Bioethics for clinicians: 9. Involving children in medical decisions

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Abstract

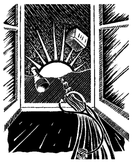
MEDICAL DECISIONS INVOLVING CHILDREN raise particular ethical issues for physicians and other members of the health care team. Although parents and physicians have traditionally made most medical decisions on behalf of children, the developing autonomy of children is increasingly being recognized in medical decision-making. This poses a challenge for physicians, who must work with the child's family and with other health care practitioners to determine the child's role in decision-making. A family-centred approach respects the complex nature of parent–child relationships, the dependence and vulnerability of the child and the child's developing capacity for decision-making.

Résumé

LES DÉCISIONS MÉDICALES QUI CONCERNENT LES ENFANTS posent des problèmes d'éthique particuliers aux médecins et aux autres membres de l'équipe de soins de santé. Même si les parents et les médecins ont toujours pris la plupart des décisions médicales pour le compte des enfants, on reconnaît de plus en plus la nouvelle autonomie des enfants dans la prise de décisions d'ordre médical. Cela pose un défi aux médecins qui doivent travailler avec les membres de la famille de l'enfant et d'autres praticiens des soins de santé pour déterminer le rôle de l'enfant dans la prise des décisions. Une démarche axée sur la famille respecte la nature complexe des relations parent–enfant, la dépendance et la vulnérabilité de l'enfant et sa capacité de décision qui commence à prendre forme.

Eleven-year-old Samantha is a bright, loving child who was treated for osteosarcoma in her left arm. The arm had to be amputated, and Samantha was given a course of chemotherapy. She has been cancer-free for 18 months and is doing well in school. She is self-conscious about her prosthesis and sad because she had to give away her cat, Snowy, to decrease her risk of infection. Recent tests indicate that the cancer has recurred and metastasized to her lungs. Her family is devastated by this news but do not want to give up hope. However, even with aggressive treatment Samantha's chances for recovery are less than 20%.

Samantha adamantly refuses further treatment. On earlier occasions she had acquiesced to treatment only to struggle violently when it was administered. She distrusts her health care providers and is angry with them and her parents. She protests, "You already made me give up Snowy and my arm. What more do you want?" Her parents insist that treatment must continue. At the request of her physician, a psychologist and psychiatrist conduct a capacity assessment. They agree that Samantha is probably incapable of making treatment decisions; her understanding of death is immature and her anxiety level very high. Nursing staff are reluctant to impose treatment; in the past Samantha's struggling and the need to restrain her upset them a great deal.



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Éducation

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Why is it important to include children in medical decision-making?

Ethics

Traditionally, parents and physicians have made all medical decisions on behalf of children. However, just as the concept of informed consent has developed over the last 30 years with respect to competent adult patients, so new ways of thinking about the role of children in medical decision-making have evolved.

Ethical principles that provide guidance in the care of adults are insufficient in the context of caring for children.[1–3] Issues related to the voluntariness of consent, the disclosure of information, capacity assessment, treatment decisions and bereavement are more complex, as is the physician's relationship with the patient and the patient's family.[3,4] Adult models presume that the patient is autonomous and has a stable sense of self, established values and mature cognitive skills; these characteristics are undeveloped or underdeveloped in children.

Although it is important to understand and respect the developing autonomy of a child, and although the duty of beneficence provides a starting point for determining what is in the child's best interest, a family-centred ethic is the best model for understanding the interdependent relationships that bear upon the child's situation.[5] A family-centred approach considers the effects of a decision on all family members, their responsibilities toward one another and the burdens and benefits of a decision for each member, while acknowledging the special vulnerability of the child patient.

A family-centred approach presents special challenges for the health care team, particularly when there is disagreement between parent and child. Such a situation raises profound questions about the nature of the physician–patient relationship in pediatric practice. Integrity in this relationship is fundamental to the achievement of the goal of medicine,[6] which has been defined as "right and good healing action taken in the interest of a particular patient."[7] In the care of adults, the physician's primary relationship is with the particular capable patient. The patient's family may be involved in decision-making, but it is usually the patient who defines the bounds of such involvement.

