Ageing & Society **31**, 2011, 386–407.
doi:10.1017/S0144686X10000966

Researching the end-of-life in old age: cultural, ethical and methodological issues

LIZ LLOYD*, KATE WHITE* and EILEEN SUTTON*

ABSTRACT

Increased life expectancy has strengthened the association between old age and death, with significant implications for gerontology and for the generation of knowledge through research. The global rise in chronic disease has had a significant impact on the duration and shape of dying trajectories in old age and their variations. This development poses ethical and methodological challenges for researchers, not least because it is often difficult to establish whether an older person is 'dying from' as opposed to 'living with' one or more diseases. This paper reports a comprehensive literature review of empirical research on the end-of-life in old age, and has two inter-related themes. It explores the social and cultural contexts of death and critically analyses the methods and ethical approaches adopted by researchers. Cross-cultural studies and studies in which cultural factors were of prime interest were selected with a view to examining the concept of a 'good death' in old age. The paper discusses the evidence of cultural similarities and differences and the impact of social and cultural change on ideas concerning a good death. It identifies contemporary influences and pressures on end-of-life care for older people and discusses the significance of communication and the roles of families and service providers. The paper concludes by identifying substantive and methodological lessons for researchers in gerontology and suggests ways in which the impact of research might be enhanced.

KEY WORDS – old age, end-of-life, culture, ethnicity, methods.

Introduction

A range of complex issues emerges from an examination of the end-of-life in old age. The particular focus of this article is on cultural concerns at the end-of-life in old age (where culture is understood as a system of shared values and practices) and the methods used in their study and explication. This is a challenging research area, not least because of the vulnerability of the research participants, and it is timely to review the associated methodological and ethical concerns. The focus on culture is also timely.

---

* School for Policy Studies, University of Bristol, Bristol, UK.

The ageing of migrant ethnic minority populations (Hayslip and Peveto 2005) and the global spread of medical and health-care practices makes this a crucially important area of practice and there is an urgent need to build the evidence base. In this article, we consider first some of the key issues from the literature about the cultural contexts of death and dying in old age. This is followed by a systematic review of empirical research that is either cross-cultural or which led to important findings about the cultural contexts. The methodological and ethical issues that arise are then discussed.

Cultural contexts of death and dying in old age

Walter (2003) pointed out that because ideas of what constitutes a good death are dependent on social and cultural norms, it follows that we should expect considerable variation in multi-cultural societies. He identified three key factors: the extent of secularisation, the extent of individualism, and how long the typical death takes. Leichtentritt and Rettig, for example, pointed out that the strict norms of Jewish culture prescribe 'one way to die, one way to be buried and one way to mourn the loss of a close family member' (2001: 86; *see also* Gamliel 2008; Wink and Scott 2005). In contrast, comparatively secular societies embrace a multiplicity of ideas about ways to die or to mourn, and tensions are evident between religious and secular positions in the framing of laws and policies concerning the end-of-life (Williams 1990). Secularisation also coincides with the growing importance of medicine and its partial substitution for religious understanding and customs. Timmermans (2005) pointed to the dominance of the medical professions in deaths in Western societies and argued that their role now encompasses that of 'death brokering', in which deaths are made culturally manageable and understandable. In this review, it is argued that the extended duration of the dying trajectory coupled with growing individualism have profound implications for older people.

Cross-cultural comparisons are particularly useful for explaining the meanings that people attach to the idea of a good death, but different cultural norms and values concerning death and dying are not always easily distinguished. Seale and van der Geest (2004) commented on the extent to which otherwise diverse cultures have common views about 'a good death', with some conceptions being near universal, for example that it comes 'after a long and successful life, at home, without violence and pain, with the dying person being at peace with his environment and having at least some control over events' (2004: 885). Seale and van der Geest also commented on the significance of different views about good and bad deaths *within* cultures along the lines of religious beliefs, age cohort, economic status, professional status and political interests. Importantly, ideas about what constitutes a good death do not always translate neatly into ideas about what constitutes good end-of-life *care*. For example, the idea of 'openness' about a person's dying status – generally considered in the West to be a prerequisite of good end-of-life care – is known to be inappropriate in other contexts.

The development of palliative care is a relatively low priority in countries where the prevention of premature deaths is still a priority. Particular issues arise in countries where HIV is a major cause of death at all ages, or where older people have lost sources of support because of migration (King and Vullnetari 2006; Williams and Tumwekwase 2001). Spence, Merriman and Binagwaho (2004) pointed out that in many African countries, health professionals are faced with the dilemma of having to choose between saving lives and easing the suffering of the dying, but also argued that major improvements can be made in pain relief at very little cost, and could be applied in palliative care.

It is also important to bear in mind the dynamic nature of cultures and the ways in which cultural norms and values can be changed or modified as a consequence of exposure to new knowledge and practices. Mani (2006), for example, identified difficulties in end-of-life care in India, including high levels of unmet need in public hospitals, unaffordable medical expenses, and the lack of training in palliative care. A complex and archaic legal code that is unclear on the law concerning the withdrawal of treatment at the end-of-life exacerbates an already difficult situation for dying people and their families (Brijnath 2008). Shanmugasundaram, Chapman and O'Connor (2006) argued that Western models of palliative care, which have been adopted increasingly over the past ten years in India, are not always appropriate and that more successful models are evident where community-level initiatives draw on traditional healing practices. Indeed, they predicted that in the future the West will learn much from such approaches.

Gu *et al.* (2007) analysed changes in the place of death of older people in China, with the aim of drawing more general conclusions about the relationship between the place of death and the level of a country's socio-economic development. They concluded that there are three stages in the evolution of place of death. During the first, because of a lack of alternatives and limited medical care, most people die at home. At the second stage, as medical techniques improve and health-care services become more accessible, hope of survival is raised and more people die in hospitals. At the third stage, there is more interest in the *quality* of care at the end-of-life, and palliative and hospice care is preferred to that offered in hospitals. In broad terms, this typology is useful, although the place of death does not provide the whole picture concerning the quality of a death, and other cultural factors need to be taken into account. Without doubt, hospice and palliative care is generally regarded as a positive alternative to the medicalised death, in which the dying person is reduced to a set of physical symptoms and their social, psychological and spiritual needs are overlooked. The chief characteristics of a good death according to the palliative care model can be summarised as follows:

- Attention to the unique physical, psychological, social and spiritual needs of the individual who is dying.
- Control of pain and other distressing symptoms.
- Death at home, accompanied by family and friends.
- Open awareness of the impending death for the dying person, their family, and those providing care and treatment.
- Choice and control by the dying patient over treatment decisions.
- Support and comfort for the bereaved both prior and subsequent to the death (Gott *et al.* 2008).

