week	3	136	Apnea Insomnia Nightmares
Adi	36	Not disclosing	26	A few times a year	1) 30 2) 19	Every fortnight	10	93	Insomnia Nightmares
Tim	41	Male	34	2-3 times a week	1) 48 2) 40	Everyday	5	141	Insomnia Restless leg Sleepwalking Nightmares
Jen	35	Female	22	Once a week	1) 53 2) 19	2-3 times a week	3	139	Insomnia Restless leg Circadian rhythm Nightmares
David	37	Male	20	Once a week	1) 30 2) 20	Everyday	2	125	Apnea Insomnia Restless leg Nightmares
Clare	32	Female	15	Once a week	1) 52 2) 25	2-3 times a week	5	96	Insomnia Nightmares

Notes:

*On GPTS, 1 = social reference, 2 = persecution; ** Self rating of sleep from Sleep 50, 1= very bad, 10 = very good; Scores on each GPTS part range from 16 – 80; Scores on sleep 50 range from 50 – 200

The sample consisted of eight participants: four men, three women and one person who chose not to disclose their gender. Their ages ranged from 28-68 (mean = 38.5; SD = 12.6). Participants had experienced paranoia for between 10-57 years (mean = 25; SD 14.5). Participants self rating quality of sleep on a scale from 1-10 (10 = good) ranged from 1-10 (mean = 4.1; SD = 2.7). On the GTPS, seven participants scored higher on the social reference items than on persecutory items, and one scored higher on the persecutory items. On the Sleep-50, all the participants met the criteria for multiple sleep disorders; all met the criteria for insomnia and nightmares, four for sleep apnea, four for restless leg, two for sleep walking and one for circadian rhythm.

In addition to the questionnaire data, contextual information about each participant was noted in a reflexive statement which written after each interview. From this journal, it is notable that all participants were living in urban locations; six in the north of England, one in the south and one was British living in Italy. Four were in relationships, three lived with their partners and one in a shared house; four were single and lived alone.

Procedure

The participants were offered a choice for their interview location for their convenience and privacy. Four interviews were held in private meeting rooms at a university, two via internet video call, one in a National Health Service (NHS) consultation room and one in the participant's home. The researcher conducted the video calls from a private office and participants were encouraged to do the same. At the beginning of each interview the information sheet was discussed, offering the opportunity for questions, following this informed consent was given by each participant. After the interview, participants were asked to complete the two questionnaires and demographics sheet. Following this, each participant was de-briefed about the interview and questionnaires. The researcher asked about the participant's wellbeing and provided information about support services for sleep and paranoia. Finally arrangements were made about contacting the participants for their feedback on the themes and the executive summary of the study.

Data collection

Data was collected using semi-structured interviews. An interview schedule was developed to guide the questions. The interview schedule was based on Smith, Flowers, and Larkin's (2009) guidelines for IPA interviews. The questions were broad and open ended, asking about experiences of sleep and paranoia. Follow-up questions were used to encourage participants to reflect on the meaning of their experiences, for example “can you describe to me how you make sense of that thought looking back on it now?” The interview schedule was developed with consultation from a representative from the National Paranoia Network and in discussions with a research supervisor and peer IPA research group. The schedule was piloted with an individual who experienced paranoia and sleep problems.

The schedule was used flexibly to develop rapport between the researcher and participant and to allow the participant to express their experiences in their own way, with the aim of producing a rich and idiographic account. The interviews lasted between 29 – 93 minutes (mean= 51.5 minutes). The interviews were recorded using a secure, digital recording device. The interviews were transcribed verbatim and anonymised by taking out all identifying information (names, places).

Data analysis

IPA was used to analyse the interview data. The analysis was based on the procedure outlined by Smith, Flowers, and Larkin's (2009):

1) Listen to recording and read transcript without taking notes once, correct any mistakes in transcription if needed. Listen to the recording again and write initial comments and reflections.

2) Read transcript and add more detailed explorative notes, Smith et al (2009) suggests 3 levels: descriptive, linguistic and conceptual. This will be written in the left hand column of the transcript. Distinct chunks of text which comprise a ‘meaning unit’ will be underlined.

3) Develop emergent themes by focusing on chunks of text and drawing out the psychological essence of the participant’s experiences. Make interpretations and abstractions grounded in the data. Describe themes with a concise statement or word to summarise the meaning. Themes will be written in the right hand column of the transcript and indicated in the transcript by highlighting the text.

4) Organise emergent themes in a table of themes and supporting excerpts. Engage in an iterative process to cluster the themes; make abstractions and interpretations, identify connections and contrasts, and consider the context of the participant and my own position.

5) Repeat 1-4 for all participants.

6) Make a masterlist of themes by collating the themes across participants. Engage in an iterative process to cluster the masterlist into a table of super-ordinate and sub-themes across all cases. Look back at all cases using the masterlist, recording reflections, interpretations and selecting key excerpts of narrative.

7) Translate the super-ordinate and sub-themes into narrative description of the themes, using extracts from the cases to demonstrate the theme through the experiences and meaning making.

Validation

Guidelines for qualitative research practice and IPA were adhered to during the research process (Elliott et al., 1999; Smith, 2011; Yardley, 2000). Transparency was upheld through the use of reflexive writing, organising analysis rigorously so there was traceable paper trail for audits and using supervision (Yardley, 2000). Audits were completed at each stage of the analysis by a peer researcher or research supervisor, both experienced in using IPA, as recommended by Smith (Eatough & Smith, 2008). The audits were used to ensure there was coherence in the analysis, any difference in opinion was discussed until a consensus was reached. To ensure the analysis remained grounded in examples, reflexive writing and excerpts of narratives were used throughout the analysis (Elliott et al., 1999). As a credibility check, the National Paranoia Network were consulted about the interview schedule and participants were sent the final themes and asked to respond with their feedback, although no responses were received (Elliott et al., 1999).

Results

The interviews contained rich accounts of lifelong experiences of paranoia and sleep dysfunction. Analysis of the accounts explored how participants understood and made sense of these experiences and what their experiences meant to them. Three super-ordinate themes emerged from the analysis: 1. a mind which won't switch off, 2. the impact of living with a mind which won't switch off, and 3. trying to getting relief. These themes and the sub-themes are shown below in Table 2.

Table 2.

Table of super-ordinate and sub-ordinate themes across all participants

Super-ordinate theme	Sub-theme
1 A mind which won't switch off	**1.1** Having a busy mind **1.2** Insomnia, nightmares and dreams **1.3** It's a dangerous world **1.4** Uncertain reality **1.5** Life-long difficulties
2 The impact of living with a mind which won't switch off	**2.1** Relationships **2.2** It's a struggle to function **2.3** You feel like you're at the edge of madness – but it's quite exciting
3 Trying to get relief	**3.1** Seeking help **3.2** Self-medicating **3.3** Adapting and coping

Each theme is discussed with supporting excerpts from the participant's narratives.

1: A mind which won't switch off

The theme 'a mind which won't switch off' captures how the participants described their experiences and made sense of living with a mind which can feel uncontrollable. For the participants, the mind is always active; analysing the reality around them and alert for danger. It was hard to 'switch off' the mind, especially at night, preventing sleep and leading to vivid dreams and nightmares. The super-ordinate theme consisted of five subthemes: having a busy mind; insomnia, nightmares and dreams; it's a dangerous world; uncertain reality; and life-long difficulties.

1.1: Having a busy mind. All participants spoke about their experiences of having a busy mind. The busy mind was characterised by racing, uncontrollable thoughts, as Mark described:

> “my brain works at about a thousand miles an hour, half the time I don’t even know what I'm thinking.”

Worry and rumination were common experiences. For all participants, except Gerry, lying in bed was a time when worry and rumination were particularly problematic. Emma expressed how thinking patterns at this time were frustrating:

> “for some reason at night and I’m tired, you know my brains exhausted and for some reason I just dwell on things that are really not that important”

Insomnia was a common experience for people who found that their active mind prevented them from falling sleeping.

In social situations the busy mind was often experienced as disruptive and critical. Most of the participants described intrusive paranoid thoughts and their mind ‘chattering’; making social interactions difficult and anxiety-provoking. Tim described the anxious running commentary he experiences in his mind in social situations:

> “…it’s like oh, what the fuck[2] should I say? And also, what are they thinking? What are they going to ask me? You know, um, and why – am I going to start speaking nonsense kind of thing, be anxious in front of them, why am I doing this? If I start talking to them now, does that mean I’m going to have to start talking to them again?”

