

Involving Children and Adolescents in Medical Decision Making: Developmental and Clinical Considerations¹

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Outlined the issues in informed consent, as well as goals for involving children and adolescents in decisions regarding their own medical treatment. This paper reviews the developmental and clinical considerations, and provides recommendations, for determining particular children's level of involvement. Finally, there are distinct roles for pediatric psychologists in this process, which are described. As medical treatment becomes increasingly sophisticated, there is an obligation for pediatric psychologists to appreciate the ethical and clinical issues in medical decision making for families.

KEY WORDS: adolescents; children; cognitive development; informed consent; medical decision making; social development.

As medical treatment becomes increasingly sophisticated, medical decision making also becomes more complex. There are growing numbers of chronically ill children, whose families are faced with complicated decisions about treatment at frequent junctures. There are fewer "right answers" for parents regarding what is the best course of action for their children's health. This evolution carries with it the obligation for pediatric psychologists to appreciate the ethical and clinical issues in medical decision making for families. We need to support minors'

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involvement in decision making, particularly for treatment decisions where the clarity of the "right choice" fades, where treatment preferences are based upon personal values and "quality of life" issues (McCabe, Rushton, Glover, Murray, & Leikin, in press; Patient Self Determination Act of 1990). This paper outlines the considerations in determining children's level of involvement in medical decision making, drawing on the theory and knowledge base in developmental, social, clinical, and health psychology.

GOALS FOR INVOLVING CHILDREN AND ADOLESCENTS

There are at least five distinct goals for involving children and adolescents in decisions regarding their medical treatment: (a) First, we are compelled by the ethical principle of patient self-determination, or autonomy (Beauchamp & Childress, 1983). This principle applies to children as well as to adults, although its application is clearly more complicated for young people. (b) Children's involvement in medical decision making improves open communication among physicians, parents, and children. Doctor-patient-parent communication is fundamental to both children and parents' satisfaction with medical care (e.g., Korsch, Gozzi, & Francis, 1968), and satisfaction with medical care is important for patient compliance (e.g., Becker & Maiman, 1975; Francis, Korsch, & Morris, 1969; Krasnegor, Epstein, Johnson, & Yaffe, 1993; La Greca, 1988). (c) Children's involvement in goal setting and treatment planning may directly facilitate their cooperation with treatment (Melton, 1983; Putnam, Finney, Barkley, & Bonner, 1994). (d) Children's involvement may also promote a sense of control (e.g., Nannis et al., 1982; Weisz & Stipek, 1982), which, in turn, may be related to positive adjustment (e.g., Averill, 1973; Miller, 1980). (e) Finally, involving children in medical decision making demonstrates respect for children's capacities, and may provide opportunities for further development (Melton, 1983).

INFORMED CONSENT ISSUES

One of the most obvious ways to explore children's capacities to participate in decision making is to apply our understanding of child development against the legal standards for informed consent. There are three legal requirements for consent to medical treatment: (a) The decision must be informed, including information about the risks and benefits of alternative treatments; (b) the decision must be voluntary, or free from coercion; and (c) the individual must be "competent" (e.g., Lidz, et al., 1984; Weithorn, 1984). There are actually various standards for competence, including (a) evidence of a choice; (b) a "reasonable" decision; (c) a reasonable decision-making process; and (d) the most stringent standard, "appreciation" of the information provided, with the ability to make

inferences about it (Roth, Meisel, & Lidz, 1977). Competence is rarely challenged in adults' medical decision making; this usually occurs when their decisions vary from prevailing opinion, and most often in choices to refuse treatment.

Parents are provided with both the right and the responsibility to provide consent for their minor children's health care. Historically this was because children were viewed as the property of their parents, with no legal rights of their own. However, when children were given protection by the Constitution, parents still maintained a right for family autonomy. The prevailing spirit underlying parental consent requirements is that parents are the most motivated and capable people to act in their children's best interests, that they often have similar interests to their children, and that they are more competent to make medical decisions than their children.

