

Withholding life-sustaining treatment: Are adolescents competent to make these decisions?

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Case report

At 12 years of age AM was diagnosed with renal failure from reflux nephropathy. Her condition was complicated by repeated abdominal infections while on peritoneal dialysis and difficulties with vascular access while on hemodialysis. At 14 she received a cadaveric kidney transplant, but within 6 months there was evidence of transplant rejection. The rejection was attributed, in part, to noncompliance with her cyclosporine prescription. AM could not remember a time when she had been well. As the function of her transplant kidney worsened AM informed her physicians that she did not want to return to dialysis; she understood this meant she would die from renal failure. AM's mother, however, was emphatic that AM be forced to return to dialysis. Legal counsel for the hospital advised that the mother had legal authority over decisions concerning AM's health care because AM was not yet 18 years of age.

Competence of adolescents to make decisions

The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgement required for making life's difficult decisions. Most children, even in adolescence simply are not able to make sound judgements concerning many decisions, including their need for medical care or treatment. —Justice Warren Burger¹

The moral and intellectual maturity of the 14 year old approaches that of the adult. —Justice William Douglas²

Justices Burger and Douglas succinctly summarize the opposing opinions on whether adolescents should be given the authority to make health care decisions.³ The principle of respect for persons includes the right of choice. Respecting autonomy means that, even if we don't agree with a competent individual's decision, we must respect their choice. Should adolescents be permitted to decide whether they receive life-sustaining medical treatment? On the basis of ethical and legal principles we argue that they should.

Being considered competent to make a decision implies:³⁻⁸

- the ability to express the choice between alternatives,
- risks, benefits and alternatives are understood when various choices are considered,
- rational and logical reasoning is demonstrated,
- the choice is "reasonable" and
- the choice is made without coercion.

Many assume, simply on the basis of age, that adolescents do not have the requisite capacities to make health care decisions. This presumption is, in general, incorrect. Jean Piaget described the abilities that most children demonstrate at different stages of cognitive development.^{3,5,6,9} Children in the preoperational stage (2–7 years of age) are unable to reason beyond their own limited experience and do not demonstrate a cogent understanding of cause and effect. In the concrete operational stage (7–11 years of age) children begin to think logically, but their ability to reason and abstract beyond personal experience remains limited. It is in the formal operational stage (11 years of age and older) that children show an intellectual capacity to reason, generalize beyond personal experience, deal with abstract ideas

Review

Synthèse

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and hypothesize or predict potential consequences of actions. According to Piaget, apart from inexperience, most individuals 14 years of age and older have the same capacities to process information that adults have.

Weithorn and Campbell³ compared the “competency,” in terms of understanding, rational reasoning and reasonable outcome, of subjects 9, 14, 18 and 21 years of age to make informed treatment decisions; 14-year-old adolescents and 18- and 21-year-old adults did not differ significantly in their ability to reason or understand treatment information provided in hypothetical dilemmas involving diabetes, epilepsy, enuresis and depression. Bibace and Walsh,⁹ who examined the development of children’s concepts of illness in light of Piaget’s theories, reported that 42% of children 11 years of age understood that disease has a physiologic basis. Research therefore indicates that children begin to understand disease processes around the age of 11 and demonstrate the competence to make a decision by the age of 14.

Canadian courts recognize that it is appropriate to let children make their own health care decisions and have rejected the notion that the “age of majority” is the age at which an individual becomes capable of giving informed consent. As Lord Nathan outlined over 40 years ago: “the most satisfactory solution of the problem is to rule that an infant [person below the age of majority] who is capable of appreciating fully the nature of and consequences of a particular operation or of a particular treatment can give an effective consent thereto, and in such cases the consent of the guardian is unnecessary.”¹⁰ Canadian “...common law recognizes the ... mature minor [as] a person who is capable of understanding the nature and consequences of the proposed treatment. When a minor is mature, no parental consent is required.”¹⁰ Many physicians and health care facilities rely on the doctrine of the emancipated minor to legitimize some adolescent’s decisions. However, this is actually unnecessary because the law states that “each individual is legally and mentally capable of giving consent in the absence of proof to the contrary. Whether a child can consent or not depends on the child in question, his or her mental ability and the treatment or procedure which the child is asked to understand.”¹⁰

It has been suggested that the “proportionality” of the decision to withdraw life-sustaining treatment should be considered when adolescents are involved.¹¹ Proportionality refers to a sliding scale of competency: the more important or serious the outcome or the greater the risk–benefit ratio involved, the higher the level of competency that should be required of the person making the decision.⁵ However, adolescents who understand that the withdrawal of life-sustaining medical treatment may result in their death should not be denied the right to make this decision. The American Academy of Pediatrics, with representation from the Canadian Paediatrics Society, has said as much in their *Guidelines on forgoing life-sustaining treatment*: “... physicians and parents should give great weight to clearly expressed

views of child patients regarding life-sustaining medical treatment, regardless of the legal particulars.”⁴

It is generally accepted that adolescents should decide whether they want to participate in research.^{12–16} The Society for Adolescent Medicine¹⁷ has stated as a general principle that “[the] developing capacities ... and emerging abilities directly affect [an] adolescent’s capacity to be involved independently in the research process. The arbitrary age threshold used to define majority ... does not adequately consider these emerging abilities.” Article 2.7 of the *Tri-Council Policy Statement* states “... where the legally incompetent individual [children and others] understands the nature and consequences of the research, the researcher shall seek to ascertain the wishes of the individual ... dissent will preclude his or her participation.”¹⁸ This relatively new recognition that adolescents are capable of making informed decisions about participating in research should be applied to decisions in clinical situations as well.

