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What is This?
Ethics

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Michael A. van Manen

Abstract
This study was a phenomenological investigation of ethical decisions experienced by parents of newborns in neonatal intensive care. I explore the lived meanings of thematic events that speak to the variable ways that ethical situations may be experienced: a decision that was never a choice; a decision as looking for a way out; a decision as thinking and feeling oneself through the consequences; a decision as indecision; and a decision as something that one falls into. The concluding recommendations spell out the need for understanding the experiences of parents whose children require medical care and underscore the tactful sensitivities required of the health care team during moral–ethical decision making.

Keywords
ethics / moral perspectives; infants; lived experience; phenomenology; van Manen

In the neonatal intensive care unit (NICU), the newborn child is the central concern of moral–ethical decision making. The child, who is vulnerable and without autonomy, relies on the parents and health professionals for ethical decisions regarding medical interventions (Miller, 2007). The parents are charged with relative authority as surrogate decision makers to determine what is in their child’s “best interest” (Buchanan & Brock, 1989).

From a bioethical perspective, an ethical decision tends to be understood as a rational, deliberative affair such that in prevailing discourses it is approached as a dilemma to be analyzed or a problem to be solved (Ladd & Mercurio, 2003; Leuthner, 2001). A number of different conceptual models have been developed to provide structured frameworks for determining and evaluating moral issues, mediating between abstract ethical theory and concrete health care practice (Beauchamp & Childress, 2001). Although the child’s “best interest” may be the rational–moral goal of decision making, the thoughtful question to ask is, What is the lived meaning of ethical decisions as they unfold at the bedside?

A phenomenological perspective gives priority to understanding the lived experiences of possible ethical decisions. To gain access to these experiences, an approach is taken in keeping with the philosophies of Emmanuel Levinas (1961/1969) and Bernard Waldenfels (2006/2011). For Levinas and Waldenfels, the ethics of a decision are situated not in abstract theories but in the lived experience of the face-to-face encounter. The phenomenal meaning of an ethical decision lies neither wholly in the subjective nor in the objective realm but rather in the manner in which parents are confronted with their child’s situatedness. The presence of multiple medical caregivers (nurses, physicians, and so forth) and the techno-medical environment itself may complicate the nature and quality of contact between parent and child in the NICU (van Manen, 2012a, 2012b).

Related Literature
A considerable amount of research has been devoted to understanding parental ethical decision making. Quantitative epidemiologic studies have identified factors that correlate with the desire for medical intervention: parental age, race, and religion; medical diagnosis and uncertainty about prognosis; and physician preference (Arad, Braunstein, & Netzer, 2008; da Costa, Ghazal, & Al Khusaiby, 2002; Doron, Veness-Meehan, Margolis, Holoman, & Stiles, 1998; Moseley et al., 2004). Although these factors are significant determinants at a population level, they do not necessarily determine what

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happens at the bedside, where competing factors frequently exist. This literature also does not reveal how parents may be relationally informed and directed by their own experience of parental responsibility. In other words, it does not show how parents may be affected by the vulnerability, singularity, and alterity of their newborns (van Manen, 2012c).

Qualitative researchers have studied decision making from various methodological perspectives. The findings of perception studies, open-ended interview, and structured survey studies are similar to quantitative epidemiological studies. Faith, religion, and spirituality; parents’ childhood, education, and profession; perception of the child’s pain and suffering; and perceived prognosis and reported hope may guide decision making (Boss, Hutton, Sulpar, West, & Donohue, 2008; McHaffie, 2001; Meyer, Burns, Griffith, & Truog, 2002; Meyer, Ritholz, Burns, & Truog, 2006; Vandvik & Forde, 2000). Researchers also discuss parents’ desire for good communication; accessible, sufficient, and accurate information; genuine relationships; honesty, compassion, and hope; and involvement, encouragement, and support during decision making (Boss et al., 2008; Brosig, Pierucci, Kupst, & Leuthner, 2007; Kavanaugh, Savage, Kilpatrick, Kimura, & Hersberger, 2005; McHaffie; Meyer et al., 2006; Pepper, Rempel, Austin, Ceci, & Henderson, 2012; Wocial, 2000).

