

How do we know what we don't know? Exploring Deaf people's experiences of supporting their Deaf family member living with dementia

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Abstract

Deaf sign language users living with dementia and their carers, some of whom are Deaf, routinely face everyday barriers in accessing information, support (both formal and informal) and services. The familial care situation is further complicated given that most Deaf people will choose a life partner who is Deaf and most Deaf couples will have hearing children. This study focussed specifically on the everyday experiences of Deaf carers and the impact of caring for a loved one with

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dementia. Drawing on data from a wider consultation about dementia care, three Deaf carers were directly interviewed in British Sign Language by a Deaf researcher about their everyday experiences of care, support, and services. Thematic analysis focussed on: access is more than the provision of interpreters; effective care for the carers; and unknowing risk taking. Findings demonstrate the multifaceted effects of barriers to knowledge and information when the care partner is also Deaf, the urgent need for effective support for Deaf carers and unrecognised safeguarding concerns that are a result of lack of access to forms of basic knowledge about living with someone with dementia and potential coping strategies. Nonetheless, the participants demonstrated novel solutions and resilience in the face of these multiple challenges. Implications are drawn for future targeted services to supported Deaf carers of people affected by dementia.

Keywords

Deaf, dementia, sign language, access

Introduction

Dementia currently affects 850,000 people in the UK (Alzheimer's Society, 2018) and it is expected that this number will increase to over a million by 2020. Sixty percent of people with dementia live at home and are enabled to do so by their carers, usually family members, supplemented with some formal care support (Chester et al., 2018, Botsford, Clarke and Gibb, 2011). In general, the everyday experiences of carers and how they manage the challenges of working with service providers is not well understood (Daly, McCarron, Higgins, & McCallion, 2013) let alone the additional challenges that might arise in situations where the *carer* is a minority language user or where they do not have English as their first language. In this article, we address the experiences of carers from one such group – Deaf people who are sign language users – who live in the UK, and use British Sign Language (BSL). In this context (Northern Ireland), some Deaf carers might also use Irish Sign Language (ISL). Although there is a small body of work on the experiences of Deaf people who are living with dementia (Ferguson-Coleman, 2016; Young, Ferguson-Coleman, & Keady, 2014), to our knowledge, this is the first study that has investigated the perspective of caring for someone with dementia through the eyes and lived experience of a Deaf person.

Background

BSL is a fully grammatical, living language distinct from English (Sutton-Spence & Woll, 1999) and formally recognised as an indigenous language of the UK with specific legal protection in Scotland (Scottish Government). There are approximately 87,000 Deaf BSL users in the UK (British Deaf Association, 2017) who are distinguished as a separate cultural and linguistic minority group from the 71% of older adults over the age of 70 who experience hearing loss and who do not use a signed language (Action on Hearing Loss, 2018). Conventionally, sign language users are distinguished by the use of an upper case 'D' for Deaf (Erting & Woodward, 1979). Recent research (Young, Ferguson-Coleman, & Keady, 2016) has estimated that numbers of Deaf people who experience dementia may range from 450 to 850 Deaf people in the UK (extrapolating from general population figures of those affected aged 65 or older). However, there are no estimates available of the number of carers of people with dementia who may themselves be Deaf and use BSL/ISL.

The situation is especially complex as over 90% of d/Deaf people (both those who sign and those who do not) will have parents who are hearing (Mitchell & Karchmer, 2004) and additionally, the overwhelming majority of adults who are Deaf sign language users will choose another Deaf person as a life partner. Consequently, a Deaf carer may be caring either for a hearing parent with dementia who are unlikely to be fluent BSL users and/or for a Deaf partner who is likely to share the same language. The vast majority of a Deaf carer's siblings and their own children will be hearing (Marschark, 1997).

