Minors' Rights in Medical Decision Making

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ABSTRACT

In the past, minors were not considered legally capable of making medical decisions and were viewed as incompetent because of their age. The authority to consent or refuse treatment for a minor remained with a parent or guardian. This parental authority was derived from the constitutional right to privacy regarding family matters, common law rule, and a general presumption that parents or guardians will act in the best interest of their incompetent child. However, over the years, the courts have gradually recognized that children younger than 18 years who show maturity and competence deserve a voice in determining their course of medical treatment. This article will explore the rights and interests of minors, parents, and the state in medical decision making and will address implications for nursing administrators and leaders.

When and how does a minor show maturity and the ability to make a meaningful, well-informed decision regarding treatment? At what age does a child or adolescent have the cognitive ability and the emotional maturity to fully understand the consequences of choosing or refusing medical treatment? And when does the state's interest in protecting life supersede either a minor's or their parents' wishes? These are questions that have created numerous ethical dilemmas and legal conundrums. Nursing administrators who may be in the midst of the conflict must be well aware of the rights and interests of all parties involved. This controversy has been the subject of much debate over the years by state lawmakers and medical professionals. Issues that have been disputed are parental rights and responsibility, minors' rights, and the vulnerability and competence of the minor.[1] This dispute has led

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to vast differences in the ways that states address these issues.

To determine the competence of a minor, courts look at age, experience, degree of maturity, judgment skills, the demeanor of the minor, evidence of separateness from parents, and the particular facts in the case.[2] Many times, the competent minor's wishes regarding medical treatment incidentally coincide with that of the parent and protect the state interests. Matters become much more complicated when they disagree.[3] Nursing administrators, who may be called upon to intervene, may need to seek legal counsel to sort out the variety of interests involved in these circumstances.

Maturity/Competence of Minors

As children grow from infancy to young adulthood, parents and guardians gradually relinquish responsibility and decision making to them, while remaining as a safety net for them. This is true for medical decision making as well. It is clear that young children lack the experience, judgment, and cognitive ability to be self-governing in all matters. States and courts have, with some exceptions, never allowed children younger than 12 years to make medical decisions for themselves and exercise self-determination.[1] For infants and young children, decisions regarding medical treatment have been in the hands of the parent or guardian. Adolescents are caught in a limbo-like state between the dependency of childhood and the autonomy of adulthood. Their cognitive ability and capacity to reason are similar to those of an adult.[4] However, adolescents may lack the moral responsibility, judgment, and experience to understand the outcome of their actions and decisions. They may have more volatile emotions and may look only at short-term consequences. Thus, they remain in an ambiguous state regarding self-determination. The legal determination of ''majority'' has been defined by chronological age (18 years in all but 4 states), marital or parental status, and self-sufficiency, whereas the ethical determination of minors' decision-making capabilities has been much more complex.[4] Determination of a minor's competence for medical decision making should include evidence that the minor has the ability to understand the purpose of treatments, risks, both long- and short-term consequences, benefits, and alternatives to treatments. In addition, evidence must be present to ensure that the minor is able to make an informed decision without coercion.[4]

Informed Consent to Treatment and Participation in Research

At the core of these issues is informed consent, which has been viewed by the courts as a basic right.[1] Informed consent and the right to refuse treatment are protected by the constitutional right to privacy. In some jurisdictions, the right to informed consent arises from the law of battery in that the patient has a right to be free from unconsented touching of their person. Informed consent presumes respect for patient autonomy and the provision of full and accurate information to a patient to enhance decision making. These mandates apply to both the acceptance and the refusal of treatment. Informed consent must include the following:

1. an understandable explanation of the condition, the recommended treatment, the risks and benefits of the proposed treatment, and any alternatives;
2. an assessment of the person's understanding of the information provided;
3. an assessment of the competence of the minor or surrogate to make medical decisions; and
4. assurance that the patient or surrogate has the ability to choose freely between alternatives without coercion.[5]

