Exploring the role of religion, spirituality and meaning-making in voice-hearing populations.

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical Psychology in the Faculty of Biology, Medicine and Health.

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List of contents

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Word count

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Paper one: Systematic review

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Thesis Abstract

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical Psychology by Alexandra Clark on 03rd June 2019

The aim of this thesis was to compare and contrast voice-hearing and meaning-making in Black clinical and Black Evangelical non-clinical voice-hearers.

It is presented as three papers: (1) a thematic synthesis of the qualitative research of how religiosity and spirituality can positively impact people with psychosis; (2) an empirical qualitative study comparing and contrasting voice-hearing and meaning-making in Black clinical and Black Evangelical non-clinical voice-hearers; and (3) a paper presenting a critical appraisal and personal reflections on the research process.

In the systematic review paper, 10 studies were identified that met the inclusion criteria. Whilst studies varied in quality, they were generally medium to high quality papers. A thematic synthesis identified three key themes: (1) religion and spirituality as a positive framework for understanding psychosis; (2) religious and/or spiritual practices for managing psychosis; (3) having faith instils hope for the future. These findings highlighted how religion and spirituality can be an important part of the lives of people living with psychosis.

The second paper compared and contrasted voice-hearing and meaning-making in Black clinical and Black Evangelical non-clinical voice-hearers. Sixteen participants (eight clinical and eight non-clinical) engaged in interviews. A thematic analysis described three superordinate themes that described both groups' experiences: (1) nature of voices; (2) meaning-making and (3) the impact. These findings highlighted the similarities and differences between Black clinical and Black Evangelical non-clinical voice-hearers.

The third paper provides further explanation of both papers, reasons for the decisions made and a critical appraisal of the work carried out, considering the wider context of clinical practice, theory and empirical evidence. Personal reflections on the research process as a whole are discussed.

Declaration

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The Author

Alexandra Clark was awarded a BSc in Applied Psychology from Liverpool John Moores University in 2010. She has worked as a Research Assistant in the Psychosis Research Unit of Greater Manchester Mental Health NHS Foundation Trust. She has also worked as an Assistant Psychologist in a Community Forensic setting, as part of the Personality Disorder (PD) pathway and in an adult Eating Disorder Service before training as a Clinical Psychologist.

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Paper one – Exploring the positive ways religion and spirituality help people with psychosis

Word count excluding (tables and figures): 7,601

This paper has been formatted according to the University guidelines and will be formatted to the publication guidelines of the Journal of Psychosis (see appendix 1).

Abstract

The purpose of this systematic review was to synthesise the existing peer-reviewed qualitative literature, in regards to how people with psychosis utilise religion and spirituality to help them live with and manage psychosis. Literature searches were conducted between November 2017 and December 2017 on EMBASE, MEDLINE, PsychInfo and Web of Science databases. Study quality was appraised. Results were integrated through a thematic synthesis, with ten studies meeting the inclusion criteria. The synthesis identified three key themes: (1) Religion and spirituality as a positive framework for understanding psychosis; (2) Religious and/or spiritual practices for managing psychosis; (3) Having faith instils hope for the future. Whilst the quality of these studies was variable and only a limited number of relevant qualitative studies were found, the findings highlighted how religion and spirituality can be an important part of the lives of people living with psychosis. Future research could employ a similar systematic review but include negative symptoms of psychosis in the search strategy, which may capture more qualitative research papers to review. Clinical implications could include more training for mental health professionals in order to understand how service users make sense of their experiences and how they utilise religious and spiritual practices to help them manage and cope with psychosis.

Key words: religiosity; spirituality; psychosis; qualitative; systematic review.

Introduction

Psychosis can be defined as a set of experiences that significantly affect a person’s perception, thoughts, mood and behaviour (American Psychiatric Association, 2013). The symptoms of psychosis are usually divided into positive symptoms (e.g. hallucinations, delusions) and negative symptoms (e.g. lack of drive, social withdrawal and self-neglect) (Herz et al, 2000). Psychosis is most commonly associated with diagnoses of schizophrenia and other psychotic disorders (National Collaborating Centre for Mental Health (NCCMH), 2014). Psychotic disorders such as schizophrenia are common and affect approximately 23.6 million people worldwide (Vos et al, 2015). Psychosis can also be commonly associated with other diagnoses such as mood disorders, post-traumatic stress disorder, anxiety and personality disorder (Cornah, 2006).

Religion and spirituality can play a crucial part in the lives of people who live with a psychosis (Mohr, Brandt, Borras, Gillieron & Huguelet, 2006; Koenig, 2009; Huguelet, Mohr, Borras, Gillieron & Brandt, 2006; Gilbert & Parkes, 2011). Religion can be defined as a system of faith or worship which seeks to understand the world and includes a transcendent being or beings (Gilbert & Parkes, 2011). Spirituality tends to be less easily defined; it is often regarded as an individual process (Cornah, 2006) and can vary across different cultures. However, it is commonly referred to within the literature as a sense of connectedness to self, others, nature, or ‘God’ and as having a sense of purpose and/or a belief in a higher power (Gilbert & Parkes, 2011; Cornah, 2006).

Studies have found a high prevalence of religiosity and/or spirituality in people with psychosis across various countries, including North America (Tepper, Rogers & Coleman, 2001) and Europe (Pieper, 2004). Nolan et al, (2012) reported that as many as 91% of participants in South-eastern United States with a diagnosis of schizophrenia engaged in private, religious or spiritual activities, with 68% reporting participation in public religious services or practices. However, until recently, research investigating religion in the context of psychosis has focused preferentially on the negatives by examining symptoms (e.g. hallucinations and delusions) with religious themes or content, which are often seen as a sign of “illness” (Siddle, Haddock, Tarrier & Faragher, 2002), rather than a helpful framework in which to understand psychosis. Furthermore, mental health professionals appear limited in their awareness and are often not aware of the importance of religion and spirituality in people with psychosis (Huguelet et al, 2006), and therefore religion and spirituality are often neglected in the treatment of people with psychosis (Koenig, 2009) which means a potential source of strength is underutilised (Blanch, 2007).

There has been a growing interest in the positive role of religion and spirituality in individuals with psychosis (Rabiee & Smith, 2014; Mohr et al, 2006; Mohr, Gillieron, Borras, Brandt, Huguelet, 2007; Huguelet et al, 2006). A quantitative literature review by Mohr and Huguelet (2004) found that religion played a central role in the process of helping participants make sense of self, and in the process of recovery. Specifically, of the papers included in the review, some of the participants had felt supported by their faith communities, uplifted by spiritual activities and felt strengthened by their belief system, however, for others it had been a negative experience, which contributed to deterioration in their mental health. Exploring how people made sense of their experiences has not been thoroughly explored and may add more insight to the important part religion can play in the lives of people with a diagnosis of psychosis. Mohr et al (2006) conducted a quantitative literature review to analyse the strengths and weaknesses of religion and spirituality in mental health difficulties, and identified that three quarters of studies found religious people to have better mental health than those who were not religious. For those with mental health difficulties, including psychosis, religion and/or spirituality can provide a useful framework to understand and make sense of their experiences. Furthermore, the review suggested that religion and spirituality need to be integrated into mental health services and offered guidance on how this could be implemented. A more recent quantitative literature review by Koenig (2009) concluded that the evidence base can vary as to whether religion and spirituality can have a positive impact on mental health difficulties including psychosis, with religious beliefs and practices often entangled with psychotic experiences, thus making it difficult to determine the usefulness of such beliefs and practices. It is acknowledged that whilst both of the literature reviews (Mohr, 2006 ; Koenig, 2009) highlighted insight into potential benefits of religiousness and spirituality, neither were systematic reviews, nor did they include any qualitative research, which is important for understanding individual experiences. Whilst it is clear that there is evidence to suggest religion and spirituality can be utilised as a helpful framework in psychosis, there is also evidence to suggest the opposite. For some people, religion induced spiritual despair and increased psychotic and general symptoms (Mohr et al, 2006), whilst other people felt overburdened by spiritual activities and rejected by their communities (Mohr and Huguelet, 2004).

Religious coping is a concept that has been developed to show how individuals use religious practices such as attending church, praying, and watching religious TV, to help them make sense of and cope with stress (Pargament , Koenig, Tarakeshwar, Hahn, 2004; Mohr et al, 2006; Pargament, Koenig and Perez, 2000). Nolan et al (2012) conducted a cross-sectional quantitative study that investigated the relationship between positive and negative religious coping and quality of life in people with a diagnosis of schizophrenia. Nolan et al (2012) found that positive religious coping was associated with higher levels of quality of life. A qualitative component to Nolan et al's (2012) research may have offered further insight into how religious coping impacted upon quality of life, including the psychological, social, physical and behavioural components of quality of life. An additional quantitative study by Huguelet et al (2006) also highlights that individuals with psychosis valued spirituality in everyday life more than the general population, but engaged less in community religious activities, similar to the findings of Nolan et al (2012). One reason for this could be that social isolation is often common amongst people with psychosis (Green et al, 2015), and therefore it is not surprising that they engaged less in community-based religious activities. Given this, it seems likely that qualitative research would help provide a much greater understanding of the mechanisms of the positive impact of religious and/or spiritual coping.

In summary, whilst there is evidence to suggest that religion and/or spirituality can hinder people with psychosis (Mohr & Huguelet, 2004; McCarthy-Jones et al, 2013), there is also growing evidence that, for many, it is an important part of making sense and coping with psychotic experiences (Grover et al, 2014; Mohr et al, 2006; Mohr & Huguelet, 2004; Nolan et al, 2012).

A recent qualitative study by Heffernan, Neil, Thomas and Weatherhead (2016) explored the role of religion in recovery from psychosis. Heffernan et al (2016) found both positive and negative aspects to religiosity in recovery from psychosis. Several important religious processes and mechanisms for recovery in people with psychosis were found, including the use of religious practices, having guidance for living, a choice of control over life, relating to others, enhancing psychological well-being and making sense of experiences. The study provided qualitative evidence on how religion can aid recovery but also highlighted that for some participants, religion hindered their recovery. It is acknowledged that there is little qualitative research available that focuses more specifically on the positive ways in which religion and/or spirituality can benefit people with psychosis (Kovess-Masfety et al, 2018). To fully understand the interrelationship of psychotic experiences and religiosity and how it can be useful, further qualitative research is needed (Kovess-Masfety et al, 2018). Furthermore, as spirituality is unique to the individual, it tends to lack generalisability and pose a difficulty for quantifiable, traditional scientific methods (Cornah, 2006). Therefore, applying qualitative research in the positive area of religion and spirituality can provide further detail on the multiple ways in which religion and spirituality can positively influence the experiences of psychosis. It can also offer a richer knowledge base for understanding how this may be applied clinically and inform best practice. To the best of our knowledge, no other systematic literature review of the qualitative literature in this area has focused specifically on the positive role that religion and spirituality can play in the lives of people with psychosis. The current systematic review aims to bridge the gap in the literature by synthesising the positive impact that religion and/or spirituality has on managing psychosis.

Method

The review followed the guidance on the conduct of thematic synthesis in systematic review guidelines (Popay et al, 2006).

Search strategy and study selection:

On 13th of December 2017, the first author (AC) conducted an electronic database search of PsychInfo, EMBASE, MEDLINE and Web of Science. Each database was searched separately using the search string (Psychosis OR psychoti* OR hallucinat* OR hearing voices, schizophrenia OR delusion* OR positive symptoms) AND (Religio* OR spiritual* OR faith OR God) AND (qualitative OR discourse analysis OR thematic analysis OR interpretive phenomenological analysis OR phenomenological analysis OR grounded theory OR content analysis OR ethnograph*). The synonym function for each database was also used to further expand the results of the database search and identify relevant studies. Searches were limited to human and English language research. Screening of the references of eligible studies and inspection of studies' citations were also conducted to identify any additional eligible data.

MeSH terms were used as part of the search strategy as a way of expanding the search terms and capturing more potentially relevant reports. The following MeSH terms were used: for Psychosis (Psychosis, experimental psychosis, depressive psychosis, schizoaffective psychosis, cocaine psychosis, cannabis induced psychosis, intensive psychosis, acute psychosis, affective psychosis, manic psychosis, paranoid psychosis), for Psychotic* (psychotic) for Hallucinat* (Hallucinations, Hallucination), Hearing Voices (auditory hallucinations), for Schizophrenia (catatonic schizophrenia, affective disorders, treatment-resistant schizophrenia, paranoid schizophrenia, schizophrenia spectrum disorder), for Delusion* (precatory delusions), Positive symptoms (positive symptoms) for Religio*(Religion, spirituality, religious beliefs, faith), for spiritual* (spirituality, religion, well-being, religious beliefs, faith, religious practices) and for Faith (Faith, faith healing), and finally for God (Religion, spirituality, religious beliefs, faith).

Inclusion criteria and exclusion criteria

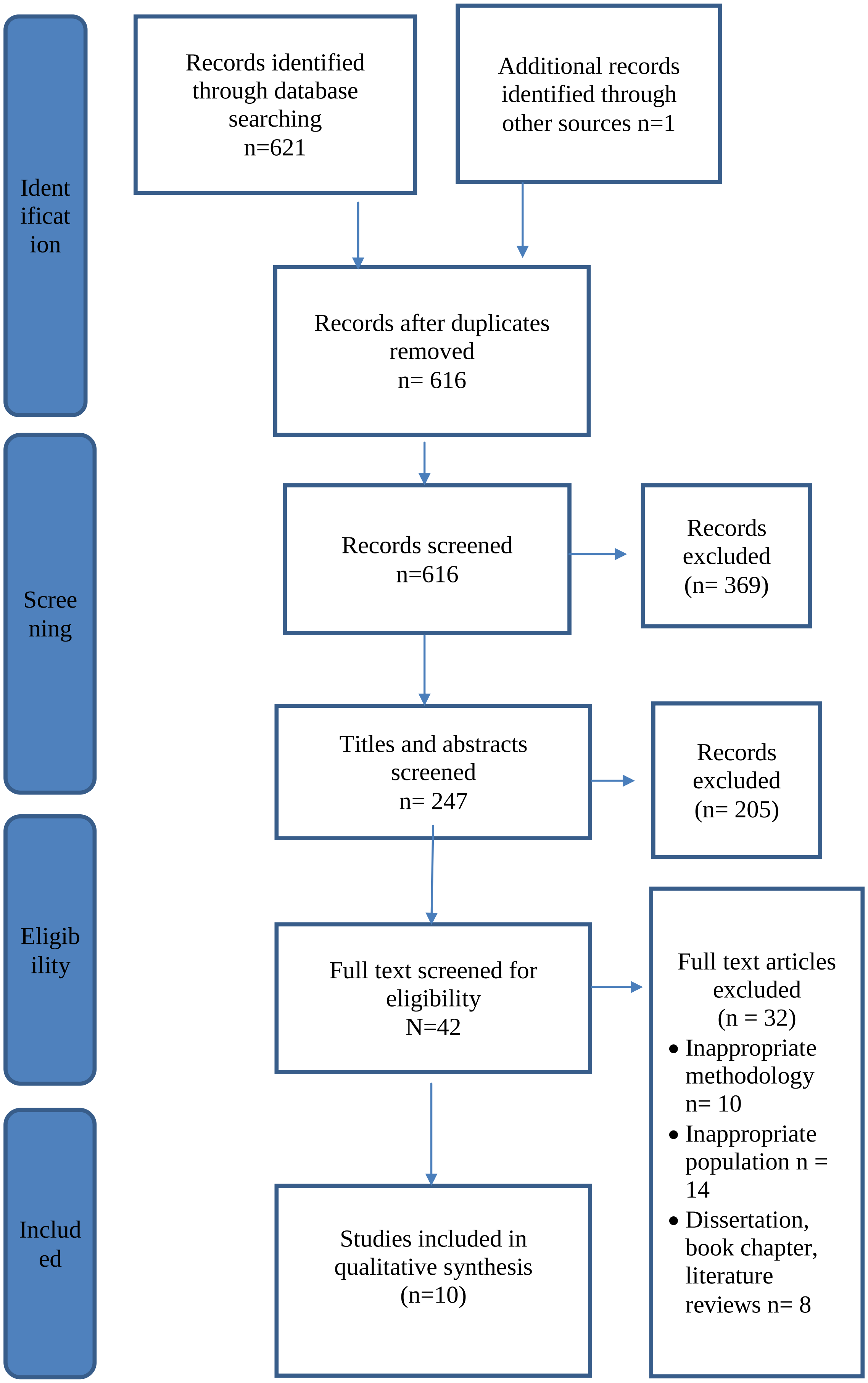
Papers were included if they reported on the following: (1) The study considered adults over the age of 18 years of age, with no upper age limit; (2) The sample consisted of participants with either confirmed (e.g. via case notes reviews or diagnostic interviews) or self-reported lifetime diagnoses of schizophrenia or related psychotic disorders; (3) The paper was published in a peer-reviewed journal and available in the English language; (4) The study employed qualitative data collection methods (e.g. in-depth individual interviews, focus groups and case studies) and qualitative analytic procedures (i.e. thematic analysis, grounded theory, etc.); (5) The study reported qualitative findings relevant to understanding the views, attitudes and perceptions of research participants on the role of religious and/or spiritual beliefs and/or practices, that impacted helpfully on their ability to manage and cope with psychotic experiences.

Papers were excluded if they reported on the following: (1) The study considered adolescents and children (under the age of 18); (2) The study reported mixed methods or quantitative findings; (3) The same data was reported in fuller form in another paper.

