

**Trauma and hearing voices. The experiences of refugees and
asylum seekers**

Neil Parrett

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OVERVIEW

This thesis is presented in three parts. Part one is a literature review, which examines the incidence of psychoses in refugee and asylum seeker populations as well as some hypothesised explanatory models. Part two is the empirical paper, which comprises a description of a study looking at the experiences of refugee and asylum seekers who hear voices and have been through traumatic events. Part three is a critical appraisal of the study undertaken. A background to the study is presented, followed by a discussion about the process of the study with some extended commentary on the future implications of the work.

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Part 1: Literature Review

Does being a refugee or asylum seeker increase your risk of psychosis? A review of the current literature.

Abstract

Within the relatively large body of research relating to mental health problems in refugee and asylum seeker populations, studies measuring incidence of psychoses are relatively rare. The literature has focused more broadly on the relationship between migration and psychoses, finding an increased incidence of psychoses (specifically schizophrenia) in migrant populations across the generations. Explanatory models have thus far focused on post-migratory factors, largely ignoring pre- and peri-migratory factors. This review specifically highlights those studies relating to psychosis in refugee and asylum seeker populations. Although many of these involve small and sometimes specific populations, the fact that all of them show increased incidence of psychoses than would otherwise be expected is noteworthy. In direct contrast to the literature relating to migration, the role of pre-migratory factors such as trauma seems particularly salient. Some biological, psychological and cultural models are presented.

Key Definitions

Human migration: 'the movement of people from one place in the world to another for the purpose of taking up permanent or semi-permanent residence, usually across a political boundary'

Impelled migration: 'Where individuals are not forced out of their country but leave because of unfavourable situations such as warfare, political problems or religious persecution.'

(National Geographic Society, 2005)

Refugee: 'A person who has a well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion and who is outside the country of his nationality and is unable or owing to such fear unwilling to avail himself of the protection of that country'

Asylum seeker: 'Someone whose application for asylum or refugee status is pending a final decision'

(United Nations High Commission for Refugees, UNHCR, 1951)

Introduction

There is currently a growing body of literature exploring the potential link between psychosis and trauma (e.g. Morrison et al. 2003 for review). There is also a great deal of literature relating to migration and psychosis (e.g. Cantor-Graae & Selten .2005 for a review). Noticeable by its relative absence in both these areas of research, are findings specifically relating to refugees and asylum seekers. This is surprising given that rates of psychosis in these populations have consistently been shown as markedly higher than those of matched samples (e.g. Eitinger, 1959). This review

aims to look at the research over the last 50 years relating to psychosis in refugee and asylum seeker populations to find out:

1. Is there good evidence to show the prevalence of psychosis is higher in these populations?
2. If so, what are the current hypotheses trying to explain this?

This review includes five sections. The first section is an overview of the potential causes and consequences of mental health problems in refugee and asylum seeker populations. This section suggests some of the different pre-, peri- and post-migratory factors that may be relevant and reviews some of the major studies relating to incidence of mental health problems in these populations. The second section briefly reviews the current literature on the role of migration (economic and impelled) in the onset of psychosis. The third section focuses specifically on the literature relating to refugees and asylum seekers and psychosis. This section forms the bulk of this review and examines the literature found relating to incidence of psychoses in refugee and asylum seeker populations over the last 50 years. Section four contains a brief overview of some cultural, psychological and biological hypotheses which, it has been suggested, may account for the difference described in the previous sections. The review concludes with a section drawing together the findings, with some suggestions of possible future directions for research.

Literature search

A search was conducted using Psychinfo and Medline, with the following words used as criteria: *Psychosis, psychoses, schizophrenia, migration, asylum seeker and*

refugee. All studies were included if they contained information relating to the presence of psychoses in refugee or asylum seeker populations. Further studies were found through references in articles obtained through the literature search. Only studies in English peer-reviewed journals were included. For section four, studies were included following the guidance of those papers found for sections two and three.

Section 1: Impelled migration and its psychological sequelae

Causes and consequences of impelled migration

By the end of 2006 there were an estimated 9.9 million refugees and 750,000 asylum seekers in the world (UNHCR, 2007). The vast majority of these individuals have found themselves with little choice but to leave their countries of origin due to group factors such as war, famine, flood and political unrest, which result in individual factors including displacement, oppression, torture and loss of livelihood.

The process of migration itself is often filled with many difficulties as people have to travel large distances with little money, food or water, often under the care of traffickers who have little concern for their personal well-being.

Once they have reached the country where they hope to seek asylum, they are faced with a whole new range of difficulties. These include national and local hostility, restricted rights, restricted services and restricted capacity for employment; as well as the constant threat of deportation (e.g. Porter & Haslam, 2005). Even if these obstacles are overcome and an individual is offered Indefinite Leave to Remain or

Refugee Status, they are still faced with the pressure of adapting to a new culture, language and way of life; often without the support of family and friends and in communities they feel isolated from joining. Given these pre-, peri- and post-migration stressors, it is not surprising that the refugee and asylum seeker populations are often characterised by high levels of mental health disturbance.

Mental health problems of refugees

Fazel et al. (2005) conducted a systematic review in order to determine the prevalence of serious mental disorder in the general refugee population. In all, 20 studies were eligible for inclusion with a total population of 6743 adult refugees from seven countries. Studies were included if they were interview based, contained information relating to the prevalence of PTSD, major depression, psychotic illnesses and generalised anxiety disorder, and were from general populations of refugees in high income western countries. Studies were excluded in which diagnosis was based on self-report or if they included refugees referred to clinical or other health care services. Prevalence rates of particular disorders were combined by summation of numerators and denominators across studies and confidence intervals calculated at 99%.

In the larger studies, ($n \geq 200$) 9% were diagnosed with post-traumatic stress disorder and 5% with major depressive disorder. The authors concluded that refugees resettled in western countries were ten times more likely than local populations to suffer from PTSD. The large population and rigor of the selection criteria make the figures highly compelling. However, this study underlines the overwhelming bias towards researching PTSD. Of the 20 studies used, 17 referenced PTSD ($n=5499$), 14

referenced major depression (n=3616), 5 referenced anxiety disorders (n=1423) and only two studies referenced psychotic illness (n=226). Within these two studies 2% of refugees were diagnosed with a psychotic illness, which is twice the percentage expected in the general population. However, as this comprises only 5 individuals in total, generalising these results to the refugee population as a whole is more difficult.

This understandable bias towards researching PTSD continues in studies of clinical populations. Lavik et al. (1996) assessed 231 consecutive refugee patients at a psychiatric out-patient clinic in Oslo. A semi-structured interview was used along with a number of standardised measures including the Brief Psychiatric Rating Scale (BPRS), the Hopkins Symptom Checklist (HSCL-25), the Global Assessment of Function (GAF) and a checklist for post-traumatic symptoms (PTSS-10). Results found that 46.6% of patients fulfilled criteria for PTSD, 16% for dysthymic and depressive disorders, 10% for adjustment disorders, 6% for anxiety disorders and 20% for other disorders not distinguished in this study. Although you would expect higher rates of psychiatric morbidity in a population attending a psychiatric out-patient unit, the proportion of individuals with PTSD is considerably higher than in a general out-patient population. Given the relatively large sample size and use of multiple standardised measures, this study's findings can be considered fairly robust and indeed other studies have similar findings (e.g. 49% in Turner et al., 2003).

Conclusions

It is clear that refugees and asylum seekers have considerably higher incidences of mental health problems than the general population. Rates of PTSD in particular are substantially higher. This is not surprising, given the sheer breadth of negative pre-,

peri- and post migratory factors that the vast majority have had to endure. Despite this fairly large body of research relating to mental health problems; studies measuring rates of psychoses are relatively rare, even though the indications are of an increased incidence.

Section 2: Migration and psychosis

This section focuses on two recent reviews of the literature relating to the incidence of psychoses in migrant populations (both economic and impelled). Although not a comprehensive review of the expansive literature in this area; it is aimed at providing a general overview of the current understanding.

Incidence Studies

Cantor-Graae & Selten (2005) conducted a meta-analysis of schizophrenia (and other psychoses) incidence studies between January 1977 and April 2003. Studies were included if they had incidence rates for 1+ migrant groups residing in a circumscribed area (or if numerators and denominators were provided for such calculations). Studies also had to have appropriate age corrections and be published in an English language, peer-reviewed, scientific journal. Eighteen studies met criteria for inclusion in the analysis. Eight were first contact incidence studies which included both in-patients and out-patients. The remaining 10 studies were hospital-based, first-admission studies. Five studies used semi-structured diagnostic interviews and six used non-standardised systems for diagnosis.

Analysis was conducted on studies of first generation as opposed to second generation migrants, as well as on a combined group. The first group containing studies of first generation migrants found a mean weighted relative risk of 2.7 (95% confidence interval [CI]=2.3-3.2), although the heterogeneity across studies was found to be significant (i.e. the different population of each study cannot be considered as uniformly representative of a given population). The second group, containing studies of second generation migrants, found a mean relative risk of 4.5 (95% CI=1.5-13.1) and no evidence of heterogeneity (although they concede the power to demonstrate heterogeneity across seven effect sizes was limited). The third group, comprising all data, found a mean relative risk of 2.9 (95% CI=2.5-3.4), again with significant evidence of heterogeneity. The analysis also found a significant association between risk and level of economic development of region of birth; with those individuals from poorer countries at increased risk. A significant association of risk with skin colour was also found. The mean weighted relative risk for migrants from countries with majority black populations was 4.8 (95% CI=3.7-6.2), this being approximately twice as great as for those migrants from countries where the majority was white or non-white/ non-black. No difference was found in effect size between male and female migrants.

By the authors' own admission, there was a great deal of heterogeneity. Populations ranged from 1 to 697 in the migrant groups and 21 to 10,726 in the reference groups. Furthermore, studies varied between mixed in-patient/ out-patient populations and hospital-based populations. Therefore, the different migrant groups cannot be considered as uniformly representative of a given population and thus the comparison of effect sizes is likely to be misleading. Also, few of the studies

examined all migrant groups in the population; usually choosing to focus on a specific group to which they had privileged access, most probably due to their high risk. Despite these problems the sheer size of the effect is extremely compelling evidence for an association between migration and psychosis and perhaps even for a diagnosis of schizophrenia. This also applies for the findings related to skin colour and economic development of the country of origin.

In a follow up paper by the same team, Selten et al. (2007) reviewed the literature between 2003 and 2006 relating to schizophrenia and migration (though again including some references to other psychoses). Reviewing the first 3 studies that used a national cohort, Hjern et al. (2004) found a two and three-fold increased risk for first and second generation immigrants not from Western Europe. Leao et al. (2005, 2006) divided the subjects into labour immigrants and refugees and found that the risk for both first generation labour immigrants and refugees was only modestly increased (RR from 1.1-1.9); though the risk for 'other' psychoses among male refugees was more substantially raised (RR=2.9). The authors note the strength of these studies as being their large populations (1.2-2 million). The inclusion of patients admitted before 1992 as new cases in 2 of the studies, resulting in a potentially lower threshold for hospital admission, and the lack of semi-structured diagnostic interviews, brings into question the accuracy of the interpretations. Another Swedish study by Cantor-Graae et al. (2005¹), was reviewed and found no significant increase in the risk for second generation immigrants. Here they suggest it may be explained by the small numbers in the study. This study supports the findings of their meta-analysis with respect to risk of developing psychotic disorders in first-generation immigrants with black skin colour (RR=5.8; 95% CI:2.8-13.4).

The Aetiology and Ethnicity of Schizophrenia and Other Psychoses (AESOP) study (Fearon et al. 2006), was given greater consideration in the Selten et al. (2007) review. This multi-centre (London, Nottingham and Bristol) study aimed to clarify whether the increased incidence of schizophrenia among African-Caribbeans in the UK was specific to schizophrenia and whether the incidence was also increased for other ethnic minority groups. The researchers obtained information from a large number of first contacts and found very high rates of psychotic disorders for African-Caribbeans (RR=4.1) compared to more modest rates in other ethnic minority groups (from RR=1.6 for 'white other' to RR=2.7 for 'mixed'). Broken down to specific psychotic disorders, some of the results were even more striking, with relative risk of schizophrenia reaching 9.1 for African-Caribbeans.

The authors concluded that the incidence studies since 2003 support the findings they had previously made, particularly with respect to migrants of black skin colour. Although there are a few minor inconsistencies, such as the increased risk for males as opposed to females in 'other psychoses' in the Leao et al. (2005, 2006) studies and the lack of significant findings for second generation immigrants in the Cantor-Graae et al. (2005¹) study, this seems generally to be the case.

Aetiological factors

The authors of the two aforementioned reviews note that after family history, the effect size for migration is greater than most other risk factors implicated in the development of schizophrenia (e.g. obstetric complications, odds ratio 2.0 in Cannon et al., 2002). The only other risk factor reaching similar levels is urbanization, (itself

related to migration) with odds ratio in one often quoted study reaching 2.75 (Pedersen & Mortensen, 2001).

In their reviews the authors challenge a number of suggested hypotheses for the increased incidence of psychosis in immigrant populations.

Diagnostic bias has often been suggested as a potential cause of increased incidence. The authors however note follow-up studies which have shown no diagnostic instability over time (e.g. Takei et al., 1998). Furthermore, Veen et al. (2004), re-diagnosed members of an epidemiological psychosis incidence cohort 2.5 years after first diagnosis; finding diagnoses more often adjusted *to* schizophrenia rather than the reverse for both Dutch nationals *and* immigrants. The implication again being, there is no diagnostic bias. However, the authors do note that evidence shows certain migrant groups are more at risk of forced admission to psychiatric in-patient units, Morgan et al (2005, 2006).

They believe methodological concerns about establishing reliable background information and correct populations statistics are unfounded. The authors claim that reliability of these figures is actually fairly good, with most of the studies being European and therefore having good access to census data and social service information.

Selective migration is another often suggested hypothesis with a long history (e.g. Odegaard, 1932). The authors suggest that this hypothesis could not account for the high incidence they found in second generation immigrants.

The authors then consider some previously suggested hypotheses including delayed exposure to infectious agents, prenatal exposure to vitamin D, nutritional standards, obstetric complications, modernization of country migrated to and use of illicit drugs. They are sceptical about all of these because they are unable to account for increased incidence in *both* first and second generation migrants. Also, as is the case with illicit drug use, the effect size is not large enough and there are no differences between males and females, which previous research would seem to predict.

The authors state that the broad spectrum of people across these studies suggests the notion of a single biological or genetic factor unlikely. Instead they favour explanations that incorporate socio-environmental elements, which they believe do not necessarily negate the genetic or biological nature of schizophrenia. Citing their own findings of substantially increased relative risk ($RR = 4.8$, 95% CI 3.7-6.2) for black skin colour, they suggest that those migrants who share this factor may also share a common exposure risk. They hypothesise that increased levels of discrimination which in turn lead to more paranoid attribution styles, may facilitate the development of psychotic symptoms. However, the authors are cautious, as higher rates of schizophrenia might also therefore be expected in African-Americans; when in fact the evidence suggests that schizophrenia may be over-diagnosed in this population (Sohler & Bromet, 2003). The authors suggest further research using more rigorous diagnostic tools with well defined denominators, would clear up the issue.

