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Good practice in working with Gypsy, Traveller and Roma communities

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Conflict of interest

None

Abstract

This article highlights important literature and good practice relevant to healthcare professionals working with and supporting Gypsy, Traveller and Roma populations in the UK. Members of these minority ethnic communities are often seen as ‘hard to reach’. Healthcare practitioners frequently identify that mutual gaps in cultural competence and knowledge exist, which can affect ways of working with these populations, leaving service users and professionals baffled and upset, with negative effects on health. By exploring the effects of social determinants of health on these groups and focusing on ways of improving communication and tailored access to services, it is possible to develop effective ways of supporting vulnerable individuals and communities while building trust, enhancing communication and increasing health literacy among potentially ‘at risk’ people.

Keywords

Gypsies, Travellers, Roma, Romani, health, best practice, innovative, community, trust, social determinants

Introduction

Romani/Gypsies, Travellers and Roma (GTR) are all recognised minority ethnic groups, with protected characteristics recognised under the Equality Act 2010. They have been identified in the UK and wider Europe as being particularly at risk of health exclusion, increased morbidity and mortality rates, and poor outcomes across a range of measures throughout their lives (European Union Agency for Fundamental Rights (FRA) 2013, European Commission 2014, Greenfields et al 2015). Despite the fact that the three communities are ‘lumped together’ in EU and UK health and associated policy, they are distinct ethnic groups with differing histories and cultures. All have a history of nomadism, which inevitably affects the health and access to services of those still practising this lifestyle (Cemlyn et al 2009, Greenfields and Brindley 2016).

The three main GTR groups in the UK can be categorised in the following ways:

Romani/Gypsies

A community that shares cultural and ethnic similarities, including certain predispositions to some medical conditions, with mainland European ‘Roma’ populations. Romani/Gypsies and Roma have a common heritage of migration from the Indian sub-continent into

Western Europe starting around 1,400 years ago (Nelson 2012, Matras 2014). Romani/Gypsy people first entered the UK in around 1500 and have been resident ever since, making them one of the oldest minority ethnic groups in Britain.

Roma

In contrast, Roma have largely migrated to the UK since the 1990s. Initially, they came as refugees from extreme racist persecution in East European and former Soviet countries. The accession to the EU of the countries from which the largest groupings of Roma migrants originate (Poland, Romania, Czech and Slovak republics) led to their exercising their legal right to migrate and settle in Britain (European Dialogue 2009, MigRom 2014). Roma people in mainland Europe and the UK overwhelmingly live in poor, overcrowded, privately rented properties, having been settled as a result of state policies throughout Europe in previous decades and centuries.

The Roma people throughout Europe were subject to persecution and genocide during the second world war in a manner similar to the Jewish community; in the post-war years, they often remained marginalised, with significant rates of social exclusion and associated effects on well-being (Matras 2014).

Travellers

Irish (and Scottish) Travellers are indigenous populations of traditional nomadic origin who are culturally and ethnically distinct from Romani and Roma. Historical records show that Irish Travellers have been present in the UK, travelling for work and offering services, since approximately the 12th century. This close tradition of movement of Travellers between the UK and Ireland continues to this day. Many 'Irish Traveller' communities in the UK – whose members may speak with Irish accents regardless of place of birth – are long-established here and members were often born locally to the sites on which they live (Greenfields and Brindley 2016).

Access to services

The obvious similarities in the circumstances of Travellers and Gypsies who live in caravans, which has an associated risk of disrupted access to services, means that these groups are categorised together in accommodation, access to health and education policies. Roma have now been subsumed into the above policy categories as well. Although Roma are typically housed, even if experiencing marginalised conditions, more logically they fit with the category of 'vulnerable migrants' under Inclusion Health's priority groups. See Aspinall (2014) for a discussion of key groups in the inclusion health rubric and issues regarding the capture of data capture pertaining to the various categories of communities or individuals. It is difficult to ascertain the precise numbers of GTRs in the UK due to their non-inclusion in many administrative datasets, including that of the NHS (Irish Traveller Movement in Britain 2012), but current estimates state there are around 400,000 Gypsies and Travellers (Cemlyn et al 2009) and between 50,000 and 200,000 Roma (Craig 2001, MigRom 2014).