Recent studies have focused on the barriers faced by Deaf people who experience dementia in the acquisition of new knowledge, timely and correct diagnosis and access to effective service provision (Ferguson-Coleman & Young, 2017; Young et al., 2016). The primary issue is not one of 'not hearing', but rather the failure to make adequate provision for the acquisition of knowledge about dementia in BSL/ISL and in a way that fits in with Deaf people's preferred ways of knowing (Ferguson-Coleman, Young, & Keady, 2014); for example the importance of visually orientated and highly contextualised explanation, such as using role plays or case scenarios, over more abstract, linear and sequential forms of explanation, such as using direct word for word translation (Ferguson-Coleman, Young, & Keady, 2014). Skilled professionals who understand the Deaf perspective are few and far between, accessible information resources that are effective are not universal (see BDA, 2017 for exceptions), specialist clinical assessment is now available but rare (Atkinson et al., 2015) and support for carers of Deaf people with dementia underdeveloped regardless of whether the carer is hearing¹ or Deaf (Parker, Young, & Rogers, 2010).

There are very few previous Deaf carer accounts of caring for someone with dementia, with most literature centred on adult hearing children's accounts of seeking services and support for their Deaf parent who has dementia (Ferguson-Coleman, 2016; Rantapää & Pekkala, 2014; Conrad, 2004). These accounts reveal frustrations over the lack of suitable services which are accessible in their parents' language and the isolation their parents have experienced in addition to the issues associated with dementia, because of unsuitable care environments, as well as the carer's own personal frustrations. Rantapää and Pekkala (2014) explored the early changes in communication for Deaf people with dementia using their personal observations of the changes in communication that their parent presented while living with dementia, but they do not offer a direct contribution from the Deaf parent living with dementia. Formal carers, such as clinicians and other service providers, have also written about the barriers they experience in providing a good service to Deaf people who have dementia but this largely addresses linguistic and communication issues debating that mainstream professionals should be fluent in sign language, or that Deaf professionals should be employed to support the transitional time of Deaf people beginning to live with dementia (Drion & Semail, 2016).

The direct experience of a Deaf carer of someone with dementia is largely absent from the literature. A rare exception is the account by Parker, Young & Rogers (2010), which focuses primarily on her struggle to establish a formal diagnosis and subsequent culturally appropriate support for her mother. In this case, the Deaf carer was an experienced professional who understood well how to navigate the UK's health and social care systems. Nonetheless, the article reveals the raw emotions she experienced in not knowing how to manage her own feelings and seek support as a daughter/carer who used a minority language that only very few around her could communicate in too.

A study of the lived experience of Deaf people with dementia (Ferguson-Coleman, 2016) also included Deaf family members in their role as carers in the data collection, although their narratives were not the primary focus of the study. This research began to reveal the complex ways in which Deaf carers became adept at supporting the continued agency of the Deaf person with dementia through subtle adaptations in signed communication to make implicit features more explicit, deliberate cueing in and signalling of turn taking to promote maximum inclusion, and the use of visual, environmental devices to support sense of place and memory (Ferguson-Coleman, 2016). However, the experience of caring from the Deaf person's point of view was in the background of this study with only occasional evidence of additional burdens of seeking access to services and support if one does not use spoken/written English well. The lack of empathy and support of other members of the Deaf community toward the carer and the Deaf person with dementia was a feature of some people's experience resulting from lack of knowledge and understanding of the condition. The double marginalisation experienced as a result of both being Deaf and having dementia or caring for someone with dementia was also evident, be it in a small sample of participants (Young, Ferguson-Coleman and Keady, 2014).

The study reported here set out to explore in far greater depth the experience of being a Deaf carer of someone with dementia (whether that person were Deaf or hearing) from a Deaf person's point of view. It was undertaken as a precursor to the development of a new model of practice to support a range of Deaf and hearing carers and Deaf and hearing people with dementia where service access, knowledge/information and support are impacted by sign language use and in the absence of a pre-existing evidence base on which to draw.

Method

The overarching research aims were:

- To explore the lived experience of Deaf carers of someone with dementia.
- To identify service and support needs and whether and how these differ from those of the wider population of carers of someone with dementia.

