

Access to primary care affects the health of Deaf people

'On Wednesday, Hazel (a Deaf British Sign Language user) felt unwell at work. She went to a walk-in clinic, where she had to communicate with the nurse by writing notes (there were no interpreters on call). Hazel can read, but like many Deaf people this is at a basic level. The nurse diagnosed a problem with her knee but told her to go to her GP, which Hazel did first thing on Thursday, but had to sit around for a couple of hours to be seen. Again, as there was no interpreter at short notice, she had to tell the GP about her 'stiffness' on her left side by writing. She could not follow what the doctor was saying except 'she should go to hospital' to be checked. She went to the emergency department, which entailed another wait and more written communication, where she was kept in overnight and on Friday morning the doctor (at least she thinks it was a doctor) wrote down she 'probably had a mild stroke'. Since she was feeling a bit better, she was told that she could go home and rest. Her condition worsened over the weekend until she could not hold a cup with her left hand. On Monday morning she went back to the GP, who took one look at her and sent her by ambulance straight to hospital for emergency admission. She was admitted for a week and was discharged back to the care of her GP, who had this time managed to get an interpreter. During this consultation it emerged that she had stopped her antihypertensives because she did not like the tablets, and she was unaware that this was meant to be a lifelong treatment.'

This story was reported in a recent study of the health of Deaf sign language users in the UK.¹ Count the cost: to the patient, an avoidable fortnight of frustration, worry, and being ignored at a time of need, all on top of a preventable stroke; to the NHS, a walk-in centre visit, three trips to the GP, one overnight stay in the emergency department, and 1 week on a ward. All of this because of lack of information on medicines and failure to use interpreters in consultations.

Deaf sign language users occupy poorer socioeconomic positions, have poorer literacy, and have limited access to communication through speech. Yet they have their own fully functioning language (British Sign Language [BSL]), their own community network, and a rich and vibrant culture.² We use Deaf (with a capital D as in English or French) to indicate membership

of the sign language using community.

DEAF HEALTH STUDY

Deaf BSL users have poorer health,^{3,4} which has been attributed to problems accessing health care and communicating with healthcare professionals.⁵ However, the true extent of unmet health and communication needs of Deaf people is not known. We have recently completed a study of BSL-using Deaf adults in the UK, the first of its kind, assessing these issues. As no register exists of Deaf people, a quota sample was designed to match the age, sex, and ethnic distribution of the population at the 2011 census.⁶ A total of 298 Deaf people aged 20–82-years-old, 47% male, with 11% from ethnic minorities were recruited. Participants underwent a structured health assessment using BSL at seven Bupa centres across England, Wales, and Scotland. The results showed, compared to the hearing population, a greater prevalence of obesity and higher levels of hypertension, high levels of self-reported depression, but low levels of reported smoking and alcohol consumption. Of particular concern were the underdiagnosis of raised blood pressure and the under-treatment of hypertension, diabetes, hyperlipidaemia, and cardiovascular disease.¹

POOR ACCESS

As part of the health assessment, participants were interviewed in BSL by Deaf health advisors on their experience of and confidence in primary health care. The semi-structured interview used questions derived from the GP Patient Survey 2011 (GPPS) for England.⁷ The first finding was that Deaf adults use primary care more frequently than the general population. However, 44% of Deaf people found their last contact with the GP or health centre to be difficult or very difficult. In comparison, 17% in the GPPS found it not very easy or not at all easy to

make contact (90% of GPPS responders said they used the telephone). Very few Deaf patients (4.7%) made contact with their GP practice online, and only 3% used text. Nearly 40% of Deaf people found the receptionist not very helpful or not at all helpful; whereas only 8% of the GPPS found the receptionist unhelpful. Over half of the GPPS found the receptionist very helpful compared to only 11% of Deaf people.

POOR COMMUNICATION

When in consultation with their GP, the preference of the vast majority of Deaf participants was for the use of signing with the doctor. However, 53% of the Deaf participants had to rely on lip-reading for medical consultations instead of a dialogue in BSL via an interpreter. Some 15% had to rely on writing notes. Neither of these allow adequate two-way communication for the GP or Deaf patient.

Those surveyed in the GPPS (89%) were much more likely than Deaf people to say their doctor was good at listening. Fourteen per cent of Deaf people thought the doctor was poor or very poor as compared to only 3% of the GPPS responders. Deaf participants rated the explanations by the GP poorer than those in the GPPS: 23% of Deaf participants thought explanations were poor or very poor, compared to only 3% of GPPS responders.

We found a clear difference between Deaf participants and the GPPS responders in the extent to which they have confidence and trust in their doctor. While most GPPS responders (67%) expressed definite confidence and trust, fewer Deaf participants expressed this trust (25%) and 18% of Deaf participants selected 'no, not at all' in response to whether they trusted their GP compared with 4% of the general population.

