Better
Health
Briefing

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Improving the quality of palliative care

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Race
Equality
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Communities
and Local Government

Key messages

1 Palliative care is mainly used by people with cancer. Cancer rates are relatively lower for most minority ethnic groups. The differing patterns of disease in minority ethnic groups has meant that the palliative care needs of those with non-cancer diseases have not been met

2 Access to palliative care can be restricted by a lack of understanding amongst professionals about appropriate referral criteria

3 Although palliative care can be given throughout an illness, use of palliative care services can be adversely affected by misunderstanding or fears about death and dying

4 People with life-limiting illnesses who do not speak the dominant language (English/Welsh) face significant difficulties in communicating with professionals

5 End-of-life decision making is assuming greater relevance with technological and legal developments. The focus in palliative care upon individual autonomy in end-of-life decision making can be problematic for patients and carers from different ethnic and cultural groups

6 Palliative care- related policy and research has emphasised the need for professionals to have training in cultural awareness/competency to enhance equity. However, there are no national standards for the training of palliative care professionals in transcultural care.

Introduction

The World Health Organisation has defined palliative care as the physical, emotional, social and spiritual care provided to people with advanced and progressive illnesses (WHO, 2002). Although palliative care is often associated with care for dying people, it is increasingly being recognised that palliative care can be given throughout the course of an illness (NICE, 2004). There has been growing concern in recent years about the accessibility and the responsiveness of palliative care to the needs of people most commonly referred to in the UK as being 'minority ethnic' (Hill and Penso, 1995; Firth, 2001). Hospices and palliative care services have also been criticised for not engaging fully with race equality (Gunaratnam, 2000).

Robust evidence of ethnicity- related disparities in access to palliative care is patchy and is hampered by the poor recording of ethnicity in key data sets and in service provision. Evidence from small- scale and qualitative research suggests that there is a lack of understanding amongst palliative care providers of the specific and varying needs of minority ethnic service users. Wider evidence suggests that specific resources and opportunities need to be established to enable the full participation of minority ethnic patients and carers in user involvement initiatives (Begum, 2006).

Differing disease patterns can lead to unmet needs and inequity in access

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The barriers to palliative care that face minority ethnic groups are complex. At a fundamental level they reflect the interaction of palliative care's historical development and specialisation in cancer care together with variations in ethnicity- related disease patterns. Epidemiological studies have shown that in general, cancer incidence rates are lower amongst most migrants to the UK (Aspinall and Jacobson, 2004). Because of their differing epidemiological profiles and because of the younger age structure of minority ethnic populations compared to white British populations, there has been a lower incidence of cancer and consequently a lower use of palliative care services amongst these populations (Smaje and Field, 1997). It is also the case that palliative care services in the UK are predominantly accessed by people with a cancer diagnosis (National Council for Palliative Care, 2006a). Inequalities in access to palliative care for non-cancer patients have been recognised by researchers, clinicians and the Government (National Council for Palliative Care, 2003; DOH, 2000). There are further concerns that even when minority ethnic patients and carers access palliative care they do not benefit fully from the holistic care approach, particularly with regard to the psycho-social aspects of their care (Beresford, Adshead and Croft, 2006).

The need to widen access to palliative care for those with non-malignant conditions is now being recognised in health policy (DOH, 2003; DOH 2006) and has significant consequences for minority ethnic groups where the most prevalent life-limiting diseases are coronary heart disease and cardiovascular conditions. Ensuring that all those with palliative care needs receive the best quality care has been further supported by the End of Life Care Programme (EoLCP, 2006). This programme aims to extend the use of tools developed to enhance end-of-life care to all settings. These tools include the Gold Standard Framework which has been used in primary care and the Liverpool Care

Resources 2

DIPEx

www.dipex.org/EXEC
The DIPEx website is a
general health-related site,
which includes palliative
care and is aimed at
patients, carers and
professionals. The site
enables you to watch,
listen or read interviews to
learn more about an
illness, experiences of
illness and treatment. It
includes interviews with
minority ethnic patients
and carers.

**End of Life Care
Programme**

*www.endoflifecare.nhs.uk/
eolc/*
The key objective of the
End of Life Care
programme (EoLC) is, '*to
offer all adult patients
nearing the end of life,
regardless of their
diagnosis, the choice and
access to high quality end
of life care*'. This website is
regularly updated and
includes briefings of recent
policy developments,
information on tools,
publications and events.

