DANCING TO A DIFFERENT TUNE: LIVING AND DYING WITH CANCER, ORGAN FAILURE AND PHYSICAL FRAILTY


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Introduction The “danse macabre” has been depicted in Europe since medieval times. Providing good end-of-life care for all patients, whatever form their last dance takes, is a global challenge.

Aim(s) and method(s) To explore typical narratives of living with and dying from advanced illnesses, to provide insights into providing effective care.

Secondary analysis of data from 8 qualitative longitudinal studies: 3 cancer; 3 organ failure; 1 frailty; 1 with South Asian participants from all 3 trajectories. Patients were interviewed up to 4 times over 18 months. Researchers from each study reviewed the data using a narrative analytic framework. The narratives were initially synthesised by illness trajectory, then compared and discussed at analysis workshops.
Results The dataset was 828 in-depth interviews with 156 patients. Cancer narratives had a well-rehearsed beginning, middle and anticipated end, with dual themes of hope for recovery alongside fear of dying. People with organ failure struggled to tell their story, being unclear when the illness began, or how one event linked to another. Fewer spoke about death, hoping instead to avoid further deterioration. Frail older people’s narratives often began with a specific event in combination with ageing, yet lost salience amidst increasing losses and future fears. Death was only fully anticipated very near the end, and feared less than nursing homes or dementia.

Conclusion(s) Patients from different illness groups gave very different accounts. Consequently the cancer-based model of end-of-life care seems poorly suited to the needs of those dying in other ways. Understanding how different patient groups perceive their deteriorating health and approaching death will inform appropriate future palliative care for all.