

'Death-confident congregations'? Lessons from the GraveTalk Pilot

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Abstract

GraveTalk was a pilot project conducted in 2013-4 to initiate conversations around death, dying and funerals within the Church of England. The scheme entailed the training of facilitators to set up café-style events within their churches, at which conversations were prompted by the use of a pack of 'conversation cards'.

Data were gathered from three sources to provide an overview of the conduct and effects of the initiative from the perspective of facilitators and participants. The sample was necessarily small and selective, and the results did not lend themselves to quantitative analysis. However, almost all participants reported positively on their experience and analysis of recurrent themes provided some important insights into the way such conversations may be structured. In particular, they cast light on the importance of a carefully-created hospitable environment in creating the conditions for group discussions of this type; and on the role and potential of conversation cards as a facilitative tool.

Keywords: death conversation; religious studies; meaning-making; death attitudes; evaluation; conversation cards

Introduction

The GraveTalk project was initiated by the Archbishops' Council of the Church of England as part of that church's response to the changing sociology of death and dying across UK. On the one hand, an increasing proportion of the population know that they have a terminal diagnosis some weeks, months or years before they die. This increases the opportunities for people to make practical (Wills, ACPs, Care Home planning, funeral planning), social (family gatherings, reconciliations) and personal (memoirs, prayer, reflection) preparation for their death. On the other, people may have fewer skills in approaching the topic of death and mortality than ever before: the improving general health of the population and our social arrangements around dying mean that it is quite common now for a person to undergo their own dying process without having had the opportunity to observe death in detail or accompany another in their dying.

Within this context, so the argument went, the Church of England should have a role to play in encouraging a rich discourse around death. It is a national body which seeks to be available to all people living in England who have need of it; it is engaged with individuals and families over decades and generations, and it has traditionally been the main provider of the rites and rituals to do with death and mortality. But the proportion of total deaths that are marked with a Church of England funeral is dropping (from 46% to 36% between 2000 and 2011 – Archbishops' Council, 2013, p.16); death and mortality are not frequent topics of discussion in Church circles, and there is no reason to believe that congregations generally are any more at ease with the subject than any other sector of the population as a whole.

The reasoning behind 'GraveTalk' was that, if the Church of England is to fulfil its role of accompanying people of all religious commitments and none through the experience of death and funerals, it must seek to develop 'death confident' congregations in which dying and mortality can be discussed relatively openly and easily.

Background: GraveTalk and the denial of death

Traditionally, the national Churches (Church of England, Church in Wales, Church of Scotland, Church of Ireland) have provided a range of services relating to death for the use of the whole population of their respective provinces. The most obvious of these are the provision of funerals and the pastoral and emotional care of the bereaved; but their influence may well be more subtle and far-reaching. For example, at the individual level there is some research suggesting that religious people deal with death differently than their peers in secular society as a whole (Bachner et al, 2011; Neimeyer et al, 2011; Abdollahi, 2012; Dobbs et al, 2012; Vail et al, 2012; Ellis et al, 2013), and may have learnt some coping strategies that could be more widely applied. Furthermore, at the level of society as a whole the recent centenary of the start of the First World War has brought home the churches' contribution both to encouraging young men to accept their own deaths, and remembering their 'sacrifice' in war memorials and public acts of remembrance.

In principle, therefore, the Church of England may be well-placed historically and culturally to host a conversation about death and dying that responds to a need in and is accessible to a wider sector of society. The need for such a conversation is widely observed and frequently restated. At the individual level, the seminal work of Kubler-Ross (1997) has led to widespread acceptance of the therapeutic importance of conversations about death (e.g. LeMay and Wilson, 2007). As well as potentially reducing the existential anxiety of those who are dying, there is an argument for engaging all adults in such conversations, in order to enable advanced planning for care needs, wills and funerals: such planning can have a significant effect upon the experience of death and bereavement both for the dying and their carers (Carr and Khodyakov, 2007; Detering et al, 2010; Dying Matters, 2014).