Pathway which was first used in care homes and acute hospitals (see
Resources). The National Council for Palliative Care (2006b) publication
Population Based Needs Assessment for End of Life Care can be used at a
local level to guide the development of services for all those with palliative care
needs, irrespective of diagnosis. In addition, Help the Hospices has produced
a briefing paper for hospice managers and trustees called *Widening access to
hospice care* (Gunaratnam, 2006a).

2 **There is need for appropriate referral criteria**

Research has identified that access to palliative care can be restricted by a
general lack of understanding amongst professionals about whom to refer
patients to, and when the most appropriate time for referral to palliative care is
(Ahmed *et al*, 2004). General Practitioners (GPs) are not always able to
recognise when a patient needs palliative care and are more reluctant than
hospital doctors to refer patients to specialist palliative care (Farquhar et al,
2002). Those from minority ethnic groups have been found to have poorer
relationships with their GPs (Airey and Erens, 1999; Koffman and Higginson,
2001) who are key gatekeepers to palliative care. It is also believed that some
GPs and hospital consultants are not referring minority ethnic patients to
palliative care because of the belief that families 'care for their own' (Karim et
al, 2000). In recognition of this, Bradford City PCT are improving the primary
care experiences of those with palliative care needs who do not speak
English. This is being done through an adapted team 'GP Facilitator' model
consisting of a Macmillan GP Facilitator with an attached Nurse Lead and a
bilingual health advocate (see Gunaratnam, 2006b). The Sheffield Palliative
Care Studies Group has produced a tool *SPARC (Sheffield Profile for
Assessment and Referral to Care)* that can be used directly by patients and
carers to identify patients with palliative care needs at the earliest stage,
thereby improving access and referral to palliative care. St Luke's Hospice in
London developed a Palliative Care Pathways Project (St Luke's Hospice,
2006) that included focus groups with local minority ethnic people to identify
reasons for the low take-up of hospice services. The hospice has produced
information resources to increase awareness about palliative care amongst
their local communities.

Fears about death and dying can restrict access to palliative care **3**

A systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals (Ahmed, 2004) found that misunderstanding and fears about death and dying could result in a reluctance by patients to be referred to palliative care. There is no reliable evidence that those from minority ethnic groups are more inhibited or anxious to talk about death and dying than majority groups. However, it is recognised that social taboos about illness and death can vary cross-culturally (Tse et al, 2003; CancerBacup, 2004). Recognition of fears and misunderstanding about palliative care in minority ethnic groups has led to awareness- raising initiatives including multi-media resources to improve understanding of palliative care. The East Berkshire Macmillan Community Palliative Care Team has used community workshops and a video *Humara Safar* (see Resources) with local South Asian communities to raise awareness about cancer, dying and palliative care. Greater Manchester and Cheshire Cancer Network has produced a leaflet and audio-cassette *Palliative Care and You* in English, Urdu, 'traditional Chinese' and 'simplified Chinese'. St Gemma's Hospice and Sue Ryder Care (Wheatfields) in Leeds have produced a poster, leaflet and audio-cassette on hospice services in English, Urdu, Bengali, Hindi, Gujarati, Punjabi and Chinese. The Policy Research Institute on Ageing and Ethnicity (see Resources) has a written guide (in English) on palliative care, using stories from minority ethnic elders and carers and a DVD featuring three patients and a carer talking about their experiences of life-limiting illnesses and care. In order to reduce social isolation and enable better choices about care, for those with life-limiting illnesses, it is important that initiatives are developed to challenge social and cultural taboos and to enable more open discussion about death and dying.

Not speaking the dominant language can put people at a disadvantage **4**

People who do not speak the dominant language (e.g. English or Welsh) can face particular obstacles in accessing and using palliative care services (Firth, 2001; Randhawa et al 2003, Gunaratnam 2006b). Difficulties in communicating with such patients and carers can lead to dissatisfaction and stress amongst professionals (Spruyt 1999; Thomas et al, 2000). Initiatives such as the provision of professional interpreters and bi-lingual health advocates, who have received specific training in working with serious illness, death and dying, have developed to help improve communication and care. Bradford Community Palliative Care Team

has two Macmillan Ethnic Minority Liaison Officers to improve the quality of palliative care provided. Evaluation of the first Liaison Officer post found that the work has led to improved communication, more accurate needs assessment, and an increase in use of hospice services by people from South Asian backgrounds (see Gunaratnam, 2006b). The 'Bengali Cancer Awareness and Advocacy Project' is an initiative developed between Bart's and the London NHS Trust and the voluntary organisation Social Action for Health. Evaluation of this project (Thomas *et al*, 2006) has shown that bi-lingual health advocates can improve the well-being of Bengali cancer patients, providing help with language barriers, information and emotional support. The findings of both these projects suggest that interpreters and advocates who are used in cancer and palliative care need to have specific training in cancer/palliative care. It is also important that professionals receive training in working with interpreters and health advocates.