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[2] Expletives have been kept in the excerpts as they were felt to reflect the participants’ language, culture and affect

People spoke about their ‘mind’ or ‘brain’ as a powerful entity, which produced thoughts that were out of their control. For a number of the participants this led to a feeling of being in a battle; fighting to gain control over thoughts and desperation for some peace. For David, this was so severe that he had to leave the classroom in school to try and silence his mind:

> “… feeling like me brain was gonna explode, like I was banging me head on the toilet wall to try and get me brain to just shut the fuck up”

In contrast to distressing experiences, the busy mind was also valued by participants; allowing them to engage in intellectual, philosophical and creative thinking.

1.2: Insomnia, nightmares and dreams. This theme reflects the most prevalent sleep experiences in the narratives. Sleeping patterns were commonly unpredictable and chaotic, this varied from broken sleep to days without sleep. This was frustrating for participants, who reflected on the process of trying to understand why their sleep was sometimes so disturbed, as Tim said:

> “when I literally can’t sleep that can go on for months, sometimes. And there isn’t a set pattern; I’ve never found a set pattern”

For some, events in their life and stress were felt to be a contributory factor, as Emma described:

> “…final year of University…it was really bad with exams and dissertation and all of that stuff and I just couldn't sleep”

Insomnia was experienced as qualitatively different from just ‘not sleeping’. Participants Tim, Jen and Clare described a different mental and physical state where they feel both exhausted and exhilarated; in this state sleep is impossible, as Jen said:

> “My head just becomes so awake, but very, very awkward, very um, oh, very stubborn – I just know in my head I’m not going to sleep, but it’s not just a feeling in my head, it’s a feeling in my body. It’s like I’m on edge, I’m awkward, and it almost feels like I’ve already had 8 hours sleep and I don’t need sleep”

All participants spoke about their dreams in great detail, often clearly recalling dreams from childhood. They described active dreams where the boundaries between sleep and wakefulness were blurred. Active dreams involved sleep walking, sleep talking, performing actions while asleep (including sexomnia[3]) and the perception of seeing real figures in the room. Most, except Emma and Gerry, described terrifying nightmares. Mark and Tim were so fearful of nightmares they were scared to sleep, as Mark described:

> “that's probably one of the reasons why I probably I don't sleep to be honest…after I have had a nightmare I don't want to go back to bed again”

It was common to search for meaning in dreams and nightmares. Some felt nightmares related to traumatic experiences and anxieties, and for Mark, the abuse he experienced in childhood was relived in his nightmares:

> “I get nightmares a lot and a lot of them are to do with my step dad”

1.4: It’s a dangerous world. All participants expressed views indicating they perceived the world as a dangerous place. These beliefs were interpreted as core schema which related to experiences of both sleep and paranoia.

At an individual level, the schema of a dangerous world was evident by the negative interpretation of social cues and interactions. David described this watchfulness for threat:

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[3] Sexomnia is a parasomnia sleep disorder characterised by sexual behaviour during sleep

> “I’ve always been a bit edgy. You know, like on the lookout for when people like when people take the piss”

Other cognitive biases which were congruent with the schema of a dangerous world included ‘post-mortems’ of social interactions focussing on threatening and negative information. Clare spoke about thinking over, in vivid detail, the facial expressions of a friend for many hours after the original interaction:

> “it wasn’t until a little later that I realised that he wasn’t quite happy in the situation, because I remember his facial expressions earlier on, and I was like ‘shit, yes, he looked like this at me. That’s not so good.’”

For Tim, vigilance for danger was a psychological and physiological experience:

> “my body was telling me that there was something very, very wrong somewhere, but my mind couldn’t work out where that was coming from, so that just completely sent me off, because I couldn’t get where the threat was – I couldn’t work it out”

In Tim’s narrative, his interpretation of his aroused, physical anxiety response maintained the idea that there is danger.

At a wider level, the schema of a dangerous world was also evident in the participants’ suspiciousness about systems such as the government and big corporations, which were viewed as dangerous, malevolent and a threat to the safety of everyone.

The schema of a dangerous world was highly distressing for participants. It was common to feel very unsafe, even at home and in bed. Feeling unsafe intensified at night for most participants, as Jen said:

> “If someone’s going to break into your house, they’re going to break in at night; if someone’s going to attack you or murder you it’s going to be at night.”

A number of safety behaviours were used by participants to reduce anxiety and fear about danger, such as repeated checking of locks, windows and under furniture, and arming with weapons. Gerry explained he is aware ‘what’s in the knife drawer at the flat’ and Jen described how she keeps two baseball bats as she ‘can’t sleep without something next to the bed’. The sense that the world is dangerous infiltrated sleep and dreams, reflected in the prevalence of nightmares and ‘acting out’ protective and defensive actions while asleep.

The participants were reflective and insightful about how they had developed their beliefs and vigilance for danger. In understanding their view of the world as dangerous, most participants spoke about their experiences in childhood. There was often a sense that participants had not been protected by adults and some had experienced significant trauma or a lack of stability when young. Jen spoke about her fear of night and related it to her home environment when she was young:

> “I grew up in a very, very rough place and you learn to watch your back. You learn, very quickly, to be switched on”

In adulthood, living in urban environments and unsafe living conditions were also significant factors in maintaining the schema that the world is dangerous. Interpersonal experiences such as being lied to or abusive relationships were also common.

Their view of the world as dangerous was felt to be adaptive, allowing participants to protect themselves and others, as Adi said:

> “Sleeping less, and being more paranoid in that state means that you’re more able to respond to a threat. Which means you’re really better – you can get away and get

> to that safe place, so there's probably an evolutionary reason for that less sleep, more paranoia, feeling sharper."

Some participants felt they were dangerous to others. Jen described feeling 'predatory' when sleep deprived and paranoid. Gerry and David both felt the need to 'attack first'.

1.4: Uncertain reality. This theme indicated how experiences of sleep problems and paranoia led to the feeling that reality was changeable and uncertain. In social situations, participants spoke about questioning what is real and what is not. Tim described this uncertainty:

> "being paranoid that people wouldn't like me or that were being, um, being visually nice, but behind it being something else"

Paranoia in social situations commonly led to questioning other people's intentions, and feeling that there is a deeper meaning to interactions than the surface reality, this experience was intensified by sleep deprivation. David described how when sleep deprived, his experience of reality is changed:

> "I start to just see like a deeper meaning to the world, I can't even describe it when I'm not pissed, but like it's kinda like its profound man, like I know the answers to all the questions and we aren't just here on this earth for this life and shit. Like it's really powerful."

For David in this excerpt, the shift in reality is interesting, stimulating philosophical thinking.

Participants spoke about a sense of liminality between sleep and wakefulness where dreams feel very real. Tim described this experience of liminality:

> “I get a very difficult transition period between um, between um kind of having my dreams you know, if I’m acting out in my dreams, so I experience what is going on around me, but I see what’s going on in my dreams”

Mark felt so confused and distressed by what is real and what is not because of his vivid dreams that he engaged in self-harming behaviour to test his reality, as he described:

> “I used to kind of lock myself in my room and kind of do silly shit like to try and prove I'm awake or not like cut myself all night if I could feel the kind of pain then …I'm actually awake”

Some participants experienced phenomena such as hearing voices and visual hallucinations. These experiences felt absorbing, vivid and real at the time. Mark and Jen both found their experiences of hearing voices so compelling and real that they acted on them. Looking back at these experiences in the interviews the participants questioned the reality of them and conceptualised them as paranoid or psychotic experiences. Jen described her experience:

> “my paranoia has got to the point where I’ve heard voices. Not – not voices talking to me, but I’ve heard voices talking about me, or at least I think – thinking that they’re talking about me. And then when I’ve looked they’re not even talking.”

Using substances such as cannabis, alcohol and hallucinogenic drugs, accentuated the perception of an uncertain reality for some participants. Adi experienced frightening visual hallucinations after smoking cannabis:

> “…there’s things in my peripheral vision that my brain is making up…it starts guessing things that aren’t there, things that are terrifying”

1.5: Life-long difficulties. All participants reflected on how sleep problems and paranoia had been life-long difficulties for them. They had all experienced sleep difficulties since childhood. It was common for sleep to be disrupted in teenage years, although most participants normalised this as a typical teenage experience. Most participants experienced terrifying nightmares and vivid dreams from a young age, as Adi recalled:

> “I’ve got really early memories of strange, strange nightmares as a child”

Nightmares contributed to a feeling of being unsafe at night, and for some participants, this led to lifelong safety behaviours to reduce fear of nightmares and anxiety at night, as Tim said:

> “I still to this day sleep with a pillow over my face, that’s part of it, so my nose is covered, because otherwise I don’t feel safe and I can’t get to sleep.”

