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A Qualitative Investigation of the Conceptualisation of Psychosis in People of a Muslim Faith

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Thesis submitted for the partial fulfilment of the requirements of the

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Declaration

I declare that the work contained within this thesis has not been submitted for any other degree, or to any other institution.

Structure

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Abstract

This thesis adds to the literature on psychosis in relation to religion and culture.

The review critically appraises the state of knowledge about explanatory models of psychosis across cultures. Twenty-one studies were reviewed employing qualitative methods, quantitative methods and a combination of both methods. The studies demonstrated a complex picture whereby people held biological, psychosocial and spiritual explanatory models to varying degrees depending on socio-cultural context. It was common for people to hold multiple explanatory models. Spiritual and religious explanatory models had greater importance in developing countries when compared with developed countries, as well as for ethnic minorities in developed countries. Recommendations were made for the use of qualitative and quantitative methods within a biopsychosocial-spiritual framework. Future research should seek to pro-actively engage with individuals with psychosis, their families, alternate healing systems and the wider community.

Research shows religion to be an important issue for some people with psychosis. The research report explored how people of a Muslim faith conceptualise their psychotic experiences and the role of religion in this conceptualisation. Eight males having experienced psychotic experiences took part in the study. Interpretative phenomenological analysis (IPA) was used as the method of analysis. Four super-ordinate themes emerged: The self in relation to others, getting help and moving on, the unseen and the mind in the wider world. The results provide support for the existing literature, in that participants utilised a variety of interpretative frameworks, with religion being important in the struggle to make sense of their psychotic experiences.

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Section 1: Literature Review

A Review of Explanatory Models of Psychosis Across Cultures

Abstract

This review critically appraises the state of knowledge about explanatory models of psychosis across cultures. Twenty-one studies were reviewed which employed qualitative methods, quantitative methods and a combination of both methods. The studies demonstrated a complex picture whereby people held biological, psychosocial and spiritual explanatory models to varying degrees depending on socio-cultural context. It was common for people to hold multiple explanatory models in relation to causality and treatment of psychosis. Some studies provided support for the holding of psychosocial explanatory models in developing countries. Spiritual and religious explanatory models had greater importance in developing countries when compared with developed countries, as well as for ethnic minorities in developed countries. Research limitations such as the reduction of qualitative data in studies that used both qualitative and quantitative methods and the biomedical bias employed by studies was explored. Recommendations are made for the eclectic use of qualitative and quantitative methods within a biopsychosocial-spiritual framework. Such research should be clinically relevant and linked to the development of services that pro-actively engage with individuals with psychosis, their families, alternate healing systems and the wider community. Furthermore increased emphasis should be given to the provision of culturally appropriate psychosocial interventions.

1. Introduction

1.1.1 Outcomes for Psychosis across cultures

There have been a number of studies that provide evidence for better outcomes for psychosis in the developing world when compared to the developed world (Murphy & Raman, 1971; Waxler, 1979; World Health Organization, 1979; Harrison et al., 2001). Cohen (1992) has critiqued the findings of such studies and more recently Cohen, Patel, Thara and Gureje (2008) have questioned this ‘axiom’ arguing that outcomes are variable in developing countries. Other researchers reviewing the area have found continuing support for better outcomes in the developing world (Isaac, Chand, & Murthy, 2007). Furthermore research within European countries suggests poorer outcomes for psychotic disorders for minority groups when compared to the host population (Hutchinson & Haasen, 2004). A recent review of severe mental illness across cultures concludes that the outcomes for severe mental illness are variable across cultures, when comparing developing and developed countries as well as in relation to migration (Bhugra, 2006). The studies of Cohen et al. (2008) and Isaac et al. (2007) highlight the need to appreciate the complexities in understanding outcomes of psychosis across cultures, such as the host of socio-cultural factors.

1.1.2 Importance of research in explanatory models

The continued interest in psychosis across cultures has been facilitated by the introduction of the concept of explanatory models (Kleinman, 1980). This has led to a more detailed examination of psychosis across cultures. Understanding explanatory models across cultures serves a number of purposes. Firstly it has the potential to give greater insight in to the variable course of psychotic disorders, in particular factors that lead to a better outcome in developing countries and poorer outcomes for migrant

communities in developed countries. Secondly, the growing provision of mental health services based on western psychiatric modes of treatment in the developing world require services to understand the explanatory models of local service users. Similarly the provision of mental health services for multicultural communities in the developed world would benefit from such research, in the provision of culturally appropriate mental health services.

The growing interest in research regarding explanatory models have been closely linked to clinical implications. Research suggests that satisfaction and better patient outcomes are more likely when there is a concordance between the patient's and the psychiatrist's explanatory model (Callan & Littlewood, 1998). However the research on explanatory models has had a limited impact on routine clinical practice (Bhui & Bhugra, 2002). The National Institute of Clinical Excellence (NICE) schizophrenia guidelines have placed emphasis on cultural competence which include using explanatory models for people from diverse cultural backgrounds, hence the potential for integration of explanatory models in clinical practice within the UK (NICE, 2009). Bhugra (2006) in his review of severe mental illness across cultures highlighted the need for clinicians to explore explanatory models of patients' illnesses and work towards bridging the patients' and clinicians' models together. There are now a growing number of studies that have investigated the explanatory models of psychosis across cultures, however to date there has been no review of the literature.

1.2 Use of terminology

The term 'explanatory model' as described by (Kleinman, 1980) refers to a person's view about the nature of their illness, its cause, severity, prognosis and treatment preferences. This term has been widely used in the field of cross-cultural studies in

mental health as represented by its incorporation in the naming of tools within the field such as the Short Explanatory Model Interview (SEMI; Lloyd et al., 1998). There have been critiques of the term such as the term ‘model’ not capturing the transient nature of health beliefs. Alternate terms have been proposed such as ‘explanatory map’ (William & Healy, 2001) and ‘system of explanation’ (Larsen, 2004). Despite its limitations the term is widely recognised in cross-cultural studies in mental health and the proposed terms have not had the recognition for them to be adopted or used simultaneously within the field of research.

The term ‘psychosis’ will be given precedence over ‘schizophrenia’ as it is widely used in the papers reviewed in line with developments in the conceptualisation of psychosis (British Psychological Society [BPS], 2000). However many studies used both terms with some giving preference to schizophrenia, therefore depending on the studies discussed both terms will be utilised. Debates in relation to the labelling of people experiencing ‘psychotic experiences’ are infamous in psychology and psychiatry and are beyond the scope of the review.

Culture refers to the set of shared attitudes, values, goals, and practices that characterise a large group of people (Kroeber and Kluckhohn, 1952). The term culture is preferred over ethnicity as it represents greater fluidity whereas ethnic identity is more likely to remain stable (Bhugra, 2006). The term culture better reflects the fluidity as a result of change in the developing world as well as the developed world. These include urbanisation, industrialisation, migration and the impact of globalisation. However it is recognised that the terms culture and ethnicity are often used interchangeably. The research area in comparing psychosis across cultures refers to ‘developed’ countries in relation to ‘developing’ countries. The research area also uses the term ‘western’ alongside the term ‘developed.’

1.3 Aim

The purpose of the review is to evaluate the state of knowledge about explanatory models of psychosis across cultures, to synthesize the findings of studies, to identify limitations and implications for future research.

2. Method

2.1.1 Database and search terms

Searches of PsycINFO were undertaken using a combination of keywords schizophrenia, psychoses, psychosis, explanatory model, conceptualisation, illness belief, and health belief. This search yielded 486 studies. Applying the inclusion and exclusion criteria outlined below identified 12 papers. The same search was then undertaken using MEDLINE, excluding duplicates, 3 additional papers were identified. A further 6 papers were identified from reference lists of relevant studies. The total number of studies reviewed is 21. The search and inclusion process is represented in Figure 1 (Appendix A).

2.1.2 Inclusion and exclusion criteria

The search was limited by English language, journal articles in peer reviewed journals, and publication from 1997 to 2010. This period was selected for the review for two main reasons. Instruments which operationalise the concept of explanatory models such as the Short Explanatory Model Interview (SEMI; Lloyd et al., 1998) and the Explanatory Model Interview Catalogue (EMIC; Weiss, 1997) were developed at the start of the review period. Secondly, the commencement of the review period coincides with developments in research and clinical practice both within psychology and psychiatry that have critically evaluated medical conceptualisations of psychotic experiences. This has led to a comprehensive conceptualisation of psychosis within a biopsychosocial framework, which recognises the importance of culture (BPS, 2000; Bracken & Thomas, 2001).

Identified studies were selected considering the extent to which they addressed explanatory models of psychosis in relation to culture. Studies employing quantitative, qualitative and a combination of methods were included in the study. Ethnographic studies were included due to their ability to evaluate socio-cultural context. Studies in developed countries were retained if they focused on a comparison between ethnic groups and if the study had a large proportion of participants from ethnic minority groups. Due to the importance given to spiritual explanatory models in studies in the developing world, research in the developed world that focused on spiritual explanatory models were included.

Studies that employed a narrow focus such as a focus on the concepts of insight, symptoms or expressed emotion were excluded from the review. Case conceptualisations and case studies were also excluded from the review due to their focus on treatment rather than the explanatory models of the individuals concerned. Studies regarding health professionals and community health workers were excluded. Applying the inclusion and exclusion criteria identified one wide-ranging review of severe mental illness across cultures (Bhugra, 2006). Table 1 (Appendix B) summarises the studies.

2.2 Assessing quality

In order to assess the quality of the qualitative studies or qualitative components in studies, which used a combination of methodologies, the guidelines proposed by Elliott, Fischer and Rennie (1999) were utilised. Furthermore the model proposed by de Jong and Van Ommeren (2002) will be used as an overall framework for evaluating the research in the area. The model proposes the eclectic use of qualitative and quantitative methodologies in cross-cultural research incorporating focus groups, in-depth

interviews, snowball sampling and population surveys. Although focused on cultural epidemiology the model has wider applications such as the assessment of community needs and the development of programmes to meet the needs of individuals with mental health problems.

3. Research areas

The main body of the review will be composed of four sections. The first section will review thirteen studies exploring explanatory models in relation to people with psychosis and their relatives. The second section will review two studies comparing explanatory models in different cultural and ethnic groups, the third section will review three studies regarding healers and Spiritist mediums and the fourth section will review two studies in relation to public explanatory models of psychosis.

3.1 Explanatory models of people with psychosis and their relatives

Generally studies categorised explanatory models as biological, psychosocial and spiritual both for causes and treatments. Summarising the quantification of explanatory models reported by these studies is difficult given the variety of categories utilised across studies. For instance some referred to supernatural and religious explanatory models, which have been included under spiritual explanatory models, to allow for comparison across studies.

3.1.1 Causal explanatory models

Studies relating to individuals with psychosis reported a high degree of spiritual explanatory models, 70% (Saravanan et al., 2007), 73% (Silove et al., 2008) and 60% (Charles, Manoranjitham, & Jacob, 2007). In contrast biological explanatory models were considerably lower at 15%, 20% and 32% respectively for the above three studies.

Similar results for biological causes were found in the studies employing relatives, for example the study by Phillips, Li, Stroup, & Xin, (2000) reported 29.6%. An exception was the study by Das et al., (2006) which reported 60%. Studies in relation to relatives

and family members found greater variability with regards to spiritual explanatory models. The studies by Srinivasan and Thara (2001) and Philips et al. (2000) reported 16% and 15.6% respectively. In contrast the studies by Charles et al. (2007) reported 54% and that of Kurihara, Kato, Reverger, & Tirta (2006) reported various spiritual causes, such as disturbance by spirits reported by 69% of participants.

The findings regarding psychosocial explanatory models for both individuals and relatives found considerable variability. For the three studies that researched individuals with psychosis, Silove et al. (2008) found 71% and Saravanan et al. (2007) found 11% of individuals reported causality categorised as psychosocial. In contrast the study by Charles et al. (2007) reported no psychosocial factors in relation to causation for both individuals with psychosis and their relatives. Similarly, the study by Das et al. (2006) did not report psychosocial stress for relatives. The two studies provided little detail of how the qualitative data were analysed thereby limiting the extent to which one can critique the methods of categorisation, which possibly contributed to the non-reporting of psychosocial explanatory models. Furthermore research employing relatives within India and other developing countries provide evidence for the holding of psychosocial causal explanatory models. Srinivasan and Thara (2001) reported psychosocial stress as the most common cause at 55%, Philips et al. (2000) reported higher levels at 84% with the study by Kurihara et al. (2006) reporting various categories of psychosocial stress, for example work stress at 23%.

3.1.2 Treatment explanatory models

Treatment explanatory models were researched by fewer studies. Silove et al. (2008) found a healer consultation rate of 81% compared to 25% for a health professional. A particular strength of the study by Charles et al. (2007) was the differentiation of

treatment explanatory models and treatments used. The research reported that 52% had beliefs about visiting a temple or other religious place for cure, with 64% having visited. 21% had beliefs regarding treatment by a traditional healer and 95% had beliefs regarding treatment by a doctor, with 41% and 100% respectively having used such treatments.

Two studies provided data regarding treatment explanatory models for family members. The study by Charles et al. (2007) reported 99% of family members felt treatment should be from a doctor. They also reported 42% of participants felt visiting a temple and place of worship could solve the problem and 4% felt help should be sought from a traditional healer. The study by Das et al. (2006) found similar rates.

The study by Silove et al. (2008) was conducted in a developing country which has little psychiatric provision, in contrast the study by Charles et al. (2007) and Das et al. (2006) recruited from medical settings in India where there is growing psychiatric provision. The method of recruitment and the location of the study therefore have a significant impact on the explanatory models reported. It is therefore not surprising that a high percentage of relatives report medical treatment explanatory models and have used such treatments, when they have been recruited from a medical setting.

3.1.3 Holding of multiple explanatory models

A key finding highlighted by the studies was the holding of multiple explanatory models in relation to causality and treatment for a significant proportion of people. The study by Srinivasan and Thara (2001) found 61% of relatives held one cause and 39% held more than one cause. Saravanan et al. (2007) reported 22% of individuals with psychosis reported more than one cause. Other studies did not measure the holding of

multiple models providing an overall percentage. The study by Philips et al. (2000) reported a mean of 2.5 causes for each family member. Kurihara et al. (2006) did not provide a figure for the holding of multiple causes, however the study reported a number of causes with high percentages.

In terms of treatment explanatory models, the study by Charles et al. (2007) reported 72% of participants used two or more systems of medicine. The study by Saravanan et al. (2007) found that 49.6% of participants held one treatment model whereas 35.9% held two treatment models. Furthermore, the studies reviewed below employing qualitative methods provide further support for the holding of multiple explanatory models by individuals with psychosis and their relatives.

3.1.4 Stability of explanatory models

Two studies conducted in developed countries employing longitudinal methods enabled exploration of the stability of explanatory models. The study by McCabe and Priebe (2004a) investigated the stability of explanatory models over a 1-year period using the SEMI at two different time points. They found the cause of illness and treatment preferences were inconsistent in all patients when comparing the two interviews. Perceived severity of illness and prognosis were more inclined to be consistent over time. The stability observed in the severity of illness may be due in part to the participants' duration of psychosis as the study recruited a long-term group of patients with schizophrenia. The stability of explanatory models may therefore vary depending on the duration of illness and the type of service recruited from.

The study by Huguelet, Mohr, Borrás, Gillieron and Brandt (2010) developed the findings of the above studies in exploring the stability of religious explanatory models

in a 3-year follow-up study. The study found spiritual visions sometimes change and are not associated with clinical and social outcomes. Over the period of the study the spiritual vision of the illness remained prominent in 31% of participants, for 30% of participants it evolved as a transient phenomenon and 38% of participants never explained their psychosis in spiritual terms. Given the interest in spiritual explanatory models, the focus of the study demonstrated an important development in the field of research.

Taken together the studies demonstrate the measurement of explanatory models at a given point of time, have limitations given the fluidity of explanatory models evident when employing longitudinal methods. This fluidity is further supported by qualitative studies such as the ethnographic study by Larsen (2004).

3.1.5 Explanatory models in relation to clinical and demographic factors

The study by Saravanan et al. (2007) assessed the explanatory models of psychosis using the SEMI. The identified explanatory models were then assessed in relation to the clinical variables of insight, symptoms of psychosis and functioning on standard scales using multi-variate analysis. The research found the holding of spiritual/mystical beliefs was related to being female, low education and traditional healer consultation. Interestingly they also reported the holding of a psychosocial model was related to traditional healer consultation as well as older age and symptom severity. A high level of insight was the only factor related to the endorsement of a medical model.

The findings of the study are partly supported by research in India and other developing countries. Srinivasan and Thara (2001) reported no relation between gender and causal attribution, family members educated to university level named hereditary and multiple

causes more often than those with less education, who named supernatural causes more frequently. Low education in relation to the holding of spiritual causes was supported by the studies of Philips et al. (2000) and Kurihara et al. (2006). The former study highlighted the relationship between rural residence and supernatural causes, and the latter community based study found supernatural causes being strongly related to no receipt of psychiatric medical treatment for the individual with schizophrenia. Relating explanatory models to demographic factors and clinical variables is complex, for example lower education, rural residence and contact with medical psychiatric services are linked. This demonstrates the difficulty in teasing out particular demographic factors and drawing conclusions from relationships identified.

Despite the research interest in outcomes for psychosis across cultures, there has been limited research with regards explanatory models in relation to clinical and social outcomes. The study by Huguelet et al. (2010) found a spiritual explanatory model was not associated with clinical or social outcome. The study by McCabe and Priebe (2004b) found the type of explanatory model held was not associated with treatment compliance, but with satisfaction with treatment. Having a biological explanatory model as opposed to a social explanatory model was linked to increased treatment satisfaction and better therapeutic relationships, which was hypothesized as being linked to the bio-medical focus of services.

3.1.6 Qualitative studies

Three studies focused mainly on individuals with psychosis and employed a qualitative methodology. Additionally, a further qualitative study (Saravanan et al., 2008) employed the use of focus groups for individuals, relatives and the community.

Redko (2003) researched how young people with a first episode of psychosis utilise religion for help and how religion frames their experience of psychosis and that of family members. The study employed an ethnographic fieldwork approach with 21 families. The study found youth used religious signifiers to frame their experience in terms of describing, coping and transforming their experience. Family members used religion to seek alternatives such as complimentary treatment as well as helping them cope. Religion was described as working in both 'progressive' and 'regressive' ways to improve and at times to negatively impact on functioning and well-being for the youth. The researcher acknowledged reflexivity in the context of the study. For example when discussing the labelling of 'progressive' and 'regressive' it was acknowledged that they were value judgements.

The Person-centred ethnographic study by Larsen (2004) took an existential anthropological perspective examining how individuals make sense of their experiences drawing on resources from the cultural repertoire. Fifteen participants who were first time patients at a Danish mental health program based on an Early Intervention model took part in the study. Longitudinal interviews were carried out over 2.5 years. The long follow up period was a particular strength of the study and allowed for the capturing of the fluidity of explanatory models, supporting the findings of the study by McCabe and Priebe (2004a). The study proposed the concept 'system of explanation' as opposed to explanatory model arguing the concept captures the creative analytic theory building work of 'bricolage' whereby people combined various systems of explanations from the cultural repertoire in making sense of their experience. The study enabled participants' narratives to be understood in the context of an Early Intervention service, thereby demonstrating how clinicians within culturally appropriate services can facilitate discourses.

The study by Leavey, Guvenir, Haase-Casanovas and Dein (2007) explored the interconnections of causal attributions and pathways into care among nine Turkish-speaking refugees and migrants in London. Illness narratives emphasised traumatic life events and migration, with physical symptoms being particularly pertinent. Participants' explanatory models were complex and fragmentary and there was a weak and complex relationship between patients' explanatory model and choice of healing modality. Participants described accessing a number of different treatments simultaneously including private doctors and traditional healers. For example patients used traditional healers despite having a superficial belief in supernatural causes. The focus of the study on treatment explanatory models makes it particularly valuable from a clinical perspective. The study extended the findings of the studies reviewed which demonstrate the use of alternate healing systems in the developing world (e.g. Charles et al., 2007), to migrants in the developed world. The method used by the study was able to capture the complexity of participants' experiences. However the use of probing questions from previous studies may have limited the expression of illness narratives in accordance with previous research.

