

Challenges of Realising Patient-Centred Outcomes for Deaf Patients

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Published online: 7 June 2017
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Abstract In general populations, it has been recognised that patients play a key role in the quality of their own healthcare. However, the idea of realising patient-centred outcomes for the signing Deaf community, who experience the world in a visual way, raises some challenging issues that are rarely acknowledged. Using published research and translational health projects involving Deaf people both in the UK and internationally, this article discusses the challenges of realising patient-centred outcomes for Deaf people who are sign language users. The discussion includes an examination of: barriers to accessing healthcare for Deaf people; the impact of an insufficient acquisition of knowledge about health-related issues; Deaf people's limited fund of information; not recognising Deaf people's values and citizenship rights; and challenges in gathering Deaf people's reported outcomes. We contend that without including Deaf people in shaping the healthcare experience for them, whether at an interpersonal level of patient engagement or at a structural level, the concept of fulfilling patient-centred outcomes for Deaf people is not achievable.

Key Points for Decision Makers

Deaf people experience poorer physical and mental health than the general population and significant health inequalities in terms of access to healthcare services.

Fulfilling patient-centred outcomes for Deaf people who use sign language is distinct from general considerations of the effects of 'deafness' because of its cultural, linguistic and community aspects.

Key principles for the better promotion of patient-centred outcomes for Deaf people include: (1) facilitating greater opportunities for Deaf patients to engage in influencing their healthcare; (2) investing in preventative and supportive programmes to build Deaf people's fund of information/knowledge concerning their health in ways that are linguistically accessible and culturally appropriate; and (3) investing in appropriate means to elicit from Deaf people their healthcare experiences so that these can be incorporated into more sensitive structures for measuring healthcare impact.

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1 Introduction

In the UK, the National Health Service (NHS) acknowledges that patient experience is one of the key components of appraising the quality of care for patients [1], as well as an important mechanism for the further enhancement of

care quality [2]. It consists not just in seeking measures of satisfaction with care, but more fundamentally in learning from the individualised experiences of patients [3]. It involves a person-centred, rather than patient-centred orientation [4] and encompasses the process of empowering patients “to express their views and be more involved in the decision-making processes” [5]. This applies both at an interpersonal level of patient engagement and at a structural level in creating formal opportunities for shaping services, e.g. through the expert patient scheme (<http://www.expertpatients.co.uk/>). Engagement of patients in such ways should also be a key component of aspirations for so-called ‘P4 medicine’, that is, Personalized, Predictive, Preventative and Participatory [6]. Patient-centred outcomes are ones in which decision making about what is an appropriate and desired outcome for a given condition addresses the wishes of the patient, pays attention to his/her individual contexts and characteristics, and enables the patient to make empowered choices about his/her care and goals.

This orientation and its aspirations interface with the Public Sector Equality Duty 2011 (section 149 of the Equality Act 2010) and requirements incumbent upon the NHS with respect to patients with protected characteristics under the Equality Act 2010 [7]. The duty to promote equality (rather than merely combat discrimination) does not just concern equality of opportunity but also equality of outcome. This is recognized by the NHS in such initiatives as the NHS Accessible Information Standard 2015 [8], Principles for High Quality Interpreting and Translation Services in Primary Care [9], and within the NHS Constitution’s [10] own commitments to equality.

For one group of patients, however, the notion of achieving patient-centred outcomes and the implementation of processes of patient engagement leading to these are particularly problematic; that group is Deaf people, who disproportionately experience persistent health inequalities both in terms of access to services and health outcomes [11–13]. Deaf with a capital ‘D’ is commonly used to describe those who identify themselves as being culturally Deaf, are part of the Deaf community and are sign language users; i.e. British Sign Language (BSL) users for those who live in the UK [14]. Deaf people are recognised as a cultural-linguistic minority whose centuries old language was finally recognised as an indigenous language of the UK in 2003 [15] and whose traditions, ways of life, and visual and ontological experience of the world is constitutive of a cultural community. In Scotland, this cultural-linguistic recognition was taken one step further with the passing of the BSL Scotland Act 2015, which conferred specific duties on service providers, employers and other institutions to take steps to promote equality on grounds of language, not on grounds of disability. Therefore, in these

terms, to be Deaf is a source of pride and a cultural asset, not a marker of deficit or disability. Those who do not identify themselves as being culturally Deaf and are spoken language users are usually described as Deaf written with a lower case ‘d’ and in number are far greater [16]. However, in the UK, it has been estimated that there are 87,000 Deaf people who are BSL users [17]. This article focuses only on BSL users rather than the general Deaf population (e.g. Deaf people who do not use sign language or those who become Deaf later in life).

