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Rights of Ohio Mothers: Best Practices for the Pediatric Patient with a Life-Threatening Illness

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Rights of Ohio Minors:

Best Practices for the Pediatric Patient with a Life-Threatening Illness

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Abstract

The purpose of this paper is to evaluate and review current best practices with regards to a minor’s refusal of life-sustaining medical treatment. The policies of other developed countries and states within the United States serve as a guide for developing evidence-based guidelines for Ohio healthcare professionals. Four specific cases were identified and then analyzed. The results showed that in three of the four cases, the wishes of the minor were followed. While each case contains its own set of complexities, creating a developmental guideline for healthcare organizations will ensure protection of the minor’s capacity to make autonomous decisions.
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Introduction and Purpose Statement

According to the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) program, the estimated prevalence of childhood (age 0-19 years) cancer among both males and females was 249,000 in 2005. The age-adjusted mortality rate for all leukemia subtypes in individuals aged 0-19 years among all races is 0.8 per 100,000 persons. The age-adjusted mortality rate for cancer of the brain and nervous system for individuals’ age 0-19 years among all races is 0.7 per 100,000 persons (U.S. Cancer Statistics, 2009).

The National Cancer Institute recognizes that cancer treatment for minors is in many ways different from treatment in adults. A fundamental difference is that physicians and healthcare professionals must recognize that children are not small adults. On the other hand, there are specific ethical concerns that must be addressed during the course of therapy. One specific concern is the complex issue surrounding the autonomy of the minor patient, and the question of respecting his/her right to determine medical care.

Evaluating and reviewing current best practices in other developed countries and states within the United States, will serve as a guide for developing a multidisciplinary approach for public health professionals in Ohio; however, only domestic cases will be used for recommendations. This culminating experience will carry out textual analysis of the current literature as it relates to minors’ rights and their rights as a patient with a non-infectious life-threatening illness (e.g. leukemias, brain cancer, and cystic fibrosis). For the purposes of this paper, certain populations are excluded such as minors in a vegetative state, infectious terminal diseases, and minors with mental disorders or mental disabilities.

Weithorn and Campbell (1982) performed a study to compare the developmental differences in competency to make informed treatment decisions. The intent of this study for
this team of researchers was to test the hypothesis that fourteen year olds do not differ in their capacity to provide competent informed consent and refusal for medical and psychological treatment from that of individuals defined by law as adults. They based their hypothesis on theory of developmental psychologist, Jean Piaget. In Piaget’s theory of development, formal operational thinking begins around age eleven in Western cultures and reaches a point of equilibrium by about age fourteen thereafter adolescents "possess the cognitive capability to reason, understand, appreciate, and articulate decisions comparable to young adults" (Inhelder and Piaget, 1958). The objective of Weithorn and Campbell’s study was to test their research hypothesis and develop legal standards of competency.

The sample for their study consisted of 96 healthy subjects, twenty four in each of four age groups (9, 14, 18, and 21). The subjects were exposed to hypothetical situations using identical stimuli to all subjects, thereby enhancing the comparability of the groups. The hypothetical situations ranged in complexity (number of treatment options), content (the type of health problem), and difficulty (the scale of which the reasonable treatment options were apparent versus ambiguous).

Weithorn and Campbell’s findings concluded that minors of fourteen years of age were able to demonstrate a level of competency equivalent to that of adults, according to four standards of competency: (a) evidence of choice (expression of a preference relative to the treatment alternatives); (b) reasonable outcome of choice (the treatment option selected corresponds to the choice a hypothetically reasonable person would choose); (c) rational reasons (the treatment preference was obtained from rational or logical reasoning); (d) understanding (comprehension of the risks, benefits, and alternatives to treatment). There were deficits in the group of nine-year-olds’ understanding and reasoning of the hypothetical dilemmas, but they
expressed clear and sensible treatment preferences when compared to those of the two adult groups (Weithorn and Campbell, 1982). The results of this study lend support to the critics of policies that limit the adolescent’s right of self-determination in treatment situations. In addition, the study results support the position that competency and the ability to make informed consent or treatment refusal decisions are not a result of some phenomenon that occurs on an individual’s eighteenth birthday, but rather a process that develops throughout one’s childhood and adolescence. For this reason, the term “minor” utilized throughout this paper will include only adolescents (age 11-17 years of age).

**Literature Review**

**International Law**

Since 1989, the United Nations Convention on the Rights of the Child (UNCRC) is the most widely ratified international instrument to incorporate the full range of human rights for minors – civil, cultural, economic, political and social rights. The convention was first signed by eighty-one heads of state and as of 2009 has been ratified by 194 countries. Only two states have yet to ratify the UNCRC, the United States and Somalia. The convention clearly states that every child has the right to self-determination, dignity, respect, non-interference, and the right to make informed decisions. There are two basic principles which can be found in the convention. The first basic principle is that “in all actions concerning children, the best interest of the child shall be the primary consideration” (United Nations Convention on the Rights of the Child, 1989). The child’s best interest can be interpreted in different ways as the meaning has changed throughout the development of Western society and varies accordingly in different cultural
settings. For example, thirteen-year-old children may be treated as responsible adults in one society but considered part of a vulnerable population in another.

In addition, the UNCRC requires that the child’s views are to be given due weight in accordance with his or her age and maturity. Article 12 of the UNCRC states that “parties shall assure to the child who is capable of forming his or her own views the right to express those views in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” (United Nations Convention on the Rights of the Child, 1989). Furthermore, the second section of Article 12 states that children have the right to be heard in any judicial and administrative proceedings affecting him or her such as education, health, and environment. Despite the significance of discussing treatment options with minors who are terminally ill, it appears that their views are rarely sought or acknowledged within the healthcare setting (Alderson and Montgomery, 1996; Coyne, 2006; Dixon-Woods et al., 1999; Savage and Callery, 2007). In fact, the literature suggests that starkly contrasting opinions exist among health care professionals on whether or not children should be allowed and encouraged to be involved in matters that affect them. The following subsections will briefly examine specific international cases and highlight how other developed nations handle matters of adolescent autonomy in health care decision making.