Furthermore, at the social level Illich (1976) successfully argued that the medicalization of death inevitably led to a loss of a sense of its meaning, of the rituals used to manage it, and the rise of a rhetoric of a 'war' against death. Society cannot be based upon an assumption that death should always be resisted, postponed or avoided (Bauman 1992), and the denial of death and suppression of the fear of death may have far-reaching social effects (Becker, 2007).

In the light of these observations, it may be argued that the Church's commitment to encourage the development of a richer and more honest discourse on death, dying and mortality is important not just for individuals but for the wellbeing of society as a whole. However, for the same reasons, in a largely secular society this task is too important to be left solely to the Church. As well as evaluating the GraveTalk pilot in its own terms, part of the purpose of this paper is to consider whether it may have wider applicability in a range of contexts.

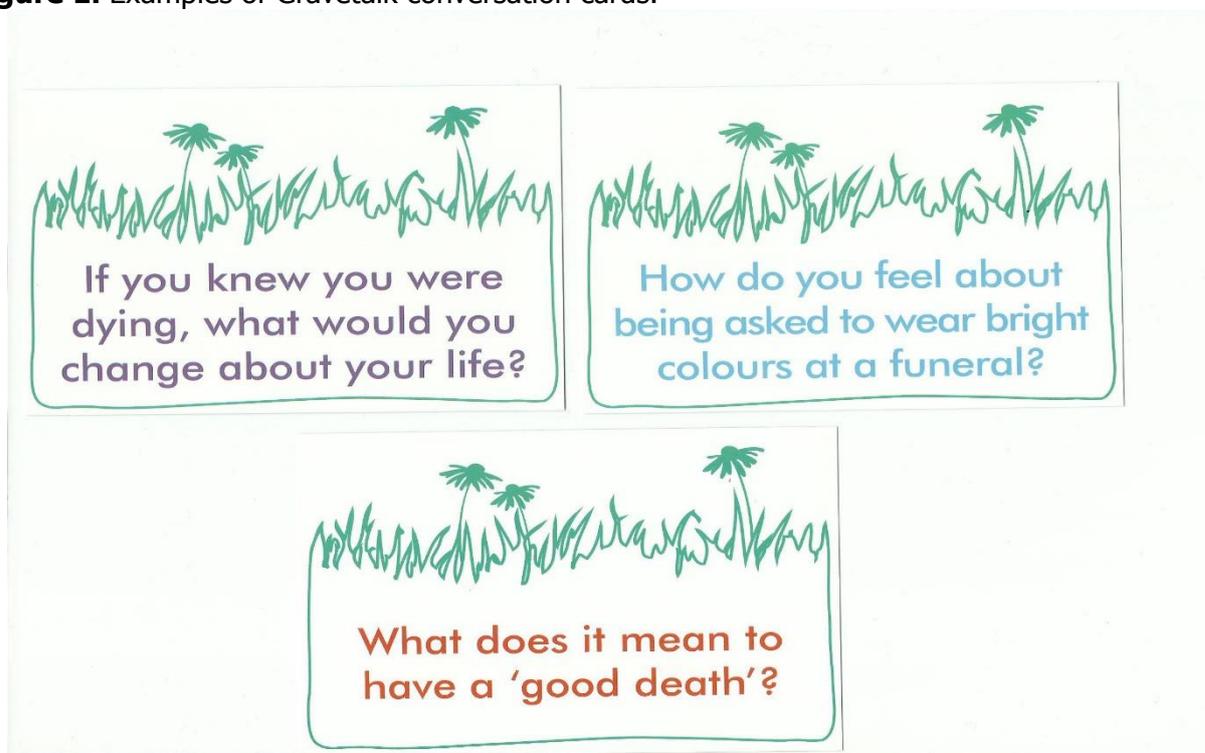
Methods

The purpose of this project was to pilot and evaluate one proposal for enriching the local church's discourse on death, by providing occasions and a structure for conversation on death, dying and funerals. In order to provide an accessible template for conversations about death and dying, the project drew upon two seminal ideas. First, it adapted the idea of a 'Death Café' as a place and occasion set apart for conversations on this subject. The Death Café movement emerged in late 2011 in the USA as a series of 'pop-up cafes': it continues to grow, and at the time of writing claims that there have been 1443 café events to date in 27 countries. The movements stated objective is *'to increase awareness of death with a view to helping people make the most of their (finite) lives'* (<http://deathcafe.com/what/>). As adapted in the GraveTalk project, the key premise is that, by providing thoughtful and thought-through hospitality and an occasion for meeting, attendees are empowered to share their thoughts on a potentially frightening and contentious group of topics.

