Moral identity and palliative sedation: A systematic review of normative nursing literature

…what defines nursing is not its tasks but rather its relationship to ideas. -*Sally Thorne*[1]

Introduction

People who are terminally ill and approaching the end of life typically experience symptoms that interfere with comfort and wellbeing; these patients rely on expert care – informed by palliative care principles – to support quality of life before death. In some cases however, despite the best possible palliative care, people continue to suffer before they die. In these situations, palliative sedation is sometimes considered. Palliative sedation is the intentional and monitored reduction or elimination of an imminently dying patient's consciousness, in order to alleviate unendurable suffering.[2] Palliative sedation should be proportional to the degree of suffering that prompts its use,[3] in order to "manage refractory symptoms unrelieved by optimal palliative care."[4(p.1)] It can therefore be mild or deep, and intermittent or continuous.[5]

The practice of palliative sedation gives rise to much attention in health ethics literature, where debate focuses on issues of inconsistent terminology, whether and how palliative sedation is ethically different from assisted death, the use of palliative sedation for so-called 'nonphysical' (i.e., mental, existential, emotional) suffering, and experiences of distress in family members and professional caregivers.[6] Further, contemporary social movements regarding end-of-life care are influencing ethical understandings of palliative sedation. During proceedings that led to the Canadian decriminalization of assisted death, for example, the court heard arguments that palliative sedation does not alleviate, but

merely masks suffering, and that it can cause harm to family members who wait for their loved one to slip from unconsciousness to death over an indeterminate amount of time.[7]

Without denying the ethical complexity of palliative sedation, practice guidelines within palliative care typically frame this practice as an appropriate and necessary end-of-life care option. A recent systematic review of such guidelines from around the world found that all emphasize palliative sedation as a 'last resort' intervention for refractory symptom management, in the presence of optimal palliative care.[8] An earlier systematic review of available guidelines however, also international, found variation concerning the articulated roles of different health professionals in decision-making.[9] This earlier review found that while most guidelines mention the importance of "involvement" of non-physician health care professionals and multidisciplinary consensus, details about what such involvement means, and how to proceed in the case of team disagreement, is often vague or absent.

As for any practice in end-of-life care, nurses are heavily involved in palliative sedation.[10-12] Engström et al[13] conducted a systematic review about palliative sedation at the end of life from a nursing perspective, concluding that contextual features of nurses' practice, such as time available to spend with patients and teamwork dynamics, influenced their experiences of "emotional burden" [(p. 29)] when participating in palliative sedation. A later systematic review of nurses' practice of sedation at the end of life reinforced and elaborated on these findings.[2] The authors of this second review reported on several factors influencing nurse-perceived burdens in palliative sedation, including (among others) frequent experiences of unclear patient and family wishes and ambivalence around determining whether symptoms are genuinely refractory. Nurses' confidence in this notion of refractoriness diminishes when patients are unknown to them, or when consciousness is

lost before thorough nursing assessments are completed.[2] Lokker et al[14] analyzed the narratives of nurses involved in palliative sedation through a lens of moral distress. Participants described circumstances in which they felt prevented from acting in their patient's best interest. These included situations where they felt pressured to administer palliative sedation they deemed inappropriate, and situations where they were prohibited from providing palliative sedation they felt was necessary. Thus, while nurses play a key role in palliative sedation care processes, and generally support its place in palliative and end-of-life care as an important last-resort option, they nevertheless experience ethical challenges with its enactment.[15-16]

Purpose

The purpose of this project is to review existing nursing ethics literature about palliative sedation, and to analyze how nurses' moral identities are portrayed within this literature. Moral identity here refers to an ongoing history of our values, our responsibilities, and our relationships[17], inclusive of the multiple and sometimes competing relational commitments that characterize nurses' work. For example, commitments to patients, to colleagues, and to wider social systems such as employers and even the nursing profession itself[18]. Drawing on feminist ethical theory, Peter and Liaschenko[19] describe morality as "a social accomplishment that happens between people as they account to each other and to themselves for that which they are responsible".[(p. 339)] These same authors also argue that "Because moral agency is intimately connected to one's identity, *moral identity work* is essential for nurses to exercise their moral agency and to foster moral community in health care organizations." [20, p. S18 (emphasis added)] Following this call, our project is an exercise in moral identity work. Specifically, we seek to review and

analyze the ways that nursing authors contribute to discourse about what nurses – in a general sense – ought to value and take responsibility for. We are further interested in the ways these authors situate their portrayals of nursing values and responsibilities within the relational contexts of nursing practice.

Methods

Design

This is a systematic review of normative literature. Such reviews are appearing with increasing frequency in the last decade, and are more common in nursing than in any other academic field.[21] This method of knowledge synthesis makes it possible to evaluate the status of ethical reasoning around important nursing topics, to identify tensions and gaps within such reasoning, and to pave the way for future work about value-laden topics that nurses face in their practice.[22-24]

