

Research paper

The role of ethnicity in end-of-life care in care homes for older people in the UK: a literature review

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What is known on this subject

- Care homes play a significant role in UK healthcare. Almost one in five of the population of England and Wales, and a third of those aged 85 years or over, will die in a care home.
- there is very little data on the ethnicity of care home residents or staff, or the implications that this will have for care preferences, or the care that is provided towards the end of life.
- Improving the quality of end-of-life care in all settings is a key priority for the Department of Health, but staff uncertainty about appropriate care for people from another ethnic group may act to exacerbate healthcare inequalities.

What this paper adds

- Care home staff and care homes residents in the UK appear to represent a wide range of cultures and ethnic groups. This may result in differences in cultural understanding which impact upon end-of-life care.
- There is an urgent need to utilise both quantitative and qualitative approaches to provide detailed accounts of residents' needs towards the end of life, and to support staff in responding to residents' individual needs.
- Care home providers are increasingly aware of the need to respond to changing resident profiles, especially in terms of ethnicity.

ABSTRACT

Care homes for older people are major providers of end-of-life care – that is, care during the last years of life. There are over half a million deaths a year in the UK, the vast majority occurring among older people, and one in five members of the population dies in a care home. Ensuring the provision of high-quality end-of-life care in care homes for older people is an important healthcare issue, and has recently been scrutinised as part of an overall review of end-of-life care in the UK. It is acknowledged that little is known either about the numbers of people from black and minority ethnic groups who are

resident in care homes, or about the extent to which their end-of-life care needs are addressed in line with their specific requirements. This paper summarises the current research evidence on cultural issues relating to ethnicity in end-of-life care in care homes, identifying the need for both monitoring and research data on the experiences and perspectives of residents from black and ethnic minorities, and their family carers.

Keywords: care homes, end-of-life care, ethnicity, older people

Introduction

It is well recognised that the UK population as a whole is ageing, as more people are living for longer (Office for National Statistics, 2005; Policy Research Institute on Ageing and Ethnicity, 2005; Tomassini, 2005a; Gill *et al*, 2007). In fact, individuals aged 85 years or over are the fastest-growing age group in the elderly population (Tomassini, 2005a). At present, the minority ethnic population of the UK tends to be younger, due to migration patterns and higher birth rates (Policy Research Institute on Ageing and Ethnicity, 2005; Commission for Racial Equality, 2007). However, as migration to the UK increases and resident ethnic minority populations grow older, the number of ethnic minority elders is predicted to rise, particularly in areas such as London and the West Midlands, and this has implications for health and social care services (Sienko, 2002; Chahal and Temple, 2005; Age Concern, 2007; Simpson, 2007). Indeed, in Birmingham, the number of black and minority ethnic (BME) individuals aged 65 years or over is predicted to increase from 21 000 in 2006 to 36 000 in 2026 (Simpson, 2007). At this stage, it is forecast that BME residents will represent around one-quarter of the city's population aged 65 years or older. It is important to note the diversity within the BME groups. The Office for National Statistics (2005) indicates that only 3.1% of the population aged over 50 years are of BME origin. Two-thirds of these individuals are of South Asian origin, including Indian, Pakistani, Bangladeshi and other national origins, membership of faith communities as diverse as Christian, Muslim, Hindu and Buddhist, and a variety of language backgrounds. Around one-third of people over 50 years of age from BME groups are 'black', of either African or Caribbean or mixed (largely UK) origin.

End-of-life care in care homes

End-of-life and palliative care in community and hospice settings has been the focus of extensive research, but only in recent years has the important role of care homes in end-of-life care been acknowledged and explored (Hockley and Clark, 2002). A focus on delivery of end-of-life care in these settings is imperative, because of the high numbers of older people living in care homes, and the increasing use of care homes as places in which end-of-life care is provided. According to the 2001 UK Census (Tomassini, 2005b), 4.5% of people over the age of 65 years live in communal establishments, and this figure rises dramatically with age. Up to 20% of men and 35% of women over the age of 90 years live in care homes or in a similar setting. It is estimated that over 405 000 people aged 65 years or over are living in care homes in the UK (Help the Aged, 2008). Approximately half this number lives in homes which provide personal care. The rest, who are more dependent, are cared for in nursing homes (Help the Aged, 2008). Almost one in five members of the UK population dies in a care home (Seymour *et al*, 2005), and typically residents suffer from multiple pathology, with over 60% having cognitive impairment.