Secondly, a set of 50 'Conversation Cards' was developed (Figure 1) for the project that could be given to a discussion group to prompt conversation. The basic principle of Conversation Cards is that one of the interlocutors in the conversation begins by turning over a card with a question that all attempt to answer, rather than simply posing one of their own choosing. Cards have been used particularly to develop conversations with children by family counsellors and in a psychotherapeutic context (e.g. <http://www.morethanatoy.com/products/conversation-cards>). Relatively recently, the concept has been developed to include a range of family, educational and health projects (see <http://finkcards.co.uk/>); and in a number of cases cards have been developed specifically to enable conversations related to death and dying. The fundamental hypothesis underlying the use of such cards is that they can usefully initiate and structure conversations when unstructured conversation may be too difficult or threatening. In relation to death and dying, the 'Conversations for Life' programme has developed a card-based game to stimulate discussion about palliative care needs with dying patients and their families (<http://conversationsforlife.co.uk/conversation-game/>) in the UK; a broader-based game has been successfully introduced in the USA, which closely parallels the GraveTalk pack of conversation cards (<http://mygiftofgrace.com/>).

There has been little research into the use of such cards in this context (Menkin 2007, Lankarani-Fahd et al, 2010, Pazart et al, 2011) and what there is tends to focus on the role of 'card-sorting' in individual decision-making in end-of-life care. But the one small study on the role of conversation cards in groups (Ball et al, 2014) suggests the device can reduce inhibitions around the discussion of a difficult subject. The reasons are unclear, but one possibility is that the device of presenting the question on a card means that nobody 'owns' the process, has prior warning, or will be offended if it is rejected.

Figure 1. Examples of Gravetalk conversation cards.

