

Paper Session B3: Pain Control and Palliative Care

Care Preferences of Home Care Patients with End-Stage Cardiac and Respiratory Illnesses

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Purpose: The purpose of this study is to describe the perspectives of people living with advanced cardiac and respiratory illnesses about their current and future goals for care, understanding about options for care at the end of life, and expectations of clinicians.

Background: Much of what is known about patients' care preferences at the end of life is based on studies of patients with cancer, often in hospice settings. Less is known about the care preferences of patients with end-stage cardiac and respiratory illnesses as they near end of life.

Methods: Using a qualitative descriptive design, two in-depth interviews were conducted with 20 participants residing at home enrolled in a community home care agency. Criterion-based sampling was used to recruit patients with NYS class III and IV heart failure and oxygen dependant chronic obstructive pulmonary disease.

Results: Participants described living with advanced illness as having engulfed all aspects of their lives. Dyspnea was singled out as the most problematic symptom that they "had to live with", interfered most with important aspects of their life, and was least discussed with clinicians. Several participants did not report worsening symptoms because: a) they knew best how to manage their health, and b) were afraid of hospitalization. While the majority of participants were uncertain about their future health, many remained hopeful they would still be alive a year from now. All expected their doctor to tell them if their illness became life-threatening.

Conclusions and Implications: Patients reported gaps in their symptom management, how they handled symptom reporting to elicit preferred clinician responses, and their preferences for information identifying when their illnesses were life-threatening. Research identifying discrepancies between patient and clinician expectations holds promise in facilitating better care for persons with life-limiting illness.