STEREOTYPES AND SEMAPHORE, LEAVE THEM COMING BACK FOR MORE, PIECES MISSING, NOTHING FITTING, COMPLICATIONS GALORE

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A girl presented to an accident and emergency (A&E) department at 7 pm. A woman of Middle Eastern appearance wearing a hijab, and an older man, also of Middle Eastern appearance, accompanied her. He spoke a few words of English but the woman spoke none. The child appeared confused and did not respond to questioning. The woman was greatly distressed and anxious. The A&E staff managed to establish that the girl was 11 years old, that her name was Mariam Abdullah, and that the adults were her parents. It appeared from what little history they were able to elicit that she had complained of pain in her left leg and had then fallen and been unable to stand since.

A thorough examination found nothing of significance. She was in early puberty, had a normal blood pressure, and no abnormal neurological findings. However, her very subservient demeanour and passivity with staff and parents was noted. With some encouragement she was able to stand. The kind and caring staff told the family that there was nothing serious about which to be concerned, and that Mariam had perhaps fainted. No follow up was arranged.

The staff felt frustrated that they were unable to elicit a full and accurate history because of communication problems. No interpreters were available. Nevertheless, they were reassured by the normal examination. In the circumstances they thought they had done their best.

COMMENT

- Staff at this unit had had no training in antidiscriminatory practice or cultural competence. Their attitude, in respect to non-English speaking patients, was for staff to manage as best they could; consequently they were unable to elicit a full and accurate history. They were not in the habit of accessing Language Line¹ (box 1), although it was available in their National Health Service trust, as it had neither been properly publicised, nor embedded within clinical practice, as a result of low prioritisation within management.
- Trained interpreters provide a better and more acceptable service than ad hoc or telephone interpreters.² However, because of logistical and resource limitations, it is unlikely that they will always be available, particularly when providing responsive unplanned care such as in A&E or maternity units, or in areas of the country with small or very diverse minority ethnic populations. A service such as Language Line enables any health care professional to communicate with almost any patient at any time.

During the next year the family attended the A&E department on four occasions, each time with a similar story. On each occasion a careful examination revealed no significant abnormality. On two of these visits the mother was tearful and cried out loudly. The girl remained quiet and passive.

Staff felt progressively more impatient with each visit. The mother was seen as over-reacting, perhaps because her culture encouraged over-demonstrative display of emotion in women. The quiet and passive demeanour of the child was thought to reflect a patriarchal culture that discouraged girls from expressing their views or needs. The family were referred back to the primary care team for follow up.

COMMENT

- Behaviours and attitudes of health professionals that end up disadvantaging minority ethnic people may be subtle, to the point that the professionals may not be conscious of them. Yet, they still have profound effects upon the care a patient receives. The most pervasive are cultural stereotypes.³ These may arise because a professional projects characteristics of one client or family from a particular ethnic group onto all subsequent members of that or similar community, or from knowledge about a culture resulting in assumptions being made about individual needs, behaviours, attitudes, and beliefs. These assumptions, which may be very inaccurate, can affect the care patients receive. If patients, as a result of communication

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barriers, are unable to put their own point of view forward, then such stereotypical assumptions are less likely to be challenged. Enabling effective communication is an important part of avoiding ethnic and cultural stereotyping.

- ▶ In this case cultural stereotyping of the child and her mother led professionals to interpret behaviours in ways that resulted in a failure to investigate the clinical situation properly. As will be seen, their behaviour was entirely understandable in the context of their predicament.

Box 1: What is Language Line?

Language line is a UK company that provides 24 hour access to telephone interpreters from a wide range of languages. Before using the service, clinicians and clerical staff need to watch a short video, but no other training is necessary. It is simple to use and readily accessible 24 hours a day from anywhere in the UK with a telephone line. It has contracts with many UK health providers and with voluntary agencies supporting ill or disabled people (www.language.co.uk).

During one of Mariam's attendances at the A&E department a full blood count was taken that led to the recognition that Mariam had α -thalassaemia trait. This information was shared with the local haemoglobinopathy counsellor so that she could arrange to visit the family and explain this finding and its significance to them. The counsellor established that the family's home language was Arabic and duly arranged a home visit accompanied by an Arabic speaking health advocate, employed by the local primary care trust, part of whose remit was to interpret.

During this visit the counsellor learned that Mariam had learning difficulties and was a pupil in a special unit within a mainstream school. Her parents were very anxious about her. They recounted, with the help of the interpreter, that once or twice a week Mariam would suddenly and unaccountably cry out, complain that her left leg felt odd, and thereafter appeared vague and difficult to engage. On several occasions they had taken Mariam to hospital because her leg had started to shake uncontrollably and she had lost consciousness for several minutes. Her mother became tearful at this point, telling how she had thought that Mariam had been going to die. She was still frightened that Mariam would die during one of these episodes, and didn't know what to do. Their general practitioner (GP) had told them that the hospital had informed him that Mariam had nothing serious wrong with her.