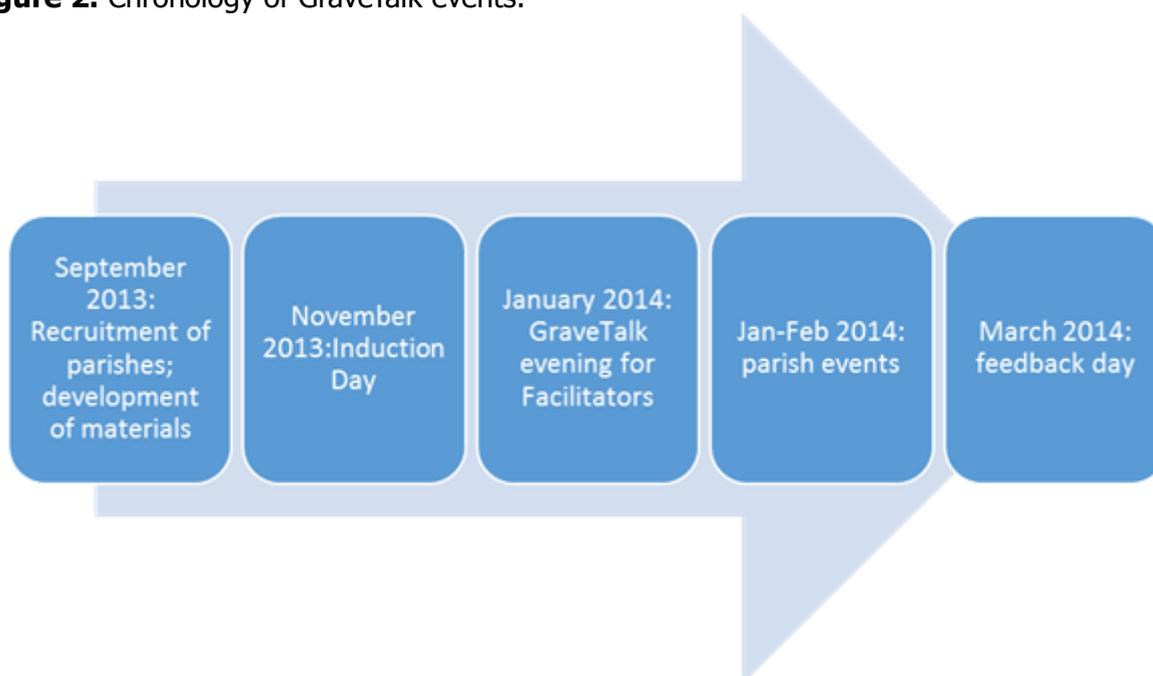


The overall structure of the pilot involved five phases (Figure 2). First, a sample of 25 parishes from the diocese of Lichfield were invited to participate. These were selected to represent a range of geographical, social and economic contexts; in addition, the

congregations which identified with these parishes varied widely in size, age and social composition. Each parish was asked to send at least one, and preferably two, participants to an induction day where the purpose of the project was explained and the key roles of 'facilitator' and host' explained. The facilitators were asked to organise and run at least one such event in their parish. They were given a simple structure for the event which they were encouraged to adopt or modify to suit the local circumstances. After the induction but before running their own events, all facilitators and hosts were invited to a GraveTalk event specifically for them, to give them first-hand experience of the process.

The GraveTalk events were organised in individual parishes by the facilitators at a time and a place decided by them within a three-month window. At the end of that period there was a final Feedback day to enable participants to share experiences and pool insights.

Figure 2. Chronology of GraveTalk events.



Data collection and evaluation

The purpose of the data gathering exercise was to identify strengths and weaknesses in the GraveTalk process with a view to making recommendations to the sponsoring body as to whether, and if so how, GraveTalk may form the basis for a national initiative. Given the scale of the pilot, it was clear that some forms of data collection would not be possible without skewing the results. Thus, for example, the presence of observers or the recording of conversations in small groups would be likely to inhibit some forms of interaction; and in-depth participant interviews were beyond the scope of the project. Instead, we gathered three forms of qualitative data from participants which we expected to give complementary and perhaps convergent information on the project's viability and the participants' experience:

1. The individual facilitator's insights were gathered in a written report for each event. This covered a range of topics from the usefulness of the training and materials, through the appropriateness of the process and setting, to the perceived responses of individuals and the group of attendees as a whole. Apart from initial questions on the numbers and timing of the event, the report took the form of free-text answers to set questions. The two authors individually analysed these for recurrent themes, then collated and further analysed the results under a set of shared headings. The

consensus tally produced is summarised in Table 1 for those themes which occurred independently in five or more reports.

2. Participant reactions were gathered by means of a short (15 mins) telephone interview with one person who had attended each event, generated at random from a list of those who had indicated that they were willing to be contacted. This provided information on the way in which the event was perceived, and how it met the needs and expectations of attendees. Results were analysed independently and thematically by two researchers, who collated their results to generate a list of recurrent themes. Themes which were present in at least five separate responses are collated in Table 2 below.
3. At the feedback day, four Focus Groups of facilitators and hosts who addressed the question, *"From your experience, if some-one else was considering running GraveTalk, what reasons would you give to recommend running GraveTalk, and what advice would you give to address potential problems?"* This provided the opportunity for participants to reflect upon and synthesise their shared experience, to identify shared perceptions which would not necessarily be identifiable in the written facilitator reports. Key themes were extracted from the recordings by two researchers by repeated independent review of the recordings, followed by the creation of a shared narrative of the main findings.

