



WORKING WITH CHILDREN IN END-OF-LIFE DECISION MAKING

*Joanne Whitty-Rogers, Marion Alex, Cathy MacDonald,
Donna Pierrynowski Gallant and Wendy Austin*

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Traditionally, physicians and parents made decisions about children's health care based on western practices. More recently, with legal and ethical development of informed consent and recognition for decision making, children are becoming active participants in their care. The extent to which this is happening is however blurred by lack of clarity about what children – of diverse levels of cognitive development – are capable of understanding. Moreover, when there are multiple surrogate decision makers, parental and professional conflict can arise concerning children's 'best interest'. Giving children a voice and offering choice promotes their dignity and quality of life. Nevertheless, it also presents with many challenges. Case studies using pseudonyms and changed situational identities are used in this article to illuminate the complexity of ethical challenges facing nurses in end-of-life care with children and families.

Introduction

Children should be seen and heard and believed. (Author unknown)

Giving children a voice in assenting to or rejecting treatment in serious life-threatening illness presents many ethical challenges. Although the United Nations Convention on the Rights of the Child¹ states that children should have the right to expression, that right is tempered by their need for safe, adequate, and appropriate health care. Parents have the legal right and responsibility to make decisions in the best interest of their children. Pediatric health care professionals, who attempt to support parents in understanding what comprises 'best interest', are often reluctant to give children any authority over care decisions.² We argue that children's autonomy in decision making is important because it gives them a voice, which enables them to ask questions and give their opinions, and assists them to more fully understand their health condition when possible.³

Address for correspondence: Joanne Whitty-Rogers, School of Nursing, St Francis Xavier University, PO Box 5000, Antigonish, NS, Canada B2G 2W5. Tel: +1 902 867 3629; E-mail: jrogers@stfx.ca

This article is a descriptive literature review that discusses the importance of promoting children's autonomy in making decisions about their end-of-life care in a western context. Relational ethics will provide the guiding tenets. Discussion will include what is meant by children's best interests, issues concerning autonomy, the decision-making capacity of children, and ethical issues that may arise when difficult decisions regarding the care of seriously ill children must be made. We propose a relational ethics approach to these issues, which highlights the importance of the relationship between nurses and patients and is therefore helpful in addressing these complex situations. Questions guiding this discussion include: Why is autonomy so important to children at the end of life? and, What is nurses' role in improving quality of life for children and families during children's end of life?

Children's best interests

Children's best interests refer to decisions made on behalf of children,⁴ a role that generally falls to parents. However, many parents need education and support in determining what is best, a role that is usually filled by health care professionals. The best interests perspective needs to include consideration of potential benefits, potential harms, and the moral and cultural beliefs of children and their families.

What is in children's best interests is subject to changing clinical contexts, and may be nebulous or could be subject to conflicting values between and among children and parents and professionals. Legal frameworks about the right to decide, which sometimes vary from jurisdiction to jurisdiction, may be involved. Carnevale⁵ argues that the 'best interests standard' and reliance on a surrogate decision process are not without issues. Carnevale⁵ asserts that in surrogate decisions: (1) research has shown that there are high rates of disagreement on treatment options between patients and health care providers; (2) it is difficult to identify what would be the most significant benefits and burdens; (3) it is difficult to distinguish children's interests from parents' own desires; and (4) there may be queries around concerns for others, such as patients' siblings, as opposed to the interests of patients themselves. Surrogate decision making is problematic because it can suppress significant issues concerning other family members and health care providers. At no time are such issues more poignant than during decision making in situations involving ill children facing a life-threatening illness.

Cultural beliefs are important considerations in determining best interests for children. For instance, many cultures do not view adolescence as a time to prepare for adulthood but instead it is a time to assume the role of adulthood, which may be at a younger age than is found in other societies.⁶ Some people believe that adolescents would have a better capacity for making decisions about their care if they were given the opportunity.⁶ In some cultures, children are not included in discussion about their medical care because parents want to protect them from receiving unpleasant news.⁷ As a result, children are not involved in decisions about their care.

Individuals' religious beliefs also need to be respected.⁸ However, in Canada, there are some limitations in instances where individuals' freedom conflicts with their basic rights.⁶ For example, when children have life-threatening health conditions that require a blood transfusion, the court system generally overrules parents of the Jehovah Witness faith who object to their children receiving blood.³ These children are made a ward of the court and given blood as a life-saving treatment.