Ethnographic studies have provided insights regarding the sociocultural context of decision making. It is clear that professionals and parents approach collective decision making differently. Physicians tend to be concerned with “distancing aspects” such as giving honest information and warning parents of possible problems that may result in poor outcomes (Alderson, Hawthorne, & Killen, 2006, p. 1320). Parents, however, tend to emphasize “drawing together aspects” such as sharing knowledge, understanding, and planning to hopefully foster mutual trust in a decision-making space (Alderson et al., p. 1320). In difficult decisions, communication between physicians and parents is important because the prognostication of outcomes may be ambivalent or indeterminate (Abel-Boone, Dokecki, & Smith, 1989; Einarsdóttir, 2009). How health care professionals express medical certainty may control or even “erase the very ethical nature of uncertainty” (Orfali, 2004, p. 2018).

Parents may not understand what it means to be involved or to take part in a decision (Einarsdóttir, 2009; Vermeulen, 2004). The meaning of involvement need not narrowly consist of parents explicitly voicing their opinion. Rather, involvement for the parent may be experienced as being present (Orfali, 2004). Parents may simultaneously desire and resist having to exercise control over choices affecting their child’s life, acutely experiencing the presence or absence of the support of health care professionals in the process of decision making (Orfali). What professionals view as major decisions may not be important decisions for parents, and vice versa. To parents, day-to-day choices such as holding, breastfeeding, and discharge planning may constitute major responsibilities, activities, and effects (Alderson et al., 2006).

Grounded theory researchers concerned with parental decision making have discussed issues such as ambivalence, information, communication, inclusion, and responsibility (Brinchmann, Forde, & Nortvedt, 2002; Carnevale et al., 2007). These studies, however, are aimed at theory development, using codification techniques that fail to provide a rich portrayal of the actual lived experience of decision making.

Existing studies of the phenomenological tradition have tended to focus more on issues related to decision making than on the phenomenon of decision making itself. For example, Kirschbaum (1996) focused on factors and values that may impact on parents’ ethical decisions: life; pain and suffering; quality of life; not self; respect for person or best interest; family; faith and nature; and, technology. Other phenomenological studies seem to have moved into explorations of parental–physician role engagement, communication, emotional reactions, and the general contextual experience of the NICU (Payot, Gendron, Lefebvre, & Doucet, 2007; Pinch & Spielman, 1989, 1990, 1993; Wiegender, 2008).

Unfortunately, many of these studies focus primarily on parents’ reflective rather than their prereflective experiences. In other words, they focus on what parents think about decision making in the NICU rather than on the actual lived sensibilities of the parental experience of an ethical decision. It appears that the parental experience of the ethical encounter with his or her child in the NICU, a relational ethics perspective of decision making, is a relatively unexplored subject.

Methodology

The aim of this article is to explore the phenomenon of the ethical decision from the perspectival experience of parents caring for their child. In particular, the focus is on parents of premature or sick infants requiring hospitalization from the time of birth in an NICU.

A context-sensitive form of interpretive inquiry, phenomenology of practice, was employed (van Manen, 2007). Phenomenology of practice is a reflective study of prereflective experience that carries the capacity to cultivate ethically sensitive understandings and morally appropriate actions in the caregivers of children. The methodology is well suited to serve practitioners who in their day-to-day practice may be unaware of or insensitive to the depths and subtleties of other people’s experiences. Although the aim of phenomenological research is
to draw near to understanding a particular phenomenon, it should be acknowledged that phenomenological research is always incomplete and tentative because the researcher cannot possibly capture a given experience in its entirety nor describe how all people will experience a particular event. As a human science research methodology, phenomenology of practice represents a blending of philosophical, human science, and philological methods (van Manen, 1990).

**Philosophical Methods**

The focus on lived experience is an application of the philosophical method of phenomenological inquiry: the reduction. It is a method of “leading back” (reducere) to the way in which a recognizable phenomenon is experienced, before the experience is conceptualized, abstracted, or theorized. In effect, the reduction involves taking up a questioning attitude of radical, reflective attentiveness to the way in which we experience the world. Merleau-Ponty (1945/1962) wrote, “I posit the stuff of knowledge when . . . I adopt a critical attitude towards it and ask, ‘what I am really seeing.’ The task of a radical reflection . . . consists, paradoxically enough, in recovering the unreflective experience of the world” (p. 280).