Screening and selection

The titles and abstracts of all identified studies were screened for relevance against the inclusion and exclusion criteria. The full text of studies was reviewed to assess eligibility. In relation to people living with psychosis, the following areas were reviewed; the usefulness of religious and/or spiritual ways of coping, and including religious and/or spiritual practices (attending church, prayer, meditation, mindfulness, yoga). An article was included when the researcher and lead supervisor (FV) agreed that it satisfied all eligibility criteria (see figure 1).

Figure 1: The PRISMA flow diagram of eligible studies (Moher et al, 2009)



Data extraction

Data was extracted from the original papers by including the following: study design; sample size; participant characteristics; religious and/or spiritual background and/or practices; self-reported or diagnosis of psychosis or schizophrenia; type of qualitative methodology; methods of analysis; main findings in relation to the research question; theme and direct quotes and limitations.

Quality assessment

The quality of included studies was examined using the Critical Appraisal Skills Programme (CASP) (see appendix 2) tool for evaluating qualitative research (Public Health Resource Unit, 2006). The CASP is frequently used within qualitative research to assess the validity of qualitative research studies. Each paper was appraised using ten items (items one to ten) reflecting specific quality dimensions which included the following: a clear aim of the research; the appropriateness of the qualitative methodology; the research design and the recruitment strategy; whether the data collection addressed the research aims; whether the relationship between researcher and participants had been addressed; ethical considerations; whether the data analysis was sufficiently rigorous; whether there was a clear statement of findings; and how valuable the research was. The items were categorised as either yes, no or can’t tell, based on the description and ‘hints’ provided in the CASP, which contributed towards the quality assessment of the included studies. The initial quality assessments were carried out by AC, with all of the papers independently assessed by a colleague external to the research team (see table 1).

The Cohen’s K was run to determine whether there was an agreement between the researcher and colleague in the quality of the eligible papers that were included in the review. There was a substantial agreement (McHugh, 2012) of, $k = .683$, $p<.001$.

Table 1: CASP quality assessment categories across the included studies

CASP Quality Assessment

	Nixon et al (2010)	Yang et al (2011)	Virdee et al (2016)	Smith & Suto (2012)	Hustoft et al (2013)	Smith & Suto (2013)	Islam et al (2015)	Hanevik et al (2017)	Wagner & King (2005)	Chan et al (2015)
Item1 Clear aims	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 2 Qualitative methods appropriate	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 3 Is it worth continuing	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes
Item 4 Recruitment strategy appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes
Item 5 Data collected adequately	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes
Item 6 Relationship between research and participant addressed	Can't tell	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes
Item 7 Ethical issues considered	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes
Item 8 Data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 9 Clear statement of findings	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Item 10 Valid research	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Methods of synthesis

Results were integrated through a thematic synthesis (Lucas, Baird, Arai, Law & Roberts, 2007; Thomas & Harden, 2008), as a way of synthesising findings from multiple studies and developing overarching themes. Thematic synthesis typically involves selecting and ordering findings, and illustrating data with words, with text and tables to explain findings (Lucas et al, 2007). The main components of thematic synthesis are: developing a preliminary synthesis of the findings of included studies; exploring relationships in the findings; and assessing the robustness of the synthesis produced (Lucas et al. 2007). Thematic synthesis tends to regroup the data from the studies and then summarises the findings with thematic headings (Dixon-Woods, Agarwal, Jones, Young, Sutton, 2005).

An integrative method of data extraction was employed, drawing on a thematic synthesis approach (Lucas et al, 2007). A step-by-step guide was followed in accordance with Thomas and Harden's (2008) recommendations; firstly, the data were extracted from each paper and organised based on a data extraction protocol into the following: study sample, recruitment procedure, type of analysis, main findings, relative themes and quotes, which all aided the interpretation of the findings. Thematic synthesis was deemed appropriate in order to summarise the diverse findings reported in the included studies, which allows for the synthesis of a heterogeneous sample. Each study was then read in detail numerous times to become familiar with the data. Narrative summaries were then developed in order to aid further analysis and help conceptualise each study. Key concepts and themes relevant to the research question, along with direct quotes from participants, were extracted from the results section of each study. These data then served as a basis for the analysis. The quotes from each study were re-read, compared and contrasted, and then grouped together in terms of similar themes across different quotes. These groups were then given thematic headings in order to represent the content, which developed the three key themes. The organisation of the themes represented a hypothetical chronological progression (White, Woodfield, & Ritchie, 2003). This started with past experiences, moving on to current struggles and then attitudes towards the future. The epistemological stance adopted when undertaking the synthesis was a critical realist position (Collier, 1994), which states that our knowledge of reality is mediated by ones beliefs and perspectives (Spencer, Ritchie, Lewis, & Dillon, 2004).

Methodological rigour

The regrouping of quotes and theme headings was first developed by the first author. In order to maximise the objectivity of the findings, whilst acknowledging that subjective bias may always be present (Tobin & Begley, 2004), the theme headings and content were checked by the lead supervisor (FV). Any uncertainty or further clarification regarding the development of these headings was discussed until a consensus was reached. The validity of the analysis and synthesis was addressed by the inclusion of original quotations to support each theme heading and external validity was checked against the theoretical and empirical literature. At each point within the review, there was consideration of the potential impact of training and personal beliefs in the process.

Reflexivity

Reflexivity is an important part of qualitative research (Reid, Brown, Smith, Cope & Jamieson, 2018). Le Gallais (2008) suggests that having an awareness of one's own subjectivity and acknowledging it with qualitative research enhances trustworthiness, transparency and authenticity and may add to the richness of the interpretation. Reflexivity was an important part of ensuring that the researcher was aware of potential subjectivity. The researcher maintained reflexivity throughout the project by discussing reflections with the lead supervisor (FV), to help gain perspective and minimise subjective bias when interpreting the data. The themes and analysis were checked throughout the process with the lead supervisor (FV) to ensure trustworthiness and authenticity of the interpretation.

Results

Study characteristics

The synthesis incorporated the findings from ten papers with 163 participants in total. The participants' age ranged from 18 to 69 years of age. Nine out of the ten included papers provided gender demographics (except Virdee et al, 2016); 53.79% of the participants were female, 46.21% were male. Table 2 provides a detailed breakdown of the characteristics of the included studies. Of these studies, four were conducted in Canada, two in Norway, one in the UK, one in Taiwan, one in Brazil, and one in Hong Kong. Seven papers focused specifically on various aspects of religion and/or spirituality in people with a diagnosis of schizophrenia and/or psychosis (Nixon, Hagen & Peters, 2010; Virdee et al, 2016; Smith & Suto, 2012; Hustoft, Hestad, Lien, Moller & Danbolt, 2013; Smith & Suto, 2013; Hanevik et al, 2017; Chan, Lo & Chen & Ho, 2015). The primary research questions in the other papers were not directly linked to the research question of the systematic review, but their results did, however, have relevant findings and were included (Yang, Narayanasamy & Chang, 2011; Islam, Rabiee & Singh, 2015; Wagner & King, 2005).

Table 2: Study characteristics

Paper	Country	Study aims	Number of participants	Sample demographics Age/Gender	Study population	Religious/spiritual background	Data collection	Theoretical approaches to analysis
Nixon et al (2010)	Western Canada	To describe the experiences of persons self-identified as having had psychotic experiences, who had perceived their psychotic experiences to be transformative	6	4 female, 4 male, 25-60 years	18 years + previous psychotic experiences especially if they had some spiritual and/or mystical experiences to them.	Yoga, meditation, & spiritual path. Shamanism, reiki, spiritual healing, mindfulness, Buddhism	Interview	Interpretive phenomenological analysis
Yang et al (2011)	Taiwan	To explore how hospitalisation and the diagnosis of schizophrenia have an impact on Taiwanese people	22	12 female, 10 male, 29-63 years	20 years + schizophrenia and hospitalised in long-term rehabilitation unit.	7 Buddhists, 4 multi-religion (Buddhism & Taoism), 6 atheists, 5 Catholics	Focus groups/ semi structured interviews	Thematic analysis
Virdee et al (2016)	Canada	To explore the construction of community through faith spaces, religion, and spirituality for persons with psychosis	31	mean age range: 45 years[2]	Diagnosis of schizoid or psychosis with spectrum major mental illness	29/31 participants described belonging to various religious groups	Focus groups	Grounded theory

Smith and Suto (2012)	Vancouver	To explore the meaning of religion and/or spirituality for people living with a diagnosis of schizophrenia.	9	4 female, 3 male, 39-54 years	19 years + diagnosis of schizophrenia	Existential, mixed religions, religious & political, theistic & mystical, religious, theistic & mystical, language phenomenological, existential, mystical, theistic, religious & cultural	Interviews	Interpretive phenomenological analysis
Hustoft et al (2013)	Norway	To deepen the understanding of what characterises spirituality in patients suffering from schizophrenia	6	3 female, 3 male, 19-54 years	Diagnosed with either/and paranoid, schizophrenia or unspecified schizoaffective disorder,	Participants either said they believed in God or a supreme power	Interviews	Systematic text condensation
Smith and Suto (2013)	Canada	To explore the experience of spiritual conversations for patients on acute psychiatric units	7	2 female 5 male age early 20's to late 60's[3]	Currently 'psychotic' but in contact with reality	Christian, spiritual, mindfulness & Mormon	Interviews & focus groups	Interpretive description analysis

Islam et al (2015)	UK	To examine the cultural appropriateness, accessibility, and acceptability of the Early Intervention (EI) for Psychosis Services	22	11 female 11 male age range 18-35 years	BME ethnic mix, current or past Early intervention in psychosis user.	Muslim, Christian, none and other	Focus groups	Thematic analysis
Hanevik et al (2017)	Norway	To explore the significance of religiousness for patients suffering from first-episode of psychosis	18	Not included by the author[4]	First episode of psychosis	First episode of psychosis	Semi-structured interviews	Thematic analysis
Wagner & King, (2005)	Brazil	To examine the perceptions of users' needs of people with non-affective psychosis	24	12 female, 12 male[5]	Purposive sample of people with Schizophrenia and other psychotic disorders defined by ICD-10	Not included by the author[1]	Focus groups	Content analysis
Chan et al (2015)	Hong Kong	To explore the concept of peacefulness among	18	8 female 10 male mean age: 24.8	Participants who were not inpatients, who were stable or	10 no religious background, other 5 PPT's Christian,	Interview	Ground Analysis

	schizophrenic patients		years[6]	early stage of illness	Buddhist, Chinese folk religion

[1] Please note: there was missing data provided by some of the studies.

[2] Virdee et al (2016) did not provide information of participant gender, or specific age ranges (only mean age) and no detail was given on what religious group’s participants affiliated themselves with, therefore this information could not be included.

[3] Smith and Suto (2013) did not provide specific age ranges for their participants; therefore this information could not be provided.

[4] Hanevik et al (2017) did not provide participant demographics, therefore this information could not be provided.

[5] Wagner & King (2005) did not provide specific age ranges for their participants; neither was the religious and/or spiritual backgrounds of their participants given and so this information could not be provided.

[6] Chan et al (2015) did not provide participants’ age range; only mean age, so this information could not be included.

Whilst most studies (n=7) did not purposefully sample participants from a particular ethnic background (Nixon et al, 2010; Virdee et al, 2016; Smith & Suto, 2012; Hustoft et al, 2013; Smith & Suto, 2013; Hanevik et al, 2017; Wagner & King, 2005; Chan et al, 2015), Islam et al (2015) explicitly sampled participants from a BME ethnic background, and Yang et al (2011) from a Taiwanese ethnic background. Seven papers considered participants with a diagnosis of schizophrenia, paranoid or schizoaffective disorder, with two papers including participants with early onset of psychosis (Islam, et al, 2015; Hanevik et al, 2017), and one paper included people who have had psychotic experiences in the past, particularly if these experiences were deemed as transformational by the participant (Nixon et al, 2010).

In terms of the religious and spiritual background of respondents, nine papers included participants from either and/or a religious and/or spiritual background (Nixon, et al, 2010; Yang et al, 2011; Virdee et al, 2016; Smith & Suto, 2012; Hustoft et al, 2013; Smith & Suto, 2013; Islam et al, 2015; Hanevik et al, 2017; Chan et al, 2015). These religious and spiritual beliefs varied amongst the studies but included religions such as: Buddhism, Taoism, Christianity, Mormonism or Islam (see table 2) with various spiritual beliefs such as a belief in God or a supreme power, existentialism, theism and/or mystical beliefs and spiritual practices. The spiritual practices included in the studies were not secular but embedded in ancient Eastern traditions such as yoga, meditation, shamanism, reiki, spiritual healing, mindfulness and prayer.

However, one paper in particular did not define the participants' religious or spiritual background (Wagner & King, 2005), as religion and/or spirituality were not part of the aims of their study. This paper was still included in the review, as a secondary theme 'need for spirituality' had emerged as part of the study's findings and was therefore relevant to this systematic review.

The majority of studies (six out of ten) included in this systematic review collected data via individual semi-structured interviews, whilst the rest used focus groups, with one study combining both. The qualitative analytical strategies that were used within the primary studies tended to vary, but included interpretive phenomenological analysis (IPA), thematic analysis (TA), content analysis, systematic text condensation and interpretive description analysis (see table 2).

In terms of study quality, CASP quality ratings varied but the included studies ranged between medium to high-quality papers. Quality ratings, in conjunction with study and participant characteristics, aided the interpretation of themes. The three key themes identified from the research synthesis were supported by studies from across the range of CASP quality ratings.

Key themes

Three key themes were identified from the synthesis; 'Religion and spirituality as a positive framework for understanding psychosis, 'Religious and/or spiritual practices for managing psychosis', and how 'having faith instils hope for the future'. The themes are illustrated in a hypothetical 'chronological order'. First, participants described making sense of their experiences within the context of religion and/or spirituality, which they perceived as a useful explanatory framework. Second, participants described the ways in which they utilised religious and/or spiritual practices to manage the symptoms of psychosis. Third, participants described how having a religious faith instilled hope for the future. Direct quotes from the primary studies are included when possible, to illustrate relevant patterns of findings. However, for the theme ‘faith instils hope for the future’, only two papers (Hanevik et al, 2017; Chan et al, 2015) included participants’ direct quotes. The other two (Wagner and King, 2005; Hustoft et al, 2013) did not, therefore direct author quotes are illustrated instead. The extent to which the three themes are represented across the papers is shown in appendix (3).

Theme 1: Religion and spirituality as a positive framework for understanding psychosis

From the included papers, three described how participants used religion and/or spirituality as a positive framework in which to understand their experiences (Islam et al, 2015; Yang, et al, 2001; Hustoft et al, 2013). It is worth noting that Yang et al’s (2001) themes were limited in relation to the aims of this systematic review, which could be due to the fact that their study aimed to explore the impact of hospitalisation, not religion and spirituality. Also, Islam et al’s (2015) study only had one secondary theme that was relevant to this systematic review. Nevertheless, a theme was developed that illustrated how religion and spirituality was a positive framework in which to understand psychosis and helped participants make sense of their experiences.

Participants described how having religious perspectives of their diagnosis helped them make sense of their experiences; it gave them a “*framework in which to understand their symptoms”* (Islam, et al, p8):

“Religion is a method for me to commit my soul to God. Every day I read Buddhist Scripture which makes you realise why I suffer from the illness, and it gives me a new direction in life. I view those difficulties in a positive way and how I get along with people. I finally feel peace and inner quietness. Although in the hospital I feel lonely, I usually

think it is a practice in Buddhism. My mother told me that I have to do some good deeds for others; it could accumulate Kong De (darshan) for me and others. I try my best to do that, because I know it is a way to diminish Karma. When one day I leave this world, my soul will go to Nirvana (the paradise in Buddhism) and I will no longer suffer from schizophrenia" (Yang et al, p 363).

Suffering was a part of living with psychosis for many of the participants and for this group of participants; it was understood as a necessary part of their religious and/or spiritual journey:

"He said that his suffering was necessary in becoming who he is today. He found comfort in the belief that God just wants the best for him, and he thinks that his anxiety also guides him through life" (author's quote used, Hustoft et al, 2013, p.134).

From the quotes above, it appeared that participants almost found comfort in knowing that the distress they experienced was in fact part of a larger spiritual process and a sense of appreciation was present for some. Participants went on to describe how religious and/or spiritual practices helped maintain and deepen this framework.

Theme 2: Religious and/or spiritual practices for managing psychosis

Participants across five studies (Nixon et al, 2010; Yang et al, 2001; Virdee et al, 2016; Smith & Suto, 2012; Smith & Suto, 2013) described how religious and/or spiritual practices helped them live with and manage psychosis. Participants described living with and managing symptoms of psychosis through various religious and/or spiritual perspectives and engagement in religious and/or spiritual practices. However, there are limitations within this theme, for example, Yang et al's (2001) paper lacked richness and depth of relevant quotes, as did Suto and Smith's (2013), with only one theme being relevant to this systematic review. Virdee et al's (2016) paper lacked quality, in regard to providing information on the participants' demographics, and failed to give a detailed account of how the analysis was conducted, as did Nixon et al's (2010) study. However, one of the included papers in this theme (Suto & Smith, 2012) did have a good overall quality and therefore it was still felt that this theme was valid.

Religious and spiritual practices are described, in this context, as practices with a religious and/or spiritual component that participants engaged in. These are often either internal practices such as meditating, mindful activities, practicing yoga asana, reading scriptures from a religious book, or practices that participants engaged with externally, such as attending church. Participants engaged in either/or both of these internal or external religious and/or spiritual practices, to help them cope and manage with psychotic symptoms and the distress often associated with these:

"If I need that extra lift, I'll go to church… When I found myself here (in Canada) by myself and going through a lot of difficulties…I had a need to involve myself going to church, so I did. And then I liked it, it felt good, so I kept going" (Virdee et al, 2016, p.1084).