Both Mark and Jen had felt that they were not comforted by their parents when they had nightmares. Mark described his experience of lack of care:

> “When I was little obviously it [nightmares] would wake you up and make you scared and my parents would just tell you to go to bed and stop screaming the house down”

Mark reflected this may contribute to why he was distressed and unable to cope with nightmares as an adult.

Participants also spoke about early experiences which they felt contributed to their paranoia. Everyone, except for Emma and Tim, spoke about being victims of bullying in childhood. Participants had lifelong experiences of feeling ‘different’ and a desire to be accepted, as David said:

> "It's funny coz when I was a kid I'd always try and get people to like me, you know, I'd do stupid shit to get noticed in class"

All participants described anxiety, paranoia and other distressing mental health difficulties as lifelong experiences, emerging in childhood or teenage years. For Tim, paranoia and anxiety started when he was a teenager:

> "when I was about 12 or 13…I got very paranoid my friends didn't like me…And I think kind of periodically from that time I started to get more anxious in kind of more social situations"

2: The impact of living with a mind which won't switch off

2.1: Relationships. This theme reflects how relationships were impacted by people's experiences of sleep and paranoia. Some people found close relationships incompatible with their sleep. As Mark said:

> "… I find quite a lot of girls eventually get pissed off like …cos you're kind of waking them up like …almost every other night and if they're working…"

Loss of relationships and isolation was common, particularly when partners were not sympathetic about sleep problems. Gerry described this impact of this on his life:

> "I sort of never really had any relationships with other people, erm I was often alone although being with someone else often for someone like me would exacerbate the sleep problems but for both of us"

Participants spoke about making sacrifices with their own sleep to allow their partners to sleep. Tim found lying in bed unable to sleep was like "being in a prison", yet if he is not in bed his partner "doesn't rest".

Lack of trust, suspiciousness and paranoia meant relationships could be difficult for people. For Gerry and David, grandiosity and contempt for others created distance in their relationships, these defence mechanisms acted to protect them when they perceived other people as threatening while protecting their self-esteem. As Gerry said:

> "to get rid of the problem of the other people…I usually sort of rant in that way"

Although relationships could be challenging, most of the participants had also experienced supportive relationships, with partners who understood their difficulties with sleep and mental health. Partners were relied on to take a protective and supportive role, rousing the participants from active nightmares and comforting them, as David said:

> "But me girlfriend has got a way now of noticing its happening, coz apparently I breathe really fast and sort of jolt me legs, and then she tries to wake me straight away."

2.2: It's a struggle to function. Maintaining daily functioning was frustrating and strenuous for participants, as Tim said:

> "it's very difficult to function, and you have to put all your effort into functioning, rather than achieving anything"

Tiredness and paranoia was found to make work and other activities challenging. Jen spoke about the desire to avoid socialising and work because she felt 'snappy' and irritable:

> "I mean I used to work in a mental health hospital and it's very difficult to do – it was very difficult for me to do a day shift there, because I'm tired, so my behaviour, the way – I would probably hide myself away from the patients"

The struggle to maintain daily functioning was distressing and stressful; in response to this, avoidance and withdrawing from life was common. Tim spoke of struggle:

> “I just didn’t cope, I completely withdrew and essentially had a mini-breakdown kind of around that time”

Some participants experienced shame, loss and anger because it was hard to do ‘normal’ activities like work and renting a house, as Clare said:

> “I worry about where my life is going, I’m 32, I’m on benefits, it’s a bit shocking”

Mark, Emma, David and Clare all spoke about loss of jobs because of their difficulties with sleep, they implied that sleep problems are not compatible with work and indicated that employers were not understanding or supportive of sleep difficulties. David explained his difficulty with work:

> “sometimes if it’s been a job in the morning then I can’t get up and I’m late and then I’m late again and get the sack”

2.3: You feel like you’re at the edge of madness – but it’s quite exciting. This theme indicates participants’ watchfulness and worry about ‘going mad again’. Poor sleep in particular had a detrimental impact on mental wellbeing, as Mark said:

> “not sleeping can like send you insane”.

Lack of sleep related to an increase in anxiety, worry, hearing voices, paranoia, delusions, visual hallucinations, self-harm and suicidal thoughts. Participants felt less able to cope with their ‘brain’ when they had not slept. Feeling exhausted - like a ‘zombie’ as Tim described it - was a prevalent experience. Exhaustion had a wide ranging impact on mental wellbeing. The feeling that the mind ‘can’t function’ and ‘can’t think straight’ was indicated by participants talking about their impaired mental faculties. Mark described the impact on his concentration and attention:

> “you can't concentrate, you kind of can’t focus properly…it's like I can't absorb any information”

Changes to mood were also apparent in all of the narratives. Irritability was a universal experience. Participants often spoke about having quite extreme mood fluctuations, from low to excitement, as Jen said:

> “I can get very hyper, or I can get really, really quiet and cut myself off’

For some, there was a conflict between the distress they experienced and the enjoyment of the ‘highs’. All participants, except for Emma and Clare, spoke about the altered state of being they experienced because of sleep deprivation and changes to their usual way of thinking; they found this altered state stimulating and fascinating. Tim described this:

> “I prefer the kind of edginess, which is a bit strange but you know, that edge of madness is quite exciting”

Jen likened it to a state of intoxication:

> “it’s almost like having drugs without drugs – it’s – you know, you can go through some very crazy thoughts. It’s um, a really interesting process”

Similarly, David enjoyed the sleep-deprived state:

> “It sounds mental, but I like the feeling of being awake for a long time, it's like…buzzin’ man, it feels good….you go kinda trippy… I can think in a clear way I can’t normally.”

Conversely to the enjoyment of the highs, low mood was also common. At times, participants felt lacking in motivation and found it hard to enjoy life. Tim described the exhaustion of living with unpredictable mental health and dysfunctional sleep:

> "…you don't get to look forward to anything, because it's always got to come with some emotional energy; you've got to try and work through how you're going to manage it. It's very corrosive, really…"

3: Trying to get relief

Participants discussed their experiences of trying to get relief from their paranoia and sleep problems. This theme indicated that participants felt desperate to get peace and space from their distressing experiences, many of them voiced that they wanted to feel 'normal'.

3.1: Seeking help. All participants except for Gerry and David had approached a doctor or mental health professional for help with their sleep or mental health. For some, this was a helpful experience. For Tim, being admitted to a mental health ward 'saved' him and medication gave him much needed relief, enabling him to sleep and socialise:

> "…old anti-depressants. But they were really helpful, in terms of what it does, it just takes away – it takes away that negative edge and um gives you enough space to kind of function. I've never liked being over-medicated, um, but it just – it gives you a sense of space"

Medication was the main treatment people were offered. Participants expressed ambivalence about medication; it was felt to temporarily help but not as a long term solution, because of concerns about tolerance and dependence. Unwanted side effects, such as blunted moods, feeling numbed, loss of creativity and loss of dreams, led discontinuation of medications.

While medication was beneficial for some as a temporary measure to give relief from anxiety and help with sleep; it was generally felt that medication does not address the underlying causes of experiences. Mark expressed that a medical approach is inadequate:

> “the Doctors have got this whole 2D kind of way of thinking like, they think like your body's like a chemical, like it's a chemical reaction, this reacts to that, that reacts to this and like if you are depressed it's a chemical imbalance”

Participants who had sought professional help often felt they were not offered adequate treatment which they were angry about, as Jen said:

> “I tried to get some help with the paranoia, but it’s just useless to be honest, I’m not being funny, but the medical service – the waiting list for anything is about 2 years now for counselling”

Participants expressed they would like to have talking therapies, like Jen in the excerpt above, however it was felt to be difficult to access or to find the right approach. Mark and Jen had both been offered group support for anxiety, which they felt was incompatible with their paranoia.

Sleep problems in particular were felt to be poorly recognised, understood, and treated by mental health services. This was frustrating for participants who were desperate to get relief from their lifelong sleep problems, and meant they had lost hope in getting help from mental health services. Mark described his anger at services:

> “I've tried to get different kind of things to help but they just fob you off, print out these sheets saying 'give yourself a routine'…I tried all of that and generally it just did absolutely 'F' all and it was just like is this a joke kind of, like I try everything.”

While Jen described feeling hopeless:

> “I don’t think there’s much out there to help with sleep disorders…unless you’re going to get given a sleeping tablet…”

Participants spoke about seeking information to help themselves on the internet, in books and from television programmes.

