Original Article

Contending With Advanced Illness: Patient and Caregiver Perspectives

Mary Ann Meeker, RN, DNS, Deborah P. Waldrop, MSW, PhD, Jaclyn Schneider, MD, and Amy A. Case, MD
University at Buffalo, The State University of New York (M.A.M., D.P.W., J.S., A.A.C.) and VA Western New York Healthcare System (A.A.C.), Buffalo, New York, USA

Abstract

Context. Despite improvements in end-of-life care, some unrelieved suffering persists for patients with advanced illness and their family members. Hospice and palliative care services can reduce suffering, but these services remain under-used.

Objectives. To investigate how patients with advanced illness and their primary caregivers experienced and responded to health care needs and decision making and how some dyads moved toward comfort-focused care.

Methods. This was a qualitative study using the grounded theory method for sample selection, data collection, and analysis. Dyadic semi-structured interviews were audio-recorded and transcribed for analysis. Twenty-two participants, 12 patients and 10 family surrogates, provided 16 interviews for this study.

Results. Participants engaged in a process of contending with advanced illness. The major phases comprising this process were suffering, struggling, and settling. Struggling included enduring the experience and fighting the illness. During the phase of settling, the focus shifted away from curative efforts and toward supportive care. Conditions that facilitated the movement into this phase included receiving clear and consistent information about the patient's health status, trusting health care providers, having attended to advance care planning in some form, and being aware of and able to acknowledge the terminal nature of the illness.

Conclusion. Findings from this pilot study offer a preliminary theoretical model to enhance the understanding of patient and family caregiver needs during advanced illness. Awareness of their perspective can inform the timing and content of clinicians' communication and interventions. J Pain Symptom Manage 2014;47:887–895. © *2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words
Advanced life-limiting illness, grounded theory, transition, palliative care

Address correspondence to: Mary Ann Meeker, RN, DNS, School of Nursing, University at Buffalo, The State University of New York, 3435 Main Street, Wende Hall 303, Buffalo, NY 14214, USA. E-mail: meeker@buffalo.edu

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Introduction

Despite improvements in end-of-life care over the past two decades in the U.S., some unrelieved suffering persists for patients with advanced illness and their family members.[1] Moreover, Trask et al.[2] found that 40% of those who died from cancer experienced distressing pain at their last place of care. The continuation of cure-focused interventions even when they have little potential for success can contribute to unrelieved suffering. Undesired aggressive treatment also contributes to high health care expenditures at the end of life.[3–5] The physical, psychosocial, and spiritual suffering that can accompany the end stage of life can have a major impact on family caregivers and also can affect their adaptation in bereavement.[6]

Within developed nations, palliative care services have been found to improve patient and family outcomes,[7] and hospice has emerged as a model for the provision of optimal end-of-life care.[8] Although hospice and palliative care services can reduce suffering, these services remain under-used. Despite eligibility for a specialized hospice insurance benefit for those with a life expectancy of less than six-months, it is well known among palliative care providers and researchers that most terminally ill persons do not initiate comfort-focused care until very late in the dying trajectory. In the U.S. in 2011, nearly 36% of patients using hospice care received services for fewer than seven days. The median length of service has been decreasing in recent years and was 19.1 days in 2011.[9]

Communication about the end of life remains a highly charged and difficult aspect of patient care.[10–13] Suffering may remain unaddressed when patients, family, and providers have difficulty discussing the dying process openly and frankly. Physicians tend to emphasize medical and technical information and to neglect emotional aspects of the interaction.[14] Families also often avoid discussions that are painful and emotional.[15] Family caregivers have been found to need guidance about end-of-life care and to benefit from earlier education about the practical, technical, and emotional dimensions of end-of-life caregiving.[16]

The transition to the final stage of life is inherently difficult and largely understudied.[17–19] Painful encounters with fear, loss, and a sense of powerlessness are common.[13,18] Understanding how a patient-caregiver dyad experiences this transition can help clinicians develop greater capacity to support them during this meaningful but difficult time period. Enhanced clinician understanding also can limit unwanted aggressive care and contribute to adaptation in bereavement.[6,20] The purpose of this study was to explore patients' and caregivers' experiences and perspectives as they responded to advanced illness and, when relevant, transitioned to comfort-focused care.

Methods

A qualitative approach was chosen to investigate the subjective experiences and meaning of advanced illness for patients and their family caregivers.[21] The study was conducted in collaboration with the inpatient palliative care consultation service of an urban Veterans Administration Medical Center in the Northeastern U.S. We recruited a purposeful sample comprising dyads that included hospitalized adult patients who met the disease-specific hospice eligibility criteria as published by the National Hospice and Palliative Care Organization[22] but who had not chosen to focus on comfort care or elected hospice services or had only done so within the past week. Initial screening for eligibility was performed by the palliative medicine physician when a palliative care consultation was requested. In this setting, requests for consultation were made primarily by medical residents and hospitalists. The study inclusion criteria for patients were as follows: a diagnosis of any life-limiting illness that was sufficiently advanced as to qualify for hospice care and the ability and willingness to communicate verbally about their experiences and perceptions. The exclusion criterion was any cognitive impairment, such as delirium, decreased responsiveness, or profound weakness that precluded meaningful conversation.

After determining eligibility and eliciting the patient's permission, the palliative physician provided each interested patient with a written description of the study and provided the researchers with the patient's name and hospital room number. A researcher then