Meeting Deaf patients’ communication needs

In this article...
- Deaf people’s communication preferences
- Communication methods used by health professionals
- Risks posed by ineffective communication

Keywords: Deafness/Hearing impairment/Communication

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A literature review revealed that health professionals’ communication with Deaf people is often inadequate, leading to lack of understanding and putting patients at risk.

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British Sign Language has been recognised as a distinct minority language in the UK since 2003. This means the rights of its users are protected under both equality and disability legislation.

Estimates of the number of Deaf people in the UK who use BSL as their first or preferred language range from 50,000 to more than 100,000, and are often quoted without rationale or basis (British Deaf News, 2013). Ladd (2003) noted that the confusion of medical and cultural criteria make it difficult to ascertain the exact number of people in the Deaf community. For many years Deaf people have been “invisible” or undercounted in national statistics, making it difficult to plan services to meet their needs. The Deaf community also falls outside most other models of culture and ethnicity (Lane, 2005). There has been continuing discrimination within the NHS and the Department of Health to provide accessible and culturally appropriate healthcare (Powell, 2014).

To guarantee compliance with the Disability Discrimination Act 1995 (DDA), healthcare providers should ensure Deaf patients have access to certified BSL/English interpreters to facilitate communication with health professionals. This enables nurses and other health professionals to obtain accurate and complete medical histories, explain treatment effectively and gain Deaf patients’ trust and confidence. Absence of an interpreter can increase the risk of misdiagnosis, medical error and non-adherence to treatment.

There is a dearth of nursing literature concerning Deaf people; many of the articles available are dated and anecdotal, most are not British in origin and may not, therefore, accurately represent the nature of Deaf people’s experiences of care. More research into Deaf people’s communication needs of care is needed and may be key in justifying compulsory deaf awareness training for all nursing staff.

DEFINITIONS

- Deaf
  In the context of this article and in conjunction with Deaf cultural beliefs (Ladd, 2003) “Deaf” with a capital D refers to people who are prelingually deaf and for whom sign language is the first language and language of choice.

- Prelingually Deaf
  The term prelingually Deaf is used to describe people who lost their hearing before they acquired a language (Gilchrist, 2000)

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Abstract: Dickson M, Magowan R (2014) Meeting Deaf patients’ communication needs. Nursing Times; 110: 49, 12-15. Effective communication between nurses and patients is a vital part of safe and effective nursing care. However, few health professionals receive training in how to communicate with Deaf people, as a result, attempts to communicate with Deaf patients is often inappropriate and undertaken without knowledge or understanding of their communication needs. This article examines the literature on ways in which Deaf patients experience communicating with, and receive care from, nurses.

Sign language is key to Deaf patients fully understanding what is said in a consultation.
of nursing Deaf people in the UK. The lack of nursing literature may indicate that this group has not been thought to require special consideration. However, knowledge that is culturally relevant and reflects their lived, contextual realities and concerns is crucial to effectively nurse these patients (Lopez and Willis, 2004).

**Access to healthcare**

Legislation such as the DDA and the Equality Act 2010 demonstrate a commitment to eliminate discrimination, reduce social exclusion and make services more accessible for the Deaf population. The DDA introduced the concept of “reasonable adjustment”, which requires service providers to take “reasonable” steps to remove barriers to accessing services (Box 1).

It is seen as good practice to include service users with disabilities in the process of considering what adjustments are appropriate, although service providers make the decisions about which to implement. For Deaf people, however, the major barriers are:
- Lack of recognition;
- Acceptance and use of sign language in all areas of life, and
- Lack of respect for their cultural and linguistic identity (Ladd, 2003).

In Scotland a mixed-methods study assessing the extent of access to public services in BSL by Deaf people found no instances of direct access to public service through BSL (Kyle et al, 2005). Participants reported frustration when contacting hearing services and considered contact with the NHS the most problematic, as well as the highest priority, public service.

Reeves et al (2003) evaluated access for Deaf people to primary and accident and emergency services in the north west of England. None of the 22 studied services had a visual patient call system, relying instead on patients responding to verbal calls; in two cases these came via public address systems. While managers said Deaf patients would be approached when it was their turn to be seen, only 27% of receptionists claimed to use this procedure.

Although 68% of the managers indicated their unit had a system for obtaining BSL interpreters, many had no experience of booking any, suggesting they were rarely used. Six departments (27%) used staff members with signing skills to interpret for Deaf patients; three of these staff were qualified to BSL Level 2, while one other was working towards that.

One unit was seeking funds for Deaf awareness training and for a staff member to learn BSL. Out of the 22 departments studied, 21 (95%) felt that access for Deaf people could be improved via Deaf awareness training (Reeves et al, 2003).

The findings of Reeves et al (2003) highlight that the difficulties experienced by Deaf people trying to access healthcare begin at reception, where their need to communicate and orientate themselves and to have an interpreter often goes unrecognised. The study also suggests that their problems arise from staff not understanding their communication needs. A major strength of this study is that data was collected, video recorded and analysed directly in BSL by a Deaf researcher, preserving its BSL nature and avoiding misinterpretation.