**United Kingdom**

The United Kingdom passed the Children Act in 1989 which requires that a child’s requests be incorporated into the medical decisions that affect him or her and permits refusal of medical or psychiatric examinations by children who are deemed competent (The Children Act, 1989). In addition, the European Charter for Children in the Hospital states that children should be protected from unnecessary medical treatment and research investigations, and children and
Parents have a right to be informed and to participate in all decision making pertaining to the child’s health care (Alderson, 1993).

When a child is able to express his or her own wishes, this becomes a factor in treatment decision making. The courts of the United Kingdom have described a category of child as “Gillick competent” if the child is deemed to have sufficient understanding and intelligence about the proposed treatment options (Gillick v. West Norfolk and Wisbech Area Health Authority, 1986). Nevertheless, a court may use its inherent authority to overrule the refusal of consent if it is required for the wellbeing of the child in question. Of notable interest is the fact that section 8 of the Family Law Reform Act of 1969 allows 16-18 year olds in the United Kingdom to give consent to medical treatment as if they were adults (Family Law Reform Act, 1969). Conversely, if the 16-18 year old is capable of making a health care decision but refuses to give his or her consent, this law does not require the courts to accept that refusal in the same manner as if he or she was an adult (Oates, 2000). There have been several cases in the United Kingdom concerning teenage patients who refuse consent to possible life-saving treatment recommended by their doctors in which the courts have been be called upon to resolve the issue(s).

The case of Hannah Jones is a case in point. In November 2008, Hannah Jones was a 13-year-old girl who needed a heart transplant due to the chemotherapy she had undergone for acute myeloid leukemia (AML) since the age of five. As a result of the chemotherapy, her heart had weakened over the years to the extent that at age thirteen only ten percent of her heart was functioning. Feeling fatigued and often left breathless, a heart transplant would prolong Hannah’s life.
Hannah had been informed by medical professionals that receiving a new heart came with complications, may not be successful, and if it was successful, she would need immunosuppressant medication to prevent organ donor rejection. In addition, Hannah had been cautioned that the immunosuppressant treatment might cause her leukemia to relapse, in which case she may need another heart transplant at a later date (De Bruxelles, 2008a).

Hannah decided not to proceed with the heart transplant, after conversing with the health care professionals managing her care plan and with the surgeons and staff that would have performed the heart transplant. Her parents were supportive of Hannah’s decision not to proceed with the treatment, as her mother was a nurse on the intensive care unit and understood the severity of the procedure. Despite a joint decision between Hannah and her parents, the child protection team at the hospital became involved and informed Hannah’s parents that they were submitting an application to the High Court (equivalent to the Supreme Court of the United States) to remove Hannah from the family home on the premise that the parents were preventing her treatment. Being the superior court of the United Kingdom, the High Court could have forced Hannah to have the heart transplant against her will (De Bruxelles, 2008b).

After the child protection team interviewed Hannah, the application to the High Court was not made and Hannah’s wishes not to undergo the heart transplant were honored (De Bruxelles, 2008b). Despite this, it was reported that in July 2009 Hannah changed her mind about the heart transplant and decided to undergo further treatment. Based on reports, Hannah made her decision after becoming aware of the fact that as she gained her physical strength the transplant carried less risk. Also, Hannah’s physicians now believed that she could make a full recovery without the possibility of needing a second transplant (Weaver, 2009). The transplant took place in July of 2009.
Belgium

The 2002 Belgian Law on Patients Rights provides that a minor’s legal rights as a patient are to be exercised by the parents or legal guardians unless the minor is deemed competent. Consequently, a minor may refuse treatment, even without parental consent, if he or she is judged to be adequately competent to make the specific medical decision. In 2004, a Belgian study was conducted to investigate the attitudes of adolescent cancer survivors toward end-of-life decisions (ELDs) and the influence of illness experience on these attitudes. The participants included eighty-three hematology-oncology patients ranging in age from 11 to 18 years of age who had been in treatment for at least two years (Pousset et al., 2009).

Participants were given a questionnaire with closed-ended questions pertaining to hypothetical cases of adolescents in terminal and nonterminal situations who wish to die. In terminal situations, 70% to 90% of the participants found requests for withdrawing or withholding life-sustaining treatments (NTDs) acceptable. In addition, a request for intensified alleviation of pain and symptoms (APS) was found acceptable by 84% of the participants with regards to terminal cases compared to 47% for nonterminal situations. Furthermore, researchers compared the results of this study to that of a similar study done previously with adolescents without a cancer diagnosis. When examples of terminal cases were compared, requests for NTDs and APS were significantly more supported among the cancer survivors than that of those who had not been diagnosed with cancer, 90% versus 69% respectively (Pousset et al., 2009).

This study appears to be the first in pediatric oncology to investigate the attitudes of adolescent cancer survivors in regards to ELDs. The findings of this study suggest that adolescents who have had the experience of a life-threatening illness are more empathetic towards cancer patients and thus more accepting of requests for an ELD that may shorten one’s
life. In addition, this study concluded that adolescent cancer survivors, like other adolescents, wish to be involved in medical decision-making towards the end of life. Furthermore, the results reveal that adolescents value autonomous decision-making without excluding parents or legal guardians from the process. This lends support for guidelines which include the participation of a minor patient and his or her family when physicians are developing a plan of care for a terminal condition.

Sweden

In 2000, Runeson and colleagues conducted a study at two pediatric wards in Sweden to identify everyday situations in medical care in which children and adolescents have been allowed to have a voice or been denied the opportunity to participate in medical decisions affecting them (Runeson, Elander, Hermerén, and Kristensson-Hallström, 2000). This group of researchers interviewed 26 hospitalized children ages 6 to 17 years, and 21 parents. The interviews concerned the children’s experiences with hospitalization, using 100 examples of situations in which the children could have had a say in decisions concerning their care and treatment.

