Life & Times

Organ donation among ethnic minorities:

how UK primary care can help promote it

INTRODUCTION

There continues to be a significant paucity of Asian organ donors despite numerous public education campaigns in the UK.[1] The prevalence of type 2 diabetes, a major cause of renal failure, is up to six times greater among South Asians, especially within the Indian, Pakistani, and Bangladeshi communities as compared with the white population.[2,3] However, the lower organ donation rates among this group result in a disproportionate number of Asian patients waiting longer for transplants.[4] Promoting organ donation in this group represents one of the major challenges facing the transplant community and, despite a number of initiatives introduced in the UK, there has been little success.

The role of GPs in influencing the South Asian community in the UK to improve organ donation is potentially significant.

Here we reflect on our work (a PhD thesis by Agimol Pradeep — not published as yet), which sought to explore the impact of education interventions in increasing the number of organ donors from the South Asian community in the north west of England.

BACKGROUND

There is a wealth of evidence describing the important role of GPs in increasing awareness of specific health-related topics among the general public.[5] There is, however, very little data on the role of GPs in organ donation and transplantation.

Some studies have demonstrated the potentially promising role a GP could take with respect to organ donation.[6,7] A study of 200 GPs working in the Republic of Ireland revealed that only a minority provided donor cards (38%) or displayed information regarding organ donation (28.2%).[6] It also identified a lack of discussion and unfamiliarity among GPs regarding organ donation.

Results from a prospective randomised study among family physicians in the US highlighted that GPs can positively influence the commitment of their patients to be an organ donor.[7]

The UK Department of Health advised GPs in 2001 to display posters in their surgeries advertising organ donation and to distribute donor cards as part of their public health promotion role. However, despite this initiative, the use of GPs to promote organ donation remains relatively unexplored.[8]

The reasons for the scarcity of South Asian organ donors are multifactorial. Surveys have shown that obtaining the trust of the South Asian community is one of the important challenges faced by the health professionals in the process of organ donation and transplantation worldwide.[9] A potential avenue by which this can be addressed is through professional advocacy and confidence, channelled through primary care.[10] Improving transplantation advocacy and confidence in the largest group of healthcare professionals is essential in promoting best practice in transplantation.[10] A potential barrier to increasing donation may be the attitudes and knowledge of health professionals, who do not always support organ donation or create the right social climate to encourage participation.[11] Furthermore, GPs may simply not have the time or the resources for such education.

REFLECTION POINTS

It has been suggested that GPs, who hold a respected position within the community and can ideally speak the community's language, could be the educators for organ donation. However, some concern over the lack of confidence to approach with this topic is an outstanding issue. One of the areas highlighted by GPs is the assumption that they are responsible for religious clarification if any of their patients raise this concern, and this was a major issue. It is not expected that health professionals should be religious experts But it is important to note that some GPs appear confident in discussing other matters linked with religion, for example, fasting during Ramadan. It is unclear, therefore, why GPs should feel worried about approaching the South Asian community on organ donation due to the uncertainty of religious clarity.

From our review, it was reflected that, even though communities feel that the role of GPs is vital in promoting organ donation, GPs do not necessarily understand or appreciate this role in promoting organ donation. Many patient participants mentioned their wish to have the discussion with their GPs due to their trust and long relationship, and felt that GPs would provide unbiased information. These views were supported by Symvoulakis, demonstrating that the implementation of family practice-driven information and educational campaigns about organ donation and transplantation has the potential to increase the numbers of new donors.[12]

MISTRUST

Distorted beliefs, negative or ambivalent attitudes, indifference, and lack of knowledge and trust in healthcare systems are often more harmful than chronic diseases, and potentially cost lives.[12] One of the reasons for this reticence could be that many Asian countries do not have a successful deceased organ donation programme in place and organ donation is considered a Western concept. Additionally, news stories on organ trafficking and misuse of organs may have further given a negative impression.[9] This can be dealt with positively if primary care takes the initiative to explain the need for more South Asian donors and addresses some of these misconceptions.

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THE PRACTICE VISIT — AN OBITUARY

I was introduced to practice visits 25 years ago under the auspices of the 'What Sort of Doctor' scheme (colloquially 'Whatsod'). These were peer-to-peer visits to practices and at their heart was a friendly but challenging discussion about what practices were actually doing to deliver good care, and how they might do it better. Their strength was that they were carried out by fellow GPs who knew that general practice is a difficult balance between efficiency and personal patient care.

In the 1990s I visited each of 51 practices in and around St Helens in north west England. My central question was, *'Would I want them to care for my mother?'* Some failed. But as I waited in some scruffy waiting rooms I frequently saw rather muddled patients coming to reception desks to be greeted by name. They were then helped to navigate systems that had confused them, whether it be a repeat prescription, a flu jab, or how to get stitches removed. Some were clearly very well known and had major mental health issues.

Every practice has a fair number of such patients and when we raise the barriers to access, such as impersonal telephone systems, the inevitable happens and they simply go and wait in A&E departments. Doubtless unconscious triage was occurring with experienced staff, usually women with families of their own, able to spot when people were actually quite ill and in need of urgent attention.

As usual I got much more out of practice visits than I put in. I returned inspired with fresh determination to try harder and look for, as Jesus pithily said, the plank in my own eye having sought the splinter in others. Unless the practice was less than mediocre I found ideas we could adopt. Occasionally these were major: a practice in Morpeth introduced me to 'birthday reviews', where annual blood tests, medication, and other review areas are aligned in the month of the patient's birthday.[1] These have enabled us to have systems for chronic disease review that are clear to patients, families and carers, pharmacists, our staff, and ourselves. This quintuple-winner alone has saved me much more time than I have spent on all the visits I have done throughout Britain.

Why did practice visits pass away so peacefully with no attempt at resuscitation? We completely failed to recognise their unique value and ability to teach us things nothing else could. It is tempting to blame QOF and appraisal, whose rise to prominence coincided with their demise. Externally generated agendas have now become the only agenda. As our nerve failed we failed to say that much that is of value in general practice can be described but not quantified. Over a decade ago we took the financial lifeline of QOF and abandoned professionally led standard-setting. Optimism initially rose, and then fell into the doldrums.

In my opinion low morale is our greatest problem. We are waiting for a government to step in, but it is unlikely that we will ever become a high enough priority for a lifeline to be thrown. Practice visits could be part of the solution and we could rediscover that much good care is still being given beyond the narrow confines of QOF and guidelines. We could affirm, encourage, and appreciate each other.

General practice is at its best when we blend technical medicine with the needs of our most vulnerable patients. A child dying of a brain tumour and a man with terminal Parkinson's disease are currently stretching my experience of a lifetime in practice, and we inevitably struggle. They and their families need excellent, continuing, accessible, responsive care from us, the best people to deliver it. The danger is that eroded confidence might lead us to abrogate their fate solely to secondary and tertiary care.

But we could become self-confident again and the drive and optimism that a host of College role models gave me could return. The key phrase is professionally led. We have learnt that this can be remarkably easily lost once financial incentives and the demands of appraisal are involved. So why not rebel and exclude practice visits from their stranglehold? There is no one whose permission we need, indeed nothing stopping us from visiting each other again.

It would be a breath of fresh air.

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