Public attitudes to death and dying in the UK: a review of published literature

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ABSTRACT

Background Public attitudes are important in shaping public policy and the political will that determines future service provision. They also help to identify priorities for public education. This paper presents a review and synthesis of published literature on public attitudes to death and dying in the UK from 1990.

Method The approach to the review was systematic and involved searching for published research in five databases combined with reviewing references proposed by experts in the field and following up relevant citations from identified sources. The selected sources were assessed by the review team and analysed using a thematic approach.

Results The review identified 22 sources reporting 19 studies which met our criteria for inclusion in the descriptive analysis. Three descriptive themes were identified: preferences relating to death and dying, attitudes to euthanasia and attitudes to life-sustaining treatments and interventions.

Conclusion The review outcomes challenge widespread assumptions about public attitudes to death and dying and identify the need for more rigorous work to better understand public views on dying and death. Such work is needed if public health services are to meet the expectations and reflect the wishes of individuals in this area in future.

BACKGROUND

The End of Life Care Strategy for England1 notes that there appears to be a lack of public openness about death. This assumed lack of awareness and failure to discuss death as part of normal life may have a number of consequences, including fear of the process of dying, lack of knowledge about how to request and access services, and a lack of awareness and openness between close family members when a person is dying.1 However, there have been limited attempts to bring together the body of evidence on which these claims are based, making conclusions difficult to draw. In addition, an increasing proportion of the population is living longer, becoming frailer and more likely to be affected by chronic and long-term conditions that will require supportive and palliative care interventions prior to death.2 3 In order to plan appropriate services it is important to understand what might influence public attitudes towards death and dying as well as perspectives on the ethical and moral challenges facing those affected by end-of-life care issues. These views are important in determining the kind of services people will want and need at this point in their lives, as well as highlighting some of the challenges associated with an increasing ability to extend and prolong life.4 Knowledge of such views might be further valued as a means of targeting education and policy campaigns to prepare for the substantial public health consequences of changing disease and population profiles.

The case for reviewing the current position of the knowledge base relating to UK attitudes is strong. This paper presents a review and synthesis of published literature on public attitudes to death and dying in the UK. It is recognised that differing healthcare systems internationally may affect how public attitudes are shaped. For this reason we have focused on a national perspective, in this case the UK, to provide a framework within which to summarise the evidence base and make recommendations for future work in this area. The review set out to identify the state of the empirical knowledge base in
this area and identify where further work may be required if we are to meet subsequent demands for appropriate and sensitive care at the end of life.

**AIM**
To identify contemporary public attitudes to death and dying in the UK from a review of published research.

**METHODS**
The review framework employed was systematic, involved a review of both qualitative and quantitative research and employed a descriptive thematic analysis of the selected studies. The review presented here follows on from a broader project which explored worldwide public attitudes to death, dying and bereavement.5

Prior to commencing the literature search the following review objectives were defined.

- To identify contemporary public attitudes to death and dying in the UK from a review of published research.
- To critically evaluate the quality and generalisability of UK research relating to public attitudes to death and dying.
- To examine variability in public attitudes according to age, gender and ethnicity.
- To meet these objectives the following inclusion and exclusion criteria were set.

**Inclusion criteria**
- Reports of research conducted in the UK.
- Reports of research published between January 1990 and August 2011.
- Reports of research that investigated attitudes to death and or dying. For the purposes of the review we defined death and dying as encompassing issues relating to cultural, religious and spiritual beliefs about the care of the dying, place of care, end-of-life decision making, use of life-sustaining treatments, advance care planning, palliative and hospice care, and modes of assisted death.
- Reports of research which accessed the views of members of the public. For the purposes of the review we defined the Public as individuals recruited from the general public not as part of a particular group such as ‘patients’, ‘informal carers’ or other service users.

**Exclusion criteria**
- Reports of research which accessed the views of individuals belonging to specific groups such as doctors, nurses, patients.
- Reports of research that investigated attitudes to bereavement, suicide relating to psychological disturbance, end-of-life care in those under 18 years of age.