Participants described key aspects of various religious and spiritual belief systems. For example, participants described how mindfulness had helped them manage and cope. However, mindfulness within this context is based on an ancient Eastern perspective rather than a secularised, ‘westernised’ practice more commonly found in mental health services (Bonelli, & Koenig, 2013). Participants’ narratives suggested that holding these belief systems seemed to be linked to a range of potentially adaptive perspectives and attitudes towards symptoms and difficult life experiences, including detachment, letting go of judgements and having an appreciation for life, which seem to be a fundamental part of their religious and/or spiritual belief system:

“*I slowly began to be free of my judgements, especially judgements of my symptoms. I’m starting to not chase as much for understanding of this (psychosis). I noticed after a few months, my mind wasn’t as crazy as it was and I started to understand, not as much understand, but sense and intuitiveness of things. Things started to clear a bit*” (Nixon et al, 2010, p.537).

Other participants described mindful approaches that are integrated through a Buddhist religion and how this had helped them be in the present moment, and not be fixated with the future or the past:

“Right, so then it’s back to the moment by moment appreciation of life, appreciation of the moment rather than projecting ahead in fear or worry about the past catching up or….. Because that would have prohibited me from coming today (to the interview) they wouldn’t have been in the moment” (Nixon, et al, 2010, p.538).

This way of thinking had helped keep participants grounded in the present moment whilst others talked about ‘centring’, a technique developed to also help to ground and anchor attention in the present moment to cultivate a sense of peace and help establish emotional regulation:

"(After an emotional moment) I think I am okay now. I have got to find my centre. You have heard that expression? I have got to find that centre. See that is what I think the (spiritual communities) are offering is centring… the centre is something that your equilibrium. You are not too emotional about this or that... Feeling centred, not too angry, not too melancholy" (Smith & Suto, 2012, p.81).

In summary, engaging in various religious and/or spiritual practices helped people manage with psychosis. In the third theme, participants described how having a faith, whether religious or spiritual, could instil hope for the future.

Theme 3: Faith instils hope for the future

Four of the papers (Hustoft et al, 2013; Hanevik et al, 2017; Wagner & King, 2005; Chan et al, 2015) had found that faith in God or a higher power was an important factor in helping people with psychosis manage in times of need and also a key factor in instilling hope for the future. However, this theme needs to be interpreted with caution, as two papers (Hanevik et al, 2017; Chan et al, 2015) included direct quotes of participants, whilst the other two (Wagner and King, 2005; Hustoft et al, 2013) did not. Therefore, direct author quotes are illustrated instead, which has contributed to an overall lack of richness and depth within the theme. Participants described various ways in which having faith in God or a higher power would help them, including finding a cure for their diagnosis, preventing them from committing suicide in times of crisis and feeling as though God can take care of their problems:

"*I worked as an assistant at a summer camp, but I could not sleep. The first few nights I slept very little on the fourth day I felt pretty bad… Then a friend said to me that "you know that you can rest in God's arms", and I just said YES, and then I felt that I could just leave myself in the arms of God and just rest. I felt well and safe and I could sleep again*". (Hanevik et al, 2017, p154).

It appeared that having a faith instilled a purpose for living and hope for the future. This seemed an important concept, especially for people living with psychosis who often experience low mood and suicidal ideation as a result:

"[direct quote from author], Elmer was influenced by his grandmother, who taught him to pray. As a grown-up, he became a believer in God when for the first time he was admitted to hospital for mental health treatment, about 20 years ago. This he takes as a sign that God wants him to live. Without his faith he told us, he would have killed himself" (Hustoft et al, 2013, p.133).

Discussion

This systematic review aimed to collect and synthesise the qualitative evidence on the positive impact religion and spirituality can have on managing psychosis. Firstly, the key findings suggested that religion and spirituality can be a useful framework for understanding psychosis. Whilst this evidence supports existing literature (Hefferman, Neil, Thomas & Weatherhead 2016; Mohr & Huguelet 2004; Mohr et al, 2006; Gilbert &

Parkes, 2011), this systematic review found how it helped. Secondly, religious and spiritual practices were seen as a valuable resource for managing psychosis, with participants describing a variety of ways that they utilised religious and spiritual practices. These findings support existing evidence that highlights the importance of religious coping in the lives of people with psychosis (Pargament, Koenig and Perez, 2000; Nolan et al 2012). Furthermore, this systematic review found how these practices helped people manage psychosis. Lastly, the review found how having a faith in God or a higher power was an important factor in times of need and helped people with psychosis manage, which also supports the religious coping literature (Pargament, 2011; Pargament, Koenig and Perez, 2000; Nolan et al, 2012). In addition to supporting these previous findings, this systematic review added to the evidence base by providing detail regarding the specific ways in which religion and spirituality can be a useful tool in helping people manage with psychosis, which will be described in more detail below.

The participants in this systematic review described how suffering was an inevitable part of psychosis, and described almost a sense of acceptance that their experiences were part of a larger purpose, which had been comforting in times of need. This evidence appears to go beyond the current literature (Hefferman, Neil, Thomas & Weatherhead, 2016; Mohr & Huguelet, 2004; Mohr et al, 2006; Gilbert & Parkes, 2011) in describing how these religious and spiritual frameworks can help people make sense of and tolerate distressing experiences that are linked to psychosis. Such evidence may have important clinical implications, for example, clinicians could explore the various meanings associated with distressing psychotic experiences, without necessarily assuming that it is an unwanted experience, in line with established approaches such as Cognitive Behavioural Therapy

(CBT) (Morrison, 2001), which emphasise the importance of interpretation in understanding distress in psychosis.

Religious and spiritual practices for managing psychosis was the most in-depth and rich theme in this systematic review. Religiosity is said to be common, with almost 80% of the world's population identifying with a religion or faith group (Pew Research Centre, 2012). Koenig's (2009) quantitative review argues that the high prevalence of religiosity in the general population may be due to the perceived benefits of religious coping, which can be a powerful coping mechanism for many (Koenig, 2009) and provides a useful framework in which to make sense of experiences, encourages autonomy over one's life and provides a code of ethics to live by (Koenig, 2009). It may not be surprising then, that for the participants in this systematic review, religious coping was an important part of life. These results go further than Koenig's (2009) quantitative findings, by describing how religious coping helped participants manage psychosis. Participants described both internal and external religious and spiritual practices as having a positive impact upon their ability to live with and manage psychosis. Having access to spiritual communities such as church seemed to be important for some, which both supports and contradicts existing literature (Mohr & Huguelet, 2004; Huguelet et al, 2006) that found mixed evidence of its usefulness. One reason for this could be that this systemic review only focused on the positive aspects, and therefore could have potentially neglected the negative impact on managing psychosis. Participants in this current study discussed how having a regular religious and/or spiritual practice such as prayer, mediation, mindfulness and yoga was beneficial and this supports the work of Heffernan, Neil, Thomas & Weatherhead (2016). The engagement of these practices appeared to offer the participants important tools such as grounding, present moment awareness, and tolerance of distress, which was a fundamental part of helping them live with and manage psychosis (Chadwick, 2014; Ashcroft, Barrow, Lee & MacKinnon, 2012).

This systematic review also highlights how such practices can be an important part in the recovery process. Whilst recovery is difficult to define and there are arguments for and against the term ‘recovery’ (Law & Morrison, 2014), it is a personal journey that varies between individuals. Heffernan, Neil, Thomas, and Weatherhead (2016) also emphasise the importance of religion in the recovery of people with psychosis and highlight how, for some, maintaining religious rituals can be difficult, but that religiousness can aid recovery and needs to be supported in services.

Limitations

There were a number of limitations and systematic biases that occurred consistently across studies, which constrain the conclusions of the review. For example, the CASP assessment tool (Public Health Resource Unit, 2006) was used to quality assess the studies. However, it is acknowledged that the CASP had some limitations. The rating options are ′ yes′,′ no′ or ‘can′t tell′, which is restrictive and does not allow for further scrutiny or recognition of subtle nuances within each item. For example, one of the questions in the assessment tool (item 6) asks whether the relationship between researcher and participant has been adequately considered. The hints and scoring guidelines were often not sufficiently clear or structured to apply a specific rating. This meant that it was challenging to accurately detect limitations of the studies and leads to contradictions in what was presented and what is reflected within the CASP.

In hindsight, the CASP does not assess many important quality features of qualitative research such as trustworthiness, credibility, triangulation, transferability, dependability and confirmability, which is argued to be an important part of assessing quality in qualitative research (Vicent, 2014). Future reviews may consider using a more sophisticated approach guided by important factors, as mentioned above, (Vicent, 2014).

Studies lacked in terms of the recruitment strategy (Wagner and King, 2005), and the process of data collection seemed vague in another study (Hustoft et al, 2013). However, the data used was secondary from a larger study which may account for the lack of clarity, although it would have been helpful for the reader, if the author had been more explicit in the paper. Furthermore, the use of reflectivity on all papers was lacking, which made it difficult to assess the transparency of the studies. For some, a lack of clarity on *how* the analysis was conducted was limited (Nixon et al, 2010; Virdee et al, 2016), as were ethical considerations (Virdee et al, 2016; Smith & Suto, 2012; Smith & Suto, 2013; Wagner & King, 2005).

Few papers within the review specifically focused on the research topic of interest. This meant that the themes that were relevant within the studies tended to be secondary themes and therefore lacked detail and richness (Yang, et al, 2011; Virdee et al, 2011; Wagner & King, 2005). There was also variability across the studies in terms of their findings. Given the limited detail and richness in some studies' findings, it is difficult to draw conclusions.

Finally, there was also considerable methodological heterogeneity in the included studies, as some studies included individual interviews with participants, whereas others used focus groups. The methodological implications for this might suggest a lack of richness and depth of individual experiences when using focus groups to address this topic area. However, focus groups may have facilitated an open space for healthy discussion and debate, which may have developed different but still relevant conversations. Within Wagner and King's (2005) study, a psychiatrist led the focus groups, but it is unclear to the reader whether or not the psychiatrist was known to the participants. Even so, a power imbalance is questionable and it is not known how able the participants may have felt to have open discussions in this type of forum. Virdee et al's (2016) description of analysis was limited in describing how the analysis was conducted and how they arrived at their findings, which lacked transparency, leaving the reader wondering how themes were developed and decisions were made. The decision to include Wagner and King (2005) and Virdee et al's (2016) studies was taken on the premise of the limited number of available papers, and that more stringent inclusion criteria would have significantly limited eligible papers. Given the need for further understanding through qualitative research, it was felt that that including these papers was appropriate; however, they should be interpreted with caution.

Although quality assessments were completed for the included studies, the findings of the synthesis may have been influenced by the reviewers' own personal and professional experience. Similarly, the search strategy and study selection process used may have impacted upon the findings. Including only English language articles, for example, may have introduced bias as potentially relevant studies published in other languages may have been missed. Also, negative symptoms were not included within the search terms, which may have limited the number of studies captured. It is also acknowledged that this systematic review focuses just on the positive role of religion and spirituality, but in fact within a few of the included papers, some participants also found religion and spirituality to be less helpful in certain circumstances. Whilst this was not a focus of this review, it is acknowledged as a limitation.

Lastly, the inclusion of only qualitative papers meant that any quantitative or mixed methods research that was relevant may have been excluded and potentially missed valid data. However, it was felt that in order to increase richness and depth of qualitative research, only qualitative studies were included.

Implications for future research

From the limitations discussed above, there are several suggestions for future research. Firstly, research could employ a similar systematic review, but include negative symptoms of psychosis when developing the search strategy, which may capture more qualitative research papers. This would also give a more balanced appraisal of the helpful and unhelpful impact of religion and/or spirituality on the presenting difficulties of people with psychosis. Secondly, using a more robust quality assessment tool that is able to scrutinise qualitative research appropriately would be beneficial in order to help the reader judge the trustworthiness of the papers presented. Lastly, whilst it is recognised in this topic area that there will generally be less studies than a quantitative systematic review, the lack of richness and depth within these studies presented made some of the themes quite thin. Therefore, as the qualitative research grows in this area, there will be new evidence that can be reviewed systematically, which may offer further insights and help inform practice.

Clinical implications

Although these results should be interpreted with caution due to the limited richness and depth within the findings, they do, however, add to existing literature by giving a more in-depth understanding of the positive role of religion and/or spirituality in psychosis. Further in-depth qualitative research is needed, which will hopefully have clinical implications on how mental health professionals assess, support and enable religiousness and/or spirituality within the care of their patients.

Whilst the Equality Act 2006 (Legislation.gov.uk, 2010) describes that no one should be treated differently because of their religious or belief system and there is an acknowledgment in the literature that this should implemented within mental health services (Huguelet et al, 2006; Koenig and Saris, 2002; Nolan et al, 2012; Mohr et al, 2006), research highlights that this need is insufficiently met (Blanch, 2007). Policies such as the Religion and Belief: A practical guide for the NHS (2009) and NHS five year forward view (Forward View) published by NHS England and other bodies (2015) also highlight that religious and spiritual needs should indeed be met within the mental health service, however, practically this may not be the case (Blanch, 2007).

In addition, in previous years, religious content within psychotic experiences has been viewed as a sign of deterioration in a person's mental health (Mohr & Huguelet, 2004). However, in more recent years, there has been a shift to understanding a person's psychotic experiences from a bio-psycho-social model, with the National Institute of Clinical Excellence, (NICE, 2014) now recommending psychological therapy (CBT), family interventions alongside antipsychotic medication. This model of understanding psychosis may still neglect the importance of understanding how an individual makes sense of their experiences from a more religious and/or spiritual context (Oxhandler, Parrish, Torres, & Achenbaum, 2015). Evidence has suggested that clinicians often do not discuss religion and/or spirituality with individuals with psychosis (Smith & Suto, 2013) and therefore these may not be integrated into their treatment. However, it is also recognised that psychological therapies for psychosis, in particular cognitive behaviour therapy for psychosis (CBTp), when competently done should actually encourage the exploration of personal meaning-making of psychotic experiences and how cultural and social meanings including religion, influence how people understand, respond and manage these experiences (Messari & Hallam, 2003).

There seem to be several parallels between the strategies discussed in this systematic review and the psychological ways of managing psychosis in CBTp. For example, self-help techniques such as learning to relax through music, breathing exercises and/or meditation are often encouraged on self-help websites (Mind.org.uk, 2018), as are recognising and challenging unhelpful thinking patterns and developing new ways of thinking and coping in CBTp (Phiri, Rathod, Carr & Kingdon, 2017). Whilst there are similarities between the strategies discussed in this systematic review – self-help and psychological ways of managing psychosis – the participants in this systematic review used these techniques as part of ancient Eastern traditions and not the secular version often used in mental health services (Dein, Cook, & Koenig, 2012).

The integration of religion and spirituality in mental health services has already made progress in that some services have a chaplaincy services and alliances between religious and spiritual groups that can offer advice to professionals and religious support in times of need (NHS Constitution, NHS England 'Putting Patients First', The NHS England Business Plan for 2013/14 - 2015/16). However, not all services adopt this approach, and research still indicates a shortcoming in meeting the religious and spiritual needs of people with psychosis (Blanch, 2007). One way to meet this unmet need is stronger alliances between church/synagogue/mosque leaders, religious and spiritual community groups and providing more resources to train staff in the usefulness of religiousness and/or spirituality in psychosis.

Conclusion

The results demonstrate that religious and/or spiritual beliefs can be fundamental for some, in helping people make sense of their experiences, manage with symptoms of psychosis and daily living, and how religious and/or spiritual practices can help and can instil hope for the future.

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Paper two: A thematic analysis comparing and contrasting voice-hearing and meaning-making in Black clinical and Black Evangelical non-clinical voice-hearers.

Word count (excluding tables and figures): 8,181

This paper has been formatted according to the University guidelines and will be formatted for publication guidelines of The Journal of Ethnicity and Health (appendix 4).

Abstract

Voice-hearing can be a complex issue. Whilst previous research has investigated clinical and Evangelical voice-hearers, no study to date has explored this phenomenon in qualitative research and in a Black UK population. This qualitative study aimed to compare and contrast voice-hearing and meaning-making in Black clinical and Black Evangelical voice-hearers. There were 16 participants (eight clinical and eight Evangelical) who took part in the interviews. A thematic analysis revealed three superordinate themes for both groups: (1) The nature of voice(s), (2) meaning-making and (3) the impact (that voice-hearing had on their lives). The findings highlighted the similarities and differences between Black clinical and Black Evangelical non-clinical voice-hearers, in particular the difference in malevolent and benevolent voice-hearing and *how* individuals made sense of their experiences and *how* this impacted upon distress and help-seeking behaviour. Future research could focus on developing insight into the ways in which religion and spirituality help voice-hearers, both clinically and non-clinically.

Keywords: Voice hearers, Evangelical, psychosis, religion; spirituality; African, Caribbean, psychosis; qualitative.

Introduction

Voice-hearing (frequently referred to as ‘auditory verbal hallucinations’ within the medical/psychiatric literature) is an experience most commonly associated with a diagnosis of psychosis and schizophrenia (Lakeman, 2001; Romme & Escher, 2000). In the UK, it is estimated that 1% of the population is estimated to have a diagnosis of schizophrenia (Perälä et al, 2007). Predominately, treatment in the West for psychosis and schizophrenia has involved the use of antipsychotic medication, with cognitive behavioural therapy and family interventions now recommended for treating people with psychosis (National Institute of Clinical Excellence guidelines, 2014).