Data were drawn from primary qualitative data collection generated by three Deaf carers of Deaf family members with dementia during a consultation exercise to assist planning of a new service for Deaf people in Northern Ireland, supported by Alzheimer's Society and British Deaf Association (Northern Ireland). The consultation was established in order to find out more about current service provision with respect to Deaf people with dementia and their families in Northern Ireland and whether and how it meets their needs. The Deaf carers were invited to share their experiences of current service provision while caring for their Deaf spouse or parent living with dementia. A qualitative approach was undertaken because this was new territory with little pre-existing evidence and an emphasis on exploration and personal perspective was paramount. Participants were first asked to draw an image that represented their personal journey with dementia service provisions made available to them. They were then invited to elaborate, in their own language, on their drawings to explain the representation and their personal journey. One Deaf carer recounted their stories within a focus group; one Deaf carer was interviewed alone and one Deaf carer was interviewed alone but in the company of two close Deaf friends who they wanted present at the interview

Table 1. Initial coding themes.

Author 1 – codes	Author 2 – codes	Final themes
Accessing services as a Deaf person caring for Deaf people living with dementia	Accessing and <i>understanding</i> information in BSL/ISL about dementia	Access is more than the provision of interpreters
Understanding information in English via a BSL/ISL interpreter	Having information in the right format and how this might enable the family to request the right level of support	
Receiving support from the Deaf community and from family members	Raising awareness in the Deaf community about how to support and empower one another	Effective care for the carers
Available care packages and their effectiveness for the Deaf carer (and their loved one)	How to support mainstream services in working with families who are Deaf and ensuring that they are included	Unknowing risk taking
Decision-making processes carried out by Deaf carers for their loved ones	Decisions made about leaving the Deaf person with dementia at home alone, or alone, while out and about	
Hearing carers and family members are unknowingly allowing these decisions to happen	Is the family member aware that they are ‘taking risks?’ – these are everyday decisions	

to support communication. The accounts were video-recorded with the participants' consent. Full ethical approval was granted via the University of Manchester Research Ethics Committee (reference number 2017–1758-3390).

There were two co-researchers present within this data collection who were both Deaf BSL users (Author 1 and Author 2). All the data collection was in BSL/ISL, without the use of a sign language interpreter. This enabled a linguistic and cultural matching designed to promote trust, rapport and ultimately a culturally normative approach to both data collection and interpretation of the data (Temple & Young, 2004). A qualitative thematic content analysis (Braun & Clarke, 2006) was used to analyse this data set. For ease of coding, the video recordings were translated and transcribed for the process of coding, but all themes were generated in the source language. Authors 1 and 2 watched the recordings of the three participants and independently generated an initial set of six themes. These were compared and some collapsed into each other to arrive at a final set of three themes that were applied to the data (see Table 1).

Participants

In the following description of Deaf carers and their family situations, care has been taken to pseudonymise some aspects of their situation in order to preserve the participants' identity. These steps have been taken to offer anonymity to the contributors coming from a small linguistic Deaf community.

Anna and Ben are both Deaf. They are married and have four hearing children. Ben's mother, Hilda, is Deaf and is living with dementia. The whole family uses BSL. They have a hearing respite carer, Grace, who comes to visit Hilda once a week – she does not sign.

Henry and Flora are a married couple and they are both Deaf. Flora is living with dementia. Henry and Flora are native BSL users. They have two sons, both hearing. One son, Jake, lives nearby to the family home and can use some sign language.

Christine and Iain are a married couple and they are both Deaf. Christine and Iain are native BSL users. Iain is living with dementia. They have one grandchild, Jessica, 17, who is hearing and can use some sign language. Jessica is the closest family relative that they have nearby.

