

Conference presentation

Ethical issues and their practical application in researching mental health and social care needs with forced migrants

DAVID PALMER

Director of Mind Bexley. David also works on an ad hoc basis for the Ethiopian Health Support Association (London).

Email: dpalmer@mindinbexley.org.uk

There is a growing interest in researching the plight, health and social care needs of forced migrants and the complex ethical issues related to researching this vulnerable group. Conducting health and social care research with forced migrants is a sensitive and complex issue and can place emotional demands on contributors, requiring high ethical and moral standards which safeguard participants, researchers and the integrity of the study. Researchers and those who review research need to be sensitive to the needs, privacy and fears of participants. In addition to the medical and personal benefits that can be obtained from undertaking research with forced migrants, there comes the risk of stigmatization, exploitation and harm. This paper identifies some, but by no means all, key ethical issues confronting researchers, these dilemmas include the complex issues of language and translation, immigration status, contextual issues, lack of familiarity with the research process, issues of informed consent and safeguarding anonymity. Confidentiality, sensitivity to cultural traditions and values, and avoiding re-traumatization also need to be considered as this knowledge can minimize research risks and protect the rights and welfare of research participants. This paper will draw upon experience of working with refugees and asylum seekers for many years and from experience gained from small-scale qualitative research undertaken with Somali and Ethiopian forced migrants. It argues for the need for a consistent, robust, ethical framework to ensure that the 'researcher' does not inadvertently 'do harm' by infringing on the security, privacy and well-being of the subjects of the research. This paper in turn adds to the knowledge base on good practice and research ethics and is hoped that it will provide useful guidance for those undertaking the ethical review for this type of research.

Introduction

There is a growing interest in researching the plight, health, and social care needs of forced migrants and in turn, the different methods used to explore issues relating to this group. Studying the health of forced migrants is an expanding field, it is therefore crucial that the adopted approaches are critical and reflective, that the rights of research participants are protected and that privacy and confidentiality is maintained. It is important that risks are minimized and that vulnerable individuals and groups give their informed consent to participation. The need for informed, knowledgeable and ethically robust research is especially important when the context within which such research exists is one in which there is a fundamental gap in knowledge of the resettlement process which can lead to settlement outcomes that frequently prove unsatisfactory. This is reflected in the fact that there has been little focus on the refugees themselves as human agents instead, they are for the most part, regarded as 'recipients' of policy [1]. There is only a limited understanding of the agency of refugees themselves in decision-making and destiny-shaping.

Critical reviews of research into the situation of forced migrants has highlighted that much of the research in this field has been inadequate with vital and appropriate research methods being ignored or given only limited attention [2]. In addition, there is also a concern that published research fails to adequately reflect the detailed information gained, and the complex and important issues raised, when participant observation and in-depth interviews are adopted as research methods [3]. There are evidently many social, medical, political and personal benefits that come from researching the mental health issues affecting refugees and asylum seekers; however it is important to acknowledge that such research raises the risk of exploitation and harm. There is a growing criticism that much of the research carried out on forced migrants does not acknowledge ethical considerations or adequately reveal the research design and methodology used. Jacobsen and Landau [3] are critical of the research ethics and methodology used by many who research this group: 'Researchers are seldom told how many people were interviewed, who did the interviews, where the interviews took place, how the sub-

jects were identified and selected and how translation or local security issues were handled’.

This paper identifies some key ethical issues confronting researchers in the field of forced migration; these dilemmas include the complex issues of language and translation, immigration status, personal, social, emotional, political and economic issues, lack of familiarity with the research process and issues of informed consent and safeguarding anonymity. Confidentiality, sensitivity to cultural traditions and values, and avoiding re-traumatization also needs to be considered as this knowledge can minimize research risks and protect the rights and welfare of research participants. This paper raises considerations that reflect some of the unique challenges and ethical issues facing researchers in this field and it is hoped that the points raised will highlight potential problems, outline ways in which these can be overcome or minimized and assist researchers and ethical committees in identifying some key issues when researching forced migrants.

Mental health and social care issues

Forced migration and the resettlement experience combine to produce a set of social, cultural, economic and psychological challenges for forced migrants, which may impact on integration, mental and physical health and access to health and social care provision [4-7].