The Scale of Degrees of Self-Determination (Hermeren, 1996) was used to rank the circumstances regarding participation in decision making. The purpose of this instrument is to demonstrate various levels of attending to people’s opinions, wishes, and values. Children were interviewed independently from and in most cases, before their parents. The participants were asked to give a narrative of what had occurred from the moment they were admitted to the hospital up until the point of the interview.

The right to self-determination is grounded in the principle of respect for autonomy (Beauchamp and Childress, 1994). A child with less autonomy is more vulnerable to coercion or unfair persuasion than a person with complete autonomy. The Runeson study concluded that
there are situations in the daily care of children who are hospitalized in which it is possible to assess the child’s degree of self-determination and thus autonomy. Further analysis of the results shows that medical staff allows and should continue to allow minors, to varying degrees, to have a voice in issues concerning their own health (Runeson et al., 2000).

A subsequent study on children’s rights and the principle of respect for autonomy was conducted to identify aspects of participation in the decision making process in medical care. Researchers observed twenty-four minor participants who were admitted to a university hospital in Sweden. Patients with life threatening diagnoses were not included in the study. The total observation time for each child was between one and 22 hours long, depending on the length of hospitalization (Runeson, Hallstrom, Elander, and Hermeren, 2002). There were two registered pediatric nurses who conducted the fieldwork in order to enhance its validity. The field notes were then analyzed by three of the researchers and the situations (n=137) were grouped into five different levels. In less than half of the situations (48 of 137), it was concluded that the minors’ opinions, wishes, and values were totally or partially respected. Moreover, of the 48 minors that were consulted, twelve agreed to what was planned after receiving treatment information and 36 expressed a wish that was respected. Despite this fact, researchers noted that there were young children who were allowed to participate to a high degree and older children and adolescents who were denied the right to participate in the decision-making process (Runeson et al., 2002). These inconsistencies exemplify the need to standardize treatment of care in pediatrics and develop a framework to provide guidelines for pediatric involvement in decisions regarding health care of children.
The American Academy of Pediatrics (AAP) published its first policy statement on informed consent in pediatric practice in 1976. As a universal rule, the AAP stated that treatment of a minor required the consent of the parent or legal guardian. The only exception was in an emergency situation when effective treatment is imperative and any form of impediment would involve serious risk to the life of the minor patient (American Academy of Pediatrics Task Force, 1976). Over the years, the physician-patient relationship has evolved from a paternalistic to an egalitarian and participatory partnership in which physicians and patients collaborate to make health care decisions instead of physicians having sole decision-making authority (Committee on Bioethics, 1995). As a result, the American Academy of Pediatrics issued an official policy statement in 1995 recommending that patients participate in their medical decision making commensurate with their psychological development (Committee on Bioethics, 1995). The American Medical Association (1992) concurs and recognizes that as minors approach and progress through adolescence, an independent relationship with their physicians becomes increasingly imperative.

The term “consent” refers to what a person can choose autonomously for oneself, for example giving permission to the health care provider to receive medical treatment (Kuther, 2003). Although parents have the legal right to give consent and make treatment decisions for their child, physicians have an ethical obligation to the pediatric patient that is independent from parental consent (Bartholome, 1989). When providing care for a minor with a life-threatening illness, physicians must remain respectful of the minor’s wishes in order to provide quality end-of-life care both for the patient and the patient’s family.
In addition, with regard to the health care of older children and adolescents, decision-making should at least involve assent. In its report and recommendations on research involving children, the National Commission for the Protection of Subjects of Biomedical and Behavioral Research (1977) defined assent as the general capability “of understanding the procedures and general purpose of the research and of indicating one’s wishes regarding participation”. The American Academy of Pediatrics has stated that to the greatest extent feasible, the assent process should include: helping the minor patient become aware of his or her illness in a developmentally appropriate fashion, telling the patient what to expect with tests and treatments, assessing the patient’s understanding of the situation and factors influencing his or her response, and soliciting the minor’s willingness (or refusal to accept) the proposed care (Committee on Bioethics, 1998). When health care professionals recognize the importance of assent, they empower children and adolescents to the extent of their capacities (King and Cross, 1989).

There are instances when a minor steadfastly refuses to assent (dissent) which may put health care professionals in an ethical quandary (Leikin, 1983). The lack of ethical guidelines on how to proceed should an adolescent refuse treatment, or when there are disagreements between parents and the minor, suggests the necessity for standards to assist healthcare providers in respecting autonomy and empowering their minor patients (Kuther, 2003; Runeson et al., 2002, Coyne, 2008; Derish and VandenHeuvel, 2000; Hinds et al., 2001). In 1994, the AAP's Committee on Bioethics published Guidelines on Forgoing Life-Sustaining Medical Treatment, which was recently reaffirmed by the Committee in 2009. The AAP clearly defines life-sustaining medical treatment as “all encompassing interventions that may prolong the life of patients” (Committee on Bioethics, 1994). In an obvious showing of respect for a minor's wishes, the Committee wrote: "Generally, parents give permission for the treatment of minors
who cannot do so themselves. However, the American Academy of Pediatrics emphasizes that physicians and parents should give great weight to clearly expressed views of minor patients regarding (life-sustaining medical treatment), regardless of the legal particulars" (Committee on Bioethics, 1994). The AAP follows this passage with a definition of competency and guidelines physicians are to use to determine a person's decision-making capacity.

Decision-making capacity and the legal term "competency" refer to the ability of a person to make decisions at particular times under particular circumstances. They are two distinct terms as one can be legally competent (age of majority) but not have the capacity to make decisions regarding their own healthcare. The AAP has derived a formula for determining decision-making capacity involving three essential elements: (1) the ability to understand and communicate information relevant to a decision; (2) the ability to reason and deliberate concerning the decision; and (3) the ability to apply a set of values to a decision that may involve conflicting elements. Each potential decision maker regarding life-sustaining medical treatment should display these abilities. However, children should have the opportunity to participate in decisions about life-sustaining medical treatment to whatever extent their abilities allow (Committee on Bioethics, 1994).

