

Résumé

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## **Le dilemme moral des infirmières concernant l'administration d'anticonvulsivants au besoin dans le cadre des soins palliatifs pédiatriques**

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Le présent article étudie le processus de décision des infirmières concernant l'administration d'anticonvulsivants au besoin à des enfants souffrant de troubles convulsifs de longue durée dans le cadre des soins palliatifs. À cet effet, on a utilisé l'étude phénoménologique herméneutique suivant la démarche méthodologique de van Manen. Six infirmières ont participé aux entretiens. L'analyse des données a révélé que la réaction globale des infirmières étaient qu'elles ne veulent pas que cela se produise quand elles sont de garde, puisqu'elles sont les témoins de ce qui se passe, elles sont à l'écoute des patients, créent des liens avec eux et savent ce qu'il faut faire. Quatre thèmes sont ressortis de l'étude : savoir ce qui se passe — ce qu'il faut savoir et les façons de savoir; prendre en note ce qui se passe au bon moment — attendre et minuter; trouver un certain réconfort personnel — développer un sentiment de réconfort, être confronté à la détresse et y répondre; et prendre la décision — reconnaître une crise convulsive, déterminer les options, peser le pour et le contre et repenser la décision. Cette étude révèle qu'en prenant ce genre de décisions, les infirmières peuvent se retrouver face à des cas de conscience engendrant une détresse morale. Elle nous permet aussi de mieux comprendre les tensions et les récompenses qui s'y rattachent.

Mots clés : processus de décision, soins palliatifs pédiatriques

# Nurses' Moral Experience of Administering PRN Anti-seizure Medications in Pediatric Palliative Care

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This article explores nurses' decision-making related to the administration of PRN anti-seizure medications to children with long-term seizure disorders in palliative care. Hermeneutic phenomenological inquiry guided by van Manen's approach was the method used. Six nurses participated in interviews. Data analysis revealed that *not on my watch* was the overarching theme in which nurses engaged in bearing witness, being attentive, creating connectedness, and finding the right thing to do. Four themes emerged: being in the know — what to know and ways of knowing; marking time — waiting and timekeeping; seeking a sense of personal comfort — developing a sense of comfort, experiencing distress, and responding to distress; and making the decision — recognizing a seizure, identifying options, weighing the options, and rethinking the decision. This study reveals the moral dilemmas and resulting moral distress that may be experienced in making this type of decision and advances our thinking about the corresponding tensions and rewards.

Keywords: chronic illness, decision-making, ethics, pediatric nursing, palliative care

Over the past several decades, palliative care in the home and in hospices has become an alternative to hospital care for children living with an incurable illness. Hospice nursing is unique because parents have spent the most time living with and managing their child's care, such as assessing their child's need for and responses to PRN (as the need arises) anti-seizure medications. As a result, nurses' and parents' decisions about the best course of action may not always be congruent and tensions may arise. There is no literature describing tensions between nurses' and parents' decisions. However, the impetus for this study was nurses' concern that they might be administering PRN anti-seizure medications more frequently than parents, indicating that their decision-making is somehow different from that of parents and could be upsetting for parents.

Since the early 1960s nurses have been examining the closely related phenomena of clinical judgement (Benner, Tanner, & Chesla, 1996), critical thinking (Brunt, 2005), diagnostic reasoning (Carnevali, 1984), and

clinical decision-making (Rashotte & Carnevale, 2004). Despite the large body of research in this area, the process of clinical decision-making is still not well understood. In contrast to the substantial literature pertaining to the decision-making process in general, there is little systematic research addressing nurses' decision-making related to PRN medication administration. Several studies have examined mental health nurses' practices regarding administration of PRN psychotropic medications (Craven, Voore, & Voineskos, 1987; Usher, Lindsay, & Sellen, 2001), but these are adult-focused. Of those studies addressing PRN medication administration in pediatric nursing, most have focused on nurses' decisions related to pain medication (Hudson-Barr, Duffey, Holditch-Davis, Funk, & Frauman, 1998; Ross, Bush, & Crummette, 1991). Both groups of studies have focused either on actual administration as documented in patients' charts or on the identification of factors influencing the administration of PRN medications. We found no studies related to nurses' decision-making associated with PRN anti-seizure medications in the pediatric acute-care or palliative-care populations.

Research on the cognitive processes of nurses administering PRN medications is even more limited and is centred on the decision-making of nurses in adult acute-care settings (Eisenhauer, Hurley, & Dolan, 2007; Manias, Aitken, & Dunning, 2005). Nurses' complex process of critical thinking has been found to include all of the following: direct patient observation, interpretation of pertinent data before and after medication administration, application of knowledge related to specific patient situations, anticipatory problem-solving in relation to a patient's clinical trajectory, communication with physicians for verification of data interpretation, patient advocacy, and prevention of adverse drug events.

