Understanding dementia: effective information access from the Deaf community's perspective

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What is known about this topic

- Deaf people who use sign language can experience dementia.
- Deaf people are less likely to be diagnosed with dementia than hearing people.
- Awareness and knowledge about dementia in the Deaf community is poor.

What this paper adds

- Deaf people want to generate awareness and information about dementia from a Deaf cultural perspective.
- Distribution of key information is seen as a cultural obligation by the Deaf community regardless of geographical boundaries.
- Insight into preferred means of awareness raising and knowledge transfer about dementia in the Deaf community.

Abstract

This study concerns older Deaf sign language users in the UK. Its aim was to explore how to enable effective information access and promote awareness and understanding of dementia from a culturally Deaf perspective. A purposive sample of 26 Deaf people without dementia participated in one of three focus groups facilitated directly in British Sign Language (BSL) without an intermediate interpreter. The sample was differentiated by age, role in the Deaf community, and diversity of educational attainment and professional experience. A phenomenological approach underpinned the thematic analysis of data. The findings demonstrate: (i) translation into (BSL) is a necessary but not sufficient condition to support understanding. Attention to culturally preferred means of engagement with information is vital; (ii) the content of information is best presented utilising structures and formats which cohere with Deaf people's visual cognitive strengths; and (iii) the importance of cultural values and cultural practices in raising awareness and building understanding of dementia. These include collective rather than individual responsibility for knowledge transfer and the pan-national nature of knowledge transfer among Deaf people(s). The discussion demonstrates how these specific features of effective information access and awareness building have universal implications relevant to public engagement and the promotion of general knowledge consistent with the National Dementia Strategy (England).

Keywords: Deaf studies, dementia, health promotion

Introduction

Timely and earlier diagnosis of dementia is a key priority in the National Dementia Strategy for England (DH 2009), as it is for many countries around the world (Alzheimer's Disease International 2011). A diagnosis of dementia is a gateway to many potential advantages including access to disease-modifying medication, time to plan for future care preferences and opportunities to express needs, wants and aspirations (Robinson *et al.* 2011). One of the components of earlier diagnosis is earlier recognition of dementia among family, friends and communities. Supporting earlier recognition encompasses public education programmes and good access to information (National Institute for Health and Clinical Excellence/Social Care Institute for Excellence 2006, Alzheimer's Disease International 2011).

For individuals and communities who do not share the majority language of a country, access to information can be problematic (Alzheimer's Society 2012, All Party Parliamentary Group on Dementia [APPG] 2013).

Furthermore, in a culturally diverse society such as that of the United Kingdom (UK) today, ensuring that information is meaningful, rather than simply accessible, requires cultural competence rather than merely translation (Nijjar 2012). Raising awareness of dementia, as a component of earlier recognition is, therefore, a challenge among families, friends and communities who might be regarded as minority on grounds of language and/or culture (APPG 2013).

The Deaf community, the focus of the study reported here, is an interesting example of this challenge. While sharing some of the features of other linguistically and culturally diverse spoken language communities, three features in particular set the Deaf community apart and raise additional considerations when considering dementia awareness and information access. First, Deaf people use an entirely visual language. It is not just that it has no written form (like some other spoken languages). It relies exclusively on visual media for the transmission of communication and capture of information. British Sign Language (BSL) is a fully grammatical language distinct from English; it is not a visual version of the spoken word (Sutton-Spence & Woll 1999). Second, Deaf people's status as a cultural minority is commonly not recognised despite BSL being formally acknowledged as an indigenous language of the UK (Department of Work & Pensions 2003) and a raft of scholarship on Deaf people's culture, history and identity (e.g. Ladd 2003) and ethnicity (e.g. Lane *et al.* 2010). For example, Deaf people were not included in the recent APPG (2013) review of dementia services for black, Asian and *Minority Ethnic* communities (emphasis ours) nor in the reference to under-represented groups in the two Alzheimer's Society (2010a,b) reports *My Name is not Dementia*.