There are, of course, decision-making situations where parents have different interests than their children, have a conflict of interests, or cannot be certain what is in their children's best interests. Parental discretion is legally challenged when (a) parents refuse life-saving treatment; (b) treatment would not be of direct benefit for the minor (e.g., organ or tissue donation, research); (c) treatment involves rights to privacy of minors, or "sensitive treatments" (e.g., reproductive care, substance abuse, psychotherapy); (d) situations arise that involve significant loss of liberty for the minor; and (e) situations arise that involve "emancipated minors" (e.g., Koocher & DeMaso, 1990; Plotkin, 1981; Weithorn, 1984). In many of these situations, minors are allowed to consent for treatment themselves. Ironically, in many states teenage parents are allowed to provide consent for their children in medical situations where they are not yet allowed autonomy in decisions for themselves.

The "best" medical decision for a given patient is based both on factual, technical information and the interpretation of this information within the context of purely subjective factors and values. As treatment decisions become increasingly subjective, children and adolescents should be afforded the opportunity for greater involvement. In fact, it is in highly ambiguous decision-making situations, which are emotionally burdensome, that parents' capacities may be compromised. The research context, and children's "assent," is relevant here, where a "correct choice" is not clear. Children may not be used as participants in nontherapeutic research without their assent, since even young children are able to understand simple information and ask questions (U.S. Department of Health and Human Services, 1983). Recent trends have seen large collaborative medical research groups requesting children's assent for therapeutic research (clinical trials) as well.

It is clear that neither rights to self-determination, nor the capacities for decision making, appear on the 18th birthday. However, applied research in children's medical decision making is limited. Most studies have involved healthy children who were asked to make decisions about hypothetical medical situations (Lewis, 1980, 1981; Weithorn & Campbell, 1982). The most creative of these studies (Weithorn & Campbell, 1982) compared decisions of four age groups (9, 14, 18, and 21 years) on outcome measures that were specifically

designed to reflect the four standards of competency to consent (evidence of choice, reasonable outcome, rational reasons, and inferential understanding). Results suggested that children in the 9-year-old group were less competent than adults in terms of the higher standards of understanding the information provided and rational reasons; not surprisingly, they used one or two concrete factors in their decisions. However, they did not differ from adults in the standards of evidence of choice or reasonable outcome; that is, they still tended to arrive at logical decisions which were similar to those of adults. In terms of all four standards, the 14-year-old group demonstrated the same level of competency as the two "adult" groups; they showed a similar level of understanding and reasoning, and made similar choices. We should continue this line of research with ill children in order to explore the impact of physical illness and emotional adjustment upon children's medical decision making.

LEVELS OF INVOLVEMENT FOR CHILDREN AND ADOLESCENTS

Figure 1 provides a schema for the process of medical decision making for families. Children's participation in this process occurs on a continuum, which can be understood in the framework of three levels of involvement: (a) information about illness, treatment; preparation for medical procedures; (b) shared decision making with parents/guardians; collaboration with caregivers, goal-setting; and (c) autonomous decision making, including choosing to defer to