Voice-hearing has been understood from medical, psychological and social frameworks (McCarthy-Jones, Waegeli & Watkins, 2013). Voice-hearing has been shown to be related to trauma, adverse life experiences, emotional distress, biochemical imbalances in the brain and spiritual emergency (Lakeman, 2001). However, not everyone who hears voices has a diagnosis of a mental health disorder, nor are people always distressed by the experience. For many, voice-hearing is a normal part of everyday life (Al-Issa, 1977; McCarthy-Jones, 2013; Mohr, Brandt, Borras, Gillieron, & Huguelet, 2006). It is estimated that between 5-28% of the general population hear voices that other people cannot (De Leede-Smith & Barkus, 2013; Johns et al, 2014), with others suggesting that this rate is anywhere between 0.6% to 84% (Beaven, Read & Cartwright, 2011). One reason for the large discrepancy could be based upon problematic comparison between studies due to methodological issues, particularly different definitions of voice hearing, due to variation in cultural factors, ethnicity and context. For example, Westernised cultures are less likely to report voice hearing, compared to more spiritually developed cultures, such as New Zealand Maori’s, where voice-hearing is revered (Beaven, Read & Cartwright, 2011). Non-clinical voice-hearers are people who experience auditory verbal hallucinations (AVH) but do not appear to be in contact with psychiatric services despite having these experiences (Larøi et al, 2012). It is thought that some regard voice-hearing as a positive, helpful and even a spiritual experience, which is part of meaningful human existence (Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014; Larøi et al, 2014; Jenner, Rutten, Beuckens, Boonstra, & Sytema, 2008). Voice-hearing is said to be complex (Fenekou & Georgaca, 2010) and although research has explored this phenomenon with clinical participants to better understand the experience, research has suggested that exploring voice-hearing amongst non-clinical samples may give further insight into the experience (Boksa, 2009; Baumeister, Sedgwick, Howes, & Peters, 2017).

Studies have explored the similarities and differences amongst clinical and non-clinical voice hearers. Honig et al's (1998) study found that the non-clinical participants reported less to no distress with regard to their voice-hearing experience in comparison to the clinical voice hearers. Research suggests two distinct differences between clinical and non-clinical voice hearers, which are high emotional negative content for the clinical voice hearers, and early onset of voice-hearing in non-clinical voice-hearers (Larøi, 2012). Furthermore, a literature review by Daalman and Diederen (2013) comparing clinical and non-clinical voice-hearers also found differences amongst the two groups with regards to emotional valence of content, distress-related characteristics of the voices, and beliefs about the voices. However, characteristics that were mostly form-related appeared similar. A more recent systematic review by Baumeister et al (2017) reported similar findings, whilst there were similarities amongst clinical and non-clinical voice-hearers in terms of volume or location of the voices, and both shared similar risk factors in terms of familial and childhood trauma. However, clinical voice-hearers had more frequent voices, more negative content and onset was late, whereas the non-clinical voice-hearers had significantly less negative beliefs regarding the voices and where impacted more positively.

Jones, Guy and Ormrod (2003) describe a variety of voice hearers, including clinical, religious and/or spiritual non-clinical voice hearers, and non-clinical non-religious/spiritual voice hearers. They found that clinical voice-hearers were more likely to find voices frightening and interpret them as negative experiences, compared to the other groups. All groups interpreted their experiences from a variety of frameworks, including a biological, psychological, social and spiritual perspective. However, further exploration across different cultures within voice-hearing experiences is needed in order to understand cultural differences and similarities.

It has been reported that in the UK, African-Caribbean[1] individuals (defined as a person who was born in the Caribbean or whose family originated there) are nine times more likely to be diagnosed with schizophrenia, with Black Africans (defined in the study as a person either born in the sub-Saharan Africa or whose family originated from that region) six times more likely to be diagnosed with schizophrenia compared with white British communities in the UK (Fearon et al, 2006). Research has suggested that social deprivation, immigration, trauma, stigma, culture (Bhui, Bhugra, Goldberg, Dunn, & Desai, 2001; Sharpley, Hutchinson, Murray, & McKenzie, 2001) and institutionalised racism (Singh & Burns, 2006) may all play a part in the significantly higher prevalence

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[1] It is noted that there are variations within the manuscript with regard to describing ethnicity. The literature uses a range of terms to refer to the UK's Black populations, including Black African, Black Caribbean, Black British, Black Other and people of 'Mixed' ethnicity. The term Afro/African-Caribbean is used to describe Black people whose origins are Caribbean but have African ancestry. For the purpose of this research, participants will be referred to as Black individuals unless describing the differing sub-groups is warranted.

within the Black population (Sharpley et al., 2001). Further ethnicity studies are needed to better understand this high prevalence amongst Black individuals and also their experiences of accessing support. Johns, Nazroo, Bebbington and Kuipers, (2002) examined the prevalence of hallucinatory experiences amongst a variety of non-clinical white and ethnic minority participants (Caribbean, Indian, African, Asian, Pakistani, Bangladeshi and Chinese). They found that hallucinations were 2.5-fold higher in Caribbean participants, suggesting differences amongst various ethnic backgrounds and the need for further exploration.

One reason for the higher prevalence of psychosis and voice-hearing could be that for many people from an African-Caribbean background, religion and spirituality are an important part of their lives (Rabiee & Smith, 2014). Quite often, religiosity is pathologised within mental health services (Lukoff, Lu & Turner, 1992; Siddle et al, 2002), and there tends to be a lack of understanding from mental health professionals (Mayers, Leavey, Vallianatou, & Barker, 2007; Poole & Cook, 2011). Furthermore, certain religious beliefs and practices such as hearing the voice of God are actively sought after and revered by individuals within these communities (Luhrmann, 2012), particularly those known as ‘Evangelicals’. Research has investigated voice-hearing experiences within clinical and non-clinical participants within a religious context, in mixed ethnicities. Davies, Griffin and Vice’s (2001) quantitative study compared clinical voice hearers, Evangelical voice-hearers and a control group. Participants were asked to rate their feelings and perceptions of their voice hearing, during and after their experience. They found that the Evangelical voice-hearers were significantly more positive about the experience of voice-hearing than the control group and the clinical voice hearers. This evidence is not surprising given that a fundamental part of being Evangelical is hearing the voice of God, which is often revered within this group. More recently, a mixed methods design study by Cottam et al, (2011) investigated how voice-hearers interpret their experiences. They found that Christians without mental health problems appeared to interpret the experience in relation to their religious beliefs and perceive voice-hearing positively, whereas the Christian patients tended not to interpret the experience within their religious framework and the voice-hearing experience was generally negative. The majority of participants reported the voices as powerful but non-clinical participants reported the power of the voice positively. Furthermore, a qualitative study explored communication from God in a sample of participants from various ethnic backgrounds, who attended an Evangelical church in London (Dein & Cook, 2015). This study found that God communicated for some through an audible voice, but also through thoughts and impressions. They also found perceptions that God would often comment on everyday life events, offered reassurance and participants had felt able to either obey or disobey God. This evidence may highlight some of the differences between clinical participants who experience voice-hearing from a clinical group, who may feel as though they have less control over the voice(s), and compared to a non-clinical Evangelical voice-hearers (Daalman & Diederen, 2013). Black majority churches, including Evangelical churches, are rapidly increasing in the UK (Osgood, 2017). Hearing the voice of God is a relatively common and revered experience within this religious group (Luhrmann, 2012) and is often associated with lower levels of distress than those from a clinical voice-hearing group (Davies, Griffin & Vice, 2001). For each of these reasons, Evangelical churches provide a useful place to recruit from when comparing and contrasting the voice-hearing experience and meaning-making to a Black clinical group.

No study to date has qualitatively compared and contrasted the voice-hearing and experience and meaning-making between clinical and Evangelical voice-hearers from a Black background in the UK. It is argued that to fully understand the complex needs of people with psychosis, a qualitative approach is needed, in which meanings and experiences can be expanded in more detail (Britten, 1995). Including Evangelical voice-hearers may add invaluable insight into the normalising voice-hearing experiences they encounter, and may help inform best clinical practice and support the needs of clinical voice hearers.

This study aimed to compare and contrast voice-hearing and meaning-making in Black clinical and Back Evangelical non-clinical voice hearers. The research question is as follows: What are the similarities and differences of the voice-hearing experience and meaning-making between Black clinical and Black Evangelical non-clinical voice-hearers?

Method

Design

The qualitative design used semi-structured interviews to compare and contrast voice-hearing and meaning-making in Black clinical and Black Evangelical non-clinical voice-hearers.

Topic guide

An interview schedule (see appendix 5) was developed by the lead author to explore voice-hearing in relation to the research question and aims. The questions covered aspects of people’s experiences of voice hearing, including onset, content of voices, impact upon personal goals, and religious and/or spiritual and cultural influences. The interview schedule was piloted with a member of the Community Liaison Group (CLG), an expert-by-experience group based at the University of Manchester. Feedback was given in regards to the language that was used and this was changed and integrated into the schedule.

Ethical approval

The study was granted ethical approval by the North West Research Ethics Committee (REC) (Reference: 17/NW/0150) (see appendix 6).

Recruitment

Participants from the clinical group were recruited through the NHS and third sector services across the North West of England, including acute inpatient wards, community mental health teams, and early intervention services. In the first instance, clinicians from these services were contacted about potential participants on their caseload, asked if they would like to be involved in the study, and provided with the Participant Information Sheet (PIS) (see appendix 7). For the Evangelical group, potential participants were recruited through advertisement via posters in mental health support groups, and attending Evangelical churches. Once a potential participant had agreed to be contacted, the researcher contacted the participant and discussed the study in more detail and screened for eligibility. If the participant showed interest in the study, met the eligibility criteria, and verbally consented, then the lead author arranged to meet the participant face-to-face in a mutually convenient location, such as the NHS, a university setting or a participant’s home address. The initial meeting included completing the consent form (appendix 8), confirming eligibility more formally using the using the general demographic information question (see appendix 9) and conducting the qualitative interview. Participants were fully debriefed (appendix 10/11) and received £7 as compensation for their time.

Participants

Sixteen voice-hearers took part in the study, including eight clinical participants and eight Evangelical participants (see table 1 for a full breakdown of participant demographics).

Table 1: Participant demographics table

Participant ID	Ethnic Background (self, parent or grandparent from Africa and/or the Caribbean)	Age	Gender
Clinical Group			
1	Parents, Ethiopia	28	Female
6	Self, Africa	28	Female
8	Parent, Nigeria	26	Male
9	Self, Caribbean	44	Male
13	Self, Somalia	48	Female
14	Self, Jamaican	40	Female
15	Parent, Ghana	67	Male
16	Self, Caribbean	63	Male
Evangelical Group			
2	Self, Nigeria	36	Male
3	Self, Nigeria	49	Male
4	Self, Nigeria	41	Male
5	Self, Africa	37	Male
7	Self, Nigeria	30	Male
10	Parent, Caribbean	40	Female
11	Parent, Caribbean	56	Female
	Parent, Jamaica	48	Female

Note: Participants were asked to state their ethnic background in relation to the eligibility criteria of the study using the demographic and clinical information questionnaire (see appendix 9) which as if either themselves, parent or grandparent were from Africa or the Caribbean.

Inclusion/exclusion criteria

Clinical participants were deemed suitable if they met the following criteria: 18 years and above; experienced voice-hearing within six months prior to participating in the study; self-identified as either of African Caribbean descent or Black African descent, including those who self-identify as ‘Black British’, ‘African-Caribbean’, ‘mixed African

Caribbean', 'Black African, or 'mixed Black African' but who have at least one African-Caribbean or Black-African parent or grandparent; having the capacity to provide informed consent; a diagnosis of schizophrenia, or psychosis-related diagnosis; and known to mental health services or receiving treatment/support from a mental health professional relating to the diagnosis – where possible this was confirmed with a clinician.

Evangelical participants were deemed suitable if they met the following criteria: were 18 years and above; self-identified as either of African Caribbean descent or black African descent, including those who self-identify as 'Black British', 'African-Caribbean', 'mixed African Caribbean', 'Black African, or 'mixed Black African' but who have at least one African-Caribbean or Black-African parent or grandparent; having the capacity to provide informed consent; no self-reported diagnosis of schizophrenia or psychosis-related diagnosis; and not receiving treatment or support from mental health services for schizophrenia or psychosis-related diagnoses. This was confirmed at the beginning of the interviews as part of the 'General Demographics Information' (appendix 9) questions.

Participants were excluded from being in either group if they met any of the following criteria: lacked capacity to provide written informed consent; the experience of voices was organic in origin (for example, hallucinatory experiences linked to traumatic brain injuries, organic psychoses, or emerging in the context of dementing conditions); have insufficient command of English to complete the research interviews and measures (validated measures are in English); are already involved in ongoing research in such a way that additional participation will constitute a burden that is unacceptable to the individual; have an intellectual disability, or severe cognitive dysfunction that might preclude the individual's ability to provide informed consent; understand the study procedure and/or fully appreciate the potential consequences of their participation; or clinicians working with people identify reasons for why participation might be potentially detrimental. All the above exclusion criteria were screened with potential participants by the researcher before they were recruited and confirmed at interview.

Procedure

Once verbal and/or written consent was gained and the participants had agreed to take part in the study, the researcher met with the participant face-to-face to conduct the qualitative interviews. The interviews ranged between 20 - 60 minutes in length and each participant completed their interview in one session. Participants were asked a number of open-ended questions, designed to enable them to describe the content of the voices, their interpretation and the meaning associated (e.g. *Please tell me what you believe about the voices?)* and how religion and/or spirituality and culture may influence their experience and understanding (e.g. *Some people say voice-hearing is an important part of their spiritual and/or religious experience, what are your views about this?).*

All interviews were audio-recorded and transcribed verbatim. The lead author transcribed 25% of the interviews and the rest were transcribed by an external transcriber who was contracted and bound by confidentiality. Following the interview, participants were fully debriefed, and asked whether they would like to receive a summary of the study findings once the study was complete.

Analysis

The analysis was conducted using a thematic approach at a semantic level (Braun & Clarke, 2006) to systematically code, organise, and develop key themes and sub-themes in relation to the research question, and which aimed to capture exactly what participants described (Braun & Clarke, 2006). The coding and analysis was based on Braun and Clarke's (2006) thematic analysis framework, following a six-phase process, which included: familiarising with data, generating initial codes, searching for themes, reviewing the themes, defining and naming the themes, and finally producing the report. All participants were assigned a number and any identifiable information that could compromise anonymity was changed or deleted. Initially, each transcript was read and re-read to familiarise the researcher with the data set, noting down initial ideas. Each line of the transcript was coded, generating initial codes, and these codes were then collated into potential themes that were then reviewed and refined by the researcher and lead supervisor. An initial thematic map (see figure 1) (Braun & Clarke, 2006) was used to visually organise the data and generate theme labels. This was then reviewed by the research team, to refine the specifics of each theme and develop the overall story of the data. Key themes were then illustrated by selected quotes from participants, in relation to the research question and existing literature. The epistemological position when undertaking the analysis of this qualitative research was a critical realist stance (Collier, 1994), which acknowledges that the process of trying to understand reality will be shaped by one's own belief system, perceptions and interpretations (Spencer, Ritchie, Lewis, & Dillon, 2004).

Trustworthiness

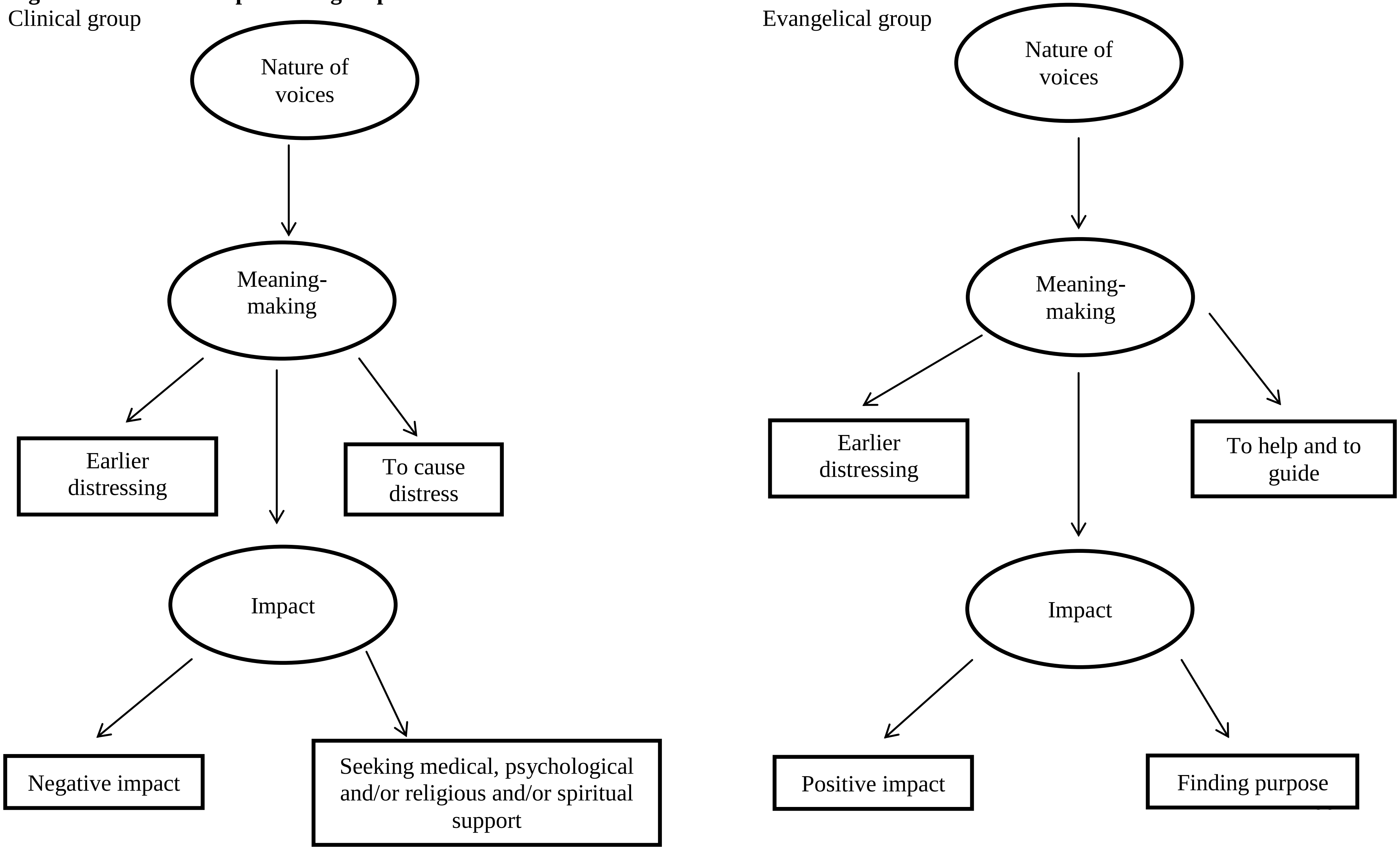
The concept of methodological rigour is a contentious one within qualitative research (Tobin and Begley, 2004). It is proposed that qualitative research must adhere to methodological rigour in order to access and demonstrate an unbiased approach that is both valid and reliable (Morse, Barrett, Mayan, Olson, & Spiers, 2002). However, it is argued that such language and thus this approach lends itself to a quantitative paradigm, and may not always be appropriate within qualitative research (Arminio and Hultgren, 2002). Tobin and Begley (2004) argue that qualitative research will always have a level of subjectivity, as the researcher(s) are human, with various life experiences, and will process and construct ideas relevant to their worldly view. Furthermore, having an awareness of one's own subjectivity and acknowledging it with qualitative research enhances trustworthiness, transparency and authenticity and may add to the richness of the interpretation (Le Gallais, 2008).