Minors can and should participate in medical decision making commensurate with their developmental level and ability. However, the concept of informed consent has only limited application in pediatric care. Only competent minors with legal empowerment have the ability to give true informed consent to medical treatment. In other situations, a parent or guardian acting as a surrogate provides informed ''permission'' for medical treatment with the assent of the child whenever possible.[5] Pediatric healthcare providers may face problems with surrogate decision making. Although the law provides parents and guardians discretion in raising their children, their religious and social beliefs may interfere with the best interests of the child. When this occurs, healthcare providers must look to the state and the legal system for answers.[5]

When a minor is deemed incompetent and unable to give informed consent, giving assent allows the adolescent's voice to be heard and promotes the perception of empowerment via participation in medical decision making. The assent process should include the following:

1. a developmentally appropriate explanation of the medical condition and the treatment,
2. an assessment of the minor's understanding of the information and how his or her decision was made, and
3. an expression of the minor's willingness or unwillingness to allow treatment.[5]

Healthcare providers have a legal and ethical responsibility to protect the rights of minors by assuring that they are well informed, confidentiality is protected, and they participate in decision making. In research, however, the inability of minors to give full, informed consent to participation creates true ethical and legal dilemmas, which have been minimally addressed with parental/surrogate consent and child assent. The paucity of medical research involving children and adolescents has been blamed, by some, for the decline

in adolescent health.[6] This lack of research is partly caused by the difficulty in obtaining true informed consent and the legal and ethical concerns regarding adolescent consent. This is true even though adolescents who have been deemed mature for medical decision making may consent to research.[6]

It is essential for minors to participate in medical decision making for treatment and research to the best of their ability, and they must understand that they can refuse without any recrimination.[7] They must also be well aware of what is being asked of them and what will be done to them.

Emancipated Minors and Mature Minors

Although parents normally have the right and the duty to make decisions regarding medical treatment, there are circumstances where the law allows an ''emancipated minor'' to receive treatment without parental consent.[8] The age at which a minor may consent to medical treatment varies from state to state and has been the topic of much debate. The courts have looked at certain circumstances in which a minor may make a decision regarding healthcare. This movement began in 1976 with several US Supreme Court cases in which ''mature minors'' were given permission to seek abortion without parental consent or notification.[4] Later cases also allowed minors access to treatment for substance abuse, sexually transmitted diseases, and contraception.[4] The courts determined that minors would be more likely to seek treatment for sensitive issues if they were not required to notify parents.[4] Minor consent and medical emancipation statutes in every state gave minors the permission to consent to treatment based on their ''status'' or on the ''service'' that they are seeking, including the following:

1. Status
   a. a pregnant minor (for medical care and surgery[8])
   b. a married minor
   c. a minor in the armed services
   d. a minor with a child (for medical and dental care, or surgery for the child)
   e. a minor living apart from parents and financially self-reliant[4]
   f. a victim of sexual assault or abuse may consent to medical care or counseling.[8]
2. Service that is sought
   a. venereal disease treatment or HIV testing
   b. contraception, prenatal care, or abortion
   c. mental health treatment
   d. emergency care
   e. alcohol or drug abuse (after age 12 years).[8]

Because there is no definitive line in the sand that is crossed when a minor becomes competent to make treatment decisions other than those listed, the courts have recognized an exception to the common law rule of parental/guardian consent for medical treatment of a minor called the ''Mature Minor Doctrine.''[2] A minor who is deemed able to understand short- and long-term consequences is considered to be ''mature'' and thus able to provide informed consent/refusal for medical treatment.[9] This ''maturity'' authorizes the minor to make decisions regarding his or her medical treatment. It does not, however, provide carte blanche permission for minors to make decisions regarding medical treatment without parental consent. Circumstances in which the mature minor doctrine permits minors to consent to treatment are the following:

1. The minor is an older adolescent (14 years or older).
2. The minor is capable of giving informed consent.
3. The treatment will benefit the minor.
4. The treatment does not present a great risk to the minor.
5. The treatment is within established medical protocols.[4]

