



CHAPTER 12

Listening Authentically to Young People's Voices: A Conception of the Moral Agency of Children¹

Franco Carnevale

“We should attend genuinely to the moral voices of children.”

IN THIS CHAPTER, I EXAMINE one of the most vexing questions in children's health care: What ethical significance should be accorded to the voices of children in decisions about their health care? I argue that we should attend genuinely to the moral voices of children, while recognizing limits to the degree of responsibility that can be assigned to their actions. I argue that this can be managed by interpreting the current standard of child assent more broadly. Specifically, I will (a) highlight the limitations of the prevalent adult-centred modes of construing the experiences of children; (b)

outline a child-centred conception of moral agency; and (c) discuss some of the corresponding implications for advanced practice nurse leaders in children's nursing.^H

In the seven Ethics in Practice cases presented below, drawn from my clinical experience, I introduce important themes to orient the discussion throughout the remainder of the chapter. Using these cases, I analyze a range of encounters lived by children that are commonly under-recognized as *moral* experiences and highlight implications for advanced practice nurse leaders.³ Such stories are frequently interpreted within adult-centred psychological frameworks that minimize the moral experiences of children as expressions of immaturity.⁴ Finally, at the end of the chapter, I will revisit each of these episodes and discuss how they could be navigated with improved sensitivity to the moral agency of children. Following the cases, I will describe the dominant practice standards that are used to examine ethical concerns in clinical care with children.

Narratives of Moral Experience

ETHICS IN PRACTICE 12-1

Coercive Moral Language

William is a five-and-a-half-year-old boy who has come in for day treatment requiring the administration of an intravenous antibiotic. His parents have indicated that William has been dreading coming to the hospital; his fears centre on the needle and the injection process. He has shed a lot of tears in the couple of days leading up to his treatment. As the nurse gently approaches William to start the intravenous, he becomes pale and silent. He readily cooperates with every instruction that the nurse gives him: holding out his arm, making a fist, and taking a deep breath as the needle is inserted. Each time William cooperates with an instruction, the nurse warmly tells him, "Good boy, William. You're such a good boy. What a big boy you are."

ETHICS IN PRACTICE 12-2*Unspoken Diagnosis*

Benjamin is a twelve-and-a-half-year-old boy with a metastasized, inoperable abdominal tumor. Benjamin's parents have been asking for help because he has been frequently crying at home; he is discouraged about all the time he has to spend at the hospital and misses his friends so much. His parents have also indicated that they do not want Benjamin to know his diagnosis, because that would discourage him further. They have been telling Benjamin that the intravenous chemotherapy he receives is antibiotics to fight an infection.

ETHICS IN PRACTICE 12-3*Anticipating Suffering*

Gloria is a six-year-old girl with a degenerative neuromuscular disorder. She has been admitted to the hospital with respiratory failure that has been judged to be an end-stage manifestation of her neuromuscular disorder. She will require long-term mechanical ventilation. Gloria's parents, who have always been by Gloria's side providing her with exceptional care and love, are devastated that she will never be able to breathe on her own again. They have decided to terminate Gloria's life support, to let Gloria die, believing this to be preferable to the long life of suffering they foresee for her. Meanwhile, most of Gloria's health care providers (HCPs) see Gloria as a playful girl who loves her hobbies, including loud music and celebrities. They have frequently observed Gloria laughing out loud as she watches videos with her parents or her favourite nurses. Gloria seems to enjoy her life.

ETHICS IN PRACTICE 12-4*Protective Secrets*

Nine-year-old Marianne has been in the intensive care unit for two days for the care of severe injuries following a major car accident. This accident took her father's life. Following two days of unconsciousness, Marianne is awakening rapidly despite her ongoing need for support of vital functions (such as mechanical ventilation). Clearly agitated, she is mouthing questions about the accident and asking for her father. Her mother and the HCPs caring for her are torn over whether it is better to tell Marianne the truth about her father's death immediately or to invent a less painful account to tell her for now, with the intent of telling her the truth at a later time.

ETHICS IN PRACTICE 12-5*Hurt in the Crossfire*

David is an eight-year-old boy who frequently comes to hospital for the management of recurrent back pain. Over the past year, he has become increasingly involved in identifying ways to manage his pain. Despite this, the frequency and intensity of his pain have increased significantly in recent months. One day David discloses that he is very upset over how much his divorced parents fight over him. He says that "They're so busy fighting all the time that they don't think about how it hurts me so much to see my mom and dad arguing over me. Sometimes I wish I wasn't there so they wouldn't have to fight so much. What good am I? Some days I wish that they would just play with me or just think about me."

ETHICS IN PRACTICE 12-6*Struggling to Escape*

Robbie is a fourteen-year-old boy who has survived a four-week stay in an intensive care unit. He received treatment for severe burns he sustained in an apparent accident while manipulating a stove. Robbie has just been taken off the ventilator with his endotracheal tube removed so that he can once again use his voice. During a particularly intense conversation talking about the painful ordeal he has just been through, Robbie says that the incident with the stove was not an accident. He says that he tried to kill himself and wanted to die because he could no longer bear to see his father physically abuse his mother every evening after his father got drunk.

ETHICS IN PRACTICE 12-7*Please Don't Tell My Parents*

Cam (a gender-neutral pseudonym) is 11 years old. They have come to a community clinic with their parents. The parents brought Cam to the clinic because they think Cam is feeling depressed. Following an initial consultation with the family, the interdisciplinary team asks the parents to leave the room so they can speak with Cam alone. The parents agree to leave. Cam reports that their parents are angry because Cam does not want to wear boys' clothing. Cam discloses that although they were raised as a boy, they feel more like a girl. Cam seems relieved to talk about these feelings. They are not seeking any particular intervention for now, but plead with the clinic's team not to tell their parents because they "would not understand" and "would be very angry."