AM had many discussions with her nephrologist about treatment options. She understood that without dialysis or a ‘rescue’ transplant she would die. She demonstrated a comprehensive understanding of her condition, reflected on treatment options and articulated her beliefs to her physician and other members of the health care team. AM’s physician disagreed with the opinion of hospital counsel (i.e., that AM was not old enough to legally decide her own fate), as did we.

Life and death are concrete concepts clearly understood by adolescents. There is a clear ethical and legal foundation for permitting competent adolescents to decide if they will accept life-sustaining medical treatment. Despite the principle of proportionality, there is no foundation to withhold this right from a competent adolescent.

Age-specific values and external influences

Arguments to limit the autonomy of adolescents focus on age-specific values and on an adolescent’s ability to decide independently. The transient and perhaps immature values of adolescents are of particular concern. For example, some treatments may result in disfigurement (e.g., radical surgical debridement for cancer), lack of acceptance from a peer group (e.g., because of dietary restriction in renal failure or diabetes) or lack of true independence (e.g., with hemodialysis). There is evidence that adolescents do reject the choices of competent adults and even younger children as “most reasonable” because of concerns about body image. In the study by Weithorn and Campbell³ a significant proportion of adolescents rejected the most reasonable treatment for epilepsy (i.e., phenytoin) because of concerns about side effects (e.g., gum swelling, excessive body hair growth or both). Gaylin¹¹ argues for the limit of an adolescent’s autonomy on the basis of “limits of experience.” “While she [a young woman with cancer] might be conscious, intelligent, rational, and probably quite perceptive, the limited nature of her experience has distorted her

capacity for sound judgement.” However, despite the obvious effects of age-specific values on some adolescents’ decisions, as Ladd and Forman¹⁹ argue, there is little empiric evidence that these values would or do impair adolescents’ decisions about life-sustaining medical treatment.

Making an informed decision requires that an individual’s choice is free of external influence and coercion. There may be difficulty in determining if adolescents are acting independently; many experience an “external locus of control, sensing that other people or outside events control them.”²⁵ There is evidence that parental influence may affect the conviction of an adolescent’s decisions.²⁰ Scherer and Reppucci,²¹ using the vignettes developed by Weithorn and Campbell,³ demonstrated that the decisions of 40 adolescents, 14 and 15 years of age, differed significantly for all vignettes when parental influence was increased in a stepwise fashion from “no influence” to “coercive.”

The interests of the parent

It is often argued that parents, because of a libertarian interest in the health of the child, must be permitted the opportunity to participate in medical decisions.²² This position has been justified: “[t]he common law rule was that even non-negligent treatment of a minor ... without parental consent gave rise to an action for assault and battery ... and gave the parent (not the child) a cause for action.”²³ However, such an argument implies children are simply chattel and is without moral foundation.^{6,21,22} Although parents have an emotional attachment to their children there is no persuasive moral argument that economic or emotional interest should supercede the opportunity for a competent child to make independent decisions. It has also been argued that parental rights are well established and must be respected and for historical, cultural and religious reasons the parent has the legal and moral authority to judge what is best for a child.²² As Gaylin wrote, “[c]an this decision [to limit adolescent decision making] be defended on logical grounds? I doubt it. It is by every definition, paternalistic.”¹¹ Parents are afforded broad latitude in making health care decisions for their children; however, parents do not have an unfettered right to make all decisions. For example, courts do not give parents the right to decide independently about procedures such as sterilization or organ removal from a living child for donation.

AM had to move to a centre with dialysis services and found the subsequent loss of independence and isolation from her peers distressing. Although AM still lived with her parents the family was not characterized by hospital social workers as emotionally supportive. The mother had always dominated the family, but as AM’s siblings matured through adolescence and became independent there was more conflict in the home. However, the loss of locus of control for the mother and AM’s age-specific values, such as independence and dietary restriction, were not the basis for her decision to discontinue dialysis. She did not believe that dialysis offered any opportunity for her to recover or get well but rather, that it would simply prolong her suffering.

It is difficult to deny AM’s choice on the basis of concern about age-specific values or her mother’s interests when her reasoning was clear.

Conclusion

The majority of health care decisions for adolescents, including those concerning life-sustaining medical treatment, are made cooperatively by the adolescent, physicians and parents in a supportive environment. Occasionally, the adolescent patient will disagree with the parent(s), physician(s) or both. In this circumstance, sound ethical practice is based on the foundation of an accurate medical assessment of prognosis and treatment options and the clinical course with and without treatment. Sincere attempts to communicate this information must be made even if this requires numerous clinical visits. The physician should assess an adolescent’s ability to comprehend and reflect on the choices, to balance values and to understand the implications of treatment decisions.^{25,26} Given that most adolescents have the capacity necessary to make competent health care decisions, the ethical physician should respect this and allow the competent adolescent the right to exercise autonomy.

After further reflection, AM returned to hemodialysis for another year; she then refused any further therapy and died at home from complications of renal failure.

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