

Special Section: Studies to Understand Delirium In Palliative Settings (SUNDIPS)

A Relational Ethical Approach to End-of-Life Delirium

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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 2014;48:191–198. © 2014 American Academy of Hospice and Palliative Medicine. 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

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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, Thorne¹ 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 Ducharme¹⁰ 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

to “keep their guard up,” (p. 311) given the context of mistrust that delirium creates.

These findings highlight the usefulness of considering EOLD from a perspective of *relational ethics*. Relational ethics is an approach to health scholarship and clinical practice that centers the quality of human relationships as the focus of our ethical attention. According to Bergum:¹²

If relational space is the location of enacting morality, ethical considerations occur in every situation, every encounter, and with every patient. If all relationships are the focus of understanding and examining moral life, then it is important to attend to the quality of relationships in all professional practices. (p. 127)

A relational ethical understanding of health care practice shines a spotlight on the relationships that matter to our patients and families and on how we engage with them in the clinical setting. When caregivers of terminally ill patients orient themselves toward relational ethical understanding of EOLD, they may become more sensitive to the ways in which this phenomenon affects the self-perceived well-being of patients and families, as well as the ways in which efforts to provide for the patient's good death are facilitated or hindered.¹³

Methods

To explore the relational ethical dimensions of EOLD, we conducted a literature review to identify empirical perspectives about how EOLD is lived in end-of-life care. A systematic search of academic databases (MEDLINE, CINAHL, and PsycINFO) was conducted, combining subject headings and key words for three main topics: 1) delirium, 2) end-of-life care, and 3) lived experience, for years 2000–2013. A research librarian assisted in this process. The first author screened the titles and abstracts of the retrieved articles (more than 300), and found 11 articles relevant for the purposes of this review. Two categories of articles were included as follows: qualitative research studies investigating the EOLD experience from the perspective of patients, families, or health care providers and case study reports containing narrative descriptions of EOLD as a lived experience. Excluded articles

included those that focused primarily on the prevalence, detection, diagnosis, or management of EOLD; reported exclusively quantitative research; did not report original research; or were not primarily focused on delirium. Table 1 lists the included articles.

Results

The key findings from the articles retrieved focus on the experiential, intersubjective, and relational ethical dimensions of delirium at the end of life from the perspectives of patients, families, and health care providers. Our analysis proposes three themes: 1) experiences of relational tension; 2) challenges in recognizing the delirious person; and 3) struggles to interpret the meaning of delirious behaviors. Together, these themes illuminate certain aspects of the delirium experience in palliative care that explain patient, family, and health care provider distress.

Experiences of Relational Tension

Interviews with patients and with families about the delirium experience demonstrate that delirium can seriously complicate intimate family relationships in the end-of-life care setting. For example, one patient with advanced cancer recalled that in delirium “I was really mad at my daughter and my sister because they wouldn't let me up. They [were] keeping me tied down ... I was mad at them—probably as mad as I've ever been.”¹⁴ (p. 167) In an interview study with bereaved family members in Australia, Greaves et al.¹⁵ reported that families felt that their delirious loved ones “hit hardest at the ones nearest them.” (p. 7) Interestingly, family members in this study talked not only about the delirious patient's behaviors toward them but also about how they themselves responded. Some participants described becoming *afraid* of the delirious person: “... I'd get the shakes when I walked in the front door [of the hospice] not knowing what [would greet me].” (p. 8) Some described lashing back, a response that provoked emotions of shame and guilt:

... I got angry at her ... [I was] sitting down on the floor with my back up against the wall looking at her ... I just said ... “Why, why do you hate me so much, what have I ever done