In cases of treatment refusal, the American Medical Association (1992) urges physicians to consider the seriousness of the medical condition or the risk-benefit ratio. What about situations in which the risk of forgoing treatment is death of the minor? How does a physician balance the autonomy of the minor patient while respecting the wishes of the parents? The following cases illustrate the complexities of navigating treatment refusal by a minor with a life-threatening illness.
Starchild Abraham Cherrix, who prefers to be called Abraham, was diagnosed with Hodgkin’s lymphoma when he was fifteen years old. As defined by the National Cancer Institute, Hodgkin’s lymphoma (also called Hodgkin’s disease) is a cancer of the immune system that is marked by the presence of a type of cell called the Reed-Sternberg cell. Symptoms include the painless enlargement of lymph nodes, spleen, or other immune tissue. Other symptoms include fever, weight loss, fatigue, or night sweats (National Cancer Institute). As part of his medical treatment, Abraham endured three months of chemotherapy which due to the side effects left him extremely fatigued, fragile, and unable to pursue his daily activities (Marques-Lopez, 2006). Following his chemotherapy, Abraham believed his health had returned to a state of optimal well-being. Unfortunately, there was a recurrence in his cancer in February of 2006. Physicians informed Abraham and his family that he would need a second round of chemotherapy to fight the recurring cancer. Refusing to undergo traditional medical therapy, Abraham and his parents sought guidance from a clinic in Mexico. They opted for prayer and an herbal remedy known as the Hoxsey method (Moore, 2006).

According to the American Cancer Society, the Hoxsey herbal treatment is one of the oldest alternative cancer treatments in the United States, dating back to the early 1920s. The Hoxsey method is a regimen that includes the use of two types of herbal mixtures: a "brown tonic" to be taken by mouth and a paste, salve, or yellow powder for external use. The caustic herbal paste is recommended for external cancers and the herbal mixture for "internal" cancers. These are also combined with laxatives, antiseptic douches and washes, vitamin supplements, and dietary changes. Food restrictions which are part of the treatment prohibit patients from consuming pork, vinegar, tomatoes, pickles, carbonated drinks, alcohol, bleached flour, sugar,
and most salt. The U.S. Food and Drug Administration (FDA) banned the sale of the Hoxsey herbal treatment in the United States in 1960 because it was a “worthless and discredited” remedy (American Cancer Society, 1990).

The Accomack County, Virginia Department of Social Services became aware of the situation and accused Abraham’s parents of medical neglect by allowing their son to refuse the recommended medical treatment. In July 2006, both a Juvenile and Domestics Relations District Judge ruled that Abraham’s parents were guilty of medical neglect and ordered Abraham to undergo a second round of chemotherapy. In addition, the judge declared that Abraham’s parents and the Department of Social Services would share joint custody of Abraham (Marques-Lopez, 2006).

Abraham appealed the court’s decision, stating that even though he was a minor, he had made an informed decision to refuse the traditional medical treatment. He went on further to state that he had studied and researched the available treatments for Hodgkin’s lymphoma and had come to the belief that chemotherapy was not the course of therapy that he wanted to pursue (Moore, 2006). On August 16, 2006, the day the appeal hearing was scheduled to commence, the parties agreed to a settlement. Abraham’s wish to forgo a second round of chemotherapy and to treat his cancer with the Hoxsey method was granted however; he agreed to be placed under the care of a board-certified radiation oncologist of his choosing. Instead of undergoing chemotherapy, Abraham was treated with immunotherapy and low-intensity radiation. Abraham’s parents were required to report the status of Abraham’s health to the court and the Accomack County, Virginia Department of Social Services every three months until either the cancer went into remission or Abraham reached the age of majority (Bishop, 2006).
By January 2007, tumors on Abraham’s neck had shrunk, but lymph nodes in his armpits had swollen, so he sought additional low-dose radiation treatment. In June 2007, Abraham received news that the tumors under his arms, in his neck and chest area had disappeared. All except one tumor had been eradicated. He was treated for the remaining tumor in Mississippi. By September 2007 Abraham’s cancer was in complete remission (Barisic, 2007). In June 2008, Abraham celebrated his 18th birthday and the completion of his requirement to report his medical condition to the courts. He reported that he was free of cancer and said, "It's exciting and invigorating to know that I will [now] be able to do what I want with my health" (Simpson, 2007). By December 2009 his cancer had returned, for the fourth time. He is currently undergoing treatment with infrared saunas, herbs and nutritional supplements (Matzke-Fawcett, 2009).

Abraham’s case points to the significance of implementing a framework to guide health care professionals and the courts as to what is best for the adolescent patient. As a result of the Cherrix case, Virginia lawmakers passed a law (“Abraham’s Law”) that states that parents of a child who is at least 14 years of age, with a life threatening condition, could refuse medically recommended treatment on behalf of the child without fear of legal liability for neglect. This legal protection is based on four conditions: (1) the parents and child make the decision in collaboration with one another, (2) the child is to be at an adequate maturity level (determined by the physician) so as to have an informed opinion about the proposed treatment, (3) other treatment options have been taken into consideration, and (4) they believe in good faith that their decision is based upon the child’s best interest (VA Code §63.2-100, 2007). As Mercurio (2007) states in his commentary regarding treatment of adolescents, dealing with a family’s refusal of treatment is a balancing act. Pediatricians are obligated to respect the mature minor’s autonomy,
to respect the family’s right to self-determination, and in some instances to protect the patient from his or her lack of perspective. Remaining cognizant of the rights of mature minors is imperative for health care providers in helping them navigate the ethical and medicolegal complexities of an adolescent’s refusal of life-sustaining medical treatment.