Around two thirds of Romani/Gypsies and Travellers live in houses. This is often the result of enforced settlement over the past century, associated with a shortage of caravan sites and shifts in policy that have reduced their potential to live traditional nomadic lives (Smith and Greenfields 2013). The rest live in caravans, although many more would like to have the opportunity to live in traditional accommodation if they could access a permanent site (Cemlyn et al 2009). Approximately 84% of caravan-dwellers live on 'authorised' (legal) sites provided by local authorities or that they own; the remaining 16% do not have anywhere legal to station their caravan and are thus on 'the roadside' or at unauthorised sites (Department for Communities and Local Government 2016) and are technically legally

homeless (Johnson and Willers 2007).

Perhaps unsurprisingly, 'homeless' Gypsies and Travellers typically experience reduced social determinants of health (SDOH) (Marmot 2005, Equalities and Human Rights Commission (EHRC) 2016, Greenfields and Brindley 2016). The limited evidence available about the health of migrant Roma seems to suggest that poor pre-migration health conditions (FRA 2011, European Commission 2014) often continue to affect their wellbeing and that the community is similar to Gypsy and Traveller communities in having increased morbidity and mortality, as well as generally poor health (Craig 2011, TS4SE 2011).

Background literature and field-based case studies show remarkable similarities in two key areas concerning access to health and associated services by Roma in their country of origin and migrant GTR populations across Europe:

Practical and administrative challenges

These include (Van Cleemput et al 2010, TS4SE 2011, Greenfields and Brindley 2016):

- A lack of appropriate documentation, including adequate citizenship documentation, which affects entitlement to services following recent migration.
- A lack of contribution-related entitlement to welfare.
- Limited access to or awareness of NHS entitlement.
- Poor or non-existent translation services for migrant Roma.
- Low literacy compounding existing barriers to concordance with treatments.
- The effects of poor or insecure accommodation and frequent movement on wellbeing or access to treatment regimens, particularly for 'homeless' Gypsies and Travellers.

Service mismatch and discrimination

This is of fundamental importance as it has all-pervasive effects on service delivery and relationships with providers of health and social care – it can minimise the ability of staff to provide care and reduce clients' opportunities to use healthcare appropriately and efficiently (Van Cleemput 2009, Greenfields et al 2015).

Health inequalities

Policies exist in the UK around GTR communities' access to healthcare. Some emanate from EU legislation requiring each member state to have a National Roma Integration Strategy (NRIS) that includes health. However, annual reviews of the progress in meeting NRIS targets have consistently highlighted the health inequities experienced by GTR communities in the UK (Ryder and Cemlyn 2014).

The European Commission (2014) analysed in depth the health of GTR people in 31 member states and found consistent inequity in morbidity and mortality between Roma and other people, most starkly in relation to life expectancy where there is a reduction of between five and 20 years for Roma. For Gypsies and Travellers in the UK, life expectancy is approximately 11 years less than the national average (Matthews 2008, EHRC 2015). As yet, no data exist about Roma life-expectancy post-migration to the UK; however, it is to be expected that their previous health status will continue to affect their life expectancy post-migration.

Health literacy among GTR populations and access to health services and preventative interventions – for example, in relation to screenings, immunisations and treatment for diseases such as TB – have been found to be especially problematic for migrant GTRs throughout the UK and Europe. Over-representation in rates of type 2 diabetes, arthritis, asthma and obesity, increasing reports of problematic substance misuse, and high rates of anxiety and depression are also common (Parry et al 2007, Greenfields et al 2015). High

rates of cardiovascular disease, hepatitis, HIV/AIDS and infant mortality, and low immunisation rates are also common across Europe (European Commission 2014, [EPHA 2014](#)).

