Delirium as letting go: An ethnographic analysis of hospice care and family moral experience

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Abstract

Background: Delirium is extremely common in dying patients and appears to be a major threat to the family's moral experience of a good death in end-of-life care.
Aim: To illustrate one of the ways in which hospice caregivers conceptualize end-of-life delirium and the significance of this conceptualization for the relationships that they form with patients' families in the hospice setting.
Design: Ethnography.
Setting/participants: Ethnographic fieldwork was conducted at a nine-bed, freestanding residential hospice, located in a suburban community of Eastern Canada. Data collection methods included 15 months of participant observation, 28 semi-structured audio-recorded interviews with hospice caregivers, and document analysis.
Results: Hospice caregivers draw on a culturally established framework of normal dying to help families come to terms with clinical end-of-life phenomena, including delirium. By offering explanations about delirium as a natural feature of the dying process, hospice caregivers strive to protect for families the integrity of the good death ideal.
Conclusion: Within hospice culture, there is usefulness to deemphasizing delirium as a pathological neuropsychiatric complication, in favor of acknowledging delirious changes as signs of normal dying. This has implications for how we understand the role of nurses and other caregivers with respect to delirium assessment and care, which to date has focused largely on practices of screening and management.

Keywords

Delirium, ethics, ethnography, hospices, nursing, palliative care, qualitative research

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What is already known about the topic?

- Delirium is extremely common in dying patients and a source of distress for patients' family members.
- Much of the literature about end-of-life delirium focuses on improving screening and management practices.

What this paper adds?

- Our study found that in hospice caregiving practice, there is a perceived usefulness to acknowledging delirious changes as signs of normal dying.

Implications for practice, theory, or policy

- This study offers insight into why caregivers might fail to engage discourses of delirium as a problem-to-be-managed in their everyday work.

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*Délire is nothing but a mental distraction, an error of the
mind during wakefulness which causes it to judge badly
of things known to all.*

DIDEROT et d'ALEMBERT (1754)[1]

Background

The discipline of hospice and palliative care is grounded
by and oriented toward the idea of providing patients and
families with experiences of a *good* death.[2–4] The good
death is a moral construct, that is, it is something that we
ought to aspire to, that imagines experiences of wellbeing
in dying. Moral experience is therefore an appropriate
framework to consider peoples' experiences of end-of-life
care. According to Hunt and Carnevale,[5]

> Moral experience encompasses a person's sense that values
> that he or she deems important are being realised or thwarted
> in everyday life. This includes a person's interpretations of a
> lived encounter, or a set of lived encounters, that fall on
> spectrums of right-wrong, good-bad or just-unjust. (p. 659)

Concept analyses of the good death highlight specific
attributes such as mental awareness, retaining control,
being comfortable, achieving a sense of closure, optimizing
relationships in facing the end of life, and peaceful
memories for the bereaved.[6–8]

Delirium is extremely common in dying patients.
Prevalence rates vary between 20% and 40% in palliative
care settings, but this rate climbs as death approaches, up
to 85%–90% in the days and hours before death.[9,10]
Delirious patients manifest a wide variety of psychiatric
and psychological symptoms,[11] including anxiety, delusions, and mood changes.[12,13] Delirium can produce a chaotic scene in which the patient's thought disturbances
convey fear, anger, and mistrust, resulting in a high level
of family distress.[14] Qualitative accounts of the delirium
experience from the perspective of bereaved family members
demonstrate that in delirium, relationships themselves
come undone. Patients can become unrecognizable to their
families, who may recoil at the patient's behavior and
struggle to interpret the meaning of what is happening.[15]
Thus, delirium appears to be a major threat to the family's
moral experience of a good death in end-of-life care.

Methods

Methodological orientation

This article draws on data from a larger ethnographic study
that sought to explore the relationships between delirium
and good death within hospice caregiving culture. In this
article, we present findings that illustrate one of the ways
in which hospice caregivers conceptualize end-of-life
delirium and the significance of this conceptualization for
the relationships they form with patients' families in the
hospice setting.

