

Background

Living and Dying Well (2008) noted that there was 'cultural resistance to acknowledge the reality of death and dying as inevitable and integral parts of life and reluctance to discuss these.' Part of Lanarkshire's response was to pilot a new programme to encourage greater openness about our own mortality and the effect that poor communication can have on care planning and quality of life.



Method

A short session was designed to address the taboo of talking about death, dying and bereavement. Although it had not been tried before and there were concerns that some participants may be distressed by the content, the observation results show that this was not a big problem. Participant responses during the session show that the audience knew quite a lot about the topic. This is helpful for peer learning but also because the session was designed as a structured conversation to encourage people to discuss the subject more openly, some mentioned that they planned some actions as a result of attending e.g. making a will or discussing their own funeral wishes with their family.



Some degree of discomfort was expected, however, the session appears to have been very positively received by most participants. Feedback from the end of the session showed that most people found the session very interesting, although others has mixed reactions, saying it was also challenging. There was a small level of not unexpected upset, and a strong desire to learn more.

Results

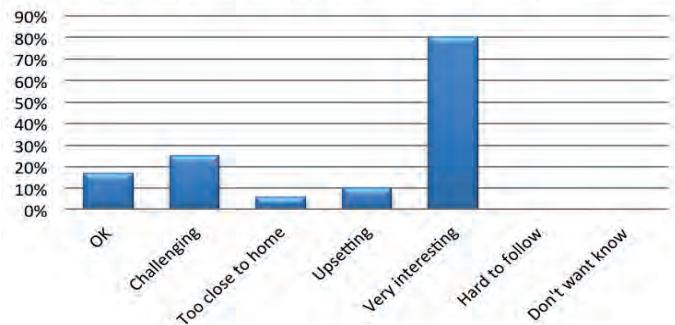
Following a successful pilot with 36 participants in a Care Home and 21 in a Community Hospital, NHS Lanarkshire funded roll-out of the programme to as many of its staff as were able to attend. The programme is designed as a one-hour structured conversation about death, dying and bereavement and is open to members of staff from any area or background. The first pilot programme included clinical staff, porters, receptionists and a couple of carers and the mix of different experiences generated very interesting discussions.

The programme has been delivered across different care settings (hospitals, care homes, community), at educational events for health & care professionals and students, and for third sector organisations. A total of 818 people have participated so far and feedback has been obtained from 540 (66%) of them.

The initial sessions included additional spiritual care/counselling support in case anyone became particularly upset, an option that was only taken up twice. Structured observation notes were completed for the first 14 sessions and these showed that although some people appeared to find parts of the session challenging, particularly if they had been recently bereaved themselves, initial concerns about creating considerable levels of distress were unfounded.

From the session feedback sheets, 313 participants (80%) said it was very interesting, 97 (25%) felt it was challenging, and 22 (6%) found it 'too close to home' (Figure 1). The majority of this group of 22 people responded that they had recently been bereaved themselves, although many said that they still found the session worthwhile.

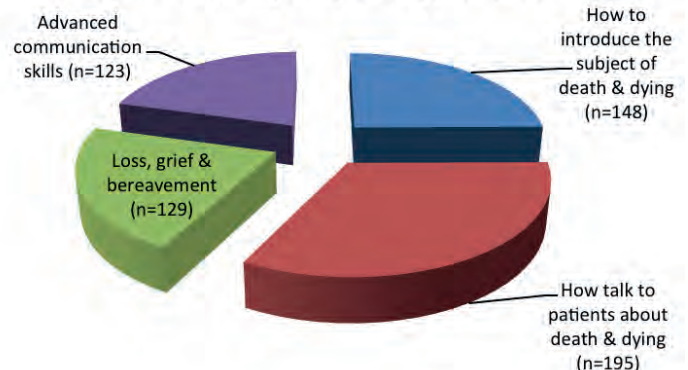
Figure 1 - Feedback on how participants found the session



When asked if they found anything in the session difficult, 272 (69%) said not, but 113 (29%) said they did. In the free text space, almost all of the 29% said mentioned the challenging 'Dying Matters' video clip. In general, this had reinforced the message about needing to be explicit about personal wishes for end of life care, but quite a few shed a tear or two.

Since this session was designed as an introduction to the subject area, participants were also asked if there was any other input they would find useful. Only 102 (26%) did not request any further training, whilst many of the remaining 291 (74%) who provided feedback were interested in more than one topic area (Figure 2).

Figure 2 - Further input requested by participants



In addition to the many people who said the session was 'thought-provoking' or who simply thanked the presenter for a great session, comments added at the end of the feedback sheet included:

"Well worth the time out. I would like more of this type of teaching/discussion."

"Not a learning need I would have identified myself, but on listening to the session, much needed and much-appreciated."

"Worthwhile topic that needs discussed more openly."

"Sensitive subject discussed in a sensitive way . . . feel more comfortable talking about this subject."

"I enjoyed it, even though I cried."

"Quite an eye opener - it's changed my view about death. I used to find it a scary subject, but after this session it is clear that it's a natural process."

Conclusion

Overall the evaluation has shown that this structured conversation session has been successful in engaging with participants across care settings and staff groups, that it did not create any great level of distress, and that there was a lot of interest in further training. The programme continues to be available to any interested groups in Lanarkshire.