**Minnesota**

All states require parental consent for medical care to minors; however, individual state statutes provide for specific exceptions (Weddle and Kokotailo, 2002). There is tremendous variability among state laws, and most states do not have laws for every situation. In states where laws do exist, knowledge and communication between health care professionals and patients and their families is crucial to prevent possible barriers to quality healthcare. Loertscher and Simmons (2006) set out to assess adolescents’ knowledge of and attitudes towards the laws in their state of Minnesota. The purpose of the assessment was to guide health care professionals in their education of adolescent patients, and also to make recommendations for future legislation on the healthcare of minors.

This team of investigators conducted a survey of 636 ninth through twelfth grade students in the three public high schools in Rochester, Minnesota. The survey was anonymous and contained sixteen questions pertaining to Minnesota consent and confidentiality laws. The survey asked students which of the sixteen statements is or is not a law in the state of Minnesota, in order to assess the respondents’ knowledge. All of the statements were actual laws. In addition, attitudes towards the laws were evaluated by asking whether or not the statement would be a good law (+1), bad law (-1), or neither (0).

The response rate for this study was 93.4% and the results showed that less than 50% of the adolescents who responded to the survey had knowledge of the laws in Minnesota. Despite
the fact that the Health Insurance Portability and Accountability Act (HIPAA) has applied federal minor confidentiality standards to state law, only 15.7% of students were aware that minors can deny a guardian access to their medical records (Loertscher and Simmons, 2006). These results indicate that not only should clinicians be prepared to educate and counsel their adolescent patients, but also that policymakers and public health officials need to understand the lack of adolescent knowledge when they are making decisions regarding health care. To further illustrate this point, a recent case from Minnesota will be examined.

Daniel Hauser is a fourteen year old boy who was diagnosed with Hodgkin’s lymphoma in 2009. The Hauser’s family physician recommended that Daniel be seen by a pediatric oncologist at Children’s Hospital in Minneapolis after suspecting that Daniel had cancer. Daniel’s parents, Colleen and Anthony, complied and the pediatric oncologist they met with recommended that Daniel undergo chemotherapy immediately, possibly followed by radiation. Daniel’s parents are both Roman Catholics, but practice an American Indian religious tradition of the Nemenhah Band, which embraces natural healing remedies and a “do not harm” philosophy (Billups, 2009). The parents refused treatment on behalf of Daniel and informed the doctor that they would seek alternative therapies; however, after strong urging told to comply with the recommended medical treatment, the Hausers consented to treatment. After the first round of treatment, Daniel became extremely ill and was admitted to the hospital for eleven days. Following his hospital stay, Daniel was still so weak from the treatment that he was unable to walk and spent several weeks on the couch. Seeing her son in such a lethargic state prompted Colleen to seek the opinion of a second pediatric oncologist. Based on the test results from the first pediatric oncologist, the second physician did no further testing but recommended that chemotherapy be started immediately. Furthermore, the physician warned the Hausers that if
they did not comply with chemotherapy within seven days, they would be reported to the Child Protective Services. In response to this ultimatum, the family hired a lawyer (Miller, 2009).

Because of the Hausers continued refusal to consent to Daniel’s chemotherapy, the state of Minnesota initiated legal proceedings to take custody away from the Hausers if they did not consent to the proposed chemotherapy. Attorneys representing the Hausers argued that based on parental rights and religious freedoms, alternative treatments should be allowed. Daniel’s cancer doctor, Dr. Brostrom, testified that Daniel had a 90 percent chance of surviving his stage 2B Hodgkin’s lymphoma with chemotherapy and without the treatment he was almost certain Daniel would die. Five different medical doctors, three of whom specialized in pediatric oncology, testified that chemotherapy was the correct course of treatment for Daniel. On the side of the defense, several experts gave their opinion in support of alternatives to chemotherapy. District Court Judge John Rodenberg ruled in favor of the state to enforce the conventional medical plan of care (*State of Minnesota v. In the Matter of the Child of Anthony and Colleen Hauser, 2009*). Of utmost importance to this paper is the fact that Judge Rodenberg also ruled that Daniel lacked the ability to give informed consent to medical procedures as well as the ability to refuse them. Rodenberg based this partially on Daniels age, and also on his limited capacity to understand his illness and the proposed treatment.

Another hearing was scheduled to identify the oncologist who would treat Daniel and also to review the results of Daniel’s court ordered chest X-ray. However, on the day of the hearing Daniel and his mother failed to appear in court. The court then issued a warrant for Colleen’s arrest, ordered that Daniel be apprehended, and ordered that custody be taken away from both parents and for Daniel to be placed in the immediate custody of the county (*State of Minnesota v. In the Matter of the Child- of Anthony and Colleen Hauser, 2009*). With Daniel
and his mother nowhere to be found, an extensive search and tremendous media coverage ensued (Miller, 2009).

After being spotted by authorities in Southern California, Colleen and Daniel Hauser returned to Minnesota voluntarily. Upon their return, a hearing was held and the mother was given a choice—compliance with chemotherapy or losing custody of her son. If Mrs. Hauser chose not to comply with the chemotherapy and Daniel remained in the custody of the state, the chemotherapy would ultimately commence without the parents’ permission (Miller, 2009). On the other hand, the physicians overseeing Daniel’s care vowed to Daniel and his parents to treat the harsh adverse side effects of chemotherapy in conjunction with non-Western medicine (Associated Press, 2009).

The Hauser family agreed to accept the chemotherapy as a direct result of being assured by doctors at Children’s Hospitals that they would be allowed to integrate alternative and natural treatments that the family preferred. The head of pediatric oncology at Children’s and co-founder of the hospital’s Center for Integrative Medicine stated that “…we believe that some of the things called complementary or alternative medicine could be helpful in dealing with the symptoms of cancer and chemotherapy,” (Associated Press, 2009). One is left to wonder whether the entire dispute could have been avoided if the offer of the integrative regimen would have come at the beginning as opposed to the end of the proceedings.

