



Published in final edited form as:

Nurs Ethics. 2010 September ; 17(5): 577–589. doi:10.1177/0969733010373009.

Moral obligations of nurses and physicians in neonatal end-of-life care

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Abstract

The aim of this study was to explore the obligations of nurses and physicians in providing end-of-life care. Nineteen nurses and 11 physicians from a single newborn intensive care unit participated. Using content analysis, an overarching obligation of creating the best possible experience for infants and parents was identified, within which two categories of obligations (decision making and the end of life itself) emerged. Obligations in decision making included talking to parents and timing withdrawal. End-of-life obligations included providing options, preparing parents, being with, advocating, creating peace and normalcy, and providing comfort. Nurses and physicians perceived obligations in both categories, although nurse obligations centered on the end of life while physician obligations focused on decision making. The findings demonstrate that, although the ultimate goal is shared by both disciplines, the paths to achieving that goal are often different. This has important implications for collaboration, communication, and improving the end of life.

Keywords

critical care; end of life; ethics; moral obligations; newborn intensive care unit; nurse; physician

Introduction

The health care professions, particularly medicine and nursing, are moral practices focused on caring and curing. For those patients who cannot be cured, the quality of caring at the end of life becomes paramount. Several consensus groups have identified quality domains for end-of-life care in intensive care units (ICUs),^{1–3} which include symptom management, shared decision making, effective communication with patients and family members, continuity of care, and family support. Unfortunately, there is considerable evidence and concern that these domains remain problematic.^{4–12} Dissatisfaction,¹³ conflict^{14,15} and moral distress^{16–18} around the end of life are not uncommon, indicating a mismatch between a professionally prescribed moral imperative to provide good end-of-life care and actual practice. One potential explanation is that, although the goal to provide good end-of-life care may be shared by different disciplines, the paths to achieve that goal may be quite different. What are these paths? What do nurses, physicians, and other providers view as obligatory accomplishments along their path?

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Conflict of interest statement The author declares that there is no conflict of interest.

Exploration of provider obligations may seem to be a step backwards in the study of end-of-life issues. However, such a line of inquiry is necessary in order to make progress in improving the end of life for patients, families, and providers. Three rationales are most apparent. First, although providers' ethical obligations in uncommon situations associated with the end of life (e.g. physician-assisted suicide and euthanasia) have been studied and debated,^{19,20} the same is not true with regard to ethical obligations in the far more commonly experienced situation of caring for dying patients. Thus, it is not known what providers' perceived duties are, and defining 'good' end-of-life care is challenging. As Levy argues, 'good' end-of-life care is like art: it is difficult to define, but you know it when you see it' (p.32).²¹ How do we know it? What are we looking for? Thus far, many end-of-life studies have been largely based on assumptions of providers' views of good end-of-life care. For example, a recent study of ICU nurses' perspectives of obstacles and supportive behaviors to providing end-of-life care⁴ revealed that the most frequent supportive behavior was providing adequate time for the patient and family to be together after death. Some would argue that this is not a supportive behavior in providing end-of-life care, but is instead end-of-life care itself. More important are the differences in the meaning of end-of-life care between disciplines. A repeated call for interdisciplinary communication and collaboration has been made,²²⁻²⁴ yet nursing and medicine continue to function within isolated 'silos'.²⁵ It is unlikely that providers are stubborn or dense on the issue of interdisciplinary collaboration. Rather, they are not speaking the same language. When nurses and physicians consider end-of-life care, they may be talking about very different concepts.