Another common legal issue that arises in North America concerns the mature minor's right to refuse life-sustaining medical treatment. A mature minor is one who is a minor with decision-making capacity.⁹ A common assumption of society and the legal and medical system is that parents are the natural decision makers and act in the best interests of their children.⁹ This assumption eliminates the opportunity to assess children's level of understanding and allow for autonomous decision making. In this instance, regardless of children's capacity to understand their medical condition and decisions about their care, they may be excluded from making such decisions and may receive medical care against their will.

Principles to guide moral decision making in health care

To ensure that children's best interests are upheld, nurses and other health care professionals need education and assistance to help them in decision making associated with end-of-life care for children. Often there are no right and wrong answers. Dealing with these complex situations requires that health care providers have a sound understanding of ethics and ethical decision making.¹⁰

Values and ethics are rooted in nursing care.¹⁰ Values are defined as 'strong personal beliefs' (p. 96).¹⁰ People's values reflect their culture, relationships and personal desires.⁸ Ethics is defined as 'a generic term for various ways of understanding and examining moral life' (p. 1).¹¹ It is concerned with right and wrong behavior. Canadian nurses follow the Canadian Nursing Association's code of ethics consisting of seven primary values, which include: providing safe, competent and ethical care; promoting health and well-being; promoting and respecting informed decision making; preserving dignity; maintaining privacy and confidentiality; promoting justice; and being accountable.¹² These values represent the nursing profession as they guide nurses in their ethical decision making.

Bioethics, a more recent theory of ethics, originated in the mid-1970s as a field of study.¹³ Specifically, bioethics addresses health care issues.¹⁰ The premise of some bioethics is that decisions are guided by four moral principles: autonomy, meaning free to make choices about oneself; beneficence, referring to doing good; non-maleficence, meaning to do no harm; and justice, referring to fairness.^{10,11,14} These principles are considered general norms that allow for flexibility.¹¹ For instance, the principle of beneficence helps to guide difficult decisions when the benefits of treatments, such as prolonging children's lives, may be challenged by the risks to their well-being or dignity.¹⁰ The principle of non-maleficence helps health care providers to balance the risks and benefits of a plan of care for children with cancer, for example, while trying to do the least harm.¹⁰ Children may voice that they wish no further chemotherapy and want to die, although health care providers may want to try a new drug to see if it is effective to treat the medical condition. It is not uncommon to provoke ethical issues when working in pediatric settings, particularly during end-of-life situations when children and families are vulnerable. The aforementioned moral principles – autonomy, beneficence, non-maleficence, and justice – assist health care professionals to avoid the risk of thinking that there is only one way forward.¹⁵

Relational ethics

Many health care professionals view ethical issues from the perspective of highly acute medical situations and fail to recognize that ethical issues occur in daily practice.¹⁶ The work of Austin *et al.* on relational ethics provides a means for assisting nurses to understand how 'ethical practice is situated in a relationship' (p. 45).¹⁷ In a later article, Austin calls individuals to consider how they interact with each other from 'professional/patient, professional/professional, professional/community' perspectives (p. 19).¹⁸ Relational ethics is about replacing objectivity with dialogue and substituting principles with relationships¹⁹ because the patient and/or professional is what is most important, depending on the context of the issue. Mutual respect is a core component of relational ethics in which power dynamics that affect interpersonal relationships are judged.¹⁸ Individuals, groups or populations may be seriously affected or disadvantaged when they are not given a voice about their care.

Relational ethics tries to 'create an ethic for health care that is grounded in our commitments to each other' (p. 46).¹⁷ Bergum identifies four themes to describe relational ethics in nursing: environment, embodiment, mutual respect, and engagement.²⁰ Environment explores critical elements or characteristics of the health care system within which nurses work and how the nature of nurse–patient–family relationships is affected by this system. Engaging in the 'lived world' of individuals at the same time as we engage in the 'lived body' is the embodiment of care in nursing. Embodiment is considered as 'an integrative consciousness – so that scientific knowledge and human compassion are given equal weight' (p. 492).²⁰ Mutual respect is the embracing of values and ideas of others as a means of developing new understandings, rather than formulating judgments of these values and ideas.²¹ Although these themes are not meant to be the only themes associated with relational ethics, they are helpful in nurses' working situations.²⁰

Ethical action requires that individuals such as nurses create an environment that provides an opportunity for self-reflection.¹⁹ Health care providers need to use self-reflection in clinical practice to help them examine the current situation and consider future actions they may take that will benefit patients and their families.

