# The occupation of accessing healthcare and processes of (dis)citizenship in UK Somali migrants: Sheffield case study

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**Abstract:** In the UK free access to healthcare is regarded as a fundamental right accorded to all citizens, but there are significant health inequities experienced by ethnic minority populations. Accessing healthcare is an everyday occupation which can be made complicated by language issues and the design of communication systems. The example of people of Somali origin living in Sheffield is used to explore the occupational dimensions of access to healthcare as part of the participatory process of citizenship. Occupational analysis of healthcare access could contribute to better service provision.

**Keywords:** citizenship, migrants, healthcare access, Somali, communication

## Introduction

Health, participation and citizenship depend on a number of social determinants of health such as poverty, relative inequality and institutional aspects of the health system which contribute to the production of health inequities (Bloom 2009; Solar & Irwin, 2010). This article is written by the members of the European Network of Occupational Therapy in Higher Education (ENOTHE) citizenship project group in conjunction with a public health researcher. The citizenship project group, whose research agenda was established to explore the relationship between occupation, occupational therapy, began with the assumption that "restriction in participation in occupations is also a restriction of citizenship" (Fransen et al, 2013, p. 1).

In this article from a citizenship perspective is used to explore the difficulties experienced by some people in the occupation of accessing healthcare. It presents a case study based on Somali people engaging with health services, from studies conducted by one of the authors (MMI) with the purpose of gathering a broad and in-depth understanding of the health needs of Black and Minority Ethnic communities in Sheffield, UK (Gerrish, Naisby, , & Ismail, 2013; 2014; Ismail, Gerrish, Naisby, Salway, & Chowbey, 2014) . In the UK the term which is widely used to describe people of non-white descent is 'Black and Ethnic Minority' (BME) (Institute of Race Relations, n.d.). We aim to highlight, from a citizenship perspective, some of the exclusions related to institutional aspects of the health care system and its contribution to the production of health inequities and dis-citizenship.

Citizenship is often discussed as a human good, with civic, political and social rights, focusing both on the relationships between state and citizens as well as between citizens (Devlin & Pothier, 2006). In the field of study of participatory citizenship, citizenship is viewed as practice, emphasizing our essential relatedness with others in the creation of our common world (Hoskins, 2006). Both the structural organisation of health care and interventions by practitioners such as occupational therapists are factors which may affect how participatory citizenship is enacted.

Human rights include the right to the highest possible standard of health (World Health Organization, 2006) and provision for health services is one of the fundamental rights that citizens expect from a government (Chapman, 2016; Mackay & Danis, 2016). In the UK equal access to healthcare is regarded as a fundamental right to all, and is a core principle in the post war social contract which British people

have with government, expressed in the National Health Service (NHS) constitution (Department of Health, 2015; Hand, Davies, & Healey, 2016). The NHS, which has long been Britain's largest employer and one of the world's largest single organisations, is a significant and revered element of British culture (Greer, 2015; Hunter, 2016). Exclusion from this public service may not only be denial of the right to health services, but a denial of citizenship (Bloom, 2009).

In the UK many healthcare staff are of diverse ethnic and cultural origins and the National Health Service has a history of recruiting its staff from other countries (Bivins, 2017). Diversity has become a contested issue in many aspects of UK life due to the impact of austerity on public services. Sealey (2016) makes the point that diversity is a significant area for policy change in the UK, which has recently seen a shift in emphasis from a weak multiculturalism which did not progress beyond the celebration of difference to demands for cultural assimilation and integration as a condition of citizenship. Mass media messages and a popular belief that migrants affect opportunities and service availability for UK born citizens are supported by official policy that has prioritised individual responsibility for integration over rights. This contributes to a pressure on professionals to uphold inequalities through complex rules restricting welfare and access to services, for example a perception that migrants indulge welfare benefit or health tourism to gain advantage of the UK's more generous public services. This generates a climate of exclusion.

Added to this is the problem that some professional groups within the NHS, such as occupational therapists have lacked knowledge of the health needs of people from cultural backgrounds other than their own (David, 1995; Howarth, & Jones, 1999;

Heaslip & Smith, 2016). This is an issue which is recognised as a global problem within the profession (Kinébanian & Stomph, 2010). While some occupational therapists in some countries have been concerned with the specific needs of Somali communities, (e.g. Smith, 2013; 2012; Smith, & Munro, 2008) the authors' electronic searches found no literature from therapists in the UK which specifically addresses Somali people.