**Washington**

On November 8th, 2007, fourteen year old Dennis Lindberg from Mount Vernon, Washington was diagnosed with acute lymphoblastic leukemia (ALL). Physicians recommended a three year program of chemotherapy followed by many necessary blood transfusions to prevent the fatal side-effects of the chemotherapy. Dennis’s doctors informed him that he had a seventy
percent chance of surviving the next five years with the recommended treatment, and without the treatment he was likely to die. Chemotherapy was initially given but was soon stopped because Dennis developed severe anemia and an enlarged heart (Ostrom, 2007).

As a practicing Jehovah’s Witness, Dennis believed that accepting a blood transfusion violated God’s law, and he refused to undergo the blood transfusions. However, his parents disagreed with their son’s treatment refusal. After officials at Seattle’s Children’s Hospital and Regional Medical Center (where Dennis was hospitalized) reported the situation to the state, the case went to court. Superior Court Judge John Meyer denied the request to force Dennis to undergo the transfusions after hearing testimony from the parents and relatives, social workers, and Dennis’s physician. During the court proceedings, Judge Meyer stated, “I don’t believe Dennis’ decision is the result of any coercion. He is mature and understands the consequences of his decision. I don’t think Dennis is trying to commit suicide. This isn’t something Dennis just came upon, and he believes with the transfusion he would be unclean and unworthy.” Hours after Meyer affirmed his right to reject the treatment, Dennis Lindberg died (Black, 2007).

According to current clinical practice guidelines, if a physician determines that a minor is competent, he or she is entitled to the same degree of autonomy in decision-making as an adult patient (American Medical Association, 1992; Committee on Bioethics, 1995). In cases where the competent minor and parent disagree on treatment, mediation should be encouraged to resolve the conflict. In addition, the American Medical Association (1992) advises that unless the law requires otherwise, competent minors should be allowed to make decisions regarding their own medical care.

Navigating healthcare law creates a complex situation among states. First, the age of majority for the purposes of consenting to medical treatment in most of states is eighteen with
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the exceptions of Alabama and Nebraska (age of majority is 19) and Pennsylvania (age of majority is 21). Minors can also become emancipated which allows them to be recognized as legally competent despite the fact that they are under the age of majority. Depending on the state, minors can become emancipated by pregnancy, marriage, high school graduation, living financially independent from their legal guardian(s), and/or military service (Hockenberry, Freedman, Winkelstein, & Klein, 2003). Second, some states have adopted the “mature minor” doctrine which provides for minors to give consent to medical procedures if it can be shown that they are mature enough to make a decision on their own. It is a relatively new legal concept, and as of 2002 only a few legislatures in states such as Arkansas and Nevada have enacted the doctrine into statute (an act of a legislature that declares, proscribes, or commands something). In several other states, including Pennsylvania, Tennessee, Illinois, Maine and Massachusetts, state high courts have adopted the doctrine as case law (Vukadinovich, 2004).

Ohio

According to Ohio law, there are specific instances when an unemancipated minor can consent to their own medical treatment decisions without parental consent. Without regards to decision-making capacity or age, Ohio minors may consent to treatment for the following: sexually transmitted diseases (STDs), alcohol or drug abuse, and HIV/AIDS (Ohio Revised Codes § 3709.241, 3719.012, 3701.242 respectively). In the instance when a minor in Ohio seeks treatment for mental health, without parental consent, it is clearly stated that he or she must be at least fourteen years of age (Ohio Revised Code § 5122.04).

After reviewing Ohio case law, no documented cases pertaining to an Ohio minor’s refusal of life-sustaining medical treatment were located. This absence argues for the implementation of evidence-based practice guidelines to aid Ohio healthcare providers in
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supplying minors with the highest attainable quality of care to which they are entitled. By comparing cases from other states, this paper serves to highlight key aspects to develop general guidelines.

Methods

This is a comparative study. There were no interviews conducted or human subject data collected for this project. Specific cases in the following countries have been examined: the United Kingdom, Belgium, Sweden, and the United States. Due to study limitations, only prominent cases from the countries mentioned were chosen. In addition, these countries were chosen because they have established extensive case law concerning the treatment of minors. Specific cases within the states of Virginia, Minnesota, and Washington were chosen to identify and analyze possible guidelines for the state of Ohio.

Academic and professional literature (journal articles and books) were obtained by utilizing the electronic databases of MEDLINE, PubMed Central, Academic Search Complete, and LexisNexis. Journal articles were retrieved from these databases by using broad search terms such as: ‘adolescents,’ ‘mature minor,’ ‘terminal illness,’ ‘decision-making,’ ‘assent,’ ‘informed consent,’ ‘children,’ ‘autonomy,’ ‘treatment refusal,’ ‘life-threatening illness,’ and ‘competence’ in various combinations. The review focused on research and literature published in the English-language between the years 1990 and 2009. This particular time frame was chosen because children’s participation in consultations and decision-making became a more prominent issue to research and document in the early 1990’s. Therefore, more literature on the topic is now available. In addition, this time frame ensures that papers are more recent and relevant to today’s issues regarding adolescent health care.
The internet was also used to provide an overview and define key terms such as ‘assent’ and ‘mature minor.’ In addition, the internet was a source for obtaining court transcripts and media publications (newspaper articles and television news reports). Studies and literature that examined adolescents’ decision-making capacities as well as studies related to adolescent competence, informed consent/refusal and assent were all included. Studies that linked any of the aforementioned topics to research participation in adolescents were excluded. In addition, studies on adolescent pregnancy and sexually transmitted diseases (STDs) were excluded as these do not relate to terminal illness.

**Analysis**

After review and assessment of the literature, similarities and distinctions can be discerned from the cases discussed in the preceding sections. Four cases were identified in the legal and ethical literature which pertained to terminally-ill minors and their request to forgo conventional life-sustaining medical treatment. These cases are summarized in Figure 1. In three out of the four cases, the court upheld the minor’s right to refuse life-sustaining medical treatment. Importantly, the parent(s) supported the child’s decision for treatment refusal in three of the four cases (the case in Washington serving as the exception).