While research has made valuable contributions in the area of clinical decision-making, little is known about decision-making related specifically to nursing interventions in pediatric palliative care. This article reports the results of a qualitative study conducted in part to understand nurses' decision-making related to the administration of PRN anti-seizure medications to children living with a long-term seizure disorder in a palliative care program.

## **Method**

We sought a methodological approach that would disclose the meaning of making this type of decision from the perspective of those who have lived the experience. Hermeneutic phenomenology as outlined by van Manen (1997), an approach in the human science tradition, employs interpretive (hermeneutic) and descriptive (phenomenological) elements. This approach, which "aims at gaining a deeper understanding of the

nature of the meaning of our everyday lived experiences" (p. 9), can lead to a more sensitive understanding of the phenomenon.

The methodological structure we employed was a dynamic interplay among six research activities (van Manen, 1997): (1) turning to a phenomenon that seriously interests us and commits us to the work, (2) investigating experience as it is lived rather than as it is conceptualized, (3) reflecting on the essential themes that characterize the phenomenon, (4) describing the phenomenon through the art of writing and rewriting, (5) maintaining a strong and oriented relation to the phenomenon, and (6) balancing the research context by considering the parts and the whole (pp. 30–31).

### ***Participants and Setting***

A sample of six registered nurses and registered practical nurses, all women, who self-identified as having made a decision about administration of PRN medications at least three times for this group of children at the participating centre willingly participated in the inquiry. We purposely sought nurses with three experiences in order to "maximize opportunities to obtain the most insightful data possible" (Morse, 1986, p. 183). Their years of nursing experience ranged from 2 to 30. With the exception of one nurse, who had been there for just under a year, all had worked at the centre since it opened, 3½ years earlier. Three participants had administered PRNs in pediatric acute-care settings before working at this centre.

The participants were recruited from an eight-bed pediatric residential hospice in the Canadian province of Ontario. The hospice provides temporary respite. It welcomes families with children who have a life-limiting illness that results in increased pain and symptoms and a progressive decline in health. Once approval was obtained from the appropriate research ethics boards, recruitment letters were left at the reception desk and distributed via internal mail by the clinical manager. The study was discussed at a staff meeting and recruitment posters were placed in several prime locations throughout the centre. Interested participants contacted the research assistant directly. Formal consent was obtained at the time of interview.

### ***Data Collection***

The nurses participated in one in-depth audiorecorded interview — the traditional data-collection strategy in this research approach — with the second author in a private, quiet setting of their choosing. The interviews lasted an average of 90 minutes. Each interview began with the prompt *Share with me an experience where you made a decision about giving a PRN anti-seizure medication in this setting.* The goals of decision-making in this

context, accounts of satisfaction and dissatisfaction with their decisions, and factors influencing time and method of PRN administration were explored using a flexible guide with open-ended questions.

### ***Data Analysis***

The thematic analysis of the textual data (i.e., the de-identified interview transcripts) was guided by three approaches suggested by van Manen (1997): the sententious or holistic approach, the selective or highlighting approach, and the detailed line-by-line approach. An initial analysis was independently conducted by the authors for each transcribed interview. The resulting aggregate of formulated meanings was organized into clusters of themes. Through the processes of reflection, writing, and rewriting, we transformed these themes into “more phenomenological sensitive paragraphs” (p. 95) using the technique of varying the examples to demonstrate the invariant aspects of the phenomenon as it came into view.

Van Manen (1997) considers an interpretive-descriptive text to be valid when it provides an “adequate explication of some aspect of the lifeworld — [when] it resonates with our sense of lived life” (p. 27), “something that others can nod to, recognizing it as an experience that one has or could have had” (p. 27). We discussed the evolving text with the participants and considered our text trustworthy when they responded with such statements as “That’s exactly how I feel” and “I didn’t realize others felt the way I did.”

### **Findings**

The overarching theme *not on my watch* captures the meaning of nurses’ decision-making experiences in this context, which involved finding the right thing to do in each seizure event in such a way that “in the absence of parents, parental care happen[ed].” Nurses’ decision-making was a balancing act of finding the right decision for each child and family in the context of the centre’s philosophy of enhancing their quality of life. In order to know when to administer a PRN medication, they needed to know the child and parents and be willing to engage in situations of uncertainty, as decision-making often took place in the context of a child’s changing seizure patterns.

