Mind the gap: Opportunities for improving end-of-life care for patients with advanced heart failure


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Abstract:

BACKGROUND: Patients with advanced heart failure (HF) experience progressive symptoms, decreased quality of life, and more frequent hospitalizations as they approach the end of life (EOL). Understanding patient perspectives and preferences regarding EOL issues is necessary to identify key opportunities for improving care. OBJECTIVE: To identify, from the patient's perspective, the major opportunities for improving EOL care for patients hospitalized because of advanced HF. METHODS: A cross-sectional survey of patient perspectives regarding EOL care was administered via interview of 106 hospitalized patients who had advanced HF in five tertiary care centers across Canada. The study compared which aspects of EOL care patients rated as 'extremely important' and their level of satisfaction with these aspects of EOL care to identify key opportunities for improvement of care. RESULTS: The greatest opportunities for improvement in EOL care were reducing the emotional and physical burden on family, having an adequate plan of care following discharge, effective symptom relief and opportunities for honest communication. The three most important issues ranked by patients were avoidance of life support if there was no hope for a meaningful recovery, communication of information by the doctor and avoidance of burden for the family. CONCLUSIONS: Advanced care planning that seamlessly bridges hospital and home must be standard care for patients who have advanced HF. Components must include coordination of care, caregiver support, comprehensive symptom management, and effective communication regarding HF and EOL issues.

Comments:

Strengths/unicomeliness:

This is a well-designed study that included multiple Canadian sites and elicited a comprehensive dataset of patient opinion on EOL care issues. The Opportunity Index construct is a useful way to focus attention on the issues most relevant to patients.

Weakness:

The results do not differentiate between patient preferences for location of care and location of death. This would be an important element to understand in improving comprehensive care for heart failure patients.

Relevance to Palliative Care:

The problem of improving EOL care for non-malignant patient populations is a major challenge for palliative care programs and health care organizations. This report is a very valuable addition to the literature in assisting advocacy and innovation in health care delivery for heart failure patients.