This model has become widely regarded as desirable best practice that should be promoted globally, but questions have also been raised about its cultural appropriateness and for the notion of imposing a single 'script' about how people should die (Gott *et al.* 2008). There are particular questions in relation to age. The palliative care approach was developed in cancer care predominantly for middle-aged people and cannot simply be transferred to the context of, for example, coronary or cerebrovascular diseases from which large numbers of older people die. The complexity of many older people's dying trajectories means that it is often difficult to determine whether they are living with a disease or dying from it. Bern-Klug (2004) referred to the 'ambiguous dying syndrome', which leaves many older people unable to access the kind of emotional and spiritual comfort and care that might be available if their dying status were more clearly established. The length and complexity of their dying trajectories means that older people's need for care and support at the end-of-life is not easily predictable (Dwyer, Nordenfelt and Ternestedt 2008; Lloyd 2004).

Whilst there is evidence to support the view that hospice care is a popular choice at the end-of-life, inequalities in access are evident (including some related to age and ethnicity) (Grande, Addington-Hall and Todd 1998; McGrath 2000). In Western countries, older people – particularly widowed women – are increasingly likely to die in a nursing home (Flory *et al.* 2004) and there is increasing emphasis on enabling older people to die at home if that is their wish (Jeppsson-Grassman and Whitaker 2007). Whilst a death at home is potentially good, especially if this is an older person's preference, it might put older people at risk of isolation or place unexpected pressure on families unless they are supported by health and social care services.

The literature review

The key questions that we wished to address through the literature review were:

- In different cultural contexts, what factors are understood to determine whether or not a death in old age is 'good'?
- What is the impact of social and cultural change on how a good death in old age is understood?
- What are the strengths and weaknesses of different research methods used to research death and dying in later life?
- How have ethical challenges, inherent in this field of research, been addressed?
- What are the implications of these findings for gerontological knowledge?

Cross-cultural research can highlight differences in life expectancy and patterns of mortality but this was not a part of this review. However, such differences and inequalities have an impact on what constitutes old age in different parts of the world, and being mindful of this we did not impose a strict definition of old age. In almost all the studies participants were aged over 60 years.

The search procedure

A search of the online databases Medline, Embase, Cinahl, ASSIA IBSS, AGEINFO, Web of Science and Web of Knowledge was conducted using the following keywords: death, dying, good death, end-of-life, end of life, mortality, ageing, aging, old*, elder*, culture, ethnicity, minor* and religion. These keywords were combined in different ways to maximise our ability to obtain all available evidence (the asterisks indicate any character; the full search strategy is available from the corresponding author). Relevant specialist gerontology, death and dying and cross-cultural journals were also hand-searched. The websites of the World Health Organization and the Palliative Care Observatory at the University of Lancaster, United Kingdom (UK), were searched for relevant publications. A search for social gerontology books published beyond the United States of America (USA), the UK and Europe was also conducted. We excluded non-English-language articles; those concerned with research on non-human subjects; articles where age was not a primary focus; studies of population trends and demographic factors; and strongly biomedical articles (concerned with treatment for a particular disease or condition).

The number and types of identified publications

The initial searches of the databases produced more than 400 papers from over 100 peer-reviewed journals. More than half of the journals were medical or nursing, including those specialising in health-care practice with older people. There were 15 social gerontology and applied gerontology journals and those from diverse other disciplines, including death studies, sociology, medical ethics, social work, psychology and anthropology. Over 50 per cent of the papers were from the USA, almost 25 per cent from the UK and 13 per cent from continental Europe (predominantly the Nordic countries and The Netherlands). There were also 25 papers from Australia, 22 from Canada, ten from Japan and six from Hong Kong. Those from the rest of the world included Ghana, India, Israel, Mexico, Singapore, Taiwan and New Zealand, although it should be borne in mind that some papers published in the USA or the UK reported research that had been conducted in other parts of the world (*e.g.* Orpett-Long 2004; van der Geest 2004). The first stage of the analysis was to group the articles into four categories:

1. Empirical research with older people and families.
2. Empirical research with professional practitioners.
3. Articles on research methods.
4. Discussion articles, including policy and ethics related to end-of-life care.

There were slightly more non-empirical than empirical studies. Of the non-empirical papers, more than half were discussions of health-care policies and practices, many of them focused on the ethics of decision-making at the end-of-life and on service quality standards. There were also secondary analyses of survey data and literature. The empirical research was predominantly qualitative, and the participants included older people, families, widows, unpaid carers, nursing staff and medical students. There were also several reports of empirical quantitative studies (around 10 % of all papers), including those on mortality predictors and place of death.

At an early stage, we did not impose strict exclusion criteria but for several reasons subsequently modified the search strategy. The preponderance of literature on the medical care of the dying presented a challenge, because the cultural factors that impinge on health care at the end of life were not irrelevant but the plethora of articles from North America and Europe on decisions and choices over end-of-life treatment, advance directives and physician-assisted dying prompted reconsideration. It was decided to confine our search to articles on empirical research that had a clear cultural focus. At the second stage, we selected those articles that aimed to produce a cross-cultural comparison *or* in which the cultural context of the research was discussed. After initial reading of abstracts, 32 articles were retained and categorised into two groups:

1. Empirical research with older people and/or their families and/or practitioners with a specific cross-cultural focus, and
2. Empirical research with older people and their families where the cultural context was significant (*see* Tables 1 and 2).

We also examined papers that provided useful contextual material, including non-empirical papers in which ethnicity and culture were significant to the discussion and papers that had a particular methodological or research ethics focus. These are not included in the tables but informed our overall analysis.

Methodological and ethical findings

The recency of this field of research is reflected in the exploratory nature of many of the reviewed studies and the frequent calls by the researchers for further work. We identified a bias towards end-of-life *care and treatment decisions*, rather than on older people's experiences of the end-of-life more generally. This perhaps reflects methodological difficulties in this area of research, especially those related to the recruitment of research participants. We also identified tendencies to regard the Western approach to end-of-life treatment decisions as the 'default position' and that health-care practice should aim to encourage older people to comply with a Western approach. Across the entire spectrum of the reviewed studies, however, the clear message was that a better understanding is needed of ethnic and cultural differences in beliefs and practices at the end-of-life in old age.

Strengths and limitations of qualitative and quantitative approaches

A number of researchers have called for more large quantitative studies in this area to produce generalisable findings (Bolmsjo 2008; George 2002; Kwak and Haley 2005). Policy makers trust epidemiological data and it is argued that small, local studies do not have as much impact. Bolmsjo (2008) argued that the quality of palliative care research has been compromised by concerns about the vulnerability of the participants. Koffman and Higginson (2001) reflected that the recruitment of bereaved relatives in their study had to be done with sensitivity and was responsible for a low response rate. Small samples sometimes reflect particular conditions in geographical or political areas. Gelfand *et al.* (2004) acknowledged such difficulties in their study of the use of hospices by Mexicans in the USA, and similar points were made by Bito *et al.* (2007) and Daaleman *et al.* (2008).

On the other hand, qualitative studies should not be regarded as methodologically the 'poor relation'. When coupled with well-informed and effective ethical strategies, they are entirely appropriate for this sphere of study and necessary for exploring older people's experiences of their worsening health, increased dependency on others, sense of dignity and fears about the future. The review also demonstrated that qualitative studies enhance understanding of culture and ethnicity. In-depth interviewing enabled Mehta (1999), Orpett-Long (2004) and Seymour *et al.* (2007) to identify subtle differences between individuals of single ethnic groups. A combination of qualitative and large quantitative studies can enhance the impact of both methodologies. Blackhall *et al.* (1999), for example, regarded the ethnographic data generated through a sub-sample of their survey as 'indispensable' in making sense of what were apparently contradictory opinions expressed in the larger study. The qualitative research conducted by Gott *et al.* (2008) was specifically designed to add depth and breadth to the large quantitative study of older people with advanced heart disease.

Ethical approaches to the recruitment of participants

Not surprisingly, most of the studies did not gather data directly from older people who knew they were near the end-of-life. One exception, by Schroepfer (2006), interviewed people who had a terminal diagnosis, so was able to use tried and tested methods. Andersson, Hallberg and Edberg (2008) first conducted interviews with people who had a life-threatening disease and/or who received palliative care, and then retrospectively analysed the data for those who died up to six months after the interview. This novel approach to obtaining data from those who were dying but not aware that this was so at the time of the interview circumvented some ethical difficulties. Although a disadvantage was that it reduced the sample to 17 of the 28 people interviewed, the approach merits wider and larger-scale adoption.

TABLE 1. *Cross-cultural studies in the review*

Study	Country	Methodology and samples
Saldov *et al.* 1998. Cultural barriers in oncology: issues in obtaining medical informed consent from Japanese-American elders in Hawaii.	USA	Exploratory-descriptive study of factors in process of obtaining consent from older Japanese oncology patients. Convenience sample of 50 health-care staff, 50% Caucasian, 21% Japanese, 16% mixed race and 14% other. Self-completion survey questionnaire, mixed quantitative and qualitative.
Mehta 1999. Ethnic differences in perceptions, preparations and rituals regarding death in Singapore.	Singapore	Qualitative study of older Singaporeans. Multiple, long interviews with 45 non-institutionalised people aged 70–84. Interviews focused on life stories, attitudes and beliefs, health, family background and levels of community involvement. Three ethnic groups: Chinese, Malay and Indian.
Blackhall *et al.* 1999. Ethnicity and attitudes towards life sustaining technology.	USA	Examination of attitudes of older people from four different ethnic groups in the USA towards foregoing life support. Survey of 800 individuals aged 65+; 200 in each ethnic group. Stratified quota sampling procedure. Interviewers of same ethnic group as respondents. Ethnographic study: 80 respondents selected (standard case sampling) for in-depth interviews.
Bowman and Singer 2001. Chinese seniors' perspectives on end-of-life decisions.	Canada	Qualitative study to examine attitudes of Chinese seniors to end-of-life decisions to improve communication and to develop a culturally appropriate Chinese advance directive document. Semi-structured interviews with 40 'non-assimilated' healthy Chinese elders in Toronto. Data analysed using 'constant comparisons'.
Koffman and Higginson 2001. Accounts of carers' satisfaction with health care at the end-of-life: a comparison of first generation black Caribbean and white patients with advanced disease.	UK	Retrospective survey of the end-of-life experiences of older black Caribbean patients (N=106) and comparison with white (N=110). Structured interviews. Contact with bereaved relatives by letter approximately 10 months after patient's death, plus phone call by interviewers.
Becker 2002. Dying away from home: quandaries of migration for elders in two ethnic groups.	USA	Ten-year qualitative (ethnographic) investigation of ethnic minority elders' experience of chronic illness to examine effect of histories on migrants' views of death. Three in-depth interviews over one year with 126 respondents aged 50+, Cambodian and Filipino Americans who had one or more chronic illness. Reflexive, open-ended questioning to elicit respondent's own interpretation of experience. Interviewed in language of own choice.
Depaola *et al.* 2003. Death anxiety and attitudes towards the elderly among older adults: the role of gender and ethnicity.	USA	Investigation of relationship between death anxiety, attitudes towards older adults and personal anxiety towards one's own ageing. Questionnaire using psychometric, multi-dimensional measure of death anxiety (MFODS). Likert-type scale questions with 198 respondents: 75.8% Caucasian, 24.2% African-American.
Gelfand *et al.* 2004. Issues in hospice utilisation by Mexicans.	USA	Examination of the limited use of hospice programmes by Mexicans in the USA. Eight focus groups with 66 people (60 women) from Mexican communities stratified by length of residence in the USA. Two focus groups with service providers (ten in each group).

TABLE 1. *(Cont.)*

Study	Country	Methodology and samples
Orpett-Long 2004. Cultural scripts for a good death in Japan and the United States: similarities and differences.	Japan, USA	Ethnographic study. Participant observation of end-of-life decisions in the USA and Japan in the 1990s. USA fieldwork: 102 patients and/or family members interviewed at time of hospital admission. Japanese fieldwork: observations and interviews in three hospitals with physicians, nurses, volunteers, 34 seriously ill patients, 23 family caregivers and 21 other professionals.
Seymour *et al.* 2004. Planning for the end-of-life: the views of older people about advance care statements.	UK	Focus group study of 32 older people on advance statements and end-of-life care decisions. Participants recruited from purposively selected community groups in Sheffield, UK. Included those often excluded from research: very old and frail; ethnic minority groups. Recruited by letter or face-to-face invitation at group meetings. Preliminary meetings with participants for reasons of sensitivity and ethical concerns.
Shrank *et al.* 2005. Focus group findings about the influence of culture on communication preferences in end-of-life care.	USA	Exploration of the content and structure of end-of-life discussions and influence of ethnicity and socio-economic status on communication preferences in end-of-life care. Six focus groups, each of 10–12 participants. Three groups non-Hispanic White patients ($N=36$), three African-Americans ($N=34$), aged 50+.
Schroepfer 2006. Mind frames towards dying and factors motivating their adoption by terminally ill elders.	USA	Qualitative study. Face-to-face in-depth interviews with 96 terminally ill elders (aged 50+). Purposive sampling for gender, 'race', education and occupation. 84.4% White, 15.6% Black. Different religious affiliations and health problems. Inductive data analysis.
Winter and Parker 2007. Current health and preferences for life-prolonging treatments: an application of prospect theory to end-of-life decision making.	USA	Cross-sectional study of health and preferences of older people in Philadelphia regarding life-prolonging treatments. 304 community-dwelling people aged 60+. 62.2% White, 36.2% African-American. Used Life Support Preferences Questionnaire (LSPQ). Analysis: repeated measure analysis of co-variance.
Seymour *et al.* 2007. Hospice or home? Expectations of end-of-life care among white and Chinese older people in the UK.	UK	Two linked studies of White and Chinese older adults compared with focus on preferred place of care at end-of-life. Participatory qualitative studies over 24 months. Phase 1 focus groups. Phase 2 interviews with 'vignettes'. 77 White and 92 Chinese people. Multi-lingual researcher employed. Purposive and snowballing sampling recruitment for focus groups.
Bito *et al.* 2007. Acculturation and end-of-life decision making: comparison of Japanese and Japanese-American focus groups.	Japan, USA	Qualitative cross-cultural analysis of changes in preferences for end-of-life care among Japanese people who had migrated to the USA or who lived in Japan. Eighteen focus groups with total of 122 participants. Five groups Japanese living in Japan, four groups Japanese-speaking Japanese Americans, nine English-speaking Japanese Americans.

TABLE 1. *(Cont.)*

Study	Country	Methodology and samples
Johnson, Kuchibhatla and Tulsky 2008. What explains racial differences in the use of advance directives and attitudes towards hospice care?	USA	A cross-sectional survey of a random sample of 205 adults aged 65+ who received primary care to examine the cultural differences between African-Americans and Whites in the use of advance directives and hospice care. Sample stratified by racial background. Questionnaire developed using tried and tested questions. Administered by telephone. Bivariate and multivariate analysis.
Matsui, Braun and Karel 2008. Comparison of end-of-life preferences between Japanese elders in the United States and Japan.	Japan, USA	Examination of immigration effects related to end-of-life preferences through comparison between Japanese people aged 60+ living in Japan and in the USA (Hawaii). Self-administered Japanese-language questionnaire, 123 older people in Hiroshima and Ube in Japan and 180 in Honolulu. A matched subset was created for age and gender, yielding 107 matched pairs. 40% of the Japanese Americans were Christian and 45% Buddhist, compared with 90% Buddhist in Japan.
Ott 2008. Views of African American nursing home residents about living wills.	USA	Exploratory qualitative research using focus group methods in three nursing homes to identify why older African American nursing home residents had not made a living will. Capacity to consent and ability to participate required. Nursing staff assisted identifying eligible people. Audio-recorded. Thematic analysis.
Johnson, Kuchibhatla and Tulsky 2009. Racial differences in self-reported exposure to information about hospice care.	USA	Survey of 200 community-dwelling adults aged 65+. 105 African-Americans and 95 Whites. Participants were read a statement describing hospice care and asked if they head heard of the hospice. Spearman's correlation coefficient used to examine the relationship between response to individual items on the Hospice Beliefs and Attitudes Scale.
Chung and Samson 2009. Does caregiver knowledge matter for hospice enrolment and beyond? Pilot study of minority hospice patients.	USA	Qualitative pilot study to examine the level of knowledge amongst care-givers of minority hospice patients aged 65+ to determine influence on hospice enrolment decisions. Twenty interviews: one patient only, ten family only and nine patient and family combined. Sixteen African-American, three Hispanic, one American Indian. Patterns of attributes derived from content analysis using NVivo Version 2.

TABLE 2. *Studies with a strong cultural focus*

Study	Country	Methodology and samples
Carmel 2001. The will to live: gender differences among elderly persons.	Israel	Investigation of the will to live by evaluating association with wish to prolong life and gender differences. Representative sample of 987 Israeli older persons aged 70+. Structured interviews in own homes. Questionnaire developed to measure will to live and wish to prolong life. Statistical analysis in three steps: descriptive, univariate analysis and multiple logistic regressions.
Fried 2003. Palliative care for patients with end-stage renal failure: reflections from Central Australia.	Australia	Examination of palliative care services for Australian Aboriginal patients with end-stage renal failure in Central Australian Palliative Care Service. Audit comparing rural and remote with urban clientele. Case study example of a 48-year-old Aboriginal woman – a mother and grandmother.
Klinkenberg *et al.* 2004. Preferences in end-of-life care of older persons: after death interviews with proxy respondents.	Netherlands	Population-based study of preferences for end-of-life care with proxies of older people who had died. After death interviews with 270 proxies (167 men and 103 women) of 342 deceased persons aged 59–91, who had been respondents in the Longitudinal Aging Study Amsterdam (LASA). Proxies established after telephone calls to relatives. Face-to-face interview conducted by trained interviewer.
van der Geest 2004. Dying peacefully: considering good death and bad death in Kwahu-Tafo, Ghana.	Ghana	Anthropological study of Kwahu-Tafo society, including research on the social and cultural meanings of growing old and exploration of ideas and experiences of death. Thematic conversations over time with 35 elderly people, including the theme of death. Questionnaires and focus groups with younger and middle-aged people. Observations and taking part in daily lives of elderly people.
Kwok, Twinn and Yan 2007. The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments.	Hong Kong	Examination of knowledge of and attitudes towards life-sustaining treatments among care-givers of older Chinese people with dementia. Face-to-face interviews with 51 care-givers, using tried and tested instruments. Use of scenarios in which life-sustaining treatments might be an option. Statistical analysis of results.
Matsui 2007. Perspectives of elderly people on advance directives in Japan.	Japan	Structured questionnaire study to highlight the perspectives of Japanese elderly people on advance directives and living wills. 565 people aged 65+ attending senior citizen centres in Hiroshima and Ube. Response rate 55.4%. Mean age 75.4. 140 females. Almost all Buddhist.

TABLE 2. *(Cont.)*

Study	Country	Methodology and samples
Pleschberger 2007. Dignity and the challenge of dying in nursing homes: the residents' view.	Austria	An exploratory study on the meaning of dignity with regard to end-of-life issues from the perspective of older nursing home residents. Qualitative grounded theory approach using narrative interviews with 20 residents then theoretical sampling and analysis of scripts using Atlas/ti.
Andersson, Hallberg and Edberg 2008. Old people receiving municipal care, their experiences of what constitutes a good life in the last phase of life: a qualitative study.	Sweden	Qualitative study to investigate ideas about a good life in the last phase of life among 28 people aged 75+ who receive municipal help and care. Participants identified through nurses, interviewed in own home. Content analysis of interviews with 17 participants who died between three days and 6.5 months after the interview conducted by researchers independently of each other then by discussion with each other.
Payne *et al.* 2008. Older Chinese people's views on food: implications for supportive cancer care.	UK	A two-phase, 24-month qualitative research study of the role of food in cancer care. Part of a larger study of older Chinese people in the UK. 92 participants, 78% had lived in UK longer than 20 years. Phase 1 focus groups. Phase 2 interviews, using vignettes.
Gott *et al.* 2008. Older people's views of a good death in heart failure: implications for palliative care provision.	UK	Exploration of older people's views and concerns about dying and whether these are consistent with the prevalent model of the 'good death'. In-depth semi-structured interviews with 40 people (median age 77) with advanced heart failure, selected from sample of 542 people aged 60+ in England from larger study. Subset to add depth and breadth to quantitative data.
Daaleman *et al.* 2008. Spiritual care at the end-of-life in long-term care.	USA	Retrospective study of spiritual care and family ratings of overall care. Interviews of stratified sample of 451 family members of 284 decedents who had lived in residential care/assisted living facilities and nursing homes. Condolence letter and consent form introducing the study sent four weeks after the date of the death. Interviewers followed up six weeks after the death to obtain verbal consent and conduct telephone interview.
Chan and Yau 2009. Death preparation among the ethnic Chinese well-elderly in Singapore: an exploratory study.	Singapore	Qualitative study using semi-structured in-depth interviews to identify factors that influence death preparation with eight Chinese older adults (aged 65) living in Singapore, married or widowed with children, residing with spouse and/or children and four interviews with ethnic Chinese adults whose parents had died after the age of 65. Case scenarios used.

Some studies collected information in particular locations, for example hospitals or nursing homes, which would indicate that the participants were in the last phase of life if not close to death (Kwok, Twinn and Yan 2007; Pleschberger 2007; Orpett-Long 2004; Ott 2008). In some cases, this was coupled with selecting participants with particular health conditions (Andersson, Hallberg and Edberg 2008; Becker 2002; Fried 2003; Gott *et al.* 2008). The participants in the study by Gott *et al.* had advanced heart disease and a similar prognosis to those with breast or prostate cancer but not a terminal diagnosis. Some cross-cultural studies have used focus groups, questionnaires and interviews with relatively healthy older participants to explore attitudes and opinions (Bito *et al.* 2007; Blackhall *et al.* 1999; Bowman and Singer 2001; Depaola *et al.* 2003; Gelfand *et al.* 2004; Johnson, Kuchibhatla and Tulsky 2008; Matsui, Braun and Karel 2008; Seymour *et al.* 2004; Shrank *et al.* 2005). Focus groups are widely used in exploratory research into attitudes and opinions and their value was amply demonstrated in the evidence of how attitudes change in the course of debate and discussion. The focus group study by Bito *et al.* highlighted the effect of acculturation on attitudes.

Focus groups generally require participants to be physically and mentally capable of participation. The study by Seymour *et al.* (2004) was an exception, since a number of their participants were frail and very old – it demonstrated that if sufficient resources are available and a good ethical strategy is developed, people who might otherwise be regarded as unable to participate can be included. Koffman and Higginson (2001), Klinkenberg *et al.* (2004), Kwok, Twinn and Yan (2007) and Daaleman *et al.* (2008) used proxy respondents, mostly bereaved relatives, and adopted a retrospective design, which was seen to have limitations as well as strengths. McPherson and Addington-Hall (2003) concluded that retrospective studies with bereaved relatives produce good evidence for use by service providers, but are less useful in producing evidence of the dying person's experience of pain.

Longitudinal research

The power of some of the smaller studies reviewed was increased by their extended duration and by numerous contacts between researchers and participants: namely Mehta (1999), Becker (2002), Seymour *et al.* (2007) and Payne *et al.* (2008). Becker's ethnographic design, with its particular focus on experiences of migration and its impact on the experience of chronic illness, necessitated such a longitudinal design. Counts and Counts (2004) argued that long-term anthropological field work has the advantages of not only studying the processes of ageing and dying but also revealing how people revise their explanations of socially-traumatic experiences (such as death) – the effects of such experiences change over time. The anthropological studies by Orpett-Long (2004) and van der Geest (2004) provided this kind of in-depth evidence from long-term immersion in the cultural settings that were observed.

Substantive findings

Cultural differences and similarities

Many of the studies reviewed supported Seale and van der Geest's (2004) point that what makes a death 'good' overlaps *between* cultures and differs *within* cultures. Van der Geest (2004) argued that the meaning of a 'peaceful death' in Ghana has striking resemblances to ideas of a good death as understood more broadly. The dynamic nature of cultures was also demonstrated in the findings of the studies by Bito *et al.* (2007) and Matsui, Braun and Karel (2008). Acculturation after migration affects people's attitudes about what is appropriate and desirable at the end-of-life, but attitudes need to be understood also in the context of available health care and other forms of support. Shrank *et al.* (2005) found that ethnicity alone does not determine older people's preferences for communication about end-of-life care. Becker (2002) argued that the experience of migration was as important as the ethnic background of the participants. Taken together, it is evident that culture and ethnicity need to be understood in context, with the clear implication for practice that assumptions should not be made concerning end-of-life care and treatment preferences based on culture and ethnicity alone.

It is evident from a number of studies that the idea of a 'good death' (described by a number of researchers as the 'revivalist script') closely associated with Western culture needs to be reconsidered for its general applicability. There are age-related and cultural factors to consider. Shanmugasundaram, Chapman and O'Connor (2006), Fried (2003), Gelfand *et al.* (2004) and Johnson, Kuchibhatla and Tulsky (2008) argued that the onus is on palliative care providers to ensure that their services are culturally acceptable and appropriate, but there are questions about the extent to which Western-style palliative care can or should be modified. In the UK, Seymour *et al.* (2007) found that Chinese participants were reluctant to use hospices because the association between hospices and death made them 'inauspicious'; they preferred the idea of a hospital death. Gott *et al.* (2008) found that the Western model of a good death is not straightforwardly applicable to older people even in a Western culture, and Winter and Parker (2007) noted that some older people were more likely to choose more aggressive therapies as their health declined.

These findings indicate contradictions within the Western model of a good death, where promoting patient autonomy in decision-making might produce the opposite of a non-technological death. Some studies identified differences by religious adherence and belief concerning a good death. Mehta (1999) and Becker (2002) identified strong views about the rituals involved at the time of death amongst different religious and ethnic groups (*cf.* Chan and Yau 2009). Winter and Parker (2007) found that stronger preferences for life-prolonging treatments were associated with both ethnicity and religiosity, but Orpett-Long (2004) found that 'religious scripts' for a good death associated with cultural background were compatible with other influences. Daaleman *et al.* (2008) found that care home residents of all ethnic backgrounds valued the spiritual care that was provided by staff over that provided by visiting specialist clergy.

Communication concerning end-of-life care

A recurring theme in the studies, and the focus of many, concerned the timing and manner of communication with older people, especially concerning their preferences for end-of-life care. Seymour *et al.* (2007) demonstrated differences between participants' opinions about Advance Directives in general and their perspectives on their own individual situation. Blackhall *et al.* (1999), Shrank *et al.* (2005) and Johnson, Kuchibhatla and Tulsky (2008) examined the apparent reluctance of African-Americans to make Advance Directives and identified problems that could not be explained entirely by cultural differences but needed to be understood in the context of inequalities in power and a lack of trust of health professionals. Some patients wondered whether the offer of palliative care was a way of withdrawing potentially life-saving treatment.

Ott (2008) highlighted that different perceptions can arise about what has or has not been communicated. While African-American nursing home residents in her study clearly stated that they had never been asked about their preferences for end-of-life care, the staff were adamant they had been asked at the time they came to live at the home. The implication of this finding is that communication needs to be done in more effective ways, perhaps a number of times, and that families should be involved. Taken together, these studies challenge the idea that older people's preferences can be established in a straightforward way with each individual making an independent and autonomous decision that should stand once and for all about their preferences for end-of-life treatment. Older people bring to such decision-making a wide range of experiences, capacities, values and relationships. Moreover, views change in the light of experience and reflection, and with changes in health and illness.

Psycho-social factors

A number of studies highlighted the interrelationship of physiological, psychological and social factors at the end-of-life in old age. Several referred to participants' perceptions and fears about dignity and increased dependency, anxieties as to the symptoms they might face and about being a burden. Depaola *et al.* (2003) concluded that fear of death is strongly related to age – the older one gets, the more likely it is that existential fears will come to dominate – and also influenced by the experiences of ageing that participants saw in others. Fear of being a burden was a major theme in the study by Pleschberger (2007), who argued that this cannot be separated from the broader cultural and social values expressed in daily reminders about the cost of caring for dependent older people.

The role of families

Concern for families was another recurring theme. Three main perspectives were identified. Firstly, families should be involved in discussions about end-of-life treatment decisions or even take the lead in these. Secondly, they should not be overburdened with their care and, thirdly, being part of a close family network at the end-of-life represents an essential feature of a good death. Bowman and Singer (2001), Seymour *et al.* (2007) and Bito *et al.* (2007) all highlighted the importance of families in helping older people to arrive at decisions about end-of-life care and treatment. Bowman and Singer (2001) and Kwok, Twinn and Yan (2007) found that the cultural value of filial piety might prevent family members from agreeing to withdrawal of treatment for an elderly relative. The Japanese-Americans in the study by Bito *et al.* (2007) regarded the involvement of families in end-of-life treatment decisions as essential to preserving harmony, even though this might entail decisions that were not in accord with their own wishes and desires. Schroepfer (2006) reported that some participants were concerned about the adverse effect on their families of a physician-assisted death and the association of the death with suicide. Close family relationships were a factor in these older participants' decisions to carry on living. On the other hand, the participants in Seymour *et al.* (2004) raised the possibility that families should have a veto over treatment decisions.

Concern over the potential burden of care on families is a challenge to the policies in many Western countries that favour enabling older people to die in their own homes. In many studies, the participants frequently referred to the competing needs and responsibilities of their adult children. This was exacerbated for the Chinese participants in the study of Seymour *et al.* (2007), who were concerned about the contaminating effects of a death at home. Relationships with family or friends are widely considered to be essential to a good death, and play an important role in helping older people to deal with fears and existential anxieties, as described above, and in providing reassurance that there would be someone who could be trusted to understand their needs. Gelfand *et al.* (2004) highlighted the importance of family involvement for migrant older people with different languages from health providers and because of the need for clear communication. Chinese older people in the UK derived comfort and support from the food provided by their families (Payne *et al.* 2008).

Having family present to accompany the dying person was considered desirable, although Pleschberger (2007) found that to an older person at the end, being alone or not was less important than who was present. Being at peace with others was a crucial feature of a good death in van der Geest's study (2004), although this was expressed more in terms of having the opportunity to draw relationships to a conclusion than actual accompaniment at the moment of death. Becker (2002) highlighted the longing of migrants to return home to familiar surroundings with family and friends at the end. The Aboriginal woman in Fried's (2003) case study chose to go back to her traditional homeland rather than have treatment for renal failure.

Conclusions

This review has identified both strengths and weaknesses in this area of research. In terms of substantive knowledge, the lack of research beyond Western countries is a considerable limitation. The model of a 'good death' that is predominant in the West has been subjected to critical commentary by a number of researchers. At a broader level, an important point made by van der Geest (2004) is that the vastly different patterns of mortality in various parts of the world have major implications for our understanding of older people's experiences of ageing and dying. Several lessons can be drawn from the methodological discussion in this review. It is notable that except for those where proxy respondents were used, almost all the studies excluded people with cognitive impairment from their samples and this remains a significant gap in knowledge and a challenge for researchers to develop ways of managing ethical concerns regarding consent to participate. The need to enhance the impact of research in this field has been identified and a number of strategies might be considered, including designing studies that build on previous work. George (2002) suggested that researchers should develop parallel studies that are comparable in terms of their research questions, methods and analytical approaches. She also argued that the need for longitudinal research is the 'highest priority' (2002: 96), a point also made in other papers in this review. George commented perceptively that most theories of dying are process theories, but that most research methodologies do not enable us to examine and test these. Arguably, we are now at a point at which, in the light of experience, the research questions and methodological and ethical challenges are clearer and provide a good basis for future gerontology research.

References

Publications included in the review are marked with an asterisk. Summary descriptions are provided in Tables 1 and 2.

*Andersson, M., Hallberg, I. R. and Edberg, A.-K. 2008. Old people receiving municipal care, their experiences of what constitutes a good life in the last phase of life: a qualitative study. *International Journal of Nursing Studies*, **45**, 6, 818–28.

*Becker, G. 2002. Dying away from home: quandaries of migration for elders in two ethnic groups. *Journal of Gerontology: Social Sciences*, **57B**, 2, S79–95.

Bern-Klug, M. 2004. The ambiguous dying syndrome. *Health and Social Work*, **29**, 1, 55–65.

*Bito, S., Matsamura, S., Kagawa Singer, M., Meredit, L. S., Fukuhara, S. and Wenger, N. S. 2007. Acculturation and end-of-life decision making: comparison of Japanese and Japanese-American focus groups. *Bioethics*, **21**, 5, 251–62.

*Blackhall, L. J., Frank, G., Murohy, S. T., Michel, V., Palmer, J. M. and Azen, S. P. 1999. Ethnicity and attitudes towards life sustaining technology. *Social Science and Medicine*, **48**, 12, 1779–89.

Bolmsjo, I. 2008. End-of-life care for old people: a review of the literature. *American Journal of Hospice and Palliative Care*, **25**, 4, 328–38.

*Bowman, K. W. and Singer, P. A. 2001. Chinese seniors' perspectives on end-of-life decisions. *Social Science and Medicine*, **53**, 4, 455–64.

Brijnath, B. R. 2008. The legislative and political contexts surrounding dementia care in India. *Ageing & Society*, **28**, 7, 736–25.

*Carmel, S. 2001. The will to live: gender differences among elderly persons. *Social Science and Medicine*, **52**, 6, 949–58.

*Chan, C. K. L. and Yau, M. K. 2009. Death preparation among the ethnic Chinese well-elderly in Singapore: an exploratory study. *Omega*, **60**, 3, 225–39.

*Chung, K. and Samson, L. 2009. Does caregiver knowledge matter for hospice enrolment and beyond? Pilot study of minority hospice patients. *American Journal of Hospice and Palliative Medicine*, **26**, 3, 165–71.

Counts, D. A. and Counts, D. 2004. The good, the bad and the unresolved death in Kaliai. *Social Science and Medicine*, **58**, 5, 887–97.

*Daaleman, T., Williams, C. S., Hamilton, V. L. and Zimmerman, S. 2008. Spiritual care at the end-of-life in long-term care. *Medical Care*, **46**, 1, 85–91.

*Depaola, S., Griffin, M., Young, J. R. and Neimeyer, R. A. 2003. Death anxiety and attitudes toward the elderly among older adults: the role of gender and ethnicity. *Death Studies*, **24**, 4, 335–54.

Dwyer, L.-L., Nordfeldt, L. and Ternestedt, B.-M. 2008. Three nursing home residents speak about meaning at the end-of-life. *Nursing Ethics*, **15**, 1, 97–109.

Flory, J., Young-Xu, Y., Gurol, I., Levinsky, N., Ash, A. and Emanuel, E. 2004. Place of death: US trends since 1980. *Health Affairs*, **23**, 3, 194–200.

*Fried, O. 2003. Palliative care for patients with end-stage renal failure: reflections from Central Australia. *Palliative Medicine*, **17**, 6, 514–59.

Gamliel, T. 2008. Performance versus social invisibility: what can be learned from the wailing culture of old-age Yemenite-Jewish women? *Women's Studies International Forum*, **31**, 3, 209–18.

*Gelfand, D. E., Balcazar, H., Parzuchowski, J. and Lenox, S. 2004. Issues in hospice utilisation by Mexicans. *Journal of Applied Gerontology*, **24**, 1, 3–19.

George, L. K. 2002. Research design in end-of-life research: state of science. *The Gerontologist*, **42**, special issue 3, 99–103.

*Gott, M., Small, N., Barnes, S., Payne, S. and Seamark, D. 2008. Older people's views of a good death in heart failure: implications for palliative care provision. *Social Science and Medicine*, **67**, 7, 1113–21.

Grande, G. E., Addington-Hall, J. M. and Todd, C. 1998. Place of death and access to home care services: are certain patient groups at a disadvantage? *Social Science and Medicine*, **47**, 5, 565–79.

Gu, D., Liu, G., Vlosky, D. A. and Yi, Z. 2007. Factors associated with place of death among the Chinese oldest old. *Journal of Applied Gerontology*, **26**, 1, 34–57.

Hayslip, B. and Peveto, C. 2005. *Cultural Changes in Attitudes Towards Death, Dying and Bereavement.* Springer Publishing Company, New York.

Jeppsson-Grassman, E. and Whitaker, A. 2007. End-of-life and dimensions of civil society: the Church of Sweden in a new geography of death. *Mortality*, **12**, 3, 261–80.

*Johnson, K. S., Kuchibhatla, M. and Tulsky, J. A. 2008. What explains racial differences in the use of advance directives and attitudes towards hospice care? *Journal of the American Geriatrics Society*, **56**, 10, 1953–8.

