Reaching out effectively to Gypsies and Travellers

In the second article of their series on dementia among Traveller communities, **Mary Tilki** and colleagues look at how service commissioners and providers can reach out effectively

Although Gypsies and Travellers generally have a low life expectancy (CLG 2012), there is growing evidence of dementia in these communities. Gypsies and Travellers (both groups will be referred to hereafter as Travellers) experience extremely poor health. Much of this ill-health is caused by cardiovascular disease and depression and potentially increases the risk of dementia. Social factors related to the lifestyle and experience of travelling people add to the risk and make it particularly difficult for them to cope with the condition. In turn, this impacts on the ability of family and community to cope, although their willingness to do so is strong.

The first article in this series (Tilki *et al* 2016) talked about the growing evidence of dementia in Traveller communities, highlighting the factors predisposing to this and examined the additional difficulties experienced by Travellers with memory problems and the families caring for them. This article suggests ways in which commissioners and providers could reach out to Travellers to offer information, support and services which are accessible and acceptable.

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Obtaining accurate information about Travellers is a challenge because literacy, travelling lifestyle and suspicion among Travellers can make it hard to collect data. In addition, the census category "Gypsies and Travellers" fails to distinguish between Romany Gypsies, Irish Travellers, Scottish Gypsies and others included in this catch-all term and ignores cultural, socio-economic and health differences between them. Further, there is a distinct lack of effort by joint strategic needs assessment (JSNA) bodies to obtain the information needed to plan services for travelling people (Prior 2013; Inclusion Health 2013; KMPHO 2014).

In the absence of data, commissioners wrongly assume that services are not needed or that Travellers choose not to access them. Limited or late access is seen as self-segregation but few attempts are made to understand why Travellers avoid using mainstream services. However, with commitment and creativity more accurate information can be obtained.

We saw last time that these issues about access to services arise in spite of the fact that the health of Travellers is poorer than that of the general population. While the travelling lifestyle puts obstacles in the way of registering with a GP, experiences of racism, discrimination and insensitivity during previous encounters with health professionals play a greater part in generating mistrust and reluctance to seek help (VanCleemput 2012). When a health professional is trusted, there is evidence that Travellers will return from long distances to consult that professional (MECOPP 2012).

Importance of data

Travellers often lack knowledge about dementia and many believe that memory loss and confusion are normal aspects of ageing so they may not seek help until a crisis occurs (Tilki *et al* 2016). But commissioners, providers and professionals should be reminded that Travellers have rights under race relations and equality legislation. They should not be defined by their travelling status and their diversity should be recognised rather than aggregated into a single category.

Local authorities and health trusts have a duty to obtain evidence and incorporate it into joint strategic needs assessments and health and wellbeing strategies. Sound creative mechanisms should be employed for data collection. For example, in the total absence of data, Leeds Baseline Census of Gypsies and Travellers 2005 (Leeds REC 2005) used a chain referral or snowball sampling method to identify community members, while data collection was undertaken by Traveller community researchers using a simple form requiring minimal

Leeds GATE chair Kim Moloney and her father Paddy Moloney at Lee Gap Horse Fair, West Yorkshire. Kim cares for Paddy, who has dementia.

Stow Horse Fair in Gloucestershire

literacy. In this sampling method initial participants help researchers find others to take part.

Travellers should be helped to understand that ethnicity data are for planning and monitoring the effectiveness of services and not for surveillance. Trusted groups such as LeedsGATE, Traveller Movement or local Traveller organisations should be funded to connect with and identify the needs of communities that can easily be suspicious of such initiatives. Traveller groups or representatives are always willing to facilitate access to sites where professionals are unfamiliar so that they can consult people about their needs and wishes (LeedsGATE 2011). Good practice suggests that health and wellbeing boards and clinical commissioning groups should have an 'inclusion champion' who knows and understands the circumstances of Traveller communities (Carr 2014).

Communicating information

Commissioners must not assume that low life expectancy or the younger age profile of Travellers precludes dementia. There is a high probability of dementia before 65 associated with a wide range of (modifiable) risk factors (LeedsGATE/Irish in Britain 2016). Travellers will accept services if time is taken to build trust, identify what they need and provide ways of working which are amenable to them. The term 'memory loss' is better, and less frightening and stigmatising for Travellers than words like 'dementia' or 'Alzheimer's'. The term 'carer' is meaningless to Travellers who see themselves as family meeting obligations to a loved one.

Given the low levels of literacy among some Traveller groups, information which doesn't rely on literacy such as face-to-face communication, DVDs, videos or animations should be tried (LeedsGATE 2011, KMPHO 2014). Traveller events or festivals can afford opportunities to consult with the community, raise awareness or give out information. But funding should be offered to acknowledge the value of the community and to cover some of the costs.

Rather than focus on the negative aspects, it is important to promote the benefits of early diagnosis so that Travellers with dementia and their families can prepare for the later stages of life. This may allow those who are suitable to be prescribed drugs which delay progress. Early recognition may also give family and community time to learn ways of adjusting to enable the person with memory loss to maintain independence. There should also be consultation about what culturally sensitive care might mean on a Traveller site, in settled housing or in residential establishments.

