

# PROFESSIONAL ISSUES

## Treatment Decision-Making When Working With Children and Adolescents

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Keywords: decision-making, paternalism, children and adolescents, informed consent and assent

*The application of ethical principles is different in working with adults than in working with children and adolescents. As children get older, more mature, and have a greater capacity for making decisions, practitioners must focus more on the importance of autonomy and less on being paternalistic. At all ages a primary consideration must be to focus on meeting the basic interests of children and of involving them in the treatment process by getting their assent to treatment after obtaining parental informed consent. The brain areas involved in decision making are not completely developed until around age 25; thus, extra care is required in presenting information during the informed consent and assent processes.*

### Introduction

Ask a medical school class whether physicians should respect the wishes of a competent adult who is a Jehovah's Witness to be allowed to die rather than accept a blood transfusion, and the immediate and unanimous response is yes. (Rothman, 1991, p. 243)

The religious beliefs of Jehovah's Witnesses include a belief that a blood transfusion cannot be given even to keep a person alive. Physicians, as pointed out in the preceding quote, accept the right of a competent adult to refuse a treatment even if the doctor believes the treatment will preserve life (Miller, 2003). The patient's decision is accepted on the basis of respecting the patient's right to autonomy (deciding freely for oneself).

If the patient being treated is not competent, things are dealt with differently. For example, young children are not considered to be competent to make life and death decisions. As such, a parent, guardian, or other proxy is responsible for representing the interests of the child. Should a physician acquiesce to the request of a parent who is a Jehovah's Witness to not provide a blood transfusion to a child if the physician believes that the

blood transfusion will save the child's life? Remember now that the parent is refusing the blood transfusion because it is against his or her religious beliefs.

Has something changed? Of course. Refusing treatment is a right of a competent adult. However, the state (government) long ago decided that children too young to be competent need to be protected from harm by others and from harm by their own actions, when possible. Every state has passed laws concerning actual or suspected physical, emotional, and sexual abuse or neglect of a child as a way of protecting children.

Generally, a parent or guardian is entrusted to protect the basic interests of their children. The basic interests of children include not only their current health and well-being (physical, intellectual, and emotional needs), but also their future health, well-being, and opportunities. It is clear that the wishes of the parent in the preceding example may well be in conflict with the basic interests of the child. The failure on the part of a parent or guardian to act in accordance with a child's basic physical, emotional, or intellectual interests can lead to charges of abuse or neglect. In life and death situations the interests of the state can and do supersede those of the parents when it appears that the basic interests of the child are being, or are likely to be, violated. Letting a child die because the parents refuse to consent to a blood transfusion is one such example. Parental rights are not absolute (Miller, 2003). Fortunately, most biofeedback practitioners are not dealing with life and death treatment decisions, yet the same ethical and legal principles that apply in such situations do apply to their daily practice decisions and actions.

A case of parental rights vs. a child's basic interests has been in the news in Utah for the last year. A child was diagnosed with cancer and the physician recommended chemotherapy and other standard treatments for dealing with cancer. The parents refused the treatment, instead wanting to use nutritional and other alternative approaches. The issue went to court and the judge ruled that the child should receive the recommended medical

treatment. To ensure that this happened, the state took the child away from the parents, and the child became a ward of the state. The parents took their child out of the state and law enforcement personnel apprehended them and they were charged with kidnapping. The kidnapping charges were later dropped and the child was treated. The state legislature is now considering a new law concerning the parameters for when parental rights should be severed. It is important for practitioners to keep up with changes in state laws that may impact what they do in working with clients. Do you know what the laws of your state are concerning children's rights? Do you know what to do when parental interests conflict with the basic interests of the child being treated? Do you know what the child abuse and neglect law entails? You should be familiar with these and any other relevant laws.

### Basic Rights of Children

According to Archard (2003), by 2003 more than 20 countries had adopted the United Nation's convention on the Rights of the Child (Alston, Parker, & Seymour, 1992; United Nations, 1989), which enumerates a variety of rights to be respected (e.g., freedom of thought, expression, conscience and religion, and of association, and the right to a standard of living adequate for physical, mental, spiritual, moral, and social development). Various professional groups have established ethical guidelines for their members on how they should behave toward and with clients. Most of these guidelines are fairly nonspecific in terms of their application to children. Striefel has written several articles concerning client rights and specifically children's rights (Striefel, 1997a, 1997b, 1998a, 1998b, 1998c, 2003a). Because the issues regarding children's rights are complex and because ethical guidelines tend to be nonspecific, state laws and rules and regulations are drafted to fill the void. Case law particularly is increasing in terms of how to resolve specific issues.