Reflexivity

Reflexivity was an ongoing process and required continuous reflections in relation to one's own views, perceptions and experiences in order to minimise subjective bias (Reid, Brown, Smith, Cope & Jamieson, 2018). It was recognised that the data were mainly analysed from the perspective of a white British female, trainee clinical psychologist, with experience of working in mental health services, and therefore pertinent reflections, a reflective journal and thought processes were shared with the supervisory team, which helped shape the analysis (further reflections in Paper 3). For example, a participant in the clinical group (participant 9) had shared how he managed unwanted voice-hearing experiences; *"…To just ignore them and say it's ok, the voices are like the enemy",* whilst the lead author had coded this sentence as 'manage voices by ignoring them', supervisor DE had wondered whether participant 9 was actually referring to the 'Devil' as the 'enemy'. This statement was then re-coded as a result which helped reduce subjective bias. Furthermore, it was recognised that the lead author had previously worked with people with psychosis in mental health services and rarely came across people who had a positive experience of voice-hearing, which supports the literature that clinical participants can often be distressed by voice-hearing (Hartley, Haddock & Barrowclough, 2012). This experience will have shaped how the lead author perceived what it may be like to hear voices, and therefore it was important to acknowledge ones' own beliefs and assumptions.

In helping to further minimise subjective bias, a reflective journal of pertinent reflections was kept and shared with supervisors in order to gain perspective and help the analytical process. For example, an excerpt from the reflective journal reads: "*…I feel as though I am putting words into the participant's mouth…the participant appeared to really struggle to elaborate on his feelings, but I sensed from the interview, just how traumatic his experiences have been…I felt I had to encourage him a lot to speak or elaborate on points. I wonder how much of the interview was shaped by my own assumptions and agenda?*

Figure 1: Thematic map of both groups


Clinical group

Evangelical group

Results

Three superordinate themes were identified using thematic analysis: 1) the nature of voice(s)', (2) how participants made sense of it – 'meaning-making' and (3) how this had 'impacted' the participants' lives and how they had responded as a consequence. Each of these superordinate themes consisted of a cluster of sub-themes (eight in total, see table 2), which illustrate pertinent similarities and differences between the two groups.

Table 2: The superordinate and sub-themes for the clinical and Evangelical Voice-hearers

Clinical participants	Evangelical participants
1) Nature of voice(s)	**1) Nature of voice(s)**
2) Meaning-making • Earlier distressing experiences • To cause distress	**2) Meaning-making** • Earlier distressing experiences • To help and to guide
3) Impact • Negative impact • Seeking medical, psychological and/or religious and/or spiritual support	**3) Impact** • Positive impact • Finding purpose

1. Nature of voice(s)

This superordinate theme described the 'nature of the voice(s)' which encompasses the characteristics and tone of the voice(s). Whilst both groups described characteristics of the voice(s), the content of these voices tended to differ greatly. The majority of clinical participants tended to experience a much more malevolent voice(s), compared to the Evangelical group, which were more benevolent.

In line with previous research findings contrasting clinical and Evangelical non-clinical voice-hearers, the Evangelical participants in this study tended to describe only one voice, and this voice tended to be calm, peaceful, empowering, more positive and coming from God:

"Most of the time I have heard his voice is, err, it's more of a voice of comfort, voice of, err, encouragement, and err,… It's empowering also." (participant 4, Evangelical group).

In contrast, participants in the clinical group described a sharper, louder, negative voice:

"*Sometime shouts, sometimes it's like someone is talking to me, sometimes, it depends on that, arguing, something like that, I have two voices arguing*" (participant 19, clinical group).

Some of the clinical participants had discussed religious and/or spiritual content to their voice-hearing experience:

"*It's like that high-pitched, it's like… Like a Demon, do you know a Demon."* (participant 8, clinical group).

However, not all of these clinical participants who discussed religious and/or spiritual content to their voice-hearing experienced negative tone or content; for some it was a softer, gentler voice:

"*God is, God is love, He talks to you in, in a, because he is, His aim is to make you happy, make you feel comfortable in yourself, so he talks gently, gentle voice, not an angry voice*" (participant 6, clinical group).

2. Meaning making

This superordinate theme described how participants made sense of their experience and interpreted their voice-hearing experiences and what they perceived was the purpose of the voice(s). Although both groups discussed how they had made sense of their voice-hearing experiences and what it meant to them, they tended to differ based on their beliefs about the origin and intention of the voices. The participants in the clinical group tended (but not all) to interpret the voices as causing distress, whereas for the Evangelical group, they had perceived the voice as being from God and there to help and guide them.

Earlier distressing experiences

This sub-theme described 'earlier distressing experiences' that had been present for both groups. All of the clinical participants described distressing times in their lives before the onset of voice hearing. For some, they had made sense of this experience as a potential trigger for their voice-hearing experience, whereas others did not. Clinical participants' most significant theme was around loss, e.g. loss of career and/or relationships:

"yeah I'd just lost my job, so I think that is a major factor, although I think it started when I was in that particular job I just didn't notice because it was that subtle" (participant 1, clinical group).

Evangelical participants also described distressing experiences which may have triggered their voice hearing. For example, people described having difficulties with alcohol, immigration, being in a life-threatening situation and loss:

"*And then I went through a period of, I went through a phase whereby everything I held secure, I lost everything.*" (participant 10, Evangelical group).

Another participant had spoken about wanting to hear from God every day, because of the dramatic difference he had experienced in his life, following distressing life events:

"….I never thought about studying I never thought about anything, but he (God) prompted me to do all those things .. I work now with people that are homeless, people that are on the streets…I try to encourage them, I try to give them a minute with their life, tell them that somebody can get out of it…it's possible, before I had all this incidents, I was an alcoholic, I drank…" participant 3, Evangelical group.

The Evangelical group tended to create positive meaning out of adverse life events, which had helped them find God, and subsequently created purpose and meaning in their lives which can be seen as related to the concept of post-traumatic growth (Sade, Blackie & Longden, 2019).

To cause distress

This sub-theme was unique to only the clinical group, and clinical participants tended to interpret the voices as mostly negative and deliberately seeking to cause them distress. For example, clinical participants described perceiving the voice(s) as tormenting them and it was clear how much distress this caused:

"*… yeah, that, that what they are, they are negative, they are negative, they target is to make you low and paranoid and shock you everything, if you wanna go toilet, take shower, they say no, they want you to stink, you will eat, they say no it's enough, don't eat, they… They are horrible…"* (participant 13, clinical group).

Clinical participants with religious and/or spiritual beliefs interpreted the voices as mostly negative if they believed the voice was the Devil. This participant described how she heard from the Devil and believed that his purpose was to harm people:

"*He's (Devil), he's a nasty man, nasty no person, he's not some… He is very angry and, He wants to kill you. He hates, he hates human beings anyway, his purpose is to destroy people, to destroy life…*". (participant 13, clinical group).

However, for a few participants, it was a more positive experience if they believed the voice was that of God or a deceased loved one:

He's just a normal human being [participant referring to God]…He speaks like a human being just like you are speaking to me now… God is love… because His aim is to make you happy, make you feel comfortable in yourself… (participant 6, clinical group).

To help and to guide

In sharp contrast to the previous theme, the Evangelical participants who interpreted the voice as being from God perceived the voice as wanting to help and to guide them. Participants spoke about various ways God did this: through an audible voice; through dreams; through confirmation from others; and it always being a positive experience:

"It's a confirmation of...you know, things that you actually pursuing your life and in the kind of guidance or getting as well, err, as to the path that you want to go, and someone else has confirmed it, so, for me it's confirmation, it's a word from God, you know, that, look, you know, I've got your back!" (participant 5, Evangelical group).

3. Impact

Lastly, this superordinate theme, 'impact', described how the voice-hearing experiences impacted the lives of both groups. The two groups differed greatly in the response to such experiences. The clinical participants tended to be impacted negatively, with social isolation being one of the most common responses. However, for the Evangelical participants, the impact was hugely positive and it enriched their lives. Not surprisingly, both groups had different responses to the impact of their voice-hearing experience.

Negative impact

This sub-theme described a range of negative consequences for the majority of clinical participants, as a direct result of their voice-hearing experiences. Clinical participants described how it had negatively impacted upon their ability to engage in employment, daily functioning and psychological well-being, with many people describing low mood and suicidal ideation:

"I couldn't concentrate on daily… At one point I couldn't even go out by myself or go out for a walk with someone … I would end up having to go back because I'd end up arguing with them and fully engaged with them [the voices] but not in a good way, it was going a bit too far." (participant 1, clinical group).

Other clinical participants described how they struggled to engage in education:

"*Voices stop me to go to education because you go, you hear teacher and the voices… both of them at the same time they talking, so who you hear, it's confusing, the teachers talking and the voices talking to me….*" (participant 13, clinical group).

Seeking medical, psychological and/or religious and/or spiritual support

As a consequence of the negative impact of the voice-hearing this theme described how clinical participants managed and responded to the impact of their voice-hearing experiences by seeking support from various sources. This is in sharp contrast to the Evangelical group, who did not seek any medical, psychological, religious and/or spiritual support for their voice-hearing experience.

One participant described how hearing voices could impact negatively on his mental health and how he had sought support from his faith to help overcome suicidal ideation:

"cos I'm a Christian, I do read me Bible every day, nearly every day. I say me prayers every day, erm, yeah, I think maybe that's something else that's stopping me from doing it [participant referring to attempting suicide]…" (participant 15, clinical group).

Whilst some of the clinical group found medication helpful in reducing the frequency of voices, others found it increased tiredness:

"*It [antipsychotic medication] was making me feel tired and drowsy… And I couldn't continue, yesterday I went to sleep about 5pm.*" (participant 8, clinical group).

All clinical participants had accessed mental health support, either through admission as an inpatient on a psychiatric ward, community-based support or, for two participants, accessing psychological therapy. Some clinical participants' involvement with mental health services had been unhelpful, whereas for others it was a helpful:

"*Like in the beginning we did like cards, and it shows you all the stages of what might happen to trigger you becoming unwell. So you know, I've got a relapse plan to make sure it doesn't happen again, but if it does, I have a strategy in place so I can work through it systematically.*" (participant 1, clinical group).

As for clinical participants with religious and/or spiritual backgrounds, they had a negative experience of mental health services, and felt there was a lack of understanding with regard to religiousness and spirituality. One participant described feeling as though the nursing staff within the hospital where she had been sectioned knew the ‘truth’ (referring that God was real) but could not challenge more senior staff:

“*Right, in, in, from my own experience, so it someone like me that believes in God, when I’m talking about my experiences, they [mental health professionals] think it’s ‘madness’… Then the Christians that are there, most of them, they are, they are nurses, they are junior, aim, they’re not doctors, so, they can’t even, they can’t voice out, even though they know the truth*”. (participant 6, clinical group).

Whilst the majority of clinical participants tended to respond to the negative impact of their voice-hearing by seeking help from mental health services, the Evangelical participants had a positive impact and therefore responded differently, as discussed below.

Positive impact

A sub-theme was developed, ‘positive impact’, mainly describing the Evangelical participants’ experience, which tended to have the opposite impact to that of the clinical participants (with the exception of some clinical participants who were impacted positively by their voice-hearing). The theme represented how having a religious and/or spiritual belief and hearing the voice of God had impacted upon their lives in a profound and positive way; for some it had been a monumental shift in their life’s direction. For example, the Evangelical participants talked about completing academic studies and finding comfort in the voice::

“It’s my life, though isn’t it, erm… I think sometimes I look back at where my life will be without Christ in it, I’d probably be in some institution… You don’t know, you don’t know where your life would, when I just feel peace.” (participant 11, Evangelical group).

The participants had talked about God changing their lives for the better, giving direction and creating purpose and meaning in life, which all impacted upon their lives significantly:

"It's something I desire to hear every day (in regard to God's voice), because I've seen the, the improvements I've made in my life, I've seen the direction." (participant 3, Evangelical group).

Other participants talked about their relationship with God and the extent to which this experience had impacted upon their life:

"Great, fantastic, one I couldn't live without [Participant talking about her relationship with God], *he's my be all and end all, he's the beginning and the end, he is my everything, without him I would be nothing, without him I would have not think, and if he never did anything else for me… I would still praise him because he died on the cross, he's given me eternal life…"* (participant 10, Evangelical group).

Some of the clinical participants also talked about the voice-hearing experience as being welcomed and having a positive impact, depending on whom they believed the voice to be, for example, God or a deceased brother:

"It's just nice to hear the voice so I suppose…[participant talking about deceased brother]" (participant 15, clinical participant).

Finding purpose

This sub-theme described how Evangelical participants responded to the impact of their voice-hearing experiences by finding purpose in their lives. For example, Evangelical participants described how these positive experiences with God had initiated a desire in them to want to help and serve others in need:

"...and so I'm also, I'm encouraging people on the street that they can still do it...it's not the end of the world that you are broken hearted, you are sleeping on the street, you don't have the roof over your head, etc., just a situation. It's not you..." (participant 3, Evangelical group).

All Evangelical participants described how this positive experience made them want to deepen their relationship experience with God. They described how religious practices brought them closer to God:

"I think the only way to be close [to God]is to actually speak to God, that's it, read the Bible, meditate and have that time with him" (participant 7, Evangelical group).

Discussion

This qualitative study compared and contrasted the experience of voice-hearing and meaning-making in Black clinical and Black Evangelical non-clinical voice hearers. The thematic analysis revealed three main themes: 1) Nature of the voices; 2) Meaning-making and 3) Impact (of voice-hearing experiences). Firstly, the key findings suggest that whilst both groups heard voices, the Evangelical group experienced the voices as benevolent, whereas the clinical group tended to experience malevolent voices. These findings are consistent with existing literature showing that non-clinical participants tend to perceive the voices as predominately positive (Davies, Griffin & Vice 2001), causing little-to-no distress (Honig et al 1998), whereas clinical participants often find their voices to be generally negative (Thomas & Leudar, 1996; Laroi, 2012), derogatory and unpleasant (Daalman & Diederen 2010).

Another main finding from this empirical study is the way in which both groups made sense of their voice-hearing experiences, which tended to differ significantly. The Evangelical group had interpreted the voice as God and it was a life-affirming experience. This is consistent with existing literature that found that religious non-clinical participants perceived their voice-hearing experience in relation to their religious beliefs, (Cottom et al, 2011) , as a revered experience (Luhrmanm, 2012) and that God had offered guidance and support (Dien & Cook, 2015). In contrast, the clinical group in this study interpreted the voice as purposely negative and wanting to cause distress, supporting existing literature that suggests that clinical voice-hearers interpret their voice-hearing as frightening (Jones, Guy & Ormrod, 2003), highly negative (Laroi, 2012) and causing distress (Daalman & Diederen, 2013).

Lastly, another important finding from this study was how both groups described similarities in terms of being impacted by their voice-hearing experiences, however, how they were impacted differed significantly. For example, in the Evangelical group it impacted them positively and was monumental in encouraging direction in life (attending university, becoming sober, fulfilling their life's purpose), which supports existing research that found perceptions that God commented on everyday life events and offered reassurance (Dien & Cook, 2015). In sharp contrast, the clinical group in this empirical study were impacted negatively by their voice-hearing experience, which reduced their ability to engage in meaningful activities and impacted upon their mental health, which is consistent with McCarthy-Jones et al’s, (2013) meta-synthesis, highlighting a loss of employment, engagement in meaningful life activities and self-esteem in clinical voice hearers.

This current study also found a number of other similarities and differences amongst the two groups. For example, in theme two, ‘meaning making’, the ‘distressing experiences’ sub-theme was similar to the findings of Daalman and Diederen (2013), who investigated traumatic experiences, both in clinical and non-clinical voice-hearers and found that both groups had experienced trauma, as did Baumeister et al (2017). However, not all participants across both groups associated their past distressing experiences with their current voice hearing, even though evidence points to a relationship between past trauma and psychosis (Morrison, Frame & Larkin, 2003; Read, Morrison & Ross, 2005; Varese, Barkus & Bentall, 2011). One reason not all participants described a link between their earlier distressing experiences and their onset of voice-hearing could be that participants had not made a connection between past distressing experiences and current experiences and furthermore, voice-hearing experiences are not necessarily linked to traumatic life experiences.

