

## Practice paper

# Researching the mental health status of asylum seekers: reflections and suggestions for practice

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### What is known on this subject

- Researchers should take into account the culture and diversity of a population in all aspects of the research, from design to dissemination of the results.

### What this paper adds

- It presents reflections, from our own experience, on some of the challenges that arise during research investigations involving asylum seekers.
- It offers recommendations for good research practice with culturally diverse populations.

## ABSTRACT

We used a multi-method approach to investigate aspects of the mental health of asylum seekers who had recently arrived in the UK. We used the Post-Migration Living Difficulties Scale, the Generalised Anxiety Disorder-7 Scale, the PTSD Symptom Scale Interview, the Clinical Outcomes Routine Evaluation and in-depth interviews. A total of 29 asylum seekers, 26 of whom were male, representing 13

countries, agreed to take part. This paper presents reflections on some of the challenges that arose during our investigation, and offers recommendations that may be of help to other researchers embarking on research in this field.

**Keywords:** asylum seekers, mental health, refugees, research

## Introduction

This paper reflects on some of the unique challenges faced by researchers in the field of mental health of asylum seekers. We begin with a brief introduction to the topic and present an overview of our mixed-methods research, which focused on the mental health of newly arrived asylum seekers living in Plymouth, UK and their experiences of health and social care services (Bernardes *et al*, 2010; see Box 1). This provides a basis for reflecting on the challenges that

we experienced during this project, and offering our suggested recommendations for ethical and culturally competent research. In particular, we reflect upon issues of accessing and engaging with participants and obtaining informed consent, language, and dealing with emotional aspects of the research. Recommendations for tackling these issues are offered.

### Box 1 Definition of terms

#### *Refugee status (with or without indefinite leave to remain)*

The 1951 United Nations Convention relating to the Status of Refugees states that a Refugee is a person who 'owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside of the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country' (United Nations High Commissioner for Refugees, 1951, Article 1A(2)).

In the UK, since September 2005 people given refugee status no longer qualify automatically for Indefinite Leave to Remain (ILR). They are now granted 5 years limited leave. This will be reviewed and ILR will be given to those who are still considered eligible to remain in the UK at the end of the 5-year period.

#### *Asylum seeker*

This is a person who applies to be recognised as a refugee under this definition. If successful, they are granted refugee status.

In the UK, if the Home Office decides that the person does not meet the necessary criteria to be granted refugee status, but considers that there are strong reasons for the person not to return to their home country, the applicant is given a discretionary right to stay for a specific period on humanitarian grounds. Currently applicants are given Humanitarian Protection (HP) or Discretionary Leave (DL). At the end of the stated period (up to a maximum of 5 years) the case is reviewed.

## Mental health of asylum seekers and refugees

Many asylum seekers demonstrate resourcefulness and resilience in the face of their experiences. For example, personal factors including cognitive strategies such as reframing the situation, relying on their inner resources, and focusing on future wishes and aspirations have been described as helpful coping strategies by Sudanese refugees living in Australia (Khawaja *et al*, 2008). Social and family support and cohesiveness have also been reported to be a protective factor associated with increased psychological well-being in refugees (McMichael and Manderson, 2004; Schweitzer *et al*, 2007). The role of religion in increasing resilience and helping refugees to cope with stress has also been documented. For example, religion was associated with resilience among Bosnian refugee women (Sossou *et al*, 2008), and with reducing acculturation stress among Hindu Bhutanese refugees (Benson *et al*, 2011) in the USA. Other factors, such as employment and job satisfaction, financial satisfaction and social support, have also been found to predict life satisfaction among refugees (Peisker-Colic, 2009). In addition, access to health and social services, freedom and positive media attitudes have all been described as enablers of successful settlement (Papadopoulos *et al*, 2004). However, some asylum seekers and refugees, and particularly survivors of torture and war, are vulnerable to psychiatric disorders such as depression, suicide and post-traumatic stress disorder (Fazel *et al*, 2005; Steel *et al*, 2009). In addition to traumatic pre-migration experiences, difficulties in the country of exile, such as detention, dispersal, social isolation and

living difficulties, including poor accommodation, unemployment, poverty, racism and discrimination, can have an impact on the mental health of asylum seekers and refugees (McCull *et al*, 2008; Sulaiman-Hill and Thompson, 2012).