Second, the end of life is not a discrete concept, nor does it occur at a particular moment in time. Rather, it is a compilation of multiple, continuous factors. Decision making, communication, symptom relief, family support, and continuity of care are factors that together comprise end-of-life care and which occur over an entire hospitalization. Thus, the end of life is a cumulative experience requiring the co-ordination of all of these factors. To do so, nurses and physicians must also co-ordinate their efforts along the illness trajectory. In general, it is understood that the medical role at the end of life is largely concerned with helping to make difficult decisions, whereas the nursing role is to usher patients and families through the end of life itself. However, some of the boundaries of professional roles (where responsibilities lie) are not so well defined. Providers may be confused about exactly what their obligations are. For example, despite the fact that nursing has much to offer in end-of-life decision making,³ its role in this context continues to be brushed aside.^{12,26-28} A French study of nurses' and physicians' views of decision making²⁶ showed that, although 91% of nurse and 80% of physician participants believed that decisions should be made collaboratively, only 27% of the nurses and 50% of the physicians believed that such collaborations occurred in practice. Furthermore, Yaguchi et al.²⁸ found that only 29% of a group of American physicians surveyed would involve nurses in end-of-life decisions. Hence, if nurses perceive an obligation of involvement in end-of-life decision making, this obligation may be largely unmet. Certainly, there is frustration and moral distress among nurses about the end-of-life decision-making process.^{10,16-18,29-31} The presence of moral distress is suggestive of an obligation, but the extent of that obligation (whether or not nurses feel compelled to occupy a seat at the table) is not yet known.

Finally, one quality domain of ICU end-of-life care that has been identified, but which has not been studied, is continuity of care. Repeated calls for collaborative, co-ordinated care^{9,32,33} have been made. At different times along the end-of-life trajectory, providers see themselves as being present, playing a role, or fulfilling a duty. Identifying these differences along the trajectory (understanding how these moral spaces are occupied by nurses and physicians) may help to illuminate a suitable and logical process for co-ordinating care, especially as a patient approaches the end of life.

Aim of the study

The purpose of this article is to report findings regarding the moral obligations of nurses and physicians in providing end-of-life care. This was one aim of a larger study to explore newborn intensive care unit (NICU) nurses' and physicians' end-of-life experiences.¹⁰ Thus, although any ICU setting would be appropriate for the exploration of moral oughts, this study reports on the findings from a NICU setting.

Methods

For the larger study exploring NICU nurses' and physicians' end-of-life experiences, a hermeneutic phenomenological approach was used. This allowed rich exploration of NICU health care providers' experiences at the end of life.¹⁰ To capture providers' moral obligations, however, a more directed, descriptive approach was used, and a content analysis of these data was deemed appropriate. The practical and ethical aspects of the study protocol were approved by the local institutional review board, and each participant provided informed consent prior to enrollment in the study. Additionally, the ethical and practical aspects of the study proposal were reviewed by the author and several colleagues with expertise in ethics in order to identify and address potential problems.

Sample and setting

Purposive sampling included NICU nurses and physicians (attending, fellow, and resident) who provided end-of-life care during the study period (January–August 2006). Float nurses, travel nurses, and medical students were excluded because it was thought that their perspectives, although valid and potentially rich and informative, would be beyond the scope of the study, which was directed specifically at NICU nurses and physicians. NICU nurse practitioners met the inclusion criteria. However, only one consented to participate in the study. Thus, nurse practitioner obligations are not presented here. The study took place in a level III NICU in a mid-Atlantic teaching hospital serving a large rural area. Ultimately, 21 infants died during the study period. The identified obligations of 21 nurses (representing 19 infants) and 11 physicians (six attending physicians, two residents, and three fellows, representing all 21 infants) are reported here. More detailed characteristics of the sample are presented elsewhere.¹⁰

Data collection

The participants completed a demographic survey and took part in a semistructured interview. These interviews took place between one day and six weeks after an infant's death, although most occurred within one week of the death. The participants were first asked to describe their overall experience with a particular infant and family around the time of death. They were then asked: What were your obligations to the infant and family? Their responses to this question are reported here.

Data analysis

Although the larger study used a hermeneutic phenomenological design and a hermeneutic circle analysis approach, the aim of identifying obligations at the end of life was more direct and compartmentalized. A conventional content analysis approach is useful for studies aiming to 'describe a phenomenon' (p.1279).³⁴ Thus, because the moral obligations of health care providers is a concept that has not been described, a content analysis approach was appropriate.^{34,35} The participants' responses to the question: What were your obligations to this infant and family? were read several times to identify common threads. A list of specific terms (e.g. taking pictures, being with parents) was generated, which was reflective of the common threads. Each participant's entire interview was then reviewed to understand how

the stated obligations had been addressed. For example, if a nurse said that an obligation was to prepare parents for their baby's end of life, the interview was reviewed with the purpose of finding a description of how this obligation had been met. The interview data were also reviewed to identify actions that appeared to be obligatory, but had not been specifically stated as such. The lists of obligations, with representative quotes from the text, were separated by discipline for further analysis and coding. The specific terms were then grouped into broader categories. For example, the specific obligation of providing privacy fitted into the 'being with' code category. The final lists of obligations and their definitions were reviewed by two experts in neonatology (one physician and one nurse) in order to determine whether these obligations resonated with their practice.