3.2: Self-medicating. This theme indicates the prevalence of using substances to relieve paranoia and sleep problems. Apart from Emma, all participants spoke about self-medicating with alcohol. Alcohol was felt to boost confidence in social situations, ameliorating anxiety and paranoia, as Tim said:

> “alcohol was very much around as well, but that was around getting confident”

Alcohol was also commonly used to help induce sleep. Alcohol was felt to stop anxious and worried thinking. It was described as ‘knocking out’ the mind to sleep and ‘numbing’ distressing emotions, or as Gerry said “you sleep zonked out”.

Cannabis use was reported by everyone, except for Emma and Clare, at various points in their lives. Most participants had stopped using cannabis after adolescence because of the detrimental impact on their paranoia and mental wellbeing in general, as Mark said:

> “weed used to help quite a bit but …basically I've noticed that kind of doesn't help your paranoia so I stopped smoking that”

Substance use was generally viewed ambivalently by participants. For some, there was a sense that substance use was an ‘easy way out’ of distress and participants felt ‘stupid’ and guilty about ‘cheating’ to get relief using substances. Although using substances could be enjoyable and helped with paranoia and sleep, they were felt to be a temporary solution and with risks to mental and physical health, as Tim said:

> “I don’t’ smoke cannabis anymore…because what goes up must come down”

Mark became stuck in a desperate vicious cycle; using alcohol, heroin and ‘downers’ to relieve his problems, leading to addiction, followed by detoxing from substances and re-emergence of symptomology:

> “I end up taking loads of dodgy things… to try and sleep… because otherwise it just drives you insane, you can't function… and then kind of… it messes you up obviously… taking all this stuff as well, it's just like one vicious cycle.”

3.3: Adapting and coping

This theme indicates adaptation to manage life with sleep problems and paranoia. Participants employed a range of coping strategies to help with their distressing experiences and poor sleep. Distraction strategies, like white noise and counting, were found to be helpful at night to stop worrying and rumination. Participants commonly made adaptations to their routine, particularly at night to help them sleep. Emma described the routine which helped her to sleep:

> “an hour before turn off the TV, read for a little bit, have a glass of warm milk, you know take off your make-up, brush your teeth, all that, get into bed and that helped”

For other participants, socialising with ‘safe’ people and avoiding ‘unsafe’ people and stressful social situations, helped to reduce their paranoia and social anxiety, as Clare explained:

> “I’m spending a bit more time with people, apart from that social circle, which is helping”

Participants spoke about needing ‘space’ from their distressing, uncontrollable thoughts. This space was obtained in a variety of ways. Walking, exercise and being in nature were all beneficial for calming the mind and aiding sleep. Meditation was another approach which was beneficial. It was felt to create mental space which allowed clearer thinking and reduced distress for Mark, Tim and Clare. Clare described the benefits for her:

> “after meditation everything is a lot calmer; the inner angst has gone, the anxiety is gone. And I’m able to see things sort of – how to deal with it rather than worrying about it”

Adapting to live with sleep problems and paranoia involved acceptance of experiences for many participants. For some, acceptance involved a process of maturation. Participants managed their experiences differently as adults compared to when they were younger. Adi described this process explicitly:

> “there’s a point you hit at 30, when your brain goes ‘let’s just rearrange this entire filing system of everything that you’ve ever learned and see if we can make sense of that so you’re better at learning those sets of skills’”

For others, their anxiety and paranoia reduced when they were adults as they were less concerned what other people thought of them and were more self-accepting.

Acceptance was indicated by a shift in identity, often participants spoke about their experiences as ‘who I am’ and felt they had learned how ‘to be me’. For some, acceptance also involved a sense of futility and hopelessness that they would never have relief from their experiences. As Emma said:

> “it’s just something that I have to live with”

For others, it acceptance felt like more of an ongoing process, with hope for recovery. Mark looked at this pragmatically:

> “I’m kind of not as nuts as I used to be, I think I kind of deal with it fairly well”

Discussion

The aims of this study were to explore people's experiences of sleep and paranoia, to understand what these experiences meant to people and how they made sense of them. Three super-ordinate themes emerged from the analysis of the interviews: 1) a mind which won't switch off, 2) impact of a mind which won't switch off, and 3) trying to get relief. The results indicate that participants' experiences of sleep difficulties and paranoia were complex, distressing and often experienced since childhood. Their experiences were characterised by uncontrollable thoughts and a struggle to achieve a quiet mind, preventing restful sleep. Experiences of paranoia and poor sleep impacted psychosocial functioning; leading to loss of relationships, roles and inability to function optimally. Participants were desperate for relief and had developed individual coping strategies, some of which were helpful and some of which maintained paranoia and sleep problems. Participants felt that their experiences were not well understood or treated by mental health professionals, particularly sleep problems.

In the results section interpretations of the participants' experiences were grounded in the narratives from the interviews. In the following discussion, further interpretations are made about the findings in the context of the research literature.

A mind which won't switch off

In theme 'having a busy mind' the prevalence of worry was highlighted. Worry is a predictive factor in the occurrence of paranoid thinking in the general population (Freeman, Stahl, McManus, et al., 2012). In a cognitive model of persecutory delusions worry and anxiety have a significant role in formation and maintenance of paranoid thinking (Startup et al., 2007). For participants, worry was sometimes focused on social evaluative concerns and 'post-mortems' of social interactions. These social concerns are consistent with models of paranoid thinking (Freeman, 2007). Participants referred to their 'mind' or 'brain' as a powerful, uncontrollable entity; reflecting the idea of external locus of control, which is associated with paranoid thinking (Pickering, Simpson, & Bentall, 2008). The feeling of uncontrollable mind and racing thoughts, related to experiences of both paranoia and insomnia. The relationship between worry and insomnia is established in research as a transdiagnostic phenomenon (Fairholme & Carl, 2012). High levels of worry and insomnia are also associated with paranoia (Freeman, Stahl, McManus, et al., 2012; Freeman, 2007). Furthermore, repetitive negative thinking (worry and rumination) is associated with reduced sleep time, and reduced sleep time is associated with impaired ability to control repetitive negative thinking (Nota & Coles, 2014). At night, participants experienced repetitive negative thinking as indicated by their preoccupation with concerns about falling asleep and rumination about the past and future, which prevented them from sleeping.

Parasomnias, particularly nightmares, were a universal experience for the all the participants, reported on the Sleep-50 and in the theme 'insomnia, nightmares and dreams'. The prevalence of nightmare disorder in the general population is 6% (American Psychiatric Association, 2013), in this study nightmare prevalence was much higher than reported in the general population. Participants described active and frightening dreams, which were disruptive to their sleep. Nightmares were so distressing for half of the participants, that they were fearful of falling asleep. In research, distress about nightmares correlates with low wellbeing, in addition, low wellbeing was found to increase negative emotions in dreams (Blagrove, Farmer, & Williams, 2004).

Nightmares are characterised by the experience of feeling under threat, resulting in states of anxiety and fear (American Psychiatric Association, 2013). When waking at night, participants found it hard to distinguish dreams from reality. In this liminal state, participants described seeing figures in the room, which were perceived as threatening. A proposed factor in the experience of paranoia is the interpretation of anomalous perceptual experiences, such as hallucinations, as threatening (Freeman & Garety, 2014). In the participants, the interpretation of vivid dream imagery in the participants may have a similar aetiology to the interpretation of other anomalous experiences in psychosis.

In addition to anomalous experiences, affect is also related to paranoia. Freeman et. al's (2002) model of paranoia proposes that individuals who experience paranoid thinking are likely to interpret symptoms of aroused affect as an indication of external threat. When experiencing nightmares, participants described waking in a state of fear and anxiety. In individuals who are vulnerable to paranoid thinking, this fear-state may lead to interpretations that their aroused affect state is indicative of external threat (e.g., a burglar). In the participants, the core schema 'it's a dangerous world' also may also contribute to the maintenance of threat-beliefs.

Distress about nightmares and threat beliefs were associated with lifelong safety behaviours for several of the participants, such as checking under the bed or sleeping with weapons. Safety behaviours have a paradoxical effect; although they reduce distress in the short term, they maintain the fear by increasing attention to it and preventing exposure to disconfirmatory evidence (Freeman & Garety, 2004; Wells, 1997). Furthermore, safety behaviours maintain paranoid beliefs and emotional distress in people with paranoia (Freeman, Garety, & Kuipers, 2001). It is possible that lifelong safety behaviours maintain the threat-beliefs and distress the participants experienced in response to their nightmares and paranoia.