*Johnson, K. S., Kuchibhatla, M. and Tulsky, J. A. 2009. Racial differences in self-reported exposure to information about hospice care. *Journal of Palliative Medicine*, **12**, 10, 921–7.

King, R. and Vullnetari, J. 2006. Orphan pensioners and migrating grandparents: the impact of mass migration on older people in rural Albania. *Ageing & Society*, **26**, 5, 783–816.

*Klinkenberg, M., Willems, D. L., Onwuteaka Philipsen, B. D., Deeg, D. J. H. and van der Wal, G. 2004. Preferences in end-of-life care of older persons: after death interviews with proxy respondents. *Social Science and Medicine*, **59**, 12, 2467–77.

*Koffman, J. and Higginson, I. J. 2001. Accounts of carers' satisfaction with health care at the end-of-life: a comparison of first generation black Caribbeans and white patients with advanced disease. *Palliative Medicine*, **15**, 4, 337–45.

Kwak, J. and Haley, W. E. 2005. Current research findings on end-of-life decision making among racially/ethnically diverse groups. *The Gerontologist*, **45**, 634–41.

*Kwok, T., Twinn, S. and Yan, E. 2007. The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments. *Journal of Advanced Nursing*, **58**, 3, 256–62.

Leichtentritt, R. D. and Rettig, K. D. 2001. The construction of the good death: a dramaturgy approach. *Journal of Aging Studies*, **15**, 1, 85–103.

Lloyd, L. 2004. Mortality and morality: ageing and the ethics of care. *Ageing & Society*, **24**, 2, 235–56.

Mani, R. K. 2006. End-of-life care in India. *Intensive Care Medicine*, **32**, 7, 1066–8.

*Matsui, M. 2007. Perspectives of elderly people on advance directives in Japan. *Journal of Nursing Scholarship*, **39**, 2, 172–6.

*Matsui, M., Braun, K. L. and Karel, H. 2008. Comparison of end-of-life preferences between Japanese elders in the United States and Japan. *Journal of Transcultural Nursing*, **19**, 2, 167–74.

McGrath, C. L. 2000. Issues influencing the provision of palliative care services to remote Aboriginal communities in the Northern Territory. *Australian Journal of Rural Health*, **8**, 1, 47–51.

McPherson, C. J. and Addington-Hall, J. 2003. Judging the quality of care at the end-of-life: can proxies provide reliable information? *Social Science and Medicine*, **56**, 1, 95–109.

*Mehta, K. 1999. Ethnic differences in perceptions, preparations and rituals regarding death in Singapore. *Omega*, **38**, 4, 255–67.

*Orpett-Long, S. 2004. Cultural scripts for a good death in Japan and the United States: similarities and differences. *Social Science and Medicine*, **58**, 5, 913–28.

*Ott, B. 2008. Views of African American nursing home residents about living wills. *Geriatric Nursing*, **29**, 2, 117–24.

*Payne, S., Seymour, J. E., Chapman, A. and Holloway, M. 2008. Older Chinese people's views on food: implications for supportive cancer care. *Ethnicity and Health*, **13**, 5, 497–514.

*Pleschberger, S. 2007. Dignity and the challenge of dying in nursing homes: the residents' view. *Age and Ageing*, **36**, 2, 197–202.

*Saldov, M., Kakai, H., McLaughlin, L. and Thomas, A. 1998. Cultural barriers in oncology: issues in obtaining medical informed consent from Japanese-American elders in Hawaii. *Journal of Cross-cultural Gerontology*, **13**, 3, 265–79.

*Schroepfer, T. A. 2006. Mind frames towards dying and factors motivating their adoption by terminally ill elders. *Journal of Gerontology: Social Sciences*, **61B**, 3, S129–39.

Seale, C. and van der Geest, S. 2004. Good and bad death: introduction. *Social Science and Medicine*, **58**, 5, 883–5.

*Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S. H. and Clark, D. 2004. Planning for the end-of-life: the views of older people about advance care statements. *Social Science and Medicine*, **59**, 1, 57–68.

*Seymour, J., Payne, S., Chapman, A. and Holloway, M. 2007. Hospice or home? Expectations of end-of-life care among white and Chinese older people in the UK. *Sociology of Health and Illness*, **29**, 6, 872–90.

Shanmugasundaram, S., Chapman, Y. and O'Connor, M. 2006. Development of palliative care in India: an overview. *International Journal of Nursing Practice*, **12**, 4, 241–6.

*Shrank, W., Kutner, J. S., Richardson, T., Mularski, R. A., Fischer, S. and Kagawa-Singer, M. 2005. Focus group findings about the influence of culture on communication preferences in end-of-life care. *Journal of General Internal Medicine*, **20**, 8, 703–9.

Spence, D., Merriman, A. and Binagwaho, A. 2004. Palliative care in Africa and the Caribbean. *PLoS Medicine*, **1**, 1, e5. doi: 10.1371/journal.pmed.0010000511, e5.

Timmermans, S. 2005. Death brokering: constructing culturally appropriate deaths. *Sociology of Health and Illness*, **27**, 7, 993–1013.

*Van der Geest, S. 2004. Dying peacefully: considering good death and bad death in Kwahu-Tafo, Ghana. *Social Science and Medicine*, **58**, 5, 899–911.

Walter, T. 2003. Historical and cultural variants on the good death. *British Medical Journal*, **327**, 7408, 218–20.

Williams, A. and Tumwekwase, G. 2001. Multiple impacts of the HIV/AIDS epidemic on the aged in rural Uganda. *Journal of Cross-cultural Gerontology*, **16**, 3, 221–36.

Williams, W. 1990. *A Protestant Legacy: Attitudes to Death and Illness Among Older Aberdonians*. Clarendon, Oxford.

Wink, P. and Scott, J. 2005. Does religiousness buffer against the fear of death and dying in late adulthood? Findings from a longitudinal study. *Journal of Gerontology: Psychological Sciences*, **60B**, 4, P207–14.

*Winter, L. and Parker, B. 2007. Current health and preferences for life-prolonging treatments: an application of prospect theory to end-of-life decision making. *Social Science and Medicine*, **65**, 8, 1695–707.

Accepted 23 September 2010

Address for correspondence:
Liz Lloyd, School for Policy Studies,
University of Bristol, 8 Priory Road, Bristol BS8 1TZ, UK.

E-mail: liz.lloyd@bristol.ac.uk