The authors also consider the effect of social poverty and low social class. Again, they are sceptical, suggesting evidence accounts for the association being caused by social *selection* as opposed to social *causation* (Dohrenwend et al., 1992). Selten et al. (2001) compared two migrant groups in a community. Both groups had lower income and poorer education and work opportunities, however only one of the migrant groups had higher relative risk when compared with the native population.

The authors note that any unifying hypothesis also needs to account for the increased risk associated with migration to areas of increased urbanisation and the protective effect of what they call ethnic density i.e. the lower risk found in communities where they are part of larger populations.

Their own suggested mechanism is the long term experience of social defeat, resulting from the long term experience of outsider status. They draw on comparison with the animal model for social defeat in the resident-intruder paradigm. A male rat is introduced into another male rat's cage; the resident attacks the intruder, causing him to display submissive behaviour. This experience of social defeat results in elevated levels of dopamine in the nucleus accumbens and prefrontal cortex (Tidey & Miczek, 1996). It is this experience, over extended periods of time, which the authors suggest may provide the common pathological mechanism for the increased risk.

The authors note the complex multi-factorial determinants in the development of schizophrenia and suggest a number of further research avenues to pursue including

comparison between urban and rural second generation migrants and comparison between migrants in different climates.

Conclusions

In both these analyses the authors have been rigorous in their attempts to elucidate common themes and where discrepancies do occur, they report them honestly. The sheer weight of evidence in support of the increased incidence of psychoses (specifically schizophrenia) in migrant populations across the generations is highly convincing. Their methodical testing of previous hypotheses is also impressive and therefore highly persuasive. However, in trying to explain these findings, the authors of these reviews and most of the papers within them have focused largely on post-migratory factors, leaving pre- and peri-migratory factors (other than genetic disposition), largely untouched. They do however urge future research to be directed at both biological and socio-environmental aspects, which is encouraging.

Section 3: Refugees, asylum seekers & psychosis.

Section two was concerned with the general population of migrants, including economic migrants as well as refugees and asylum seekers. As a result, hypotheses about the increased risk of psychoses were largely related to post-migratory factors. This section is concerned more specifically with the refugee and asylum seeker populations. They will largely be considered as one group, although differences will be explored where the literature allows e.g. Iversen & Morken (2004). Some papers mentioned in the previous sections will be re-examined in greater depth, along with the rest of the somewhat limited literature. Pre- and peri-migratory factors, in

particular trauma, as mentioned in the first section, will form the focus of explanations.

Case studies

During the literature search several case studies were found exemplifying the frequent clinical observations which help justify more formal investigations. Looj & Drew (1996) reported on a Chinese refugee who had been tortured and presented with an acute, paranoid psychosis. Rjinders et al. (1998), reported on a Middle Eastern asylum seeker and a Yugoslavian refugee who had both experienced severe psychologically traumatic events, and whose disturbances fitted psychotic diagnoses rather than PTSD. Finally, Wenzel et al. (1999) reported on two survivors of torture exhibiting psychotic symptoms and commented on the rarity of this in the literature.

Specific refugee population studies

Westermeyer (1988) surveyed psychiatric disorders among Hmong refugees in the United States. From a sample of 102 refugees who had been used in a previous study, 97 took part. All participants completed a questionnaire addressing both demographic and social variables. The questionnaires were administered by a Hmong research assistant; they included two self rating scales: the SCL-90 and the Zung Self-Rating Depression Scale. The questionnaires were followed by a clinical interview, conducted by the author, without knowledge of the questionnaire scores. The author then completed a 5-axis DSM-III assessment using: The Hamilton Rating Scale for Depression, The Brief Psychiatric Rating Scale (BPRS), the Mini-Mental State, The Global Assessment Scale and the In-patient Multi-dimensional Psychiatric Scale. A diagnosis was then made based only on the current presentation. Results

indicated 13 had DSM-III described psychiatric disorders, 2 of which fulfilled criteria for paranoia, with the author reporting onset since arrival in the USA. In addition to this, the author notes a patient with paranoid personality disorder and one with schizoid personality disorder; although he is cautious, given the highly culturally-bound nature of Axis II disorders and lack of inter-rater reliability in ascribing them. Although rigorous in its design, the small and specific sample makes generalisations more difficult, particularly with respect to psychoses. However, the figures do suggest the possibility of increased incidence among this particular group of refugees.

Kinzie & Boehnlein (1989) found that among one hundred consecutive Cambodian refugees evaluated and treated at a specialist Indo-Chinese psychiatric clinic between 1982 and 1987, most had PTSD and seven had psychotic symptoms that met DSM-III-R criteria for schizophrenia or schizoaffective disorder. This did not include one patient with a prior history of psychosis in Cambodia, one with a schizophreniform disorder and one with severe depression who became manic when treated. The authors note that although DSM-III-R criteria for PTSD mentions hallucinations, they are described as brief and transient. This was not the case for any of the seven included in their study, most of whom had other psychotic symptoms as well. Interestingly none of these individuals' demographic information (e.g. family history of psychosis) set them apart from the rest of the sample. The authors noted that 7% may not be a very accurate incidence of psychosis in traumatised populations given the highly selected population. They are however convinced that there is a clear link between severe, chronic psychosis and massive psychological trauma. They report that the content of hallucinations and delusions generally centred on the traumas they

had experienced, with a latency of between five to eight years between time of trauma and onset of psychosis. Although again this is a small, highly specific sample, the thorough nature of the study does once again support the possibility of increased incidence among this particular group of refugees.

Hauff & Vaglum (1995) interviewed a consecutive community cohort of 145 Vietnamese boat refugees on their arrival in Norway (T1) and three years later (T2). The sample represents 98% of those asked to take part. 114 were men and 31 women (age range, 15-58). All were interviewed by the first author within three months of their arrival in Norway using a semi-structured schedule specifically designed for the study. A Vietnamese version of the SCL-90 was used on both occasions, along with the Global Severity Index (GSI). At the follow up interview, the Present State Examination (PSE) was used to assess psychiatric disorders. The authors paid particular attention to the possible trans-cultural implications of hallucinations and delusions by interviewing subjects about their spiritual and magical experiences and their tradition in Vietnam. Additional information was gathered including: demographics, traumatic pre- and peri-migratory experiences, social support, family separation and post-migratory experiences. Results showed that after three years there was no reduction in self-rated psychological distress with almost 25% suffering from a psychiatric disorder. Three young men were diagnosed with a paranoid psychosis. The authors also comment in the discussion section that at least 5% of the cohort suffered a psychotic breakdown at some stage during their time in Norway. This study is particularly rigorous given its attempts to mediate for trans-cultural issues when ascribing hallucinatory and delusional symptoms. Despite this, the figures remain unexpectedly high, even when only taking into account those with

paranoid psychosis (the study did not show figures relating to other psychoses).

Although again, the small and specific population means the results should be viewed with caution when generalising.

Grisaru et al. (2003) reviewed psychiatric admissions of Ethiopian immigrants to an in-patient unit in Israel between the time of their arrival (approx nine years previously) and 1 January 1993. 17 individuals were identified. The authors note that although the rate of hospitalisation was similar to that of the general Israeli population (1.8% vs. 1.9%); most of the Ethiopians were hospitalised during their first 2 years in the country and thereafter the rate was much lower. Of these 17 individuals, 10 were suffering an acute reactive psychosis, as based on the opinion of two senior psychiatrists' reviews of case notes. The authors conclude a nine year incidence of acute reactive psychosis at 1% and suggest that the severe stress and traumatic experience of these individuals had expressed itself in the form of psychotic symptoms as opposed to 'classical' PTSD. Although the prevalence is much lower in this sample, the design was much less rigorous and more opportunistic than in the other studies mentioned. Also, data from services other than the acute in-patient admissions of the study centre were not included, from which you would expect increased numbers. The authors are explicit that their data supported a connection between prior traumatic experiences and reactive psychosis. They also report that of these 10 only two were re-hospitalised, suggesting a more positive long-term outcome.

Mixed refugee population studies

Lavik et al. (1996), assessed a consecutive sample of 231 refugee patients referred to an out-patient refugee centre in Oslo over four years. Individuals were seen over three to five sessions in order to gain trust and allow time for thorough investigation. Information gathered using a semi-structured interview included socio-demographic background, history of trauma and asylum status. The Brief Psychiatric Rating Scale (BPRS), the Hopkins Symptom Checklist (HSCL-25) and a checklist for post-traumatic symptoms (PTSS-10) were used to measure psychiatric symptoms. Individuals were then classified according to DSM-III-R, Axis I and DSM-III-R, Axis IV (Global Assessment of Functioning, GAF). 48% of the sample satisfied criteria for PTSD, 16% for adjustment disorder and 10% for anxiety disorder. A further 20% were classified as having 'other disorders'. Unfortunately, no specific figures are presented for the proportion of individuals with schizophrenia or other psychoses, though it is likely they make up a portion of the 20% of 'other disorders'. The authors did however conduct a common-factor analysis on the 18 items in the BPRS which resulted in a four factor solution they then gave an oblique rotation. Factor I was psychotic behaviour, factor II was emotional withdrawal, factor III was anxiety/depression and factor IV was hostility/aggression. The authors say these results were comparable to other, non-refugee populations in terms of structure. Factor I and factor IV showed a substantial correlation, indicating that those refugees in the sample with hostile and aggressive attitudes in the interview also tended to be worse integrated, with more psychotic symptoms. This suggests that there were at least a number of individuals in the sample who had psychotic symptoms. The authors then conducted four multiple regression analyses of the four factors compared to background, trauma history and exile. Interestingly, none of the

variables came out with a significant effect on psychotic behaviour, which the authors interpret as suggesting that stress and trauma connected to the refugee situation do not, per se, have a decisive impact on the development of psychotic symptoms.

This study was thoroughly conducted with no exclusion of potential participants and a great deal of time and care taken to engage participants in order to gain meaningful information. The lack of data regarding number of participants with schizophrenia and other psychoses is limiting, but their findings on symptom correlations with previous factors are particularly interesting given the aims of this review, as they appear to be at odds with other findings which suggest traumatic experience can increase the risk of psychotic symptoms. If we assume that numbers of individuals with psychoses in this sample are similar to those in other samples (approx 10%) then the total number of individuals is actually quite small. Extrapolating conclusions to the general refugee population based on results from this small sample must therefore be done with caution.

Wenzel et al. (2000) investigated psychological disorders in survivors of torture. All patients who presented at the University of Vienna Hospital because of sequels to torture between 1990 and 1993 were included; as long as they spoke English or German to a level which permitted a complete diagnostic evaluation. The structural clinical interview schedule (SCID) was used, with modifications relating to trans-cultural concepts and possible re-traumatisation. Symptoms evaluated as arising as part of PTSD were not used for further diagnoses and the interview was limited to current diagnosis as severe memory impairment is often a characteristic of PTSD.

Exclusion criteria included the presence of physical injury or pain. Additional information collected included social background; length of exposure to torture; time since torture; physical sequels and behavioural symptoms not included in the PTSD list of symptoms. In total 44 patients were included out of a possible 72 who had adequate documentation. Two were female and the total population's age ranged from 20-54. 37 were refugees without permanent permission to remain in Austria. 70% originated from the Near East (Turkey, Iran, Iraq), with the rest coming from Bosnia, Bangladesh, Nigeria, Somalia and Albania. 40 (91%) fulfilled criteria for PTSD. 30 fulfilled criteria for at least one more current diagnosis. Delusional disorder or functional psychosis was found in five patients; all of whom remembered the onset of symptoms as subsequent to the torture. The focus of this paper's findings relates to the high levels of PTSD and its implications. The authors comment that psychosis was present in five patients, with symptoms developing on the background of a negative family history of psychiatric disorder, in patients healthy prior to torture. This suggests potential genetic risk factors triggered by the torture. However given that later in the paper the authors report only three patients in the entire sample reported a positive family psychiatric history, this cannot necessarily account for all these patients (though self report of family history in a cultural setting is not particularly reliable). Furthermore, throughout the text, the authors refer to five patients with a delusional disorder or functional psychosis, whereas in the abstract and accompanying table it refers to four. The relatively small numbers, particularly when considering those with functional psychoses, increases the possibility of error when generalising to larger populations as the influence of anomalies will be exacerbated. The exclusion of people who were unable to speak German or English to an appropriate level, when the nature of their experiences and mental health

problems make it more difficult for them to learn a new language, further reduced the overall numbers. This resulted in the exclusion of patients with lower levels of education and those more recently arrived to the country without the opportunity to learn. Furthermore, the large amount of overlapping symptoms suggests the use of more extensive investigation before diagnosis would have potentially been more appropriate. Despite these limitations the results clearly show high rates of functional psychosis (approx. 10%) in this clinical population and represent a much higher rate than would normally be expected. The authors suggest that a simple diagnosis of PTSD may be restrictive and that broader conceptualisations might be more useful.

Iversen & Morken (2004) retrospectively reviewed all asylum seekers (n=53) and refugees (n=45) acutely admitted to a psychiatric hospital in Norway between 1995 and 2001. Diagnoses were obtained from case notes in accordance with ICD-10. Demographic information gathered included asylum status, gender, age, marital status, employment status, length of stay in hospital and frequency of torture (if applicable). Comparisons were then made between asylum seekers and refugees. In total 28 patients (29%) were diagnosed with schizophrenia, though whether this differs to rates expected in a general in-patient sample is impossible to tell. The authors report that patients suffering from schizophrenia reported the experience of torture more seldom than other patients, whilst those suffering from PTSD reported it more frequently. They also report that none of the asylum seekers or refugees from Africa met criteria for a diagnosis of PTSD. The authors speculate this may be attributable to different cultural backgrounds of patients, ways of expressing, adjusting to and coping with traumatic events.

Table 1. Comparison of diagnoses in refugee and asylum seekers

Diagnosis	Refugees (%)	Asylum Seekers (%)
PTSD	11	43.4
Schizophrenia	62.2	15

Unfortunately the study only reports on schizophrenia and PTSD, therefore drawing comparisons with the findings of other studies relating to other psychoses is not possible. However, the marked differences in these often grouped populations underline the complexities when trying to generalise findings and underlines the need for caution when doing so. The finding of no PTSD in individuals from Africa echoes the findings in section two.

Population comparison studies

Eitinger (1959), reviewed all refugees who settled in Norway between 1st January 1946 and December 31st 1955. Members of the diplomatic services, people who could return home if they wished or German war criminals were excluded. The author estimated from various governmental documents a total population of 1,879.