Literature search

In March 2018, we searched the databases of Medline, CINAHL, Nursing and Allied Health, and Philosopher's Index using subject headings and keywords specific to three concepts: 1. Palliative / end-of-life care, 2. Sedation, and 3. Ethics (Table 1). We developed this search, which included no limits, with the assistance of a Health Services librarian. We subjected all retrieved citations to two levels of screening. First, two reviewers independently screened titles and abstracts of all citations to determine broad eligibility (i.e., any non-empirical paper about palliative sedation). We reached consensus through discussion for all conflicts. Second, the full texts of all citations identified as possibilities for inclusion at level 1 (or for which no abstract was available during level 1 screening) were considered for inclusion. We examined these articles in relation to the following inclusion criteria: 1. Article is a discussion paper, not based on original research data; 2. The first

author of the article is a nurse and the article reflects a nursing ethics perspective; and 3. The full article focuses on palliative sedation (we excluded articles that embedded consideration of palliative sedation within or alongside a wider discussion about other end-of-life care practices). Other reasons for exclusion included: articles clearly off-topic, articles not available in English, and articles of a 'roundtable' format (where multiple authors from different disciplines discuss palliative sedation, each taking only a few paragraphs to articulate their own perspective). Finally, we adopted an existing critical appraisal checklist for opinion papers, in order to screen out papers that either: a) Did not contain a logical argument developed through an analytical process, or b) Did not make any reference to extant literature.[25] Figure 1 illustrates the selection process.

In order to operationalize our criterion regarding palliative sedation as the exclusive topic of focus, we adapted the definition for palliative sedation used in the most recent systematic review of empirical literature regarding nurses' attitudes and practices of palliative sedation.[2] We chose this definition because it is complete, and because it will enable symmetry of comparison between our review of normative literature and Abarshi and colleagues' review of empirical literature.[2] While their definition refers to a state of decreased or absent consciousness *until death,* we omitted 'until death' from our definition to allow for palliative sedation that is intermittent. For the purpose of our review, palliative sedation is the act of "inducing a state of decreased or absent consciousness…in the last phase of life of a terminally ill patient, by monitored use of sedatives, as a last resort means of relieving unbearable symptoms or suffering."[2(p. 916)]

Analysis

We followed the *Qualitative Analysis Guide of Leuven,* an analytic procedure developed at the University of Leuven in Belgium.[26] Although originally published as a method of analyzing qualitative interview data, it is also used in reviews of normative literature.[27] The following features characterize this analytic procedure: deep reading, reflective and multidimensional thinking, contextual analysis, and interpretation. The process is iterative; researchers read the source material, develop analytic impressions of its content, discuss these impressions as a team, and return to reading the source material.

Articles were read multiple times, with ideas about their content brought forward for team discussions amongst co-authors. We drafted summary reports for individual papers that tracked the authors' main messages, the logic of their arguments, the definitions and normative meanings they attributed to palliative sedation, and ultimately the ways that their writing spoke to our specific research question about nurses' moral identities. Following multiple rounds of discussing these reports as a team, we created concept schemes (a higher-order summary than the original reports) for individual papers that highlighted the main concepts found within the papers and our ideas about how these concepts related to one another.[26] From these concept schemes, we began to draft texts in response to our research question. These texts eventually led to writing the findings section of this manuscript. We present an example of our analytic process in Table 2.

Results

Our final sample comprised 21 papers about palliative sedation from a nursing perspective. The earliest paper was published in 2000 and the most recent in 2017. Over half of the papers (n=13) were written by American authors. Other countries represented

were Canada (n=4), United Kingdom (n=3), and Belgium (n=1). Three of the papers were short one or two page commentaries,[28-30] while the rest were full-length manuscripts.

Across the sample, authors emphasized the boundaries between palliative sedation and assisted death, the (in)appropriateness of palliative sedation for existential distress, questions of artificial nutrition and hydration during sedation, issues of language and terminology (e.g., terminal v. palliative sedation), and the meaning of refractory suffering at the end of life. Authors also offered descriptions of how nurses care for patients and families, before, during, and after palliative sedation. As we read and re-read these papers, we focused on the values, responsibilities, and relationships reflected in authors' portrayal of the nursing role. This analysis resulted in three main findings. First, we found that authors variably emphasized two distinct attitudes that nurses should adopt in relation to palliative sedation: moral clarity and moral reflectiveness. Second, we found that while all authors agreed on the alleviation of suffering as a fundamental nursing responsibility, they differed in their analysis of this responsibility in relation to other values in end-of-life care, including those that depend on consciousness. And finally, we found that authors emphasized the importance of subjective and experience-based understandings of palliative sedation, which they argued as depending on nurses' proximity to patients and families in end-of-life care.

Moral clarity and moral reflectiveness

Among the papers, we observed a striking difference with respect to the overall *tone* of writing. In many papers, the tone was educational. Authors sought to clarify the ethics of palliative sedation, in order to build capacity amongst readers for knowledgeable and competent practice.[28, 29, 31-37] By contrast, a second tone was more critically reflective,

where authors unpacked, analyzed and challenged dominant moral understandings about palliative sedation.[38-41] Importantly, these two tones were not mutually exclusive. Authors conveying an overall educational tone also sought to challenge readers to think critically about the topic of palliative sedation,[e.g., 42-43] and authors conveying an overall critically reflective tone also sought to enhance clarity about the practice.[e.g., 44-45] Nevertheless, a clear difference was apparent, which reveals two distinct aspirations at play within nursing authors' ethical framings of palliative sedation in end-of-life care.

