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Participatory action research with asylum seekers and refugees experiencing stigma and discrimination: the experience from Scotland

ABSTRACT

Using evidence from a participatory action research process with over 100 asylum seekers and refugees in Scotland, this study explores participants' views on mental health problems, stigma and discrimination. The study found migration can have adverse effects on mental health and well-being, linked to people's social circumstances such as racism and the asylum process and that this is exacerbated by stigma and discrimination. It suggests the importance of a socio-cultural context for understanding and addressing stigma, influenced by both social and cultural causal factors, including fear, past trauma, isolation, racism and the stress of the asylum process coupled with negative cultural beliefs about mental health problems. The paper considers the international relevance of this approach and the value of a model grounded in principles of community development and grassroots action.

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INTRODUCTION

The mental health and well-being of asylum seekers and refugees

The mental health and well-being of asylum seekers and refugees is affected by many factors, including disrupted social ties and sense of belonging (Al-Rasheed 1994), being detached from kin and other social networks (Bloch 2000; Robinson et al. 2003), being a target of violence, prejudicial attacks and harassment (Schuster 2004), unemployment (Bloch 2004) and homelessness (Deborah 2006). This all leads to a sense of disempowerment, being deprived of choice and the ability to decide about one's own life, treated as worthless with little chance to contribute anything to their new country, lowers the asylum seekers' self-esteem and negatively affects their mental well-being (Refugee Council

2006). Many asylum seekers who experience destitution experience severe mental and emotional effects such as acute anxiety and stress, feelings of extreme vulnerability and powerlessness. Not being able to secure access to food and accommodation often leaves asylum seekers with a growing sense of hopelessness. This can create uncertainty, powerlessness and lowered self-esteem (Green 2006). Whilst asylum seekers and refugees are often referred to as a 'community, often they lead very isolated lives.

The temporary nature of asylum means asylum seekers live a life 'in between' their home country and their potential future life in the UK. Uncertainty about how long an asylum seeker is going to have to wait before receiving the final decision on their claim and about the outcome of the decision means living a suspended life, leading to serious consequences for individual mental well-being (Stewart 2005). The fear of detention and deportation and the stress of having to sign at a reporting centre/police station on a regular basis and not knowing whether or not will come out again creates enormous fear and anxiety (Raj and Reading 2002). Uncertainty about re-housing decisions and a lack of stable contact with the local neighbourhood due to constant displacement or racial harassment affects refugees' overall physical and emotional well-being and ability to feel 'at home' in the host community (Ager and Strang 2008). The trauma that asylum seekers and refugees experience in the country of resettlement through racism, violence, social isolation and hostility has further implications for their mental health. The post-migration experience of exclusion and racial harassment also appears to have a cumulative effect, with both pre-migration trauma of violence and persecution in the home country having negative implications for refugees' well-being. This post-migration stress adds to the effects of previous trauma and creates a risk of ongoing post-traumatic stress disorder and depression (Turner et al. 2003). Furthermore, asylum seekers who are detained in the host country experience a further and more specific set of stressors, including loss of liberty, uncertainty about the future, and

social isolation, which affects their mental health and often leads to anxiety, depression, post-traumatic stress disorder and self harm (Robajant 2009).

There is a strong correlation between the experience of a physical or intellectual impairment and mental health problems among asylum seekers and refugees (Roberts and Harris 2002, Harris 2003, Ward et al 2008). Roberts and Harris (2002) found that disabled asylum seekers experienced significant isolation and this was a major contributing factor to deteriorating mental health. Ward et al (2008) found that mental health issues are by far the most significant cause of disability among asylum seekers and refugees. Harris (2003) found that the extreme experiences undergone by asylum seekers and refugees, such as torture, war and the creation of impairment by hostile forces, had a significant negative impact on health, along with the severe anxiety of leaving behind family and friends in the country of origin. The experiences of oppression and persecution undergone in the country of origin (on grounds of religion, politics and disability) presented barriers to safety so severe that the respondents had no alternative but to flee. Once in the UK disabled refugees and asylum seekers needed to surmount considerable barriers if they are to access social services, the benefits system and social contact and considerable barriers also existed to accessing the basic necessities of life: food, shelter and warmth. The picture that emerges is one of poverty, inadequate and unadapted housing, and failure to render accessible both the social service and benefits system. Policy makers, many refugee communities and the disability movement fail to consider the needs of disabled refugees and asylum seekers (Roberts 2010). asylum seekers with disabilities continue to face numerous barriers in the assessment of their claim, in the asylum procedures and with regard to reception conditions. More advocacy on behalf of asylum seekers with disabilities is needed to encourage a shift towards the social and human rights based approach to disability (Straimer 2011).

The problem of dual stigma

The poor mental health and well-being experienced by asylum seekers and refugees is compounded by stigma. Stigma against people with mental health problems creates a significant social and health impact, including exclusion within families and communities and discrimination in employment, education and housing (WHO 2001). Patterns of stigma and discrimination are not evenly distributed and excluded groups can experience dual or even multiple stigma, on the basis of their social identities. In relation to ethnicity, minority ethnic individuals with mental illness may face double discrimination due to the combination of racism and mental health stigma ~~their ethnic background and mental health problems~~ (Byrne, 2001). For many communities, the stigma of mental health problems is layered upon racism and other forms of discrimination, which compounds the level of marginalisation and powerlessness ~~leaving individuals and their families in a complex, highly vulnerable and often helpless situation~~ (Scheffer 2003).

Ethnic minority communities often have different explanatory frameworks for mental health problems and experience structural discrimination and multiple forms of stigma, including racism and disempowerment (Gary 2005). International studies of the three major ethnic minority communities in Scotland have highlighted significant levels of stigma, shaped by factors including community and family structure, beliefs about mental health problems and experiences of racism and migration (Knifton in press). The experience of isolation and social exclusion are evident at the level of individual, family and society, compounded by the discrimination and racism associated with membership in an ethnic minority community. There are strong parallels here with stigma associated with physical disability. In the study by Ward et al (2008) it was noted the issue of stigma around disability can be a major barrier to refugees and asylum seekers accessing services from both the voluntary and statutory sector. A number of service providers commented on the particularly negative attitudes that some communities and cultures have towards certain types of disabilities, with the mental health problems associated with rape and torture cited as good examples of this in the study.

Albrecht et al (2009) found that disabled asylum seekers are generally excluded from society and discriminated against in terms of citizenship, education, jobs and general acceptance by society. In addition, national anti-stigma programmes are often culturally inappropriate; omitting multi-racial images and role models from their campaigns and failing to use appropriate media channels, clear language, and translated materials (Tilbury et al. 2004). As such, mental health problems and stigma amongst ethnic minority and communities needs to be understood and addressed within both their social and cultural context. It could be argued this is best achieved through community-based participatory research and action, in order to which contributes to empowering improve the living conditions and reduce the discrimination and alienation within the marginalised community (Knifton in press).

Sanctuary

Whilst there has been work to understand and address stigma and discrimination experienced by settled ethnic minority communities using participatory action research (Knifton in press), there has been less of a focus on how these issues impact asylum seekers and refugees. With Scotland hosting increasing numbers of asylum seekers and refugees, their mental health needs have become more prominent. The Sanctuary Programme, started in 2008, brings together national, regional and local partners to undertake an action research project seeking to: understand mental health problems amongst asylum seekers and refugees in Glasgow; identify patterns of stigma and discrimination; and explore solutions. At the heart of this work are a number of key principles. Sanctuary uses a process of partnership, involving universities, public organizations and community groups across refugee and mental health sectors in developing a community of practice (Wenger 1998). It aims to empower communities, build capacity within communities to tackle stigma and discrimination and enable communities to create a more positive identity. It also aimed to stimulate learning about mental health,

beliefs, stigma and social circumstances from community perspectives - informed by a community development ethos.

METHOD

The aim of this study was to investigate the different beliefs and attitudes to mental health problems amongst the asylum seeker and refugee population in Glasgow, explore patterns of stigma and discrimination within these communities and identify barriers to help-seeking and how these could be overcome.

In developing a method for the study, the explicit aim was to draw upon principles of community-based participatory research, ensuring that communities are research partners rather than the research subjects (Knifton in press) and acknowledging community perspectives on mental health and community priorities for action (Quinn and Knifton in press). This is an ethical imperative when working with communities that can experience marginalisation and injustice and follows the principles of social action research, a systematic effort to gather, analyse, and interpret information that describes problems and suggests solutions (Rubin & Rubin 2008). Community groups involved in the Sanctuary process were keen to develop capacity in research skills, but also sought assurances that they would be involved in shaping and taking forward actions to address the issues arising from the study. As such, the study maintained a balance between developing an understanding of the key issues relating to mental health and stigma experienced by asylum seekers and refugees, whilst at the same time enabling participants to identify actions that could be developed collaboratively to address these issues. The partnership group oversaw a process involving a series of validation sessions throughout the duration of the study, which enabled an iterative process in which study design, findings and conclusions were continuously reviewed by the research partners.

The main method of collecting data was through focus group research with pre-existing groups of asylum seekers and refugees, held in the north and east of Glasgow. Experienced researchers trained and supported members of asylum seeker and refugee communities to undertake the research. This approach helped to build capacity within communities. Two ~~asylum seekers and~~ refugees were employed as peer researchers to set up and facilitate ten focus groups. They were recruited because of their experience of doing group work with asylum seekers and refugees and knowledge of local networks. Potential participants were invited by their local contact and the peer researchers to attend the focus group. The researchers used their local contacts to seek out pre-existing groups of asylum seekers and refugees and worked with the group leaders to set up the focus groups. A total of 101 asylum seekers were recruited to the focus groups, mainly women, who had migrated from a range of countries, spanning different nationalities, including Somalia, Eritrea, Pakistan, Iran, Iraq, China, and Sri Lanka. The 'countries of origin' for each group were monitored at the planning stage to ensure most of the main nationalities of asylum seekers and refugees were represented in a way that reflected recent statistics.

Ethical approval was sought for the project from the NHS. Participants were given information verbally about the focus group and this was supplemented by a written information sheet that was translated into their own language. It was made clear that the discussion would be confidential and anonymous and an interpreter was provided, if required. Each focus group was also attended by a support person, who had extensive experience of providing support to people with mental health problems. Their role was to help the participants deal with any difficult emotions that may have arisen during the course of the focus group discussion and signpost to appropriate help.

The focus group data was analysed qualitatively using a thematic approach to draw out overall themes and issues. An important goal of this research project was that the final report should contain practical recommendations for action. As such, the final report was to be

disseminated to communities and all partner agencies and made available on the websites of partner organisations. In addition, a dissemination event was arranged to which all stakeholders were invited to shape future actions to address these issues.

RESEARCH FINDINGS

The findings spanned a wide range of issues, including causes of mental health problems, attitudes towards people with mental health problems, help-seeking and sources of support.

The findings contain quotes from individuals within groups, although these quotes did have a lot of consensus amongst group members.

Causes of mental health problems

Many people related the causes of mental health problems to the status of being an asylum seeker, linked to a feeling of low status:

'Because we are seeking asylum, we feel an inferiority complex' (Pakistani group)

'Everywhere people ask you if you are an asylum seeker or refugee. There is a two-tier system' (Iran/Iraqi group)

Many indicated that they had swapped the stress of living in a war-torn or impoverished country with the stress of the uncertainty and isolation of living in this country, especially the fear of detention and deportation:

'Human beings are the same everywhere but different circumstances cause mental health problems. In Somalia, it's poverty and civil war. But it's different here – worse – because of the isolation, not being supported by many people and fear of being deported back. In this country, we can't relax. We can become sick and stressed inside with bad news from the Home Office' (African women's group)

Furthermore, many of the participants reported that their lives as asylum seekers are dominated by loneliness, isolation and feeling homesick:

'In Africa, soldiers might come to the house and threaten you or hit you....but we're isolated here, that is the problem' (African women's group).

For many participants, this isolation was exacerbated by racism:

'Young white people are very rude – they can't change, it's a reality.'(Iranian/Iraqi group)

Attitudes towards people with mental health problems

Participants were asked how they thought people would react to someone with a mental health problem, for example, a neighbour. One of the most common reactions was rejecting and avoiding the person:

'They are not part of society; they are rejected' (African women's group);

Most groups started by saying that people's reactions would depend on the severity of the illness. In general, if the problem was severe most people would avoid the person because they were concerned about being on the receiving end of violent or aggressive behaviour.

People would be more likely to help if the problem was mild, like stress or depression.

Participants were also more likely to help someone with a mental health problem if they knew the person, and especially if it was family member; they had knowledge about mental health issues; or they knew the law in relation to people with mental health problems.

'If I try to help someone and they hurt themselves, I might become a suspect. We don't know the laws in this country and we are scared' (Iranian/Iraqi group)

Most of the groups were prompted to comment on possible links between marriage and mental health problems, for example whether they felt people might avoid marrying a person

with mental health problems, or avoid marrying into a family in which someone had mental health problems. The Pakistani group highlighted this: *'people with mental health problems won't get marriage proposals'*.

Help-seeking

The stigma associated with mental health problems can be a barrier to seeking help.

Participants were asked about getting help for mental health problems and who they would go to for help if they had a mental health problem. For most groups, participants said that the first port of call would be trusted friends or family if the problem was mild. Being able to trust that person to keep things confidential was important, for example, *'A good friend keeps a secret, a bad friend talks everywhere. There needs to be trust'* (Iranian/Iraqi group). Some participants said that they would prefer to seek help outside the family and community because of the potential for gossip. This issue was expressed mostly strongly in the Sri Lankan group, *'The last place you would go is your own community. It will spread very fast because of the shame'*.

However, for more severe problems, it was acknowledged across all groups that people would seek medical help first, usually from a GP, *'You need to go for help. It won't go away by itself'* (Sri Lankan group)

Participants were asked if they thought that opinions towards people with mental health problems would affect the sort of help people might seek. Overall, there seemed to be a sense, in most groups, that people would be reluctant to seek help because they want to hide the problem.

'Secretly I'd take them to a doctor. Yes, I'd try to get help for them, but quietly' (Pakistani group).

Two groups mentioned that they felt that asylum seekers are not trusted, and are not listened to, by the authorities, leading to a sense of hopelessness that may discourage asylum seekers and refugees from seeking help, for example:

'To tell you the truth, we think no-one believes us and they think we don't tell the truth. When we seek help, they are very nice to you but once we are in the office, they ignore you'

(African women's group)

'People pretend to listen to you but they are false, even the GP is trying to get rid of you because of colour of your skin. There was a doctor who was racist, everyone know it.'

(African women's group)

Sources of support

Participants were invited [to](#) give information about which local organisations they would use for general help and support. Participants in each group said they would use the Scottish Refugee Council as one of the first points of contact if they needed help. The main housing provider was also cited as an important source of help, although a number of negative comments were received about accommodation providers:

'They don't listen and they don't come when they say they will'. (Chinese group)

Other sources of support included solicitors, Women's Centre, the National Asylum Seekers Support Service (NASS), a specialist NHS asylum team working with asylum seekers and refugees and the Medical Foundation for Victims of Torture (African women's group), churches (African and Sri Lankan groups), interpreters (Sri Lankan group) and city-wide Chinese community projects (Chinese group).

Participants in all groups also highlighted that discussion groups would be a very effective way to raise awareness about mental health issues:

'It would really help as most people have the same problems' (Eritrean group)

Some groups even said that they would be more likely to help someone with mental health problems as a result of having attended this focus group discussion:

'After being to this group, it will change my reaction – I would go and help now but before I would be afraid' (African women's group).

Participants were invited to suggest any additional ways in which they felt ideas about mental health problems could be communicated. Groups suggested public education on TV (Iranian/Iraqi group, Pakistani group), targeting children and young people through schools and colleges (Somali group), holding large-scale group events and seminars (Iranian/Iraqi group), or using the internet as a source of information (Sri Lankan group).

Participants were asked if they could think of any barriers or opportunities that we might face in trying to change opinions. For most groups, language was expressed as being the main barrier, *'Language is the main barrier as it causes misunderstanding'*. The other barrier was resistance to change because of strongly held attitudes (African women's group) and the possible unpopularity of ~~the~~ mental health as a subject (Sri Lankan group).

ACTIONS ARISING FROM THE RESEARCH

The partnership group has developed a range of responses to the issues arising from the research. This includes campaigning for better provision for asylum seekers and refugees through seeking to influence national policy relating to asylum seekers and refugees. The group have submitted a response to the new Mental Health Strategy for Scotland 2012-2015 arguing for the provision of better mental health and support and services for asylum seekers and refugees. Partners from the group also play a key role in the Scottish Refugee Integration Forum, which brings together all the major stakeholders in Scotland relating to asylum seekers and refugees, including the Home Office, which allows the group to raise

issues such as destitution, unemployment, being deprived of choice, not being able to secure food etc that are the major causal factors of poor mental health and take steps to influence these factors. There has also been work to address stigma within communities through the development of peer-led mental health awareness workshops, which have been delivered to asylum seeker and refugee communities. and the delivery of mental health awareness training to health and housing staff in order to tackle institutional discrimination.

~~In response to this community research, asylum seekers and refugee community members and the organisational partners in the research process developed a community development approach to address stigma and discrimination, entitled 'community conversation'. Community conversation aimed to explore mental health and stigma in safe, supportive workshops. Community members and organisations led the design and evaluation of the workshops, to ensure the process was culturally sensitive in terms of language, process and content. A continuous process of learning and development was undertaken to inform the development of the model. The workshops were delivered to over 300 people. An evaluation of the workshops suggested that the Community Conversation workshops effectively engaged participants, reduced reported stigma in terms of perceptions of safety and social interaction, increased optimism in relation to recovery of people with mental health problems and increased confidence about supporting peers with mental health problems (Quinn et al 2011). The importance of the link between mental health support and providing help with the asylum process, money and practical issues was stressed, which links with wider studies on the need to address the social stressors experienced by asylum seekers.~~

~~The initial study also highlighted the need to tackle institutional discrimination experienced by asylum seeker and refugee communities. Given the lack of awareness amongst health and housing provider staff of the mental health issues affecting asylum seekers and refugees, a key action was to ensure agencies understood the mental health needs of~~

~~communities and offer appropriate and culturally sensitive services. Individuals and communities involved in the research developed a tailored training programme for housing and health practitioners, exploring the impact of asylum seeking on mental health. The training programme included a film, 'Inside Stories', produced by participants to capture the personal experiences of asylum seekers and refugees in Glasgow, which has been screened at several public events including a national human rights film festival and Scottish Refugee Week. Over 20 courses have now been delivered to almost 300 health and housing staff and an evaluation is underway. In addition, the community members and partners have produced a resource, which packages the film and training materials for use by education and voluntary sectors nationwide.~~

DISCUSSION

The study largely confirms existing literature internationally on how migration can have adverse effects on mental health and well-being. It reveals how beliefs about mental health problems are frequently connected to underlying social and cultural beliefs about causation and that people's social circumstances in terms of racism, housing, poverty, unemployment and unresponsive services can increase mental health problems. especially fear and anxiety in relation to the uncertainty of the asylum process and the fear of detention and deportation.

The study also adds to the body of knowledge of how being a migrant and a person with mental health problems can result in stigma, discrimination and prejudice. Asylum seekers and refugees with experience of mental health problems face multiple forms of prejudice. Asylum seekers and refugees experience prejudice institutionally as a result of the asylum system and interpersonally from host communities. In addition, if you have mental health problems then there is additional stigma and discrimination resulting from rejection and avoidance from your own community, as a result of deeply held beliefs about people with mental health problems, as well as institutional discrimination and racism from a range of service providers and institutions.

This has profound implications for individuals as they internalise this rejection and discrimination, and coupled with the lack of opportunities to contribute that actually exist, leads to asylum seekers and refugees -devaluinge their role and contribution to their local communities and society. It affects the way one defines oneself and can lead to self-stigma. This in turn leads to shame as individuals further devalue their contribution to society. The prejudice that migrants with mental health problems face is complex, involving a mix of social circumstances and cultural beliefs, which originate from outside the community, both from the state as well as the general public but also from within communities themselves. This suggests any solution designed to tackle exclusion and promote a more affirmative identity for migrants needs to address this complex range of factors and highlights the importance of the socio-cultural context for understanding and addressing stigma. It is interesting that participants appeared to look for support from specialist NGOs working with minority ethnic and asylum seeker/refugee communities rather than governmental health or social work services, which suggests that mainstream service providers need to work harder to engage with communities to develop service responses that more effectively address these social and cultural influences, by developing culturally competent practice that meets the specific social needs of asylum seekers and refugees, whilst acknowledging and working with particular cultural beliefs about mental health problems that might be held. The need to link mental health support with practical help emerges from the study however the link between these issues needs to be explored further. One area to explore is the cost of reducing destitution, poverty etc, compared with the costs of responding to poor mental and physical health. There does not appear to be any research on this area and this would be an important area for future research in order to establish future policy and practice priorities for asylum seekers and refugees.

The study adopted a participatory action research approach and demonstrates the role of this approach with asylum seekers and refugees in identifying issues and suggests solutions

(Rubin & Rubin 2008). It also suggests the value of a model to tackle stigma based on community development principles and grassroots action (Knifton in press). This is at odds with current national policy [in Scotland \(Towards a Mentally Flourishing Scotland 2008-2011, Mental Health Strategy for Scotland 2012-2015\)](#) on promoting mental health and well-being (including help-seeking) and preventing mental health problems and suicide, which in general uses a public education approach based on the principles of health gain at a population level. There is a danger in developing such a campaign that it may fail to reach those communities who experience multiple disadvantage and dual stigma, such as asylum seekers and refugees. This public education approach may fail to address stigma experienced by those most at risk and therefore widen mental health inequalities (Knifton in press). In addition, the diversity in beliefs that exists between different communities must be recognised, as we cannot assume that new migrant communities will share the same bio-medical view of mental health problems. The implication is that we need to develop mental health promotion and prevention work in partnership with communities, the benefits of which this study has demonstrated. There are also interesting links between the community development approaches and the wider international evidence about how to tackle stigma and discrimination, in particular the value of positive personal contact with people who experience mental health problems and the importance of approaches based on community dialogue (Corrigan et al 2001). It is useful to note that the partners involved in this participatory research have continued to work collectively to address the stigma and discrimination faced by asylum seekers and refugees using the same community development principles developed throughout the project.

There are limitations to the study. The wide range of nationalities and cultural groups that took part in the study meant that there were only a small number of participants from any one country and therefore it was not possible to draw any meaningful conclusions about the impact of culture on the nature of stigma experienced by asylum seekers and refugees.

Similarly, the impact of gender or generational differences on the experience of stigma was not assessed, which ~~Building on the Mosaics study with settled communities (Knifton in press), this~~ would be an interesting area for~~of~~ future research ~~with asylum seeking and refugee communities~~.

CONCLUSIONS

Despite the limitations, the study makes an important contribution to our understanding of the nature of beliefs about mental health problems, their causes, the associated stigma and discrimination and how this interacts with social factors such as racism and the stress of the asylum process. Although confirming existing knowledge about the impact of migration on mental health, given the lack of attention internationally to stigma and discrimination experienced by asylum seekers and refugees, it adds to our understanding of this issue and the wide range of factors that contribute to this problem. In understanding and addressing stigma, we need to understand the inter-relationship between social and cultural factors rather than studying these factors in isolation. The study also demonstrates the value of a participatory action research model in shaping community responses to this problem. Finally, in terms of the wider international relevance of this work, there may be~~we see the~~ potential for community-based participatory research to help us gain ~~create~~ better insights into the needs of other marginalised groups within society~~of a wide range of devalued and discriminated social identities~~— and how to respond more effectively~~what to do about it~~.

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