Third, Deaf people's identity(ies) sit at the intersection of culture and disability (Corker 1998). In medical terms, Deaf people may have a 'hearing impairment' or be regarded in a social policy context as 'disabled' people. Yet, Deaf people assert their cultural identity on entirely different terms. To be Deaf is to be part of a community with its own cultural history, traditions, perspectives and preferences associated with language use and shared identity(ies), in the same way as we might talk about Polish people and their community, for example (Ladd 2003, Young & Temple 2014). The use of a capitalised 'D' (Deaf) to refer to sign language users as distinct from those who are not ('d'eaf) emphasises this point. To be *Deaf* is not an audiologically determined definition; it is a culturally determined one. However, social policies and laws behave towards Deaf people largely in terms of equality on grounds of disability (e.g. Equality Act 2010).

While poor access to health-related information in signed languages has been identified as a significant component of health inequalities for Deaf communities around the world (Sign Health 2009, Graybill *et al.* 2010, Alexander *et al.* 2012, Fellinger *et al.* 2012, Rogers *et al.* 2013, Sign Health 2014), there has been little attention to dementia in this respect. Some information on dementia has been produced in BSL on DVD (Scottish Intercollegiate Guidelines Network 2007, Deaf Connections 2008), but no evaluation has been carried out of whether the media of its distribution is effective nor whether it has resulted in increased awareness and understanding. There are neither reported studies of Deaf populations' attitudes to and awareness of dementia nor of the community's preferences for information and support either in the UK or internationally. There is good reason to assume however, that awareness of the early signs of dementia might be very low among Deaf communities and understanding of the meaning and implications of dementia is likely to be poor. For example, health-related information in a written language may appear to present barrier-free access to information for Deaf people because it is not dependent on hearing, but many Deaf people are not fluent in the spoken/written language of the majority community around them. Early deafness interferes with processes of spoken language acquisition meaning that the phonological basis of reading can present key challenges (Powers *et al.* 1999, Mayer 2007). Furthermore, the written/spoken language of a country is not a *preferred* means of access to information for many Deaf people; a signed language is (Young & Hunt 2011). Therefore, it is not just lack of linguistic access that creates barriers to effective engagement with information but also a lack of cultural equivalence in supporting access to information. The language(s) we prefer are also an assertion of our cultural identity(ies).

Finally, determining the numbers of Deaf people in the UK who might have dementia is not straightforward because the precise number of Deaf BSL users in general is unknown. Estimates for the BSL using population vary between 22,000 England and Wales only (Office of National Statistics [ONS] 2013) to the GP patient survey estimate of 125,000 for England alone (IPSOS GP Patient Survey 2009–2010). Conservative estimates suggest a population of Deaf BSL users of between 50,000 and 100,000. Extrapolating from general population estimates (ONS 2012) of over 65s constituting 17% of the population, rising to 23% by 2035, this suggests a population of Deaf over 65s of between 8500 and 17,000 rising to 11,500 and 23,000 by 2035. Using a conservative estimate of 5% of the over 65s

having dementia (Alzheimer's Society 2007), this would approximate to between 450 and 850 Deaf people currently living with dementia rising to approximately 1150–2300 by 2035. However, dementia is not necessarily evenly distributed across all cultural groups (APPG 2013) and there is no firm epidemiological evidence from population-based prevalence studies whether Deaf people are more or less likely to experience dementia than other cultural-linguistic groups.