Archard (2003) and Striefel (1997a) have both pointed out that for each and every client right there is a correlated and enforceable duty. Parents/guardians and health care professionals have specific duties in the care of children, but often there is disagreement on exactly what these duties are. Because the capacity of children to make rational and reasonable choices varies based on their age, maturity, and level of experience, the duties of parents and professionals also vary based on these variables (Miller, 2003).

More specifically the approach to working with children ethically shifts from being very paternalistic, in which beneficence (do good) takes priority, to autonomy or self-determination as the child matures into being a young adult (whereby the individual can choose more and more in terms of what is desirable to him or her).

### Paternalism

Paternalism occurs when a professional ignores the presumed or expressed wishes of a competent client (in the case of a child the competent person is the parent) in order to prevent a harm or to produce a good for the client, or when these wishes express a negative right (e.g., refusing a needed beneficial treatment or demanding a nonbeneficial treatment; Miller, 2003). Giving a needed, life-saving blood transfusion to a child although the parents are Jehovah's Witnesses and refuse the treatment or refusing to answer a client's questions in order to reduce client anxiety are both examples of paternalistic behavior, but they may well be justified. There are also legal risks in ignoring the wishes of a parent (e.g., being sued for negligence, for causing harm, etc.). It is best not to overrule a parent's desires in regard to their child's treatment without careful consideration of the best interests of the child and the legal and ethical risks that might ensue. It is also best not to agree without due consideration of the relevant issues. Consultation with an attorney and/or colleague trained and competent in such issues is prudent whenever a practitioner is uncertain on how to proceed, when the issues are complex, and when the risks are high.

Simply, paternalism means a practitioner believes he or she knows better than the client/patient or parent what is good for the client (Striefel, 2005a, 2005b). Of course, practitioners who behave paternalistically can in fact make some serious mistakes in treatment, because in most cases no one knows a child's health history, sensitivities, values, religious beliefs, or response to previous treatments as well as the parent. Not considering their position carefully can result in making a treatment decision without having all of the necessary or available information.

It is generally paternalistic to withhold or distort information necessary for making the needed treatment decisions during the informed consent process (paternalistic by omission or distortion). Of course, it is also dishonest to distort or withhold needed information. So the issues can quickly become complicated (e.g., withholding

information that would produce anxiety is seldom justifiable when treating a competent adult, but it might be justifiable to withhold some information that would produce unnecessary anxiety if the client is a young child). Knowing when information will produce vs alleviate anxiety can be difficult to do.

### **Therapeutic Alliance, Informed Consent, and Assent**

Honesty, trust, and complete disclosure are essential to forming a good therapeutic alliance. Generally, child clients benefit the most when a good therapeutic alliance has been developed between the health care practitioner, the child, and the child's parents or guardians (Miller, 2003). Intentional use of deception, especially with children, may be harmful because it can impact development in a negative way (e.g., not trusting any adult or health care professional in the future; Miller, 2003; Striefel, 2003b). It is generally best not to induce false expectations or give false feedback to children about their performance during treatment. It is also important after obtaining parental informed consent to treatment to attempt to get the child's assent (agreement) to treatment by providing the needed information to the child at a level of language that he or she can understand (AAPB, 2003). One would not withhold treatment just because the child does not assent if providing treatment would likely prevent harm or produce a beneficial outcome. However, care must be taken when working with an adolescent to ensure that his or her concerns are considered and addressed. Otherwise, he or she may well sabotage treatment by not cooperating. The current and future well-being of the client is of paramount importance in the treatment decision process.

In working with children it is important to make a distinction between liberty rights (e.g., self-determination) and welfare rights (e.g., health, bodily integrity, privacy; Archard, 2003). Children have a right to receive the goods they need and cannot get on their own and to be protected from harm. United Nation's principle 12.1 states that a child who is capable of forming his or her own views has the right to express those views freely in matters affecting the child, and the child's views should be given merit or weight based on the age and maturity level of the child (Alston, Parker, & Seymour, 1992; United Nations, 1989). Therefore assent to treatment takes on more and more importance as a child gets older and more mature. Responsible practitioners try to protect the basic interests of the child within the context of a good therapeutic alliance with the child and his or her

family. Parents also have responsibilities for protecting the basic rights of their child, and sometimes practitioners need to help parents understand the limitations imposed on the parents' rights by the state (e.g., information on what constitutes neglect).

From an ethical prospective, the responsibility for caring for others is based on (Miller, 2003):

1. The principle of universality: There are universal duties owed to all persons and special duties owed to specific persons (e.g., a practitioner has special duties to clients just as a parent does to his or her child).
2. The fact of vulnerability and dependence in all humans, especially in young children who need others to look out for their basic interests. What are my duties to the child, to his or her parents, and to the family per se?