### ***Bearing Witness***

An essential aspect of *not on my watch* was bearing witness, but this was not easy to endure. Nurses described watching a child seize with such statements as “it breaks my heart” and “it really, really hurts.” Bearing

witness was particularly “distressing” for nurses who were less experienced. It was more difficult when seizures were prolonged or were perceived as causing the child distress, such as when the child had tearing, cried out, made whimpering sounds, or showed signs of physiological compromise. Yet bearing witness was different from nurses’ responsibility to be objective observers for the purposes of intervention and documentation. The nurses wanted to ensure that the child was not alone in his or her suffering; they engaged in caring acts, such as patting, stroking, holding and rocking, and giving gentle reassurances.

### ***Being Attentive***

Of necessity, *not on my watch* meant being attentive, which meant being on constant alert for any changes in the child’s behaviour. It was also an essential strategy for learning to know *this* child. The nurses paid attention to the small but significant details of the child’s movements that were indicative of a seizure, such as the “star formation that [one child’s] arms and legs go in” or “this child leans to one side and the eyes flutter.” Being attentive to *this* child enabled them to recognize the need to engage in decision-making and to verify parental reports when seizures had not yet been captured on an electroencephalogram.

### ***Creating Connectedness***

Nurses embraced parental partnerships, and creating connectedness became an essential aspect of *not on my watch* if they were to provide parental care in the parents’ absence:

*With kids with chronic conditions, you feel like you’re on a team with them [the parents]; it really is a dialogue. If they’re there, you talk to them about the seizures, and if the child is having a seizure when you’re both there, you ask them, “What do you think about this one?” They even make the decision and explain why they made it. You develop a relationship with the child and parents so that you feel more comfortable when it comes to making a decision on their behalf.*

The nurses believed that parents were experts in their child’s care and regularly sought opportunities for parents to teach them how to identify their child’s seizures and about seizure management. Engagement in this type of dialogue facilitated the creation of trust, which influenced nurses’ decisions: “I felt like I should have given [Ativan] earlier but I deferred to the parents. Even though she wasn’t there, I knew she really knew her child. I trusted her.” Nurses were transparent with parents about the seizure events, their decision-making process, and even their uncertainty.

They asked parents if they had done the right thing or if there was another choice the parents would have made.

### ***Doing What Is Right***

“I just wanted to do it right. I wanted to treat the ones that should be treated and not treat the ones that [shouldn’t be].” The right thing to do during a seizure event was not always easy to determine. Many children lived with extremely complex and unpredictable seizures, ranging from “very quiet, with just an eye roll, a little grimace” to drop seizures, full upper body twitching with head back, to prolonged grand mal seizures with bradycardia, cyanosis, and apnea. Some children also lived with infantile spasms that could easily be confused with seizure activity. Others experienced multiple types of seizures that could occur separately or in combination during the same seizure event, each requiring different medications. Seizure patterns could suddenly change, rendering a child non-responsive to his or her PRN medication. Medications could unexpectedly become ineffective for a type of seizure. One nurse said, “For each of these children there’s an evolution in what their seizures look like over time,” so that what nurses may have known about a child’s seizures on one visit would not necessarily hold true on the next.

Nurses indicated a number of goals for their nursing care. These included stopping the seizure, reducing the number and length of seizures, making the child comfortable, preventing over-sedation, reducing body stress, preventing harm — especially “not hav[ing] the seizure kill the child” — and meeting parental goals for seizure care. The nurses worried about making a decision that would cause parents to lose trust in them. On the one hand, doing the right thing involved seeking a balance between giving children “enough anti-seizure medication so that they’re not seizing all the time but not giving them [so] much that they’re sleeping all the time”; on the other hand, it involved finding a balance between keeping the child safe until the parents’ return and providing seizure care as the parents would have done, sometimes in a context of uncertainty about the parents’ wishes, particularly if the child was new to the palliative care program or to the centre. *Not on my watch* is best summarized by the adage “better safe than sorry,” an expression the nurses used when alluding to the hidden complexities of their decision-making.

The overarching theme *not on my watch* is supported by four themes simultaneously at play: *being in the know*, *marking time*, *seeking a sense of personal comfort*, and *making the decision*. These themes speak to how nurses struggled to create strong connectedness with each child and parent to better enable them to make the right decision.

***Being in the Know***

Being in the know was not always easy, as some children visited the centre for respite care only once or twice a year. Nurses used the word “knowing” to describe the knowledge they required to make a decision. What to know and ways of knowing constitute this theme.