Whilst both groups interpreted and made sense of their voice hearing, *how* they made sense of their experiences differed greatly, depending on their belief about the voice. Supporting existing literature that also found similar differences between clinical and non-clinical voice-hearers (Daalman & Diederen, 2013; Jones et al., 2013). For the Evangelical group, findings were similar to that of Luhrmann (2012), who investigated religious voice-hearing from a similar religious background (Evangelicalism) and found that hearing from God is a fundamental part of their lives and one that is revered. Furthermore, Peters et al (2017) conducted a quantitative study that examined the role of appraisals in psychotic experiences amongst clinical (people with a diagnosis of a psychotic disorder), non-clinical (people in the general population with persistent psychotic experiences) and controls (people in the general population with no psychotic experiences). The study found that the clinical group tended to express more paranoid, personalising interpretations of their psychotic experiences, and were less likely to have normalising or supernatural explanations for their experiences compared to the non-clinical group. The clinical group also tended to appraise their psychotic experiences as more negative, dangerous, abnormal and less controllable than the non-clinical group, which supports the evidence provided in this qualitative study. In this empirical study, the Evangelical group perceived the voice as benevolent and the voice of God; they also tended to be enriched and enhanced by the experience and it positively impacted their lives e.g. by encouraging them to attend university, and giving them direction and purpose in life. However, for the clinical group, they tended to experience a malevolent voice, which wanted to purposefully cause them distress and impacted upon their lives negatively, reducing their access to living a purposeful and meaningful life. In summary, the difference of perceived intention of the voice is consistent with the literature (Peters et al, 2017; Jones, Guy & Ormrod, 2003; Daalman & Diederen, 2010) and also the cognitive model of psychosis (Morrsion, 2001), which states that distress is a result of maladaptive beliefs about voice-hearing experiences.

Furthermore, in theme three, ‘impact’, both groups were impacted significantly differently, for example, social isolation, poor education attainment, employment and general daily functioning was significantly impacted for the clinical group, which is consistent with evidence that highlights that these issues are much more prevalent amongst Black populations (Singh & Burns, 2006; Bhugra & Bhui, 2001; Sharpley et al, 2001). However, for the Evangelical group, the impact of their voice-hearing experience created purpose and meaning, which is consistent with Luhrmann (2012). How the participants interpreted the voices depended on how this impacted individuals, which influenced how people responded. For example, the Evangelical voice-hearers had positive experiences of their voices and did not perceive them as problematic so therefore did not seek professional support, consistent with Jones et al’s (2013) findings. All participants within the clinical group had received support from mental health services and received anti-psychotic medication, which was helpful for some, in reducing the frequency and volume of the voices, but unhelpful for others who experienced significant side effects. These findings support existing research that found medication was helpful for individuals with psychosis (Steele & Berman, 2002), and unhelpful for others (Romme et al, 2009). Although all clinical participants were given medication, the majority of clinical participants were not offered psychological therapy, which is consistent with Williams, Turpin and Hardy’s (2006) literature review. The National

Institute of Clinical Excellence (NICE, 2014) recommends cognitive behavioural therapy, family intervention and antipsychotic medication for those with psychosis. Psychological therapy was not routinely offered to the majority of clinical participants within this study, with only two out of eight participants being offered therapy. Whilst all clinical participants had access to mental health support, it was generally accessed initially through crisis point (Morgan et al, 2006). These findings were similar to existing literature (Memon et al, 2016; Edge et al, 2016). However, these findings are not surprising given the amount of literature highlighting that people from Black backgrounds have a negative experience of mental health services in the UK (Lawlor, Johnson, Cole & Howard, 2012).

Religion had been instrumental to the lives of the Evangelical group and for some in the clinical group, which is consistent with the literature (Heffernan et al, 2016; Grover, Davuluri & Chakrabarti, 2014; Mohr et al, 2006; Huguelet, Mohr, Borras, Gillieron, & Brandt, 2006; Ano & Vasconcelles, 2005) and for many people from Black backgrounds, it is an important part of their lives (Hayward & Krause, 2015). However, for some of the clinical religious and/or spiritual voice-hearers within this study, such beliefs were not supported with mental health services.

Strengths and limitations

One of the main strengths of this study is that it is the first to qualitatively compare and contrast voice-hearing and meaning-making amongst Black clinical and Evangelical non-clinical voice-hearers in the UK. One potential limitation within this study is that the Evangelical group is a specific form of Christianity and therefore not generalisable to other religious backgrounds. Secondly, whilst the interview schedule explored religion and spirituality, the participants were not asked whether they explicitly identify with a particular religious and/or spiritual affiliation. In retrospect, a formal way of assessing participants' religious and/or spiritual identities should have been included. Although for all the Evangelical participants within the study, and for some of the clinical participants, religion and/or spirituality was helpful (Heffernan et al, 2016), this was not the case for everyone. It is also possible that religious voice-hearing can cause distress for individuals living with psychosis (Watkins, 2008), and this was consistent with the findings in this research. In hindsight, more of the topic guide could have focused on religion and spirituality which may have led to richer and more in-depth data and subsequent themes. However, considering that the topic guide was used for both groups (a clinical and a religious group), it was considered appropriate when the study was designed. Lastly, participants were not asked to self-identify their ethnicity; rather we focused on ensuring participants met the eligibility criteria by asking participants if either themselves, a parent or grandparent identified as being from an African Caribbean descent.

Future research

From the limitations highlighted above, it is clear that further qualitative research is needed within this topic area in order to explain the nuances within the clinical group. Firstly, it is recognised that religiosity and spirituality are separate constructs. Whilst they share similarities (Cornah, 2006), religion is usually described as a system of faith and worship, whereas spirituality is less easily defined and seen as more of an individual process (Gilbert & Parkes, 2011). Therefore, further research could focus on this distinction in order to better understand the similarities and differences and how these impact voice-hearing. It is proposed that developing a measure that explores a range of religious and spiritual frameworks is needed but may prove challenging in maintaining the uniqueness, characteristics and distinctions of religious and spiritual traditions (Seybold &Hill, 2001). Furthermore, of the participants in the clinical group who expressed religious and/or spiritual content to their voice-hearing experience, not all of them described the experience as being pathologised, even though the literature suggests this is a common experience for people with psychosis (Lukoff, Lu and Turner, 1992; Siddle et al, 2002). This may be due to the fact that participants in this study did not share their religious and/or spiritual beliefs with mental health services. Future qualitative research could explore Black clinical religious and/or spiritual voice-hearers and their experiences of their diagnosis and mental health services to add further understanding. Having a clearer idea of the similarities and differences within these two groups would lend greater knowledge and insight for understanding voice-hearing, contributing to improved services that better support the needs of those individuals seeking support. It was unclear what aspects of religion and spirituality practices were helpful for voice-hearers. Future research focusing on this could develop insight into the ways in which religion and spirituality help voice hearers, both clinically and non-clinically.

Clinical implications

The findings in this study suggest that the way in which participants made meaning from their voice-hearing experiences had a significant impact upon their lives. For some of the clinical participants, they experienced distressing voices but also comforting voices such as God or a deceased family member. This may have important implications for clinicians working with Black clinical voice-hearers.

NICE guidelines (2014) recommend that cognitive behavioural therapy (CBT) and family therapy with medication are best practice, when working with people with psychosis. CBT for psychosis (CBTp) Burns et al, 2014), for example, emphasises the importance of understanding individual experiences and interpretations of psychotic experiences (Turner et al, 2014), which are consistent with the key findings in this study as mentioned above. CBTp should encourage personal meaning-making and therefore, if appropriate to the individual, explore the role of religion and spirituality and how this may impact upon the interpretation, response and management of psychosis. Furthermore, it is important that culture and context are carefully considered: beliefs and voices that are not related to distress should not be a target problem for treatment (Brabban, Byrne, Longden & Morrison, 2017).

It has been suggested that many mental health professionals are under-equipped to deal with religiousness, (Morgan, 2001). The Royal College of Psychiatry’s (2013) position statement summarises the evidence base on the importance of religion in mental health and offers guidance on good clinical practice. One way of increasing mental health services and professionals' understanding is to have better liaison with faith leaders and advisory services that can offer guidance on whether or not a person's psychotic experience is in-line with their belief system, in order to better equip the staff and reduce unnecessary treatment.

Clinicians may also require additional training about the lived experience of voice-hearers from a Black ethnic population, in order to broaden their awareness and understanding of psychosis within this population. Whilst it is difficult to draw conclusions about clinical psychology services within this study (as only two participants had access to psychological therapy, and both with very different experiences), it does highlight a lack of access for such services and that clinical psychology services need to meet the psychological and clinical needs of people from ethnic minority groups (Williams et al, 2006).

Conclusion

In summary, both groups described characteristics of voices and distressing times in their lives; however they differed in the content, perceived origin of the voice(s) and its purpose. Evangelical participants tended to perceive the benevolent voice as God, which was to help and guide them, whereas the majority of the clinical participants interpreted the benevolent voice as wanting to harm and cause distress, with the exception of the participants with religious and/or spiritual beliefs, who generally found that the voice was a positive experience. Finally, one of the main strengths of this study is that it provides some of the first qualitative evidence comparing and contrasting the similarities and differences and meaning-making amongst clinical and Evangelical voice-hearers from a Black ethnic background. It is clear from the results of the study that voice-hearing is a complex phenomenon and further exploration of Black clinical religious and/or spiritual voice-hearers is needed in order to better equip clinicians and aid mental health services, to ensure the best possible holistic care for its service users.

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Paper 3: Critical Appraisal and Refection

Word count 4, 785

Overview

The aim of this paper is to provide the reader with a critical appraisal of the research process as a whole, to put both papers presented into the wider context of evidence and practice, and to present personal reflections on the work. This critical reflection paper is organised into three sections. The first discusses the strengths and difficulties of the systematic review, the second the strengths and difficulties of the empirical research and the final section is a personal reflection of the research journey of Paper 1 and 2.

Reflections on Paper 1

Rationale for the topic choice

This topic choice was decided after a preliminary scope of the existing research and gaps within the positive area of religion and spirituality in mental health. After a number of discussions with the supervisory team it was decided to focus on psychosis rather than mental health in general, given the topic of the empirical paper and the recommendations outlined in key research (McCarthy-Jones, Waegeli & Watkins, 2013). It was felt that this would be a worthwhile systematic review, synthesising existing qualitative research in this area with a hope to inform future studies and clinical practice.

Having worked in a variety of mental health services whilst as a trainee clinical psychologist, it was felt that there was a general lack of awareness by professional's regarding the importance that religion and spirituality has on the psychological wellbeing in services. The topic was therefore motivated not only by the existing theoretical and empirical literature (Huguelet, Mohr, Borras, Gillieron,& Brandt, 2006; Mohr et al., 2010; Grover, Davuluri, & Chakrabarti, 2014; Cornah 2006) but also by professional experience. It was therefore felt that synthesising the existing qualitative literature in order to have an overall picture of the research was important, although it is recognised that this is an evolving and growing research area that needs more robust and in-depth qualitative research to increase understanding of the lives of those with psychosis within the context of religion and spirituality.

Rationale for conducting a thematic synthesis techniques

Initial scoping of the literature revealed that whilst there where many quantitative studies in the area of religion and spiritualty, there was no systematic literature review, synthesising the qualitative research. Whilst there are various ways to synthesise qualitative research; grounded theory synthesis (Eaves, 2001), meta-ethnography (Noblit & Hare, 1988), meta-study (Paterson, Thorne, Canam & Jillings, (2001), it was originally felt (after discussion with the lead supervisor for the systematic review, Dr Filippo Varese) that a meta-synthesis (Stern & Harris, 1985) may be most appropriate as it uses rigorous qualitative methods to synthesise existing qualitative research (Erwin, Brotherson & Summers, 2011) and allows the integration of results from a number of different but interrelated qualitative studies (Walsh & Downe, 2005). However, given the difficulties within the research projects and the timescale (discussed later on in the text), and the limited number of results from the full-text screening, it was decided that either a thematic synthesis or meta-ethnography could be used. A meta-ethnography may have been used in this systematic review as it useful for a small number of studies however meta-ethnography usually works better for thicker and richer data (Tong et al, 2012). After the full text screening had been completed it was apparent that some of the eligible studies lacked in richness and depth. A thematic synthesis is useful for thinner studies (Tong, Flemming, McInnes, Oliver, & Craig, 2012) and therefore a combination of both a narrative synthesis which allows integration of various types of evidence (Mays, Pope, & Popay, 2005) and incorporating thematic synthesis techniques was decided. This was partly due to the small numbers of qualitative studies, but also that thematic techniques allow for the regrouping of themes, comparing and contrasting similarities and differences, and the development of overarching thematic headings (Lucas, Baird, Arai, Law, & Roberts, 2007**).**

Limited number of eligible studies

There were a particularly small number of relevant studies eligible for the systematic review. This was due to the fact that the research area is underdeveloped in terms of qualitative literature (Cornah, 2006) and some of the included studies were not all directly related to the proposed research question. Subsequently, themes that were grouped in this systematic review, were developed from secondary themes in several of the papers (Yang, Narayanasamy, & Chang, 2012; Virdee et al., 2011; Wagner & King 2005), which therefore impacted upon the richness and depth of the findings.

In hindsight, one way of overcoming this could have been to include mixed method design studies, which may have yielded a greater number of relevant papers. The rationale for only including qualitative studies in the systematic review was to keep homogeneity within the research design of the studies, in a hope that solely qualitative research may have provided a richer and more in-depth analysis than a mixed methods design.

Quality assessment – CASP

The CASP (Public Health Resource Unit, 2006) quality assessment tool was used to assess the quality of the included papers. Myself and a colleague, external to the project completed the CASP tool separately to reduce bias. The Kappa score revealed a ‘substantial agreement’ according to McHugh, (2012). However, as there was a limited amount of included papers, judgement about the quality of the papers may have been influenced, as there was not a wealth of studies to compare and contrast to, which may have caused bias. However, the inter-rater reliability confirmed an overall agreement.

Inclusion/exclusion criteria

The stringent inclusion and exclusion criteria that was applied when developing our systematic review, meant that studies with participants under the age of 18 were excluded.

This was based on the fact that adults in this population are autonomous, the peak onset of psychosis is 19 years and above (Gogtay, Vyas, Testa, Wood, & Pantelis, (2011) and to keep homogeneity of the analysis.

The decision to only include English language papers was based on a limitation to access funds to have any possible eligible papers transcribed, however it is recognised that some otherwise eligible papers may have not been included because they were not written in English and, given the topic area may raise some limitations of the studies included in this review.

Clinical implications

One of the clinical limitations of the systematic review is that the participants included in the review were 18 years and above. Therefore, the findings cannot be extrapolated to individuals below this age range.

Overall reflections

On the basis of the review, recommendations were made for further qualitative research with in this topic area, to further synthesise and draw conclusions regarding the usefulness of religion and spirituality in people living with psychosis. However, from the systematic review it was clear that for many living with psychosis, religion and/or spirituality can be fundamental to helping them manage and cope. The literature has highlighted the extent to which religion and spirituality are not routinely assessed and incorporated within mental health services (Blanch 2007; Nolan et al., 2012; Mohr et al., 2006; Cornah 2006,), with health professionals feeling unequipped to explore such experiences and a lack of time and resources (Koenig, 2004). Another potential barrier could be due to the Westernised medical model of understanding psychosis, with psychiatry potentially struggling to adopt a model different to the one that they are invested in (Cornah, 2006). One other possible reason for the difficulty in implementing such holistic ways of working, could be due to the current financial climate of the NHS, meaning training opportunities are slim, and morale is low (Robertson, Wenzel, Thompson, & Charles, (2017).

As a newly qualified clinical psychologist working within a mental health service, it will be important to utilise this knowledge learnt to enable better clinical practice, which can be adapted to a variety of clinical populations. Being sensitive and attuned to the role that religiosity and spirituality plays within individuals presenting at services could enable a more holistic assessment and formulation to the individual's needs. In May 2018 the British Psychological Society (BPS) published a special issue booklet in the Clinical Psychology Forum called: *Spotlight on holistic practice within clinical psychology*. One of the articles by Yusupoff (2018) highlighted the importance of holistically informed assessment and formulation, offering practical guidance in assessing clients from a more holistic stance. Whilst there is a significant amount of literature and key documents providing guidance on the best ways of working within the context of religion and spirituality, it was felt that clinical training did not cover this issue as fully as it could have done. More training is needed to equip clinical trainees with the awareness, knowledge and skills needed in order to be able to understand a person's mental health problems within the context of religion and spirituality. One way of overcoming this is to add the role of religion and spirituality within the curriculum. Having teaching co-facilitated with an expert by experience may help to bring to fruition the concept and generate conversations about the possible benefit and drawbacks of religion and spirituality in mental health.

Furthermore, it is recognised that integrating religiousness and spirituality with a mental health services may prove difficult (Morgan et al., 200; Koenig, 2004). As a newly qualified clinical psychologist joining a team, it will be important to be aware of service needs and current financial climate in understanding the service and team. Building a rapport and a good professional working relationship will be paramount in affecting change within a service. Producing a presentation and an overview of the current literature to the team may be one way to help raise awareness and at the very least start a conversations about the role that religion and spirituality can have on the psychological well-being of the service users.