A great deal of research focusing on the mental health of asylum seekers and refugees has focused on symptoms of distress, namely post-traumatic stress disorder, which has led some to question whether western conceptions of 'diagnosis' and 'distress' can be meaningfully applied (Bracken *et al*, 1995; Summerfield, 1999; Breslau, 2004). More recently, some authors have started to make use of a variety of research methods, such as participant observation and in-depth interviews, in order to capture the multidimensional nature of the asylum-seeking experience (e.g. Bernardes *et al*, 2010; Misra *et al*, 2006; Papadopoulos *et al*, 2004; Sulaiman-Hill and Thompson, 2012). These methods are crucial for making explicit the details and complexity of asylum seekers' and refugees' experiences.

## Investigating the mental health and service experience of asylum seekers in Plymouth

We used mixed-methods research to investigate asylum seekers' perspectives on their mental health and their views of local health and social services (Bernardes *et al*, 2010). Our project examined the mental health of asylum seekers who had recently arrived in the UK by using mental health screening questionnaires, as well as by conducting interviews

that explored subjective experiences of the asylum process and its potential impact on their mental health, and participants' suggestions for tackling mental health needs. Ethical approval for our project was granted by the local research ethics committee (Ref. 08/H0203/209) and NHS trust (Ref. PCT0646).

## Sample and procedure

Asylum seekers who were waiting to hear the outcome of their first asylum application, aged 18 and 65 years (criteria set by Adult Mental Health Services) and living in the dispersal area of Plymouth, UK, were included in the study. Over a 6-month period (February–September 2009), 52 people were invited to take part in a mental health screening while attending a health clinic; of these, 13 individuals agreed to take part. Asylum seekers who were receiving psychological support from the local Asylum Seeker and Refugee Mental Health Team were approached. Sixteen further participants were recruited in this manner, giving a total of 29 participants. All of them were assured that taking part in the research would not affect their applications for asylum, and that they could withdraw from the study at any time without their medical and legal rights being affected. All of the participants gave their written informed consent. All of them completed all of the questionnaires, except for four participants who did not complete the PTSD Symptom Scale Interview. In total, 19 participants (65%) were interviewed with the assistance of accredited interpreters; the remaining interviews were conducted in English.

## Measures

To decide on which mental health screening measures to use, we started by reviewing the literature on asylum seekers' and refugees' mental health. We then invited asylum seekers, refugees and local practitioners working with them to review our findings and choose a final set. The measures used included a shortened version of the Post-Migration Living Difficulties (PMDL) scale (Schweitzer *et al*, 2006) on which six items (such as 'worry about family back home') were rated on a 5-point scale from 'no problem' to 'a very serious problem.' The Generalized Anxiety Disorder-7 (GAD-7) scale (Spitzer *et al*, 2006) was included to assess the presence of generalised anxiety disorder and the severity of anxiety. Seven items (among them 'feeling nervous, anxious or on edge';  $\alpha = 0.88$ ) were rated on a 4-point scale from 'not at all' to 'nearly every day.' Scores were aggregated to provide the overall scale score. Cut-off points of 5, 10 and 15 were interpreted as representing

mild, moderate and severe levels of anxiety, respectively. The Clinical Outcomes Routine Evaluation–Outcome Measure (CORE-OM; Evans *et al*, 2002) was used as a general measure of distress. This measure consists of 34 items ( $\alpha = 0.93$ ) covering four domains, namely subjective well-being, symptoms, life functioning and risk. The sum of scores for all items was used to ascertain levels of distress, in which cut-off points of 20, 34, 51, 68 and 85 represented low, mild, moderate, moderate to severe, and severe levels of distress, respectively (CORE Net, 2008). A mean total score was also calculated and multiplied by 10 so that meaningful differences between scores were whole numbers (scores range, 0–40). A cut-off value of 10 has been assumed to discriminate between clinical and general populations (Connell *et al*, 2007). Finally, the PTSD Symptom Scale–Interview (PSS-I; Foa *et al*, 1993) was used as a measure of trauma and PTSD symptoms. Participants were presented with a list of 16 traumatic events or situations (e.g. having experienced 'adult physical assault or abuse' or 'sudden death of someone close to you'), and were asked to select all of those that they had witnessed or experienced. Participants were then asked to focus on the traumatic event which 'bothers you the most' and asked to rate 17 items (e.g. 'feeling distant or cut off from people around you';  $\alpha = 0.88$ ) on a 4-point scale from 'not at all' to 'five or more times per week/very much.' These provided both diagnostic and severity information about each of the DSM-IV criteria (American Psychiatric Association, 2000) for PTSD. Sums of raw items were calculated (score range, 0–51), and cut-off values of 11, 21 and 36 were interpreted as moderate, moderate to severe, and severe levels of PTSD, respectively.