Findings

The central obligation of both nurse and physician participants was to create the best possible experience for infants and their parents. Although this was common to both groups, there were similarities and differences in how this obligation was met. Differences were due largely to the foci of the professional roles. For example, the majority of physicians' stated obligations occurred during decision making, a time of great importance in the medical role. Nurses, whose role in providing care for dying people is critical, described obligations based on this aspect of the end-of-life period. However, there was significant overlap of obligations in key areas.

Obligations in end-of-life decision making

There was a sense among both cohorts that how end-of-life decisions are made could influence the end-of-life experience for parents and infants. If decision making went smoothly, parents might be more likely to have positive memories of the experience and infants might have a more peaceful death. To that end, two major obligations were found among physician participants during this phase: talking to parents and timing the withdrawal of treatment.

Talking to parents—Nearly all physicians stated that talking to parents (finding the right words to explain the clinical situation, ensuring that parents understood what was happening clinically, and showing clinical evidence of a poor prognosis) was a critical part of the decision-making phase. Physicians described using ultrasound pictures, laboratory results, and hand-written drawings to demonstrate an infant's clinical status. A key issue here, however, was that knowing how much information to give to parents was difficult and different for each family. Judging how much information parents needed was made easier when there had been continuity of caregivers and a good provider–parent relationship:

I think just talking with them early on. Laying the groundwork. I felt like they trusted me so I think that that was something that was really important. I think it is easier to talk to parents about things if you've developed that rapport. I was somebody that they recognized. (physician)

However, talking to parents about end-of-life decisions was complicated when mothers were teens:

We were in that spot where mom initially was refusing to come up [to the hospital] and saying she couldn't face it. You can't really talk about withdrawal of support and ... comfort measures only with the grandmother ... because mom's responsible for the baby. (physician)

Talking to parents was also complicated when their wishes for the child did not align with the reality of the situation:

That family has always made me feel odd because I did meet with them on several occasions ... I did talk with them several times on the phone. I just never really felt like I got anywhere with them ... [We] were just talking to trees. (physician)

A second aspect of talking to parents was trying to relieve them of the burden of end-of-life decision making. A majority of physicians who discussed end-of-life decision making during their interviews expressed their belief that it should not be solely the parents' burden:

Another thing that's really important and that has changed over time in my approach to end-of-life care for babies – I think the decision to withdraw support is the absolute worst thing that you can do to a parent. It used to be that I thought well you should tell them things are really bad and that there's really not a good chance that the baby's going to make it ... What do you want us to do? And basically you're expecting them to verbalize that they want their baby to die. That's totally unfair to the parents. (physician)

Another physician stated:

I did it the way I always do it. `This is a shared decision, we're not asking you to make a decision. We're doing this together.'

On this obligation of talking to parents to help relieve the burden of decision making, many nurses agreed.

I think the biggest thing for me is [that] we have to find a better way of helping parents come to the decision that needs to be made. It wasn't just me. It was several of us ... talking about it, because you talk about it afterwards. Many of us have said ... the way we're putting [decision making] in the parents' hands isn't fair. We're having them make a decision that many of us as parents can't or wouldn't ... be able to make. I just don't think the [doctors] realize that necessarily. I don't think they're insensitive, I just think they realize that that needs to be done – that the parents need that step. (nurse)

An interesting coincidence occurred during the study period, which generated several discussions among the nursing staff. The Department Chair and NICU Nurse Manager shared an article³⁶ with the nursing staff. Three nurses commented on this article in their interviews and all had a similar perspective:

This article that I read that was emailed to all of us ... and we were all talking about it today and we were like, `Well, I hope they sent this to all the [attending physicians].' It really is exactly what the nurses would LOVE for the doctors to do. Don't put it in the parents' control. You can't expect them to make a decision like that. (nurse)

Timing the withdrawal—A second obligation of physicians during the decision-making phase was to ensure that, once the decision had been made, the withdrawal was timed such that it was not rushed, but also was not delayed. Embedded within this obligation were subobligations to minimize suffering and to create a sense of calm for parents.