**Literacy and health-related vocabulary**

Communicating through spoken or written English poses many challenges to Deaf people, as there is no written form of BSL, and it differs from English in grammar and syntax (Kyle and Woll, 1985). Linguistic studies have also demonstrated only 30-45% of the English language is discernible through lip reading – contextualisation and guessing determine the remainder (Lieu et al, 2007; Barnett, 1999; Conrad, 1977a).

Although not a reflection of their intelligence, Conrad’s (1977b) seminal research noted that the average reading age of Deaf adults is that of a nine-year-old. Berkman et al (2011) noted that the likelihood of accessing, processing and understanding health-related information is strongly associated with levels of literacy in adults, yet in the absence of a BSL interpreter, health professionals often resort to communicating with Deaf patients in writing.

Deaf people are commonly at an increased risk of what has been termed a “low fund of information”; this refers to the knowledge individuals accumulate from picking up facts and common-sense understanding through casual conversation and access to media (Young and Hunt, 2011). Coupled with low levels of literacy, this often leads to knowledge deficits about illnesses, their symptoms and causes, treatment options and risks, medication and preventive care.

Although printed materials about health topics may be available to Deaf adults, the information may not be written at a level appropriate for them, putting them at a considerable disadvantage. This has serious implications for the process of obtaining informed consent and the consequent safety of Deaf patients. Few rigorous evaluations of health literacy-related interventions for Deaf people have been carried out. Pollard and Barnett (2009) explored health-related vocabulary knowledge in a sample of 57 Deaf people in the US. Participants were asked to complete a modified version of the Rapid Estimate of Adult Literacy in Medicine (REALM) screening instrument (Davis et al, 1993), which requires users to read a list of 66 health-related vocabulary terms and indicate their level of comprehension. Although 81% of participants possessed college degrees, almost a third (31.6%) produced scores that were considered below the level of understanding of a 14-15-year-old, which is considered indicative of low health literacy.

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**BOX 1. REASONABLE ADJUSTMENTS IN HEALTHCARE**

The Disability Discrimination Act 1995 requires healthcare providers to make three types of adjustment to remove barriers that make services difficult for people with disabilities to access or use services, providing it is reasonable to do so:

1. **Change aspects of service provision such as:**
   - Policies
   - Rules
   - Practices

2. **Adapt physical features of healthcare facilities such as:**
   - Steps and stairs
   - Passageways and paths
   - Entrances and exits
   - Internal and external doors
   - Toilets
   - Signs

3. **Provide auxiliary aids or services such as:**
   - Portable induction loops for people with hearing aids
   - British Sign Language interpreters
   - Information in alternative formats, such as Braille or audio CDs
   - Extra staff assistance
Words that were not understood included "obesity", "constipation" and "smear". The study did have limitations, as Deaf people often indicate they have understood healthcare information to avoid embarrassment (Ubido et al, 2002). The sample was voluntary and highly educated, so the results cannot be generalised.

**Healthcare experiences**

Steinberg et al (2006) conducted four semi-structured focus groups exploring the healthcare experiences of 91 Deaf adults in the US. Participants expressed communication difficulties, with a recurrent theme of fear of the consequences of miscommunication. Positive experiences were characterised by the presence of medically experienced certified interpreters, health professionals with sign language skills, and doctors who made an effort to improve communication. However, alternatives to the use of certified interpreters, such as lip-reading and written communication, were common.

Parise (1999) conducted semi-structured individual and focus group interviews exploring the healthcare experiences of 10 Deaf participants in Quebec. Participants expressed feeling alienated, rejected and powerless when in contact with health professionals due to ineffective communication methods used. They found lip-reading and writing to communicate health issues laborious, overwhelming and emotionally draining, and identified the provision of a certified interpreter as creating a sense of ease in healthcare encounters.

Participants in Steinberg et al’s (2006) study spoke of bringing family members to healthcare appointments to interpret, but feeling excluded from these conversations. They also noted that this method of facilitating communication compromised their privacy. This supports the findings of a descriptive pilot study by Wright (1993) in the UK, in which participants who used ad-hoc interpreters, such as family members, felt they were being spoken about and not spoken to.

Inadequate interpreting services leading to using family and friends increases the risk of medical error and is fraught with legal and ethical problems.

Steinberg et al (2006) stated that many participants who felt negatively about their healthcare experience had limited knowledge of their legal rights and/or complaints procedures in the healthcare system. Similarly, the British Deaf Association (2012) stated there is a paucity of knowledge about how legislation works and how it can be enforced within the UK Deaf community.

These two studies reinforce the findings of Gilchrist’s (2000) US study exploring 11 Deaf adults’ experiences of communicating with nurses, what health meant to them, and their attitudes towards nurses. Participants expressed a need to see signing, gestures, facial expressions and body language to make sense of their environment. Without being able to visualise words (through use of an interpreter) they noted that communication was diminished.

