

- VOLUME ONE -

A PSYCHOLOGICAL UNDERSTANDING OF THE ELEVATED INCIDENT RATES OF
PSYCHOSIS, WITHIN SPECIFIC ETHNIC MINORITY POPULATIONS

by

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THESIS OVERVIEW

This thesis was submitted to fulfil the requirements for a Doctorate in Clinical Psychology. It is comprised of two volumes, the first contains a literature review and empirical paper, whilst the second contains five Clinical Practice Reports (CPRs) completed by the author as a Trainee Clinical Psychologist, within the National Health Service (NHS).

Volume I: Literature Review and Empirical Paper

The literature review explores the psychological evidence that has been used to explain the higher incident rates of psychosis in specific ethnic minority groups. Ethnic differences in psychotic-like experiences (PLEs) and perceptions of inequality were the psychological factors most robustly explored in the literature. However, due to several conceptual and methodological limitations, the extent to which these factors directly explained the higher rates of psychosis remained unclear. The empirical study further built on this theme, through the narrative accounts of Black-Caribbean patients. Several key experiences in the life of the participants emerged, including negative social interactions, the effects of unemployment and the use of cannabis. Greater levels of stress, trauma, and social marginalisation were some of the possible psychological explanations, for the known ethnic disparities in the rates of psychosis.

Volume II: Clinical Practice Reports (CPRs)

The second volume is split into five separate reports. The first contains a psychological formulation of client's difficulties with anxiety and low mood from two different models. The second contains a service report on the provision of psychological therapy for individuals with psychosis. The third report presents a single case experimental design of the efficacy of behavioural intervention targeting the challenging behaviour of a young child with developmental delay. The fourth report presents the trainee's contribution to the delivery of a leadership and consultancy model, within an inpatients setting for older adults. Finally, an abstract of a case study is presented, of the psychological work conducted with a young man at risk of developing psychosis.

For

Jennifer

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CHAPTER ONE – LITERATURE REVIEW

UNDERSTANDING THE DISPROPORTIONATE INCIDENT RATES OF PSYCHOSIS AMONGST ETHNIC MINORITY GROUPS: A 10-YEAR LITERATURE REVIEW OF THE PSYCHOLOGICAL EVIDENCE

Understanding the Disproportionate Incident Rates of Psychosis amongst Ethnic Minority Groups: A 10-Year Literature Review of the Psychological Evidence.

Abstract

Introduction

Previous research has consistently shown that ethnic minority groups in the Western-World, experience disproportionate rates of psychosis, in comparison to those from the ethnic majority. Although negative social-environmental factors are cited as the dominant causal explanation of this phenomenon, there currently remains a lack of consensus about the key psychological processes at play. The review addresses this limitation by systematically reviewing the psychological evidence over a 10-year period.

Method

A systematic search of the literature published between 2007 and 2016 was conducted to identify research that had attempted to explain the disproportionate rates of psychosis by taking into account at least one psychological factor (i.e. social-psychological, clinical-psychological/psychiatric, and neuropsychological). A comprehensive keyword search strategy was employed using the MEDLINE, EMBASE AND PSYCHINFO databases. Methodological quality criteria were also applied to each study, using an adapted version of the CASP review tool.

Results

In total, 13 papers met the inclusion and exclusion criteria of the review. Studies were mainly conducted in the United Kingdom (UK) and the Netherlands (NL) and varied in their methodological quality (50%-86%). Four themes emerged in the types of psychological factors explored. These were: 1) psychotic-like experiences and symptom profile during at risk mental states; 2) perceptions of inequality; 3) ethnic and national identity; and 4) neuropsychological and cognitive processes.

Discussion

Psychotic-like experiences and perceptions of inequality were the psychological factors most robustly investigated in the literature. However, due to key methodological limitations and the confounding effect of social-environmental factors, the extent to which these factors explained the relationship between ethnicity and psychosis remained unclear. Implications for future research are also discussed within.

Introduction

What is Psychosis?

The very notion of psychosis is a contestable one. While it is clear that a subset of people within the general population experience a range of experiences that are bewildering (e.g. hearing or seeing 'things' that others don't, holding idiosyncratic beliefs not shared by others), there is less clarity about how these experiences should be conceptualised (The British Psychological Society, 2014). Within the medical model, these experiences are conceptualized as symptoms (e.g. hallucinations and delusions) of an underlying biological condition that is assigned a diagnostic label (schizophrenia or other psychotic illnesses, referred to as psychosis from here onwards). The medical model has, however, received heavy criticism for the following reasons. Firstly, many years of psychiatric research has failed to produce a clear evidence base to substantiate an underlying biological cause to the diagnostic categories of psychosis (Bentall, 2003; Boyle, 2014). Secondly, the classification systems for diagnosis are unreliable, and do not accurately capture the symptom experience from episode to episode within an individual, or enable accurate comparison between individuals. Thirdly, many people in the general population have experiences similar to those labelled as psychosis, but are not distressed by them (The British Psychological Society, 2014). An alternative way to view delusions and hallucinations, is as a psychological response to the social and personal experiences of the individual, rather than a biological disease (Bentall, 2003). Others adopt a broader intermediate biopsychosocial perspective that permits the possibility of all three factors (biological, psychological and social) making a contribution (Shan & Mountain, 2007).

This review focuses on ethnic variation in psychosis. Research in this field is often conducted from the perspective of the medical model, in which the evidence tries to under whether and why ethnic variation in the incidence rates of particular psychiatric diagnoses exist. However, as psychosis-related diagnoses rely very heavily on self-report, the research data also addresses the question of whether and why there is ethnic variation in the occurrence of such experiences. Consequently, the relationship between ethnicity and psychosis-related experiences can be examined regardless of whether one commits to a medical, a psychosocial or a biopsychosocial model.

What is the impact of Psychosis?

Although the incident rates of the psychotic disorders are relatively low in comparison to other psychiatric disorders (Kirkbride et al., 2012; McGrath, Saha, Chant, & Welham, 2008), the illness is universally costly to society, the family and the individual. Symptoms are often highly distressing and pervasive, which negatively impacts upon social and occupational functioning. Contemporary theories about the aetiology of psychosis point to a combination of both genetic and environmental risk factors. There is also good evidence to suggest that psychosis exists on a continuum with normal psychopathology, and that the manifestation of the clinical disorder is dependent on personal and cultural factors, such as coping, illness behaviour, societal acceptability and developmental impairment (Johns & van Os, 2001; van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). Research has also identified the role of one's vulnerability to stress (Nuechterlein & Dawson, 1984; Zubin & Spring, 1977), neurobiology (Goh & Agius, 2010) and specific cognitive and emotional states (Ben-

Zeev, Ellington, Swendsen, & Granholm, 2010; Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Kuipers et al., 2006).

Ethnic Variation In The Incident Rates of Psychosis

Research has consistently demonstrated that individuals from ethnic minority and migrant groups have higher rates of psychoses than non-migrant groups (Elizabeth Cantor-Graae & Selten, 2005). In the Netherlands, those of Surinamese, Dutch-Antillean and Moroccan backgrounds have been shown to have elevated rates of psychosis in comparison to those with Dutch native ancestry (J. P. Selten et al., 2001). Similar results have also been found for migrant groups in Denmark, Sweden, Australia, United States of America (USA) and United Kingdom (UK) (Bresnahan et al., 2007; E. Cantor-Graae, Zolkowska, & McNeil, 2005; Fearon & Morgan, 2006). An international review and meta-analysis estimated that migrant groups were between 2.7 and 4.5 more likely to develop psychosis than those of native backgrounds (J. P. Selten, Cantor-Graae, & Kahn, 2007). More recently, a review found that Black-Caribbean migrant groups in the UK were 4.7 times more likely to experience psychosis than comparators (Tortelli et al., 2015).

What Factors Contribute To Ethnic Variation In Incident Rates?

With a lack of substantial biological explanations (E. Cantor-Graae, Pedersen, McNeil, & Mortensen, 2003; Morgan, Charalambides, Hutchinson, & Murray, 2010) and claims of misdiagnosis unsubstantiated (Kirkbride et al., 2006), sociological processes are widely accepted as the dominant explanation for ethnic variation in the rates of

psychosis. Research has shown that various proximal variables of social disadvantage, such as unemployment status, social deprivation, income equality, social economic status, education and social isolation are important (Kirkbride et al., 2008; Kirkbride, Jones, Ullrich, & Coid, 2014; Reininghaus et al., 2008). There is also evidence to suggest that these variables have a cumulative effect, and increasingly predispose migrant groups to psychosis in an additive way (Morgan et al., 2008). Other sociological processes have also been demonstrated to explain high incident rates of psychosis in migrant groups; such as factors relating to the process of migration (Morgan et al., 2007; Veling, Hoek, Selten, & Susser, 2011). However, recent evidence has suggested that, as psychosis is elevated in both migrant groups and their descendants (Bourque, van der Ven, & Malla, 2011; Coid et al., 2008), contributory factors are likely to be related to their position within society rather than factors related to the migration process itself. Research has also pointed to the role of neighbourhood-ethnic composition (Boydell et al., 2001). Such literature has shown that negative relationship between the rates of psychosis and the compositional make-up within the local population. For example, ethnic minorities living with fewer of their own group are at a greater chance of developing the disorder. This phenomenon has been referred to in the literature as the 'ethnic density effect' and has been confirmed by a recent meta-analysis (Termorshuizen, Smeets, Braam, & Veling, 2014).

What Theories Have Been Proposed To Explain Higher Incident Rates?

Currently, two dominant theories have attempted to explain why various social factors can lead to higher rates of psychosis in ethnic minority groups. The social defeat hypothesis (Elizabeth Cantor-Graae & Selten, 2005; J.-P. Selten, van der Ven, Rutten, &

Cantor-Graae, 2013) argues that long-term exposure to the negative experience of being excluded from the majority group (referred to as 'social defeat') leads to sensitization of the mesolimbic dopamine system (neurobiological processes thought to be important in psychosis) and thus increases the risk of psychosis. The socio-developmental model (Morgan et al., 2010) argues that exposure to social trauma interacts with an underlying genetic risk that impacts on brain development and stress sensitivity. These processes create a psychosis predisposition which is primarily psychological (i.e. social cognitive biases, psychosis-like experiences, and affective disturbance) that becomes manifest as psychosis in the event of further cumulative stressors and/or substance abuse. It is clear from both these models that greater exposure to negative social experiences, in-turn, alter one's psychological susceptibility to psychosis. However, there currently remains limited empirical consensus about exactly what these psychological processes are, specific to the ethnic minority groups affected. The aim of this review is to address this limitation, by systematically identifying the psychological literature that explains ethnic variation in the rates of psychosis. The last review in the area, using a systematic search strategy, was published in 2008 (Pinto, Ashworth, & Jones, 2008). An update on this work was therefore required to consider the breadth of studies published since this time.

Review Aim:

To identify and review the outcomes and methodological quality of the psychological literature that attempts to explain ethnic variance in the incident rates of psychosis.

Method

Search Strategy

A systematic review of the literature published between 1st of January 2007- to 1st of January 2016 was conducted. A keyword search strategy was employed, using the databases MEDLINE, EMBASE AND PSYCHINFO through the OVID search function. Keywords were clustered into three groups 1) psychosis-related terms, 2) ethnicity-related terms 3) epidemiology, and incident-rate-related terms. Each cluster was derived by conducting individual keyword search terms independently, and then by combining them using the [OR] search term Boolean operator. Once this was done, all clusters were combined using the [AND] Boolean search term function.

Search Term Clusters

Psychosis-related Terms: Schizophren\$.mp, Psychosis.mp; Psychoses.mp;

Ethnicity-related Terms: Ethnic\$.mp; african.mp; migrant\$.mp; Caribbean\$.mp; immigra\$.mp; African-Caribbean.mp; Black-Caribbean.mp; Afro-Caribbean.mp.

Epidemiology-related terms: Epidemiolog\$.mp; aetiolog\$.mp. Incidence.mp; prevalence.mp,

Once retrieved, further OVID search exclusion terms were applied based on inclusion /exclusion criteria (see below). Of the remaining articles, the titles and abstracts were then further scrutinized using the inclusion/exclusion criteria. The full texts of potentially eligible articles were then read in full and further scrutinized against the

exclusion criteria. Papers passing this stage were then carried forward into the review. A snowball search strategy was also employed, which involved reading the introduction and references of the retrieved article and identifying further papers published in the review timeframe.

Inclusion Criteria

1. Empirical studies that focus primarily on Western European populations
2. Peer-review empirical papers
3. Studies that explore psychological factors (defined as emotion, neuropsychological, perception, cognition, psychotic experiences, individual experiences and clinical /psychiatric)
4. Exclusive focus on psychosis (defined by ICD 10 or DSM criteria or if the authors specifically reference diagnosis)

Exclusion Criteria

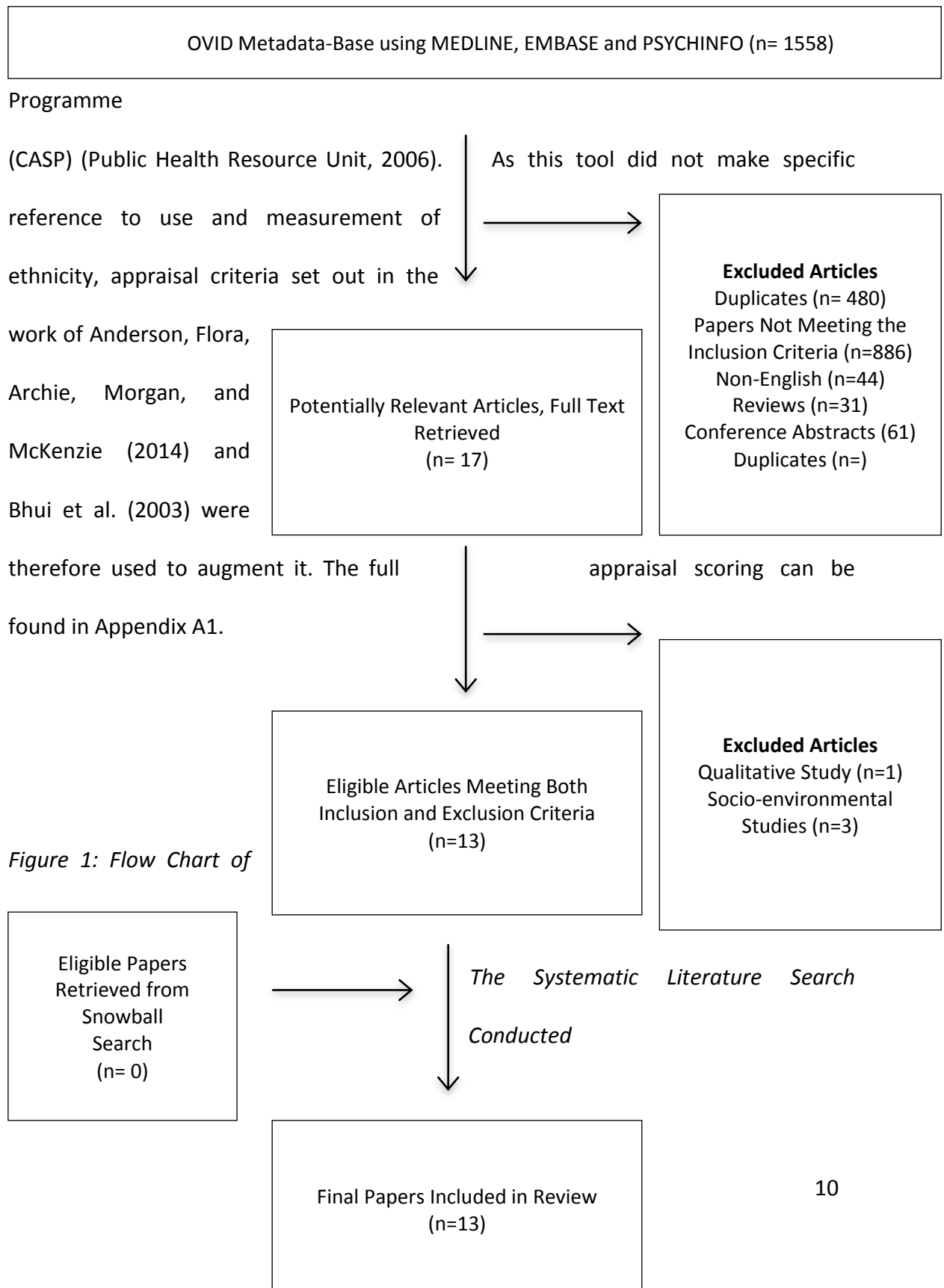
1. Studies not in English
2. Conference abstracts and proceedings
3. Studies that only focus on epidemiological incidence rates
4. Studies or evidence that only focused on forensic population
5. Studies that focused on ethnicity in psychosis with comorbid conditions
minorities differ in symptom- experience disproportionate rates of psre
needed in this area, to establish if trauma and dissa
6. Studies that focus solely on social-environmental factors or experiences
7. Studies that focus solely on differential rates of drug and alcohol use/abuse.

8. Qualitative papers

9. Review papers

Methodological Appraisal

Retrieved articles were methodologically appraised by the Critical Appraisal Skills



Results

example, in the study conducted by Veling et al. (2007), incident rates of psychosis were correlated with levels of experienced discrimination in the general population. Conversely, other studies compared ethnic differences in specific psychological variables in clinical and sub-clinical samples; using patients diagnosed with psychosis and at-risk mental states (Adriaanse et al., 2015; Reininghaus et al., 2010; Stouten, Veling, van der Helm, Laan, & van der Gaag, 2013; Velthorst et al., 2012). The study conducted by Reininghaus et al. (2010) used this method, and attempted to explore the relationship between ethnic identity and the odds of psychosis in a sample of first-episode patients. Finally, there were some studies that used a mixture of these approaches (Veling, Hoek, & Mackenbach, 2008; Veling, Hoek, Wiersma, & Mackenbach, 2010). Further details about each of the studies are given in Table 1.