In a majority of cases, the withdrawal of aggressive treatment was not urgent. The physicians expressed a need to reassure parents that withdrawal could be delayed by hours or days after a decision had been made. Allowing time between the decision and withdrawal helped to give the end of life a sense of calm, and provided time for parents to gather loved ones and to make funeral plans. One physician stated his obligation in general terms:

One thing I think is important, when you have the end-of-life discussion and the parents have sort of made the decision that they want to withdraw support or they

agree with our assessment that it's time to withdraw support, that you make sure you don't pressure them to do it right then – OK well let's do it in the next 12 hours. (physician)

Another spoke specifically about a mother:

[Mom] asked if we could wait until her mom got there. We said, 'Sure, we can wait until later today, tomorrow, you know, whenever. We're not in a rush.' (physician)

On the other hand, there were instances in which delaying withdrawal would create further suffering for the infant. This occurred mainly in acute situations such as necrotizing enterocolitis totalis. A few physicians described having to be direct with parents so that they understood the situation:

The best thing is to let him die but to make it a comfortable thing for him ... We need to achieve that for him today because the longer we drag the more discomfort he's going to be in no matter what we do and the more we're really not doing him any good. (physician)

It was preferable to be able to give parents time to prepare for withdrawal but, when infants were suffering or clearly dying, the infant took priority.

The nurse participants conveyed a similar feeling, although the focus of their sense of urgency was not so much on those with acute illness as on those who had received prolonged, aggressive treatment with, in their view, little likelihood of recovery. Their concern was for the continued, seemingly needless suffering of infants who were unlikely to survive despite aggressive measures. According to the nurses' retrospective reflections, the moment at which they began to feel urgency about the need for withdrawal appeared to occur long before an infant was actively dying. The data were not clear about whether or not the nurses had spoken up in these situations, or, if they had voiced concern, whether or not these concerns had been heard. In any case, these were situations in which nurses felt unable to minimize suffering, and in which moral distress was apparent. Although some physicians acknowledged the necessity of withdrawal in situations of prolonged treatment and demonstrated moral distress, none voiced the same sense of urgency and frustration as the nurses. The point at which withdrawal urgency was perceived as warranted was notably different between the physician and nurse cohorts.

Obligations during the end of life

Creating the best possible experience for parents and infants during the end-of-life phase was expressed in terms of six obligations: providing options, preparing parents, being with, providing comfort, advocating, and creating peace and normalcy. Some of these obligations (providing options, preparing parents, and creating peace and normalcy) were intricately woven into the end-of-life experiences of participants and are described in that context elsewhere.¹⁰ Three obligations to parents (providing options, preparing parents, and being with) and one obligation to infants (providing comfort) were similar for both groups. The nurses, whose role was deeply within the end-of-life moment, described two additional obligations to parents (advocating and creating peace and normalcy).

Providing options—Both disciplines stated that providing options gave parents some control and some opportunity for meaningful input. Parents' desires regarding the presence of other family members or a chaplain (when withdrawal should take place), and whether they wanted to be present during that time, were commonly described.

I gave them different options, including if they wanted to hold the baby while he was on the ventilator, and have a little bit of time with him that way or did they

want us to take him off the ventilator and then bring him to them in the family room ... so they would not have to see all the equipment and all the tubes and everything. (physician)

Preparing parents—Both cohorts described the obligation of preparing parents for the death of their infant, specifically color changes, the likelihood that the infant might linger (I said, “Her heart beat will just slowly fade away.” (nurse)), the possibility of gasping, and reassurance that pain medication would be provided throughout. This obligation was fulfilled by nurses and physicians separately, with neither cohort seeming to know that the other was also preparing parents. This duplication of effort may speak to the depth of the obligation, that helping parents to brace themselves for a tragic moment extended beyond professional boundaries into the realm of simply being human.