Of the three cases that occurred in the United States, all of the minors refused treatment on the basis that it violated their religion. The AAP currently emphasizes that all children and adolescents who need medical care that is likely to prevent substantial suffering or death should receive that treatment. The Academy goes on further to state that it opposes religious doctrines that advocate resistance to medical treatment for sick children (American Academy of Pediatrics,
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1997). One should also recognize that the only U.S. case of the three in which the minor is in remission is the one in which the court mandated standard therapy.

Figure 1. Court Cases in Which an Adolescent with a Life-Threatening Illness Refused or Withdrew Standard Medical Treatment

<table>
<thead>
<tr>
<th>Case and Reference</th>
<th>Patient Age (years)</th>
<th>Diagnosis</th>
<th>Patient's Desired Alternative to Standard Treatment</th>
<th>Court's Decision</th>
<th>Patient Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom (De Bruxelles, 2008a)</td>
<td>13</td>
<td>Acute myeloid leukemia</td>
<td>Forgo heart transplant</td>
<td>Upheld patient's right to choose</td>
<td>Patient reversed her decision and underwent recommended surgery; Recuperating</td>
</tr>
<tr>
<td>Minnesota (Billups, 2009)</td>
<td>14</td>
<td>Hodgkin’s lymphoma</td>
<td>Nemenhah treatment</td>
<td>Mandated standard conventional therapy</td>
<td>Completed standard treatment therapy; currently in remission</td>
</tr>
<tr>
<td>Washington (Ostrom, 2007)</td>
<td>14</td>
<td>Acute lymphocytic leukemia</td>
<td>Forgo therapy</td>
<td>Upheld patient's right to choose</td>
<td>Patient expired on the day of judge’s ruling</td>
</tr>
</tbody>
</table>

Each case is noticeably different and fact dependent. In 1999, The International Society of Pediatric Oncology published suggestive guidelines for assisting terminally-ill minors. In this document, the Society emphasizes that an absolute policy for healthcare providers in the treatment of terminally-ill minors does not exist and is impractical. Instead, they encourage each healthcare organization, each physician, and each family member to find a treatment solution based on their own cultural and spiritual resources and traditions, religion, philosophy, and values (Masera et al., 1999).
Figure 2 illustrates a general decisional framework that may be useful in the healthcare setting while also supplying healthcare professionals with the flexibility needed to simultaneously respect the autonomy of the adolescent patient and provide the highest attainable quality of care. In addition, this model provides a developmental approach commensurate with a minor’s decision-making capacity, as suggested by the American Academy of Pediatrics (Committee on Bioethics, 1995) and the International Society of Pediatric Oncology (Masera et al., 1999).

The first branch of Figure 2 distinguishes the two groups according to the age of the minor (≥ 14 years old or < 14 years old). The rationale for this is two-fold. First and foremost, it is based on the study performed by Weithorn and Campbell (1982) which compared the developmental differences in competency to make informed treatment decisions. In this study, they were able to conclude that minors of fourteen years of age were able to demonstrate a level of competency equivalent to that of adults. This study was further corroborated by Leikin (1983), who observed that many minors attain the cognitive developmental stage associated with the elements of consent by age fourteen. Secondly, based on the literature review of the U.S. cases in this paper, all of the minors were at least fourteen years old. While fourteen represents a chronological guideline, it is not absolute. This is exemplified by the U.K. case of Hannah Jones. Hannah was only thirteen years old, but when evaluated by professionals she showed maturity far beyond her years. "I'm not a normal 13-year-old," Hannah stated. "I'm a deep thinker. I've had to be, with my illness. It's hard at 13, to know I'm going to die, but I also know what's best for me," (Barkham, 2008). Ultimately, physicians should use their best judgement when determining the maturity of the minor.
The third branch of Figure 2 pertains to the decision-making capacity of minors---those that have the capacity to make treatment decisions and those that do not. Based on the review of the cases, the capacity to make treatment decisions was a key aspect in all of the cases. The case of Daniel Hauser clearly represents this fact. The reason the judge rejected Daniel’s refusal of treatment was based primarily on the conclusion that Daniel lacked the capacity to understand his illness and the proposed treatment options. In contrast, the judge in Dennis Lindberg’s case sided with Dennis because he felt that Dennis was mature and understood the consequences of his decision. In cases where the terminally-ill minor is at least fourteen years old and has the capacity to make decisions, Figure 2 proposes that the medical team should ultimately respect the wishes of the minor regardless of parental agreement.

The fourth branch of Figure 2 is applicable to cases where the minor patient and his or her parent(s) lack the ability to come to an agreement on the proposed treatment. In circumstances where the minor has the capacity to make decisions, but yet has a life-threatening illness, a situation of ambiguity is created. In the case of a terminal illness, the figure suggests that if the patient is at least fourteen years of age, physicians should respect the wishes of the minor regardless if the parent(s) and the minor come to an agreement regarding treatment. This comes with the understanding that the minor’s wishes are reasonable, legal, and in the patient’s best interests. In a recent study published in the Journal of Adolescent Health, it was reported that randomly sampled pediatricians were most likely to respect a minor’s refusal when prognosis was poor and when the parent and minor agreed in their decision of forgoing treatment (Talati, Lang, and Ross, 2010). Additionally, when parents and the patient disagreed, pediatricians were more likely to accept treatment refusal by a sixteen year old versus an eleven year old. The guidelines proposed in Figure 2 suggest that hen the minor is at least fourteen
years old, has the capacity to make decisions, and there is disagreement between the patient and the parents, the nature of the treatment side-effects should be considered. If the side effects are mild, the medical team should suggest an integrative treatment regimen such as in the case of Abraham Cherrix which would include both conventional and complementary therapies.