An indication of the importance that people attach to the perceived quality of end-of-life care can be obtained from NHS data (Healthcare Commission, 2007), which reveal that over half of the complaints received are about end-of-life care. Although these findings cannot necessarily be extrapolated to care homes, they do provide an insight into the importance that family and friends attach to care during the last stage of life.

Care home staff are expected and required to provide end-of-life care that is compassionate, sensitive and appropriate to the dying individual (National

Council for Palliative Care and NHS End-of-Life Care Programme, 2006). In an ideal care scenario, elderly people who require care at the end of life should be able to remain in their own home – in this context, the care home. If care facilities do not support this, residents may be transferred to a hospital bed via an Accident and Emergency department, resulting in a transition from the community to the acute care sector. Such transitions can be traumatic for all those involved – residents, their families and care home staff (Shemming, 1996). In addition, there are revenue implications for the NHS.

Efforts are being made to help care home staff to provide quality end-of-life care and to avoid such transitions. For example, work evaluating the impact of the Gold Standards Framework for End-of-Life Care (www.goldstandardsframework.nhs.uk) indicates that offering a development programme has potential to help staff avoid such traumatic transitions by providing them with simple tools to manage the end-of-life care experience in care homes. Preliminary indicators suggest that, if care home staff can manage care effectively, transfers of residents to hospital at the end of life can be reduced by 12% (Badger *et al*, 2007). This evaluative work is ongoing. However, a key issue arising from this is the extent to which the use of supportive programmes can have an impact on the increasingly diverse population to be found in the care home sector, and BME groups have been identified as having unmet needs with regard to the provision of end-of-life care (National Audit Office, 2008). Ethnic diversity among both residents and care home staff may be a key factor influencing the extent to which complex care transitions are made. However, as will be seen below, it is an area that is still relatively unexplored.

Ethnic diversity in care homes

At present, little is known about access to and use of care homes by BME groups (Bebbington *et al*, 2001; Mold *et al*. 2005a, 2005b; Gill *et al*, 2007). The numbers of BME older people in the UK are currently low, and attempts to determine current representation of BME older people in care homes have proved difficult (Bebbington *et al*, 2001; Banks *et al*, 2006). Limited recording of data on ethnicity is not restricted to care home settings. A recent survey of health databases reported that less than half of them had a question on patient ethnicity, reflecting the limited importance accorded to this data (Sultana and Sheikh, 2008). In their report for the Joseph Rowntree Foundation, Banks *et al* (2006) evaluated the census data from 1991 to 2001, and found that the proportion of elderly BME people living in UK care homes was small

compared with the rest of the population. It was suggested that this could reflect the fact that family care at home was more common, a view that is thought to be widespread among care providers and policy makers (Sienko, 2002; Policy Research Institute on Ageing and Ethnicity, 2005; Banks *et al*, 2006), and more prevalent among some ethnic groups, such as the Asian/Asian British population, than others (Chahal and Temple, 2005; Tomassini, 2005b). The possibility that this low level of representation could be due to issues of access and suitability of care homes for BME elders was also acknowledged (Banks *et al*, 2006). This view is echoed in the report by the Policy Research Institute on Ageing and Ethnicity (2005), which looked at minority elder care in Europe, and raised concerns about minority elders' access to and use of health and social care services. With regard to end-of-life care, BME groups are also under-represented as a proportion of those who access hospice services (National Audit Office, 2008). However, it is important to bear in mind that the location of the care home may well affect the ethnic ratios within the home. BME people live mainly in urban areas, so are more likely to represent the majority population in care homes in such settings. Furthermore, some BME nurses have set up BME-run care homes, and some organisations specifically care for BME groups. It is possible that there is much to be learned about providing services for BME groups from these organisations.

However, it is also clear that the overall under-representation of BME older people in care homes, compared with white older people, is not solely a consequence of their lower numbers in the general population. The view that BME groups are more likely than the indigenous population to care for older family members is one which is increasingly being challenged as expectations change, and the lower numbers in care settings may be a consequence of lack of suitable provision, rather than being due to other factors (Bains, 2006; BBC, 2008). Evidence presented to the end-of-life care review by organisations representing a range of ethnic groups indicated that minority groups did not regard care homes as accessible, due to differences in language, culture and diet. In addition, older people were doubtful about the ability of staff to support their cultural or religious practices (Department of Health, 2008).

