Thursday's child has far to go

“We emerge deserving of little credit; we who are capable of ignoring the conditions that make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced.[1] Nearly 40 years ago, John Hinton drew attention to the deficiencies that were evident in the care offered to many patients with advanced disease and their families. While we have witnessed a dramatic growth in palliative care provision and a greater understanding of the needs of patients, actual access to services has been wholly inequitable.

In the UK, older patients,[2] those from black and minority ethnic communities,[3] and the poor[4,5] are less likely than younger patients, white patients, and more affluent groups to access appropriate treatment and care. These findings are even more significant when contrasted against evidence that the use of services elsewhere in the healthcare system by patients from black and ethnic minority community groups and lower socio-economic groups is either equivalent, or higher, than their white British, or more affluent counterparts, even after adjustment for crude measures of need.[6] Other socially excluded groups include those with severe and intractable mental health problems, those with learning disabilities, travellers, the street homeless, drug users and those within the penal system.[7]

Possible reasons for disparities in access to palliative care include: referral patterns to specialist palliative care are exacerbated by healthcare professionals' lack of understanding about what palliative care is; gate-keeping by services; preferences for more aggressive or curative care or a mistrust of end-of-life care; strong religious and familial support systems; and a lack of awareness and knowledge of palliative care and related services among patients with advanced disease.

Important policy initiatives have potential in improving the uptake of palliative care. However, none will work in isolation or without the widespread commitment of the state and the voluntary sector. In the UK, NHS Direct – the national nurse-led telephone helpline – aims to raise the profile of local services. Its purpose has been to provide ‘easier and faster advice and information for people about health, illness ... so that they are better able to care for themselves and their families'.[8] While customer satisfaction is high, it is currently underused by older people, ethnic minorities and other disadvantaged groups.[9] Local and regional implementation groups that examine and plan palliative care services offer great potential to explore the uptake of services. Examples include *Palliative Care in Wales: Towards Evidence Based Purchasing*[10] published by the Welsh Office and *Palliative Care for Londoners: Needs, Experience, Outcomes and Future Strategy*.[11] Lastly, the charitable sector is uniquely positioned to support new initiatives that extend palliative care to the point where they can be accepted and integrated into mainstream services. Help the Hospices is working with representatives from local hospices and other key organisations on a Widening Access Project (WAP). The project aims to work with local adult and children's hospices to reduce barriers to hospice and palliative care that people face as a result of social exclusion.

Although silent sections of the population are no longer being ignored, complacency remains our ever-present enemy

Although silent sections of the population are no longer being ignored, complacency remains our ever-present enemy. We must continue to recognise that good quality care towards the end of life is a basic human right that must be extended to all those who can benefit from it.”

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