Information regarding refugee patients was obtained from all Norway's psychiatric departments and hospitals and the author then visited all of the patients remaining in the country and personally examined them, as well as reading their case notes. Those no longer in the country only had their notes examined. Results indicated 60 refugees had become psychotic during the observation period representing 3.19% of the population. 14 were diagnosed with schizophrenia and 42 with a reactive psychosis.

This incidence was five times higher than found in a corresponding Norwegian

population group. The author suggests pre-morbid personality (this refugee sample represent what the author calls a 'minus selection' with respects to schooling, socio-economic status, motivation for emigration etc.) and external stress, as the causes of such high incidence. Although the author uses a number of estimations, the size of the sample and methodological rigour are impressive. The increased incidence compared to a normal population sample is also large enough to suggest that the results are more than just a statistical quirk.

Zolkowska et al. (2003) examined all patient admissions to the psychiatric clinic in Malmo during the months of the NATO campaign in Kosovo (March 24th 1999 to June 10th 1999) and matched control months in 1997. Asylum seekers were excluded as potential confounders due to the likelihood of increased numbers entering the country during that particular period. All cases were re-diagnosed by the primary author using DSM-IV on the basis of case notes and complementary information from attending doctors. Diagnostic reliability was assessed via random sampling and independent diagnosis by a senior psychiatrist, with satisfactory diagnostic agreement being found ($\kappa = 0.871$, $p < 0.001$). Two categories were used: schizophrenia-like psychosis (SLP) which included cases meeting DSM-IV criteria for schizophrenia, schizophreniform disorder or non-affective psychosis; all other psychiatric diagnoses defined as non-SLP. Information relating to demographics and background (including history of torture, war, imprisonment etc.) were obtained from case notes and ward staff. Cases where accuracy of information was considered uncertain were regarded as cases with missing data. 1011 admissions representing 835 patients were included. Results indicated a sharp rise in the percentage of immigrants admitted for SLP during the experimental months compared to the

control months (41.6% vs. 29.5%). Interestingly, the increased proportion of SLP patients admitted during the experimental months was largely accounted for by immigrants from Africa, Asia and the Middle East (Fisher exact test, $p=0.03$) and not by those from the former Yugoslavia. The authors found that exposure to extreme duress (war, imprisonment or torture) was the only difference found in demographic and background information when comparing immigrants admitted for SLP during the experimental time as opposed to the control time (49%). Post-hoc analysis of these individuals showed they were more often male, had lived in Sweden for a shorter period of time and had shorter illness duration. The authors suggest that for these individuals subsequent exposure to extensive media coverage may have been singularly provoking. They conclude that cumulative trauma, either solely or in combination with current stress may possibly contribute to risk for psychosis amongst immigrants.

As a naturalistic design, these findings should be considered with caution. The authors were not able to measure the degree to which patients were concerned by or even knew of the NATO campaign. Although the total sample size for all those included was high; broken down, immigrant numbers totalled approximately 50 for each category and could have been susceptible to other environmental fluctuations. The authors do however discuss these and the fact that the proportion of non-SLP migrants remained unaltered in the experimental condition, does add some weight to the findings being particular to psychoses.

Tolmac & Hodes (2004) conducted a cross sectional survey of London adolescents aged 13-17 years who were residents of Greater London and who were in-patients in

psychiatric units on one particular day (randomly selected). Information was collected from case notes or from anonymised case summaries from a data sheet designed for the study. Psychiatric diagnoses were assigned according to DSM-IV criteria. 113 adolescents were identified with 110 having complete data for analysis. 55 individuals (49%) were admitted for assessment and treatment of either definite or suspected psychotic disorder. Of these 55, 10 were refugees and of those, 8 were black African. They reported that of this group, there were high levels of social and family adversity, with many having experienced recent migration, poverty and not living with family. They found that, while highly represented, this group were less likely to suffer from schizophrenia. The authors suggest that a high level of exposure to stressors, including war and organised violence may be a factor. They also note that PTSD may occur co-morbidly with non-schizophrenic psychosis and that cultural variations in the experience of hallucinatory experiences may also be different. This study's design is very thorough with very few participants excluded. Once again there is a higher representation of refugees than would normally be expected. In contrast to Lavik et al (1996), the authors here suggest that psychosis is related to previous experience of trauma; although they believe trauma is more highly associated with 'other psychoses' and not schizophrenia.

The largest study identified was by Leao et al. (2006). In this study they followed over 2.2 million individuals in Sweden between 1992 and 1999, from first admission to hospital for schizophrenia or other psychoses. First admission actually meant first admission during the study period, which Selten et al. (2007) point out as a potential source of inaccuracy. Immigrants were split into eight groups: First and second generation Finns, labour immigrants and refugees; and two groups of second

generation immigrants with 1 parent of Swedish origin, in order to determine if there was any protective effect of having a native parent. Other variables included age, gender, income and immigrant status (refugee v labour immigrant as defined by country of origin).

Table 2. (From Leao et al., 2006) Age-Adjusted Incidence Rates (per 100,000 Persons per Year) of First Hospital Admissions for Schizophrenia and Other Psychoses, by Immigrant Status and Gender: Women and Men, aged 20-39, January 1, 1992, Followed Until December 31, 1999, Sweden.

Table 2. Shows the incidence of schizophrenia amongst 1st generation refugees was increased in both men and women when compared to the Swedish reference group. These rates were comparable to 1st generation labour immigrants and substantially less than 1st generation Finns. Interestingly, incidence of ‘other psychoses’ were much higher in the 1st generation refugee population (particularly wrt men); with the rates being comparable to those of 1st generation Finns, as opposed to 1st generation labour immigrants. In 2nd generation refugees, incidence of schizophrenia remains

around twice that of the reference group, but incidence of ‘other psychoses’ drops back. It would seem from these findings that there is a factor which results in markedly higher incidence of ‘other psychoses’ in first generation refugees that does not continue in the second generation. Though not commented on in the paper, history of trauma would be one possibility. The authors conclude that their results support previous findings of increased risk of psychotic disorder in 1st and 2nd generation immigrants, and that it was not mediated by the impact of income.

As with Selten et al. (2005, 2007), the authors focus on post-migratory factors in explaining their findings. They suggest chronic discrimination may give rise to psychosis-like phenomena such as delusional ideation. They also mention increased incidence in country of origin, selective migration of those genetically at risk, migration stress, conflicting cultural identity with host country and misdiagnosis as potential causes. However, it seems strange the authors mention trauma in their methodological justification of separating refugee and migrant workers, but do not go on to follow this up with any discussion. The authors acknowledge that not using out-patient figures, using only one measure of socio-economic status, the potential for misdiagnosis and the possible presence of residual confounding variables may all be limitations. However, the scale of this study, both in terms of numbers and duration, make the findings highly compelling.

Conclusions

Although many of the studies reviewed here involve small and sometimes specific populations; the fact that all of them show increased incidence of psychoses than would otherwise be expected, make the findings particularly compelling. The larger

population based studies, which all show greatly increased risk, are particularly convincing. A number of the papers suggest previous traumatic experience as a possible root of the psychoses found (e.g. Kinzie & Boehnlein, 1989), with only one paper questioning this possibility (Lavik et al., 1996). However, the lack of detail in this paper and the small numbers used to generate the conclusion make its claims less than convincing. Finally, some of the research also seems to be suggesting that the psychoses tend to be shorter lived and with better long term outcomes (e.g. Tolmac & Hodes, 2004, Grisaru et al., 2003 and Zolkowska et al., 2003).

Section 4: Psychological and Cultural Hypotheses

Psychological Hypothesis

Section three clearly implicates the role of trauma in the development of psychoses in refugees and asylum seekers. Morrison et al. (2003) reviewed studies of the relationship between trauma and psychosis. In considering whether trauma could cause psychosis they note that Romme & Escher (1989) found 70% of voice hearers developed their hallucinations following a traumatic event. This suggests that in addition to 'flashback experiences', other perceptual intrusions can arise with no direct relevance to the event. Indeed they may even be a coping strategy, albeit without fully conscious awareness or control. The greatest bulk of evidence the authors draw from is in the research related to childhood sexual abuse amongst people with psychosis, quoting a range of studies with incidence of around 50% (e.g. Friedman & Harrison, 1984). Although they also mention higher incidence in concentration camp survivors (Eitenger. 1964 & 1967); Pacific theatre prisoners of

war (Beebe, 1975) and also more recently the Kinzie and Boehnlein (1989) study of Cambodian refugees.

It is worth noting that other models such as complex PTSD (Herman, 1992), Cumulative Trauma Disorder, (CTD) (Kira, 2006) and the Disorder of Extreme Stress Not Otherwise Specified (DESNOS) (Ford, 1999) are also attempts to integrate symptoms into a syndrome which goes beyond the basic PTSD diagnostic category. What is interesting is they all share a common theme, that it is the accumulation of traumatic incidents which may result in symptoms spanning the profiles of both 'classical' PTSD and functional psychosis diagnoses.

Morrison (2001) has proposed a cognitive model for the possible mechanism by which hallucinations and other 'anomalous experiences' may occur. As this has its roots in cognitive models of anxiety disorder it is highly pertinent to this issue. Firstly he suggests that positive psychotic symptoms can be conceptualised as intrusions into awareness, or culturally unacceptable interpretations of such intrusions. In turn it is the interpretation of these intrusions which leads to the individual's distress. The nature of these intrusions is determined by distorted knowledge about self and the social world. In turn the whole process is maintained in a cognitive, behavioural, physiological and mood related vicious cycle e.g. selective attention, safety behaviours and control strategies.

Morrison uses as a basis Wells and Matthews' (1994) concept of intrusions into awareness as being one of three types: external stimulus information, cognitive state information and body state information. Morrison then draws comparison between

cognitive models of OCD and anxiety which have interpretations of intrusive thoughts as a central component (e.g. Clark, 1986). These are then maintained through safety behaviours. Morrison suggests that a trigger, such as a traumatic event, results in a normal auditory hallucination being misinterpreted as threatening the psychological or physical integrity of the person. This in turn results in negative mood and physiological arousal. These then result in more hallucinations which feed back into a vicious cycle. The cycle is then maintained by safety behaviours such as hyper vigilance. Morrison suggests it is the cultural unacceptability of these phenomena which results in them being classified as psychotic.

Cultural Hypothesis

Johns et al (2002) interviewed 5196 individuals from ethnic minorities and 2867 white individuals aged 16+. The ethnic minority sample was recruited from areas identified in the 1991 census on the locations of ethnic minority populations in England and Wales. The sample frame included areas of high and low ethnic minority density. Actual respondents were identified through a modified household sampling process called 'focused enumeration', whilst the white sample was identified using a stratified design. Respondents were interviewed using parts of the revised version of the Clinical Interview Schedule (CIS-R) and the Psychosis Screening Questionnaire (PSQ). The responses to two questions relating to psychotic symptoms were examined. 4% of the white sample responded positively to a question about hallucinations. This compared to 9.8% for the Caribbean sample and 2.3% for the South Asian sample. Interestingly the researchers did not find an increased rate of psychosis in the Caribbean sample and suggest that ethnic

differences in the experience of hallucinations should be taken into account when diagnosing psychiatric disorders.

The authors acknowledge a number of limitations; in particular the use of only two questions does not necessarily allow the full extent of the individual's experience of hallucinations to be fully explored clinically, which in turn may lead to errors.

However the large sample and size of the differences does provide good support for the idea of cultural variations in the experience of hallucinations. This in turn suggests a greater cultural acceptability amongst certain ethnicities. Therefore, given a more clinical sample population, one would hypothesise these findings would be amplified.

Conclusions

Undoubtedly there are many possible mechanisms for the development of psychoses in refugee and asylum seeker populations. These will undoubtedly continue to develop and change as more research is done. What seems increasingly clear is that a single, simple and discreet model of psychotic disorders is increasingly unlikely, with a range of predispositions and life events likely to play varying roles for different individuals. Kroll (2007) comments on some of the studies reviewed here on trauma and migration as well as findings relating to other external factors such as malnutrition, substance abuse and in-utero development as significant risk factors in the development of psychoses. He concludes that 'present classification of the psychoses is in urgent need of re-conceptualisation'.

General Conclusions

In this review I have attempted to draw together the literature relating to refugees and psychosis. Section one outlined some of the causes and consequences of impelled migration before reviewing some of the major psychopathological findings in refugee populations. Given the range of adverse pre-, peri- and post-migratory factors, it is not surprising that there are such high rates of psychiatric illness. Rates of PTSD in particular are consistently higher. Within this relatively large body of research relating to mental health problems; studies measuring incidence of psychoses appear to be relatively rare, despite indications of incidence being increased.

Section two focused on two reviews of the literature relating to migration and psychoses. The sheer weight of evidence in support of the increased incidence of psychoses (specifically schizophrenia) in migrant populations across the generations is highly convincing. However in trying to understand the findings, the authors focused only on post-migratory factors, ignoring completely the possibility of pre- and peri- migratory factors.

Section three formed the focus of this review. Although many of the studies involve small and sometimes specific populations; the fact that all of them show increased incidence of psychoses than would otherwise be expected, make the findings persuasive. The larger population based studies, in particular Leao et al, 2006, are convincing in their support of increased incidence of psychoses in refugee and asylum seeker populations. Accounting for these differences, previous traumatic

experience was a common theme (e.g. Kinzie. & Boehnlein, 1989). Finally, some of the research reviewed here suggested, either directly or indirectly, that the psychoses tend to be shorter lived (e.g. Tolmac & Hodes, 2004 and Zolkowska et al., 2003).

Section four explored some different explanatory models that had been suggested at the psychological and cultural level. Undoubtedly, as more research is conducted, these will continue to develop. What is clear, is that a single model of psychotic disorders is not likely, and our understanding of psychosis requires a re-conceptualisation (e.g. Kroll, 2007).

One area of research which seems to have been overlooked throughout the literature is, what it is actually like for these individuals? What is their experience? And what are their views and opinions on what has happened to them and the effect which it has had? A greater depth of understanding of these issues is surely vital in helping to diagnose and treat them more effectively. As such this review recommends a greater depth of research through the use of qualitative methods. This should allow us to direct future methods of inquiry more effectively to best help us serve this often overlooked group of people.

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PART 2: Empirical Paper

Trauma and hearing voices. An investigation into the experience of refugees and asylum seekers.

ABSTRACT

The link between trauma and psychosis is currently being debated in the mental health literature. This study's aim is to take a more detailed approach to the area, in a population often overlooked. Nine refugee and asylum seekers who have experienced trauma and auditory hallucinations were interviewed. Their experiences, views about their origins as well as the issues most important in their lives were discussed. Analysis using IPA uncovered important domains including 'Meaning and purpose', 'experience of life' and 'surviving'. The extent to which individuals connected past trauma to their auditory hallucinations varied in terms of themes and content.