Table 1: Summarising Table Of Articles Included In This Review With Appraisal Scoring

| Author | Sample Size (n) | Country | Description Of Study | Rating of ethnicity (I) and methods of comparison in analysis (II) | Measurement of Psychosis | Primary psychological measures and method of assessment | Key Findings | Appraisal score |
|--------------------------|--|---------|---|--|---|--|--|-----------------|
| 1. (Veling et al., 2007) | 618 (Morocco, Surinam, Netherland-Antilles, Turkey, Other Non Western-Countries, Western Countries and Native-Dutch) | NL | Population-based comparison of incident rates of psychosis and levels of experienced discrimination between several ethnic groups | I. Third Party (State Assigned) II. Comparisons made between specific ethnic groups | Incident rates of psychosis were measured using: Comprehensive Assessment of Symptoms History (CASH) Instrument for the Retrospective Assessment of the Onset of Schizophrenia (IRSOS) DSM-IV diagnosis by two Psychiatrists | Experiences of Discrimination: Non-standardised measure of discrimination in a community sample Local level assessment, measured by the Hauge-Anti Discrimination Bureau | Across the ethnic minority groups, higher incident rates of psychosis were positively correlated with higher levels of discrimination. All migrant groups had significantly higher reported experiences of discrimination than the native Dutch group. The trend remained after controlling for confounders. | 86% |
| 2. Cooper et al. (2008) | 482 (White British vs. Black) | UK | Population-based comparison of incident rates of psychosis and levels of experienced discrimination between several ethnic groups | I. Self-ascription via UK census categories II. Crude assessment | Incident rates of psychosis were measured using: Diagnosis of a first episode of psychosis ICD-10, codes F-30-F33 and F10-29) | Perceptions of Disadvantage: The Cultural and Identity Schedule – 2 (CANDID-2) | Participants from the black group were 4 times more likely to have psychosis than those from the white group. Higher incident rates of psychosis in the ethnic minority group were attenuated by greater perception of disadvantage along with other socio-economic factors. | 71% |

| | | | | | | | | |
|--------------------------|--|----|--|---|---|---|--|-------|
| 3. Veling et al. (2008) | 263 (Moroccan, Turkish, Surinamese, Other non-Western) | NL | Exploration of the relationship between perceptions of discrimination and psychosis in an ethnic-minority-only sample, with non-psychosis participants used as controls. | I. Third party (State Assigned) II. Individual ethnic groups amalgamated for main analysis | Diagnosis of Psychosis: Composite International Diagnostic Interview (CIDI) Diagnosis Schizophrenia spectrum disorder (DSM IV: schizophrenia, schizophreniform disorder, schizoaffective disorder) | Perceptions of Discrimination: International Comparative Study of Ethno-cultural Youth (ICSEY) Discrimination Scale | There were no sig. difference in the levels of discrimination between psychosis patients and controls. Findings still remained after controlling for confounders. | 75% |
| 4. Stouten et al. (2013) | 496 (Dutch native vs. Immigrants) | NL | Comparison between ethnic groups on various indices of cognitive ability in an early psychosis sample. | I. State-assigned, third party II. Crude comparisons | Measurement of Psychosis: First Episode DSM IV (schizophrenia, schizophreniform disorder, schizoaffective disorder, brief psychotic disorder, delusional disorder and psychotic disorder NOS) Comprehensive assessment of symptoms history (CASH) | Cognitive Ability: Rey's Auditory Verbal Learning task (immediate and delayed recall) Continuous Performance Task (Attention) | Immigrant psychosis groups scored sig. lower on all three cognitive ability assessment measures Second-generation immigrants show better performance than first-generation immigrants Results remained after controlling for confounders | 62.5% |

| | | | | | | | | |
|------------------------------|--|----|---|--|---|---|---|--------|
| 5. Akdeniz et al. (2014) | Unclear, number of participants differed throughout paper (German vs. 2nd generation migrants) | DE | FMRI comparison study exploring the neural processing in social-stress between German participants and immigrants | I. Unclear II. Crude comparisons | N/A – Population sample (Healthy Controls) | Neuro-processes of stress: FMRI Social stress task | Ethnic minority group showed significantly increased levels of pACC (region of the brain useful in the regulation of negative emotion) in comparison to German controls. Higher levels of perceived discrimination relative to personal discrimination in ethnic minority group. Positive correlation between paCC and ventral striatum activation with perceptions of group discrimination. Chronic stress significantly mediated the relationship between perceived discrimination and paCC and Dacc coupling | 59.09% |
| 6. Reininghaus et al. (2010) | 373 (White British vs. BME – Black-Caribbean, Black-African and Asian) | UK | Comparison between ethnic groups | I. Self-ascription via UK 2001 Census II. Crude comparisons (BME-vs. White) | First Episode of Psychosis: ICD-10, codes F-30-F33 and F10-29 | Ethnic identity: The Cultural and Identity Schedule – (CANDID-2) Perception of Disadvantage | Positive relationship between ethnic identity and the odds of psychosis in BME group but not the white group. However, this relationship was attenuated and non-sig. when controlling for perceived disadvantage | 79.16% |
| 7. Veling et al. (2010) | 263 (Non-Western Dutch migrants 85% were from Morocco, Surinam, Netherland-Antilles, Turkey) | NL | An exploration of the association between psychosis and ethnic identity in a mixed psychosis and non-clinical community sample of Dutch ethnic minority | I. State assigned, third party II. Crude comparisons | Psychosis was measured using: Compressive Assessment of Symptoms History (CASH) Instrument for the Retrospective Assessment of the Onset of Schizophrenia (IRSOS) DSM-IV diagnosis by two psychiatrists | Ethnic Identity: Scale of Ethnic and National identity by the International Comparative Study of Ethnocultural Youth (ICSEY) | Patients with psychosis had greater negative ethnic identity than controls. Relationship remained after controlling for confounding variables. | 68.3% |

| | | | | | | | | |
|-----------------------------|--|----|---|---|-------------------------------------|--|--|-------|
| 8. Vanheusden et al. (2008) | 2258 (Dutch natives, Turks, Moroccans, Surinamese/ Antilleans, Indonesians, other non-Western immigrants (mostly from Africa or Asia) and Western immigrants (mostly from Western Europe)) | NL | Cross-sectional non-clinical population survey of the rates of self-reported visual and auditory hallucinations | <p>I. State-assigned, third party</p> <p>II. Comparisons made between specific ethnic groups</p> | N/A – Non-clinical community sample | <p>Psychotic-like experiences:</p> <p>Adult Self-Report (ASR)</p> | <p>All non-Western immigrant groups were significantly more likely to report hallucination than the Dutch native group.</p> <p>Various markers of social adversity attenuated the odds of reported hallucinations in all the non-Western immigrant groups.</p> | 68.3% |
| 9. Laurens et al. (2008) | 595 (African Caribbean, White Other, White-British, Black-African, South-Asian, Oriental, and Other Ethnicity) | UK | Case control school-based population sample | <p>I. Self-ascription via UK 2001 Census categories</p> <p>II. Ethnic comparison made with intact ethnic groups</p> | N/A – Non-clinical community sample | <p>Psychotic-like experiences:</p> <p>Adapted version of Diagnostic Interview Schedule For Children</p> <p>Triad of putative antecedents Standardized parental questionnaire assessing predictive markers for schizophrenia 1) Developmental delay 2) Internalizing and externalizing behavioural problems 3) Reported experience of PLE</p> | <p>African-Caribbean children had significantly higher reports of PLEs than White-British Children.</p> <p>These findings remained after controlling for confounding variables.</p> <p>South Asian and oriental children were also more likely to report PLEs than White British patients, but only half as much as Black-Caribbean</p> <p>African-Caribbean children were significantly more likely to report punitive triad than White-British children.</p> | 81% |

| | | | | | | | | |
|------------------------------|--|----|--|--|------------------------------------|--|--|--------|
| 10.. Morgan et al. (2009) | 372 White British, Other White, Black Caribbean, Black African, Asian (all) Other | UK | Case control population sample | I. Self-ascription via UK 2001 Census categories II. Ethnically intact comparison | N/A Match control community sample | Psychotic- like experiences Psychosis Screening Questionnaire (PSQ), | When compared with White British subjects, both Black Caribbean and Black African subjects were more likely to endorse psychotic-like experiences. The association between Black Caribbean ethnicity and psychotic-like experiences no longer with indicators of social disadvantage. | 77.27% |
| 11. Das-Munshi et al. (2012) | 4281 (Black-Caribbean, Bangladeshi, Indian, Pakistani, Irish and White-British) | UK | Case Control population sample, exploring psychotic-like experiences in the general population | I. Self-ascription via UK 2001 Census categories II. Ethnically intact comparison | N/A Match control community sample | Psychotic- like experiences : Psychosis Screening Questionnaire (PSQ), Experiences of racism & discrimination Chronic strains and difficulties | Low ethnic density was associated with higher reports of psychotic-like experiences. Decreasing in own group density was associated with an increase in experiences of discrimination and poor social support. Interactive effect was also observed: Higher levels of ethnic density and social support and lower chronic life strain were associated with increasing lower levels of psychotic-like experiences. | 81% |
| 12. Velthorst et al. (2012) | 201 (Dutch-Native, Moroccan, Turkish, Surinamese, Other-Western & Other Non - Western) | NL | Comparison in symptoms between different ethnic groups in a sample of patients with at-risk mental states for psychosis. | I. State-assigned, third party II. Crude comparisons (Ethnic minority-vs. Dutch-Native) | N/A- At-risk mental state sample | Symptom profile of at-risk mental state: Comprehensive assessment of at-risk mental states (CARMS) Young et al. Ethnic and national identity Comparative Study of Ethno-cultural Youth (ICSEY) scale Co-morbid mental health difficulties | Ethnic minority groups were significantly more likely to report total ARMS negative symptoms than White-British patients. This remained after controlling for confounding variables. Ethnic minority groups also reported higher rates of depression and social anxiety symptoms than Dutch-natives. Ethnic minority groups reported higher national identity and lower ethnic identity. Higher scores in ethnic identity were associated with less severe ARMS psychopathology and lower negative scores. | 50% |

| | | | | | | | | |
|-----------------------------|--|----|--|---|-------------------------------------|--|---|-----|
| | | | | | | <p>Schedule for Clinical Assessment in Neuropsychiatry (SCAN)</p> <p>Beck Depression Inventory II</p> <p>Calgary Depression Scale (CDS)</p> | | |
| 13. Adriaanse et al. (2015) | 1545 (Dutch, Turkish-Dutch and Moroccan-Dutch) | NL | Comparison between school children in the reported rates of psychotic-like experiences | <p>I. Self-ascription, national categorisation</p> <p>II. Ethnically intact comparisons</p> | N/A – Non-clinical community sample | <p>Psychotic- like experiences:</p> <p>Kiddie Schedule for Affective Disorders and Schizophrenia</p> <p>Perceived discrimination</p> <p>Discrimination:</p> <p>Questionnaire assessing whether children perceived personal discrimination based on skin colour, origin or religion during the past year</p> <p>Trauma Diagnostic Interview Schedule for Children</p> | <p>Ethnic minority youth reported more psychotic-like experiences.</p> <p>This difference remained after accounting for cultural context.</p> | 68% |

Key Findings From Retrieved Papers

Of the 13 studies retrieved, three dominant themes were evident in the psychological factors under investigation. These were; 1) psychotic-like experiences and symptom-profile during At-Risk Mental States (ARMS); 2) perceptions of inequality; and 3) ethnic identity. An additional theme on (4) neurological and cognitive processes also emerged from the literature search; however, this theme was less dominant, in comparison to the other categories.

In this next section, each theme will be described in detail with reference given to outcome of all the studies included within each theme. Some studies contain information pertaining to more than one theme and so appear across the four broad categories described.

Psychotic-Like Experiences And Symptom Profile

van Os, Hanssen, Bijl, & Ravelli, (2000) and Verdoux & van Os, (2002) argue that psychosis exists on a continuum and that psychotic-like experiences (PLEs) are an important step in the development of the disorder. Four papers attempted to understand ethnic variation in the rates of psychosis, by exploring ethnic variation in PLE in the general population using standardized assessment measures (Psychosis Screening Questionnaire (PSQ), Adult Self-Report (ASR) scale). In a general population sample conducted in the Netherlands, Vanheusden et al. (2008) found that all non-native Dutch groups were significantly more likely to report PLEs than native Dutch groups. Similarly, Laurens et al. (2008) found that African-Caribbean, South Asian and oriental children had significantly higher reports of PLEs than White-British children. Their findings were again reported in a study by Adriaanse et al.

(2015) who found that Moroccan-Dutch and Turkish-Dutch youth reported significantly more psychotic experiences than native Dutch children. The work by Morgan et al. (2009) also supports these findings, and showed that Black-Caribbean and Black-African participants were significantly more likely to report PLEs than White-British patients. However, this association was significantly reduced when the authors accounted for the confounding variables of childhood and adult social disadvantage. Finally, in a study conducted in the UK, Das-Munshi et al. (2012) found higher reports of PLEs in their ethnic minority sample in areas where they made up a smaller proportion of the population (referred to in the literature as the 'ethnic density effect'). The authors therefore suggested that psychotic-like experiences were buffered in neighbourhoods where residents were more ethnically similar.

In summary, the literature distinctly demonstrates that ethnic minority groups in the general population experience more PLEs than non-migrant groups. However, this association is likely to be mediated by exposure to social disadvantage and possibly ethnic density. Furthermore, the literature was unable to establish a linear association between higher levels of PLEs and higher rates of psychosis in ethnic minority groups. The extent at which higher levels of reported PLEs in the ethnic minority population contributes to the disproportionate rates of psychosis therefore remains unclear.

'At-Risk Mental States' (ARMS) is a term used to categorise those individuals who are at a greater risk of developing psychosis and who experience psychotic-like symptoms (PLE). In a study conducted in the Netherlands, Velthorst et al. (2012) explored ethnic variation in the

symptoms in groups of patients who met ARMS criteria. The results of the study found no difference between the ethnic groups in positive symptoms; however, ethnic minority groups did have significantly higher levels of negative symptoms. Transition from the ARMS group into a full psychotic illness is predicted by attenuated positive symptoms when followed by distress and negative symptoms (Cannon et al., 2008; Velthorst et al., 2009; Yung et al., 2005). As this study found no ethnic difference in positive symptoms, it is difficult to assess the extent to which these findings help explain ethnic variation in rates of psychosis. The generalizability of this evidence is also questionable. In psychosis, ethnic minority groups are significantly more likely to come to service through compulsory measures (i.e. under the Mental Health Act) and less likely through voluntary services (i.e. GP) (Anderson, Fuhrer, & Malla, 2010). As patients who use ARMS services are referred by voluntary means, it could be possible this evidence does not adequately reflect the true clinical profile of those who make transition into psychosis.

Perceptions of Inequality

Perceptions or experiences of discrimination and disadvantage (collectively referred to from here onwards as 'perceptions of inequality') were explored by four of the twelve articles retrieved. This psychological variable was most commonly assessed through questionnaire designs, in which participants had to indicate past discriminatory or disadvantageous experiences over a given period of time. Two of the three studies attempted to assess whether perceptions of inequality in the general population were correlated with the incident rates of psychosis (Cooper et al., 2008; Veling et al., 2007). The results from the study by Veling et al. (2007) demonstrated that ethnic minority groups in the general

population reported significantly higher levels of inequality than non-ethnic minority groups. Furthermore, increasing levels of experienced inequality were indeed positively correlated with increased odds of developing psychosis within the ethnic minority groups. This finding was also supported in the work of Cooper et al. (2008), who found that higher incident rates of psychosis in the ethnic minority group was partly attenuated by greater perception of disadvantage along with other socio-economic factors, such as social class, education, religious adherence, and employment. This evidence therefore suggests that there is indeed a link between perceived discrimination and psychosis; however, this link might be mediated by other factors in the social, cultural and economic environment. Ethnic density could be one of these factors, as the study by Das-Munshi et al. (2012) found that a reduction of one's own ethnic group increased the reports of experienced discrimination. Finally, the study by Veling et al. (2008) compared perceptions of discrimination between ethnic minority patients with psychosis and general population controls (matched by ethnicity). This study found no difference between the control and patient group in reported levels of discrimination, even after controlling for confounding variables.

The literature does generally seem to suggest that there is a relationship between ethnicity and rates of psychosis and perception of inequality; however, there are some limitations about this research that should be acknowledged. Firstly, the study by Veling et al. (2008) was the only study to explore ethnic variability in perceptions of inequality between a general-population and psychosis sample. Intriguingly, this study found no difference in the perceptions of discrimination between the two groups. This finding is important because, if perceptions of inequality were indeed a direct factor that leads to ethnic disparities in rates

of psychosis, one would expect to see higher levels of perceived inequality in patients with psychosis than in their general population counterparts. Research therefore seems to suggest that the association between perception of inequality and psychosis is non-linear and could be mediated by other factors. The study by Cooper et al. (2008) alluded to the role of other factors, such as social class, education, religious adherence, and employment; however, as of yet, no study has explored association within a psychosis population. It is therefore clear that further research is required to help illuminate the connections between perceptions of inequality and the elevated rates of psychosis. Finally, it is worth noting that research in this area is primarily correlational in nature, and hence, it is difficult to assess the extent to which the association between rates of psychosis and perceptions of inequality are linear, directional, and not mediated by some unknown variables or alternative process.

Ethnic and National Identity

An individual's association to their own ethnic identity or group may act as a buffer to the negative social experiences that contribute to poorer mental health. Veling et al. (2010), attempted to explore the relationship between psychosis (rate of psychosis) and ethnic identity in a mixed clinical and non-clinical sample from non-Western immigrant groups (first and second generation). The results of the study found that patients with psychosis were more likely to have negative views about their own ethnic identity than general population controls. This association remained after controlling for the confounding variables; marital status, unemployment, self-esteem, social support and cannabis use. Furthermore, the study showed that patients with psychosis more often had an 'assimilated' identity (i.e. they identified more with the Dutch group than their own) or 'marginal identity' (i.e. they

identified with neither Dutch nor their own ethnic identities). This evidence suggests that within the ethnic minority population, those with psychosis are less likely to identify with both their own and the majority ethnic group as compared to those without psychosis. These findings were further replicated in a separate sample of young people at risk of developing psychosis (ARMS group) (Velthorst et al., 2012). Conversely, Reininghaus et al. (2010) explored the relationship between ethnic identity and ethnic grouping in a sample of patients with psychosis and community controls. The study found a positive relationship between ethnic identity and the odds of psychosis in the BME group, but not in the White-British group. This relationship however, was attenuated and was no longer significant when accounting for perceptions of inequality.

In summary, the evidence on ethnic identity as an explanation for elevated rates of psychosis remains equipoise. Some studies show an inverse relationship between ethnic identity and the rates of psychosis, whereas other research suggests the opposite. There is also evidence to suggest that perceptions of inequality rather than ethnic identity per se is also important when considering the role of ethnic identity, as it is likely to be a mediating variable. This evidence is therefore unclear, and furthermore, limited by the lack of replicable research.

Neuropsychological Processes of Stress and Cognitive Processing (Emergent Theme)

The final psychological variable identified in the literature was related to ethnic variation in the neuropsychological process of stress and intellectual impairment. The study by Akdeniz et al. (2014) was particularly interesting, as it explored the neurocognitive process of stress

in a community sample of German natives and second-generation German ethnic minority group. Stress vulnerability is thought to be a key mechanism in the development of psychosis and so the authors attempted to see if those from a community sample of ethnic minority groups had different stress processes, in an experimental Functional Magnetic Resonance Imaging (fMRI) task. During the stress task, ethnic minority groups showed significantly increased levels of perigenual anterior cingulate cortex (pACC) activation (i.e. higher activation in the regions of the brain responsible for the regulation of negative emotion) in comparison to German controls. It was therefore concluded that ethnic minority groups had greater reactivity to stress than non-minority groups. This study was however conducted in a general population sample, hence further research on neuro-stress process in the psychosis and ARMS population would be needed before the links to ethnic differences in incident rates can be made.

We are aware, from the wider literature, that cognitive impairment is also common during, before and after the development of psychosis (Wood et al., 2007). Research has therefore attempted to see if there is ethnic variation in the various components of cognitive function in an attempt to understand ethnic variability in psychosis rates. In an ethnically mixed sample, Stouten et al. (2013) found that although all FEP patients showed signs of cognitive impairment in a cross-sectional design, Dutch immigrant patients scored significantly lower on all three cognitive assessments (two verbal memory assessments and a sustained attention assessment) than native Dutch patients. Secondly, the study showed that all second-generation immigrants scored better in their cognitive performance than first-

generation immigrants. The authors concluded that ethnic variability in psychosis rates are related to poor cognitive functioning in immigrant groups and not misdiagnosis.

Although the reported methodology used in this study was robust, there are some questions about the inferences that authors made that should be acknowledged. Firstly, the study failed to include normative data on cognitive ability between the ethnic groups, to make comparisons between scores obtained and scores within the general population. It was therefore difficult to know the ethnic differences observed were related to more cultural variability in the cognitive domains tested rather than true between-group differences. Secondly, the notion of ethnic difference in intellectual function is quite obviously a contentious issue, and hence little research has been conducted within the psychosis literature. It is therefore difficult to contextualize these findings to a wider body of knowledge or to estimate the extent to which these measures of cognitive ability were ethnically and culturally sensitive. Another limitation with this study is the author's inability to control for other important clinical variables that could influence cognition, such as current medication, the Duration of Untreated Psychosis (DUP) and drug usage.