The first aspiration is moral clarity, where authors focused their writing on addressing – and decreasing – the ethical ambiguity that nurses might feel regarding palliative sedation. Here, authors emphasized the rights of patients to be relieved of suffering and the responsibilities of nurses in providing this relief. Arnstein and Robinson[31], for example, suggest that "Sedating a patient with intractable symptoms at the end of life is a good action, even a moral obligation".[p. 52] They reassure their readers that "While these conversations [about palliative sedation] can be highly emotional with conflicting points of view, *you can feel assured* that palliative sedation, in the right circumstances with the right intentions, is both legally and ethically permissible. [p. 50, emphasis added] Claessens and colleagues[33] also appeal to a logic of obligation, criticizing nurses' individual moral hesitancies as potentially interfering with patients' abilities to access the care that they require and deserve: "The implementation of palliative sedation is a moral duty in the exceptional cases of untreatable symptoms *and cannot be a source of concern* to nurses." [p. 102, emphasis added] To enhance moral clarity, several authors emphasized the importance of ethics education and the virtue of discernment, such that nurses might clarify their values and beliefs regarding palliative sedation and align these with the ethical

commitments implied by their professional role.[34,43,46] Some authors acknowledged that moral conflict might persist among some nurses, but dismissed such situations as stemming from 'personal' objections, ostensibly remedied by transferring care to another nurse.[31,36-37]

We further observed a strong influence of medical ethics on how nursing authors sought to educate readers about the definitions and associated normative meanings of palliative sedation. Authors defined palliative sedation by citing physician-authored sources, and devoted considerable space in their papers to discussing ethical issues already widely considered in medical ethics literature; especially the moral boundary between palliative sedation and euthanasia. Authors emphasized that palliative sedation is a controversial-but-legitimate and last-resort option in end-of-life care, with much emphasis placed on the doctrine of double effect[*] to support this claim.[30-32, 34-35, 37, 42, 46]

The second aspiration is moral reflectiveness, where authors seemed less concerned with teaching readers about the ethics of palliative sedation, and instead focused on exploring moral ideas related to this practice. Here, authors disrupted the idea of moral certainty as a necessary feature of nurses' moral practice, encouraging instead an attitude of deliberation around questions that elude definitive answers. For example, in a paper about the ethics of using sedation in situations where patients are incapable of providing consent, Raftery and Willard[45] encourage reflection about suffering itself, "to justify [sedation] without consent, it is necessary to address what it actually means to suffer" (p.

[*] This doctrine holds that an action with two effects, one good and one bad, is morally permissible if the bad effect is not intended (even if it is foreseen) and is not the means by which the good effect is achieved. The doctrine features prominently in ethical analyses of end-of-life care practices that appear to have the good effect of promoting comfort but the bad effect of (potentially) shortening life.[47]

[178)]. In considering the ethics of palliative sedation for existential distress, Bruce and Boston[38] assert that existential suffering is itself so poorly understood and ill addressed within contemporary healthcare, that coming to conclusions about this type of suffering as 'refractory' are problematic. For Sadler,[40] acting too quickly to sedate a dying patient can be a form of therapeutic nihilism that results from the nurse's own pre-reflective desire to disengage from a situation that is causing them pain. For Beel and colleagues,[44] clinical decisions about refractory suffering are inherently subjective and shaped by the local cultural dimensions of specific care contexts. We are encouraged to think about how institutional values of ease and efficiency create institutional pressures on clinicians, for whom palliative sedation might become a treatment of choice for the wrong reasons.[38]

Suffering and (un)consciousness

Across our sample, irrespective of tone (educational or critically reflective), authors emphasized the alleviation of suffering as a fundamental nursing responsibility. They differed, however, in the extent to which they considered how this responsibility intersects with other nursing values in end-of-life care, including those that depend on consciousness. One such value is helping people to find meaning in their (painful) experiences. Beel and colleagues[44] argue that while a nursing goal to be 'present' with people who suffer is appropriate, a zealous commitment to accompaniment can overshadow a more basic recognition of patients as the moral authority on their own experience, which risks undermining their autonomy. Woods[48] articulates a similar argument as follows:

> "…nursing is not committed to the view that dying people are under an obligation to experience their own dying process nor is it conceivable that imposing such awareness on a dying person, by refusing their request for sedation, should ever be justified." [(p. 247)]

Raftery and Willard,[45] for their part, are more direct. For these authors, “simply ‘being with’ a patient in times of immense suffering is not enough to fulfil the duty of beneficence.”(p. 181)

As mentioned above, several authors mobilized the doctrine of double effect (DDE) as a source of wisdom to inspire nurses’ moral confidence to fulfill their responsibility to alleviate suffering. Others were more skeptical about the relevance or utility of double effect logic in this context, but still found it important to speak to it in their papers.[28,38,40,43-44,49] Noteworthy is that across articles, the ‘bad’ effect considered in the double effect analysis was always hastened death, not lost consciousness. Outside of double effect reasoning, some authors did analyze the taking away of consciousness in end-of-life care as a consideration worthy of moral analysis in its own right. Pesut[39] encourages a reflective awareness that while palliative sedation might appear to a clinician as the most ‘appropriate’ treatment in a given situation, from the perspective of the family, “there may yet be cognitive work to be done.” (p. 424) Sadler[40] suggests that to induce unconsciousness at the end of life is to provoke a form of social death. Through a case study, Raftery and Willard[45] point out that for some patients, their goal is to remain alert as they die. In different ways, then, some authors in our sample encourage nurses to take responsibility for recognizing the ways in which consciousness matters, as an influential determinant (either as a source of suffering or a source of value) for patients’ and families’ moral experiences at end of life. Taken as a whole, however, our sample reveals that authors are articulating these arguments about consciousness from underneath a more dominant discourse, which emphasizes hastened death as the primary issue of ethical concern.