INTRODUCTION

The mental health of refugees and asylum seekers

Refugees and asylum seekers are by definition more likely to have been through traumatic experiences such as war, torture, political repression, ethnic cleansing and multiple bereavements (Tribe, 2002). Numerous studies have shown the high rates of psychiatrically defined mental health problems within this population (e.g., Lavik et al. 1996; Turner et al. 2003). A common theme amongst these studies has been the prevalence of PTSD, with rates of 9% in general populations (Fazel et al., 2005) rising to 46.6% in clinical samples (Lavik et al., 1996). Despite these high rates of mental health problems, there has been little research detailing psychosis within these populations.

Migration and psychosis

The link between migration and psychosis has been a topic of research for a number of years. In their recent meta-analysis, Cantor-Graae & Selten (2005) found a significant association between risk of schizophrenia and level of economic development of region of birth; with those individuals from poorer countries at increased risk. Furthermore, the mean weighted relative risk for migrants from countries with majority black populations was 4.8 (95% CI=3.7-6.2), this being approximately twice as great as for those migrants from countries where the majority was white or non-white/ non-black.

Researchers have focused on post-migratory stressors such as local hostility/ discrimination in trying to explain their findings. Furthermore most of the research has focused on migration in general, included economic migrants as well as refugees and asylum seekers.

Refugees, asylum seekers and psychosis

Eitinger (1959) assessed all refugees who settled in Norway between 1st January 1946 and December 31st 1955. Results indicated that 60 refugees (out of a total population of 1,879) had become psychotic during the observation period, representing 3.19% of the population. 14 were diagnosed with schizophrenia and 42 with a reactive psychosis. This incidence was five times higher than in a corresponding Norwegian population group. The authors suggest the cause to be pre-morbid personality (as this refugee sample represent what he calls a 'minus selection' with respects to schooling, socio-economic status, motivation for emigration etc.), combined with external stress.

Leao et al. 2006 followed over 2.2 million individuals in Sweden between 1992 and 1999, for first admission to hospital for schizophrenia or other psychoses. The incidence of schizophrenia amongst 1st generation refugees was increased in both men and women when compared to the reference group. These rates were comparable to 1st generation labour immigrants. Interestingly, incidence of 'other psychoses' were much higher in the 1st generation refugee population compared to 1st generation labour immigrants. In 2nd generation refugees, incidence of schizophrenia remained around twice that of the reference group, but incidence of 'other psychoses' dropped back. It would seem from these findings that there is a factor which results in markedly higher incidence of 'other psychoses' in first generation refugees which does not continue in the second generation. Though not commented on in the paper, history of trauma would be one possibility.

Several studies have suggested an association between PTSD and psychosis in refugees. Wenzel et al. (2000) focused on a group of 44 exiled survivors of torture who presented over a period of three years. They found that criteria for functional psychosis was fulfilled in four patients and suggested that a simple diagnosis of PTSD was over-restrictive. Monasterio & Neumann (2005), also focusing on survivors of torture, found that in a random sample of Chilean political migrants taken between 1977 and 1992, torture was associated, in 9% of cases, with a psychotic reaction. Similarly, Kinzie. & Boehnlein, (1989) found that among 100 consecutive Cambodian patients with PTSD, seven had psychotic symptoms. Grisar et al., (2003) reviewed all 17 psychiatric admissions of Ethiopian immigrants in an in-patient unit. Of these 17 individuals, 10 were suffering an acute reactive psychosis. The researchers suggested that severe stress and traumatic experience expressed itself in the form of psychotic symptoms as opposed to 'classical' PTSD.

Tolmac & Hodes (2004) conducted a cross sectional survey of London adolescents aged 13-17 years who were residents of greater London and who were in-patients in psychiatric units on one particular day. 113 adolescents were identified. 55 individuals (49%) were admitted for assessment and treatment of either a definite or suspected psychotic disorder. Interestingly, of these 55, 10 were refugees and of those, eight were black African.

With the exception of Leao (2006) et al., most of these studies draw on specific and relatively small populations. Despite this, the consistency of the findings suggests that refugees and asylum seekers with psychotic symptoms constitute a small but significantly higher proportion of their populations than would be expected.

Trauma and psychosis

The potential link between traumatic events and psychosis has been gaining credence in recent years (see Morrison et al. 2003 for a review). Some of these accounts have focused on observed commonalities between psychological processes in psychosis and PTSD. Given the similarities between hallucinations and 'flashbacks' it has been argued that the diagnosis of PTSD may simply involve an extension of the model e.g. complex PTSD (Herman, 1992), Cumulative Trauma Disorder, (CTD) (Kira, 2006) and the Disorder of Extreme Stress Not Otherwise Specified (DESNOS) (Ford 1999) all of which attempt to integrate symptoms into a syndrome which goes beyond the basic PTSD model.

However, Hardy et al (2005) found that in a group of individuals who had experienced trauma and had a diagnosis of a non-affective psychosis, only a minority (12.5%) had hallucinations with similar themes and content to their trauma. These findings suggest there is room for debate about the origins and processes which link the phenomena. Many studies, including this one, have noted the role of repeated traumatic experiences such as sexual abuse and bullying were most likely to be associated with hallucinations. No studies were found which involved a more detailed examination of refugees or asylum seekers experiences of hallucinations following trauma.

Syndromes versus symptoms

There is a growing body of research questioning the validity of psychiatric diagnoses (e.g. Kirk & Kutchins, 1992; Boyle, 2002 & Moncrieff, 2007). Psychosis

in particular has come increasingly under fire from those proposing a move away from a syndrome-based to a more symptom-based perspective (e.g. Bentall, 2003). Psychologically speaking this alternative approach allows for a much deeper understanding of each individual's pattern of difficulties, allowing for a more tailored approach to treatment. It would therefore make sense for research to be directed in this same manner. Papers detailing individuals' experiences of psychosis have begun to appear, Knudson & Coyle (2002) examined the experience of hearing voices in two individuals using Interpretative Phenomenological Analysis (IPA) and Campbell & Morrison (2007) investigated the differences between the experience of paranoia in patients with psychosis compared to those with no psychiatric history, again using IPA. These suggest there is some scope for a qualitative approach.

Researching refugee and asylum seeker populations

The diversity of refugee and asylum seeker populations means that there are few standardised quantitative tools which could meaningfully be applied, particularly if more than one cultural group is involved. Furthermore, while quantitative lists of symptoms are useful for some purposes; they cannot really convey the nature of these experiences and how they cohere holistically for the individual.

There has been a call for qualitative research within the refugee population '...to allow participants to describe their healthcare concerns and their management of them' (Halabi, 2005). In relation to this research, only one qualitative study was found examining the consequences of refugee trauma (in this case, upon the family). Weine et al. (2004) analysed field notes from group meetings using a grounded-theory approach. The population was drawn from the Bosnian refugee

community in Chicago involved in multi-family support and education groups. Four different realms of family life were identified: Family and roles obligation, family memories and communication, family relationships with other family members and family connections with ethnic community and nation. Within each of these, multiple adverse consequences and helpful family responses were specified and detailed.

Summary

There is a general paucity of research relating to refugees, asylum seekers and psychosis, particularly in the area of qualitative research, which at the time of investigating included no papers relating to psychotic symptoms. Furthermore, the current debate on the role of trauma in the development of psychosis includes relatively few articles relating to refugees and asylum seekers, who, as demonstrated here, are over-represented in their respective populations. Finally, with DSM-IV-R coming close to being replaced, there are growing questions over the validity of the syndromes it describes. It is with these considerations in mind that this piece of research was designed.

Aims

This study aims to understand the life experience of refugees and asylum seekers living in the UK who have suffered traumatic events and who hear voices. Most of us cannot understand or begin to imagine what these experiences are like.

The research aims specifically to elaborate on the following areas:

- The experience of self: Does the person feel they have been changed? Are their interactions with others any different? What specific experiences occur .e.g. auditory hallucinations.

- What do they find to be helpful/ unhelpful in coping with their problems?
- Possible perceived links, if any, between traumatic events and the development of auditory hallucinations.

Given these aims I have chosen the methodology of Interpretive Phenomenological Analysis (IPA) as it is concerned with trying to understand experiences from the individual's personal perspective (Smith, 2003).

METHOD

Context

All participants were recruited from within an NHS Mental Health and Social Care Trust. The project was presented at a Trust-wide conference on 'Recovery from Psychosis' and at each of the community mental health team meetings for the borough. Any health professionals identified who knew of any potential participants were then contacted directly at a later date to discuss particular cases.

Ethical approval was obtained from the Barnet, Enfield and Haringey NHS Trust Ethics Committee (see Appendix 1) and the study was registered with the Trust Research and Development Department (see Appendix 2).

Participants

14 individuals were originally suggested by clinicians. Of these, four declined to take part and one was used as a pilot for the interview as upon interviewing it was found that he did not fulfill inclusion criteria for the experience of trauma.

Inclusion criteria

1. Participants must be refugees or asylum seekers living in the UK.
2. Participants must have been subject to at least one traumatic event as defined in DSM-IV-R for Post-traumatic Stress Disorder.
3. Participants must be under the clinical care of a healthcare professional e.g. psychiatrist, psychologist.
4. Participants must be described by that healthcare professional as having auditory hallucinations.

It is worth highlighting that co-morbid alcohol or substance misuse was not used as an exclusion criterion, though this was considered. The main aim of this research was to understand any major themes in the experience of individuals within this largely ignored population, and drug use may or may not be part of that experience. At the potential risk of making the results difficult to interpret, I decided with supervisory discussion, to allow this potential heterogeneity in the interests of avoiding an over-restrictive sample.

Language use

Although in order to satisfy the board of ethics, non-English speaking participants were not formally excluded, the researcher aimed primarily to identify individuals who were able to speak English. Although this may have introduced a sampling bias, it was thought the potential problems would outweigh this. As IPA aims to explore in detail the participant's view of the topic under investigation, I felt that to introduce a translator would add further complexity to interpretation, potentially moving further away from the actual experience of the participant.

Procedure

Suitable participants were contacted by their health professional and invited to attend a joint meeting with myself. At this point the research was explained and the individual left with an information sheet (see Appendix 3) giving them time to consider whether or not to take part. Those who agreed attended a further one or two sessions to complete the interview. All interviews were conducted by me in a private room in the psychology department at St Ann's Hospital in Haringey. Participants were paid £10 for each session they attended. Before the interviews began, participants were again informed of the nature of the study and asked

whether they had any questions. They were then asked to sign the consent form (Appendix 4). The interviews were recorded using a digital recording device made entirely obvious to participants.

Interview

The interview schedule was designed based on questions proposed by clinicians working in the area and the relevant literature (e.g. Halabi, 2005 and Knudson & Coyle, 2002).

Given the nature of this population's experience, specific consideration was given to the possibility of raising unmanageable feelings during the interview and therefore topics deliberately avoided direct questioning about previous traumatic experiences. In addition to this, participants were specifically told during both recruitment and prior to the first interview that they would not be asked specifically about any previous traumatic experiences.

Following the initial design of the interview, which involved discussion with my supervisor, feedback from the departmental peer review process was taken into account in the design of questions. The initial interview schedule was then piloted on an individual identified by a clinician as a potential participant, who in practice turned out not to fulfil all the criteria for inclusion. The schedule was then redesigned taking into account difficulties the interviewee had with certain questions. The resulting schedule was used as the guide for all remaining participants (see Appendix 5).

Transcription

The process of transcribing the interviews was done as each interview was completed. Careful attention was placed on language and meaning but not on the formalised recording of linguistic features of speech such as intonation or pauses as discursive practices were not the focus of analysis.

Analysis

Interpretive Phenomenological Analysis (IPA) comes from a philosophical stance (phenomenology) which focuses on the world as it is subjectively experienced by individuals. It takes into account their particular historical, cultural and social contexts. IPA however, goes a step beyond this by acknowledging the impact of the researcher on the process and how their interaction will influence the findings in the form of interpretations of the participant's account. These interpretations are based on the researcher's own conceptions, beliefs and experiences (Smith et al., 1999). As a result a sense of reflexivity is expected from the researcher who should explicitly present their own perspectives in order to further illuminate the analysis (Willig, 2001).

IPA takes a realist approach to knowledge, believing that an individual's narrative is a result of their thought processes and while not necessarily supporting the view that the narrative itself is an accurate reflection of those cognitions, it works on the assumption that this understanding can be achieved through the analytic process. In this sense IPA is influenced by hermeneutics. Although IPA accepts that social interactions can affect individuals' subjectivity, it stops short of the idea that an individual's narrative actually constructs its own reality.

IPA can also be idiographic in its approach as it allows the researcher to establish links between themes within and across cases. It also allows researchers to interact with existing literature in order to illuminate theories while at the same time being open and inductive, allowing new or unexpected themes to emerge.

IPA is a particularly appropriate means of analysis for this research due to its focus on the meaning that individuals give to their experiences, and therefore the analysis is expected to be highly subjective.

Strategy

The first stage of analysis involved the reading and re-reading of transcripts in order to become as familiar as possible with the material. During this process notes were written in the left-hand margin about anything viewed as significant or interesting. In particular this involved summarising, noting associations or connections and any preliminary interpretations. The second stage involved the noting of emerging themes and clusters which could be grouped together. Key words began to emerge which elicited the essential quality of the text. The third stage involved a process of connecting and grouping themes together. This process was repeated for each interview. Finally, similarities of themes from each interview were grouped to create a 'master list' of themes. Throughout the process emerging themes were cross-checked back with the original data to ensure that they remained grounded in the data. The analysis was cyclical and dynamic, returning to the themes and clusters throughout the process.

This process is similar to that adopted in grounded theory. However as Willig (2001) explains; whereas grounded theory allows the researcher to study social process, IPA allows the researcher to gain an insider's view into each participant's view of the world.

Credibility

A second researcher with experience in using IPA, specifically with refugees and asylum seekers, cross-checked the analysis of themes in all the interviews.

Differences in opinion were discussed at regular meetings throughout the analysis process and re-worked until a consensus was reached. In addition the main project supervisor, who had extensive experience of working with Jonathan Smith, cross-checked the themes in a selected number of interviews. Suggestions and improvements were again discussed at regular meetings throughout the analysis stage until consensus was reached.

Researcher's Perspective

Researchers using IPA recognise that their analysis is by its very definition a subjective process. In this piece of research my interpretations of participants' accounts are influenced by my experiences as a psychologist working with refugees and asylum seekers on a regular basis.

My interest in the potential link between traumatic experiences and psychotic symptoms followed a piece of work with a patient during my first year on the doctoral course. My treatment of this patient and subsequent reading of the literature, particularly texts by Morrison, have led me to believe in a link between traumatic experience and the onset of psychosis. It was from this perspective that I

began designing this research. As I have said, the findings of this study are the product of the interaction between the participants and myself. They should therefore be considered tentatively and limited to those specific individuals who took part (i.e. myself and the participants).