Discussion

The purpose of this review was to help identify the key psychological processes that explain the known ethnic disparities in the rates of psychosis. The results of the systematic review revealed four overarching themes in the psychological literature. However, due to discrepancies of results between studies, the effect of confounding variables and methodological limitations, it was difficult to assess the extent to which the identified

psychological factors contributes to known ethnic disparity in the rates of psychosis. Despite this, some key assumptions about the role of the psychological factors identified through this review can now be made, that might be useful for further research.

Do psychotic-like experiences (PLEs) and symptoms profile during at-risk mental states (ARMS) lead to disproportionate rates of psychosis for ethnic minority groups?

While it is clear from this review that ethnic minority groups do differ in their psychotic-like experiences (PLEs), there is a lack of evidence to suggest that PLEs directly contribute to the known ethnic variability in the rates of psychosis. Furthermore, the review showed that ethnic variation in PLEs might also be mediated by social-experiential factors, like childhood and adult victimisation, as well as ethnic density. It is therefore unclear from the literature if the correlation between PLEs and rates of psychosis in ethnic minority groups is a linear one, and not mediated or moderated by other social proxies of importance. In addition, it is also unclear from the review whether ethnic minorities differ in symptom-profile during ARMS and if ethnic variability in symptoms during ARMS contributes to differing rates of psychosis. More complex research using more sophisticated quantitative designs are therefore required, to explore the directional links between PLEs, ARMS symptoms and psychosis in ethnic minority groups, in comparison to non-minority patients. Future research could possibly use retrospective methods to compare the reported levels of PLEs or ARMS symptoms in patients who have already made transition into psychosis. This approach could ask patients in early psychosis about the development of illness and then compare the chronology of symptom development between ethnic groups for differences. Suitable measures could include the Interview for Retrospective Assessment at Age at Onset of Schizophrenia (IROAS) or the Nottingham Onset Schedule (NOS) (Hafner et al., 1992; Singh

et al., 2005). Such designs should also account for key confounding factors, such as various indices of social disadvantage in adulthood and childhood. Statistical analysis should also be conducted multi-factorially.

Are ethnic minority patients' perceptions of inequality responsible for their disproportionate rates of psychosis?

In general, the literature does suggest that ethnic minority groups experience higher levels of perceived inequality (discrimination and disadvantage) in comparison to non-migrant groups, and that this is correlated to their rates of psychosis. However, further research is needed to unpick the connections between these relationships, as current research indicates that perceptions of inequality and psychosis are non-linear and also mediated by various social factors, as well as ethnic density. Limitation to the ways in which perceptions of inequality are measured should also be acknowledged when evaluating the data, and qualitative research should be used to identify the ways in which homogenous minority groups perceive their unequal treatment, to help inform more ecologically robust quantitative designs. It would also be interesting to see how the ethnic minority groups in the ARMS group also vary in their perception of inequality and if perceptions of inequality are associated with PLEs and varying symptom profiles.

Other Factors

Although the role of ethnic and national identity was explored in the literature, it currently remains unclear if this factor contributes towards ethnic variation in the observed rates of psychosis. Research on neurobiological and cognitive process is less frequently and less

robustly designed, and so it remains premature, at this stage, to infer the role of these factors in our understanding of the disproportionate rates known. The study by Akdeniz et al. (2014) was particularly interesting and was the only paper to explore ethnic variability in stress processes. Within the broader psychosis literature, the role of stress vulnerability in the aetiology of psychosis is dominant and so it was surprising to find that only one study attempted to explore this line of scientific inquiry. It would be interesting to see if future research could capture how different ethnic minority groups vary in their moment-to-moment reactivity to stress, using approaches such as the Experience Sampling Method (ESM). It would also be interesting to compare the frequency and nature of micro-stresses in the day-to-day lives of different ethnic groups prior to the development of psychosis.

Limitations and Methodological Quality of The Evidence.

This review is limited to roughly a 10-year period and so the findings here might not represent all the psychological evidence in this area. Studies found in the literature were only conducted in DE, UK and NL and the findings in this review are not representative of all ethnic minority groups in Western Europe, despite this being an inclusion criterion of the study. The methodological quality of all the studies ranged between 50%-86% on the quality criteria (see Table 1). All studies were able to give a clear rationale about the scientific justification of the research, used appropriate and often standardised measures and gave good definition in their measurement of psychosis. However, across the majority of the studies, there were areas of consistent weakness. Firstly, of the 13 studies, none gave a sample size estimation or power calculation, which made it difficult to assess the extent to which the studies were sufficiently sized to detect a genuine difference between the groups.

Secondly, roughly half of the studies (6/13) failed to describe the representativeness of the sample (Akdeniz et al., 2014; Das-Munshi et al., 2012; Reininghaus et al., 2010; Vanheusden et al., 2008; Veling et al., 2010; Velthorst et al., 2012) and 8 of the 13 studies failed to describe the non-participant rate (Akdeniz et al., 2014; Cooper et al., 2008; Das-Munshi et al., 2012; Reininghaus et al., 2010; Stouten et al., 2013; Vanheusden et al., 2008; Veling et al., 2008; Velthorst et al., 2012). It was therefore difficult to assess the extent to which the samples used in these studies were either biased in the process of sample selection or reflective of the wider population from which the ethnic groups were derived.

There were also some limitations in methodology specific to some of the studies. For example, in the studies exploring perceptions of disadvantage and discrimination, all studies failed to provide an overarching conceptual framework against which the measurements of inequality were constructed. This was problematic as it made it difficult to assess the extent to which the measures used were valid and reliable assessments of real life experiences of discrimination and not some arbitrary concept. It was also unclear if these measures were culturally sensitive to the ethnic minority groups under investigation and a true reflection of the types of discriminations or disadvantage that were common within these groups. For example, some ethnic groups may have experienced racial discrimination alone (based on skin pigmentation and physiological traits), whereas other groups may experience a combination of racial and cultural discrimination (religious beliefs and cultural traditions). Future research may wish to address this limitation by drawing on theoretical models from social and clinical psychology sub-disciplines, to more robustly explore how social experiences alter the psychological states of an individual. This could be done by drawing on

social identity theory to understand how different ethnic groups respond to each other in a given context, or cognitive behavioural theory to understand how negative social cognition could maintain psychological states of mind that predisposes an individual to the development of psychotic experiences.

Conclusions

A number of psychological factors have been used to understand why ethnic minority groups experience disproportionate rates of psychosis. However, while PLEs and experiences/perceptions of unequal treatment are the factors most likely to be important, there still remains a lack of clarity about exactly how these factors contribute to different rates of psychosis. More empirical, robust research is therefore needed, that equally considers the role of psychological and social factors simultaneously and uses clinical and general population samples collectively. Research should also begin to define the probable psychological pathways to psychosis development, for specific ethnic groups, from a conceptual perspective, to help develop more robust paradigms in this area. It could be possible that there are several distinct psychosocial pathways that are important in understanding why ethnic minority groups experience higher rates of psychosis. If so, it is imperative for further research to conceptually define these routes when deriving new hypotheses or discovering novel research findings.

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CHAPTER TWO – EMPIRICAL PAPER

A PSYCHOLOGICAL UNDERSTANDING OF THE EXCESSIVE RATES OF PSYCHOSIS IN BLACK-CARIBBEAN PATIENTS: A QUALITATIVE STUDY

A Psychological Understanding of the Excessive Rates of Psychosis In Black-Caribbean Individuals: A Qualitative Study

Abstract

Introduction

It has consistently been shown that ethnic minority groups in the United Kingdom (UK) experience disproportionate rates of psychosis. Socio-environmental adversity is cited as the dominant cause of this, however, it currently remains unclear how this increases ethnic minority groups predisposition to the development of the disorder. Further research is therefore required to understand the connections between socio-environmental adversity and the development of psychosis within specific ethnic minority populations.

Method

Twelve qualitative Life Story Interviews (LSI) were conducted with Black and Black-British Caribbean patients, who had experienced one or more episodes of psychosis. During the interview participants were asked to describe and reflect upon salient life experiences, prior to the development of their first psychotic episode. They were also asked to make explicit connections between their life experience and psychosis. Interviews were then analysed using template analysis (TA). In the discussion, a further stage of analysis was also conducted, in which the researcher synthesised emergent themes in a conceptual way, using literature and psychological theory.

Results

Interpersonal relationships and social interactions; employment; hobbies and interests; lack of educational attainment; cannabis use; migrating to England; religiousness were the most salient life experiences described by the participants. When explicitly asked, participants also linked the development of their psychosis to the effects of being ill-treated by others, their use of cannabis and the cumulative effect of all of life's circumstances.

Discussion

Four overarching conceptual themes were also revealed through the process of synthesis. The effects of trauma and stress were of particular importance in explaining the development of psychotic illness, specific to the life experiences described by participants. The dual role of cannabis was also speculated on, as well as the role of several key protective factors.

Introduction

Ethnicity and Psychosis

Research has consistently shown that the rates of schizophrenia and other psychoses (referred to as psychosis from here onwards) are significantly higher for those from ethnic minority and migrant backgrounds, than those of majority ethnic status (Coid et al., 2008, Agius & Ward, 2009, Morgan et al., 2006). In the Netherlands; Surinamese, Dutch-Antillean and Moroccan ethnic groups have been shown to have elevated rates of psychosis in comparison to those with Dutch native ancestry (Selten et al., 2001). Similar patterns have also been found for various migrant groups in Denmark, Sweden, Australia, USA and Canada (Fearon & Morgan, 2006, Bresnahan et al., 2007, Cantor-Graae et al., 2005). In England, a recent review and meta-analysis found that individuals from Black-Caribbean backgrounds are 5.6 times more likely to have psychosis than people of White-British backgrounds. Similar findings have also been demonstrated for those of Black-African backgrounds (Kirkbride et al., 2012).

The Role of Socio-Environmental Factors

Although factors related to migration, genetics and diagnosis have all been used to explain ethnic variability in the rates of psychosis; socio-environmental factors are currently cited as the main cause of the higher rates of psychosis in ethnic minority groups (Cantor-Graae et al., 2003, Morgan et al., 2010, Kirkbride et al., 2006). For example, several studies have pointed towards ethnic difference in social disadvantage as a potential causal mechanism. In a multi-centre study conducted in the UK, C. Morgan et al. (2007) compared various

indicators of social disadvantage in patients with psychosis and their relative controls. The study demonstrated that indices of social disadvantage (educational attainment, past and present employment status, living status, housing arrangements, relationship status, and social network quality) were significantly higher in patients than controls, regardless of ethnicity. Intriguingly, the study showed a cumulative effect, whereby Black Caribbean patients were significantly more socially disadvantaged (on multiple indices of social disadvantage) than White-British patients. The role of unemployment has also been explored in the work of Boydell et al. (2013). In a defined area of London, the study used census data to explore the association between unemployment levels and the incidences of psychosis between ethnic groups. Incident rates of psychosis were high and comparable in unemployed groups regardless of ethnicity (i.e. roughly a 12-fold increase for all groups). The study therefore concluded that higher rates of psychosis were probably linked to the higher rates of unemployment for ethnic minority groups shown, rather than the stresses or meaning of being unemployed.

Parental separation in childhood has also been proposed as a candidate. In a study conducted in the UK, C. Morgan et al. (2007) compared levels of childhood parental separation and death in patients with psychosis and normal controls. Parental separation was 2-3 times higher in patients with psychosis in comparison to matched controls. Furthermore, separation from a parent was more common amongst Black-Caribbean controls than White-British controls. Although the experience of migration may explain some of the variance in diagnosis, this is unlikely to be the whole explanation. Another

potential socio-environmental factor is the experience of being in a minority in one's neighbourhood. For example, the work of Boydell et al. (2001) and Termorshuizen et al. (2014) have shown that ethnic minorities living with fewer of their own group are at greater risk of developing the disorder in comparison to those living in areas where they make up a greater proportion of the population (Boydell et al., 2001, Termorshuizen et al., 2014). This is referred to in the literature, as the 'ethnic density' effect and has been replicated in various other studies (Kirkbride et al., 2007; Shaw et al., 2012).

Research on the role of other socio-environmental factors is also limited. Lower socio-economic status (SES) is associated with immigration; however, there is limited evidence to suggest this is a contributory factor for higher rates of psychosis in ethnic minority groups. In a study conducted in London, Kirkbride et al. (2008) compared rates of psychosis between different ethnic groups, taking into account SES for each ethnic group using census data. The results of the study demonstrated that even after adjusting for SES, age and gender, Black and Minority Ethnic (BME) groups still had elevated rates of psychosis. There is good evidence to suggest that there is a link between psychosis and cannabis (Henquet et al., 2005, Moore et al., 2007). However, despite conventional thought, there is limited evidence to suggest that this explains raised levels of psychosis (Morgan et al., 2010, Pinto et al., 2008). Studies conducted in the UK reported no difference in the rates of cannabis use between White-British and Black patients with psychosis (McGuire et al., 1995, Cantwell et al., 1999).

The Black Population in Britain

After the Second World War, Britain saw an influx of groups migrate from former countries of the British Empire, including countries like India, Jamaica and other islands in the Caribbean (Perry, 2015). According to the 2011 census, ethnic minority groups in Britain now constitute 14% of the general population. Of these, 3.3% are defined as Black, constituting those of Black-African, Black-Caribbean and Black-Other descent (Office for National Statistics, 2011). The majority of these groups lived in large urban areas where there was greater opportunity for employment, such as London, Birmingham, Manchester and Leeds (Office for National Statistics, 2011). The social position of the Black population in Britain is different to that of the White majority. According to the 2005 TUC report, Black rates of unemployment are high, at 16% in comparison to the White population (12%) and other ethnic groups. The report also showed the rates of poverty and low income were two-to-three times higher in Black groups, with child poverty being at 50% (TUC, 2005). The reasons for such disparities in economic resources currently remain unclear, but a 2014 study by the Black Training and Enterprise Group (BTEG) found that young Black males cited racism and negative stereotyping as the main reasons for their high unemployment rate (BTEG, 2014)

The Psychological Evidence

A recent systematic review of the psychological literature (Brown, 2016) identified several themes that could explain ethnic variability in the rates of psychosis. Firstly, the review found that the BME general population had significantly higher rates of psychotic-

like-experiences (PLEs) than the non-minority group. Research on PLEs is important because the broader literature informs us that psychosis exists on a continuum, and that PLEs are a key step in the development of psychotic illness. It could be argued that elevated rates of psychosis for BME groups are the result of a greater susceptibility within the BME population to the precursors of the illness. However, the review suggested that this research was unable to establish an association between higher levels of PLEs and higher rates of psychosis in ethnic minority groups, and failed to account for the confounding effect of key socio-environmental differences. The review also suggested a role for perceptions of inequality (racism, discrimination and disadvantage). The literature revealed, firstly, that there was a positive relationship between perceptions of inequality and rates of psychosis and secondly, that BME groups in the general population reported a higher level of perceived inequality than non-BME groups. Taken together, these two strands of evidence suggest that perceptions of inequality might predispose BME groups to a greater susceptibility to psychosis. However, this postulation was tentative, as the review was unable to establish whether BME patients with psychosis experienced greater levels of perceived inequality than White British patients. There was also evidence to suggest that associations between psychosis, ethnicity and perceptions of inequality are non-linear and mediated by other socio-environmental factors. The review also highlighted the potential role of ethnic identity as being a potential causal mechanism, but the evidence here was less robust and clear.

Limitations and Study Rationale

The psychological and socio-environmental evidence has elucidated some of the factors surrounding the higher rates of psychosis in ethnic minority groups. Despite such advances, these associations are, at best, tentative; as the question of causation has been difficult to establish through the quantitative-epidemiological approaches typically employed. Furthermore, these approaches fail to adequately account for various interactions between variables of importance, which make it difficult to identify the underlying causes of this phenomenon. For example, no research has established how ethnic density, and high PLE level collectively lead to higher rates of psychosis in BME groups, or if there is an cumulative interaction between the high levels of unemployment and perceptions of inequality.

It is these questions that currently remain unanswered by contemporary research in this area, along with many others. It is therefore apparent that existing research, at best, provides only a crude picture of the connections between ethnicity, socio-environmental and psychological factors, and psychosis. It, therefore, stands to reason that further research is needed to help refine and clarify current thinking in this area, to help move the existing paradigms in this area forward.

Qualitative methods have a particular advantage in their ability to generate an in-depth understanding of a complex process. By asking a smaller sample of participants about their subjective experiences, a richer and more complex understanding of their world can

be revealed. Once analysed, this approach provides a detailed account that can be useful in revealing the core essence of the experience in question and the many connections within. In applying qualitative methods to understand why BME populations have higher rates of psychosis, this study asks Black-Caribbean individuals to reflect on the life experiences that are significant to them, the meaning or impact that they have and the connections they perceive exist between these experiences and the development of their first psychotic episode. It is through this approach that this study aims to better understand the connections between ethnicity, psychosis and the various socio-environmental and psychological factors that help best explain elevated rates of psychosis.

Primary Objectives

1. To identify the life events and circumstances significant to the participants interviewed
2. To explore the sense that the participants made of those experiences

Secondary Objective

3. To explore whether and how these experiences are connected to the development of their psychosis

Method

As the research aims of this study are novel, it was difficult to know how broad or narrow to focus the content of the qualitative interviews in order to identify the life events and

circumstances significant to the Black-Caribbean participants interviewed. In addressing this issue, a two-stage approach to the research process was purposefully selected.

The first stage had a more exploratory and descriptive focus, in which a semi-structured interview was used to guide the discussion between the researcher and the participants. This was to elicit common themes in the types of life events experienced by the group. The second stage has a more in-depth and explanatory focus in which key life events identified in the first stage would be carried forward into a new separate analysis. This second stage would have more of an in-depth sense-making focus, rather than a descriptive focus.

For the purpose of this thesis, however, only the first stage of this process is presented, due to the constraints of word limit. The second stage is being conducted by a masters' student at the University of Birmingham, who is completing the more in-depth sense-making analysis on a sub-set of the interviews collected from the first stage. This process is being completed under the joint supervision of the author of this report.

In addressing the first objective, special attention was given to the methodological approach chosen. Often, qualitative approaches recruit participants who have a shared a similar experience, in order to elicit common themes in the way these experiences are made sense of. However, as the focus of this study was primarily focused on identifying these shared experiences, a method for collecting the data called the Life Story Interview

(LSI) was selected (McAdams, 1995). The reasons for selecting the LSI method are explained in the following section.

Selection of McAdams' Life Story interview (LSI)

The aim of this study was to identify the life events and circumstances significant to the participants, and to explore the sense that the participants made of those experiences.

In achieving this aim, a narrative approach was selected because of suitability in eliciting the narratives that people tell about themselves. People tell stories about their lives and the lives of those around them for many reasons (Crossley, 2000). One of the main reasons is to facilitate a shared understanding with others, about the things that have occurred in life that are significant. These are often sequentially ordered in a way that meaningful and made sense of during the process of the story telling. Accessing these narratives, for the purpose of this study, represents an effective way of identifying what events and circumstances are considered important by the individual, and identifying what sense they have made of them.

The LSI was chosen, because of its commitment to accessing these narratives in a way that was structured and comparable. Because of the questions that are asked within the approach, the participant is channelled towards providing narratives about significant events and circumstances within their life. Through asking the same questions of each

participant, it also allows comparison across participants, and this may, in turn, enable the identification of common themes.