Proximity

We noticed repeated references to the proximity that nurses have to their patients as a basis for unique insights that should inform decision-making and care processes involving palliative sedation.[32-33, 40, 49] Authors emphasized that decisions about palliative sedation happen over a period of time – not a single conversation – during which the nurse should be available to clarify understanding and to provide support.[31,33] In speaking about the ethical uncertainties nurses face in this context, Reifsnyder[30] argued that nurses "need to recognize their responsibility as moral agents. Deferring the difficult moral decisions to someone we perceive as a 'higher authority' – like the unit manager, administrator, physician, or hospital counsel – is an abdication of nursing responsibility." [(p. 12)] Instead, this author sees nurses as capable of and responsible for participating in ethical deliberation and decision-making.

When palliative sedation begins, authors describe nurses as occupying a primary role. For example, nurses enact vigilant attentiveness of the sedated patient, focusing on subtle signs and signals of comfort or distress and responding to these with immediacy and urgency.[32, 42] Nurses safeguard their patients' wellbeing by attending to cleanliness, pain control, skin integrity, and social presence.[35-36] Authors were explicit in describing how nurses promote the personhood and dignity of their patients, including in unconsciousness. For example:

> "The nurse checks whether the patient is lying quietly, comfortably, and safely. Mouth care is performed regularly and sometimes can be taught, partly or wholly, to the family keeping watch, which often makes them feel that their presence has more use."[33(p. 105)]

This last passage also reflects a concern for the moral experience of family, and a role for the nurse to support this experience. Indeed, concern for family members as having

something unique 'at stake' in palliative sedation care processes was a recurring idea,[31,35] as exemplified in the following quote:

> The patient's family experiences moral dilemmas and is often left with the guilt and consequences of their decision or support of palliative sedation. It is frightening to think that their loved one will never wake up again. It is certainly anguishing to watch the patient die. The family may struggle with whether their loved one has already died and is just the body or shell of a person….On the other hand, it is agonizing to watch a loved one suffer from unrelenting pain and other uncontrolled symptoms."[42 (p. 323)]

Given the possibility for such ambivalence, authors spoke of a role for nurses in reinforcing for families that the decision to provide palliative sedation was the "right decision",[32 (p. 456)] and being confident themselves in the "correctness" of this end-of-life care intervention.[29(p. 367)]

Some authors offered epistemological reflections about how nursing proximity and experiential wisdom should be accounted for within the wider landscape of end-of-life care ethics. Beel and colleagues[44], for example, suggest that predominant approaches to writing about palliative sedation are "nested solidly in the positivistic tradition" [(p. 198)], and argue that these approaches are incomplete. These authors call for broader understandings about how "health professionals and family members *experience* situations in which this intervention [palliative sedation] is used." [(p. 198, emphasis added)] They remind their readers that such experience-based understanding should emphasize personal and subjective interpretations, the conscious construction of meaning, and the sociocultural contexts of experience. One included article in particular exemplifies such an experience-based understanding. Drawing on the work of nurse philosopher Sally Gadow, Pesut[39] argues that nurses must cultivate a deep understanding of how values and beliefs explain individuals' engagement with one another in ethically challenging situations such as palliative sedation.

Analyzing a case in which nurse and family disagree about the appropriateness of palliative sedation, she encourages nurses to recognize that their own values about what matters in end-of-life care are just that, values. They derive from specific systems of thought that patients and families do not necessarily share. The nursing role then, for Pesut, is to explore the apparent certainties that shape different peoples' moral perspectives, and to open these certainties to deep reflection. Ultimately, she suggests that such exploration and reflection can lead to "a nuanced understanding of the issues involved" (p. 423) and the co-construction of "emancipatory narratives [that] inform the complex process of decision-making". (p. 426)

Discussion

Our purpose in this project was to analyze the portrayal of nurses' moral identities within nursing ethics literature about palliative sedation. Consistently, authors emphasized the alleviation of suffering as a core nursing value and the responsibility of nurses to participate fully in care processes involving palliative sedation. Portrayals differed, however, in relation to whether and to what extent nurses should consider lost consciousness as an ethical concern in its own right, independent of hastened death. Portrayals also differed in their emphasis on two distinct nursing attitudes; for some authors, nurses should feel clear and confident about the appropriateness of palliative sedation in certain circumstances, while for others nurses should be asking critical questions about the ethics of this practice.

Based on our findings, in this section we develop three suggestions for future writing by nurses about palliative sedation. First, we argue that insofar as proximity appears to be a major theme of nurses' moral identity in relation to the ethics of palliative

sedation, this proximity should form the basis for stronger understandings about how (un)consciousness affects peoples' moral experiences of end-of-life care. Second, we argue that moral uncertainty about the ethics of palliative sedation is not anathema to good practice, and can instead be a catalyst to moral agency. And finally, we argue that nursing literature about palliative sedation ought to move past the logic of double effect, and take up analyses in relational ethics.