All of the participants who underwent the mental health screening were invited to take part in in-depth interviews 1 month later. Eight participants agreed to be interviewed about their experiences of seeking asylum, their mental health experiences while in the UK, and their perspectives on how to tackle any mental health problems. Accredited interpreters were used when requested by participants ( $n = 6$ ), and responses were regularly clarified and repeated back verbatim to the respondents for confirmation during the interview. Participants were asked six general questions about seeking asylum and mental health, elaborated in consultation with asylum seekers and practitioners. Examples of these questions include 'Can you tell me about your story of seeking asylum?', 'Can you tell me about how being an asylum seeker is affecting your mental health/well-being at the present time?' and 'What has been your experience of the local services, such as GPs, mental health team or other services in helping you with your mental health? What are your recommendations for services?' Questions were not presented in a fixed order, but were introduced

following the participants' thought associations (Hollway and Jefferson, 2000). Six interviews were taped and transcribed with the participants' consent. Two participants did not consent to their interviews being taped but agreed to the compilation of process notes afterwards. The interview data were analysed using the free-association narrative interview method, which focuses on gestalt principles (Hollway and Jefferson, 2000).

## Sample characteristics

In total, 26 of the 29 participants were male (90%). The mean age of participants was 29.5 years (SD = 8.5 years), and they originated from 13 countries: Iran ( $n = 9$ ), Zimbabwe ( $n = 3$ ), Afghanistan ( $n = 3$ ), Iraq ( $n = 2$ ), Sri Lanka ( $n = 2$ ), Eritrea ( $n = 2$ ), Ethiopia ( $n = 2$ ), Guinea ( $n = 1$ ), Morocco ( $n = 1$ ), Cabinda ( $n = 1$ ), Sudan ( $n = 1$ ), Kuwait ( $n = 1$ ) and Turkey ( $n = 1$ ). In total, 18 participants (62%) had been in the UK for less than a year, four (14%) for 1–2 years, three (10%) for 2–4 years, two (7%) for 4–6 years and two (7%) for 6 or more years. The average waiting time for the asylum application was 19.8 months (SD = 29.3 months). The longest delay was 9 years. In total, 14 participants (48%) were single, 13 (45%) were married, one was divorced (3%) and one was widowed (3%). Before migrating to the UK, 73% ( $n = 21$ ) of the participants were employed, and 14% ( $n = 4$ ) were students. None of them had ever been employed in the UK. In total, 25 participants (87%) were living temporarily in shared accommodation, and the remainder were living alone or with friends or relatives.

## Quantitative findings

In total, 16 of the asylum seekers in our sample presented with PTSD (76%), and 24 participants (86%) presented with moderate or severe anxiety on the GAD and moderate levels of psychological distress on the CORE-EM. Asylum seekers' scores on the CORE-OM were significantly higher than those of an indigenous sample of mental health service users (Evans *et al*, 2002) and a primary care service user sample (Barkham *et al*, 2005) in the domains of 'well-being' and 'life functioning.' Indeed, the asylum seekers in our sample presented with significant post-migratory living difficulties, mainly acculturation problems ( $n = 22$ ; 76%), not being allowed to work ( $n = 24$ ; 83%), and worries about their family back in their home country ( $n = 24$ ; 86%). Other common problems were communication ( $n = 20$ ; 69%), discrimination ( $n =$

15; 52%), and accessing health and welfare services ( $n = 15$ ; 52%) (Bernardes *et al*, 2010).

## Qualitative findings

The interview data corroborated the quantitative data and provided further insight into asylum-seeking experiences. For example, all of the participants who were interviewed ( $n = 8$ ) reported feeling fear and sadness about the uncertainty of the outcome of their asylum application, while fear of deportation affected their ability to carry out activities of daily living. Moreover, participants reported difficulties related to their wish for personal independence and to make a new life while being dependent on others, and their need for sanctuary. Social support was very important to them in helping them to cope with these difficulties, but opinions about sharing accommodation with people from the same nationality or ethnic background were mixed, with some participants finding it helpful and others viewing it as problematic.

These findings corroborated other evidence that both past and present social living experiences are important determinants of asylum seekers' mental health (Schweitzer *et al*, 2006), and highlighted the prevalence of post-migratory living difficulties. They also indicated that psychological distress may be common among asylum seekers. In the following sections we reflect on our experience of this project and the challenges that we encountered. We have grouped these into five sections, namely enhancing the cultural relevance of the research, engaging with participants and the wider community, informed consent, language, and dealing with safety and emotional issues. This was the first time that the leading researcher and the research team had undertaken a project with asylum seekers, which may help to contextualise our reflections.