As a physician working in multiple NICUs, I am continually confronted with the task of talking with parents when situations call for ethical decision making. Still, I tend to be removed from much of the conversations, reflections, and deliberations that parents engage in away from medical professionals. Clearly, although I have existing knowledge about ethical decision making in neonatal intensive care, I have significant inexperience with the actual experience of ethical decisions from a parental perspective. As a clinician researcher, the phenomenological reduction requires a continual reflexive effort to “lead back” to question, Is this indeed what the experience of an ethical decision may be like for a parent? This investigating of lived experience should be conducted in a manner that is critical and rigorous, yet also open and tentative.

Evidently, the notion of the reduction is quite complex, articulated in a variety of ways in the philosophical literature. To those familiar with continental philosophy, this is neither surprising nor necessarily problematic because the philosophical tradition of phenomenology is eclectic, constantly questioning and rediscovering itself (see Lewis & Staehler, 2010, for a concise introduction).

**Human Science Methods**

A central feature of phenomenology of practice is a reliance on qualitative empirical methods to gather a field of descriptive evidence: lived experience descriptions, from which underlying patterns and structures of meaning may be drawn (van Manen, 1990). Gathering examples of a lived experience is not an isolated research practice. The activity is woven into the explorative questioning of a particular phenomenon of interest.

For the purpose of this study, parents were recruited for interview from four local hospital nurseries in a western province of Canada spanning the scope of acuity seen in neonatal intensive care. Parents were sought out who had a premature or sick infant requiring hospitalization from the time of birth in a NICU whereby direction-of-care decisions were anticipated. More specifically, attending neonatologists were asked to identify parents of children for whom they foresaw a high likelihood of a decision regarding limiting life-support therapies (e.g., mechanical ventilation, cardiovascular support, or artificially delivered nutrition) or a decision marking a shift toward a particular direction of care (e.g., tracheostomy, complex congenital heart disease surgery, or organ transplant).

Parents were invited to participate in the study only if and when both attending neonatologist and research staff felt it was morally appropriate after giving consideration to such issues as parental psychosocial distress and involvement in multiple studies. In total, 14 parents participated in the study. Admitting diagnoses of their children varied, including extreme prematurity, complex congenital anomalies, and neurologic compromise. Parents ranged in age, ethnicity, education, and socioeconomic background. This number of participants is in keeping with other studies of this methodology to allow gathering of sufficient experiential material to write a rich phenomenological text (van Manen, 2012a).

Experiences of ethical decision making were elicited by interview. In empirical phenomenological human science research, the interview serves the purpose of gathering and exploring experiential narrative material (van Manen, 1990). Therefore, although the interview is “unstructured,” it is clearly “oriented” to opening up the lived experience through uncovering meaningful stories and anecdotes. Timing of interviews was sensitive to the situational stresses and personal preferences of the individual parents such that parents were interviewed concurrently and/or retrospectively to their decision-making experiences. Most parents participated in multiple interviews spanning the duration of their child’s admission to the NICU, allowing revisiting of their experiences and exploration of certain meanings and significances of their experiential descriptions. Parents often described multiple decisions that provided a broad range of varieties of ethical decision experiences. Interviews were audiorecorded and transcribed verbatim.

In keeping with this phenomenology of practice, analytic–reflective methods (thematic analysis, guided...
existential reflection, linguistic tracing, and exegetical reflection) were used to identify and reflect on variant and invariant meaning aspects of the phenomenon as a starting point for phenomenological writing (van Manen, 1990). Thematic analysis involved wholistic and line-by-line readings of transcript material attending to the meanings embedded in the text. Through guided existential reflection, fundamental lifeworld themes were used as heuristic guides for reflecting on parental experiences: lived space (spatiality), lived body (corporeality), lived time (temporality), lived things and objects (materiality), and lived human relation (relationality). Linguistic tracing involved attending to the conceptual and etymological aspects of the language used in ethical decision making. Exegetical reflection involved the study of related and sometimes seemingly unrelated literary and phenomenological texts.

**Philological Methods**

Phenomenology of practice is a textual form of qualitative inquiry such that writing is closely fused to the research process. The goals of the writing are not only to describe, to explicate, and to question phenomena of the lifeworld but also to evoke understandings that may be beyond the reach of propositional discourse (van Manen, 1997). In other words, the ambition of phenomenological writing is contact: to touch the lived meaning of a phenomenon to be able to be touched by it (van Manen, 2002).

