The Adolescent Right to Refuse Life Saving Medical Treatment

November 3, 2017
It Begins With a Call…

“… a 14 year old male with ALL who is a practicing Jehovah’s Witness. We need to know if he can refuse transfusions just in case…so we know where we stand.”
What Kind of Consult is This?

- Clinical
- Forensic
- Administrative
- Curbside (informal)
What is the Principle of Agency

The principle of Agency:

To whom is the evaluator beholden to, who does the physical evaluation belong to and who is the patient?
First Question to Win a Prize:

Who holds agency?

• Patient
• Patient’s parents
• The judge who will hear the case
• The medical team (the person requesting the consult)
• Risk Management and the hospital’s attorneys
Second Question to Win a Prize:

When asked to do a forensic evaluation, the evaluation should *always* be conducted…?

- According to the principles and practices of the discipline’s governing body, such as American Academy of Pediatrics, American Academy of Child and Adolescent Psychiatry, etc.
- According to researched practice parameters set forth in the literature contained in recognized peer reviewed journals and agreed upon by the discipline’s certifying body. Certification and re-certification examinations may test a diplomate on questions pertaining to the manner and practice of this evaluation
- According to local jurisdictional law
“However, no child who in good faith is under treatment solely by spiritual means through prayer in accordance with tenets and practices of a recognized church or religious denomination shall for that reason alone be considered to be an abused or neglected child. Further, a decision by parents who have legal authority for the child or, in the absence of parents with legal authority for the child, any person with legal authority for the child, who refuses a particular medical treatment for a child with a life-threatening condition shall not be deemed a refusal to provide necessary care if (i) such decision is made jointly by the parents or other person with legal authority and the child; (ii) the child has reached 14 years of age and is sufficiently mature to have an informed opinion on the subject of his medical treatment; (iii) the parents or other person with legal authority and the child have considered alternative treatment options; and (iv) the parents or other person with legal authority and the child believe in good faith that such decision is in the child’s best interest.”
Dr. Yu Dong’s Four Possibilities:

- Parents and child both want treatment
- Parents want treatment but the adolescent does not
- Adolescent wants treatment but the parents do not
- Parent and child both refuse treatment
Since it became quickly clear to the consultant that death is likely if a “sufficiently mature” adolescent is found, the consultant requests a consult.

- **Who did the consultant request a consult from and why?**
Competency to Be Executed Evaluations

- Although now moot due to the Supreme Court’s decision that imposing the death penalty on adolescents is unconstitutional, the American Academy of Child and Adolescent Psychiatry had placed in bylaw that it was “unethical” for a Child and Adolescent to perform an evaluation that led to capital punishment of an adolescent.
- This is based upon research finding that adolescents lack a mature brain.
The Ethicists’ Response

- You bring voice to the child’s request
- Your assessment is not determinative
So Wait a Minute!
Dilemma?

Can an adolescent be sufficiently mature to refuse life saving medical treatment while also being immature and therefore excused from the death penalty?
Fourth Question to Win a Prize:

Which Supreme Court Justice was attributed to saying:

“You can’t have your psychological cake and eat it to.”
The Lecture: Can We Have our Psychological Cake & Eat It Too?

- Mature Minor Doctrine
- Background and research that supports adolescent’s ability to consent or refuse to accept medical treatment
- Research on the maturing adolescent brain
- How you can have your cake and eat it too (adolescents can be both mature and immature depending on context)
- Implications for assessment to refuse life saving medical interventions
Mature Minor Doctrine

“The mature minor doctrine is an American term for the statutory, regulatory, or common law policy accepting that an unemancipated minor patient may possess the maturity to choose or reject a particular health care treatment, sometimes without the knowledge or agreement of parents, and should be permitted to do so.”

Holder, A R. Legal issues in pediatrics and adolescent medicine, 1985, p 133
The Inevitable Conflict:
On One Hand...

Parens patriae: Literally, parent of the nation or parent of the fatherland. “The power of the state to act as guardian for those who are unable to care for themselves, such as children or disabled individuals.”

Wex Legal Dictionary
The Inevitable Conflict: On the Other Hand...

- 1st and 14th amendments of the Constitution
- First Amendment “Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof” and “That Congress shall make no law abridging the freedom of speech…”
- Fourteenth Amendment: “The Due Process Clause protects citizens from unwanted intrusions in their bodily integrity.”