Once these three sources of data had been analysed separately, the findings were combined to form a conspectus which comprises the major part of the 'Conclusions' section below.

Results

Facilitator Report Feedback

Of the facilitator reports, one report was in narrative form and had to be discarded; three combine the findings from two events in the same parish. This gave a total of 28 reports covering 31 events. The suggested format for the GraveTalk event was followed in 24 events, with only minor alterations/adaptions (e.g. to the introduction, leaflets, closing comments) made for the others.

The first part of the facilitator report was structured to provide basic information on the conduct and perceived success of the event. All but one report (no reply to the question), stated that participants found the experience 'valuable'. Facilitators reasoned this was due to the sharing of thoughts and feelings of the topic. Six events reported some participants finding the event unpleasant/distressing, explaining this was due to experience of bereavements or issues that were raised, rather than event content. Nine events reported tears, but felt this was natural due to nature of the topic, rather than evidence of distress. In addition, they reported laughter alongside tears.

"People were surprised at how easily they talked"

"There was a good balance of laughter and deeper discussion on each table"

"No one showed signs of being upset. Several asked, 'How do we initiate a discussion with family?'"

"There were two people that got a bit upset but it was because of the relief they felt about being able to talk freely about experiences they had in the past."

On the basis of these comments, it seems safe to conclude that facilitators generally considered GraveTalk in a very positive light, and that there was little cause for concern that participants would leave the event in distress or with a negative experience. These overall conclusions could be cross-checked and later proved to be borne out in the participant interviews.

As can be seen from Table 1, when asked 'What went well?' and 'What was difficult/disappointing', most comments fell under a few distinct categories. Chief of these were:

- *Hospitality*, including refreshments, layout, planning and seating. This was by far the most frequently-reported positive theme, and the poor quality or planning of refreshments in some cases was also seen as a serious shortcoming.
- *Interpersonal interaction*, primarily the quality of the conversation and the enthusiasm with which participants engaged. Most facilitators commented positively on this and a number expressed surprise at the willingness with which people engaged in the process. In the few cases where the facilitator was disappointed in the response, it was around a particular exercise or facility (such as the option to light a candle).
- *Group composition and management*. A number of facilitators expressed their disappointment at low numbers, and the fact that the group comprised mainly or solely churchgoers. In addition, a number (4) reported difficulty with one of the conversational groups although at this stage did not give detail. This point was further developed in the Focus Groups (see below).
- *Conversation cards* were generally seen as a very useful tool, but with criticisms of some particular questions.

Table 1. Reported aspects of events that went well and were disappointing (items independently reported five times or more).

What went well	What was difficult/disappointing
Quality of conversation (14)	Low numbers (9)
Refreshments (12)	Refreshments/logistics (6)
Quality of interaction (10)	Only Church goers (6)
Layout (9)	Questions wrongly chosen/hard to understand (5)
Enthusiasm/engagement (7)	No time for questions/debrief/follow-up (5)
Planning (6)	
Cards/topics (5)	

Telephone Interview Feedback

One willing participant from each event completed a short structured telephone interview about their experience of GraveTalk, giving a total of 31 interviewees. Only two of the 31 participants reported a negative experience, but this presumably reflects the fact that those with a positive experience are most likely to volunteer to be interviewed. Although participants were invited to offer themselves for interview before the session began, they were not asked to commit themselves (by giving contact details) until the point of departure, and in this sense the sample was clearly self-selecting.

