



# Opening Doors: Improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities. Commentary on palliative care

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**Abstract** To put Council's project on improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities into context, palliative care will be defined, and the scope of palliative care services currently available in the UK outlined.

Palliative care is the active total care of patients whose disease no longer responds to curative treatment. It is provided through a network of home-care, day-care, hospital support and hospital or hospice based in-patient services. These services are accessed mainly through GPs or hospital consultants and the extent to which people are referred depends on the knowledge of hospital consultants and GPs, and their perception of the value of the palliative care service to their patients.

Council's project on improving access was supported by Cancer Relief Macmillan Fund and Help the Hospices as well as receiving a grant from the NHS Ethnic Minorities Unit. The report describes how the specialist palliative care services are currently provided in three areas with high minority ethnic populations and contains a series of recommendations around ethnic monitoring, equal opportunities strategies, staff training, communications and the provision of a more culturally sensitive service provision.

Palliative care is the active total care of patients whose disease no longer responds to curative treatment. It focuses on controlling pain and other symptoms and is concerned with the quality of life remaining, integrating the psychological and spiritual aspects of care and offering support to families during the patient's illness and into their bereavement. It is provided through a network of home-care, day-care, hospital support and hospital or hospice based in-patient services.

The Hospice Information Service based at St. Christopher's Hospice collects data on hospice and palliative care services, which is published in their annual directory.<sup>1</sup> There are now over 3000 hospice beds; 533 in the 46 NHS specialist palliative care units, 2196 in 142 independent voluntary hospice/specialist palliative care units, around 290 in 11 Marie Curie Cancer Care Centres, and 163 in 9 Sue Ryder Homes. About 250 hospitals now have "hospital support teams" which either serve the whole hospital or are based in oncology departments. They range from a single nurse to a consultant-led team. Most are pump-primed by the charity Cancer Relief Macmillan Fund (CRMF), the NHS taking over the funding after an initial three years. There are approximately 400 home-care teams and a few "hospice at home" services. Some independent hospices fund their own home-care nurses, but many of the home-care nurses, often known as Macmillan nurses, are also pump-primed for their first three years by CRMF, after which the NHS funds them. Home-care teams work with the primary health care team, who undertake most of the direct care. District nurses can also access Marie Curie nurses who provide hands-on care, the cost being shared between the NHS and Marie Curie Cancer Care. There are approximately 230 day-hospices - some freestanding, some linked to in-patient and/or domiciliary services or attached to an oncology department. A network of voluntary children's hospices, one per region, provide services for children with life-threatening illnesses.

The voluntary sector provision of specialist palliative care is extensive and complex. If the voluntary income of the 142 independent voluntary hospices, CRMF, Marie Curie Cancer Care, Sue Ryder Foundation and Help the Hospices is added together, palliative care is the biggest voluntary income generator in the Charity Aid Foundation's statistics.<sup>2</sup> Like all voluntary organisations, hospices are finding fundraising more difficult: reasons include an increase in the number of charities, the recession, the impact of the National Lottery and competition from fundraising by NHS services which were previously

virtually totally state-funded. NHS funds allocated for specialist palliative care were originally a ring-fenced grant, but are now incorporated into each health authority's baselines. The level of NHS funding for an independent voluntary hospice now depends on its contracting relationship with its local purchasers. The average contribution from the NHS to voluntary hospices is 38%, varying from 10% to 70%.

Of the 160,000 people who die of cancer each year, the Hospice Information Service estimates that 28,000 die in hospices and over 80,000 have contact with home-care teams. To offer people the choice of dying at home is often seen as an important outcome measure. In a recent paper<sup>3</sup> Anne Naysmith, consultant in Palliative Medicine at the Pembridge Unit (an NHS hospice in London) pointed out that for the patients and families that she is concerned with, if the last day or two is spent in a hospice after months or weeks of caring at home, the family still see that as a home death. We know from other research that a patient's wish to die at home may change as their illness progresses.<sup>4,5</sup> Lack of domiciliary services<sup>6</sup> and socio-economic factors also affect the choice.<sup>7</sup>

There should be cooperation between, and coordination of, seamless services, phrases that in theory cover the transition from a predominantly curative phase to a predominantly palliative phase. However, within an NHS which promotes an internal market, such cooperation can be difficult to achieve. There can be competition between NHS and voluntary providers, and even competition within the voluntary sector. The National Council's 16 elected regional representatives play an important role in bringing together all those involved in providing palliative care services.

Specialist palliative care services are accessed mainly through GPs or hospital consultants. Whether a patient is referred depends on their doctor's knowledge and perception of the value of palliative care services. Local hospice units find GPs' attitudes vary: from those who want to manage their own patients with no support or advice from local specialist palliative care services, through to those who make sure that any patient who needs palliative care gets it.

Specialist palliative care implies specialist training. This is now available for nurses and social workers, and palliative medicine is now a distinct specialty with its own training programme within the United Kingdom. The palliative care approach should be part

of clinical practice everywhere. It takes the best of specialist palliative care: a multidisciplinary team, a holistic approach to the patient, recognition that psychosocial needs are no less crucial than physical, open and sensitive communication, a focus on the quality of life remaining (including good symptom control) and care for family and carers. However, shortage of resources can be a major barrier to achieving this standard of care.