The data reported in this article are taken from a multi-faceted research project, the first of its kind internationally, whose objective overall was to address the barriers to early identification of dementia among Deaf sign language users (see Young *et al.* 2013, 2014, Ferguson-Coleman *et al.* 2014). The research project included studies focussed on the development of linguistically appropriate screening instruments (previously there were none); the personal experience of Deaf people with dementia (they had never been previously directly interviewed); and how to facilitate better access to information and Deaf community awareness about dementia (findings reported here). The formal aim of this component of the overall research project was to explore how to enable effective information access and promote awareness and understanding of dementia from a culturally Deaf perspective. Its objective was to develop a culturally coherent understanding of the most effective means of promoting better dementia awareness among Deaf people. The team who undertook this study comprised a dementia care expert with no prior experience of working alongside Deaf people, and two fluent BSL users, one Deaf and one hearing who between them had over 40 years experience of working and being in the Deaf community. Our own cross-cultural, cross-linguistic and multidisciplinary dialogues were used as a source of critical reflexivity throughout the study.

Method

Design

The study did not set out to provide the Deaf community with information about dementia or to test the effectiveness of a pre-designed information resource. Rather, an inductive qualitative design was chosen through which key concepts and ideas would emerge as a result of interaction and dialogue between community members facilitated by a researcher (Ferguson-Coleman) identified as a cultural insider within the community. This broadly phenomenological approach (Groenewald 2004) was selected because in a field where so little prior evidence exists, it was important to capture perceptions

and conceptualisations of phenomena without seeking to impose criteria or definitions that may not be culturally coherent for those participating. The second assumption underpinning the research design was that engagement with information to build knowledge, awareness and understanding was not simply a linguistic matter. Knowledge acquisition also has a cultural component in that we learn better through means that are recognised as culturally coherent with our identities and preferences. We therefore sought to design the study in such a way as to enable the identification of culturally normative preferences for increasing awareness and building understanding that extended beyond which language or register was most helpful.

Data collection

Focus groups were the preferred means of data collection because of their capacity to provoke shared exploration of ideas and to support 'the group' as a strengths-based means of participating in research (Gibbs 1997). Deaf communities all around the world are regarded as collective, rather than individualistic, communities (Ladd 2003, Mindess 2006), and group discussion is a culturally familiar means of engagement (Emery 2011). The groups were facilitated by a Deaf BSL user (Ferguson-Coleman) in BSL.

Three focus groups were held in the southern part of England in autumn 2011. A purposive sample was sought differentiated by three criteria which with respect to pre-existing knowledge/experience of dementia were likely to include an heterogeneity of perspectives: (i) Older Deaf people over age 60 who did not have a diagnosis of dementia. The over 60s age bracket was chosen because this is the usual age at which adults are defined as 'older' for purposes of social care in England; (ii) Deaf people working in professional roles, not necessarily in connection with service delivery or dementia, age 18–60 and who had good educational and vocational qualifications as judged by their current employment status; and (iii) Any members of Deaf clubs aged between 18 and 60 (many of whom would not meet the second criteria for involvement). The purposive sample was not intended to be statistically representative of Deaf people nationwide, but to have high relevance to the research aim we were seeking to explore. All participants were to be Deaf BSL users who saw themselves as culturally Deaf.

Participants were recruited via advertising through Deaf professional networks, online Deaf community sites, posters in Deaf clubs, word of mouth/sign of hand and through the Royal Association for Deaf

People (RAD) who support a range of luncheon clubs for older Deaf people. No prior knowledge of dementia was required for participation and involvement was purely voluntary. Information to support informed consent was provided in BSL both in a fixed form to enable re-watching and reference (i.e. online open access signed presentation or takeaway DVD) and in an interactive form (the consent of those taking part was checked in person before the focus groups took place and opportunities to ask for further clarification directly in BSL were provided). The study was approved by the University of Manchester Research Ethics Committee (Ref. 11/NW/0669).

Prior to taking part in the group, participants were provided with a short summary of the main topics for discussion. This was to enable them to consider the issues in advance and to prevent the group discussion feeling like some kind of on-the-spot test of knowledge. The topic guide contained more subject areas than are the focus of this article (see Ferguson-Coleman *et al.* 2014 for analysis of other topics covered). The three specified topics relevant to the data reported here were: What does dementia mean to you and how would you recognise it? Where would you go for information and support? What kind of services would help Deaf people with dementia and their carers?