The overarching goal of contemporary ethnography is to
"describe, interpret, and understand the characteristics of a
particular social setting with all its cultural diversity and
multiplicity of voices" (p. 348).[16] The methods of ethnography,
which include participant observation, interviews, and
document analysis, are implemented through prolonged
fieldwork during which the researcher is immersed in the
cultural environment under study. The ethnographic
approach therefore provides for a triangulation of methods
to arrive at as holistic an understanding as possible,[17] generated
through the researcher's active dialogical and participatory
engagement with the research setting.[18]

Setting of data collection

For this ethnography, we entered the landscape of hospice
care and committed to see, hear, participate in, and understand
the realities as lived by members of this caregiving
community. The setting for this study was a nine-bed freestanding
residential hospice, located in a suburban community
of eastern Canada. Hospice caregivers included
registered nurses and registered nursing assistants, physicians,
patient care attendants, counselors (psychology and
social work), and volunteers (including pastoral care and
music therapy). All of the patients cared for in this hospice
were living with incurable, terminal disease. The average
length of stay, from admission to death, was less than
2 weeks, with approximately half of all patients dying
within 5 days.

Description of sample

Ethnography is "typified by the priority placed on gaining
an emic perspective" (pp. 384–385).[19] For this reason, its
hallmark method is participant observation, where the
researcher seeks to understand how the various players
who inhabit a social setting "think, believe, and behave"
(p. 1029)[20] and ultimately, "how they understand their
world" (p. 218).[21] Participant observation is a means to
study human relationships, patterns, events, and environmental
context.[22] Fieldwork for this study ran for
15 months, beginning in June 2010. During this time, the
first author (D.K.W.) conducted 320 h of participant observation
over 80 field visits, including day, evening, and
night shifts.

A total of 28 hospice caregivers also participated in
semi-structured, audio-recorded interviews. This sample
of participants included registered nurses ($n = 6$), registered
nursing assistants ($n = 5$), nursing leaders ($n = 2$),
patient care attendants ($n = 3$), physicians ($n = 4$), psychologist
($n = 1$), social worker ($n = 1$), volunteers ($n = 5$),
and volunteer coordinator ($n = 1$). Each of these participants
was interviewed once. The average interview length

was approximately 45 min. The interviews began 3 months after fieldwork had commenced and were designed to enable participants to reflect about the nature of their work, about delirium, and about good deaths. The elapsed time between the onset of fieldwork and starting the interviews meant that D.K.W. had time to establish familiarity with hospice caregivers and the context of their daily practice. He had accompanied them in their work and had met many of their patients and families. Therefore, the interview conversations were rich discussions of specific cases and specific situations. This project received approval from the Research Ethics Board of the authors' university (File number H-10-09-04) as well as from a research ethics committee internal to the residential hospice. All participants provided informed consent.

Findings

Helping families to let go: "Death is a series of little goodbyes"

In this setting, we observed hospice caregivers to draw on a culturally established framework of *normal dying* to help families come to terms with clinical end-of-life phenomena. Specifically, they communicated to families an attitude reflecting the following beliefs: (1) death is a natural life event that need not be feared; (2) normal dying occurs through a series of predictable changes, including changes in consciousness and cognition; and (3) bearing witness to such changes facilitates preparation for eventual death. Guiding families through fear and uncertainty, and helping them to move to a place of peace and acceptance, was considered a noble caregiving goal in this setting. As the following volunteer described,

> If we make it [death] normal, and be there for support, and it'll be okay. It's not frightening, it really isn't frightening. If we think about it, things that are upsetting to us are things that are frightening because we don't know that that's the way it is. It's a first-time experience. (Volunteer)

In this setting, patients and family members were openly encouraged to acknowledge and talk about death. In contrast to medical environments where impending death is often obscured and denied,[23,24] the hospice gave rise to a counterculture in which ideas of openness toward death predominated. In every patient room, a poem was mounted on the wall that contained the following words: "We will be with you in your living and in your dying." As one nursing assistant explained,

> … people are scared in the hospital. People are petrified. And especially when they don't know what's going on with them. Here at least people know one thing. They know that they're dying. (Nursing assistant)

In helping family members through their unfamiliarity with the dying process, hospice caregivers demystified and normalized dying as a series of predictable changes. Furthermore, a major caregiving focus was helping family members to *let go* in the face of such changes; letting go of ideas of cure or illness reversal; letting go of wanting the patient to eat, drink, or get out of bed; letting go of previous patterns of communicating with the patient; and eventually, letting go of the patient himself or herself. As the following registered nurse articulated, guiding family members toward explicit acknowledgement of such predictable losses was believed to be beneficial to family members' psychological adjustment to impending death:

> Really we lose our loved ones in stages … Death is a series of little goodbyes. There's a goodbye to your mobility. There's a goodbye to everything, to wanting to eat, a goodbye to drinking. And then there's a goodbye to being able to talk, sometimes. And so, and then they see that their loved one is sleeping more. It's like, they're seeing these steps. And in some ways, if they've been, if there's been explanation, if there's been talking and exploring with them, they will actually very naturally themselves start to see it as, see it in those steps. And I think it can help them with the final, the final departure. When the person does physically leave their body, and that's it. You know? (Registered nurse)

Delirium as part of normal dying: "The brain's letting go"

As patients died, family members were perceived by hospice caregivers to be at risk for being harmed by experiences that they did not understand. Delirium was potentially threatening to the family's good death because it could produce frightening scenes that would be carried forward by family into bereavement. Delirium in dying was also disturbing because the subjective ways in which the patient lived through his or her delirious experience was a mystery. One of the most common questions families asked as their loved ones were dying was "Can he/she still hear me?" This speaks to the uncertainty families felt concerning the social presence of the dying patient. Because of the lack of cognitive access to patients in delirium, families struggled to interpret the extent to which their loved ones were comfortable or distressed in their delirious states. As one daughter of a delirious patient described, it is "… so difficult, not knowing what this is like for them."

In hospice, creating positive and peaceful images that would be remembered by family was a source of shared pride among hospice caregivers. In some cases, hospice caregivers helped families to progress from initial uncertainty and distress over delirious manifestations toward an appreciation of delirium as a positive experience. In the following example, a physician describes framing for

family hallucinations of deceased relatives as "beautiful," "privileged," and "comforting":

> [Sometimes] delirium [is] more specific to these kinds of visions, the deathbed visions [they] are commonly called. And that, I try to reassure the family that this is a very beautiful moment that you are witnessing now. We are very privileged that you can see your loved one not being alone right now … And this is extremely comforting for the family. Family members, when they witness that, are amazed and ecstatic. Because they say, "Wow, maybe my mother is with him now," or, "Maybe my brother came back." (Physician)

Hospice caregivers anticipated that their patients would change in the ways that they related to others and to the world around them. It was considered normal, in this setting, for patients to become withdrawn, confused, somnolent, or restless. Patients' thought processes, as assessed by hospice caregivers through everyday interaction with them, appeared to slow down. Rather than communicate to families that these conscious and cognitive alterations were disturbances, hospice caregivers normalized them, weaving them into a coherent system of meaning that preserved the integrity of the good death idea. The process of supporting families toward a normalized understanding of delirium happened not only orally but also in writing. Families were given "literature" on the dying process, which consisted of a 4-page typed document outlining the various "signs and symptoms" of imminent death. The document was titled "Preparing for approaching death" and stated that it was "a guideline, a road map." With this text, families were introduced to the various bodily changes in dying as the "normal, natural way in which the body prepares itself to stop." This document was also explicit in suggesting to families ways of responding to the person experiencing the conscious and cognitive changes associated with delirium. For example, with respect to disorientation, "Identify yourself by name before you speak rather than to ask the person to guess who you are." With respect to restlessness, "Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet, natural way." And with respect to vision-like experiences,

> Do not contradict, explain away, belittle or argue about what the person claims to have seen or heard. Just because you cannot see or hear it does not mean it is not real to your loved one. Affirm his or her experience. They are normal and common.

Messages such as these were thus targeted efforts at establishing for families a normalized understanding of delirious changes as inherent to a natural dying process. It was hoped that such messages would facilitate the family's letting go of the patient, as described by the hospice psychologist in the following quote:

> … it's the physical changes … and delirium's another one that gets people moving toward … "Okay, this person's changing" … the little deaths that that person is having, um, are, the person is changing and leaving. You know, and in the big picture, that's helpful to the family. Hard at the moment, but … it does help the reality check, and get us talking about the elephant in the room … Yeah, that the brain's letting go. Because each system is letting go. (Psychologist)

Externalizing moral responsibility: "That wasn't your Dad"