The Adapted Method of the Life Story interview (McAdams, 1995)

The LSI is a narrative-based approach, with an evolving structure, that asks each participant to identify, describe and reflect upon significant or meaningful life experiences prior to the onset of their first psychotic episode. At the end of the interview, participants were then invited to reflect on the cause or reason for their first psychotic episode, in light of the significant life experiences discussed during the LSI. This section of the study aimed to draw connections between the patient's life experiences and the development of their first psychotic episode.

LSI Questions

1. Defining Life Chapters: Participants were asked to segment their life into meaningful and discrete periods of time, right up until their first psychotic episode. A brief summary of the content of each chapter was also discussed and participants were invited to give each chapter a title if they wished.
2. High and Low Scenes: Participants were then asked to identify key events in their life that were particular fun, pleasant or exciting (highs) and upsetting, difficult or stressful (low).

3. Turning Points: Participants then identified key moments in their life that had marked an important change in them or their life circumstances
4. Challenges: Participants were asked to describe and reflect upon significant interpersonal loss as well as the aspects of their life that they saw as a failure or a regret.
5. Desires: Participants were invited to describe and elaborate on the dreams, hopes, and plans that they have had for their lives. Additionally, they were asked to identify and describe any barrier or obstacles that have prevented them from achieving these desires.
6. Coping, Strengths and Positives: Participants were asked to describe the aspects in their life that have enabled them to continue with life despite the adversities discussed.

Epistemology

It has been recommended by Squire et al. (2014) that narrative researchers should make explicit the epistemological assumptions that underpin their work. This study uses the narratives (stories) that a person tells about their life through the LSI, to reveal the social reality of that individual, as well as the personal impact or interpretation of their social reality. Epistemologically, the LSI sits within the Narrative Psychology family, and is a social constructivist approach. Narrative approaches are unique in that they attempt to understand the psychosocial nature of a patient's world through an exploration of their narratives and language. These narratives were viewed as a means to understand the lived

experience of those interviewed and not as a way to understand how these experiences were constructed through the telling of the narrative. Furthermore, the narratives derived through the LSI were thought to be influenced by external realities, and not solely a linguistic construction of the individual. It was also assumed that the narratives derived through the LSI were influenced by other factors during the interview process, such as the participant's memory, willingness to disclose sensitive information, and rapport with the interviewer/s. This study focused on the content of the narratives, and the researcher's interpretation of these narratives is clearly separated by its inclusion in the Discussion rather than the Results sections.

Ethical Approval

Full ethical approval was received from the National Research Ethics Service, UK (Appendix B2)

Recruitment

It was estimated that 10-20 participants would be sufficient to answer the research objective set, based on the sample sizes of recent studies that have used the LSI methodology in youth and minority populations (Neville, Oyama, Odunewu, & Huggins, 2014; Toolis & Hammack, 2015). Participants were recruited from several Early Intervention Services (EIS) in Birmingham, England, UK; a specialist mental health NHS service for young people in early psychosis. In recruiting the sample, an electronic list was compiled of all patients within the service who ascribed themselves as Black-Caribbean or

Black-British on the United Kingdom (UK) census ethnicity rating. Care coordinators of eligible participants were first approached to see if their patients were suitable to participate. If agreed, information sheets and consent forms were given to them, to pass onto the eligible participants at the next appropriate encounter (Appendix B3). Patients who expressed an interest in the study were then contacted by one of the researchers, who explained the study in greater detail and answered any questions the participants had. If the participant gave verbal consent a date and time was arranged for the interviews to be conducted.

In total, 13 qualitative interviews were conducted with Black-Caribbean patients who had experienced a first episode of psychosis (FEP). One interview was excluded from the study, as the participant became distressed during interview and began discussing other complications in his life not relevant to the study (QUB004). The final tally consisted of 12 interviews, which were all included in the final analysis

Inclusion

Patients aged between 16-35 years

Patients with a diagnosis of psychosis (ICD-10 F20–F29, F30–F33)

Patients currently in receipt of care from EIS

Patients who identify as being Black-Caribbean on the UK ethnicity census categories

Exclusion

Patients currently at risk to self or others

Patients from Mixed-Caribbean backgrounds

Procedure

Interviews were conducted at either the participant's current address or a local mental health centre, in a quite secluded space free from distractions. Written consent was obtained on the date of the interview, prior to the conduction of the interviews. The interviews were carried out by two researchers; typically, one lead researcher conducted the LSI, while the other offered support in the administration of the interview. All interviews were digitally recorded and later transcribed verbatim. Interviews varied in length, but ranged between 30 minutes and 1 hour 59 minutes (see Table 1 for further details). During each interview, participants were also provided with a roll of poster paper and set of multi-coloured pens. Participants were invited to diagrammatically draw or write down the key chapter and events in their lives, to help retain the information discussed throughout the interview, and to help bring clarity between the interviewer and the participant. In some cases, a second researcher completed this process, if this was preferable to the participant. All data analysis was conducted on NVIVO 11 for Mac and Windows. Transcripts were imported and the analysis process conducted directly within the program.

Table 1: Participants' Demographics

| Participant | Age | Gender | Migrant Generation | Country of Birth | Religious Affiliation | Marital Status | Living Status | Employment Status | Education Attainment | Interview Duration |
|-------------|-----|--------|--------------------|------------------|-----------------------|----------------|-----------------------|----------------------|----------------------|--------------------|
| QUB001 | 22 | Male | 3rd Generation | UK | Christianity | Single | With Parents/Guardian | Unemployed | GCSEs | 1 hr 14 mins |
| QUB002 | 32 | Male | 3rd Generation | UK | Islam | Single | Alone | Unemployed | No Qualifications | 50 mins |
| QUB003 | 17 | Female | 2nd Generation | UK | Christianity | Single | With Parents/Guardian | Unemployed | GCSEs | 1 hr 11 mins |
| QUB004 | 25 | Male | 3rd Generation | UK | Christianity | Single | Alone | Unemployed | No Qualifications | 35 mins |
| QUB005 | 27 | Female | 1st Generation | Jamaica | Christianity | Single | Alone With Child | Unemployed | No Qualifications | 30 mins |
| QUB006 | 24 | Male | 3rd Generation | UK | None | Single | Alone | Unemployed | GNVQ | 1 hr 6 mins |
| QUB007 | 25 | Male | 3rd Generation | UK | None | Single | With Parents/Guardian | Unemployed | A-Levels | 1 hr 51 mins |
| QUB008 | 26 | Female | 3rd Generation | UK | Christianity | Single | Alone | Unemployed | Degree | 34 mins |
| QUB009 | 37 | Female | 1st Generation | Jamaica | Christianity | Single | Alone | Unemployed | NVQs | 1 hr 34 mins |
| QUB010 | 24 | Male | 3rd Generation | UK | None | Single | Alone | Full-Time Employment | BTEC | 1 hr 20 mins |
| QUB011 | 21 | Female | 3rd Generation | UK | None | Single | Alone | Unemployed | GCSEs | 1 hr 17 mins |
| QUB012 | 33 | Female | 1st generation | Jamaica | Christianity | Single | Alone with Child | Unemployed | No Qualifications | 35 mins |
| QUB013 | 24 | Male | 2nd Generation | UK | Islam | Single | With Parents/Guardian | Unemployed | GCSEs | 59 mins |

Qualitative Analysis – Template Analysis

Template analysis is a form of thematic analysis that attempts to analyse qualitative data through the development of a hierarchical framework. Brooks, McCluskey, Turley, and King (2015) outline several key aspects to template analysis. Firstly, the framework is achieved through the construction of an initial coding template which focuses on the data that are the richest and most relevant to the purposes of the research project. This is achieved through the application of a priori coding template that is useful in answering the research objectives set. This coding template is then applied to a subset of the data and then further applied to broader data in an iterative way, through a process of revision and refinement.

Rationale for the Selection of Template Analysis

Template Analysis (TA) is considered particularly useful when there may be considerable diversity in the source material (King, 2004). Although the LSI was intended to elicit material about important events and circumstances in the lives of the participants, there was no guarantee that all the interview material would be focused on these things. In adapting to this methodological challenge, TA was chosen because it ensured that the analysis is focused on the research aims and on commonalities across participants. The approach also allowed a distinction between a more descriptive stage of analysis (in which there was an attempt to summarize the narratives of the participants through the template) and a more interpretative stage analysis (in which the themes within the template were related to existing literature, and their more general meaning and

significance was considered). Some other approaches (e.g. IPA) blend description and interpretation in a way that can raise questions about the credibility of the analysis, because it is not always clear how much interpretation is involved. Having said this, a critical realist approach was adopted (Hammersley, 1992). It is acknowledged that the data generated through the analysis process, are dependent on the researcher's inability to truly stand outside of his or her own position in the social world. However, it also acknowledges that the phenomenon in question is independent of the researcher and knowable through the analysis and research processes (Brooks et al., 2015).

Method of Template Analysis Brooks et al. (2015)

In analysing the LSIs, the method of template analysis outlined in the work of Brooks et al. (2015) was closely followed. This approach was also augmented with several external checks, to improve the credibility of the analysis process. In total, the following six steps to the analysis process were conducted:

| | <i>Description</i> | <i>Process</i> |
|----------|--|---|
| 1 | General familiarisation with a subset of transcripts | <ul style="list-style-type: none"> - Three qualitatively rich LSI transcripts were selected and read in full by two researchers independently (Author and Masters' Student). - Qualitatively rich transcripts were selected based on discussion and reflections of the Author and Masters Student, after two thirds of all the interviews had been transcribed. |
| 2 | Application of the a priori template | <ul style="list-style-type: none"> - An a priori coding template was then applied to the transcripts that the researchers were familiarised with in stage 1, by two researchers independently. - The a priori template consisted of following three initial themes, which were derived from the three research |

| | | |
|----------|--|---|
| | | objectives from the study: I) Salient life experiences, II) Sense-making of these experiences, III) links to the development of psychosis. |
| 3 | Generation of initial codes | <ul style="list-style-type: none"> - Emergent themes generated through the preliminary coding process were then organised into meaningful thematic clusters by each researcher separately. - This process is reflected in a hierarchical structure, in which the clusters are nested within a superordinate category. |
| 4 | Generation of the Primary Coding Template | <ul style="list-style-type: none"> - Independently generated themes and clusters were then compared and contrasted to each other for credibility purposes. - These codes were then amalgamated, to develop a primary coding template (PCT). The PCT is a coding framework which is then used as a basis for coding the remaining interviews. - Through discussion and reflection, the researchers also assessed the extent to which the PCT was an accurate representation of the data analysed thus far and its likely generalizability to the remaining transcripts. |
| 5 | The application and modification of the PCT to additional transcripts | <ul style="list-style-type: none"> - The PCT was then applied to three further transcripts and modified accordingly. If themes and clusters were not adequately reflected in the PCT, the template was modified and new themes inserted. It is through this process of applying the PCT to new data in an iterative way that a more complete and comprehensive template was generated. |
| 6 | Final template applied to the remaining transcripts and adjusted accordingly | <ul style="list-style-type: none"> - The final template was applied to the remaining data, with slight amendments and adjustments made where necessary. The names of the themes and subthemes were then adjusted to most accurately represent the content of the themes generated. |

Descriptive vs Interpretive Themes

In an attempt to answer the three research objectives, the analysis process was separated into three discrete steps. The first step (Descriptive Themes) identified the life experiences that were most salient to the participants as well as an account of how these experiences were understood. The second step (Interpretive Themes– participant-generated) attempted to capture the explicit links that the participants made between these significant life experiences and the development of their psychosis. In the final step (Interpretive Themes – researcher-generated), the researcher generated broader overarching themes from the previous two steps, using existing literature and theory where suitable. This stage was kept separate from the other results until the Discussion section, in order to increase the transparency of the interpretive process.

Credibility

Several credibility checks were taken to ensure the data analyses were credible and reliable. To reduce the influence of researcher bias, two researchers independently coded three transcripts, as part of the initial stages of the template, using a priori coding framework. Codes derived from this process were compared and contrasted to each other and were later amalgamated. The amalgamated template was then applied to the remainder of the transcripts, which was then reviewed by an external supervisor. To increase the transparency of the coding process, a table was created which consisted of a list of all the themes and subthemes, accompanied by the number of interviews and

references which contributed to each theme as a log (see Appendix B1). Finally, a preliminary draft of the themes was sent to a group of clinicians with experience of working with young minority groups with psychosis. Their feedback helped to establish how credible the results generated were.

Personal Reflexivity

Elliot, Fischer and Rennie (1999) acknowledge the importance of making explicit the personal influences that are both known in advance of the project as well as the ones that arise during the research process.

Dominant within the academic field of psychosis is the medical model which views abnormal experiences (i.e. hallucinations and delusions) as symptoms of an underlying disease process. Existing literature on ethnic differences in the rates of psychosis draws heavily on this model, and has identified many of the important explanatory factors. As a psychologist and an academic researcher, I have found this way of thinking problematic. Firstly, it fails to acknowledge the interaction between the individual and the broader systems around them. Put differently, these approaches construct a debate that is far too simplistic, which side-lines the role of the interpersonal and the psychological. Secondly, these ways of thinking also limit future routes to intervention. If evidence-based methods of intervention are to be developed, more holistic understanding of the ethnic variability in psychosis rates will be required. With a lack of focus on the interpersonal and

psychological, existing literature limits the potential for development of effective intervention strategies to reverse these ethnic inequalities at the individual level.

A prior motivation in developing this project was therefore to help bridge this gap. In doing so, I was keen to contribute to the existing literature by bringing a more individual and experiential understanding of the phenomenon. I envisaged that this approach would help start a discourse about the role of the individual in the context of the medical theories already in discussion. By virtue of this consideration, I deliberately framed my work within the medical model, in order to help my research sit more appropriately within the existing debate, as well as add to it.

During the research process, I also became aware of several other factors that contributed to the conduct of this study. Firstly, my own ethnicity and personal connection to the city of Birmingham gave me a deeper awareness of implicit and explicit references made by the participants about their lives and experiences. I was familiar with specific locations or regional events that were important to the participants interviewed. I was also able to understand the specific nuances in language or cultural references that were unique to them. The impact of these factors on the research process is unknown. However, during the analysis process, the Masters' student, my supervisor and I often reflected on how these personal connections helped us gain a deeper insight into the lives of the participants.

Another factor that contributed to the conduct of this project is my past experiences of conducting research with people with psychosis. Most of my professional career prior to clinical training has been with individuals who have experienced psychosis. This experience has granted me a greater level of understanding of the types of experiences common in the development of the disorder, as well as an understanding of how ethnicity and culture can shape subjective understanding of symptoms and help-seeking. I feel this insight gave me a greater connection to the types of narratives the participants shared with me during the interview, which I feel improved the quality of the interviews conducted.

Results

Descriptive Themes: Life Experiences and Sense-Making

Seven superordinate themes emerged from data that described the significant life experiences of the participants and their sense-making, prior to the development of their first psychotic episode. These were; 1) Interpersonal Relationships and Social Interactions, 2) Employment, 3) Hobbies and Interests, 4) Lack of Educational Attainment, 5) Cannabis Use, 6) Migrating to England and 7) Religiousness. In this section, each theme and sub-theme will be described in detail, with examples and quotes used for illustration. As the purpose of the initial stage of the analysis was descriptive, themes that appeared in fewer than two separate interviews were excluded from the final results. A diagrammatic representation of all superordinate themes and subthemes can be found in Figures 1 and 2.

Figure 1: Superordinate and Subordinate Themes Generated From The Template Analysis

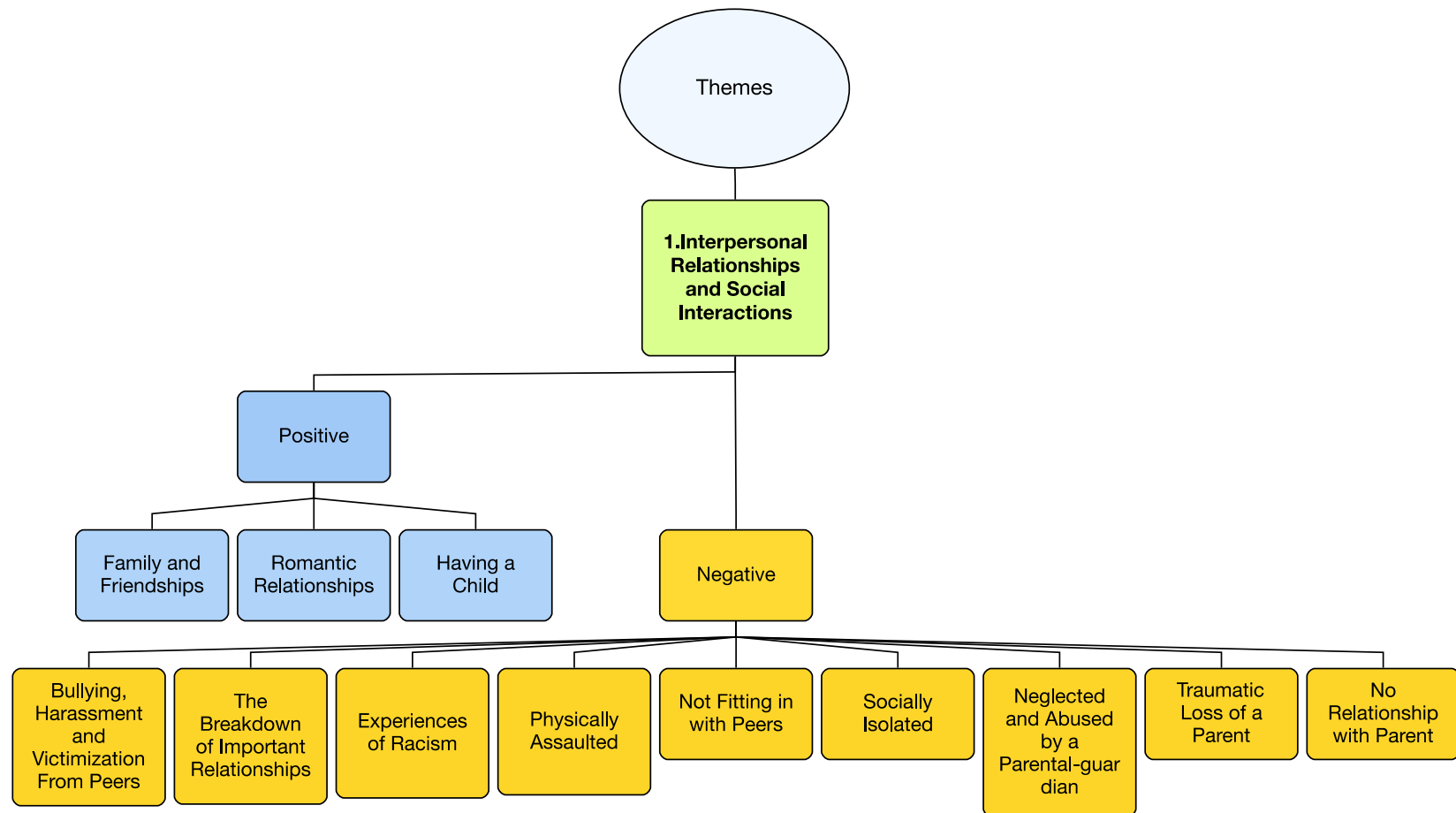
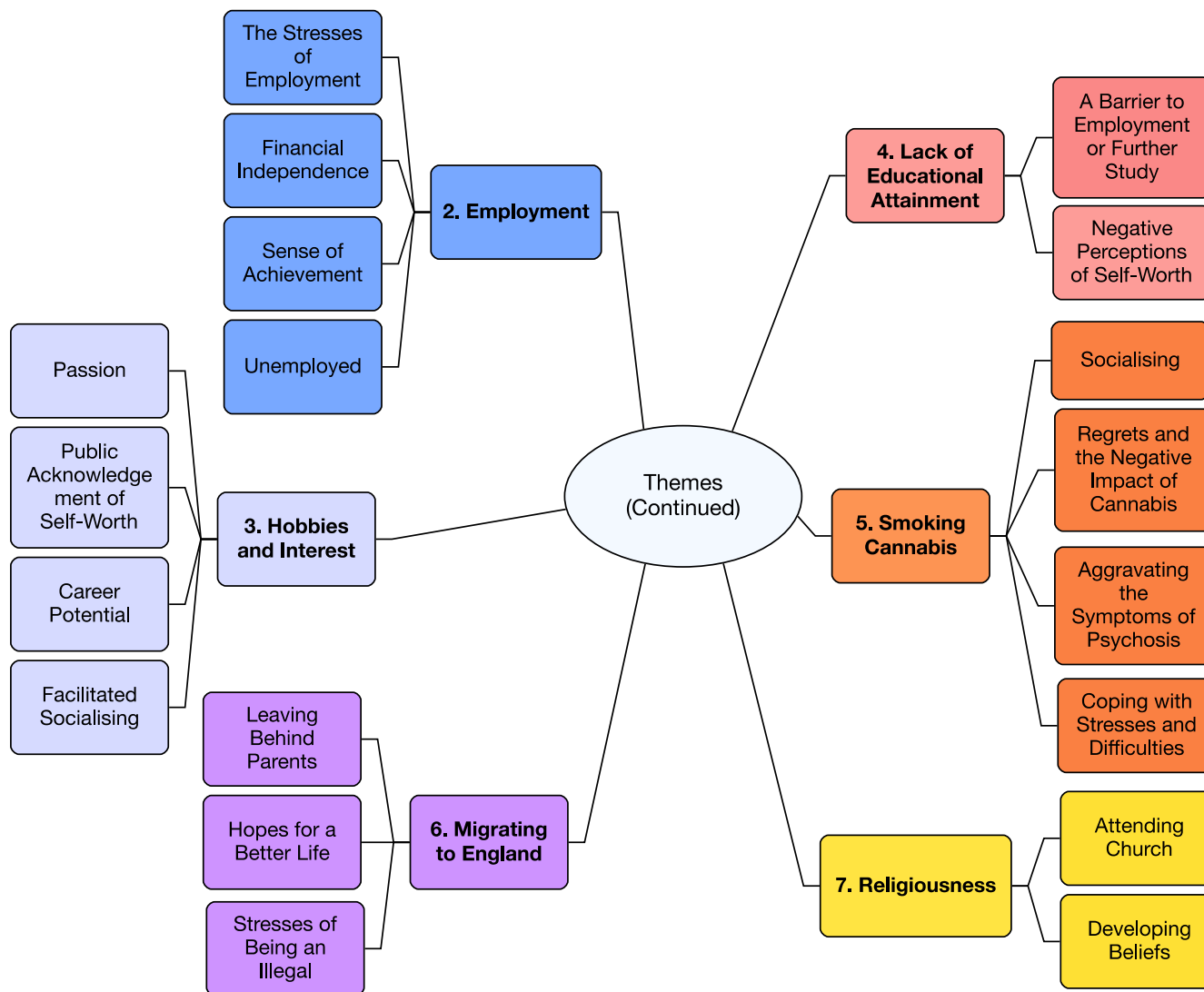


