Traveller health and primary care in Ireland: a consultative forum

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Abstract

Travellers in Ireland continue to experience health disparity, cultural fragmentation and a lack of visibility in health service provision. This paper reports on a pilot study exploring factors that affect Traveller health and the experiences of primary care services from the perspectives of key Traveller health stakeholders in Ireland. The study was designed as an initial consultative forum using a single focus group (n=13) in order to yield specific recommendations for the development of a designated primary care service framework for Travellers. A thematic analysis of the narratives identified key areas of interest – emerging issues in Traveller health, recognition of Traveller culture and ethnic identity, Traveller uptake of primary care services, the role of the primary health care Traveller (PHCT) worker, and recommendations for a primary care service framework for Travellers in Ireland. The findings highlight the importance of consulting Traveller communities in the design of a primary care service framework within each local needs analysis. The promotion of Traveller advocacy, visible access and referral pathways can therefore be achieved, with PHCT workers acting as a 'bridge' between Travellers and the designated area primary care team.

Key words

Travellers, primary care, health inclusion

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Background

The Irish Travellers are a small indigenous group, typically nomadic, who have been part of Irish society since the Middle Ages and are defined as 'a community of people commonly so called who are identified (by themselves and others) as a people with a shared history, culture and traditions, including, historically, a nomadic way of life on the island of Ireland' (p5).[1] Travellers in Ireland are not recognised officially as a minority ethnic group, but maintain their identity as an ethnic nomadic group in Ireland by choice and reinforcement of their detachment from the 'settled' community.[2] Limited opportunities for interaction between Travellers and the sedentarist population exacerbates the negative perception of Traveller culture and fuels institutional discrimination.[3] Poor housing conditions for Travellers in Ireland, amid coercive assimilatory government efforts, remain fundamental to Traveller health disparity, poor educational outcomes and high unemployment.[4]

The health status of Travellers and Gypsies in the UK is significantly worse than the general population, with greater self-reported symptoms of ill health than other UK-resident, English-speaking ethnic minorities and economically disadvantaged white people.[5] The average life expectancy of Travellers in the UK is low, particularly among men, and Traveller families have one of the highest birth rates in the EU, but experience high levels of infant mortality, high rates of still births, low birthweight and premature deaths of older offspring, with some evidence of hereditary disease caused by consanguinity.[5] Travellers are also more likely to suffer from self-reported anxiety, asthma, chest infections, heart disease, diabetes, stroke, cancer, disability, diarrhoea, infections and other health complications linked to compromised life circumstances.[6,7]

In Ireland, there is a lack of systematic data collection on Traveller health and an absence of Traveller ethnic identification within health service systems. The most current research on Traveller health status was conducted in 1987,[8] and reported that life expectancy for Travellers was significantly lower than the national average – again, in particular for Traveller men – with high infant mortality from still birth and sudden infant death, and high fertility rates.[8] The study also reported high use of obstetric services and lower uptake of family planning clinics, a lower breastfeeding rate, and less uptake of antenatal, postnatal, child immunisation, developmental paediatric and specialist child health services.[8] Anecdotal evidence suggests a widening health gap between Travellers and the sedentarist Irish population.[1-3,9] In 2007, the All-Ireland Traveller Health Study was initiated to provide baseline data on Travellers' health status in the Republic of Ireland and Northern Ireland, assess health service provision and identify factors that influence Traveller mortality and health disparity. This is due to complete in 2011 and will inform the policy debate surrounding Traveller service provision.

In recent times, progress has been made in Ireland as a result of equality legislation, dedicated health policies and appreciation of Traveller culture, amid greater lobbying efforts on the part of Traveller organisations seeking to address Traveller health and the lack of culturally appropriate service provision. However, traditional health service provision in Ireland is designed to serve mainstream society in terms of language, literacy, information and access to services, which contributes to further Traveller exclusion and lack of Traveller cultural acceptance.[2] In 2002, the national Traveller health strategy stated that 'this strategy re-affirms the right of Travellers to appropriate access to healthcare services that take into account their particular needs, culture and way of life' (p9).[9] The prejudice and discrimination experienced by Travellers is therefore inherently relevant both to Traveller health status and health service provision. However, according to the national Traveller health strategy review in 2005,[2] deficits still existed in Ireland:

- A lack of ethnic identification and data collection on Traveller health

- A dearth of focus on Traveller psychiatric health, intellectual disability, substance use, gender differences and suicide
- Continued problematic access to and uptake of health services
- The need for training about racism for health service staff.