Data were audio recorded by an interpreter producing a simultaneous translation from BSL into English. The interpreter had no role in the running of the focus groups and was, to all intents and purposes, ignored by participants. This approach encouraged a natural conversation style among participants in the strongest language. Although it was possible to have filmed the focus groups using multiple cameras and later digitally to align recordings into a simultaneous visual stream, the time and technical demands involved was judged excessive for the modest aims of the study.

Analysis

The audio-recorded, simultaneously translated data were transcribed into written English by an interpreter who also assigned individual person markers to the translated segments, so that the resulting script could be differentiated by the participant. Transcription which also involves translation results inevitably in some loss of meaning in the search for both semantic and cultural equivalence (Temple & Young 2004). This was offset by the researcher who had facilitated the groups checking and amending the transcript translations with additional notes based on her visual memory of the BSL dialogue. Data from the three focus groups were treated as a single data set, but the use of the sort and retrieve programme QSR NVIVO 8

enabled easy identification of the origins of any data segment to particular groups and individuals within those groups. The transcripts were read by two of the authors who independently generated an initial list of themes that emerged from the data, following a thematic content analysis approach (Silverman 2000). The themes did not necessarily map onto the three topics, discussed previously, which structured the groups but followed the flow of the resultant discussion (inductive rather than deductive). These initial theme lists were compared for similarities and differences resulting in a final coding framework of 10 themes. The data reported here are drawn from three of those original themes: accessibility, information and expectations. Each theme underwent a further process of analysis to draw out the key conceptual issues illustrative within its content, hence 'accessibility' is presented below in terms of engagement with information, 'information' is presented in terms of the structure, not just content of that information, and 'expectations' is presented in terms of the cultural obligations and practices that were implied.

Findings

Sample

Twenty-six people took part in the focus groups in total, 11 participants over the age of 60, 6 professionals and 9 others between the ages of 18 and 60. There were 14 men and 12 women in total. Only a minority had direct experience of caring for someone with dementia or cited their second-hand experiences through a friend or acquaintance. Among the professional group of participants, eight worked in roles that were of direct relevance to health or social care services in general. None worked specifically with people (Deaf or hearing) who had dementia.

Engagement with information in BSL – translation is not enough

Although it was made clear that the focus group was not an information-giving activity, the majority of participants, regardless of differences in composition between the groups, saw participation as an opportunity to learn about dementia. This was mainly because a structured discussion was taking place in their strongest and preferred language (BSL) without a mediator (interpreter). Furthermore, a professional recognised as a cultural insider was facilitating discussion. The potential for barrier-free engagement with the topic was seen as a priority and highly valued with repeated reference to how little access to

information Deaf people had and its likely consequences (Box 1).

Access to information was vital because it was seen as the gateway to service provision as well as to better awareness among the Deaf community of the early signs of dementia (see Ferguson-Coleman *et al.* 2014).

Among participants, there was a diverse range of language abilities with some having greater English skills. Regardless of this variation, which is common in the Deaf community, everyone felt more information in BSL was vital particularly for those members of the Deaf community who had little or no English skills. Yet, all three groups also concluded that linguistic access in BSL of itself did not ensure effective understanding.

In part, the medium for conveying information was seen as problematic in the case of resources for reference. Watching a DVD or online video might deliver information in BSL, but passively watching allows no possibility of questioning, exploring and checking understanding (Box 2).

Watching to become informed was not seen to be as effective as discussing and interacting to become informed, provided the knowledge source used could be trusted. The other main advantage of accessing knowledge through collective discussion, rather than reading/information watching (in BSL), was the opportunity to explore its personal relevance. One participant discussed how unsatisfactory he had found it to work through his concerns about his mother based on information sourced through the Internet (Box 3).

This participant had good written English skills and did not particularly see the language of the information as a barrier. The problem was the processing of information and needing to do that through interactions and conversations with others who knew his mother.