However, relational ethics is not without challenges in health care practice. These may occur when there is disagreement between children and parents. Parents may have a different point of view about end-of-life care, which creates a strain on the relationship between them and their children. When parents disagree with each other another challenge arises. There may also be pre-existing family discord or other forms of relationship trauma between or among parents and children, which creates further disharmony. Another challenge may occur when parents' own emotional grief and confusion may prevent them from seeing their children's needs and concerns. Emotional grief experienced by parents refers to trying to cope with knowing that their child is going to die. The suffering that parents go through is thought to be associated with the fact that the child should not die before them, a sequence of events that is unnatural. The hopes and dreams that parents have for their children are all of a sudden gone.²² The aforementioned examples can all be explained within relational ethics because understanding individuals are situated within family and community relationships. Even when individuals feel alone and want to live out their life, the diminishment of these relationships influences them. Using a relational ethics approach therefore means more than just following a code of ethics or standards of care for nursing; one needs to consider the relationship between nurses and patients.²⁰

An important aspect associated with relational ethics is autonomy. The authors of this article believe that relational ethics and autonomy are complementary to each other. In this section, they describe the relationship between autonomy and relational ethics. Autonomy originates 'from the Greek *autos* ("self") and *nomos* ("rule," "governance," or "law") ...'¹¹ Autonomy means that individuals can act freely in a manner they have chosen and have the capacity to accept or refute information or desires independently of another's manipulation or coercion to accept. Keatings and Smith view autonomy as 'the hallmark of free and informed consent to treatment' (p. 184), founded on the principle of respect.¹⁴ Autonomy is the most deeply seated moral principle; so reducing an individual's autonomy can lead to reducing dignity. Although the principle of autonomy is key to the development of people's rights, the concept of lived autonomy is related to individuals' connection with others. That being said, an individual's choice includes responsibility and being connected to other people. In this article, relational ethics helps us to understand how the relationships of children are interconnected with their parents and health care providers. Patients' choice is influenced by their beliefs and values, which are developed through personal encounters.²³ Hierarchical structures and societal pressures within the health care system strongly affect health care providers' decisions and choices.¹⁸ Acknowledging the shared responsibility of care for patients is paramount to the role of health care providers. Relational ethics reminds us to examine who else should be involved in the decision and how eliminating children from taking part in decisions about their care goes against health care providers' responsibilities towards others. Parents and health care providers therefore need to work closely with each other and with children to ensure the latter have a voice in their own care.

Children's autonomy in decision making is important because it gives them a voice, which enables them to ask questions and express their opinion.³ When parents and professionals listen intently to children's voices, rather than trivializing them, partnership, mutual respect, and an awareness of the moral lives of children can be fostered.³ According to the American Academy of Pediatrics, decisions involving medical treatment for older children and adolescents should include assent and parental consent.²⁴ Assent means that children are informed, and understand the nature of their condition and what to expect from treatment.

However, many health care professionals are ill prepared to address the complex issues concerning the autonomy of children in health care decisions because research about autonomy is primarily based on adult models.⁴ Furthermore, the cognitive and emotional development of children is foundational to their capacity for decision making; however there is significant variation within and among age groups.²⁵ Hence, the ability of individual children to make decisions must be considered.

Cognitive development

The level of cognitive development influences children's world views. According to the classic cognitive developmental theory of Piaget,²⁶ children progress from sensorimotor awareness in infancy, to fantasized interpretation of reality in the preschool years, to the ability to see the world concretely and logically in the school-age years, to being able to think abstractly in adolescence. Their level of cognitive development mediates the things that children think and worry about.²⁷ Hence, children's interpretation of

their bodies, of illness causation, illness treatment, and life and death follows this cognitive path. Moreover, when children experience high levels of stress associated with serious illness, they commonly exhibit defense mechanisms such as regression, or return to behaviors found in earlier stages of development.²⁸ Such realities challenge our adult understanding about how children think.

