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Dementia and the Deaf community: knowledge and service access

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Objectives: This study concerns culturally Deaf people in the United Kingdom who use British Sign Language (BSL). Its objective was to explore how Deaf people's knowledge about dementia and access to services is mediated by their minoritised cultural–linguistic status.
Methods: Twenty-six members of the Deaf community participated in one of three Deaf-led focus groups in BSL corresponding with the sample of: Deaf people over the age of 60 without dementia; Deaf people aged 18–60 working professional roles unconnected with dementia services; ordinary members of the Deaf community aged 18–60. Data were subjected to a thematic content analysis.
Results: Participants' concerns about their poor levels of knowledge and understanding of dementia were augmented by their awareness that without sustained social contact in BSL opportunities for earlier recognition of dementia would be lost. Although primary care services were identified as the first port of call for dementia-related concerns, there was widespread mistrust of their effectiveness because of failures in communication and cultural competence. Confirmed diagnosis of dementia was not viewed as a gateway to services and support because Deaf organisations, dementia-related organisations and mainstream adult services were perceived to be ill-equipped to respond to the needs of Deaf people with dementia.
Conclusions: Locating problems of late diagnosis within the Deaf community's poor awareness and knowledge of dementia fails to recognise the structural barriers Deaf people face in timely access to services and accurate recognition of dementia-related changes.

Keywords: Deaf; sign language; access; dementia

Introduction

According to recent reports, less than half of people with dementia living in the United Kingdom (UK) are formally diagnosed with the condition (All-Party Parliamentary Group [APPG], 2012; Alzheimer's Society, 2013). Strategies to combat the under-detection and under-reporting of dementia are also central to each of the 24 National Dementia Plans that are currently available across Europe (Alzheimer Europe, 2013) with a recent World Alzheimer's Report going as far as to suggest that the provision of a diagnosis of dementia should be seen as a human right (Alzheimer's Disease International, 2011, p. 27). Timely diagnosis of dementia is a gateway to a host of service responses to support better quality of life, whether from a medical or social care point of view (Alzheimer's Disease International, 2011; Department of Health, 2013; Hutchings et al., 2010; National Institute for Health and Clinical Excellence/Social Care Institute for Excellence [NICE/SCIE], 2006). It also ensures maximal time for the person with dementia and their family and friends to make individualised choices that can support preferences about living well with dementia on a day-to-day basis (Department of Health, 2013; Ward, Howorth, Wilkinson, Campbell, & Keady, 2012).

However, the opportunities for earlier recognition, diagnosis and timely service responses are not evenly distributed amongst the growing population of people who will experience dementia. For example, black, minority, Asian and ethnic communities (BAME) in the UK face greater barriers to earlier diagnosis because of poor access to information tailored to specific language needs and/or cultural perspectives (APPG, 2013). At a European level, the quality of diagnostic and care services for younger and older people with dementia are unevenly distributed on a geographical basis (Jones, Mackell, Berthet, & Knox, 2010) and pathways to care lack integration and systematic evaluation (Mukadam, Cooper, & Livingston, 2011). Examining how social, cultural and service-related factors mediate recognition of dementia and service access is important in initiating effective change for individuals and/or communities who are behind the curve of earlier diagnosis and timely care and support.

In what follows we examine how the characteristics, context and social positioning of one specific cultural–linguistic group, the Deaf community, mediate these fundamental goals of early recognition of dementia and timely access to care and support. Our data are drawn from the Deaf community in England; however our observations and findings have transnational significance for other Deaf communities around the world. The Deaf community is of particular interest in considering disparities in early diagnosis and inequitable access to care, because it

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has characteristics that transgress and invert a wide range of expectations associated with language, disability, culture and community. Accordingly, their needs and strengths in relation to early diagnosis of dementia and timely care are particularly complex. Furthermore, there are generalisable lessons to be learnt from their experiences in appreciating the impact of intersecting inequalities, such as those arising from language diversity *and* disability. First we review the distinct characteristics of Deaf people(s) and the Deaf community before presenting findings from a study of the recognition of dementia in the Deaf community and experiences of service response.