Examining the Conventional Framework

The clinical care of children often raises complex ethical issues, as illustrated in the case narratives above.⁵ One of the most challenging (and least resolved) of these issues concerns the extent and type of involvement that children should have in decisions regarding their health care. As with adults, in health care, informed consent is required for the treatment of children. If a person has the mental capacity to do so, consent must be provided, and must be based on the provision of all relevant information. Consent must also be free of any undue influence or coercion. Some Canadian provinces and territories have legislated a specific age of consent for health care treatment, below which a minor cannot autonomously provide legally valid consent.⁶ For example, in Quebec, minors have the right to provide consent for treatment required by their state of health—with some limitations—at 14 years of age. In many other jurisdictions throughout Canada and the United States, no specific age threshold is legislated. The child's capacity should be assessed on a case-by-case basis, although it is largely agreed in practice that this capacity should be recognized at about 14 years in general. This leeway allows for the assessment of children younger than 14 on the basis of their demonstrated capacities.

The Canadian Pediatric Society (CPS) has published seminal statements regarding health care treatment decisions involving children (Coughlin, 2018; Canadian Pediatric Society, 2004). These statements reflect the legal and ethical norms that are widely agreed upon throughout Canada and the United States (Katz et al., 2016). The CPS states:

Capacity is not age- or disease-related, nor does it depend on the decision itself, but is a cognitive and emotional process of decision making relative to the medical decision. ... Children who have partial skills to make decisions should be recognized as having some authority over their own health care. ... Children and adolescents should be appropriately involved in decisions affecting them. Once they have sufficient decision-making capacity, they should become the principal decision maker for themselves. (CPS 2004, pp. 100–101)

The CPS highlights that some pre-adolescent children, particularly those with more experience with illness, may have greater capacities to make health care decisions than other children their age (like eight-year-old David's pain management in *Ethics in Practice* 12-5). Alderson et al. (2006) have demonstrated that children with juvenile (Type 1) diabetes who had decision-making experience in the past were subsequently more capable of making other decisions regarding their health care. Age was not found to be a distinguishing factor in the determination of capacity. McPherson (2007), in her examination of children's participation in chronic illness decision making, challenged the prevalent view of decision making as a discrete, autonomous, decontextualized process. McPherson uncovered the contextual basis of children's participation; relational processes indistinguishable from everyday decisions, embedded in children's relationships with parents, teachers, friends, and HCPs. Children's participation involved two domains: first, the resonance of children's voices (i.e., opportunities and abilities to formulate and express their views), and second, the relevance of children's voices (i.e., the standing children achieved within decisional processes).

In short, these researchers suggested that children's decisional capacities vary widely. Prior decision-making experience can significantly enhance a child's capacities. Thus, individualized assessment of a child's participation in decision making is important, both in terms of properly recognizing the child's current capacity, and in promoting the child's ongoing capacity development.

Although there is some recognition of children's capacity to consent by organizations like the CPS, the prevalent bioethical and legal framework for health care decisions involving children usually reflects the *best-interests standard* (Coughlin, 2018; CPS, 2004; Katz et al., 2016; Miller, 2010). This standard requires legally authorized, surrogate decision makers to weigh the burdens and benefits associated with each treatment option. However, many cases present complex scenarios in which the benefits and burdens are difficult to judge, as they relate to goods that cannot be ranked according to any universally agreed upon criteria. For example, in *Ethics in Practice 12-3*, Gloria's parents and HCPS do not agree on whether the burdens in her life render it unworthy of ongoing support.

Furthermore, how can the significance of quality of life be ranked in relation to the sanctity of life as a good in itself? Some members of diverse ethnocultural or religious communities argue that the preservation of human life is mandatory, regardless of the quality of that life. Others argue that life is only valuable in terms of the quality of life that can be achieved (Carnevale, 2005a). Disagreements between parents and HCPS regarding a child's best interests—and which benefits and burdens should be attributed greater weight—may inadvertently perpetrate social injustices. Some forms of living may be tacitly valued and considered worthy of support (for example, people who are able-bodied or those with unaltered mental functions), while other forms of living are considered “futile,” warranting withdrawal of life-sustaining interventions (for example, people with some form of disability) (Carnevale et al., 2006).

In light of the difficulties inherent in reconciling such ethical problems, the most widely accepted view is to recognize parents as the surrogate decision makers for minors (Coughlin, 2018; CPS, 2004; Katz et al., 2016; Miller, 2010). This can be traced to the modern Western value assigned to the autonomy of families. It is

largely held that families should be enabled to establish their own respective moral norms because such judgments should be based on the loving intimacy that is commonly inherent in familial relationships (Nelson and Nelson, 1995).⁷

It is also recognized that the cultural and religious freedom of families should be respected (*Canadian Charter of Rights and Freedoms*, 1982). Here, too, the state imposes some limitations in situations where such freedoms conflict with more fundamental rights. For example, in cases where a minor has a life-threatening condition that can be effectively corrected with a blood transfusion, the courts have commonly overruled the objection to such transfusions by Jehovah's Witnesses, declaring that a child's right to have their life preserved overrides their family's religious freedom.⁸ However, while substantial strides have been made in the arena of children's rights by rulings like this and by organizations like the CPS, there is still much work to be done.