***What to know.*** Nurses indicated that what to know included seizure disorders as a medical entity: the different types of seizures, seizure presentations, and the consequences of repeated, prolonged seizures, as well as seizure care in general, such as how to monitor a seizure, types and dosages of seizure medications, management of adverse effects of seizures and medications, and administration techniques for specific drugs. It also involved knowing *this* child's seizure story: “It's more who knows the child better than who knows seizures.” Knowledge about *this* child's seizure pattern, including frequency, duration, body involvement, intensity, and triggers, helped nurses to discern an important change in the child's condition and to make sense of the event. Knowing who *this* child was in terms of his or her normal behaviour, level of interaction, and mood was essential knowledge for identifying a seizure.

What to know also included parental expectations for *this* child's seizure care — such information as how long to wait before giving a PRN if it was different from the protocol, if and when to call the parents about a seizure and PRN administration, and when to notify the physician. Knowing the parents' comfort level with their child's seizure behaviour was critical to nurses' decision-making, but “sometimes it's a couple of visits before you really get to understand that this PRN has been given a bit more often or not as much at home, and you find out that they tend to just ignore those [particular seizures] because they don't want [the child] too sedated all the time.”

***Ways of knowing.*** An essential way of knowing was nurses' dialogue with parents on their arrival at and departure from the centre, during visits, and over the phone during specific seizure events. This knowledge was so crucial that a “getting to know you” form was developed within the first year of the centre's operation. The information gathered from the parents by the admissions coordinator prior to every scheduled admission was translated into a care plan in a standardized format “so that nurses always know where to look for the information.” Other written resources that facilitated ways of knowing included the centre's records of the child's previous stays, seizure logs, and seizure protocol. The seizure protocol, provided by parents upon the child's arrival, was a formal letter from the child's neurologist akin to physician orders, detailing the dosage, route, and timing parameters for each PRN. Nurses also frequently turned to their nursing colleagues, the centre's interprofessional palliative



care team, and other care providers, such as those at the child's school or rehabilitation centre, to better know the child and family. Knowing the child and parents grew out of the connectedness that developed over time. Nurses gradually learned the child's rhythms and idiosyncrasies as a result of experience with the child as well as from hearing and reading stories about the child: "After they've been to see us maybe two, three, or four times, we know the child better; we know what to expect; we can say, 'He's behaving differently than usual.' You just get a feel for the child because you're more familiar with them."

### **Marking Time**

There was an uncomfortable sensory awareness of time during or surrounding the seizure event, which, nurses admitted, affected their judgement. Time moved too slowly — "It just seemed like forever." Waiting and timekeeping constituted this theme.

**Waiting.** Waiting was associated with the seizure itself — waiting for it to start, stop, change pattern, and turn into a nurse's worst fear, such as a respiratory or cardiac arrest, or even death. Waiting was also associated with the treatment — waiting to initiate the seizure protocol, repeat the PRN, or administer a new PRN, as well as waiting for the PRN to take effect or for its side effects to wear off. Finally, waiting was sometimes associated with waiting for the other: waiting to connect with parents, physicians, or other health-care providers to help the nurse better know the child and the parents' expectations or to help the nurse make a decision. This experience of waiting and living with mounting worry was described by one nurse, who "prayed, 'Please, please, please don't arrest — don't let this seizure kill you'."

*That seizure went on for about 5 minutes . . . So we give him the Ativan, but it takes him a little while to respond to it, so we waited a while. But his seizures . . . were getting worse and his [oxygen desaturations] were more prolonged . . . So once the 10-minute mark passed . . . we gave him the second dose . . . Then he started to have decreases in his heart rate . . . so we started getting out the Paraldehyde but . . . it was too soon after the last Ativan and we were supposed to wait a certain time period, like we would have to wait another 10 minutes, which I wasn't comfortable with. So we called the doc and mom and . . . waited for them to come.*

**Timekeeping.** In the more traditional sense, nurses learned to watch the clock — "a kind of reflex" — as part of routine seizure care; consequently time was experienced objectively when it was being chronologically measured. Ironically, watching the clock helped nurses to control their feelings of distress as they watched the child seize. As one nurse noted, looking at the clock "is a comfort too. You look to it and then

you're, like, okay, it's only been this long — because often it feels longer than it is." Watching the clock involved monitoring the start and stop times of the seizure and specific seizure movements, the time of change in the pattern of movement, and the time between each seizure event. It also involved noting the time when adverse physiological events became manifest. Timekeeping was an essential part of the decision-making process, as seizure protocols were framed within specific periods: "For some, if they're having a tonic-clonic seizure for 5 minutes, we treat it, whereas they'll have to have 10 to 15 startle seizures over 10 minutes [before a PRN is given] . . . Others, if they have 10 seizures in 24 hours, you treat at the moment of the 10th seizure."