Deaf people(s) and the Deaf community

The term 'Deaf' with a capital D refers to people who use a signed language such as BSL (British Sign Language) as distinct from the larger population of deaf people who might have lost their hearing as part of the usual ageing process and/or people who are deaf and primarily spoken language users (Young & Hunt, 2011). The convention arose in part to make this distinction and in part to emphasise that to be Deaf is a cultural-linguistic identity (Padden & Humphries, 1988; Woodward, 1972) in the same way as we might capitalise French or Polish (not french or polish). The cultural characteristics of Deaf people(s) around the world are well documented and encompass, like any other cultural group, distinct traditions, values, norms, shared experiences, politics, history and social divisions (Ladd, 2003; Lane, Hoffmeister, & Bahan, 1996). For some, the combination of language, community and multi-generational structures of cultural transmission mean that to be Deaf fulfils the conditions also of being classified as an ethnicity (Lane, Pillard, & Hedberg, 2010). Whilst the vast majority of Deaf people will, in audiological terms, have a hearing impairment, this is not the distinguishing feature of identity; cultural affiliation and sign language use is. Hence, it is possible for some hearing children with Deaf parents to be culturally Deaf too (Preston, 1995).

Signed languages, such as BSL, are fully grammatical living languages whose linguistic structures have been studied in detail (Stokoe, 1960). BSL is not a visual version of English (Sutton-Spence & Woll, 1999). Written English (or whatever the dominant spoken language of a country might be) does not present a barrier-free means of communication for Deaf people, despite not being dependent on sound. This is because deafness from birth or early childhood interferes with the usual processes of spoken language acquisition that in turn affects the phonological basis of how children might learn to read (Mayer, 2007). As such, many Deaf people have poor reading skills with a median reading age of just under nine years on leaving school remaining significantly less than that of the general population (Conrad, 1979; Powers, Thoutenhoofd & Gregory, 1999).

Finally, the Deaf community is highly internally diverse resulting from a host of differences such as age of acquisition of a signed language, age of hearing loss, quality of educational experiences, disabilities resulting from genetic or syndromic origin of deafness, familial culture and so forth (Hereditary Hearing Loss, 2013; Marschark & Hauser, 2010; Young & Temple, 2014). Consequently, whilst some Deaf people are strongly bilingual in BSL and English (or multilingual in more than one signed and/or written language) most are stronger in BSL than in English, and a minority have very poor linguistic skills in general.

From the view of the majority society, these characteristics create difficulties of classification. For example, sign language use is not mentioned in the Equality Act 2010 but deafness is. The vast majority of social policy treats Deaf people as disabled (e.g. Disability Discrimination Act, 1995) but the UK government has formally recognised BSL as an official indigenous language of the nation (Department of Work and Pensions, 2003). Publications and studies of minority cultural communities overwhelmingly exclude Deaf people and their community because they are 'disabled' whilst studies concerning disabled people struggle to accommodate the differences posed by Deaf people's self-identity as a cultural–linguistic (not disabled) minority with many failing to mention it (Obasi, 2008; Purdam, Afkhami, Olson, & Thornton, 2008). The Office of National Statistics (ONS) includes BSL as a distinct language classification (ONS, 2013), yet the review of standard data classifications for disability would subsume BSL users under their disability revisions (White, 2011; Young, 2013). In other words, being Deaf is located at the crossroads of language, culture and disability (Corker, 1998). Attendant rights of citizenship and access as well as reasonable adjustments and cultural sensitivity risk falling between the cracks of these intersecting features (Emery, 2011; Young & Temple, 2014).

Studies of access to healthcare services for Deaf people consistently demonstrate that Deaf people tend to seek health-related support much later in the progression of illnesses than the average (Sign Health, 2009). Professionals often fail to recognise Deaf people's distinct language preferences and needs presuming they can get by in English (spoken or written down). As a result, errors in diagnosis and errors in compliance with medication and health advice abound (Alexander, Ladd, & Powell, 2012; Fellinger, Holzinger, & Pollard, 2012). Very little general health advice and guidance is available in signed languages thus reducing the possibilities of self-management and preventative self-care. Standard psychological and cognitive assessments are often inappropriate because they are not accessible linguistically, or if translated not normed on Deaf populations (Denmark, Marshall, Woll, Roy, & Atkinson, 2013, submitted; Rogers, Young, Lovell, & Evans, 2013). Overall, Deaf people experience considerably poorer health outcomes than hearing people (Alexander et al., 2012; Sign Health, 2009).