From Moral Object to Moral Subject

Throughout this chapter, I argue that children should be regarded as moral subjects—agents who are highly capable of moral awareness and understanding. However, several researchers have demonstrated that children are frequently exploited, not as moral subjects, but moral objects. In other words, children are regarded as a means to the moral pursuits of the more powerful adults in their lives (Carnevale et al., 2021; Greene and Hogan, 2005). As a result, a child's right to informed consent regarding their own health care is frequently subjugated.

Recognizing such rights for children is a fairly modern concept. The moral worthiness of the lives of individual children has not consistently been a universally held value. In his analysis of this topic in England at the turn of the twentieth century, Wright (1988) argued that a drop in infant mortality due to advancements in medicine corresponded with a period of urbanization and diminution of family size, increasing each child's worth as a future source of labour and revenue. In effect, while the worth of children's lives increased, that worth still pivoted on their economic value rather than their inherent moral value. The moral objectification of

children was also critically examined by Scheper-Hughes and Sargent in *Small Wars: The Cultural Politics of Childhood* (1988). Children were construed socially as both material possessions and as “selfish” burdens on their surrounding adults.

While the language and motivations may have changed, the moral objectification of children continues to be found in contemporary clinical encounters. Parents commonly speak of the enormous burden they feel to do right by their children and ensure that they get the care they deserve (Carnevale et al., 2006; Carnevale et al., 2007). Parents are often overwhelmed by their sense of duty about being a good parent. They also struggle with profound apprehensions about the possibility that their child may die. Although parents are often the most suitable advocates for their child, the child's interests are intertwined—and sometimes even conflated—with the parents' own interests.

Similarly, conscientious HCPs may be authentically concerned about a child-patient's interests. However, these interests are sometimes difficult to distinguish from an HCP's own interests in attending to other patients. Furthermore, having a reasonable quality of work-life while pursuing opportunities for clinical innovation may be beneficial for the child, and yield professional recognition for HCPs. Health care institutions (e.g., hospitals), too, may be motivated to ensure that patients get the care they require while also balancing that care with the hospital's own interests in containing costs or pursuing politically meaningful goals. Thus, although an ill child may be surrounded by various adults claiming to advocate for the child's best interests, these adults are also pursuing their own interests. Given the significant power imbalance between these adult agents and the largely silent, morally subordinated children, the latter run a significant risk of moral objectification. This objectification can further perpetuate the social injustices experienced by children, as the interests of adults can prevail over those of significantly disadvantaged children.⁹

What About the Voice of the Child?

As HCPs use the best-interests standard to assess ethical concerns related to children, they may cast children in a highly passive role,

depending on how this standard is applied. Children's voices are commonly muted. I attribute this problem to two phenomena: first, underestimation of the "maturity" of children's moral reasoning, and second, the "adult-centredness" of how the best-interests standard is commonly used. I will discuss these topics separately in the following two sections.

Recognizing the "Maturity" of Moral Reasoning in Children

Children (or legal minors) are more capable of engaging in what is regarded as "mature" moral reasoning than is typically recognized. In a 1990 brief submitted by the American Psychological Association (APA) in the *Hodgson v. Minnesota* case, the APA stated: "[By] age 14 most adolescents have developed adult-like intellectual and social capacities including specific abilities outlined in the law as necessary for understanding treatment alternatives, considering risks and benefits, and legally competent consent" (Schneider et al., 1989, pp. 8–20, cited in Melton, 1999).

No universally accepted standard exists for determining when a child's voice is to be regarded as a sufficiently capable expression of an autonomous will.¹⁰ Children's voices matter, but when and how they matter is determined by a case-by-case interpretation of the child's decisional capacities. This may imply that six-year-old Gloria in Ethics in Practice 12-3 may not be considered to have adequately developed capacities to be attributed significant ethical and legal weight regarding her life-support treatment preferences. Similarly, this view could be extended to Benjamin's parents withholding a grave prognosis in Ethics in Practice 12-2, on the basis of their belief that he would be unable to process such news.

Confronting the Adult-Centredness of the Best-Interests Model

The best-interests standard is commonly imagined and operationalized within an adult-centred conception of moral agency (Carnevale et al., 2021). This conception corresponds with the doctrine of self-determination underlying ethical decision making in adults. Adults are regarded as self-determining agents capable of independently judging their respective moral interests. Fur-

thermore, it is understood that persons should not be impeded in their pursuit of these interests.¹¹

This ideal of autonomy is further expressed through the use of the leading psychological frameworks where moral development plays a key role (Erikson, 1950; Levinson, 1978). In these frameworks, a moral norm for mature adults as highly rational and autonomous is articulated. Children are consequently regarded as less mature—or immature—and therefore as not worthy of comparable recognition as moral agents.¹² Consequently, these immature agents, construed as incapable of rationally discerning their own moral interests, are classed as moral minors who are dependent upon adult custodians for the care of their interests. However, the cases of David, Robbie, and Cam in *Ethics in Practice* 12-5, 12-6, and 12-7, wherein the young people are concealing their principal concerns or diminished sense of self-worth, demonstrate how adult custodians can be highly misinformed or mistaken in their understanding of children's moral lives.

