

Journal Watch

Mapping hospice patients' perception and verbal communication of end-of-life needs: an exploratory mixed methods inquiry

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Abstract

Background: Comprehensive "Total Pain" assessments of patients' end-of-life needs are critical for providing improved patient-clinician communication, assessing needs, and offering high quality palliative care. However, patients' needs-based research methodologies and findings remain highly diverse with their lack of consensus preventing optimum needs assessments and care planning. Mixed-methods is an underused yet robust "patient based" approach for reported lived experiences to map both the incidence and prevalence of what patients perceive as important end of life needs.

Methods: Findings often include methodological artifacts and their own selection bias. Moving beyond diverse findings therefore requires revisiting methodological choices. A mixed methods research cross-sectional design is therefore used to reduce limitations inherent in both qualitative and quantitative methodologies. Audio-taped phenomenological "thinking aloud" interviews of a purposive sample of 30 hospice patients are used to identify their vocabulary for communicating perceptions of end-of-life needs. Grounded theory procedures assisted by QSR-NVivo software is then used for discovering domains of needs embedded in the interview narratives. Summary findings are translated into quantified format for presentation and analytical purposes.

Results: Findings from this mixed-methods feasibility study indicate patients' narratives represent 7 core domains of end-of-life needs. These are (1) time, (2) social, (3) physiological, (4) death and dying, (5) safety, (6) spirituality, (7) change & adaptation. The prevalence, rather than just the occurrence, of patients' reported needs provides further insight into their relative importance.

Conclusion: Patients' perceptions of end-of-life needs are multidimensional, often ambiguous and uncertain. Mixed methodology appears to hold considerable promise for unpacking both the occurrence and prevalence of cognitive structures represented by verbal encoding that constitute patients' narratives. Communication is a key currency for delivering optimal palliative care. Therefore understanding the domains of needs that emerge from patient-based vocabularies indicate potential for: (1) developing more comprehensive clinical-patient needs assessment tools; (2) improved patient-clinician communication; and (3) moving toward a theoretical model of human needs that can emerge at the end of life.

Strengths

- Mixed methods design (qualitative and quantitative)
- Patient-centered design for exploring end-of-life needs
- Emphasis on patient-based language

Weaknesses/Limitations

- Sampling limitations (single palliative organization; United States hospice setting, which includes both inpatients and patients at home)
- Patient characteristics regarding functional status and survival not clearly described
- Potential subgroup differences (e.g. cancer vs. non-cancer)
- Potential for researcher bias (data collection and analysis by one person)
- Detailed description of approaches for addressing trustworthiness issues not provided
- Conclusions may be an overgeneralization of findings
- Conceptual mixing of research methods (think aloud, phenomenology, grounded theory)

Relevance to Palliative Care

The ultimate goal of palliative care is to provide services that identify patients' and family members' needs and address their goals of care. Patients may have difficulty expressing their needs when receiving palliative care services. The findings from this study provide an initial patient-centered framework for further exploration of this timely and important topic at end of life.