When asked for the reasons behind their positive impression, most participants referred to Participants' overall impression of the events was positive due to the organisation/facilitation, the open atmosphere and the refreshments; they also appreciated the way the 'café space' enabled them to discuss a taboo subject and to share information and insights on death, dying and funerals. These findings broadly reflect the perceptions of the facilitators on the importance of hospitality and the quality of the interpersonal interactions: the persistence with which these two themes are linked suggests a causal connection, with thoughtful hospitality providing the basis on which it becomes possible to broach difficult or taboo subjects. Conversely, the five negative comments typically came from participants who were disappointed that discussion was left to the groups, rather than

led by the facilitators, suggesting that these individuals felt inhibited by what they considered to be negligent hospitality.

When participants were asked what prompted them to attend the event, they answered with one or both of the following: personal contact and commitment such as an invitation, support for organisers or friendship; or a recent or repeated experience of death, either among close relatives or through having a terminal disease. This suggests that there are 'push' and 'pull' factors contributing to the decision to engage in this form of conversation about death, dying and funerals: participants are 'pulled' by their social group, but also may be 'pushed' because the issues have become particularly relevant for them.

"Enjoyed' is probably not the right word, but I enjoyed the event. I found it helpful to talk, even though it was in a church setting, about death. Death isn't something you can normally talk about. The event got you thinking."

"Last year 2 close friends died, and the husband of work colleague died. I have been thinking about death due to these recent events. I went with friends from church. I would normally avoid the subject, but went for the exact reason – 'to talk'. I wanted to know what you do if you find someone dead."

"I am old and thinking about end of life. My wife wouldn't talk about it, but having gone to the event has changed her perception. I had questions about funerals etc. in mind, but the event was much wider than that which has led to a more balanced perspective"

"The cards were really good – they were helpful in starting conversations, thought provoking. Small groups were good, probably easier than large groups but a large group would have allowed more mixing between tables and maybe access other cards."

"Disappointed – there was no input from the organising team. They simply left it to the people in groups to lead. This resulted in people's opinions only being shared."

Table 2. Responses of interviewees (frequency in brackets)

Question 1: Overall impression	Question 2: Reasons for attending	Question 3: What did you enjoy/dislike
Positive: able to discuss a taboo subject (12)	Personal contact: invitation, support for organisers (15)	Positive: atmosphere (24)
Positive: organisation/facilitation (6)	Recent experience of death (9)	Positive: taboo subject (8)
Negative: not enough organisation		Positive: info on funerals etc (6)
		Positive: question cards (6)

Focus groups

The intention behind gathering information from Focus Groups was to explore how participating facilitators reinforced or nuanced each other's perceptions of the GraveTalk events. It will be recalled that facilitators had been encouraged at their training day to consider how to adapt GraveTalk to their local context. Although almost all used some variation of the suggested timetable and structure for the event itself, they more freely adapted the arrangement of the space, hospitality and key roles to suit local circumstances, and in the Focus Groups discussed some of these decisions.

As might be expected by this stage, facilitators stressed the importance of hospitality, organisation and attentiveness to the quality of the interaction in the small groups. However, it emerged that facilitators had adapted their role in different ways. In some cases, facilitators simply oversaw the event, whereas one participant suggested having a facilitator at each table as a 'chairperson'. One of the focus groups concluded that more than one facilitator is necessary, so that should anyone become distressed one facilitator can "go and support her whilst group continue to function" with other facilitators still

present. There was no consensus as to whether the facilitators should be members of the clergy or lay people, with benefits of both discussed. It was suggested that people may "want reassurance of clergy [presence]", but lay people as facilitators may lead to inclusion of wider community.

The importance of good refreshments was reiterated during the focus groups, although it transpired that there was wide variation in the how these were provided. This, perhaps, reiterates the importance of deploying facilitators who are sensitive to local conditions and norms: in all cases hospitality breeds trust, but the appropriate forms of hospitality vary widely.