Lived experiences of (un)consciousness and moral proximity

We noted in our findings that a significant but obscured area of moral exploration concerns patients' lived experiences of consciousness, and the degree to which remaining conscious in dying may or may not have important value for patients and families at the end of life. According to Seymour and colleagues,[50] palliative sedation is commonly used "to achieve the pain free, humanly managed death that features so strongly in our collective understandings of the good death." (p. 1688-89) And yet for some, sinking quietly into unconsciousness is not at all compatible with personal visions about what it means to die well. Gloria Taylor, a plaintiff in a successful constitutional challenge to Canada's end-of-life care laws that resulted in the decriminalization of assisted death, wrote the following about palliative sedation in her affidavit to the court:

> "While I appreciate that others may feel differently about it, personally, I find the idea of [palliative] sedation repugnant…It is not rational to choose to waste away slowly while unconscious, but still alive. There is no closure in that, no dignity"[51, para 37]

In media interviews, Taylor elaborated on this position, expressing fear that dying while sedated would produce a disturbing image for her grandchildren, should they be present at her bedside while she lay unconscious.[52] Taylor's perspective makes clear that people will

place different weight on the value of consciousness, and its importance in their own end of life experience. For some, social presence and participation is more important than comfort. For others, unconscious sleep is preferable to living through distressing symptoms. The importance of attending to moral experiences of consciousness is particularly pressing, given a study that suggests that no one, physicians or nurses, are particularly concerned about consciousness as an important focus in the ethics of palliative sedation. Rys and colleagues[53] conducted a qualitative content analysis of opinion pieces written by physicians and nurses – mostly physicians – about continuous sedation until death. Considerations of consciousness did not feature prominently in this opinion literature:

> "Strangely, although reducing or removing consciousness is a main characteristic of [continuous sedation until death], it is kept largely out of the discussion… Thus, it seems physicians are more concerned about the risk of hastened death than about the patient's level of consciousness. This could potentially be interpreted as insensitivity to the argument that removing a patient's consciousness results in a form of death." (p. 179-180)

Based on the results of our review, it seems as though nurses, too, are more concerned about the (perceived) risk of hastened death than about the ethical implications of deliberately diminishing consciousness. This represents an important gap to be addressed in future nursing ethics work on palliative sedation. Indeed, authors of our included papers repeatedly emphasized that nurses are the caregivers who are closest, in time and in space, to the patient and family during the moments that precede and follow a decision to use palliative sedation. We suggest that this focus on proximity in nursing relationships, then, can and should contribute to interpretations around the extent to which peoples' individual experiences of (un)consciousness interfere with comfort at end of life.

Malone[54] offers an account of proximity in nursing that is three-fold: physical, narrative, and moral. Physical proximity, the "nearness within which nurses physically touch and care for patients' bodies" (p. 2318) creates the possibility for narrative proximity, an appreciation for the local and particular features of the patient's story. Ultimately, it is through this physical and narrative closeness that nurses interpret the moral significance of their patients' situations and of their actions in response. In her words, "moral proximity is nested within physical and narrative proximity…the patient must be *emplaced* (as a person-in-place) in a life context in order to interpret what is a moral course of action." (p. 2319-2320, original emphasis) There are parallels to be drawn here between Malone's theoretical triptych about proximity in nursing and the ethical judgement and actions of nurses when caring for patients for whom reduction or elimination of their consciousness is being considered. First, an appreciation for the inherent uniqueness of every individual patient and family imbues the nurse with an understanding that there is tremendous variability between people in how they will value consciousness over sleep (or vice versa) at the end of life. Nursing observations about patients' lived experiences of consciousness are therefore crucial. In every individual case, nurses are in a position to assess the extent to which a particular person appears to enjoy quality awake-time, and the extent to which they appear to be suffering in consciousness. Nurses are also in a position to support families at risk for feeling that their loved one has experienced a form of social death as a result of lost consciousness. In a study with bereaved family members about their perspectives on palliative sedation to manage end-of-life delirium,[55] participants who were initially supportive of palliative sedation for their loved one later became ambivalent. According to the author, "It seemed at the time that there had been no choice, but some

family members now wondered whether it might not have been handled differently." (p. 457) Because of their proximity, nurses can engage with families such as these, as their interpretations of palliative sedation *evolve* over the hours and days that their loved one is sedated. Nurses can recognize, and offer support, if these family members appear to be disturbed by the images they are seeing or by the amount of time elapsing between sedation and death. Given that moral proximity is a key concept in contemporary nursing ethics, there is room in the literature about palliative sedation for nursing authors to now move beyond discussion of the decision to sedate, toward the many moments that unfold before sedation, as well as while the patient is sedated and the nurse is engaging with the family.

Engaging moral uncertainty

As we noted in our findings, there was a tendency amongst some authors to admonish nurses for their moral uncertainty, and to rely heavily on either education or transfer of care as panaceas for nurses' experiences of moral conflict regarding palliative sedation. The ethical nursing care of patients and families considering and/or receiving palliative sedation, however, requires more than becoming confident in the legitimacy of this practice as an appropriate end-of-life care option, although this is important. These are delicate caregiving situations in which much is at stake, and in which different people will have unique perspectives, grounded in individual values, beliefs, and practices about what is good and right.[56] A recent research study[14] demonstrates multiple influences on the moral experiences of nurses in relation to palliative sedation. These include differences in how nurses, physicians, and families each interpret, and dialogue with each other about, the suffering of patients; power differentials between nurses and physicians regarding

decision-making authority; and the unique location of the nurse, in time and place, within the social organization of care. [14] Therefore, lack of knowledge and 'personal' objections of conscience are not at all sufficient for understanding and addressing the reasons that nurses may feel morally conflicted about palliative sedation.

