End of Life care and South Asian kidney patients

Nationally there are a low number of referrals to palliative and end of life care services for people from Black & Minority Ethnic (BME) communities. Reasons for this include culturally insensitive services and a perception that services are only for the white middle class.

Healthcare providers of palliative and end of life care services have seen a poor uptake from ethnic minorities due to variety of reasons including limited understanding and awareness of the services available in hospice settings, cultural and language barriers, and difficulties in addressing issues around death and dying.

This infers that nationally BME people do not receive the best care possible at the end of their lives. Palliative and end of life care is important, because it provides relief from pain and other distressing symptoms. It offers a support system to help patients live as actively as possible until death, a support system to help the family cope during the patient's illness and in their own bereavement. Importantly, it also integrates the psychological and spiritual aspects of patient care.

One of the main aims highlighted in the End of Life Care Strategy, is to deliver high quality end of life and palliative care for everyone who needs. Nonetheless, there remains a poor uptake of such services amongst BME communities.

It is recognised that both between and within BME communities there are disparities in terms of general health, disease patterns, and personal health and well-being. Overall there is still compelling evidence that a large number of people from BME backgrounds tend to experience poorer health, and are less successful in accessing health-related services. Even more so end of life care.

In the area of kidney (renal) disease, there are further inequalities. For example, BME people are up to five times more likely to develop kidney failure and an Asian person with diabetes is ten times more likely to develop the disease than their Caucasian counterpart with diabetes. Diabetes is the leading cause of kidney failure; Kidney dialysis or transplantation can replace kidney function but will not cure the kidney problem. Some people choose not to have dialysis or deteriorate despite dialysis; some may need end of life care. Kidney failure patients reaching the end of their life also have choices and can access valuable local services such as hospices and Macmillan support (a referral based on clinical need and discussion with a doctor is required). However, there are cultural issues that do make this access difficult, as mentioned.

Kidney Research UK was founded in 1961 and is the leading UK charity dedicated to funding research aimed at finding better treatments, and ultimately a cure, for kidney disease. The charity has recently completed an end of life research project (funded by The Big Lottery Fund), working with the University of Bedfordshire and four renal units in the UK. This project focused on the South Asian community where the prevalence of kidney disease is greater compared to other community groups.
BME people have a greatly increased chance of renal disease, yet cultural issues can make access to end of life care services difficult

Key findings

- Patients experience varying and variable end of life care in the kidney setting depending on modality of treatment.

- Some care providers particularly nurses in dialysis units felt unable to have conversations about end of life care because of lack of confidence and time.

- There was a lack of awareness by patients of the concept of end of life care, supportive care or palliative care generally.

- The issue of communication and clear translation was highlighted and good practice and barriers were identified i.e. ethnic minority support worker, lack of access to translator & using language line.

- The role of families and carers emerged as a key area for enquiry as a proxy for patient experience as well in understanding the carer’s experience from their perspective.

Therefore the dissemination part of our project has been addressing these issues through training and awareness with staff, patient groups and the South Asian communities nationally and locally. This has included presenting our findings to professional groups, policy makers, at conferences and publishing papers and developing a training package, as far as the non patient groups are concerned. With regards to patients and the wider South Asian community, we have trained Peer Educators, lay people (sometimes patients) from the community who can relay information about the concept of end of life, what (often free) services and facilities are available locally that are culturally competent and meet the religious needs of the patients and their families. We are reaching out to many people, raising awareness with a good response.

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