



## Poster # 44

**Title of poster:** Assessing patient and family perceptions of palliative and end-of-life home care interventions

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### Abstract

**Background:** Quality care at the end of life is about achieving the goals of the patient, as well as supporting caregivers. In Southeastern Ontario, two interventions—an advanced care planning tool and symptom response kits—were implemented to enhance and maintain quality care of terminally ill patients at home. These interventions are being evaluated to determine their impact on place of care and place of death. Additional evaluation is needed to determine family caregivers' perceptions of these interventions in the context of publicly-funded home care services.

**Aim:** To determine the most appropriate method of assessing the quality of palliative home care from the perspective of family caregivers.

**Methods:** A scoping literature review was conducted using the York framework. 47 peer-reviewed articles were identified from the Medline, CINAHL, EMBASE, and Health and Psychosocial Instruments databases. A numeric analysis of common approaches used to ascertain perceptions of palliative home care was performed by the first author. Themes emerging from the numeric analysis were then mapped onto the “Seven key benefits for individuals and families” identified in the Ontario Ministry of Health and Long-Term Care's 2011 policy document “Advancing High Quality, High Value Palliative Care in Ontario”. Gaps in the literature were identified.

**Results:** 41 articles were published since 2000 and reflect a diversity of palliative care interventions delivered at home. Six studies were conducted in Canada; 4 in Ontario. 83% of the studies used qualitative approaches, relying primarily on face-to-face interviews with a small number of caregivers. More than two-thirds of studies took place before the patients died, of which only three included follow up after death. Studies were typically broad in scope, asking questions about satisfaction, expectations, and positive and negative aspects of palliative home care. Of the seven benefits, “individual and/or family member engagement in care” and “keeping patients and families fully informed” were most commonly raised by patients and family

caregivers. In contrast, the benefits of “inter-professional teams” and “consistency of staff/services” were rarely mentioned. Additional themes that did not map onto the seven benefits included staff competency, symptom control, and caregiver support (emotional and practical) pre- and post-death.

Discussion: The methods used in assessing patients’/family caregivers’ perceptions of palliative home care varied depending on the intervention under study and the level of detail sought. The nature of the intervention tended to guide the selection of particular benefits on which the evaluation was focused. The seven benefits identified by Ontario’s policy document do not fully encompass all that patients/caregivers value; other issues need to be included when evaluating palliative home care interventions. These preliminary results will be confirmed by having co-authors independently review selected papers.

Conclusion: Evaluation of palliative home care interventions should include all seven benefits in addition to other important themes identified. The methods used should be adapted to the context, and should take into consideration relevant methodological challenges. When evaluating the two Southeastern Ontario interventions, we recommend developing a standardized, self-administered questionnaire for increased representativeness, followed by an in-depth face-to-face interview guide for increased understanding.