This diverse group have different needs at different times and experience issues that can affect any community. However, research and data available have highlighted that they are particularly disadvantaged in relation to mental health experience. This disadvantage is likely to be due to the combined influence of traumatic pre-migration experiences such as torture or imprisonment, and with living in exile and the wider experiences of post-migration including social determinants such as employment, housing, immigration status, and isolation [8-10]. My own research undertaken on the Somali and Ethiopian communities in London highlighted the link between depressive and anxiety disorders and the stressors of the exile experience [11,12]. These stressors included high levels of social and economic deprivation, anxiety about immigration status and encompassed isolation and cultural bereavement; the most widely expressed stressors were predominantly linked to ‘cultural bereavement’ which entailed the loss of country, cultural values, family, relatives and friends [13].

Researchers examining the roles of race, ethnicity, and culture on mental health need to consider how these wider contextual factors and minority status add an additional layer of vulnerability which is reinforced by social, economic and institutional prejudice and inequality. Ethical research planning involving

diverse populations therefore requires flexibility and sensitivity to the contextual challenges and concerns of each ethnic group and research area.

Cultural understandings

Approaches to, and understandings of mental health inevitably vary between cultures and at different times throughout history [14]. Foucault in ‘Madness and civilisation’ [15] discusses how mental illness may be culturally determined and how societies generate definitions of mental illness, which can change as societies change. The health of forced migrants can be underpinned by culturally-specific understandings of mental health, stigmatization of mental health issues and the role of treating illnesses. Many societies and cultures stigmatise mental health and the diagnosis of mental illness may be unreliable cross-culturally. Cultural differences and interpretations about psychological distress, trauma and mental health may be viewed differently in different parts of the world particularly given associations with ‘madness’:

If someone is stressed they say ‘Waa waa she’ which means mad. It is quite extreme, there is nothing inbetween. Stress is less than mad but Somalians talk about being mad [11].

Ethiopians are afraid of talking about mental health problems as there is a strong stigma attached to it in their culture. They are not open about it until it gets a critical stage. They mainly associate mental illness with spiritual and religious beliefs. Many lay people with little knowledge or exposure with the western world or life-style are unable to express what is wrong with them in English. The usual method of dealing with these problems is seeking help from traditional healers and through the church [12].

A consequence of this reality is that whilst undertaking research, behaviours can be interpreted in different ways and subsequent findings will vary in accordance with the dominant understandings and practices. In the design and development stage of researching the Somali community in Camden, the phrasing of questions for service users ‘topic guide’ was discussed at length with participants to ensure validity and reliability in the context of cross-cultural research. The topic guide was extended by a number of prompts and probes to ensure greater interviewee-interviewer consistency. The words of respondents were used throughout the research to avoid imposing interpretations or presumptions. Those who participated in the study where also invited to comment on the draft version of the research. Responses were treated as data and incorporated in to the final study.

This collaboration is an important approach to alleviating some of the ethical dilemmas presented by current research on refugees and asylum seekers [3].

Cultural understandings and dominant practices also influence engagement with mental health services [14]. Many psychiatric treatments as practiced within the UK are rare or unknown in other countries, raising issues of confidence and trust. For example, many cultures do not have ‘counselling’ in their culture and find emotional safety in religious or traditional treatments of illness and this often results in the western mental health model of counselling being viewed with suspicion as an alien concept, even when it is available in home languages. Furthermore mental illness has often been deemed to bring ‘shame upon the family’ [16]. All of these factors will influence how individuals place themselves on the continuum of mental health need, and will also therefore influence how they interpret their own behaviour and how they potentially represent these issues within a research framework. Knowledge of traditional cultural beliefs, systems and values and other relevant variables is therefore essential when undertaking research and ethical considerations need to be in line with these principles as they may either facilitate or interfere with responses.

Engaging with the community

Effective preparation is crucial when planning and undertaking research with forced migrants. Knowledge and understanding of the cultural aspects and challenges of the community in question is of prime importance, such preparation ensures approaches are appropriate and demonstrate tact and sensitivity. During each stage of the research process from recruitment, implementation, and dissemination, investigators need to be aware of the issues of cultural interpretations and understanding of mental health and the possibility of stigmatisation. These realities mean that the researcher should take extra precautions to protect the privacy and identity of research participants, their families, and their communities. The initial stages of research planning should incorporate advice and participation from the community, church and other prominent leaders in order to better cultural understandings and address the specific needs of the research participants, to include advice on how to make initial contact with interviewees. This initial collaboration should also ensure that the researcher is made aware of any gender-specific needs or necessary language support. This dialogue therefore aims to strengthen the merit of the research informing the methodology and design, the implementation, and the dissemination of findings. This relationship and the mutual exchange of information and knowledge should inform the study’s goals and aims and engage with community

members as true collaborators. The involvement of the community in the ethical challenges of mental health research also impacts on the success of the planned research by increasing the potential for enhanced community and individual support and participation. Respectful and successful community and participant consultation often depends on relationships of trust that are established early in the research design phase and are continued through the data interpretation, implementation, and dissemination phases.