Table 1
Studies Identified Through the Literature Search

Source	Year	Study Methodology
Cohen et al. ¹⁴ "Delirium in advanced cancer leading to distress in patients and family caregivers."	2009	Qualitative research; semi-structured interviews with patients ($n = 34$) and family caregivers ($n = 37$) in the U.S.
Greaves et al. ¹⁵ "Family caregivers' perceptions and experiences of delirium in patients with advanced cancer."	2008	Qualitative research; semi-structured interviews with bereaved family members ($n = 10$) in Australia.
Agar et al. ¹⁶ "Making decisions about delirium: a qualitative comparison of decision making between nurses working in palliative care, aged care, aged care psychiatry, and oncology."	2012	Qualitative research; semi-structured interviews with nurses ($n = 40$) in Australia.
Brajtman ¹⁷ "Terminal restlessness: perspectives of an interdisciplinary palliative care team."	2005	Qualitative research; focus groups with interdisciplinary palliative care health providers in Israel.
Brajtman et al. ¹⁸ "Caring for patients with terminal delirium: palliative care unit and home care nurses' experiences."	2006	Qualitative research; semi-structured interviews with nurses ($n = 9$) in Canada.
Shury ¹⁹ "Managing delirium in the palliative care of older people."	2002	Case study
Cameron ²⁰ "Toward understanding the unrepresentable in nursing: some nursing philosophical considerations."	2006	Case study
Namba et al. ²¹ "Terminal delirium: families' experience."	2007	Qualitative research; semi-structured interviews with bereaved family members ($n = 20$) in Japan.
Brajtman ²² "Helping the family through the experience of terminal restlessness."	2005	Qualitative research; semi-structured interviews with bereaved family members ($n = 20$) in Israel.
Brajtman ²³ "The impact on the family of terminal restlessness and its management."	2003	As above (same research study as Brajtman ²²)
Barham ²⁴ "The last 48 hours of life: a case study of symptom control for a patient taking a Buddhist approach to dying."	2003	Case study

to deserve this, because I just cannot understand why you are behaving like that to me ... I was extraordinarily ashamed of myself for actually saying those things to her ... I was just so tired. (p. 8)

Challenges in Recognizing the Delirious Person

Health care providers are emotionally affected by the suffering they witness in delirium and report that these experiences are incompatible with their own expectations of a peaceful and dignified death for their patients.^{16–18} One way in which delirium can undermine a dignified death may be that, when delirious, patients behave in ways that are surprising and disturbing to those who know them. As one family member said:

I would cope better seeing [my husband] like this if I knew for sure he wasn't aware of the way he is behaving. He would hate to know he is so agitated, saying the things he is saying and sounding so aggressive. It is not like he has ever been before.¹⁹ (p. 17)

Cameron²⁰ presents a case study about a terminally ill patient in hospital who becomes delirious overnight. She describes the dialogue that occurs the following morning between the night nurse and the day nurses during change-of-shift report. In their discussion, these nurses systematically consider various medical hypotheses that might explain the mental status change observed, and they implement various pharmacological and non-pharmacological interventions in response. Simultaneously, the nurses interpret the patient's delirious experience through what they know about him *as a person*. Specifically, they venture hypotheses about the meaning of the delirious experience in the context of what they know of his relationship with his wife and of his current feelings concerning his diagnosis and impending death. For example, when considering his visual hallucination that pieces of the sky are falling and hitting him on the head, a nurse reasons:

He is just plain scared. He needs to work out that this may be his last exacerbation ... His sky really is falling down ... Last night I think he really saw what is stretching out in

front of him and he is very very frightened.
(p. 27)

About this case, Cameron concludes that:

At first sight we could say that this is a man with an episode of delirium. Yet this is the first layer to understand the text of this situation, an initial albeit necessary approximation only. If we stayed with this layer alone, we would be unable to understand the interwovenness of the many texts present here ... [the] nurse is able through her present engagement to see the hidden texts that lie behind this delirium. (p. 28)