On a positive note, improved culturally appropriate health promotion materials and programmes are emerging, with the recognition of Traveller literacy issues leading to increased use of visual media to explain a variety of health topics, increased Traveller involvement in Traveller health units, recruitment of designated Traveller public health nurses, and the development of roles for primary health care Traveller (PHCT) workers – who are Travellers themselves – for involvement in peer-led training and health education. This strategy recognises the importance of a community development approach in dealing with Traveller health inequalities:

- Creating empowerment for community and individual health ownership
- Peer-led services
- Development of roles for Travellers as service planners, providers and promoters
- Providing an accessible, equitable and Traveller-sensitive health service.[2]

Travellers have the right to access health services that consider their specific cultural needs, health practices and way of life.[1,2,9]

The Department of Health and Children (DoHC) in Ireland has recognised that Travellers 'have a right to have their culture recognised in the planning and provision of services' (p15).[9] Primary healthcare programmes for Travellers have been identified as a cornerstone of this,[1] with such Traveller-led PHCT programmes being developed across Ireland to provide advocacy and address health needs. However, there is a growing need to ensure that these Traveller-led programmes are not used in isolation to deal with Traveller health disparity. While showing promise, they may further exclude Travellers until such time as primary care teams advocate a culturally accepted method of treating Travellers within current healthcare provision.[1,2] In the UK, the NHS has a dedicated Traveller and Gypsy primary care service framework (PCSF)[10] with a focus not on providing separate services for Travellers and Gypsies, but on presenting a series of components to ensure that these communities can utilise high quality mainstream primary care services. In Ireland, even with the presence of efficient and community-oriented PHCT projects, the development of such a protocol within the primary care setting is needed urgently.

This paper presents an exploratory account of stakeholder perspectives of Traveller needs relating to Traveller health and primary care provision in Ireland, and was conducted as a pilot consultative forum for the identification of guidelines for a Traveller PCSF in Ireland.

Methods

Data collection

A single focus group was conducted with Traveller health unit stakeholders (n=13) from each health board area. The stakeholders had contact with Travellers in the course of their work on a national level. Some were Travellers themselves (n=6), and so well positioned to detect recent developments in the lives and health outcomes of Travellers. The researcher facilitated the focus group, guided by a structured schedule that was based on identified issues relating to:

- Physical and psychosocial health
- Cultural beliefs surrounding health
- Life circumstances
- Primary care needs, experiences, access, cultural acceptance and utilisation
- Potential considerations for the development of an Irish Traveller PCSF.

The focus group was audiotaped with permission of the participants.

Ethical considerations

The Traveller Ethics, Research and Information Working Group was established by the DoHC in 2002 as a Traveller Health Advisory Committee sub-group. Its terms of reference set the standards of ethical conduct for this pilot study – participants were informed fully about the research and any risks involved, confidentiality and anonymity were respected at all times, participation was voluntary and free from coercion, with withdrawal possible at any stage, and the independence and impartiality of the researcher was made clear throughout the process. In order to protect the identities of participants, the research did not engage in debate involving specific geographical areas.

Data analysis

Following transcription, a content and thematic analysis of the discussion using the qualitative software package NVivo was conducted. This involved generating 'a list of key ideas, words, phrases, and verbatim quotes; using ideas to formulate categories and placing ideas and quotes in appropriate categories; and examining the contents of each category for subtopics and selecting the most frequent and most useful illustrations for the various categories' (p35).[11]

A certain level of synchronic reliability was achieved, whereby two or more perspectives between the narratives were in relative agreement. The analysis mapped the narratives relating to primary care service provision for Travellers in terms of:

- Emerging issues in Traveller health and life circumstances
- Recognition of Traveller culture and ethnic identity
- Traveller uptake of primary care clinics
- The role of the PHCT worker
- Recommendations for a PCSF for Travellers in Ireland.

Results

The stakeholders recognised that Traveller tradition, nomadism and beliefs surrounding health are fundamental to addressing Traveller health disparity and to achieving health equity and culturally sensitive responses in primary care. Most observed that health disparities continued in spite of service and PHCT efforts to engage with Traveller communities. The lack of up-to-date ethnic identification in health records was deemed to compound problems in health tracking, such as regarding immunisations, appointments and transience.