Findings

Access is more than the provision of interpreters

It is well evidenced that Deaf sign language users experience widespread linguistic difficulties in accessing mainstream health services, which influences health inequalities in terms of health outcomes (Alexander, Ladd, & Powell, 2012; Ringham, 2013; SignHealth, 2014; Emond et al., 2015; Young et al., 2017; Rogers, Ferguson-Coleman & Young, 2018). In part, this is because of a lack of awareness of Deaf people's language requirements for information in BSL/ISL, and in part because of a lack of interpreter provision, often despite the legal requirements to ensure it is available (NHS England, 2016). This study focussing on Deaf carers, rather than Deaf patients, evidenced how the complexities of 'access' to health and other services went beyond the linguistic and exposed how the provision of interpreters could nonetheless mask problems of access to knowledge and understanding.

All of the participants recounted examples of when a close family member was used to interpret during appointments concerning the Deaf person with dementia. This could be a hearing child of the parent who was undergoing treatment or assessment who was given this role or in some instances the spouse of the Deaf person with dementia even if they were deaf or hard of hearing if it was deemed they could lipread well and use spoken English.

For example Henry explained how he tried to understand what was happening with his wife, Flora. Henry said he had relied on his hearing son, Jake to 'interpret' for him at the GP appointments that were arranged for his Deaf wife, Flora. However, Henry did not know that he had the right to ask the GP to book a BSL interpreter, as he is from an older Deaf generation when qualified BSL interpreters were not the norm for health care appointments. Jake is not a qualified BSL interpreter but has grown up using sign language within the family unit. The GP did not intervene or see this arrangement as inappropriate, preferring to view Jake as a language broker who met his parents' preference for communication, yet it was apparent from Henry's story that this arrangement did not guarantee Henry full access to the information he required about his wife's condition. Jake could not be expected to be able to convey the complexity of and the depth of information without the relevant interpreter training to do so. It was unknown how much information had been simplified, summarised or not conveyed despite the son's best efforts. Also the emotional burden for the son to act in such a role about his mother was unacknowledged.

In this case and other examples we were provided with, Deaf carers' apparent preferences for access were permitted to predominate over concerns about the quality of the information accessed. Yet such choices and preferences are not informed ones, they are constrained by a lack of knowledge of what might be acceptable alternatives (e.g. a professional interpreter paid for by the health service) and by the expediency of a situation that means that the

health care professional does not necessarily intervene to support a higher quality of linguistic access if it might mean delaying an appointment.

However, even when health services successfully provided interpreters to make appointments and treatment accessible both for the person with dementia and their carers when both were Deaf, this did not necessarily solve all problems. Anna shared a story about her husband Ben who was attending hospital appointments with Hilda while she was receiving treatment. Ben had a BSL/ISL interpreter present with him to be able to discuss Hilda's treatment with the consultant while they were on their rounds. However, Ben struggled with understanding the information being given to him, regardless of the fact it was in BSL, and was not given enough time to ask questions about what has been said. Anna elaborates how they managed this situation between them via online video calls in sign language:

Ben gets the information in BSL via the interpreter, but doesn't understand what it means. He then rings me on FaceTime while I am at home and I go onto Google to check what the words are. I read up on it then FaceTime him back to let him know what the words mean. Ben then goes back to the ward to check that this is right with his interpreter present.

Anna is fortunate in that she can read English and make sense of it and convey the meaning back in sign language to her husband, whereas this would not be the same for many Deaf people whose comprehension of the English language would not be within the same range as Anna's (Emond et al., 2015). Ben was equally fortunate in that he is then able to clarify the same information again when he returns to the ward as there is a BSL/ISL interpreter there that enables him to do so. However, the consultant and other health care professionals in this case remained completely unaware of what had happened behind the scenes to ensure that Ben was able to support Hilda in the best way possible for her needs. The assumption was that the good practice of providing an interpreter was sufficient to ensure understanding and participation by the Deaf carer – it was not.