Thematic statements were formulated as “figures of meaning” in concert with the above analytic–reflective methods to help point to possible eidetic meaning aspects of the phenomenon (van Manen, 1990). Eidetic refers to the unique or more invariant patterns of meaning that may make a particular phenomenon distinct ("what it is"). These thematic statements were used to structure the presentation of anecdotes and research text.

Phenomenological anecdotes were drawn from the interviews to assist the reader of the research to access the subjectivity of the experience of an ethical decision (van Manen, 1989). Anecdotes were constructed from the interview material and refined to attend to the subjective rather than objective aspects of experience. No effort was made to verify whether a parent’s description of an event was in keeping with the way things actually happened. The aim was simply to portray the experiential event as the parent may have felt and experienced it. Thus, the aim was to arrive at plausible descriptions of possible human experiences.

The aim of phenomenological writing is to find rigorous and rich language sensitive to a phenomenon such that the reader may experience heuristic questioning, experiential richness, interpretive depth, strongly incarnated meaning, reflective rigor, evocative awakening, and situated epiphany (van Manen, 1990). Therefore, drafts of the text were reviewed with diverse groups of health care team members (physicians, nurses, respiratory therapists, dieticians, social workers) and parents of children who had been cared for in the NICU to ensure the descriptions and reflections resonate with lived life, triggering instants of recognition and evoking immanent (subjectively felt) phenomenological evidence.

**Ethical Issues**

Permission to conduct this study was obtained from the university health ethics review board and appropriate administrative authorities. Strategies to diminish the possibility of participant identification included use of pseudonyms, careful selection of anecdotal examples, and alteration of specific information that might increase the likelihood of identification. To avoid conflict of interest between my roles as researcher and clinician, I neither enrolled nor interviewed families at a time when I was involved in their care.

**Findings**

The inquiry into the phenomenon of the ethical decision yielded the following interpretive themes around which the research text has been composed: (a) a decision that was never a choice; (b) a decision as looking for a way out; (c) a decision as thinking and feeling oneself through the consequences; (d) a decision as indecision; and (e) a decision as something one falls into. These themes are treated as figures of meaning that help to point to the manifolds of lived meaning that may relate to the phenomenon of the ethical decision. In reading this phenomenological text, the reader may ask questions such as the following: What may the experience of an ethical decision be like for a parent? What may a parent encounter in an ethical decision situation? And how may parents uniquely or commonly experience ethical decisions?

**The Ethical Decision as the Decision That Was Never a Choice**

Sometimes it is the outcome of an investigation that announces the urgency of a decision, such as a head ultrasound showing severe brain injury in an ill infant. Other times, it is the constellation of intensive therapies being utilized in the deteriorating condition of a child that signals a decisional juncture. In such moments, health care professionals may call on parents to consider options—the possibility of a decision. The alternatives may include initiation, limitation, or withdrawal of medical therapies. For parents, the choice is not always seen:
The doctors kept on asking us about withdrawing care. We felt pressured to decide, almost hounded, to take Sam off life-support. It was as if they thought that we did not get it. But we knew that he could be severely disabled, that his chances were so poor. Yet, how could we kill him? How could we have a part in ending his life? We avoided the staff to avoid the discussion. We avoided coming in to see our son, just to avoid being confronted with the predicament of having to face some kind of impossible decision. We just wanted to let him have a chance. If he was to die, he would die on his own. We did not want to take his death away from him.

From the health care professionals’ catechizing call, “to take Sam off life-support,” and the parents’ inability to respond in consideration, “how could we?” we may discern that sometimes an ethical decision is experienced as a choice without choice.

The notion of choice seems to imply some degree of free decision. But there is a contradiction to the power of choice: it is not fully free. To decide for others means a responsibility for the “other” and for the sake of the other experienced as a demand on “me” (Levinas, 1961/1969). As such, we could say that there is accountability to an ethical decision that emerges from the demand of responsibility. The decision presents weight, burden, and charge. So as the parents are being asked to make a decision for their child, “to take his death away from him,” we may wonder, how is this choice within their control? Is deciding to take part in ending their child’s life a choice? Are the parents asking too much?