Emerging issues

Emerging Traveller health needs relating to disability, mental health and drug dependency were deemed to incur stigma and shame within the Traveller community, with Travellers often seeking to address these in another health board area to avoid recognition and discrimination:

Primary care teams and [PHCT workers] need to link... especially in the case of drug treatment and counselling for depression or suicidal thoughts... the stigma will limit what services are accessed... Travellers are very private... they wouldn't tell the [PHCT workers] if they thought they would have to access services where other Travellers known to them are.

Other common needs included poor uptake of immunisation programmes and of antenatal and postnatal services, and issues relating to domestic violence. It was

felt that local Traveller knowledge around health and cultural practices needs to be recognised and built upon, to highlight and target services to cater for these specific needs in each health board area:

The GP network needs information – the local stuff is vital... building everything into this primary care team would help Travellers.

Key points

- Travellers in Ireland have a less favourable health status than the sedentarist population
- A pilot consultative forum was held of stakeholders from each health board area
- The forum identified emerging health issues, a need for cultural and ethnic recognition, problems in uptake of primary care services, the importance of the primary health care Traveller worker role and recommendations for a primary care service framework

Recognition of culture and identity

Some stakeholders described difficulties for Travellers in engaging with primary care team professionals, difficulties in recruiting primary care professionals to attend 'Integrated Traveller and Primary Care' days, and a general need for race and cultural awareness training for primary care staff. Some observed a lack of visibility of Traveller health needs in written health educational leaflets. Other stakeholders observed the need for the primary care team to meet Travellers in their own settings – such as caravan bays, halting sites or group housing projects – in order to observe and understand the reasoning behind cultural health traditions (for example, relating to immunisation or alcoholism) within an overall recognition of the life circumstances of this ethnic group. Many primary care staff had little or no contact with Travellers in the course of their day-to-day life, which was deemed to increase levels of suspicion and discrimination. Others felt that if the PHCT worker had a designated space in the primary care clinic, discriminatory instances could be reduced for Travellers. This highlights the importance of the PHCT role within the primary care team:

Travellers need to feel they belong... whilst Travellers hear it best from a Traveller... at the same time, they need to feel an appreciation of where they come from and what they are dealing with in life.

Uptake of primary care services

In terms of primary care uptake, GP lists were perceived to be problematic as the only existing mechanism of entry into primary care services, contributing to overuse of hospital accident and emergency services by Travellers:

Historically, private clinics didn't treat Travellers fairly.

Travellers are entitled to access and not just [through] GP lists.

Some stakeholders felt that private or geographically based primary care clinics could contribute to further exclusion of Travellers, particularly where GPs are over subscribed with or refusing to take Travellers, and with the unavailability of specific services in areas with large Traveller communities, such as physiotherapy, speech and language therapy, disability services and addiction treatment. Others commented that geographic establishment of primary care teams could offer greater health equity for Travellers:

The GP list has often 80% Travellers... to maintain continuity of treatment, geographic lists are better located to deliver equity for Travellers and ensure confidentiality... Travellers won't go if they think other Travellers could find out their problems.

Some PHCT programmes had dual registration of Travellers through the local GP and the primary care team, in order to achieve some equity of care:

You need dual registration of GP and primary care settings... just to ensure equity... and the right care.

Most of the key stakeholders commented on a general lack of communication between primary care service settings and Traveller communities in terms of poor referral systems, difficulties in securing appointments, lack of clarity for some Travellers with respect to their rights to an explanation of medication and treatment pathways, and unsatisfactory primary care service experiences overall:

There's a lack of community consultation, outreach and networking between each other and between the Traveller groups.

Sometimes they can't get an appointment, sometimes the public health nurse just doesn't follow up... there's no relationship between [primary care staff] and the Travellers.

Role of the PHCT worker

The majority of stakeholders observed the need to empower the Traveller community to take ownership and responsibility for their own health, and reflected that this could only occur via PHCT mediation. The stakeholder group felt that the PHCT worker has the potential to act as a 'bridge' between the Traveller community and designated primary care team in each locality. The role needs to be viewed as professional or semi-professional, and expanded to provide outreach to needy Travellers, assist in the case of illiteracy, aid in access, referrals and post-care tracking, and act as advocate for Traveller rights and needs surrounding their health, within a confidential setting. Local needs assessments facilitated by the PHCT worker with improved cohesion between the primary care team and Traveller families would help to create an initial benchmark of need:

Travellers should be in the network with the primary care team... the primary care delivers... but you need a team involving the [PHCT worker] to help with appointments, referrals and advocacy... the current infrastructure is weak.