The American Cancer Society defines complementary therapies as those that are used along with conventional medicine to help relieve symptoms, lessen side effects, or provide psychological benefit (Eyre, Lange, and Morris, 2002). In addition, the International Society of Pediatric Oncology (ISOP) published guidelines for using non-conventional therapies in childhood cancer (Jankovic et al., 2004). When a complementary treatment does not pose any harmful effects to the patient, this integrative treatment plan can be useful and valuable to the patient. The ISOP advocates for non-harmful complementary therapies on the basis that they (a) often make the child/adolescent patients and their families feel better, (b) give them a sense of having wider control over the decision-making process, (c) help reduce psychological and physical pain, (d) can improve the quality of life, (e) might offer some relief from the side effects of conventional therapy, and (f) can help boost the immune system.

When the side effects are severe, the minor’s wishes to refuse life-sustaining medical treatment should be respected as suggested by the AMA and AAP (American Medical Association, 1992; Committee on Bioethics, 1995). The National Hospice and Palliative Care Organization (2002) states that there is no absolute obligation to provide life-sustaining treatment and that life-sustaining treatments maybe be withheld or removed when the burden of using them outweighs the benefit to the adolescent. This is exactly what happened in the Washington case of Dennis Lindberg. Dennis requested to forgo medical treatment, and even though both of his parents opposed his decision, the medical team supported Dennis’s wishes.
In cases where the minor is at least fourteen years old, has a life-threatening non-terminal illness but lacks decision making capacity, the patient’s prognosis without treatment should be evaluated. When there is a low chance of survival without treatment an integrative treatment regimen should be suggested. Conversely, when the chance of survival without the proposed treatment is high, the wishes of the parent(s) or legal guardian should be respected.
Unemancipated Minor who Refuses Treatment

≥ 14 years old

Terminal Illness

Decision-making capacity

Parental/Minor agreement

Parental/Minor disagreement

Respect wishes of parent(s) or legal guardian

Respect minor's wishes *

Life-threatening non-terminal Illness

No decision-making capacity

Respect wishes of parent(s) or legal guardian

< 14 years old

Terminal Illness

Life-threatening non-terminal Illness

No decision-making capacity

Respect wishes of parent(s) or legal guardian

Figure 2. Proposed Model for Healthcare Providers to Assist in the Inclusion of Minors in Medical Treatment Decision-Making

*Respect minor’s wishes if the wishes are reasonable, legal, and in the best interest of the patient
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Discussion

Adolescence is marked by a period of significant development---emotional, cognitive, social, and physical. This paper analyzed four specific court cases in which an adolescent refused to undergo life-sustaining medical treatment for his or her life-threatening illness. While other researchers have evaluated minors’ competency and decision-making capacities in the healthcare and research setting, this is the only known report that reviews current best clinical practices for minors with a life-threatening illness in the state of Ohio.

Clinical practice guidelines can be defined as “systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances” (Institute of Medicine, 1992). Upon review of the current scientific and professional literature, it is evident that creating a rigid framework for hospital and legal policymakers with respect to a minor’s refusal of treatment is unrealistic and inadvisable because each case is fact-dependent. Of the four specific court cases studied, three of the four presiding judges ruled in favor of the minor. These results comport with the recommendation by the American Academy of Pediatrics which states “…those who have been judged mature for purposes of medical decisions may refuse unwanted medical intervention” (Committee on Bioethics, 1994). While stringent guidelines may be inappropriate for legislative purposes, Ohio physicians and hospitals should develop and maintain general written policies permitting mature minors to forgo life-sustaining medical treatment. This would allow the health care team the flexibility needed to make decisions on a case-by-case basis.

An overarching limitation to this study is that each case is heavily fact dependent and should therefore be considered on its individual merits. This makes it difficult for Ohio legislators to enact a general “mature minor doctrine” into statute. An additional limitation is
that all data was collected from documents, both public and private. While careful attention was made to check for qualitative validity (accuracy of the findings) with documents such as newspaper articles and television programs, interviewer bias is still a concern. As a result, the concept of data triangulation is utilized. This allows different data sources to be examined and based on the evidence from the sources, a consistent interpretation can be obtained (Patton, 2002).

The underlying public health implications of this culminating experience encompass the “policy development” and “leadership and systems thinking skills” domains (Public Health Foundation, 2010). Given that cases involving a minor’s refusal of medical treatment should be dealt with on a case-by-case basis, developing general guidelines for the state of Ohio seems feasible. These guidelines would be based on cases in other jurisdictions, evidence-based research, and current recommendations from organizations such as the American Academy of Pediatrics.
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References


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Ohio Revised Code § 3701.242 (1994)
Ohio Revised Code § 3709.241 (1971)
Ohio Revised Code § 3719.012 (1982)
Ohio Revised Code § 5122.04 (1989)


VA Code § 63.2-100 (2007)


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Appendix

Public Health Competencies

Analytic/Assessment Skills
- Defines a problem
- Determines appropriate uses and limitations of both quantitative and qualitative data
- Identifies relevant and appropriate data and information sources
- Evaluates the integrity and comparability of data and identifies gaps in data sources
- Applies ethical principles to the collection, maintenance, use, and dissemination of data and information
- Makes relevant inferences from quantitative and qualitative data
- Recognizes how the data illuminates ethical, political, scientific, economic, and overall public health issues

Policy Development/Program Planning Skills
- Collects, summarizes, and interprets information relevant to an issue
- States policy options and writes clear and concise policy statements
- Decides on the appropriate course of action
- Develops a plan to implement policy, including goals, outcome and process objectives, and implementation steps

Communication Skills
- Communicates effectively both in writing and orally, or in other ways
- Solicits input from individuals and organizations
- Uses the media, advanced technologies, and community networks to communicate information

Basic Public Health Sciences Skills
- Identifies and retrieves current relevant scientific evidence
- Identifies the limitations of research and the importance of observation and interrelationships

Leadership and Systems Thinking Skills
- Creates a culture of ethical standards within organizations and communities
- Helps create key values and shared vision and uses these principles to guide action
- Uses the legal and political system to effect change