POORER HEALTH

The reasons behind the increased prevalence

"The Equality Act 2010 requires that service providers must make reasonable adjustments to improve service for customers with disabilities ... reasonable adjustments are clearly not always being made for Deaf patients."

Box 1. Ten top tips to improve access and communication with Deaf patients

1. Organise a Deaf awareness training session for all staff including receptionists.
2. Promote online booking of appointments and requesting of repeat prescriptions. Back this up with the offer of text (SMS) messaging for appointments and test results.
3. Ask each Deaf patient how they prefer to communicate and record the patient's preferred method of communication in their medical records. Make a note of the interpreter whom the Deaf person prefers to use.
4. If British Sign Language is preferred, arrange for a registered qualified interpreter to attend consultations if possible; if none is available, use a video link interpreting service.
5. Ensure a system is in place for booking interpreters; ensure all staff are aware of it and that it can often take 2–3 weeks to find a free interpreter.
6. Remember that unless your Deaf patient requests it, using lip-reading, writing things down, or asking for a family member or friend to interpret for consultations are not a 'reasonable adjustment' under the Equality Act.
7. In the waiting room, make sure there are visual alerts, and do try to go to meet the Deaf patient rather than having their name called out.
8. In the consultation room, make sure:
 - you keep eye contact when you are talking;
 - your face is well lit;
 - be visual — use props, pictures, drawings, gestures;
 - show first, then talk;
 - look at the Deaf person when they are talking or signing to you.
9. Take time! Often double appointment sessions are needed to allow time for interpretation and effective communication.
10. Deaf sign language users have their own language but are rarely proficient in English. They are quite different from hard of hearing people (usually older and can speak and read and write English), who are happy to receive written information and leaflets. Deaf sign language users will need careful explanations of medical conditions, investigations, and treatment plans.

of risk factors for chronic health conditions demonstrated in the Deaf population are complex. They are not simply due to difficulties in accessing health care and communicating with health professionals, and the subsequent lack of understanding of, or confidence in, advice given. Social, environmental, and lifestyle factors are important determinants of ill-health for Deaf people just as in the hearing population. However, the Deaf responders reported that poor communication in consultations with their doctor is a barrier and that this affects their trust in their GP. As a result, understanding of chronic conditions,⁸ adoption of changes in lifestyle, and adherence to treatment are compromised.

IMPLICATIONS FOR CLINICAL PRACTICE

The findings of this cross-sectional survey are probably representative of the BSL-using Deaf community across the UK. Indeed, the results are probably an underestimate of the amount of ill health and chronic disease in the Deaf population, as participants had to opt-in to the research. Our study highlights the need for considerable change: in Deaf awareness for health professionals, and in health awareness for Deaf people.

The Equality Act 2010 requires that service providers must make reasonable adjustments to improve service for customers with disabilities who would otherwise be at a substantial disadvantage compared with people with no disabilities: reasonable adjustments are clearly not

always being made for Deaf patients. Many of these are simple and cost-neutral (Box 1), such as collecting Deaf people in person from the waiting room, booking appointments on line or communicating using text messaging as an alternative to the telephone. Where a BSL interpreter is required to allow effective and safe communication in a consultation, this should be provided in person or by video link. However, it is important that doctors and nurses realise that the interpreter is as much for them as for the Deaf person.

Deaf awareness training is necessary for all healthcare staff so that they become aware not only of the barriers faced by Deaf people in accessing their services, but also that these barriers are putting them at risk of ill-health and potentially reduced life expectancy.

For want of adequate communication about her medication, the NHS spent thousands of extra pounds on Hazel, and cost her a fortnight of illness, anguish, and misery. A lack of reasonable adjustments to address barriers in communication could also have cost her health — or her life.

Alan Emond

Professor, School of Social and Community Medicine, University of Bristol, Bristol.

Matthew Ridd

Senior Clinical Lecturer, School of Social and Community Medicine, University of Bristol, Bristol.

Hilary Sutherland

Research Associate, Deaf Studies Trust, The Vassall Centre, Bristol.

ADDRESS FOR CORRESPONDENCE

Alan Emond

School of Social and Community Medicine, University of Bristol, Oakfield House, Oakfield Grove, Bristol BS8 2BN.

E-mail: alan.emond@bristol.ac.uk

Lorna Allsop

Research Associate, Deaf Studies Trust, The Vassall Centre, Bristol.

Andrew Alexander

Medical Director, SignHealth, Beaconsfield.

Jim Kyle

Emeritus Professor Centre for Deaf Studies, University of Bristol, Bristol.

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