Burk, 2016, Virginia Law Review
The Inevitable Conflict: 1st & 14th Amendments

- Amendments apply to the age of majority
- Supreme Court in *Tinker v. Des Moines Independent Community School District* (1969) (minor wears a black arm band to protest the Vietnam War)
- Supreme Court in *Parham v. J.R.* (1979) (commitment to mental hospital)
- *Smith v. Seibly* (1967) vasectomy when 18 (1961). Mr. Smith had MS and did not wish to burden his wife with more children. Age of majority in Washington State was 21. Sued when 21 as he was a minor and was unable to provide consent when he provided written consent at the age of 18.
Mature Minor Doctrine

• Hybrid right 1st and 14th amendments
• “If minors have a due process right to bodily integrity and the First amendment has been held to protect them, then the freedom of a minor to consent to or refuse medical treatment because of her religious beliefs may be constitutionally demanded as a hybrid right.”
• It is the tension that exists between parens patriae and the recognition that an adolescent can have some rights of an adult (Texas, Jane Doe and the request for an abortion)

Burk, 2016, Virginia Law Review
The Adolescent’s Self-Determination of Health Care

Planned Parenthood of Central Missouri v. Danforth, 1976

- Two physicians brought suit against an abortion law that required a woman under the age of eighteen to receive a blanket approval from her presents or guardians before the procedure could be performed.
- “entitled to the same right of self-determination now explicitly accorded to adult women, provided she is sufficiently mature to understand the procedure and to make an intelligent assessment of her circumstances with the advice of her physician.”
Mature Minor Doctrine Generally Allows For:

- Adolescents (state dependent) have the right to consent to medical procedures such as birth control, pregnancy related care, diagnosis of sexually transmitted diseases, the treatment of substance and alcohol abuse and mental health care.
- These laws were enacted due to public health needs.
- Limit medical professionals’ liability
- “…it is not surprising that most, if not all, statutes permitting minors to consent to general medical treatment were motivated not by a respect for the autonomy of mature adolescents but rather by a desire to limit the liability of health workers who care for minors in circumstances in which their parents are either unavailable or unwilling themselves to consent on their children’s behalf.”

Coleman, et al, The Legal Authority of Mature Minors to Consent to General Medical Treatment, Pediatrics, 2013
• The tension between protection (parens patriae) and the rights of a “mature” adolescent for self determination have been present since the 1960’s

• There remains a narrow range in most states regarding what adolescents can consent to when it comes to medical care and you should not presume one state is like another

• These conflicts exist prior to most if not all of the research to be discussed
The Influence of Science & Medicine on Law

• “Doctors shared a consistent viewpoint with the uneducated layperson that saw no inconsistency with rationalistic explanations of treatments and traditional spiritual values, “if drugs failed, it expressed merely the ultimate power of G-d, but no reason to question the truth of either system of belief” (mid-19th century)

  Charles E. Rosenberg, The Therapeutic Revolution: Medicine, Meaning and Social Change in Nineteenth Century America”, 1977

• “In 1903, a contentious case came before the New York courts. The father of a girl with pneumonia declined to seek medical care, believing that religion would heal his child. Initially the father was found guilty as the law at the time was a parent must “furnish medical attendance by a qualified doctor.” Appellate court reversed and found “ordinary household nursing by the members of the family” was sufficient…and… that the parents were not required to give “such medicines” as the science of the age would say would be proper… New York Court of appeals reversed this looking to the modern advances of medicine and surgery and cited the first medical licensure law of 1880 as grounds for this.

  Burk, 2016 , Virginia Law Review
The Role of Science in the Creation of Laws

• We understand that science contributes to court findings and laws. However, as you have seen most of the research on adolescent decision making came after the previously cited legal cases and the research on adolescent brain development has been present only for the last 15 years.

• Legal determinations dependent on either case law or legislative law
Can an Adolescent Make a Rational Medical Decision? What Science has Influenced Court Decisions & Legislation?

- “...by age 14 years many minors attain the cognitive developmental stage associated with the psychological elements of rational consent...there appear to be no psychological grounds that for the general assumption that minors 15 years of age or older cannot provide competent consent.”

Leikin SL. Minors’ assent or dissent to medical treatment. J. Pedatri 1983

- Based on a Piagetian view of development and the presence of formal operations

- Wisconsin v. Yoder (1972), Justice William O. Douglas in is dissenting view stated that the Court should consider the choice of the child citing Piaget, Kohlberg, etc. and stated, “the moral and intellectual ability of a 14-year-old approaches that of an adult.”
Studies

Raymundo and Goldim, 2008. Moral psychological development related to capacity of adolescents and elderly patients. Journal of Medical Ethics

- Looked at “ego development” in medical patients that were either elderly or adolescent.
- Adolescents and the elderly were similar


- not specific to medical decisions
- 19 item questionnaire showed increasing sophistication of metacognition with from 13 to 15 year olds, n = 43/41

Many “position” papers
Competency of Children & Adolescents Making Informed Treatment Decisions
Lois Weithorn and Susan Campbell, 1982, Child Development

- Studied children, 12 females/12 males, ages 9, 14, 18 and 21
- Four vignettes: epilepsy, depression, diabetes, enuresis
- Children presented with medical dilemmas and had to “put themselves in the place of the character in the story and to consider which of the proposed treatment alternatives they might select in that situation.”
- Measured “competency”:
  - Evidence of choice (voluntariness)
  - Reasonable outcomes; “reasonableness”
  - Rational reasons (had they considered other outcomes)
  - Understanding: 1. Rote recall 2. Inference (appreciate – “what happens if a person misses an injection of insulin?”
  - Responses rated by “20 experts in the respective fields”
• Found that 14-year-olds demonstrated same capacity as older subjects
• Even nine-year-olds demonstrated considerable capacity
Consensus

“...the presumption on the part of physicians and other health professionals should be that all adolescent patients between fourteen and seventeen have the capacity to make health care decisions, including end-of-life decisions, except when individual patient’s demonstrate that they do not have the necessary decision making capacity.”

