Patterns of Social, Psychological, and Spiritual Decline Toward the End of Life in Lung Cancer and Heart Failure

Reference: Murray SA, Kendall M, Grant E et al. J Pain Symptom Manage 2007; 34(4):393-402.

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Abstract:

Typical trajectories of physical decline have been described for people with end-stage disease. It is possible that social, psychological, and spiritual levels of distress may also follow characteristic patterns. We sought to identify and compare changes in the psychological, social, and spiritual needs of people with end-stage disease during their last year of life by synthesizing data from two longitudinal, qualitative, in-depth interview studies investigating the experiences and needs of people with advanced illnesses. The subjects were 48 patients with advanced lung cancer (n = 24) and heart failure (n = 24) who gave a total of 112 in-depth interviews. Data were analyzed within individual case studies and then cross-sectionally according to the stage of physical illness. Characteristic social, psychological, and spiritual end-of-life trajectories were discernible. In lung cancer, the social trajectory mirrored physical decline, while psychological and spiritual well-being decreased together at four key transitions: diagnosis, discharge after treatment, disease progression, and the terminal stage. In advanced heart failure, social and psychological decline both tended to track the physical decline, while spiritual distress exhibited background fluctuations. Holistic end-of-life care needs to encompass all these dimensions. An appreciation of common patterns of social, psychological, and spiritual well-being may assist clinicians as they discuss the likely course of events with patients and carers and try to minimize distress as the disease progresses.

Comments:

Strengths/uniqueness:

1. Secondary analysis of qualitative datasets is now recognized internationally as an important, valid and expanding area of research methodology
2. The qualitative approach allows an in-depth understanding of the issues that patients found most distressing, while the serial interviewing enables end-of-life distress to be accurately charted over time
3. Synthesis of earlier data was appropriate because the same research team had worked on the two primary studies and data generation/analysis was comparable to both
4. The study participants were selected to be representative of the local demography for each condition

Weaknesses:

1. The four dimensions of distress can often interact, making it difficult to disentangle them
2. The trajectory approach is itself limited because there is no definitive ‘typical’ patient journey – cases evolve in various ways and patients often react differently to the same circumstances
3. The number of patient interviews varied considerably across the study participants
4. It is unclear to what extent the findings of this south-east Scotland based study can be reliably extrapolated to other populations and groups

Relevance to Palliative Care:

1. Palliative care should be provided to all patients at the end-of-life, not just those with cancer
2. Patients reaching the end-of-life have multidimensional care needs but the relative intensities of each component of patient distress fluctuate over the last year of life
3. Holistic, four-dimensional care planning is needed to optimize quality of life and quality of death