Jaakola and Slaughter found that children's understanding of the location and function of various body organs develops factual correctness between the ages of 4 and 10.²⁹ A five-year-old may think the heart is for loving rather than for pumping blood. An eight-year-old may think the lungs are in the back of the throat. Similarly, Speece and Brent concur that the 'adult' concept of biological death as irreversible, non-functional, and universal is typically not reached until adolescence.³⁰ Children have varying concepts of death as partially functional (certain body functions persist following death), potentially reversible (some people can be brought back from the dead), and that certain people (such as children or Superman) are immortal.

If assent for treatment is to be 'informed assent', it is essential that health care professionals strive to understand how children individually think about their body and the nature of their illness.³¹ Misinformation cannot be clarified if we do not hear children's voices first! It may be difficult to elicit assent for nasogastric feeding from a child who thinks the tube curls up in the brain rather than following food's natural anatomic path to the stomach, or from a child who remembers his grandmother had an intravenous infusion three days before she died. Fantasy and reality often co-exist in children's interpretation of their bodies, of illness causation and treatment, and of biological life and death. Informed choice at children's respective levels of understanding therefore requires hearing their voices concerning what they think about.

Many developmental psychologists believe that the average child has the ability to understand his or her illness between 12 and 14 years of age.³² It is at this age that they comprehend the causes of their illness in what Piaget terms the formal operations stage of development.²⁶ Autonomous decision making is associated with personal characteristics that are related to their moral self-government.³² Although this moral self may be incompletely formed, it is important to realize that it is evolving and not decreasing, and influences how children and youth give informed consent for treatment.

Traditionally, physicians and parents have made decisions regarding children's health care.^{4,33} In a United States Supreme Court decision in 1925, parents received legal rights to consent or not consent to medical care, based on the premise that they who raise a child carry the emotional and legal obligations associated with a situation.³⁴ However, surrogate permission giving for children through promoting parental autonomy to make these decisions may not always be in the children's best interests because it may be unclear what these are, and decisions made by surrogates may not always be what children want.³

Gradually, as the informed consent process evolved over the last 30 years, so too did the notion that children should have a voice in decisions about their care.⁴ More recently, the Canadian Pediatric Society²⁵ has taken a stand that decisions involving children should be made in collaboration with the children, their parents and members of the health care team. Once it is determined that children have the capacity to make decisions, which entails full understanding of a situation, and fully grasping the main purpose of interventions, the consequences of consent and the overall extent of what could occur, they should be the primary decision makers.²⁵ For example, laws governing the rights of emancipated minors in their mid to late teens vary among jurisdictions.

Children under 16 years of age in some Canadian provinces cannot consent to medical treatment.¹⁴ In these situations their parents or legal guardians are asked to give consent. For example, in New Brunswick the age of consent for treatment is 16 years, while in Quebec it is 14.³⁵

The issues of assent and consent are ethically challenged in practice with children and adolescents when the legal surrogate decision makers (parents or legal guardians) and children or adolescents disagree despite adherence to a standard of 'best interest'. Different issues may motivate children and parents, which will be discussed in the following sections.

Conflicting perspectives on what is 'best': the case of Tina

Tina is a 14-year-old girl recently diagnosed with cancer. Doctors are guarded about her prognosis and chemotherapy is recommended. Her parents, reeling in anguish and confusion, quickly defer to the medical staff: 'Whatever you think best, doctor, we are placing her life in your hands.' Communication between Tina and her parents is strained because everyone looks terrified. Tina is polite but almost wooden in her reactions as nurses try to connect with her. Although the nature of her disease and the purpose of chemotherapy were realistically explained, Tina said little other than a meek 'I suppose' of assent to treatment.

As treatment continued and mounds of hair fell out into the bedclothes Tina became withdrawn and angry. When the team came in one morning to administer chemotherapy, Tina screamed at them and flatly refused, throwing pillows and blankets at anyone who dared approach her space. Her grief-stricken parents, in moral distress of their own, were seemingly unable to reach out to their teenage daughter at this time. They begged her, 'You *have* to have the chemo; the doctor said you could die without it.' 'I'd sooner die than have my hair fall out!'

Cindy, a registered nurse, worked intensely with this family over the following days. Tina was slow to trust her, but Cindy persevered respectfully. One morning Cindy sat down and painted Tina's fingernails and Tina tearfully gushed out her feelings. Most of Tina's anguish was related to body image issues common to teenagers and, although Tina was afraid of the cancer, the thought of losing her hair was virtually intolerable.