Figure 2: Superordinate and Subordinate Themes Generated From The Template Analysis (Continued)



1.1 Positive

1.1.1 Family and Friendships:

Across all the interviews, it was clear that the participants' relationships with their family and friends formed a significant aspect to their lives. Many participants spoke about how pivotal their friends and family were in supporting them through difficulties and hardships, or described how helpful they were in processing everyday life experiences.

“QUB006: I've had, I got two good friends that help me cope with a lot of this and one of them is named (friend's name) and one of them is named (friend's name). And they both helped me through some tough times in life. Helped me cope with it, get through it, just been generally good mates.”

Participants also noted how their social interactions with their family and friends would often bring them enjoyment and pleasure. For example, one participant reflected on the great times he had with his friends when they started going out clubbing together (QUB001), while another talked about her enjoyment of spending time with her cousin over the Christmas holidays (QUB008).

“QUB008: ... because my cousin, she's a nurse and she knew, she's my next of kin, she knows that I'm positive [HIV], and she treated me normal, she didn't change towards me or anything. So every Christmas, I spend with her, it was enjoyable and things like that”

Several of the participants talked about how their family and friendships gave them a sense of belonging or a feeling of being wanted, which was viewed positively.

“QUB006: I came back down to Birmingham after having a little adventure a while, coz I’d moved to London. And I/ and I met back up with all my old friends and it was pretty cool coz I hadn’t seen them in a long time. Yeah erm, I felt like I had everyone was just waiting for my return coz everyone made me feel so welcome when I come back. Erm, Yeah and it was just cool man because I hadn’t seen anyone in a long time, and they made it feel like erm....”

1.1.2 Romantic Relationships:

Participants also talked about developing romantic relationships, as well as the significance that these relationships had in their lives. Some participants talked about having their first significant relationship in their teens or reflected on the stages in their life when they actively began seeking romantic relationships. With regards to sense-making, romantic relationships were seen as important because they were aspects of the participant’s life where they were valued and appreciated.

“QUB012: Because he was just a lovely person, he was good to me, and very nice to my daughter as well, he was like a father figure in my daughter life. He was a good man, so it was a happy moment”

1.1.3 Having a Child:

Three participants noted that becoming a parent was a significant and positive period in their lives. All participants noted that having a child was life-changing in a positive way, and that their own life was now dedicated to the care and protection of their son or daughter.

“QUB002: That’s the best thing that’s happened to me in my twenties – my children, two beautiful girls (Names of participant’s children) ... They are my life right now, that’s what I live for”

1.2 Negative

1.2.1 Bullying, Harassment and Victimization from Peers:

Another sub-theme that emerged from the interviews was the experience of bullying, harassment and victimization. People talked about being bullied by peers, which they often found upsetting, stressful or psychologically damaging in some way. One participant talked about feeling bullied by a boss at work (QUB10) while another talked about being bullied online by people in her neighbourhood (QUB008). For many, bullying occurred during their school years, by people within their social network.

“QUB009: Errm, throughout these five years I had a lot of bullying take place when I was in primary school.

Interviewer: What was that about?

QUB009: I was gonna say probably for the fact I wore glasses, I got called four eyes quite a lot. I got kicked and punched by one guy that was a year above me. That was something that was quite traumatizing to be fair”

1.2.2 The Breakdown of Important Relationships:

The breakdown of important relationship was also reflected upon during the interview, as well as the effect that this had on their lives. Some described the loss of close friendships or family connections that had broken down after some incident or disagreement.

“QUB003: Erm, it was, it started after I broke up being friends with my friend. Like it was a really big like shock how we stopped being friends anymore like, she started yelling and shouting at me and she was really angry with me and I really didn’t do anything. (Pause) Erm, she said it was because I was giving her dirty looks....”

One participant described their experience of falling out with her close aunt, and how stressful she found it (QUB012), while another participant described the breakdown of her relationship with her sister as upsetting (QUB005).

“QUB012: well, it’s/it’s really stressing, stressful. It really made me feel very sad, very low in myself, because I really loved my aunty, and knowing that she was not going to be in my life anymore, it was really really sad”

1.2.3 Experiences of Racism:

Two participants talked explicitly about experiences of racism, in which they experienced difficult social interactions with ‘White people’, which they attributed to being because of their racial background. One participant talked about being beaten up by a gang of White young men (QUB001), while another lady talked about experienced racial remarks from people in her neighbourhood (QUB008).

“Interviewer: You mentioned before about the racism that you had. How did that impact on you?”

QUB008: It made me feel alone, errr, I really isolated myself really from the neighbourhood.

Interviewer: Why?

“QUB008: Because they made me feel like it was wrong to be Black, but I didn’t ask God to make me Black, God made me this way for a reason”

1.2.4 Physically Assaulted:

During the interviews, five participants talked about being physically assaulted. Two participants talked about getting stabbed, while others talked about being beaten up.

“QUB006: I said ‘listen I never said anything about you so just drop it’ and he carried on and carried on until we both stood up and then I got him in a headlock, the person whose house it was was under the influence as well –he was sleeping and then he got up and told me to let him go. As soon as I let him go the person ran off into the kitchen, grabbed a knife and then proceeded to stab me in the chest.”

The impact of these events was variable, with some participants talking about feeling highly stressed by the experience, while others talked about feelings of anger or becoming more vigilant or paranoid. One participant described how angry he became with himself for not confronting the perpetrator of his assault. He also described his thoughts about seeking ‘vengeance’ (QUB006).

1.2.5 Not Fitting in with Peers:

Four of the participants described not fitting with peers as being a difficult experience during their adolescence. This was often characterized as feeling different from other people or not fitting in.

“QUB007: I remember that as an early memory, standing on the fringes of social convention or maybe, not disrespecting social convention, but kind of not fully accepting it”

1.2.6 Socially Isolated:

Closely linked to this theme, was a feeling of social isolation. Two participants talked about how difficult they found life without contact with their friends and family.

“QUB006: Because I was in an area that I didn’t know. I had nothing to do, so I was just staying inside all day long. Cooped up in the room, no friends, nothing. Nothing, nothing that’s going on for me. Yeah, just literally feeling isolated”

1.2.7 Neglected and Abused by a Parent/Guardian:

Difficult relationships with parents and guardians were also noted by some of the participants. Four participants talked about experiencing physical and psychological abuse and/or neglect by someone responsible for them during childhood. In two cases, participant’s biological parents were unable to look after them, and so were living with guardians, who treated them badly. In both these cases, the abuse by guardians occurred in Jamaica.

“QUB005: Well I was stopping with my, with a lady who my Dad knew, and my Dad was paying her money to look after me. After the money finished and everything then she wasn’t treating me very well”

“QUB006: Because, her husband was very horrible to me. He used to beat me, he used to give a lot of work to do. And it really messed with my education, because I couldn’t get to concentrate on my schoolwork. He was a very horrible man”

1.2.8 Traumatic Loss of a Parent Through Death:

Three participants also shared the devastating impact the death of significant caregiver had on them during their childhood. In one case, a participant's father was murdered in Jamaica and his body mutilated, she later went on to speak about her inability to get over this loss in her adulthood.

"QUB008 It impacted me really hard, because I, since I left Jamaica, I did not really communicate with my Dad, errrm, it just hit me really hard, because they disfigured him, my Dad, like, they did not need to stab him so many times like

Interviewer: Okay, how did you cope?

Respondent: I didn't cope very well, I was very emotional at college and stuff like that

Interviewer: So you were very emotional, what effect did it have on your life then?

Respondent: I cried a lot and stuff, I still haven't got over it, because I did not go to my Dad's funeral and stuff"

1.2.9 No Relationship with Parent:

Finally, three participants highlighted how difficult their childhood was without contact from a birth parent. Two participants met their biological father later on in life, however, one participant found it difficult that her father was not fully accepting of her when they finally met.

"QUB011: Erm at 7 I first met my dad. Erm that was a weird experience where he kind of ignored me, and was more interested in talking to/getting back with my mum.

Interviewer: Okay

QUB011: So..

Interviewer: And how was that for you?

QUB011: Erm, I just felt lost a bit, like out of place erm like he didn't, just didn't want anything to do with me really so.. Yeah"

2. Employment

The second most dominant theme generated in the interviews was related to employment (8 of the 12 participants). Participants made explicit reference to the role of employment in their lives or discussed the impact of not having work. It was apparent from the interviews that work had both a negative and positive influence in the lives of participants. The types of jobs that were discussed were primarily unskilled positions, and many began working during their late adolescences.

2.1 The Stresses of Employment:

For some, the workplace was described as being quite stressful. This was often related to demands or pressure of the workload or responsibilities. Two participants found work so stressful that it resulted in them leaving their employment (QUB009, QUB011). One participant described his inability to cope with the expectation of his manager to hold a more senior position within his company (QUB007).

"QUB007: Yeah, the reason I left work was the immense amount of stress that culminated.

Interviewer: What were you doing?

QUB007: It was working the cinema, and err, I started just sweeping up and shovelling popcorn and greeting customers and ripping tickets and then

eventually they moved me into the cash office, so I was counting the money. Doing the drops, checking the tills, and then they tried to move me up/ they wanted me to be a supervisor instead of the cash office, but I didn't really want to do supervisor at that time. I thought I was going to move onto something else, and I was planning to do this other thing, and so I was putting that in the works, but with work it was pulling me back into work, but I was like, the people around I didn't want to start bossing them around and telling them what to do you know the people who I was on a level with already, so so."

2.2 Financial Independence:

For some, having employment afforded them an income which, in turn, gave them greater independence. Participants described how their income enabled them to buy new clothes, socialize with peers or invest in the aspects of their lives that they enjoyed. A good example of this is in the quote from participant QUB007, who described how his employment supported his pursuit of his interest in motorbikes and computers.

"QUB007:I learned how to ride a motorbike, I learned how to drive a car, I was riding my BMX a lot more and I was watching videos and buying parts with money that I was earning, computer parts as well"

2.3 Unemployment:

Unemployment was also something that was mentioned during the interviews by the participants. Some described how difficult it was to find work, while others found the process of unemployment stressful because of the financial limitations they experienced. In two cases, this stress was exacerbated by external influences, like family members or employees

“QUB012: I didn’t have any money, I had a young child and it was just struggling because my cousin used to constantly be on my back, to find work, and she knew it wasn’t easy to find work, because I didn’t have any paperworks. So it was just hard

Interviewer: How did not having work impact you?

QUB012: It made me very stressed”

2.4 Sense of Achievement:

The role of employment in the lives of those interviewed was not always viewed in negative ways. Some participants described how their work gave them a sense of pride and achievement. One participant felt proud in his job, because his bosses promoted him to team leader (QUB10), while another participant described feeling good about himself because he was simply able to gain employment (QUB001).

“QUB009: And I really was proud of myself coz when I looked at my CV to that date from when I graduated, my jobs that I had/ I had/ like I said I was working (name of store) six years, I had my other 2 jobs on the side. And at that point I was also, my last year of Uni I was working in a care home. Erm was doing night shifts then.”

3 Hobbies and Interests:

Six participants talked in depth about the place that hobbies and interest had in their lives. Some participants talked about being involved in team sports like football and basketball, while others talked about more solo activities like rapping, creating music and making art. These experiences were all meaningful to the participants in some way, and were often described as life passions. For others, their hobbies and interests were a way in which they received public acclaim and social contact.

3.1 Passions:

These hobbies and interests were often described in very positive ways by the participant, and were often aspects of their lives that were perceived as being highly enjoyable and pleasurable. Some described their hobbies as their main 'love in life' or talked about how passionate they were about their particular area of interest.

"Interviewer: Why was the football thing so important to you? I mean you told me that you lived for football.

QUB002: That's what I lived for, yeah.

Interviewer: When you say 'live'/what do you mean by live?

QUB002: I slept, ate, drank, talked, everywhere I was going, everywhere I went I had a football with me. I took my ball everywhere with me, so to become a footballer. Wow! That was a dream come true man. You know"

3.2 Public Acknowledgement of Self-Worth:

For some, their hobbies and interests were a way in which their worth and value was publically acknowledged by others. One participant described his experience of obtaining a trophy for playing basketball (QUB10), while another described the feeling of worth he received when he performed a rap for the first time in front of his peers (QUB001).

"QUB001: ... and there was a dance and that was the first time that I performed in front of a crowd."

Interviewer: Oh, really?

QUB001: Yeah

Interviewer: How did you feel, going up for that?

QUB001: It made me feel good still. It made me feel good.

Interviewer: What did people say afterwards, can you remember?

QUB001: People were congratulating me still, say that I sounded sick still"

3.3 Career Potential:

Three participants talked about the potential opportunity that their hobbies and interest had in leading to a full-time career. Two participants described the active steps they had made to seek employment in their respected areas of interest (QUB007, QUB002), while another talked about his dreams of becoming a professional rapper (QUB001). The following quote is one participant's description of finding out that he could play football professionally.

"QUB002: Yeah and I met a few famous footballers through playing football

Interviewer: Yeah

QUB002: It did, it shocked me. And then I found out that I could get paid from it.

Interviewer: Oh right okay

QUB002: So I could do it instead of going to work, I could play football, and get paid for kicking a ball!"

3.4 Facilitated Socializing:

Three participants talked about the social elements of their hobbies and interests. It was clear in these accounts that their hobbies and interests involved socializing with peers, or enabled them to make new friends. One participant talked about his interest in music and rapping and how his friendship group was also a part of his creative expression.

“QUB001: Me and my friends just use to beat box around the table at school and I got home I just starting making lyrics. I made a little crew [rap group] as well “

4. Lack of Educational Attainment

In seven of the interviews, participants also discussed the impact of not having formal qualifications. Some participants described having no qualification at all, while others talked about failing their GCSEs or not getting the grades that they expected to. A lack of education attainment was also described as being important in other ways; namely, it was seen by some as a barrier to further study and negatively influenced their perceptions of self-worth.

4.1 A Barrier to Employment or Further Study:

Several participants talked about how a lack of qualifications prevented them gaining employment or being able to continue in further education. One participant believed that having a lack of formal qualifications prevented him from obtaining a better job and from further developing his skills (QUB002)

“QUB002: I needed a good job. I coulda had a better job, I coulda got a good job, now I can’t get a job and I got all the knowledge but I just ain’t got it down on paper. You know, and to start and go through it all and to go to college and start. I should have, I should have kept on going, left school and went to college or went to university and kept it, kept the ball rolling, but I never man”

4.2 Negative Perceptions of Self-Worth:

Three participants talked about how much they perceived their lack of education and attainment negatively, and regarded it as a regret or personal failing.

“QUB003: Errm, I think the biggest failure was when I didn’t pass my erm, my college course.”

Others felt as if the lack of a qualification was a negative reflection on their personhood, which made them feel bad about their self-value.

“QUB006: I guess I just/ I was just down in the dumps (incomprehensible) I was a bit hard on myself because I just didn’t. I really wanted to do well but I never done, I never done, I never worked hard enough. So it was a real failure in that time. I never worked hard enough I never gave it enough attention. I never (pause) thought anything about it coz I was too busy getting high all the time. Yeah”

5. Smoking Cannabis

In five of the interviews, the use and abuse of cannabis was also mentioned. The role of cannabis in the lives of the participants was multifaceted, as it was positive when used recreationally for social purposes and problematic when it affected their lives. For many, cannabis use began during their middle to late adolescence, whilst they were in school. Some participants described their use of cannabis as a method of self-medication to alleviate their stresses.

5.1 Socialising:

Several participants described in detail the social component to their use of cannabis. For example, two participants described how it was introduced to them via their friends (QUB10, QUB06), while another described how smoking cannabis was a social activity, which involved a level of mutual respect and shared acknowledgement between all those involved (QUB011)

“QUB011: Erm. There’s like a respect in smoking with other people. Like when you pass it on and then you say ‘safe’ or and then you take your three drag pass and everyone takes their three drag pass so it’s kind of like everyone’s like (pause) I dunno”

5.2 Regrets and the Negative Impact of Cannabis:

Some participants described how their use of cannabis had a negative impact on their social life, in particular their ability to work, study and socialise. Some participants described the regret they felt about starting using because of this impact, or recalled the period in their teens when they began to first notice these negative effects.

“QUB011: Erm smoking weed more than obviously, just like every day sort of thing. I was smoking weed everyday around that age. And, that’s when I had my first get of blip when I kind of realised this is kind of bad. Like my habits getting bad”

5.3 Aggravating the Symptoms of Psychosis:

Two participants described how the symptoms of psychosis were exacerbated whilst they were under the influence of cannabis. One participant described becoming more

paranoid, whilst another described the impact it had on his experience of hearing voices (auditory hallucinations).