Participants also recounted examples of when there were no interpreters provided for health care interactions because despite the person with dementia being Deaf, the primary carers (family members) were hearing and it was to these that the health care professional addressed their remarks. However, the point made about such situations was far broader than the obvious one where the person with dementia was not included in the conversation. To illustrate further, Anna's reflections centred on the fact that hearing carers, even if family members, still lacked the life experience of what it is like to be Deaf:

It must be worse for hearing carers with Deaf parents, as they do not share the same understanding of what it is like to be Deaf when hearing (professionals) automatically talk to hearing (carers) and exclude the Deaf person out of the loop.

Anna's point here is that she knows how to deal with a situation like the one described because she has that lived experience and so she knows how to support her mother-in-law when faced with this barrier. She can deal with mainstream health care professionals who make such mistakes of only talking with other hearing family members and educate them about how to work with BSL interpreters and so on. By contrast, she felt that if there was only a hearing carer present, the attitude of professionals would not be challenged and the Deaf person would be taken out of the equation because the hearing professional would

focus on communicating in their first language, spoken English, rather than making the effort to include the Deaf person present.

In summary, Deaf people with dementia and their carers face repeated challenges concerning access to communication that are linked to the provision or lack of provision of sign language interpreters. However, the complexities surrounding gaining new knowledge about an unfamiliar condition are not necessarily solved or guaranteed by ensuring there is an interpreter present. Unfamiliarity with rights to language provision, the differences between communication and ensuring understanding, the supporting of family preferences versus quality of communication access, and the role of Deaf life experience in challenging situations of linguistic exclusion are also part of the multi-layered picture. Interpreter provision is vital but of itself does not ensure access to knowledge and understanding; communication in BSL/ISL does not of itself imply quality of interaction.

Effective care for the carers?

For all of the Deaf carers who participated, coping with the knowledge that there are no specialist dementia support services for Deaf sign language users in Northern Ireland was a heavy burden. Their focus was firmly on the needs of the Deaf person with dementia for whom they were seeking to care. Responding to questions about their own needs as carers was more difficult, partly because it seemed less important to them as they were not in a position to think about their own needs, and partly because they had not really had the opportunity to think about it before and also discuss these needs with another Deaf person. The few examples given were nonetheless illustrative of the additional problems of ensuring that there was effective care for the carers if you were Deaf.

Anna and Ben said they faced problems in using mainstream support groups for people living with dementia yet this was not primarily because of a language barrier (as they would need BSL/ISL interpreters to do so). The problem for them was also an intercultural and relational one. Within the life-long lived context of a mainstream world where Deaf people can be patronised, ignored or asked prying questions about being Deaf, Anna and Ben did not want to go through what they saw as the added emotional burden of explaining themselves as Deaf people – how they saw their identity, their communication requirements and why their experience might be different from those who were hearing and were carers – before they could begin to engage in relating to others in terms of support. Consequently, Anna and Ben said they found it easier to stay within what they described as their ‘deaf carer – deaf person living with dementia family unit’ for support and care. Anna strongly felt that supporting one another within their family where they shared the same language offered enough to carry them through the difficult times.

Furthermore, Anna did not feel satisfied in considering whether she and Ben could access support in their own community. Upon being asked if she would attend a specialist support group for Deaf carers in the Deaf community, she remarked:

I don't know about that. I'd have to keep explaining things and really, I want the support group to ask me about *me*, not my mother. It would not be *my* time.

Anna was fully aware that there is a distinct lack of access to information about dementia in BSL in the Deaf community (Young, Ferguson-Coleman and Keady, 2014) and that her needs as a carer would be superseded by the needs of other people asking her in their own

language about the specific presentation that her mother-in-law had as a person living with dementia. This is not unusual within the Deaf community where Deaf people will use such gatherings as an opportunity to glean information for the first time in BSL (Young, Ferguson-Coleman and Keady, 2016). However, Anna agreed that for other Deaf people finding themselves in these circumstances, being in a support group with others like oneself (as a Deaf BSL/ISL user) was preferable over support services to which one would always be an outsider (the only Deaf person present within the care process).