Timekeeping also consisted of writing it down, which meant documenting the seizure event in a variety of records. One essential informal record was the seizure log, a record of the child's seizure activities that belonged to the parents and travelled with the child. The log was a place where nurses "tried to write as much detail about the timing, just to get the pattern down" and other aspects of the seizure event, such as how it was treated and the child's response to the PRN. Writing it down communicated the child's seizure story and became an essential component of knowing *this* child. Nurses shared the story with the parents, who then shared it with other care providers. In this way, the nurse contributed towards helping others to know the right thing to do. Unexpectedly, writing it down enhanced nurse-parent connectedness and the building of trust. Nurses' written accounts indicated that they had borne witness; demonstrated that what the parents had observed had now been observed by others, making the parents feel less alone; and enhanced parents' credibility when they shared the log in health-care settings where they and their child were not yet known.

### ***Seeking a Sense of Personal Comfort***

The nurses experienced a sense of comfort when they perceived that they would be able to do the right thing, specifically to meet the goals and expectations of the child, the parents, the centre, and oneself. Being comfortable with one's decision-making was individual and personal; it was not static; it had a threshold — the point at which distress was experienced. Distress informed nurses that their comfort level had been breached and thus served as a moral compass for their decision-making.

***Developing a sense of comfort.*** Developing a sense of personal comfort with making a decision about PRN administration was intricately and dynamically intertwined with nurses' development of competence and confidence about the various components of seizure care. Experience was the best tool: The greater their exposure to seizure events, the more comfortable they felt. The recognition and trust of

parents and colleagues also increased their confidence in their critical thinking abilities and culminated in a “comforting feeling that I didn’t do anything wrong.”

Being comfortable meant developing a trusting relationship with parents. Nurses described a need to feel secure with the parents’ rationale for their decisions about seizure care before feeling comfortable proceeding in a similar fashion. One nurse described her comfort with the decision to bear witness to a child’s seizure for 45 minutes without administering a PRN, based on her trust in the parents’ decision-making: “I had talked to the family. They knew exactly what they were doing and how they were doing it and what their approach was. And they gave good, intelligent answers [with respect] to their decision. So then I said, ‘Okay — we’re willing to give this a try with you and see how it works.’”

Comfort was also enhanced when nurses’ personal values and beliefs about nursing care were or became congruent with the centre’s philosophy of care. For example, nurses who had moved from acute-care settings acknowledged that they had initially experienced distress waiting to administer a PRN in a palliative care context. In acute care, stopping a seizure was the primary goal, and, as a result of immediately administering a PRN anti-seizure medication, bearing witness to the seizure event became less frightening: “What the one great thing about the medications is, as a nurse you didn’t have to feel totally helpless: ‘Good, I can actually do something here’.” An indication that nurses had undergone a philosophical transformation was their concern that they might “jump the gun” and needed to learn patience. “When I first started, seizures scared me more, and I think I was less patient with them. Whereas now I’m more patient. I’ll watch them for a bit longer before I treat them, because sometimes they will settle out on their own . . . and it’s what the parents would have wanted and is a better quality of life for the child if he’s not over-sedated.” Embracing the centre’s philosophy fostered a sense of comfort because it supported the decision to follow parents’ wishes, which meant that bearing witness to a seizure with the intention of withholding a PRN (whenever possible) was a legitimate nursing action.

**Experiencing distress.** Distress regarding the decision-making process was experienced as being scared, frightened, worried, anxious, stressed, and distressed, and it was the antithesis of being in the know. “The first time a child is here and he has a seizure,” said one nurse, “you’re questioning a lot more about when you should be giving it to him and how often he has seizures and whether this is a norm for them, that kind of thing. Those all have to go through your head.” They experienced distress if they began to second-guess themselves or if they perceived an incongruity in the answers to a series of questions they asked themselves during the decision-making process: When should I act? Whose call

should I respond to — the child's or the parents'? What is the right thing to do?

**Responding to distress.** Nurses were never alone. They turned to others for advice or reassurance, particularly if they did not know the child and parents well. Answers to questions such as *Is this a bad seizure for him?* or *Have you seen him do this before?* from nurses who knew *this* child well calmed and reassured them about their assessments or helped them readjust their perception of the situation. Physicians offered direction based on what they knew about the child's medical condition and the parents' wishes, although they reiterated that responsibility for the decision remained with the nurse in the parents' absence. One nurse recounted a conversation with a medical colleague: "Ultimately, it's your decision to treat it. You're the one who's there and seeing it." Whenever possible, nurses contacted parents during the seizure event if they were uncertain as to the right course of action; they wanted to ensure that parental goals were met. It was not uncommon for parents to reassure the team with their "calm demeanour" and to choose to be with their child at this time, when they would make decisions together.

