Public attitudes to death, dying and bereavement: a systematic synthesis.

Executive summary

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INTRODUCTION

This is a report of a systematic synthesis of national and international literature on public attitudes to death, dying and bereavement. It reports on sources published in the last 20 years. The project was commissioned by the National Council for Palliative Care and the National End of Life Care Programme following publication of the End of Life Strategy for England. In the Strategy it is argued that there persists a lack of public openness about death, which is likely to have a number of negative consequences, including: fear of the process of dying, lack of knowledge about how to request and access services, lack of openness between close family members when a person is dying and isolation of the bereaved.

REVIEW OBJECTIVES

- To review published research based literature and 'grey[1]' literature produced since 1988[2] in the UK[3] and internationally which relates to public attitudes to death, dying and bereavement.

- To examine issues of diversity and similarity within the material across age, culture and ethnicity, social-economic location, gender, sexual orientation and other salient dimensions.

- To scope what public awareness campaigns relating to death, dying and bereavement have occurred in the last 10 years, which organisations led them, what form they took and to collate any published reports or commentaries relating to their outcomes.

- To describe the range and character of initiatives focused on raising public awareness of death, dying and bereavement issues.

- To evaluate the limitations, benefits and other outcomes of initiatives focused on raising public awareness of death, dying and bereavement issues.

- To consult with a network of national and international colleagues relating emergent thinking in modes of raising public awareness in this field.

KEY DEFINITIONS

Here we set out definitions of key terms:

- The Public: research participants recruited by virtue of their membership of a particular community or social group rather than by definition of their status as 'patients', 'informal carers' or other service users; or the intended audience of campaigns to raise awareness.

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[1] Grey literature includes local projects and reports, case studies, narratives, dissertations and theses.
[2] Where there are critical or seminal sources pre 1988, these have been included according to our judgment, particularly to demonstrate changing attitudes over time.
[3] We were subsequently asked by the commissioners of this report to include a section which reports specifically on market research conducted in the UK in the last five years, so that the comparative findings could be used to inform the work of the Dying Matters Coalition, hosted by the National Council for Palliative Care. This material is available in the full report.

- <u>Death, dying and bereavement:</u> encompassing issues relating to cultural, religious and spiritual beliefs about the care of the dying and the bereaved; care of the dead body and funeral rites; processes and models of bereavement and their salience; models of service delivery to those approaching the end of life and options in styles of care, including: end of life decision making, use of life sustaining treatments, advance care planning, palliative and hospice care, and modes of assisted death.

It should be noted that internationally the terms 'palliative care' and 'hospice' have a variety of meanings, which makes clear comparisons challenging.

METHODS

To achieve the agreed review objectives, a search strategy was designed by the research team to find a range of pertinent literature. The review included:

1. Primary and secondary research papers (including case reports) and scholarly reviews published in academic and professional journals in the fields of community and public health, nursing, medicine and social sciences;

2. Summaries of themes from relevant surveys of public attitudes commissioned by various charities and other campaigning bodies;

3. Reports of campaigns undertaken to raise awareness among the public of issues relating to death, dying and bereavement, and

4. Reports of local projects, unpublished theses and policy reports from governmental bodies.

NUMBERS AND TYPES OF SOURCES REVIEWED
- 113 research reports in peer reviewed journals or monographs, relating to 111 studies.
- Unpublished PhD theses completed in the UK (n=6)
- UK 'market research' surveys (n=16) conducted in the last five years and reported in 6 sources;
- A mix of web based, audio-visual and written materials relating to 42 campaigns/campaigning organisations associated with public awareness and attitudes to aspects of death, dying and bereavement.

MAIN FINDINGS

PUBLIC ATTITUDES

METHODOLOGICAL ISSUES
- Most research takes the form of quantitative surveys, offering respondents little opportunity to reflect and discuss their views, or to express contingent or ambivalent views. Most research emerges from resource rich countries in the west.
- Much research is hypothetical, i.e. relating to a fictional case or 'other'. This limits the transferability of findings to real decision making.
- Where research uncovers experiences, these appear to affect attitudes in important ways.

- There is a lack of research about the ways in which lack of information or knowledge influences attitudes.
- Qualitative research (of which there is comparatively little) shows that preferences for end of life care are highly contextual, often contradictory and shift according to circumstances and past experiences.

