EMPOWERMENT AND EDUCATION FOR FAMILY CARERS

PREPARING FOR CHANGE: WHAT HELPS FAMILY

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EMPOWERMENT AND EDUCATION FOR FAMILY CARERS SUPPORTING SOMEONE AT END-OF-LIFE: AN EVALUATION OF HOSPICE-LED COMMUNITY SESSIONS

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a starting point to discuss care tailored to patients’ wishes. The Good Death Questionnaire can help assess these diverse perspectives. This questionnaire consists of 15 items that represent patients’ wishes on what a good death is. Unfortunately, the Indonesian version of the questionnaire has not yet been available.

Aims We aimed to conduct a cross-cultural validation of the Good Death questionnaire in the Indonesian language.

Methods Our study context was the Minangkabau community, a matrilineal, communal, and Islamic community in West Sumatera, Indonesia. First, we translated the Good Death questionnaire into Indonesian, then translated it back into English. Seventy-one participants, consisting of patients and families, doctors and nurses, and community leaders, filled out the Indonesian version of the Good Death questionnaire. Afterward, we conducted semi-structured interviews to explore their responses to the questionnaire.

Results Participants agreed on most items in the Good Death questionnaire. However, some conflicting perspectives occur on items that give the impression that patients could decide on their death, for example, the time or place of death. Such wishes were considered ‘overruling God’s will’ and, therefore, in a culture with a strong Islamic religion, were less acceptable.

Conclusions The Good Death questionnaire could be validated in Indonesian with some revisions tailored to the cultural and religious context.

Impact An Indonesian version of the Good Death questionnaire is practical and beneficial for palliative care services, education, and research.

REFERENCE


PREPARING FOR CHANGE: WHAT HELPS FAMILY CARERS WITH RELATIVES IN CARE HOMES HAVE DISCUSSIONS AND MAKE DECISIONS ABOUT FUTURE DETERIORATION IN THEIR RELATIVE’S HEALTH

Introduction Many older people in care homes are moving towards the end of life. Whilst it is important to ensure residents are involved in discussions about their care, for example what they would like to happen when their health deteriorates, high levels of cognitive impairment amongst residents can make these discussions and decisions challenging. In some instances, family members may need to advocate, leading discussions with the resident and care staff. Peer support is known to be valuable to family carers but there is limited understanding of whether formal peer mentoring could be useful in a care home context.

Aims To determine whether peer mentors might support families to prepare for discussions and decision-making as their relative’s health deteriorates.

Methods Semi-structured interviews with up to 20 current and 15 bereaved family carers will be iteratively analysed in line with a constructivist approach to grounded theory.

Results Preliminary findings suggest few family carers had discussions and plans in place regarding future deteriorations prior to moving into a care home. Factors that appear to influence whether discussions had occurred included; whether the transfer into a care home was planned or emergency, previous experiences of end-of-life situations and existing family dynamics. Family carers stated they would like practical and emotional support throughout the support journey. They suggested that engaging with a peer mentor earlier, for example when considering moving into a care home, would enable them to develop trusting relationships.

Conclusions Peer mentoring represents a potential opportunity to support families of care home residents to prepare for change and to be involved in discussions and decisions as the person’s health deteriorates but it is crucial explore caveats to this before implementing new services.

Impact As our understanding develops, we will consider whether and how to operationalise peer mentors in practice.