Ethical challenges occur in instances when there is an obligation to treat children who refuse care. Health care professionals need to balance a duty of care with respect for these children's capacity for autonomy.³⁶ Forcing treatment on someone who is unwilling is an affront to autonomy regardless of age, and raises ethical concerns.

In the above situation, nursing care involved a relationship of trust between this one nurse and this girl, and attending to her self-concept by praise and by assistance with grooming and appearance. What seemed to be, at surface level, a refusal of treatment, revealed a deeper call for support with common but intense adolescent turmoil involving body image concerns, now further challenged by the body-altering effects of cancer and chemotherapy. Only when this child's voice was heard, and only when she was energized by a nurse's supportive relationship, could she truly assent to treatment. The relational ethics of comfort, touch, solace, and presencing, although

invisible,³⁷ were as essential to this child's cancer care as the highly visible technical and pharmacological interventions.

Telling children the truth: the case of Andrea

Jane, a pediatric nurse, reflects on her first memory of facing the death of a child, recollecting the last weeks with her own childhood friend, Andrea, who died at age 13. Andrea had spent months complaining about a sore leg. Her complaints were initially trivialized, then treated with pain medication, but when a cough set in she was diagnosed with osteogenic sarcoma with lung metastasis. Palliative care was arranged. 'She mustn't know' the doctors and parents agreed, and 'We have to make sure none of her friends "tell".' Although the girls were allowed one last chance to be together, all conspired to keep the silence, and Jane did not 'tell'. Instead, the last time they were together Jane tried to pretend that she did not notice the commode and intravenous infusion in the living room, or her friend's bruised body.

It felt so strange talking about the teen schoolyard politics that seemed so trivial. We both knew what was going on, and it was the weirdest goodbye, but we both kept the silence to protect our parents. Now that I'm a pediatric nurse, I have promised myself, in Andrea's memory, to tell children the truth so that they can speak up too. Just like Andrea and I could read the unspoken, so can any child, and when they read inauthenticity in the words we speak, I think it is wrong somehow.

Informed consent/assent is impossible without complete and truthful information.³⁸ In some clinical situations, and particularly when children are involved, parents and professionals, who are generally motivated by a sense of wanting to shield children from hearing 'bad news', try to block children's knowledge of the harsh realities of life and death.³⁸ As a result, some frightened parents have told children mistruths or partial truths about what is wrong. For example, those with bone cancer have been told they have arthritis, or that infusing chemotherapy is a megavitamin solution to make them strong. It is not uncommon for parents and others involved in children's care to acknowledge indirectly the seriousness of the illness and avoid discussing the possibility of death.⁷ Hence, cultural practices must be considered when dealing with end-of-life care in children.

Children's access to full and unbiased information may be challenged by parental motivation to act beneficently in what parents see as children's best interests by sheltering them from the truth. Affronts to veracity such as mistruths, partial truths, and sugar-coating the truth raises ethical issues. Children have the capacity to understand and deserve to be told the truth about their health condition.³⁹ In many instances, children intuitively know when something is wrong and thus evading an issue or twisting the truth is not viewed as ethical.³⁹ Furthermore, telling the truth can avoid misunderstanding between children, parents, and health care professionals.³⁴ Although children are generally surrounded by adults who sincerely care about their well-being, they may have their own interests in mind. This situation gives rise to a power imbalance between adults and children, whereby children serve the needs of parents. The surrogate decision maker needs to determine the highest benefit, among a number of options, to ensure the 'best interests standards' are upheld.

What may be needed in similar situations is skilled and sensitive support for parents and children throughout times of bad news. Regrettably, many health professionals find conveying bad news to be stressful and some adopt insensitive and inappropriate ways of coping, a reality that does not help families.³⁹ Opinions and practices about the honest disclosure of terminal diagnoses fluctuate considerably among doctors and nurses, who, while avoiding outright lies, commonly use omissions or vague or euphemistic responses to skirt the issue.³⁸

If health care professionals need additional communication skills training in how to deliver bad news sensitively,⁴⁰ what then are the experiences of parents of diverse cultures who are called to relate bad news, by proxy, to a beloved child? One of the ethical struggles faced by parents of children with life-threatening illness is whether or not to talk openly about death.⁴¹ Because this is so difficult, many do not do so, despite the call to be open and honest with children. Only limited research has been conducted about how parents actually talk to terminally ill children about death. However, in one study exploring parents' memories/experiences of talking openly about death to their dying children with severe malignant disease, no parent who talked openly about death reported that they later regretted doing so, and parents who did not talk openly about death – yet sensed their children were aware of their own death – later reported that they regretted not being open. Giving voice to children with a life-threatening illness requires intensive support for parents, grounded in a relationship of compassion and sincere presencing.