Although not every state has a mature minor doctrine, courts have recognized the need to look with scrutiny at certain case laws involving the ability of mature adolescents to make medical decisions. This scrutiny is essential to balance the rights and interests of all parties involved.[4] Although the mature minor doctrine is not recognized by the US Supreme Court or all states, courts in Illinois, Pennsylvania, and Massachusetts have recognized this doctrine and used it to determine the maturity of a minor in medical decision making.[10] Other states recognize the doctrine but may choose instead to place greater emphasis on parental decision making.[10] However, recognition of the mature minor concept is an emerging trend that promotes the autonomy of the minor and places value on their input.

Minors and Religious Affiliation

Does a minor have the right or ability to refuse medical treatment, lifesaving or otherwise, based on his or her religious beliefs or values? Adolescents are in the process of developing a ''moral self,'' and their ability to form values and religious beliefs varies.[4] In the case of *In re E.G.* (1989)[11], the court's weighty task was to look at the state's rights and responsibilities to protect the sanctity of life of a minor and determine the ability of the minor to exercise her right to refuse treatment. Although E.G. raised the issue based on her 1st Amendment rights to exercise religion, the court decided the case based on the ability of the minor to consent.[11] The court determined that E.G. was mature enough (based on a standard of proof of clear and convincing evidence) to make the decision to refuse treatment based on the common law right to consent.[11] In this landmark case involving E.G., a 17-year-old

minor, the Illinois Supreme Court reversed the trial court decision, which forced E.G. to undergo life-saving blood transfusions. They further determined that E.G. was a ''mature minor'' and capable of appreciating the consequences of foregoing medical treatment of leukemia based on her religious beliefs as a Jehovah's Witness. In short, they determined that she had the right to refuse treatment. The Supreme Court also reversed the finding of a lower court that held that E.G.'s mother had been a neglectful parent in refusing blood transfusions for her daughter. The Supreme Court looked instead at E.G.'s status as an autonomous individual rather than the parent's behavior.[11]

Confidentiality and Disclosure

The medical information of every individual is protected by federal and state constitutions, statutes, regulations, and previous court decisions. However, the ambiguous state of self-determination of adolescents presents challenges to confidentiality safeguards. Some states couple the ability to consent with the ability to make decisions regarding disclosure of medical information, whereas others permit disclosure of information even against the wishes of the minor.[4] These instances include mandatory reporting of sexual or physical abuse or if the minor poses a threat to himself/herself or others.[4] However, in other instances, the wishes or objections of the mature minor should be honored regardless of issues of competence and confidentiality.[3]

The American Medical Association affirms that, with the exception of life-threatening situations, confidential care of adolescents is essential to their overall health, and parental consent or notification should not be a barrier to medical care. The American Academy of Pediatrics has a similar view of mature minor confidentiality issues.[12] There are 3 specific instances where protected health information of a minor may be disclosed to them without parental authorization:

1. mature minors (allows minors who have been deemed to be ''mature'' decision making and control over the disclosure of medical information),
2. emancipated minor (described above), and
3. sensitive situations and issues (birth control, sexually transmitted diseases, and pregnancy) in which minors may not seek medical attention because of reluctance to inform parents or guardians.[12]

Contraception, Abortion, Sexually Transmitted Disease, and Substance Abuse

Several Supreme Court rulings have also determined that minors have a limited right to privacy in regard to family planning matters.[8] The US Supreme Court extended the right to privacy to include the right of minors to seek contraceptive care without parental consent.[6] States realize that minors may not seek contraception if parental notification is required and therefore allow physicians to provide birth control services to minors. Most states also provide prenatal services to minors without parental notification.[6]

Abortion on a patient of any age is a very controversial topic. However, adolescent abortion presents additional ethical and legal dilemmas. States vary in their interpretation of parental consent and notification requirements as to adolescent abortion. The US Supreme Court has allowed mature minors to consent to abortions without parental approval based on constitutional privacy rights.[11] Most states, however, have laws requiring notification and/or permission of a parent except in circumstances such as incest or rape.[1]

All states allow a minor older than 12 years to seek confidential testing or treatment of sexually transmitted disease.[8] Some states allow a physician to notify a parent if it is determined that this information is necessary to the parent, especially in HIV testing.