To be clear, supporting nurses toward clarity and confidence about their values and responsibilities in relation to suffering and end-of-life care is essential. But an (over)emphasis on moral clarity about palliative sedation can contribute to a 'grand narrative'[57] about what it means to be an ethical nurse in this context, marginalizing and dismissing the perspectives of nurses whose ethical questions remain unanswered, and thereby aggravating their moral distress. As for any issue in healthcare practice that is ethically challenging, nurses' moral agency with respect to palliative sedation is stronger – not weaker – when their approaches to ethical deliberation are critically reflective and demonstrate a willingness to see things from different points of view.[58] We agree with Abarshi and colleagues, who concluded their systematic review of nurses' attitudes and practices regarding sedation at the end of life with the following statement: "…nurses should be encouraged to approach [palliative sedation] with both reluctance and caution." [2(p. 923)] As Hermsen and Ten Have[59] have pointed out, "although the final decisions reached by way of moral deliberation may be reflective and prudent, they are necessarily uncertain." [(p. 566)] Such uncertainty keeps open a space for new information to come to light, new perspectives to be articulated, and new insights to be developed, all while patients' and families moral experiences of dying unfold and evolve over the days, hours, and minutes that they spend in our care.

Toward a relational nursing ethics of palliative sedation: beyond double effect

Within the wider literature, and as rehearsed within the sample of articles we reviewed, a clear argument is apparent that palliative sedation is not euthanasia, ethically or empirically. To be sure, clarity on this distinction is valuable. Yet, the ethics of palliative sedation remain complex, for reasons that have little to do with euthanasia or the doctrine of double effect. Billings and Churchill[60] observe that the doctrine of double effect dominates bioethical discussions about palliative sedation, eclipsing other relevant moral frameworks and contributing to a poverty of moral analysis on this topic. These authors argue, "The rule of double effect should not pre-empt additional moral reflection or serve as the final word on justifying palliative sedation and related acts. A monolithic moral framework deprives us of the diversity of viewpoints that can inform and deepen our ethical understanding." [(p. 712)] We likewise found that the doctrine of double effect dominated much of the authors' attention in our sample, as did other issues that are already widely discussed in non-nursing literature. When these issues were engaged by the nursing authors in our sample, it was seldom with explicit attention to how nurses' "unique angle of vision"[1(p. 283)] should inform these arguments and debates.

There are many ethical issues related to palliative sedation and nursing that require normative analysis, which receive little attention in wider medical or bioethics literature. Some of these issues appeared in the papers we reviewed, for example, the protection and promotion of patients' personhood and dignity while unconscious, and the moral experience of family members who hold vigil in the interval between reduced consciousness and death. It is around issues such as these that we suggest future normative work about palliative sedation and nursing should continue. For example, there is much to

unpack about how nurses attend – through their caregiving relationships – to the *vulnerability* of their patients receiving palliative sedation. According to Gastmans,[61] "Ethics manifests itself *par excellence* in situations where a person's dignity is threatened due to his or her vulnerable situation and where the person is unable to force a respectful attitude from the fellow human being." [(p. 146)] For Gastmans, these include situations in which a person's rational capacity is minimal and their corporeal vulnerability is heightened, which are both obviously the case in situations of palliative sedation. Further relational ethics examinations of the palliative sedation care process would thus contribute much to advancing understanding about the specific ways that nurses attend to values at stake, such as personhood and dignity, when their patients' consciousness is reduced or absent. As articulated by Sofronas et al, "Relational approaches to nursing care are important to personhood; their presence enhances personhood, and their absence contributes to its extinction or loss." [62(p. 412)] Such examinations would offer the potential to respond to the concerns of some that dying under palliative sedation is "repugnant" [51, para 37] or represents a form of social death.[40]

Of course, relational ethical examinations should not be limited to the interpersonal dynamics between nurses and patients and nurses and families. Relational ethics is also concerned with the wider systems of relation that nurses are embedded within, and that facilitate or constrain their potential for ethical practice.[63] Malone's[54] analysis of proximity in nursing, referred to earlier, is not only a theoretical description of how nurses come to ethical knowing through physical and narrative proximity, but also a detailed critique of how the contemporary social organization of nursing care directly interferes with the possibility for such proximity in the first place. Contemporary nursing, she argues, is

"increasingly constrained by spatial-structural practices that disrupt relationship and reduce or eliminate such proximity." [54(p. 2317)] Further, we know that nurses' experiences of moral conflict around palliative sedation arise out of the relational context of their practice and the social organization of care. To give just one example, consider a situation where the team, patient, and family have agreed to initiate palliative sedation, but only if suffering reaches a point of crisis, as defined by the patient. This crisis might occur in the middle of the night, during which time a nurse might find herself alone with the patient and family, without a willing on-call physician to follow through on the agreed upon treatment plan, and without the professional autonomy to initiate it herself.[14] Although many authors of papers in our review elaborated detailed descriptions of nursing care processes for patients and families experiencing palliative sedation – all of which took for granted the proximity that nurses enjoy with patients and families – attention to the wider geographical, social and structural context of palliative and end-of-life care nursing was minimal. According to Liaschenko and Peter[20] "the most challenging moral problem of the 21st century [may] be the relationship between the individual moral agent and the practices and institutions in which the moral agent is embedded." [(p. S18)] Thus, it is insufficient to consider the nursing ethics of palliative sedation by focusing on the values and reasoning of individual nurses alone. Future normative work in this area should pay specific attention to the network of relations, inter-personal, organizational, and political, that influence nurses' work in caring for people at the end of life who are considering and/or receiving palliative sedation.