Piaget (1932/1965), a pioneer in the formulation of such psychological frameworks, characterized moral development in terms of three stages: constraint, cooperation, and generosity. Kohlberg (1981) drew on this Piagetian model to develop his own three-level framework for moral judgment in adolescents and adults: pre-conventional, conventional, and postconventional levels. An individual at the pre-conventional level is self-centred; the individual formulates moral norms in terms of their own needs and is essentially incapable of construing socially shared views. In conventional morality (associated with the preadolescence-adolescence juncture), the “good” or “right” thing to do is contextualized by social values and moral norms that sustain relationships, communities, and societies. The postconventional level involves a reflective view that transcends the conventional, seeking to discover—through a process of personal enlightenment—a universal construal of morality.

Kohlberg's framework is differentiated along a six-stage (three-level) model of moral development. The child is characterized by Kohlberg as starting at an egocentric and individualistic view of rightness based on avoidance of punishment and individual need (stages one and two). From there, they progress to an under-

standing based on “The Golden Rule” (that is, putting oneself in the shoes of the other person) and shared conventions of societal agreement (stages three and four). Finally, the child develops a principled understanding of morality that upholds the basic rights and values of society and a free-standing logic of universal principles that all humanity should follow (stages five and six) (Kohlberg, 1981). For Kohlberg, the ultimate morally mature person is capable of drawing on a highly deductive logic and engaging in rational reasoning to arrive at an ethically principled conception of justice.

The conceptual soundness of these leading theories of moral development has been challenged by Gilligan in her book *In a Different Voice: Psychological Theory and Women’s Development* (1982) when describing her study of moral experience among girls and women. She has argued that the Piaget and Kohlberg models are based on studies of boys and men and consequently give rise to a male-centred conception of moral development.¹³ While Piaget and Kohlberg have argued that humans (i.e., men) strive to become *independent* moral agents, Gilligan reported that girls and women strive to be *interdependent*. Girls and women, Gilligan argued, speak of moral matters in a different voice.

Gilligan’s moral orientation toward care and responsibility distinguishes the moral agency of women from the moral agency of men. According to Gilligan (1982), men are primarily concerned about justice and the preservation of the rights of individuals, with an entitlement to freedom from interference in their pursuit of self-fulfillment. Proponents of this feminist challenge to the conventional, male-centred view of morality have suggested that women may employ a different moral framework than men, raising the plausibility that additional distinctive moral frameworks can exist. In the next section, I argue that although children may not reason according to the prevailing adult, male-centred Kohlbergian morality, nor the female-oriented framework advanced by Gilligan, there exists a significant body of evidence indicating that children are capable of a rich degree of moral awareness. The moral viewpoints of children should not be judged in terms of how they might resemble or approximate adult moral reasoning, but instead warrant recognition on their own merits.

The Moral Awareness of Children

Numerous authors have highlighted that children have a greater awareness of morally significant matters than is commonly granted. Yalom (1980) asserted that children's first awareness of death can emerge as early as three years of age. Bluebond-Langner (1978) published a seminal ethnographic study of three- to nine-year-old children's encounters with leukemia. She revealed the silent experiences of children's struggles with sickness and dying, demonstrating a depth and richness in the children's comprehension that far surpassed the understandings attributed to them by the adults in their lives. Particularly remarkable was how these children willfully complied with social taboos and respected the silence that adults seemed to prefer in relation to the children's foreseen mortality. These findings correspond with Benjamin's case in *Ethics in Practice 12-2*. Children's silences should be interpreted thoughtfully. Their silence may sometimes demonstrate their motivation to conform to socially desired behavioural norms for children, rather than an incapacity to understand what is happening or moral immaturity.

Sourkes (1995), when discussing the experiences of children with life-threatening illnesses, found a rich depth of awareness in these children's thoughts about death. Sourkes reported (a) accounts of anticipatory grief among children facing their own deaths; (b) children's temporal understanding of death, with a comprehension of contributory causes and consequences; and (c) children's abilities to reflect on matters pertaining to a broad moral order. In the cases of Benjamin and Gloria (*Ethics in Practice 12-2* and *12-3*), both children seem to have a limited awareness of their situation. This can be partially attributable to restrictions in the information that was available to them. In light of Bluebond-Langner's (1978) findings, they may have also realized that the adults in their lives prefer that they inhibit expressions of their moral experiences.

Davies (2017) demonstrated how children actively strive to make sense of their world and find ways of being following the death of a sibling. Attig (1996) argued that children are able to anguish existentially and wondered about how they viewed their "finite

existence, the nature and purpose of life, God, punishment, fate, what is fair, and the meanings of suffering and death” (p. 21). In *Ethics in Practice 12-5*, David described himself as a cause of his parents’ fighting while also expressing moral outrage toward the unfairness of their spending insufficient “quality time” with him.

Coles (1986) examined the moral experiences of children in his acclaimed book *The Moral Life of Children*. He related accounts from poor families in the southern United States to convey that children do not simply express the views of their parents; they are capable of formulating and asserting their own independent sense of how the world should be. He explained that the moral life of children can be characterized as charitable, but also “by extended stretches of moral stinginess, amoral self-absorption, even a persistent immorality that takes the form of spitefulness, rudeness, assaultiveness” (p. 44). Coles argued that children’s actions that are sometimes characterized as immature misbehaviour can at times reveal a greater moral awareness and intentionality than usually considered. Even when children act “badly,” this behaviour can be considered a demonstration of their moral agency.