Nurses also turned to internal reflection to work through their feelings of distress. Thoughts such as "if only I'd known the parents' expectations for this type of situation" and "if only I'd known this child better" filled their minds for days after an event if they felt they had not "hit the mark." However, each event was a learning opportunity, as expressed in the reflections of one nurse: "I should have figured that one out, but now I know and . . . I'll do better next time." Engagement with others and an internal dialectic brought comfort. A personal transformation in making this type of decision was evident in statements such as "Just because the parents don't affirm the nurse's decision doesn't necessarily mean the nurse made the wrong decision."

### ***Making the Decision***

Making the decision about PRN administration in this setting entailed a series of complex cognitive processes. It comprised four elements.

**Recognizing a seizure.** Nurses were attentive to visual and auditory signs that alerted them to the possibility of a seizure. These cues could be either overt or subtle and were often unique to the particular child, such as the release of a moan, tearing, screaming, and yelling; agitation and irritability; evidence of pain; or inability to interact with or pay attention to the caregiver. Cues could also include changes in the child's colour, breathing pattern, facial features, posture, muscle tension, and physiological responses — anything suggestive of a change in the child's normal behaviour.

Following recognition of a behavioural change, nurses decided whether the behaviour indicated an actual seizure event. They first considered whether it fit with the parents' description of a normal seizure for their child; if it did not, their decision-making increased in complexity. They also considered whether the seizure warranted an intervention. Because some children experienced many seizures in their day-to-day lives, nurses interpreted the event in light of the normal character and frequency of seizures for *this* child. The seizure was also interpreted in relation to its possible threat to the child's well-being: "This one looked like it was bothering him . . . his whole body was involved, so I decided to give the PRN med."

**Identifying options.** Decision-making involved the identification of intervention options. This included whether to administer a medication, wait and watch, consult with others, administer supportive care, or send the child to the emergency department. If nurses chose to administer a PRN, they identified another set of options, including whether to administer the PRN as per the protocol or earlier than instructed and whether to administer a maintenance medication earlier than scheduled.

**Weighing the options.** "It's a lot of different things to balance out." Nurses next weighed the options in a complex series of cognitive processes activated in the form of a list of questions rapidly asked and answered, consciously or subconsciously, throughout the seizure event. If an option was congruent with the various goals of seizure care and the seizure protocol, it was usually chosen with confidence and comfort. However, when nurses' experienced feelings of distress, weighing the options became more difficult.

**Rethinking the decision.** Rethinking decisions was common practice. Nurses debriefed the event with their colleagues at shift report and later with members of the palliative care team. Days later, they often sought out others who had cared for the child during a seizure. They discussed and shared their experience with the parents, looking for cues as to their level of satisfaction. One nurse stated, "After talking to the parents, it has changed how I give medication to some children." Nurses frequently ruminated over having "jumped the gun," wondering whether the seizure would have ended on its own if only they had waited another 2 minutes. Yet they also wondered if they should have acted sooner: "You try and treat the seizure before it gets so bad . . . Maybe [I] waited a little too long to treat that seizure." They struggled with the fact that their decision-making was not always ideal. Rethinking helped nurses to eventually come to terms with the choice made when a sense of comfort had not been achieved at the time of the seizure:

*We have a child who will seize for an hour and you just sit at his bedside and watch him, and with all your heart you just want it to stop, because it's hard to witness that, but you know that at home this is how they handle it. And you feel like maybe you should be treating it a bit more often. But then, if he's happy, he's having a good quality of life, although he's having a lot of seizures, why am I treating them? He's functioning and the seizures don't seem to be causing any further damage . . . So it may break my heart to watch and I worry that he might be in pain, but the parents want this and he's not lethargic and drowsy and sleeping for 24 hours, so I know the reason behind it and it makes it easier. I can live with the decision.*

### **Discussion**

The findings of this study begin to uncover the complex, largely invisible, nature of nurses' decision-making with regard to the administration of PRNs to children with long-term seizure disorders in a palliative care setting. The findings demonstrate that nurses in this situation can experience tremendous decision-making tension as they struggle to find the right thing to do in each seizure event. Much of the reported tension arose from a desire to make the decision that the parents would make while ensuring that the child not suffer or come to harm on the nurse's watch. Meeting these goals was not always easy, because a child's seizure pattern could unexpectedly change, the seizure protocol did not necessarily fit with what was being witnessed, and sometimes parents' expectations for the imminent situation were unknown.