Deciding when to stop treatment: the case of Natasha

Natasha is a 10-year-old girl in the terminal stages of lung disease. She is struggling with air hunger, anxiety, and signs of worsening renal/hepatic failure and knows she will soon die. Her grief-stricken parents are still hoping for a miracle. Natasha declares that she wants a trip to her grandfather's horse farm, and to ride her favorite pony one last time. Natasha has lived with deteriorating health all her life and says she always knew her time would be short.

Natasha's parents seem reluctant to give up their hope for a miracle, and know that traveling – oxygen, aerosols and medication included – will tax Natasha's weakening, immunocompromised body. The doctors indicate that it is unsafe for her to ride a horse in her condition, fearing for the exposure to animal danders and barn dirt, and the safety concerns of mounting an oxygen tank on a saddle.

However, her parents insist that she gets her wish, and with the help of a palliative care nurse and a therapist with experience of helping disabled children to ride horses, and her family, and a gentle old pony named Rocky, she rides one more time at her grandfather's farm. She died peacefully at this farm three days later. Her grandparents also broke all farm rules and led Rocky into the house for part of her last day, and Rocky quietly munched his hay in the family room, while Natasha's anxiety subsided and she drifted into a final sleep. Her parents achieved some comfort in declaring that they listened to her and that she had her last wish.

In serious illness, decisions may be required when it is ethically acceptable to stop medical treatment. These decisions are always difficult to make, in particular when they are made by proxy on someone else's behalf. When children are involved, parental anguish is commonly enormous and parents require time and support for this final

decision about their child. Listening to children involves hearing what children think about palliative care, when and how to stop treatment, and last wishes. To be authentic, these last wishes must be the child's, and may involve things a parent or professional might not ever think of. Last wishes may be as simple as a taste of favorite food or a cuddle with a pet rather than an expensive toy or exotic vacation. The latter may, for example, be an adult's perception of what a child might want or a last bequest a parent wishes to offer. Carnevale³ calls for a more sincere recognition of the moral agency of children to ensure that children's voices are central to the ongoing dialogue with their best interests at heart.

Deciding when to stop treatment: the case of Joey

One night, in between dressing changes and pain medications, position change and aerosols, somewhere in that clinical space where hope and despair intersect, the mother of a 14-year-old boy named Joey tells her son's pediatric intensive care unit nurse: 'I've prayed to God to make him better; I prayed to God to take him. God has done neither. Maybe it's time to ask Joey what to do.' Joey died peacefully in his mother's loving arms the following night, after his mother accepted his permission to stop some treatments.

In this situation, as they shared the work of heavy bodily care for a dying boy, Joey's mother was able to vent her anguish and express her own decisional conflict to her son's nurse. Her relationship with this nurse, strengthened by trust and sharing in intensive bodily care, enabled her to work through relinquishing control about end-of-life care to her son. This nurse enabled the mother's courage finally to talk openly with Joey, and to hear his wishes about this weighted decision of when to 'let go'.

Conflicts among decision makers: parents and professionals

Unlike competent legal adults who decide on their own behalf, when children are involved there are always proxy decision makers: parents, influenced by professionals. Carnevale⁵ states that in past research involving decision making on coping, clinical situations and managing ethical dilemmas, there has been significant reliance on self-reporting methods such as interviews, but little focus on the context of the decision-making process. Nursing is a practice discipline, therefore nurses need to be concerned with interpreting and fostering changes in the clinical settings, as well as considering individual thoughts and feelings that shape their understanding. To this end, understanding decision making in terms of human practice requires striving methodically to understand the context in which situations occur.⁵

Conflict between and among surrogate decision makers is common because parents and professionals struggle with 'what is best' as they try to decide on behalf of children. Such conflict can occur on several levels: (1) between two parents; (b) between parents and professionals; and (c) among professionals.

Between two parents

Outside the surgical ward, Ben can hear his parents fighting. About him. Again. This time it's about whether or not to go for that research drug, and dad wants it and mom doesn't. 'I don't want to pick sides here, and I don't know what to do either,' Ben tells his nurse, 'but I just wish they would ask me too.'