There's a unique selling point here... the [PHCT worker] needs to be seen as a potential contribution to the community, especially for localised needs assessment... Travellers need to be consulted for these needs assessments, otherwise they won't be catered for... the census data needs to be used within a wider policy framework.

PCSF recommendations

The stakeholders highlighted these key themes for the development of an effective Traveller PCSF:

- Establishment of an analysis of local Traveller needs
- Improved health data records and tracking of Travellers
- Active partnerships and consultative forums between Travellers and primary care staff
- Development of bridging initiatives using the PHCT worker to raise Travellers' awareness of primary care services, and to act as outreach and advocate in improving access, utilisation and referral care pathways
- Inclusion of specific services targeted to emerging Traveller health needs, such as disability, mental health and addiction

- Mandatory cultural and racism awareness training for all primary care staff.

GP registration, whether within a private primary care setting or based on a geographic health board list, should be as unobtrusive as possible, and take communication, registration, tracking and comprehension difficulties into consideration with an empathetic, considerate approach.

Discussion

The pilot project provided an exploratory consultative account of potential methods to recognise Traveller health needs, incorporating Traveller culture, improving Traveller uptake of services and service experiences into the design of a dedicated Traveller PCSF in Ireland.

Traveller health status in Ireland and the UK is disparate when compared with the mainstream sedentarist population.[5-8,12-14] Factors such as housing, poverty, discrimination and marginalisation need to be addressed in a broader perspective of social exclusion and inequality, and will hold the most promise for improvement of Traveller health status. This represents a move away from consideration of Traveller culture and ethnicity in isolation and toward the process of community development. In the UK, community partnership and intersectoral collaboration between Gypsies and Travellers and healthcare agencies are key factors in the success of PCSFs.[7,12,13]

Travellers in Ireland require specific consideration within the primary care setting due to their ethnicity and culture, different perceptions of health, disease and care and their distinct health and disease problems when compared to mainstream sedentarist society. Barriers to primary care access reflect previous UK research[7,12,14] and include the refusal of some GPs to register Travellers, experiences of discrimination, lack of treatment continuity and overall lack of cultural awareness, empathy and understanding in treating Travellers. Geographic establishment of primary care clinics, whether public or private, remains a concern in terms of GP refusal to subscribe Travellers, or indeed the oversubscription of Travellers in certain private or public primary care clinics. Emerging health needs such as drug dependency, suicide and developmental disabilities need to be catered for, in a safe and secure setting free from confidentiality concerns and stigma. A collaborative approach between Traveller groups and the primary care team is advised in order to utilise local knowledge of Traveller needs, give a voice to Travellers in the planning and implementation phases, reduce racism and negative service experiences for Travellers, heighten cultural awareness among healthcare professionals, improve access and referral, and increase primary care service visibility in each area where Travellers reside. In this process, the Traveller community would be empowered to address their own diverse health needs through improved advocacy, representation within community and primary care settings, and consultation in management of culturally accepting PCSFs.

Conclusions

The Traveller community in Ireland is a distinct cultural group presenting with inherent health disparity,[1] and with different health problems and cultural beliefs than the mainstream sedentarist population.[2,8,9] The core value of achieving equity in primary care provision remains central not only to equality of access, but also to equality of participation, health outcome and the recognition that Traveller communities require an empowered, innovative and inclusive approach to provision, planning and implementation.[1] The involvement of Travellers in local needs assessments and the potential of PHCT workers cannot be underestimated in presenting the ideal link between Travellers and primary care teams, whether private or public, in terms of advocacy, education, administration, community training and political lobbying for Traveller health-related needs, and ultimately improving Traveller quality of life, life expectancy and health status.

This pilot project involved an initial consultative forum of national stakeholders, with these exploratory findings contributing to the development of a PCSF for Travellers and lobbying document for the Irish DoCH in 2009. However, it is noted that this study was limited by the smallscale nature of the sample, potential power differences and dynamics of individuals in the group, and varied appreciation of Traveller culture. Future research efforts plan to sample Traveller communities, PHCT workers and primary care teams in each health board area to further explore the need for the development of a national set of guidelines for an improved PCSF for Travellers.

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