RESULTS

Sample characteristics

The sample consisted of nine participants, including seven males and two females. Seven participants were from sub-Saharan Africa, one from North Africa and one from the Middle East. An interpreter was only used with one participant. All participants had been given a diagnosis which included psychotic symptoms, although only two were diagnosed with schizophrenia. All had auditory hallucinations described in their notes, along with many other symptoms from across the psychotic, depressive and PTSD spectrum of mental health problems. Five had obtained refugee status, one was waiting on the result of their application and three were waiting on appeal following an initial rejection of their case (see **table 1.** for summary).

Domains and themes

Analysis of the data revealed a variety of domains and themes. The predominant three are presented below.

1. Meaning and purpose
2. Experiencing life
3. Surviving

Within each of these domains there were a number of themes and subthemes (see table 2. for complete overview). In this section each of these themes will be briefly described with direct quotations to highlight points. As table 1 demonstrates, participants have experienced dramatically different trauma histories, therefore common threads and individual differences between the participants will be drawn out where appropriate.

Table 1. Outline of the basic details for each participant

Participant.	Gender.	Age	Language.	Area of Origin	Asylum Status	Diagnosis: C=current P = past	Positive Psychotic Symptoms	Trauma	Other relevant issues
1	M	39	French (interpreter used)	Central Africa	Refugee	Psychotic depression - c	Auditory Hallucinations	Torture & War	
2	M	29	English	West Africa	Waiting on Appeal	Paranoid Schizophrenia - p	Auditory Hallucinations, Paranoia	Prisoner of war, torture	HIV
3	M	37	English (Native French)	Central Africa	Waiting on Appeal	PTSD & psychosis - p	Auditory & Visual Hallucinations	Witnessed family murder. Torture in prison	
4	M	26	English	West Africa	Waiting on Appeal	PTSD & psychotic symptoms - c	Auditory Hallucinations	Witnessed family murder.	
5	F	30	English (Native French)	Central Africa	Refugee	PTSD & psychotic symptoms - c	Auditory Hallucinations	Rape & Torture	
6	M	39	English (Native Somali)	East Africa	Refugee	PTSD & Psychotic illness - c	Auditory & Visual Hallucinations, Paranoia	Child soldier, War. Victim & Perpetrator.	Alcohol misuse
7	M	31	English (Native French)	West Africa	Waiting on application	PTSD & psychotic illness - c	Auditory, Visual and olfactory hallucinations, Delusions	London Bombings	
8	M	43	English (Native Arabic)	North Africa	Refugee	Paranoid Schizophrenia - c	Auditory & Visual Hallucinations, Paranoia	Torture	
9	F	35	English (Native Fasi)	Middle East	Refugee	PTSD & psychotic symptoms - c	Auditory Hallucinations & Paranoia	Torture	Epilepsy

Table 2. A complete overview of domains and themes

Meaning and purpose	Experiencing life	Surviving
<i>Making sense of voices</i> – links to trauma 1,3,4,5,6,7,8 – cultural explanations 4, 7,9 – professional explanations 5,6,7	<i>Feeling stuck</i> In the system 2,4,7 In life generally 4,5,8	<i>Contact & communication</i> – talking 1,2,3,4,5,6 – time with friends 1,2,3,4,5,6,7 – doing things 1,3,4,5,7,8 – shared experience 4,7,9 – professional support 6,8
<i>Comparison with how life was</i> 1,2,3,4,5,8,9	<i>Emotional experience</i> – hopelessness about future 1,2,3,4,6,8,9 – overwhelmed 5,7,9	
<i>Wish to live and find a purpose vs.</i> <i>Wish to die</i> – God's purpose 2,4,7 – carry on family name 4 – justice and revenge 4 – building a normal life 1,2,3,4,5,6,7,9 – suicidal thoughts 3,4,5,9	<i>Changed</i> 4,5,7,8,9 <i>Loss of trust</i> – difficulty trusting professionals 4,6 – paranoid distrust 2,7,9 – difficulty trusting friends 2,4,6,7,8	<i>Positive philosophies</i> – faith 1,3,4 – coping philosophy 4,6 <i>Things that don't help</i> – thinking too much 1,3,4 – people not really understanding 4,9 – repeating things 4 – isolation 9

NB: numbers denote participant to which each theme applied,

Themes denoted by *italic*

Meaning and purpose

This domain involves the past and the future and describes the various ways participants try to understand, through active processes of meaning making, what happened, what they are currently experiencing and what they believe about the future. As participant 7 explains while discussing his involvement in the London bombings:

'I have two parts inside me, Mr Why and Mr If. Mr If said if he could turn my life back, if he could make me later that day and continue my life in London. Mr Why says why me? Why me not you?'

This idea recurred throughout the interview with Participant 7. It suggested his preoccupation with these two distinct thoughts had resulted in the creation of identifiable characters from them. By questioning them he is attempting to make sense both of what happened and what could have been had it not. These are questions that by their very nature are unanswerable. This left participant 7 caught in a cycle ruminating on the varying possibilities.

This struggle to make sense of events beyond the normal realm of human experience, through the creation of meaning, was a major area of discussion for participants. Most commonly they used their past traumatic experiences as a reference point from which they could explain their current experiences. They also frequently used comparisons between their current situation and their past lives. Clearly the struggle for these individuals has been great and at times unbearable, leading in turn to thoughts of self harm or suicide. At other times, individuals communicated a desire to find purpose and build a successful life, highlighting the variable internal world they experience.

Making sense of voices

All but one of the participants spoke about how they made sense of their voices. Some made only vague causal links between their voices and the trauma, while others used a variety of different explanations, jumping between them at different points during the interview. Participant 7, for example, drew conclusions both from his cultural background and from professional explanations:

'Some people in my country believe strongly that if something happen to you like me, you have to do some ritual to cast out the devil and cut your body with a knife or a razor blade...the devils are so strong they will kill you... maybe I have a real spirit inside my head.'

'My psychologist explained to me there are no spirits inside me; I was in the wrong place at the wrong time. Everyone suffers with stress and depression when your memory is affected like yours. It has been tricked'

'One lady she pushes me because the train was so crowded. I ran to go to the third or fourth carriage and this lady she pass away and she died. I think this lady follow me and her voice still in my head like she blame me for her death.'

The first two explanations are in direct opposition to one another, highlighting his struggle over what to believe. On one hand there is the rational, professional opinion that something has gone wrong, with scientific labels including 'depression' and 'stress' which he can attach to the explanation. The other explanation is more supernatural, based on what others from his country think. In this instance the labels 'devil' and 'ritual' are used. Despite an apparent bias towards the professional explanation, doubt remains. He finishes with a query that perhaps they are right, perhaps a spirit is responsible. Indeed the final explanation seems to favour supernatural rather than scientific explanation.

This diversity and uncertainty of explanation may reflect the uncertainty in health communities about the origins of auditory hallucinations compared to the certainty

from cultural communities about their supernatural origin. On the one hand, participant 7 clearly sees himself as an educated and intelligent person who should take a more rational approach, yet doubts remain in his mind.

In trying to understand the voices he hears, participant 4's own explanation also seems to be drawing from cultural narratives:

'She is telling me 'come join us'. So for me, she came to get me ... [Maybe] they are trying to communicate with me, maybe they are trying to send me a message.'

He is describing here his belief that his mother, who was burned to death, is speaking to him from beyond the grave. He too has heard the rational and scientific explanations from a whole range of professionals, yet the way he understands draws more from supernatural explanations. For participant 4, this is linked to another narrative which runs through his interview about the struggle he has in trying to continue, and how he frequently thinks about killing himself to end the suffering.

The extent to which individuals had made sense of their experiences and their symptoms varied considerably. Whereas participants 4 and 7 had clearly invested some time into thinking about origins and explanations from a number of different angles, for others the connection between the voices they hear and their traumatic experiences were more straightforward, perhaps blurring the boundary between definitions of PTSD and psychotic symptoms.

'I hear these voices saying 'Stop, arrest him. Kill him. Kill him. Like the soldiers used to say in my country.' – participant 1

'Some voice I have its like from the past. But some of them are not from the past. I don't know. Sometimes it's like a voice of the thing that was done to me when I was back home. When I was tortured. Sometimes I hear the voice of that person.' – participant 5

Trying to understand the participant's experiences of symptoms in the interview, it became clear that while the differences between a voice, a flashback or a nightmare may be important to me, these differences had little significance for the individual. They generally saw them as interchangeable. For participant 9 everything was so mixed up it was almost completely inexplicable.

'The symptoms are very complicated to be honest. The most important thing is, you know, when you feel angry then you feel sad you can't find a word to describe that but sometimes my feeling is very complicated. I really don't know how to call that, to find a word to describe it, you know what I mean.' – participant 9

Although explanations for most of the participants covered a range of different ideas, for one, making sense of his symptoms went no further than its sequence in time:

'I think it happened in [country of origin] when the people killed my brothers, since that time I have not been feeling well at all.' – participant 8

For this participant it seemed that he was overwhelmed by what he was going through and was no longer able to step back and try to understand why:

'I don't know, I don't know exactly. I can't give you the reason I hear these voices. I don't know.' – participant 8

Interestingly only one participant drew no link at all between their voices and their past trauma. Despite persistent questioning, participant 2 simply replied that he did not know why he had them or where they came from. It seemed that he had made no attempt to make sense or meaning of the experience. However, he no longer hears voices and has since been diagnosed with HIV. The worry of this diagnosis now occupies much of his narrative and it is possible that any meaning he had created regarding his voices had simply been forgotten. Participant 2's description of his voices was also qualitatively distinct from those of the other participants, whose voices were at least in some way related to their respective traumas:

'When I make friendship with someone, I can hear them come to my house to provoke me. I hear their voices but don't see the person. Sometimes I hear them from the wall, sometimes the cupboard.'

Wish to live and find a purpose versus wish to die

These themes were simultaneously expressed by a number of participants. At times during the interviews they spoke openly about the seemingly insurmountable struggle and the suicide attempts they had made; while at other times they spoke about their hopes and wishes to continue and build a purposeful new life. This sense of conflict

illustrates the many difficulties these individuals face in trying to make sense of their lives.

For three participants, their faith in God's purpose for them was an important factor.

For participant 7 it was very straightforward.

'I trust in God and if God saved my life twice, it's because God had a purpose for me.'

For participant 4 it went beyond simply trusting God's purpose and involved finding out what that purpose was. He was overwhelmed, as the only reason he could find, so far, was for him to suffer.

'God kept me alive for a reason, but I'm trying to find that reason, but it has taken me ages to find why I didn't die that day with my family. I am trying to find out why, but it is a big why you know? I still can't get my head around it... The only answer I came up with was to suffer.' – participant 4

Once again participant 4's narrative is entwined with his wish to die, in this instance it is his fear of the consequences which hold him back.

'I do think about the religion side. I might be scared or a bit upset and finally say OK, I finally commit suicide. But then I might be having a problem with God, because he has told me not to do so, and I am kind of scared of being in trouble with him.'

A wish to build a normal life and integrate into this country was expressed by all but one of the participants. For him, life was too overwhelming and the thought of a future was simply too much.

'I don't have something to push me to do something in my life. I was like that in a sense before 1999. But now I can't do nothing. I did nothing. I do nothing.'

participant 8

However, for the rest of the participants, some of whom also seemed to be completely overwhelmed by their experience, there was a sense of trying to integrate and build a life.

'I want to integrate into this country. I want to have qualifications and work here.'

– participant 1

'If I live over here I can do better, I can do more. Maybe I can go to college, I can learn something better for me to do with my life.' – participant 2.

'I was thinking you know, maybe one or two years and everything will be OK. I will have a normal life. But for now the dream will continue.' – participant 5

For one participant, justice, revenge and a desire to carry on the family name were important in finding a purpose for his life.

'I will keep my family name alive. I am the only person alive, so if I die everything else is gone ... Maybe one day we will come across the people who committed this crime against my family. Then one day convince the international community to bring these people to justice. Basically this is a kind of revenge thing.'

– participant 4

Comparison with how life used to be

This theme incorporates all the participants' reflections on how they used to live. In the same way that participants expressed a wish to integrate, fit in and be normal, many also spoke about a past life in which they were just normal and did everyday things. As highlighted in the quotes below, participants seem to look back wistfully on a happy, normal and stable past which contrasts radically with their current situation.

'Before this bad experience happened to me, I was living a normal life ... like most other kids, you know what I mean? Mums, dads, uncles, school, birthday parties, hanging out with my family and having a pretty decent life like any normal kid could have.' – participant 4

'I used to be a man, I used to be with my family. I used to be happy. But since then, I'm not happy at all.' – participant 3

The phrase 'used to be a man' suggests participant 3 defined himself in terms of his role as a man. Given the subsequent mention of his family, it seems likely this

involves a view as the provider and protector. Given what has happened to him he is unable to fulfil these defining roles and as a result no longer feels that he is a 'man'.

Experiencing life

Themes within this domain describe what it feels like for participants to live their lives. Given the highly subjective nature of their descriptions and the broad range of experiences these particular individuals had been through, the themes have multiple crossovers. Those common themes identified were largely bleak in outlook and include: feeling stuck, hopelessness for future, feeling changed and loss of trust. This view of their ongoing experience in some way allows us to glimpse what it must be like for these individuals and the degree of adversity they face.

'It's like I'm on the track running. I am an athlete running, but I never see the finish line. Other people run on the track, they have a finish line, even if they are running a marathon. But I have been running since 1999. I never see a finish line, so I don't know how long I will continue to run.'

Here participant 4 likens his existence to a never ending race. He is not stuck in one place, but is instead constantly running, suggesting a struggle and competition against others. He has to work hard to carry on, while at the same time is unable even to dare to hope for the finishing line.

Feeling stuck

A common experience in this domain was a sense of being stuck, unable to do anything and unable to move on. For three of the participants, their wait on the asylum process was a major cause:

'I am very disappointed with the system, I want to move on with my life. I want to finish my studies, find a job and move back to France. It's like I'm stuck in a prison and I can't move.' – participant 7

The comparison to prison is striking and suggests a sense of being trapped by authority, and having freedoms restricted. It also suggests feeling like a criminal, cast out from society.

It is worth noting that two of the individuals who expressed this feeling of being stuck had been granted refugee status. For them the feeling came more from a profound sense of being stuck at a point in their lives:

'I was 25 and had dreamed to find a good job and career. But everything stopped because of what I went through. I'm trying to do things, but I can't, it's hard for me.'
– participant 5.

Here participant 5 is locating the source of her problems in what happened to her, with the trauma she had experienced clearly having stopped her life. For participant 8, this feeling goes even further. It is not just that life had stopped, but it has in some

way changed and become unrecognisable, this is why he feels unable to move on and life has become a monotonous routine:

'I think life for me has become like a stranger. I cannot deal with her. I can't work, I can't have a good job. Day after day is just the same, like a routine. I don't think I can change for the better, always just the same.' – participant 8

The personification of life as a female stranger is interesting. Why is it like a stranger? Perhaps because strangers do not talk, or interact, or make the person feel like they belong, or have a place that is familiar.