The qualitative study of Saravanan et al. (2008) explores a wide variety of local people's perceptions of psychosis and psychiatric services. The study employed 10 focus groups consisting of five focus groups for relatives, four for the general public and one for recovered patients. The study found multiple and apparently contradictory beliefs were simultaneously held, thereby supporting previous research done using quantitative methods (e.g. Srinivasan & Thara, 2001). Interestingly, they found indigenous healing methods were seen as complimentary to allopathic healing, a finding supported by research conducted in other developing countries when researching the explanatory models of healers (Teuton, Bentall & Dowrick, 2007a). Given the focus of

quantitative findings in the studies at the same location (e.g. Saravanan et al., 2007), this study was able to explore the findings of previous studies giving important insights, thereby facilitating a more comprehensive understanding of explanatory models. Future research by the research group, should seek to employ a variety of qualitative methods, moving from focus groups to in-depth qualitative research with individuals as recommended by de Jong and Van Ommeren (2002).

All the qualitative studies reviewed above provided rich extracts to illustrate the themes identified. The studies were able to capture the complexity of explanatory models held with regards to psychosis. Furthermore the ethnographic studies were generally more adept at acknowledging reflexivity in comparison to the other qualitative studies.

3.1.7 Development of an educational intervention

The study by Das et al. (2006) develops the field of research from gaining a better understanding of explanatory models to working towards the development of an educational programme to aid better clinical outcomes. The randomised control trial examined the effect of a structured educational programme on explanatory models of relatives. The SEMI was administered before and after a 2-week educational intervention. A reduction in non-medical causal explanatory models was found when compared with the control group. However no difference in non-biomedical treatment explanatory models were found between the two groups.

The bio-medical focus was the primary limitation of the study. The educational programme aimed to present the bio-medical model as an alternative without dismissing or directly challenging local beliefs, however little detail is given with regards how this was achieved. Furthermore the study describes many of the indigenous explanatory

models as having 'persisted' and being 'resistant' to change. The study measured the reduction of non-biomedical models as an indication of a positive outcome. This has limited validity in relation to improved clinical outcomes, as the research to date has not established a link between particular explanatory models and clinical outcomes. Further the study did not cite relevant research in support of the outcomes used. The provision of future educational programmes should actively engage with non-biomedical models as well as employ a variety of clinically relevant outcome measures such as the ability of the relative to cope with the patient's difficulties. Outcome measures should include satisfaction with the training programme, which could be elicited by a combination of qualitative and quantitative methods.

3.2 Comparisons of explanatory models between cultures

3.2.1 Comparison within a country

McCabe & Priebe (2004b) compared explanatory models of schizophrenia in four ethnic groups and their relationship with clinical and psychological factors. The SEMI was used to assess explanatory models and a wide variety of validated measures were used to assess clinical and psychological factors such as treatment compliance. The study found comparison of biological causes with supernatural causes showed the white ethnic group cited biological causes more frequently than the three non-white groups, who cited supernatural causes more frequently.

The study by McCabe & Priebe (2004b) has an important limitation questioning the reliability and validity of the findings. The method employed in categorising the qualitative data to allow for quantitative analysis was problematic. Participants may have mentioned more than one category in relation to cause and treatment, however only the first response was utilised for the purpose of statistical analysis. Other studies

reviewed demonstrate the evidence for the simultaneous holding of multiple explanatory models. This important finding was overlooked due to the inappropriate reduction of the data to allow for statistical analysis.

3.2.2 Comparison across countries

The study by Conrad et al. (2007) compared 27 patients in Jordan from an Arab-Islamic cultural background with 29 patients in Germany from a western European background. The study found 29% of Jordanian patients sighted a spiritual (esoteric) cause compared to 0% of German patients. There was a high level of belief in psychosocial explanatory models for both groups of patients. 50% of Jordanian and 61% of German patients named only one cause. 29% of Jordanian and 17% of German patients described several related causes, whereas 21% of Jordanian and 13% of Germans reported several unrelated causes. The findings provide support for studies conducted in the developing world in relation to psychosocial explanatory models (e.g. Philips et al., 2000) as well as providing evidence for the holding of multiple explanatory models in patients from a western European background. In contrast to the above two studies, other research reviewed with people mainly from a western European background found support for the relevance of spiritual explanatory models (Huguelet et al., 2010; Larsen, 2004). The study provided incomplete demographic information with no record of the religion of the participants from Germany as well as the ethnic origins of participants for both groups.

The sample size employed in this study was similar to the study by McCabe and Priebe (2004b). The relatively small sample size employed in both studies may have only allowed for large differences being detected between the groups. As acknowledged in the study by McCabe and Priebe (2004b) this may have accounted for the similar

findings amongst the non-white groups. In comparison to the other studies reviewed using a combination of qualitative and quantitative methods, the study by Conrad et al. (2007) presented findings from the qualitative component of the study. Those studies employing the SEMI have sufficed in using it as a tool for enabling quantitative study and have not reported the qualitative findings.

3.3 Explanatory models of healers and Spiritist mediums

Previous research has highlighted how patients with psychosis seek intervention from traditional and religious healers and how they may play an important role in patients' understanding of their difficulties (Saravanan et al., 2007; Leavey et al., 2007). An important research development has been the three studies reviewed below which explore the explanatory models of healers and Spiritist mediums, giving insight into the alternative healing systems.

3.3.1 Indigenous and religious healers in Uganda

The qualitative study by Teuton et al. (2007a) explored how a small diverse group of 20 indigenous and religious healers conceptualised psychosis in Uganda, with the view to inform integrative service delivery models. A purposeful sampling process using a snowballing technique was used as recommended by de Jong and Van Ommeren (2002) enabling the recruitment of a difficult to access group.

The study found healers were able to hold a number of models simultaneously. Indigenous healers primarily understood psychosis as spiritual or physiological, with religious healers holding psychological models in addition to spiritual and physiological models. Both sets of healers viewed the self as being inextricably linked with the spiritual world. Religious healers drew on a wider range of concepts from the bio-

medical model compared to indigenous healers and provided psychological models of psychosis more consistent with western psychological explanations of distress. Furthermore the religious healers engaged in counselling as part of their healing repertoire.

A follow up study by the same research group developed the findings of the above research by examining the attitudes of indigenous healers, allopathic healers and religious healers towards each other (Teuton, Dowrick & Bentall, 2007b). In addition to interviewing indigenous and religious healers, structured in depth interviews were undertaken with psychiatric staff regarding a vignette using the Explanatory Model Interview Catalogue (EMIC). The study demonstrated spiritual explanatory models are not uniform and can contradict each other. They found that indigenous and religious healers were tolerant of allopathic healers whereas the relationship between the religious and indigenous healers was one of conflict. The study demonstrates opportunities for greater dialogue between the different healing systems.

The research used the EMIC for interviewing psychiatrists as opposed to the methods used for the healers. The categories obtained from the analysis of the healers was used for the analysis of the data from the psychiatrists, with the reasoning that it was in order to counter the tendency to impose western concepts and values. However this may have led to a categorisation of the data that was not appropriate for the psychiatrists and did not fully conceptualise their views. Furthermore using the same research tools for all groups, would have led to greater consistency in the conduct of the study.

3.3.2 Spiritist mediums in Puerto Rico and Brazil

The study of Moreira-Almeida and Koss-Chiokino (2009) provided an integrated discussion regarding data from Brazil and Puerto Rico in researching how Spiritist mediums frame and treat people with psychotic symptoms and how this differs from a traditional psychiatric approach. The recruitment of a large sample of Spiritist mediums was a particular strength of this study. The Spiritist model of mental disorders was described as accepting fully the biopsychosocial model with the addition of a spiritual component, with the study researching the extent of this integration. The research described how Spiritist mediums provide treatment free of charge, in Puerto Rico where there is a separation between Spiritist treatment and medical care, however in Brazil Spiritist centres also provide free medical treatment for physical and psychiatric problems.

The Spiritist mediums distinguished between physical madness credited to hereditary and spiritual madness being often due to a spirit being interlocked onto the person. In exploring different explanatory models held by Puerto Rican Spiritist mediums and mental health professionals they found that the Spiritist mediums did not identify a category of symptoms labelled hallucinations or delusions. They found that beliefs and practices of Spiritist healers differed substantially from that of mental health professionals. This study went beyond the studies reviewed above by providing evidence for intervention by Spiritist mediums to improve patient outcomes. Using researcher observations' and participant self reports the study reported Spiritist mediums' intervention demonstrated positive outcomes such as improved social adjustment and less frequent symptoms. However the integration and contrasting of data from two countries impacted on the clarity and coherence of the study. Furthermore the

study did not provide extracts of interviews to allow for a validity check of the data in relation to the interpretations and analysis of the researcher.

Overall the above studies provide a deeper understanding in relation to the role of healers and spiritist mediums in the care of individuals with psychosis in the developing world. In comparison to the other areas of research reviewed, the studies in this section conducted research from a holistic perspective.

3.4 Public explanatory models

3.4.1 Public explanatory models in Pakistan

The study by Suhail (2005) assessed public mental health beliefs using a large-scale survey (n = 1750) through the development of the Mental Health Literacy Questionnaire (MHLQ). The study employed an appropriate sample size, however the imbalance in the sample size between urban and rural participants limited the validity of the comparisons made between the two groups. Participants were presented with case vignettes describing a person with psychosis or major depression. Participants were four times more likely to identify the depression vignette correctly (18.75%) compared to the psychosis vignette (4.94%). The study found that 72.8% of participants identified professional help (GP, psychiatrist and psychologist) as the appropriate mode of treatment, this was considerably higher than those who identified alternative treatments (homeopath, magic healers, religious healers) at 29.6%. Despite being given the option to select more than one treatment model, there was little evidence of this. The study concluded by suggesting a need to initiate large mental health movements in Pakistan to increase the mental awareness of people, in particular to those with low levels of literacy and from rural areas.

The study of mental health beliefs in the general population is an important area of research and seeking to increase the mental awareness of the population in relation to mental health is a worthy cause. However the concept of ‘mental health literacy’ employed in the research requires revision particularly the importance given to the ability to recognise specific disorders. Furthermore, the theoretical assumptions of the author with regards the provision of mental health services, research and clinical perspectives in western countries was limited to a bio-medical model.

3.4.2 Comparison of public explanatory models across countries

Wahass and Kent (1997) explored community attitudes to auditory hallucinations in the United Kingdom (UK) and Saudi Arabia (SA). The overall sample size of 281 (131 UK and 150 SA) was very small and inappropriate for a study comparing public attitudes across cultures, particularly when compared with the study by Suhail (2005). A questionnaire was developed covering basic demographic information, the presentation of a brief description of auditory hallucinations followed by questions in relation to causes of auditory hallucinations, efficacy of interventions and levels of social rejection. The study found the Saudi sample had a higher rate of belief in spiritual explanatory models (49%) compared to the UK sample (7%), supporting the cross-cultural research conducted in clinical samples (Conrad et al. 2007). The Saudi sample indicated religious intervention most suitable whereas the UK sample identified medication and psychological therapies. However, despite these findings the proportion of the Saudi sample indicating psychological therapy (33.1%) formed a significant proportion of the sample. There was a greater degree of social rejection in the Saudi sample, however this was linked with educational level.

The research recruited from GP practices, and it was reported that the practices were selected as they served patients from a range of socio-economic backgrounds. Bearing in mind the purpose of the study it were surprising no data was provided regarding the ethnic groups of the samples as well as their religious affiliation. The study regularly referred to Islam in relation to the Saudi sample whilst no reference was made to religion in relation to the UK sample. Future research should seek to recruit individuals from more neutral settings, when researching mental health beliefs in the general population.

4. Research issues and clinical implications

4.1 Adoption of a biopsychosocial-spiritual model

Many of the studies employed varying levels of bio-medical bias and did not encompass a broader biopsychosocial model in line with developments in psychiatry and psychology in western countries (BPS, 2000). A proportion of studies focused on biological explanatory models and spiritual explanatory models (eg. Charles et al., 2007) excluding psychosocial models or paying limited attention to them. Studies employing a bio-medical bias did not seek to acknowledge or critically analyse research findings, which demonstrate better outcomes for psychosis in developing countries. Furthermore many of the studies recruited from medical settings.

Bhugra (2006) suggests a clear conceptual framework to enable the management of severe mental illness across cultures that includes biological, psychological and social factors, with the recognition that cultural factors influence the three factors to varying degrees. However for this to become a reality at the clinician level, the research within this area must first adopt a clear conceptual framework, namely the biopsychosocial model. There was support for the holding of psychosocial explanatory models in developing countries and it is hypothesised that greater focus on culturally appropriate intervention in this sphere may be aligned closely to the explanatory models held by individuals with psychosis, their family members and the wider community. Such interventions can be provided by current community resources and alternate healing systems as well as by services based on a western model.

A greater challenge is the incorporation of religious, spiritual and indigenous beliefs with the bio-medical model. Some of the studies reviewed highlighted the importance of religious, indigenous and spiritual explanatory models and successfully employed a

wider conceptualisation of psychosis (eg Huguelet et al, 2010; Teuton et al. 2007a). Research employing a biopsychosocial-spiritual model (Moreira-Almeida and Koss-Chioino, 2009) where one particular component does not have pre-eminence, have the potential to improve service provision across cultures. However, it is appreciated that researchers will have their particular backgrounds, allegiances and interests. Future studies should seek to clearly outline the role of the researcher in the process of the research. Although such analysis is more closely aligned to qualitative methodologies, quantitative research must also seek to pay greater attention to researcher bias.

4.2 Is 'explanatory model' the best term?

The term explanatory model is the preferred term used in the research reviewed. However within the studies reviewed limitations of its use have been discussed such as the term 'model' giving the impression of a fixed entity. Research in relation to explanatory models across cultures has often lost site of the dynamic and changing nature of explanatory models. Therefore, studies such as that of McCabe and Priebe (2004a) have focused on evidencing the instability of explanatory models to readdress this balance. Alternative concepts have been proposed such as 'exploratory map' (William & Healy, 2001) which capture the fluidity of beliefs, as discussed in the study by McCabe and Priebe (2004a). The study by Larsen (2004) proposed the term 'system of explanation' which was described as having advantages over the term explanatory model as it better accounts for individuals creative analytic and theory building work. The term 'system of explanation' and 'exploratory map' can be seen as complimentary to the term explanatory models as they represent more closely the process by which an individual combines different explanatory models in understanding psychotic experiences. Furthermore the concept explanatory model is located within an illness framework, this may limit its ability to capture the complexities of mental illness in

particular psychosis. Incorporation of phenomenology within the concept of explanatory model is recommended, which will enable capturing the complexity and fluidity of explanatory models, as demonstrated by the qualitative and ethnographic studies reviewed. Replacement of the term is not recommended due to its wide acceptance in the field of research, utility in the development of clinically relevant research and its incorporation in government clinical guidelines in the UK (NICE, 2009).

4.3 Use of the Short Explanatory Model Interview (SEMI)

Seven studies employed the use of the SEMI in the context of combining qualitative and quantitative methodologies. This allowed for the quantification of data as well as linking explanatory models to clinically relevant variables. However a limitation was the reduction of data leading to a lack of appreciation of the complexities of explanatory models regarding psychosis. This was particularly problematic in the study of (McCabe and Priebe (2004a). The study by Charles et al. (2007) did not include psychosocial explanatory models and did not provide information with regards the process of analysis. In view of the SEMI not providing clear data-analytic steps and the absence of interview process rules (Bhui & Bhugra, 2002), it is important that due consideration is given to the process of analysis at every step and these are clearly outlined in the method section of studies. The SEMI has been preferred over the EMIC, which was used only by one study (Teuton et al., 2007b). This may be partly due to the brevity of the SEMI in comparison to the EMIC. Future research should also seek to present qualitative findings when employing the use of the SEMI.

4.4 Use of questionnaires

Six studies used questionnaires in researching explanatory models. However there has been limited attention paid to issues with regards reliability and validity of the questionnaires. In the development of measures varying levels of details were given with regards ensuring measures were relevant to the cultural context of the research. In the study by Philips et al. (2000) which developed the Causal Models Questionnaire for Schizophrenia (CMQS) the qualitative research which informed the development of the quantitative measure was appropriately described. In ensuring measures were appropriately adapted studies paid particular attention to accuracy and appropriateness of the method of translation. For example, Wahass and Kent (2007) developed a questionnaire originally in English, it was then translated in to Arabic and back-translated in to English, by experienced translators. Srinivasan and Thara (2001) reported developing a list of causes combined from two previous studies without providing details of how this was achieved. The study by Suhail (2005) developed the Mental Health Literacy Questionnaire and provided descriptive details with regards the sections of the questionnaire, without evaluating how the sections were relevant to the cultural context of the research, thereby possibly contributing to the bio-medical bias of the study.

Only three studies provided psychometric properties, with the studies by Philips et al. (2000) and Kurihara et al. (2006) reporting test-retest reliability for the CMQS. Additionally the former study reported interrater reliability for the CMQS. The study by Conrad et al. (2007) provided Cronbach alpha measures for both versions of the adapted Causal Belief Questionnaire (Angermeyer & Klusmann, 1988). Future research should provide detailed descriptions of the development and adaptation of questionnaires, in

ensuring their validity in measuring explanatory models in a particular culture. This should incorporate details of psychometric properties of the measures.

4.5 Limitations of the review

The study of explanatory models forms only part of the cross-cultural research regarding psychosis. Hence, the research should be seen in the context of other research directions such as, studies comparing symptoms and problems in the diagnosis of psychotic disorders across cultures. The review generally did not include studies of indigenous people in western countries. Although a few of the studies reviewed made such comparisons, or had multi-cultural samples, the limits of the review preclude a comprehensive comparison between western and non-western countries. Currently there are some empirical data from the studies reviewed to suggest spiritual explanatory models are not as important for indigenous people in western countries (e.g. Conrad et al. 2007), with other studies showing evidence to the contrary (e.g. Larsen, 2004).

4.6 Future Research

The area of research should adopt a methodological framework, allowing for studies which combine qualitative and quantitative methods, as well as studies solely employing qualitative methods or quantitative methods (de Jong and Van Ommeren, 2002). Many of the studies have provided a quantification of explanatory models across cultures. The research area should now move on to understanding the complexities of holding varying explanatory models, in particular spiritual explanatory models, psychosocial explanatory models and the holding of multiple explanatory models. This should be integrated or linked to research, which seeks to provide culturally appropriate clinically effective services within a biopsychosocial-spiritual model.

A number of promising directions were evident in the studies reviewed. The use of qualitative methods and ethnographic methods, have the potential for developing our understanding of the complexities of explanatory models held across cultures. Therefore further qualitative and ethnographic studies are required including focus groups and studies from the perspective of the person experiencing psychosis.

Despite the research interest in outcomes of psychosis across cultures the field of study is yet to comprehensively link explanatory models with clinically relevant outcomes. Longitudinal studies are required to assess the relationship between explanatory models and clinically relevant outcome measures, such as that employed in the study by Huguelet et al. (2010). Further research should explore the stability of explanatory models in people with a first episode of psychosis and with people with various durations of psychosis. The use of randomised controlled trials in assessing the impact of educational programmes should seek to employ clinically relevant outcome measures, rather than seeking to change non-medical explanatory models.

Another promising direction in the literature is the adoption of a collaborative stance which seeks to understand alternative healing systems and seek to pursue an integrative approach to managing mental health problems. Further studies such as that by Teuton et al., (2007b) and Moreira-Almeida and Koss-Chioino (2009) should be conducted in both developing and developed countries, as well as research developing the findings of such studies.

In seeking a comprehensive understanding of explanatory models across cultures, research should seek to gain a better picture of the prevalence of spiritual explanatory models in indigenous people in western countries, both within clinical populations and

the wider public. The findings of the research can then be compared to studies in the developing world. Future research should seek to compare mental health beliefs in the general population with clinical populations. Studies at the population level should seek to employ a heterogeneous large sample, representative of the whole population, or the particular section of the population under study.

5. Conclusion

The studies reviewed demonstrated a complex picture whereby people held biological, psychosocial and spiritual explanatory models to varying degrees depending on socio-cultural context. A significant proportion of people held multiple explanatory models. Some studies provided strong support for the holding of psychosocial explanatory models in developing countries. Spiritual and religious explanatory models had greater importance in developing countries when compared with developed countries, as well as for ethnic minorities in developed countries.