Previous research with family members about their experiences at end of life demonstrates that delirium seriously complicates intimate family relationships. Family members have described emotions of fear, shame, and guilt concerning their loved ones' delirious behavior, as well as the ways they themselves responded to them during such difficult relational encounters.[15] In conceptualizing delirium as an expected change in dying, hospice caregivers invited family members to externalize responsibility for such disturbing encounters. This means that they proffered an interpretation of delirium as causally related to the disease process, beyond the family's control and unrelated to the patient's personality and family relationships. Recall that the family's good death is a moral experience in which *values that matter* are at risk of being thwarted by traumatic events. Thus, by constructing and sharing an interpretation of delirium as an unfortunate but normal phenomenon, for which family members are not to blame, hospice caregivers strived to protect the integrity of the family's good death. Such efforts were particularly relevant when clinical reversal of delirium was impossible:

> Sometimes we can't make it [delirium] better … we pull out every stop, and everything we do sometimes can't help. But comforting the family, and explaining [to them] what's going on from our perspective, can help the family's anxiety.
>
> Interviewer: So what sorts of things do you do to comfort or to reassure the families?
>
> Well the first thing is, you might take them out of the room. And you sit down and talk to them. And tell them that, try and explain what's happening with their loved one. Um, and try to explain to them that it's not, nothing that they're doing, that's for sure. And it's not, sometimes the patient's, it's out of the patient's control. (Registered nurse)

Thus, in order to minimize the threat of angry delirious communication to a family's moral experience of dying, hospice caregivers would conceptually isolate the patient's behavior from his or her personhood, attributing it instead as an unfortunate but inherent feature of disease:

> Sometimes helping the family to realize that sometimes, the delirium, it's the disease. The delirium speaking … and the

person has totally changed personality. And in a sense they'll realize they've already suffered the death of the person they knew. Now they're dealing with the disease person … And yes sometimes it's to give people the space, and say "Yes, it's okay to mourn that." And to recognize it … You just try and help people realize that sometimes disease will do things. And it's not necessarily the same person that we've loved. It's almost like a Jekyll and Hyde thing that we're talking about. And so that's all you can do. All you can do is offer them that. Yeah. And what they do with it, in the long run, obviously they need to integrate that. (Volunteer pastoral care provider)

This passage shows that in helping family members to create a moral experience of the good death that they will be able to "integrate" over time, there is usefulness to the idea of social, personal, and/or relational death as preceding bodily death in delirium. Families were encouraged to realize that the person before them, behaving in unsettling and even horrifying ways, was actually *not* their loved one.

While offering to families interpretations that relied on understanding the dying delirious person as absent, missing, or already dead served a purpose as described above, it is important to note that hospice caregivers were nonetheless engaged in promoting a reverence and respect for the lived life of the delirious person. In other words, while they might have, for the sake of the family's good death, offered explanations that denied the patient's social presence, they simultaneously affirmed the identity of delirious patients as existential beings whose life's value was unaffected by delirium, as articulated in the following reflection:

> When you can show that you're caring for a person by the thoughtfulness of how you do the care, that you're still speaking to the patient, that you're still being very considerate of how you do it, that's also very reassuring for the family too. And it helps them know that they can still hold their loved one's hand, they can still be present … Because the family … they have a hard time sometimes losing the patient's awakeness. And yet, they also realize, "Well when my loved one's awake he's totally confused, and that's no good either." And so it's teaching them how they can be present still to their loved one, even though their loved one can't talk back anymore. (Registered nurse)

Discussion

According to Geertz,[25] "A people's ethos is the tone, character, and quality of their life, its moral and aesthetic style and mood; it is the underlying attitude toward themselves and their world that life reflects" (p. 127). Our experience of fieldwork allowed us to generate insight into the ethos of hospice. In the preceding sections, we elaborated on findings that illuminate this ethos, and subsequently described one of the ways in which it influences the conceptualization of delirium and the care of families when patients become delirious before they die.