Strengths and Limitations

To our knowledge, this is the first analysis of nursing's moral discourse about palliative sedation through a systematic review of normative literature. The majority of papers reviewed were American, and all were from developed Western countries. The results of our analysis may have limited transferability to jurisdictions not represented in our sample, where palliative sedation (and end-of-life care more broadly) may be organized very differently.

Conclusion

The views that nurses hold about palliative sedation will influence the way they enact their role regarding this practice.[2] Normative literature about the ethics of palliative sedation from a nursing perspective contributes to a shared disciplinary understanding about what our role should be, as nurses, when providing care to patients and families who are considering or receiving this intervention. Insofar as our moral identity is a constantly evolving history of our values, responsibilities, and relationships,[17,20] we suggest that nursing ethics authors are well-positioned to support the evolution of nurses' moral agency in relation to palliative sedation. They can do this by encouraging nurses to take responsibility to attend to the ways that (un)consciousness *matters* as a salient ethical concern in end-of-life care, by emphasizing moral reflectiveness as an opportunity to mobilize – not eliminate – moral uncertainty, and by analyzing the multiple relationships – at all levels – that impact on nursing practice in end-of-life care.

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Table 1 Search strategy

MEDLINE (total: 769)		Nursing & Allied Health (Total: 184)		Cinahl (Total: 415)		Philosopher's Index (Total: 76)	
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	palliative care/ exp terminal care/ terminally ill/ hospices/ "hospice and palliative care nursing"/ (palliat* or terminal* or death or die or dying or hospice or (end adj1 life)).ti.ab.kw. 1 or 2 or 3 or 4 or 5 or 6 sedat*.ti.ab.kw. "hypnotics and sedatives"/ or deep sedation/ conscious sedation/ 9 or 10 8 or 11 "dissent and disputes"/ exp morals/ exp ethics/ exp philosophy, nursing/ (ethic* or moral* or debat* or right* or responsibil* or virtu* or controvers* or conflict* or dut* or argument*).ti.ab.kw. 13 or 14 or 15 or 16 or 17 7 and 12 and 18	1 2 3 4 5 6 7 8 9 10	mesh("hospice and palliative nursing") or mesh("palliative care") or mesh("terminally ill") or mesh("hospices") mesh.exact.explode ("terminal care") or mesh.exact.explode ("terminal care") ti(palliat* or terminal* or deaths or die or dying or hospice or "end of life") or ab(palliat* or terminal* or deaths or die or dying or hospice or "end of life") ti(sedat*) or ab(sedat*) mesh("hypnotics and sedatives") or mesh("deep sedation") or mesh("conscious sedation") su.exact("dissent disputes") mesh.explode("morals:k.01. 752.566") or mesh.explode ("morals:f.01.829.500") mesh.explode("philosophy, nursing") mesh.explode("ethics:k.01.7 52.566.479") or mesh.explode("ethics:n.05.3 50") ti(ethic* or moral* or debat* or right* or responsibil* or	1 2 3 4 5 6 7	(mh "hospice and palliative nursing") or (mh "hospice and palliative nurses association") or (mh "hospices") or (mh "national association for home care & hospice") or (mh "palliative care") or (mh "terminally ill patients+") or (mh "terminal care+") ("palliat*" or "terminal*" or "end of life" or "death" or "die" or "dying" or "hospice") (mh "sedation") or (mh "hypnotics and sedatives") or (mh "conscious sedation") sedat* (mh "ethics+") or (mh "morals+") or (mh "patient autonomy") or (mh "ethics, nursing") or (mh "ethics, medical") or (mh "philosophy, nursing") or (mh "codes of ethics") or (mh "ethics, organizational") ethic* or moral* or debat* or right* or responsibil* or virtu* or controvers* or conflict* or dut* or argument*	1 2 3 4 5 6	ti(Palliat* OR terminal* OR deaths OR die OR dying OR hospice OR "end of life") ab(Palliat* OR terminal* OR deaths OR die OR dying OR hospice OR "end of life") ti(sedat*) OR ab(sedat*) (ti(ethic* OR moral* OR debat* OR right* OR responsibil* OR virtu* OR controvers* OR conflict* OR dut* OR argument*) OR ab(ethic* OR moral* OR debat* OR right* OR responsibil* OR virtu* OR controvers* OR conflict* OR dut* OR argument*)) OR (ab(ethic* OR moral* OR debat* OR right* OR responsibil* OR virtu* OR controvers* OR conflict* OR dut* OR argument*) OR ab(ethic* OR moral* OR debat* OR right* OR responsibil* OR virtu* OR controvers* OR conflict* OR dut* OR argument*)) 1 or 2 3 and 4 and 5

			virtu* or controvers* or conflict* or dut* or argument*) or ab(ethic* or moral* or debat* or right* or responsibil* or virtu* or controvers* or conflict* or dut* or argument*)		(s5 or s6) and (s3 or s4) and (s1 or s2)		
		11	1 or 2 or 3				
		12	4 or 5				
		13	6 or 7 or 8 or 9 or 10				
		14	11 and 12 and 13				

Table 2 – Excerpts taken from each of the critical appraisal, summary report, concept scheme, and ongoing reflection stages of our analysis. All excerpts pertain to the same article: Bobb B. A review of palliative sedation. *Nurs Clin North Am* 2016; 51: 449-457. We followed the same process for other articles in our sample.