In what follows we analyse the ways in which the cultural–linguistic status of Deaf people, society's response to it and the barriers that exist in accessing health services are experienced specifically in relation to dementia; its early diagnosis and access to care and support. This is a specific focus of concern currently because of the lack of appropriate diagnostic services and linguistically inaccessible care and support services mean that Deaf people with dementia are generally diagnosed very late in the onset of the condition, if at all, and services are unable to respond to Deaf people's particular needs and cultural preferences (Atkinson et al., 2011; Denmark et al., 2013, submitted; Young, 2013; Young, Ferguson-Coleman, & Keady, 2013, submitted).

Methodology

The formal aim of this study was: to explore the understanding of and attitudes towards dementia in the Deaf community in so far as these relate to its identification, familial/community support, and service access. In another article we have reported findings concerning access to information in general about dementia and culturally embedded approaches to building community understanding of dementia (Young et al., 2013, submitted). In this paper we focus on data segments concerning verification of knowledge about dementia and access to services to gain knowledge. We do not address the process of diagnosis and subsequent care and support.

Full details of the study design and methodological underpinning are available elsewhere (Young et al., 2013, submitted) but in summary, we adopted a qualitative exploratory approach broadly guided by phenomenological principles for two reasons. First, there was extremely limited prior evidence generated by and through the Deaf community concerning dementia. Second, it was important to capture perspectives and concepts that were of significance through Deaf people's cultural lens and experience, rather than seeking to impose a structure on that experience. Therefore, a means of data collection was required that would enable priorities to emerge and preferred ways of explaining and understanding issues to be naturally generated. We used focus groups because this is a means of data collection that is recognised as culturally appropriate within Deaf communities (Young et al., 2013, submitted; Young & Temple, 2014) and has been successfully used previously (Bisol, Sperb, & Moreno-Black, 2008; Crowe, 2003; Emery, 2011).

We purposively sampled three groups of people to participate in data generation, all were BSL users who identified as culturally Deaf: (i) Older Deaf people over the age 60 who did not have a diagnosis of dementia (n = 11); (ii) Deaf people working in professional roles, not necessarily in connection with service delivery or dementia aged 18 to 60 and who had good educational and vocational qualifications as judged by their current employment status (n = 6); (iii) any member of Deaf clubs aged between 18 and 60 (n = 9). In this way we sought a diversity of Deaf people in order to minimise stereotypical representations of a cultural group. Overall, 14 men and 12 women participated. Twenty-five described themselves as White British and one described themselves as British Muslim. Participants were recruited through advertising through Deaf professional networks, online Deaf community sites, posters in Deaf clubs, word of mouth/sign of hand, and with support from RAD (the Royal Association for Deaf People) who provide a range of luncheon clubs for older Deaf people. No prior knowledge of dementia was required for participation and involvement was on a purely voluntary basis. Twenty-six people took part in one of three focus groups that corresponded with our purposive sampling strategy.

The groups were facilitated by a Deaf BSL user (Ferguson-Coleman) identified as a cultural insider. Data were generated in BSL without an interpreter ensuring participants were able to use their strongest language in as natural a way as possible. Data were captured by means of a simultaneous translation from BSL into English by two interpreters who sat outside of the group and took no part in the group's facilitation. Although changes in language between the language of data generation and the language of data analysis are problematic, and inevitably result in some loss of meaning (Temple & Young, 2004), in this case it was considered less intrusive and more pragmatic than attempting to capture a group discussion with multiple video cameras and subsequent digital editing. In addition, at the point of transcription from the audio recording to the written word, the facilitator added her own notes based on her visual and BSL memory to extend and expand on the semantic content with reference to the original language. A straightforward thematic analysis (Silverman, 2000) was applied to the data with the themes being generated from the facilitator's close reading of the transcripts. Themes consisted of subjects discussed and also emotions and attitudes expressed. Initially 10 themes were generated and the transcripts coded accordingly utilising the sort and retrieve programme QSR Nvivo 9. The three themes presented in the following relate specifically to the issues of knowledge and service access. Other publications present data from the remaining themes (Young et al., 2013, submitted).