A number of the participants had experienced adverse life events and trauma which influenced their experiences of sleep, paranoia and belief that 'it's a dangerous world'. Childhood adversities, such as bullying; traumatic events, like sexual abuse and abusive relationships, and substance use have been indicated to increase the risk of developing psychosis (Freeman & Fowler, 2009; Varese et al., 2012). When experienced together, these factors have an additive, synergistic effect on the risk of psychosis (Morgan et al., 2014). Moreover, bullying increases the risk of paranoid thinking and negative schemas (Birchwood, Meaden, Trower, Gilbert, & Plaistow, 2000; Valmaggia et al., 2015) and cannabis use has also been linked to the onset of paranoia specifically (Freeman, Dunn, Murray, & Evans, 2014). In the participants, childhood bullying and cannabis use were frequent, and some had experienced abuse. For a subset of participants, traumatic experiences were relived in their dreams and nightmares. Nightmares and sleep paralysis are a diagnostic feature of PTSD (Ohayon & Shapiro, 2000). In PTSD, it is common for people to relive their traumatic experiences in dreams, as well as experiencing an increased vigilance to threat (Zeitlin & McNally, 1991).

In the theme ‘life-long difficulties’, participants experienced distressing nightmares and anxieties since childhood. In these accounts, it seemed that nightmares were experienced prior to the experience of paranoia or anxiety. Prospective research has found that sleep disturbances, namely nightmares and sleep terrors, in childhood were associated with psychotic symptoms in adolescence at age 12 (Fisher et al., 2014). Furthermore, nightmares in childhood predict psychotic experiences at age 18 (Thompson et al., 2015).

The impact of living with a mind which won’t switch off

Sleep dysfunction and paranoia had wide ranging impact on participants’ relationships and psychosocial functioning. Difficulty maintaining and loss of relationships was common. Dysfunctional sleep was often not compatible with relationships. Social anxiety and paranoia also impacted relationships; some found it hard to trust people, while others were avoidant and dismissive of relationships. These finding are consistent with current research. Interpersonal sensitivity is common experience for people with paranoia

(Freeman & Garety, 2014). It has been proposed that rejection of others acts to protect the sense of self-esteem in people who experience paranoia (Trower & Chadwick, 1995). This idea was also indicated in withdrawal from social roles for some participants. Some people had supportive relationships, with partners who helped them manage their sleep and paranoia. Supportive relationships are an important factor in wellbeing; a sense of connectedness, being understood and being supported is related to positive recovery in psychosis (Allen et al., 2013; Harris et al., 2012).

Daily functioning was detrimentally impacted by sleep and paranoia, captured in the theme 'it's a struggle to function'. The struggle to function was perpetuated by exhaustion-feeling like a 'zombie'. These experiences have also been found in research. Poor quality sleep has been related to a lowered quality of life (Kyle, Espie, & Morgan, 2010; Strine & Chapman, 2005). More specifically, poor sleep and insomnia have an been found to impact on occupational functioning (e.g., work; Kucharczyk, Morgan, & Hall, 2012) . This was reflected by the participants' difficulty maintaining jobs and the impact on their wellbeing, leading to losses, shame and self-criticism. These experiences are consistent with research findings about employment in people with psychosis. In another IPA study, participants reported difficulties in maintaining employment and lack of support from employers (Nithsdale et al., 2008).

The impact of sleep problems and paranoia on psychological functioning was indicated in the theme 'you feel like you're at the edge of madness – but it's quite exciting'. The feeling of 'going mad' because of lack of sleep is consistent with psychosis research. In people with schizophrenia, sleep dysfunction is associated with increased symptom severity (Afonso, Brissos, Figueira, & Paiva, 2011). Mood, memory and concentration were all affected by sleep and paranoia. The impact on psychological functioning was frustrating and distressing for the participants who wanted to 'feel normal'. The relationship between sleep and cognitive functioning is well established. Adequate sleep is necessary to maintain proper cognitive performance in all areas, for example in memory (Diekelmann & Born, 2010) and attention (Mitchell, Mogg, & Bradley, 2012). The combination of sleep problems and paranoia appeared to have had an additive effect on mood stability for the participants, who reported high and low in their mood when sleep deprived. In research, paranoia and insomnia have been found to lead to lowered mood (Freeman, Pugh, Vorontsova, & Southgate, 2009). Enjoyment of altered perceptual states and elevated mood in people with sleep problems and paranoia is a novel finding.

Trying to get relief

Participants spoke about their desperation in trying to relieve their sleep problems and paranoia. Support from professionals was generally felt to be inadequate, with medication being the main intervention offered. Pharmacological intervention for insomnia is supported by clinical practice guidelines. The National Centre for Clinical Excellence (NICE) guidelines for the assessment and treatment of insomnia advise the short term use of hypnotic medication for insomnia (NICE, 2004). Concerns about the use of medications were common, due to the risk of addiction and dependence.

Substances were used to relieve anxiety and paranoia in social situations and to promote sleep. This had a counter-productive effect for some participants, who found cannabis in particular exacerbated paranoia. This counter-productive effect is supported by research evidence. The role of cannabis in increasing paranoia is well established in laboratory research (Freeman et al., 2014; Mason & Morgan, 2008). In addition, substance use, including alcohol and cannabis, has also been associated with increased sleep disturbances (Garcia & Salloum, 2015). In contrast to these findings, and reflecting the conflicts of self-medicating, the hypnotic effects of cannabis and alcohol can reduce the length of time it takes for people with insomnia to fall asleep (Tringale & Jensen, 2011). In addition, the conflict of substance use, for example the shame of ‘cheating’, participants spoke about may have been a reflection of the stigma related to substance use, the participants may have felt ashamed and worried that the interviewer would judge them.

In ‘adapting and coping’ a range of strategies were used for coping with experiences of sleep and paranoia. Distraction was a commonly used coping strategy for both sleep and paranoia. Distraction is cited in research literature as a strategy people with persecutory delusions use to end episodes of worry (Startup et al., 2014). In participants, distraction may be effective for managing sleep and paranoia by stopping worried thinking. Interestingly meditation was helpful for some participants; it reduced anxiety, cleared the mind and enabling coping. Mindfulness meditation has gained much research attention as an effective intervention for psychological wellbeing in a range of mental health presentations (Keng, Smoski, & Robins, 2011). In people with paranoia, two research studies have indicated that mindfulness training is associated with improved clinical functioning and lowered distress (Chadwick, Hughes, Russell, Russell, & Dagnan, 2009; Ellett, 2013). Mindfulness meditation has also been adapted for use with insomnia and has shown improvements in sleep in clinical trials (Ong et al., 2014). In adapting to living with paranoia and sleep problems, acceptance of experiences was evident from some participants. In research, acceptance is an important stage in the process of recovery (Mapplebeck et al., 2015). In some participants acceptance was felt to be a natural process of maturation. This process may indicate increased self-acceptance and self-awareness, which are processes related to recovery from psychosis (Mapplebeck et al., 2015).

Limitations

The main limitation of this study was in recruitment. Recruiting participants was challenging and recruitment had to be extended because an insufficient number of participants volunteered. Online recruitment was added during the recruitment period due to the poor response to the poster advertisements. Freeman (2007) posits that participants experiencing paranoia and persecutory delusions can be hard to recruit because of their distressing beliefs. In addition to paranoia, these participants also experienced sleep difficulties. There was a high attrition rate after initial contact, and sleep difficulties were cited by a number of potential participants as the reason for dropping out or not attending arranged meetings. The option of internet video calls was also added midway through recruitment. The use of video calls was intended to enable participants more flexibility in the location and time of the interview, and to reduce the anxiety which may prevent participation in a face-to-face interview.

A limitation in data collection was the use of the Sleep-50 measure. The Sleep-50 is not a commonly used measure in the research literature, which may limit comparison to other studies in the field. The Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989)may have been more appropriate as it is used in other sleep and psychosis studies. This is in contrast to the use of the Green Paranoid Thought Scale which is commonly used in other studies and allows comparison to other studies.

A further limitation which may have impacted all stages of the study was that the study was conducted by one primary researcher. The researcher characteristics may have affected the type of participants being recruited, influenced the discourses in the interviews and interpretation in the analysis. For example, all of the participants were also White British and criticism of psychiatric medication was a common narrative. A collaboration between a group of researchers may have reduced this effect. To counter this, the transparency about the researcher characteristics and the use of audit and supervision in this study was a relative strength. Inclusion of research characteristics allows the reader to make their own inferences about how the researcher characteristics may affect the findings (Elliott, Fischer, & Rennie, 1999).