Being with—A third obligation of nurses and physicians was to be with parents and infants at the end of life, although the period of being with was defined differently by the two disciplines. For physicians, being with meant staying with families after withdrawal had taken place. This was difficult for most physicians because they thought they were being intrusive:

I left – it was hard; I stayed for a little bit, but I felt like I was hovering. And then I felt like – this is a really private moment – like what am I doing here. I didn't want to leave either because I [didn't] want them to feel like [I'd] got to go do something else. I [didn't] know what to do, so I stayed for a couple minutes and then I said, ‘You guys can have as much time as you want – all the time you need. Just come get us, or let somebody know or I'll come back and check on you.’ So I left. (physician)

A few physicians expressed that their obligation to be with parents after withdrawal depended on their relationship or on the amount of support that parents had had with them:

Given the circumstance ... and given my lack of a real relationship with them, and that the fellow was here, and that this particular fellow would do a good job in the circumstance, I'm not sure that I would've come in anyway. (physician)

One physician described a moment in which the mother had no other support so he stayed with her throughout the dying period:

I think it's a big obligation ... When the baby finally passed away, I just sat with the mom, helping her hold, helping the nurses do things for her, and I spent probably a couple hours with her. (physician)

For one physician, being with the family throughout the dying process was obligatory:

I'm usually there the whole entire time ... Being there every step of the way so they don't feel like now that they've made this big momentous decision everyone deserts them and there's nobody there any more and they're left with their decision and their dead baby. (physician)

Although physicians stated their obligations to be with parents in terms of being at the bedside at withdrawal and afterwards, many had also been with parents prior to withdrawal, when they were preparing parents and providing options.

For most nurses, being with contained the full scope of the end-of-life period: before, during, and after withdrawal. For example, one nurse described simply sitting with parents prior to withdrawal as a way to provide silent support:

Sometimes saying something is not the thing. I think just being there is the most important thing ... I try to be close, physically on mom's level – even a hand on her shoulder. Just something that lets her know that there's support in this. It's OK. It's OK for it to be silent. It's OK for it to be a void. It's [an] awful, devastating quiet. (nurse)

The nurse cohort explicitly expressed an obligation to provide privacy. In general, creating privacy involved shielding parents from the rest of the unit, not necessarily separating the nurse from the family:

I tried to make it as private as possible. It was nice in that unit; we had the curtains. We had kicked all the other families out. We said, 'We're doing a procedure.' We just said something to give [Mom] as much privacy as possible. (nurse)

Although nurses remained in that private space on many occasions, there were some instances in which the boundaries between the obligations of being with and providing privacy were blurred. Unease with being intrusive, similar to the physicians, was apparent, although it was not openly described as such. Instead, they described themselves as being 'within earshot' or 'just outside the door'.

Advocating for parents and infants—An obligation unique to nurses was advocating for parents and infants. This mainly involved requesting adequate doses of narcotics to manage pain and acting as a liaison between physicians and parents. For example, in one instance, an autopsy procedure was necessary within a short time after an infant's death. The nurse caring for the infant felt pressured to rush the withdrawal process, but did not allow that feeling to reach the parents:

[The residents] came to me at one point ... and they were saying, 'This kind of needs to happen.' They wanted things to happen faster but I didn't really feel comfortable saying [to the parents], 'OK, we need to hurry this up because ...' So I was like, 'Whatever.' I gave [the parents] as much time as they needed. (nurse)

This nurse later described not wanting to risk the accuracy of the test required, but also not wanting to make the parents feel rushed through their daughter's death. Advocacy is a central nursing role. At the end of life the nurses' actions of advocacy were directed towards helping to relieve the parents' burdens, relieve pain, and promote a 'best possible' end-of-life experience.

Creating peace and normalcy—Another nurse-focused obligation was to create peace and normalcy at the end of life. Recognizing that their baby's end of life would be reflected upon by parents forever, the nurses wished to convey a sense of calm rather than chaos in what is often a chaotic environment. This was frequently accomplished by carrying out simple, seemingly benign tasks, such as cleaning the bedside, bathing and dressing the infant, and removing unnecessary equipment. As mundane as these tasks seem, they were profoundly meaningful rites for both parents and nurses, as noted elsewhere.¹⁰ For example, giving the final bath and going through boxes of baby clothes to find just the right outfit were often solitary rituals performed by nurses. These acts provided a sense of closure for the nurses because none of them had attended funerals for these infants or personally kept in touch with parents after an infant's death. Instances in which mothers bathed their infant were opportunities for them to see their infant as a whole person.

