

A Consumer Commentary: Interventions for Preparing for Conversations with Patients and their Careers and Families about End-Of-Life Care Decisions

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Short Communication

End-of-life (EoL) care conversations between health practitioners and the patient and their family and/or carers are an important and difficult component of care that goes well beyond the scope of a “difficult conversation.” An important aspect of EoL care is to also support family and carers’ continued involvement with the dying person. Such involvement has been reported to allow for consensus decision-making, development of realistic care goals, and assists the family to deal with their distress [1-3]. A systematic review of relative experiences in EoL care clearly links family and carer satisfaction with their experiences of communication and support from the healthcare team [4,5]. Only by being involved from the “other side”, as the patient or their family/carer, can the impact of the EoL conversation, or its omission, be fully appreciated. A consumer (patient/family/carer) perspective provides a very different lens for reflecting on this EoL conversation.

My personal EoL journey—caring for my mother who was diagnosed with advanced ovarian cancer—clearly focused this consumer lens. The first difficult conversation we had was breaking the “I have cancer” news. This was followed by many difficult conversations with health practitioners about the treatment options, the extent of the palliative surgery, the chemotherapy and about the progression of the illness. However, none of these difficult conversations directly addressed EoL care decisions. Despite attempts to facilitate a joint EoL conversation with my mother and the health care professionals, it never happened. As my mother’s health continued to deteriorate, it became obvious that this was a conversation we would not have. On the day before my mother died she said to me “You have done all you can do for me now”. I remember thinking that this was an unusual comment for my mother to make; I now believe she was acknowledging that her death was near and, perhaps, it was her way of saying goodbye. In the early hours of the next morning my mother died peacefully at home. Over this two-year journey her wishes for EoL care were never clarified. Silent, but always looming, the EoL conversion remained unresolved.

While it is frequently acknowledged that health professionals need to be skilled in talking about this difficult subject, even when patients may not be able to, it is recognised that the pervasive curative medical model often combines with mismatched perspectives that create barriers to open communication about EoL and impending death. EoL

care planning and the EoL conversation are coming under increasing review in the health care sector. “Death, dying and bereavement are all an integral part of life; however reflecting on, and discussing death, can be profoundly confronting and difficult. Open and frank discussion of death and dying including end of life care options, approach to futile treatment, caring and bereavement should be encouraged within the profession and in the wider community” [6].

While there is limited detailed evidence supporting specific interventions used for enhancing the preparation for EoL conversations, there are guidelines in the literature for communicating prognosis and end of life. Key questions raised are: 1) How do health practitioners prepare for the EoL conversation? 2) What interventions exist for preparing for the EoL conversation? 3) What levels of evidence exist to confirm the interventions used to plan for EoL conversations? 4) What research still needs to be undertaken to support this critically important area? Further research would investigate the most effective strategies for supporting health care practitioners prepare for EoL conversations. Successfully implementing research outcomes in practice would reduce and potentially eliminate what is often the unspoken element of the EoL journey; the frank discussion about death and dying including end of life care options.

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