In my own work with critically ill children and their siblings, I have witnessed rich expressions of children’s moral lives (Carnevale, 1997, 1999a). Bereaved siblings, ranging from five to nineteen years of age, expressed feelings of guilt about the ways they may have acted toward their deceased sibling, demonstrating a capacity for moral contemplation. Many siblings expressed outrage towards the attention accorded to their seriously ill or deceased sibling. Although their parents might have regarded such sentiments as amoral, they nonetheless expressed the child’s sense of right and wrong. David, in *Ethics in Practice 12-5*, expressed outrage toward his father because he frequently did not follow through on his promises to make time for him: “He thinks only about himself. He’s selfish! I feel like I’m useless to him—just a bother for him.” Here, David condemns what he perceives as morally wrong parenting.

Although their demeanours may sometimes fall short of what adults might consider virtuous, children nonetheless express a moral stance toward their world. Children are morally aware; sometimes with rich complexity, at other times with a simplistic matter-of-factness. Although the moral values children hold may

sometimes correspond with those commonly held by adults, their moral awareness should not be judged according to an adult-centred standard. Given their unique perspectives on the world, it is understandable that children may hold some distinctive moral outlooks. Rather than construing these moral views as immature forms of what is to follow later in their developing lives, according to adult-centred moral development models, the moral views of children merit recognition in their own right. The works outlined above justify a call for the recognition of the moral voice of children—a further “different voice”¹⁴ (Carnevale et al., 2021; Esser et al., 2016).

What About Moral Responsibility?

Some may argue that it is mistaken to speak of moral agency in children without a direct implication of moral responsibility. In this line of reasoning, the moral agency of children should be construed narrowly because of the limited formal responsibility that can be assigned to their actions, given the limited understanding some children may have of the world around them. On the other hand, it could be argued that if health care providers want to broadly acknowledge the moral agency of children, then they ought to assign them a proportional degree of responsibility (Campbell et al., 2011).

This relating of responsibility with moral agency can be traced to Aristotle's *Nicomachean Ethics* (350 B.C.E./1985).¹⁵ Aristotle rooted moral responsibility in the voluntariness of human action. He further elaborated two conditions that preclude an act from being voluntary: ignorance or compulsion.¹⁶ Perhaps some children's actions could be considered morally involuntary in light of two factors: their variable understandings of the morally significant particulars in their surrounding world and their occasional, apparently compulsive urges to gratify emerging needs. Ignorance and compulsion may both be manifested, for example, in an act of running across a highly dangerous street to chase after a ball.

Following Aristotle's framework, it can be argued that the degree of moral responsibility that ought to be assigned to children's actions should vary according to the genuine voluntariness of their actions. Although there may be grounds for limiting their responsibility for the consequences of their actions, this should not

imply a diminution of their moral agency. Considering the depth of moral awareness of which children are capable, they can experience moral distress, guilt, remorse, indignation, and pride—a full range of conscientious sentiments. Therefore, they should be accorded significant recognition as moral agents. That is, children’s voices merit genuine attention—not just a curious listening to the perspective of an immature moral inferior. Children’s voices should not be discounted by adults wanting to accomplish what they consider required, using coercion as they judge necessary, for example, as with William in *Ethics in Practice* 12-1.

Agency Within a Moral World

I have argued throughout this chapter for a maximization of our attentiveness to the moral voices of children. I should add that attending to the moral lives of children consists of more than solely recognizing their individual moral experiences. In light of their relative position of disempowerment, consideration should also be given to the fragility of their “moral worlds.” Given their limited capacities to shape their own particular worlds, children rely on the significant adults in their lives—who model enactments of “right and wrong” ethical comportment—to help build and sustain their world’s moral order. Moral order refers here to the ways concepts such as right and wrong, good and bad, and just and unjust are defined by the child’s social and cultural context (Carnevale, 2005a). Children also form their own moral outlooks, in the manner outlined in this chapter. They forge modes of coexistence, continually negotiating cooperation with adults in their lives. Cooperation enables children to develop their particular moral character, a character they can then express and cultivate within their adult-dominated moral order.

Some traumatic experiences for children may rupture their moral order, resulting in extreme moral distress (Carnevale, 1998). To gain insight into a child’s moral order, it is useful to consider Robbie, the boy featured in *Ethics in Practice* 12-6. Robbie expressed that his life felt meaningless because he repeatedly witnessed his father assault his mother. His distress could be traced to the disruption in his moral order. He experienced profound discon-

tinuities in the everyday web of relationships that constituted his social world and moral order. Traumatic experiences like this can disrupt a child's socially mediated moral order and their ability to rely on adults as sources of comfort and protection against the threats in their everyday lives. While positive experiences can support moral inspiration and the constitution and maintenance of the child's moral system, negative disruptions in moral order can create extreme distress. In turn, preservation or restoration of positive moral orders can serve as vital sources of comfort.

Therefore, attending meaningfully to the moral lives of children ought to consist of not only authentic listening, but also of genuine consideration toward securing a child's moral order—their moral world. Within the clinical context, this requires optimizing the stability of relationships that are morally significant for children. In the next section, I discuss how conversations with children to seek their assent for health care can be used as a way to facilitate a child's expression of their agency.

Toward a Broad Conception of Assent

I argue in this chapter that we should attend genuinely to the moral voices of children, while recognizing limits to the degree of responsibility that can be assigned to their actions. The genuine attention I am implying here resembles the “authentic listening” advocated by Rogers (1951) in his client-centred therapy framework, where a clinician seeks a profoundly empathic attunement to the experiential perspective of the patient (Carnevale, 2020).¹⁷ This can be managed by interpreting the current standard of child assent more broadly.¹⁸ Obtaining assent implies seeking a child's willingness to accept the proposed care based on information that has been provided to them about their health condition, proposed investigations, and interventions. This information must be adapted to their language level and intellectual capabilities to optimize their understanding. The American Academy of Pediatrics (AAP) recommends that for children who cannot consent to care themselves, their parents should be responsible for granting permission while giving great weight to the views expressed by the child. Situations involving older children and adolescents should

also include the assent of the child to the greatest extent possible (Katz et al., 2016).

