



Palliative Care
Managed Clinical
Network



ADDRESSING THE GREAT TABOO *of talking about death and dying*

Evaluating the first pilot of a structured conversation

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ADDRESSING THE GREAT TABOO:

Evaluating the first pilot

INTRODUCTION

The majority of people in Scotland (70%) think that as a society we do not discuss death and dying enough (SPPC, 2003). This cultural resistance can contribute to poor communication when planning of end of life care (Scottish Government, 2008). To ensure that health care professionals have the skills and confidence to care for anyone nearing the end of life, a brief session was designed to address the great taboo of talking about death and dying. The national survey tells us this is what the general public wants us to do.

The pilot was designed to enable people to explore their current knowledge and apply some of the theory surrounding loss and grief. Individual support was available in case anyone became upset during the session.

METHODS

Each session was structured around a presentation on End of Life care. Participants were taken through a series of questions to prompt group discussion. Each question built upon the previous one to accumulate a shared understanding of the issues and encourage a level of comfort with the subject matter. Participants recorded their views on flipcharts and completed feedback sheets (Appendix 1). In addition the participants were observed during the session so that their response could be assessed to check any distress created by the content. Observations were recorded on a structured proforma (Appendix 2).

The evaluation gathered the following data:

- Participant responses to the questions posed during the session
- Completed participant feedback sheets
- Observer notes on structured proformas
- Number of people seeking individual support after the session

RESULTS

The first pilot site was a care home in South Lanarkshire and 36 people participated. Of the 34 who signed the attendance sheet, 3 were student nurses, 12 care assistant/support workers, 4 staff nurses, 1 care home liaison nurse, 2 managers, 1 maintenance staff member, 1 kitchen assistant, 1 domestic, 1 occupational therapist, 1 administrator, 2 visitors, 1 retired person and 4 others. The pilot comprised two sessions on the same day, one in the morning the other in the afternoon.

a] Participant responses to the questions posed

Responses recorded on flipcharts at each table are shown in Table 1. There was considerable similarity between each table and the morning and afternoon sessions, so the flipchart contents have been amalgamated into a single table.

Table 1 – Participants’ responses during the session

	Pre Health Service (1948)	What happens now?
Where the majority of people die	At home, more acceptable Asylums/sanatoriums/ mental hospitals Churches (made provision for hopeless and destitute – St Vincent de Paul) Poor house People couldn’t afford treatment Convents/Charities – nursed by nuns In pain In silence In war	More people dying in hospital Pain free Majority of participants chose home to end their life, when asked. If support mechanisms there – people choose home to die Personal choices – ‘Everybody Different’
Caring for them in their last illness	Neighbours/ neighbours helped out Family looked after relatives Local doctors War medics Friends Nurses Volunteers – charity Nuns	Everybody is entitled to healthcare (no class divide) Family Carers Provision for end of life care – Care homes, hospice, hospital, GPs, health centres, district nurses
Taking care of last offices	Family Friends Church people ‘Worthy woman’	
Local funeral customs	Doctors declared a death Home or church – buried next day Wakes within the home Body back to house/ service in house Gravediggers – family/local men/ community dug graves for the deceased. This helped with grieving/ closure (good or bad) by being with them - support. Undertakers Minister attending Men only No women at graveside till flowers laid Paupers grave	Death certificate - law Funeral directors plan funerals Legal aspects Health & safety Cost
Bereavement support	Family/friends Nuns Soldiers Nurses Neighbours, communities, prayers/beliefs, cups of tea, faith Charities Priests/ministers – people together offering support. People were religious, more so then.	Family/friends support – not as close Family further detached from care physically De-personalized – loss of ‘community spirit’, ‘cold’, ‘clinical’, family have little input at times at home Community spirit gone and everyone busy working Expectations different

Table 1 shows that the participants had a fairly good understanding of the difference that society has witnessed in the processes surrounding death since the inception of the National Health Service (NHS).