Deaf people, both in the UK and in culturally comparable Deaf communities around the world, face inequalities in a range of domains, including educational attainment and employment. In 2015, over half (58.9%) of d/Deaf young people in England failed to achieve at least five General Certificates of Secondary Education with grade A*–C (including English and Maths), which is the UK government’s expected benchmark, compared with just 35.8% of those young people without special education needs [18]. This figure is true regardless of whether they sign and/or speak at the age of 16 years, and d/Deaf young people are far less likely to go on to higher education [19]. The unemployment rate in the UK across all d/Deaf people is four times higher than that in hearing populations [20]. General health outcomes as well as the prevalence of specific conditions such as obesity, heart disease and diabetes mellitus are considerably worse in the Deaf population [21, 22], and a higher prevalence of common mental health problems including anxiety and depression exists within the d/Deaf community [23]. Against this background, this article discusses the main issues and challenges in realising patient-centred outcomes in Deaf patients, drawing on a range of published research and translational health projects amongst Deaf people in the UK and internationally.

2 Access to Healthcare for Deaf People

It has been well reported that Deaf people face barriers in access to healthcare [11, 12, 22]. Tak et al. [24] identified that how well a doctor explains things to the patient and how well the doctor listens to him/her influences the patient’s perception of the care he/she received. However, this can be challenging when considering the communication barriers between a doctor and their patients, arising from lack of a shared language and/or use of an interpreter. One of the main barriers to accessing healthcare for Deaf people is poor communication strategies between Deaf patients and healthcare professionals [11, 25]. This includes a lack of understanding by health professionals of how to use an interpreter, over-estimation of communication skills whether by the patient or professional, and

barriers arising from the provision of written information in the absence of signed information [9]. It is a common misperception that writing something down provides accessible information because it is not dependent on hearing, when in fact, literacy is a significant barrier for many d/Deaf people [16]. It has been well cited that the median reading age of a d/Deaf school leaver is approximately 9 years, which is significantly lower than their hearing counterparts [26, 27] and this gap is generally not made up in adult years.

Deaf people express considerable dissatisfaction with their experiences in healthcare settings both in the UK and elsewhere [28–30]. Furthermore, Deaf people's experience of inaccessible and unsatisfactory communication within healthcare is one of the factors directly contributing towards poor health states and outcomes amongst Deaf people [22]. This is because of a reluctance to engage with health professionals because of communication barriers, which means that conditions are only detected when they have escalated; there is little encouragement for the maintenance of health through consistent engagement; and a perception, in general, that health services are for 'hearing people'. Deaf people's presentation within the health system is often perceived by them as a last resort strategy, rather than a first port of call [22]. The achievement of patient-centred outcomes is impossible without patient engagement, the provision of accessible services and the confidence that communication will result in worthwhile gains. These factors are all commonly lacking amongst Deaf patients. Initiatives to value and learn from Deaf patients' experiences of access to healthcare are vital to building trust [2] and ultimately to achieving more satisfactory patient-centred outcomes for Deaf people.

3 Acquiring Knowledge on Health-Related Issues

As previously stated, educational attainment for d/Deaf people is usually less than optimal. This has consequences for Deaf people's health and management of health states because of its impact on the general and specific acquisition of knowledge, sometimes referred to as Deaf people's "fund-of-information deficit" [31]. Fund of information refers to the extent of one's general, if not specialised knowledge, about a whole host of topics linked with everyday life. In practical terms, it can be a half-understood idea or concept that the person might have seen, read or heard of somewhere else that prompts he/she to link a personal experience with a wider subject or requirement. In relation to healthcare, people do not need to understand the intricacies of a heart condition to understand that if they are experiencing some symptoms they need to seek health advice. However, if the fund of information is quite

limited, then the awareness of potential triggers of concern and the ability to seek out relevant advice and information and to act on these are also limited. For example, findings from a survey with Deaf people reveals that their knowledge of heart disease symptoms, risk factors and emergency response is significantly lower than that of the hearing population [32] and, in general, research has demonstrated that Deaf people have low health literacy skills in comparison with hearing populations [31]. Opportunities for Deaf people to enhance their fund of information and improve their health literacy are not helped by the very limited access to health-related information in signed languages [11]. For the most part, Deaf sign language users throughout their lives are receivers of information that is not delivered in their first and preferred language, namely BSL, within the UK. More commonly, information might be relayed through a third party, e.g. an interpreter, which reduces autonomous access to information when an individual might require it, or through written English, which many Deaf people struggle with, leading to the potential for considerable misunderstanding of crucial information. Although in the last 10 years with the onset of social networks and the willingness of organisations to provide information in BSL online and via DVDs [33, 34] the situation is improving, information delivered in these formats is not always readily understood because of the limited background knowledge on which to build [31]. Deaf people's fund of information and pre-existing health literacy may not always be sufficiently adequate for this new information to be properly absorbed [35].

