Special Article

A Relational Ethical Approach to End-of-Life Delirium

David Kenneth Wright, PhD, RN, CHPCN(C), Susan Brajtman, PhD, RN, and Mary Ellen Macdonald, PhD

Department of Biomedical Ethics (D.K.W.); and Faculty of Dentistry (M.E.M.), McGill University; Department of Palliative Care (D.K.W.), Jewish General Hospital; Pediatric Palliative Care Research (M.E.M.), Montreal Children's Hospital of the McGill University Health Centre, Montreal, Quebec; School of Nursing (S.B.), University of Ottawa; and Bruyère Research Institute (S.B.), Ottawa, Ontario, Canada

Abstract

Delirium is a condition of acute onset and fluctuating course in which a person's level of consciousness and cognition become disturbed. Delirium is a common and distressing phenomenon in end-of-life care, yet it is underrecognized and undertreated. In this article, we review qualitative descriptions of the delirium experience in end-of-life care, found through a systematic search of academic databases, to generate insight into the intersubjective nature of the delirium experience. Our analysis of retrieved studies advances an understanding of the relational ethical dimensions of this phenomenon, that is, how delirium is lived by patients, families, and health care providers and how it affects the relationships and values at stake. We propose three themes that explain the distressing nature of delirium in palliative care: 1) experiences of relational tension; 2) challenges in recognizing the delirious person; and 3) struggles to interpret the meaning of delirious behaviors. By approaching end-of-life delirium from a perspective of relational ethics, attention is focused on the implications for the therapeutic relationship with patients and families when delirium becomes part of the dying trajectory. J Pain Symptom Manage 2013;■:■—■. *© 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Delirium, end-of-life care, hospice, palliative care, qualitative research, relational ethics

Introduction

Patients are fundamentally and irreducibly complex. An appreciation of patients as *whole persons* has motivated a paradigm shift within contemporary health care, urging that integrated attention be paid to the dynamic and multidimensional nature of how health is experienced and lived.

Health care providers of terminally ill patients combine approaches that focus on diagnosis and management of medical problems together with approaches that focus on the

Address correspondence to: David Kenneth Wright, PhD, RN, CHPCN(C), McGill University, 3550 University Avenue, Suite 030, Montreal, Quebec H3A 2A7, Canada. E-mail: dwrig079@uottawa.ca

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emotional, social, and spiritual aspects of the experience to promote well-being and quality of life. End-of-life care, therefore, requires working with concepts of health and illness in ways that advance both scientific and experiential understandings. Writing from a nursing perspective, Thorne[1] argues that clinicians engage both objective and subjective approaches to fully grasp "the dynamic, complex, and difficult-to-articulate realities reflective of the holistic, sensate, individualistic agents we understand the targets of our care to represent."[1] (p. 277) By integrating scientific and experiential knowledge, end-of-life caregivers can better understand and care for their patients. Collectively, this knowledge furthers our appreciation of what it means to be fully human as our patients live their health, illnesses, and deaths.

A key element of palliative care wisdom is the concept of total pain. This was the term used by Dame Cicely Saunders to underscore and direct caregiving attention to the physiological, psychological, social, and spiritual dimensions of a patient's suffering. The idea of total pain within palliative care "both reflects and reinforces a relational, intersubjective notion of the person/self."[2] (p. 159) It is meant to alert caregivers of the dying that suffering at the end of life goes beyond *and* is underpinned by the "physical agonies of the dying experience."[3] (p. 390)

Delirium, like pain, is a phenomenon for which a holistic meaning-oriented understanding is relevant and important. Patients with delirium experience a paradoxical reality of contradictions (e.g., real-unreal, awake-dreaming, present-past) and live through scenes that are dramatic and provoke strong emotions such as anger, fear, panic, and insecurity.[4] Breitbart et al.[5] conducted a prospective systematic evaluation of delirium recall and related distress in a sample of 101 patient/family/nurse triads. Of this sample, severe distress was reported by 80% of patients, 76% of family members, and 73% of nurses. More recently, Bruera et al.[6] found that in a sample of 99 advanced cancer patients with a resolved delirium, 74% of these recalled the experience, and many were distressed by memories of delusional thoughts, psychomotor agitation, and disorientation to time and space. Delirious patients have difficulty communicating the nature of their distress and feel misunderstood by those around them, and families and health care providers are at a loss for how to reach these patients to create meaningful and supportive moments of interpersonal connection.[7–9]

Over the past two decades, delirium research has collectively focused almost exclusively on pathophysiology, incidence, etiology, prognosis, prevention, detection, evaluation, and management.[10] Modern medicine tends to reify clinical syndromes and symptoms as problems located in the body and of a natural order for which evidence-based solutions can be developed and implemented. Thus, conceptualization of end-of-life delirium (EOLD) as a *problem to be managed* dominates the current medical discourse. This perspective, although important and valuable, is incomplete. For example, whereas it is necessary to understand and respond to biomedical etiologies of delirium (e.g., hypercalcemia, dehydration, infection), manifestations of delirium also can lead health care providers to ask important questions about the patient's psychosocial experience of dying, including expressions of fear, uncertainty, unpreparedness, unfinished business, and emotional unrest.[11] Knowledge about EOLD for palliative care research and practice should account not only for clinical assessment and management but also for how delirium may affect the interpersonal relationships between patients, families, and health care providers in end-of-life care.

The relevance of attending to the interpersonal and intersubjective dimensions of the delirium experience has been demonstrated in qualitative studies about delirium in the acute care setting. A review of such studies by Bélanger and Ducharme[10] describes that, with delirium, patients feel anxious, isolated, scared, and frustrated. Patients in a delirious state of mind seek to protect themselves by hiding their confusion and flee from or fight off what they perceive to be a personal threat. Nurses, meanwhile, have difficulty trusting their delirious patients, who "became strangers who seemed to be in a separate world and whose reactions were unpredictable." (p. 311) In delirium, relationships between nurses and their patients, therefore, are threatened. Nurses approach their patients with a desire to be present and helpful yet also feel a need

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