Clinical Implications

Experiences of paranoia and sleep were complex and varied, for example, for some people sleep disturbances were their main concern and reason for seeking help and for others the social impact of paranoia was more distressing. No two participants experienced the same phenomena in the same way. When seeking professional help, sleep problems in particular were not well recognised, understood or treated, indicating a need for better assessment of sleep problems in this population. These findings have clinical implications, namely supporting the use of psychological formulations in practice. A thorough assessment and individually tailored psychological formulation could be used to ascertain how problems with sleep and paranoia affect the individual, recognising diversity and the importance of individual experiences (BPS, 2014). Individually tailored formulations enable practitioners to apply psychological interventions which target the symptoms which cause the individual most distress (Van der Gaag, Valmaggia, & Smit, 2014).

In considering appropriate psychological interventions for people who experience paranoia and problems with sleep, the prevalence of nightmares has significant clinical implications. For people who experience paranoia, psychological therapies targeting nightmares may be an appropriate strategy in clinical practice. In PTSD, imagery rehearsal therapy (IRT) is used to target distressing nightmares; it is clinically effective to reduce nightmares and daytime distress (Nappi, Drummond, & Hall, 2012). IRT involves psychoeducation about nightmares, exposure to fearful nightmare imagery and cognitive restructuring. A recent case-series has investigated the use of IRT for nightmares in people with psychosis (Sheaves, Onwumere, Keen, Stahl, & Kuipers, 2015). This small scale study (*n*=5) found promising results for the use of this IRT. Participants reported a positive repose to the intervention, with a reduction in nightmare distress and reduction of delusional severity in two participants.

Similarly to targeting nightmares, targeting specific experiences such as insomnia or worry may also be an appropriate area for clinical intervention for people who experience paranoia. As discussed earlier, the BEST study has indicated that CBT-I is effective in reducing insomnia in individuals who experience persecutory delusions (Freeman et al., 2015; Myers, Startup, & Freeman, 2012). For worry, a recent randomised controlled trial found that a brief CBT intervention targeting worry in individuals who experience persecutory delusions was effective at reducing worry and delusions (Freeman, Dunn, et al., 2015). The participants also indicated that meditation was beneficial to calm their ‘active mind’. This has clinical implications for the use of mindfulness meditation with people who experience sleep problems and paranoia.

The finding that participants experienced life-long problems with nightmares has implications for early intervention in childhood, which may prevent later onset of paranoia and other psychotic experiences. Identifying people ‘at-risk’ of psychosis is a valid approach in the early intervention and prevention of psychosis (Morrison et al., 2012; Yung, McGorry, & McFarlane, 2004). Detection and assessment of nightmares in childhood could form part of the assessment for young people ‘at-risk’ of psychosis.

Loss of work and difficulty in maintaining jobs was a common experience for participants and had a detrimental impact on participants’ wellbeing. This highlights that employers may not be supportive of people who experience sleep problems and paranoia. There is potentially a role for mental health practitioners to work with employers to support people with mental health and sleep difficulties to remain in work.

Further research

The first suggestion for further research is based on the premise that research on sleep and paranoia is heavily focussed on insomnia. There are two small studies of recent research on nightmares and psychosis (Sheaves, Porcheret, & Tsanas, 2015; Sheaves et al., 2015). The findings of this study suggest, that sleep dysfunction, in particular nightmares, may be a significant problem for people who experience paranoia. This indicates a possible direction for future research to focus on different types of sleep dysfunction and paranoia.

Secondly, the result of this study suggested that sleep disturbances may have preceded the onset of paranoia. This hints that that there may be a causal direction in the sleep-paranoia relationship, although in this small sample qualitative study the finding is tentative. Although, epidemiological research has indicated that sleep problems predict the onset of mental illness (Breslau et al., 1996) and nightmares predict the onset of psychosis in adolescents (Thompson et al., 2015). There is a possible role for further research in this field, to investigate the sleep-paranoia developmental trajectory.

Finally, mindfulness was reported to be helpful for a number of participants, research has indicated that mindfulness meditation is effective in reducing distress and paranoid thinking (Chadwick & Hughes, 2009; Ellett, 2013) and reducing insomnia (Ong et al., 2014). Given the strong relationship between sleep dysfunction and paranoia, future research to investigate the effect of mindfulness on sleep dysfunction more generally, and paranoia and sleep dysfunction may be warranted.

Conclusion

People who experience paranoia and sleep problems described lifelong experiences of managing life with an ‘active mind’. The mind ‘won’t switch off’; leading to insomnia, nightmares, worry and vigilance to threat. These experiences were exhausting – leaving people feeling like a ‘zombie’ and ‘on the edge of madness’. These experiences had a wide ranging impact on daily functioning, relationships and wellbeing. Desperation for relief from experiences often led people to alcohol and substance use. Some positive strategies, such as meditation, were helpful to ‘calm the mind’. Currently, it is felt that there is inadequate understanding or support for people with these experiences, particularly concerning sleep. People seeking help often feel ‘fobbed off’ with medication. This emphasises a role for clinical practice to support people with therapeutic work, such as the promising CBT-I intervention or mindfulness. The findings also indicate directions for future research to develop conceptual understanding of sleep dysfunction and paranoia.

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Appendices

Appendix 1. Quality Checklists *(removed for copyright)*

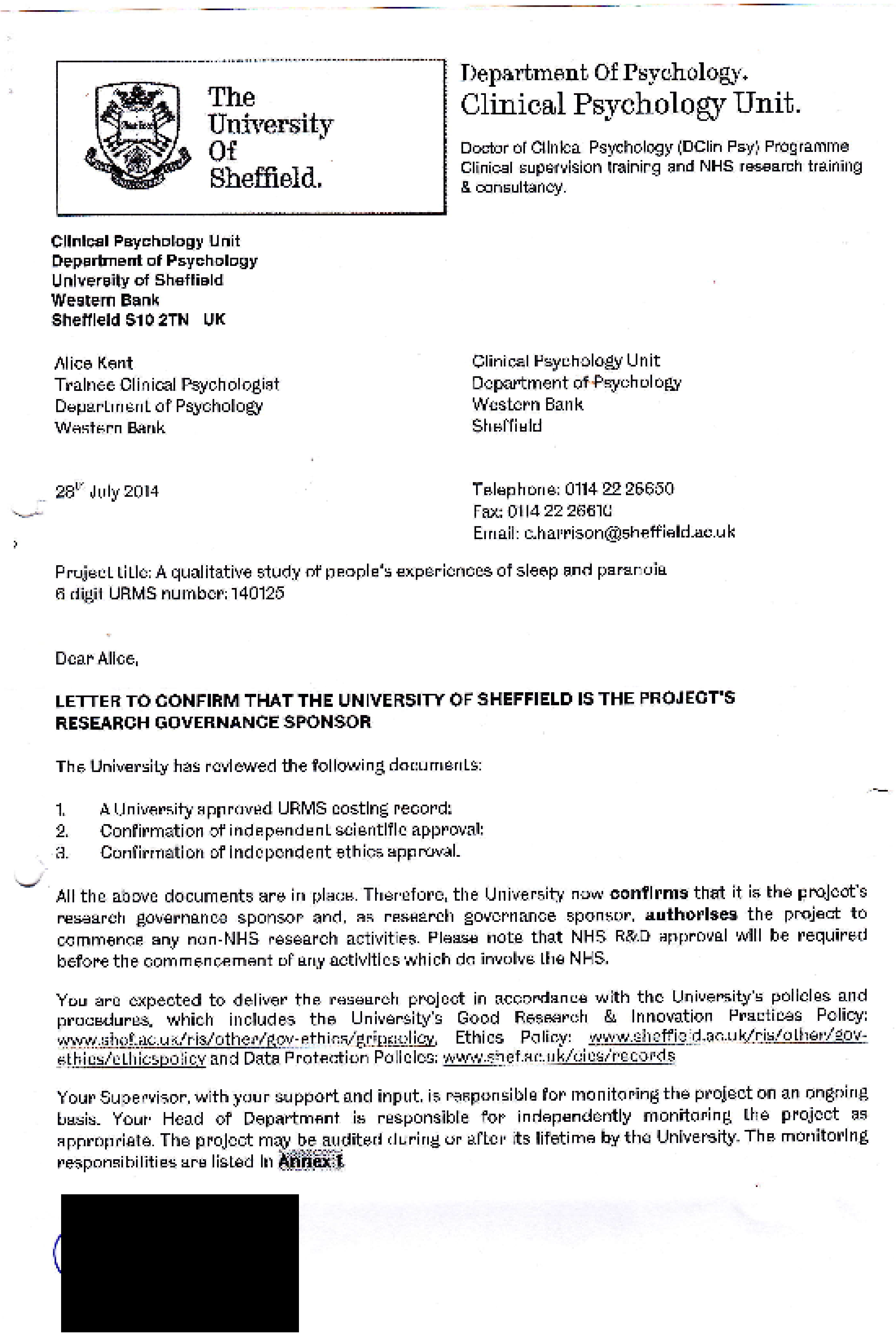
1) Qualitative research quality checklist from the Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 2006)