Lack of exposure to the everyday environmental learning opportunities is another issue common for d/Deaf people, compared with hearing people's ability to pick up information through radio or through overhearing conversations in a café, for example [36]. Ninety-five percent of d/Deaf people are born to hearing parents [37] who may have little or no knowledge of how to communicate with their children, with Deaf adults reporting their childhood experiences of, for example, 'dinner table syndrome' (being excluded from daily family discourse) [38]. As the consequence of a lack of exposure to daily discourse and incidental learning opportunities, d/Deaf people might have not acquired sufficient cultural capital to navigate well through structures and systems such as those that deliver healthcare [38]. From the Deaf community's perspective, they are often aware of the gaps in their knowledge, but do not have the means to acquire new knowledge in a 'hearing-based' majority culture, as information is often not available in their own language of BSL or delivered in ways that match Deaf people's preferred ways of learning. Although translation attempts to bridge the language differences between the two languages, translation alone is insufficient to address other differences such as cultural

and life experiences of Deaf people [35, 39, 40]. It is far better to build the means of information distribution and knowledge acquisition that builds on Deaf people's cultural assets, such as their visual cognitive strengths [41]. Additionally, the properties of a visual spatial language mean that some types of description and explanation are far easier to grasp than those afforded through the usual linear ways of thinking and explaining of hearing people [35]. Patient-centred outcomes require health literacy, and health literacy cannot be divorced from linguistically and culturally matched means of acquiring that. Simple translation into BSL of information designed for hearing people is a long way short of providing an accessible means for building knowledge.

4 Not Recognising Deaf People's Values and Citizenship Rights

Respect of individuals' values and preferences is important to the identification and achievement of patient-centred outcomes. However, mainstream society may not always recognise Deaf people's values because they do not recognise their cultural-linguistic identity. It is far more common to consider Deaf people in terms of meeting needs arising from disability, rather than considering rights arising from cultural, linguistic or ethnic status. In theory, the Equality Act 2010 [7] brings together issues of discrimination and the promotion of equality from whatever perspective into a single approach that encompasses disability, gender and ethnicity. However, in reality, policies and practices in healthcare in relation to disability are often falsely implemented with respect to Deaf people and those that promote cultural sensitivity fail to include Deaf people in their purview. Patient characteristics/equality monitoring forms are a case in point. They leave Deaf patients with a dilemma—to tick the 'Deaf' box does not recognise their language and culture, yet being Deaf as a cultural identity is always missing from the ethnic origin boxes. Recognition of values requires recognition of identity, yet systems designed to capture that can conspire to negate it.

Healthcare providers, amongst others, are also generally not aware of the linguistic constraints that can be placed on a Deaf person throughout their everyday interactions caused by the lack of BSL within the mainstream. For example, Deaf people can be often misunderstood or mislabelled as lesser citizens because of their use of signed languages because these languages carry a lesser socially inscribed value being neither phonic nor orthographic [42, 43]. More directly, misunderstandings, misdiagnosis and misrepresentation can abound if it is assumed that these languages are not adequate to convey meaning or hearing people's poor understanding of them is not

questioned. Hunt et al. [44], in their study exploring residential care choices for Deaf people in Wales, discuss how they met with a Deaf care home resident who had been diagnosed with cognitive issues by the home's hearing care staff who could not sign. The research team member quickly identified that this person did not actually have any symptoms of dementia and was instead simply isolated because of a lack of any communicative partners or opportunities for communication in their first language, BSL.

Additionally, Deaf people have often not been supported in making choices in their lives (health related or otherwise) as historically, hearing people around them have, at times, made those choices on their behalf owing to the fact that interpreters have not been present at health-related appointments [22, 45]. Decisions that are made on a daily basis by hearing people who are caring for Deaf people would cloud how to successfully measure patient-centred outcomes. Deaf people are often left out of the decision-making process within healthcare because of the lack of awareness that the hearing professional involved in their care has in valuing what it is like to live as a Deaf person. Therefore, those outcomes are only measured via the hearing person's frame of reference in taking control of a situation that they cannot manage owing to not sharing the same language or culture as the patient, and assuming that the patient lacks capacity because he/she is unable to speak 'clearly' in the hearing-dominant language.