The foregoing discussion of the moral awareness of children implies that this AAP recommendation ought to be applied with an a priori valuation of the significance of the moral lives of children. What children say should be regarded as morally meaningful, and the adults in their lives (e.g., parents and HCPs) should genuinely seek to reconcile any matters that seem to be causing any moral concern for the child. This would involve attending meaningfully to their questions, possible objections, and even their silences.

Some clinical situations can involve complex phenomena—clearly oriented toward the child's long-term good—that a child may not seem to grasp fully (e.g., emergency surgery for a four-year-old with appendicitis). Although the responsible adults in such a situation (typically the parents) might authorize surgery despite the child's objections, such an authorization should follow the adults' best efforts to foster the child's understanding and acceptance of such an intervention. In the end, if it is judged by those with a duty of care for a child that some interventions may be considered optimal toward promoting a child's best interests despite the child's objections, such a coercive overriding of the child's moral voice should still be regarded as a form of moral wrong. Although overriding a child's expressed preferences in such a situation may be considered permissible in terms of their best interests, it should still carry the moral significance of a harm—a consequence that should be prevented and ameliorated as much as possible.¹⁹ This scenario can be distinguished from the approach used by Benjamin's parents in *Ethics in Practice* 12-2. Here, morally significant information that would help Benjamin understand what is happening to his body and enable him to express his own preferences toward his care is withheld by his parents, requiring him to undergo chemotherapy without his consent or his assent. In light of my arguments presented in this chapter where I outline the depth of children's moral awareness and capacities and, subsequently, the moral harms that can be attributed to neglect of their moral agency, the withholding of morally significant information from Benjamin is difficult to justify.

Implications for Advanced Practice Nurse Leaders

The narratives I presented at the beginning of this chapter highlight a diversity of moral concerns that can be experienced by children in clinical settings. The occurrence of such concerns suggests the potential for children's moral experiences to be under-recognized by adults, including their families and HCPS. Some implications for clinical care can be inferred from this analysis of moral agency. Advanced practice nurse leaders can mobilize their nursing ethics expertise as well as interdisciplinary collaborations to redress these concerns.

First, this discussion calls for an authentic recognition of the moral voices of children. The views and sentiments of children have moral worth and ought to be treated as such. For example, there exists a significant body of evidence justifying the requirement of consent for treatment decisions from young adolescence onward (Coughlin, 2018; CPS, 2004; Katz et al., 2016; Miller, 2010). Second, HCPS should strive to maximally apply the standard of assent, with a genuine stance toward the (spoken and bodily) voices of children. HCPS should regard children's views as worthy in their own right and not just as immature expressions requiring attention and pacification—the latter arising from an adult-centred conception of children's moral agency. In short, children's views should be attributed “due weight” in discussions and decisions that may affect them.²⁰

Working towards the increased recognition of children's participation in treatment decisions, Kenny et al. (2008) have proposed a framework for the respectful involvement of children in medical decision making. They argue for the participative assessment of (a) what the child wants to know; (b) what the child can understand; (c) the extent of the child's decision-making capacity; and (d) what the child needs to know to participate adequately. In practice, this involves adapting communication practices to each child's ways of understanding and expression. This is optimized through an empathic attunement with the child—continually striving to understand the child's thinking and sentiments regarding their care.²¹ This involves using voice elicitation methods that draw on verbal and nonverbal methods (including play- or art-based methods, and

drawing on parents and others who know the child well as communication interlocutors or interpreters). Next, it requires interpretation methods that help discern how the child's communication expresses their moral agency. The approaches used by advanced practice nurse leaders are very important: they can facilitate or impede the child's agential expression, directly affecting the ability of HCPS to understand the moral dimensions of their experiences (Carnevale, 2021; Carnevale et al., 2017).

Finally, advanced practice nurses and HCPS should also attend to children's moral order, which is predominantly constituted and sustained by the web of significant relationships in their social world. This would require (a) identifying the persons who matter (morally) in each child-patient's life; (b) seeking to understand how these persons matter; and (c) striving to find ways to preserve the continuity of such relationships within the context of clinical care. To illustrate, hospital policymakers should facilitate the presence of significant adults for children (Brinchmann et al., 2002). In addition to serving the psychological needs of these adults, these policies can be crucial in minimizing the traumatization of children. So-called hospital "visiting policies" imply a subordination of the significance of families (Carnevale, 1998, 2005b). When parents tend to their hospitalized children, they are parenting, not "visiting." Characterizing significant family members as "visitors" marginalizes their importance and justifies limiting their presence through restrictive policies. Given children's complex interdependencies within their families and how children's well-being is interrelated with their families' well-being, clinical practices should involve ongoing family assessment and the promotion of required family supports (Carnevale et al., 2017). Moreover, advanced practice nurse leaders should seek to understand the socio-cultural outlooks of children and their families, and strive to adapt their practices accordingly (Carnevale et al., 2017).