### Enhancing the cultural relevance of the research

'Cultural capability' is defined as 'improving the capacity of the organisation in providing high-quality service, irrespective of the ethnic or cultural background of the people using the service. This is not simply about making services more aware or sensitive to the perceived cultural needs of individual users, but is about improving the quality of care, by providing good-quality but equal services to all those who come into contact with mental health agencies' (National Institute for Mental Health in England, 2003, p. 22). Achieving 'cultural capability' depends on a number of organisational strategies and processes that are

required in order for services to be culturally competent and capable. This includes 'developing the workforce' to ensure that staff possess the 'attitudes, behaviours, knowledge and skills necessary to work respectfully and effectively with people from minority ethnic communities' (National Institute for Mental Health in England, 2003, p. 22). At an organisational level, it is argued that 'statutory mental health providers must work collaboratively with [the] local voluntary sector in developing and sustaining a variety of service models to meet the needs of minority ethnic groups' and that 'mental health services should ensure that services provided are congruent rather than conflicting with cultural norms', and the need for 'ensuring language access for persons who prefer a language other than English' is highlighted (National Institute for Mental Health in England, 2003, p. 23).

In research terms, 'cultural capability' can be defined as taking into account the culture and diversity of a population when developing research ideas, conducting research and drawing conclusions about the applicability of the results (O'Brien *et al*, 2006). Implicit here is the importance of learning about and reflecting on one's own culture, historical roots, beliefs and values. This requires awareness not only of other cultures and their values, but also of our own attitudes towards those values (Fernando, 2002).

One of the challenges in our research was to ensure that the design, methods and questions were culturally relevant. It was not possible to know in advance about the 13 countries from which our participants originated, so we began by establishing a research team of asylum seekers and professionals with long-standing experience of working with asylum seekers and refugees with mental health needs. We found that the ensuing collaboration was extremely valuable, enabling us to learn about traditional cultural beliefs, systems and values, and to incorporate these into the research design. Our aim was to ensure that the measures selected were sufficiently culturally appropriate for the participants to trust us. The topic guide for interviews was discussed and piloted with two asylum seekers, whose feedback led to changes that made the questions clearer from their perspective. We came to realise that, in addition to 'cultural capability', we also had to be sensitive to the socio-political context from which participants originated; this involved familiarising ourselves with current affairs. Bringing these reflections to supervision and discussing them with the research supervisor and other professionals was also helpful in terms of making sense of and trying to understand participants' stories.

'Cultural capability' when undertaking research with asylum seekers is dependent on meaningful engagement with the research participants throughout each study. Participation in diversity training, reading, informal media (e.g. books, movies, radio programmes)

and interaction with people from diverse cultural backgrounds are just some ways in which the researcher can be helped to develop an understanding of the participants' perspectives. In a wider context, 'cultural capability' requires official policies and processes that enable organisations to improve access to and quality of services for individuals from diverse populations.

### Engaging with participants and the wider community

In the initial stages of our research, considerable time and energy were spent on planning the research and mapping local community services working with asylum seekers. The aim was to identify possible research partners and community resources. However, other issues soon became apparent. The representative of a community group expressed her fear that collaborating in the research would compromise the trusting relationships that had been established with asylum seekers. Participants also voiced their fears of saying anything that might undermine their asylum applications. In response, we tried to ensure that we presented transparent research aims and that we were as clear as possible about how we would protect the identity of potential participants and community groups. Palmer (2008) has suggested that a steering group which reflects the community within which the research is based can help to enable continuous communication between researchers and those who are being studied. Following his advice, we found that establishing a consultative group of local asylum seekers and professionals from the outset was extremely helpful for developing trust. It provided a safe space in which to discuss different points of view, and an opportunity to share experiences.

However, this consultative group was not sufficient to convince everyone. In total, 23 individuals declined to take part; 12 people specifically mentioned fears about how the information was going to be used. To overcome this problem, a member of the research team, who himself had sought asylum, contacted potential participants to explain the aims of the study. This helped to foster trust between researchers and participants. We also told every participant that their participation was voluntary, completely independent of any decisions about their status, and that withdrawal from the study would not affect their legal rights. However, we also had to recognise the power difference between ourselves and the participants. We have the legal status to work and live in the UK, whereas the asylum seekers were still in the process of finding out whether they would be given this right. This difference in legal status could lead some individuals to agree to participate in the research on the grounds that refusing

would compromise their asylum applications. In our study, we used reflection, supervision and consultation with community services and groups to help researchers to clarify, both for themselves and for the participants, their roles as researchers.