**Search strategy**
The following databases were searched: Medline, Embase, Cinahl, British Nursing Index and PsycInfo.

Two sets of searches were developed under the guidance of an information specialist. The first consisted of the search terms relating to the views of the general public (see box 1) and the second consisted of terms relating to death and dying (see box 2). The results of the two searches were combined to provide a list of the sources most likely to be relevant. In addition, we considered references proposed by experts in the field, relevant citations from identified sources and hand searched journals of particular relevance. Results of the searches were managed in Endnote VX4. The process of screening and reviewing the search results is summarised in figure 1. International studies which included data from the UK were included only if UK data were presented separately. All materials were appraised by more than one member of the research team to achieve consistency of approach and ensure consensus about inclusion.

**Data extraction, review and synthesis**
Following retrieval of relevant citations each of the 22 sources were independently examined by at least two of the research team. Extracted data were recorded in table format and key themes were discussed within the team as part of the thematic analysis of the findings.

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**Box 1 Search terms relating to public attitudes**

<table>
<thead>
<tr>
<th>Terms</th>
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<tbody>
<tr>
<td>(“public belief**” or “lay belief” or “general belief” or “public attitude**” or “lay attitude**” or “general attitude**” or “adults attitude**” or “people’s attitude**” or “public experience**” or “lay experience**” or “general experience**” or “public opinion**” or “lay opinion**” or “general opinion**” or “perceptions of people**” or “people’s view**” or “people’s perspective**” or “public view**” or “lay view**” or “general view**” or “public preference**” or “lay preference**” or “general preference**”).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]</td>
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**Box 2 Search terms relating to death and dying**

<table>
<thead>
<tr>
<th>Terms</th>
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<tr>
<td>(“Death and dying” or “End-of-life care” or “End of life care” or “End-of-life decision**” or “End of life decision**” or “End of life situation**” or “Good death” or “Lifesustain treatment**” or “Life-prolong treatment**” or “life-prolonging” or “Assisted dying” or “Assisted death” or “euthanasia” or “Physician-assisted suicide” or “suicide” or “Terminal illness” or “Terminal care” or “supportive care” or “hospice” or “Palliative care” or “Palliative treat**” or “persistent vegetative state” or “life-support” or “DNR” or “Do not resuscitate” or “resuscitat” or “natural death” or “advance care plan**”).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]</td>
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The review identified 22 sources describing 19 studies which met our criteria for inclusion in the descriptive analysis (see table 1). Of the 19 studies, 6 were survey based, 11 utilised interviews or focus groups and two used a mix of a survey and qualitative interviews. Six studies had a wide age range in their sampling frameworks. The majority of the reviewed work was concentrated on older adults with samples ranging from 50 to over 80 years. The majority of the respondents in the study samples were described as white British.

Three over-arching themes were identified from our thematic analysis of the 22 sources: preferences relating to death and dying; attitudes to euthanasia and attitudes to life-sustaining treatments; and interventions. Each theme is presented below.

Preferences relating to death and dying
Sixteen sources reported research which had addressed issues relating to preferences relating to death and dying.6–21 Three of these7 8 15 used a survey-based approach to data collection. One6 used a survey and interviews. The remaining 11 adopted qualitative approaches to data collection through focus groups, interviews or written accounts. One survey7 had a large sample size (n=4117). The qualitative studies had smaller sample sizes (range n=12–77). Most study samples were composed predominantly of older adults (aged 50 and over). Across these studies respondents were generally reporting on how they themselves would wish to be cared for at the end of life and articulated a number of preferences that they considered important as part of good end-of-life care. It appeared these views and attitudes were often shaped by previous death-related experiences.9 10 12 17

Preferences for place of care and death were often moderated by prior experience and concerns about being a burden.7 14 15 17 20 In a study of older people’s attitudes towards death, preparing for death and palliative care15 most respondents expressed a preference for hospice care rather than home but older respondents (75 years+) expressed a preference for hospital care compared with home. Charlton1 reported a preference for home as a place of death (63%) but notes that those individuals in the group who had personal experience of death were not so positive about this option (52%). Gott et al14 identified that while the respondents in their study expressed a preference to be cared for at home at the end of life, this view was moderated by concerns about being a burden and intruding on private space. In a qualitative study, Seymour et al17 identified that older Chinese respondents living in the UK expressed a preference for hospital care.