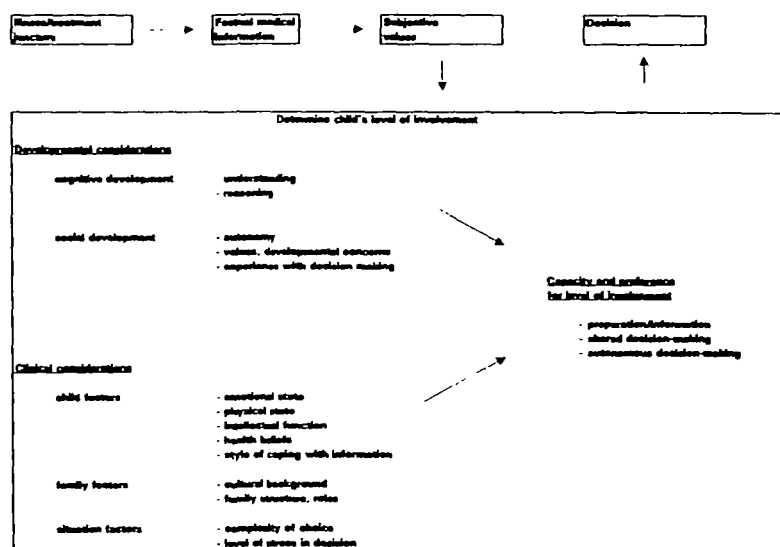


Fig. 1. Schema for children's involvement in the process of medical decision making.

parents (proxy decision-maker) (Weithorn & McCabe, 1988). As Figure 1 illustrates, children's level of involvement should be determined by both their capacity and preference, which are based upon developmental and clinical considerations.

DEVELOPMENTAL ISSUES

We need to consider children's cognitive and social development in relation to the capacities of adults in similar decision-making situations. There is wide variation in individual rates of development, and many adults do not achieve "maturity" in one or more lines of development. Further, maturity is situation-specific; immaturity in one dimension does not presuppose impairment in other areas (Weithorn, 1983, 1984).

Cognitive Development

Children's cognitive development will determine their ability to understand their own illness and treatment situation (see Figure 1). Formal operational thought is a prerequisite for the "appreciation" standard of competence, or full understanding and inference about the technical information provided (Piaget & Inhelder, 1969). Children need to understand illness and treatment concepts, including bodily functioning, in terms of interdependent organ systems; illness causality, including the role of symptoms in signifying disease processes, and the reversibility of illness and mechanisms of treatment (e.g., Bibace & Walsh, 1980, 1981; McCabe, 1983; Perrin & Gerrity, 1981; Perrin, Sayer, & Willett, 1991; Susman, Dom, & Fletcher, 1987).

Children's capacity for abstract reasoning is also critical for their appreciation of information about the risks and benefits of medical treatment. Medical decision making requires the ability to understand new information without experience; reason about hypothetical probabilities (e.g., side effects); weigh more than one factor, and prioritize abstract variables; take a future time perspective; engage in inductive and deductive reasoning; and demonstrate a flexible focus of concentration.

Social Development

Children's social development determines their capacity to achieve the "voluntariness" standard in informed consent (see Figure 1). Specifically, conformity/nonconformity, or the child's relational style with authority, is especially relevant. There appears to be a curvilinear relationship between age and conformity, with a peak of conformity at preadolescence (10–13 years); in midadoles-

cence we can expect most children to be capable of voluntary decision making (Grisso & Vierling, 1978). There are additional concepts in social psychology that describe individual differences in autonomy; for example, beliefs in personal control increase the likelihood of assertiveness, as does freedom from social desirability (Damon, 1983).

An additional area of development to consider in determining children's level of involvement is their identity development, or stability of values, which will influence the stability of their choices (Damon, 1983). The nature of developmental concerns will determine children's focus in decision making regarding medical treatment (e.g., physical restriction, body image). There will also be individual differences in values regarding specific medical treatments, prominent by adolescence, which are related to family experience, religiosity, and cultural values (Blotcky, Cohen, Conatser, & Klopovich, 1985).

Finally, children's preferences and capacity for involvement in medical decision making will be heavily influenced by their prior experience with taking responsibility in decisions. Relevant experience includes practice in different types of decisions in their daily lives (e.g., bedtime), with health behaviors being the most important (Lewis, 1983).

CLINICAL ISSUES

Clinical factors in the child, family, and situation can facilitate or impede the child's use of developmental capacities (Piaget, 1954/1981; Piaget & Inhelder, 1969) and are important independent considerations in determining their level of involvement in medical decision making (see Figure 1).