There is also a normative sense to choice: it is good, right, or proper. When health professionals present treatments as options of choice, each treatment may be marked by the trace of benefit. In other words, each treatment foresees a potential advantage for the patient—otherwise there would be no option to present. Therefore, it may be difficult to say, “No, stop, or discontinue” a therapy.

Sometimes there is no choice option that aligns with a parent’s values. The possibility of choice may be constrained by religious or cultural convictions. It may also happen that an offered choice is just too different from what a parent can envision for his or her child. The decision to withdraw treatment may be incommensurate with what a parent may feel that he or she can do as a parent. There simply is no choice. So it may happen that in such a moment when we think we are dealing with an ethical decision, for the parent there exists no real choice except to continue on: to let the child have a chance at life.

**The Ethical Decision as Looking for a Way Out**

There are ethical situations that seem to demand information. The decision is not resolvable in the moment but instead may require reasons, calculation, deliberation, and even meditation. The parents are looking for evidence to clear away uncertainty.

The choices were that we could keep her on the ventilator without giving her dexamethasone knowing she was going to deteriorate slowly; that we could give her the dexamethasone and see where that takes us; or, that we could withdraw treatment. The first was not a decision for us. We did not want her to suffer. We so wanted to help her, but at what cost? I remember taking a walk with my husband after talking with the doctors. We talked about quality of life. We knew that while the dexamethasone could be good for her lungs, it could be bad for her brain. We talked about what we were prepared to live with. We knew that if she was severely disabled that we would be unable to handle that. We did not want that for our child. We talked about what we knew and what we didn’t know—the uncertainty of it all. It really felt like there was no clear right answer. And we felt like we did not have time, there was no time to make a clear decision. Time was pressing; we almost decided to withdraw treatment. But we really did not want to let her go. Perhaps we were kind of looking for an excuse to give her the dexamethasone. As we were walking back, still unsure, my husband brought up, well, what about if we ask for a head ultrasound to confirm that she does not have a brain bleed? ‘Cause if she had had a brain bleed, we were not going to go on with it, ‘cause then we would know that there was brain injury. So we said if there is no brain bleed, we will go ahead with it. We felt that this would be a way out of having to decide.

As the parents try to work a way out, the sense of the need for an ethical decision may be forestalled. What the parents may look and long for is not just the raw information of how a drug, such as dexamethasone, may affect the lungs and brain. The parents look to anticipate the inevitability of an unavoidable course of action or inaction.

The existential meanings of choice options are crucial—to cause our child suffering, to let our child go, or to carry on with our child. So the parents wonder: What will life be like for our child? What will life be like for us? What can we live with? Looking for a way out, the decision moment is not really experienced as a choice. The decision is deferred by surrendering to the “fateful” outcome of an investigation, the head ultrasound. Perhaps the ultrasound provides the parents with a different picture, a hopeful situation where everything may still turn out all right, by showing them a child who has no definitive evidence of brain injury. But the ultrasound has turned into a fateful coin that is tossed to find a way out of an impossible choice.

**The Ethical Decision as Thinking and Feeling Oneself Through the Consequences**

In deliberating a decision, rational calculation may not resolve uncertainty. Instead, one may need to feel oneself through what is to come.
They told us that it would be for the best if we were to discontinue life support. Our answer was “No.” We were just not ready. It was a shock. And we had not had time to discuss it. We felt so rushed, pushed to come to a decision. They wanted an answer. We went back to our room. I was thinking, he is my little boy. I pictured him in the isolette as I stared at the pictures of him on the table. He was with us in that room. We searched the Internet, pulled everything up on the computer on what he had and what the outcome could be. We looked at the worst of the worst given his brain injury. We asked ourselves, can we handle it? It is going to be a daily-life thing for us, and if that is how he is going to be, can we deal with it continuously day-in and day-out? We started talking about different home situations and stuff—even to the point of bedroom space and such—room colors, pictures, bedding. We were putting him at home in our thoughts. I don’t think we were deliberating and weighing medical alternatives, it was just, can we do this? And it was at that point, as his parents, we knew we could do anything, that, no matter what, we could handle it. And if he wanted to go, he would have to go on his own.