The study was approved by the University of Manchester Research Ethics Committee (Ref: 11/NW/0669).

Findings

How will I know?

For many people who participated in the focus groups, this was the first occasion they had ever considered the topic of dementia. Levels of knowledge and understanding varied with the majority basing their awareness on first-hand experiences with family members. Overall, the main features that were mentioned of someone living with dementia were poor memory, having to repeat information, starting but not completing tasks and sometimes not being sure where they were. Most people understood that there was no cure and most believed that there was nothing anybody could do to prevent it, likening it to a diagnosis of cancer. However, myths, misinformation and misunderstandings were also shared for their merits to be considered, as these two extracts reveal:

> We have to be careful, the police say be careful of somebody, don't approach them because this person is a risk to the community and I don't know if that's because they are mentally ill or if they have dementia.

> If there was a person wearing funny coloured clothes, bright yellow socks and boots with a funny hat, with a strange smell about them, does that mean they have dementia?

There were also some uncertainties expressed about what actually happens as a consequence of being recognised as having dementia:

> That's what happens with hearing people, they get sent to hospital, but I'm not too sure what happens with Deaf people…

As the group discussions progressed many participants started to realise that they did not have a firm grasp of the facts or a clear understanding of dementia. However, they were not particularly surprised, shocked or worried by this. On the contrary, it was expected and in many ways regarded as normal. Participants framed their lack of knowledge and uncertainty as yet another example of the ways in which Deaf people lag behind hearing people in their knowledge and awareness of a range of topics because of poor access to information in BSL. Participants' life-long experience was of far fewer opportunities to gain knowledge and understanding; consequently, many had a normative and internalised expectation of not necessarily fully grasping the topic, yet.

For some, the uncertainty of their knowledge created an eager and energetic desire to understand and verify knowledge from sources they might identify as trustworthy. Who or what is a trustworthy source was fundamentally mediated by the accessibility of the information. With so little information available in BSL, was it possible to be sure that the English had been fully understood? It is interesting to note, that the queries about whether a written information source could be understood correctly were largely concerned with the level and complexity of the English and not with the potentially unfamiliar content of the information or the concepts used.

Certainty about knowledge and understanding however was not just a matter of dementia in the abstract. For many participants it was also highly personal and individualised. Participants in two of the focus groups in particular became concerned about how they would recognise themselves whether they were experiencing changes that may be indicative of dementia. There were two aspects to this anxiety both fundamentally linked to their social positioning within the Deaf community.

The first was consequent on participants' awareness that the stock of knowledge about dementia in their own cultural–linguistic community was low. Therefore, even in environments and networks where participants experienced barrier free communication, shared language and cultural understanding of each other would not guarantee opportunities for others to notice that something was changing or something might be 'wrong'. If the community in which one is most embedded is not equipped to recognise and respond to early signs of dementia then how might an individual know if others do not tell them? On the other hand, some participants felt that other Deaf people had a far better chance of recognising that a person's memory or language was different than previously in comparison with hearing people, even if the hearing people were dementia-related professionals:

> I think a professional would notice it more on a hearing person, but I think as a Deaf person in the community you'd notice it because of your friendship because of the closeness in the community.

Consequently, there were concerns about the effects of losing social contacts with the Deaf community and networks of Deaf friends. Particularly, in the focus group of older Deaf people there was much discussion of the effects of ageing meaning that individuals might be more inclined to live alone and be less able to make efforts to go out and socialise with other Deaf people and participate in the everyday life of the Deaf community. Living alone was perceived as a greater risk for lack of recognition of the early signs of dementia because of significantly reduced opportunities for others who share a language to recognise changes in their Deaf friend and fellow community member. The exchange below captures this relational dynamic:

> Participant A: I'm just wondering if I can recognize whether I have Dementia myself and know to go to the doctor about it.
>
> Participant B: Maybe a friend might think you're behaving differently or you're forgetting things and maybe they'll be able to help.
>
> Participant A: But remember, but now I'm busy but as I get older I may be home a bit more, I have lots of hobbies but if I slow down and people don't come to visit it may come as a shock to find out I have dementia and nobody had told me and I'm just wondering whether I'd be able to live alone or not. Would I be allowed to live on my own?

