Deaf peoples’ experiences the last time they visited their GP

Making an appointment

Two in five of the Deaf people had some difficulty making their last appointment. Most weren’t able to contact the surgery directly, so had to go in person or ask someone to telephone for them.

Three people made contact via a textphone in the surgery. Four other practices possessed a textphone but these were seldom switched on, or weren’t answered when the Deaf person called. Fourteen people made contact using TypeTalk.

Communication support

Nearly two-thirds said it was “very important” for them to have someone help them communicate with their GP, yet more than half were alone at their last appointment. About a quarter were with a family member who could hear and sign. Just 17 of the 98 people had a professional sign interpreter. Use of interpreters was not related to the urgency of the appointment.

More than half said they would have preferred an interpreter, but many did not have one because of the difficulty of obtaining an interpreter in time for the appointment.

You might like to know….

“TypeTalk” is a relay system operated by British Telecom and RNID that allows communication between users of textphones and standard telephones. At the time of this research TypeTalk was limited to registered users. Registration is no longer necessary and the system can be used by anyone simply by dialling a prefix (18002 from a standard telephone, 18001 from a textphone) before the number being called.
At reception

Three receptionists could communicate in sign language.

People who attended with a family member or interpreter relied mainly on them for communication with the receptionist. Although most receptionists were said to have done their best to communicate, one-third of the lone Deaf people understood only ‘some’ or ‘very little’ of the receptionist’s communication. Many of the problems resulted from receptionists not really understanding the communication needs of Deaf people.

Twenty percent of the people who went alone had a problem knowing when it was their turn to see the GP, usually because they missed their name being called out. Only one in five surgeries had a visual patient call system (e.g. an electronic name display).

With the GP

One GP had a qualification in British Sign Language and communicated in sign.

The presence of professional communication support made a big difference to the success of the consultation. Nearly 90% of the people with sign interpreters asked all the questions they wanted, gained a better understanding of their illness, and left the surgery fully understanding the GP’s advice on what to do next.

In contrast, more than half the people who saw the GP alone felt unable to ask all the questions they wanted, while two in five gained no greater understanding of their illness, and the same proportion left not fully knowing what they were supposed to do next. The experience of people who attended with family was only slightly better, usually because family members were selective in what they passed on.

Around one-third of lone Deaf people felt that the GP had not tried their best to communicate. In addition, lone Deaf patients were twice as likely to get less than five minutes with the GP, and twice as likely to say they hadn’t had enough time. Most GPs did, however, make good efforts to communicate, and Deaf people praised doctors who followed basic precepts of Deaf Awareness.

You might like to know....
A Deaf Awareness training course usually addresses provision for both Deaf and hard-of-hearing people. Topics typically include (amongst others): do’s and don’ts of communication; making your service ‘deaf friendly’; working with interpreters; useful signs; telephone skills. Deaf Awareness is also taught as part of ‘Disability Awareness’ training, but usually in far less detail.
Other findings

Forty percent complained or felt like complaining about something that had happened during a visit to the practice in the last year. This is four times as high as for the general population (‘The National Survey of NHS patients. General Practice: 1998’. London, Department of Health, 1998). Most of the complaints were about poor communication or staff attitudes.

A quarter of all Deaf people had worried about a medicine prescribed for them. Many thought they had been given the wrong medicine. Others had not been told what the drug was for or if it could have side-effects. As a result of poor communication, two people had been seriously ill after drinking an external medicine.

In over 80% of consultations with lone Deaf people GPs used writing to communicate. Yet many of these patients still did not understand their GP. Either they could not decipher the GPs’ handwriting, or the words used were unfamiliar to them. (GPs may not appreciate that due to a lack of exposure to aural language, many Deaf people have a reading age of under 12 years, and a quite limited vocabulary of common medical terms.)

What do GP practices currently provide for Deaf patients?

As part of the study, practice managers at 31 practices in the North-West were interviewed and asked about the things they provide for Deaf patients. Here are some of our findings.

- Four practices had evaluated the service they provide to Deaf patients.
- Only one practice had a textphone, but this was not always switched on. All practices had a fax machine, with most (81%) making this available to patients.
- About a quarter of the practices had a visual patient call system.
- Five practices claimed to allow more time for consultations with Deaf patients.
- Three practices (10%) said they could arrange sign interpreters, but only one had ever booked an interpreter for a patient. The other two practices had not told Deaf patients about the service and could not say who was responsible for paying.
- Four practices had staff with a British Sign Language qualification.
- Staff at seven practices (27%) had Deaf Awareness Training, but doctors and nurses took part at only two. One practice had introduced annual training in basic sign for all staff.
The costs of improving access

A basic package of access measures for Deaf people would consist of Deaf (or Disability) Awareness Training for staff, sign interpreter support (when required), a combined voice-and-text phone, a visual patient call system, and written instructions about medication and after-care. We suggest a combined voice-and-text phone because installation and use is simpler than for a dedicated textphone. We also think it important that medical staff – not just reception staff - receive Deaf/Disability Awareness Training (this is an ‘essential recommendation’ in the NHS guidance to providers on implementation of the Disability Discrimination Act - see bottom of page).

The direct costs of implementing this package in practices of various size are given in the table below. To implement the package across the whole of a medium-sized PCT of 30 practices would cost around £73,000 in the first year, and £46,000 in subsequent years.