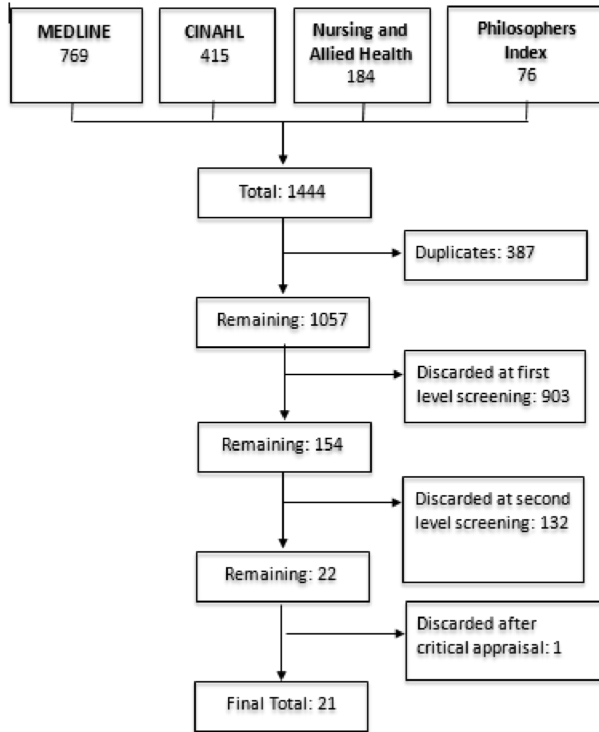
Critical appraisal (screening):   1. Does the author articulate a logical argument developed through an analytic process?   Answer: Yes. Normative claims are grounded in appeals to ethical principles: proportionality, principle of double effect. Normative assumptions are also conveyed through detailed descriptions of nursing care processes. The author presents a case study, however does not discuss it explicitly.
Analysis step 1: Summary report (Excerpt only)   This is an article directed at a clinical audience. The article opens with a brief introduction, proceeds to a case study, reviews terminology, indications and types of palliative sedation, provides an overview of treatment options (i.e., pharmacology), and briefly summarizes the positions of nursing and other professional organizations. The author then discusses the "ethical considerations" surrounding palliative sedation, organized around the following themes: 1. Proportionality, euthanasia, and DDE; 2. Determination of refractory suffering; 3. Informed consent; 4. Existential distress as controversial indication. Finally, the author devotes considerable space to describing the nursing process of care, which he titles "Nursing Care", organized around the following categories: 1. Before initiating palliative sedation, 2. During the process of palliative sedation, 3. After palliative sedation. The paper concludes with a reiteration of the following messages: Palliative sedation is an "established" practice, primarily in a context of physical (vs. existential) suffering; Palliative sedation neither intends to hasten death (normative claim), nor does it hasten death (empirical claim); nurses play a "vital role in helping ensure that this process goes smoothly and that both patients and families are comfortable throughout this difficult process".
Analysis step 2: Concept scheme (Excerpt only)   • Palliative sedation is widely accepted, although raises "a range of ethical questions"   • Patients have a right to relief of pain and other symptoms   • Nurses share a proximity (in time) to patients in care   ➔ This proximity enables relationships of trust and rapport, as well as specific knowledge (uniquely available to nurses) about the patient's experience and suffering

- From this unique position nurses should influence the plan of care
  - Nurses should be present during consent to sedation
  - They serve as a “bridge” between the patient and the primary provider
  - They respond to patient and family questions in the moments outside of meetings with the primary provider
- Nurses’ therapeutic presence is characterized by a calm and non-judgemental demeanor.
  - They encourage and reassure patients and families to feel that they are making the right decision
  - They show investment by working hard to achieve patient comfort, and making this work visible to the patient and family
    - They are vigilant in monitoring the patient under palliative sedation and make suggestions for any necessary adjustments to the plan of care
    - They enact a care process over time during and after palliative sedation that reflects the following values: bodily integrity, family involvement and wellbeing, environmental aesthetic

<u>Ongoing analytic questions - Reflections while (re)-reading the papers:</u>

This idea of ‘acceptance amidst controversy’ raises questions about the stance that authors take with respect to the fact that palliative sedation is debated at all. Do the authors identify palliative sedation as a legitimate moral issue, one in which reasonable ethical questions can and should be asked on either ‘side’ of the debate(s)? Or do authors attribute the very existence of a debate as a symptom of moral confusion, and see their role as enlightening others toward a certain moral clarity that they themselves feel they have reached? (Notes taken while reading Bobb 2016).

Figure 1 – Search diagram



Reasons for exclusion at second level screening:

- Not nursing literature (First author not a nurse and/or no discernible nursing perspective) (n=77)
- Palliative sedation not the exclusive focus (n=23)
- Off-topic (n=13)
- Not English (n=11)
- Empirical (n=4)
- 'Roundtable format' (n=4)

Reasons for exclusion at critical appraisal

- No reference made to extant literature (n=1)