

Is it possible to ethically research the mental health needs of the Somali communities in the UK?

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ABSTRACT

This article summarises ethical issues that arise when researching common mental disorders within the Somali communities in the UK. It addresses the danger of researching these disorders from a Eurocentric perspective which risks overlooking the difference in conceptualisation of mental illness between different cultures in the West and Somalia. An ongoing study exploring Improving Access to Psychological Therapy (IAPT) for Somali people in the UK is presented. The participants' own meaning of mental health and illness as well as their conceptualisation of anxiety and depression are examined. In developing the study, standard research paradigms are critically examined in order to take account of the unique aspects of Somali culture and experience. Focus group method is adopted to uphold both ethical and methodological rigour in the research. A participatory approach for developing ethical protocols within different refugee communities is recommended.

Key words:

Focus groups, research methods, ethics, mental health, depression, Somali.

Background

The United Nations High Commissioner for Refugees (2006) recorded that there are over 301,100 Somali refugees around the world (these figures are from just the nine most developing countries in the world). In the UK, the 2001 census recorded over 43,470 Somali refugees living in the United Kingdom whereas other sources have argued that this figure is over 90,000 (ICAR,

2007; Hopkins, 2006). The large presence of Somalian refugees in the UK is due to the ongoing atrocities, wars, violence, and torture in Somalia (Wilson & Drozdek, 2004) which, according to Home Office's Country of Origin report (2008), continue unabated in Somalia.

Since the collapse of Somali central government in 1991, Somalians in Somalia have not had full access to mental health and psychiatric help (Pumroy, 2008; Tyler, 2008). The World Health Organisation (WHO, 2005, 2006) reported that the whole mental health service set-up within Somalia is based on the efforts of the General Assistance and Volunteer Associations (GAVO) and a local Somali NGO that attempt to provide basic mental health services to psychiatric patients. They also help street children and train primary health care personnel. The report also mentions that the conditions of the three mental health hospitals in Somalia are appalling as there is no psychiatric inpatient service and no specialised drug abuse treatment program. In fact, there is no mental health training facility in the whole country. It appears that most mental health care providers in Somalia lack adequate training and knowledge.

The UK experience

Common mental disorders are highly prevalent within the UK Somali community (Bhui et al., 2006; Warfa et al., 2006; McCrone et al., 2005) and this community is increasingly isolated from the mainstream population (Casciani, 2006)

Social research has consistently reported that Black Minority Ethnic (BME) communities, which include Somalians, are not accessing psychological therapy (Department of Health, 2007; Sainsbury Centre for Mental Health, 2004). In response, the Department of Health has introduced a new initiative called, "Improving Access to Psychological Therapy" (IAPT); part of its

agenda is to help BME communities access psychological therapy through primary mental health services. For this initiative to succeed, research is needed to identify barriers these communities face in accessing mental health services. Given the lack of mental health knowledge, and the taboo and fear surrounding mental illness that is pervasive within the Somali community, this article poses the following question: "How can researchers conduct ethical mental health research within the Somali community?" They are a vulnerable population that can be exploited as they are not familiar with research governance.

Research that specifically investigates Somali mental health issues is scarce (Ellis et al., 2007) and is acutely needed (Leaning, 2001). The IAPT research programme being conducted at Roehampton University in the UK is proceeding with careful consideration of the ethical and cultural sensitivity requirements of this unique research undertaking. This project has three goals. Firstly, IAPT aims to improve the Somali service user's and their carers' experience and satisfaction, while at the same time giving them more choice and access to clinically effective psychological therapy services. Secondly, IAPT aims to improve inclusion and employment status which Somali people desperately need (Khan et al., 2003; Bloch, 2002; 2004; Sare, 2008). Thirdly, research findings can be proactively disseminated among those working closely with the Somali community whilst also ensuring that the results will be put into practice (BPS, 2006, p. 5).

Key ethical and methodological issues

Psychologists conducting research in this area are trying to eliminate the recognised lack of equality in access to psychological therapies within the BME community in the UK (see Health Commission, 2007; Fernando, 2005; Bhui et al., 2003; Sashidharan, 2003). They are attempting to understand why the Somali community members in the UK are not accessing psychological therapy in the first place. In particular, they are trying to understand how this community conceptualises common mental disorders and not presume that they experience depression and anxiety the same way as people in the west do.

One of the most important early research observations is that participants do not have any idea about what common mental disorders are. It is unclear whether members of the Somali community can actually differentiate common mental disorders from their everyday struggles and suffering. For instance, it is very difficult to describe what anxiety means in Somali language. Anxiety is understood as just a fleeting situational discomfort that passes away; it is not conceptualized as a potentially chronic or persistent state. Furthermore, an anxiety disorder is difficult to diagnose because most mental disorders manifest as physical symptoms or states within this culture; Somalians are not likely to reflect or report on their distress in psychological terms (Bhugra & Flick, 2005). Researchers, then, have to be open to the complex and unique ways that mental disorders express and manifest themselves within this community; one way of achieving this is to talk to the community members and find out what they make of their life experiences, challenges and struggles in the UK.