There is therefore an urgent need for effective and culturally congruent practice interventions to deal with the 'ticking time-bomb' of GTR health needs.

Good practice examples

There are significant barriers for healthcare practitioners to overcome if they want to engage creatively and effectively with supporting and improving the health of GTR people. Communities are not routinely included in health statistics, although the optional patient READ- Code category (16+1) entered on to GP practice databases is being used in some localities to enumerate, and, in time, map the health status of, GTR patients (Traveller Movement 2014). There are some indications that NHS England will update the Data Directory codes to include these patients (Traveller Movement 2015). However, this has yet to occur and so it is strongly recommended that staff with managerial responsibilities or who lead on inclusion health for GTR people push for this category to be used in their areas, to enable effective monitoring of health status and increase the effectiveness of interventions.

There is a well identified gap in the cultural competence of people working with GTR communities – particularly in relation to health beliefs, family and community practices, engaging with GTR patients in a manner that allows for mutual dialogue and is not perceived as patronising, or simply taking into account literacy problems and so on (Van Cleemput 2009, Greenfields et al 2015). There is therefore a need for pre- and post-qualification training for staff in hospitals and the community that includes information on these groups, alongside more generic sessions on working with black and minority ethnic populations. Davis and Lovegrove (2016) found that few practitioners received specialist information on working with GTR communities, although they identified several examples of good practice and specialist outreach services. These provided, for example, double-length consultations, trained GTR community advocates to participate in surgeries and tailored 'in-reach' to Gypsy sites or locations with large Roma populations.

Overall, the good practice that exists tends to be driven largely by individual practitioners, who are interested in working with the populations after personal contact or the identification of a need in a locality. Clinical commissioning groups (CCGs) need to lead in meeting the health needs of GTR communities, but CCGs do not typically perceive these communities as a 'core group' when commissioning services. There is a tendency to overlook the profound needs of these populations, despite NHS guidance having been issued on best practice in commissioning effective services to support their healthcare needs that emphasises the social and financial cost of failing to support such vulnerable groups (NHS Primary Care Contracting 2009, Inclusion Health 2013). This guidance also says that trust needs to be developed with these communities to identify their needs, and highlights what has worked and failed in terms of engaging with local GTR populations needs to be evaluated.

An important element of understanding the evidence base to ensure services are appropriate and fit for purpose, and thus cost-effective, is to work with senior staff to influence the design of joint strategic needs assessments and joint health and well-being strategies to include GTR people in target groups, enabling effective strategic planning to engage with the health inequalities they experience. For example, a specialist survey of the health needs of Gypsies, Travellers and Boaters living on unofficial moorings or 'continuously cruising' without access to services (Greenfields and Lowe 2013) revealed significant levels of unmet need and rapid deterioration in conditions when interventions

were not made. As a follow-up, the local CCG commissioned a specialist outreach service through a local homelessness service non-governmental organisation (NGO) that incorporated fast-track access to services, including collaborative working with mental health teams and housing officials, offering the beginning of a wrap-around service to support these vulnerable groups.

An important way to enhance success when specialist services are commissioned or a decision is made in primary care to develop extended services or outreach to the communities is to work with NGOs and agencies that already have an established relationship with local GRT populations. In addition, it should be ensured at this stage that there is sufficient scope for interested community members, typically women, to input. Given their access and established relationships with their own communities, these members may also be willing to receive training and work alongside healthcare professionals as 'community health peer advocates'.

Greenfields (2009) outlined a typical example of a short training programme in a safe and culturally congruent learning environment that enabled women from Gypsy and Traveller communities to develop their own health literacy knowledge, as well as engage in discussions about 'difficult' topics such as 'mental health first aid', substance misuse and domestic violence. The programme also developed their practical skills such as cardiopulmonary resuscitation and awareness of the signs of stroke.

Activities being developed in some areas include replicating practices that have helped in engaging with subgroups of the GRT population, such as:

- Social events for older people that incorporate gentle physical activity.
- Healthy-eating initiatives that use traditional Gypsy/Traveller recipes cooked in healthy ways.
- 'Drop in' sessions with healthcare professionals at accessible venues such as GTR sites, church halls and community centres (McBarnett 2010).