<table>
<thead>
<tr>
<th>Practice list size (all ages)</th>
<th>2000</th>
<th>4000</th>
<th>6000</th>
<th>8000</th>
<th>12000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated number of adult patients with severe/profound hearing loss¹</td>
<td>39</td>
<td>78</td>
<td>117</td>
<td>156</td>
<td>234</td>
</tr>
<tr>
<td>Estimated number of adult Deaf patients (adults whose main means of communication is sign language)²</td>
<td>2-3</td>
<td>5</td>
<td>7</td>
<td>10</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Costs for first year</th>
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<tbody>
<tr>
<td>Purchase of combined voice-and-text phone</td>
</tr>
<tr>
<td>Purchase of visual patient call system³</td>
</tr>
<tr>
<td>One-day Deaf/Disability Awareness Training course for up to 20 staff</td>
</tr>
<tr>
<td>Hire of Sign Interpreters⁴</td>
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<tr>
<td><strong>Total</strong></td>
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<tr>
<th>Subsequent years</th>
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<tbody>
<tr>
<td>Half-day Deaf/Disability Awareness Training course for up to 20 staff</td>
</tr>
<tr>
<td>Hire of Sign Interpreters⁴</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

¹Based on a rate of 1 adult in every 40 (MRC Hearing Research Institute); ²Based on a rate of 1 adult in every 650 (British Deaf Association); ³Single-line display of twenty 5cm high characters, includes £50 installation costs; ⁴Assumes 50% of Deaf patients require an interpreter and 6 appointments per patient per year (as found in our study), at a cost of £60 per appointment.

You might like to know....

Under the Disability Discrimination Act 1995, service providers have a duty to take reasonable steps to:

- Change practices, policies or procedures which make it impossible or unreasonably difficult for disabled people to use a service;
- Provide ‘auxiliary aids’ or alternative services that would make it easier for, or enable, disabled people to use a service.

From 2004 physical barriers that restrict or prevent the access of disabled people to services will have to be removed, or the service provided by alternative means.

Conclusions

This study shows that many Deaf people are severely disadvantaged when they use primary care. Issues of communication are central to the problems Deaf people experience. Good two-way communication is vital for both a successful GP consultation and for patient safety. In this study poor communication resulted in many patients leaving the consultation without knowing much more about their illness, what they were supposed to do next, and in some cases how to take the medicine prescribed for them. The cumulative effect of poor communication across all aspects of care is perhaps best reflected in the finding that 40% of the Deaf people had complained, or felt like complaining, about some aspect of the service received from their GP practice in the last twelve months. One person had taken their GP to court.

Communication problems are most pronounced amongst Deaf people who consult alone, and the use of pen and paper for communication is often of little benefit. In contrast, the presence of a sign interpreter eliminates nearly all obstacles to communication. Even in the absence of an interpreter, by following some basic rules for communicating with Deaf people (e.g. http://www.royaldeaf.org.uk/simple17.htm) the GP can make the consultation a much more productive and pleasant experience for both the patient and themselves.

Many Deaf people are reluctant to admit when they haven’t understood their GP, which may help explain why 87% of GPs in a nation-wide survey believed they were effective at communicating with their Deaf patients (‘Can you Hear Us? Deaf People’s Experience of Social Exclusion, Isolation and Prejudice’. RNID, London, 1999). This highlights the necessity for the GP to double-check that the patient has understood important advice, and to provide instructions on medication and aftercare in clear and simple writing.

Recommendations

Our report to the North West NHS Executive made a number of recommendations relevant to GPs:

• All GP practices should know how to obtain qualified sign interpreters. They should offer to book an interpreter for any Deaf patient who needs one.

• All staff who work directly with patients should receive Deaf or Disability Awareness training. It is particularly important that medical staff receive training.

• All practices should have a way for Deaf people to contact them directly to make an appointment.

• All Deaf people should be given information about aftercare and the use of medication in writing before they leave the premises. This should be in plain English.

• Practices should consider installing a visual patient call system.

• All practices should have a policy on access for Deaf people. The policy should state what is to be provided for Deaf people, and include guidelines for staff.

• Primary Care Trusts should ask Deaf people their views about existing services and ways in which these can be improved. The views of Deaf people need to be made known at all levels of decision-making.
About the research

The “Access to Primary Care and Accident & Emergency Departments for Deaf people” project is independent research undertaken by the National Primary Care Research and Development Centre at the University of Manchester and Central Manchester NHS Primary Care Trust. The research was funded by North West NHS Research & Development Directorate (prior to NHS reorganization in 2002) and carried out by David Reeves, Brian Kokoruwe, Jackie Dobbins and Valerie Newton. The researchers are particularly grateful to Manchester Deaf Club and the British Deaf Association for the help and expert advice they provided at all stages of the project. (The Victoria University of Manchester © 2003).

This research won an award for the way it involved Deaf people in research on health services

Left to right: David Reeves, Valerie Newton, Brian Kokoruwe, Jackie Dobbins

Brian is a researcher who lost all his hearing to meningitis at age 14. Brian interviewed the Deaf people and visited A&E departments.

Jackie is a research nurse. Jackie interviewed practice managers and A&E managers.

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