Hopelessness for the future

Linked to feeling stuck, this theme goes further in expressing not just participants' difficulties with the present, but also their fears about the future:

'It feels like you don't have a life, you don't have hope. It feels like your heart is paining you.' – participant 3

I feel like I'm finished. There's no life, there's no future, there's no anything anymore. I think everything is going to become like darkness.' – participant 8

Once again it is participant 8 for whom the hopelessness is most profound, cutting right to the core of his being. Unlike participant 4, he is not even running. He is

finished and the darkness suggests a pervasive nihilism has overtaken him and everything else has disappeared.

Feeling changed

Five of the participants' narratives include a sense of being somehow changed by their experience. For two participants this was in a very visceral way, they have been damaged and broken by their experience:

'And while physically I've tried to move on. Mentally the people damaged my mind.' – participant 7

'... and sometimes I feel like I am broken. Everything is broken and I can't find how to make it better.' – participant 8

Participant 8 went even further:

'just my face and my pictures are still this man, inside I am totally different'

This suggests that participant 8 feel he has been utterly changed by his experiences. Only on the very surface is he the same person. Inside, at the very core of his being, he has been completely altered.

Participant 1 felt differently. For him it was his personality that had been changed by his experiences.

'My emotional state has changed and my personality has changed, but my character has stayed the same.'

Previously, participant 1 had described how he had frequently helped people in need and this was central in defining himself. Therefore the reference to his character here suggests he believes those core moral qualities remain unchanged.

Before his experiences participant 4 would prefer to stay quiet for fear of the consequences; now he is ready to stand up and fight. It seems he has almost gone to the opposite extreme having been pushed and pushed until he finally cracked:

'I used to be very scared, but now, for some small thing, I want to fight you like a bulldog. Get very agitated, in your face. I just won't let it go.'

This quotation does not seem to suggest a complete change in his core, but merely a reaction to the adverse events he is facing in his life.

For participant 5 the change is in her perception of life. A sense of confusion and disorientation as she struggles to differentiate between what is real and what is not:

'The difference between a dream and reality, or person who's talking or isn't, I don't know. Everything is mixed up in my heart.'

Difficulty trusting others

Given the extreme nature of these individuals' experiences it is no surprise that trust was a theme for many of them. For three it was a major element throughout their narratives, while for others it was simply about being able to trust the people you confide in:

'I am trying to keep to myself because you just don't know when you meet people if you can trust them. I cannot tell them I am sick because I don't have trust. If I tell them maybe they think I am funny.' – Participant 2

Participant 2 is talking about the disclosure of his HIV status. He is understandably afraid of what other's reactions might be and that he may be rejected or stigmatised. He returns to the subject of trust later on:

'I know I am a stranger here, so it is kind of difficult. When I meet them I have to study them, I have to take my time. Whereas back I home I was free, I know them, this is my country.'

Here it seems that the additional difficulty of being a stranger in a foreign society makes it even more difficult to determine with whom it is safe to talk.

For others the loss of trust was more complicated. Not only were they cautious of trusting potential friends, but they were suspicious of professionals too. Participant 4 returned to the theme of trust throughout his narrative. In the extract below he

discusses how he no longer believes it when people say they are going to help. He has heard it so many times the words have lost their value:

'If I come to you and you say 'don't worry, I will help you', then go to someone else who says the same thing. I have, maybe meet 20 or 30 people in the past 5 year saying the same thing. It's like you are a composer, you can make the music for my ear, and you know what I mean? So, it's going to be very hard for me to rely on other people to trust them. Yes you can say whatever you want to say, but I do not believe a word you are saying.'

Here he is talking about his difficulty trusting people in his social life. It is more than just being careful about what you tell people. For him it seems more profound; he has totally lost the ability to trust others and feels he can no longer forge a real friendship. Instead he has decided to withdraw in order to protect himself for fear of getting hurt should someone betray that trust:

OK I have friends. But right now they are the type of friends I don't need. They trust other people. They might trust me. But I don't trust them. The relationship is not going to work. I got this trust problem, so I distance myself a bit from these people.'

For two participants this lack of trust in others is more visceral and fearful, bordering on paranoid ideation. Looked at from the outside, these feelings seem to straddle symptoms of both PTSD and psychosis, and the difference between them, at least from the participants' perspective, was often indistinguishable. Here participant 7 is describing his thoughts about a professional who is working with him:

'Before I give my friendship to someone I do not know what it will be like. Maybe it will be difficult, maybe she is a spy and she wants to kill me, maybe she wants to follow me. Why is she there? Why? She don't know me, I am not her friend, I am not her family. Why she want to help me move on? '

He is suspicious of others wanting to be his friend and has some extreme suggestions for their genuine motives.

Surviving

This domain describes ways the individuals have found to cope, as well as those things which make coping more difficult. Again there is considerable overlap with other themes, in particular 'Wish to live and build a purposeful life' and 'loss of trust'. Despite the somewhat bleak picture described in the previous domain – characterised by feeling stuck, hopeless, changed and untrusting – most of the participants were also able to think about coping and future hopes, at least to some extent. Indeed the range of positive coping strategies employed by participants as shown in table 2 is encouraging. For some it was more difficult than for others; however, even participant 8, one of the most overwhelmed, disturbed and hopeless was able to identify something that eased his pain:

'Last summer he [a friend] took me outside, I cannot remember which place, but it was a nice place. There I felt something was good, I just felt relaxed. '

Contact & Communication

This theme included all those ways in which participants had been able to make contact with other people. The most prevalent strategies under this theme involved talking, spending time with friends, keeping occupied and sharing experiences.

Talking

Six participants described the benefits of talking. On the one hand this could be seen as surprising given they were all from non-western cultures whose methods for coping do not necessarily share a Western philosophy. On the other hand they had all been through the mental health system in the UK and therefore represent a biased sample. Either way, the experience of talking seems to provide a relief for individuals as vividly exemplified by participant 6:

'The more I talk the more relief I get. It's like unscrewing a bottle of fizzy drink and it sprays everywhere.'

For him the process of talking releases what he appears to experience as an internal pressure.

Spending time with friends

All but participant 9 felt spending time with friends helped them to cope better with their situation. For participant 9, there were no friends, every attempt she had made had been unsuccessful and she felt people did not want to know her:

'I don't want to be in contact with many people to be honest. I feel more comfortable when I'm alone. People just increase my problem. I've had some friend from my community, maybe one or two time they contact me then they discontinue with me. They say you just talk about bad things.'

For the rest however, friends provide a source of support and allow them to move on in their lives:

'They give you support. Like crutches. At first you walk like a baby, you fall down. But then at the end of the day the baby starts to walk itself. It is like the crutches that support you. In the end you have to walk on your own.' – participant 7

Here participant 7's metaphor of a baby suggests a return to a childlike state, and one where help is needed for even the most basic things.

For others, being with friends allows them some escape from their troubled thoughts:

'When I visit my friends I feel calm compared to when I'm alone.' – participant 1

The overall impression is that communication allows individuals to feel more normal:

'You know when I am with M it makes me feel good. He doesn't make me feel different. He treats me like a younger brother and he has given me the help I need and is helping me to live like a normal human being' – participant 2

Keeping occupied

For more than half the participants, keeping busy and occupied was helpful. For some it involved doing something practical such as studying, while for others it simply meant visiting friends or getting out of the house. Conversely, being alone and having time to think about things was when the voices and other problems returned:

'Staying quiet or alone is when the voices come, but when I go to the college and I'm talking or doing something, I feel more involved in life then.' – participant 5

'If I have something in my timetable I am going to do everyday then by the time I get home I will just want to eat and sleep. But if I have nothing, the only thing to preoccupy my mind is to think. And that's what I do, a lot.' – participant 4

Shared experience

For a third of participants, the opportunity to be with people who have had similar experiences was cited as helpful. It allowed trust to build more easily given a mutual understanding:

'The group meeting is definitely helping. You sit down with different people, with whom you basically have things in common. You can share your experience, you can easily build up trust that way.' – participant 4

Being with people who had not experienced similar things made it difficult, if not impossible for participant 9. For her there was no way anyone could really understand and this resulted in her feeling even more isolated and alone:

'My big problems are that I'm isolated and nobody understands me. The people don't understand me, they can't understand me and I can't describe myself, and because of that I'm not in touch with anybody.'

Positive philosophies

A third of the participants also spoke about a life philosophy, be it faith-based or simply a motto they kept in mind as a source of strength:

'I take every day as it comes.' – participant 6

'One philosophy that I always repeat to myself is that it's good to fail, but it's not good to give up. So if I fail today or tomorrow, for me it is OK. But if I give up then it is the end of the world for me.' – participant 4

DISCUSSION

Overview

The phenomenon for these individuals involves a sense of being overwhelmed, both in terms of their past experiences and in their current situation. 'Feeling stuck', either in the asylum process or, more profoundly, in the process of living is common, as is a sense of hopelessness about the future. Many feel they have been changed in some way, feeling broken or damaged by their experiences, with a loss of trust featuring frequently in participants' narratives.

While for some, the experiences appear to have been completely overwhelming, others have found ways of beginning to manage and cope. Talking, spending time with friends and doing other things to keep them busy proved crucial.

Creating meaning out of events was also a central component. Most have come to some sort of understanding about the origins of their problems, which almost without exception involved the traumatic experiences they had been through. For some this meaning had evolved and developed over time, drawing from cultural and professional explanations; whilst for others it remained a simple causal link.

Findings

The broad aims of this piece of research were to elaborate on the participants' experiences: what it was like for them, what they were experiencing and whether they felt changed. Secondly, the research intended to investigate what they found helpful

or unhelpful in managing their lives. Finally, any perceived links between traumatic events and the development of their auditory hallucinations were to be investigated.

The domains 'experience of life' and 'surviving' largely cover the first and second aims, while the domain 'meaning and purpose' is most relevant to the third. Each domain will be discussed in relation to the relevant literature. It is quite striking how similar some of the themes identified here are to those identified by Goodman (2004), who investigated how 14 unaccompanied Sudanese youths coped with trauma and hardship. Using a case-centred narrative approach Goodman identified 'collectivity and communal self', 'suppression and distraction', 'making meaning' and 'emerging from hopelessness to hope' as major themes. These include similar ideas to those found in this study relating to the role of faith in creating meaning, feelings of hopelessness, keeping busy and the understanding of others. This suggests that despite huge variations in individuals' stories, there are a number of common experiences in refugee and asylum seeker populations.

Meaning and purpose

Perhaps the most illuminating domain identified was 'meaning and purpose', which draws together themes representing the different ways in which individuals had drawn meaning out of their experiences. Creating some sort of meaning is a theme frequently identified in the literature. Taylor (1983) identified the importance of creating meaning out of threatening events, suggesting that it was a cognitive adaptation central to an individual's attempt to try to regain mastery over their situation. Creating meaning during the early stages of learning to cope with voices has been discussed by

Romme and Escher (1989) who believed it could help reduce anxiety in the face of frightening experiences. More recently, Knudson & Coyle (2002) also found a discourse of meaning in their analysis of the experience of hearing voices, again noting its relationship to coping.

For those who participated in this research, the extent to which they were trying to make sense of their past and present situations was quite varied. For some there was no link between their voices and their trauma. Others were only able to link the onset of their problems to the time of the trauma. For a few more the link was quite specific, the voices they heard were those of people involved in the traumatic event. For two, creating meaning seemed to have gone a step further. These participants had begun to weave their understanding into personal, cultural and professional explanations which had been presented to them over the course of time. This had resulted in fairly sophisticated and varied meaning systems for those individuals.

Hardy et al (2005) found that in a group of individuals who had experienced trauma and fulfilled criteria for a non-affective psychosis, 12.5% had hallucinations with similar themes and content to their trauma, 45% had hallucinations in which the themes were the same but not the content and 42.5% had no identifiable associations between their hallucinations and the previously experienced trauma. Although formally comparing the percentages to our sample would be meaningless, the presence of these three groups is consistent with the findings here.

To extrapolate these findings any further goes beyond the objectives of this research. It does however suggest that at least in terms of most of these individuals' personal

experiences, the traumas they have been through form an important reference point from which they are able to make sense of their current symptoms.

Also noted in this domain were the often conflicting ideas of their wish to die versus their wish to live and build a purposeful life. The vast majority of participants spoke meaningfully about wanting to build a worthwhile life for themselves and for their families. Often they spoke simply of wanting to be normal and to integrate with society, reflecting back to times when they felt normal in the past. This hope and desire to build a life through study and work, to pay their own way and contribute to society at other times conflicted with a wish to die and give up against the struggle. These ideas are similar to those found by Goodman (2004) in the theme 'Emerging from hopelessness to hope', in which participants reflected on their past difficulties and feelings of hopelessness and in some instances suicidality, while at the same time hoping to obtain an education and have a good life. Some also saw their faith as providing a reason or purpose to carry on, another theme identified by Goodman (2004) among her Sudanese youth refugees.

Experience of life

Changed

A belief that they had somehow been changed by their experience was expressed by a number of the participants, who used words like 'broken' or 'damaged' to vividly describe their feelings. This reflects a number of studies which have specifically identified a connection between trauma and changes in self-concept and identity (e.g. McNally et al., 1995 and Sutherland & Bryant, 2006). Interestingly a recent study

comparing cultural differences in personal identity following PTSD found that individuals from interdependent cultures defined themselves less in terms of their trauma than did those from independent cultures (Jobson & O’Kearney, 2008). It would be impossible to compare our findings with this study; however it does suggest scope for future research in this area taking a more qualitative approach to understanding those differences.

Feeling stuck and hopeless for the future

This was another common theme amongst participants and reflected for some their situation as an asylum seeker, waiting on a decision as to whether or not they could remain. For others it represented something more profound, the impact of their experiences on their sense of self as they struggled to cope and move on with their lives. These themes are consistent with previous findings relating to asylum seekers (e.g. Tribe, 2002), individuals who have experienced trauma and people living with psychosis (e.g. Warman et al., 2004). It is not surprising that they also apply to individuals who fulfil all of the above.

Trust

Given the extreme nature of these individuals’ histories, it is not surprising that trust was found to be a major theme for most. For some it was expressed by a more tentative approach to friendship, testing out the water before committing themselves and opening up. In this sense it is consistent with much of the evidence relating to the loss of trust following trauma (e.g. Lewis et al. 2004).

For others it was more profound and led to a general mistrust of those they met both socially, and professionally through the healthcare system. Gross (2004) investigated the effects of migration politics on asylum seekers and refugees and on the Swiss health services, using a grounded theory approach. She found the psychiatric concept of trauma and a more popularised discourse of traumatic memory were so strongly emphasised they had led refugees to develop tactics of identifying with the trauma discourse in order to become “good refugees” and achieve refugee status. Her analysis of their interactions with health professionals showed that they take place in an environment of social and economic insecurity resulting in mistrust. This idea could be applied to many of those individuals described here, but perhaps most obviously to participant 4. He clearly expressed a fatigue at reliving his experience over and over again to countless professionals as if it was something he had to do because of his powerless position in the relationship.