“QUB001: Smoking, smoking, smoking weed that made me more paranoid I think”

“QUB002: Yeah. I don’t smoke it no more though coz it affects the voices that I have in my head”

5.4 Coping with Stresses and Difficulties:

For some, however, the role of cannabis was not always seen as a negative feature in their lives. Five participants described in detail how cannabis was useful in helping them cope with difficult experiences. In these instances, cannabis was almost described as a form of self-medication, and the participants would describe using the drug to block out difficult or unpleasant emotions or as a way of escaping from hardships in their life.

“QUB006: Well when you get high you don’t really think about what it is that’s stressing ya. You kinda just get on with it and go through. So yeah, that’s what I think about smoking cannabis it really did help me through some tough times. Getting high was a way of escaping.”

6. Migrating to England

In three of the interviews, the experience or impact of being a migrant was talked about by the participants. In all cases, participants described migrating from Jamaica when they were children, and came to live in England with a relative, such as an aunt, sibling or grandparent, leaving their parents behind. For some, migrating to England was viewed positively, while others described the stresses of being a migrant.

6.1 Leaving Behind Parents:

Two participants described migrating to England as a child without their parents. In both these cases, the participant had limited or no contact with their biological parents once they arrived in England.

“QUB008: I came from Jamaica when I was 10 years old,

Interviewer: Oh, okay. Would you say that that was a chapter?

Respondent: Yeah, because I left my mom and dad in Jamaica”

6.2 Hopes for a Better Life:

For some, the prospect of moving to England was viewed positively, and seen as an opportunity to better their life. However, these expectations were not always the reality once they arrived.

“QUB012: Because I was moving from Jamaica out of the struggle, and I was coming to somewhere, that I thought at the time, would make me much happier, so, that’s why”

6.3 Stresses of Being an Illegal Immigrant:

For reasons that were not explicitly clear during the interview, some of the participant’s legal status’ once they migrated to England, was uncertain. Some participants described how this uncertainty led them to feel stressed in their daily lives, while others described how their unofficial status prevented them from gaining access to public funds, employment, education and housing. One participant described relying on her boyfriend and family to support her and her daughter during this time,

which she found difficult. The following quote describes how difficult one participant found life in England to be, prior to her receiving her legal residency.

“QUB005: Because before, I was destitute before

Interviewer: When you say destitute what do you mean?

QUB005: No course of public fund, nothing like that

Interviewer: Really!

QUB005: Yeah

Interviewer: So how did you kind of survive or..?

QUB005: Coz I had to live in a pregnant/ when I was pregnant I had to live in a pregnant house where the Home Office looked after us, but then it wasn't assured that we was gonna get our status. It was terrifying for me”

7. Religiousness

Finally, some participants also talked about the role of religion or spirituality in their lives. With regards to this theme, participants mentioned attending church and developing spiritual beliefs.

7.1 Attending Church:

For example, one participant described how the church played a significant part in his upbringing (QUB007), while another talked about attending church more regularly during her early twenties (QUB009).

“QUB007: ... they were the two big institutions in my life at that moment that I had to commit to. So you know, it was five days a week for school, and then a couple of days a week for church as well, definitely on a Sunday, but then also on you know, we could go on a Thursday night and stuff like that.”

7.2 Developing Beliefs:

Other participants talked about the significance of gaining spiritual beliefs in their lives. For example, one participant talked about gaining more interest in Rastafarianism (QUB001), while another talked about the development of his beliefs in Islam (QUB013).

“QUB001: I was into my weed init, smoking and getting into/ how can I say it, not beliefs, but like Rastafarianism and that.

Interviewer: Was that going on for a long time, these beliefs about Rastafarianism?

QUB001: Yeah

Interviewer: So you had spiritual beliefs that were changing?

Interviewer: Do you think it was because of psychosis or that you were genuinely interested in it?

QUB001: Yeah, I was genuinely interested in it”

Interpretive Themes – What links do people make?

Three themes emerged from the data that categorised the explicit links that the participants made between their life experiences and the development of their first psychosis episode. These were 1) Ill-treatment by Others 2) cannabis use and 3) cumulative effect of all of life's difficult circumstances. Although they made an explicit link between these factors and the onset of psychosis, participants did not go into great detail about the rationale for their chosen links except in the case of the cumulative effect of difficulties. Instead, the links were grounded in data from the rest of the interview that had been discussed previously. Consequently, it was difficult to find single discrete quotes that adequately reflect these themes. In this section, the

themes are therefore described by summarizing the relevant contextual information from the interviews of individual participants.

Ill-treatment by Others

By far the most common link that the participants made between their life events and the development of their psychosis was the experience of being ill-treated by another. Of the twelve participants recruited into the study, eight participants cited various negative social experiences as being the cause of their psychosis.

“Interviewer: Okay, so we’ve talked about your psychosis, and we’ve talked about a lot about your life so far. Are there any links between what has happened in your life and the development of your psychosis?”

QUB001: eerm, yeah.

Interviewer: Do you want to talk to me in detail about what some of those links are?”

QUB001: Getting rushed/attacked basically, here (pointing to the life story map)”

Earlier in the interview, the participant from the above quote described an account where he was severely beaten by a group of young boys. This participant later went on to say that this experience made him become more paranoid and changed his beliefs. There were other examples where participants linked the developments of their psychosis to the abusive actions others. For example, participant QUB006 cited the time when he was stabbed, while participant QUB006 described their psychosis as being the result of being bullying and harassment. Racial abuse was also described by participant QUB008,

“QUB008: Yeah, well I was diagnosed in 2013, because of the experiences that I had. Where I was living in (name of area) they use to call me monkey and things stuff like that”

Another participant attributed the psychosis to being bullied and harassed by his manager at work (QUB10).

Ill treatment from within one’s social network was also cited by some participants as the cause of their psychosis. For example, two participants thought their psychosis was because they were stolen from and treated badly by friends (QUB011, QUB006). This was also mirrored in the account of participant QUB010, who thought his psychosis was caused by the fact that he was lied to by his friends.

“QUB010: The most relevant thing yeah, I’d say, is the same friends I was talking about in the beginning (referring to the beginning of the interview). It’s just, lying, being lied to”

Similarly, one participant thought her psychosis was linked to the fact that her boyfriend completely disowned her when she became pregnant with their child (QUB005).

“QUB005: Okay. I think it’s all the stress/ getting pregnant. I had to go through it all by myself coz the baby father wouldn’t care. I phone him up and he just put the phone down on me”

Cannabis Use

As revealed in the descriptive analysis, cannabis use was commonly featured in the lives of Black-Caribbean patients. When participants were explicitly asked about the factors or reason for their psychosis, four participants cited their use of cannabis as a reason. The link made to cannabis varied. Two participants described how cannabis exacerbated the symptoms of psychosis (QUB001, QUB002), while two other participants stated that it was their abuse of cannabis that was problematic and that the negative impact on their life, led to the development of their illness (QUB006, QUB011).

Cumulative Effect

Finally, two participants stated that their development of psychosis was linked to a multitude of factors in their life. In these accounts, participants did not attribute their psychosis to solely one experience, but rather, to a build-up of difficult life circumstances that all had a contributory role.

“QUB008: I think everything, that I’ve been through in my life has contributed a bit to my psychosis, because I didn’t deal with situations when they happened really, I kept them locked up inside, when I should have really dealt with them, but errm, but the most is the sexual abuse, and stuff, what I went through in Tipton. That I had to run away in the end”

“QUB010: Erm, used to watch a show with my mum it’s called ‘seconds from disaster’ and it erm pieces together the, the happenings the coincidence that cause a disaster. Like there’s never really one thing that happens, It’s always a sequence of events and I think everything in my life led up to it. Everything. I mean there’s, there’s more I could probably tell you around it. Like the best way to think about it is erm, you know when you watch them time travel films and they say don’t step on a bug. Coz even if/ that smallest thing, can lead to something bigger, it changes the world in ways that can/ that’s how I think about it. I think if I went back and I changed one/ anything, it wouldn’t happen. It might be worse it might be better but it would not happen the way it happened”

Discussion

Although it is clear the rates of psychosis in the Black-Caribbean population are elevated, existing research fails to clearly explain why. Previous work has pointed towards the role of various socio-environmental factors; however, this evidence has failed to shed much light on the mechanisms of this phenomenon. In addressing this issue, this study used the qualitative interviews to identify the most significant social experiences in lives of Black-Caribbean patients prior to the development of their first psychotic episode. It also attempted to understand how the participants psychologically understood these experiences. Finally, the study explored the connections that this group makes between their life experiences and the development of their psychosis. It was hoped that through these stages of investigation, a richer and fuller understanding of the processes that contribute to the higher rates of psychosis for Black-Caribbean individuals would be revealed.

In the following sections, an attempt will be made to expand on these descriptive themes and participant-generated links from the results section. The accounts of these events and circumstances, together with the meaning that the participants made of them, are synthesized into a number of broader over-arching themes. Theory and quantitative evidence are used to guide this synthesis. These broad themes are offered as researcher-generated explanations of how certain social and environmental factors may lead to elevated rates of psychosis in the Black-Caribbean population.

Conceptual Synthesis

1. Social Rejection and Exclusion

Prominent in the accounts of most of the participants were descriptions of being socially rejected, excluded and marginalised. There were two forms of this. Firstly, participants described being actively rejected by friends and family, not fitting in with peers, being on the fringes of social groups and being socially isolated (*social rejection*). Secondly, participants described being rejected and excluded from wider society, and they described experiences of racism and many barriers to employment (*social exclusion*). For many of the participants, social rejection was explicitly highlighted as the cause of their psychosis.

Within the broader literature, there is evidence to suggest that social rejection and exclusion do play a role in the development of mental health difficulties. According to some theorists, the need for interpersonal affiliation and belonging, are essential human drivers and are essential to the development of self (Maslow, 1970). Moreover, many psychological theories emphasise the importance of early relationships and

childhood attachments in the development of an individual (Baumeister & Leary, 1995). It is therefore understandable why rejection can lead to distressing psychological states. In a recent review of 21 studies, Rosenbach and Renneberg (2011) found a positive relationship between social rejection sensitivity (i.e. one's tendency to; anxiously anticipate, overreact and to readily perceive rejection from others) and various mental health problems (e.g. depression, anxiety and personality disorder). The study concluded that one's sensitivity to rejection plays a key role in the aetiology and maintenance of psychological disturbance.

In commonality with research on social rejection, a connection has also been established between social exclusion and psychological distress. Unequal access to society (social inequality) and financial resources (poverty) are thought to produce psychosocial stress (Wilkinson, 1997). There is also evidence of a correlation between the levels of social inequality within a society and the rates of mental illness (Wilkinson & Pickett, 2010). The review conducted in the first half of this thesis also supports this idea, as it demonstrated a connection between perceptions of being disadvantaged and discriminated against (excluded) and high rates of psychosis in ethnic minority groups (Brown, 2016).

There is also further evidence to suggest that Black-Caribbean people in England experience greater levels of social exclusion more generally. For examples, research has shown higher levels of exclusion from material resources, social relations, civic activities, statutory services, educational setting and neighborhood networking, in comparison to the general population (Palmer, Rahaman, & Kenway, 2002; Scharf,

Phillipson, & Smith, 2005). Given the high levels of social exclusion that Black-Caribbean people experience, in compared to the general population, and given the likely role of rejection and exclusion in contributing to psychological distress and psychotic experiences, it is plausible to hypothesise that social rejection and exclusion may partly explain the raised levels of psychotic experiences in the Black-Caribbean group.

1.1 The role of stress

Although the association between social rejection and exclusion in the development of psychosis has been established, there is less clarity about the specific connections between these variables. One potential explanation might be the role of stress, as stress has been shown to be a key mechanism in the development of psychosis. Summarised by the diathesis-stress model, it is argued that psychosis develops when an underlying genetic predisposition interacts with environmental stressors that exceed an individual's capacity to tolerate such stress (Nuechterlein & Dawson, 1984; Zubin & Spring, 1977).

During the interviews many of the significant life experiences and events described during the interviews were explicitly described stressful. For example, some described the stressful effects of being bullied, harassed, physically assaulted and racially abused (Social Rejection). Stresses associated with employment were also discussed; in particular, the effects of being unemployed, barriers to work related to a lack of education (Social Exclusion), as well as performance related stresses within the workplace. There were also instances where the migration process itself was also described as distressing, in particular the stress of being an illegal immigrant.

Moreover, some of the participants explicitly implicated the distress associated with these events and circumstances in the onset of their psychosis. It was therefore clear that stress, associated with a range of negative social and environmental life events, rejection and exclusion, played a significant role in the lives of the Black-Caribbean participants, prior to the development of their first psychotic episode.

It could be that a greater exposure to negative life and environmental factors, in turn, increases the levels of intolerable-stress for this group, which further leads to higher rates of psychosis. Within the broader literature, there are several strands of evidence that suggest that this postulation is plausible. Firstly, contemporary models about the aetiology of psychosis highlight the role of greater exposure to socio-environmental adversity (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Selten, van der Ven, Rutten, & Cantor-Graae, 2013). Empirically, this link has been established in several meta-analyses and reviews, which have shown a correlation between childhood and adulthood social and environmental adversity and incident rates (Beards et al., 2013; Craig Morgan & Fisher, 2007; Varese et al., 2012). We are aware that, in general, the Black-Caribbean population in Britain experience greater social and economic disadvantages than the general population (TUC, 2005). We are also aware that greater exposure to such disadvantages in comparison to White-British patients has been empirically shown to account for the higher rates of psychosis in this group (Boydell et al., 2013; C. Morgan et al., 2008). What is currently missing is evidence that the link is mediated by the stress caused by the social disadvantage. Does the Black-Caribbean population generally experience greater levels of stress, and, if so, do these raised stress levels explain the link between raised levels of social disadvantage and

psychosis seen in this population? Although it is clear that further research in this area is needed, there is some limited evidence to suggest ethnic minority groups experience different stress responses. In a neurocognitive Functional Magnetic Resonance Imaging (fMRI) study of stress processes, Akdeniz et al. (2014) found that ethnic minority groups in the general population demonstrated significantly increased levels of perigenual anterior cingulate cortex (pACC) activation (i.e. higher activation in the regions of the brain responsible for the regulation of negative emotion) in comparison to German controls. It was therefore concluded that ethnic minority groups had greater reactivity to stress than non-minority groups.

1.2 The Dopamine System

There may, however, be a more specific link between social rejection, exclusion and psychosis. The social defeat hypothesis argues that long-term exposure to being excluded from the majority group, may lead to the sensitization of the dopamine system which, in turn, increases the risk of psychosis (Selten et al., 2013). In this model, sensitization is a process by which exposure to a given stimulus, namely stress, enhances the response of the dopamine system to subsequent exposures. Although this model is still in its infancy, experimental research has suggested that chronic psychosocial-environmental stress can bring about changes in dopamine neurotransmission, and functioning. For example, in studies where animals have been deliberately socially defeated, research has demonstrated alterations in the binding capacity of dopamine transporter sites (Selten et al., 2013).

There is evidence to suggest that ethnic minority group in Britain are more socially excluded (Palmer et al., 2002; Scharf et al., 2005) and that social exclusion lead to stress and psychosis (Wilkinson, 1997). These findings raise the possibility that the elevated rates of psychosis in the Black-Caribbean population may be due the raised levels of social rejection and exclusion and in turn raised levels of stress which effect the dopaminergic system.

2. The Effects of Trauma

Many of the negative social experiences described by the participants in this study could be described as traumatic. Being physically assaulted with knives, having close family members brutally murdered, and experiences of childhood abuse were some of the events described during the life chapter interview. Although there is limited evidence about the Black-Caribbean population specifically, a recent review has established that traumatic and stressful life events are more common in those of lower SES and from ethnic minority groups (Hatch & Dohrenwend, 2007). While it is likely that ethnic minority groups experience greater traumatic life events, this study was unable to clearly describe how such experiences predispose the Black-Caribbean population to greater levels of psychosis.

There is an increasing body of evidence that has explored the connections between trauma (particularly childhood trauma) and the development of psychosis (Matheson, Shepherd, Pinchbeck, Laurens, & Carr, 2013; Schäfer & Fisher, 2011). For example, in a longitudinal twin study, Arseneault et al. (2011) found that children who experienced maltreatment from an adult or bullying from other children were significantly more

likely to report psychotic symptoms at age 12 than a twin who did not experience this. There was evidence of this process in our study, and QUB001 described becoming more 'paranoid' after he was assaulted by a gang of 'White youth'. Another way in which trauma might lead to increased rates of psychosis is through stress (see previous subsection). It could be possible that increased levels of trauma in the Black-Caribbean group, subsequently leads to a higher level of stress, which, in-turn, predispose them to the development of psychosis.

3. Protective Factors and Resiliency

In contrast to the overwhelming negative aspects described, participants also discussed the many positive experiences in their lives prior to the development of their illness. For example, some described how socialising with their family and friends brought them pleasure, support and a sense of belonging. Hobbies and interests were described by some as being their passion and love in life, whilst others described how their hobbies or interests were a way in which their self-worth was publically acknowledged. It was also interesting to see how some hoped their hobbies would become careers for them. From a conceptual perspective, it was curious to see how these factors contrasted against the theme of social exclusion and rejection. For example, we have seen how being socially excluded on the one hand can lead to stress. Could social inclusion protect against these effects, through feelings of pleasure, joy and a sense of belonging? Similarly, a lack of vocation was described by some as bringing about social defeat, stress and feeling of low self-worth, whilst having a hobby had an opposite effect.

Protective factors are characteristics within the individual, family, and wider environment that reduces the negative effect of adversity (Muris, 2010). For example, emotional and practical support by one's social network could reduce the stressful impact of social disadvantage and adversity. Similarly, having a hobby or interest that promotes good self-esteem might protect against the negative effects of being unemployed or failing at important educational milestones. In this study, social interaction and connection could therefore be seen as a protective factor, that mitigates against the negative psychological impact of being excluded. In attempting to understand ethnic variability in the rates of psychosis, it would be useful to explore whether these protective factors are less available to the Black-Caribbean population, making them less resilient to the effects of stress, trauma and social exclusion and, thereby, more vulnerable to psychosis. Future research is therefore needed in this area.

4. The Dual Role of Cannabis

As discussed in the introduction, there is no convincing evidence to suggest that higher levels of cannabis use can explain raised levels of psychosis in the Black-Caribbean population (Morgan et al., 2010, Pinto et al., 2008). Studies conducted in the UK reported no difference in the rates of cannabis use between White-British and Black patients with psychosis (McGuire et al., 1995, Cantwell et al., 1999). Despite this, findings of the present study suggest that cannabis may play a complex role in the onset of psychosis. On the one hand, cannabis was explicitly mentioned by some participants as being the cause of their psychosis. It was revealed through the analysis that some participants thought their use of cannabis exacerbated their symptoms, and

that others regretted the use of the drug because of the negative social impact it had on their lives. Conversely, cannabis use was described by some people as having a positive effect, in particular, the social connection brought about through smoking the drug with peers or how it was a method to relieve stresses as a form of self-medication. In terms of the overarching themes outlined earlier (stress, trauma and social exclusion), cannabis may assist in alleviating stress, but its longer term use may create further stress (e.g. by perpetuating unemployment); and it may promote social inclusion with other cannabis users, but lead to social exclusion from wider society.