As the parents pass from hesitation to choice, the ethical decision may be experienced not so much as a deliberative affair of weighing alternative benefits and burdens, but rather an asking, “Can we do this?”

Paul Ricoeur (1950/1966) wrote, “There are no decisions without motives” (p. 66). Motives are not simply causes, instincts, or drives. Motives are in the sensible core of the ethical decision regarding my child: the child with hair that has never been brushed; the child with skin that has not seen the sun; the child who, although being marked by profound illness and scared by medical interventions, is still innocent to the parent. The decision only has sense, only has meaning, in relation to the child as my child. As such, the answer to “Can or should we do this?” may not simply be a response to a question of feasibility. Rather, the answer involves feeling the weight of the decision “day-in and day-out” for this child. The eidetic meaning of the ethical decision is found in the neverending experience of the appeal of this child’s being and this child’s face.

Feeling oneself through the consequences of an ethical decision may result in consenting to the appeal: “putting him at home in our thoughts.” Consent is not simply the outcome of a deliberated judgment. Consent is in “the act of the will which acquiesces to a necessity” (Ricoeur, 1950/1966, p. 341). As the parent feels him- or herself through the daily traumas of the consequences, an initial decision may unravel from what was initially perceived as an option.

The Ethical Decision as Indecision

The decision moment may be experienced as an ethical encounter that places the parent in a predicament of impossible responsibility.

We were asked to make a decision about Isaiah. We needed to decide whether to carry on, or whether to stop. They told us that, if he survived, he would almost certainly be severely impaired: never walk, never talk, and likely never see. He would not share our world, at least in the way that we live it. Thinking of Isaiah, I thought of my other children. I remembered their faces when they were young. I thought of the dreams we had for them. I thought about what continuing on with Isaiah would mean for them. We would have less time for them. There would have to be sacrifices. Sacrifices that I would never want my children to have to make. Still, Isaiah is also my child. His face is also my child’s face!

What ought to be decided for Isaiah? How much is too much for Isaiah’s siblings to bear? How many challenges are too many for any child? The ethical appeal of each child transcends rationality; the father is faced by the faces of all of his children.

The etymology of “decision” means “to cut off” and derives from the Latin de-caedere. Cutting, inevitably, deselects (an)other option. Each decision divides each time, existentially located between what can and cannot be resolved, what is anticipated and unforeseen, and what is tentative and decisive (Derrida, 1999/2008). A truly ethical decision is more than a cognitive or deliberative affair. An ethical decision cuts between responsibilities.

In the father’s ethical response to his children’s faces lies a deep sense of responsibility. He knows himself to be responsively responsible for Isaiah, and he is also responsible for all of his other children. The responsibility does not originate from himself but from the others: his children. Consequently, the significance of the decision may be felt in the experience of being held in indecision: the father cannot satisfy the demands of responsibility for all his children at the same time. Perhaps all the father can responsibly and responsibly do is defer the decision as indecision, to endure the indecision.

The Ethical Decision as Something One Falls Into

A difficult decision may haunt the parent and refuse to settle:

I find myself coming back to the decision. I go to brush my teeth, and I find myself thinking about it. It is like a mood that does not seem to go away. Even though I made my decision. I still think of it as not closed, not finished, not done. I still see it as a possibility. This morning we were eating our breakfast, but I just found myself distracted. Their conversation seemed to interrupt me as some kind of deliberation goes on and on. Really, whatever activity I am caught up in—eating, drinking, driving, whatever—I am still in this moment of decision. It is exhausting but I am just not ready to accept my decision. To remain decided. I am, and I am not, where I need to be. I am back there beside the
incubator looking at her. I am back there looking at her face. I am reliving the discussions, reliving the decision. I am revisiting the decision as if unmaking it. It is like the decision is a place that I cannot get settled in but also cannot leave from.

Here is an NICU situation where a mother still seems to live in indecision: distracted, preoccupied, and torn. The decision will not settle. Still, when a child continues to get worse and an ethical decision is forced, we may wonder if the decision—uncalculable and unthinkable—may sometimes be resolved not by thinking but rather by falling into it or by taking a sudden leap:

I do not know at what moment it was, but at some point, I stopped hearing the risks of transplantation, and I finally knew what we had to do. We had been struggling, trying to understand what we should decide. We were going through the process again—how they would qualify her for listing, what being listed would mean, the risks of transplantation, the benefits—all of it. I was listening to what they were saying when I remember suddenly feeling settled. It was done, completed. I was moving on. The decision between palliative care and heart transplantation was made. I had to give her the chance of transplantation no matter the risks, no matter what she may have to go through, even if she died on the waiting list. I had to do that as her mother. I went back to her bedside after the meeting and sat there, looking in her eyes, seeing her face. She was my daughter needing a transplant.