Policy

There is evidence of growing awareness among policy makers of the importance of identifying the needs of BME elders. The National Minimum Standards for Care Homes (Department of Health, 2003, Standard 4.3) require that the 'needs and preferences of specific

minority ethnic communities, social/cultural or religious groups catered for are understood and met, including preferences about death, rituals and practices and food', although as Mold *et al.* (2005a) have pointed out, specific guidance on how this should be achieved is not included. The Commission for Social Care Inspection (CSCI), which regulates and enforces the national minimum standards in care homes in England, is in the process of implementing its Race Equality Scheme (Commission for Social Care Inspection, 2005) and an Equalities and Diversity Strategy (Commission for Social Care Inspection, 2006). Although the CSCI (2005, p. 6) states that 'social care services should be delivered in a culturally sensitive and appropriate manner', their review of current practice revealed that this was not always the case. They found inconsistencies and variation across the UK with regard to social care services for BME communities, and although there were some improvements, many councils appeared to be slow to adapt services in response to increased awareness of need (Commission for Social Care Inspection, 2005). There were some examples of good practice in providing care for BME elders, but on the whole provision was inadequate and therefore led to poor outcomes. The widespread commitment of local authorities and service providers to develop racial equality was again undermined by a lack of defined action points or targets.

The Healthcare Commission, the CSCI and the Audit Commission have reviewed the progress of local authorities in meeting the standards set out in the National Service Framework for Older People (Healthcare Commission, Audit Commission, and Commission for Social Care Inspection, 2006). They found awareness of diversity issues to be in the early stages of development, with much more work needing to be done to ensure that BME elders received culturally sensitive and appropriate services. Ongoing diversity training for health and social care staff was recommended. It was anticipated that this would engender respectful attitudes and help to ensure that mainstream services make provision for different cultural and religious needs (Healthcare Commission, Audit Commission, and Commission for Social Care Inspection, 2006). A recent guide to end-of-life care in care homes (National Council for Palliative Care and NHS End-of-Life Care Programme, 2006) recognises that cultural and language differences between staff and residents can affect end-of-life care, but offers no solutions to this potential problem. A subsequent publication by the same group provides examples of innovative practice (National Council for Palliative Care and NHS End-of-Life Care Programme, 2007, p. 8), and states that end-of-life care needs to be underpinned by 'sensitivity to personal, cultural and spiritual beliefs and practices.' Two vignettes about improved end-of-life care illustrate how cultural and spiritual differences

between both staff and residents can affect attitudes to death and dying and create barriers to the provision of appropriate care. It is suggested that if staff are able to acknowledge these issues and are offered training and support, the resident can be respected and given care that is appropriate to them (National Council for Palliative Care and NHS End-of-Life Care Programme, 2007).

The academic literature on the needs and experiences of BME elders in UK nursing care homes is somewhat limited (Mold *et al.*, 2005a, 2005b; Higginson *et al.*, 2007). However, there are some notable exceptions to this, and the literature pertaining to BME elders in general is more extensive. Bowes and Dar (2000) looked at the development of appropriate services for minority ethnic groups, and concluded that user perspectives are crucial. Modood *et al.* (1997) explored the experiences of ethnic minorities in the UK, providing a comprehensive picture of multi-cultural society. In addition, Lowdell *et al.* (2000) looked at the implications of the ageing BME population for London's health services. Their projections demonstrated that although London's older population as a whole will decrease over the next 10 years, the proportion of that population which is comprised of BME groups will increase significantly. They also highlighted the fact that the BME groups experienced higher levels of poverty and social exclusion. However, in general the limited information about the use of nursing homes by BME elders makes it difficult to evaluate current service provision in the UK, and hinders discussion of how service access and provision can be improved (Mold *et al.*, 2005b). Mold *et al.* (2005b) have called for research that explores the perspective of the resident/user, along with the views and experiences of current nursing care providers.