It was suggested that this was very different from hearing people's experience where even if they lived alone, there were still many others who could communicate with them in everyday life and many more opportunities for someone to raise a concern. By contrast Deaf people were left with the worry of: how would I know because there would literally be nobody to tell me as the surrounding everyday environment ('the hearing world') would not offer this support.

Verifying my concern – Who can I trust?

The overwhelming majority of focus group participants retained a strong respect for their general practitioner (GP) as the professional who would be their first port of call if they were concerned about changes in memory, language or behaviour:

> I don't think I would know where to go to get any support. I think I would probably go to my GP initially and ask them for advice. I can't think of any other resources I would use, I would have no idea.

Yet, at the same time participants shared numerous stories about being misunderstood by their doctor, of not really being sure that they could trust their doctor to correctly diagnose problems and of leaving consultations not being fully sure they had been understood. These difficulties arose because there was either no interpreter present during consultations or the doctor had not seen the necessity of providing information in anything other than written English because such a medium was not dependent on hearing:

> It's fine to go to the GP but some GPs have a really bad attitude. There are some who would just print out the information and give it to you for you to read at home and you think, oh that's great but I don't understand written English I need it in sign language.

> Well that's why I moved, to access a better GP. I actually moved because he gave me a misdiagnosis and I went mad because we'd been passing notes backwards and forwards and he made a diagnosis that was wrong and I was really angry, that's because he didn't have any Deaf awareness. So I decided to move to a different doctor and I felt really relaxed with this doctor.

How was it possible both to hold a respectful belief in the GP's wisdom and knowledge and a significant concern that communication could not be trusted and therefore the potential for correct diagnosis being uncertain? Particularly amongst older participants in the focus groups there was a strongly internalised social respect for GPs and a hierarchical view of their role in general society. Amongst the younger and the more professionally qualified focus group participants the significance of the GP was far less acute with the main criticism being that GPs simply did not have enough time to sit and communicate. Nonetheless there were concerns that health professionals in general would not be able to accurately spot early signs of dementia and not just because of language barriers. Participants discussed how hearing society held stereotypes and false beliefs about Deaf people that make it easier to dismiss something that seems strange as just someone being Deaf. This was seen to be true also of a Deaf person's hearing family and friends:

> Say if there's a Deaf couple – let's use that as an example – it could be the wife, the husband is questioning whether something is going on with the wife, if there's a change in the wife's behaviour and the husband is looking for the information and can't fully understand the information and take it on board, I think more than likely they'd maybe ask a relative but then you'd have to question would the relative be able to really be a good observer in that situation? They might just go 'oh they're Deaf, it's a Deaf couple'. I think it's a sticky situation to put somebody in because of the uncertainty.

An exception to this picture of services not to be trusted were social workers but only if they were specialists working with Deaf people and in the Deaf community. Their knowledge was more trusted and participants were more confident of their ability to recognise and respond to the early signs of dementia amongst Deaf people. However, there were considerable concerns about the scarcity of specialist social workers working with Deaf people and many participants commented on the changes in social care that meant that far fewer were available and funded to work with Deaf people than in the past. This potential source of trustworthy knowledge exchange/service signposting was seen as having eroded rapidly. Another door was felt to be closed:

> I'm not sure about social workers for Deaf people, those roles have been discontinued and the social workers have been moved into an overall Disability team. Social Services, they do have a duty to care for Deaf people but whether the social workers are able to sign very well or use interpreters is another issue.

Overall, therefore, participants were pessimistic about the opportunities for changes indicative of early dementia to be spotted by themselves or others around them. Furthermore, even if they were, the routes to verification or refutation of concerns were not necessarily trusted. How will I know and how can I trust that others know? Access to earlier diagnosis of dementia was seen as being limited by personal knowledge, community understanding and service competence combined.