A number of concerns about dying were identified across all these studies. These included leaving families behind, fear of the unknown, not wanting to be kept alive at all costs, not wanting to die alone, pain control, and the importance of quality of life over length of life when there was no hope of recovery. Concerns about ‘being a burden’ are also present in a number of these studies.6 9 17 19 Arber et al 19 provide a particular perspective on this, noting how the older women in their study were more likely to be concerned about being a ‘burden’ on others during a final illness while the men were more likely to have concerns about quality of life, capacity and independence.

Preparations and planning for death such as will making, funeral planning and thinking about place of death were also a key feature of discussions relating to death and dying. For example, the study by Catt et al12 found that most respondents had made a will. The use of advance statements and advance care planning is examined by Seymour et al13 and Vandrevala et al.11 These studies report that advance statements and advance care planning were understood as a means to support personal integrity and a way of opening up a dialogue about death and dying.

Public attitudes to euthanasia
Eight sources7 8 15 18 22–25 were identified which explored public attitudes to euthanasia. Of these, six were survey based with large sample sizes. Four of these were general surveys about death and dying, which included specific questions on attitudes to euthanasia.7 8 15 25 Three sources analysed data gathered as part of the British Social Attitudes survey.12–24

Levels of support for euthanasia appear relatively stable, rising from 75% in 1984 to 82% in 1994 and then falling to 80% in 2005.22 Results from published studies suggest that people make clear distinctions between the acceptability of assisted dying in different circumstances depending on the nature of a person’s illness and/or who would be involved in the process. Clery et al22 report that levels of public support for voluntary euthanasia carried out by doctors were as high as 80% when asked in relation to a request from ‘a person suffering with an incurable and painful
### Table 1 Table of studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Study aims</th>
<th>Sample</th>
<th>Setting</th>
<th>Method</th>
<th>Relevant findings</th>
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<tbody>
<tr>
<td>Arber et al&lt;sup&gt;19&lt;/sup&gt;</td>
<td>To examine gender differences in attitudes towards the use of life-prolonging medical technologies among older people</td>
<td>69 participants; age range 65–93; 52% women</td>
<td>General practices in southeast England</td>
<td>Qualitative interviews</td>
<td>Older women twice as likely as men to oppose the use of medical technologies to prolong life&lt;br&gt;Women more likely to voice ‘other oriented’ reasons for their opposition, primarily the wish to avoid burdening others&lt;br&gt;Men more likely to express ‘self-oriented’ views</td>
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<tr>
<td>Catt et al&lt;sup&gt;15&lt;/sup&gt;</td>
<td>To determine relationship between age and attitudes to death and preparation for death, and knowledge about and attitudes to cancer and palliative care</td>
<td>256 participants; 129 participants aged 55–74 years, 127 aged 75+; 55% women; 81% white</td>
<td>General practices in London</td>
<td>Structured interviews</td>
<td>Older age group: &lt;br&gt;- more concerned about dying alone†&lt;br&gt;- preference for death in hospital compared with hospice†&lt;br&gt;Younger age group: &lt;br&gt;- more open to discussion about death and dying†&lt;br&gt;- more supportive of euthanasia/PAS†</td>
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<tr>
<td>Charlton&lt;sup&gt;7&lt;/sup&gt;</td>
<td>To survey views of GP attenders about death and dying</td>
<td>4117 respondents; mean age 36.4 years; 70% women</td>
<td>9 general practices in southwest Scotland and 1 semirural/urban practice in England</td>
<td>Survey</td>
<td>63% expressed a preference to die at home&lt;br&gt;When asked what they feared about dying: &lt;br&gt;- 44% stated leaving their families&lt;br&gt;- 24% stated fear of the unknown&lt;br&gt;- 16% stated fear of pain&lt;br&gt;- 3% stated fear of going into hospital&lt;br&gt;- 54% supported PAS and 34% were opposed to it</td>
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<td>Charlton et al&lt;sup&gt;8&lt;/sup&gt;</td>
<td>To explore attitudes to death and dying in the UK, New Zealand and Japan</td>
<td>981 from all countries; 223 from the UK, 81 of whom were members of the general public</td>
<td>UK, New Zealand and Japan</td>
<td>Questionnaire survey</td>
<td>High levels of support expressed for openness and honesty relating to death and dying&lt;br&gt;A majority of the UK general public respondents indicated support for euthanasia and a preference for death at home&lt;br&gt;Worries about death included pain, leaving family and the unknown</td>
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<td>Clarke et al&lt;sup&gt;16&lt;/sup&gt;</td>
<td>To explore older peoples’ concerns about end-of-life care</td>
<td>74 participants; age range 60–88; 67% women</td>
<td>Community groups in North England, South England, Scotland and Wales</td>
<td>Focus groups</td>
<td>Concerns raised included that: &lt;br&gt;- ageism was responsible for poor end of life care&lt;br&gt;- doctors, nurses and other care staff lack motivation and or skills to care for older dying people&lt;br&gt;Many participants were anxious about the process of dying, place of care and who would look after them&lt;br&gt;People perceived that they had little control over these issues</td>
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<td>Clery et al&lt;sup&gt;22&lt;/sup&gt;</td>
<td>To report public views about assisted dying</td>
<td>1700 respondents</td>