For many people engaging with health services is a significant occupation, although as Magasi (2012) notes, one that has been rarely acknowledged. Whether because of their own health condition or that of someone they care for, users of health services often find the need to maintain regular contact with a range of professionals who are involved in health and social services. However, like many Western societies, the UK has multiple, intersectional communities composed of different groups of people, who, like the Somali community migrated to the country to work in the post-war economy, or in response to regional crises. Around 13% of the UK population was born outside the country, and 8.4% hold a non-UK nationality (Office for National Statistics, 2015). This diverse population needs to access services which were originally designed around the needs of a less divergent culture, and which have evolved to mostly reflect the dominant perspectives of health need in subsequent years. Since 1948, when the National Health Service (NHS) was first launched, the demographics of the UK have changed dramatically (Bivins, 2017; Marmot, 2010). By the beginning of this century 189 first languages could be found in cities such as Sheffield (Cheeseman, 2001). For many people living in the UK, English is a second, third or even a fourth language, which they may not speak well or be able to read. Many languages may not be well known, such as the range of

dialect which is spoken within different Somali communities. Interpretation and translation services may be difficult to locate. Somali people have been chosen as a case study example because they have been found to have problems accessing and maintaining contact with healthcare services (Bloom, 2009; Fox et al. 2017).

While language and identity may be broadly interlinked this may only be the surface of an intersectionality through which people incorporate identities related to ethnicity, gender, privilege and ability in multiple and individual ways (Anthias, 2016). Issues such as health needs, the status of older people, women and children, or the expression of pain are usually less visible aspects of cultural identity than the knowledge that people may share of art, food, or dress, and require deeper knowledge (WFOT, 2009). Therefore, a focus on a single domain to critically understand issues such as health inequity is necessarily incomplete (Bauer, 2014; Hassan, Musse, Jama, & Mohamed, 2013) and may be reinforced by working processes in healthcare environments. In recent Canadian occupational therapy studies Carrier, Freeman, Levasseur, & Desrosiers (2015) reviewed standardised referral processes which favoured institutional perceptions of need over those identified from the clients' specific context; Durocher, Kinsella, Ells, & Hunt (2015) found that practitioners tended to focus on a narrow and institutionalised perception of clients' needs derived from the structures within which they are working, rather than addressing the wider contextual social, political, and economic constraints which restrict clients in obtaining the healthcare they need.

**Case example: Somali migrants seeking access to UK health services**

The real-life-occupation of accessing healthcare is affected by people's culture/ethnicity and language as well as by the multiple social positions that they hold or in which they are positioned. In this case study some of the problems are identified to present a picture of how Somalis may experience exclusion from health services.

The Somali community is the one of the oldest minority ethnic communities in Sheffield, and the second largest, estimated to be around 10,000 persons (Gerrish et al 2014). It is also one of the largest migrant communities in the UK, with origins going back to the 1860s (Hassan et al., 2013). As data collected on Somali populations has often been aggregated under Black African or BME categories but some local authorities have recently begun classifying Somalis as a separate ethnic group there are no accurate statistics. Hassan et al. (2013) estimated that the UK has the largest Somali diaspora in Europe with over 200,000 people forming significant populations in some cities.

Somali migration to the UK has occurred in different phases during a complicated period in Somali history. The Somali diaspora has complex recent origins and this can affect their entitlement to UK citizenship either because of the different political, national and quasi-national structures which have held power in the part of East Africa from which they originate, or because of the route through which they came to Britain. Somalis may originate from Somalia (a federal state in the Eastern horn of Africa) and Somaliland (a former British colony which is organised as a republic, but has no international recognition) and their autonomous regions). Other Somalis are first generation UK citizens, or have travelled from Europe (mainly Scandinavia and

the Netherlands) sometimes as EU citizens, or as asylum seekers (Aden, Rivers & Robinson, 2007; Hassan et al., 2013). They may also come from neighbouring East African countries and the Yemen. While people coming to work in the Sheffield steel industry in the 1950s and 1960s mostly came from colonial British Somaliland, those fleeing civil war in Somalia in the 1990s came from a territory with a failed government. Some regional areas are centralised under a clan organisation with varying degrees of independence or local control, but none of these have international recognition (Bloom, 2009). This creates difficulties for recently migrating Somalis in establishing their legal citizenship status in their country of origin (Landinfo, 2009) which is necessary to be able to access healthcare services and welfare benefits (Sealey, 2016). If the regime which issued the documents is not recognised as a state their documents cannot be verified.