In order to establish effective and continued engagement with the community and research participants I would encourage researchers to set up steering groups which reflect the community within which the research is based and involve participants in ongoing feedback and evaluation on all aspects of the research. In addition, researchers from all ethnic backgrounds can benefit from an examination of their own cultural viewpoints and potential biases, this self-reflective knowledge can work to better inform the researcher of the importance of acknowledging and incorporating cultural realities and understandings and the design and conduct of the research can benefit from multiple perspectives. This self-reflection and preparation can also help to avoid pan-ethnic labelling, helping to appropriately define the ethnic group researched and creating an awareness of individual differences which are continuously shaped and redefined by social, political and intuitional processes within ethnic groups. In my research experience I have found this approach to be an invaluable way-in to building trust and understanding, which is particularly successful and appropriate when undertaking research with forced migrants who are suffering from mental distress, providing the research participant with a non-judgemental, informed ‘safe space’ within which to express their individual and specific needs. Furthermore, by involving the community and participants in the various stages of the research process and demanding that I as ‘researcher’ self-reflect and examine my own identity, culture and assumptions the research participants are no longer simply passive recipients being scrutinized under a magnifying glass rather they are seen as individuals with different, but equally valid life experiences to my own.

Safeguarding confidentiality and anonymity

Researchers should recognize that their primary responsibility is to ensure that the rights and welfare of participants in their study are protected. To maintain good research practice and promote confidence in any research process, information obtained for research purposes should be sensitive to cultural values and be subject to the requirements of confidentiality, including adherence to the Data Protection

Act. Specific confidentiality and disclosure policies must be explained to participants during informed consent procedures.

The ethical aspects of implementing respectful informed consent procedures, ensuring confidentiality and anonymity from design through to dissemination are particularly important when researching complicated and sensitive issues. A lack of familiarity with the research process and terminology can also be a potential barrier to participation. This unfamiliarity may lead to confusion about the role of the researcher and instil a fear that failure to consent may lead to a discontinuation of service. Researchers therefore need to clarify and enhance their role by providing a clear description of, and purpose of the research study and implementing culturally appropriate informed procedures which, can be enhanced by arranging for translation into the interviewees language preference or involving 'respected community leaders' to speak about the research. This provision enables individuals to have time to consider the information and make an informed and rational choice whether or not to participate. In exceptional circumstances, detailed documented oral consent maybe sufficient as long as an independent witness with language skills and cultural understanding of the individuals verifies the interviewee understands the procedures and processes.

Confidentiality and anonymity are especially relevant considerations when researching forced migrants and mental distress. It is important that participants are not obviously identifiable in research reports or when results are shared with the community. Over identification can lead to harmful social labelling and stigmatization from sections of the community and can cause anxiety regarding immigration status. Information obtained for research undertaken on the Ethiopian community highlighted the complexity and anxiety surrounding legal status.

Frustration at the Home Office, that's the main problem. Early morning before you open the door you have to watch for that brown envelope. People are very worried about it in the community and we (the community) are now sending information in white envelopes. Unemployment is high. Many are educated, unemployed and isolated. Lack of status affects everything. You can't plan, you can't study, and you don't feel part of society. It affects every aspect of daily living [12].

The experience of uncertainty results in individuals living with a terrifying fear that they may be deported back to their country of origin. This atmosphere of fear and anxiety may, for some forced migrants, create an additional anxiety when being

asked to sign an 'official looking' informed consent form. The signing of such a form may be viewed with suspicion, seen as a possible official tool for tracking refused asylum seekers or undocumented migrants. Such concerns are very real when the research may elicit sensitive information which may place participants in legal jeopardy if disclosed beyond the research setting. As a result, it is crucial that researchers need to be completely aware of issues which may impact on participation and responses, and procedures for informed consent should ensure participants are fully aware of the security provided by consistent and robust confidentiality and anonymity procedures. The participants should also be confident in the knowledge that they can withdraw, without consequence, at any stage and request that any recordings made, or information obtained is destroyed. A refusal to be tape-recorded should also be respected.

Socio-economic barriers to participation

Research planning needs to incorporate a consideration of the social and economic realities of potential participants. It is important to acknowledge that socio-economic adversity may be a barrier to participation. It is therefore important to consider the need for financial compensation for expenses incurred due to participation. Consultation with individuals and community leaders can offer guidance on culturally appropriate approaches to providing expenses payments. Some individuals who participated in the Somali study refused to take financial expenses as they viewed the research as having wide-ranging benefits to the community, however participants should not feel pressured to refuse much needed expenses payment for the sake of the 'greater good'. It is therefore important to ensure confidentiality of all financial arrangements.