This article has described just one of the ways that hospice caregivers conceptualize delirium and the influence of this on their care. Our larger study enabled us to discern other conceptualizations, and these will be the focus of forthcoming publications. Briefly, our larger analysis revealed that delirium was seen by hospice caregivers to be an embodied experience of mental suffering or mental wellbeing, where these interpretations were informed by observations of patients' consciousness, cognition, emotions, and relationships. Mental suffering and mental wellbeing appeared to be organizing constructs that oriented and directed hospice caregivers in their facilitation of good deaths. The central concern, to hospice caregivers, was whether a patient or family was distressed. Distress demanded response, as it undermined the patient and family's experience of inhabiting a safe place as death approached. This article has focused on one such response, offering to families' interpretations of delirium that will protect their moral experience of a good death.

In our current era of evidence-based practice, we are striving for consistency of definition for delirium and the standardization of clinical approaches to assessment and management, with the assumption that this will improve practice.[10] This is thought to be a particularly pressing need given the widespread concern that currently, many patients with delirium are missed, particularly by palliative care nurses, and thus receive inadequate care.[26–29] In order to comprehend and to address this issue, we require a stronger understanding of how nurses and other caregivers construct their daily practice. To date, studies appear to reflect that nurses too often fail to identify the core features of delirium in their patients, and that they fail to make use of the notion of delirium in their clinical language and reasoning, thus rendering their mental status assessments superficial and unhelpful.[30,31] Some authors have sounded an alarm of ethical concern for the wellbeing of delirious patients perceived to be neglected through substandard nursing.[32,33] According to Agar et al.,[34] who interviewed 40 nurses about their perspectives on delirium assessment and management, the problem is that nurses are not contextualizing their assessments and observations of patients within a "delirium definitional framework" (p. 8). The conventional wisdom is that nurses in practice should be better sensitized to the concept of delirium—primed to better observe for, identify, and respond to situations of delirium as a routine and integral aspect of their everyday work.[35]

We do not dispute the importance or relevance of considering the care of delirious patients from a screening and management perspective, and no doubt nurses everywhere should be competent in delirium best practices. Our findings, however, demonstrate that the issue of delirium for hospice care is about more than merely understanding how to "recognize" and "manage" delirium. We found in this study that there is usefulness in hospice caregiving practice to deemphasizing the conceptualization of delirium as

a pathological neuropsychiatric complication, in favor of acknowledging delirious changes as signs of normal dying. Accounting for the relational work that nurses and other caregivers enact with families in end-of-life care should deepen our understanding about how and why caregivers engage, or fail to engage, discourses of delirium as a problem-to-be-managed in their everyday work. In this study, we found that the practice of offering to families explanations about what normal dying looks like is more than provision of information. Rather, it is a process of structuring family moral experience—offering explanations of illness-in-dying that are commensurate with the good death paradigm. Hospice caregivers provided a meaning scaffold through which images and experiences that challenged the good death, including perturbations of consciousness and cognition perceived to be upsetting, were positively reframed as morally acceptable. This work was believed to be important in supporting families through the death of their loved one, and also to set them up for a healthy bereavement.

Johnson et al.[36] examined dialogue between team members and families regarding the withdrawal and withholding of life supportive interventions in the intensive care unit. Discussions between caregivers and families in their study were interpreted as contributing to a therapeutic narrative, meaning "a story which frames therapeutic events as well as the patient's illness experience in a meaningful and psychologically comforting way for families and health care providers alike" (p. 275–276). The authors suggested that the motivation for striving toward such an overarching story lies in "its promise to bring desperately desired coherence, meaning, and a confident basis for action" (p. 277). We observed a similar search for coherence and meaning concerning delirium to be a feature of caregiver–family relationships in this hospice. Families often lacked any prior experiences with death and dying or did have previous experiences that were traumatic. Hospice caregivers supported these families by providing consistent messages about what normal dying looks like, as well as by reframing potentially negative interpretations into more positive ones.

Hadders[37] conducted a study in a Norwegian hospital palliative care unit that examined the ways in which nurses prepare family members for the death of the patient and include them in after-death care. His findings are relevant here for understanding the ways hospice caregivers engaged with families toward helping them to structure a moral experience of hospice that would be comforting to them over time. According to Hadders,

> Biomedical signs of imminent death play an important role when it comes to including relatives in good time and making them aware of the fact that biomedical death is approaching. Information about medical signs of imminent biological death constitutes a powerful tool for nurses as they negotiate

relatives' participation in leave-taking events. Unfamiliar biomedical phenomena are explained and put in a timeframe. (p. 227)