Transposition of information into meaningful knowledge is, in one sense, no different from what everyone new to a topic will do. We seek to understand new information and ideas by making sense of them in our terms. However, for the Deaf participants, there was an additional dimension; namely, an overriding sense that information usually is constructed and offered for someone else's needs – hearing people. It does not begin from the concerns and questions of Deaf people. In short, information in BSL was seen as a necessary condition to promote knowledge and understanding, but not a sufficient condition. It had to exist alongside a preferred means of engagement which was discursive, interactional and among others who are linguistically and culturally the same.

Structure and format not just content

How information is structured and the format in which it is delivered was also identified as a key component in ensuring information is meaningful over and above its presentation in BSL. Participants felt that not all Deaf people will grasp information in the same way, therefore it was the Deaf community's responsibility to adapt information for other Deaf people (Box 4).

The problem was that it usually did not happen that way with hearing people taking the lead at the outset. Participants suggested that by the time Deaf people became involved, key decisions about the content, form and structure of information had already been made. Furthermore, apparent adaptations to standard material often did not begin with and from the Deaf community's strengths, needs and perspectives.

Box 1 Deaf man, no first hand experience of dementia

'I think it's really easy for hearing people. You know, they can go to support groups, they've got quick access to it, they can make phone calls, they've got help lines to make that phone call and get the information but what's happening with Deaf people?'

'As you know Deaf people don't get as much information as hearing people, we do miss some information that hearing people know already. So, if we do have access to good information will we stay as healthy as them?'

Box 2 Deaf woman with some indirect knowledge of dementia care

'…a DVD might leave you wondering, you might want to ask questions but have no one to talk to'.

'…you said before that there are interpreted clips on the websites but it's all one-way and you can't ask the interpreter what it means. Maybe they're using medical jargon and a Deaf person doesn't understand that and they're watching it, but they become confused and they lose the thread because they don't understand that particular jargon'.

Box 3 Deaf carer of hearing mother with dementia

'I know we can Google information like [name] has mentioned before but it was finding that information that was relevant to me, relevant to my mum and *whether it was a mum thing or a dementia thing* and making sure it was the right information I was accessing, just trying to figure out which one it was, whether it was an age thing or dementia'.

Box 4 Deaf woman, from a professional background

'You'd need to get to know them . . . adapt our language, adapt information, make it much more basic and use a lot of pictorial/visual stuff to make it accessible'.

'If you've got eczema and you see the word but you don't really know what it is, but if you can see diagrams of what it looks like that's really helpful. With coloured diagrams or photos, that's very visual so that would help you to identify what it is . . . So, pictures like that on the Internet with the name of the condition would be really helpful. I think you need it in sign language, in text and some form of visual aid'.

In this respect, participants drew attention to Deaf people's fundamental visual orientation that encompasses, but extends beyond, the recognition that BSL is a visual language. Deaf people structure their environment to be as visually accessible as possible. Vision is a prerequisite for communication; space and movement convey meaning in the literal linguistic sense of structuring the grammar of signed languages and in the aesthetic. Participants pointed out that because Deaf people rely on their eyes rather than listening, they are far more aware of the visual world than hearing people. There are also consequences for how memory works too, with Deaf people having strong visual/spatial recall and being far more attuned to three-dimensional rather than two-dimensional stimuli.

Consequently, participants emphasised that it would make sense if information designed to increase awareness and understanding of dementia exploits the visual advantages that Deaf people have. For example, the use of role play and drama as media for learning was mentioned. The physical enactment of information through storytelling seemed a very natural way to engage and think about the content that was being promoted. It is fundamental to Deaf cultures around the world. Drama combines the visual orientation with this cultural value to maximal effect.

