Original Article

Different Experiences and Goals in Different Advanced Diseases: Comparing Serial Interviews With Patients With Cancer, Organ Failure, or Frailty and Their Family and Professional Carers

Marilyn Kendall, PhD, Emma Carduff, PhD, Anna Lloyd, MSc, Barbara Kimbell, PhD, Debbie Cavers, PhD, Susan Buckingham, PgDip, Kirsty Boyd, FRCP, Liz Grant, PhD, Allison Worth, PhD, Hilary Pinnock, MD, Aziz Sheikh, MD, and Scott A. Murray, MD

Primary Palliative Care Research Group (M.K., E.C., A.L., B.K., D.C., S.B., K.B., L.G., H.P., S.A.M.) and Allergy and Respiratory Research Group (S.B., H.P., A.S.), Centre for Population Health Sciences, The Usher Institute of Population Health Sciences & Informatics, The University of Edinburgh, Medical School, Edinburgh, Scotland, United Kingdom; Division of General Internal Medicine and Primary Care (A.S.), Brigham and Women's Hospital/Harvard Medical School, Boston, Massachusetts, USA; and Wellcome Trust Clinical Research Facility Education Department (A.W.), Western General Hospital, The University of Edinburgh, Edinburgh, Scotland, United Kingdom

Abstract

Context. Quality care for people living with life-limiting illnesses is a global priority. A detailed understanding of the varied experiences of people living and dying with different conditions and their family and professional caregivers should help policymakers and clinicians design and deliver more appropriate and person-centered care.

Objectives. To understand how patients with different advanced conditions and their family and professional caregivers perceive their deteriorating health and the services they need.

Methods. We used a narrative framework to synthesize eight methodologically comparable, longitudinal, and multiperspective interview studies. We compared the end-of-life experiences of people dying from cancer (lung, glioma, and colorectal cancer), organ failure (heart failure, chronic obstructive pulmonary disease, and liver failure), and physical frailty and those of their family and professional caregivers in socioeconomically and ethnically diverse populations in Scotland.

Results. The data set comprised 828 in-depth interviews with 156 patients, 114 family caregivers, and 170 health professionals. Narratives about cancer typically had a clear beginning, middle, and an anticipated end. Cancer patients gave a well-rehearsed account of their illness, hoping for recovery alongside fear of dying. In contrast, people with organ failure and their family caregivers struggled to pinpoint when their illness began, or to speak openly about death, hoping instead to avoid further deterioration. Frail older people tended to be frustrated by their progressive loss of independence, fearing dementia or nursing home admission more than dying.

Conclusion. These contrasting illness narratives affect and shape the experiences, thoughts, and fears of patients and their carers in the last months of life. Palliative care offered by generalists or specialists should be provided more flexibly and equitably, responding to the varied concerns and needs of people with different advanced conditions. J Pain Symptom Manage 2015;50:216–224. © *2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Cancer, organ failure, frailty, serial interviews, qualitative longitudinal research, palliative care, end-of-life care, illness trajectories

Introduction

Quality care for people living with life-limiting illnesses is a global priority. Extending a palliative care approach to people with all advanced chronic conditions is a major challenge, particularly to those with noncancer illnesses who are relatively underserved.[1] Although early specialist palliative care can improve

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Address correspondence to: Scott A. Murray, MD, Primary Palliative Care Research Group, Centre for Population Health Sciences, The University of Edinburgh, Medical School, Teviot Place, Edinburgh, Scotland EH8 9AG, United Kingdom. E-mail: Scott.Murray@ed.ac.uk

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patient experiences and outcomes in parallel with oncology treatments,[2] palliative care is still strongly associated with cancer and preparing to die in the minds of patients, family caregivers, and professionals. A detailed understanding of the varied experiences of people dying with different conditions and their family and professional caregivers can help policymakers and clinicians design and deliver appropriate and person-centered services.[3,4] This is particularly important at a time when new specialist and generalist models for sustainable palliative care are being developed and reviewed globally in response to increasing demographic needs.[2,5,6]

Many people formulate personalized narrative accounts in the face of life-threatening conditions to help them make sense of events and reconstruct their identity or sense of self.[7] It is important for clinicians to gain narrative competence, so as to be able to hear and respond to patients' histories.[8] It can be helpful to draw on narrative methods to understand the biographical disruption that can accompany advanced illness from beginning to end.[9–11] Over the last decade, three typical patterns of functional decline in the last phase of life have been described and widely accepted.[12] These trajectories include acute decline (typically aggressive cancers), fluctuating deterioration (typically organ failure), and gradual decline (usually frailty or dementia), as illustrated in Fig. 1.[13] Physical changes are usually accompanied by psychological, social, and existential fluctuations in the well-being of patients themselves and also in their family caregivers.[14,15] We expected that experiences might differ significantly among these proposed patient groups. We thus sought to compare and contrast how patients with different advanced conditions, and their family and professional caregivers, perceived their deteriorating health to gain insights into how best to provide effective person-centered care for people living with these three different patterns of decline.

Methods

Study Design

In-depth analysis of data from comparable studies can generate unique insights into complex issues that are important in developing patient-centered health care.[16] We synthesized data from eight qualitative longitudinal studies carried out by the authors over the past 10 years. The studies were all with patients nearing the end of life, their family caregivers, and key professionals and were conducted using the same methodology, namely serial in-depth interviews using a narrative approach.[17,18] Three studies explored experiences of cancer—lung, glioma, and colorectal.[19–21] Three were with people with organ failure—heart failure, chronic obstructive pulmonary disease (COPD), and liver failure.[22–24] One study was of older people with frailty (unpublished PhD thesis) and one with South Asian participants representing all three trajectories.[25] In each study, we had used purposive sampling to gain a broad range of perspectives encompassing age, gender, deprivation, and social diversity, as well as clinical indicators of advanced illness in each patient group. All the patients were considered to be at risk of dying within the next 12 months by the clinicians who helped enroll them into the studies. We had used qualitative, longitudinal, and multiperspective interviews to explore the complex and dynamic experiences in the last years of life.[17,18] The patients had been

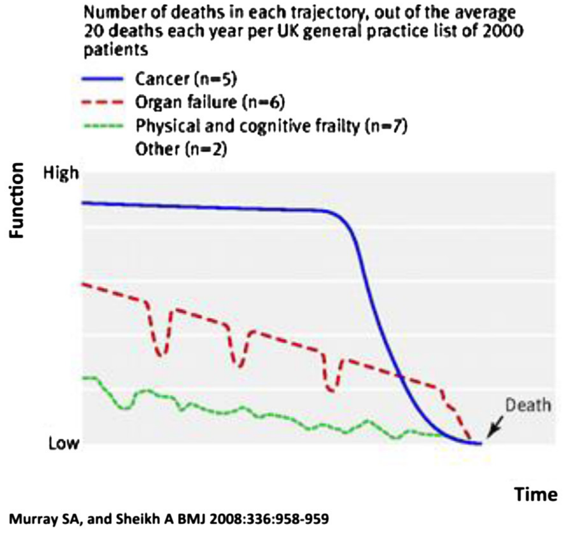

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Fig. 1. The three main trajectories of decline at the end of life.