Finally, the care of children requires many complex, overlapping areas of expertise. Their care is therefore optimized when diverse interdisciplinary teams can be adapted to each child's particular needs, drawing broadly on experts in nursing, medicine, social work, child psychology and psychiatry, child life, childhood education, pastoral care, and clinical ethics, among others, as well as

subspecialists within these disciplines (Carnevale, 2003; Carnevale et al., 2017; CPS, 2004).

Revisiting the Ethics in Practice Narratives

I end this chapter by returning to the Ethics in Practice narratives presented at the beginning of the chapter to discuss the corresponding implications for advanced practice nurse leaders. I discuss each situation briefly. An authentic approach to these discussions requires a commitment to examining the particularities of each narrative. The goal is to uncover the specific moral phenomena that are involved and corresponding circumstances at issue within each case.

One of the most profound messages that runs through each of the Ethics in Practice narratives (adapted from experiences within my practice as an advanced practice nurse leader) is that we ought to listen to the moral voices of children in a deeply engaged manner, and not trivialize them. In Ethics in Practice 12-1, for instance, this meant sitting with William to listen to his fears rather than only rewarding the behaviour we wanted. In Ethics in Practice 12-7, it was important to listen attentively to Cam's call for privacy regarding their gender identity experiences to better understand their concerns and what might be at stake, should their confidentiality be breached (Noiseux et al., 2019). After a private space was provided for in-depth discussion, Cam revealed that they were able to feel more authentically like themselves. This was crucial toward promoting a better self-understanding for Cam as a basis for deciding which actions would optimize their well-being.

For Robbie, in Ethics in Practice 12-6, engagement meant ensuring that Robbie was able to continue to express his psychological as well as his physical pain. In fact, after expressing my dismay over the possibility of losing him in my life—by which I aimed to emphasize his moral significance—Robbie told me that my relationship with him helped him to talk about his pain and lighten the meaninglessness he felt in his life.

The promotion of authentic listening is particularly important for fostering a deepened awareness of the moral lives of children among the significant adults in their world. Parents are often moved

by their children's expressed wishes, especially when they are articulated with a demonstration of the richness of the child's moral awareness. In *Ethics in Practice* 12-3, where six-year-old Gloria's parents wanted to end her life-support, we were able to engage Gloria in a dialogue through which she was able to explicitly express that she enjoyed many aspects of her life. Although she was frustrated by her dependence on technology, she clearly indicated that it was better to be alive in this manner than to not be alive at all.

In *Ethics in Practice* 12-5, David demonstrated that he was highly capable of assessing his chronic pain in an ongoing manner and determining which pain-management strategies would be most effective in different circumstances. He was able to make important decisions and assume significant responsibility for his care. However, he was so distraught over his parents' fighting that he was unable to speak with them about how this aggravated his pain. In *Ethics in Practice* 12-6, Robbie's inability to speak about his pain gave rise to suicidal feelings. Children in such situations can benefit from advocacy that facilitates the revealing of their masked sentiments. For example, when I arranged a family conference to help David express his feelings, he said that he felt safe knowing that I would be there as an adult who would ensure that he was heard. David's parents were very upset after hearing their child's despair. They promised him that they would do everything they could to stop fighting.

In *Ethics in Practice* 12-2 and 12-4, the cases of Benjamin and Marianne each involved situations in which some of the adults in the children's lives were withholding significant information from them. Although keeping such secrets may be intended to protect children from emotional pain, they may in fact distance the children from the significant moral matters at hand. This can impede the children's ability to understand what is happening, as well as their ability to express how this matters to them. In such situations, I have found that parents themselves appear morally distressed about such secrets. Commonly, parents demonstrate a form of relief once the secret is broken (because they believe, on some level, that it is wrong to not tell the truth). As a result, a deeper intimacy between the parents and the child is fostered. It is also important to recognize that most parents strive to protect their

children from harm, which can give rise to a profound sense of burden when they acquire emotionally painful information about their children's lives.

The promotion of authentic listening is also important for enhancing advanced practice nurse leaders' awareness of children's moral worlds. In caring for children like William, in Ethics in Practice 12-1, this can involve discussing how the use of normative terms such as "good boy" can significantly limit the range of feelings that children will openly express while privately experiencing fear, pain, and distress.

Conclusion

Much has been written regarding ethical issues surrounding intervention decisions for children. The authors of this literature have predominantly focused on what adults are called upon to decide on behalf of children, and the normative standards that should be employed for such decisions. In this chapter, I draw attention to the voices of the silent agents who are the objects of these decisions: morally aware young subjects living their own moral experiences. I have highlighted ways in which advanced practice nurse leaders can draw on these richer understandings of children's experiences to inform their ethical practice in children's nursing and advocate for stronger and more respectful recognition of children's voices.

QUESTIONS FOR REFLECTION

1. *How does this chapter affect your understanding of the role of parents?*
2. *Identify a situation from your practice where a child's moral agency was under-recognized.*
3. *How would you approach a child differently after reading this chapter?*