Even if we know will it help?

Participants reflected on the broader Deaf community's resources and capacity to respond to the knowledge that some of its numbers were living with dementia. Given that the Deaf community is characterised by strong and valued traditions of collective responsibility toward and care of its 'own', this was an important consideration. In terms of support, there was an active debate about who might be best placed to offer this. Organisations identified as 'Deaf organisations' – in that they work with the Deaf community – were generally seen as those who should be taking responsibility to deliver services and support Deaf people with dementia and their carers. This was because they were perceived to understand and/or be part of the Deaf culture and to be able to communicate in BSL. However, their lack of knowledge about dementia and experience in working with people with dementia raised significant concerns.

On the other hand, mainstream organisations representing the voice of people with dementia and care partners, such as the Alzheimer's Society, were not perceived to be fit for purpose for Deaf people. Although they possessed valuable knowledge and had a broad portfolio of information and services, none of it was really accessible to Deaf people. In essence, skilling up local Deaf organisation to be knowledgeable about dementia was seen as far easier than skilling up mainstream dementia organisations to be knowledgeable about Deaf people, BSL and Deaf culture.

A model of peer-to-peer support within the Deaf community was also favoured with many ideas about networks of support groups run by Deaf people for Deaf people:

> I'm sure with Hearing people that have lots of problems they can discuss these issues but for Deaf people, I'd like

> something like that for us too. A place where we could go and discuss things.

There was also awareness in how Deaf professionals would need to adapt their own communication and supporting skills in supporting a Deaf person living with dementia. These concerns demonstrated their knowledge in the cultural mediation changes that they'd need to make in ensuring their communication was effective for the Deaf person needing support, as shared by this participant:

> I need to adapt what I'm doing, the way in how I'm working with this person. I'd have to use (different) signs, copy the way they use sign language, use more pictures and graphics, match their level of communication.

However, there were also stories told within the focus groups of how longstanding members of the Deaf community who had developed various difficulties in older age were in effect being rejected by their own community. This rejection ranged from life-long friends no longer visiting them or socialising with them, to active examples of people being asked to leave community events because their behaviour was disruptive or they were seen to be a liability in some way; for example, they could not be relied upon in games, social activities or discussions because they made mistakes and could not follow what was happening.

Whilst some participants saw the potential contradiction between Deaf-led community support and some of the attitudes of Deaf community members, others did not. Also, the discussion of best support and care for Deaf people with dementia and their care partners was largely framed in terms of support for 'them' as if through the diagnosis of dementia the individual no longer occupied an insider position within the community. There were limits, be they largely inadvertent and unacknowledged, to the inclusion of Deaf people with dementia within the Deaf community.

Discussion

In this paper we have examined how the relationship between knowledge and service access for Deaf people with dementia is mediated by their social positioning as a minority cultural–linguistic community whose status is subject to misapprehension by wider hearing society. We have illustrated how concerns that are common to the general public with regard to dementia knowledge take on an additional dimension with regard to the Deaf community. *How will I recognize I might have dementia* is far more of a concern if there are limited numbers of people with whom to interact meaningfully and therefore fewer opportunities for another to hold a mirror up to changes they may observe in you. *How can I check out if my concerns are justified* is far bigger a barrier if you cannot trust that the relationship with a knowledgeable professional will be effective and result in accurate knowledge and not misunderstanding. *How will I be supported and cared for* is far less certain if the community to which you have belonged all of your life lacks the expertise to respond and enough awareness to be sympathetic and supportive.