[Mom] was happy. She was laughing during it. She was saying, 'Look at this' and, 'Look at that.' She touched her [baby's] fingers and her toes and she was able to explore her [daughter] as she would if she was a regular newborn. (nurse)

Perhaps the most important and most commonly stated way to create normalcy and peace was to facilitate parents' holding of their infant, before, during, or after death.

Mom never got to do skin to skin and she had wanted to breastfeed so ... I offered if she wanted [the baby] to be just against her. She liked that, rather than just holding him in this delicate bundle that you're afraid to touch. (nurse)

At times, creating a sense of peace and normalcy was challenging, particularly when an infant's condition warranted a true sense of urgency for withdrawal:

She was actually to the point where we were wrapping her in chucks because she was oozing out so much ... We couldn't keep blankets clean for parents to hold her. So it was pretty much like, 'Get [the dress] on her and get a picture – quick! Quick!' Trying to take out as many wires as we could for the parents made it seem like their baby instead of ... I mean we had femoral lines in, trached on a ventilator, G tube ... she had all kinds of things so we took out as much as we could. Tried to wrap her up, get a hat on her head. (nurse)

Providing comfort—Up to this point, all of the stated obligations of nurses and physicians were to parents. Only one obligation was directed toward the infant: providing comfort. As with the obligation of timing the withdrawal, providing comfort helped to minimize suffering. All physicians who described this obligation focused on pain control:

I felt like my first obligation to the [infant] was that he wasn't going to suffer any more – that we were going to stay on top of his pain ... I can't imagine what it feels like to have bowels die inside of you and be so sick and ventilated and everything else – it just can't be comfortable. So my first priority is the baby. (physician)

For nurses, providing comfort included pain control, but also warmth and love (in the form of being held). Comfort had a dual meaning too in that it was being provided to the infant, but the benefit of that comfort was intended also for the parents, so that they did not see their infant suffering:

Very much I believe the baby should be pain free as much as possible, and the parents, I don't think they should see the baby suffering. I'm a strong advocate for making sure sedation is appropriate. That's a priority for me. (nurse)

Discussion

Exploration of the deeply held moral oughts of caring for dying patients revealed that a common overall obligation of both nurses and physicians was to create the best possible situation for infants and their parents. This logical finding carries important meaning in that it establishes a moral path to follow, a way to speak the same language about end-of-life care. The implementation of palliative care measures in the NICU remains conceptually challenging.^{37–39} If the familiar path of aggressive treatment were accompanied by a parallel path of creating a best possible situation, what we *do* could be better aligned with what we *intend*. In addition, the overarching obligation was not to do what was best for the infant, although this was certainly an important factor. Rather, the emphasis was on how parents would accept this death and reflect on the moment as their lives carried on. This focus on preservation of the family after tragedy is a richly 'ethic of care' driven perspective. Perhaps it is time to acknowledge the centrality of this method of moral reasoning and its influence on health care providers' moral practice.

Creating a best possible experience for infants and parents was accomplished differently by nurses and physicians, thus supporting the idea that these disciplines are speaking different languages. Provider obligations generally centered on a particular sphere of influence. For

nurses, that sphere was the actual end of life, while, for physicians, the sphere was largely end-of-life decision making. However, just as the end of life is not a discrete entity or moment in time, these spheres were not exclusive of each another. As a result, obligations overlapped at times, indicating that one's end-of-life language is not completely foreign to the other. These overlaps can be interpreted in two ways. First, a common conception, rooted in the histories of the professions, is that physicians are not directly involved in end-of-life care, which was not fully supported by this study's findings. Although physicians were less likely than nurses to be at the bedside at the actual end of life, they were intimately involved in the preparatory moments, in providing options and preparing parents. No conflict was found between physicians and nurses with regard to these obligation overlaps. Instead, these overlaps illuminate the more subtle aspects of involvement at the end of life, which was described by several participants as a privilege of being a health care provider.