<td>UK wide</td>
<td>British Social Attitudes Survey, 2005</td>
<td>People make clear distinctions between the acceptability of assisted dying in different circumstances&lt;br&gt;Certain groups are particularly opposed to euthanasia—especially those with religious beliefs&lt;br&gt;Attitudes to euthanasia have remained remarkably stable over time, given the public debates that have taken place over the last decade</td>
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<td>Daveson et al&lt;sup&gt;20&lt;/sup&gt;</td>
<td>To identify English and German understandings of end-of-life care</td>
<td>30 respondents; 15 from the UK; 15 from Germany; age range 17–81; 60% women</td>
<td>UK and Germany</td>
<td>Interviews</td>
<td>Common themes between UK and Germany included the importance of social and relational dimensions, dynamic decision making comprising uncertainty, a valuing of life’s quality and quantity, and expectations for holistic care involving autonomy, choice, and timely information from trusted professionals</td>
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<td>Donnison and Bryson&lt;sup&gt;23&lt;/sup&gt;</td>
<td>To explore public attitudes to euthanasia</td>
<td>984 respondents</td>
<td>UK wide</td>
<td>British Social Attitudes Survey, 1994</td>
<td>Over 80% support PAS for a person with a painful, incurable and terminal illness Less support for non-physician assisted death or when assisted death is requested by someone with a non-terminal illness</td>
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<td>Field&lt;sup&gt;10&lt;/sup&gt;</td>
<td>To examine commentaries provided by older people who responded to the 1994 Mass Observation Survey directive</td>
<td>54 accounts; age range 65–80; 48% written by women</td>
<td>UK</td>
<td>Secondary qualitative data analysis of written accounts</td>
<td>Evidence of extensive experience of death in childhood and in World War II Respondents more concerned about the manner of their dying than of death itself—alongside continuing desire to live as long as possible in spite of advancing age</td>
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<td><em>Gott et al</em>&lt;sup&gt;14&lt;/sup&gt;</td>
<td>To explore the attitudes of older people towards home as a place of care when dying</td>
<td>32 participants took part in eight focus groups; 45 participants were interviewed; age range &lt;55 to &gt;85; 68% women; 95% white, 4% black</td>
<td>Community groups in Sheffield, UK</td>
<td>Focus groups and interviews</td>
<td>Participants identified that home was more than a physical location, representing familiarity, comfort and the presence of loved ones Participants anticipated that home would be their ideal place of care during dying However various concerns regarding care at home were expressed, such as: • the necessity of having an informal carer • the worry of becoming a ‘burden’ • the prospect of family members witnessing distressing suffering • receiving intimate care from their children • inadequate pain and symptom relief</td>
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<td>Howarth&lt;sup&gt;9&lt;/sup&gt;</td>
<td>To explore perspectives of older people about maintenance of autonomy and independence</td>
<td>72 participants; age range &gt;75</td>
<td>Two contrasting districts of a north London borough</td>
<td>Qualitative interviews</td>
<td>No direct questions about death, dying and bereavement. 58% of interviewees raised these issues spontaneously People’s thoughts about their own death were categorised into four themes: ‘good’ and ‘bad’ death; the extent of control which they might be able to exert over this final status passage; the way in which death could be legitimated or made meaningful; and the question of funeral rituals and the desire to be remembered</td>
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<td>Lloyd-Williams et al&lt;sup&gt;18&lt;/sup&gt;</td>
<td>To explore how older people living in the community perceive issues around death, dying and the end of life</td>
<td>40 participants; age range 80–89; 60% women; 100% white</td>
<td>The Wirral, Merseyside, UK</td>
<td>Qualitative interviews</td>
<td>Issues associated with end of life included fear of how they would die, fear of becoming a burden to others, wanting to prepare for and have a choice with regard to where and when they die and issues relating to assisted dying</td>
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<td>O’Neill et al10</td>
<td>To establish and critically examine societal attitudes to PAS and FAS</td>
<td>Not provided</td>
<td>UK wide</td>
<td>Secondary analysis of data from: 1983, 1984, 1989 and 1994 British Social Attitudes Surveys</td>
<td>Findings demonstrate a slight increase in support for PAS from around 75% to around 84% over the 11-year period in the UK. A much lower level of support (54%) was recorded in relation to FAS. Strength of religious affiliation found to be a significant determinant of opposition to legalisation of both PAS and FAS. Education, income, sex, marital status, longstanding illness and age not significant predictors of attitude.</td>
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<td>Phillips and Woodward11</td>
<td>To explore how healthy older people feel about resuscitation and the decision not to resuscitate</td>
<td>17 participants; one focus group held with people in their 50s the other with people in their 70s</td>
<td>No information given</td>
<td>Focus groups</td>
<td>Younger age, desire to live and good quality of life identified as factors for resuscitation. Younger age group wished to be involved in any decision themselves; the older group said they would not wish to be consulted, citing fear and risk of distress.</td>
</tr>
<tr>
<td>*Seymour et al12</td>
<td>To examine older people’s assessments of the risks and benefits of morphine and terminal sedation in end-of-life care</td>
<td>32 participants; age range 60–87; 72% women; 81% white, 9% black</td>