The Somali community in Sheffield lives in some of the most deprived neighbourhoods, with high rates of mortality and morbidity, poor quality of housing, high rates of unemployment, low income and low educational attainment (Director of Public Health report Sheffield, 2016). Somalis who arrived as refugees since the 1990s have shown lower rates of English literacy than other migrant groups. Bloch & Atfield (2002) found UK Somali migrants have literacy rates of 41% in English and 75% in Somali. The overall literacy rate in Somalia is 19.2%, one of the lowest in the world. This appears to be related to the disruption of and chronic poor access to education during recent Somali history. Somali children often perform significantly poorly in UK schools compared to other minority groups (Demie, et al. 2015), due to social factors related to poverty, poor housing and overcrowded family environment with consequences for their future access to employment and training. As English is

not spoken at home, most pupils acquire their English fluency during schooling, which may delay progress (Bloom, 2009; Demie, et al. 2015).

Those Somali people with good English may still not understand clinical or complicated terminology (Straus, McEwen, & Hussein, 2009). Many people from Somali culture prefer oral communications over written information, and a hospital letter can easily be put aside and the appointment forgotten in the midst of managing the multiple issues which often arise in families (Straus, McEwen, & Hussein, 2009). Additionally, some western health concepts such as depression, stress and anxiety are not present in the Somali culture and language (Elmi, 1999; Guerin, Guerin, Diiriye & Yates, 2004). Thus, good interpreters (i.e. who speak Somali dialects and English, can explain untranslatable concepts between languages) are sometimes hard to find. Confidentiality may be compormised where friends and family members may be used to translate. Within some Somali groups adherence to social expectations may be especially important features of in-group communication and relationships, and these may be prioritized over individual needs in order to avoid disapproval (Scuzzarello, 2015). Somali people may be reluctant to reveal some health issues, and often feel that UK health professionals do not listen to them or communicate adequately; non-verbal communication is important in Somali expectations of patient-therapist consultations (Straus, McEwen, & Hussein, 2009).

Language and communication is only one of many issues. Many recently migrated Somali people may have extended families with many competing demands. They may not know whether other family members are out of danger in the process of migration. Their poor housing often leads to combinations of adverse health

conditions (Bloom, 2009). Women explain that their relationships founder under the pressures of coping in the host culture, leading to loss of support (Straus, McEwen, & Hussein, 2009), which can make them particularly vulnerable. For example, as many families are on low income and depend on social benefits, meetings at benefits offices are prioritised over health appointments in case a missed meeting means that payments are suspended (Khan, Ahmet, & Victor, 2014). On public transport, travel time across the city to hospital appointments can be lengthy and unpredictable, so individuals without cars may rely on more distant relatives for transport and others for child care. With competing needs across the family, these transport needs can often be overlooked.

Health service cultures in many wealthy countries, such as the UK, have re-examined the relationship between health, individual responsibility and choice, determining that some conditions result from lifestyles and behaviours which could be averted (Chapman, 2016). This perspective has been adopted by practitioners with the result that health service users may be blamed for certain conditions such as obesity (Ulijaszek & McLennan, 2016). Such health problems may arise when migrants try to manage family cooking and other food related occupations in a host country in different conditions to those to which they are used (Aronsen Torp, Berggren & Erlandsson, 2013). Health service users may also be blamed for not keeping appointments where health structures, messages and appointment systems may differ from their previous experience (Gerrish, Chau, Sobowale, & Birks 2004; Gerrish, Naisby & Ismail 2013; Guerin, Guerin, Diiriye & Yates, 2004).