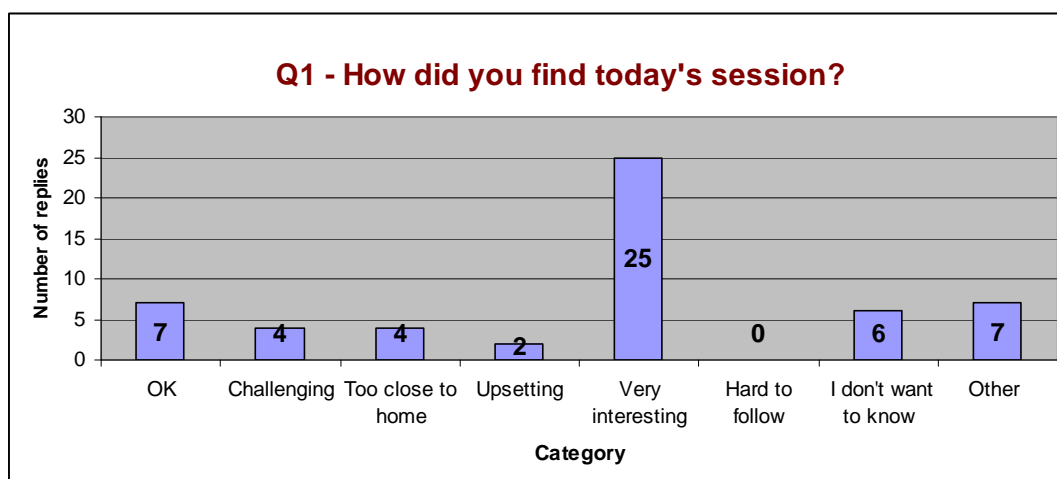
b] Participant feedback sheets

At the end of each session, all participants were asked to say what they thought of it, using the proforma in Appendix 1. A total of 34 completed feedback sheets were returned and since the results were not obviously different between the morning and afternoon, they have been combined.

b.1] Views on the session

People were asked to tick as many of the response options as applied to them (Figure 1).

Figure 1 – Participants' views on the sessions



The seven 'other,' mainly positive comments were:

'Made you think'

'Thought provoking'

'Reinforced my thoughts and wishes for my death and planning for it and sharing information with family'

'Felt at ease with the discussions we had. Found the information interesting.'

'Although light-hearted, always personal.'

'I found it difficult to see the point'

'Educational'

These responses show that whilst the majority of participants engaged positively with the material presented and the discussions (found it 'very interesting'), others were less positive (felt it was 'OK'), and some admitted to a degree of unease (found it 'challenging' or they 'didn't want to know'). Since all but three people ticked at least one of the more positive responses ('very interesting' or 'OK') as well as some of the negatives ('I don't want to know' or 'challenging') the results show that views on the sessions were mixed. One person only ticked negative responses ('upsetting' and 'too close to home') and another two did not tick any.

b.2] Any difficulties encountered during the session

When asked if they found anything difficult during the session, 32 participants did not but two did. An additional comment from one of those who had encountered difficulties said they found it difficult 'talking about family death.'

b.3] Further learning requested

Participants were asked to tick as many of the topics listed that they would like to learn more about (Table 2).

Table 2 – Topics participants wished to learn more about

Topic	No.
How to introduce the subject of death and dying	11
How to talk to patients about death and dying	19
Loss, grief and bereavement	14
Advanced communication skills	12
Other *	1

* Coping mechanisms for staff involved

Table 2 shows that the most popular request was for input on talking to patients about death and dying, although there was a strong appetite for all of the topics listed. More than two thirds (n=23) of the respondents ticked more than one topic suggesting they strongly identified with the need for more training. If it was possible to combine how to talk to patients about death and dying with introducing the subject or loss, grief and bereavement, this would meet the needs of two thirds of the group.

b.4] Is there anything else you want to say about today's session?

Many people made use of the space at the bottom of the feedback sheet to add extra comments (Table 3).