When people are invited to tell their stories of EOLD, further understanding is built concerning such “hidden texts,” that is, the multiple layers of meaning that people attribute to experience. Namba et al.²¹ conducted interviews with bereaved family members of cancer patients who had delirium in the two weeks before death. Participants stressed that incoherent speech that was perceived as strange to health care providers often held meaningful significance in the context of the patient’s and family’s personal life story. Participants, therefore, expressed a desire for health care providers to respect the subjective world of patients during delirious episodes and actively inquire about what a patient’s delirious behavior might mean, instead of adopting a dismissive or reality-orientation approach. From the perspective of these family members, recognizing the delirious patient as who they are and understanding an underlying meaning to his or her communication seems to be important. In essence, it appears that a major source of family distress is the patient becoming *unrecognizable*, given behaviors that are drastically out of character for that person. When patients become unrecognizable, families experience this as *loss of the person* that they know and love.¹⁵

Struggles to Interpret the Meaning of Delirious Behaviors

Research by Brajtman^{22,23} shows that suffering in EOLD spans physical, emotional, and spiritual dimensions. Family members in her research described a diversity of beliefs concerning the behavioral manifestations of EOLD. For example, some families interpreted agitated behavior as though their loved ones were scared

to die and were “expressing their feelings toward the enemy [death] who was advancing relentlessly toward them.”²² (p. 76) Other family members believed that patient restlessness was instead a bodily expression of anger, frustration, or feeling out of control. The interesting common thread to these beliefs is the attribution of agency to the delirious person and an inferred sense of purpose that underlies the behavioral manifestations witnessed. These findings are similar to a case study report by Barham²⁴ that describes a family’s interpretation of terminal delirious behaviors as the presence of previously deceased loved ones coming to comfort and accompany the patient during her dying:

Sarah became very restless ... having hallucinations/visions and would toss and turn while moaning, pluck at her sheets and sometimes reach out to someone or something in the air ... *The family believed* that because of Sarah’s kindness and compassion during her life, she was experiencing blissful heavenly visions and was meeting loving friends and enlightened beings who had already passed/died before her. (p. 248, emphasis added)

In the aforementioned example, the family infers a cause for the patient’s restlessness and hallucinations, and this appears to bring them comfort. In other cases, however, family members experience profound uncertainty as to the source of delirious suffering. These family members need to understand a *cause* for their loved one’s delirium, and some may blame medications as the source of the problem.¹⁴ Others may interpret delirious behavior as a sign of impending death or as a cry for assistance. These family members are likely to feel profound helplessness and may benefit from reframing interventions that provide a physiological explanation for the disturbing behavior.¹⁹

During the end-of-life phase, families are likely to place a high value on the opportunity to engage in meaningful communication with the dying patient, including the opportunity to say good-bye. When family members do not understand the cause of EOLD, they may feel ambivalent about palliative care interventions, such as analgesia or pharmacological sedation. A family member in Brajtman’s²³ study stated that “... I didn’t know everything that I needed

to know, but because I didn't ask didn't meant that I didn't want to know." (p. 458) When families do not receive the information they need, it is possible that this erodes their trust in health care providers. Greaves et al.¹⁵ suggested that the family members in their study:

... experienced dilemmas in relation to HCPs who instigated treatments that they perceived added to the delirium or caused other cognitive impairment, such as sedation. These experiences may have resulted in *loss of faith* in the HCPs caring for their family members, and further contributed to their *regret and guilt* about treatment decisions. (p. 10, emphasis added)

Discussion

Based on our literature review, it is evident that delirium poses unique relational challenges for patients, families, and health care providers in end-of-life situations. These are important to understand because of their potential impact on the overall end-of-life experience in palliative care settings. For example, a recent ethnographic study of a residential care hospice demonstrated that delirium undermines hospice caregiving efforts to provide patients and families with a *safe place* for dying.¹³ This happened not only because of discomfort and suffering but also through total transformation of the caregiving relationship. When patients became delirious, hospice caregivers were thrust into roles of vigilantly monitoring patient behavior and regulating patient-family interactions.