Deaf people can have multiple life experiences of not being understood by others and the feelings of isolation and frustration this can provoke, so they are fully aware of the impact for the carer of not being able to communicate with their family member (the person with dementia) is a deeply emotional one, not just a practical problem. This further experience of isolation, as a Deaf person in a predominantly hearing world, can be exacerbated where the number of potential communicative partners is far less than for hearing people. Henry touches upon this when he describes his relationship with Flora changing:

Flora just sits there and is quiet. She doesn't talk about things anymore. I try to talk but she doesn't reply.

Christine elaborates on this new experience of isolation from her life partner further:

It is difficult to talk to him (Iain). He can't follow the conversation any more. We talk less and less every day.

Christine goes on to explain that she has support from her Deaf friends in the local Deaf club once a week. She values the opportunity to recharge her batteries and to catch up with her peers. However, she does not explain whether she discusses dementia-related issues or whether she considers this as just her time to be Christine.

Of the three families who took part, only Anna and Ben had experience of any kind of respite care. Whilst on the one hand the provision was welcome, it was also experienced as problematic. For example Anna and Ben had a respite carer who came into the family home twice a week to look after Hilda while they went out to catch up on shopping and so on. It did not relieve anxiety or provide a break for them because they struggled with the inappropriate communication skills of Grace (the respite carer). Anna explains:

Well, I was really uncomfortable in leaving her with Grace. Grace was lovely but she couldn't sign and I could see Hilda really struggling to understand her. So I'd be there with my coat on, ready to go out, but turning back on myself to go and communicate between the two of them, before I could feel comfortable about leaving the house.

Anna, as a Deaf sign language user, clearly recognises that Grace does not have the communication skills that Hilda needs, but struggles with balancing her own personal needs in looking after her family and needing a break. She appreciates Grace's presence in enabling her and Ben to leave the house for a couple of hours, but wrangles with the knowledge that Hilda cannot understand her and therefore is more isolated *even with Grace there looking after her*. As Anna concludes:

That's not real respite.

In summary, Anna and Christine both share their different experiences in how they support their family member, while trying to look after their own personal needs. This demonstrates their resilience in facing the unknown in caring for their loved one while they are living with dementia but maintaining their connections within their family and their wider communities. In both instances the added complexities of the carer's language requirements makes the lack of care for the carer more acute.

Unknowingly taking risks

Throughout the interviews, while there were no direct questions linked to how the families carried out their day-to-day care of their loved one, some elements of difficult decision making processes linked to their loved one's care began to surface. Two of the three Deaf carers shared their personal experiences in struggling to manage their everyday lives while caring for their spouse living with dementia. Henry and Christine gave separate examples of how they had made decisions based on the here and now, which, unfortunately, appeared to trigger some safeguarding concerns from the research team's perspective. These actions were not done out of malice or neglect, but simply because Henry and Christine, in their new roles as carers, did not know any different or have the knowledge to discern that their decisions might be risky. Deaf people do not always have the opportunity to contribute towards everyday decision-making processes (and also they have no access to everyday conversations where other carers of people with dementia might discuss such issues) so therefore may not be familiar with what might be the 'right' or 'wrong' thing to do while caring for someone living with dementia.

Henry shared his story in how he tried to entertain Flora one day by taking her out in the car, as it was so difficult with no two-way conversations happening at home. He thought it best to take her out:

I was in the street outside the car, trying to (entice her) to come out for a walk. Flora just wanted to stay in the car to sleep. I thought well, best to leave her there, go for a wee walk by myself, and so I went to buy her an ice-cream. I came back to the car to check she was alright and gave her the ice-cream.

Throughout the re-telling of this scenario, Henry appeared not to appreciate or understand the potential risks involved in leaving Flora in the car alone or how it might be frightening to her. Instead, from his point of view, he was respecting what his wife wanted to do. He did not have the opportunity to clarify with someone else nearby what he could have done as an alternative, or whether there were other ways he might have handled the situation. This kind of tacit knowledge and carer expertise can only be built up through contact with other carers, effective professional support and in many cases a lot of self-education through looking up information only available in the written word/online. If a carer is isolated from other carers because they are Deaf, cannot access information in English, and support services are routinely unable to communicate effectively, then there is little opportunity to build up this know-how.