2) Guidelines for assessing the quality of IPA (Smith, 2011a) *(removed for copyright)*

Appendix 2. Example of Table of Primary Research Features

Code	1st Author	Year	Psychosis experience	Theoretical orientation	Methodological (inc quality rating)	Major findings (take-home message)
01	Mapplebeck	2015	Recovery from psychosis	Post traumatic growth after psychosis .	Borderline IPA – insufficient quotes CASP No reflexivity, no mention of ethics, limited detail about analysis and how themes were derived does not include all participants in the write up. Interesting themes about recovery processes	Seven people who had experienced psychosis talked about their experiences of personal growth following the traumatic experience of psychosis. 4 subthemes: 1) finding meaning and purpose, 2) support and understanding, 3) inner strength and determination, 4) self-acceptance and awareness. Discussion of implication of using PTG processes for therapy,
02	Solli	2015	Psychosis, inpatient treatment	Recovery User perspective Music therapy	Met all of CASP criteria Good IPA Only criticism is no interview schedule.	Nine people on inpatient ward in Norway with psychosis diagnoses participating in music therapy. 4 main themes 1) Freedom 2) Contact 3) Wellbeing 4) Symptom relief. Music therapy promotes agency and personal and social identity; important factors in recovery from psychosis, particularly in the context of a compulsory inpatient admission.
03	De Wet	2014	Recovery from first episode psychosis	Recovery	Unacceptable IPA CASP Missing relationship between participants and researcher and rigour in analysis Novel factor was the location and country of the research, limited research from SA, so considering factors specific to this culture is interesting.	Seven people in Cape Town, South Africa in recovery from 1st episode psychosis. Themes: Having a job; Support ;Taking responsibility for themselves or independence; Insight into the illness and knowing what to expect in the future; positive attitudes; awareness of limitations; having to care for one another; adapting to and accepting circumstances; stigma; spirituality Support is very important in recovery. The barriers to this in SA is discussed

Appendix 3. Ethical approval



The
University
Of
Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinica Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
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28th July 2014

Telephone: 0114 22 26650
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Email: c.harrison@sheffield.ac.uk

Project title: A qualitative study of people's experiences of sleep and paranoia
6 digit URMS number: 140125

Dear Alice,

LETTER TO CONFIRM THAT THE UNIVERSITY OF SHEFFIELD IS THE PROJECT'S RESEARCH GOVERNANCE SPONSOR

The University has reviewed the following documents:

1. A University approved URMS costing record;
2. Confirmation of independent scientific approval;
3. Confirmation of independent ethics approval.

All the above documents are in place. Therefore, the University now **confirms** that it is the project's research governance sponsor and, as research governance sponsor, **authorises** the project to commence any non-NHS research activities. Please note that NHS R&D approval will be required before the commencement of any activities which do involve the NHS.

You are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Good Research & Innovation Practices Policy: www.shef.ac.uk/ris/other/gov-ethics/grippolicy, Ethics Policy: www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy and Data Protection Policies: www.shef.ac.uk/cics/records

Your Supervisor, with your support and input, is responsible for monitoring the project on an ongoing basis. Your Head of Department is responsible for independently monitoring the project as appropriate. The project may be audited during or after its lifetime by the University. The monitoring responsibilities are listed in **Annex 1**.

[redacted]

Appendix 4. Information sheet for participants

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
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University of Sheffield
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Telephone: 0114 2226650
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Email: pcp12amk@sheffield.ac.uk
Website: http://www.shef.ac.uk/

PARTICIPANT INFORMATION SHEET

A qualitative study of people's experiences of sleep and paranoia.

You have received this letter because you responded to an advert for people who experience paranoia and sleep problems; thank you for responding to the advert. When you read the advert you answered 'yes' to these questions:

1) Do you experience paranoia?
2) Do you ever have problems with sleep?

If you do not answer 'yes' to both of the above questions, then you probably do not want to consider participating any further. Because of the nature of the research it is also essential that you speak fluent English as you will be asked to talk about your experiences. If you do not speak fluent English, then you probably do not want to consider participating any further. Thank you.

If you do answer 'yes' to the above questions and you speak fluent English and you think you would like to participate in some research, then please read the following information about the study and think carefully about whether you would like to participate. You can contact the researcher if you have any questions you would like to ask before you consent to participate.

What is the purpose of the study?

The study hopes to learn about how people who experience paranoia also experience sleep problems. We are interested in what these experiences mean to them and how they make sense of these experiences. At the moment there is very little research in this area.

Paranoia is a common experience – some research has found that 18% of the population experience paranoid thoughts. It can be a difficult experience for many of these people. Sleep disorders are also experienced by a lot of people; about 20% of the population seek help from medical professionals at some point in their life for sleep problems. By gaining a deeper understanding of how people experience these together, we hope to be able to develop ways of helping people with paranoia and sleep problems.

Who is carrying out the study?

The study is being carried out by Alice Kent, a Trainee Clinical Psychologist at the University of Sheffield and Sheffield Health and Social Care NHS Trust, in collaboration with Dr. Georgina Rowse, a Clinical Psychologist and Senior Lecturer at the University of Sheffield and Sheffield Health and Social Care NHS Trust. The project has been approved by the University of Sheffield Research Ethics Committee.

What happens if you decide you do not want to be involved in the study?

Participation in this study is voluntary. You can refuse to participate at any stage leading up to the meeting with the researcher. At the meeting you can refuse to answer any questions that you do not wish to answer. If you decide to participant in the study, but then change your mind, you can withdraw within a month of your meeting with the researcher. After this point the study will have progressed to the analysis stage and it will not be possible to separate out information from individual participants.

What is involved in your participation?

If you decide to participate in the study you will need to complete the consent form included with this letter and return it in the envelope provided. The researcher will then contact you to arrange a time and a place for the interview which is convenient for both of you, this will probably be somewhere like an NHS meeting room because it is quiet and private, but this can be negotiated with the researcher to find somewhere convenient for you. You will be reimbursed for any travel costs.

You will meet with a researcher to talk about your experiences of sleep and paranoia. The researcher will ask you some questions about your personal experiences and what they mean to you. The meeting is expected to last for about an hour, but sometimes it takes more or less time, depending how long you talk for.

What will happen to the information from the conversation with the researcher?

The conversation will be tape-recorded and then transcribed (typed).This will then be analysed to explore how different people experience paranoia and sleep. The researcher may also contact you at this point, if you want, to talk about the ideas which were developed from the analysis. These ideas will then be discussed in the research report. All information will be stored securely.

The ideas from your conversation with the researcher will be used in a research report at the University of Sheffield. It may also be used in articles published in psychology journals, this is expected to be in 2015.

Some extracts of your conversation with the researcher may be printed in a research report, in future publications or in teaching related to the research. Although your words may be used, all identifying information will be removed or changed. Identifying information includes your name, any other names you talk about, places etc. We will ensure that your identity is kept confidential.

In 2015, when the report has been written, a summary of the findings from the study will be written for the people who participated. You can tell the researcher whether or not you would like this summary when you meet with them.

After the study has finished all the tape recorded information from the conversations with the researcher will be destroyed. The transcripts will be kept securely while they are being used for future research publications, this is normally for about 5 years, and will be kept in line with university policies on storing research data. Your information will not be shared with anyone not involved in the project.

What can you gain from the study?

Participation this study is voluntary, participants will not be paid for their participation. Although there will be no gains intended by the study for participants, some people find it helpful and enjoyable talking about their experiences. The study is also hoping to contribute to research about paranoia, so your participation may help other people who have difficulties with paranoia and sleep by helping us understand what it is like to experience these.

What happens if you find participating in the study upsetting?

Sometimes it can be upsetting to talk about your personal experiences, if you feel upset or worried at any point during the meeting let the researcher know and you can have a break or end the meeting. The researcher will also provide you with information about places where you may be able to get support.

It is up to you what you would like to disclose about your experiences. You do not have to answer any questions you do not want to.