Likewise, in our study, teaching about the signs of normal dying functioned as a tool for hospice caregivers as they helped family members negotiate a good death experience. When delirium appeared irreversible and was distressing, hospice caregivers appealed to the idea that the patient had already experienced a form of social death. This was meant to soften for families the pain caused by delirious behavior that was perceived as hurtful. Importantly, such appeals did not detract from hospice caregivers' commitment to a person-centered approach to care that involved engagement with the patient's social biography. Thus, hospice caregivers engaged competing and contradictory interpretive frameworks in their care of delirious patients and their families. While they might encourage families to acknowledge that "this is not my father talking," they were also careful to demonstrate a recognition of personhood to families, conveying an impression that "this nurse is not just caring for a patient, she's caring for my Dad." In Hadders' study, when families chose to participate in after-death care with the nurse, Hadders found that "Throughout post-mortem care, [palliative unit] nurses and relatives oscillate between attitudes of nearness to and distance from the deceased, who can be experienced as both a sentient being and an inanimate body" (p. 231). For Hadders, through post-mortem care, nurses engage in "parallel processes [that] accentuate both social life and social death" (p. 231). In this way, just like in our current study, palliative caregivers facilitated for families a process of letting go while holding on.[38] The implication then for the diverse ways in which delirious patients in our study were conceptualized is not about which interpretation prevails (i.e. the patient as person or the patient as a dying body) as both interpretations can be meaningful, serve a useful purpose, and be simultaneously held by caregivers and families. While such competing interpretive frameworks were surprising to discover during fieldwork, it is reasonable that in the context of a condition which by definition follows a fluctuating course, caregivers and families require a flexible and creative approach to working through the variety of delirious manifestations that they witness. Such an approach is probably especially relevant given the ways in which delirious patients interact with and relate to the world around them, which often change from one moment to the next.

Conclusion

We found in this study that conceptualization of end-of-life delirium is culturally bound, that is, influenced by the broader values and priorities of hospice caregiving practice. One such value is a commitment to offer to families

interpretations of the dying experience that will be comforting to them over time. Other practice settings seeking to improve their practices with respect to delirium should think more broadly than best practices of screening and management and engage in a critical reflection about their own local cultural ethos. We suggest the following questions to facilitate such a reflection: What does a good death mean in our context? What do ideas of family care mean in our setting? What is at stake for the good death when our patients become delirious?

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The authors have no conflicts of interest to declare.

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References

1. Berrios GE. Délire: in Encyclopédie ou dictionnaire raisonné des sciences, des arts, et des métiers (Volume 4, 1754) DIDEROT et d'ALEMBERT. *Hist Psychiatr* 1999; 10: 536–541.

2. Broom A and Cavenagh J. Masculinity, moralities and being cared for: an exploration of experiences of living and dying in a hospice. *Soc Sci Med* 2010; 71: 869–876.

3. Clark D and Seymour J. *Reflections on palliative care.* Philadelphia, PA: Open University Press, 1999.

4. Coward H and Stajduhar KI (eds). *Religious understandings of a good death in hospice palliative care.* Albany, NY: State University of New York Press, 2012.

5. Hunt MR and Carnevale FA. Moral experience: a framework for bioethics research. *J Med Ethics* 2011; 37: 658–662.

6. Kehl KA. Moving toward peace: an analysis of the concept of a good death. *Am J Hosp Palliat Me* 2006; 23(4): 277–286.

7. Kring DL. An exploration of the good death. *Adv Nurs Sci* 2006; 29(3): E12–E24.

8. Ruland CM and Moore SM. Theory construction based on standards of care: a proposed theory of the peaceful end of life. *Nurs Outlook* 1998; 46(4): 169–175.

9. LeGrand SB. Delirium in palliative medicine: a review. *J Pain Symptom Manag* 2012; 44: 583–594.

10. Leonard M, Agar M, Mason C, et al. Delirium issues in palliative care settings. *J Psychosom Res* 2008; 65: 289–298.

11. Macleod AD. *The psychiatry of palliative medicine: the dying mind.* 2nd ed. New York, NY: Radcliffe Publishing, 2011.

12. White S and Bayer A. Delirium—a clinical overview. *Rev Clin Gerontol* 2007; 17: 45–62.

13. Stagno D, Gibson C and Breitbart W. The delirium subtypes: a review of prevalence, phenomenology, pathophysiology, and treatment response. *Palliat Support Care* 2004; 2: 171–179.