The counsellor was concerned that Mariam may be having convulsions and so, with the permission of the GP, she made an immediate referral to the local paediatric outpatient department.

COMMENT

- ▶ These are examples of good practice. The clinician identified the communication needs of the family, organised appropriate interpreter support, and consequently established a level of communication and trust that enabled her to reveal the existence of a potentially serious medical condition.

- ▶ When working with interpreters it is important to choose someone who is appropriate for the job.⁴ Using family or community members, although occasionally unavoidable, has many pitfalls, including potential or actual breaches of confidentiality and the risk of the interpreter manipulating the interview for one reason or another.² Using children to interpret is inappropriate and unethical since they may be harmed by having to share highly sensitive and emotionally painful information with their parents.³
- ▶ Even with the provision of appropriate interpreting services, adequate communication will not be achieved if clinicians choose not to work with them. It is also desirable for clinicians to be trained in how to work with interpreters (box 2)—it is not an instinctive skill.⁵ The Department of Health has recently published guidance on the development of local communication support services and strategies, which includes detailed good practice notes on working with interpreters.⁶

A consultant paediatrician saw Mariam. He confirmed the history and found no abnormalities on full clinical examination. An electroencephalogram (EEG) was performed that supported the diagnosis of complex partial seizures. With the help of the health link worker, he explained the significance of the diagnosis to Mariam and her family and agreed a treatment regimen and school plan with the parents and gave safety advice. Mariam was commenced on sodium valproate with a written schedule in Arabic and English of the dose increments required. The paediatrician agreed with the link worker that the latter would visit the family at home one week later. This she did to confirm that the family had understood what

Box 2: How to work with interpreters⁶

Beforehand

- ▶ Identify the language needs of the patient/family
- ▶ Arrange for the appropriate interpreter to be present (that is *your* responsibility, not the family's)
- ▶ Arrange an interpreter even if you share a language with one parent; for a number of reasons they may be unable to interpret effectively
- ▶ Introduce yourself and explain the purpose of the appointment
- ▶ Establish that the interpreter works to a professional standard of confidentiality

During the session

- ▶ Introduce yourself and the interpreter to the family
- ▶ Establish eye contact with the patient/family
- ▶ Explain that what is said will be kept confidential by you and the interpreter
- ▶ Allow plenty of time—it can take twice as much
- ▶ Speak clearly
- ▶ Avoid colloquialisms and local idioms
- ▶ Check you have both understood and been understood
- ▶ Give the family opportunity to ask questions

Afterwards

- ▶ If the interpreter is not employed by your trust sign the appropriate attendance forms
- ▶ Ask the interpreter to help with booking follow up appointments
- ▶ If the session was distressing for one reason or another, ensure that the interpreter has access to appropriate support or debriefing

had happened, to discuss concerns with them, to relate any misunderstandings back to the paediatrician, and to ensure that the parents were accurately following the prescription.

COMMENT

- Only after enabling effective communication were stereotypes dismissed, and this girl's needs properly recognised, ensuring that she received the treatment needed. The Race Relations Amendment Act 2000⁷ requires service providers in the public, private, and voluntary sectors to ensure that all clients have equality of access to services. This is clearly not achieved if professionals are unable to communicate with clients. Bophal argues that this is an example of institutional racism:

"According to the Macpherson Report⁸ institutional racism is 'The collective failure of an organisation to provide an appropriate and professional service to people because of the colour, culture or ethnic origin'. A simple example would be the failure of the healthcare system to make accurate diagnoses because it fails to provide the training and facilities (interpreters) to achieve quality communication."⁹

- Apart from preventing clinicians obtaining the information they require to make an accurate diagnosis, failure to work through interpreters can result in families not understanding diagnoses, not being unable to negotiate treatment options, and not obtaining the information needed to comply with treatment.
- Although few informed professionals would dispute Bhopal's view of what is or is not institutional racism, what is not clear is whether or not failure to facilitate communication, in clinical situations in which professionals and clients do not share a common language, is a breach of the Race Relations Amendment Act. Such cases have yet to be tested through the courts or addressed by the Commission for Racial Equality.

The consultant paediatrician was very concerned that this child's epilepsy had been missed, despite her being seen several times in the local A&E department over a considerable period of time. He felt that this amounted to a serious clinical incident that could have had serious consequences for this child, and so notified the clinical director of the A&E department of his intentions to report it as such. The paediatrician indicated that similar problems—of poor communication and ethnic stereotyping—had been experienced in his own department. In response, staff training in cultural competence and antidiscriminatory practice had been implemented. This training was now provided regularly and had been very helpful in improving practice.

