

Health Policy Research Program Summary of Research Results

Title:	Improving the Quality of End-of-Life Care in Canada: Understanding the Perspectives of Seriously Ill Hospitalized Patients and their Caregivers
Investigator Name:	Dr. Daren Heyland
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Institution:	Kingston General Hospital
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Summary

Background: Initiatives to improve satisfaction with end-of-life (EOL) care are hampered by our nascent understanding of what quality care means to patients and their families. The majority of previous related studies survey attitudes and preferences of cancer patients and their families whereas the majority of decedents are elderly, seriously ill, hospitalized patients with end-stage medical disease. Understanding patients' and family members' perspectives on the relative importance of elements of end-of-life care and their satisfaction with those elements will help prioritize quality improvement initiatives at the end of life.

Objective: To describe what seriously ill hospitalized patients and their family members consider the key elements of quality EOL care and how they ranked their satisfaction with the care delivery on these items.

Method: We administered a face-to-face questionnaire to eligible subjects in 5 hospitals across Canada. The questionnaire included 28 elements related to quality end-of-life care derived from existing literature, focus groups with experts, and interviews with patients. Respondents rated the importance of each element and how satisfied they were with the delivery of each element.

Participants: Elderly patients with end stage medical disease or advanced cancer and their family member.

Results: 440 (78%) of 569 eligible patients and 160 (91%) of 176 available family members agreed to participate. The elements rated as extremely important most frequently by the *patients* were: “To have trust and confidence in the doctors looking after you” (55.8% of respondents), “not to be kept alive on life supports when there is little hope for a meaningful recovery” (55.7%), “That information about your disease be communicated to you by your doctor in an honest manner” (44.1%), “To complete things and prepare for life’s end” (life review, resolving conflicts, saying good-bye) (43.9%), and “To have an adequate plan of care and health services available to look after you at home upon hospital discharge” (41.8%). There were significant differences in ratings of importance among different patient groups and between patients and their family members.

No patient or family member was completely satisfied with all elements; 29% of patients and 17% of family members responded that they were not completely satisfied; with any of the individual elements. *The elements rated as “extremely important” and not “completely satisfied” most frequently by the patients and caregivers were: “To have an adequate plan of care and health services available to look after you at home upon hospital discharge,” “To have relief of symptoms,” “To not be a physical or emotional burden on your family,” “To have trust and confidence in the doctor,” “To receive adequate information,” and “To be involved in the decisions regarding the treatments and care provided.”*

Conclusion: Seriously ill patients and family members identified key elements related to quality end-of-life care. Variation in their perception of what matters the most indicates the need for customized or individualized assessments in end-of-life care. Most patients and their family members in our survey are not completely satisfied with end-of-life care. *Continuity of care and discharge planning, symptom management, supportive care, communication and decision making, and patient-physician relationship issues emerge as high priority targets for quality improvement initiatives.*

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- The print version of the full report can be obtained in the language of submission from the Health Canada Library through inter-library loan.

- An electronic version of the report in the language of submission is available upon request from Health Canada by e-mailing rmddinfo@hc-sc.gc.ca.

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