Most Somalians have a categorical rather than a dimensional view about mental illness; one is either sane or insane (Guerine, Guerine, Omar, Yates, 2004). Additionally, the common belief is that mental illness entails violent behaviour. Such a conceptualisation of mental illness makes it unlikely that Somalians would seek help from mental health professionals. It also makes it difficult to conduct mental health research within Somalian immigrant communities around the world. Immigrants fear having mental illness or being labelled with it, and there is a great and enduring cultural taboo surrounding mental illness (Guerin et al., 2004; Schuchman, 2004; Palmer, 2007; Warfa et al., 2006; McCrone et al., 2005; Bhui et al., 2003).

Appropriate mental health services

We know there is a high prevalence of mental illness within this community (Warfa et al., 2006) and that Somalis have a great reluctance to access any sort of psychological therapy. The Somali community sees such services as inappropriate for their needs. Even when these services are made available to them, there is an inherent lack of knowledge about these services. Fear, shame and scepticism about mental illness leads to concealment (Whittaker et al., 2005) and rejection of service options. Of note, Somali males might not access CBT and other bona fide psychotherapy treatments (Stiles et al., 2006, 2008) because they see this sort of therapy as 'feminising'.

CBT (cognitive behavioural therapy) is already available to Somalians through the National Health Service. Insofar as CBT might challenge the belief system and thought patterns of the Somali patient, he or she might feel that their religious, cultural and spiritual belief system is being challenged; this might cause unintended harm. To date, most research on CBT has been carried out with only Western participants (Beck et al., 2003; Chorpita, Plummer, & Moffitt, 2000; Cook et al., 2004; Joiner & Lonigan, 2002; Ollendick et al., 2002, see also Brown et al., 1998; Burns & Eidelson, 1998), or suffers methodological shortcomings such as the use of students only (Joiner et al., 1999); it does not take cultural background into account.

There are no treatment protocols that are empirically supported as specifically helpful for Somali service users. This work needs to be done or we run the risk of offering ineffective treatment and undermining trust.

Additional barriers to research

Given their social history, suffering, and displacement, most Somalians remain vulnerable and are still fearful of authorities. This, more often than not, will lead study subjects to worry about discussing mental illness with researchers. There is a risk, too, that if research participation is discovered by their community, they might be ostracised. What these participants need, therefore, is reassurance and trust, that must be protected and reciprocated.

When researchers first establish contact with this community great power attributed to them. Researchers are seen as having special

knowledge of insanity, as well as great authority and status as representatives of health authorities. Thus, they find themselves in a position of great responsibility as they are trusted by a community that respectfully 'puts them first'. Psychologists (Loewenthal, 2006, Fisher, Fried & Mast, 2008) and philosophers (Levinas, 1961; 1985) have written about 'putting the other first' as a way guiding ethical choice. 'Putting the other first' is a critical value determinant for Somalians who may engage in research because they hope their participation will make a meaningful difference for their loved ones. In Somali culture, loved ones are always put first.

Researchers have to be careful not to abuse their inherent power; this can be achieved by respecting the cultural and ethical norm of 'putting the other first' (i.e. the research subject). Furthermore, the Somali community may think that researchers coming into their community will help them solve their problems. Therefore, researchers need to consider not just obtaining data from these participants, but also gaining knowledge and insight about the expectations this community has of them.

Appropriate research tools

As highlighted by Ellis et al., (2007), there are yet to be specifically devised, reliable and psychometrically validated psychological measures for the Somali community. (Note: we have translated IAPT outcome measures into Somali, and they are currently being validated.) Accordingly, focus groups were selected by the IAPT researchers as an ethical way of eliciting necessary service provision needs and suitability information.

Focus group methods are the most appropriate way of investigating marginalised groups with inadequate literacy and or language in the dominant culture which prohibits participation in traditional research methods using validated research instruments (Clark et al., 2003). The distinctive feature about this method is that it generates interactive data. Research shows that focus groups are the most appropriate and ethical way of investigating this community (Green & Thorogood (2004); Garvais, 2008; Halcomb et al., 2007) as it gives participants the chance to express their unique experiences from their own point of view while providing rich descriptions of the meanings that are attached to how common mental disorders are conceptualised and experienced within this community (Warfa, 2006). Further, the oral nature of the Somali culture makes focus groups the most suitable and comfortable research method, which is why previous Somali mental health research has been thus adapted (Warfa et al., 2005; Upvall, Mohammed, Dogde, 2008; Herrel et al., 2004; Straus, McEwen & Hussein, in press; Finnstrom & Soderhamn; 2006). An important proviso is that researchers must be familiar with clan divisions within the Somali community for successful group composition.