Treatment of substance abuse is another area where minors 12 years and older may consent.[8] Healthcare providers are encouraged to involve family members if such involvement does not impede the treatment and/or counseling of the minor.[1] However, they may not inform family members without the consent of the minor unless it is necessary to protect the minor or others from harm.[13]

States' Rights—*Parens Patriae*

Although the court in the case of *In re E.G.* determined that mature minors possess common law rights to consent or refuse medical treatment, they cautioned that this right is not absolute and must be considered along with 4 other state interests, including the following:

1. preserving life,
2. protecting the interests of third parties (most significant in the eyes of the court; if E.G. had refused treatment against the wishes of her mother, the court would have looked more closely at her mother's requests),
3. preventing suicide, and
4. maintaining the ethical integrity of the medical profession.[11]

As the court discussed, these 4 elements are part of the states' *parens patriae* interests. *Parens patriae* refers to the ability and protective duty of the state and the courts to enforce restrictions on the rights of minors.[6] Although parents and guardians have the right and duty to make decisions for their minor children, the state's interests in protecting the health and well-being of the minor can supersede those of the parents if the parents refuse life-saving or therapeutic treatment for the minor.[14] Courts will also intervene if a parent or

guardian refuses life-saving treatment for a child because of religious or philosophical beliefs.[8]

States protect and value the sanctity of life. When minors express a desire to withhold medical treatment, which may greatly affect or end their life, the courts usually require clear and convincing evidence (a heavy burden of proof) of their maturity to consider their wishes.[11] That determination is made by looking at the individual circumstances and several factors, including, but not limited to, the minor's age, behavior, education, competence, and knowledge.[2] In addition, the state has the duty and responsibility to protect incompetent minors and has the authority to submit minors to treatment against their wishes. *In re E.G.* (1989),[11] the courts initially forced the minor to undergo blood transfusions against her will. As the minor becomes ''mature,'' or if the nature of the medical treatment is inconsequential, the state's *parens patriae* power begins to dwindle.[11]

Parental Rights and Interests

Although there are gray areas surrounding minors' rights in medical decision making, the courts have been clear about parental decision making for a minor in life-threatening situations; the interests of the child and the state outweigh the religious and/or philosophical rights of the parent. Parents do not have the right to refuse life-saving treatment for their child based on their religious beliefs.[10] If parental religious or philosophical beliefs place a minor in danger, states have the right to intercede.[10] The courts have been very clear about the fact that the parents' religious freedom does not include exposing a minor to harm or death.[11]

Conclusion

There is no simple or easy way to determine the decision-making rights and abilities of a minor. Fortunately, the law has provided certain circumstances in which minors may participate in decision making regarding their medical treatment.[4] However, nursing administrators and leaders need to be aware of the special issues of confidentiality and potential conflicts in treatment choices that can arise when caring for minors. Fortunately, these circumstances are rare and often arise only when parties disagree as to what treatment option is in the best interest of the child. Laws regarding the medical decision-making capabilities of minors are evolving and shifting toward allowing mature minors to make informed decisions.[2] Although the courts have given some guidelines from which to make these difficult decisions, nursing administrators who are placed in the middle of the conflict must always be aware of the interests of the minor, the parents, and the state. This requires careful and meticulous attention to autonomy, privacy, and respect. Consideration must be given to all parties' interests. However, respect for autonomy, self-determination, and the best interests of the minor must *always* be at the forefront. It is imperative that any nurse manager or administrator becoming involved in a situation involving a question of a minors' right to consent or a conflict between family/patient and the healthcare team over treatment decisions for a minor contact the facility's risk manager and attorney early in the process. Doing so can help healthcare providers avoid missteps, which may adversely affect patient outcome and create liability for the providers and the facility.

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