5 **A focus on individual autonomy in end-of-life decision making can be problematic**

A review of the qualitative literature on ethnicity and end-of-life decision making found collective research findings to consistently suggest that *'..choices involving end-of-life medical treatment decisions may be more related to ethnicity and culture than to age, education, socio-economic status, or other variables'* (Jones, 2004). A study on end-of-life decision making and ethnicity in the United States has found that those from minority ethnic groups are less likely to use advance directives and tend to favour the use of aggressive medical treatments at the end of life (Baker, 2002). Other research studies on ethnicity have identified ethical issues in end-of-life decision making as relating to disclosure and truthtelling within families (Gardner, 2002), and to informed consent (Werth *et al*, 2002). A critical problem is seen in the potential conflict between Western ideals about a 'good death' involving a patient who is fully aware of their diagnosis and is able to make autonomous decisions about their care; and 'familial' cultures where family members may take on decision making roles and may even ask that information about a diagnosis is withheld from the patient (Firth, 2004). Whilst it is important that attention is given to cultural variations in attitudes to end-of-life decision making, it is equally important for practitioners to recognise relationships between cultural practices and oppressive power relations within families. Training in cross-cultural care can play a vital role in enabling practitioners to respond sensitively to variations and changes in cultural practices within and between different ethnic groups. It can also address the ethical issues involved in conflicts and tensions between practitioners and patients/carers and between patients and carers.

National transcultural care training and standards are needed   **6**

Research into hospice and palliative care has found that care is not always either culturally sensitive or 'competent' (Hill and Penso, 1995; Firth, 2001). The report *Wider Horizons* published by the umbrella organisation the National Council for Palliative Care recommended that: *'Training in culturally competent nursing should begin at undergraduate level and continue as in-service programmes…'* (Firth, 2001). The National Institute for Health and Clinical Excellence in its guidance on *Improving Supportive and Palliative Care for Adults with Cancer* (NICE, 2004), recommended 'cultural awareness training' for health and social care practitioners. This was a recommendation broadly similar to one made by the House of Commons Health Committee fourth report on palliative care (2004) which emphasised the need to ensure that all services are culturally sensitive and that this should form an important dimension of the training of both generalist and specialist palliative care staff. Resources in palliative care are developing to address these training needs, but these initiatives are currently *ad hoc* developments. The PROCEED Project (Professionals Responding to Cancer and Ethnic Diversity) has developed a DVD, workbook and website on cancer and cultural diversity (see Resources). A joint Masters degree programme on palliative care between St Christopher's Hospice and King's College (London) includes teaching on ethnicity and culture. Guy's and St Thomas's NHS Foundation Trust has run communication and cultural awareness training courses accredited by the Royal College of Physicians, to improve communication between professionals and patients (see Gunaratnam, 2006b). As minority ethnic populations age and the incidence of cancer and other life-limiting conditions increases, need for palliative care amongst these populations is likely to also increase. It is vital therefore that training in transcultural care for palliative care professionals is addressed at a national level.

Conclusion

In the past decade increasing attention has been paid to the need to widen access to palliative care for minority ethnic groups. Some palliative care service providers have developed innovative provision and resources to improve the use and quality of their services. However, there remains a need to improve existing knowledge about ethnicity- related patterns in health and illness, inequalities in access to services and successful policy and service initiatives. This is in order to develop more equitable palliative care services for the future.

Resources 5

The Policy Research Institute on Ageing and Ethnicity (PRIAE)
www.Priae.org
The institute aims to influence policy on work with minority ethnic elders. It has a palliative care project (PALCOPE) that has produced written information for older people on palliative care and a DVD of stories from minority ethnic patients and a carer.

The PROCEED Project
info.cancerresearchuk.org/ proceed/
The PROCEED resource is a multimedia training tool for educators within the health and allied professions. It consists of a book and DVD and offers background information, learning materials and suggestions. The DVD contains simulated clinical scenarios useful for prompting discussion amongst trainees. The price is £150 for public sector organisations and £300 for private sector organisations (inclusive of VAT).

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We welcome feedback on this paper and on all aspects of our work. Please email *briefings@racefound.org.uk*

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