What happens if you are not happy with the way the study has been conducted?

If you are not happy with the way the study has been conducted and would like to make a complaint please contact Dr. Georgina Rowse at the University of Sheffield on 0114 222 6650. You can also make a complaint via the university: Dr. Philip Harvey, Registrar and Secretary's Office, University of Sheffield, Firth Court, Western Bank, Sheffield, S10 2TN.

Thank you for reading this information. If you have any further questions you can contact Alice Kent by calling the Research Support Officer on 0114 222 6650 and leaving a message (include your name, your phone number and the name of this research project 'Paranoia and Sleep') for Alice to ring back, or via the email address below and she will be happy to discuss any queries. Please note: the researcher officer cannot answer any queries relating to the study.

If you would like to participate in the research study please carefully read the consent form included with this letter. When you have read and signed the consent form, please return it in the envelope provided. The researcher will then contact you to arrange a time for the meeting.
Kind regards,
Alice Kent
Trainee Clinical Psychologist
Clinical Psychology Unit
University of Sheffield
Western Bank
Sheffield
S10 2TP Tel: 0114 2226650 Email: [redacted].ac.uk

Appendix 5. Consent form for participants

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (Dclin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Telephone: [redacted]

CONSENT FORM

Title of the project: A qualitative study of people's experiences of sleep and paranoia.

Name of researcher: Alice Kent, Trainee Clinical Psychologist, University of Sheffield.

Please carefully read the following statements and write your initials in the box when you have read and agreed with each statement.

Once you have completed this form please return it in the Freepost envelope included. The researcher will then contact you to arrange a meeting.

Thank you.

Please initial the box:

1. I have read the information sheet dated (insert) and I fully understand it. ☐
2. I have had the opportunity to ask the researcher any questions I have about the research. ☐
3. I understand that the conversation with the researcher will be recorded. ☐
4. I understand that extracts from my conversation with the researcher may be used in the future in publications or teaching related to the research. ☐

Any information that could identify me or anyone I talk about will be removed or changed to another name so I cannot be identified.

5. I understand that my participation is voluntary. I do not have to answer any questions I do not want to. I can withdraw within one month of my meeting with the researcher, without giving any reason, by informing the researchers ([redacted]). ☐

6. I agree that the researcher can contact me on the contact details I provide to arrange a meeting. ☐

7. I agree to take part in the study. ☐

Name of participant	Signature	Date

Name of researcher	Signature	Date

Appendix 6. Sleep-50 *(removed for copyright)*

Green et al. Paranoid Thoughts Scale *(removed for copyright)*

Appendix 7. Extract from transcript analysis from Jen.

Line.	Emergent themes.		Interview transcript.	Exploratory notes.	Context/ themes/ metaphors
	sleeplessness		sleep I'd just sleep on the sofa. I don't know why, ha, I don't	'Regular routine' of not sleeping	awareness – it's ok on her
	Finding ways to cope		know why it worked, but it worked, so, um. And then I started		own but not with others
25			getting insomnia, which was a whole different – it wasn't just	Insomnia worse than not sleeping	Not understanding insomnia
	Games with thoughts		not sleeping, that was where the games start in your head, for		
			me.	Experience of thoughts/head with	Emphasise 'whole different'
				insomnia	relationship with thoughts –
		I	What does that mean? Games start in your head?		'games'
30	Me Vs brain (out of			Insomnia is something hard to explain	
	control/separate from	P	Hm, um, I haven't actually quite worked out how to explain	Never been able to get over insomnia –	
	me)		insomnia to myself, but um, you know when it – you know	hopeless	Long Search for
			when you're not going to fall asleep. It's not a matter of 'I	Had it for 20 years – lifelong	meaning/understanding -
	Fighting thoughts		might fall asleep in a minute or I might give it an hour', um,	'Knowing' insomnia – recognising what	
35			I've never figured a way to sleep though insomnia and I've had	it feels like	Relationship with insomnia-
	Difference between		that for probably over 20 years. All I know is that when I get	Experience of insomnia in body – it	its familiar
	brain when slept or not		this thought in my head, I know, my whole body changes, my	changes whole body feeling	Acceptance/surrender
	slept		whole head changes so I don't bother fighting it anymore, I		'battle' language – insomnia
			just stay awake. Um, but then that's when paranoia start,	Paranoia starts when sleep deprived	is strong
40	Turbulent inner world		because it's catch 22, because you get the sleep deprivation	Racing thoughts	'Catch 22' no escape from
			and then you start getting paranoid. Um, yes, when I can't	Playing games with thoughts – try to	paranoia/insomnia
	Controlling thoughts		sleep I either get really racing thoughts, everything, and it's	control them - not in control of them	
			like 1000 thoughts a minute – you can't – what I used to do		Distress – racing thoughts
	Racing thoughts		was play games with myself to try and control it –		
45					
		I	Control the thoughts?		
	Imaginative			Using imagination/imagery to control	

Line.	Emergent themes.		Interview transcript.	Exploratory notes.	Context/ themes/ metaphors
	Strategies to stop	P	Um, yes, I would. I would imagine myself slowing them down,	thoughts – cognitive strategy to slow	
	racing thoughts		actually physically trying to push them backwards, so it would	thoughts down	Fighting thoughts – need to
50			be like a real turning and turning and turning, so I would try		control them
	Mind in overdrive		and turn it the other way and physically try and stop it and	Used to help but doesn't anymore	Using imagery
			slow it down. It used to work, it doesn't work so much now,	Need imagination for this to work	
	Imagery		but it used to work when I was younger and more imaginative.	Difference from younger to now – more	Sense of time/ journey –
			Um, yes.	imaginative, less able to cope now?	learning experience
55				More hopeless?	
		I	When you say insomnia, what does that mean for you?		
	Stubborn head				
		P	Oh, um, for me it – it just means that I can't – I'm not going to	Hopeless when get feeling of insomnia	Talking about 'head' as if it is
	Cant sleep vs wont		sleep. My head just becomes so awake, but very, very	– it is going to win.	different to her –
60	sleep		awkward, very um, oh, very stubborn – I just know in my head	Change from 'normal' self to insomnia	control/powerful head
			I'm not going to sleep, but it's not just a feeling in my head, it's	self. It takes over.	
			a feeling in my body. It's like I'm on edge, I'm awkward, and it	Impact how how feel –awkward, edgy,	Can't sleep vs wont sleep
	Mind in overdrive – out		almost feels like I've already had 8 hours sleep and I don't	social impact	
	of control		need sleep. But I know I need sleep, especially if I've got work	Feel like dont need sleep	
65			the next morning. Um, if I lie there, then my thoughts start	Recognising you do need seep	Impact on life – work – need
	Rumination on		coming and then I'll start thinking about anything bad that's	Distressing thought – going over past,	sleep
	negative		happened in the past; I'll think of bereavements, I'll think of	dark thoughts	Learning to cope
			juts the nasty stuff, and I spent many years winding myself up	Punishing self with bad thoughts – if lie	Its better not to lie in bed
	Ambilient abot		and doing that. I was put on diazepam, which was good and	in bed when can't sleep	and have dark thoughts
70	medication		helped, but um, there's a history in my family of addiction to	Medication – concern about it not	
			that so I've not um – I find my own ways to deal with it. Um,	being a good solution –addiction	Creative
	Find ways to cope		generally, my mind becomes fully awake and I start writing, I	Cope on my own/ my own way	Sense of independence –

Appendix 8. Excerpt from reflective journal

Mark: Excerpt from Coordinated management of meaning reflective tool

Personal assumptions, biases, prejudices, previous experience: Communication from participant by email prior to interview about how they had not slept for 5 days –original interview postponed. We had to consider whether he was well enough to do interview. I assumed he was experiencing a crisis or was currently unstable in his mental health (hearing voices, insomnia). He had already told me doctors said they 'can't help me' when he had an assessment at A&E recently – I felt he would probably be quite hopeless about MH services – which he was in the interview – meeting my prior assumption. I also wondered if he was trying to get me to help him or get drawn into the idea he was un-helpable ie. really serious/bad case of insomnia. I reflected that I felt aligned with this hopelessness as I had recently had had a similar experience in my clinical work of someone not being 'picked up' by services after presenting to A&E in crisis. I think this also bias and previous experience influenced the interview. I felt quite 'fired up' talking about how psyc liaison services had not helped him. I think my belief in psychological or non-pharmaceutical approaches in MH recovery also influence my line of questioning –I chose to follow lines of questioning supporting and exploring these beliefs = bias?.