Poole and Mott²⁵ conducted a focus group study with nurses working in a large teaching hospital about their work with agitated older patients, including but not limited to those agitated as a result of delirium. They found that nurses' often felt feelings of frustration and irritation toward such patients. Nurses felt that agitated patients took too much of their time, for example, "nothing else gets done" (p. 309) and that this time pressure seriously affected the way they organized care of their agitated patients: "Sometimes it [mechanical restraint] makes them more agitated but you'd rather that so you can get out and get some of the other work done and come back to them later and calm them down." (p. 309) Comments by

these nurse participants such as "Here we go again," "You can have her," and "Why do I have to look after him?" (pp. 309–310) demonstrated that agitated delirium can irrevocably threaten the relational engagement between nurse and patient. Similarly, a participant observation and critical discourse analysis study of nurses' linguistic framings of delirious patients in hospital²⁶ shows how nurses describe their acutely confused older patients as disruptive, destructive, aggressive, threatening, and uncontrollable. During acute confusion, such discursive constructions take precedence over discourses of dignity and compassion, where the idea of "patients as persons who were undergoing a potentially frightening experience rarely featured in the nurses' constructions." (p. 172)

The implication here is that there is a crucial distinction between health care providers who primarily conceive of the challenges associated with delirium as problems for themselves and their work, and health care providers who primarily recognize and respond to delirium as a problem for the patient's and family's moral experience. By approaching EOLD from a perspective of relational ethics, attention is focused on the implications for the therapeutic relationship when delirium becomes part of the dying trajectory. For example, in the ethnographic study referred to earlier,¹³ a relational caregiving ethic of holistic patient-centered care was firmly established within the cultural fabric of the hospice setting. Therefore, despite the challenges to relational engagement that delirium posed, hospice caregivers in that setting continued to treat the patient as a *moral agent* when cognitive acuity was diminished. This meant recognizing that personhood and dignity remain at stake for the patient and family and, therefore, tailoring care in ways that continued to honor the patient's identity as a human being. Comments from hospice caregiver participants included, "I still try to treat them as, very much a human being with a disease" and "They're not objects that you're caring for, they're people, so um, you're still very much caring for a person." (p. 202)

There is wide consensus among researchers and educators working in the field of EOLD that educational efforts should be directed at raising awareness of how to detect delirium in the clinical setting and of standardized

evidence-based approaches to assessment and management. Whereas we acknowledge the significance of these very relevant and important educational goals, we recommend also that educational interventions be focused more broadly on how to engage with delirium as a *lived* experience. The goal should be to nurture a reflective awareness of the relational implications of the delirium experience for our patients and their families. Interprofessional educational interventions are particularly well suited for this purpose.²⁷ By bringing people from a variety of disciplinary perspectives together, the knowledge and skill of different team members will synergistically contribute to a deeper and more sophisticated understanding of how delirium in dying relates to quality of life and suffering, and ultimately how team members can best situate themselves in response.

Recommendations for Future Research

Given the significant implications of EOLD for the relational experiences of all who inhabit the palliative care setting, research is needed to further expand our insights about the ways in which delirium affects the end-of-life experiences of patients, families, and their professional caregivers. Qualitative inquiry, either as stand-alone research or as integrated into a mixed-method study, is particularly well suited to respond to this imperative.⁷ Qualitative methodologies, through their focus on understanding the multiple meanings that participants attribute to their own experiences,²⁸ are a powerful resource to: 1) understand our patients and their families through a holistic lens, 2) engage with their stories, and 3) tailor our care to match the complexity of their lived experience. Qualitative research about EOLD, such as the studies referred to above, can change the ways we hear our patients, the ways we engage with families, and the ways we interact with colleagues. Examples of questions to explore through future research might include: In what ways do patients and families from diverse ethnocultural backgrounds live through the delirium experience and approaches to care? In what ways do practices of delirium care differ between contexts in which people die?

A stronger understanding of the ways in which delirium affects the lived experiences of patients, families, and caregivers will develop

a knowledge base from which to develop supportive interventions. Ultimately, our future work should be geared toward developing knowledge that can inform us in how we respond as health professionals to the *total human experience* of delirium in end-of-life care.

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