

1. Background

Death holds a special significance both personally and for society. The need for End of Life Care is likely to grow, with 537,000 who could benefit from palliative care annually by 2040¹.

Community Based End of Life Care

Use of a 'Community Based' approach has been proposed as a means of meeting this need and providing more equitable care². Abel and Kellehear³ envisage 'teams of carers, families, friends, neighbours and volunteers working directly with palliative care nurses to provide support for the last phases of life'. This distinctive approach has been shown to produce practical outcomes and community development⁴. Delivering this will require tackling of the social taboo surrounding death and dying.

The Omega Course

The Omega Course is an education project run in the town of Kenilworth. Since 2016 8 courses have been run with groups of up to 12 people. The course aims to tackle taboo relating to death and enable future planning.

2. Method

Anonymous questionnaires, asking respondents how comfortable they felt discussing death, fear about death and future planning, were sent to 62 participants of The Omega Course aged 22-94. 24 responses (38.7%) were received, thematic analysis and inferential statistics were used.

3. Results

Theme	Codes
Feelings	Emotions, Perspectives, Own ideas
Fear	Fear about manner of death, Fear about dying, Resolution of fear
Spirituality	Afterlife, Spirituality of dying, Enabled by faith
Future plans	Aspirations about plans, Achievements about plans, Encouraged to take action
Community	Ability to help others, Taboo subject
Development	Developed conversation skills, Improved understanding, Easier to discuss death.
Conversations	Enablers to discussing death, Barriers to discussing death, Setting of conversations, Groupwork
Next steps	Seeking further advice, No change from course, Opinions on the course

Figure 1: Results of thematic analysis showing themes and associated codes

Question	T test
Q1. How comfortable do you feel discussing death and dying with friends and relatives?	P<0.01
Q2. How often do you discuss death and dying with friends and relatives?	P<0.01
Q3. How afraid do you feel about dying?	P<0.05
Q4. How prepared do you feel about planning for your death?	P<0.01

Figure 2: Results of Paired Two Tail T-test comparing 'before' and 'after' responses

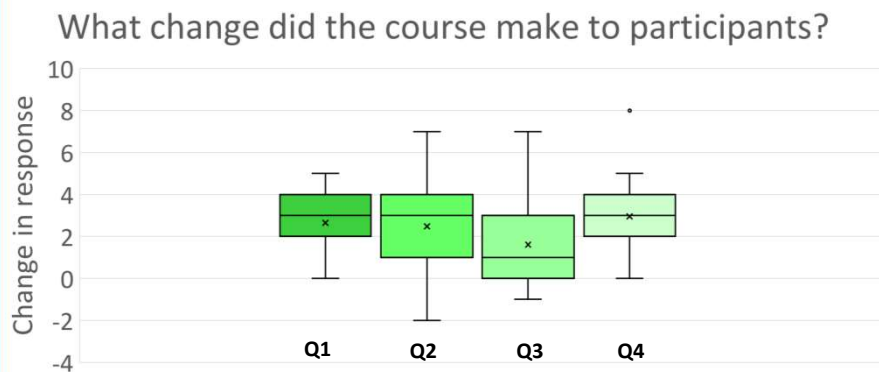


Figure 3: Box and Whisker plot showing the change in responses. The 'Whiskers' show the range and 'Box' the 25th to 75th centiles. X indicates the mean and horizontal line the median.

References

1. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson LJ, Murtagh FEM. How Many People Will Need Palliative Care in 2040? BMC Medicine. 2017, 15(102) 2. Abel J, Sallnow L, Murray S, Kerin M, Each Community is Prepared to Help, The National Council For Palliative Care, 2015. 3. Abel J, Kellehear A, Palliative Care Reimagined: a Much Needed Shift, 2016, 6(1), 1-6 4. Sallnow L, Richardson H, Murray SA, Kellehear A, The Impact of a New Public Health Based Approach to End-Of-Life Care: A Systematic Review, 2016, 30(3), 200-211

4. Discussion

Change to mindset

- Reflecting 'Feelings' and 'Fear' about death and dying
- Participants acquired new skills and knowledge
- Participants were 'less afraid about dying' (P<0.01)

"The determination of the medical profession to keep me alive at all costs is not attractive"

"I'm more aware of what I can do to influence the process and treatment"

Change to behaviour

- Change seen in the 'Conversations' and 'Future plans' themes
- Participants felt 'more prepared to plan for their own death' (P<0.01)
- This change translated effectively into aspiration, but less reliably into actioned change

"It [The Omega Course] allowed me to discuss end of life items with close family members"

"I haven't made any changes at this moment in time, but understand it will be important to put some things in place sooner rather than later"

Encouraging community action

- The 'Community' theme shows features of community action developing
- It is perhaps too early to expect tangible outcomes in the short time the course has been running

"Good discussions with my partner although I'd like her to attend the course so we can move forward together"

"I'm able to give people advice to give a level of control"

What does the course offer participants?

- The 'Development' and 'Next steps' themes suggest how the course helped participants
- For example through groupwork or scenario training

"[The Course] provided an excellent environment for discussing issues surrounding death and dying"

"I felt more confident to try and start a conversation, having done or watched role play"

5. Conclusion

The Omega Course offers participants the chance to discuss death and dying in a supportive environment, provides information and develops conversation skills. Through this it tackles fear about death and dying and promotes planning for the future. With time this may produce tangible health outcomes and community action.