<td>Community groups in Sheffield, UK</td>
<td>Focus groups</td>
<td>Findings suggest that older peoples’ evaluation of the risks and benefits of morphine administration and terminal sedation depend on moral concerns that are social, contextual and bound up in the desire to protect, care and represent the identity of dying family members.</td>
</tr>
<tr>
<td>*Seymour13</td>
<td>To examine older people’s beliefs and risk perceptions regarding the use of innovative technologies in end-of-life care</td>
<td>32 participants took part in eight focus groups; 45 participants were interviewed; age range &lt;55 to &gt;85; 68% women; 95% white, 4% black</td>
<td>Community groups in Sheffield, UK</td>
<td>Focus groups and interviews</td>
<td>Findings highlight the variety of understandings that older people have about life-prolonging and basic care technologies and the need to deliver end-of-life care in ways which respect understandings about love, comfort, obligation and burden during dying.</td>
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<td>*Seymour et al14</td>
<td>To explore older people’s views about advance statements and the role these might play in end-of-life care decisions</td>
<td>32 participants; age range &lt;60 to 87; 72% women; 81% white, 9% black</td>
<td>Community groups in Sheffield, UK</td>
<td>Focus groups</td>
<td>Advance statements were understood primarily in terms of their potential to aid personal integrity and to help the families of older people by reducing the perceived ‘burden’ of their decision making. Concerns included the perceived link between advance care statements and euthanasia, their future applicability, and the possibility that preferences for care may change. Participants reported worries related to thinking about and discussing death and dying.</td>
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<td>*Seymour et al15</td>
<td>To compare experiences and expectations of end-of-life care between white and Chinese older adults living in the UK</td>
<td>169 participants; age range 50–85+; 70% women; 54% Chinese, 46% white</td>
<td>Community groups and general practices in Sheffield and Manchester, UK</td>
<td>Qualitative focus groups and interviews</td>
<td>Only one-quarter of Chinese respondents had heard of the term ‘hospice’. For these, hospices were regarded as repositories of ‘inauspicious’ care. They instead expressed preference for care in hospital. Among both groups preferences for institutional death seemed to be related to concerns about the demands on the family that may relate to having to manage pain, suffering and the dying body within the home.</td>
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<td>Vandrevala et al&lt;sup&gt;11&lt;/sup&gt;</td>
<td>To examine older people’s perspectives on end-of-life decisions and advance care planning</td>
<td>12 participants; age range 60–79; 50% women</td>
<td>Community groups in southeast England</td>
<td>Qualitative interviews</td>
<td>Older people indicated that they wished to talk with their doctors and family members about end-of-life issues. An emphasis on curative treatment and a desire to avoid causing distress to patients were perceived as reasons why doctors may not talk to patients about end-of-life issues. Fear of burdening family members was identified as a reason why older people may not talk to their families about end-of-life issues.</td>
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<tr>
<td>Vandrevala et al&lt;sup&gt;27&lt;/sup&gt;</td>
<td>To examine the views of healthy older people about end-of-life care decision making, specifically the use of cardiopulmonary resuscitation</td>
<td>48 participants; age range 65–80+; 58% women; 98% white</td>
<td>Community groups in southeast England</td>
<td>Focus groups</td>
<td>Quality of life identified as the central value underlying the dilemma of whether or not to attempt resuscitation Women more likely than men to take perception of burden into account when considering resuscitation.</td>
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<td>Williams&lt;sup&gt;6&lt;/sup&gt;</td>
<td>To complete an in-depth ethnographic and survey-based study of attitudes to death and illness within one community</td>
<td>70 people interviewed; 619 people in survey; age range 60+</td>
<td>Aberdeen, Scotland</td>
<td>Mixed methods study involving a qualitative interview study and a complementary survey</td>
<td>Respondents indicated concepts of ‘good’ death drawn from a variety of cultural and historical influences deeply affected by biographical and experiential influences: some respondents preferred ‘ritual dying’ in which achieving readiness for death was combined with an emphasis on the importance of the reunion of the dying with those close to them. Other respondents expressed a preference for ‘disregarded dying’ which combined the moral expectation of death in old age with the ideal of a quick, unaware death. Third group of respondents exhibited patterns of ‘transitional’ ideas about death, in which elements of ritual and disregarded dying were combined. A minority group expressed a preference for ‘controlled dying’ in which the ordering of one’s own fate was paramount.</td>
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<td>Williams et al&lt;sup&gt;25&lt;/sup&gt;</td>
<td>To elicit the views of the general public on euthanasia and life-sustaining treatments in the face of dementia</td>
<td>725 respondents; age range 14–90; 47% women; 69% white, 7% Asian, 6% black</td>
<td>Stations, shopping centres and GP surgeries across London and southeast England</td>
<td>Quantitative survey</td>
<td>Respondents were more conservative in decisions about others than themselves. Majority supported PAS in severe dementia. Young favoured resuscitation post cardiac arrest more than older people.</td>
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</table>