Reflections on Paper 2

Rationale for the research

It was felt that the empirical research was a pertinent and important topic area, given the high prevalence of psychosis amongst people from a Black ethnic background (Fearon et al., 2006), higher prevalence of religion and spirituality within this group (Rabiee & Smith, 2014) and the lack of culturally sensitive mental health services (Lawlor, Johnson, Cole, & Howard, 2012). It was hoped that the research would increase understanding into Black clinical and non-clinical voice-hearers.

Issues arising during the design of the project

This research project was part of a larger scale mixed methods design project which aimed to compare and contrast voice-hearing and meaning-making in Black clinical and Black Evangelical non-clinical voice-hearers. This study used a qualitative design with semi-structured interviews to explore hearing-voices and meaning –making.

There were difficulties within the research team at the stage of developing the design of the project, with a disagreement regarding a suitable number of participants. Initially it was proposed that 40 participants were needed for the qualitative project. However this was raised by the course research sub-committee as a potential problem with regard to what was achievable on a doctoral level programme, and subsequently it was agreed amongst the research team that 20 participants would be sufficient in reaching data saturation and warranting a doctoral level thesis.

Sampling and recruitment

Although the intended recruitment target was 20 participants (10 from each group), 16 participants were successfully recruited into the project. This was due to difficulties in recruiting participants. Participants were difficult to recruit for a number of reasons, including a stringent inclusion and exclusion criteria, access to participants, and in particular for the clinical group, and a lack of support from mental health services with the recruitment stage.

A stringent inclusion and exclusion criteria meant that it was extremely difficult to recruit participants. For example, only people who either self-identified as Black-African or Black-Caribbean, or had a parent, or at least one grandparent from either Africa or the Caribbean were included in the study. This was due to a rationale that participants from beyond third-generation heritage would be more likely to be embedded within a British culture.

Furthermore, part of the recruitment strategy was promoting the project through presentations and liaison with targeted mental health services. However, the logistics of organising such meetings and presentations proved to be difficult, with services having little time to offer this space. Mental health professionals appeared to struggle to hold the project in mind after such presentations and only a small number of mental health professionals identified potential participants for the study. Given the increasing demands on mental health services and lack of resources (Roberston et al., 2017) within teams, it was understandable that they struggled to identify potential participants. It was also noted within the project that some mental health professionals where ‘gatekeeping’ and had made a decision about whether or not their clients would benefit from such a project. However, as part of the recruitment strategy, posters (see Appendix 12) were placed within key mental health services in order to overcome such barriers. However, this still did not did not prove beneficial.

The contingency plan, which was originally to expand the ethnic group to include all Black Minority Ethnic (BME) groups, was not implemented as doing so would of course increase the variance between the samples and therefore the research would not have been specific to Black groups, which was at the forefront of why the research was being conducted. The supervisory team and wider course team agreed that the benefits of maintaining homogeneity of a small sample outweighed the benefits of getting a larger one that was heterogeneous in ethnicity.

As the project was a mixed methods design, it had been agreed that the participants for the qualitative project would be selected from the larger quantitative project. In order to make the workload fair, it was agreed that both trainees (AC and another trainee) would share the recruitment. Nevertheless, the recruitment still proved extremely difficult. One way of aiding recruitment was to attend church on a Sunday service, and an 'African and Caribbean' wellness conference. Attending church proved an excellent way of recruiting non-clinical participants for the study, and worthwhile.

This project has given me the opportunity to work within a wider research project with different strands to the research. It has enabled some joint working which I found both beneficial and at times required additional organisational and communication skills to ensure both project aims were met.

Originally, a sampling framework had been designed into the study as a way of guaranteeing variance amongst the participants. It was proposed that the first five participants from both the clinical and Evangelical non-clinical group would be recruited, with the next five from each group purposefully sampled in order to create variance amongst the two groups. For example, if the first five from each group were all-male between the age of 35 and 55, then the next five participants from each group would focus predominantly on females in a younger or older category. However, given how difficult it was to recruit participants, especially for the clinical group, it was decided that this would not be implemented, as it would have further limited recruitment.

The extent of the difficulty in recruiting participants for this study meant that the majority of research time was dedicated to the empirical research project with liaising with services, attending meetings, advertising the study, and seeing participants. This meant that the systematic review suffered as a consequence, as did the empirical research in terms of monthly recruitment targets. Several research review meetings were organised between the trainee, research supervisory team and the wider course team, in order to complete the thesis within a timeframe that did not require rescheduling the viva. It was decided that recruitment would end in December 2017 and that 16 participants was sufficient, given how far behind both projects were.

Methodological reflections

Analysis

Thematic Analysis (TA) (Braun and Clark, 2006) was used in order to code, organise and develop themes and subthemes across the data. Whilst various other qualitative analytical methods could have been used such as, grounded theory (GT) Glaser and Strauss, (2017), or interpretive phenomenological analysis (IPA) Smith (2010), TA seemed most appropriate. GT focuses on developing theory from the data but given there was a clear research question, this did not feel most appropriate. Furthermore, IPA focuses on the lived experience of individuals and can be utilised to generate themes across a small number of participants. Whilst IPA could have been used to answer the research question in this empirical study, it was felt that due to the research design exploring the similarities and differences across the dataset, TA was more suitable, given its flexibility in identifying and analysing patterns and themes within the text (Braun & Clarke, 2006).

Interpretation

Culture was originally thought to have been an important area of discussion within this client group, and was therefore implemented into the interview schedule (see Appendix 5). However, the concept of culture did not appear to be as important as initially thought and therefore no themes were developed in this area. One of the reasons for this could be that the concept of culture in itself is difficult to define, and is a fluid concept rather than static (Gjerde, 2004). ‘Black’ people can tend to be grouped into one cultural group (Agyemang, Bhopal, & Bruijnzeels,(2005). However, there is variance amongst this that goes beyond people’s ethnic background. For example, the majority of participants identified with a West-African origin, with other participants from an East African, African and the Caribbean heritage, and whilst there are similarities, there are also differences in terms of food, language, and religious beliefs.

The interview schedule may not have been sensitive to these differences within cultures, as the culture questions within the interview schedule did not go into any great detail about specific cultural contexts. In future, these specific differences within cultures should be incorporated into the interview schedule, in order to initiate conversations around these similarities and differences.

Reflexivity (the process of conducting research and one’s own role) is an important part of qualitative research (Le Gallais 2008), especially during the analysis and interpretation stage.

Tobin and Begley (2004) propose that we as humans, with our lived experience will have subjective bias. Therefore, as a novice researcher, it felt important to be aware of one's own subjective bias, beliefs and values, and how this may impact upon the interpretation of the data. Throughout the process reflections and observations were documented in order to help acknowledge the positioning of one's self to the data. Pertinent reflections were discussed in supervision with the lead supervisor (DE) to try and gain perspective and be objective (as objective as possible). Engaging in such a process can add understanding into the participants experiences and also enhances one's own reflexivity (Le Gallais, 2008).

Overall reflections, future research and clinical implications

Overall, despite its challenges the project has provided a greater insight into Black clinical Black Evangelical and non-clinical voice-hearers. This area would benefit from further research especially qualitative research. It has also highlighted the need for more culturally adapted mental health services within the UK.

There were a number of challenges in completing this research in terms of the research design phase and recruitment. There was also a challenge from one of the third-sector mental health services that this research was exclusively designed to support people from African and Caribbean backgrounds. Several members of staff within the mental health service had questioned the usefulness of the research, having previously been involved in an African and Caribbean research project before and feeling less than satisfied with the outcome. One staff member in particular had commented how *'I did not know what it was like for people like them'*. This comment was perceived as being an acknowledgement of the ethnic difference between the trainee and the staff and service users within the service. Another member of the team had felt strongly about the amount of money (£7) that participants were gifted for taking part in the research project. The staff member articulated her *'disgust'* and felt strongly that this was undervaluing potential participants. This was a difficult situation to manage, however the staff member’s disgruntlement was acknowledged, whilst explaining the process and limitations of a doctorate in clinical psychology research project.

It was evident that there were possible racial tensions being projected within the service and it was difficult to manage other people’s assumptions and expectations, given previous experiences. The purpose of the research project may have felt tokenistic to the service, and this may be a possible reason for the disgruntlement amongst staff members. Also, being a white European female and possibly perceived as being from a middle-class background may have been a barrier to gaining trust with the service. On reflection, being more open and transparent about the motives of the researcher, supervisory team and the project as whole, may have encouraged better working relationships.

Attending several Evangelical churches to aid recruitment was an unfamiliar but worthwhile experience. Being in a church, amongst the few white European people within the room had evoked a sense of uncomfortableness. On reflection, I wondered whether this ‘uncomfortableness’ was due to being in a religious setting where people were singing and dancing or whether it was because it was my first experiences of being ‘an ethnic minority’.

This was an invaluable experience in helping to think about how it might feel for Black service users encountering predominantly white mental health professionals in mainstream services. Black people often experience discrimination, racism and prejudiced because of their ethnicity (Singh & Burns, 2006). Therefore, it is understandable why people from this ethnic background may feel mistrustful, frightened and wary of the motives of services. It also initiated a deeper level of understanding of the privileges that white European people have compared to this ethnic background and how these may be potential barriers within services. It is wondered whether mental health professionals are aware of their potential prejudice and how this may impact upon service development, access and engagement.

This project has initiated a desire to want to learn more about Black history and has offered new insights into the tragic suffering and horrific events that have taken place (and still do). As a result, it has cultivated a deeper sensitivity to the needs of Black individuals and highlighted how services are underequipped to deal with these needs.

Personal reflections on the research journey

My interest in the role of religion and spirituality within mental health services was first initiated through my clinical work. When working in services, I was struck by how many people used religion and spirituality as a resource and strength. I was fascinated how infrequently services acknowledged this as protective factors, and even, at times interpreted it as part of the problem. During my training, I developed an interest in hearing people's stories of how religion and spirituality aided their recovery. Alongside this clinical awareness I was also developing my own personal spiritual journey. Through my own most challenging times, when I already had therapeutic support, spirituality gave me another dimension in which to understand my experiences and develop skills to manage and cope with distress. I have worked to develop my understanding of religion and spirituality over time, through travelling to Eastern parts of the world, indulging in various cultures and having conversations with religious and spiritual leaders. For me, spirituality has been both a comfort and strength in difficult times. As a consequence of the profound impact upon my life, I completed my 200-hour Yoga Teacher Training program in India in 2014. These clinical and personal experiences have made it important that I become a Clinical Psychologist who hears respects and values the beliefs of my clients.

Specific learning difficulty

Having a specific learning difficulty (SLD) such as dyslexia, has meant that managing the competing demands of the research projects, alongside the clinical and academic aspects of the course, has been challenging at times. A particular challenge has been in organising multiple tasks simultaneously when I am aware these tasks take me longer than my peers. I have developed resilience through having to push for getting the correct support (e.g. study coach, Alison), to accessing additional disability student allowance for software and to being understood within the different supervisory relationships.

Opportunities for further personal development and awareness

My clinical and research experience has shown me how, for some people voice-hearing is a normal part of everyday life which is revered whereas, for others it can be problematic. My professional experiences made me aware of how voice-hearing can often be hidden and not obvious to others. I have been struck through my clinician and research experience interviewing participants, how much voice-hearing can impact upon daily living. It made me reflect on our culture and society and how difficult it can be for voice-hearers to be open and honest about their experiences, without feeling judged or dismissed. Having dyslexia made me reflect on how I too have an ‘invisible’ difficulty. Whilst this may not be obvious to others, it affects me daily, though organising, planning and managing tasks, which takes me longer to complete than others without a specific learning difficulty.

Like some of the participants I have had to hide my difficulties. Struggling with processing information, reading and writing meant that I often felt ashamed and embarrassed in school. As a consequence, I would often hide my struggles and learned to live with it. Until later on in life, I received a name for my difficulties ‘dyslexia’. This was one of the first experiences of having my difficulties validated and given an explanation. Whilst I feel somewhat uncomfortable with the concept of diagnoses in general, without this, I would not have been able to access support. I feel that there are strengths to my difficulties, like creativity, problem solving and visual processing, similarly how there are many positives to voice-hearing.

My personal experiences made me reflect on the similarities I share with some of the voice-hearers, in that they too have learned to live with their struggles and had to wait a considerably long time to access support. Even when they have accessed support, people are often still misunderstood, judged and invalidated. It made me reflect on who the ‘problem’ is for and whether living in a society that pathologises experience creates the ‘problem’ rather than the ‘problem’ itself. This awareness has made me have a new level of appreciation and respect for the participants in this study. To have experienced all they have and still managed to cope, show their strength, determinations and resilience.

Self-care

One of the main ways I have managed the challenges throughout this process is through self-care. For me, self-care is a paramount part of maintaining healthy mental health. Yoga, meditation and a healthy balanced diet have enabled me to manage stress, give me a more balanced perspective and the energy needed to manage and cope with these difficult times. It has made me reflect on the similarities I share with some of the participants within this research project. For some, they utilised their religious and spiritual beliefs in order to help them manage and cope with distress and difficult times in their lives. I too have drawn on my spiritual practices to help me overcome struggles. Although these experiences have been difficult, I have gained further resilience, a deeper understanding of struggle, and new assertiveness about the importance of hearing my own voice/needs. I feel that these will be important skills when qualifying as a Clinical Psychologist and working within services. Not only for myself, in accessing support, but also helping to think about how hard it can be for people to have their needs met and the journey they may have been on, just to get to this point. I feel all of these experiences have helped me develop into a more sensitive, attuned and empathetic clinician.

Conclusion

Being involved in this research process has highlighted the importance of the role of religion and spirituality for people with psychosis, whether clinical or non-clinical voice-hearers from a Black ethnic background. Further understanding of the role of religion and spirituality is needed within services such as developing better liaison with outreach groups, volunteer and religious organisations. The wording of letters or descriptions of psychological interventions may also need to be thought about thoroughly and sensitively. Consulting with experts by experience from this ethnic background would also be important, as well as the engagement of community, families and outreach programs. Finally, it has highlighted the courage and resilience of people living with psychosis and challenged potential biases which may be unconscious in our daily awareness. It has been a challenging, yet worthwhile project and I am grateful to have had the opportunity to be a part of it.

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Appendices

Appendix 1: Author guidelines for the Journal of Psychosis

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Appendix 2: Critical Appraisal Skills Programme (CASP) Checklist

CASP
Critical Appraisal
Skills Programme

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Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the tight methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher’s arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-

based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 3: A Table highlighting the themes represented across the data

A table highlighting the themes represented across the data

	Theme 1: Religion and spirituality as a positive framework for understanding psychosis	**Theme 2: Religious and/or spiritual practices for managing psychosis**	**Theme 3: Having faith instils hope for the future**
Nixon et al, (2010)		x	
Yang et al, (2011)	x	x	
Virdee et al (2016)		x	
Smith and Suto (2012)		x	
Hustoft et al, (2013)	x		x
Smith and Suto (2013)		x	
Islam et al, (2015)	x		
Hanevik et al, (2017)			x
Wagner & King (2005)			x
Chan et al, (2015)			x
Total	3	5	4

Appendix 4: Author Guidelines for the Journal of *Ethnicity and Health*

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

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Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

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Appendix 5: Topic guide (interview schedule for participant)

Interview schedule:

Research title: Exploring experiences and distress in African and Caribbean clinical and non-clinical voice-hearers: A mixed methods study.
The main aim of this research is to explore voice hearing in African Caribbean (A-C) and Black African (B-A) people who have been diagnosed with mental illness and those who have not. We are particularly interested in the relationship between voice hearing, culture and spirituality. The study also aims:

- i) To explore the way in which people interpret, manage and respond to their voice hearing experiences.
- ii) To increase understanding of what makes voice hearing distressing for some people and not others.
- iii) To understand how experiencing voice hearing as distressing or not affects people's goals and motivations.
- iv) To promote a more culturally sensitive understanding of voice-hearing healthcare professionals.