The over reliance on biomedical models and biomedical bias in the area of research and clinical practice has particular limitations. Adopting a biopsychosocial-spiritual framework is recommended, within which psychosocial interventions and the contribution of alternate healing systems are given increased attention. The field of research may benefit from the eclectic use of qualitative and quantitative methods. This includes employing qualitative methods with groups and individuals as well as the measurement of clinical outcomes in relation to explanatory models.

Understanding what may contribute to better outcomes of psychosis in developing countries as well as developed countries will allow greater appreciation and cross fertilisation of understandings, thereby contributing to better outcomes for psychosis across cultures.

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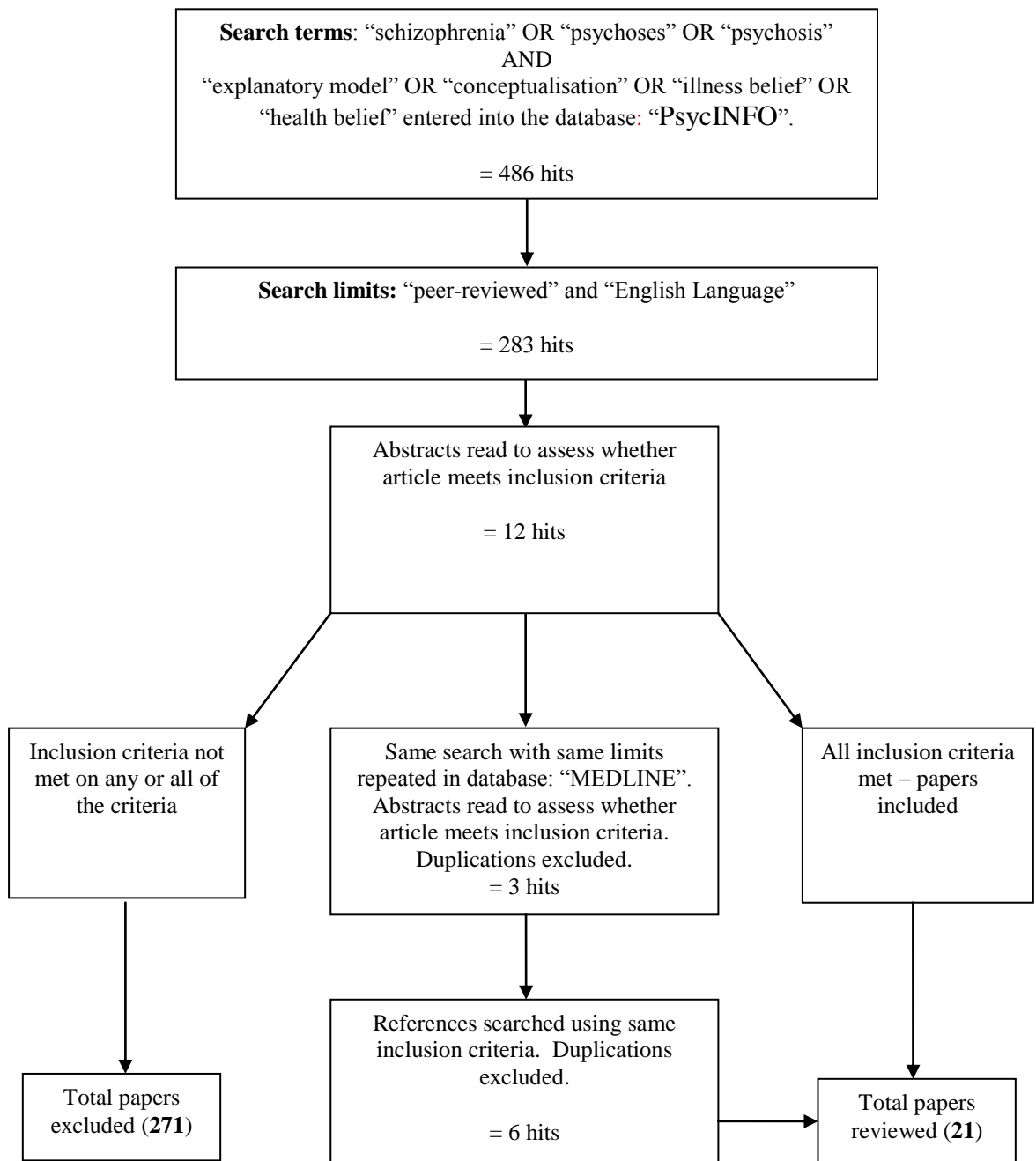
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Literature Review Appendices

Appendix A

Figure 1: Literature Review Search and Inclusion Process.



Appendix B Table 1 – Summary of the studies reviewed

| Authors | Sample size | Sample/recruitment | Country | Method | Focus of Study | Results |
|--|-------------|---|----------------------|---|---|--|
| Explanatory models of people with psychosis and their relatives | | | | | | |
| Charles et al. (2007) | 100 | Outpatients with a diagnosis of Schizophrenia and their relatives Recruitment: Dept of Psychiatry, Christian Medical College | India – Vellore | Semi structured interview Short explanatory model interview (SEMI) | Explore the association between stigma and beliefs about the cause and treatment of schizophrenia | Patient-causal explanatory models 60% Spiritual (e.g. Karma, Black magic) 32% Biological (disease) Patient -treatment models 52% Visit temple, 15% Shaman, 21% Traditional healer, 95% Doctor Relatives -causal explanatory models 54% Spiritual, 26% Biological (disease) Relatives-treatment models 42% Visit temple, 9% Shaman, 4% Traditional healer, 99% Doctor 72% used 2 or more systems of medicine/treatments Total stigma scores for patients were associated with a number of factors including male gender, total number of causal models, total number of non-medical causal beliefs, the disease model of illness and visiting the temple or other places of worship. |
| Das et al. (2006) | 100 | Relatives of patients with newly diagnosed schizophrenia 50 intervention group 50 control group Recruitment: Dept of Psychiatry, Christian Medical College | India – Vellore | Semi structured interview SEMI Randomised controlled trial | Examine the effect of a structured educational programme on explanatory models of relatives | Relatives -causal explanatory models before intervention 43% Spiritual (black magic, evil spirits), 43% Spiritual (previous deeds) 43% Spiritual (punishment by God) 60% Biological (disease) Relatives -treatment models before intervention 33% Visit temple, 9% Shaman, 5% Traditional healer, 99% Doctor After intervention A reduction in non-medical causal explanatory models compared with control group. No difference in non-biomedical treatment explanatory models between the two groups. |
| Huguelet et al. (2010) | 92 | Diagnosis of schizophrenia Recruitment: Public psychiatric outpatient facilities | Switzerland - Geneva | Semi structured interview | 3-year follow-up study assessing the development of explanatory models and to examine their relationship with the spiritual visions of treatment. | Explanatory models frequently involve a religious component, are independent of denomination and likely to change over time. A spiritual explanatory model was not associated with clinical or social outcome. |

| | | | | | | |
|---------------------------|-----|---|-------------|---|---|---|
| Kurihara et al. (2006) | 39 | Relatives of a person with schizophrenia Recruitment: community based door-to-door survey. | Bali | Questionnaire - developed listing 15 causes based on previous qualitative research | Investigate causal beliefs regarding schizophrenia held by relatives of individuals screened positive for Schizophrenia | Relatives -causal explanatory models Spiritual various e.g. 69% Disturbance by spirits 69% God's will or fate Biological 44% Brain disorder 28% Hereditary Psychosocial various e.g. 23% work stress 15% family stress Families attribution of supernatural causes was strongly related to no receipt of psychiatric medical treatment by the individual with schizophrenia |
| Larsen (2004) | 15 | First episode psychosis Recruitment: Community based Early Intervention program | Denmark | Person-centred ethnographic study Multi-method approach including longitudinal interviews over 2.5 years. | Examine how individuals make sense of their experiences drawing on resources from the cultural repertoire. | Concept 'system of explanation' has advantages over 'explanatory model' Concept captures creative analytic theory building work of bricolage combining various systems of explanations from the cultural repertoire. |
| Leavey et al. (2007) | 9 | First Episode Psychosis Turkish speaking migrants and refugees/asylum seekers Recruitment: First episode family intervention program | UK - London | Illness narratives with probing questions regarding symptoms, causes, help seeking and attitudes of patient and family. | Relationship between explanatory models and help seeking | Explanatory models complex and fragmentary and their relationship to help seeking non-linear. Access a number of different treatments simultaneously including private doctors and healers. |
| McCabe and Priebe (2004a) | 8 | Diagnosis of schizophrenia – long term patients from 4 ethnic groups Recruitment: Secondary community mental health services. | UK - London | Semi structured interview SEMI | Assess the stability of explanatory models | Concept, cause of illness and treatment preferences inconsistent over time. Perceived severity of illness and prognosis remained consistent. |
| Philips et al. (2000) | 245 | Relatives of a person with schizophrenia Recruitment: Provincial neuropsychiatric hospital | China | Questionnaire – The causal models questionnaire for schizophrenia (CMQS). | Develop the CMQS to assess the causal models of illness with the view to improve adherence to interventions. | Relatives -causal explanatory models 15.6% Spiritual (and mystical) 29.6% Biological (and physical) 84% Psychosocial (and interpersonal) Identified a mean of 2.5 causes Disparity between family members and professional views (biomedical model) regarding causes of schizophrenia. |

| | | | | | | |
|-------------------------|-----------|--|--------------------------|---|---|--|
| Redko (2003) | 21 | Families with a young person with First episode psychosis Recruitment: Psychiatric emergency service of a large public university hospital. | Brazil, Sao Paulo | Ethnographic study - minimum 6-month period. Semi structured interview – Turning Point Interview (TPI) | Explores how young people with a first episode of psychosis utilise religion for help and how religion frames their experience of psychosis and that of family members. | Use of religious signifiers to frame their experience in terms of describing, coping and transforming their experience. Family members use religion to seek alternatives such as complimentary treatment as well as helping them cope. Religion worked in both 'progressive' and 'regressive' ways to improve and at times to negatively impact on functioning and well-being. |
| Saravanan et al. (2007) | 131 | Patients with schizophrenia at first contact with service Recruitment: Dept of Psychiatry, Christian Medical College | India – Vellore | Semi structured interview SEMI | Assess explanatory models of psychosis and their relationship with clinical variables such as symptom severity and insight. | Patient -causal explanatory models 70% Spiritual (e.g. Evil spirits) 15% Biological (disease/hereditary) 11% Psychosocial 22% Held multiple causal models 49.6% Held one treatment model 35.9% Held two treatment models Multivariate analysis showed three factors associated with holding of mystical/spiritual factors (female, low education and visits to traditional healers) Only a high level of insight associated with adopting a biological model. |
| Saravanan et al. (2008) | 57 | Relatives of a person with psychosis– 5 groups General public - 4 groups Recovered patients – 1 group Recruitment: Dept of Psychiatry, Christian Medical College and local area | India - Vellore | Focus groups | Explores a wide variety of local people's perceptions of psychosis and psychiatric services | Multiple and apparently contradictory beliefs simultaneously held Indigenous healing methods seen as complimentary to allopathic |
| Silove et al. (2008) | 16 (1544) | 16 Cases of psychotic disorders identified from initial sample. Recruitment: Total population survey- Household informant survey and screening. | Timor Leste (East Timor) | Epidemiological methods Semi structured interview SEMI | Estimate prevalence of key clinical disorders including psychotic disorders. Assess explanatory models influencing help seeking behaviour. | Patient -causal explanatory models 73% Spiritual (supernatural) 20% Biological (physical) 71% Psychosocial (social and trauma) Treatment 81% traditional healer 25% health professional In contrast those with depression and PTSD attributed problems to social and traumatic events and had received little treatment Psychotic disorders most disabling, |

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|--|-----|--|-----------------------|--|---|---|
| Srinivasan and Thara (2001) | 254 | Relatives living with patients with chronic schizophrenia Recruitment: Outpatient clinic of the Schizophrenia research foundation. | India- Chennai | Questionnaire - List of causes combined from two previous studies. | Assess beliefs about causation of schizophrenia and the extent to which relatives subscribe to supernatural causes. | Relatives -causal explanatory models 16% Spiritual (Supernatural /God/fate) 55% Psychosocial 29% Biological (Hereditary/brain dysfunction) 61% held one cause 39% held more than one cause Common combination of causes hereditary and psychosocial stress and personality defect and psychosocial stress |
| Comparisons of explanatory models between cultures | | | | | | |
| Conrad et al. (2007) | 47 | 24 Jordanian 23 German with schizophrenia Recruitment: Public psychiatric hospitals | Jordan and Germany | Semi structured interview – content analysis Questionnaires- Illness concept scale and causal belief questionnaire | Comparison of explanatory models of schizophrenia across countries | Patient -causal explanatory models Spiritual (esoteric) -29% of Jordanian patients 0% of German patients. Psychosocial - 83% of Jordanian patients 61% of German patients Biological (and Hereditary)- 0% of Jordanian patients 26% of German patients With regards treatment only Jordanian patients regarded religion as an important factor. |
| McCabe and Priebe (2004b) | 119 | 4 ethnic groups patients with a diagnosis of schizophrenia Recruitment: Secondary community mental health services. | UK - London | Semi structured interview SEMI | Comparison of explanatory models of schizophrenia in four ethnic groups and their relationship with clinical and psychological factors. | Comparison of biological causes with supernatural causes showed whites cited biological causes more frequently than the three non-white groups, who cited supernatural causes more frequently Biological explanatory model not related to treatment compliance but with treatment satisfaction |
| Explanatory models of healers and Spiritist mediums | | | | | | |
| Moreira-Almeida and Koss-Chioino (2009) | 164 | 49 Spiritist mediums in Puerto Rico and 115 in Brazil. Recruitment: Spiritist centres Community health clinics | Puerto Rico Brazil | Semi structured interviews | Explore how Spiritism (a popular religion in Latin America) provides healing to people with Psychosis | Spiritist mediums distinguished between physical madness and spiritual madness being due to a spirit Beliefs and practices of Spiritist mediums differed substantially from that of mental health professionals. Spiritist mediums' intervention demonstrated positive outcomes - improved social adjustment and less frequent symptoms |

| | | | | | | |
|----------------------------------|------|--|--------------------------|---|--|--|
| Teuton et al. (2007a) | 20 | 10 Religious healers 10 indigenous healers Recruitment: Snowball sampling in the community | Uganda | In-depth interviews alongside Case vignettes | Explore explanatory models held by religious and indigenous healers | All healers hold a number of models simultaneously All healers viewed the self as being inextricably linked with the spiritual world Indigenous healers understood psychosis as spiritual or physiological Religious healers understood psychosis as spiritual or physiological, also holding psychological models |
| Teuton et al. (2007b) | 26 | 10 Religious healers 10 indigenous healers 6 Psychiatric staff Recruitment: Snowball sampling in the community National psychiatric hospital – Psychiatric staff | Uganda | Semi structured interview - Explanatory model interview catalogue (EMIC) –Psychiatric staff In-depth interviews alongside Case vignettes | Follow up for the above study Examine the relationship between service providers (indigenous, religious and allopathic healers) providing care for people with psychosis. | Indigenous and religious healers were tolerant of allopathic healers Relationship between the religious and indigenous healers one of conflict Allopathic healers made little mention of religious healers and were ambivalent towards indigenous healers |
| Public explanatory models | | | | | | |
| Suhail (2005) | 1750 | General public Recruitment: Door-to-door survey | Pakistan | Questionnaire - Mental Health Literacy Questionnaire (MHLQ) | Assess public mental health beliefs | From the vignette depression was four times more likely to be diagnosed than psychosis. Public- treatment explanatory models 72.8% - professional help (GP, psychiatrist and psychologist) 29.6% - alternative treatments (homeopath, magic healers, religious healers) |
| Wahass & Kent (1997) | 281 | General public 131 UK 150 Saudia Arabia Recruitment: General Practices in both countries | UK and Saudi Arabia (SA) | Questionnaire developed covering causes, efficacy of interventions and levels of social rejection. | Community attitudes to auditory hallucinations across cultures | Public -causal explanatory models Spiritual (magic/satan) -49% of SA, 7% of UK. Psychosocial (stress) – 31.3% of SA, 73.6% of UK. Biological (brain/ear damage)- 19.3% of SA, 60.5% of UK. Public -treatment explanatory models Religious assistance -66.2% of SA, 10.9% of UK. Psychological therapy – 33.1% of SA, 55% of UK. Medication- 4.6% of SA, 21.7% of UK. Medication and psychological therapy 23.2% of SA, 63.1% of UK. Great degree of social rejection in the Saudi sample, however linked to education |

Section 2: Research Report

A Qualitative Investigation of the Conceptualisation of Psychosis in People of a Muslim Faith

Abstract

Background

Research shows religion is an important issue for some people with psychosis. Although there has been greater interest in the interpretative frameworks of people experiencing psychosis, there have been few studies that have focused on religion, and more specifically on people's experiences of psychosis from a particular religion.

Aims

Explore how people of a Muslim faith conceptualise their psychotic experiences and the role of religion in this conceptualisation.

Methods

Eight males having experienced psychotic experiences took part in the study. Interpretative phenomenological analysis was used as the method of analysis.

Results

Four super-ordinate themes emerged: The self in relation to others, getting help and moving on, the unseen and the mind in the wider world.

Conclusion

The results support the existing literature, in that participants utilised a variety of interpretative frameworks, with religion being important in making sense of their psychotic experiences. Limitations and clinical implications are considered.

1. Introduction

The conceptualisation of psychotic experiences has been and continues to be an area of much research and debate. Understanding the conceptualisation of psychosis by appreciating the interaction between biological, social and psychological factors has been recognised (British Psychological Society [BPS], 2000). This has allowed for the development of psychological interventions for people with psychotic disorders (Bentall, 2003).

Researchers have increasingly acknowledged the value of considering spirituality and psychosis together (Menezes & Moreira-Almeida, 2010). Some researchers see this as contributing to a better understanding of both spirituality and psychosis, whilst others are primarily interested in understanding psychosis, in particular the challenge posed by the religious content of psychotic communication (Clarke, 2001). Furthermore particular emphasis has been given to the role of ethnicity and cultural factors in the conceptualisation of psychosis and in relation to inequalities in service provision for Black and minority ethnic (BME) groups (Bracken and Thomas, 2001; Department of Health [DOH], 2005).

A recent review of the literature on religion, spirituality and psychosis by Menezes & Moreira-Almeida (2010) divided the current research in to two large groups, studies researching religiousness and its impact on psychotic patients and differential diagnosis of spiritual experiences from psychotic disorders. The review concluded religion influences the content of patients' thoughts, behaviour and patient outcomes in people with psychosis. It highlighted that the theme is under explored with many gaps in the literature. The Mental Health Foundation (2006) review regarding the impact of spirituality on mental health drew attention to the over reliance on quantitative methods

employed currently within the field of research and the need for greater qualitative studies.

Mohr, Brandt, Gillieron, Borrás and Huguelet (2006) used semi-structured interviews about religious coping with 115 outpatients with a psychotic illness. The patients were mainly of a Christian faith (61%), with 9% coming from other traditional religions, 12% from minority religious movements and 18% having no religious affiliation. Many of these patients used religion to cope, with 71% reporting that it instilled hope, purpose, and meaning in their lives, although for 14% of patients it induced spiritual despair. Religion was reported to increase social integration in 28% of patients and social isolation in 3% of patients. It contributed to adherence to psychiatric treatment in 16% of patients and was in opposition to psychiatric treatment in 15% of patients.

Another study by the same research group (Huguelet, Mohr, Borrás, Gillieron & Brandt, 2006) compared spirituality and religious practice of outpatients with schizophrenia with their clinicians. They found religion to be an important issue for patients with it often not being related to the content of delusions. Clinicians were commonly not aware of their patients' religious involvement, even if they reported feeling comfortable with this issue. Research by Crossley and Salter (2005) focused on the experiences of clinical psychologists addressing spiritual beliefs in therapy. They found clinicians used different approaches to achieve the goal of remaining in harmony with spiritual beliefs. When spiritual beliefs were perceived to be contributing to distress, clinicians experienced difficulty understanding the appropriate process for respecting spiritual beliefs.