Other useful resources

LeedsGATE (2013) "Gypsy and Traveller Health - Who pays?" Health pathways: cost benefits analysis report. Leeds Gypsy and Traveller Exchange/Real-Improvement

LeedsGATE/Irish in Britain (2015) Dementia in Gypsy and Traveller communities. Leeds Gypsy and Traveller Exchange.

MECOPP Carers Centre, which supports ethnic minority carers, offers useful pages on its website, including "Gypsy/Traveller Carers Project" and "Gypsy/Traveller Seminars". Go to www.mecopp.org.uk and click on "services" to find the headings.

Roma Support Group: Empowering the Roma Community since 1998. A Roma-led charity which works with east European Roma refugees and migrants. Go to http://romasupportgroup.org.uk

The Traveller Movement website has an advocacy and support section and other helpful materials. See the health and wellbeing link under advocacy and support. Go to www.travellermovement.org.uk

Outreach working

Open door policies do not work with Travellers so they must be reached out to (Carr *et al* 2014). Culturally appropriate help brokered through trusted professionals is likely to make an impact, although outreach works best when potential users are involved in planning and decision making to establish trust, reduce suspicion and shape services acceptable to marginalised people.

Outreach must be more than a one-off event. It is a long-term activity and should help to develop the capacity of Traveller communities to improve their own health (Carr *et al* 2014). Providers and professionals must understand that outreach is not unidirectional. It is about engaging with disengaged communities and working with them to change the systems and processes which currently exclude them.

Effective outreach does not impose a particular viewpoint, but seeks to find out what works by cooperating with people who understand the community. It recognises the existing strengths of communities, learning about and building on support systems and networks. Members of the Travelling community can be equipped as 'lay trainers' to provide basic information, advice and support. However, one size fits all approaches should be avoided: for example, lay trainers may be right for some Travellers or to address some health matters, but trusted professionals may have greater credibility for others (Carr *et al* 2014).

The involvement of lay trainers or Traveller groups in consultation or health promotion is not cost free, but a modest investment in these services can result in considerable cost savings for acute services in the long term. Cultural awareness training delivered by Travellers can be effective in improving knowledge and understanding among professionals too.

Building on assets

Suitably equipped Traveller groups can bridge the gap with commissioners and providers as an aid to the flow of information. They can have a significant role in consulting with communities (Inclusion Health 2013; LeedsGATE/FFT 2015). Travellers, equipped as lay trainers, can raise awareness of dementia and offer information and support to family carers. And they can promote health, both among people with dementia and carers, in relation to cardio-vascular disease, smoking cessation, weight management and healthy living, cutting the risk of dementia or slowing down its onset.

Travellers can be trained up as dementia champions or to provide enjoyable and stimulating culturally appropriate activities. Although travelling people are reluctant users of residential care and nursing homes, when they do go into these settings their beliefs and traditions are generally misunderstood. Lay trainers can help staff understand the barriers and learn how to provide care in ways that respect their culture and way of life.

Conclusion

The growing incidence of dementia is an issue of concern in travelling communities, which often feel overlooked despite the increasing attention to the subject in wider UK society. More research is clearly necessary but, if dementia is to be prevented or delayed, commissioners and providers will have to engage with them more effectively.

Distinct evidence already exists of success in harnessing the expertise of Traveller organisations in outreach work around health generally. There is much to be learned from these experiences that can be adopted in the specific instance of dementia.

References

Carr S, Lhussier M, Forster N, Goodall D *et al* (2014) Outreach programmes for health improvement of Traveller Communities: A synthesis of the evidence. *Public Health Research* 2(3).

CLG (2012) *Progress report by the ministerial working group on tackling inequalities experienced by Gypsies and Travellers.* London: Department for Communities and Local Government (CLG).

Inclusion Health (2013) *Standards for Commissioners and Service Providers: The Faculty for homeless and service providers*. London: Inclusion Health/Faculty for Homeless and Inclusion Health/College of Medicine/Pathway

KMPHO (2014) *Kent Gypsy, Roma and Traveller Populations: JSNA Chapter Update 2014.* Maidstone: Kent and Medway Public Health Observatory.

LeedsREC (2005) *Leeds Baseline Census of Gypsies and Travellers*. Leeds: Leeds Racial Equality Council.

LeedsGATE (2011) *How to engage with Gypsies and Travellers as part of your work*. Leeds Gypsy and Traveller Exchange / Inclusion Health

LeedsGATE/FFT (2015) *The National Gypsy and Traveller Health Inclusion Project 2012- 2015*. Leeds Gypsy and Traveller Exchange /Friends Family and Travellers (FFT).

LeedsGATE/Irish in Britain (2016) *Dementia in Gypsies and Travellers: brief guide for commissioners and providers.* Leeds Gypsy and Traveller Exchange/Irish in Britain.

MECOPP (2012) *Hidden carers, Unheard voices: informal caring within the Gypsy/ Traveller community in Scotland*. Edinburgh: MECOPP.

Prior P (2013) Support and care for people living with dementia from minority communities. Newcastle: North East Dementia Alliance.

Tilki M, Curran C, Moloney K, Jones H (2016) Dementia among Gypsies and Travellers. Journal of Dementia Care 24(4) 12-13.

VanCleemput P (2012) Providing healthcare to Gypsy and Traveller communities. Nursing in Practice May/June 26-28.