*Seymour et al<sup>11 21</sup>; Seymour<sup>12</sup> and Gott et al<sup>14</sup> report different aspects of the same study. The Seymour et al 2007 paper compares data from 32 focus group participants (Seymour et al<sup>11 21</sup>; Seymour<sup>12</sup>; Gott et al<sup>14</sup>) with a later study of Chinese older people living in England. †Statistically significant finding. FAS, family-assisted suicide; GP, general practitioner; PAS, physician-assisted suicide.
illness, from which they will die—for example, someone dying of cancer.1

A number of sources22–24 also explored attitudes to non-voluntary euthanasia (ie, when individuals are unable to request euthanasia due to physical or cognitive limitations, such as when in a coma on a life support machine). In the study by Clery et al22 the views of relatives appeared to be a determining factor in peoples’ responses to issues of non-voluntary euthanasia. In a scenario when relatives and doctors were in agreement, 79% of respondents supported euthanasia but this fell to 34% if relatives did not agree with doctors. However, Clery et al22 asked participants to respond to a scenario where the patient had set out their advance preferences for treatment (including refusal) in a living will or advance directive, and 76% of respondents thought that the patient’s wishes should be adhered to even if they were counter to the wishes of close relatives. The study by Williams et al25 of views of the general public on euthanasia and life-sustaining treatments in the face of dementia highlighted that respondents were consistently more conservative in decisions relating to their relatives than for themselves.