Improving services for BME groups has been and continues to be a government priority in the UK. The Delivering Race Equality (DRE) programme aimed to support the development of better mental health services to reduce inequalities in service provision for BME groups (DOH, 2005). The recent UK cross-government mental health outcomes strategy seeks to build on the successes of the DRE programme. The strategy recognises the relationship between ethnicity and religion, highlighting more people from ethnic minority backgrounds identify themselves as religious and the role of religion in people's explanations for their mental health problems will affect engagement and success of treatment (DOH, 2011). The National Institute for Clinical Excellence (NICE) guidelines for schizophrenia recommends using explanatory models for people from diverse ethnic and cultural backgrounds (NICE, 2009). Hence research which enables a better understanding of the interpretative frameworks of people from diverse ethnic, religious and cultural backgrounds has particular relevance for improving clinical practice and providing culturally appropriate services.

Culture has been shown to impact on patients' experiences of their illness, for example, Alverson et al. (2007) described the importance of working with patients' discursive accounts of their experience of illness in the context of the patients' ethnocultural background. Falot (2001) in emphasising the reasons for giving increased attention to spirituality and religion in relation to serious mental illness, concluded that it is often essential to understand religion's place in a particular culture in order to offer culturally competent services. In this context, the current study will explore the conceptualisation of psychosis within a framework that appreciates the interaction between culture, religion and mental health.

Exploring the conceptualisation of psychotic experiences by paying particular attention to the interpretative frameworks of people experiencing psychosis and the ways in which they attempt to understand their experiences, has been the focus of a limited but growing number of qualitative studies within the current literature on psychosis. A grounded theory analysis of the personal accounts of young men's experience of psychosis found four themes common to all the accounts: experience of psychosis, immediate expression of psychotic experiences, personal and interpersonal changes and personal explanations. The explanations of participants covered a broad spectrum of factors both internal and external which influenced the onset of psychosis (Hirschfeld, Smith, Trower and Griffin, 2005).

Kinderman, Setzu, Lobban and Salmon (2006) examined the beliefs of 20 people with schizophrenia using qualitative interviews and thematic analysis. They found people entertained disparate and changing explanatory frameworks in making sense of their experiences. The participants' understandings of their experience were considerably different from those of conventional physical illnesses. They concluded methods for assessing beliefs in mental illness should be tailored to the nature of patients' beliefs about mental illness.

Studies employing the use of Interpretative phenomenological analysis (IPA) have contributed to understanding the individual experience of people with psychotic experiences and the sense they make of their experiences. Knudson and Coyle (2002) used IPA to study the relationship between an individuals' conceptualisation of psychosis and how this might influence their personal coping styles. They found a relationship between the meaning which people attributed to their voices and the coping style adopted.

Marriott (2007) used IPA to investigate the relationship between psychotic experiences, spiritual and religious beliefs in a sample consisting of people from various religious denominations. The study found spiritual explanations for experiences were often used for both positively and negatively appraised experiences. All types of explanation were characterised by a sophisticated reasoning approach, considering alternatives and engaging in testing of explanations. Furthermore individuals were concerned with both hiding their experiences and their explanations of such experiences.

The current study aims to build on previous research by focusing on the conceptualisation of psychosis in people of a Muslim faith. People of a Muslim faith make up a significant minority of the UK population. After Christianity, Islam was the most common faith with nearly 3 per cent describing their religion as Muslim compared to 72% for Christianity (Census, 2001). Focusing on particular groups of individuals may help identify areas of shared phenomenology and conceptualisation between individuals of a particular group (Marriott, 2007).

Aims of the study

- 1) Explore how people of a Muslim faith conceptualise their psychotic experiences.
- 2) Explore the role of religion in the conceptualisation of psychotic experiences in people of a Muslim faith.

2. Method

Design

A qualitative methodology was chosen as the conceptualisation of psychosis in relation to religion is under-researched and represents a complex area of study (Smith, 1996). Interpretative phenomenological analysis (IPA) was chosen as the most appropriate qualitative research method as the research is interested in exploring participants 'lived experience,' in making sense of their psychosis (Smith, 2004). IPA is a distinctive qualitative approach, which offers a theoretical foundation and a detailed procedural guide. IPA is phenomenological in its principle focus on the individual's experience and is interpretive in its recognition of the researcher's centrality to analysis and research (Brocki & Wearden, 2006).

Choice of qualitative method

Alternate qualitative methodologies have been considered and IPA was judged to be most suited to the topic of study due to its intense idiographic focus. Grounded theory has not been chosen due to its suitability in the development of psychological theory and studying social processes (Brocki & Wearden, 2006). Discourse analysis on the other hand is less suited to exploring meaning making in psychosis as it pays particular attention to linguistic construction in specific contexts, which may detract from how the individual makes sense of such a complex experience (Smith & Osborn, 2004). Template analysis (King, 1998) was considered but not utilised due to the use of a priori codes and the use of an initial template to analyse the whole data set. The use of an initial template may limit an in-depth analysis of the individual narratives of the participants, which may lead to the missing of divergent and idiosyncratic narratives.

Researcher characteristics

The similarity as well as differences between the participant and researcher requires attention to the micro-social interactions within interviews. This requires attention to more than one category of difference or similarity between the participant and the researcher (Gunaratnam, 2003). IPA's concern with sense making on the part of the participant and researcher (Smith, 2004) make it particularly suitable for this study, as it allows one to tune in to such micro-social interactions. Hence reflexivity is considered throughout the research process. In setting the context of the research, it is therefore important to ensure transparency in acknowledging the characteristics of the researcher and supervisors.

I am a 30-year-old male and am of a Muslim faith. I am an Asian-British Bangladeshi. I was born and brought up in the U.K. I am currently a trainee Clinical Psychologist in the third year of my clinical psychology training. I have some experience of working with people with psychosis prior to my training within day care settings and in-patient settings. During my training I have developed my skills and experience working with people with psychosis completing a first year placement in an Assertive Outreach team and a third year placement in an Early Intervention service. However I have limited experience of working therapeutically with people with psychosis of a Muslim faith. I have an interest in religion, spirituality and culture in relation to mental health.

My academic supervisor Georgina Rowse (Principal Clinical Psychologist) works clinically in an Early Intervention service for young people with psychosis. Her research interests are within the area of psychosis and she has previously supervised IPA research studies. My NHS supervisor Rasjid Skinner (Consultant Clinical Psychologist) works clinically in an older adult service. He has clinical and research interests in

historical and cultural variations in battle trauma, adaptation of psychological therapy for diverse communities and the application of Islamic models of psychology.

My interpretative frameworks and expectations prior to the development of the interview schedule included, religious frameworks would play a role in the conceptualisation of psychosis for people of a Muslim faith, such as that of 'spirits' which are commonly understood in the community to be related to unusual experiences. In view of the development of Early Intervention services, I also expected that there would be a greater appreciation of a biopsychosocial model as opposed to a medical model in the conceptualisation of unusual experiences. These along with other expectations were discussed with supervisors and the use of bracketing, particularly during the process of interviewing was utilised to ensure participants' narratives are the sole focus and are not unduly influenced by the interpretative frameworks of the researcher. The analysis of the transcripts were undertaken by the researcher. Supervisors audited the fit between the interpretation and the narratives' of participants and did not engage in the process of interpretation alongside the researcher.

Recruitment

Participants were recruited from both statutory and non-statutory services in Bradford and Sheffield. Ethical approval and governance approval was obtained from relevant NHS statutory bodies. Ethical approval was gained from The University of Sheffield for recruitment from non-statutory services (Appendix 2).

Participants were informed of the study by a member of the service working with the participant such as the care coordinator or community development worker. An advertisement in the form of a poster was used to help in the recruitment of participants

(Appendix 3a). Interested individuals were provided with a copy of the relevant information sheet (Appendix 3b and Appendix 3c). Participants opted in to take part in the study.

Inclusion and exclusion criteria

Participants were considered eligible for the study if they were of a Muslim faith and had experienced psychotic experiences. Due to developments in the conceptualisation of psychosis and provision of services for people with psychosis that embrace diagnostic uncertainty, a flexible approach was adopted in the recruitment of participants. This did not require people to have a diagnosis, although they must have experienced unusual experiences (psychotic experiences) including hearing voices (hallucinations) and/or holding unusual beliefs (delusions). Due to the services from which recruitment took place, it was expected that participants, might have received a diagnosis of a psychotic illness included in the schizophrenia spectrum.

Participants were required to be fluent in English, as a key feature of the research methodology is that of the dynamic relationship between the participant and researcher. This would be difficult to evaluate with the use of an interpreter, particularly as this was the first IPA study conducted by the researcher. Recruitment was restricted to people registered with a GP or under the care of statutory mental health services in Bradford and Sheffield in accordance with ethical and governance approval

Due to the qualitative nature of the study, people who were unable to take part in an interview between 30-60 minutes in duration and unable to talk about their experiences in some detail were excluded. People unable to give informed consent were also excluded from the study.

Participants

Eight male Muslim participants took part in the study. Participants' ages ranged from 28-44 years (mean 34 years). Seven of the eight participants considered themselves as practicing Muslims. All except one of the participants were in receipt of statutory secondary care mental health services. Four participants were recruited from statutory services and four participants were recruited from non-statutory services. Table 1 shows the individual demographic characteristics of participants along with their pseudonym.

Table 1 Demographic characteristics of participants

| Pseudonym | Age | Diagnosis | Recruitment: Statutory service /Non-statutory service | Ethnic origin |
|------------------|------------|---------------------------|--|----------------------------------|
| Zubair | 34 | Schizophrenia | Non-statutory service | Asian or Asian British Pakistani |
| Bilal | 30 | No psychiatric diagnosis | Non-statutory service | Asian or Asian British Pakistani |
| Dawood | 30 | Schizophrenia | Non-statutory service | Asian or Asian British Pakistani |
| Ilyas | 30 | Schizophrenia | Statutory service | Asian or Asian British Pakistani |
| Umar | 28 | Paranoid Schizophrenia | Statutory service | Asian or Asian British Pakistani |
| Wasim | 43 | Paranoid Schizophrenia | Non-statutory service | Asian or Asian British Pakistani |
| Yusuf | 33 | First episode psychosis | Statutory service | Asian or Asian British Pakistani |
| Adam | 44 | Schizo-affective disorder | Statutory service | Other Ethnic groups- Yemeni |

Procedure

Each participant was interviewed in a suitable room to maintain confidentiality at a service location or at the participants' home. The author conducted the interviews and they ranged in length from 40 minutes to 120 minutes. With the exception of one participant all interviews were conducted in one session. At the start of the interview the information sheet was reviewed followed by completion of the relevant consent form (Appendix 3d and Appendix 3e). Participants were then interviewed using a semi-structured interview. Participants were debriefed at the end of the interview.

Semi-structured interview

The semi-structured interview was developed according to the guidelines of Smith and Osborn (2004). The interview schedule was developed in discussions with academic supervisors and a service user. Demographic details were gathered before the semi-structured interview commenced. The semi structured interview schedule focused on two areas. The first area covered their unusual experiences and its impact. The second part focused on how the participant made sense of the unusual experience. Within the second part after the use of generic questions, specific questions covered the role of religion in understanding unusual experiences (Appendix 3f). The semi-structured interview schedule was used flexibly during the interviews and the order of the questions depended on the needs of the particular participant. The flexibility allowed participants to enter an area not considered in the interview schedule but was pertinent and enlightening to the overall research question (Smith, Flowers & Larkin, 2009). Specific prompts were developed in anticipation of participants who may find it difficult to give their account.

Analysis

The interviews were transcribed by an approved transcriber for the Clinical Psychology Unit (CPU). The transcriber completed a confidentiality form (Appendix 3g). Identifiable data were anonymised through the transcription process. The accuracy of the transcripts were checked and as anticipated words that would be unfamiliar to the transcriber were added to complete the transcription.

Interviews were analysed using the heuristic frameworks for analysis set out by Smith et al. (2009) and Smith and Osborn (2003). These frameworks draw on the processes, principles and strategies typically employed by IPA researchers. Each transcript was engaged in separately before connections were analysed across cases. The following steps outline the process of analysis.

1. The most striking recollections of the first interview were noted at the start of the process of analysis. The audio recording of the interview was listened to whilst reading the transcript. The transcript was subsequently read and re-read. This allowed for the participant to become the focus of analysis.
2. Whilst reading the transcript observations, summaries, connections and preliminary interpretations were then noted on the right hand margin of the transcript. This provided a comprehensive set of exploratory notes broadly falling in to three categories; descriptive, linguistic and conceptual notes.
3. Using primarily the comprehensive set of notes, emerging themes (sub-themes) were then documented in the left hand margin of the transcript. In developing

the sub-themes attention was given to capturing what is crucial in the particular section of the text bearing in mind its context within the whole text.

4. The chronological set of sub-themes, were typed up as a list and printed on to paper. Each sub-theme was then cut up. Connections between sub-themes were then identified to develop clusters of sub-themes. The next stage involved producing a table of the sub-themes ordered coherently with clusters given a name representing the super-ordinate themes. Super-ordinate themes and sub-themes were selected and distinguished using a number of factors including, prevalence, richness of passages that highlight the theme and how the theme brought understanding to other themes.
5. The above process was repeated with the remaining seven transcripts. Each individual transcript was analysed on its own terms separately. Although it was important to appreciate that one will inevitably be influenced by the previous analyses. To ensure this was minimised, alongside the first step strong reflections from the previous analyses were also noted to allow for them to be bracketed off.
6. Once each transcript was analysed a final table of super-ordinate and sub-themes was constructed for all participants, which required the prioritising and reduction of the data. This final table is known as the masterlist. The emerging masterlist was tested against each transcript, due to the iterative nature of IPA. The masterlist was then translated in to a narrative account, explained and illustrated with examples from the transcripts.

Validation methods

The four broad principles of Yardley (2000) were adhered to in the conduct of the research as recommended by Smith et al. (2009). The principles consist of sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. For example, transparency has been maintained by ensuring reflexivity in the conduct of the study, through the use of reflexive notes, ongoing discussions in supervision and by acknowledging the background of the researcher throughout the research process.

The guidelines of Elliot et al. (1999) were used in addition to the principles of Yardley (2000), as they are located within a phenomenological-hermeneutic tradition (Willig, 2001). Implementing the guidelines included grounding the study in examples allowing the reader to appraise the fit between the data and its interpretation as well as the use of participant feedback, as a credibility check. Participants were sent a summary of the analysis and replied in writing.

Ongoing supervision by supervisors as well as peer supervision with other trainees using IPA was used to ensure the research was critiqued through the process of data collection, analysis and write up. The supervision included an independent audit as recommended by Yin (1989). This was conducted in the form of mini audits at various stages of the research process (Smith et al., 2009).

3. Results

Four super-ordinate themes emerged from the analysis: The self in relation to others, getting help and moving on, the unseen and the mind in the wider world. These super-ordinate themes along with their sub-themes are shown in Table 2.

The super-ordinate themes and sub-themes capture the rich and complex discourses of participants in understanding their unusual experiences. Excerpts from participants' narratives will be used to illustrate the themes.¹ The super-ordinate themes are both discrete and inter-connecting, this being evident in the narratives of participants as they develop across the course of the results section.

Table 2. Final table of super-ordinate themes and corresponding sub-themes

| Super-ordinate theme | Sub-theme |
|--|---|
| 1 The self in relation to others, | 1.1 The changing self 1.2 Being listened to and understood 1.3 Loss and gain in relationships |
| 2 Getting help and moving on | 2.1 The medical model and its limits 2.2 'Alternative' services 2.3 Religious practice and coping 2.4 Getting involved 2.5 Concentrating and ignoring |
| 3 The unseen | 3.1 Jinn and black magic 3.2 The whispers of the devil and thoughts 3.3 Honouring spiritual experiences 3.4 Greater meaning and purpose |
| 4 The mind in the wider world | 4.1 Stressors 4.2 Socio-political and cultural context 4.3 Paranoia grounded in reality 4.4 Own subconscious mind |

¹ Transcript notations: after each quotation, the participant's pseudonym will be reported in round brackets(); material omitted to protect anonymity or for ease of comprehension will be denoted by three full stops ...; explanatory material added to facilitate understanding will be contained in square brackets [].

1. The self in relation to others

The self in relation to others captures participants' narratives relating to how their unusual experiences changed them as a person and how they affected their relationships with other people. This super-ordinate theme contains three sub themes: the changing self, being listened to and understood and loss and gain in relationships.

1.1 The changing self

This theme describes the loss of normality and the 'envisaged self' due to the unusual experiences evident in many of the narratives of participants. In understanding their loss of the 'envisaged self' some participants compared themselves to peers and siblings of a similar age.

"I was poorly, very poorly, one of my weddings were, you know, first girl I was supposed to get married to, they got rejected because they said he's poorly. So, but my brother got married to her sister so it's okay, you know, they're okay, they've got a house of their own, kids, you know everything." (Dawood)

In the above extract Dawood, after referring to his loss, briefly mentions his brother in an idealised way. Similarly other participants' narratives highlighted the extent of the loss of the 'envisaged self.'

For one participant the loss of the 'normal self' was coupled with a special view of the self as a result of the unusual experiences.

"I think I'm quite good and I can, er make peace, make peace and stuff like this, make peace between religions and stuff and I've got special powers." (Umar)

Despite Umar feeling special, the negatives of the unusual experiences outweighed the positives and like other participants he described the process of working towards getting on with life.

“I'm working and got a good job, I'm going to get on with my life now and just work and live a simple life.” (Umar)

Within participants' narratives patient perseverance was evident in the new realistic view of the self, working towards normality and goals in life.

“If that lady in Pakistan says no to me, I don't get married it will be bad but it's, it's how I make my decisions, do you get me? Or if, er, if I, because I'm trying to do my driving now...I did a mock test yesterday, got thirty out of fifty, I failed but it was the first time I'm doing so I'm, I'm going to go again. So if, if everything works out, you know, even slowly, or surely you know, it will be okay.” (Dawood)

The above quote was typical of the participants' narratives demonstrating the process of coming to a new realistic view of the 'envisaged self,' emphasising the return to normality and regaining a sense of agency.

However for some participants the new view of the self was an acceptance of the loss of normality and an acceptance of not being able to reach previously envisaged goals in life.

“I was very muscular and you can see my, my body have, you know, I was really and now my body gone look, er, gone down, er, athlete. I was an athlete you know, erm, that's how I get my happiness and everything, but Allah don't want it this way.” (Adam)

1.2 Being listened to and understood

The participants' discourses highlighted the importance of being listened to and understood. Many of the participants' narratives reflected a distancing in their relationships when they did not feel listened to and understood.

“I've had really funny experiences of a, I can't actually tell my friends but they don't listen, they say oh, its just happened to you, it won't happen to us.” (Zubair)

Some participants spoke about not feeling understood by professionals working with them. Reflecting on his therapeutic relationships Wasim spoke about the skills required within a therapeutic relationship that would allow people to feel listened to and understood. The words, “when you come back” are referring to the interviewer, demonstrating how Wasim was addressing the interviewer in the wider context.

“To be a good doctor, a good psychologist, you must first understand the person's problems and try to help the person, and don't be, you know, when you come back, when they come out fresh, the doctors and the psychologists, they always want to listen to the person, yeah? But later on the y-, as the years progress, yeah, they seem to be stuck in their own line of thinking.” (Wasim)

1.3 Loss and gain in relationships

All the participants' accounts covered loss and gain in relationships as a result of their unusual experiences. Relationship difficulties and loss in relationships both preceded the onset of the unusual experiences, as well as being a consequence of the unusual experiences.

“I just come home, stay away because I don't want to say anything wrong to anyone, thinking that they've said something to me, which they haven't. You know, that's when they thought I've become dangerous or something init because I'm hearing voices I probably assume someone's said something to me and get into an argument with them.” (Yusuf)

However the loss in relationships was multi-faceted and not seen as negative by some participants. Although participants acknowledged the difficulties associated with loss they also reflected on how their previous relationships were a contributory factor in the development of their difficulties and how these relationships may also hinder the process of recovery.

“It's bad for me if I, if I be around people that smoke cannabis because I get tempted.” (Zubair)

Zubair was given consistent messages in relation to cannabis being a major contributory factor leading to his psychosis, from statutory services, non-statutory services as well as one of his friends. Hence he came to the conclusion, “maybe it was my own fault for smoking cannabis.”