ASSISTED DYING

- There has been a preponderance of research about views on euthanasia and physician assisted suicide, often funded by 'right to die' movements but also featuring in regularly occurring large scale public opinion polls and peer reviewed research.
- The latter suggest public support for euthanasia has hovered between 60-80% since the mid 1970s on both sides of the Atlantic, with similar levels of support emerging for physician assisted suicide.
- In the United States, swings of more than 30% have been reported in relation to views about assisted dying, depending on the framing of questions. Such nuances are not visible in surveys presenting respondents the option of only a limited range of responses (often a choice between 'yes' or 'no') to short hypothetical scenarios.
- Support is higher in relation to a fictional scenario than for self or for relatives.
- A report of the 2005 British Social Attitude Survey shows that people make clear distinctions between the acceptability of assisted dying in different circumstances, with 80% of respondents agreeing that the law should allow voluntary euthanasia to be carried out by a doctor for someone with a painful, incurable and terminal condition but less than 50% in agreement when the illness is painful, but not terminal. Very few respondents support family assisted suicide.

DISCLOSURE OF TERMINAL PROGNOSIS

- Among some ethnic minority groups there is a perception that open discussion about death may speed up the process of death. Western models of palliative care may not be universally acceptable or appropriate.
- Open disclosure of terminal prognosis is highly valued in the west; this finding is mirrored in the results of a survey of a representative sample of the general public in England, Wales and Scotland conducted in 2009 by NatCen for the 'Dying Matters' coalition, where 88% of respondents favoured open disclosure.
- Southern European and Japanese research suggests variable stances on disclosure exist internationally.

IMPORTANT FACTORS IN END OF LIFE CARE

- There is strong agreement across cultures and socio demographic groups on factors that are important in end of life care and which contribute to the 'good death'. These include: being with friends and family; pain and symptom relief; not being a burden; being listened to and receiving respect.
- Different groups may rank the factors contributing to the good death or good end of life care in slightly different ways. For example, women are more likely to be concerned about not

burdening others during a final illness, while men express more 'self oriented' views, including desires to live longer.

- Death is revealed in several studies to be perceived not as the 'end of life' but rather as part of the natural life cycle, as the 'after life' of the person who has died and a source of continuing meaning in the ongoing life of the bereaved.

PREFERENCES FOR PLACE OF CARE AND DEATH

- 'Dying in place' is a strong preference (whether this is the person's home, a retirement complex or care home), although hedged by worries about burden on care givers and by fears of dying alone.
- A survey of a representative sample of the general public in England, Wales and Scotland conducted in 2009 by NatCen for the 'Dying Matters' coalition found that one third of respondents who expressed a preference to die at home would be willing to do so, even if support was lacking.
- Preference for home death has been found to be associated with younger age, better physical health, poorer mental health and being male. Men have fewer concerns about home death than women. Women tend to report a preference for hospice over hospitals.
- Among older people, preferences for place are subject to change, especially when the person has had experience of caring for someone who died.

PERSPECTIVES ON ADVANCE CARE PLANNING

- A majority of people appear to welcome clinicians who are willing to initiate discussions to inform an advance statement about preferences for care (such as place of care), or an advance directive (AD) about medical treatment at the end of life.
- Some socio demographic characteristics are associated with positive stances towards advance care planning and completion of either ADs or health care proxies: being white, female and highly educated. Most studies also show an association with older age and with personal experience of illness or death.
- The few qualitative studies suggest that people regard advance care planning as highly personal, tightly linked to experiences of illness and death and as an opportunity to consider values and goals for care, for strengthening family relationships, considering spiritual, emotional and social circumstances and preparing for death.
- In spite of positive stances towards open disclosure in terminal illness, few people have talked either to their families or to their doctors about advance care planning issues and few have recorded their wishes.
- Findings of a survey of a representative sample of the general public in England, Wales and Scotland conducted in 2009 by NatCen for the 'Dying Matters' coalition showed that 71% of respondents had not talked about such issues and only 4% had written advance statements. A survey of 501 UK GPs[4] using the same survey tool found that over two thirds of GPs

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[4] The survey of 501 GPs was conducted by ComRes on behalf of The King's Fund, fieldwork was conducted online between 4th - 9th November 2009. Full tables are available at: www.comres.co.uk

(68%) have similarly not discussed the type of care they themselves would like at the end of their lives with their own doctor, family or friends.

- People from minority ethnic groups in their country of residence are less likely to have completed ADs or heath care proxies and more likely to favour family decision making and initiation of discussion by physicians

- Knowledge of a relative's views about willingness to donate organs if brain dead is influential in decisions about authorizing donation after the relative's death.

USING MEDICAL TECHNOLOGY AT THE END OF LIFE

- Studies of beliefs about brain death and views about organ donation reveal some confusion about definitions of 'death' in a brain death scenario.

- Women are consistently found to be less in favour of life-sustaining treatments than men although this difference is less pronounced when confounders are adjusted for.

- Life-sustaining treatments are considered more preferable if the scenario relates to an 'other' rather than the respondent themselves.

- Greater preference for life-sustaining treatments (and conversely, lower support for withdrawal and withholding) is associated with being a member of a black or ethnic minority group a western country and greater religiosity.

- Life-sustaining treatments are considered more futile in situations of mental incapacity rather than in the presence of physical health problems such as cancers with metastatic disease.