Christine shared a similar story in that she needed to leave Iain at home while she went to the Deaf club. The local Deaf club opens once a week on a Thursday evening and Christine strongly feels that this is her opportunity to have some downtime with her friends:

What I do is I ask the carer who comes to clean the house to lock up the house when she leaves at 8.30 pm. I ask her to draw the curtains and to tell Iain to keep them shut. I make sure he has a cup of tea and a biscuit until I get back at 10 pm.

Christine does not see the potential number of risks in leaving her husband alone at home, particularly as he is mobile, as she feels that she has done all the right things in asking the carer to lock up and also to draw the curtains so no-one can see inside the house. However, the paid carer does not sign (as Christine explained this earlier during the interviews) and it is not clear whether the carer understands that Iain is being left alone for one and a half hours, or whether the carer is in agreement with the choices made by Christine.

In summary, Henry and Christine, in their new assumed roles, have to make everyday decisions while caring for their spouse. Their lifelong relationships with their spouse leads them to believe that they are making the right choices even though we, as outside observers, can see where there might be potential risks. Even if we were to directly challenge these practices, Henry and Christine would not appreciate straightaway what the issues of risk were. Only carefully designed training opportunities, which embrace visual methods, with thorough explanations in BSL, with supporting images and role-plays would be an effective way to explain those risks and what can be done to avoid them (Young, Ferguson-Coleman, & Keady, 2016).

Discussion

We frame this discussion around key questions that the data have provoked and that are foundational in developing better support services for carers who are Deaf.

Double impact of being a Deaf carer

The impact of being a Deaf carer is manifested in different ways. Deaf people do not have access to information about dementia in BSL (Young, Ferguson-Coleman & Keady 2014) therefore they have to learn the best way to support their loved one through daily living experiences. Although in some respects, learning through experience can be true of every carer, whether hearing or Deaf, the key difference is that Deaf people have far fewer channels to support their learning through experience (Kritzinger, Schneider, Swartz, & Braathen, 2014). Gaining knowledge and having effective communication, whether formally or informally, with hearing people who do not use the same language is far harder for Deaf people and asking someone close in the Deaf community who encounters the same access issues for support is a major barrier for Deaf people. Web searches are not straightforward if the main information found is in the written word and the scope for misunderstanding in a language you are not fluent in is high (Young, Ferguson-Coleman & Keady, 2014). Health care professionals do not share the same language as you (Emond et al, 2015; Alexander et al., 2012) so you are not able to clarify first-hand what is happening for your family member. Indeed, the experiences of Anna, Christine and Henry demonstrate not just challenges such as these, but also the double the time required to overcome them, which adds to the time spent on caring for a Deaf person living with dementia and highlights the impact these challenges have on carers' time, effort and tenacity. For example, the doubling of time is reflected in how Anna has to manage information about dementia in a three way process to support Ben while he is supporting his mother, Hilda, in hospital.

Questions to consider

How can Deaf carers be supported with their knowledge and understanding of dementia?
What is the best way to ensure information is comprehensible and understandable?

How can Deaf carers be supported in understanding what risks there are in leaving their loved one alone at home?

Do health care professionals appreciate the double isolation experienced by Deaf carers who may have nobody to 'talk to' about their everyday concerns?