Some participants spoke about gain in relationships as a result of their unusual experiences. Gains in relationships were associated with feeling understood and supported in the process of coping and recovery. The quality of the relationships rather than the number of relationships was crucial. In the process of recovery Zubair developed a relationship with a friend who also had psychosis. The relationship was mutually supportive and his friend helped him give up cannabis as well as supporting him cope with his voices.

“So he's kept me, he's kept me alright, he's kept me under his wing like I'm alright, like I don't, when I do, when I do hear voices he'll say don't, don't talk to yourself, it's okay, there's no, no, nothing's wrong.” (Zubair)

2. Getting help and moving on

This theme captures the journey of participants through the process of getting help and moving on. Participants reflected on their experiences, the help available to them, their ability to cope and the process of recovery. This super-ordinate theme contains five sub themes: the medical model and its limits, ‘alternative’ services, religious practice and coping, getting involved and concentrating and ignoring.

2.1 The medical model and its limits

The theme the medical model and its limits describes the narratives’ of participants in terms of getting help from statutory services, the experience of taking medication and understanding their experiences within a medical model.

Many participants spoke about their unusual experiences within the context of a medical model. Participants’ narratives contained terms such as “ill,” “sick” and “poorly”

possibly representing a medical understanding. It was important for some participants to explore whether there was a cure for their difficult unusual experiences.

“Even my own psychiatrist said that this could, this could be, you know, could take years to get anywhere and there's no, there's no guarantee that we could even cure the problem, it might be still there for years.” (Wasim)

As in the above extract some participants came to understand that their difficulties didn't fit within a medical model in terms of finding a cure, but rather as a long-term illness. Furthermore the extract highlights uncertainty with regards to the future.

The impact of the side effects of medication was particularly pertinent for more than half of the participants.

“I ask...does it affect the sex, he said [the psychiatrist], I think it does and I want to get rid of this medication, but how?” (Adam)

Adam considered the side effects of the medication on 'sex' and the impact of this on his relationship with his wife. However for Adam and other participants the internally weighed cost benefit analysis of taking the medication led to a continuation of taking it.

“I need it, I need it, I need it, since that Allah made, er, made it for me I, I will take it, from Allah I will take it Alhamdullilah [all praise is for Allah], anything bad or good, that's Qadr [fate] you have to believe in it, and you have to believe in the medication also. But what I, what I, I'm afraid about is what happened to

me in 1990s when he m-, when he, when I, when I, when I was ner-, nervous breakdown happened to me.” (Adam)

The above extract demonstrates how Adam’s medical understanding was interrelated with his religious beliefs, which helped him to continue taking his medication. The extract also illustrates Adam’s fear of the potential cost of not taking his medication.

In contrast Wasim had stopped taking his medication continuously. However he continues to “rarely” use his medication when needed to “dampens things down” when it’s bad.

“I just keep my medication there as when and if needed. I mean I took it for a spell continuously and I felt worse and the voices were still there and the experiences and my visions were still there so I, I, I couldn't' really see a point to it.” (Wasim)

Many of the participants’ narratives drew attention to the medical focus of services.

“They haven't got answers to everything, the NHS, these medical mental team, mental health team, there's Sarah [pseudonym of care co-ordinator] and I don't know all of them, they've got medication but that's not the cure.” (Yusuf)

The medical focus of services and the search for the ‘best-fit’ medication led to a distancing in Yusuf’s relationship with his care co-ordinator.

“It slowed it down but, erm, they haven't really stopped, I'll be honest with you, I say to Sarah [pseudonym of care co-ordinator] sometimes that they've stopped and that's because I'm sick of the medication they keep giving me.” (Yusuf)

For Wasim the medical focus of services led to a disconnection and strong feelings towards services and their impact on the lives of people with psychosis describing them as “the lost few” and being in a “vegetative state.”

... “they're always saying, oh take different forms of medication, I say I don't want any different forms of medication. Oh, let's go in and put you in, er, Willow [in-patient mental health ward] for observation and, so basically I'm a, I'm a goldfish in a tank and they're going to observe me, well, you know, up and down, I don't think so. If they can't cure the problems there's no point in really going further with them or is there? So you're damned if you do and you're damned if you don't.” (Wasim)

Ilyas considered the medical model in greater depth. He considered why he had developed psychosis whereas his sister didn't despite having “the same genetics” and “the same paranoia, scared, when we were growing up.” Ilyas described an episode of psychosis and how he was unable to do his logical routine activities and linked this to understanding his unusual experiences within the medical model.

... “because it is a dysfunctionality [in the brain] because it stops you from doing logical things to a certain degree.” (Ilyas)

The benefits derived from taking medication provided support for there being a dysfunction in the brain.

“I was on Olanzapine before yeah, and I've been on Clozapine since. I actually have less delusions...delusions of seeing things so I, I don't see things but I hear voices still so. It could be the medication, it could be my brain, so, it's gone away a lot but it comes and goes.” (Ilyas)

2.2 ‘Alternative’ services

The theme ‘alternative’ services encapsulates the varying ‘alternative’ services participants utilised which included the Hearing Voices group, clerics, healers and a community development mental health organisation. Some participants’ narratives in relation to ‘alternative’ services showed how they felt listened to and understood in comparison to their experiences in statutory services.

“For some reason I felt more secure with, with Ted's [pseudonym of Clinical Psychologist] group [Hearing Voices group] than anywhere to openly talk about my problems and, you know, erm, because you're s-, getting it, sharing it or getting it off your soul it seems to relieve me and I feel comfortable in the group and the people support each other in the group.” (Wasim)

Bilal was the only participant who had no contact with statutory mental health services. In understanding his unusual experiences he made no reference to framing them within a medical model. He briefly mentioned, “I couldn’t tell anyone, to my doctor or anyone else.” Bilal got a talisman for his unusual experiences.

“I’ve got a sort of talisman from this, er, person so, so and then they gave me some kind of candles to burn, so it sort of helps me with my jumping and stuff and that and you know, er, turning or hearing voices. So I’m not hundred percent convinced whether it’s because of that or, or, it hasn’t happened since then.”
(Bilal)

Umar consulted a cleric to help with his unusual experiences in relation to jinn. He spoke about how “he’s killing the jinn off” using Quranic recitation as one of the means.

“The Somalian cleric just gave me, a Quranic recitation in my ear, made me listen to tapes, something like this, and he was quite good.” (Umar)

The above extract shows satisfaction with the Somalian cleric. However Umar also mentioned going to a healer and how he was dissatisfied with this particular consultation. The lack of transparency and explanation of methods possibly contributed to this.

“...a so called, you know, a healer and he gave me, er, water to drink made me, er, sit in a room on my own and I got quite angry really.” (Umar)

Dawood also reported going to more than one person outside statutory services. He gained most benefit from going to a pir saab (spiritual guide) at the mosque.

“When I go there I like doing zikr [remembrance of God] with him, understand, and then basically he reads namaz (daily prayers) and we read after him...then he talks to all of us individually but he knows what everybody’s problems are,

differently, he probably knows this somehow. But he talks to them and he tells them, you know, what to do or what to read. He told me he was going, he was going to give me some words to read, to get better.” (Dawood)

Zubair described how the community mental health development organisation he attends helped him. The organisation allowed Zubair to develop an alternate social circle thereby facilitating his recovery. An important feature of the organisation for Zubair was the atmosphere, which allowed him to talk about his problems openly.

“If I've got any problems I just, I don't tell the doctor, I tell these lot because these lot, they don't, they don't force medication on you or anything.” (Zubair)

2.3 Religious practice and coping

The accounts of many participants described how religious practice was valuable in the process of coping and recovery. Some participants mentioned how praying to God for recovery helped.

“I knew if like, if I prayed to Allah then I might get better and I did get better inshaa Allah [God willing].” (Zubair)

The participants' narratives included specific religious practices.

“I mean going in the mosque and stuff keeps me balanced, straight, in the straight and narrow you know.” (Yusuf)

Recitation of the Quran was important for some participants. In the following extract Dawood describes how he derived both physical and spiritual benefits from reciting the Quran.

“When I read it [Qu’ran] I, I, I don't read much, you know, I read in the Namaz [daily prayers] properly but Qu'ran I only read a bit init, you know like a page a day or something like that. But the thing is, it's like a current and it's like, it gives you a bit of energy, bro, to be straight with you, it gives you a bit of you know that toughness you know, in your heart.” (Dawood)

Many participants spoke about the recitation of the Quran being used as a remedy and for protection. The recital of specific chapters or verses of the Quran and specific prayers were mentioned.

“If I do get scared I just read Kalimah (declaration of faith) and just, just blow on myself.” (Zubair)

2.4 Getting involved

In the process of coping and recovery it was important for participants to get involved in activities, learn new skills and go on holiday. Zubair describes how his move from the acute in-patient ward to an in-patient rehabilitation ward facilitated recovery and gave him a sense of achievement.

“It was a bit better there because we used to go out to, er, do things like, I got involved with a gardening group, got involved with, er fitness group, we used to

go swimming at the gym and we used to do self cooking, so I know how to cook as well now.” (Zubair)

Dawood highlighted the importance of his friend in getting involved and how going on holiday helped.

“My mate took me out, you know to Blackpool and he said, you know, get the air, look at the people, see how they're feeling, you know, and that helped a lot, because you know, when you're always in one place and you don't go for a holiday or owt, sometimes it could get to you.” (Dawood)

2.5 Concentrating and ignoring

Some participants described how they had difficulties with concentration, with a couple emphasising this in the interview process. One participant mentioned ignoring and due to the strength of the narrative it has been included.

Yusuf talked about developing the coping strategy of ignoring the voices, which he found helpful.

“I'm hearing less voices now but, erm, but I'm wandering about talking to myself still, outside, but when I realise I'm doing it I just ignore it.” (Yusuf)

In the following extract Wasim describes how over time he has been able to concentrate on one of the multitude of simultaneous experiences happening in his time zone. This ability to concentrate helped Wasim to cope, partly helping him to adopt a position where he could “co-exist” with his voices.

“Seven or eight people are talking to you, yeah, about seven or eight different subjects and you're s-, how can you concentrate on one subject? So what you've got is flashes of faces and, and bits of words, but after time you, you'll be able to concentrate maybe on one subject, you might be able to pull the words out and glue it together to be one subject.” (Wasim)

3. The Unseen

This super-ordinate theme captures how Islamic beliefs regarding the unseen were important for all participants in understanding their unusual experiences. Islamic beliefs in the unseen mentioned by participants included belief in Allah (God), angels, jinn (spirits), the devil (shaytan) and black magic.

This super-ordinate theme contains four sub themes: Jinn and black magic, the whispers of the devil and thoughts, honouring spiritual experiences, and greater meaning and purpose.

3.1 Jinn and black magic

This theme describes how participants made sense of their experiences in relation to jinn and black magic. Some of the participants' narratives linked jinn and black magic or explored them together in making sense of their experiences.

“I felt something inside me so, sometimes I heard voices and I felt like some kind of jinn.” (Bilal)

In the above quote Bilal mentions the physical manifestation of the jinn inside the body, which was unique to Bilal. For other participants the experiences in relation to jinn were experienced as external to the body, impacting on the external environment or experienced as voices. Bilal considered the experience of the jinn as a consequence of black magic. He made sense of this in the context of family conflict whereby he was able to identify people within the family responsible for the black magic. Bilal became “more convinced” of his belief in black magic in relation to his unusual experiences when his mother later developed a serious medical illness which he attributed to black magic. Despite his unusual experiences having stopped, he continues to use a talisman to protect himself from the effects of black magic.

In making sense of his unusual experiences Umar considered both black magic and jinn. In contrast to Bilal he eliminated black magic as a cause and accepted the explanation of jinn in relation to his voices.

“Lots of people say to me it’s a ta’weez, you know like a charlatan it’s some kind of black magic or something...Well it’s hard, you can’t really blame it on that. Like recently my brother said last, the last person someone wants to do magic on is, is on you but this is what people say, it’s what you hear from people like from the Muslim faith.”(Umar)

The above quote is representative of some of the participants’ accounts that placed emphasis on both the influence of community perceptions and the views of family members. The views of family members held greater weight as they were able to engage deeply in the process of meaning making with the individual. Umar mentioned how he felt the community put too much emphasis on black magic as a cause of difficulties.

“There could be a case (of black magic) but it could be two out of ten.”(Umar)

In making sense of his voices Umar differentiated them from his mental health problems.

“I can't believe it's just a symptom (the voices) I believe I've got a mental health problem but this is not a symptom this, this is not a symptom, this is real life stuff. There is definitely, er, jinn and stuff like this.” (Umar).

Understanding the contrasting narratives of Bilal and Umar highlights how participants made sense of their experiences testing possible hypotheses against the evidence and then rejecting or accepting hypotheses in relation to themselves.

Wasim described how he has over time been able to “study it and make some sort of conclusion” with regards to his unusual experiences. His conclusions illustrate the complexities and subtleties in understanding unusual experiences in relation to the unseen. Wasim thus describes his understanding of his experiences, which he believes are due to black magic.

“They (visions) and these voices I believe are, are mischievous spirits that wander the earth and somehow I'm a receptacle, antenna, radar that picks up on these, er, voices and images.” (Wasim)

We now focus on how Wasim made sense of these experiences with his parents. Wasim described his parents as people of wisdom, to whom people come for advice regarding difficulties.

“Well they believe that, you know, it's a gift and you can, these troubled spirits need to be, you know, helped and aided so they can get to the next level, transgress to a higher, you know, wherever but it's n-, I don't think that I, I'm in the same league as my parents so I can't really see what I can do for them. They should just leave me be and I'll live a normal life.” (Wasim)

The above extracts demonstrate Wasim and his parents share the understanding that his experiences are due to troubled spirits. In the subsequent theme ‘greater meaning and purpose’ Wasim shares his parents’ understanding with regards to the experiences being a test from God. Furthermore, Wasim accepts that for his parents the experiences are a gift, but importantly he does not accept this in relation to himself.

Wasim questioned the efficacy of exorcism as a cure, explaining how he hasn’t met anyone to this day who has gone through such an experience and been cured. He explained how “the English believe exorcism, er, is a cure for these sort of problems” and how for Muslims, “it's just an endless struggle.” Wasim’s view differed from other participants who had gone to see people who could be considered to use ‘exorcism’ to help with such experiences.

Some participants were unsure of the extent to which jinn were related to their unusual experiences.

“But I, sometimes I get feeling it's a jinn, bro [brother]. So how, how can a recorded TV listen to your thinking? That's what I can't understand and other people know, they're definitely, they're listening, they might be able to hear me in front of me but how can a recorded TV listen to it? That's what I can't understand.” (Dawood)

Dawood's consultations from 'alternative' services added to this struggle to make sense. Dawood had benefited from going to see the pir saab and respected him, however he was frustrated that he didn't say anything about jinn.

“If I go to my pir saab, pir saab doesn't say nothing about jinn, what am I supposed to do?” (Dawood)

Dawood and his father went to see a person who told him, “nothing's your fault, you're being driven by a jinn.” However Dawood and his father mutually decided not to pursue intervention as they felt the person was not credible. Dawood also identified the cost of consultation as a barrier.

It was important for Yusuf and in particular his mother to eliminate the possibility of the unusual experiences being as a consequence of spirits. Yusuf eliminated spirits as a possible cause of his difficulties, this conclusion was supported by an amulet not helping.

“I thought it was just spirits, like my mum thought I was possessed, you know, she got ta'weez (amulet) and all of that, but its not, nothing worked.” (Yusuf)

3.2 The whispers of the devil and thoughts

Some participants spoke about the deviating influence of the devil with a couple of participants mentioning the whispers of the devil. Umar describes in the extract below, how whispers of the devil are like an “idea.” Use of the words “idea” position whispers of the devil amongst the realm of thoughts as opposed to voices.

“In the Muslim faith there's a, a feeling when they say the Devil gives you a whisper, the Devil gives you a whisper and this whisper, it's not like a voice it's, there's no voice there it's like an idea. It's, it's an idea and how you perceive that.” (Umar)

In contrast other participants considered whether the voices came from the devil and made no reference to whispers of the devil.

“Sometimes I hear voices, I don't know whether it's from shaytan or from, er, from, er, from my head.” (Adam)

Yusuf initially attributed his voices to the devil.

“I thought it was the shaytan [devil] talking to me, giving me voices, you know, making me hear voices and stuff.” (Yusuf)

Overtime, Yusuf re-attributed his voices as possibly being from his own subconscious mind. His use of the word “whispers” below was in relation to the quality of the voice rather than being linked to the devil.

“I’ll hear voices like I don’t know, whispers, maybe it’s just my subconscious mind.” (Yusuf)

3.3 Honouring spiritual experiences

Some participants considered the extent to which their experiences could be considered spiritual experiences. On reflection some participants were able to acknowledge their initial impressions of their unusual experiences were mistaken. In Yusuf’s case, he described how he misinterpreted his paranoia as a “warning” from God. Ilyas and Umar distinguished between unusual experiences in relation to psychosis and unusual experiences in relation to spiritual experiences.

Ilyas described the death of his mother and the experiencing of immense light, he described how this was an unusual experience but different from the unusual experiences in relation to psychosis. He made sense of his unusual experience using his Islamic knowledge with regards to the coming of an angel at the time of death.

*“According to Islam is that an angel comes and takes her soul away so we could have left her room and the angel came, that’s why there was immense light.”
(Ilyas)*

When describing his psychotic experiences Ilyas explained them in terms of seeing a jinn, as opposed to seeing an angel in the case of the spiritual experience. Ilyas then explored his spiritual unusual experiences in relation to his psychosis.

“Had I gone through the experience of my mother dying being ‘normal,’ like my sister, she didn't have voices. I would have experienced maybe my mother dying a different way, I might have become depressed or whatever. So it, it changed the way my, my mind felt about things.” (Ilyas)

The above extract is taken to illustrate how Ilyas is making sense of his spiritual experience, linking the medical model with his spiritual experiences. Ilyas hypothesised that having ‘psychosis’ may have made him more open to spiritual experiences. He further describes the context of his sense making which potentially limits his ability to link religious and medical interpretative frameworks.

“But the thing is that we're not looking at it from an Islamic theology point of view when we look at it from psychiatry in this country because unfortunately it's a model that's European so I can't really say to you that, they'll say, they'll call it psychosis when you think that you see something, maybe these things that are coming to me and I'm experiencing are angels, trying to protect me.” (Ilyas)

Umar explained how God can show him what other people can't see, which he differentiated from his mental health problems.

“I believe God can show me what other people can't see, they call this Kashf, they call discretion, only some people get this. I'm not making myself out to be so pious. I'm not so bad, I'm a Muslim and try, try my best up to my own standard.” (Umar)

3.4 Greater meaning and purpose

Many participants spoke about how the unusual experiences led to considering the greater meaning and purpose of life. Participants considered their unusual experiences being a test from God.

“I actually believe that God tests you in different ways maybe and maybe this is my test in one way that he's set out. Maybe it is a stupid test, maybe it isn't, you know, so, but that's my analysis of it, of what I think, it's not an Imam telling me something.” (Ilyas)

For other participants in making sense of their unusual experiences in terms of the greater meaning and purpose, they had come to this understanding considering the views of significant others.

“I think God in His infinite wisdom the supreme has, you know, just testing me, some sort of imthihaan [test], my parents would say this is an imthihaan and only the few who rise to the occasion and get the end certificate.” (Wasim)

Wasim developed the concept of a test further which helped him cope with the “constant struggle.”

“I've been going through this for maybe years and years but, you know, but, we are only here on this planet for a, a minuscule amount of time compared to the next life, if you can follow that one.” (Wasim)

Adam's narrative had the greater meaning and purpose as a recurrent theme. In accepting his difficulties he considered how his illness prevents him from future sins. Adam regarded his difficulties as God helping him to stay within the limits of his religion, which in good health he was unable to do.

"I feel that Allah give me my head, I'm like a fox, I'm dangerous, I will go around like this, make Zina [adultery]." (Adam)

4. The mind in the wider world

This theme represents stressors in relation to unusual experiences and the wider context of these experiences. This super-ordinate theme contains four sub themes: stressors, socio-political and cultural context, paranoia grounded in reality and own subconscious mind.