Somalis have sometimes reported problems with accessing and maintaining contact with health services (Gerrish, Chau, Sobowale, & Birks 2004; Gerrish, Naisby & Ismail 2013; 2014; Ismail et al., 2014) and feeling that staff may be prejudiced or subject people to procedures they have not properly explained (Davies & Bath, 2001). Translators may be poor in quality and have not been trained to manage upsetting information in the complex traumatic situations which some Somalis have experienced as a consequence of war (Arafat, 2016; Bloom, 2009; Elmi, 1999). Misunderstandings arise and Somalis may assume they and their needs are disregarded or not important, or that their condition is not serious. People can become confused and lose confidence in the services (DeVoe, Wallace, & Fryer Jr., 2009; Pinder, Ferguson, Møller, 2016). While different levels of health literacy can pose limitations which require active intervention to enable groups such as Somalis to enjoy their right to healthcare (Bloom, 2009), NHS staff may not sufficiently understand the complications produced by such conditions as female circumcision, which is common amongst Somali women, and not trust the knowledge of Somali women themselves about what must be done (Straus, McEwen, & Hussein, 2009).

These issues interpose significant difficulties in addressing Somalis everyday problems of health (Bloom, 2009; Straus, McEwen, & Hussein, 2009) and limit the individual ability to develop the required conditions for accessing the healthcare system.. Health professionals such as occupational therapists, may not understand or be aware of this combination of factors and assume that people from the Somali community are less co-operative.

**Discussion**

The problems of UK minority groups with accessing healthcare and maintaining contact are well documented (DeVoe et al., 2009; Larson, Nelson, Gustafson, & Batalden, 1996; Marmot, 2010; Office for National Statistics, 2014; Pinder et al., 2016; Thomas, Groff, Tsang, & Carlson, 2009) but the literature may lack depth. For example, a recent report on individual patient involvement in health in the UK (Foot et al., 2014) noted the lack of engagement by members of ethnic minority groups but did not explore the relationship between experiences of cultural exclusion and engagement**.** Some of these issues have been identified above: low literacy, limited English skills, lack of education, barriers to care, limited access to employment and training, or culturally specific aspects of seeking health care. Thus cultural exclusion for the Somali community may not be simply about language differences, but involve a complex combination of economic and social circumstances, the political climate of representation both in the UK and in the commissioning of services, the geography and infrastructure of the environment, cultural and socio-political perceptions, family circumstances and the availability of education, issues which need action from the host community (Bloom, 2009). Due to the "translocational" (Anthias, 2016, p.172) status which arises from this complex intersectionality across and between many different components of social belonging including culture and nationality, people of the Somali community can experience multiple deprivations and disadvantages, all having a bearing on the daily occupations of accessing healthcare.

A brief account of the NHS is given in the Home Office (2017) guide to *Life in the United Kingdom* for citizenship applicants as one of the important aspects of recent

national history. The 2015 NHS constitution (Department of Health, 2015, p.2), "sets out rights to which patients, public and staff are entitled" the first of which is "the NHS provides a comprehensive service, available to all", and later that the NHS will "support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers". Accessing healthcare is an occupation which is clearly connected to the official British conception of citizenship. Citizenship is described by Devlin and Pothier (2006, p. 1-2) as "a process", "as a practice where citizenship activities locate individuals in the larger community". Devlin and Pothier (2006, p1-2) use the term 'dis-citizenship' to refer to how individuals, as members of intersecting disadvantaged groups in society, experience barriers to participation and become "dis-citizens', a form of citizenship-minus". This paper has argued that British Somali citizens' access to healthcare can be restricted through health service institutions' difficulties in recognising their linguistic and cultural diversity and is limited by combined wider social, political and economic effects (Bloom, 2009; Sealey, 2016). As a result of these factors, migrant groups within Britain are sometimes perceived as 'hard to reach' (Bhui, et al., 2006, p. 400; Dowrick, et al, 2009, p226) implying that the issues are their problem.

**Conclusion**

Healthcare systems and services, are organised to meet the needs of the dominant population and may not adapt easily to address the issues presented when populations become more diverse. In a country like the UK, where healthcare is perceived to be a benefit of citizenship status and a personal responsibility

significant barriers can arise over social and cultural differences which expose institutional limitations in health systems. The case study has explored how an apparent lack of engagement in the occupation of accessing healthcare is complex (Foot et al., 2014) involving aspects of different social and cultural identities (Anthias, 2016) which combine with restrictions in the processes of citizenship (Fransen et al., 2013). There may be implications for occupational therapists in considering access to healthcare as an occupation particularly with those groups who may experience difficulty in doing so, and in working with service users and colleagues across health practice, policies and documentation to enable efficient, flexible and sensitive ways of meeting the health needs of their diverse populations.

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