Longitudinal studies of cannabis use are therefore needed to unpack these findings. For some individuals, already feeling socially excluded and stressed, cannabis use may be a method to manage negative feelings arising from this. As a side effect, the use of cannabis in this way might lead to further psychological destabilisation of the individual, which, in turn, further predisposes them to the development of psychosis. Cannabis use, in this context, may also have a direct biological effect on the onset and maintenance of psychotic symptoms (S. T. Wilkinson, Radhakrishnan, & D'Souza, 2014). Some participants explicitly described a build-up of stress in their lives as a contributor to their psychosis. It could be that such a culmination of life stresses leads to a gradual increase in cannabis use as self-medication, further predisposing the individual to the onset of psychosis.

Limitations

There are several limitations that should be acknowledged when evaluating the contributions of this paper. It is often the case in psychiatric research, that more

positivistic approaches to knowledge production are used. Qualitative approaches in this area are therefore rare, as they are inherently seen as biased, subjective and less scientific. Based on these assumptions, it could be argued that the usefulness of the claims generated in this study is limited to this regard. Notwithstanding this, many psychological models about the cause of psychosis highlight the importance of individual difference, in particular the role of subjective and atypical experiences and cognitive appraisals (Garety et al., 2001; Johns & van Os, 2001; van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). One could argue that it is only by an in-depth qualitative examination of a patient's inner world, that an accurate understanding of the processes that lead to psychosis can be understood.

Another critique of this work is bias introduced by the researcher. It could be argued the themes generated could be less grounded in the data and more in line with the preconceived ideas that the analyst has about the subject matter. In preventing such biases affecting the data generated in this study, several methodological steps were taken. Firstly, two researchers independently coded a sub-set of the data, which were later amalgamated to form the primary template that was applied to the remainder of the data. It was through this joint coding process that a less biased and more objective method of analysis was achieved. Furthermore, themes generated were shared with an external supervisor and professionals within the field with expert knowledge on the subject matter. Feedback from these sources increased the consistency in data analysis as well as the credibility of results.

Questions of generalizability should also be acknowledged when evaluating this work. Although a strategic approach to recruitment was used, participation in this study was primarily opportunistic. Some patients who were eligible to take part in the study declined to do so, while others, who were deemed too unwell by clinical staff or who were currently disengaged from services, were not approached. The effect of this potential recruitment bias is unknown, but it could be possible that those patients unable or unwilling to participate could have differing views or experiences than those recruited in this study. A limitation of this study, therefore, is the unknown extent to which the experiences discussed in this study are representative of the wider Black-Caribbean population.

Further Research

As discussed in the previous sub-sections, there are several areas where further research is needed. While it is apparent that the links between social-environmental stress and psychosis is clear, and that Black-Caribbean patients experience greater socio-environmental disadvantage; there is limited evidence to suggest that this group experience greater levels of stress. Future research is therefore required to unpick this link, to see if differential stress processes, related to social environmental disadvantage, lead to higher rates of psychosis in this group.

Similar research is also needed on the effects of trauma, to establish whether stress related to traumatic life experiences contributes to the higher rates of psychosis. It would be interesting to see if other processes related to trauma, such as disassociation, also play a contributory role. Spiegel and Cardena (1991) described

disassociation as the structured separation of mental processes (i.e. thought, emotion, connotation, memory and identity) that should otherwise be integrated. In the face of a traumatic event/s, Terr (1991) argues that an individual may experience a state of hyperarousal accompanied by elaborate processing of the experience. If the individual has inadequate capacity to process such trauma, disassociation is employed, which can include distorted internal representation of the event, the altering of intrapsychic structures (i.e. lower self-esteem, increased feeling of guilt, shame), development of a fantasy of omnipotent power and control over the trauma, or the employment of denial strategies to remove the experience from conscious awareness. In short, these methods serve as a method to protect against the effects of the trauma that are too overwhelming for the individual. There is good evidence to suggest that there is an overlap between disassociation and psychotic-like experiences (A. Moskowitz, Schafer, & Dorahy, 2008; A. K. Moskowitz, Barker-Collo, & Ellson, 2005). Could it be possible that high rates of psychosis in the Black-Caribbean community is an effect of a greater tendency by this group to employ disassociation, in the face of greater experiences of trauma? We already know that the ethnic minority population experiences higher rates of PLEs (Brown et al., 2016). Could the same also be true for disassociation? Further research is therefore needed in this area, to establish if trauma and disassociation can help account for ethnic variability in psychosis rates.

The role of social exclusion and the beneficial role of protective factors were also highlighted in this work. However, more evidence is needed to establish whether there are raised levels of social exclusion in this population in comparison to other groups. Similarly, further research is needed to establish whether the nature and availability of

protective factors within the Black-Caribbean community are comparable to other ethnic groups. Both these factors would then need to be explored in a more explanatory way, to see what role they play in contributing to the higher rates of psychosis known. It would also be interesting to see what interaction these factors have in contributing to the themes of stress and trauma already established.

Clinical Implications

For services that provide care for young people with psychosis, this study has been useful in revealing the types of social experiences and trauma that predate the development of psychosis, as well as some of the potential protective factors. If it turns out that these factors do play an important role in the onset of psychosis, then it would be useful for services to assess these factors as a matter of routine. This could be important for both symptom recovery and social recovery. Within the early intervention, there has been a steady increase in the clinical importance of social-recovery in addition to symptom recovery in the treatment of psychotic illness and disability (Hodgekins et al., 2015). Understanding the complexity of the social lives of young Black-Caribbean patients may enable the service to provide more effective psychological and social interventions targeted to reducing symptoms and improving social integration and participation.

Conclusion

From the outset, this study aimed to further understand the factors that contribute to the higher rates of psychosis for Black-Caribbean individuals. It could be argued that existing research in this area is limited in several ways. Firstly, it was unclear if the

known social, environmental and psychological variables correlated with the higher rates of psychosis in the BME population were causal. Secondly, there was limited research that explored the interactions between key variables of interest. It could be argued that the effect of both these factors cloud our understanding of the underlying causes of the processes, which is important because it prevents the development of more robust research and theory. More importantly, it ill-equips us with the knowledge necessary to reverse these known health disparities for future generations.

In addressing these issues, the qualitative approach employed in this study has allowed for a deeper understanding of how social environmental risk factors can lead to the development of psychosis within the Black-Caribbean population. Firstly, this study revealed the emotional and sense-making processes that this group makes in relation to these adverse social environmental experiences, as well as how these factors interacted with each other. It was through these processes, that the links to development of psychosis specific to this group were revealed, through a number of empirically and theoretically grounded conceptual themes. We are now aware of the likely role of social exclusion/rejection and traumatic and stressful life experiences, in predisposing this group to psychosis. More broadly, stress response and possibly disassociation might be the underlying mechanisms by which these socio-environmental risk factors increase the rates of psychosis in the Black-Caribbean population specifically.

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CHAPTER THREE – PUBLIC DISSEMINATION DOCUMENT

UNDERSTANDING THE PSYCHOLOGICAL CONNECTIONS BETWEEN ETHNICITY, SOCIAL ADVERSITY AND PSYCHOSIS

Understanding the Psychological Connection Between Ethnicity, Social Adversity and Psychosis

Is Psychosis More Common In People From Ethnic Minority Backgrounds?

Psychosis is a collective term that describes a range of mental health disorders where people experience either hallucinations or delusions. The most commonly known diagnosis within the psychosis family is Schizophrenia, and many find the symptoms of the illness distressing and disabling. For a number of years, research has shown that individuals from ethnic minority backgrounds are significantly more likely to develop psychosis. This finding has been shown in various countries, such as the United States of America, the Netherlands, and in many places in Western Europe (Bresnahan et al., 2007; Cantor-Graae, Zolkowska, & McNeil, 2005; Fearon & Morgan, 2006). More recently, a review of different research studies conducted in the United Kingdom (UK) found that Black-Caribbean and Black African people were almost five times more likely to develop psychosis than those from White-British backgrounds (Tortelli et al., 2015). These findings are alarming and it is understandable why many within the health care profession and minority community, are concerned about such differences in mental health. Further understanding and intervention is therefore needed in this area, to reverse these inequalities for future generations.

Why Do Ethnic Minority Groups Experience Higher Rates Of Psychosis?

Currently, there remains a lack of evidence that clearly explains why people from ethnic minority groups experience higher rates of psychosis. Biological research has failed to provide any plausible explanations, as well as the claims that this problem is

linked to miss-diagnosis (Cantor-Graae, Pedersen, McNeil, & Mortensen, 2003; Morgan, Charalambides, Hutchinson, & Murray, 2010) (Kirkbride et al., 2006). Instead, modern day research has pointed toward the impact of various socio-environmental processes, in particular factors of social adversity and disadvantage (i.e. Being unemployed, deprived, poor, living with fewer people from your own background and low educational attainment) (Kirkbride et al., 2008; Kirkbride, Jones, Ullrich, & Coid, 2014; Reininghaus et al., 2008). Despite these great strides in our understanding, further research is needed find out how these social risk factors directly lead to the increased risk of psychosis; in particular, the connections between social adversity and psychosis specific to lives of certain ethnic minority groups. It was the aim of this thesis to address this issue in the following two ways;

1. To identify the psychological research that best explains the excessive rates of psychosis in ethnic minority groups in Western Europe.
2. To identify some of the connections between the social lives of ethnic minority groups and the development of psychosis, through conducting interviews with you Black-Caribbean patients.

Can Specific Psychological Factors Help Us Understand Why Psychosis Is More Common In People From Ethnic Minority Backgrounds?

A 10-year review of the psychological research that has attempted to understand why psychosis is more common in ethnic minority groups was conducted. In total 13 unique research studies were found across three main countries in Western Europe. Across

these studies, four themes emerged in the types of psychological factors used to explain the higher rate of psychosis.

Firstly, psychotic-like experiences (PLEs) are symptoms similar to those found in psychosis (e.g. hearing voices, seeing things that appear strange or unreal), however, they are less severe and less frequent. PLEs are important because they are believed to be a key step in the development of psychosis in healthy individuals (van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). Collectively, the psychological literature suggests that the higher rate of psychosis in ethnic minority groups could be due to higher levels of PLEs within the ethnic minority population more broadly. However, the research was unclear, as to whether PLEs directly caused the higher rates of psychosis, as it was closely linked to higher levels of social disadvantage as well as other important factors.

Secondly, within the literature, research has shown that higher rates of psychosis are associated with higher levels of perceived inequality (disadvantage and discrimination). However, in similarity with the research on PLEs, there was a lack of evidence to suggest whether perceptions of inequality directly caused the high rates of psychosis in ethnic minority groups.

Ethnic identity and cognitive processes were the third and fourth theme to emerge, however, as this evidence was less commonly researched and methodologically robust, it remains difficult to assess how much these factors contribute to the higher rates of psychosis.

In summary, research on PLEs and perceptions of inequality provide the most likely psychological factors to explain ethnic differences in the rates of psychosis. However, this research can only explain part of the puzzle, as other socio-environmental factors are also likely to be important.

Can The Life Stories of Black-Caribbean Youth with Psychosis, Help Us Understand Why Ethnic Minority Groups Have Higher Rates of the Disorder?

In furthering our understanding of the connections between life experiences and the higher rates of psychosis in ethnic minority groups, 12 qualitative interviews were conducted with Black-Caribbean patients who had experienced psychosis. Participants were asked to describe the most significant experiences in their lives prior to the development of their first psychotic episode through the Life Story Interview (LSI). They were also asked to reflect on these experiences and to make explicit connections between their life and development of their first psychotic episode. Through the template analysis conducted (TA), several important themes emerged from the data; including the impact of negative social interactions and relationships (i.e. bullying, harassment victimisation or assault), lack of education, the impact of being unemployed, cannabis use, as well as the positive role of having hobbies and interests. Broader psychological theory and research was then used to hypothesise how these themes could increase the development of psychosis in ethnic minority groups. Through this process, four overarching psychological themes emerged. These were; an increased level of stress in this group, greater experiences of trauma, an increased level of social rejection and marginalisation and the role of cannabis. Discussion was also had about the role of several protective factors.

Summary and conclusions

Ethnic minority populations in the UK and Western Europe experience higher rates of a mental health condition called psychosis. Although many socio-environmental factors have been used to help us understand this problem, there currently remains a lack of evidence that clearly explains how these factors increase the risk of psychosis in specific ethnic minority groups. The psychological evidence has been useful in address this issues to some extent. Research has pointed towards the role of psychotic-like experiences and perceptions of inequality; however further research is need in the area. Qualitative interviews conducted with young ethnic minority groups with psychosis have revealed the influential role of stress and trauma as a potential psychological explanation. There is also evidence to suggest that being socially marginalised and cannabis use also play an important role.

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Appendix A

A1: Methodological Appraisal Scoring Chart

Appendix A1: Methodological Appraisal Scoring Chart

| | | 1. Veling et al., 2007) | 2. Cooper et al. (2008) | 3. Veling, Hoek, and Mackenbach (2008) | 4. Stouten, Veling, van der Helm, Laan, and van der Gaag (2013) | 5. Akdeniz et al. (2014) | 6. Reininghaus et al. (2010) | 7. Veling, Hoek, Wiersma, and Mackenbach (2010) |
|----|---|---|---|---|--|--|--|--|
| 1 | Did the study address a clearly focused issue? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| 2 | Did the authors use an appropriate method to answer their question? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| 3 | Representativeness of participants | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Unclear (0) | Unclear (0) | Unclear (0) |
| 4 | Non-participation rate | N/A | No description (no) | No (0) | No (0) | No (0) | No(0) | Yes (2) |
| 5 | Adequacy of sample size | No (0) – No power calculation | No (0) -No power calculation or justification of sample size | No (0) -No power calculation or justification of sample size | No(0)- No power calculation or justification of sample size | No(0) -No power calculation or justification of sample size | No (0) No power calculation or justification of sample size | No(0) No power calculation or justification of sample size |
| 6 | Did the authors define the method of categorising psychosis in their study? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | N/A | Yes (2) | Yes (2) |
| 7 | How did the study capture the ethnicity of the participants? | Third party (1) | Self report (2) | Third party (1) | Third party (1) | Unclear (0) | Self-report (2) | Third party (1) |
| 8 | How was ethnicity used in the statistical analysis? | Separate analysis no amalgamation (2) | Dichotomisation of ethnicity (0) | Aggregated groups of ethnicity (1) | Aggregated groups of ethnicity (1) | Aggregated groups of ethnicity (1) | Separate analysis no amalgamation (2) | Aggregated groups of ethnicity (1) |
| 9 | Did the authors account/control for confounding in the analyses conducted? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| 10 | Did the authors use a validated method to assess the psychological variables in question? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| 11 | Was the exposure accurately measured to minimise bias? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| 12 | How precise is the estimate of the psychological factors in each sample? | Narrow Confidence intervals (2) | Moderate confidence intervals (1) | Narrow Confidence intervals (2) | Unclear (0) | Moderate confidence intervals (1) | Moderate confidence intervals (1) | Narrow Confidence intervals (2) |
| | Total | 19 | 17 | 18 | 16 | 13 | 17 | 18 |
| | Max score | 24 | 24 | 24 | 24 | 22 | 24 | 24 |
| | Percentage score | 86% | 70.83% | 75% | 66.66% | 59.09% | 70.83% | 75% |

| | 8. Vanheusden et al. (2008) | 9. Laurens, West, Murray, and Hodgins (2008) | 10. C. Morgan et al. (2009) | 11. (Das-Munshi et al., 2012) | 12. Velthorst et al. (2012) | 13. Adriaanse et al. (2015) |
|---|---|---|---|---|--|--|
| Did the study address a clearly focused issue? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| Did the authors use an appropriate method to answer their question? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| Representativeness of participants | Unclear (0) | Yes (2) | Yes (2) | Unclear (0) | Unclear (0) | Unclear (0) |
| Non-participation rate | Unclear (0) | No (0) | No (0) | Yes (2) | No (0) | No (0) |
| Adequacy of sample size | No (0) no power calculation or justification of sample size | No (0) No power calculation or justification of sample size | No (0) no power calculation or justification of sample size | No (0) no power calculation or justification of sample size | No(0) no power calculation or justification of sample size | No(0) no power calculation or justification of sample size |
| Did the authors define the method of categorising psychosis in their study? | N/A | N/A | N/A | N/A | N/A | N/A |
| How did the study capture the ethnicity of the participants? | Third party (1) | (2) Self-reported | (2) Self-reported ethnicity | (2) Self-reported | Third party (1) | Third party (1) |
| How was ethnicity used in the statistical analysis? | Separate analysis no amalgamation (2) | Separate analysis no amalgamation (2) | Separate analysis no amalgamation (2) | Separate analysis no amalgamation (2) | Dichotomisation of ethnicity (0) | Separate analysis no amalgamation (2) |
| Did the authors account/control for confounding in the analyses conducted? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) |
| Did the authors use a validated method to assess the psychological variables in question? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes(2) |
| Was the exposure accurately measured to minimise bias? | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes (2) | Yes(2) |
| How precise is the estimate of the psychological factors in each sample? | Imprecise (0) large confidence Intervals | Narrow Confidence Intervals (2) | Moderate confidence intervals (1) | Narrow Confidence Intervals (2) | No confidence intervals given Unclear (0) | Narrow Confidence Intervals (2) |
| Total | 15 | 18 | 17 | 18 | 11 | 15 |
| Max score | 22 | 22 | 22 | 22 | 22 | 22 |
| Percentage score | 68% | 81% | 77.2% | 81% | 50% | 68% |

