

Practioner's Blog

Still the children of a lesser God

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We often consider barriers to communication in healthcare as simply down to language or poor health literacy but this is an oversimplification of what is a very complex issue. As our populations expand and we become increasingly globalised and living longer, we are encountering challenges in communication in health care that call for not just a greater understanding but a renewed receptiveness to the reality of diversity and a commitment to responding appropriately. There are so many variations on the theme of communication that we need to be continuously creative in our thinking and willing to adapt our approaches to meet patients' needs.

It is often our patients who are best at highlighting to us our shortcomings in communicating and demonstrating how we need to change. This was the case recently when a 50 year old gentleman attended the hospital with his partner complaining of a weakness in his left arm. He was particularly anxious as his father had suffered a stroke at an early age. He had had a similar episode two months previously and his GP had diagnosed it as a trapped nerve. The doctor who assessed him in the emergency department did not find any clinical abnormality and advised the patient to take simple analgesia and to see his own GP if it did not settle down. Some days later the patient attended again and was finally diagnosed as having had a stroke and was admitted. However this was not explained properly to him and the enormity of the situation for him seemed to have been glossed over. He also needed to have an anaesthetic while in hospital but received only a minimal explanation for this. He was eventually discharged home bewildered and upset by what had happened to him.

This man's encounter with the health service was very distressing as he understood very little of what was happening and was anxious and frightened all the time he was in hospital. At the same time it was very difficult for staff to understand what was causing his distress and reassure him .This patient did not have a learning difficulty or a language barrier in the conventional sense but both the he and his partner were profoundly deaf and used sign language. They had asked for a deaf interpreter at their first attendance and on a number of occasions while in hospital but none was ever found. He had a close friend who was able to interpret for him when she visited. However, while she made every effort to be there as much as possible, she lived some distance from the hospital and could not be there all the time. On the day he had an anaesthetic she was allowed to go as far as the anaesthetic room and stay with him until he was asleep and she was called by the recovery room staff when he woke up from the anaesthetic. Whilst it was helpful for the patient to have his friend interpret for him, it is not in any way an acceptable practice. Best practice does not usually recommend friends or family as interpreters (Donini-Lenhoff and Hedrick 2000, Bischoff and Hudelson 2010)

Requesting language interpreters is now standard practice when caring for patients who do not speak English but it seems we are falling short in ensuring Sign interpreters for deaf people. This patient's friend complained on his behalf and stated that while in hospital he felt isolated and ignored. This is a sad indictment of a system that was originally set up to deliver universal and equitable health care to all who needed it particularly the vulnerable. It is unlikely that staff were deliberately ignoring the patient but felt at a loss as to how to communicate effectively as very few healthcare staff are competent using Sign language. This is an issue that needs to be urgently addressed in healthcare.

The statistics relating to deafness are constantly changing but the latest figures suggest that approximately 9 million people in the UK have a hearing loss, that is 1 in every 7 persons. The majority of people with a hearing loss have become deaf or hard of hearing later in life having acquired spoken language. These people are unlikely to use Sign but those who are born with a profound hearing loss, described as 'prelingually deaf', form part of the 'Deaf Community'. They have their own distinctive language (British Sign Language) and culture and are completely dependent on Sign to communicate. Approximately 50,000 deaf people in the UK use British Sign Language (BSL) as their first or preferred language (Deafness-UK http://www.disability.co.uk/sites/default/files/resources/UKStatistics%26Facts.pdf).

Sadly there appears to have been little focus to date on the health needs of deaf people but Edmond, Ridd, Sutherland *et al.* (2015) conducted a large scale cross sectional study to assess the current health of the deaf community in the UK in comparison to the general population. They undertook a health assessment and interview with 298 deaf people aged between 20 and 82 years and although the study had some limitations, they found that deaf peoples' health is poorer than that of the general population with probable under diagnosis and under treatment of chronic conditions. They found that deaf people are twice as likely as the general population to have undiagnosed hypertension and, where it is diagnosed, deaf patients are three times less likely to be treated effectively. The study found similar disparities in the treatment of heart disease and diabetes where profoundly deaf people with high cholesterol are half as likely as the general population to be prescribed medication to lower their cholesterol. They also found that 30% of the study population were obese with a BMI > 30. In a more qualitative vein, a study by Kyle, Reilly, Allsop *et al*. (2012) found that deaf people have very limited access to public services. Many regard themselves as members of a cultural minority (Fellinger *et al*. 2012) and have low expectations of health care. Some described feelings of surprise and relief when, on rare occasions, they found staff who could Sign. Attempts at communication commonly left them feeling frustrated, annoyed and embarrassed and they often withdrew from such situations (Kyle *et al.* 2012). A report by the Deaf Health Charity SignHealth (2015) describes the health access situation for deaf people as *'unintentional neglect, likely to lead to shortened lives', 'A basic lack of knowledge on the part of health professionals is leaving a vulnerable community with inadequate healthcare*' to the extent that there is a likelihood of reduced life expectancy in Deaf people (SignHealth 2015).

Helen Keller long ago described deafness as *'the loss of the most vital stimulus--the sound of the voice that brings language, sets thoughts astir and keeps us in the intellectual company of man'* (Keller 1933 p68). Whilst we have come a long way since 1933, communication barriers and accessing health services are still the greatest barrier to Deaf people getting health care that is equal to the general population. Lack of healthcare information in an accessible form is another major problem (SignHealth 2015). Edmond *et al*. (2015) in their study found that access to health information or leaflets in Sign language to be almost non-existent. Some of these shortfalls may be due to a shortage of Sign interpreters. Even where they are available, Sign interpreters are expensive but this should never be an excuse for not calling on their services.

The cost of communication breakdown and misdiagnosis both physiologically and emotionally is incalculable. Health services should be responsible for the provision of, and payment for, registered sign language interpreters so they can communicate safely with Deaf people in primary and secondary healthcare settings (Heslop and Turnbull 2013).

As this blog testifies, deaf people are still a hidden population whose needs are overlooked in our health care system. Clinicians have a responsibility to our Deaf patients to ensure they have equal access to health care. In response to the recommendations set out in the *Sick of it Report,* NHS England (2015) has published the Accessible Information Standard. This standard details how healthcare professionals should communicate with people who are disabled or have sensory impairments. Healthcare organisations will be expected to meet these standards by July 2016 (NHS England 2015). Perhaps it is time to include some basic Sign language in healthcare training; this would help to reassure our Deaf patients of our commitment to delivering equitable care. Something more immediate and simple would be for us to consider and act on the words of Mark Twain who is alleged to have said ˙Kindness is a language which the deaf can hear, and the blind can read', (Goodreads https://www.goodreads.com/quotes/18058); we must remember this and not fail our deaf patients in the future.

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