Not all families live in harmony, and marital conflict can intensify when difficult decisions must be made. Parents may share legal rights, but some do not always work as a unit. When difficult decisions are made in the context of life-threatening childhood illness, they are always made in the context of these relationships, with the harmony and disharmony that characterizes any relationship. In the above situation, mediation was possible only when Ben's perspective was considered.

Between parents and professionals

Conflict may occur if the values and beliefs of parents differ from the health care team. For example, parents may wish to continue treatment that professionals consider futile; or parents may have requests that professionals consider unusual or unorthodox to standard practice. Parental decisions should be respected unless there is evidence to suggest that it is not in the best interests of their children. However, this too is subject to interpretation.^{25,31}

Issues concerning respect, trust, and power emerge as complex elements in trying to resolve ethical dilemmas.⁵ In serious illness situations, families often feel a sense of loss of control because they lack the specialized knowledge and skills to participate and/or engage in a relationship with health care professionals. As a result, the differences in moral views create uncomfortable tensions.

Dealing with families in emotionally charged situations requires sensitive abilities to explain, teach and listen. Health care professionals must provide children and families with appropriate information to allow them to make informed decisions and hear their voices. One of the more humbling realities of teaching is that what we say and teach is not necessarily what people hear. Mitigating conflict among decision makers requires full appreciation of others' viewpoints, a process that Carnevale⁵ terms 'rapprochement' (p. 239), or coming together.

Among professionals

Ethical challenges involving everyday hierarchical relationships and traditional power structures lead to problems in the provision of relationship-based nursing care.¹⁶ A study was conducted to examine how nurses experience ethics, moral agency and challenges in clinical practice.¹⁶ The problems included not being heard and being dismissed by physicians even when nurses were alerting them regarding observations that could be life saving. Furthermore, technology and the channeling of resources into medical equipment, rather than allocating them for end-of-life supportive care, angered nurses. Nurses also described working the 'in-betweens', when they encountered such conflict and spoke of choosing a battle and sometimes letting it go. The nurses in this study described their experiences 'as relational and highly contextual' (p. 323).¹⁶

Nurses' role when the path is unclear

What do we do when the path is unclear? How should we act when doing what parents ask feels as if we are forcing traumatizing procedures on children who do not want them? Or when palliative care is not enough to ensure the best chance of survival, and questions about quality of life beget emotion-charged debate? What might our response be, when ongoing family conflict, or interprofessional conflict, or both, mitigates against the development of 'healing relationships' and of comfort and peace?

Nurses who work with children and families play an important role as 'advocate informants and communicators' (p. 368).⁴² According to Gadow, advocacy safeguards but contributes positively to the exercise of self-determination. Gadow maintains: 'It is the effort to help persons become clear about what they want' in a situation, to assist them in discerning and clarifying their values and examining available options (p. 85).⁴³ Nurses need to be emotionally engaged in patients' experiences to gain a clearer understanding of what they are experiencing.⁴³ Understanding patients' experiences are paramount to nurses' ability to gain meaning and better assist patients in making decisions.

A prime concern when caring for children at the end of life needs to be aimed at what is in their best interests.⁴⁴ Decision-making power needs to be shared between children, parents or legal guardians, physicians and other professionals.³¹ Although many regard children as less mature than adults and less capable of having moral interests, Carnevale³ contends that children have more moral awareness than they are given credit for.

The protection of autonomy is often threatened in health care settings because patients are frequently ill and need to depend on health care professionals, thereby leaving them feeling powerless and vulnerable.⁴⁵ Moreover, patients may possibly be coerced into decisions that they might not have chosen if they had been given the opportunity to decide.⁴⁵ Using a relational ethics approach helps nurses to become more sensitive to the situation, resulting in open conversation between patients such as children and nurses.¹² This approach values patients' perspective by addressing their feelings, thus demonstrating an appreciation of their circumstances.¹⁷

Robertson conducted an ethnographic study and found that nurses and physicians held different views on patient autonomy.⁴⁶ In this study, nurses were primarily concerned with daily patient care and promoting patient independence where possible, whereas doctors were concerned with organ function and the overall technical process. Robertson's study exemplified the value that the nurses placed on the importance of autonomy, while physicians tended to ascribe to beneficence in caring for patients. Promoting patient choice in health care is central to nursing⁶ and one of the nursing values that guides their practice.¹² Additionally, the International Council of Nurses ethical code for nurses respects 'human rights, including cultural rights, the right to life and choice, to dignity ...' (p. 1).⁴⁷ Nurses must work in a collaborative relationship with patients, families and the multidisciplinary team to encourage patients to express how they feel and not be intimidated by others.²⁴