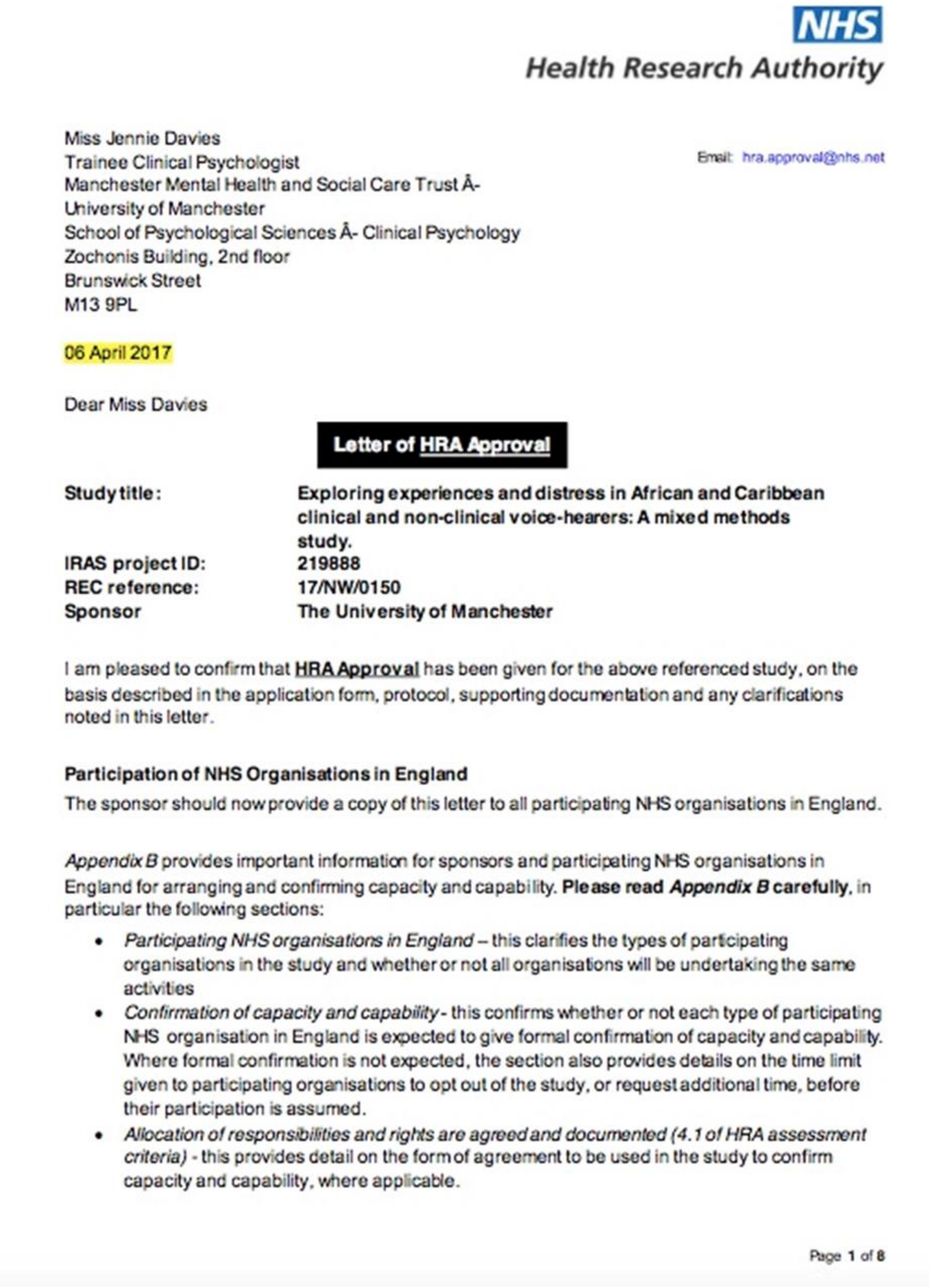
Interview schedule:
Preamble: Hello, my name is Alex. I'm going to ask you some questions about voice hearing. Explain procedure, including what to do in case of distress/want to stop. Give reassurance re confidentiality and anonymity. Confirm consent to record.

Q1. When did you first experience voice hearing?
Probe (if needed) – How did it feel at the time? What did you make of it? What did you think was happening?
Q2. What do the voices say? Do they say the same thing/ Has this changed over time?
Q3. How would you describe how the voices sound?
Probe - angry, calm, soothing etc
Q4. What kind of things do the voices say?
Probe - Does this vary if so, in what way?
Q5. How do you make sense of your voice hearing experiences?
Probe - what does it mean to you, are you able to explain it to other people, if so, what do you tell them, how do people react?
Q6. Please tell me what you believe about the voice(s)?
Q7. How would you describe your relationship with the voice(s)?
Probe - Do you like the voices? Do you find voices comforting? Are you fearful of the voices? etc
Q8. Do the voices ever cause you distress, if yes how?
Probe - Can you think of a time when this was particularly distressing? If so, what was that like?
Q9. How do you manage your voice hearing experiences?
Q10. How much of an impact does voice hearing experience have on your life?
Probe – In what way? Does it impact upon personal goals you may have?
Q11- In your experience/view, is there a relationship between spirituality or religion and voice hearing? Please explain why you think that.
Q 12 - Some people say voice hearing is an important part of their spiritual/religious experience. What are your views about this?
Q13. Do you think culture affects voice hearing experiences? Please say why you think that?
Probes- Specific aspects of culture: family culture, society etc.

Q14. How could mental health (and other?) services be improved for people who hear voices?
Q15. Is there anything I’ve missed that you think is important to add?

Appendix 6: Letter of HRA approval

HRA approval



NHS
Health Research Authority

Miss Jennie Davies
Trainee Clinical Psychologist
Manchester Mental Health and Social Care Trust Â-
University of Manchester
School of Psychological Sciences Â- Clinical Psychology
Zochonis Building, 2nd floor
Brunswick Street
M13 9PL

Email: hra.approval@nhs.net

06 April 2017

Dear Miss Davies

Letter of HRA Approval

Study title:	**Exploring experiences and distress in African and Caribbean clinical and non-clinical voice-hearers: A mixed methods study.**
IRAS project ID:	**219888**
REC reference:	**17/NW/0150**
Sponsor	**The University of Manchester**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Appendix 7: Participant information sheet

Division of Psychology and
Mental Health
The University of Manchester
Zochonis Building (2nd Floor)
Brunswick Street
Manchester
M13 9PL

Title of Project: Voice hearing in an African and Caribbean population
Names of researchers: Alexandra Clark and Jennie Davies

Information for Participants

We would like to invite you to take part in a research study. Before you decide whether or not you would like to take part, please take time to read the following information. If there is anything that isn't clear or that you would like to know more about, feel free to ask – my contact details are at the end of this leaflet.

What is the purpose of the study?

We would like to find out more about the experience of hearing voices among people from Black African or Caribbean backgrounds. This includes people who regard themselves as 'Black British', 'Mixed' heritage but who have at least one parent or grandparent who was born in Africa or the Caribbean. Specifically, we want to hear about how people people interpret, manage and respond to their voice hearing experiences.

We know that many people who hear voices do not have any mental health problems and regard their voices as a positive part of their lives. Some people who hear voices, however, find the experience difficult and frightening. We hope this research will help us to understand what makes hearing voices pleasant or distressing for people from African or Caribbean backgrounds, what this experience is like and they deal with these experiences.

Who can take part in the study?

We would like to speak with people from African or Caribbean backgrounds who have heard voices within the last six months. We are interested in speaking to people who have all different kinds of experiences of hearing voices, be that negative, positive or neutral. We hope to speak to about 40 people in total.

What will happen if I decide to take part?

If you decide to take part in this study, you will be invited to meet with Jennie Davies, who is a Trainee Clinical Psychologist, for the first part of this study. You can meet at a location that suits you. Wherever you meet the researcher, you will be able to talk in private. This part of the study will take approximately 1 hour. You can complete the study within one single meeting or, if you prefer, over two or more shorter meetings. During this time, you will be asked to complete some interviews and questionnaires.

At the beginning of this meeting, you will be asked to give some general information about yourself, including your name, contact details, age, ethnicity and if you have ever been given a mental health diagnosis.

Following this, the researcher will ask you to describe some of your most important goals (experiences that you generally try to achieve, like spending more time with your family, or perhaps avoid, like being rude to people), and will interview you to understand the reasons why these goals are important to you. You will also be asked to tell us how happy or unhappy you would feel if you managed to achieve your goals.

You will then be asked some questions about your experience of hearing voices, including a bit about what they are like for you and what you think about them. There are no right or wrong answers and the researcher will not judge you. You do not have to answer any questions that you don’t want to answer, and you can choose to stop altogether at any point without giving a reason. At the end of the meeting you will receive £7 as a thank-you for your time.

Following the first part of the study, and with your permission, a number of people will be contacted to be invited to meet with Alexandra Clark, who is also a Trainee Clinical Psychologist, for the second part of this study. As before, you can meet at a location that suits you, and you will be able to talk in private. This part of the study will take approximately an hour to an hour and half. During this time, you will have the opportunity to talk about your experience of hearing voices and how you have made sense of the voices. This interview will be audio-recorded. Again, there are no right or wrong answers and the researcher will not judge you. You do not have to answer any questions that you don't want to answer, and you can choose to stop altogether at any point without giving a reason. At the end of the meeting you will receive a further £7 as a thank-you for your time.

Will what I tell you be kept private?

Yes. The information collected as part of the study will be handled in strict confidence. The data will be stored in a secure place at the University of Manchester and only researchers will have access to it. There is one exception to this: if you tell us anything that makes us think that you or anyone else is at risk of serious harm, we will have to share this information (for example, with your GP or with your keyworker in case you have one). However, we would always want to discuss this with you before we spoke to anyone else.

Part of the interviews you may be asked to complete will be audio-recorded. Once the study is finished, the researcher will write up the content of these interviews and destroy the original recordings to protect your privacy and confidentiality. The researcher will not write up any information that could directly identify you such as your name or names of people or places you talk about.

The results of the study will be written up to be published in a journal. This will not include any information that could identify you.

Do I have to take part?

No. It is entirely up to you whether you decide to take part or not. If you decide not to take part, this will not affect any care that you are receiving at all. If you do decide to take part, you will be asked to sign a consent form. You are free to change your mind and withdraw from the study at any time, and you don't need to give a reason. Please note that once we have combined the information you give us with other people's, it will not be possible to do this. However, we would make sure that none of the information you share will be quoted.

What about paying for travel?

If you are travelling to the appointments with the researcher by standard-fare public transport (bus or Metrolink), we can reimburse your travel expenses. This would need to be agreed with the researcher beforehand. Please make sure you keep tickets/receipts to give to the researcher as we will not be able to give you the money without this.

Are there any disadvantages to taking part?

None that we are aware of. However, some of the questions are sensitive. If you find anything particularly upsetting, the researcher will be there if you would like to talk about it. She will also be able to give you information about how you can get extra support.

Who is organising the research?

The main researchers are Alexandra Clark and Jennie Davies. They are Trainee Clinical Psychologists at the University of Manchester. This research will form part of their training. Alexandra and Jennie are supervised by Dr Dawn Edge, Dr Filippo Varese and Dr Warren Mansell.

Please get in touch if you would like to ask any questions or if you would like to take part.

Who has reviewed the research?

This project has been approved by NHS and the University of Manchester Research Ethics Committees (insert refs)

Contact Details:

Alexandra Clark Tel: 07895873542

Jennie Davies Tel: 07895892447

Email: ***VoicesResearchManchester@gmail.com***

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If there are any issues regarding this research that you would prefer not to discuss with members of the research team, please contact the Research Practice and Governance Co-ordinator by either writing to 'The Research Practice and Governance Co-ordinator, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL', by emailing: Research-Governance@manchester.ac.uk , or by telephoning 0161 275 7583 or 275 8093.

Thank you very much for showing an interest in this study and for taking the time to read this information.

Appendix 8: Consent form

Consent Form

Study Title: Research title: Exploring experiences and distress in African and Caribbean clinical and non-clinical voice-hearers: A mixed methods study.
Chief Investigator: Jennie Davies
If you are interested in taking part in this study and would like the researchers to contact you please give your details below. You should only provide the information if you are happy to be contacted in that way. For example, if you do not want to be contacted by phone then do not provide a phone number.
Please note the following points in relation to the processing of your data:

- Data will be held securely by the research team on behalf of the University of Manchester according to the University's data protection and information security policies.
- Access to the data will be restricted to the research team for the sole purpose of contacting you about this study.
- Your data will not be shared with any third party without your written permission.
- The details collected will only be stored for as long as required to find out if you wish to take part in the study. Once no longer needed, that data will be destroyed securely.
- If you decide to change your mind about being contacted about the study or would like your details to be destroyed you can contact: Jennie Davies, Tel: 07895892447 or Alexandra Clark, Tel: 07895873542 (researchers on the study) or by email at hearingvoices@manchester.ac.uk.

Once you have completed your details, please ensure that you have added your signature. Tear off and return the part of the form below, please keep the top half for your records.

Alternatively, if you wish to contact us directly, please do so on the contact details above.

✂---

I am happy **to provide/for my health care professional to provide** (delete as appropriate) my personal details so that I can be contacted about this study.

Name	
Signature	
Today's date	

Please complete the details below or hand back to your health care provider to complete on your behalf

Contact by letter	Address	
	Post Code	
Contact by phone	Preferred contact number	
	When would you prefer to be contacted? (please circle)	Morning/ Afternoon/ Evening/ Don't Mind
Contact by email	Email address	

Appendix 9: General demographics

Research title: Exploring experiences and distress in African and Caribbean clinical and non-clinical voice-hearers: A mixed methods study.

Contact Information

Participant Number:	
Name:	
Address:	
Tel Number:	
Email:	

THIS PAGE IS TO BE KEPT SEPARATE FROM RESEARCH DATA

Demographic Information

Group	Clinical / Non clinical
Gender	Male Female Other:
Age	
Ethnicity	Self Parent Grandparent
First Language	
Are you married? No – were you ever?	Y or living with someone as if married Widowed Divorced/ annulled Separated Never married
Highest level of education	
Are you working or studying at the moment?	Unemployed Working Studying

Diagnosis / treatment (if recruited from NHS, fill in with care-co)

Have you ever seen a health professional for emotional / psychiatric problems? If yes, what for? When was this? Last 6 months Y/N?	
Has a health professional ever told you, or do you believe that you have psychosis, schizophrenia or something else that has caused you to hear voices?	

Appendix 10: Debrief sheet clinical participants

Division of Psychology and Mental Health
University of Manchester
2nd Floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL

DEBRIEFING SHEET

Research title: Exploring experiences and distress in African and Caribbean clinical and non-clinical voice-hearers: A mixed methods study. (Phase two)

Thank you for your participation. This is a summary of the main aims of our investigation, which the researcher explained to you in more detail at the end of this phase of the study.

Hearing voices is **not** in itself a sign of mental health difficulties. Research has shown that hearing voices is quite common among people with no history of mental health difficulties. Distress seems to be the main factor determining whether a voice hearer requires mental health support or not. This study tried to look at some of the reasons why hearing voices is perceived as problematic and distressing by some individuals, while others see it as a positive and sometimes constructive experience.

Specifically, we are trying to understand how people understand their experiences and what determines whether or not voices are perceived as distressing for people with an African or Caribbean background. We hope this research will help to explore whether this is true for people with different cultural backgrounds, and to start to look at whether this is the best explanation for differences in distress caused by voices.

We will analyse the interviews carried out as part of this study, and we hope that the findings of this study will help us to develop better ways to support individuals with distressing voices.

If you would like further information concerning the aforementioned topics, or would like to be kept informed about the progress and results of the study, please contact Alexandra Clark or Jennie Davies at (hearingvoices@manchester.ac.uk), or 07895873542 or 07895892447. We understand that some of the topics covered in this investigation and the materials used in this study might have caused you some discomfort. If you still feel upset as a result of the procedures involved in this study, don’t hesitate to contact Alexandra Clark or Jennie Davies at the above contact details, or Warren Mansell at Warren.Mansell@manchester.ac.uk, who can provide advice about available support.

If you experience distress in future, you can talk to your care coordinator, GP or other members of your clinical team to receive further support. You can also approach the Samaritans. The Samaritans can offer confidential support either by phone (Tel: 08457 90 90 90) or face-to-face consultations (by visiting their local branch). In addition, A&E services can help you to deal with situations of serious distress or risk.

Appendix 11: Debrief sheet for Evangelical on-clinical participants

Division of Psychology and Mental Health
University of Manchester
2nd Floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL

Exploring experiences and distress in African and Caribbean clinical and non-clinical voice-hearers: A mixed methods study. (Phase two)

Thank you for your participation. This is a summary of the main aims of our investigation, which the researcher explained to you in more detail at the end of this phase of the study.

Hearing voices is **not** in itself a sign of mental health difficulties. Research has shown that hearing voices is quite common among people with no history of mental health difficulties. How people interpret and manage their voice hearing experiences seems to be the main factor determining whether a voice hearer requires mental health support or not. This study tried to explore some of the reasons why hearing voices is perceived as problematic and distressing by some individuals, while others see it as a positive and sometimes constructive experience.

Specifically, we are trying to understand how people understand their experiences and what determines whether or not voices are perceived as distressing for people with an African or Caribbean background. We hope this research will help to explore whether this is true for people with different cultural backgrounds, and to start to look at whether this is the best explanation for differences in distress caused by voices.

We will analyse the interviews carried out as part of this study, and we hope that the findings of this study will help us to develop better ways to support individuals with distressing voices.

If you would like further information concerning the aforementioned topics, or would like to be kept informed about the progress and results of the study, please contact Alexandra Clark or Jennie Davies at (hearingvoices@manchester.ac.uk), or 07895873542 or 07895892447. We understand that some of the topics covered in this investigation and the materials used in this study might have caused you some discomfort. If you still feel upset as a result of the procedures involved in this study, don’t hesitate to contact Alexandra Clark or Jennie Davies at the above contact details, or Warren Mansell at Warren.Mansell@manchester.ac.uk, who can provide advice about available support.

If you will experience distress in future, you can talk to your GP to receive further support. You can also approach the Samaritans. The Samaritans can offer confidential support either by phone (Tel: 08457 90 90 90) or face-to-face consultations (by visiting their local branch). In addition, A&E services can help you to deal with situations of serious distress or risk.

Appendix 12: Study advertisement

Participant advertisement

Study title: Exploring experiences and distress in African and Caribbean clinical and non-clinical voice-hearers: A mixed methods study

MANCHESTER
1824

The University of Manchester

Division of Psychology and Mental Health
The University of Manchester
Zochonis Building (2nd floor)
Brunswick Street
Manchester
M13 9PL

NRES approval reference:

Do you hear voices that other people can't hear?

Do you identify yourself as of Black African or Caribbean background*?

For some people, hearing voices can be difficult to manage and cope with. For others, it can be a positive part of life. We want to try and understand why this is.

We are looking for people who wold like to take part in a research study, sponsored by the University of Manchester, to try and increase our understanding of voice hearing within this group of people. Participants will be reimbursed for their time.

***This includes people who regard themselves as 'Black British' or of 'Mixed' heritage who have at least 1 African or Caribbean parent or grandparent.**

For more information about the study please contact either Alexandra Clark (Tel: 07895873542) or Jennie Davies (Tel: 07895892447) or Email: hearingvoices@manchester.ac.uk

Alexandra Clark & Jennie Davies
Email: hearingvoices@manchester.ac.uk
Tel: *07895873542 or 07895892447*

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IRAS ID: 219888

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