Second, a consistent obligation to minimize suffering, similar to the findings of Oberle and Hughes,⁴⁰ was found as an undercurrent in many obligations. This obligation was most clear in providing comfort to the infant through pharmacological and non-pharmacological means. Minimizing suffering was less apparent, but no less important, when participants described situations of urgency. For physicians, tending to pain and suffering in an actively dying infant was very important. For nurses, the focus of urgency and suffering was on those infants who had experienced a long period of aggressive treatment with little hope of a good outcome. Such situations often create moral distress,^{16-18,29,41,42} and did so in this study. This was true even for some providers who had not been involved directly with the patient. Thus, an inability to minimize suffering appeared to be a violation of an obligation. However, although minimizing suffering was rooted in a sense of urgency, which was ultimately centered on an obligation of timing withdrawal during decision making, there were no clearly articulated obligations of nurses during decision making. Other studies have found, similarly, that the nursing role in decision making is either unclear or lacking.^{12,26} These studies focus mainly on external causes, such as a lack of collaboration. The findings of the present study suggest an internal component as well. The nurse participants recognized a general obligation to attend to situations of prolonged suffering, but there did not appear to be a nursing obligation to be involved in this process. This lack of obligation may stem from nurses' lack of role in end-of-life decision making, thus creating a circular argument. Nonetheless, involvement in end-of-life decision making requires not only an externally grounded unit culture that supports multidisciplinary collaboration, but also an internally motivated obligation to be actively involved.

This study is limited in that it was conducted in a single, highly specialized unit. The aim of qualitative studies is not to produce generalizable results, but rather (in this case) to illuminate a phenomenon. The findings may therefore not resonate in other settings or institutions. Reports of provider obligations at the end of life are scant and this study provides an early description of these. A second limitation is that the identification of providers' moral obligations was a secondary aim of a larger study. As such, some of the obligations are lacking in depth. A more pointed, in-depth study of these obligations would be likely to provide a richer portrayal. Additional limitations include an insufficiently large sample to discern differences between attending, fellow, and resident obligations, gender differences, and the obligations of nurse practitioners. Differences between physician levels are likely, given the finding by Levy et al.⁴³ that physician roles influence perspectives of end-of-life care. Only one nurse practitioner participated in this study. Given that the nurse practitioner role is different from that of physicians and nurses, her data were not included in this analysis. Finally, although health care providers answered the question: What were your obligations to this baby and family? their responses have been interpreted here as moral obligations. There is some question about whether obligations and moral obligations are the same thing. Openly asking about 'moral' obligations was believed to be potentially

confusing or off-putting for participants. Hence, this word was omitted from the interviews. A liberal view of moral obligations was thus taken and is a limitation of the study from an ethics perspective.

Avenues for future research include exploring the obligations of providers in other settings and other disciplines (social work, chaplaincy, respiratory therapy), a deeper examination of nurses' obligations during decision making, and development of multidisciplinary interventions that acknowledge a common goal and the different ways of arriving at that goal.

Conclusion

The findings of this study begin to inform about how nursing and medicine view their moral duties in providing end-of-life care. That the ultimate goal of this care is shared by these disciplines establishes an avenue for moral and practical conversation and collaboration. Additionally, the more subtle undercurrent obligation to minimize suffering was an important aspect of creating a best possible experience, and helps to tie obligations in decision making together with obligations at the end of life. The identified differences in end-of-life obligations highlight how end-of-life care is defined and approached differently by nurses and physicians. They also demonstrate the moral spaces occupied by nurses and physicians at different times, and the critical influence of these disciplines at the end of life. Recognizing these moral spaces may help to address ways in which provider roles and obligations can more effectively work in concert rather than in conflict. Understanding the similarities and differences in the disciplines' obligations is an important charge if we are to move forward in improving the end of life in ICU settings.

Acknowledgments

The author gratefully acknowledges Ann Hamric, PhD, RN, FAAN, for her mentorship throughout the study, as well as Susan Card, RN, and Alix Paget-Brown, MD, for their assistance in interpretation of the findings. Additionally, Susan Card was instrumental in the recruitment of participants. I would also like to thank Margaret Mohrmann, MD, PhD, for her helpful conversation about the ethic of care.

This study was supported financially by the National Institutes of Health through National Research Service Award grant (1F31 NR009466-01) between October 2005 and January 2007.

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