14. O'Malley G, Leonard M, Meagher D, et al. The delirium experience: a review. *J Psychosom Res* 2008; 65: 223–228.

15. Wright D, Brajtman S and Macdonald ME. A relational ethical approach to end-of-life delirium. *J Pain Symptom Manag* 2014; 48(2): 191–198.

16. Holloway I and Todres L. The status of method: flexibility, consistency and coherence. *Qual Res* 2003; 3(3): 345–357.

17. Maxwell JA. *Qualitative research design—an interactive approach.* 2nd ed. Thousand Oaks, CA: SAGE, 2005.

18. Atkinson P, Coffey A and Delamont S. *Key themes in qualitative research.* Walnut Creek, CA: AltaMira Press, 2003.

19. Savage J. Ethnographic evidence: the value of applied ethnography in health care. *J Res Nurs* 2006; 11(5): 383–393.

20. Brink PJ and Edgecombe N. What is becoming of ethnography? *Qual Health Res* 2003; 13(7): 1028–1030.

21. Delamont S. Ethnography and participant observation. In: Seale C, Gobo G, Gubrium JF, et al. (eds) *Qualitative research practice.* Thousand Oaks, CA: SAGE, 2004, pp. 217–229.

22. Robinson-Wolf Z. Ethnography: the method. In: Munhall PL (ed.) *Nursing research: a qualitative perspective.* 4th ed. Sudbury, MA: Jones and Bartlett Publishers, 2007, pp. 293–330.

23. Costello J. Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *J Adv Nurs* 2001; 35(1): 59–68.

24. Kaufman SR. Intensive care, old age, and the problem of death in America. *Gerontologist* 1998; 38(6): 715–725.

25. Geertz C. *The interpretation of cultures: selected essays.* New York, NY: Basic Books, 1973.

26. Barnes J, Kite S and Kumar M. The recognition and documentation of delirium in hospital palliative care inpatients. *Palliat Support Care* 2010; 8: 133–136.

27. Rao S, Ferris FD and Irwin SA. Ease of screening for depression and delirium in patients enrolled in inpatient hospice care. *J Palliat Med* 2011; 14(3): 275–279.

28. Rice KL, Bennett M, Gomez M, et al. Nurses' recognition of delirium in the hospitalized older adult. *Clin Nurse Spec* 2011; 25(6): 299–311.

29. Smith J and Adcock L. The recognition of delirium in hospice inpatient units. *Palliative Med* 2011; 26(3): 283–285.

30. Inouye SK, Foreman MD, Mion LC, et al. Nurses' recognition of delirium and its symptoms. *Arch Intern Med* 2001; 161: 2467–2473.

31. Steis MR and Fick DM. Are nurses recognizing delirium? A systematic review. *J Gerontol Nurs* 2008; 34(9): 40–48.

32. Dahlke S and Phinney A. Caring for hospitalized older adults at risk for delirium: the silent, unspoken piece of nursing practice. *J Gerontol Nurs* 2008; 34(6): 41–47.

33. Kjorven MC. *An exploration of the discursive practices that shape and discipline nurses' response to postoperative delirium.* Vancouver, BC, Canada: The University of British Columbia, 2009.

34. Agar M, Draper B, Phillips PA, et al. Making decisions about delirium: a qualitative comparison of decision making between nurses working in palliative care, aged care, aged care psychiatry, and oncology. *Palliative Med* 2012; 26: 887–896.

35. Day J, Higgins I and Koch T. The process of practice redesign in delirium care for hospitalised older people: a participatory action research study. *Int J Nurs Stud* 2009; 46: 13–22.

36. Johnson N, Cook D, Giacomini M, et al. Towards a "good" death: end-of-life narratives constructed in an intensive care unit. *Cult Med Psychiat* 2000; 24: 275–295.

37. Hadders H. Negotiating leave-taking events in the palliative medicine unit. *Qual Health Res* 2011; 21(2): 223–232.

38. Bruce A, Schreiber R, Petrovskaya O, et al. Longing for ground in a ground(less) world: a qualitative inquiry of existential suffering. *BMC Nurs* 2011; 10(12): Article 2.