

“Hospice Scares the Life Out of Me”: Breaking Down Barriers to Communication with Young Adults with Terminal Cancer

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Objectives: A terminal prognosis amongst young adults is usually unexpected. Those with incurable cancer often have an awareness of their imminent death and experience distressing psychological death anxiety and anticipatory grief. Hospice and palliative care teams are able to offer significant support to manage these symptoms, and yet referral is rarely timely and planned. One finding from our mixed methods study to explore the experiences of people aged 16-40 with cancer for which cure is not likely is examined to offer some reflections on practice.

Methods: Qualitative interviews with three separate groups of informants from five specialist treatment centres in England: 33 young people with cancer aged 16- 40 with a prognosis of less than 12 months; 14 of their family members; 22 healthcare professionals delivering their care. Data analysis revealed typical scenarios then examined in workshops with 47 health and social care professionals and 19 bereaved family members.

Results: How health professionals used terminology with people with cancer affected their access to and utilisation of services such as hospice care. The term ‘hospice’ was used with caution, due to misconceptions of a hospice being a place where only old people go to die. Those offered and accepting hospice care appreciated the benefits provided including maximising an active lifestyle and providing family support. Professionals acknowledged reticence within practice to introduce hospice despite being aware of the potential benefits.

Conclusions: Use of appropriate language by health and social care professionals could improve the experience of younger people with cancer and their families who face a poor prognosis. In particular, introduction of the term ‘hospice’ may facilitate not only symptomatic relief and psychological support to people with cancer and their families, but also assist professionals in breaking down barriers and initiating difficult conversations around death and dying.