Table 3 – Additional comments about the sessions

	No.	
Enjoyment	7	I enjoyed reflecting on how people dealt with the dying before the NHS and how some traditions still take place I enjoyed the parts that gave a bit about the history of a funeral and traditions that have been in the past Enjoyable despite the topic Really enjoyed training session Really enjoyed the session, easy to listen to, easy to follow Enjoyed discussions with staff members and families Glad I came
Explanation/information	7	Very good introduction to topic. Thought provoking Very helpful - gave a new perspective This was very informative and glad that I participated in it. Thanks! Very good - explained things more clearly Very helpful, very informative, shared how people deal with death/loss Very interesting, feel like I have learnt a lot from this session It was very interesting and helped me to get some knowledge
Method/content	10	Good discussion method very helpful The session was very well presented It is good to get people talking Very well delivered Would have liked it to have lasted longer and discuss some of the other topics listed I could learn more about Reinforced two-day training I had in St Andrews Hospice in 2010 Removes the fear related to death - it can be discussed in a light-hearted way, doesn't need to be a serious and upsetting conversation Important topic of discussion very relevant in care homes like this Gave me some thoughts about funeral arrangements The reason for this course is unclear
Affirmation	1	I found today's sessions very good and helpful as most of it I am doing. Know that I am doing it right
Diversity	1	Each and everyone have their own personal point of view

Table 3 shows that 25 people took the time to add extra comments about the sessions (one added two comments) and 24 of these were positive. Only one person noted that they were unclear about the reason for the session. Both the content and method of delivery were viewed positively, although some expressed surprise at having enjoyed the topic.

c] Observations during the sessions

Two observers completed proformas in the morning and three in the afternoon. The observations were similar in both sessions, so the responses have been combined.

c.1] Participant reactions

The different reactions that were observed are listed in Table 4.

Table 4 – Participant reactions during the session

Initial reactions	All groups gave a positive response to opening discussion with animated murmur in the room – all gave some answers Initial concerns ‘I might cry.’ Became relaxed
Level of interest	Many listening intently Generally interested and willing to engage
Surprise	Some startled, surprised, nonplussed Surprise at some of the historical information
Anxieties/ comfort	Anxieties about dying at home because of memories left with children One participant appeared uncomfortable

Table 4 shows that the overt emotional responses to the session were mixed, even at the start. Some were initially concerned, whilst others responded positively to the opening discussion. The majority appeared interested, with elements of surprise, but there was also a level of anxiety and discomfort for a few people, at least at the start.

c.2] Level of engagement in discussions

Observations around level of engagement during the session are collated in Table 5.

Table 5 – Participant engagement in discussions

Initial engagement	People quieter at first, noise level increased over session Varied to begin with – some looked bit confused, some laughter All engaged after first half an hour Initial question resulted in all groups giving same answer
Ongoing engagement	Variable – frequent episodes of laughter which can suggest embarrassment but in this case seemed very genuine Mixed views about discussion around own death and not having that discussion
Change in level	Further into the meeting volume levels around debate points/ questions went up and all appeared to speak of same points Two relatives – not enjoying but joined in by 3 rd question One staff member not engaged (same table as two relatives above) with chair back from table but moved chair in after half an hour
Non-engagement	Some not engaging fully – BME difficulty, one lady, one care worker All except one were fully engaged
Noise levels	Good buzz – some tables more than others Some more quiet than others One table more lively than others – all staff, one relative (quieter) Some voices carrying more and dominating a bit
Possible barriers	Cultural differences were openly spoken about/differences explored both from gender and ethnicity perspectives

Table 5 shows that initial levels of engagement were varied, most people being initially a bit quiet, others looking confused but with some laughter as well. The noise level increased during the sessions as people began to join in more, but one person remained unengaged throughout. There were noticeable differences that could be construed as barriers to engagement, both in terms of gender and ethnicity.

c.3] Any noticeable distress

There was a concern when the sessions were designed that the content could cause considerable distress amongst participants due to their own circumstances e.g. recent bereavement, sticking at one point in the bereavement cycle. For this reason, observers specifically looked for any signs of distress in the participants (Table 6).

Table 6 – Any distress observed in participants

No distress	Not noticed any Some questioning faces, no noticeable distress
Enjoyment	Happy, smiling, enjoying it Laughing and thoughtful Quite a bit of laughter, smiles
Change in level	At the beginning participants were noticeably nervous/tentative, this eased as talk progressed except for one female member
Finance	Not impressed about costing of own funeral

Apart from one participant who seemed to remain nervous/tentative, Table 6 shows that there was no apparent level of distress during the sessions. There was a level of negativity around costing of own funeral, but this was not classed as distress.

c.4] Any other observations of note

Other observations of note are outlined in Table 7.