### **Age and Maturity**

The President's Commission (Miller, 2003) stated that a patient is competent when he or she has "sufficiently stable and developed personal values and goals, an ability to communicate and understand information adequately, and an ability to reason and deliberate sufficiently well about choices" (p. 45). The younger the child, the less capacity he or she has for making important independent decisions, especially those concerning his or her health and well-being. This is often called having diminished capacity, or in simple terms not yet being competent. Generally, children become more and more competent and mature as they become older. For example, until age 9 or 10 years many children cannot give a reason for the decisions that they make, from ages 10 to 14 years children often try to please adults, and after age 15 adolescents are often considered competent to give voluntary informed consent or assent (Miller, 2003). Remember that the parents have the legal responsibility for giving informed consent for their minor child; however, getting the adolescent's informed consent, or at least assent, can go a long way in terms of helping to establish good rapport with the child and helping to motivate him or her to be involved in the treatment process. There is a wide range of variation in the degree of competence of children and adolescents of the same or different ages.

### **Brain Development**

There are some very interesting data concerning the competence and maturity of adolescents that practitioners may wish to consider. Justice Anthony Kennedy, writing

for the U.S. Supreme Court, recently stated that “Juvenile criminals lack maturity and are particularly susceptible to peer pressure” (Biskupic, 2005, p. B1), and therefore it would be cruel and unusual punishment to execute them for a crime. He went on to say that age 18, which is the age used by most states for differentiating between childhood and adulthood, should be the age at which a teen criminal becomes eligible for a death sentence. Are teenagers younger than age 18 too immature to make some other decisions, such as treatment decisions?

Davis (2005) wrote an article pointing out that 16-year-old drivers are too immature to drive today’s cars and to handle roadway risks. One in five of them has an accident while driving. The rate of car accidents is far lower in 17-year-old drivers. Most countries use age 17 or 18 as the legal age for driving. Davis (2005) included functional magnetic resonance imaging data from the National Institute of Mental Health to show that the judgment center of the brain is one of the last parts of the brain to develop fully and that it does not do so until about 25 years of age. Thus the teenage brain has more difficulty in controlling impulses and weighing risks (Davis, 2005). Glaser (2005) agrees that “The teenage brain is really a work in progress” (p. C1) and that the teenage brain lacks some of the circuitry needed for decision making until the early 20s. Such data clearly support the importance of getting informed consent from parents and trying to get assent from the teenager. The more complex the decision and the more risks involved, the more important parental involvement becomes.

Most states have a legal age called the “age of majority,” below which a person is considered to be incompetent unless proven otherwise or unless there is an exception to the law. The age of majority is 16 to 18 years in most states. The exceptions range from adolescents who have been declared by a court to be a mature or emancipated minor to those who are seeking help for problems such as sexually transmitted diseases or drug abuse. Most states allow adolescents to seek help for certain problems without parental consent because failing to do so might well prevent them from getting help. What is the age of majority in your state and what are the exceptions?

Ultimately it may be important for practitioners to use a sliding scale of competency when working with adolescents. In doing so, one would consider the risks and level of complexity involved in the treatment decision (Miller, 2003). The higher the risk and the more complex the information and decision, the higher the level of ability (capacity and maturity) the patient/client

must demonstrate to establish the competence necessary for making the decision. For example, accepting a low-risk life-saving procedure requires less competency than refusing that treatment does. If the decision to refuse treatment involves a higher level of risk than consenting, then the question of competence is automatically raised and a practitioner must have further discussion with the client/patient to ensure that he or she understands the decision they are making and the likely consequences of consenting or not consenting. Some adolescents are not deemed competent to make decisions when risks are high or when information is complex. However, trying to get their assent to treatment is still important.

### Conclusions

It is important to present information during the informed consent and assent processes in simple terms so the client and his or her parents can understand it. Some parents of young children being treated are young themselves (under age 20) and may or may not be mature enough to make complex decisions about the treatment of their child, especially if the information is presented in a complex manner. Assent to treatment by a child or adolescent is on a continuum from paternalism to autonomy. Obtaining true informed consent shows respect for the client and client’s parents’ right to autonomy in decision making.

Do no harm, whenever possible do good, respect the rights of those you serve to choose their own treatment destiny, and help protect and encourage the future good life of clients. Adolescents might well make a “feel good now” decision (e.g., no treatment) without realizing the long-term consequences of the decision (e.g., the impact of not treating severe depression on grades, the opportunity to go to college, getting a job, mood, and the quality of life in general).

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