

Initial perceptions of palliative care: An exploratory qualitative study of patients with advanced cancer and their family caregivers

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Anna Collins, Sue-Anne McLachlan and Jennifer Philip

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Presented by: Tim Gutteridge (PGY-3, Palliative Care)

ABSTRACT:

Background: Despite evidence for early integration of palliative care for people with advanced cancer and their families, patterns of late engagement continue. Prior research has focused on health professionals' attitudes to palliative care with few studies exploring the views of patients and their carers.

Aim: To explore initial perceptions of palliative care when this is first raised with patients with advanced cancer and their families in Australian settings.

Design: Cross-sectional, prospective, exploratory qualitative design, involving narrative-style interviews and underpinned by an interpretative phenomenological framework.

Setting/participants: Purposively sampled, English-speaking, adult patients with advanced cancer ($n = 30$) and their nominated family caregivers ($n = 25$) recruited from cancer services at a tertiary metropolitan hospital in Melbourne, Victoria, Australia.

Results: Three major themes evolved which represent the common initial perceptions of palliative care held by patients with advanced cancer and their carers when this concept is first raised: (1) diminished care, (2) diminished possibility and (3) diminished choice. Palliative care was negatively associated with a system of diminished care which is seen as a 'lesser' treatment alternative, diminished possibilities for hope and achievement of ambitions previously centred upon cure and diminished choices for the circumstances of one's care given all other options have expired.

Conclusion: While there is an increasing move towards early integration of palliative care, this study suggests that patient and caregiver understandings have not equally progressed. A targeted public health campaign is warranted to disentangle understandings of palliative care as the 'institutional death' and to reframe community rhetoric surrounding palliative care from that of disempowered dying to messages of choice, accomplishment and possibility.

STRENGTHS:

- Various cancer types, settings, and stages of disease
 - Included some patients not yet referred to palliative care
- Included both patients and family caregivers
- Detailed qualitative approach with 40-120 min interview and interpretative phenomenology analysis

WEAKNESSES:

- Single center (in Australia), limited to English-speaking patients
- Did not include non-cancer patients
- ?Room for bias (single interviewer, purposive [non-random] sampling)

RELEVANCE TO PALLIATIVE CARE:

- According to paper:
 - "While there is increasing health system focus on early integration of palliative care in order that benefits are realized, this study suggests that understandings of patients and carers have not equally progressed. In order that we reduce the significant stigma that remains associated with palliative care, there is a clear need for a targeted public health campaign aiming to change the narrow understandings of palliative care and reframe underlying narratives of disempowered dying."
- Clinical practice
 - Perceptions of palliative care may need to be explored and addressed (especially initially)
 - May need to be explicit with alternative message of "choice, accomplishment, and possibility"
 - ?Consider "Pain and Symptom" terminology at times (controversial)