Three of the studies22–24 explored social and demographic variables that might be associated with levels of support for euthanasia. Clery et al22 identify that the factor most closely negatively associated with views on euthanasia was frequency of attendance at a religious service. Income,24 gender,23 24 marital status,23 24 longstanding illness24 do not appear to be significant predictors of attitude. However, one study24 identified that education was not a predictor of attitude while another23 suggested that qualifications (arguably a proxy for education) does.

Public attitudes to life-sustaining interventions

With one exception (Williams et al25), studies of public attitudes to euthanasia were based on large-scale quantitative surveys. In contrast, the five studies exploring public attitudes to cardiopulmonary resuscitation (CPR) and/or other life-sustaining treatments in end-of-life care12 19 25–27 were primarily small-scale qualitative pieces and focused on older people’s views and attitudes. These studies identify that issues surrounding quality of life seem to be key to attitudes on life-sustaining interventions.

A number of sources identify gender and ethnic differences in preferences expressed for life-sustaining technologies. For example, Arber et al19 identify that older women were twice as likely as men to oppose the use of medical technologies to prolong life. Women were more likely to voice ‘other oriented’ reasons for their opposition, primarily the wish to avoid burdening others (a similar finding to that reported in Vandrevala et al).27 Men were more likely to express ‘self-oriented’ views such as wishing to ‘live longer’.19 Williams et al25 note that white respondents in their survey were more likely to reject/anticipate refusing life-sustaining treatments than black and Asian respondents.

Seymour12 identified that understandings about decisions to use or withhold/withdraw life-prolonging technologies were poor. Involvement in decision-making was also a feature of other studies examining issues associated with the use of life-sustaining technologies.26 27 Phillips and Woodward26 note that while the younger age group in their study wished to be involved in any decision themselves, the older group said they would not wish to be consulted, citing fear and risk of distress. Vandrevala et al27 identify that respondents recognised a number of dilemmas raised by involving others in decisions about the use of life-sustaining treatment, in particular the challenge to personal autonomy and the burden placed on others who have to make such decisions.

DISCUSSION AND CONCLUSIONS

The quality of the research reviewed was variable. As noted earlier, the majority were small-scale qualitative studies. Studies which use such approaches can provide real insight into the issues under investigation. However, they have limited generalisability to a broader population. A number of the studies which used surveys to capture individual views were poorly described and had limitations associated with their approach to sampling. Surveys are also not well suited to exploring attitudes to complex and indeterminate issues. Probably the most reliable survey-based work arises from the British Social Attitudes Survey. Given the large and diverse sample achieved and the repetitive nature of the survey, it is generally considered to be high-quality reliable data and forms the foundation of our understanding of attitudes to euthanasia within the UK. The majority of studies reviewed here focused on older adults. As a result we have a limited understanding of younger adults’ (under 50) attitudes to death and dying and the ethical and moral challenges associated with a more medicalised and technology-driven healthcare system that they are likely to experience.

The evidence considered in this review indicates that public concerns about death and dying have remained relatively constant over the past 20 years, particularly in relation to attitudes towards euthanasia. The evidence available would suggest that concerns about the nature of dying and being a potential burden to others shape an individual’s attitude to dying and death and in particular their views on preferred place of care during dying and death, euthanasia and the use of life-sustaining treatments. In addition, gender, ethnicity and previous experience of death appear to be influential factors that shape attitudes in this area with a great deal of complexity and heterogeneity in the attitudes, views and perspectives being reported.

This review highlights a number of important findings in relation to public attitudes to death and dying.
First, the nature of the evidence base is inadequate in terms of volume, depth and quality. Second, the evidence available suggests that public attitudes are much more complex and equivocal than can be easily accommodated within current policy in this area. The range of views and associated rationales for preferred place of dying and death, for example, further suggest that widely held assumptions about public attitudes require greater critique and challenge. Current policy cannot be considered evidence based, or to reflect an understanding of, and sensitivity towards, public attitudes to death and dying. End-of-life care is becoming a major public health issue. It raises social, economic and personal challenges which will stretch far into the future. A sound understanding of public attitudes to death and dying is a prerequisite for engaging in a dialogue about death and for appropriately managing future needs, expectations and resourcing of end-of-life care.

The very limited nature of the evidence currently available highlights a real need for more rigorous research better able to capture public views on dying and death and builds a robust evidence base to inform the development of public health services in future.

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REFERENCES
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