Endnotes

- 1 This chapter is adapted and revised from: Carnevale, F. A. (2013). Listening authentically to youthful voices: A conception of the moral agency of children. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 315–332). Pearson.
- 2 The term “children’s nursing” is used here, rather than “pediatric nursing,” to reflect a current shift away from the latter, which has been centred primarily on medical pathologies, to the former, which focuses primarily on the child as an active human agent (Carter et al., 2014).
- 3 Portions of these narratives have been modified to preserve the anonymity of the persons involved. For example, all of the names presented are pseudonyms.
- 4 These cases involve complex socio-cultural and Indigenous diversities. These dimensions have been excluded from the case description, despite their tremendous significance, to guard against the risk of cultural profiling. Thoughtful examinations of these dimensions would require significantly expanded discussions of each case. For a detailed examination of these dimensions and a “thick” analysis of two clinical cases, see Carnevale (2005a).
- 5 This discussion is exclusively limited to the context of decisions regarding clinical care. Children’s consent to participate in research also raises a number of challenging questions (Carnevale et al., 2008; Ross, 2006), but these are beyond the scope of this paper.
- 6 For a detailed review of how consent standards vary by jurisdiction throughout Canada, see Coughlin (2018).
- 7 Although the family is generally viewed as the most suitable unit for creating the moral milieu conducive for fostering the healthy growth of children, it is also recognized that, on occasion, some families can neglect or mistreat children. In such cases, there is some acceptance of state interference in family life.
- 8 See *B. (R.) v. Children’s Aid Society of Metropolitan Toronto* (1995) and *A. C. v. Manitoba (Director of Child and Family Services)* (2009).
- 9 Children can be considered disadvantaged *physically* (e.g., they are generally smaller and less physically powerful than adults), *psychologically* (e.g., they commonly have less relational experience than adults and therefore have limited capacities to judge the trustworthiness of particular relationships), *socially* (e.g., they are usually economically dependent on adults for support of their basic necessities of life), and *legally* (e.g., they require an adult interlocutor to have their legal rights recognized). These disadvantages can make children vulnerable and predispose them to maltreatment and other risks.
- 10 Decision-making capacity should be judged on the basis of an ability to understand relevant information, think and choose with some degree of independence, and assess the potential for benefit and harm, as well as the achievement of a fairly stable set of values (Miller, 2010). Decisional complexity among adolescents has been further discussed by Coughlin (2018).
- 11 This view can be traced to a fundamental ethos of individualism in modern Western societies, wherein each human ought to become an independent or autonomous agent capable of judging morally significant matters through a developed faculty of rational discernment (Carnevale, 1999b).

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- 12 This highlights a fundamental tension whereby cognitive maturity is presumed as a necessary condition for moral agency. Moral development is linked to the development of general skills of rational reasoning (Kohlberg, 1981; Piaget, 1932/1965). This presumption is valid for an adult-centred conception of moral agency. However, I argue for a recognition of children's moral agency, regardless of their level of cognitive development, especially in light of the ways in which child development models are sometimes used to discount the moral significance of children's voices (Carnevale, 2021; Carnevale et al., 2021; Greene and Hogan, 2005).
 - 13 Kohlberg subsequently put forth a reformulated theory that attempted to address criticisms of his earlier work (Kohlberg et al., 1983). The new theory was regarded as too complex and unclear, such that his earlier publications persisted as his most influential work (Shweder et al., 1987).
 - 14 Although I am employing the metaphor of voice in this discussion, drawing on Gilligan's (1982) acclaimed work, "listening" to the moral experiences of children should not be limited to attending solely to their verbal expressions. Children commonly express outrage and protest or comfort and acceptance through various modes of bodily and verbal expression (Carnevale, 1998; Carnevale, 2021). See also Kagan & Lamb (1987) for a discussion of the relation of culture to moral development in children.
 - 15 For my discussion of moral responsibility, I am deeply indebted to Carl Elliott (1996) for his philosophical analysis of responsibility in mentally ill offenders.
 - 16 According to Aristotle, the type of ignorance that can make an action involuntary refers to an ignorance of the particular circumstances of an action (e.g., injuring someone in response to a suspected yet false threat constitutes an ignorance-based, involuntary injury). Compulsion refers to an act where the drive resides outside the person. This essentially refers to acts committed out of necessity or duress, wherein many would agree that the individual could not really have done otherwise under those particular circumstances.
 - 17 This is further related to professional practice with children in Carnevale (2020) and Carnevale et al. (2021).
 - 18 Assent should be distinguished from consent. Free and informed consent is legally and ethically recognized as a necessary condition for providing care, even with children. If the child does not have the decision-making capacity to provide consent for a specific form of care, then this consent should be provided by the legally-authorized surrogate decision-maker for the child (e.g., a parent). Assent is not legally recognized as a standard for clinical care, although it is a standard within research (e.g., a child's voluntary cooperation is required to involve them in a non-therapeutic study). I am arguing for the recognition of assent as an ethical standard that can provide a way to recognize children as legitimate participants in discussions and decisions that affect them, when they do not have the legal right to provide consent for themselves.
 - 19 This acknowledges the importance of retaining some form of the best-interests standard for a preliminary discernment of which treatment options might be best for a child. It also encourages HCPS to continue to recognize the significance of parents as surrogate decision makers because the common intimacy of their relationship predisposes them (more than most other adults) to think in terms of the child's interests. However, a corresponding recognition of the moral views of children problematizes objections or exclusions they experience toward treatment

- decisions made by their parents. This fosters a greater consideration of the child's voice and also enriches the parents' understanding of the benefits and harms attributed to various treatments by better recognizing that certain courses of action are morally distressing for the child. It is noteworthy that in the context of research, it is widely held that a child's expression of dissent should be respected (Carnevale et al., 2008). "Children can be seriously harmed by having something done to them without their knowledge or understanding" (Baylis et al., 1999, p. 8).
- 20 The term "due weight" is adapted from Article 12 of the *Convention on the Rights of the Child* regarding children's participation rights (United Nations, 1989).
 - 21 I have published a detailed description of how "empathic attunement" can be operationalized in practice and in research, using the concept of "thick voices" (Carnevale, 2020).

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