COMMENT

- This paediatrician has recognised that a group of children, in this case those belonging to the black and ethnic minority (BEM) communities, are experiencing discrimination in his NHS trust and that this disadvantages them. He is also aware that he has a duty to advocate on behalf of these children and their families and thereby improve their health care. He has acted appropriately in informing his colleague but, importantly, he has also provided advice and information to allow appropriate remedial action to be taken.

- An advocate is, according to the Oxford English Dictionary, "one who pleads, intercedes or speaks for another". Paediatricians have an important advocacy role.¹⁰ This is often on behalf of individual children, but, as here, it may also be on behalf of specific groups of children or even whole populations who are experiencing disadvantage.¹¹ The Royal College of Paediatrics and Child Health (RCPCH) recognises advocacy as a core duty of the College and its members, and to this end it has established an Advocacy Committee that has published guidance for individual paediatricians.¹²

The clinical director of A&E decided that it was important to implement this training in her department. However, she had a very tight training budget and was short staffed. She approached the medical director who in turn suggested that she contact the trust equal opportunities manager. This manager informed her that the trust did indeed have a legal obligation to ensure that people from the BEM communities do not experience discrimination, and that he would be supportive of any actions to improve services to them. The A&E clinical director requested financial support for training but was told that this was not available, although the manager stated that he would be supportive of any training initiative.

COMMENT

- *Saving lives: our healthier nation* highlights that we live and work in a diverse community, where services need to be accessible to all, including deprived or socially excluded groups.¹³ The Race Relations Act (2000) requires service providers in the public, private, and voluntary sectors to ensure equality of access to services.⁷ Evidence to the Stephen Lawrence Enquiry emphasised the need for effective antiracism training and not just awareness sessions.⁸ The Commission for Racial Equality has consistently recommended that training on race issues should not be conducted in isolation but should be part of operational training.¹⁴ There is thus an abundance of informed opinion that appropriate training of the workforce is important.
- Unfortunately the equal opportunities manager in this case is making an empty gesture and doing nothing material to enable the clinical director in A&E medicine to fulfil any of these obligations. In a resource limited health service he must prioritise requests but nevertheless he is, in effect, marginalising the needs of BEM communities by failing to provide appropriate support for this training.

The A&E clinical director, having made the decision to implement training as best he could within his available resources, subsequently approached the child health directorate for assistance. This directorate had done a considerable amount of groundwork before implementing their own training. They had opted for cultural competence training rather than training that provided cultural facts and information to staff. Between them they implemented a rolling programme of training for A&E staff using material previously purchased by the child health directorate and modified to meet their specific needs.

DISCUSSION

The effective treatment of any particular disease depends not only on biomedical factors, but also on social factors. Cultural competence training, like communication skills training, explores the social context of disease and health care.

Ignoring this context may lead to ineffective interventions, even if the intervention chosen has a strong evidence base, because important factors such as trust, concordance, and compliance can be adversely affected by poor communication and lack of partnership between clinician and patient. This is particularly important in paediatric practice. Parents (or their substitutes) provide and deliver most childcare needs. Professionals may provide direct care to children but their contribution is usually one of advice and support to the primary carers. Partnership with parents is thus a prerequisite if services are to be delivered effectively.

Training that provides facts on cultural norms, and descriptions of cultural differences—a “what Somali refugees eat for breakfast on Thursdays” approach—does little to challenge stereotypes, and may even encourage them. Even if it was a helpful approach, it is not practical to expect professionals to carry such a weight of knowledge—on language, religion, belief systems, foods, child discipline, weaning practices, naming systems, etc—on the vast array of different groups that inhabit the major conurbations of the developed world. Even a small city like Cardiff (Wales, UK, population 340 000) has over 40 language groups.

Such an approach also ignores the complexity of people's lives. Minority ethnic families do not live within one fixed culture with extra-familial contact with other fixed cultures. They live at the intersections of usually many cultures, with widely different cultural norms, all of which change with time and place and influence one another.

This author could not identify any experimental studies measuring the effectiveness of cultural competence training in child health services. This may be because changes following such training may comprise subtle, and often private, adjustments in communication style or practice that are difficult or impossible to pick up observationally. One qualitative evaluation¹⁵ has shown that it is:

- ▶ well received
- ▶ perceived to be relevant
- ▶ changes behaviours and practice including promoting good communication
- ▶ improves professionals' perceived confidence.

True cultural competence is a process that depends on self reflection and self awareness and a tolerance of difference. It

enables professionals to respond flexibly and work in partnership with families from whatever background. Tervalon and Murray-Garcia¹⁶ call it cultural humility—“a commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations”.

This case is based on experience from several cases. Details have been altered to ensure patient anonymity

Conflicting interests: The author provides cultural competence training on a commercial basis on behalf of her academic department

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