The care of children, on the other hand, has been described in terms of a "triadic" relationship in which the child, his or her parents and the physician all have a necessary involvement (Dr. Abbyann Lynch, Director, Ethics in Health Care Associates, Toronto: personal communication, 1992). When there is disagreement between parent and child, the physician may experience some moral discomfort in having to deal separately with the child and parent.

The assumption that parents best understand what is in the interest of their child is usually sound. However, situations can arise in which the parents' distress prevents them from attending carefully to the child's concerns and wishes. Simply complying with the parents' wishes in such cases is inadequate. It is more helpful and respectful of the child to affirm the parents' responsibility for the care of their child while allowing the child to exercise choice in a measure appropriate to his or her level of development and experience of illness and treatment. This approach does not discount the parents' concerns and wishes, but recognizes the child as the particular patient to whom the physician has a primary duty of care. This approach seeks to harmonize the values of everyone involved in making the decision.[6]

Law

The legal right to refuse medical treatment is related to, but not identical with, the right to consent to treatment. The patient's right to refuse even life-saving medical treatment is recognized in Canadian law[8,9] and is premised on the patient's right to exercise control over his or her own body. Providing treatment despite a patient's valid refusal can constitute battery and, in some circumstances, negligence.

To be legally valid the refusal of medical treatment must be given by a person deemed capable of making health care choices, that is, capable of understanding the nature and consequences of the recommended treatment, alternative treatments and nontreatment. In common law the notion of the "mature minor" recognizes that some children are capable of making their own health care choices despite their age.[10] In common law and under the statutory law of some provinces patients are presumed capable regardless of age unless shown otherwise; in other provinces an age at which patients are presumed capable is specified.[11] When a child's capacity is in doubt an assessment is required.

In the case of children who are incapable of making their own health care decisions, parents or legal guardians generally have the legal authority to act as surrogate decision-makers. The surrogate decision-maker is obliged to make treatment decisions in the best interest of the child. Health care providers who believe that a surrogate's decisions are not in the child's best interest can appeal to provincial child welfare authorities. The courts have the authority to assume a *parens patriae* role in treatment decisions if the child is deemed to be in need of protection. This issue has arisen most commonly with respect to Jehovah's Witnesses who refuse blood transfusions for their children on religious grounds, and courts have authorized treatment in recognition of the state's interest in protecting the health and well-being of children.[12] Every province has child welfare legislation that sets out the general parameters of the "best interest" standard. Courts are reluctant to authorize the withholding or withdrawal of medical treatment, especially in the face of parental support for such treatment.

A special point to consider involves the use of patient restraints. The wrongful or excessive use of restraints could prompt an action of false imprisonment or battery. Restraint can involve the use of force, mechanical means or chemicals. The use of restraint compromises the dignity and liberty of the patient, including the child patient. Restraints should never be used solely to facilitate care but, rather, only when the patient is likely to cause serious bodily harm to himself or herself or to another. If restraint is required, the health care provider should use the least restrictive means possible, and the need for the restraint (as well as its effect on the patient) should be assessed on an ongoing basis.

Policy

The Canadian Paediatric Society has no policy regarding the role of the child patient in medical decision-making. The American Academy of Pediatrics statement on this question articulates the joint responsibility of physicians and parents to make decisions for very young patients in their best interest and states that "[p]arents and physicians should not exclude children and adolescents from decision-making without persuasive reasons."[13]

Empirical studies

As they grow, children develop decision-making skills, the ability to reason using complex concepts, an understanding of death[14] and the ability to imagine a future for themselves.[15] Children with a chronic or terminal illness may have experiences that endow them with insight and maturity beyond their years. Families often encourage children to participate in decision-making. Allowing even young children to make decisions about simple matters facilitates the development of skills that they will need to make more complex decisions later on.[16–18]

Because tools developed to assess the capacity of adults have not been tested with children, health care professionals working with children should be sensitive to the particular capacity of each child. Children are constantly developing their physical, intellectual, emotional and personal maturity. Although developmental milestones give us a general sense of capacities, 2 children of the same age will not necessarily have the same ability to make choices. Even when they are deemed capable of making health care choices, children need support for their decisions from family members and the health care team.