Informed consent

Mackenzie, McDowell & Pittawell (2007) have recently argued that getting formal informed consent from a refugee is not enough because it is very difficult to construct a valid or authentic ethical consent process with people who have experienced conflict and

crisis. This precisely describes the Somali community who have been through considerable trauma (Ellis et al., 2008; Jaranson et al., 2004; Braken, Giller & Summerfield, 1995). MacKenzie and Colleagues (2007) argue that genuine informed consent is needed from these communities and the only way to achieve this is to take fully into account, and respond to, refugee participants' potentially altered capacity for autonomy. These authors argue that researchers should make a concerted effort not to just minimise harm but to design and conduct research projects that aim to bring reciprocal benefits for the refugee participants and/or to the community in question. This actually means that research psychologists should think about what positive impact their research is going to have on the people that they are researching.

It is not just sufficient to ask these communities to participate in research projects without ethically and critically evaluating what is in it for them. Both Ellis et al., (2007) and Leaning (2001) have highlighted this. Getting informed consent is an extremely delicate process which impacts on the Somali community in a unique way because Somali people are not used to being asked for informed consent; they are used to dictators and coercive governments which makes it difficult for them to say no to external demands. Furthermore, the collectivist nature of the Somalian culture (see Triandis, 1994; Hofsted, 2001) can hinder individual informed consent (Leaning, 2001). Somalians value social and familial support because, for Somalians, the family is the source of all the resources one needs to progress in life. The Somalian person views the world from a collectivist perspective which researchers need to consider if they want to gain valid informed consent. For example, if a male Somalian person marries, he is still part of the original family that makes important decisions for him, but he is also responsible for his spouse's decision making process (Wiklund, 2000, p.110). This makes it difficult for researchers to gain direct face to face informed consent, and it also makes it hard for Somali participants to give informed consent autonomously as their decision making process is dependent on not just themselves but on family members, spouses and faith leaders. This means that the western notions of autonomy and self-determination might not be applicable to them and researchers need to be very mindful about this. One way of achieving this mindfulness, therefore, is to acquire extensive background information and familiarity in understanding the circumstances that Somalians have been through, which include stress, acculturation, loss of employment (Palmer, 2007), torture, bereavement, and forced separation (Mollica et al., 1992; Miller et al., 1992). Knowing about these problems allows the researcher to empathise with their participants and, as a result, will help them to ethically conduct their research.

A Pilot Project

The IAPT researchers contacted Community Officers (CO) working voluntarily with the Somali community in Wandsworth. Once researchers and COs established face-to-face contact, informal conversation provided insight into the community's perspectives about mental illness and access to psychological therapy. The researchers also provided information about the aims of the research project and invited the COs and the community leaders to attend a research advisory board at the university. The aim of this board was to address research issues relating to the project

and the invitation was a way of giving voice to the community so that they could have input into the project.

Initial set up of the focus groups has been completed and now the second stage is to collect the data qualitatively by audio recording of these discussions and transcribing them. Thematic analysis will follow.

Participants will be given ample opportunity to understand the nature, purpose and the anticipated consequences of this research project so they can give free consent to the extent that their capabilities allow. The consent process will be recorded so that researchers can check to see if consent appears genuine and informed.

Community consultation

To evaluate the risk and benefits of the project and to provide additional review of the project, consultation was made with the Pan Somali group (a Charity Organisation in Lambeth, London) and members of the community who determined the benefits of the research. This also added a social value to the study as both the 'experts' of the community as well as the real participants were asked to give feedback on the study. The forum was firstly sceptical about the study as they questioned the need to conduct this study at all. Secondly, they had great concerns about the way information from the study would be used. They commented that it was typical for researchers to extract data from the community, take it, use it for their purposes and then leave without giving anything back to the community. This is the reason that some researchers call the Somalian community the 'invisible community' because they like to keep to themselves by not participating in research. The forum was reassured that the data will be used to gain knowledge about the barriers that prevent Somalians from accessing psychological therapy. Once the data interpretation is complete it will be verified with them and once the findings are published, it will help and encourage the National Health Service to modify and improve the services provided to this community. The results of this research will also be directly sent to the COs who educate and inform the Somali community.

Next steps

We look forward to reporting on the results of this research endeavour, and we hope that it will serve the Somali community well.

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Acknowledgements: *The Department of Health IAPT initiative has provided support for the production of this article.*

Competing Interests: none

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