Surviving

For a couple of participants the mere thought of dealing or coping in some way with their problems was completely beyond their capabilities, such was the extent to which they felt overwhelmed. They had seemingly chosen to try to manage their problems by isolating themselves and avoiding situations they feared would make them worse. This is consistent with the role of avoidance in the development of psychopathology in cognitive behavioural models of both PTSD and psychosis (e.g. Ehlers & Clark, 2000 and Garety et al., 2001).

Nevertheless, for most there were at least a few ways in which they could begin managing their problems. Indeed the breadth of ideas was encouraging. Talking, spending time with friends and generally keeping themselves occupied were undoubtedly the most common strategies for participants. These directly contrast to the struggle most of them face, either because of the restrictions placed on them by their asylum status or the overwhelming nature of their experiences. Again these findings are consistent with much of the evidence relating to helpful coping strategies for individuals with psychosis, PTSD or indeed most other mental health problems. For example, in a recent investigation into coping strategies used by individuals with psychotic symptomology, 'talking' and 'hobbies' came out as the most efficacious strategies employed (Hayashi et al., (2007).

Conversely, having too much time to think and dwell on the past was the most frequently identified obstacle to coping. Understanding through similar experiences, or time taken to really listen and try to help, was one way identified which allowed the development of trust in people. Both these themes compare directly to those identified by Goodman (2004) called 'thinking a lot can give you trouble' and 'what is happening is not happening to me alone'.

Sample characteristics

As previously mentioned, the sample was not intended to be representative and any generalisations to larger populations must be undertaken cautiously. Nevertheless there are observations about the population demographics which are worthy of note. The fact that seven of the nine participants who took part were originally from sub-

Saharan Africa is striking. Recruitment took over eight months and only 14 individuals were proposed from across the psychological and psychiatric services in the borough (three of the excluded participants also being from sub-Saharan Africa). The findings are even more striking when considering a recent audit of the psychological service by Bodinetz (unpublished) who found only 15% of service users in the borough originated from sub-Saharan Africa versus 64% from the Middle East and 15% from Eastern Europe. These findings are in line with those of Selten & Cantor Graae (2006, 2007) in which the relative risk for psychoses was highest amongst migrants from Africa and the Caribbean. They also reflect the findings of the London based study by Tolmac & Hodes (2004) who found a relatively higher proportion of black African in-patients amongst the refugee group (8/10).

This may also represent a meaningless statistical anomaly, a racial bias among clinicians, or more likely a cultural difference in the explanation of hearing voices. As participant 7 noted in his interview, people from his country of origin had interpreted his problems as supernaturally based. Research has shown that in non-clinical samples, where there are no differences in rates of psychosis, Caribbean individuals are twice as likely to experience auditory hallucinations as white individuals (Johns et al., 2002).

Limitations

Perhaps the greatest limitation of this piece of research is the heterogeneity of the sample. Although great effort was made to draw individuals from as homogenous a group as possible, a number of the individuals do represent possible confounding

factors when trying to generalise the findings. In particular participants 8 and 9 were from North Africa and the Middle East, as opposed to sub-Saharan Africa as with the rest of the sample. Cultural differences, particularly with respects to spiritual beliefs may have been quite different for these individuals. Given their importance for some individuals in making sense of their situations, this difference represents one possible area of heterogeneity that may make the results less generalisable.

Similarly, participant 7, whose trauma occurred post-migration, in some ways represents an even greater anomaly. Although culturally similar, his life experiences are quite different to the rest of the sample. Despite these problems and possible confounding factors, many of the themes drawn out here still seemed to apply to these individuals from different cultures and with different trauma histories. Suggesting there are common themes for all refugee and asylum seekers worth considering.

The analysis and interpretation of interviews described here was conducted by myself in the context of my own cultural, professional and personal biases. Given my own personal view on the relation between trauma and psychosis it is quite possible that these may have been influential in directing the questioning.

Although I was involved in these interviews as a 'neutral' researcher, it is unlikely this is exactly how participants viewed me. The interviews were conducted on hospital premises and they had been recruited through their respective clinicians. Indeed one participant referred to me as doctor during the interview, even though I had never referred to myself by that title. Cultural beliefs about power roles in health

care settings combined with the powerless role of the asylum seeker as highlighted by Gross (2004) were likely to be salient in this situation.

The results presented in this paper only represent those themes common to the group. Themes such as guilt, difference to other asylum seekers and revenge were core but unique themes to some individuals. However, because of their uniqueness, this particular analysis did not focus on those themes and as a result some interesting material has been excluded.

When conducting the interviews I was most interested in understanding the experience of hearing voices. With this in mind I attempted to differentiate these from other symptoms (e.g. flashbacks and nightmares). This did not prove to be particularly successful. For the participants, the distinction between hearing voices and flashbacks seemed to be fairly meaningless. When voices were mentioned, participants often spoke about them interchangeably with what I would consider to be flashbacks. This could be the result of language and cultural differences resulting in misunderstanding. Furthermore, I come from a profession familiar with western psychiatric definitions of mental health problems which are not likely to correspond with the models of mental health understood by participants. This particular idea was clearly demonstrated by participant 7 who reflected on, and struggled with cultural and professional meanings when trying to make sense of the voices he heard.

An interpreter was used only once and the resulting interview was, from my perspective, one of the least enlightening. It was my first attempt at interviewing and the participant also seemed less able to think in psychological terms, preferring to

give more straightforward, definitive answers which allowed for little interpretation of meaning. Furthermore, the process of interpreting itself brings about a new level of interpretation. As with clinical practice, the interpreter themselves bring their own views and ideas to the situation and may, for example, feel they need to edit material, particularly when dealing with difficult material, as in this instance. Given the heavy reliance of IPA on language in order to then suggest interpretations, the use of interpreters seems particularly unsuitable. However, Smith (2004) remains pragmatic about the situation saying 'If the gains speaking to this particular group sufficiently outweigh the costs from not speaking the same language... then yes, it may be necessary to conduct research with an interpreter' (p. 50). For this particular study I think it was acceptable to be open to the possibility of using interpreters, and although it did not produce a particularly fruitful interview here, future research in this area may find it necessary.

Although language skills were foreseen as a potential obstacle, this appeared to be the case for only one participant whose subsequent interview seemed more limited by their language constraints. The richness of the data was in fact felt to be one of the greatest strengths of the research, and has been commented on by a number of researchers with experience in using IPA.

Some interesting themes which arose during the interview process were not followed up. This was mostly due to my lack of experience, resulting in a focused approach less responsive to new ideas. It was only during the analysis that the relevance of ideas including supernatural and spiritual beliefs were found to be of such importance to certain individuals. On reflection a deeper examination of these ideas could have

been insightful. Their relation to the creation of meaning could have been interesting to examine, particularly given the extensive literature suggesting such a link (e.g. Johns et al. 2002).

Themes were developed in consultation with two individuals with extensive experience using IPA and this process proved particularly useful in trying to gain a broader perspective on the phenomena. During the analysis at times I would become overly involved in the detail, resulting in a loss of overall perspective. Being able to discuss ideas and themes more broadly with people who already had extensive experience allowed for a deeper understanding. It also allowed for the development of some of the interpretations of meaning which I had initially found to be a distinctly foreign process. Eventually, through discussion I was able to develop a greater confidence in my interpretations.

Future directions

There may be some value in a deeper analysis of the two richest interviews. Smith himself has recently suggested the analysis of fewer interviews in a deeper fashion (Smith, 2004). Although much has been learned and understood about the similarities between these individuals, the disparate nature of their experiences warrants closer examination.

The role of meaning was an important theme in this research, which echoes other studies in the area (e.g. Knudson & Coyle, 2002 and Goodman, 2004). Future

research could focus more directly on this theme, investigating its therapeutic value for individuals who have experienced traumatic events.

The role of religious and spiritual beliefs in creating meaning out of experience was one area not fully explored. Future research could investigate this theme more exhaustively, particularly when trying to understand its role in the creation of meaning.

Similarly, guilt and revenge, which appeared as important themes for particular individuals may also warrant further exploration. Sub-populations such as torturers and those tortured could make for interesting comparisons on such themes.

Comparison between different sub-groups could also broaden our understanding. For example the differences between refugees and asylum seekers was touched upon in this research in exploring their feelings of 'being stuck'. Future research could aim to further expand on these differences.

Clinical Implications

The importance of meaning making is clear in this study, and suggests clinicians should spend time considering the different ways clients try to understand their symptoms and their lives in the context of the trauma they experienced. The link between the traumatic experience and the voices was a particularly consistent theme in this research and it was apparent that individuals drew from a range of cultural,

professional and personal narratives in trying to make sense of what had happened to them.

This research also underlines the often conflicting feelings that clients who have been through such extreme difficulties often have. On the one hand many are determined to build a new life, whilst at the same time feeling completely overwhelmed or stuck by their situations resulting in a wish to end their lives. The clinical implication of this being that services may need to work particularly hard in engaging these individuals and remaining in contact, because whilst everyone in this sample expressed a real desire to move on with their lives, the sheer weight of their problems could potentially result in them finding it more difficult to remain engaged in services. This idea is further underlined by the theme of ‘surviving’, which similar to many other mental health problems, showed the importance of contact and communication for those individuals who were finding a way to cope. Service provision, possibly through outreach may be one way of helping this vulnerable group remain engaged.

A greater emphasis on the development of regular groups and activities, and potentially some form of meaningful work is another area that could be developed. Groups should involve individuals who have been through similar experiences, in order to allow them to talk more openly. Such groups may help them to develop trust more easily and to build friendships. This in turn may allow them to start thinking about the future instead of being consumed by their past.

Conclusions

The themes and sub-themes identified here are largely consistent with the literature. Many of the participants actively engaged over time in a process of creating meaning despite the horror and senselessness of their experiences. For some, these presented insurmountable challenges to the meaning systems they appeared to hold before the trauma.

The experience of life for these individuals is clearly shown here to present great struggle and hardship, often involving conflicting internal emotions. Nevertheless, these individuals have survived, despite what seem to be insurmountable odds. They have a wish and a desire to build lives for themselves and to eventually integrate and live a normal life.

In that sense these accounts should also give us hope. That individuals can survive in the face of great adversity demonstrates a great strength of character, which it is our role as health professionals to encourage and develop.

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Part 3: Critical Appraisal

Introduction

This critical appraisal outlines the various stages in the conception, development and execution of the project. It begins with the background to my interest in the area, followed by the various stages of the process and reflections on some of the issues and decisions about the direction it took. The appraisal finishes with some reflections on how the research has altered my own perception of the phenomenon.

Background

My interest in working with refugees and asylum seeker issues began during my first placement on the clinical psychology training course. Previously, my understanding of refugee and asylum seeker issues had come through the national press, and although I was by no means persuaded by the overwhelmingly negative reports, it was a cultural narrative which was familiar to me.

As I began my work with refugees and asylum seekers I read more widely around the subject and I began to feel a real sense of the injustice these people were facing.

Listening to clients' stories and understanding the obstacles they had faced in search of a better life, was a humbling experience.

What struck me most was the terrible inequalities many continued to face in the country in which they hoped to find sanctuary; a country which was openly hostile on a number

of different levels. Although psychology is certainly a more liberal and broad minded profession, it quickly became apparent that even psychologists were often unwilling to get involved; perhaps feeling that the breadth of the problems including language and cultural difference and histories frequently including multiple traumas, was too much to cope with. As a result, refugees and asylum seekers in the service I was working at were having to wait longer to be seen, another way in which they were being discriminated against.

It was in this context that I felt I wanted to develop my interest, both clinically and academically. At this time I also began seeing a young man recently arrived from central Africa. The notes indicated that he suffered from PTSD but was also experiencing psychotic symptoms. The report noted that during the GP appointment he had said that three men were stood behind him, the same three men who had been involved in his torture. Having only a brief understanding of PTSD and psychosis, this struck me as unusual. I began talking to people at UCL and was introduced to the literature currently debating the role of trauma in the onset of psychosis (e.g. Morisson et al., 2003). Following a literature search which identified only a handful of papers concerning this phenomenon in refugee and asylum seeker populations, the direction of my research became clear.

Research Development

Following consultations with a number of psychologists with an interest in the area, it became apparent that a qualitative approach would be the most viable option. The paucity of literature, particularly with respect to qualitative research, suggested an exploratory piece of research trying to identify what it was like for these individuals could form an interesting project. The lack of standardised measures for working with individuals from varied cultures was also considered, along with the foreseeable difficulty in recruiting a large and homogenous enough sample to conduct a viable statistical analysis.

Rigour versus flexibility

In designing the study a great deal of consideration was given to the extent to which validity, trustworthiness and rigour could be established whilst at the same time remaining flexible in order to deal with the potential difficulties which may arise given such a potentially difficult research population to study.

The literature on rigour in qualitative studies is itself quite sizeable and opinion ranges from those who believe qualitative research should be judged according to the same criteria as quantitative research (e.g. Field & Morse, 1985); to those who question the very idea of any predetermined criteria for judging such concepts (e.g. Rolfe, 2004). For the purpose of this piece of research I followed principle outlined by Meyrick

(2008) and chose a pragmatic middle ground aiming wherever possible to be systematic and transparent in order to claim a degree of scientific rigour.

Specifically, I clearly laid out my own perspective in the methodology section. I used a second researcher and also my supervisor who had a great deal of experience using IPA to cross-check and discuss differences in themes. I conducted all the interviews myself using an interview schedule which had been designed to include particular topic areas thought important for discussion to maintain consistency, whilst at the same time being flexible to allow for individual stories to emerge.

Interview schedule design

Given the lack of research in the area, topics for the interview schedule were chosen based largely on mine and my supervisors' interest in the area. Perceived links between trauma and psychotic symptoms was the most obvious category, given the origins of the project. Secondly, as a group which had not been extensively researched, their everyday experiences of life in general were thought to potentially yield a great deal of understanding. Finally, how people coped, given the extreme nature of their past experiences and current difficulties, would potentially help in identifying practical suggestions which could be applied clinically.

Inclusion criteria

Given that the broad aim was to investigate the experience of refugees or asylum seekers, with positive psychotic symptoms who had experienced trauma, it was felt that

the potential pool of participants was already limited. There were initial concerns about finding individuals who fulfilled these broad criteria and would be able to talk articulately about those experiences. Further limitations in order to create a more homogenous sample were considered including using only refugees or asylum seekers, using only survivors of torture or using individuals from a specific area of the world. In the end these were rejected in favour of broader inclusion criteria which could later be narrowed down if the opportunity arose. Originally the sample was to include all positive psychotic experiences and it was not until afterwards that it was found they all experienced hearing voices. Similarly, the sample was nearly completely from sub-Saharan Africa.