CAMPAIGNS AND INITIATIVES TO RAISE PUBLIC AWARENESS OR CHANGE BEHAVIOUR

- We found campaigns spanning 8 areas of activity; three of which can be seen as social 'movements', namely: the hospice movement; the right to die and requested death movement; and the palliative care movement. Four categories of campaign focus on the following topics: 1) death, dying and bereavement; 2) end of life care; 3) older age; 4) consent and organ donation. Finally, there is one category which relates to developing modes of successful campaigning in relation to public awareness and attitudes.

- The selected campaign organizations and projects are based in eight countries, all of which are resource rich, with one exception.

- Some campaigns relate to locally bounded activities, whereas others take the form of cross national collaborations. Many are charities.

- Some of the campaigns take on a primarily advocacy role, whereas others take on a primarily monitoring role, examining and tracking views about their key issue. Some actively lobby political opinion as pressure groups.

- The degree of politicization of the groups/campaigns varies greatly. Some are clearly promoting a particular 'solution' to the problem of death, such as 'palliative care' or 'assisted dying'. Others are more neutral in tone.

- Several of the campaign organizations have similar aims and discourses: for example, the terms: 'mission' ; 'stimulating debate' ; 'promoting conversations' and 'giving voice' feature frequently. Two have the aim of 'transforming cultures'.

- Most provide information, many provide education and training, and some provide services in line with their aims.

- Most campaigns operate by bringing networks of people and organizations into contact with each other, and making strong links to the press and other types of media.

- The most substantial campaign located was the 'Project on Death in America' (PDIA) In the USA; a large scale programme seeking to change the culture and character of dying in America. This was funded by Mr George Soros and located in the Open Society Institute from 1994-2003. It has become an important driver for large-scale innovation in relation to death, dying and bereavement across the state, entrepreneurial and voluntary sectors in the USA, although its discrete outcomes have been difficult to establish at the level of the whole programme of work. It has ongoing African and East European/Russian initiatives.

- The PDIA supported a wide ranging conventional research and practice/ service development programme, a progamme of literary, visual, and performing arts projects to identify and convey meaning in facing illness, disability and death, and community initiatives about bereavement and grief. Many of the arts and community based projects involved thousands of people who reported lasting value. However, the overall impact on public attitudes is necessarily difficult to measure.

- From the outset of the PDIA, raising public awareness was regarded as just as vital as the policy and practice developments needed to address seemingly intractable problems in the care of the dying in the States

- Those campaigns that are part of international collaborations use the vehicle of international conferences to promote discussion and debate and to highlight research which is conducted in line with their subject.

- Many campaigns have gathered public opinion data, but this has been less for evidence of impact and more for generating information to inform the direction and focus of their campaigning activities.

- We located one review, published by the Joseph Rowntree Foundation, which provides a useful characterization of nine factors that can help campaigns be successful, namely: Long term commitment, Ownership of the problem, (Re)Framing the problem and changing social norms, Understanding the target/s, Planning, Positive offerings, Multiple approaches and Research[5].

- The conclusion for the review published by the Joseph Rowntree Foundation notes that complex problems need complex solutions; that culture and norms take time to change; and that research is the foundation of effective action. 'New ideas' such as branding and relationship building are highlighted as important, strategic planning is described as essential and competitive analysis useful. The use of positive appeals, humour and empathy, as well as dire warnings, can work.

- Evidence of evaluative activities demonstrating effectiveness is lacking for most of the campaigns, with some exceptions.

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[5] Stead, M., R. Gordon, I. Holme, C. Moodie, G. Hastings, and K. Angus, *Changing attitudes, knowledge and behaviour. A review of successful initiatives*. 2009, Joseph Rowntree Foundation. p. 110.

'Outcomes' of Campaigns and Initiatives to raise public awareness or change behaviour

Below we summarise the range of 'outcomes' identified from the campaign materials reviewed. It should be noted that outcomes are not usually made explicit in the latter materials; the categories listed here are labels denoted by the team to assist understanding of the variety of activities which might be classed as outcomes. Evidence of outcomes is in many cases difficult to determine since many of the campaigns have neither clearly articulated aims/ objectives nor any apparent concern with 'evaluation' of impact.

Publications and products
- Leaflets or briefing documents
- Academic papers/ books
- Websites
- Films/ documentaries/ arts displays

Subjective outcomes: perceived impact and shared learning
- Effectiveness in terms of perceived support to target audience, where services provided, sometimes qualitatively (a feature of bereavement support campaigns and of the St Christopher's Hospice outreach activities)
- Events to share learning or disseminate lessons learnt for practice
- Comments posted/ written/ communicated by members of the public or who have been involved in activities

Narrative outcomes
- History/ track record of activities and publications: in annual reports or similar
- Overall campaign effectiveness over time: narrative reports with metrics or commissioned books reporting history (e.g. Motor Neurone Disease Association; PDIA)

Metrics
- Numbers of funded, commissioned or published academic articles in area of campaigning
- Additional funds/ grants levered to continue their activities
- Numbers of people who have taken up services/ information; mapping or scoping of partners involved.