On reflecting on our experience, we recommend that researchers are clear about the purposes of their research from the beginning. They must be careful to avoid raising expectations, as some people may believe that participation in research will increase the likelihood that their asylum application will be successful. Researchers should also be as clear as possible about the extent to which information is confidential, and reflect on situations in which confidentiality may be compromised (e.g. the use of interpreters, referral to a mental health team, managing risk). Another suggestion is that, when planning the research, consideration should be given to the social and economic realities of potential participants. Although the NHS research governance guidelines do not approve of monetary incentives for participation in research (Department of Health, 2005), this is a matter that researchers ought to consider, as asylum seekers are not entitled to work, and they often live in deprived circumstances. A consultative/steering group may help to elucidate culturally appropriate ways of providing compensation, such as expenses payments for research participation and travel. In retrospect, we could have offered travel vouchers or supermarket vouchers to our participants as a way of reimbursing them for their participation in the research, provided that these did not compromise their benefits.

### Informed consent

Health and social care researchers have a duty to ensure that participants' rights are protected, that they are adequately informed about the research, and that consent is freely given (Department of Health, 2005). This is particularly important when undertaking research with asylum seekers, many of whom will have experienced complicated and traumatic events. Fears of deportation, if their applications to stay in the UK were refused, were a constant source of anxiety (Palmer, 2008).

We found that although all of the participants gave oral consent to participate in the study, two asylum seekers were reluctant to give written consent. This can be understood in terms of the concerns that asylum seekers may have about formal documentation. For example, one may speculate about fears of how their information could be used against their asylum application. Similarly, two out of eight participants who agreed to in-depth interviews did not consent to audio recording. Past experiences of forced confessions or other negative past experiences may

underlie these choices. The latter point demonstrates that insistence on a signed consent form may not always be achievable or desirable, especially if it increases the participants' anxieties. Informed consent should encompass all aspects of the research participation process, as some individuals may consent to some aspects but not to all of them.

### Language

For consent to be free, informed consent forms and participant information sheets should be available in a format that participants can access. This means that researchers should ensure that both documents are translated into the relevant languages by accredited professionals. In our study, information was presented verbally by telephone interpreters because we could not anticipate which languages participants would prefer. Even when we knew which languages a participant spoke, we could not anticipate how that person might wish to communicate. For example, one participant who spoke Kikongo, but who was also fluent in Portuguese, the first language of the lead researcher, refused an interpreter and wanted to speak in English in the study 'because I want to adapt to life in the UK.'

Before the study commenced, these interpreters received training about confidentiality and anonymity and were briefed about the research. They conducted 19 of our 29 interviews, usually by telephone. This was a complex task because the translation of research terminology is not always straightforward and word-to-word translation is often impossible. It is important that enough time is available to enable adequate explanation and clarification of concepts. Good practice should always be followed when working in partnership with interpreters (Tribe, 2007), ensuring due consideration not only of language but also of dialect and/or gender, and of any potential political conflict between interpreter and interviewee. On reflection, it would have been helpful if the researcher who was carrying out the mental health screenings and in-depth interviews had had prior training in working with interpreters in order to foster alliance formation.

### Dealing with safety and emotional issues

In this section we reflect on the management of risk and the emotional issues that can arise when undertaking research with asylum seekers and refugees. In our study, the safety of both researchers and participants was considered and a careful risk assessment was conducted before data collection started. Whenever possible we conducted the interviews in places where

there were other people about to provide support if necessary.

We also recognised the possibility that some participants might experience high levels of distress. All of the participants were given information about mental health services, and were provided with contact numbers for local health and mental health organisations. Eight out of the 13 participants who were assessed at the health clinic were referred, with their consent, to mental health services.

Interpreters were debriefed at the end of each interview. We suggest that researchers should be mindful of the potential risks to themselves posed by the emotional impact of their data, as well as the risk of re-traumatisation of the participants (Palmer, 2008). Some practical ways of managing these issues include the following:

- listening to the needs of participants and using clinical judgement
- avoiding booking one interview straight after another, to allow researchers enough time to process the information gathered and debrief with the research team
- having clear supervisory arrangements that include supervision not only about the research process but also about the content (i.e. focusing on what the stories told by asylum seekers evoke in the researchers)
- keeping a reflective diary in which feelings and thoughts evoked during the project are noted and then brought to supervision for discussion. For example, the lead researcher noted that while carrying out in-depth interviews she felt compelled to adopt a 'rescuer role' towards asylum seekers. Supervision was helpful in providing a space in which these feelings could be openly discussed.

## Conclusion

Researching asylum seekers' experiences may create numerous challenges which need to be thoughtfully considered and addressed. We hope that our reflections on some of these challenges, and our practical suggestions, will be of use to others working in this field.

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#### CONFLICTS OF INTEREST

None.

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