How should I determine the appropriate role of a child in medical decision-making?

Most children fall into one of three groups with respect to their appropriate involvement in decision-making.[19,20]

Infants and young children

Preschool children have no significant decision-making capacity and cannot provide their own consent. As surrogate decision-makers, parents should authorize (or refuse authorization) on their child's behalf, basing their decisions on what they believe to be in the child's best interest.

Primary-school children

Children of primary-school age may participate in medical decisions but do not have full decision-making capacity. They may indicate their assent or dissent without fully understanding its implications. Nonetheless they should be provided with information appropriate to their level of comprehension. Although the child's parents should authorize or refuse to authorize treatment, the child's assent should be sought and any strong and sustained dissent should be taken seriously.[21]

Adolescents

Many adolescents have the decision-making capacity of an adult.[22,23] This capacity will need to be determined for each patient in light of his or her

- ability to understand and communicate relevant information,
- ability to think and choose with some degree of independence,
- ability to assess the potential for benefit, risks or harms as well as to consider consequences and multiple options, and
- achievement of a fairly stable set of values.[24]

Many children and adolescents, particularly those who have been seriously ill, will need assistance in developing an understanding of the issues and in demonstrating their decision-making capacity. Age-appropriate discussions, perhaps with the assistance of teachers, chaplains, play therapists, nurses, psychologists or others skilled in communicating with children, are helpful. The child's participation may be facilitated by the use of art activities, stories, poems, role-playing and other techniques.[25,26]

Physicians should ensure that good decisions are made on behalf of their child patients. Although the interests of other family members are important and will influence decision-making, the child's interests are most important and are unlikely to be expressed or defended by the child himself or herself. Anxious, stressed or grieving family members may need assistance in focusing on what is best for the child. This may be especially difficult when a cure is no longer possible; in such cases a decision to stop treatment may seem like a decision to cause the child's death.

Whether or not the child participates, the following considerations should bear upon a treatment decision concerning that child:

- The potential benefits to the child
- The potential harmful consequences to the child, including physical suffering, psychological or spiritual distress and death
- The moral, spiritual and cultural values of the child's family

The case

For Samantha, resuming aggressive treatment will have a serious negative effect on her quality of life. The chances of remission are small, yet a decision to discontinue treatment will likely result in her death. Because death is an irreversible harm, and decisions with serious consequences require a high level of competence in decision-making,[27] the capacity required would be very high. It has been determined that Samantha does not have this capacity.

Nevertheless, Samantha is included in discussions about her treatment options, and her reasons for refusing treatment are explored.[28] Members of the team work hard to re-establish trust. They and Samantha's parents come to agree that refusing treatment is not necessarily unreasonable; a decision by an adult patient in similar circumstances to discontinue treatment would certainly be honoured. Discussions address Samantha's and her parents' hopes and fears, their understanding of the possibility of cure, the meaning for them of the statistics provided by the physicians, Samantha's role in decision-making and her access to information. They are assisted by nurses, a child psychologist, a psychiatrist, a member of the clergy, a bioethicist, a social worker and a palliative care specialist.

Discussions focus on reaching a common understanding about the goals of treatment for Samantha. Her physician helps her to express her feelings and concerns about the likely effects of continued treatment. Consideration is given to the effects on her physical well-being, quality of life, self-esteem and dignity of imposing treatment against her wishes. Spiritual and psychological support for Samantha and her family is acknowledged to be an essential component of the treatment plan. Opportunities are provided for Samantha and her family to speak to others who have had similar experiences, and staff are given the opportunity to voice their concerns.

Ultimately, a decision is reached to discontinue chemotherapy and the goal of treatment shifts from "cure" to "care." Samantha's caregivers assure her and her family that they are not "giving up" but are directing their efforts toward Samantha's physical comfort and her spiritual and psychological needs. Samantha returns home, supported by a community palliative care program, and is allowed to have a new kitten. She dies peacefully.

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