Child Factors

First, the child's emotional state, particularly level of anxiety and depression, influences his or her information processing and reasoning (Horowitz, 1986). We know from other contexts that there is an optimal level of arousal for understanding, memory, and reasoning; excess anxiety or depression can impede these functions (Kahneman, 1973; Yerkes & Dodson, 1908). Further, depression may include the experience of helplessness, which can affect the child's level of participation, as well as the experience of hopelessness, which is likely to affect actual choices.

The child's physical state influences his/her attention span and concentration, particularly factors such as pain, discomfort, and a variety of medications. The child's level of intellectual functioning, including any information processing difficulties, also determines his/her ability to learn and remember medical information.

Children of the same age vary greatly in their preference regarding level of involvement in medical decision making. In addition to prior experience with responsibility for decisions, described earlier, a number of other factors contribute to children's comfort in this regard. For example, both children and adults vary in terms of their seeking or avoiding information in medical situations; optimal coping appears to occur when there is a match between level of information provided and the patient's preferred style (Peterson, 1989). Children's health beliefs, particularly attributions for responsibility in their own health, may also influence their preferences regarding their level of involvement in decision making (La Greca & Hanna, 1983).

Family Factors

There are family factors that also help to determine children's level of involvement, which apply to any system of caregivers who participate in medical treatment and decision making with children or adolescents (e.g., extended families, foster families). Cultural background and religious affiliation influence both children and parents' values in medical treatment, their style of interaction with health care providers, and their comfort with open communication regarding illness (e.g., Blotcky et al., 1985; Chesler, Paris, & Barbarin, 1986). Family structure and roles influence the family's preferences regarding children's level of involvement in medical decision making (e.g., Chesler et al., 1986; Rolland, 1989).

Situation Factors

Decisions, in and of themselves, vary in their degree of difficulty. For example, a choice between a positive and negative event is relatively easy (approach/avoidance), while a choice between two equally aversive events, common in medical decision making, is the most complex type of decision (avoidance/avoidance) (Dollard & Miller, 1950). Immediate consequences are difficult to weigh against long-term consequences in decision making. For example, immediate discomfort might be given more priority than long-term benefit. Finally, the greater the degree of uncertainty in outcome, the more abstract and difficult the choice will be (e.g., Tversky & Kahneman, 1974). If a treatment choice is too complex, or the consequences of the choice are only negative, then decision making itself can produce significant anxiety.

The level of stress in the decision-making situation is also an important consideration in determining children's level of involvement. Time constraints for communication and decision making can make it more difficult to understand information, and therefore make a choice more difficult. Differences of opinion

between two parents, between parents and grandparents, or between parents and physicians, can make a decision-making situation more burdensome, and therefore more difficult. Attributions of shared responsibility (child–parent–physician) are important in these situations, in order to protect children from excessive anxiety or other negative sequelae resulting from their participation.

CASE ILLUSTRATIONS

The following case examples from pediatric oncology illustrate the complex interplay among developmental and clinical considerations in children's level of involvement, as shown in Figure 1. S. was a 7-year-old girl with an identical twin sister and a single mother. She had a precocious style, which encouraged her mother to treat her like a peer in many aspects of family decision making. S. was diagnosed with a solid tumor, and underwent chemotherapy for over a year. She experienced repeated and prolonged hospitalizations due to a number of complications, and needed to endure both a special diet and much pain. When her disease recurred at 8 years of age, experimental chemotherapy was recommended. Both S. and her mother demonstrated accurate understanding of the disease and poor prognosis. S. expressed a desire to her mother to stop treatment, because further therapy would require continued hospitalization and suffering. Despite her own wish to continue with therapy, S.'s mother shared decision making with her daughter, and conceded to her wishes regarding quality of life.