From an ontological perspective, Deaf people have always faced barriers to full access to healthcare for the reasons outlined above. However, navigation of this experience has strengthened resilience [46] and enabled the development of coping strategies [47] to deal with everyday experiences that are within the norm for a Deaf person living in a mainstream 'hearing' society. Coping with illness and healthcare systems and professionals is no different. In one study exploring the everyday experiences from the perspective of Deaf people, who were fluent BSL users, living with dementia and their carers [33], it became evident that their everyday experiences of health interventions were similar to their everyday and lifelong experiences of being Deaf in a world not set up to recognise and meet their requirements. For example, a well-meaning referral to a specialist dementia-friendly environment for a Deaf person with dementia and their care partner to congregate with other hearing people with dementia and their families was yet another exercise of structural exclusion, as the first activity was focussed on auditory-based activities such as singing together. Nonetheless, the Deaf couple were grateful to be included in some way and accepted this undeliberate exclusion as just one of those things, an everyday barrier that was no different from usual.

In another example, Deaf carer engagement with a carers group designed to offer peer support and access to helpful information resulted in the opposite, as there were no resources available to provide any interpreters for the sessions. The carer, however, found the information valuable even if she could not fully understand it in English and in this case asked the researcher who was Deaf to translate it for her as part of her research participation. Such examples abound. Although they may be described in terms of consequences of inadequate linguistic access, more fundamentally, they are testimony to a lack of respect and priority in engaging a Deaf person on their own terms, respecting their own language, culture and values and without which engagement in the mutual identification of patient-centred outcomes is simply not possible. While considering the measurement of patient-centred outcomes with Deaf people, it is important to remember that the above stories were directly shared with a Deaf researcher who is fluent in BSL (author Ferguson-Coleman). The richness and depth of these narratives would be extremely difficult to elicit if the use of mainstream methods in questioning how Deaf patients feel about their healthcare experiences was carried out with this population. The written formats used to gather this type of data are not appropriate, as for most Deaf people, it would be difficult to fill in a written questionnaire because of limited literacy skills amongst Deaf people.

5 Gathering Deaf People's Reported Outcomes

Questionnaires and surveys are the most commonly used tool to assess patient experience, which is one of the components of measuring quality of care [3]. Outcome measures are usually developed and standardised with a particular population and can be norm referenced, so that the individual outcome score from that same population can be compared to it [48]. It is easy to assume that Deaf people are just like hearing people, as the tasks of reading and writing do not involve the use of hearing, but as previously remarked this is erroneous. Standardised written assessments are not accessible for many Deaf people whose preferred language is BSL. Yet, the use of instruments in English to assess outcomes for Deaf people who are BSL users persists in many aspects of healthcare. Using surveys that are only available in English and not in sign language will put Deaf people at a disadvantage and prohibit their opportunities for engagement. However, more fundamentally, using English-based instruments excludes a language-using group from the pool of available data in health services used to understand the diversity of health outcomes and to recognise health inequalities where they occur. In other words, the format and language of the

means of collecting patient outcomes can serve to render invisible those whose experiences are unsatisfactory in the first place and to reinforce that position.

A basic problem is that there are very few standard assessments and outcome measurements available in BSL in any health domain for Deaf populations in the UK; this is true in many countries with respect to their signing populations. The practice of simply using the standard one in English with an interpreter is not good enough because the translation is not validated; therefore, the psychometric properties are not established for the BSL version, and translations may differ from one interpreter to another. Recent work has resulted in validated versions of several instruments whose psychometric properties and reliability have been tested and published [49–51]. The simple existence of these validated instruments is an important step in ensuring that patient outcomes can be measured appropriately for Deaf patients and that Deaf patients are able to understand in their own language what such assessments are about and participate in their self-completion on their own terms. The adoption of validated assessments and outcome measurements in signed languages is an issue for mainstream healthcare settings not just specialist services for Deaf people.

However, there is a further issue with the Deaf population, whose cultural values and language are different from those of the population that the standardised outcome measure has been originally established with. This concerns establishing population norms specific to language-using and cultural groups without which it is not appropriate to compare outcomes between different populations. Yet in the case of Deaf people, it is quite common to compare outcomes between Deaf and hearing people without the clinical instrument being appropriately calibrated for the Deaf population as it is for hearing people in their own language(s). An example of this would be the recent work on establishing the appropriate clinical cut-offs for the validated psychological assessments PHQ-9 BSL and GAD-7 BSL [49]. These were found to be lower than those of the English version for the hearing English-speaking population [52]. Confirming the appropriate clinical cut-offs is central to the inclusion and discharge from psychological therapies and the reduction of false positives and false negatives arising from inappropriate measurements of illness and outcome. It is one example of the significance of ensuring that assessment is meaningful to the Deaf population, which will enhance the measuring and monitoring of the patient experience for Deaf people. Without these first steps, confidence that patient outcomes are being captured cannot be assured; without a culturally and linguistically means of doing so, then the instrument will not meet the standard of being person centred.

6 Promoting Better Patient-Centred Outcomes for Deaf People

The issues that Deaf people face, for example, barriers to healthcare, acquiring health-related information, not recognising their differing values and the lack of standardised assessments to measure outcomes, raise challenges for Deaf people to achieve what would ultimately be *patient-centred* outcomes. There is much work that needs to be done to fulfil patient-centred outcomes for Deaf people, and that cannot be achieved without including Deaf people both in terms of patient engagement and opportunities to shape the healthcare experience for them. The key principles for considering better promotion of patient-centred outcomes for Deaf people include (but are not limited to):

- Patient engagement with Deaf patients must be founded on a recognition that Deaf people experience the world visually both in a linguistic and non-linguistic sense and have distinct cultural values and life experiences that arise from being sign language users. These should direct the methods and approaches of patient engagement not as an exception to what is the norm for the general population, but as an opportunity and set of requirements to be respected.
- Collaborating with members of Deaf communities will serve to build trust between Deaf communities and healthcare providers, as well as building the fund of information to tackle health inequality issues.
- Simple translation of information into BSL alone is insufficient to build an appropriate fund of information for Deaf people. For example, service providers should take cultural and life experiences of Deaf people into account when producing information into sign language. They need to make clear choices about what should be translated and consider adding layers of new information.
- Meaningful methods must be employed to elicit from Deaf people their healthcare experiences. For example, producing a visual and accessible survey in their preferred language to get the information needed to better understand their experience. Information about the purpose of the survey will also need to be made accessible for Deaf people to provide informed consent.
- Using culturally and linguistically appropriate tools to measure and monitor Deaf people's experience of healthcare.

To maximise fulfilling patient-centred outcomes for Deaf people, Deaf people need to be engaged in different aspects

of healthcare, such as policy, research and education, to influence positive patient-centred outcomes for Deaf people. Having Deaf people as part of a healthcare workforce will not only serve to benefit Deaf people themselves, but also their hearing colleagues. Working together through a visual language would lend itself well to identifying and valuing non-verbal communication and its clues. Deaf people are highly visually attentive and those skills would contribute to enhancing everyday patient care. In the context of policy, the NHS Patient Experience Framework has outlined that cultural issues should be taken into account when respecting the values, preferences and expressed needs of the patient [53]. Information, communication and education have also been outlined as being important factors in a patient's experience. Additionally, a report on the vision for a better NHS envisages a service that "is genuinely centred on patients ...", "eliminates discrimination and reduces inequalities in care" and "gives citizens a greater say in how the NHS is run" [54]. As of 2016, the NHS in the UK is legally required to follow the Accessible Information Standard guidelines, which will ensure that Deaf people are given information that is accessible to them and that they can communicate effectively with healthcare professionals [8]. The Accessible Information Standard should, in theory, be the way forward to improving the experiences of Deaf people in healthcare settings; however, the report on how effective the guidelines have been in practice, and whether they enhance patient-centred outcomes, is still a work in progress.

Compliance with Ethical Standards

Funding Katherine D. Rogers, Emma Ferguson-Coleman and Alys Young received grant funding for some of the studies included in this review. Funding to support the original work was from the National Science Foundation, National Institute for Health Research, National Deaf Children's Society, British Society for Mental Health and Deafness, Alzheimer's Society, Economic and Social Research Council, and the Welsh Assembly Government. Views expressed in this article are those of the authors and not necessarily those of these funders. In all cases, the authors confirm that required ethical approvals were granted.

Conflict of interest Katherine Rogers, Emma Ferguson-Coleman and Alys Young have no conflicts of interest directly relevant to the content of this article.

Author contributions KDR is the lead author, and was a co-applicant on some of the studies on which the review is based including contributing to their design, data collection, data analysis and original reporting. EFC contributed to the article and contributed to the data collection, data analysis and reporting of some of the work on which parts of this article are based. AY co-wrote the article and was the principal investigator for some of the studies included in this review. All authors approved the final manuscript.

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