4.1 Stressors

All participants talked about stressors or a transition in life in relation to unusual experiences. A variety of stressors and transitions were mentioned including bullying, racism, marital problems, bereavement, a change in job and starting university. Most participants highlighted the stressors generally, often describing more than one stressor and not specifically linking them to the start of their unusual experiences. Dawood was able to specify the most significant stressor.

"It started because of, er you know, I don't know, I used, I used to have a friend and, er, he passed away and from that day, you know, my head wasn't right."
(Dawood)

In contrast, Bilal was unsure about the relationship between stressors and his unusual experiences.

“It just happens from a single parent family so, can you mention this” (Bilal)

4.2 Socio-political and cultural context

The narratives of participants’ drew attention to the socio-political and cultural context of their experiences. Some of the participants’ narratives were regarding being in a hostile environment.

Bilal had unusual experiences, which started during childhood in a hostile environment experiencing bullying.

“It's just that I'm from a single parent family, that can be very rare to come from a single parent family, my mum being divorced in the eighties, we're talking about, even why, even in western culture it's very rare at that time so I was looked down on, I was bullied at school, was bullied in the streets, everywhere so. I had to take a lot of abuse and stuff, even my mum did and stuff.” (Bilal)

During the process of recovery from a psychotic episode Adam unknowingly moved to a hostile area to live. The un-containing context further exacerbated his difficulties.

“They don't like black people there, no black people enter that place, coloured or black whatever, they don't want anybody.”(Adam)

Ilyas's unusual experiences started in 2000, he described watching films and reading books in which "2000 meant...that the end of the world was coming in Christian theology." He mentioned how his hallucinations weren't an "Indo-subcontinent type of spiritual, you know, hallucination" but rather a "European-American style." Ilyas explained how his thinking in making sense of his experiences was linked to society here.

"My thinking is linked to society here so it's Islamic, the majority of thinking here is either Christianity or Judaic which is similar to Islam." (Ilyas)

In understanding the genesis of Yusuf's paranoia, one needs to consider the socio-political context with regards the 'War on Terror' bearing in mind factors such as surveillance and media coverage in relation to young British Pakistani Muslims.

"I thought someone had grassed me up or someone mentioned me to the police saying look he's a bit extreme and that, check him out, so I thought the police were watching me. So I was going about, started getting paranoid and then I started hearing these voices like there is police watching you and that." (Yusuf)

4.3 Paranoia grounded in reality

Some of the accounts of participants emphasised the importance of appreciating the paranoia was grounded in reality.

For Umar his context meant he had greater uncertainty regarding the extent to which his paranoia in relation to the police was grounded in reality.

“I was hanging about with, er, people what get into crime and stuff, so the police could have pulled me for that, so it’s hard to say I was, er hallucinating, hard, hard to say.” (Umar)

The extent to which the unusual experiences were grounded in reality was important for participants. Zubair described how he talked to himself about real people.

“Well I started talking to myself a lot, but it wasn't about, I didn't talk about people that wasn't there, it was real people that I met in the hospital and stuff like that.” (Zubair)

Zubair described how his sisters didn’t appreciate the complexities of his experiences.

“My sisters, they make jokes of it, they think he's imaginary friend, they say he's imaginary.” (Zubair)

4.4 Own subconscious mind

In making sense of his experiences Yusuf came to his own conclusion regarding the voices being possibly from his own sub-conscious mind. This led to Yusuf moving away from an external focus to an internal focus in relation to his unusual experiences.

“I think it's just my mind, like I'm hearing my own self like, you know like your sub-conscious mind.” (Yusuf)

Dawood considered his voices as “hearing my thinking,” however he felt “people can hear my thinking.”

The following quote demonstrates Dawood’s shared meaning making with his family, regarding people being able to hear his thinking.

“My doctor says that I'm not going to judge you, yeah, my dad says I don't believe it, that this thinking can go aloud yeah? My family say, if you're thinking went out aloud, then it would be easy for somebody like Mr Blair or whoever to take over the world, if something like that could happen, you understand? Because he would use that technology to do anything then, can't they, you know what I mean, that's what they were saying but, I, I, I always kept feeling no, it's gone out, it's gone out, it's gone out.” (Dawood)

Participant feedback

Three participants provided written feedback regarding the summary analysis. Bilal reported he felt the summary analysis did not fully reflect his experiences. He highlighted that he would have liked a summary of his own interview and the opportunity to meet to discuss the feedback. He reported he enjoyed the interview, as it gave him the opportunity to discuss his experiences, which he found unable to do with someone from a different background. Dawood reported he felt the summary analysis was very good, he also highlighted the constraints of the interview process, mentioning there was more to talk about, but not enough time. Zubair reported the summary analysis was good and it was good to explore his experiences. It is hypothesised that the limits of the method of gaining participant feedback precluded in-depth feedback and highlighted the need for individual feedback, as mentioned by Bilal.

4. Discussion

This study presents a detailed exploration of the experiences of eight participants of a Muslim faith in relation to how they conceptualised their unusual experiences. The analysis of the data produced four super-ordinate themes: The self in relation to others, getting help and moving on, the unseen and the mind in the wider world. In the discussion particular emphasis will be given to the results section in relation to the aims of the study.

The results of this study show, despite the homogeneity of the sample particularly in terms of ethnic origin and gender, the way in which participants made sense of their experiences was complex and it was important to pay attention to the subtleties in the narratives of participants. Participants used a variety of interpretative frameworks simultaneously in making sense of their experiences. Religious interpretative frameworks, particularly those relating to the unseen were important in the struggle to make sense of their unusual experiences.

The research supports the findings of Kinderman et al. (2006) showing participants entertained disparate and changing interpretative frameworks in the struggle to make sense of their experiences. In the inpatient sample, in the study by Kinderman et al. (2006) participants used scientific and spiritual frameworks interchangeably, not regarding them as inconsistent and not linking them. This applied to some participants in this study, however other participants made attempts which demonstrated interaction and some integration of a variety of interpretative frameworks. This was consistent with the study by Larsen (2004) where individuals engaged in a creative analytic and theory building work of 'bricolage,' selecting, adding and combining various systems of

explanation. Furthermore, participants in the current study engaged in testing of explanations in relation to their unusual experiences as in the study conducted by Marriot (2007).

The discourses of the participants in the theme *the self in relation to others* were consistent with findings in the literature, which show how people with psychosis experience the loss of normality, seek to maintain their sense of themselves and how they reconnect with the environment developing relationships in the process of recovery (Forchuk, Jewell, Tweedell, & Steinnage, 2003; Bentall, 2003; Hirschfeld et al., 2005). The narratives of participants demonstrated the multifaceted nature of the rebuilding of the self and relationships, highlighting the importance of being listened to and understood in this process.

The theme *getting help and moving on* captured the richness of the journey of participants through the process of coping and recovery. Participants engaged with a broad range of alternate services and their narratives support the utility of alternate services in supporting people with psychosis, through the provision of Hearing Voices groups (Romme & Escher, 2000) and community development approaches (Thomas, Bracken & Yasmeen, 2009; May, 2007). Some participants engaged with a variety of religious or spiritual alternate services including healers. This study supports the findings of research conducted with 25 South Asian Psychiatric patients, which showed patients resort to traditional forms of healing in collaboration with western psychiatric treatments (Dein & Sembhi, 2001).

Participants highlighted the need for greater choice and the medical focus of mental health services. This was similar to the findings in another IPA study which researched

the process of recovery in psychosis in a sample consisting mainly of people of a White ethnic group (Pitt, Kilbride, Nothard, Welford & Morrison, 2007). This indicates the experiences of people of a Muslim faith in the current study, may be similar to the experiences of other groups of people. However it is important to appreciate both similarities and differences, as the current study demonstrated utilisation of a wider variety of alternate services for people of a Muslim faith when compared to the participants in the study of Pitt et al. (2007).

The narratives of participants showed a complex relationship between the meaning which people attributed to their unusual experiences, the help they got and the way in which they coped with their experiences. This supports the findings in the study by Leavey, Guvenir, Haase-Casnovas and Dein (2007) which explored the interconnections of causal attributions and pathways into care among nine Turkish-speaking refugees and migrants in London. The study found a non-linear relationship between patients' explanatory model and choice of healing modality.

The role of religion played a significant part in the conceptualisation of psychosis for the participants in this study, which was particularly captured within the theme *the unseen*. A religious framework was important to different aspects of conceptualising their unusual experiences including from the perspective of causes in the form of black magic and religious practices helping them to cope. Furthermore a religious framework was used in framing the experiences more widely, considering the greater meaning and purpose of their difficulties. This supports the finding of the study by Redko (2003) that religions have the potential to provide a framework and set of meanings, which contribute to placing an alienating and personal experience in a stable framework.

Many participants considered their experiences being related to jinn to varying degrees with some accepting this as an explanation. This is consistent with the findings of Dein, Alexander and Napier (2008) which showed appeal to jinn explanations at times of psychological disturbance and unexplained physical symptoms were common in the community as a whole, within a Bangladeshi Muslim sample. The findings of the current study extend these findings in showing how people with unusual experiences make sense of their experiences in relation to jinn. Furthermore they demonstrate how explanations in relation to jinn link with other religious explanations, in particular black magic.

The theme *the mind in the wider world* highlighted the significance of wider economic, social, political and cultural factors impacting on the conceptualisation of psychosis for the participants (Isaac, Chand, & Murthy, 2007). Understanding this context allowed appreciation of the stressors associated with the unusual experiences as well as the extent to which unusual experiences were grounded in reality. The process of recovery for some participants involved a move away from an external focus to an internal focus. Participants' narratives highlighted psychological mechanisms such as attributing voices to one's own subconscious mind, which have resonance with cognitive theories of hearing voices (Bentall, 2003).

Clinical implications

As a qualitative study employing a small sample size, the study does not claim empirical generalisability but rather transferability to persons in contexts which are more, or less similar to the participants in this study (Smith et al. 2009). The findings of this study have the potential to contribute to the provision of culturally and religiously appropriate, clinically effective services.

The study may aid clinicians in appreciating the complex interaction of a variety of interpretative frameworks in people of a Muslim faith in making sense of their unusual experiences, thereby helping them to appreciate these in a therapeutic context. For example, the narratives of the participants' highlight possible professional misunderstandings of psychological distress and the limits of the over-reliance on ethno-centric and Eurocentric conceptual frameworks (Williams, Turpin and Hardy, 2006) in particular a bio-medical model (Bracken and Thomas, 2001). Pitt et al. (2007) suggested there is a need for service users to access stories of recovery, sources of inspiration that offer insight, hope and knowledge of people's journeys of recovery. Hence the current study may be used in such ways with service users where appropriate.

The study supports the findings of Mohr et al. (2006) who highlighted that religion is neither strictly personal nor strictly cultural and that the complex relationship between religion and illness requires a highly sensitive approach to each unique story. Training in cultural competence should therefore develop competence at a number of different levels; understanding of beliefs of a particular religion, their cultural expression in a particular community and how this plays out in the individual's understanding of unusual experiences.

Services are required to adopt a biopsychosocial-spiritual model (Moreira-Almeida & Koss-Chioino, 2009) in the provision of services. In view of the medical focus of services pertinent in the narratives' of participants it is important that a bio-medical model is not given pre-eminence (Read, 2005; Bracken & Thomas, 2001). Similarly, in the provision of psychological therapy cognitive conceptualisations of unusual experiences should not be given pre-eminence over spiritual and religious conceptualisations. The holistic model should be evident across service provision, for example in terms of the provision of information and across professional boundaries.

In the provision of psychological therapy, therapists should develop competency in working with explanatory models for people from diverse ethnic and cultural backgrounds (NICE, 2009). The process of formulation may seek to aid the individual make sense of different interpretative frameworks. The use of a narrative approach in the process of assessment and formulation may best capture the complexities of the individual's understanding paying particular attention to the interpersonal context (Gumley & Schwannauer, 2006). A recent study seeking to develop culturally sensitive Cognitive Behaviour Therapy for psychosis highlighted the need for therapists to be aware of religious explanations for psychopathology, particularly in view of the finding that therapists felt overwhelmed when confronted with religion and spirituality and tended to avoid dealing with this (Rathod, Kingdon, Phiri & Gobbi, 2010). In the narratives of some participants cognitive impairments in concentration were pertinent, hence there is potential for expanding the range of psychosocial interventions to include cognitive remediation (McGurk et al. 2007).

The narratives of participants suggested the need for greater collaboration with patients and a greater flexibility in the provision of medication for people with psychosis (BPS,

2000; Deegan & Drake, 2006). For example, in implementing clinical guidance (NICE, 2009) it may be appropriate to openly discuss non-routine pharmacological interventions at an early stage, such as the use of anti-psychotic medication only during periods of relapse and symptom exacerbation. This may prevent patient dissatisfaction and disconnection from services, for some patients.

Statutory services need to appreciate the wide variety of alternative services available, such as community development mental health organisations, clerics and healers. Research regarding the conceptualisation of psychosis and other mental illnesses from the perspective of healers conducted in developing countries show faith healers' and traditional healers' conceptualisation incorporate biopsychosocial perspectives to varying degrees, hence the potential for greater collaboration with statutory services (Ally & Laher, 2007; Teuton, Dowrick & Bentall, 2007). Collaboration with alternate healing systems may potentially create a more positive environment within which to share modes of treatment. Furthermore there is potential for developing collaborative training, cross referral and research projects (Teuton et al. (2007). This would allow professionals to consider the extent to which alternative interventions can be complimentary or in opposition to interventions offered by services, and work towards different systems of healing working functionally together.

Limitations

The study has a number of limitations, which require further discussion. Recruiting people of a Muslim faith may have selected participants for whom religion was particularly significant in making sense of their experiences. Seven of the eight participants self reported as practising Muslims given the options yes/no. However the

validity of the measure is limited given there is no available criteria with regards what constitutes a practising Muslim.

In line with the requirements of IPA the study attempted to recruit a relatively homogenous sample, however the study included a participant who was particularly divergent from the remainder of the sample. The participant had no contact with statutory mental health services and no diagnosis of a psychotic illness, this meant some themes reported were not reflective of the participants' interview. Recruiting participants from non-statutory services may have accessed people who were particularly critical of statutory services. Furthermore in view of the qualitative nature of the study, it may have selected people who have assimilated their experiences to a certain degree, thereby enabling them to take part in the research.

The characteristics of the researcher as a male Muslim trainee clinical psychologist may have facilitated particular discourses as well as limited other discourses during the interview phase as well as affecting the type of participants recruited. For example, although no gender was specified in the recruitment phase no females took part in the study.

In terms of participant feedback, the low response rate and the type of method used limited the value of this method of validation. It may have been more appropriate to allow for meeting participants for a second brief interview, as well as providing individual feedback from each interview in addition to the summary analysis for all participants. More detailed participant information could have been gathered for example the duration of contact with statutory services and the length of time participants have been experiencing unusual experiences.

Future research

Further research is required with people of a Muslim faith from different ethnic minority groups, females and those who do not speak English. Research in relation to healers and clergy in the UK will allow greater understanding of the wider context. More widely research in relation to religion and psychosis requires researching different religious groups as well as considering spiritual interpretative frameworks in people who may not identify with a particular faith. Further research may also recruit participants on the basis of ethnic origin, the findings of such research can then be compared with those recruiting on the basis of religious affiliation. Researching from a particular type of service e.g. Early Intervention services may increase the clinical transferability of findings.

5. Conclusion

This study presents a detailed exploration of the experiences of eight participants of a Muslim faith in relation to how they conceptualised their unusual experiences. The results provide support for the existing literature, in that participants utilised a variety of interpretative frameworks in the struggle to make sense of their psychotic experiences. Religion was important in making sense of their experiences at a number of different levels, from the perspective of causes in the form of black magic, religious practices helping them to cope and in framing their unusual experiences in terms of the greater meaning and purpose. In light of the findings, clinical and research implications are considered such as greater collaboration with alternative services and similar studies in different religious groups.

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Section 3: Appendices

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Appendix 1 – Formats

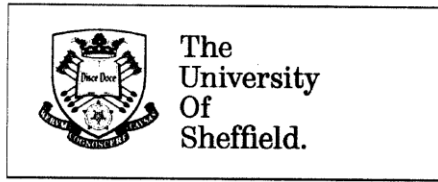
- a) Approval of nominated journals
- b) Clinical Psychology Review instructions for authors
- c) Transcultural Psychiatry instructions for authors

Appendix 2 – Ethical approvals

- a) NHS Ethical approval
- b) Research governance approval – West Yorkshire Mental Health Research and Development Consortium
- c) Research governance approval – Sheffield Health and Social Care NHS Foundation Trust
- d) Ethical approval from the Department of Psychology Ethics sub-committee

Appendix 3 – Other

- a) Advertisement
- b) Information sheet NHS
- c) Information sheet The University of Sheffield
- d) Consent form NHS
- e) Consent form The University of Sheffield
- f) Interview schedule
- g) Transcriber confidentiality form
- h) Analysis Exemplar



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26 March 2010

Mahbub Khan
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Mahbub

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

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Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'A. Thompson'.

Dr Andrew Thompson
Director of Research Training

Appendix 1b - Clinical Psychology Review instructions for authors

Clinical Psychology Review Guide for authors



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Preparation

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A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

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Appendix 1c – Transcultural Psychiatry instructions for authors

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All manuscripts should follow the style of the *Publication Manual of the American Psychological Association, 5th Edition* and must be typewritten and double-spaced. Original articles and overviews should be accompanied by an abstract of no more than 100 words and about five key words, plus a cover sheet providing authors' postal/email addresses and tel/fax numbers. UK or US spellings are acceptable but must be consistent. Titles and section headings to be given in three weights: A, B or C. Quotations over 40 words to be displayed, indented, in the text. Notes and References should appear at the end of the text. Tables and figures should have short descriptive titles. Line diagrams should be supplied preferably as EPS or TIFF files, 800 dpi - b/w only. Photographs should be supplied as TIFF files, 300 dpi.

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Corresponding authors will receive copies of the printed journal (up to a maximum of 5 copies per article) and a restricted quantity pdf of their article after publication.

Address correspondence to: L.J. Kirmayer, Editor-in-chief, transcultural psychiatry, Division of Social and Transcultural Psychiatry, McGill University, 1033 Pine Avenue West, Montréal, Québec, Canada H3A 1A1.

Tel: (514) 398-7302; fax (514) 398-4370 [email: transcultural.psychiatry@mcgill.ca]

English Language Editing Services: Please [click here](#) for information on professional English language editing services recommended by SAGE.

If you wish your article to be freely available online immediately upon publication (as some funding bodies now require), you can opt for it to be included in SAGE Open subject to payment of a publication fee. Manuscript submission and refereeing procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE Open. For further information, please

visit <http://www.uk.sagepub.com/sageopen.sp>



National Research Ethics Service
South Yorkshire Research Ethics Committee

1st Floor Vickers Corridor
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Telephone: 0114 226 9153
Facsimile: 0114 256 2469
Email: joan.brown@sth.nhs.uk

27 October 2009

Mr Mahbub Khan
Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield
S10 2TN

Dear Mr Khan

Study Title: A Qualitative Investigation of the Conceptualization of
Psychosis in People of a Muslim Faith
REC reference number: 09/H1310/58
Protocol number: 3

Thank you for your letter of 19 October 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk> *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|--|----------------|------------------|
| Academic Supervisor's CV | | |
| Confidentiality form for transcribers | 3 | 03 April 2009 |
| Guidelines for transcribers | 3 | 03 April 2009 |
| Semi-structured interview schedule | 3 | 03 April 2009 |
| Advertisement | 3 | 03 April 2009 |
| Protocol | 3 | 03 April 2009 |
| Investigator CV | | 14 July 2009 |
| REC application | | 16 July 2009 |
| Guidelines for home visits | 3 | 03 April 2009 |
| Peer Review | | 08 April 2009 |
| Statement of indemnity arrangements | | 23 April 2009 |
| Letter from Sponsor | | 23 April 2009 |
| Participant Information Sheet | 4 | 18 October 2009 |
| Participant Consent Form | 4 | 18 October 2009 |
| Letter responding to points raised in provisional opinion letter | | 18 October 2009 |
| GP/Care Co-ordinator Letter | 1 | 18 October 2009 |
| Letter from M Shabbir, CEO Sharing Voices Bradford confirming support for research project | | 09 February 2009 |
| Response to Request for Further Information | | |
| Letter from Dr R May, Clinical Psychologist, Bradford Assertive Outreach Team, confirming support for research project | | 12 October 2009 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES directorate within The National Patient Safety Agency and Research Ethics Committees in England

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H1310/58

Please quote this number on all correspondence

Yours sincerely

Joe Brew-

JP Miss Jo Abbott
Chair

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: R&D Department, Sheffield University, New Spring House,
231 Glossop Road, Sheffield, S10 2GW

Research Governance Administrator, Sheffield Health & Social
Research Consortium, Research Office, Fulwood House, Old Fulwood
Road, Sheffield S10 3TH

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES directorate within
The National Patient Safety Agency and Research Ethics Committees in England



Our Ref: 2009/159/B

West Yorkshire Mental Health R&D Consortium
Research & Development Department
North Wing, St Mary's House,
St Mary's Road
Leeds LS7 3JX

E-mail: john.hiley@leedspft.nhs.uk
Direct Line: 0113 295 2387
FAX: 0113 2952412

Mr Mahbub Khan
Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield
S10 2TN

11 November 2009

Dear Mahbub,

RE: A Qualitative Investigation of the Conceptualization of Psychosis in People of a Muslim Faith

Following the recent review of the above project I am pleased to inform you that the above project complies with Research Governance standards, and has been approved by the relevant Consortium Trust management. We now have all the relevant documentation relating to the above project. As such your project may now begin within **Bradford District Care Trust**.