It is at the moment when a decision refuses to settle that suddenly the unexpected may happen. One falls into a decision that suddenly seems utterly decisive and final.

**Discussion**

This study shows how parents may experience ethical decisions in a complex variety of ways. For some parents, there are ethical decisions that are not quite decisions. And if there is no perceived choice, the health care professional’s need for a decision may turn into a moment when the parent can only express his or her wants and desires for his or her child. So although the decision may come from the parent, owned as “my” decision, we may wonder if the decision is truly a decision at all, or rather simply a documentation of the wishes of a parent for his or her child.

Of course, from a rational perspective, this kind of “nondecision” or “indecision” can be seen as a decision as well. But the point is that health professionals need to understand that this kind of nondecision is a possible situation that parents may encounter. By no means does this acknowledgment resolve the potential moral impasse or distress that may occur when parents and professionals truly disagree on what is “good” or “best” for a particular child. Nor does it resolve the health professional’s need for consent from parents to support a decision that they wish to pursue. Rather, understanding an ethical decision as a nondecision may prompt professionals to reconsider their approach to a particular moral—ethical situation.

Other decisions may be experienced by parents as problems in need of deliberation and information. In such situations, professionals clearly need to meet the informational needs of parents in a caring and compassionate way. These situations require not only a “thinking through” but also a “feeling through.” Resolution requires not just the weighing of benefits and burdens but also the resolve from parents to ask themselves: What do we feel comfortable with? Does the decision feel right? And ultimately, can we live with it? This manner of proceeding does not necessarily position an ethical decision away from the “best interests of the child.” Instead, it may situate the decision relationally in the parent’s encounter with his or her child as the parent asks: What ought “I” to do for my child? Recognizing that reasoning or calculation may not resolve uncertainty may also call into question how we support such parents and resolve decisions that need to be made. The practitioner should recognize that it is not only information that informs a decision.

Although contemporary health law may dictate that decisions be made in the “best interests of the child,” we need to be aware of the subtle and complex reality of ethical decision making that may involve considerations beyond the child: How are the parents to live their own lives? What can they bear? What are the effects of decisions on other important people in their lives, their other children and family members? An ethical decision deals with responsibilities not only to the child but also to the self as an “other” and others as “other.” Such an understanding, while illuminating the reality of ethical decision making, also highlights the importance for ongoing research into the moral—ethical implications of various health care practices.

If in the end a parent cannot settle into a decision—necessitating the appeal to technology, nature, or fate—the health professional may find him- or herself drawn deeper into the ethics of the decision. Such situations of indecision are likely to become more common as the medical landscape changes, incorporating advanced technologies, often in the context of differing or conflicting cultural values, and so forth. Situations of indecision emphasize the need for a collaborative, or even at times a delegated decision making whereby the professional assumes a greater role (Madrigal et al., 2012). Collaborative and delegated decision making may also benefit from policy-level deliberations as resources become limited even in highly technologized health care systems.
Insights into parental experiences of decision making need not lead to generalization but instead an acknowledgment that different parents may experience the moments of ethical decisions contingently in different ways. And just as an ethical decision may be a complex predicament for the parent, much is also demanded from the health professional confronted with the responsibility of helping a family navigate difficult life predicaments (Boss, Hutton, Donohue, & Arnold, 2009). Additional research is needed to gain insight into the experiences of health professionals who support patients and families faced with difficult decisions.

Conclusions

Although ethical decision making tends to be understood theoretically as a rational, emotional, and deliberative process based on the patient’s best interests, the actual lived experience of this event may be more ineffable and difficult to grasp. Decision experiences may not lend themselves to being conceptually simplified for generalization nor be fitted into a procedural schema or resolution framework. Instead, health practitioners may do well to develop critical yet nuanced understandings of the possible experiences that parents may undergo in an ethical decision in the NICU.

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