Outcomes in form of commissioned evaluations/ research/ arts and humanities projects
- Some have funded research based evaluations examining discrete questions which reflect one aspect of their mission or aims (e.g. NHS End of Life Care Programme; Marie Curie Delivering Choice Programme).
- Some are primarily fund research in line with their overall mission (Joseph Rowntree Foundation; PDIA)

Concluding note on organizing and evaluating campaigns
Organizers of campaigns should note the conceptual framework promoted in the work of Professor Allan Kellehear, where end of life care is seen as an issue of public health. Kellehear advises that public health programmes and activities can be interrogated with regard to the following questions:

1. In what way do they prevent social difficulties around dying death, loss or care
2. In what ways do they seek to minimize harm or difficulties?
3. In what ways can activities be seen as early interventions?
4. In what ways do activities alter or change a setting or an environment?
5. In what ways are the proposed activities participatory?
6. How sustainable will these activities be without your future input?
7. How will you evaluate their success or usefulness?

(adapted from: Kellehear, A (2005) *Compassionate Cities. Public health and end- of- life care*. Routledge, London and New York, p156)

IMPLICATIONS AND LESSONS FOR RAISING PUBLIC AWARENESS

- This review has shown that there is a consensus among the public, across different cultures, on factors contributing to good end of life care. However, most people have not talked about these issues either to family or professionals.

- Most research has been cross sectional and has used quantitative measures to assess attitudes. This provides respondents with little opportunity to reflect during the research process on their views. This is important since taking part in a research study may be a comparatively rare opportunity to think about end of life care issues.

- Qualitative research shows that views and experiences are tightly linked and that views and opinions can shift when people are given the opportunity to think about the factors at play in an end of life care scenario or issue.

- Lack of information about 'options' or issues in end of life care decision making (for example, about how pain and symptoms are managed at the end of life), allied with a strong media emphasis on assisted dying, may account for strongly positive views about assisted dying elicited in cross sectional surveys. Media images of assisted death have been described as engaging with a social discourse of 'heroism' complemented by a media tendency to present other modes of dying as 'intolerable'[6]. The lack or breakdown of other 'narratives' for understanding death (for example, a religious narrative) in many communities means that the assisted dying discourse has had an opportunity to fill a vacuum.

- The lead authors of this report (Seymour and Kennedy) have developed a model of 'peer education' involving older members of the public or advocates for older people, acting as volunteer peer educators in end of life care[7]. We have developed this work recently. Such a model fits with the notion of information and education for end of life care as a public health issue, which can, with the right drivers, become a focus of participatory community action. Citizens' juries are another way of generating community based action in this field.

- The role of volunteers features in a number of campaigns, and could be further examined as a route to community based action in this field.

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[6] McInerney, F., *Heroic frames: discursive constructions around the requested death movement in Australia in the late-1990s.* Social Science & Medicine, 2006. **62**(3): p. 654-667

[7] Seymour JE, Almack K, Bellamy G, Clarke A, Crosbie B, Froggatt K, Gott M, Kennedy S, Sanders C, Welton M . *A peer education programme for end of life care education among older people and their carers.* 2009. Final report submitted to the Burdett Trust for Nursing. **Available on request**.

- Most people report preferences for the provision of information via their family, friends or GP, something highlighted by the survey of a representative sample of the general public in England, Wales and Scotland conducted by NatCen for the Dying Matters Coalition in 2009. This highlights the importance of community based approaches, backed up with the availability of a range of information using multi-media approaches. Television programmes may be valuable.

- Information provision about end of life care needs to reflect the importance of 'family' (however constituted) relationships, rather than making assumptions about the pre eminence of desires for 'autonomy'. Desires for family focused or individual focused decision making can be seen as a continuum, with different socio-demographic and cultural influences affecting a person's location on the latter.

- Learning vicariously from the experiences of others features in many of the campaigns, for example, many of the initiatives promoted by the Project on Death in America (PDIA) have websites in which individuals recount their story. Such an approach is also seen in bereavement support campaigns.

- Arts and humanities initiatives have a role to play in allowing individual and community expression of experiences of illness, death, and grief and to encourage conversation and thoughtful reflection. These types of opportunities may enable the development of a variety of 'narratives' to emerge about death and dying, which are not determined by dominant voices in the media or in large scale social movements. Difficulties in evaluating 'outcome' of such initiatives need to be creatively addressed.

- There are models in existence which can provide a conceptual framework for the development and organization of successful campaigns.