These media for the passage of information and building of knowledge were not just about its format. They were also about the structure of information. Different formats enable the exploitation of different kinds of explanations. In this respect, participants emphasised the importance of diagrams, pictures and animations because these enabled possibilities of visually grasping an idea and were more in tune with Deaf people's cognitive strengths. A stream of information whether in BSL or English was not necessarily as powerful as structuring knowledge in such a way as it could be grasped holistically, as in the visual representation of a term or idea.

For example, spontaneously, as participants signed about dementia, a range of four-dimensional visual descriptions emerged (four dimensions because the usual three are further augmented by movement over time in signed languages) (Stokoe 1960). In one instance, a participant was seeking to describe the effect of someone's short-term memory capacity decreasing in dementia, but long-term memory, particularly of events in childhood, being retained and becoming of greater importance to the individual. She signed this by showing with one hand a small sphere and with the other a large sphere. The former represented the distant memories when the childhood brain was yet to reach capacity and the store of memories was small. The latter was the adult brain full of a lifetime of memories and therefore larger in dimensions. As the effects of dementia became more pronounced, she showed how the larger sphere shrank as it could no longer hold the full capacity of a lifetime of memories and simultaneously the smaller sphere grew representing the growth in the importance of distant and childhood memories. The visual representation of the complex cognitive process was immediately graspable.

The role of *cultural values and cultural practices* in raising awareness and building understanding

Beyond the issues of language, structure and format of information, participants drew attention to cultural features of the Deaf community which played a part in the building and transmission of knowledge. For example, despite being a geographically dispersed minority, information passes with great speed among Deaf people because of priority given to communication in a shared language. As one group discussed, there was nothing unusual about having knowledge of a Deaf couple in a different region, several hundred miles away accessing the Alzheimer's Society for support. Although not relatives or friends, their struggle for accessible support in BSL was the 'talk' of the community. Deaf networks over large distances facilitated through strong bonds of families, friends (and increasingly through social media) mean that information can pass quickly and ideas are shared widely beyond geographical constraints. For some participants, information exchange was seen as a fundamental cultural obligation.

Participants strongly expressed the view that information shared by a Deaf person is perceived as more valid than that shared by an outsider to the community. In part, this is because of shared bonds of identity. However, it is also because participants thought that Deaf people were best suited to tuning

into the variations in information needs among the wide variety of people in their community. For example, it was proposed that Deaf people could easily spot 'nodding head syndrome' among other Deaf people and challenge it. Nodding head syndrome refers to instances when a Deaf person will walk away having nodded their assent to understanding new segments of information. However, if questioned later, it transpires they did not understand and felt unable or confident to show this and to ask for further explanation.

Another key value concerned the willingness to share personal experiences for the common good. Deaf communities on an international basis are identified as generally being more open than many hearing societies. The boundaries between the private and the public are usually drawn differently than the societies that surround them to emphasise kinship and prioritise knowledge exchange in a context, where the majority world is largely inaccessible (Lane *et al.* 2010). Participants across all of the focus groups were enthusiastic about the extended sharing and use of community members' personal experiences of dementia and/or caring for a person with dementia as a means of community-based awareness raising and learning in a more formal sense. Case studies were seen as potentially highly effective because of the recognition value that underpinned them (Box 5).

Historically, hearing communities have tended to treat Deaf people as 'them' and do things 'for them' which is at odds with Deaf people's own heightened sense of responsibility to each other and doing things for the whole community through each other. It is a fundamental collective cultural value which underpins preferences already discussed such as information shared by another Deaf person being seen as more valid, and Deaf people's heightened awareness of the wide variation in language skills and abilities among their community.

Discussion

In this study, we have focussed on access to information and effective knowledge transmission to build awareness and understanding of dementia in the

Box 5 Deaf man, aged over 60

'Also case studies. For example, someone who is signing about their own personal experience so you can put yourself in their shoes. The text [on the website] is interesting, but a particular case study of someone who is able to describe what they've been through in sign language; they can really go into detail in their explanation and give you a really good understanding'.