There are two ways to evaluate these findings. On the one hand, it is possible to look at the Deaf community, the attitudes, assumptions, questions and expectations underpinning our findings, and conclude simply that this is where hearing communities were 25 years ago (for a review see Keady, 1996). The dominant discourse at the time focused on the person-with-DEMENTIA and the challenge was to reverse the emphasis and embrace a much more creative, personalised, biographical and embodied approach that celebrated the PERSON-with-dementia (Kitwood, 1997, p. 7). There was no purposive, public narrative about dementia that located it as social and of-the-community such as the 'living well with dementia' discourse that frames the policy response today (Department of Health, 2009). Dementia was an individual and private matter, attracting a degree of stigma and shame both for the person with dementia and those associated with them. So perhaps our findings here are no more than the equivalent of year zero for the Deaf community who are yet to travel the journey that that the majority hearing community has. Better access to information, public awareness campaigns within the Deaf community and Deaf people advocating for better access to services based on their personal experiences and those of the community will mean the Deaf community 'catches up'.

To some extent that will be true. We have previously published research on effective engagement with the aim of building understanding having to consist of more than mere translation of resources into signed languages (Young et al., 2013, submitted). However, there are several problems with assuming our findings mirror the hearing world 25 years ago and that the processes of transformation that have worked in society at large will be effective also in the evolution of Deaf people's awareness of dementia and improvements in service access.

First, the effects of the same social process are not equivalently experienced by all sectors of society. For example, whilst raising general public awareness of the early signs of dementia may be helpful in supporting earlier diagnosis in the general public, it will have little impact between peoples who cannot communicate with each other. The mechanism of advantage (such as spotting there may be an issue and opening a dialogue with the person concerned to visit their GP) is entirely dependent on shared communication and mutual understanding. This is not usually a problem because even if one lives alone or does not have close family there is an expectation of social and communicative discourse with others around you. However, as our data have demonstrated being alone for Deaf people is fundamentally a linguistic not a social state. If there is nobody to communicate with in sign language, there is nobody to recognise that something might be changing. A significant increase in general public awareness of dementia is not going to make a difference to that.

Furthermore, even if there were to be tailored and successful knowledge building and awareness-raising campaigns within the Deaf community about dementia, this too will not make a difference unless individuals are in a socially communicative relationship with that community. In other words, raising general awareness of dementia amongst the Deaf community will not be effective in supporting earlier recognition of dementia unless continuity of social access for older people who are Deaf with other Deaf people is simultaneously prioritised. One without the other eradicates the *opportunity* for recognition of the early signs of dementia. Yet, recent evidence suggests that such linguistic and social continuity with one's cultural community is easily denied in older Deaf people (Hunt, Oram, & Young, 2010; Young, 2013).

Second, institutionally or attitudinally produced barriers do not have equivalent effects for all communities. Consequently, solutions to tackle them may not be universally effective. For example, concern that GPs are inadequate to respond to concerns about dementia is not unique to the Deaf community. The Department of Health (2010) report *'Quality outcomes for people with dementia'* found that only a third of GPs believed that they have 'adequate training in the diagnosis and detection of dementia' (p. 10). This may well go some way in explaining why tension and uncertainty exists in primary care practice over presentations of the first signs of (undiagnosed) dementia (Ahmad, Orrell, Iliffe, & Gracie, 2010) and how much education remains necessary to build up a proficient response (Turner et al., 2004; Wilcock et al., 2009). However, the barriers Deaf people reported in our data and in other studies (Sign Health, 2009) were multi-layered. It was not just that ensuring effective mutual communication might be challenging. Some GPs did not recognise cultural competence as a relevant concern and were unreflective of the possible limitations of their interaction and understanding with Deaf people. Professional education in early dementia on its own will not remove that barrier. Seeing professional education about early recognition of dementia within the context of language and culture, might just.

Conclusion

Increased information and awareness in the Deaf community about dementia, leading to a concomitant increase in diagnosis, will naturally create opportunities for post-diagnostic support. But how should this support be structured? From an analysis of the focus group data it would appear that the Deaf community would like Deaf organisations to take the lead in organising, co-ordinating and facilitating such support. As we move forward, the relationship between mainstream voluntary and service organisations in dementia and their mission to reach out to all people living with the condition will need some thought and clarity if partnerships are to be built with Deaf organisations. A dialogue within the Deaf community and between the hearing and the Deaf communities needs to start and start very soon or else a marginalised group will stay exactly there, on the margins. That is simply unacceptable in today's climate of change and all-embracing discourses about living well with dementia and a dementia friendly community that is accessible to all.

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