Table 7 – Other observations of note

Language/terminology	Sometimes difficult to get participation – may be due to poor language skills and lack of understanding of terms used
Ethnicity/gender	There were participants from ethnic minorities Three people from Black and Minority Ethnic communities did not know UK pre-NHS history – told ok to use own cultural experience Only two males present, clear cultural and age differences between them Females – a broad age range
Participant input	Lot of talking, less writing Some very good suggestions – effect and use of alcohol Some participants seemed uncertain to state that they had learned from the course
Explaining non-engagement	One participant not wanting to plan for death, not wanting to upset dad and not already thought what they want at end of own life. Two participants left early – end of shift

Table 7 shows that a range of people of different ages, genders and ethnic backgrounds participated in the sessions. Although the presentation was designed to be understood by everyone, it appeared that some encountered a little difficulty due to their ethnic background (no knowledge of the UK before the NHS) or level of comfort talking about the subject matter (may be due to poor language skills). It was felt that people were doing a lot more talking than writing, which may mean that the flipchart notes were less comprehensive than they might have been. Also, although some uncertainty was observed about people saying what they had learned from the

sessions, it was clear that many of the participants had a lot to contribute to others' learning. One person was not happy about planning for their own death because it might upset their parent.

c.5] Asking participants where they wish to die

People were also asked at the end of the session whether they wanted to die at home or in hospital (Table 8).

Table 8 – Where participants said they wished to die

	Want to die at home	Want to die in hospital or hospice
Morning session	18	2
Afternoon session	9	4

Table 8 shows that the majority of participants said they wanted to die at home.

d] Participants seeking individual support after session

Additional support was available from the session presenter and two counsellors and everyone was invited to approach them at the end if they wished to talk anything over. Only one person made use of this support.

DISCUSSION

This short session was designed to address the taboo of talking about death and dying. This first pilot was carefully evaluated because it had not been tried before and there were concerns that some participants may be distressed by the content. The observation results show that the majority of participants were initially a little unsure and quieter, but that the noise level rose as the session went on. A few people were slower than others to join in, but only one did not do so over time. Those from different ethnic backgrounds struggled with UK history before the NHS, but felt more comfortable when it was clarified they should contribute on the basis of their own culture. The one person who did not engage much had missed the beginning of the session, therefore did not know why he was there.

Participant responses during the session show the audience knew about the topic. This is helpful for peer learning and it is likely that expertise is even greater than recorded since there was more talking than writing much of the time. This is not a criticism since the session was designed to encourage people to talk.

Feedback from the end of the session showed that most people had mixed reactions, finding it both very interesting and challenging or they didn't want to know. Quite a few commented that they had found it enjoyable despite the topic, which chimes with the observations. Two people found some of the content difficult, and the one who explained this said it related to family death. A total of 26 participants asked for further input, the most popular topic being 'How to talk to patients about death and dying.' Three quarters of those present requested more training, which suggests a need that should be met.

Only one person sought support after one of the sessions which suggests that the level of distress was not excessive for the vast majority. Some degree of discomfort was expected, hence the presence of counselling support. However, from this first pilot, the uptake was small.

REFERENCES

Scottish Government (2008) *Living and Dying Well*. Edinburgh: Scottish Government
Scottish Partnership for Palliative Care (2003) *Public awareness of palliative care*.
Edinburgh: SPPC.

ADDRESSING THE GREAT TABOO

It would help us enormously if you would answer the following questions about today's session. This is a new course and we may need to alter what we do in future on the basis of your answers.

1] How did you find today's session?

Please tick as many boxes as apply to you.

OK Challenging Too close to home Upsetting
 Very interesting Hard to follow I don't want to know

Other - please say what: _____

2] Did you find anything about today's session difficult?

Yes No

If yes, what was difficult? _____

3] Is there anything you want to learn more about?

We would like to hear if you need any training in this area so we can plan future events.
 Please tick any of the following you want to know more about.

How to introduce the subject of death and dying

How to talk to patients about death and dying

Loss, grief and bereavement

Advanced communication skills

Other – please say what _____

4] Is there anything else you want to say about today's session?

Many thanks for taking the time to attend today and for your feedback

ADDRESSING THE GREAT TABOO

Observation notes from: WRITE VENUE DETAILS

Observation date and time: DD / MM / YY HH:MM

Number of participants: Number

1] Participant reactions

2] Level of participant engagement in discussions

3] Any level of noticeable distress amongst participants

4] Any other observations of note

5] Number of participants seeking individual support after session