

‘We look after our own’: Dementia in Gypsy and Traveller communities

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We undertook a piece of research to find out more about awareness of the symptoms of dementia in Gypsy and Traveller communities, awareness of ways to reduce the risk of dementia, and to find out more about access to care and support for dementia.

Key findings

- Campaigns raising awareness about risk reduction activities to prevent dementia are often not reaching Gypsy and Traveller communities.
- A significant number of Gypsies and Travellers would not attempt to access support for dementia because they feel that they would not receive culturally appropriate care.
- The majority of Gypsies and Travellers share a strong preference for carers from within the Gypsy and Traveller communities.

Introduction

‘They don’t understand the culture – we look after our own. They might want to take them away and lock them away’

As the population ages and lives for longer, dementia is becoming a growing challenge. It is estimated that 850,000 people in the UK live with dementia¹. Dementia mainly affects people over the age of 65 and the likelihood of developing dementia roughly doubles every five years. As Gypsy and Traveller communities are thought to live between ten and 25 years shorter than the national average, theoretically there are likely to be smaller numbers of Gypsy and Traveller people experiencing dementia.

We spoke to 20 participants from Gypsy and Traveller communities to gain an understanding of how Gypsy and Traveller communities perceive and experience the services available to those with dementia. Despite the relatively low life expectancy of Gypsies and Travellers in the UK, our research found that 80% of participants knew someone in the Traveller community who had been diagnosed with dementia.

Awareness of dementia

Whilst the majority of those surveyed identified forgetfulness and confusion as signs of dementia, only 65% recognised that changes in behaviour which are out of character is a sign of dementia. This shows a reasonably high awareness of the signs of dementia, with some room for improvement. However, from the group surveyed, 55% of the participants said that they did not know that eating healthily, doing more physical activities or managing existing healthcare could help to reduce the risk of dementia. This shows that there is a lack of awareness of ways to reduce the risk of dementia.

¹ <https://www.england.nhs.uk/mental-health/dementia/>

There are a number of reasons why health messages about reducing the risk of dementia may not be reaching Gypsy and Traveller communities. A key barrier identified is that many health messages rely on written word. In 2016/2017, 45% of Friends Families and Travellers service users had low or no literacy. This is in-keeping with the 2011 Census of England and Wales which found that only 40% of Gypsies and Travellers had any formal qualifications². Whilst this number is higher than many other communities, the National Literacy Trust found that 15% of adults in England were ‘functionally illiterate’³. This reinforces the importance of sharing health messages in a number of formats and asking people how they want to receive health information, so that everyone has the best chance of living healthy and happy lives.

Fear around accessing support for dementia

Of those surveyed, 20% of Gypsies and Travellers said that they would not see a doctor if they or a family member had one or more of the symptoms of dementia. One respondent said that they wouldn’t go and commented that this was “because the symptoms don’t seem dangerous”. Another respondent said that they wouldn’t attend the doctor “because they don’t understand the culture – we look after our own. They might want to take them away and lock them away”.

Of those surveyed, over 35% said that they would not make use of services (gardening, singing, cooking and music making) available to those with dementia if they had it. Comments shared included, “If it was me probably not because I wouldn't want to take someone with me and burden them” and “No, because there would be no Travellers involved”.

It seemed that those surveyed had a real fear that they might not be understood by health professionals and the wider community. Many participants felt that there was no guarantee that professionals would consider their interests and preferences around their care and in particular that there was a lack of understanding around culture. These fears may often be backed up by very real experiences of discrimination or lack of understanding.

Caring for Gypsies and Travellers with dementia

Of those surveyed, over 55% said that if someone in the Gypsy or Traveller community was diagnosed with dementia, they would not let someone from outside of the community to care for them. There were a number of comments to explain this including, “Because us Travellers look after our family, and wouldn’t want to get locked up in a home”, “They should be cared for by family”, “They don’t understand our culture and afraid to be locked up in a home”. One respondent said, “My late mother in law had it and my wife did most of the care”.

In many Gypsy and Traveller families, care for the old, young or vulnerable is seen as the responsibility of the family, often women within the family. In the 2011 Census of England,

²<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/whatdoesthe2011censustellusaboutthecharacteristicsofgypsiorishtravellersinenglandandwales/2014-01-21#qualifications>

³ <https://literacytrust.org.uk/parents-and-families/adult-literacy/>

Gypsies and Travellers were found to be the ethnic group with the highest number of providers of unpaid care⁴. In some cases, members of Gypsy and Traveller communities may not be aware of the support, financial or otherwise, that is available to carers within the family, and this is an area where families may benefit from help in identifying potential sources of support. Where possible and desired, arrangements should be made which allow and assist carers from within the communities to support those who need it within their family.

Recommendations

- Clinical Commissioning Groups should develop resources on dementia in partnership with Gypsy and Traveller community members, ensuring these are accessible for anyone with low literacy.
- Clinical Commissioning Groups should ensure that health practitioners working with people with dementia and their families are committed to providing culturally appropriate care and support.
- Clinical Commissioning Groups should commission services to deliver assertive outreach to Gypsy and Traveller communities who may otherwise not be linked into services.
- GPs should ensure that memory assessment questions are relevant to Gypsy and Traveller communities and do not depend on literacy to take part.
- Adult Social Services should ensure that, if preferred, Gypsy and Traveller people with dementia should be cared for by members of their own community.
- Adult Social Services should ensure that wherever possible, those with dementia should be supported to stay in the accommodation of their choice.

About us

Friends, Families and Travellers is a leading national charity that works on behalf of all Gypsies, Roma and Travellers regardless of ethnicity, culture or background. Friends, Families and Travellers is a member of the VCSE Health and Wellbeing Alliance, which is a partnership between voluntary sectors and the health and care system to provide a voice and improve the health and wellbeing for all communities.

⁴<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/whatdoesthe2011censustellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales/2014-01-21>