This approval is granted subject to the following conditions:

- You must comply with the terms of your ethical approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform the relevant ethics committee and us immediately.
- You must comply with the Consortium's policy on project monitoring and audit.
- You must comply with the guidelines laid out in the Research Governance Framework for Health and Social Care¹ (RGF). Failure to do this could lead to permission to carry out this research being withdrawn.

¹ Details from:

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv

The Consortium members are:

- Bradford District Care Trust
- Leeds Partnerships Foundation Trust
- South West Yorkshire Partnerships Trust
- Leeds Metropolitan University
- University of Bradford
- University of Huddersfield
- University of Leeds

- You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines.
- If you encounter any problems during your research you must inform your Sponsor and us immediately to seek appropriate advice or assistance.
- Research projects will be added to any formal Department of Health research register.

Please note that suspected misconduct or fraud should be reported, in the first instance, to local Counter Fraud Specialists for your Trust. Consortium R&D staff are also mandated to do this in line with requirements of the RGF.

Adverse incidents relating to the research procedures and/or SUSARs (suspected unexpected serious adverse reactions) should be reported using **Trust incident reporting procedures in the first instance and to the chief investigator²**.

They should also be reported to:

- The Consortium R&D Department
- the Research Ethics Committee that gave approval for the study
- other related regulatory bodies as appropriate.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Changes to the agreed protocol MUST be approved by both the Trust/s and Research ethics Committee granting initial approval, before any changes in protocol can be implemented. Copies of revised documents must be provided to the R&D Office. Advice on how to undertake this process can be obtained from R&D.

Projects sponsored by organisations other than the Consortium Trusts are reminded of those organisations obligations as defined in the Research Governance Framework, and the requirements to inform all organisations of any non-compliance with that framework or other relevant regulations discovered during the course of the research project.

Once you have finished your research you will be required to complete a Project Outcome form. This will be sent to you nearer the end date of your project (Please inform us if the expected end date of your project changes for any reason).

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public. You must provide this information on request.

² SUSARS – this must be within 24 hours of the discovery of the SUSAR incident

The Consortium members are:

- | | |
|--|--|
| <ul style="list-style-type: none"> • Bradford District Care Trust • Leeds Partnerships Foundation Trust • South West Yorkshire Partnerships Trust | <ul style="list-style-type: none"> • Leeds Metropolitan University • University of Bradford • University of Huddersfield • University of Leeds |
|--|--|

If you have any queries during your research please contact us at any time. May I take this opportunity to wish you well with the project.

Yours sincerely



Mr John Hiley
Research Governance & Programme Manager

The Consortium members are:

- Bradford District Care Trust
- Leeds Partnerships Foundation Trust
- South West Yorkshire Partnerships Trust
- Leeds Metropolitan University
- University of Bradford
- University of Huddersfield
- University of Leeds



Sheffield Health and Social Care **NHS**
NHS Foundation Trust

04 November 2009

Mr Mahbub Khan
Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN

MEDICAL DIRECTORATE
Research Development Unit

Fulwood House
Old Fulwood Road
SHEFFIELD
S10 3TH

Tel: (0114) 2718804
Fax: (0114) 2716736
E-mail: shsrc@shsc.nhs.uk
www.shsrc.nhs.uk

Dear Mr Khan

Project Reference: ZK79

Full Project Title: A Qualitative Investigation of the Conceptualization of Psychosis in People of a Muslim Faith

You now have **Research Governance approval** from this office to carry out research as described in documentation you have supplied to us.

We also advise you of the following conditions which apply to all receiving Research Governance Approval through this office:

- 1. Please inform us of the actual project start date immediately you do start and at that time inform us also of the expected end date.**
2. In order to comply with the NHS Research Governance Framework, please copy this office into all future project monitoring forms that you send to the relevant Research Ethics Committee, including the "Declaration of End of Study".
3. We recommend the attached format for maintenance of your project site file to ensure all documentation is readily accessible.
4. You will also need to seek approval for every future change to protocol or project title and I suggest you do this by sending us a draft of the submission you will also have to make to the NHS REC and that you do so at the same time as that submission to the REC. See the following web reference for details:
<http://www.nres.npsa.nhs.uk/applicants/after-ethical-review/amendments/>
5. We recommend the attached amendment log in order to track amendment submissions to, and approvals from, the relevant REC and R&D office(s)
6. As Chief Investigator, you have an obligation to report all research-related adverse events directly to this office.
7. As Chief Investigator, you are reminded of your obligations in relation to the Mental Capacity Act 2005. See the following web reference for details:
www.rdforum.nhs.uk/docs/mca_guidance.doc

8. You are reminded to familiarise yourself with our partner organisation(s) Information Governance policies and procedures regarding the storage of patient-identifiable data
9. You need to seek approval from this office for any additions to your research team not already included in documentation sent to us. For this purpose, please send a short CV, preferably in the format required by the NHS REC.
10. This Research Governance approval is given on the understanding that the findings of the research will be appropriately disseminated in peer-reviewed journal(s) and to research participants and any organisations representing their interests.

We wish you every success with the project and please feel free to contact us if you need further assistance from this office.

Yours sincerely



Dr Adrian Carr
Director

Enc Site File Guidance
Amendment Log

Cc Dr Tom Ricketts
Project File



The
University
Of
Sheffield.

MM Khan <pcp07mmk@sheffield.ac.uk>

Ethics of "Conceptualisation of psychosis"

p.sheeran@sheffield.ac.uk <paschal.sheeran@googlemail.com>

19 October 2009 10:41

To: M M Khan <pcp07mmk@sheffield.ac.uk>

Cc: Georgina Rowse <G.Rowse@sheffield.ac.uk>, Josie Levick <j.levick@sheffield.ac.uk>

Dear Mahbub:

I have now obtained three reviews of your submission to the Department of Psychology Ethics Sub-committee ("A qualitative investigation of the conceptualisation of psychosis in people of a Muslim faith" [single study]). All three reviewers believed that the proposed methods and procedure conform to the BPS Ethics Guidelines.

I am therefore pleased to inform you that the ethics of your research are approved.

Yours sincerely,

Prof Paschal Sheeran
Chair, Department of Psychology Ethics Sub-committee

--

p.sheeran@sheffield.ac.uk
<http://sheeran.socialpsychology.org/>
<http://www.erosresearch.org/>

**Have you experienced any of the
following?**

**Unusual beliefs
Psychotic experiences
Hearing voices**

Are you a Muslim?

**Do you want to take part in
research?**

My name is Mahbub Khan and I am a Trainee Clinical Psychologist at the University of Sheffield and Sheffield Care Trust. I am carrying out a research project about the above experiences.

If you have answered 'yes' to the questions above then we would like to hear from you. I will be interviewing people like yourself to try and understand your experiences. If you think you might be interested or for more information contact me using any of the methods below:

E-mail: Mahbub Khan on: pcp07mmk@sheffield.ac.uk

You can phone and leave a message for Mahbub Khan or Dr Georgina Rowse with the Research Support Officer. One of us will return your phone call as soon as possible. Please note the Research Support Officer – Christie Harrison will only relay messages and will be unable to answer any queries.

Tel: 0114 2226650.

You can also send your name and address to the following address FREE. No stamp is required.

Mahbub Khan, Clinical Psychology Unit, University of Sheffield, FREEPOST NEA4492, Sheffield, S10 1BQ.

Your information will be kept confidential and will not be passed to any other service. Taking part in the research will not affect any services that you currently receive. Re-imburements will be provided.

Appendix 3b - Information sheet NHS



Sheffield Health and Social Care



NHS Foundation Trust

Psychological Health Sheffield

Sheffield Health and Social Care
Fulwood House
Old Fulwood Road
Sheffield
S10 3TH

Telephone: 0114 271 8528

Fax: 0114 271 6399

Information sheet: A Qualitative Investigation of the Conceptualisation of Psychosis in People of a Muslim Faith

(Understanding of unusual beliefs, psychotic experiences and hearing voices in people of a Muslim faith)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your GP, Care co-ordinator, friends, relatives and others as you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study hopes to build on research exploring the importance of religion and culture in making sense of unusual experiences/psychotic experiences/hearing voices. It also hopes to build on research, which give us a deeper understanding of these experiences. The study has the following aims.

- 1) Explore how people of a Muslim faith make sense of unusual experiences/psychotic experiences/hearing voices.
- 2) Explore the role of religion in understanding unusual experiences/psychotic experiences/hearing voices in people of a Muslim faith.

We hope the study will provide information to help provide better services in the future which meet the religious and cultural needs of those experiencing unusual experiences/psychotic experiences/hearing voices.

Who is conducting the study?

The study is being carried out by Mahbub Khan (Trainee Clinical Psychologist - University of Sheffield and Sheffield Care Trust) in collaboration with Dr Georgina Rowse (Clinical Psychologist and lecturer - University of Sheffield and Sheffield Care Trust), and Rasjid Skinner (Consultant Clinical Psychologist- Bradford District Care Trust).

Why have I been chosen?

You responded to an advert that you may have seen in a number of places such as an NHS health centre or you may have been passed the advert by a health professional or community development worker. You probably responded because you answered 'yes' to the three questions on the poster shown below.

1. Have you experienced any of the following? Unusual beliefs/Psychotic experiences/Hearing voices
2. Are you a Muslim?
3. Do you want to take part in research?

If you do not agree with all three questions then you probably do not want to take part any further. You must also be fluent in English, this is because of the way we are interviewing people and using the interviews.

What will be involved if I agree to take part in the study?

Taking part in this study would involve being interviewed by Mahbub Khan about your experiences. The interviews will last approximately between half an hour and one hour. We can arrange the interview at a time and place that is convenient to you. This may be at a local NHS site, at the University of Sheffield or at your home. The interview will be audio-recorded and transcribed. The interview will have several open ended questions to help you talk about your experiences and how you made sense of them. Your GP or your Care Co-ordinator will be informed of your participation in the study. They will also receive a copy of this information sheet. Reimbursements will be provided for travel expenses.

After we have completed all the interviews you will be contacted to give feedback on the themes that have been developed from all the interviews. You can choose how you would like to give the feedback. (e-mail, in writing, over the phone or in person).

Can I withdraw from the study at any time?

Yes. You are free to refuse to join the study and may withdraw at any time or choose not to answer certain questions. You do not have to give a reason for your withdrawal. You will receive the same quality of care and have access to the same services whether you join the study or not.

Will the information obtained in the study be confidential?

Anything you say will be treated in confidence, no names will be mentioned in any reports of the study and care will be taken so that individuals cannot be identified from details in reports of the results of the study. As part of the research process other people including the transcriber and other researchers will have access to the information. All of these individuals are bound by codes of confidentiality and will not pass the information on. If you say something that indicates you are at risk to yourself or others we may have to tell someone else. Before we do this we will discuss it with you. All recordings and transcripts will be stored securely. In the report of the study or any publication in research journals, all information from interviews and quotes will be anonymised.

What will happen to the results of the study?

The results of the study will be part of Mahbub Khan's Doctorate in Clinical Psychology. We hope to publish the results in a relevant research journal. All participants will be given a summary of the findings. We also hope to present the findings in professional and service user forums. You will be invited to attend any arranged presentations in service user forums.

What if I feel upset during the interview or after the interview?

Please speak in the first instance to Mahbub Khan. We will explore the best way to proceed, this may include taking a break, discussing further support you might need and the best way of accessing this. You may want to speak with your GP or your Care Co-ordinator. You can also contact Dr Georgina Rowse to discuss your concerns. Our details are at the end of this information sheet. We may also contact your GP and/or your Care Co-ordinator.

Who has reviewed this study?

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

What if I wish to complain about the way in which this study has been conducted?

If you have *any* cause to complain about *any* aspect of the way in which you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you and are not compromised in any way because you have taken part in a research study.

If you have any complaints or concerns at any point through the course of the study please contact the Principal Researcher in the first instance: Dr Georgina Rowse, on 0114 2226570.

Otherwise you can use the normal Trust complaints procedure and contact the following person: Wendy Hedland, Complaints Dept Sheffield Health and Social Care, Fulwood House, Old Fulwood Road, S10 3TH. Tel: 0114 271 8956. E-mail: complaints@shsc.nhs.uk

Otherwise you can use the normal University complaints procedure and contact the following person: Dr David Fletcher, Registrar and Secretary's Office, University of Sheffield, Firth Court, Western Bank, Sheffield S10 2TN.

Who do I contact if I have any further questions?

If you would like to ask any further questions, please contact Mahbub Khan or Dr Georgina Rowse at the Clinical Psychology Unit using one of the methods below.
E-mail: Mahbub Khan on: pcp07mmk@sheffield.ac.uk

You can phone and leave a message for Mahbub Khan or Dr Georgina Rowse with the Research Support Officer. One of us will return your phone call as soon as possible. Please note the Research Support Officer – Christie Harrison will only relay messages and will be unable to answer any queries.
Tel: 0114 2226650.

You can also write to the following address FREE. No stamp is required.
Mahbub Khan, Clinical Psychology Unit, University of Sheffield, FREEPOST
NEA4492, Sheffield, S10 1BQ.

Appendix 3c- Information Sheet 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: 0114 2226570
Fax: 0114 2226610
Email: dclinspsy@sheffield.ac.uk

Understanding of unusual beliefs, psychotic experiences and hearing voices in people of a Muslim faith.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and others as you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study hopes to build on research exploring the importance of religion and culture in making sense of unusual experiences/psychotic experiences/hearing voices. It also hopes to build on research, which give us a deeper understanding of these experiences. The study has the following aims.

- 1) Explore how people of a Muslim faith make sense of unusual experiences/psychotic experiences/hearing voices.
- 2) Explore the role of religion in understanding unusual experiences/psychotic experiences/hearing voices in people of a Muslim faith.

We hope the study will provide information to help provide better services in the future which meet the religious and cultural needs of those experiencing unusual experiences/psychotic experiences/hearing voices.

Who is conducting the study?

The study is being carried out by Mahbub Khan (Trainee Clinical Psychologist - University of Sheffield and Sheffield Care Trust) in collaboration with Dr Georgina Rowse (Clinical Psychologist and lecturer - University of Sheffield and Sheffield Care Trust), and Rasjid Skinner (Consultant Clinical Psychologist- Bradford District Care Trust).

Why have I been chosen?

You responded to an advert that you may have seen in a number of places such as an NHS health centre or you may have been passed the advert by a health professional or community development worker. You probably responded because you answered 'yes' to the three questions on the poster shown below.

1. Have you experienced any of the following? Unusual beliefs/Psychotic experiences/Hearing voices
2. Are you a Muslim?
3. Do you want to take part in research?

If you do not agree with all three questions then you probably do not want to take part any further. You must also be fluent in English, this is because of the way we are interviewing people and using the interviews.

What will be involved if I agree to take part in the study?

Taking part in this study would involve being interviewed by Mahbub Khan about your experiences. The interviews will last approximately between half an hour and one hour. We can arrange the interview at a time and place that is convenient to you. This may be at a local NHS site, at the University of Sheffield or at your home. The interview will be audio-recorded and transcribed. The interview will have several open ended questions to help you talk about your experiences and how you made sense of them. Re-imburements will be provided for your time, inconvenience and any travel expenses.

After we have completed all the interviews you will be contacted to give feedback on the themes that have been developed from all the interviews. You can choose how you would like to give the feedback. (e-mail, in writing, over the phone or in person).

Can I withdraw from the study at any time?

Yes. You are free to refuse to join the study and may withdraw at any time or choose not to answer certain questions. You do not have to give a reason for your withdrawal. You will receive the same quality of care and have access to the same services whether you join the study or not.

Will the information obtained in the study be confidential?

Anything you say will be treated in confidence, no names will be mentioned in any reports of the study and care will be taken so that individuals cannot be identified from details in reports of the results of the study. As part of the research process other people including the transcriber and other researchers will have access to the information. All of these individuals are bound by codes of confidentiality and will not pass the information on. If you say something that indicates you are at risk to yourself or others we may have to tell someone else. Before we do this we will discuss it with you.

All recordings and transcripts will be stored securely. In the report of the study or any publication in research journals, all information from interviews and quotes will be anonymised.

What will happen to the results of the study?

The results of the study will be part of Mahbub Khan's Doctorate in Clinical Psychology. We hope to publish the results in a relevant research journal. All participants will be given a summary of the findings. We also hope to present the findings in professional and service user forums. You will be invited to attend any arranged presentations in service user forums.

What if I feel upset during the interview or after the interview?

Please speak in the first instance to Mahbub Khan. We will explore the best way to proceed, this may include taking a break, discussing further support you might need and the best way of accessing this. We may contact your GP. You may also contact Dr Georgina Rowse to discuss your concerns. Our details are at the end of this information sheet.

What if I wish to complain about the way in which this study has been conducted?

If you have *any* cause to complain about *any* aspect of the way in which you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you and are not compromised in any way because you have taken part in a research study.

If you have any complaints or concerns at any point through the course of the study please contact the Principal Researcher in the first instance: Dr Georgina Rowse, on 0114 2226570.

Otherwise you can use the normal University complaints procedure and contact the following person: Dr David Fletcher, Registrar and Secretary's Office, University of Sheffield, Firth Court, Western Bank, Sheffield S10 2TN.

Who do I contact if I have any further questions?

If you would like to ask any further questions, please contact Mahbub Khan or Dr Georgina Rowse at the Clinical Psychology Unit using one of the methods below.

E-mail: Mahbub Khan on: pcp07mmk@sheffield.ac.uk

You can phone and leave a message for Mahbub Khan or Dr Georgina Rowse with the Research Support Officer. One of us will return your phone call as soon as possible. Please note the Research Support Officer – Christie Harrison will only relay messages and will be unable to answer any queries.

Tel: 0114 2226650.

You can also write to the following address FREE. No stamp is required.

Mahbub Khan, Clinical Psychology Unit, University of Sheffield, FREEPOST NEA4492, Sheffield, S10 1BQ.

Appendix 3d - Consent form NHS



Sheffield Health and Social Care



NHS Foundation Trust

Psychological Health Sheffield
Sheffield Health and Social Care
Fulwood House
Old Fulwood Road
Sheffield
S10 3TH

Telephone: 0114 271 8528
Fax: 0114 271 6399

Title of Project: **A Qualitative Investigation of the Conceptualisation of Psychosis in People of a Muslim Faith**

(Understanding of unusual beliefs, psychotic experiences and hearing voices in people of a Muslim faith)

Name of Researcher: Mahbub Khan

Participant Identification Number for this project:

Please initial box

1. I confirm that I have read and understand the information sheet dated [] for the above project and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. *Contact number of lead researcher: 0114 2226570 (please leave a message for Mahbub Khan)*
3. I understand that the interview will be audio recorded, that recordings will be securely stored and destroyed.
4. I understand that my responses will be anonymised before analysis. Anonymised comments from the interview may be used in the written report, and in research publications.

