Beyond simple planning: existential dimensions of conversations with patients at risk of dying from heart failure

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ABSTRACT

Introduction
Despite the recent promotion of communication guides to improve decision-making with patients nearing the end of their lives, these conversations remain challenging. Deeper and more comprehensive understanding of communication barriers that undermine discussions and decisions with patients at risk of dying from heart failure (HF) are vital for informing communication in healthcare.

Objectives
To explore experiences and perspectives of patients with advanced HF, their caregivers and providers, regarding conversations for patients at risk of dying from HF.

Methods
Following Research Ethics Board approval, index patients with advanced HF (NYHA III or IV) and consenting patient-identified care team members were interviewed. A Team Sampling Unit (TSU) was formed when the patient plus at least two additional “team members” participated in interviews. Team members included health professionals (e.g., cardiologist, family physician, HF nurse practitioner, social worker, and specialists such as respirologist, nephrologist, palliative care physician), family caregivers (e.g., daughter, spouse, roommate, close friend) and community members (e.g., minister, neighbor, regular taxi driver). Our dataset included 209 individual interviews clustered into 50 TSUs at five sites from three Canadian provinces. Key informants, identified as practicing experts in the field, reviewed our initial findings with attention to relevance to practice as a form of triangulation. Iterative data collection and analysis followed constructivist grounded theory procedures with sensitizing concepts drawn from complexity theory. To ensure confidentiality, all participants were given a pseudonym.

Results
Participants’ reports of their perceptions and experiences of conversations related to death and dying suggested two main dimensions of such conversations: instrumental and existential. Instrumental dimensions included how these conversations were planned and operationalized, and the triggers and barriers to these discussions. Existential dimensions of these conversations included evasive
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