Some of our findings are similar to those of other researchers. For example, in this study the use of cues emerged as part of nurses' decision-making. This has two interrelated and interconnected core components: cue recognition and weighing of the options. Cue recognition is the sensing of cues that nurses see, hear, feel, or know about the child and the situation. It is an in-the-moment perceptual awareness of visual and auditory cues, combined with the nurse's general knowledge of seizures and specific knowledge of *this* child's story. The finding that clinical decision-making requires attention to specific information, or cue pattern matching, as part of the initial phase in decision-making is supported in the literature (Thomas & Fothergill-Bourbonnais, 2005).

Other salient contextual information that nurses considered included the parents' perspective and the centre's culture and norms. Contextual factors rendered decision-making even more complex and multidimensional. Some of these factors are identified in the literature (Bucknall, 2003). For example, nurses explained that knowing parents and their goals and expectations for PRN administration is often revealed over

time through the development of a trusting relationship with them, which enables nurses to individualize decision-making to meet the specific needs of both the child and the parents. As part of deciding how and when to treat a seizure, nurses question whether their decisions are congruent with parental, personal, and the centre's goals for seizure care, as well as the seizure protocol. Nurses carefully determine the significance of their perceptions and corroborate their impressions with those of others in a process of weighing the options, which has been previously reported (Benner et al., 1996).

Decision-making on PRN administration in this context is also revealed as a moral experience. Nurses experience distress if they feel that their decisions might cause parental distress or negatively impact the nurse-parent relationship. They worry that the choices they make might mean that the child will receive less than the best care possible. They worry that they have not done or will not do the right thing on their watch. When nurses express worry or make comments such as "It breaks my heart," they reveal a state of moral distress, defined here as uneasiness about not doing everything one can to fulfil one's moral obligations (Wilkinson, 1987/88). It occurs when there is conflict between a nurse's belief system and the elements of the situation. Concerning the decision about PRN administration in this context, moral distress is often experienced as a result of a moral dilemma: What is the right thing to do in *this* situation? How am I to balance the multiple goals that I wish to achieve during this seizure event? In response to the question What am I to do? — what Frank (2004) describes as a microethical moment — the nurses in this study chose to "hold to the difficult" (Frank, 2004) in the interpersonal, locally contextualized, moment-to-moment. They committed to receptivity and attentiveness to the actual and potential suffering of the child and parents and to meet with parents in an attitude of respect and attention. This required that they engage in bearing witness.

To bear witness is "to dwell" with the child during a seizure event in the sense meant by Heidegger (1971): "to cherish and protect, to preserve and to care for" (p. 347). Bearing witness is the means through which the nurse and child remain engaged even though the child shows a level of absence during the seizure. It allows nurses to be ready to choose another course of action if necessary. It is also a means for nurses to demonstrate their commitment to parents and to ensure that they will not fail them. But as bearing witness is a human experience, nurses suffer when they watch and wait.

Ricoeur (1992) writes of bearing witness: "Because someone is counting on me, I am accountable to another" (p. 165). Levinas (1996) teaches that the meaning of suffering lies in the opportunity for the other

to respond to it, to embrace the sufferer and, in so doing, fulfil their humanity and find existential meaning in life. For Levinas, the face is a means through which the vulnerable Other is revealed. As vulnerability is revealed, we realize that we have been summoned to assume responsibility. "The Other becomes my neighbour precisely through the way the face summons me, calls for me, begs for me, and in so doing recalls my responsibility, and calls me into question" (p. 131). The nurses in this study experienced intense feelings of vulnerability embedded in feelings of culpability about their decision-making when they realized that they had the potential to inflict harm on the child and the parents. The distress they experienced during and after some seizure events reveals their awareness of and commitment to the Other.

Decision-making around PRN administration sometimes requires that the nurse choose among the face of a seizing child, the face of a sedated child, and the face of a potentially distraught parent. In the act of administering a PRN, they have a sense of being helpful, of potentially diminishing the harm caused by the seizure. Stopping the seizure also reduces the nurses' suffering. Yet they quickly learn that administering a PRN is not always the best choice. The face of the sleeping child may indicate that the child's quality of life has been compromised because of the loss of connection with their world.