Care home residents

The cultural mix of both care home staff and residents can have implications for the provision of appropriate end-of-life care. Bebbington *et al.* (2001) found that the health of BME elders admitted to care homes was generally poorer than that of older people from the white UK population. Discussions about end-of-life care may therefore be more urgently needed for BME elders (Bebbington *et al.*, 2001). Gunaratnam (2007) demonstrated that decisions about palliative care for BME elders can potentially give rise to conflict between the Western concept of patient autonomy and the notion of familial involvement in decision making, which has been identified as a feature of some BME groups. Jones (2005, p. 450) mentioned the importance of recognising that 'the basic values, principles and assumptions of Western medicine and bioethics

are themselves historically situated and culturally determined.’ From his review of the qualitative literature, Jones (2005) concluded that in relation to decisions about end-of-life care, considerations of ethnicity and culture were more important than other variables (including age or socio-economic status).

Living and being cared for in a place where one’s cultural needs are understood, respected and responded to has implications for individuals’ sense of dignity, self-respect and well-being. These principles of care can be regarded as central to current health and social care policy in relation to older people (Social Care Institute for Excellence, 2006; Office of the Deputy Prime Minister, 2006). In addition, the implications of implementing patient-centred care for BME elders are far-reaching in terms of staff training. An important point to note is the concept of treating care home residents as individuals, and not basing care on perceptions of or assumptions about ethnicity. However, care home providers are not ignoring these issues, and are now recognising the challenges associated with the changing resident profile with regard to ethnicity (Green, 2009).

Care home staff

Little is known about the ethnicity of care home staff, although the CSCI is currently reviewing its ethnicity and diversity policies and introducing racial monitoring of its staff (Commission for Social Care Inspection, 2005, 2006). An employment survey commissioned by the Royal College of Nursing (Pike and Ball, 2007) suggests that both UK-qualified and internationally recruited BME nurses are more likely to be employed in care homes than white UK-qualified nurses or internationally recruited nurses, although these figures may not take into account the more recent influx of nurses from Eastern European countries. In addition, it is not uncommon for nurses from abroad to work in care homes in order to gain sufficient practice experience to register in the UK (Smith *et al*, 2006). This group, sometimes referred to as ‘adaptation nurses’ (Department of Health, 2003), may have different cultural, faith and linguistic backgrounds both to residents and to other staff. Smith *et al* (2006) found that adaptation nurses from some African countries had little understanding of what a nursing care home was. The authors suggested that this was because care establishments were relatively uncommon in the adaptation nurses’ home countries, because elders are usually cared for at home by family members. It was also reported that conflicts could arise between staff due to different cultural understandings and expressions of nursing care.

The current demographic situation in the UK may therefore perhaps lead to a cultural mismatch between care home staff and the residents for whom they provide care. It has been found that health professionals often experience considerable uncertainty when caring for ethnically diverse patients, even after they have received training in cultural competency. This uncertainty can lead to hesitancy and inertia, resulting in failure to do what is best for the patient, and thereby exacerbating ethnic healthcare inequalities (Kai *et al*, 2007). The need for staff to be sensitive to a range of different religious beliefs, or to the absence of belief, and to be culturally sensitive when caring for those nearing death, in order to provide good-quality care, has already been identified (National Council for Palliative Care and NHS End-of-Life Care Programme, 2007). Linked with this, Lee (2004) acknowledges that the cultural values and beliefs of residents must go hand in hand with the recognition that the nurse, too, is a culturally grounded individual with expectations, values and beliefs that may contrast sharply with those of residents. In addition, Gebru *et al* (2007) insist that healthcare professionals need to develop an awareness of their own value systems with regard to health, illness and death, as these will affect both the way in which they view events and people, and their own actions.

Conclusion

It is only in recent years that the important role of care homes in the provision of end-of-life care has been acknowledged, and information on the care that is required by and provided for residents from BME groups is lacking. Although the available figures indicate that there are currently low numbers of residents from BME groups, this figure is likely to increase, and the scale of change will have more of an impact in some localities than in others. This brief overview clearly indicates that little is known about the impact of cultural diversity on care home residents, or about the numbers of residents from different BME groups. However, such information is urgently required if appropriate services to support end-of-life care are to be developed and implemented, in line with current policy. Although accurate data on the numbers and groups of BME residents are important, qualitative research that incorporates the perspectives and experiences of residents, families and staff is also essential, in order to ensure that service providers can respond appropriately to BME users’ needs with regard to end-of-life care in care homes. Qualitative research is needed to help to develop appropriate training and support, to facilitate care home staff in providing care that meets the individual needs of residents and their families at this important stage of their lives.

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CONFLICTS OF INTEREST

None.

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