Other innovative practices that have boosted immunisation levels and preventative screening among GRT communities include 'pop up clinics' at Gypsy/Traveller horse fairs such as Appleby or in shop-fronts in areas with large Roma populations. These allow for screening, onward referral or immediate interventions for those at risk of cardiovascular disease, children requiring vaccinations and patients with diabetes (Roberts et al 2007).

There are also longer term, 'slow burn' initiatives that rely on building trust and confidence. A Doncaster GP practice combined trained 'health ambassadors' from local Gypsy communities with longer appointments, opportunistic screening/immunisations when on sites and handheld medical records for nomadic travellers. The result was an increase in immunisation rates from 4% in 2003 to more than 70% in 2014; similarly, in 2004, no local GRT women received cervical smear tests, but 55% did in 2014 (Millett 2014).

Outreach services offering culturally-congruent maternity pathways, fast-tracking for 'at-risk' women and longer appointments were developed in Leeds. These increased the uptake of maternity services and engagement at an earlier stage, leading to greatly enhanced outcomes for women and the development of ongoing health relationships with other family members (Bennett 2013).

In all these initiatives, staff and commissioners developed and demonstrated an awareness of the overarching impact of the SDOH on GRT communities, recognising that health improvements and healthy living cannot simply be taken in isolation without a clear understanding of the stressors and tensions experienced by these marginalised populations.

Conclusion and recommendations

There is no single 'right way' to develop outreach and enhanced working with GRT communities. However, best practice initiatives that increase the uptake of service and observable measures that enable core targets to be met demonstrate flexibility, innovation,

patience, the development of trust between healthcare professionals and service users, and close collaboration with communities. It is possible to adapt existing services that have 'worked' with other minority ethnic populations, but without understanding the specific needs of GRT people and ongoing dialogue, these are likely to be less effective than anticipated.

In a climate of short-term commissioning, services need to demonstrate rapid change if they are to be recommissioned. There is therefore a need to move the parameters of health improvement activities so that working with GRT people is not seen merely as a 'preference' or a marginal task undertaken by some practitioners, but as something that is intrinsic to all healthcare professionals' jobs. One way to do this is to ensure that cultural competence training includes the needs and awareness of GRT groups and is routinely provided to all staff pre- and post-qualification. Incentives could be provided such as offering CPD points or clinical rotations that include some time spent with specialist agencies or NGOs that support GRT populations.

Discussions with commissioners and healthcare professionals who have participated in research studies (for example, Van Cleemput 2009, Greenfields and Lowe 2013) repeatedly demonstrate that fear and misunderstanding create barriers between professionals and service users. In addition, there needs to be recognition that GRT community members are a part of the population and they require provision just as much as housed residents in leafy streets do. Otherwise, they will be continually viewed as an 'optional' group whose needs are overlooked when planning or providing services.

To minimise this risk and save money, it can be effective to work across CCGs to jointly commission for these populations. Engaging strategically with local projects can also help – for example, by providing a nurse-led clinic in a drop-in centre for GRT people where they routinely access advice on benefits or accommodation.

A further strategy is to retain a file of contacts, details of experienced staff, for example, who speak Roma dialects or who have community contacts, and a resource library. When GRT people access primary or secondary care and unmet needs are identified, it is then possible to ensure that knowledge is pooled, appropriate referrals are made and information is shared between teams. For example, a family experiencing repeated eviction and seeking help are automatically and opportunistically able to have their health needs taken into account. Similarly, a health emergency that affects other SDOH can be supported by interdisciplinary teams, who may be able to assist in meeting social care, educational or other household needs.

Finally, there is no substitute for reading and learning more about the needs of GRT people and most of all, arranging to spend time with members of the community by engaging with NGOs and experienced colleagues. In this way, primary healthcare professionals can make real changes in the health and wellbeing of GRT people.

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