Initially, nurses may be unsure as to how to help the child and are left with doubts and heartbreak as they watch and wait for the seizure to stop or to give them some cue that a PRN is indicated. However, the parent's face also summons them. They feel a responsibility to make the decision that the parents would have made. A sense of comfort with decision-making is most evident when they can respond to both summonses. As this is not always possible, they have to find a way to live with their nursing practice, which includes PRN decision-making.

Kafka (1993), in his short story *At Night*, helps us understand the creation of new meaning. It is the story of a "flock" of people asleep in the open air under a cold sky on cold earth in a deserted region. They are being tended by watchmen, who keep a fire burning as they are attentive to the dangers that lurk nearby:

And you are watching, are one of the watchmen, you find the next [danger] by brandishing a burning stick from the brushwood pile beside you. Why are you watching? Someone must watch, it is said. Someone must be there. (p. 404)

The watchers remind us of the perils of bearing responsibility; but there is something else in this story — firelight in their hands. Nurses in this setting make choices in relation to others, holding to their values (e.g., parental partnerships, respect and consideration for the parents'



needs and for the child's quality of life), and that "holding" leads to a kind of illumination. It is their face-to-face relationship with the child and the parents that reveals the possibilities for their nursing practice.

We suggest that when nurses realize that the goals of seizure care cannot always be met, they find new meaning with respect to the outcomes of the choices they have and the decisions they make. They learn from their own reflecting and parents' feedback that bearing witness is valued. They seek reassurance, particularly from parents, that they have done the right thing in each event, and they learn to live with the heartache entailed in bearing witness. They learn that part of bearing witness is the quality of quietly *being with* the child during the seizure. Bearing witness, in the form of watching and waiting, becomes as dominant a nursing action in this setting as administering a PRN in the acute-care setting. The new meaning that the nurses ascribe to the event results in a reprioritization of nursing actions during other seizure events. Apparently the goal is not to relieve the tension but to develop gratifying relations with the parents. It is conceivable, then, that the experience of moral distress in this type of situation is, as posited by Austin, Lemermeyer, Goldberg, Bergum, and Johnson (2005), desirable insofar as it suggests an ethical sensitivity on the part of the nurse and is a function of moral sensitivity.

Knowing the child and parents is required, so that nurses can provide safe passage during the child's stay at the centre. "Knowing" refers to understanding the child, grasping the meaning of the seizure situation for the parents, and recognizing the need for a particular intervention. Moral distress arises when nurses do not know. However, building connectedness and developing a "responsive interdependence" with parents in order to engage in a relational ethic of care facilitate this knowing. Bergum and Dosseter (2005) teach us that it is in the relationship that possibilities for the right action for a particular situation can be discovered and grasped through discussion and reflection. The relationship with the child and parents provides the nurse an opportunity to consider not only the medical facts about the seizures, but also other components of the child's lived reality — the mind-body-spirit wholeness of the individual as a unique, autonomous person, while each individual is also part of a whole family and a whole community. Certainly, nurses purposely created a relational space for relational ethics to emerge. Decisions were negotiated and renegotiated with the parents as partners in the child's care, in order to create shared meanings about what needed to be done.

How do nurses make the connection that leads to decision-making within a framework of relational ethics? The findings reveal that *how* we enter into conversations and *how* we create the relational space are vital

to decision-making. The “getting to know you” form and the pre-admission interviews are examples of how we can set the stage and begin to see each other. Connecting with parents at the time of the seizure event and discussing the decision with them after the event also help to create and maintain this space. Questions such as the following suggest how we might create relational space: What are the most important outcomes for you and your child? Given what is happening, what do you think is the fitting thing to do? Did we do the right thing? Such questions also show us that engaging in decision-making that embraces a relational ethic “requires deliberation, self-questioning, uncertainty, and contemplation” (Bergum & Dosseter, 2005, p. 59). Although ethical questioning and a degree of distress are part of each decision as a result of a relational ethics approach, they can also lead to self-understanding.

### **Concluding Remarks**

We have not reported parents' decision-making, thus limiting the reader's appreciation of the similarities and differences in nurses' and parents' decision-making. The homogeneity of the population is a limitation of this study, and the findings cannot be generalized. However, the findings reveal that a nurse's decision whether to treat a seizure in the pediatric palliative care context can entail intense involvement with the child, parents, and the seizure event. Nurses showed a commitment to relational ethics and to the creation of a legitimate space where parents' voices are welcome, and heard, in the decision-making process. They demonstrated this commitment by creating opportunities to know the child and parents, inviting parents to take part in the decision-making process, and being transparent about their decisions. The findings of this study reveal the moral dilemmas and resulting moral distress that may be experienced in this type of decision, and they advance our thinking about the corresponding tensions and rewards.

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