Supporting carers' resilience

Resilience is defined as the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources that are within the individual, within their lives and their environment facilitate this capacity for adaptation or 'bouncing back' in the face of adversity (Windle, 2011, p. 163). Moreover, while a person is living with dementia, they might experience a negative impact with social inclusion and equitable citizenship becoming problematic and their agency or personhood being diminished. To challenge these negative experiences, research literature has supported a citizenship approach which enables the narrative identity of the person with dementia, meaning that their agency and presence in society gives them equitable opportunities to make decisions, actively influence choices and recognise the support of carers who are within their environment (Bailey et al., 2013; Bartlett & O'Connor, 2007). However, asserting agency and being resilient as a Deaf BSL/ISL user caring for someone living with dementia may be problematic if the professionals supporting the Deaf person do not understand the cultural and linguistic issues that the family unit may face and if they do not use sign language themselves, their isolation can be further exacerbated (Ferguson-Coleman, 2016; Young, Ferguson-Coleman & Keady, 2016). Supporting Deaf carers in being resilient is clearly a need that has to be addressed as the stories of Anna, Christine and Henry have shown.

Questions to consider:

How can families and health care practitioners work together to ensure that carers are empowered and able to make informed decisions in their new role?

In what ways can the Deaf person living with dementia be 'heard' throughout?

Informing health care practitioners about interpreters

There is evidence that Deaf people do not have a clear understanding of their current health condition because clinicians do not book interpreters and rely on the written word to communicate, therefore leading to misunderstandings and misdiagnoses (SignHealth, 2014). However, there is supporting legislation such as the Accessible Information Standard (NHS England, 2016) and the NHS England (2015) published principles for high quality interpreting service provision within primary care settings that protects the rights of Deaf people when they attend appointments linked to their health care. Within the context of Northern Ireland, there is a guide: 'Making Communication Accessible for All' (Belfast Health and Social Care Trust, 2015) – however, this is not mandatory legislation. This

legislation is not always supported or enforced within all primary care settings, nor do older Deaf citizens, who are not always aware that these policies are in place, argue these issues. As our data have shown, some Deaf people may state their preference that their family member interprets for them at their appointment because they are used to one another's home signs; however, there should still be a BSL/ISL interpreter present in order to support effective communication between all parties and reduces the potential for errors that can occur (NHS England, 2015).

Questions to consider:

How can health care professionals ensure that Deaf carers are supported? Do they know how to source a BSL/ISL interpreter?

How do we maintain the agency of the Deaf person living with dementia and ensure that they are heard in the face of inconsistent interpreter provision?

Conclusion

The Deaf carers who shared their experiences in this study all wanted to become good carers, effectively anticipating and meeting the needs of those they cared for. However, this was not an easy task. From an Actor Network Theory (ANT) (Law, 2007) perspective, the challenges might be understood as a disruption in the means of acquiring knowledge and skills that are embodied in one's environment through social interactions and interpersonal networks. ANT suggests that knowledge is a social construct, not a cognitive process, and the means of its acquisition is social too, played out through defined roles in both formal (doctor/patient) and informal (social chit chat amongst friends) contexts. But as our data have shown Deaf people are largely excluded from social networks and social processes, where knowledge is embodied and shared through particular role relationships. It is not just a question of not hearing everyday conversations or requiring interpreters to access information, it is also that within one's community, cultural and social networks, the knowledge about dementia and effective care is also missing, which means that the social networks in which one is embedded do not naturally produce/reproduce that knowledge to be learned through one's roles within those networks and communities. How, then, can we effectively support Deaf people to become carers if they do not have access to the everyday social world of which hearing carers may have the privilege? Deaf carers act their roles out as carers from what they think they know works within their family unit; rather than from the acquisition or learned knowledge that hearing carers may achieve in their new roles and through their new networks.

Therefore, the importance of communicating the shared everyday experiences of Deaf carers of Deaf people living with dementia is not to be underestimated. The idiography of these Deaf carers' stories, while unique to each family unit, all share one common theme, in that the Deaf experience of becoming carers to a loved one with dementia is a shared one in facing everyday challenges with barriers to information and limited access to effective support strategies. The depth in which we are able to begin to value these everyday experiences has huge potential for the development of future service provision for this community, based on shared cultural knowledge through opportunities to express this in their first language.

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Note

1. The word 'hearing' within this context is used to describe people who can hear as opposed to those who cannot.

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