Does this complex network of services reach people from black and minority ethnic communities? Public and professional perceptions such as "they look after their own" may come into play. People from minority communities are less likely to know people who have been in a hospice, or know volunteers in hospices, and are less likely to ask their GPs for access to the services. Older GPs and GPs not trained in this country may be among those least familiar with the complex web of palliative care provision. They may not know, for example, that voluntary hospices are free, and, despite the religious connotations of some of the names, that all religions and groups are welcome.

Council's project on improving access to specialist palliative care services by members of the black and minority ethnic communities was established in response to observations on how "white" many hospices appear to be. For example, in a large town with sizeable Asian and Afro-caribbean populations, the hospice is in a suburb that is predominantly white, the patients and staff are predominantly white, and the very positive efforts being made to attract black patients were not being very successful. Whilst the project was being formulated, Council published *Guidelines for the Creation and Implementation of an Equal Opportunities Policy*<sup>8</sup> to encourage voluntary hospices to introduce, and work to, equal opportunities policies when recruiting staff and volunteers.

The project was supported financially by CRMF and Help the Hospices as well as by the NHS Ethnic Minorities Unit. The study was carried out in two London boroughs - Brent and Newham - and in North Birmingham. Black and Asian minority groups constitute more than 4% of the population of the UK: 60% of the black population and 36% of the Asian population reside in the Greater London area, with Leicester and Birmingham having the next highest percentages. The project's report, *Opening Doors: Improving Access to Hospice and Specialist Palliative Care Services*,<sup>9</sup> describes how palliative care services are currently provided in each of these three areas of high minority ethnic population. It focuses on the delivery of these services and the implications of caring for black and Asian patients and their relatives and carers.

One significant finding was to realise that the lack of patients from black and minority ethnic communities may have been less of a problem than originally envisaged. Cancer is the major disease for which people receive hospice and palliative care, and the incidence of cancer in the black and Asian communities appears to be lower than that in the general population. Cancer is predominantly a disease of the elderly and the age profile of the minority ethnic population means there is a relatively small proportion of elderly people. The lack of information available to minority ethnic patients and their carers, which meant that they were not being told about services available, was a second crucial finding. The report was launched by the Minister with responsibility for palliative care, Baroness Cumberlege, at the Department of Health in January 1995 and was followed by publicity in the minority ethnic press, and elsewhere, and with several radio interviews, intended to bridge the information gap.

Council's report makes a series of recommendations around ethnic monitoring and equal opportunities strategies - crucial for

staff and volunteers - as well as on staff training, communications and on issues around providing a more culturally sensitive service. A complementary publication by South Thames Regional Health Authority is *Palliative Care Service Provision for Black and Ethnic Minority Groups*<sup>10</sup> which aims to ensure that structures and mechanisms for assessing need and providing for action are available to enable health care practitioners to have the necessary frameworks and resources available to deliver that care effectively and appropriately. It also identifies the issues that require attention when assessing, planning and delivering patient care services.

The location of hospices is important - they are often found in white middle-class areas. For example, Trinity Hospice in Clapham, which is a large voluntary hospice operating in inner London within a multicultural local community, believes its work to ensure equal access is beginning to have positive results in terms of staff and volunteers as well as patient referrals. And social class may be important too: *Opening Doors* could have been printed putting "working class" instead of "black, Afro-Caribbean and Asian" and may well have reached very similar conclusions.

The research demonstrated that palliative care services are being used by some people from these communities and will increasingly be needed as the proportion of the black and Asian population aged 55 and over will rise over the next decade. More consultation and contact between both NHS and voluntary providers and potential users of their service is crucial.

The findings have identified a need for hospices and palliative care services to provide culturally sensitive services in respect of language, religion, spiritual and dietary needs, and for particular attention to be given to providing appropriate and accessible information to these communities, and to those doctors who make the crucial "refer" or "not refer" decisions. Although hospices have done much to meet the differing needs of their patients from minority ethnic groups, policies and systems need to be put in place now to meet future requirements. Ethnic monitoring is being addressed by a Council project on minimum information data collection, which will be asking all palliative care services for a range of information including ethnicity of in-patients, day-patients and patients at home.

Good information is crucially important in the drive to achieve more consistent referral arrangements from GPs and hospitals, particularly when dealing with such a complex range of services. Staff training is necessary if the needs of black and minority ethnic patients are to be met - who will pay?

A great deal depends on purchasing strategies and Council therefore widely distributed its Briefing Pack for Purchasers in June 1995. It contained two publications from the Working Party on Clinical Guidelines in Palliative Care - *Information for Purchasers: Background to Available Specialist Palliative Care Services*<sup>11</sup> and *Outcome Measures in Palliative Care*.<sup>12</sup> *Opening Doors* was included in the Briefing Pack in an effort to place the issues raised in the report on the purchasing agenda.

Raising hospice and specialist palliative care up the public, political, hospital and primary care agenda is the major objective if access for the black and minority ethnic community is to be increased, and if palliative care is to be an integral part of cancer services at all levels of care, as the Expert Advisory Group recommends.

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