5. I understand that identifiable data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

6. I understand that if the researcher has any concerns about risk to myself or other people, he may be obliged to share this with other agencies, but he will discuss this with me first.

7. I agree to take part in the above research project.

Name of Participant

Date

Signature

Lead Researcher

Date

Signature

To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix 3e - Consent form The University of Sheffield



Department Of Psychology.
Clinical Psychology
Unit.

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

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

Telephone: 0114 2226570
Fax: 0114 2226610
Email: dclinpsy@sheffield.ac.uk

Title of Project: Understanding of unusual beliefs, psychotic experiences and hearing voices in people of a Muslim faith.
Name of Researcher: Mahbub Khan

Participant Identification Number for this project:

Please initial box

1. I confirm that I have read and understand the information sheet dated [] for the above project and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. *Contact number of lead researcher: 0114 2226570 (please leave a message for Mahbub Khan)*
3. I understand that the interview will be audio recorded, that recordings will be securely stored and destroyed.
4. I understand that my responses will be anonymised before analysis. Anonymised comments from the interview may be used in the written report, and in research publications.
5. I understand that my identifiable data may be viewed by authorised persons for monitoring and auditing purposes – by the Research Support Officer and by a representative of the local research governance office.

6. I understand that if the researcher has any concerns about risk to myself or other people, he may be obliged to share this with other agencies, but he will discuss this with me first.

7. I agree to take part in the above research project.

Name of Participant

Date

Signature

Lead Researcher

Date

Signature

To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix 3f - Interview schedule

Introduction

The interview will start with an introduction about my role and description of the research project. We will review the information sheet the participant has already received. We will then complete the consent form.

Demographic and other participant information to be obtained as follows:

Name:

Participant identification number:

Gender:

Age:

Do you consider yourself as a practising Muslim? Yes/No

Self reported diagnosis:

GP details/Contact with statutory services:

How would you like to be contacted to help validate the master list of themes?

Ethnic Group:

White

British

Irish

Other White

Mixed

White & Black Caribbean

White & Black African

White & Asian

Other Mixed

Asian or Asian

British

Indian

Pakistani

Bangladeshi

Other Asian

Black or Black

British

Caribbean

African

Other Black

Other ethnic

categories

Chinese

Other Ethnic Groups

Before starting on the interview schedule below, we will decide on the word to be used that best describes his/her experience (e.g. hearing voices, unusual experience, psychotic experience). The particular word used by the participant which best describes the experiences will be used during the course of the interview. This will be substituted where the word 'experience/s' is placed. The taping will then begin

(A) The experience/s and the impact

Q. Can you tell me about your experiences (use word of choice)?

Prompts

Can you give me an example/s of a particular situation/event during this time?

How did it affect you? (physical, psychological, religious, social, work)

How did it start?

What did you notice in the beginning?

Describe the experience?

What did other people notice?

What and who helped you cope/recover?

(B) Making sense of the experience

Q 1. Looking back at your experience how have you made sense of what has happened to you?

Prompts

How do you understand what has happened to you?

How have you come to this understanding?

What factors/people have influenced your understanding of your experiences?

Has this understanding changed over time?

Q 2. What role did your religion have in understanding your experience?

Prompts

How did your religion affect your understanding of the experience?

What affect did the experience have on your religious beliefs?

Debrief and discussing the impact of the interview

At the end of the interview I will ask if there is anything that he/she would like to talk about that has not been covered. I will also ask about whether I should ask any other questions to future participants or re-word any of the questions.

I will enquire about the emotional impact of the interview and address any issues relating to this. Then I will discuss any concerns relating to confidentiality. I will remind the participant that he/she will be contacted at a later date to help validate the masterlist of themes that have emerged and find out what is the best method of doing this (post, e-mail, phone). I will also ask the participant how they would like feedback once the research project is completed. I will finish by thanking the participant for taking part.

Appendix 3g - Transcriber confidentiality form



Department Of Psychology.
Clinical Psychology
Unit.

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

Clinical Psychology Unit
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Sheffield S10 2TN UK

Telephone: 0114 2226570
Fax: 0114 2226610
Email: dclinpsy@sheffield.ac.uk

Confidentiality Form

Type of project: Research thesis

Project title: A Qualitative Investigation of the Conceptualisation of Psychosis in
People of a Muslim Faith

Researcher's name: Mahbub Khan

The tape you are transcribing has been collected as part of a research project. Tapes may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University.

We would like you to agree:

Not to disclose any information you may hear on the tape to others,
To keep the tape in a secure locked place when not in use,
When using the tape to ensure it cannot be heard by other people,
To adhere to the Guidelines for Transcribers in relation to the use of computers, and
To show your transcription only to the relevant individual who is involved in the research project.

If you find that anyone speaking on a tape is known to you, we would like you to stop transcription work on that tape immediately and inform the person who has commissioned the work.

Declaration

I have read the above information, as well as the Guidelines for Transcribers, (appendix 8) and I understand that:

1. I will discuss the content of the tape only with the individual involved in the research project
2. I will keep the tape in a secure place where it cannot be heard by others
3. I will treat the transcription of the tape as confidential information
4. I will adhere to the requirements detailed in the Guidelines for transcribers in relation to transcribing tapes onto a computer

5. If the person being interviewed on the tapes is known to me I will undertake no further transcription work on the tape

I agree to act according to the above constraints

Your name _____

Signature _____

Date _____

Occasionally, the conversations on tapes can be distressing to hear. If you should find it upsetting, please stop the transcription and raise this with the researcher as soon as possible.

Appendix 3h – Analysis Exemplar - Wasim

| Sub-theme | Dialogue | Notes |
|--|---|---|
| <p>Traumatising</p> <p>Negative impact on relationships</p> <p>Devious and evil</p> <p>Mischievous spirits-certainty I'm radar picks them up</p> | <p style="text-align: center;"><u>INTERVIEW 6</u></p> <p>R: ... is that the best way to describe the experiences just by calling, calling them experiences, er, so can you tell me about your experiences? (.)</p> <p>P: Well, to put it in, put in, er, layman's terms, erm (.) I hear voices and I see visions, erm, voices (.) that sometimes can be very (.) traumatising to myself, they, they try to scare me, try to trick me (.) try (.) to put me against people, my family, my relatives, my neighbours, they try to confuse me and, er, and they are very devious and evil. They (.) and these voices I believe (.) are, are mischievous spirits that wander the earth and somehow I'm (.) a receptacle, antenna, radar that picks up on these, er, voices and (.) images and, er (.) s-, and they are, they have been put there (.) for whatever reason that (.) to basically wander the earth and (.) cause mischievousness.</p> <p>R: <i>Would you like to tell me a, a bit about how</i></p> | <p>Hear voices and see visions</p> <p>Traumatising, scare me, trick me</p> <p>Put me against family</p> <p>Voices are mischievous spirits</p> <p>Receptacle, antenna, radar that picks up</p> |

| | | |
|--|---|--|
| <p>Depress me traumatise me Emotional impact Psychological confuse. <i>[End of original transcript page 1]</i></p> | <p><i>these sort of (.) voices make you feel?</i></p> <p>P: Yeah, at times they can, er (.) depress me, traumatise me, er, put me down, er, confuse me (.) make me very (.) sick, er, tired (.) <u>angry</u></p> <p>R: <i>mm</i></p> <p>P: aggressive</p> <p>R: <i>When you're feeling, er, upset by these voices</i></p> | <p>Impact on emotions - depress, traumatise, confuse, angry</p> <p>Aggressive</p> |
| <p>Behaviour aggressive</p> <p>Impact on family</p> | <p><i>what sort of thoughts go through your mind?</i></p> <p>P: Oh, er, all sorts of things, I mean they, they try to put me against my parents, my fam- (.) family, I just get aggressive, sometimes I break things, sometimes I, I get, I get, I shout, swear, get abusive, erm (.) I mean where does the list end? (small laugh) I can be your worst nightmare, I can also be your best friend at times though. [.] Erm, that's (.) I think that's basically, you know, what's going on in my mind at times. [.]</p> <p>R: <i>And, er (.) when you, er, think about your experiences, how have you made sense of, er, what</i></p> | <p>Try put me against parents</p> <p>When voices (spirits) bad worse nightmare</p> |
| <p>Emotional/Behavioural impact</p> <p>Parent conceptualisation - gift</p> | <p>P: I, I can</p> <p>R: <i>happens to you?</i></p> <p>P: I think, my parents say I have a gift, I think I've got, I'm cursed, er, with these experiences which I don't really want to have (.) but, you</p> | <p>When not best friend</p> <p>Parents say gift, I'm cursed</p> |

| | | |
|--|---|---|
| <p>I'm cursed I don't want</p> <p>Want a normal life - but can't</p> <p>Loss of normal life</p> <p>Inhibits life struggle</p> <p>[Page 2]</p> <p>Compulsions-checking</p> <p>Use of diary cope with compulsions</p> <p>Constant struggle</p> <p>Not consumed by rage /hatred</p> | <p>know, voices, hear the voices or see the visions, er, I mean I'd like to live a (.) a normal life, you know, get up in the morning, go to university or college or get a job that, you know, I, live a steady life, go out with my friends, it inhibits what I can do and where I can go. [.] It's a struggle sometimes to go to places because they're in your head all the time and saying, oh don't do this, don't do that, sometimes I go to bed and they're constantly saying to me, you've left the door open or you've turned that, you've left the gas on or (.) and I have to go down and check the door and then, for some reason I get mesmerised by what they're saying and then they say, oh you've left the door open and I forget that, that I've been down to check and then I have to go again to check the door's open or locked and then so, then , you know, I have, I have to write a diary and make lists of things that I've done so I don't get confused. [.] And it's just a constant struggle to survive and keep on going and (.) to not be (.) not be consumed by the rage or the hatred or (.) or, or get sucked into their world where, where it's just endless darkness and you just see hate and (.)</p> | <p>Not want voices just want a normal life, examples, work/educati ons, inhibits normal life.</p> <p>Loss of friends, struggle to go places</p> <p>Voices saying don't do</p> <p>Check doors etc compulsions</p> <p>Coping with compulsions - diary</p> <p>Constant struggle to survive and keep on going consumed by rage/hatred, sucked in to</p> |
|--|---|---|

| | | |
|---|---|--|
| <p>Darkness of voices and visions</p> | <p>everywhere and (.) the r- rivers of blood and (.) gory visions or, you know, just, mm, you know (.) just sickening things.</p> <p>R: <i>Er, you mentioned about, er, your, your parents and how you view things. Could you tell us more about that?</i></p> | <p>world of darkness</p> |
| <p>[Page 3]</p> <p>Negative impact of relations with parents.</p> | <p>P: Well, I mean they're pensioners and they're old and I don't really want to (.) cause them any stress but they, they tend to make me, try to make me and at times they are, they're convincing (.) confuse me to believing that my parents are the enemy</p> <p>R: <i>mm</i></p> | <p>Voices put against elderly parents</p> |
| <p>Prey on paranoia</p> | <p>P: and my family are the enemies, they are the cause of, of all my problems (.) and that's why they are on top of me so (.) they prey on paranoia and (.) hate and things.</p> <p>R: <i>How have you made sense of what's happened to you? How have you understood what's happened to you?</i></p> | <p>Family are enemies - voice tells</p> <p>They prey on paranoia</p> |
| <p>Cursed, black magic, topped up</p> | <p>P: I think I, I've been cursed (.) you know, someone's done ta'weez on me (.) and basically they keep on topping it up to make it (.) carry on</p> <p>R: <i>Can you tell us more about that?</i></p> <p>P: Well, I mean (.) ta'weez is basically, you</p> | <p>Cursed, done ta'weez and topping up</p> |

| | | |
|--|---|--|
| <p>Black magic done deliberately</p> <p>No cure</p> <p>English believe exorcism, not a cure.</p> <p>[Page 4]</p> <p>Muslims endless struggle</p> <p>Scar, emotional problem when gone away</p> <p>Not 100% cured 100% normal-high bar 'normal'</p> | <p>know, what we call, er, black magic and someone has (.) done this to (.) deliberately for (.) whatever reason in the past (.) and, you know, deliberately maybe put a magnet, magnet to me so I can pick up on all these voices and all these things that are happening around [.] but unfortunately there is no cure for it because it just keeps on going on and on and on. The English believe exorcism, er, (.) is a cure for these sort of problems but, I mean I don't think, you know, I don't know what the statistics are, how many exorcisms they've done and how many people they've cured and how many haven't been cured but (.) for us Muslims that don't, I think it's just an endless struggle, I don't think I, I, I'm not, I, I've been told people that are cured but I don't know if they are pr-, you know, I've not met anybody to this day who said that he's gone through such an experience and then the experience has gone away (.) without leaving some sort of scar or emotional problems or whatever, something hanging around it. Never been hundred percent cured and hundred percent normal. [.]</p> <p>R: <i>So can you tell me about how you, you've</i></p> | <p>Black magic</p> <p>Pick up on voices like a magnet</p> <p>No cure keeps going and going</p> <p>English believe exorcism is a cure</p> <p>Don't think exorcism is</p> <p>Can't get cured</p> <p>Gone through experience, better but leave emotional problems never 100% cured and normal</p> |
|--|---|--|

| | | |
|--------------------------------|---|---|
| I'm cursed | <p><i>come to your understanding of what's happened to you? How have you come to this understanding?</i></p> <p>P: From whatever, from whatever masked around me and things [...] I, I believe that I'm cursed. [...]</p> | I'm cursed |
| Parents conceptualisation v RP | <p>R: <i>Because you talked about the black magic and ta'weez</i></p> | |
| Constant battle | <p>P: No, I, that, that (.) my (.) my parents just say, just say that, you know, you have to come to terms with it, it's not a (.) it's not a hindrance, it can be a gift if it's used in the right ways but unfortunately I have never been able to come to terms with it, I've not been able to control it, I can't switch it on or off and it just follows me around.</p> | <p>Parents say come to terms with - it can be a gift</p> <p>Can't come to terms with it</p> |

Clusters of sub-themes

The chronological set of sub-themes from the left hand margin of the transcript, were typed up as a list and printed on to paper. Each theme was then cut up. Connections between sub-themes were then identified to develop the clusters of sub-themes below. The numbers at the end of each sub-theme refer to the page number in the original transcript. This allowed for a trace of the sub-themes to the original transcript, facilitating the selection of quotes.

Cluster 1

Emotional/behavioural impact. 2
Emotional impact. 1
Depress me traumatise me. 1
Traumatising. 1
Not consumed by rage/hatred. 3
Darkness of voices and visions. 3
Psychological confuse. 1
Behaviour aggressive. 2
Compulsions-checking. 3
Impact on family. 2
Negative impact on relationships. 1
Negative impact of relations with parents. 4
Illness impact on religious practice. 21
Restriction on travel. 21
Hajj can't do, hope will be able to. 21
Need to be able to escape. 21
Loss of normal life. 2
Childhood voices. 12
Got worse university. 12
Want a normal life- but can't. 2
Normal life. 6

Cluster 2

Studying it, coming to an understanding. 13
meaning making with parents. 17
Parents conceptualisation v Research participant.5
Parent conceptualisation- gift. 2
Parents believe trouble spirits need help and aid. 6
Not reject their view but not in same league. 6
Parents help people with problems. 6
I'm cursed I don't want. 2
I'm cursed. 5
Black magic done deliberately. 4
Cursed, black magic, topped up. 4

Devious and evil. 1
Mischievous spirits-certainty. 1
I'm radar picks them up. 1
Pray on paranoia. 4
Parasite. 16
I don't understand myself. 17

Cluster 3

God wisdom test from God. 17
Test get through it and pass get reward. 17
Comparison of this life to life in next life – coping. 18.
Fraction compared to next. 19
Test from God. 19
Accept from Allah. 20
Accept from God. 19

Cluster 4

Care pathway, GP, Psychiatrist. 12
Mental Health services journey. 8
Tried to section. 12
Been lucky, no bed to put me in. 13
Loss of power. 12
Loss of power admission. 13

Cluster 5

Meds- tranquillise, dopey. 7
Vegetative state. 23
Danger of meds- side effects. 7
Meds not take problem away. 7
Not just me loads of people living vegetative lives. 9
Meds confuse psychological impact. 9
Devastating side effects of medicine. 26
Continuous meds worse. 10
Hospitals as holding facilities. 23
Lack of personal human interaction – goldfish. 8
Hospital for observation. 8
Medical model about cure. 25
Psychiatrist no cure. 10
Medication not cure. 8
Medication not helpful. 23
Only medication. 7
Medical model not working. 24
Psychiatrist say not able to cure. 24
Pharmaceutical industry. 9
Change medication. 10
We are stuck in the middle. 9
Medication limit intake. 9

Cluster 6

Alternative. 10
If meds not working what's the point. 8
Alternate ways to help these people. 25
Sharing problems. 10
Support each other. 10
Equal power dynamics in group. 11
Wisdom comes out. 11
Mutual help. 11
Normalization. 11
Do something different. 24
More money to alternate ways, more groups. 24

Cluster 7

Psychiatrist no compassion just clinical. 12
HV group felt secure to talk about voices. 10
Professionals should try and understand the person. 25
New - open to listening. 25
Professionals stuck in own line of thinking. 26
Need to understand person before helping. 26
Theory driven, medically driven. 26
Hope to change services. Change me. 27
Empathy- own family member what would you do. 27
Professional empathy. 27

Cluster 8

Can't explain constraints of interview. 19
Limit of interview. 22
Audience not want to hear. 23

Cluster 9

Not curable. 13
No cure. 4
English believe exorcism, not a cure. 4
Inhibits life struggle. 2
Constant struggle. 3
Muslims endless struggle. 5
Scar, emotional problem when gone away. 5
Not 100% cured 100% normal- high bar 'normal' 5
Constant battle. 5
Always boiling constant struggle. 16
Never goes. 16

Cluster 10

Day by day cope. 17
Unable to plan ahead. 17
Alternative ways to cope – not focus on understanding. 7
Use of diary cope with compulsions. 3
Rarely take meds. 9
Acknowledge sometimes/ rarely helpful. 9
That's a good way of explaining it. 13
Co-exist. 13
Certainty. 13
Ability to focus. 14
over the years able to make sense of voices. 14
Mish mash 14
Simultaneous events in time zone. 15
Ability focus on one subject. 16
Difficulty coping. 15
Focusing on one subject. 16
Coping switch off aggressive. 16
Get out of house and walk. 16
Build up tolerance to it. 16
Fight and cope. 9

Cluster 11

Hope of better days in this world. 20
Hope. 21
Prepared for worse and hope of recovery. 21
Do have up and downs. 20
Hope of overcoming. 20

Final table of super-ordinate themes and sub-themes

The next stage involved producing a table of the sub-themes ordered coherently with clusters given a name representing the super-ordinate themes. Super-ordinate and sub themes were selected and distinguished using a number of factors including, prevalence and richness of passages. This involved reducing and amalgamating the number of sub-themes.

| Super-ordinate theme | Sub-theme |
|-----------------------------------|---|
| Impact of experiences | Emotional/psychological |
| | Behavioural |
| | Religious practice |
| | Loss of normal life |
| Coming to an understanding | Studying it |
| | Parent conceptualisation v research participant's |
| | Cursed-black magic |
| | Radar picks up mischievous sprits |
| | Greater meaning and purpose |
| | Test from God |
| | Accepting |
| | Time comparison with life Hereafter-help coping. |
| Coping | Constant struggle |
| | Medications use as and when/rarely |
| | Simultaneous events in time zone |
| | Developed ability to focus |
| | Peaceful co-existence |
| | Get out of house and walk |

| Super-ordinate theme | Sub-theme |
|--|---|
| Mental health services /medical model | Fear of admission |
| | Devastating side effect of medication |
| | No cure |
| | Medical model not working |
| | Not help with voices |
| | Power dynamics |
| Alternatives | Lack of alternatives and lack of investment |
| | Hearing Voices Group |
| | Mutual help – shared wisdom |
| | Equality in relationships |
| Professional relationships | Need to show compassion not just clinical |
| | Try and understand person |
| | New (researcher) v experienced |
| | Empathy – own family member |