N. is the oldest of three children and only son in an intact Asian family. He was diagnosed with leukemia at 13 years of age. One year later his disease relapsed, and a bone marrow transplant from the donor registry was recommended. N. fully understood his disease and treatment, and planned for his long hospital stay with the same level of foresight and detail that he gave his school and athletic achievements. However, he did not want to be involved in conferences between his parents and physicians to discuss the medical details of the transplant, nor did he want an active role in decision making. N. reported that this was an unfamiliar role for him in his family and culture, and the nature of the decisions was too difficult. Instead, he was comfortable with routine information about his condition and treatment, while his parents took responsibility for decisions.

R. is a 17-year-old young man who was "living on the streets," having moved back and forth between divorced parents. He had numerous emotional and social problems, including having dropped out of school, involvement with alcohol and drugs, and probable depression. Upon diagnosis with leukemia, his mother consented to treatment against his protest. Despite his good prognosis, R. insisted that he would discontinue treatment once he turned 18 years of age. However, R. engaged in psychotherapy, and his family relationships and quality

of life improved. He got his GED, began working, and enrolled in college. R. continued his full course of chemotherapy independently, emphasizing that he did not need "risk-taking" now that he had a life-threatening illness.

ROLES FOR PSYCHOLOGISTS

There are unique roles for pediatric psychologists in the process of determining children's involvement in medical decision making. First, pediatric psychologists can provide knowledge regarding child and adolescent development, as well as quality of life issues, for their medical colleagues (e.g., Kent, 1994). Similarly, they can assess developmental and clinical issues for the determination of children's level of involvement. Third, pediatric psychologists can make specific recommendations regarding particular children's level of involvement. Finally, pediatric psychologists can facilitate doctor-parent-child communication. Specifically, they can help parents and physicians understand children's concerns; help physicians understand parents' uncertainty and anxiety; and help parents understand physicians' goals.

RECOMMENDATIONS

There are specific recommendations for pediatric psychologists regarding the *process* of determining children's level of involvement in medical decision making. First, psychologists need to be aware of their own values regarding children's and parents' rights and capacities, which will influence the process with particular families (McCabe, Rushton, Glover, Murray, & Leikin, in press). It is important not to assume impaired decision-making competence, for either children or parents, if they make socially undesirable treatment decisions based on a different set of values. Second, assessment of children's capacities and preferences for involvement in medical decision making should occur repeatedly at illness and/or treatment junctures (e.g., diagnosis, surgery), as suggested in Figure 1, which occurs naturally with open communication (King & Cross, 1989).

Third, psychologists must be sensitive to children's language of nonresponsibility. For example, if they express that they "don't want treatment x," it does not necessarily mean they would prefer to go without the treatment. Rather, it may mean that they merely do not *want* to undergo the treatment, similar to the meaning of "I don't want to go to bed," or "I don't want to go to school." These statements are common because children are not usually responsible for unpleasant choices; rather, they do things which are in their best interests which they do not "want" to do through firm encouragement by parents and other adults. Therefore, children's language may require clarification in the decision-making

process, and it may suggest the need for adult encouragement in this context as well.

Fourth, it is necessary for psychologists to be active in soliciting children's preferences. Children are not socialized to be assertive in the world of unfamiliar adults, as in the medical system. We should allow parents to choose their own role in soliciting involvement from children (e.g., they may choose not to be present for children's questions or participation).

Fifth, it is critical for us to work with parents to address their concerns about children's involvement. The process needs to be respectful of both children's rights to self-determination *and* the integrity of families, since family friction can be more harmful than not involving the child. Parents may benefit from clinicians' experience with children in illness situations, and it is helpful to predict the degree of control parents will have about their child's involvement (e.g., "Your child may ask one of the staff a question in the middle of the night that you won't be able to control, and we will not lie to your child.>").

Sixth, children should be allowed to exercise their capacity and preference for involvement in decision making, but should not be required to make decisions that are beyond their capacity. In particular, children should be protected from serving a tie-breaker role in situations of differences of opinion. We should continue to be cautious regarding children's involvement, and their attributions regarding level of responsibility, in those decision situations that are difficult for the adults involved.

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