Appendix B

B1: Template Analysis Coding Matrix

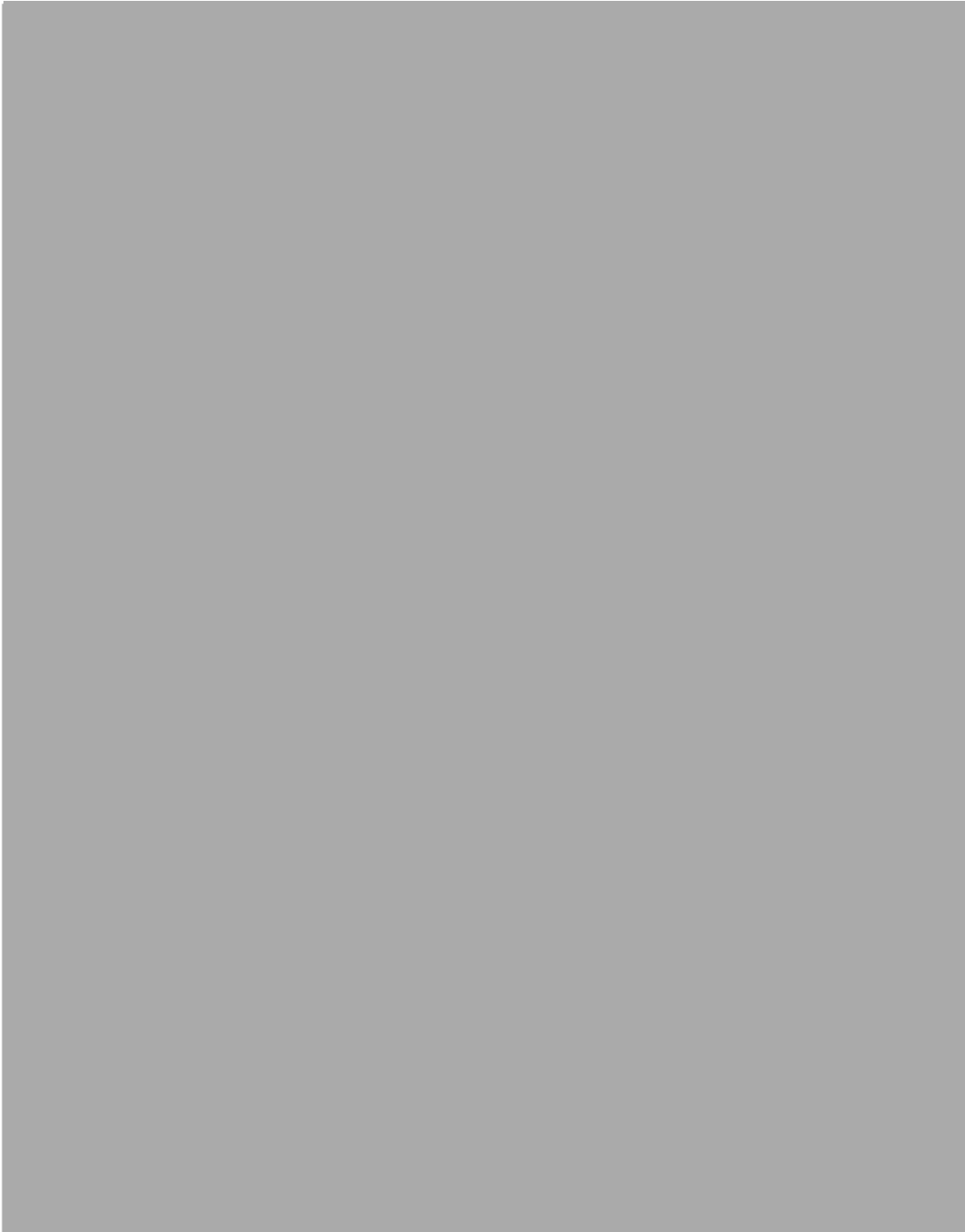
B2 Ethics Approval

B3: Information Sheets and Consent forms

B4: Examples of Coding Process

B1: Template Analysis Coding Matrix

| 1. Interpersonal Relationships and Social Interactions | | | Number of Participants | In Text References |
|--|----------|---|------------------------|--------------------|
| 1. Interpersonal Relationships and Social Interactions | Negative | Bullying, Harassment and Victimization from peers | 12 | 237 |
| | | The Breakdown of Important Relationships | 12 | 135 |
| | | Experiences of Racism | 9 | 38 |
| | | Physically Assaulted | 6 | 17 |
| | | Not Fitting in with Peers | 2 | 3 |
| | | Socially isolated | 6 | 25 |
| | | Neglected and abused by a parental-guardian | 3 | 8 |
| | | Traumatic Loss of a Parent Through Death | 5 | 11 |
| | | No Relationship with Parent | 4 | 10 |
| | Positive | | 4 | 15 |
| | | | 3 | 5 |
| | | Family and Friendships | 12 | 102 |
| | | Having a child | 11 | 74 |
| | | Romantic Relationships | 3 | 11 |
| 2. Employment | | | 7 | 11 |
| | | | 3 | 3 |
| | | | 3 | 5 |
| | | | 6 | 7 |
| | | | 3 | 3 |
| 3. Hobbies and Interest | | | 6 | 39 |
| | | | 4 | 7 |
| | | | 2 | 6 |
| | | | 3 | 6 |
| | | | 3 | 4 |
| 4. Lack of Educational Attainment | | | 6 | 31 |
| | | | 5 | 7 |
| | | | 3 | 6 |
| 5. Smoking Cannabis | | | 5 | 57 |
| | | | 3 | 5 |
| | | | 3 | 6 |
| | | | 2 | 2 |
| | | | 4 | 6 |
| 6. Migrating to England | | | 3 | 26 |
| | | | 2 | 4 |
| | | | 2 | 3 |
| | | | 2 | 4 |
| 7. Religiousness | | | 4 | 11 |
| | | | 2 | 8 |
| | | | 2 | 3 |



B3: Participant Consent Form And Information Sheet

THE QUBES STUDY: Qualitative Understandings of the links between Black-Caribbean Life Experiences and Schizophrenia and other psychotic disorders.

Please put your initials in the boxes and sign below

1. I confirm that I have read and understood the information sheet for the above study, dated 07.09.15. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction and that I agree to take part in the study.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected
3. I understand that all information that I provide is strictly confidential and will not be shared with anyone outside of the research study team.
4. I understand that all information I gave will be anonymised and that only non-identifiable data will be kept by the University of Birmingham, on an encrypted network server.
5. I understand that the research interview will be audio-recorded on encrypted digital recorder and will be transcribed by the researcher and/or a professional transcriber.
6. I understand that following the interview, I can request for copies of my transcript to review its content and ask amendments to be made. At this point I can also ask for my interview to be withdrawn from the study entirely
7. I understand that direct quotes from interviews may be used as examples to illustrate themes. However, my name or any identifiable information will not appear in any report, publication or written thesis of this study (electronic or hard copy).
8. I understand that my psychiatrist will be informed of my participation in the study.
9. I understand that the research will have to inform the police if I disclose information regarding serious criminal activity.
10. I understand that the research will need to inform my clinical team and in some cases the police if I indicate that my self or others are in danger of harm.
11. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Birmingham regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

| | | |
|---------------------------------------|------------------------|-----------------------------|
| ----- Name of participant ----- | ----- date ----- | ----- signature ----- |
| Name of researcher | date | signature |

PARTICIPANT INFORMATION SHEET (PIS)

THE QUBES STUDY: Qualitative Understandings of the links between Black-Caribbean life Experiences and Psychosis

Researcher: Dr Luke Brown (Trainee Clinical Psychologist)

You are being invited to take part in a research study (QUBES Study), conducted by a trainee clinical psychologist at part of a clinical doctorate at the University of Birmingham. The study uses qualitative interviews help understand the links between life experiences and psychosis from the perspective of Black-Caribbean people who have experienced a first episode of psychosis (FEP). Before you decide on whether you want take part or not, please take time to read this participant information sheet carefully.

What is the purpose of this research?

Over a number of years, health research has shown that people from Black-Caribbean backgrounds have higher levels of a mental health disorder known as psychosis. A lot of research has been used to try to understand why, and has discovered many important risk factors in a person's life as potential causes. Although the evidence in this area is growing, there is currently no dominant explanation, which suggests that more research is needed. The QUBES study asks Black-Caribbean people who have experienced psychosis about the most important experiences in their lives, and if they think these things are linked to their first experiences of psychosis. The study aims to interview 15-20 people about their experiences and then see if there is any new and important information that can help researchers understand the problem in more detail.

Why have I been invited to take part?

The study aims to recruit 15 people of Black-Caribbean origin who have experienced at least one episodes of psychosis. You have therefore been selected because you meet this criteria and your early intervention support team thought that you might be interested in taking part. Your involvement in this study is completely voluntary (you own choice), and if you decided not to take part, your care from early intervention will not be affected, either now or in the future.

What will happen to me if I agree to take part?

If after reading this information sheet you think that you would like to take part in this study, your care coordinator will arrange for you to be contacted by Dr Luke Brown (Researcher). Luke will spend a little time explaining the study in more detail, and will give you the chance to ask any questions that you may have. If you are still happy to take part at this point, he will make an appointment to meet you where you will be asked to sign a consent form about your involvement in the study. A time and date will then been arranged when the interviews can take place, and this can be at your home address if this is easiest. All the researcher will ask is that this is a quiet place free from distractions.

THE INTERVIEW

The interview is semi-structured, which involves you being asked some standard questions about many aspects of your life, from when you were a small child right through until your first

episode of psychosis. There are no right or wrong answers, and it is helpful to view the interview as conversation about you and your experiences rather than a list of questions to answer; we are interested in understanding how you make sense of your life and experiences. The interview will last between 1-2 hours, but it is completely up to you about how long you are willing to talk, and how much information you wish to share. Interviews can also be split over multiple sessions if this easier for you.

THE STRUCTURE OF THE INTERVIEW

The content of the interview is split into sections, called 'life chapters' and are similar to chapters in a book or scenes from DVD. The researcher will ask you to split your life into these 'life-chapter' and get you to explain how you decided to break your life down in this way. Big sheets of A3 paper will also be provided if you wish to write down these chapters, and you will be asked to give these chapters a name. Other questions about your life will also be asked, important events and experiences, relationships (both positive and negative) and your hopes for the future. You will then be asked to talk about your first episode of psychosis and the things from the others chapters that you think have links to it.

Confidentiality

All the information that you give during the interview will be kept strictly confidentially and will not be shared with anyone outside of the research team. However, information will be shared with your clinical team in instances where you disclose current thoughts of risk to yourself or to others. In these cases Luke (the researcher) will inform you of his decision to inform your clinical team.

ANALYSIS

The interviews will be recorded on an encrypted Dictaphone, so that the researchers will be able to convert all that you say into written text for analysis. However, this document will be strictly confidential and any information that identifies you will be removed (e.g. names, places, other people). The audio file will then be destroyed after the awarding of the degree associated with the project and all information will be kept securely on a password protected and encrypted computer at the University of Birmingham, available only to the Luke and the research team. Written documents and printed transcripts will securely locked in a metal filing cabinet. This data will be non-identifiable and you name and other indefinable details about will be replaced with a unique identifying number and pseudonyms. Each interview will be analysed by the QUBES study team, to identify similar patterns and important themes in what has been shared.

What will happen if I do not want to carry on with the study?

You have the right to withdraw from the study at any point; this also applies until two weeks after you've been interviewed, as this data will have been analysed and difficult to remove from the study. For some, sensitive and distressing events may be shared however; you are able to give as little or as much information that you feel comfortable with. If during the interview you

get upset and wish to discontinue from participating this is perfectly fine. You may also wish to reschedule the rest of your interview for a later date, this again is also acceptable.

Expenses and payments

To compensate you for your time in the study, we intend on paying you a cash sum to reimburse you for your involvement (£10) and travel. More information can be provided about this directly from Luke or you care-coordinator.

What will happen to the results of the research study?

The QUBES study is being conducted as part of a qualification in Luke Brown's training as a Clinical Psychologist. The results of the study will therefore be published as a thesis for examination and submission to the University of Birmingham library (electronic and hard copies).

We also envisage sharing the results of the study with others; including health care professionals involved in the study, people with psychosis, and other researchers interested in the topic in the form of scientific journal articles, conference abstracts and presentations. However, in doing this, no names or identifiable information will be used and your identity will be protected.

What happens if I have any further concerns?

The chief investigator and academic supervisor of the study will also be available to answer any questions or concerns that you have and their contact details can be found at the end of this sheet.

Should you have any other concerns about the study or the way you have been approached, and wish to talk to someone independently, outside of the QUBES study team please don't hesitate to contact the research and innovations managers within your local NHS Trust. Alternatively, you have the ability to contact the Patients Advice and Liaison Service (PALS) service within your trust.

B4: Examples of Coding Process (NVIVO)

Apple NVivo File Edit Create Data Analyze Query Explore Layout View Window Help Sat 10:21 am

QUBES

Home Create Data Analyze Query Explore Layout View

Open Get Info Edit Paste Copy Cut Merge Item Clipboard Format Paragraph Styles Editing

SOURCES

- Internals
- Externals
- Memos

NODES

- Nodes
- Cases
- Node Matrices

CLASSIFICATIONS

COLLECTIONS

- Sets
- Memo Links
- Annotations

QUERIES

OPEN ITEMS

- betrayal by close relationships
- Cannabis
- Getting physically attacked
- Cumulative effect of all of life'...
- Negative

| Name | Sources | Referer |
|---------------------------------|---------|---------|
| 1 Salient Experiences | 0 | |
| 2 How are these experien... | 0 | |
| 3 Explicit Links | 10 | |
| 4 Interpretive links betwe... | 3 | |
| 5 Initial Template Salient E... | 0 | |
| Church and spirituality | 4 | |
| Employment | 9 | |
| Hobbies and Interests | 7 | |
| Interpersonal Relations... | 12 | |
| Negative | 12 | |
| Bullying, harassm... | 9 | |
| Feeling socially Is... | 2 | |
| Getting Stabbed... | 6 | |
| Lack of contact w... | 3 | |
| Neglect & abuse... | 4 | |
| Not fitting in soci... | 5 | |
| Racial insults & pr... | 2 | |
| The break down o... | 6 | |
| Traumatic loss of... | 4 | |
| unrealistic expect... | 1 | |
| Positive | 12 | |
| Lack of educational att... | 8 | |
| Migrating to England | 3 | |

Summary Reference

started

Reference 5: 0.01% coverage

QUB001: because it got my mind off things #00:37:06-6#

Interviewer: Well it would do. Can you remember that time/ going back to that time. Cast your mind back. it sounds like what was going on for you was quiet difficult. it makes sense that you would like to distract from those feelings. but what were you feeling though? #00:37:27-7#

QUB001: Anger #00:37:33-5#

Interviewer: Anger about what #00:37:33-5#

QUB001: That it happened to me #00:37:31-9# #00:37:37-8#

Reference 7: 0.69% coverage

QUB001: Anger (long pause). sad as well, feeling sad #00:37:47-7#

Interviewer: what were you feeling sad about? #00:37:55-1#

QUB001: that it happened to me again, why me basically #00:38:06-7#

NODES > Nodes > 5 Initial Template Salient Experienc > Interpersonal Relationships & Social Interactions > Negative

Page 93 of 130 2 of 31080 Words English (UK) 51%

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Example of within transcript coding

Within participant coding of specific theme

The screenshot displays the NVivo software interface. On the left, a hierarchical tree structure is visible under the 'NODES' section, including 'Nodes', 'Cases', and 'Node Matrices'. Below this, the 'CLASSIFICATIONS' section shows 'COLLECTIONS' with 'Sets', 'Memo Links', and 'Annotations'. The 'QUERIES' section is also visible, showing 'OPEN ITEMS' with a list of items including 'Cannabis', 'Getting physically attacked', 'Cumulative effect of all of life...', 'Negative', and 'Bullying, harassment & victimi...'. On the right, a table lists sources and references for various nodes. The table has columns for 'Name', 'Sources', and 'References'. The 'Bullying, harassm...' node is highlighted in yellow, showing a count of 9 sources and 0 references. Other nodes include '1 Salient Experiences' (0 sources, 0 references), '2 How are these experien...' (0 sources, 0 references), '3 Explicit Links' (10 sources, 0 references), '4 Interpretive links betwe...' (3 sources, 0 references), '5 Initial Template Salient E...' (0 sources, 0 references), 'Church and spirituality' (4 sources, 0 references), 'Employment' (9 sources, 0 references), 'Hobbies and Interests' (7 sources, 0 references), 'Interpersonal Relations...' (12 sources, 0 references), 'Negative' (12 sources, 0 references), 'Feeling socially ls...' (2 sources, 0 references), 'Getting Stabbed...' (6 sources, 0 references), 'Lack of contact w...' (3 sources, 0 references), 'Neglect & abuse...' (4 sources, 0 references), 'Not fitting in soci...' (5 sources, 0 references), 'Racial insults & pr...' (2 sources, 0 references), 'The break down o...' (6 sources, 0 references), 'Traumatic loss of...' (4 sources, 0 references), 'unrealistic expect...' (1 source, 0 references), 'Positive' (12 sources, 0 references), 'Lack of educational att...' (8 sources, 0 references), and 'Migrating to England' (3 sources, 0 references).

| Name | Sources | References |
|---------------------------------|---------|------------|
| 1 Salient Experiences | 0 | 0 |
| 2 How are these experien... | 0 | 0 |
| 3 Explicit Links | 10 | 0 |
| 4 Interpretive links betwe... | 3 | 0 |
| 5 Initial Template Salient E... | 0 | 0 |
| Church and spirituality | 4 | 0 |
| Employment | 9 | 0 |
| Hobbies and Interests | 7 | 0 |
| Interpersonal Relations... | 12 | 0 |
| Negative | 12 | 0 |
| Bullying, harassm... | 9 | 0 |
| Feeling socially ls... | 2 | 0 |
| Getting Stabbed... | 6 | 0 |
| Lack of contact w... | 3 | 0 |
| Neglect & abuse... | 4 | 0 |
| Not fitting in soci... | 5 | 0 |
| Racial insults & pr... | 2 | 0 |
| The break down o... | 6 | 0 |
| Traumatic loss of... | 4 | 0 |
| unrealistic expect... | 1 | 0 |
| Positive | 12 | 0 |
| Lack of educational att... | 8 | 0 |
| Migrating to England | 3 | 0 |

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Interpretive Themes – What links do people make?

1 Ill-treatment by Others

Internals\\QUB005 - § 1 reference coded [0.62% Coverage]

Reference 1 - 0.62% Coverage

QUB005: Okay. I think it's all the stress, getting pregnant. I had to go through it all by myself coz the baby father wouldn't care. I phone him up and he just put the phone down on me.

Internals\\QUB010 - § 1 reference coded [0.27% Coverage]

Reference 1 - 0.27% Coverage

QUB010: The most relevant thing yeah, I'd say is them same friends I was talking about in the beginning like it's just, just lying. Just lied

Internals\\QUB011 - § 1 reference coded [0.18% Coverage]

Reference 1 - 0.18% Coverage

QUB011: Err being/ Erm, having friends steal from you, treat you like shit stuff like that

Internals\\QUB001 - § 1 reference coded [0.12% Coverage]

Reference 1 - 0.12% Coverage

QUB001: errrm, getting rushed/attacked basically. #01:06:54-8#

Internals\\QUB006 - § 1 reference coded [0.16% Coverage]

Reference 1 - 0.16% Coverage

QUB006: When I got stabbed, when my friend stole my phone

2 Cannabis Use

Internals\\QUB001 - § 1 reference coded [0.14% Coverage]

Reference 1 - 0.14% Coverage

QUB001: smoking, smoking, smoking weed. that made me more paranoid I think ,

Internals\\QUB002 - § 2 references coded [0.67% Coverage]

Reference 1 - 0.20% Coverage

QUB002: Smoking drugs, cannabis. I smoked cannabis, that could be one of effect..

Reference 2 - 0.47% Coverage

QUB002: Yeah. I don't smoke it no more though coz it affects the voices that I have in my head. I don't have them as much as I used to coz I'm on a depo injection now, and to be fair with ya it does help me

Internals\\QUB006 - § 1 reference coded [0.68% Coverage]

Reference 1 - 0.68% Coverage

QUB006: I guess it's from abuse of my body man, taking too much drugs. Taking err, the introduction of cocaine didn't help. Erm, (pause) having regrets about not (pause) taking what I'd say vengeance on people that I guess have done me wrong.

Internals\\QUB011 - § 1 reference coded [0.41% Coverage]

Reference 1 - 0.41% Coverage

QUB011: Weed, because obviously it's/ like how it's been described to me many times like someone's pulled a wire out your brain and everything's kind of going in the

3 Cumulative Effect

Internals\\QUB008 - § 1 reference coded [1.49% Coverage]

Reference 1 - 1.49% Coverage

Respondent: think everything, that i've been through in may life has contributed a bit to my psychosis, because i didn't deal with situations when they happened really, i kept them locked up inside, when i should have really dealt with them, but erm, but the most is the sexual abuse, and stuff, what i went through in tipton. That i had to run away in the end #00:32:06-3#

Internals\\QUB010 - § 1 reference coded [1.45% Coverage]

Reference 1 - 1.45% Coverage

QUB010: Erm, used to watch a show with my mum it's called seconds from disaster and it erm pieces together the, the happenings the coincidence that cause a disaster like there's never really one think that happens. It's always a sequence of events and I think everything in my life lead up to it. Everything. I mean there's, there's more I could probably tell you around it. Like the best way to think about it is erm, you know when you watch them time travel films and they say don't step on a bug. Coz even if/ that smallest thing, can lead to something bigger, it changes the world in ways that can/ that's how I think about it. I think if I went back and I changed one/ anything, it wouldn't happen. It might be worse it might be better but it would not happen the way it happened.

