Low functional health literacy: an unequal partnership in healthcare

An elderly Portuguese woman attended an Emergency Department in central London because she was unwell. She had minimal English and was waiting for a friend, whom she had asked to interpret for her. While she was waiting, the nurse practitioner decided to use Google Translate (http://translate.google.com) to obtain some basic information and, if possible, to reassure the patient. The woman sat down beside the nurse, who duly began to type questions into the computer in English; these were then translated into Portuguese. The woman sat and gazed at the computer; she was clearly perplexed and looked questioningly at the nurse, gesticulating to indicate that she did not understand. The nurse practitioner typed in another question and got the same response from the woman. Other clinicians in the vicinity suggested using a larger font size in case the woman could not read the small print. The larger font size did not help.

The woman’s friend arrived and an anxious conversation took place between them, after which the friend explained that the woman had never learned to read or write. In Portugal, when she was a child, her family were poor and it was not unusual for a girl not to be sent to school. The woman was embarrassed by the exposure of her illiteracy. The nurse practitioner was sorry to have been the cause of this embarrassment, and felt that she had made things worse for the woman by adding to her problems.

Lack of literacy is rarely considered in healthcare, possibly because, in developed nations, it is customary to assume that everyone can read. The temptation, therefore, in circumstances such as those described above is to assume that the problem arises from cultural idiosyncrasies or language barriers. In a city with a highly diverse population this assumption may often prove correct. In the past decade we have become more informed and aware of the need for cultural competence in healthcare, and of the fact that some of our patients may be disadvantaged because they have a different language or culture to the mainstream. In busy Emergency Departments, where staff are under pressure to treat increasing numbers of patients within a shorter time period, a patient who is struggling to express him- or herself may be assumed to have a language barrier when in fact the problem may be much more complex and perhaps not so easily resolved.

To be unable to read is a significant social handicap. Street signs, the labels on food and household items, children’s school reports and accessing the Internet are among the many aspects of daily life that depend on the ability to read. Illiteracy marginalises the individual from society, and may be a source of great shame. Parents of well-educated children may be mortified by the disclosure of their own inability to read.

Even in developed countries it is not at all unusual or difficult to find people who are completely or functionally illiterate. In the UK alone over 1 million adults have the literacy skills of children aged 5–7 years (Department for Business, Innovation and Skills, 2012). Even when people can recognise words on a page they may not be able to understand their meaning. An estimated 5.2 million adults in England:

can be described as 'functionally illiterate.' They would not pass an English GCSE and have literacy levels at or below those expected of an 11-year-old. They can understand short straightforward texts on familiar topics accurately and independently, and obtain information from everyday sources, but reading information from unfamiliar sources, or on unfamiliar topics, could cause problems.

(National Literacy Trust, 2012)

In healthcare these problems may be acute, particularly with regard to adherence to medical treatment. Patients are sometimes labeled as non-compliant with treatment when the reality is that they cannot read or understand the instructions. A recent study by Bostock and Steptoe (2012) found that one-third of
older adults in England have difficulty reading and understanding basic health-related written information. Not surprisingly, poor understanding and lower health literacy is associated with poorer mental and physical health and higher mortality (Berkman et al, 2011), and those most likely to have low functional health literacy are the elderly, individuals without any educational qualifications, and members of some ethnic minorities. These groups are often already disadvantaged, and the elderly in particular are especially vulnerable to long-term conditions and the diseases increasingly associated with longevity. When managing long-term healthcare needs, health professionals are expected to involve their patients as partners to develop innovative and pro-active solutions that enable the patients to retain their independence (Department of Health, 2010). However, patients who are completely or functionally illiterate will find it very difficult to be active partners in their care if they are unable to participate on an equal basis because they cannot read information. The essential links between health and ability to read have been referred to as health literacy, which has been defined as follows:

the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.

(World Health Organization, 2011)

Health literacy is therefore about much more than accessing the information which health professionals deliver. Patients have to be able to understand it and use it to make appropriate decisions about their health.

The more individuals need to learn about managing their health, the more health professionals need to consider how best to meet their needs. Professionals need to be alert to the possibility that some patients may be unable to read and that, although a proportion of these will be migrants, a sizeable number will be members of the home population. Developing new approaches such as audio- or video-recorded instructions may be helpful, but it is the ways in which these are used to offset embarrassment that are most important.

REFERENCES

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