Language provision

Language can be a significant barrier to research. As with all research the interview procedure 'involve(s) more than just a literal transfer of information' [17]. In cases where there is no shared language, trained interpreters should be recruited. The onus is on the researcher to 'ensure that the best possible communication and services are maintained' [18]. Researchers should therefore ensure that all consent forms and information on the study are translated into all relevant languages and that accuracy is ensured by the use of paid trained professional interpreters/translators. The challenge of constructing appropriate consent procedures is more complex in research involving ethnic minority groups where there is no shared language. Differences in language proficiency, preference, and communication styles can result in misrepresentation or misunderstanding of consent information. This can often be resolved by the oral presentation of informed consent information in conjunction

with a short written consent document in a language/style understandable to the participant. This consent procedure should be witnessed by an independent individual fluent in both English and the language of the interviewee.

The issues of anonymity and confidentiality are especially important when selecting interpreters/translators. The ethical considerations need to be fully explained and understood and the individuals involved need to sign a confidentiality agreement. It is particularly inappropriate and unprofessional to simply select the most readily accessible and available interpreter, such as a family member or known community member as this inevitably influences the open and honest response information and can undoubtedly lead to breaches in confidentiality, exploitation, or harmful dual-role relationships between the prospective participant and the interpreter.

In selecting translators for my own research, priority was given to interpreters with considerable translating experience. It was also important to incorporate gender and cultural considerations often necessarily involve more than one interpreter/translator. Interpreters were also fully briefed on the aims of research and were instructed to take care when translating concepts and terms so as not to imbue the responses of interviewees with their own meaning or terminology. The translation of research terminology is complex, in some circumstances it may not be possible to translate word for word especially when there is no direct correspondence between western concepts/words and those contained in the culture of the participant. It is therefore important to allow adequate time for explanation and clarification. In my research on the Somali community the interviews were conducted with immediate translation between interviewer and respondent allowing the translator to double check on the meaning or phrasing of questions or concepts and allowed for the repetition or rephrasing of questions if necessary. This was inevitably a lengthy process, but time invested in this way produced the most accurate and interesting results and was therefore beneficial to the integrity of the research study. It is also good practice to carry out post-interview debriefings in order to discuss issues of wording, behaviour and attitude in order to maximise the reliability of data [19]. The trained interpreters used in my research were recruited from the Traumatic Stress Clinic and had a sound knowledge base about cultural and mental health and an excellent reputation as translators in the field of forced migration and mental health.

Re-traumatization: systems in place to deal with emotional issues

My research undertaken on the mental health issues of Somali forced migrants applied exclusion criteria when considering potential interviewees. The vulner-

ability of the individual and the possibility that an interview may result in 're-traumatization' were issues discussed before a decision was made on whether or not an individual was approached. If there was any doubt over the possible negative impact of questioning the individual was not selected. To minimize any psychological risks I believe with the consent of the interviewee it is good practice to engage with clinicians or other support networks involved with the participants in order to avoid participants becoming emotionally distressed. It is also important to recognize that situations may be unpredictable and it is therefore an important ethical component to provide for such eventualities and ensure referral systems are in place to deal with adverse reactions. It may also be worth considering the possibility of clinical supervision for researchers if available, this not only allows for the discussion of the often very difficult and traumatic information obtained in interviews, but also allows for clarification of issues and confirmation that ethical considerations in terms of 'doing no harm' are confirmed and reiterated. Formal and informal support therefore not only provides support for the interviewer but adds integrity to the study as it monitors and reviews the adherence to ethical standards and practices.

Conclusion

In this paper I have aimed to explore some of the complex ethical and methodological issues that present when researching refugees and asylum seekers. The purpose has been to discuss and argue for the need for a consistent, robust ethical framework to ensure the safety and welfare of the participants and researchers and to ensure the integrity of the study. It is evident that conducting health and social care research with forced migrants is a sensitive and complex issue and requires significant preparation and information gathering requiring collaboration and engagement with a wide variety of interested parties in order to ensure cultural differences are acknowledged and incorporated. It is especially important that researchers and those who review research need to be sensitive to the needs, privacy, fears and personal, social, economic, political and emotional realities of participants. It is hoped that the issues discussed in this paper provide an insight into issues related to researching this vulnerable group and will add to the knowledge base on good practice and research ethics.

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