Nurses are in an ideal position to influence end-of-life decision making.⁴⁸ More than most other professions, they are involved in caring for the body, mind, and soul of highly vulnerable people. They provide the lion's share of intimate bodily care – the dressing changes, the baths, the pain-relief positioning – as well as the technical/biochemical care such as administering pharmaceuticals via infusion pumps. Nurses are at the bedsides of very ill children when, at 2 am, after a long silence, a

parent or child wants to talk. They also claim a commitment to holistic health in every philosophical statement about the nature of nursing work. This is a powerful position of trust, particularly in our relationships with those who are poor and marginalized or with broken bodies or minds, with very young children and very old people, and those experiencing crippling levels of pain, nausea, air hunger, or fear. The potential for betrayal of trust – by disconnecting, by judging, by insensitivity – is enormous. Being honest and open with children instills hope and provides support to them.⁴⁹

Conclusion

Giving children a voice during end-of-life care is associated with many challenges, as demonstrated throughout this article. Ethical issues pertaining to topics such as religion and blood transfusions in the Jehovah Witness faith, mature minors, cultural issues, and disagreements among parents and/or health care professionals tend to complicate an already complex health care situation. When children have a serious illness and medical care should be discontinued, these decisions are often made by parents and/or health care providers, without considering the children's voices in these scenarios. Health care professionals, who have the children's best interests at heart, tend to limit children's involvement in their own care. However, the authors contend that children need to have autonomy in decision making because this helps them to ask questions and understand the care they are receiving. Children have a right to be active participants in their care because truly informed consent means that they need to be actively involved.¹⁹

As many would agree, children's cognitive and emotional development varies, depending on their age and capacity to understand. Each situation is unique and requires individual examination to determine what is in the best interests of children and what is their capacity to understand. In addition, the age for consent varies among provinces in Canada, so this factor must be considered in the decision-making process for children.

The clinical situations described in this article reflect the complex ethical challenges that nurses meet daily in caring for children and their families when facing end-of-life decisions. All are based on our clinical experiences as nurses but pseudonyms have been used and situational identities altered so that the real persons involved are not identifiable. Virtually every nurse who works with this patient population could tell similar stories; the themes resonate time and time again.

It takes courage to be a nurse – to be fully present when the predominant cultural response is to run and hide, or at least emotionally distance oneself.⁵⁰ Certainly, the impending death of a child can remind us that we are all vulnerable to the worst that life can impose. The profession we have chosen commonly situates us to walk with our patients and their families between the world of the living and the world of the not living. It is a situation of profound trust and relationship with people. Across cultures and eras, nurses are called to care and have compassion. Caring is the human mode of being; caring is a response to one's experience of connectedness.⁵¹

In nurses' efforts to support children and families and to ensure all voices are heard, they may be guided not only by ethical principles – justice, autonomy, beneficence, non-maleficence – but by relational ethics. Relational ethics is not a recipe but merely a guide to resolving ethical issues.¹⁸ It is concerned with interdependent relationships

and can help to address practice issues from a perspective of 'caring, compassion and commitment' (p. 20).¹⁸ This approach to ethics reinforces the call to connectiveness and compassion, and a commitment to those in one's care. In the anguish of end-of-life decision making involving children and adolescents, their families, and their caregivers, there are no easy questions and no easy answers. Yet clinical realities demand that decisions be made. The relational context in which decisions are made involves ethical, legal, and profoundly human/spiritual ramifications. Clearly, much more is involved than decisions about whether and when to stop treatment and what is 'fair', and/or whose decision it is. What is equally important is the intricate and intimate web of relationships between and among children, families, and those who become deeply involved with them in times of profound life significance.

To learn how children think, nurses must first listen to children to be able to relate to them. Hearing children's voices fosters their choice.

Conflict of interest statement

The authors declare that there is no conflict of interest.

Joanne Whitty-Rogers, Marion Alex, Cathy MacDonald and Donna Pierrynowski Gallant,
St Francis Xavier University, Antigonish, NS, Canada.

Wendy Austin, University of Alberta, Edmonton, AL, Canada.

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