Recruitment

Potential recruitment problems were identified at an early stage in the design of the study. A number of presentations at trust-wide conferences and mental health services were organised early on in order to bring awareness of the project into potential recruiters' minds. At first I simply presented at these events and although many people expressed an interest, none actually got in touch. I then became more proactive, taking names of clinicians who seemed interested and following them up with emails and telephone calls. Unfortunately during the time of recruitment the mental health services were undergoing a major restructuring and many clinicians had swapped or changed clients they had been working with. As a result many were unfamiliar with their new client lists and were not sure where potentially suitable clients they had been working

with were now being treated. When it became clear most participants being suggested were from sub-Saharan Africa, this became a major focus in the recruitment drive during the last three months. Unfortunately the last two hoped for participants from sub-Saharan Africa, who would have made for a more homogenous sample, did not materialise.

As already mentioned in the limitations section of the empirical paper, this lack of homogeneity for some participants represents the most problematic aspect of the research. On the one hand, given the nature of the phenomenon under investigation and the population being investigated, it was vital to allow a certain degree of flexibility in the inclusion criteria to maximise the recruitment pool. In the end, it was felt that the sample was able to balance flexibility with the rigour required in a scientific endeavour. Indeed the homogeneity of the results would seem to back that up.

Although clinicians were overwhelmingly supportive and favourable towards the research, one clinician expressed his concern at identifying potential participants only through their experience of positive psychotic symptoms. He pointed out that if one is to use DSM-IV-R criteria, the diagnosis of psychosis and schizophrenia always comes with a caveat criterion which states that this condition could not be better explained by another disorder, such as in this case, PTSD. For this clinician, in the context of PTSD, voices were a form of flashback if they in anyway resembled the trauma. Furthermore, caveats, such as the one described above, which by its definition rules out trauma as a potential causation, results in an over-emphasis on the biological causes of psychosis.

This ignores the growing evidence pointing to a range of environmental and psychological factors (e.g Kroll 2007). As previously mentioned, the arguments for and against these various positions are currently under debate in the literature (e.g. Morrison et al. 2003) and go well beyond the realms of discussion for this paper. This research was also an exploratory piece and was not seeking to generalise to any particular population, but rather to lead to useful suggestions for more closely focused research.

Interviewing

The aim of IPA, to understand the phenomenon from the individual's point of view, requires a particular type of interviewing technique, one quite different to clinical interviews. In some ways the emphasis is similar, you are seeking to understand the individual, however in other respects it is quite different. Interviewing for IPA requires techniques which often felt intrusive as you question the participant, often repeatedly, about particular instances in order to learn as much as possible from their perspective. This seemed particularly difficult when considering the histories of these individuals. As a result my first interview felt quite superficial; however with guidance and the opportunity to role play with my supervisor, my technique improved. Although at times I pulled back when topics became distressing for participants, the eventual quality of the interviews was extremely rewarding and for me represents the most successful aspect of this research.

Despite being offered payment for their participation, a number declined, feeling very deeply that if they could in any way help other people through their stories, that was payment enough. The depth and honesty of participants' interviews was for me a particularly humbling experience.

One early concern was the potential richness of the data for analysis. Psychological mindedness is a western idea and working with refugees and asylum seekers over the past three years I have found that meaning can often become confused. Furthermore, many are more somatically focused, finding it difficult to think and talk in psychological terms. In addition to this, participants were experiencing distressing psychotic phenomenon which can be highly disorientating. This could have potentially lead to brief and confusing interviews for analysis.

Analysis

Most of my previous research experience had been with quantitative techniques, and as a result this project brought with it a whole new range of methodological and practical challenges. The process of analysis was the most challenging and took the greatest time. Immersing myself in the data through reading over and over the interviews was the most crucial aspect. At the beginning of the analysis, trying to draw together themes, I frequently lost sight of the bigger picture. Undoubtedly, having the opportunity to discuss ideas and themes with a number of individuals with experience

and expertise in the process was extremely helpful and allowed me to develop my, initially superficial, interpretations into a deeper meaning.

Results

This research aims to describe the experiences of those individuals who took part in order to understand what life was like for them. I feel that the quotes and subsequent interpretations have been able to do this. Although certainly not the most insightful analysis possible, it represents the best of my abilities at this time. It has allowed a much greater exploration and understanding of individuals' circumstances and experiences than would normally be undertaken in clinical practice and has therefore facilitated a greater insight into what their experience is. Interestingly, the results are similar to those of Goodman (2004), whose research was not found during my original literature search using Psychinfo or Medline. It was only in the week before submitting the thesis that someone drew my attention to the piece of research. Although, ideally it would have been better to have seen it and considered the findings before I started my own investigation, it is encouraging to see many of the same themes in a population similar to the one I investigated. This suggests the findings have some validity.

PTSD vrs Psychosis

Although not directly investigated, given its relevance of the debate surrounding trauma and psychosis, what can be learnt from these findings? The role of culture in the application of diagnoses is certainly an important factor. There has been much written

regarding the validity of applying western defined psychiatric problems to non-western cultures.

Summerfield (2003) has argued that the over-representation of refugees in studies of psychiatric morbidity comes from a lack of cross-cultural validity in the measures used. He argues that the ways in which human beings experience a traumatic or disturbing life event vary, depending upon the social context in which it occurs. Meaning and understanding, he believes, are attached according to this context, which cannot itself be measured or captured within a psychiatric category. Furthermore, pathologising refugee distress results in social and collective meaning being reassigned as individual and biological.

Even when diagnoses are broken down into more psychological/ phenomenological concepts such as 'flashbacks' or 'voices', as was done in this research, the differences were not necessarily meaningful when talking with these individuals. Perhaps this was a result of language barriers, but it could equally have been something more fundamental. Given the research relating to cultural variations in the experience of psychiatric symptoms (e.g. Johns et al., 2002) it is regretful that I did not pursue further participants' social and cultural narratives in their creation of meaning. Greater insight into these experiences may act as a useful starting point in really trying to understand and ultimately to help these individuals deal with their problems.

Personal reflections

Before I began this research I had only a basic appreciation of PTSD and psychosis.

Teaching on the course began to expand this, and my first experiences working with individuals whose symptomology appeared to span both profiles developed this even further. Even in these situations, the knowledge acquired through learning and clinical practice is largely focused on the development of clinical skills to 'treat' the 'problem'.

Ultimately, the experience of conducting, analysing and then interpreting these interviews has given me a greater insight into and the lives of these individuals. I now have a deeper understanding of what life is really like for them and with that a huge amount of respect for their courage and openness in sharing their thoughts with me.

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Appendix 1: Ethical Approval Letter

Barnet, Enfield & Haringey Local Research Ethics Committee

R&D Dept,
Royal National Orthopaedic Hospital
Brockley Hill
Stanmore
HA7 4LP

Telephone: 020 8909 5318
Facsimile: 020 8385 7151

03 May 2007

Mr John Rhodes
Consultant Clinical Psychologist

Dear Mr Rhodes

Full title of study: **The experience of refugees and asylum seekers with severe mental health problems following traumatic events**

REC reference number: **07/Q0509/28**

The Research Ethics Committee reviewed the above application at the meeting held on 24 April 2007.

Ethical opinion

The members of the Committee present gave a **favourable ethical opinion** of the above research on the basis described in the application form, protocol and supporting documentation.

Issues discussed at the review

- The answer to Question A43 was incorrect as the researcher would have access to the participant's medical records as mentioned in the interview schedule. Mr. Parrett agreed he would make the necessary change to reflect this
- It was agreed that interpreters would be provided for non English speaking participants in the event of problems being experienced in recruiting enough English speaking participants.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	1	05 April 2007
Investigator CV		27 October 2006
Protocol	1	
Letter from Sponsor	1	27 March 2007
Interview Schedules/Topic Guides	1	01 April 2007
Participant Information Sheet	1	29 March 2007
Participant Consent Form	1	

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from
<http://www.rdforum.nhs.uk/rdform.htm>

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

<https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx>

We value your views and comments and will use them to inform the operational process and further improve our service.

07/Q0509/28	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely

Chair

Email: alison.okane@moh.nhs.uk

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
Standard approval conditions*

*Copy to: Barnet, Enfield and Haringey Mental Health trust
[R&D office for NHS care organisation at lead site]*

Barnet, Enfield & Haringey Local Research Ethics Committee

Attendance at Committee meeting on 24 April 2007

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present?</i>	<i>Notes</i>
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Consultant Paediatrician
GP
Lay Member
Consultant in Old Age Psychiatry
Clinical Psychologist
Consultant in Respiratory Medicine
Principal Lecturer - Research
Lay Member

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
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Committee Co-ordinator

Appendix 2: R&D Approval Letter

**R & D DEPARTMENT
ST. ANN'S HOSPITAL
ST. ANN'S ROAD
LONDON N15 3TH**

E-mail: research.department@beh-mht.nhs.uk
Direct Line: 020 8442 6503

13 July 2007

Dear Mr Rhodes,

Title of Study: **The experience of refugees and asylum seekers with severe mental health problems following traumatic events**

REC reference number: **07/Q0509/28**

I am pleased to note that you have received the favourable opinion of the Research Ethics Committee for your study.

All projects must be registered with the Research Department if they use patients, staff, records, facilities or other resources of the Barnet, Enfield and Haringey NHS Mental Health Trust.

The R&D Department on behalf of Barnet, Enfield and Haringey NHS Mental Health Trust is therefore able to grant approval for your research to begin, based on your research application and proposal reviewed by the ethics committee. Please note this is subject to any conditions set out in their letter dated 03 May 2007. Should you fail to adhere to these conditions or deviate from the protocol reviewed by the ethics committee, then this approval would become void. The approval is also subject to your consent for information to be extracted from your project registration form for inclusion in NHS project registration/management databases and, where appropriate, the National Research Register.

Permission to conduct research is also conditional on the research being conducted in accordance with the Department of

Health Research Governance Framework for Health and Social Care*:

- Appendix A to this letter outlines responsibilities of principal investigators
- Appendix B details the research governance responsibilities for other researchers. It also outlines the duties of all researchers under the Health and Safety at Work Act 1974. Principal investigators should disseminate the contents of Appendix B to all those in their research teams.

It is required that all researchers submit a copy of their report on completion and details on the progress of the study will be required periodically for longer projects. Copies of all publications emanating from the study should also be submitted to the R&D Department.

Furthermore, all publications must contain the following acknowledgement.

"This work was undertaken with the support of Barnet, Enfield and Haringey NHS Mental Health Trust, who received "funding" from the NHS Executive; the views expressed in this publication are those of the authors and not necessarily those of the NHS Executive".

"a proportion of funding" where the research is also supported by an external funding body; "funding" where no external funding has been obtained.

Best wishes and every success with the study.

Yours sincerely,

Assistant Director R & D

*Further information on research governance can be obtained on the DH web pages at <http://www.doh.gov.uk/research/>

Appendix 3: Participant Information Sheet

Participant Information Sheet

PART 1

The experience of Refugee and Asylum Seekers following traumatic experiences

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the aim of the study?

The aim of the study is to try and understand the experiences of refugee and asylum seekers in this country who have had traumatic experiences such as witnessing violence against their families, or against themselves and who are now having psychological difficulties such as low mood or psychotic symptoms (e.g. hallucinations or delusions).

Why have I been chosen?

You have been chosen because you are either a refugee or asylum seeker and your doctor or psychologist has told us that in the past you had some traumatic experience. We are hoping to interview around 10 people who have had similar experiences to yourself.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. If you withdraw from the study at any time any data will be deleted immediately.

What will happen to me if I take part?

You will be interviewed by a researcher 2 or 3 times over the period of 1 or 2 months. Each interview will last approximately 1 hour. Interviews will take place at St Ann's Hospital. The interviews will be recorded.

Expenses and payments:

At the end of each session you will be paid £10 to cover travel and participation

What do I have to do?

You will be asked a number of questions covering a range of topics. It is hoped you will give as detailed answers as possible in order to help us understand your experiences as best as possible.

PLEASE NOTE WE WILL NOT ASK YOU SPECIFICALLY ABOUT ANY SPECIFIC TRAUMATIC EXPERIENCES

What are the potential problems with taking part?

It is possible you may find talking about some of the topics distressing. Although the interviewer will try to avoid distressing topics if you find this is the case you are free to stop the interview completely or ask the interviewer to move onto a different topic.

Psychological support will be available afterwards and at any point there in the future should you wish

What are the possible benefits of taking part?

Talking about experiences can often be helpful for individuals, however we cannot promise the study will help you but the information we get might help improve the treatment of people with mental health problems in the future.

What happens when the research study stops?

After the study has been completed you will be contacted and offered information regarding the results of the study

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Will my taking part in the study be kept confidential?

Yes. No information from the interview will be used such that it would allow others to identify you. The details are included in Part 2.

Contact Details:

Neil Parrett
Sub-department of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if relevant new information becomes available?

If any new information of relevance becomes available, then you will be informed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions 07736429347. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Harm:

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against Barnet, Enfield and Haringey Mental Health NHS Trust, but you may have to pay your legal costs.. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).'

Will my taking part in this study be kept confidential?

If you join the study, some parts of your medical records and the data collected for authorised persons will look at the study. People may also look them at from the university or, by representatives of regulatory authorities and by authorised people from the Trust to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site.

Involvement of the General Practitioner/Family doctor (GP)

Your own GP, Psychiatrist or Psychologist may be notified of your participation in the trial, but only with your consent.

What will happen to the results of the research study?

The results of this research will form part of thesis to be submitted to University College London. It is hoped that the results will be published. You will be contacted and offered copies of the final report with an opportunity to ask questions You will not be identified in any report/publication unless they have consented to release such information.

Who is organising and funding the research?

University College London is funding the project and Barnet, Enfield and Haringey Mental Health NHS Trust are organising it.

Who has reviewed the study?

University College London and Barnet, Enfield and Haringey Research Ethics Committee.

Appendix 4: Consent Form

(Form to be on headed paper)

Name:

CONSENT FORM

The experience of refugee and asylum seekers following traumatic events

Please initial box

1. I confirm that I have read and understand the information sheet dated 29/03/2007 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
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 relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to my GP being informed of my participation in the study. ☐
5. I agree to take part in the above study. ☐

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Appendix 5: Interview Schedule

Interview schedule.

- **Past Experiences**

We will not ask you to recount the trauma itself but:
Do you believe your experiences had an impact on you? How?

- **Symptoms**

Do you agree with our notes that say...?
When did they start?
Can you describe them in detail?
Why do you think you have/had them?
Do you believe they are connected to your past experience?

- **Problems & Coping**

What do you believe are your biggest problems at the moment?
Can you tell me about things you find helpful in coping/ managing these?
Can you tell me about things that make it more difficult?

- **Current Life experiences (the experience of self.)**

Can you tell me generally about your life right now?
Are you different now to how you were?
How is life in the UK?
Can you tell me about the people you have around you? Friends/ family/ professionals?
How do you feel and behave now with other people?

- **Future & Strengths**

What are your fears for the future?
What are your hopes for the future?
What are your greatest strengths?

Demographic Information:

Sex:
Age:
Marital Status:
Place of Origin:
Time in UK:
Stage of asylum process: