

Questions of inclusion and exclusion. Are there ways of achieving 'real participation' of users from refugee and asylum seeking groups in service development at an institutional and treatment level?

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Abstract

Refugees are among the most socially excluded and marginalised groups in the UK. This paper examines ways in which the refugee service user's voice can be heard and the power imbalance between service provider and service user addressed. Lessons learned from addressing the needs of refugees can be extrapolated for other disadvantaged groups.

Key words

refugees; user participation; power imbalance; mental health; trans-cultural psychiatry

Introduction

Research into the mental health needs and the experience of black and minority ethnic refugee (BMER) groups has shown that they are likely to experience poorer mental health than native populations and are among the most vulnerable and socially excluded people in our society (Littlewood & Lipsedge, 1997; Fernando, 1995, 2002; Tribe, 2002; Palmer & Ward, 2007). Studies have also found that BMER groups are more disadvantaged in relation to health care access than the 'white' British population. This is due to the experience of migration, the stress associated with racism, social and economic disadvantage, misdiagnosis and unequal access to provision as a result of institutional racism and the power relationships that exist between

health care workers and the 'service user' (Fernando, 2002; Bhui & Olajide, 1999; Barnes & Bowl, 2001). Refugees and asylum seekers (forced migrants) experience various practical difficulties in addition to the personal and administrative migration process and accessing services, such as health care. Without knowledge of the system and the English language, accessing the right service can be daunting, and refugees and asylum seekers often face multiple barriers in both the initial stages and any subsequent participation. Symptoms of psychological illness are much more common in this group compared to the general population and other migrants, however, symptoms of psychological distress do not necessarily signify mental illness. Symptoms need to be understood in the context in which they occur – distress and suffering are not in themselves pathological conditions. Social and cultural isolation, English language difficulties, poverty, hostility and racism, ongoing factors of severe stress due to lack of immigration status, fear of deportation, lack of occupational status and lack of family and community support have been shown to have compounding negative effects on well-being.

The relationship between the refugee and 'participation' in service development is, however, about more than the rules governing entitlement; it incorporates debates about the basis for entitlement and membership of the community as well as practices concerning the social integration of citizens and newcomers.

The issue of migration is vast and complex, and as such it would be impossible to adequately cover all aspects in the confines of this paper. It is therefore necessary to prioritise one particular migrant group in order to adequately explore and discuss the relevant theory, research and experience. This paper will therefore concentrate on forced migrants in the UK rather than economic migrants¹. In addition, while acknowledging that there is a complex relationship between mental health, well-being and physical health, this paper will concentrate on mental health service provision.

Forced migrants can be seen as 'pioneers', people who have survived a range of experiences that include extreme mobility, family and societal breakdown, poverty, personal trauma, injury and massive loss. It is important to note that lessons learned in the provision of appropriate services to refugees can be extrapolated to other 'hard to reach' groups.

Treatment

Approaches to, and understandings of mental health inevitably vary between cultures and at different times throughout history. A consequence of this reality is that behaviours can be interpreted in different ways and subsequent treatments will vary in accordance with the dominant understandings and practices (Fernando, 2002; Pilgrim & Rogers, 1999). Studies of the demography of mental illness indicate that there are strong links between social disadvantage and mental distress (Brown & Harris, 1978). In this way ethnic minorities, and more specific to this discussion, refugees, can occupy the most disadvantaged strata in society and are therefore more vulnerable to the ravages of mental distress (Harris & Maxwell, 2000). The disadvantages that refugees experience are multi-faceted, being influenced both by the pre- and post-migratory experience, specifically the post-migratory socio-demographic variables including the wider experiences of unemployment, housing, poverty, poor health generally, access issues, discrimination and hostility (Watters, 2001; Summerfield, 2001; Palmer & Ward, 2007). Psychiatric theory acknowledges a number of social and environmental factors that are associated with mental ill health in both a contributory and consequential way. However, these are not perceived as the primary causes of the major mental illness, rather as

secondary contributory factors. The logical conclusion to the medicalised categorisation of the causes of mental distress is a medicalised solution; physical treatments will therefore take priority over perhaps more long-term practical holistic initiatives, which would mitigate against the social and political disadvantages mentioned above. Derek Summerfield (2003) points to the limits of psychiatric and therapeutic treatments in treating a trauma victim '*who had not lost his mind but his world*' (Summerfield 2003, p268). He argues that, '*recovery is not primarily a mental process, subject to technical intervention by experts: it is embodied in the practical struggle to re-establish a life made viable by a sense of coherence*' (Summerfield, 2003, p268). There exists a very real and dangerous potential link between a narrowing of diagnosis and inappropriate response/service provision:

'The voice of the refugee is only heard within predefined and compartmentalised contexts that conform to and reinforce institutional structures within the health and social care field'
(Watters, 2001 p1710).

Fernando (1995 and 2002) highlights the fact that mental health service users from minority ethnic groups (to include refugees) access and utilise mental health services differently to 'white groups', have more aversive pathways to care, and importantly, are more likely to be diagnosed as suffering from schizophrenia, to be compulsorily detained under the Mental Health Act, and to be offered physical treatments such as medication, or coercive treatments and aggressive methods of restraint (Harris & Maxwell, 2000). Bhui and Olajide (1999) write extensively on the impact of institutional racism within western psychiatry. They criticise psychiatric services for adhering to a 'Euro-centric' understanding of mental illness, perpetuating a belief in the invalidity of black world views and judging different representations of mental illness against an established western 'norm'. Dominant cultural understandings affect interpretations and behaviour and evidently influence the propensity for users to access services and the subsequent diagnosis of mental health symptoms. Psychiatric diagnosis requires doctors to make judgements based on their understanding of their patients' mental states and emotional processes, and relate these to a 'normal' or 'healthy' standard.

¹ We are especially interested in the area of refugees and health provision; we have both worked with forced migrants for the last ten years in projects which are specialised in the area of health access and health provision with an emphasis on mental health.

Questions of inclusion and exclusion

Clearly, this exercise is at the very least much more difficult where doctor and patient do not share a language, a set of concepts around the nature of mind and emotion, and an understanding of what behaviours fall within and without each other's cultural norms (Littlewood & Lipsedge, 1997).

Is participation possible when considering treatments for mental distress?

In reaction to these realities, trans-cultural psychiatry has begun to recognise the value of culturally congruent therapeutic interventions and aims to move away from imperialistic, ethnocentric preoccupations of diagnostic labels and psychiatric models of trauma (Fernando, 2002). Importantly, this acknowledges the existence and influence of alternative belief systems, and how religious observance can influence ideas and behaviours within communities in terms of their preferred and accepted methods of dealing with mental illness. Examining how problems would have been dealt with in country of origin may allow for the traditional coping strategies to be '*re-activated in exile for the benefit of the community*' (Harris & Maxwell, 2000 p203). This would therefore require that the social, cultural and political inequalities of power between different groups and within systems are taken into account when developing services with users. In relation to user participation it would initially require service planning working parties and committees to work with community and religious leaders in a mutual exchange of information and practice, and then for services to either incorporate or adapt different treatments in accordance with the needs and requirements of the individual refugee user. When institutional care is unavoidable is user participation still possible? If such care is truly unavoidable there exist many barriers to real user participation. First, 'total' institutionalisation works to segregate the individual from all social interaction and 'normal' daily activities, and can act to reinforce and maintain the compliance and effective 'silence' of the patient. It would therefore be necessary to give the patient back control of these activities in order to increase autonomy and independence and consequently move towards greater participation. More recently, psychiatric services have gradually begun to adopt practices that confer greater responsibility and decision-making to

service users (Brown & Smith, 1992). However, it remains evident that much of the main decision-making concerning the real and influential aspects of the institution continues to be determined by the staff and management. Participative decision-making will only be effective if it occurs within an arena of shared power (Friere, 1972). Although radical, it seems that user-led initiatives can be developed within psychiatric services, but this would require that the hierarchies that exist within the mental health system would need to be greatly reformed in order to allow for shared power and influence, and users would need training to develop the confidence to manage their own projects.

It is evident that there are many different approaches, treatments and solutions to 'mental distress'. It is therefore necessary to take a wider, more holistic perspective of mental health needs. If service provision was approached in this way the inevitable implication would be the adoption of a variety of treatments, and a more appropriate and radical approach to combat the multitude of legal, social, economic and practical difficulties experienced by refugees. In this way, much of the labelling of problems as 'mental illness' and subsequent medical interventions will in fact be shown to be an unnecessary and inappropriate response. As stated by Harris and Maxwell (2000),

'If the key problem is one of isolation or boredom, rather than unbearable memories or emotions, then the scheduling of activities may be the most appropriate intervention' (p209).

The traditional roles of mental health professionals and user-led organisations and community groups would therefore need to be re-examined and re-modelled allowing for a broader range of interventions, to also include preventative early practical and social interventions.

The National Health Service: equality for all – can participation work?

The importance of user groups within service care provision can be established in terms of a 'general' adherence to this recent ideological phenomenon. However, there is a significant difference between 'perceived' support for user involvement and establishing a real level of involvement in terms of the actual discernable influence or impact users have had on their

services. There exists a fundamental distinction between tacit support of such user involvement and the establishment of clear, transparent and democratic processes to ensure success. This complex situation is particularly relevant to refugee service users, therefore it is now important to explore the position and influence of refugees within the mental health and social care services to establish exactly how important their voice is within establishing good quality care. 'Citizen participation' not only requires equal access to services but equal control and contributions to the planning and delivery of specific services. The term 'equality' itself represents a complex ideology and has many practical implications when used as a tool to justify a given strategy. It is necessary to explore the issues concerning access to services in order to fully understand the barriers facing cultural minorities within service provision, and therefore influence strategies aiming to achieve 'citizen participation'.

User involvement in health service development has been established as a legal requirement, this was set out in the 'Community Care Act 1990'. The Department of Health states that all mental health service provision must be planned and implemented in partnership with local community groups, and involve service users and their carers (DoH, 1999). This purportedly enables ethnic minorities to acquire the power to participate in planning and decision-making. The issue of equity raised by the trans-cultural debate again figured in government policy when Labour took office in 1997. It was given greater impetus in 1998 when an African-Caribbean patient named David Bennett died in a secure psychiatric unit whilst detained under the Mental Health Act (1983) (DoH, 2005). The subsequent inquiry found the NHS to be '*institutionally racist*' giving the Department of Health (DoH) the leverage it needed to demand a response from health services (DoH, 2005). The response to this inquiry has been slow; several publications were produced focusing on the large established minority communities – African-Caribbean and south Asian, following consultation responses, the most recent report, 'Delivering Race Equality: An action plan for reform inside and outside services' (DoH, 2005) makes some actual reference to 'refugees' and works to establish its broad understanding of the term 'black and minority ethnic'. The document proposes a programme based on three 'building blocks':

- more appropriate and responsive services
- community engagement
- better information.

For statutory bodies, this is a major and worthwhile challenge. The government, it seems, is well aware of the deficiencies in the quality of mental health care provided to BME groups. There is a clear political agenda to redress these issues in respect of major established ethnic minority communities, especially the African-Caribbean and south Asian communities. However, the recent policy documents continue to give very little reference to the particular and specific needs of the refugee community within the BME category.

At a European level, the Bratislava Declaration (European Council, 2007) *People on the Move: Human Rights and Challenges for Health Care Systems*, signed by the 47 member states of the Council of Europe, emphasises the need for states to work towards eliminating the practical obstacles and barriers to the enjoyment of equitable access to health protection of all people on the move, including those in an irregular situation.

The challenge of the system: institutional issues – barriers to real participation

The potential refugee service user is also confronting many vast and complex institutions in the form of the mental health establishments. The place of the 'user' within this system is significantly more complex due to the specific historical construction of the services within it. Fernando (1995) argues that minority ethnic groups meet with a number of racist attitudes, beliefs and practices within the mental health care system and he argues that these beliefs have become institutional practices that have been implemented over long periods of time. Refugee community organisations and refugee service users are one group among many competing for resources in a system that has historically prioritised the needs of the most vocal groups in society, namely the educated white middle classes (Bhui & Olajide, 1999). There remains enormous potential for improving the health of refugees. Mental health services need to promote an inclusive multicultural strategy addressing distinctive cultural and linguistic needs. An understanding of social factors and specific cultural understandings and experiences of refugee service

users and an understanding of the migration process is therefore essential in the provision of specialist services. Central to such understanding is the 'refugee themselves', placing the refugee in such a position is important in order to provide authenticity, transparency and quality of care.

As discussed previously, recent UK government policies have aimed to shift mental health service ideology from a hierarchical culture to a participative, inclusive and solution-focused approach, that seeks to empower users, and work in partnership with community and voluntary groups in order to improve mental health services and access (DoH, 1999, 2003, 2005). However, the reality for refugee service users is often very different. The fact of institutional racism is one of the biggest challenges facing refugees and service providers. Research by Barnes and Bowl (2001) has highlighted that despite a shift towards service user involvement, minority ethnic groups are not involved in the planning or delivery of mental health services. This reality places great importance on the need for refugee voluntary and community groups working as effective pressure groups for the often silent minority refugee user. Work and research on London mental health services has highlighted the gaps in service provision, indicating that the refugee voice has not been adequately heard or taken into account when planning and implementing services. This research, a mapping exercise undertaken for the PPI (Public and Patient Involvement in Health) in 2005, highlighted that only five of the 11 mental health trusts in London provide specialist services that are specifically designed with the needs of this group in mind. In addition, the research highlighted that services are difficult to locate and that commissioners and equality and diversity managers are unaware of some of the services available and funded (Ward & Palmer, 2005). Within such a system there would appear to be very little equality of opportunity from the perspective of the refugee. Consequently the individual refugee service user would appear to have very little real influence upon the services provided. This reality makes the existence of refugee voluntary and community groups working as effective pressure groups a necessary implication of user participation for refugees. The involvement of such groups is necessary if providers are to combat such potential inherent disadvantages. The participation of service users within the mental health system therefore needs to be carefully planned and implemented.

Making participation possible – the building blocks to change

Perhaps the initial principal barrier that forced migrants face in accessing any service, and having any real power within a participatory strategy, is that of language. Any service seeking to respond to refugee needs must have a range of language skills available in a highly flexible way. Various studies have identified language as the biggest single barrier to access and as a major issue for providing health care to refugees (Aldous et al, 1999; Palmer & Ward, 2007; Harris & Maxwell, 2000). A review of the effectiveness of partnership work has shown that initiatives between public, private and community groups have proven to be most beneficial (Gillies, 1998). In this way the sharing of experience, information, knowledge and understanding can lead to more appropriate responses to the challenges presenting refugee users. In the first instance, community organisations have access to bilingual interpreters who are able to represent the needs and desires of the individual refugee within a user participation forum. Second, such organisations can be involved in education and training for individuals to allow for independent representations at the service level and to help develop and support culturally competent services. An inevitable implication for successful refugee participation would therefore be to ensure effective training in trans-cultural awareness for mental health professionals and community groups. Such training would need to recognise the importance of health awareness programmes that focus on mental health issues. Community group workers would need specific training so that they were able to recognise the symptoms of mental ill health and importantly to work with refugees in a supportive environment to combat any negative attitudes and stigma associated with mental illness. In this way, community workers would have a better understanding of the specific needs of refugee and BME service users, be able to better encourage users to access the appropriate services, and be able to represent their interests with greater confidence and authenticity (Ward & Palmer, 2005).

Community groups can also provide a good link/liason between the individual refugee service user and the institutions within the health care system. A good example of how this can work in practice is provided by the London based Kurdish organisation (*Derman*). This organisation has developed a culturally competent counselling service, which

is undertaken by a bilingual Kurdish worker who is trained in trans-cultural mental health. Being bilingual helps build up a trusting relationship and alleviates much of the stress, stigma and alienation associated with accessing the current mainstream health and social care services. This effective means of building and developing trusting relationships with users is reported to be a means by which services can empower their clients to take part in service planning and delivery, which meets their individual and specific needs. The Migrant Refugee Communities Forum's 'Refugee Health Professionals Programme', is another example whereby refugee doctors are encouraged and supported to resume their medical careers in the UK and work towards developing culturally competent services within mainstream provision. The 'Refugee Health Professionals Programme' acts as a forum in which individuals and organisations can exchange information, share experiences and work on specific health projects with members of their community. These events can highlight issues and gaps in service provision on which lobbying is needed.

Another example of good practice whereby an effective partnership is established between mental health organisations and the refugee community is that of the 'Vietnamese and Chinese well-being support project'. Operated by Mind in Bexley, this innovative and culturally specific health project is run in partnership with the Bexley Vietnamese and Chinese communities and the Bexley Council for Race Equality. This is a culturally specific 'self user-run' project that addresses mental well-being by working holistically. Based on a social health model, members of the Vietnamese and Chinese community, with the support of staff from Mind in Bexley, provide culturally holistic support to Vietnamese and Chinese service users to improve their well-being and help them access other voluntary and mainstream services. Mainstream day centre services are not appropriate because of language and cultural barriers. As a result, the support involves a range of activities and day centre provision, which aim to reduce isolation and to improve interaction with other health and social care services. The project works to address some of the social, bureaucratic and cultural dimensions of a person's life that may impact on their mental health. In this way the solving of mental health 'problems' encompasses aspects of the person's social life, beyond the symptoms of the health problem – for example, isolation, community

support, legal status, language support, education and training. This is a good example of a third sector, not for profit, mental health organisation (Mind) linking with a local community in order to find ways of establishing new relationships and co-operate in improving mental health and social care services to users. In addition, it highlights the effort some voluntary groups are making to reach out to minority ethnic groups, a model which needs to be replicated across London and other NHS trusts.

The Ethiopian Health Support Association (EtHSA) also provides an example of an organisation that has developed a model of care that enables Ethiopian forced migrants in distress to gain access to culturally appropriate and adequate health care. EtHSA actively promotes good mental health for all members of the Ethiopian community, tackles stigma and discrimination relating to mental illness and works to promote the social inclusion of those from the Ethiopian community with mental health problems. Through a variety of projects including bilingual advocacy and self-help initiatives, EtHSA works with individuals to develop the necessary skills to stay free of, or minimise the effects of, mental ill health at stressful times in their lives and survive challenging mental health episodes.

The Brent New Deal for Communities 'Jigsaw' advocacy project has tried to acknowledge many of the issues discussed in this paper and provides a good example of how service user participation has resulted in a mutually beneficial exchange resulting in a vastly different approach to the provision of mental health and social care. The project focuses on tackling exclusion and disempowerment through facilitating and supporting access to services and offering an environment and opportunity where community members can share and challenge their experiences of isolation and oppression. This approach is primarily based on a combination of some approaches emphasising partnership working, good communication, empathy and a respect for the users and their communities' views, and joint action. It also requires that the workers in the project examine their own identity, culture and assumptions through ongoing training and involvement in holistic and therapeutic service provision. The placing of the individual at the centre of the process is a crucial aspect of its success, building on the needs, strengths and achievements as identified by the client themselves.

Transforming the planning and provision of services – the future for user participation?

The benefits and advantages of user participation, if done well and appropriately, can be evidenced, especially in terms of ensuring quality, relevant and culturally appropriate services. However, it is important to acknowledge the barriers to such participation, particularly on an individual level, and look to possible solutions to such barriers. Such exploration is particularly relevant to the refugee service user where such participation is still in a process of development. An important implication of user participation for refugees is the framework and delivery of services. Such provision would need to be adapted to ensure that they were involved in service planning and that services provided a platform for users. Planned activities with user consultation is a positive 'way-in' to building trust and understanding and allowing the user the opportunity and a safe space within which to express their individual and specific needs.

As this paper has shown, not all user groups have the same influence or organised voice; much depends on the power dynamics within society and the structure, organisation and internal priorities of the relevant institutions themselves. Central to the problems and possibilities explored throughout this paper, has been the recognition that for service user participation to be successful for refugees, the provision and planning of services would inevitably need to change. Our own work experience has shown that a mental health access point and support service for refugees can often most effectively be provided through a more generic 'helping' service in order to provide a greater opportunity for engendering trust and encouraging involvement. As discussed, refugee service users are often some of the most vulnerable of users; the disadvantages they experience before, during and after the migratory experience inevitably influence their motivation, ability and opportunity for involvement in service provision. The many different experiences of exclusion have disempowered them and corroded many aspects of their lives.

Conclusion

It is necessary to ensure that the individual is not lost within a complex system involving many different organisations. In this way, open and transparent communication between organisations and, importantly, in partnership with the client, is an essential aspect of a service that meets the needs of users. The client therefore plays an active role in their own care provision and an important aspect of the work of service providers is to work to maintain this active participation through ongoing evaluation on different levels including service user questionnaires, feedback sessions and in-house team meetings. Ensuring participation inevitably requires a flexible approach based on the different and complex individual requirements, and importantly allows for user involvement in the planning and delivery of their own individual service provision, to include treatment options and longevity of treatment programmes. Such an approach also, therefore, strives to redress the power balance and inequalities and promotes self-esteem with an emphasis on the client being their own best 'expert'.

The design of such service provision on a micro level needs to be replicated on a macro-mainstream level to ensure that provision is transformed at every level of mental health and social care service.

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