By comparison with the individual facilitator reports, the importance of group dynamics and good group management was a more prominent theme. Through the focus groups facilitators discussed how important it was to separate those who came together, as well as being mindful of individuals who dominated discussions. One facilitator commented that, due to knowing the participants, they could "engineer" the groups to avoid issues. Another facilitator shared an experience of having to sit with one group as they were not letting one participant who had learning difficulties contribute to the conversation.

The 'Conversation cards' device was widely appreciated as it provided the necessary structure for a conversation which might otherwise be difficult to initiate. There was extensive detailed discussion of individual cards in order to inform the revised edition, but it falls outside the scope of this paper.

Finally, a theme which had appeared in both the facilitators' reports and telephone interviews was highlighted here: the importance of setting aside time for feedback at the end, as "we had lots of folk who wanted to sit down and discuss".

Discussion and conclusions

The GraveTalk project pilot was a small enterprise, limited in both generalizability and scope. In interpreting the data, it needs to be remembered that the parishes and groups of Churches that volunteered were a self-selecting sample, who might be expected therefore to respond positively to the challenge; and that at this stage no attempt was made to extend GraveTalk to the wider community. The 'user voice' from each event was represented by only one interviewee, who was again largely self-selecting, and the interview data (while consistent) do not show the necessary signs of 'saturation': in other words, further interviews would yield further insights.

Reviewing the data as a whole there can be little doubt that, for most participants consulted, GraveTalk was welcome and useful: for many, it addressed a need to talk about death and dying which was not being fulfilled elsewhere and some reported a deepening of their interpersonal relationships and/or a reduction in their anxiety as among the main benefits. It seems equally clear that the basic strategy, of training Facilitators and Hosts to stage an event through an induction day, providing them with a model but then encouraging them to adapt it, proved valuable as a way of both providing a supportive structure and leaving enough to individual discretion to allow the Facilitators and Hosts to 'own' the process. Finally, the primary tool supplied, the Conversation Cards, seems to have made a major contribution to the success of the project.

In addition, the data have yielded some useful insights into the potential role of structured conversations about death, dying and mortality which may have wider applicability to the currently under-researched 'death café' movement. In particular, the following themes emerge from the data which appear to reinforce each other:

1. *The importance of hospitality* as a set of gestures which collectively communicate the message that the event is being competently and thoughtfully managed; that participants' needs have been anticipated; and that the context is therefore a relatively 'safe' one for conversations on a challenging topic. One of the important

aspects of hospitality as understood here is the display of sensitivity entailed in adaptation to local context, adjusting the timing, location and semiotics of the event in response to local needs.

2. *Personal and Interpersonal dynamics* both within and beyond the boundaries of the event itself. Positively, their role is detectable in the fact that a large proportion of participants attended through personal contacts or loyalties; and in the value participants placed upon the quality of the group discussions. Less positively, facilitators reported on difficulties with overly-assertive individuals; and on the difficulties of separating couples who had arrived together. 'Personal dynamics' are manifest in the observation that a number of participants attended because the subject had recently become particularly relevant to them because of a terminal diagnosis or bereavement. This serves as an important reminder that, however general the event may appear, for some participants it will have a pointed and immediate significance. A practical response to this was offered by one of the Focus Groups with the suggestion that time be set aside at the end for a 'debrief'.
3. *The role of Conversation cards*. There was general appreciation of the value of a device of this sort in order to initiate and steer the conversation in individual groups, although particular cards were rejected by some as misleading or unhelpful. The principle of using conversation cards in this way seems sound, although further research and experimentation would be valuable in order to cast light on their actual role in practice and their most appropriate use.

On the basis of these findings, the sponsors of the research concluded that the GraveTalk structure could, with modifications, form the basis of a national programme within the Church of England. But there was nothing in the data that we gathered for the evaluation which implied that any specifically religious context was required as a condition of a successful event. Although the usefulness of the event appears to depend on a level of common interest, mutual trust and a network of personal contacts, these may equally be found in a range of other situations such as elderly day care, schools and wellbeing groups. Given these findings, it is reasonable to speculate that, GraveTalk could be usefully adapted to a range of such situations.