Deaf community, a community whose cultural-linguistic status remains largely unacknowledged in policy and practice discourse on dementia (e.g. APPG 2013). Although in England, the National Dementia Strategy (DH 2009) recognises that information should be tailored to meet the diversity of community and cultural needs, there are few examples of how this is being achieved in practice other than the translation of standard information sources in multiple languages. This study, although concerning one community, has sought to move beyond any simple notion of ensuring information is made linguistically accessible, no matter how vital that is, and offers three potentially generalisable propositions for effective knowledge transfer.

First, that linguistic access is a necessary but not sufficient condition for promoting understanding; culturally coherent means of engagement with that information is also required. A key factor is the facilitation and tailoring of engagement from those within the community who understand the community. Second, that cultural-linguistic communities may have distinct preferences for the form and structure of knowledge exchange. Bringing in members of linguistic-cultural communities at later stages of information production when the form and content is already decided not only misses opportunities for creative contribution but also risks alienation as information is not perceived as owned by community, that is its target audience. Third, that cultural characteristics and practices may be a source of additional strengths and advantages in ensuring effective awareness raising and accurate information sharing. These may be unique to specific communities and reflect culturally normative social practices. For example, individual responsibility for knowledge and understanding is not a universal value. For some cultures, such as that of Deaf people(s), collective responsibility for each others' understanding and engagement with necessary knowledge is a stronger influence (Ladd 2003, Young & Temple 2014).

Effective public engagement with dementia is a key theme in current strategies such as those promoted through government and leading national organisations (e.g. Alzheimer's Society 2013). However, as this study demonstrates, seeking to impact a community's stock of knowledge can never be only about ensuring that information is available and accessible. It also requires active engagement with the processes of how that information becomes culturally meaningful (Moriarty *et al.* 2011). Culture is not an artefact; it is a process (McGrew 1998). If general awareness of dementia is to grow in diverse communities, then the promotion of understanding cannot be separated from engagement with everyday cultural praxis (Bauman 1999).

With respect specifically to the Deaf community, one important future direction revealed by this study might entail the packaging of key messages in dementia in the form of drama. There are overlaps here to the hearing community through public awareness and knowledge about dementia communicated by creative arts-based activities and media, especially theatre work (Basting 2001, Gould 2013). Conversely, Deaf people's fundamentally visual orientation and visual cognitive strengths have potentially much to contribute in opening up to the wider world alternative means to grasp and convey complex information about dementia through two-, three- and four-dimensional imagery. As Bahan (2008) argues, Deaf people should be considered as a 'visual variety of the human race' and it is the detriment of all if the capacities, emphases and gains that Deaf people bring to human diversity are not acknowledged and utilised for everyone (Bauman & Murray 2010). The Deaf community's contribution rather than the Deaf community's needs is currently overlooked.

Conclusion

This study has sought to deconstruct the relationship between linguistic access, cultural practices and information about dementia with respect to one specific community – the Deaf community in England. The wider lessons drawn are meaningful for engagement with awareness raising and knowledge building about dementia in the context of cultural and linguistic diversity in the UK. The primary limitations of the study are that it has involved a relatively small number of Deaf people in an exploratory study at a fixed point in time whose views are not necessarily representative of the full diversity of Deaf people(s). Its strength is that it is the first study to have engaged the Deaf community in a guided exploration of what constitutes a culturally coherent means of engaging with information and knowledge about dementia from their perspectives.

The impact of participating in this research project has been considerable. Although not intending to provide information about dementia, participation in this and other aspects of the wider project has opened up the topic among Deaf people because of their experience of barrier-free, culturally coherent access to discussion on dementia. Four years on from its inception, there is a strong social media dialogue through BSL about dementia, several Deaf-led film productions, adaptations of standard information about dementia into BSL, a diagnostic clinic and new follow on studies underway aimed at familial and social support (see http://www.manchester.ac.uk/deafwithdementia).

Conflict of interests

There are no conflicts of interest to report.

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