Participants described feeling proud to be Deaf and part of a tight-knit community with its own language. When in contact with nurses, however, they felt objectified because of their deafness and felt that no caring or compassionate connection developed. They emphasised that not all Deaf people understand written English, nor do they feel they need or want to. Participants also viewed nurses as living in doctors’ shadows, and said nurses did not clarify any situations for them despite participants communicating a desire to be informed and empowered to take control of their health.

Inaccurate translation threatens the credibility and therefore trustworthiness of results, so a central concern of cross-cultural research is the development of cultural understanding and translation procedures. Parise (1999) and Gilchrist (2000) both required the use of interpreters to carry out their interviews, and to present the limitations of their studies. Threats to the validity of each of these studies emerge from the analysis being undertaken in a language that is not that of the participants. As detailed descriptions of the translation process were not provided it is unclear how far removed they are from the original data.

Another limitation of these studies and that of Steinberg et al (2006) lies in the nature of the sampling method. All relied heavily on “snowball sampling”; this is used where no sampling frame exists (Bowling, 2009) and accesses human networks to gather a sample or identify potential participants. The method is most effective when contacting hidden or hard-to-reach groups (Grove et al, 2013), but while it is the most common, effective way of obtaining samples from the Deaf community, it may not provide a sample that is representative of the Deaf population (Padden and Humphries, 2006).

Snowball sampling involves a researcher locating a few participants with the necessary criteria and asking for their assistance in contacting others with similar characteristics. Despite the potential for sampling bias, the evidence from these studies of Deaf people’s access to healthcare is consistent; when anecdotal reports are taken into account, the evidence is also consistent over time suggesting that little has changed despite implementation of the DDA.

**Deaf awareness**

Many of the studies reviewed concluded that Deaf participants most valued being able to communicate in their preferred language with someone who is aware of the cultural differences between Deaf and hearing people. There are currently no plans to train health professionals en
misse in BSL, which highlights a discrepancy between patient preferences and the services available in the UK (Middleton et al, 2010).

Despite attempts by the UK government to offer patient choice and a willingness to meet their communication needs, it is not feasible for the NHS to train health professionals to the level required to fluently communicate with Deaf patients in BSL, due to the small size of this patient group. In the absence of health professionals who can sign adequately, Deaf awareness and access to certified BSL interpreters should, therefore, be a priority. The Department of Health (2005) recommended that all NHS frontline staff receive Deaf awareness training to enable them to respond appropriately and sensitively to the needs of Deaf people, providing a more accessible service and supporting compliance with the DDA.

Hoang et al (2011) carried out a study in the US to establish a link between knowledge about Deaf culture and Deaf patients, and completion of a Deaf Community Training (DCT) programme that incorporated elements of Deaf culture and linguistics. The results indicated that DCT significantly increases participants’ capacity to care for Deaf patients, reducing health inequalities.

However, in a survey assessing US doctors’ knowledge and beliefs regarding communication with Deaf people, although almost two-thirds (63%) knew that effective communication with Deaf patients is achieved through use of a certified interpreter, only 22% used this more frequently than other methods of communication (Ebert and Heckerling, 1995). Writing was the most frequent method used to communicate with a Deaf patient and was used in 34% of encounters despite only 32% of participants believing it to be effective.

Conclusion

There is clearly a lack of public and professional awareness of the barriers to healthcare services that Deaf people encounter. Their communication preferences are often ignored and they are expected to “get by”. Although deaf awareness can improve health professionals’ knowledge of how to appropriately and effectively communicate with Deaf patients, even if they know and understand Deaf patients’ communication needs, health professionals often resort to inadequate methods such as lip-reading and writing. This does not reflect current NHS strategy that promotes person-centred care (McCormack and McCane, 2010).

There is a dearth of recent British literature on Deaf people’s experiences of healthcare, but anecdotal evidence suggests they often experience ineffective communication with health professionals has remained consistent over time. The lack of nursing literature may indicate that this linguistic group has not been thought to require special consideration. Further study of Deaf experiences of nursing care may help to justify provision of compulsory Deaf awareness training for all nursing staff. To effectively nurse Deaf patients it is important to develop knowledge that is culturally relevant and reflects their lived, contextual realities and concerns.

Further research could add to the literature, suggesting the need for national guidelines on the provision of translation and interpreting services within the NHS, to secure high-quality interpreting services for Deaf patients. Information on complaint procedures should also be made accessible to BSL users so they can highlight issues such as inadequate facilitation of communication and lack of adherence to legislation such as the DDA.

As the communication needs of the UK population continue to change, it is essential that nurses are educated to provide culturally responsive care that is sensitive to the needs of minority ethnic groups such as the Deaf community. As Montgomery (1981) stated: “There are few places where it is more inconvenient or even dangerous to be misunderstood than a busy hospital ward.”

Better communication is not an option; barrier-free communication is regarded as a basic human right and vital to patient safety. Nursing Deaf patients needs to become a more inclusive relationship, in which patients are affirmed as partners rather than recipients of care; the recognition of, and adherence to, language preferences is vital to achieving this person-centred approach.

References


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