

POSTER ABSTRACT

Barriers to engaging in end-of-life communication in advanced illness management: Perceptions of patients with heart failure and their family caregivers

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Introduction: Growing numbers of people are living longer with complex conditions. Integrated care models have been found to be effective for people with complex conditions such as heart failure. Heart failure is a serious illness characterized by symptoms, comorbidities, acute exacerbations and sporadic decline. Integrated care programs for heart failure management often emphasize patient education and self-care activities for illness management. Despite heart failure being a life-limiting illness, models of care for heart failure management often do not address its terminal nature. Consequently, end-of-life communication is uncommon in people with heart failure and the quality of end-of-life care remains suboptimal. This study explores patients and caregivers' perceptions of engaging in end-of-life communication in advanced illness management.

Methods: A qualitative study was conducted among patients and their family caregivers from a large outpatient heart function clinic in Ontario, Canada. Fourteen semi-structured interviews were conducted with 19 participants. Audio-recordings of interviews were transcribed verbatim and thematic inductive analysis was performed alongside data collection.

Results: Limited understanding of illness and caregiver readiness to discuss end-of-life care were identified barriers to engaging in end-of-life communication. Most patients did not seem to understand the seriousness or the implications of having advanced heart failure. When discussing end-of-life care, patients were willing to share their end-of-life thoughts and care preference but they seldom do so with their providers or family members. However, caregivers were reluctant to engage in end-of-life discussions, yet once they did, they expressed distress related to patients' transitioning to the end-of-life.

Discussion: Findings suggest that end-of-life communication may be difficult to integrate into advanced illness management as patients and caregivers do not perceive advanced heart failure

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as a serious illness. While patients are willing to engage in end-of-life communication, caregivers may not be ready. Regardless, caregivers' expressed distress relating to the end-of-life suggests a need for end-of-life communication. This requires further attention given that caregivers play an integral role in managing patients' health conditions in day-to-day living and their role in decision-making at the end-of-life.

Conclusion: Insights from patients with advanced heart failure and their caregivers suggest that end-of-life communication is not necessarily part of advanced illness management. Addressing patients and caregivers' understanding of illness may help to engage in end-of-life communication earlier in the illness trajectory. Models of care should be inclusive of caregivers and assess their readiness to engage in end-of-life communication.

Lessons learned: To integrate end-of-life communication into advanced illness management, integrated care programs should address patient and caregiver understanding of illness beyond educating patients and caregivers in self-care activities and routinely include caregivers in patient care.

Limitation: Patients and caregivers were recruited from one outpatient clinic, thus findings may not be transferable to other care settings.

Suggestions for future research: Further research is needed to explore providers' experience facing these barriers to understand ways to overcome such obstacles and integrate end-of-life communication into advanced illness management.

Keywords: advanced illness; end-of-life communication; older adults; heart failure