Ethics

Ethical approval was sought and obtained from the Faculty Ethics Committee, Faculty of Health Sciences, Staffordshire University in conformity with the WMA Declaration of Helsinki 1964-2013. Full details may be obtained by application to the authors.

References

- Archbishops' Council (2013) *Statistics for Mission 2011*, London: Archbishops' Council.
- Bachner, YG, O'Rourke N & Carmel S (2011) Fear of death, mortality communication, and psychological distress among secular and religiously observant family caregivers of terminal cancer patients, *Death Studies*, vol.35, no.2, pp.163-187.
- Ball GD, Farnesi BC, Newton AS, Holt NL, Geller J, Sharma AM, et al (2013) Join the Conversation! The Development and Preliminary Application of Conversation Cards in Pediatric Weight Management, *Journal of Nutrition Education and Behavior*, vol.45, no.5, pp.476-478.
- Bauman Z (1992) *Mortality, immortality and other life strategies*, Oxford: Polity.
- Becker E (2007) *The Denial of Death*, New York: Simon & Schuster [1st Edition 1974].

Carr D & Khodyakov D (2007) End-of-life health care planning among young-old adults: An assessment of psychosocial influences, *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, vol.62, no.2, pp.S135-S141.

Detering KM, Hancock AD, Reade MC & Silvester W (2010) The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *British Medical Journal*, 340, doi: <http://dx.doi.org/10.1136/bmj.c1345>.

Dobbs D, Emmett CP, Hammarth A & Daaleman TP (2012) Religiosity and death attitudes and engagement of advance care planning among chronically ill older adults, *Research on Aging*, vol.34, no.2, pp.113-130.

Dying Matters (2014) <http://www.dyingmatters.org/> (last accessed 6th January 2015)

Ellis L, Wahab EA & Ratnasingan M (2013) Religiosity and fear of death: a three-nation comparison, *Mental Health, Religion & Culture*, vol.16, no.2, pp.179-199.

Field C (2012) 'Listening to England', obtainable from <http://www.brin.ac.uk/news/2012/listening-to-england/> (last accessed 19th March 2014).

Howarth G (2007) *Death and dying: A sociological introduction*, Polity.

Illich I (1976) *Limits to medicine: medical nemesis: the expropriation of health*, London: Marion Boyars.

Kubler-Ross E (1997) *On Death and Dying*, New York: Simon & Schuster.

Lankarani-Fard A, Knapp H, Lorenz KA, Golden JF, Taylor A, Feld JE & Asch SM (2010) Feasibility of discussing end-of-life care goals with inpatients using a structured, conversational approach: the go wish card game, *Journal of Pain and Symptom Management*, vol.39, no.4, pp.637-643.

Menkin ES (2007) Go Wish: a tool for end-of-life care conversations, *Journal of Palliative Medicine*, vol.10, no.2, pp.297-303.

Neimeyer RA, Currier JM, Coleman R, Tomer A & Samuel E (2011) Confronting suffering and death at the end of life: the impact of religiosity, psychosocial factors, and life regret among hospice patients, *Death Studies*, vol.35, no.9, pp.777-800.

Pazart L, Vidal C, Chalon DF, Gauthier S, Schepens F, Cretin E, et al (2011) "Card sorting": a tool for research in ethics on treatment decision-making at the end of life in Alzheimer patients with a life threatening complication, *BMC Palliative Care*, vol.10, no.1, pp.4.

Vail KE, Arndt J & Abdollahi A (2012) Exploring the existential function of religion and supernatural agent beliefs among Christians, Muslims, Atheists, and Agnostics, *Personality and Social Psychology Bulletin*, vol.38, no.10, pp.1288-1300.