Virginia Law Cited as an Example

- The statute in Virginia was in response to a case in which a 15 year old youth refused additional chemotherapy for Hodgkins Disease
- This is discussed in terms of a trend in state laws
  - Adolescent Refusal of Lifesaving Treatment: Are we asking the right questions?
    - Dikema, Adolesc Med, 2011
- Against the tide: arguments against respecting a minor’s refusal of efficacious life-saving treatment.
  - Cambr Q Healthc Ethics, 2009
AACAP Position on the Death Penalty for Minors
October 24, 2000

“Our society recognizes that juveniles differ from adults in their decision-making capacities as reflected in laws regarding voting, driving, access to alcoholic beverages, consent to treatment, and contracting. For the following reasons, special consideration for crimes committed prior to age 18 should be made. Adolescents are cognitively and emotionally less mature than adults. They are less able than adults to consider the consequences of their behavior, they are easily swayed by peers, and they may show poor judgement. We also know that teens who have been victims of abuse or have witnessed violence may show increased levels of emotional arousal and a tendency to overreact to perceived threats.”

- “inherent immaturity of adolescents relative to adults mitigated teenagers’ criminal responsibility to the extent that it barred the imposition of capital punishment for crimes committed under the age of 18, regardless of their heinousness”
- “Although neuroscience was not mentioned in the Court’s majority opinion in Roper, it was discussed during oral arguments, and it was central to several of the amicus briefs submitted by scientific and health care organizations urging the Court to abolish the juvenile death penalty and was referenced explicitly by Justice Kennedy in his majority opinion, prohibiting the use of life without parole as a sentence for juveniles convicted of nonhomicides.”

Adolescent Brain Development in a Nutshell
(Five Structural Brain Changes: #1)

• There is a decrease in gray matter in prefrontal regions of the brain reflective of synaptic pruning, the process through which unused connections between neurons are eliminated, creating a more efficient information processing network.

• Occurs during pre and early adolescence
  • Steinberg L, Does Recent Research on Adolescent Brain Development inform the Mature Minor Doctrine. Journal of Medicine and Philosophy, 2013
At the time of puberty there are substantial changes in density and distribution of dopamine receptors in pathways that connect limbic system, where emotions are processed and rewards and punishments are experienced, and the prefrontal cortex.

There is more dopaminergic activity in these pathways during the first part of adolescence than at any other time in development.

- Galvan A. Adolescent development of the reward system. Frontiers in Neuroscience. 2010
- Spear, L. The behavioral neuroscience of adolescence. 2009 Norton
Adolescent Brain Development in a Nutshell
(Five Structural Brain Changes: #3)

Continued

- There is an increase in white matter in the prefrontal cortex that is the result of myelination.
- This continues well into late adolescence and early adulthood.
- This improves brain efficiency.
  - Schmithorst V. Yuan W. White matter development during adolescence as shown by diffusion MRI. Brain and Cognition. 2010
Adolescent Brain Development in a Nutshell
(Five Structural Brain Changes: #4)

Continued

- There is an increase in the efficiency of connections between prefrontal cortex and the limbic system.
- This anatomical change is especially important for emotion regulation, which is facilitated by increased connectivity between regions important in the processing of emotion information and those important to self-control.
Adolescent Brain Development in a Nutshell
(Five Structural Brain Changes: #5)

Continued

• Bonus Prize question – the only fact I want you know when you walk away from this lecture.

• “Final brain maturation tends to occur from ______?”
  • Dominant to non dominant hemisphere
  • Non dominant to dominant hemisphere
  • Front to back
  • Back to front
Adolescent Brain Development in a Nutshell
(Five Structural Brain Changes: #5)
Continued

“Final brain maturation tends to occur from “back to front,” with the prefrontal
cortex – that part of the brain associated with high-level reasoning, executive function,
weighing of consequences, planning, organization, emotional regulation, and rational
decision-making – being among the last to mature.”

• Adolescent Refusal of Lifesaving Treatment: Are we asking the right questions? Dikema,
Adolesc Med, 2011

• Gogtay, N, Thompson P. Mapping grey matter development: implications for typical
Adolescent Brain Development Overall

- Improved self-regulation comes with time (you have a wider array of brain networks available when solving problems)
- There is an increase and then decrease of activation of reward centers (rewards feel stronger when you are an adolescent than either for children or adults. This is particularly true for anticipated rewards)
- Response to stimuli is highly arousing to an adolescent and over time becomes less arousing as more brain areas come into play when stimulated
Can We Have Our Psychological Cake & Eat It Too?

Yes we can…maybe…sort of…theoretically
A Two Brain System

• Parallels what we theorize in autism, borderline personality disorder and aggression
  • The work of Simon Baron Cohen and his paper on “Mindblindness”
  • The work of Marsha Linehan and her conceptualization of Borderline Personality disorder
  • So called hot and cold aggression (the impulsive and emotionally motivated versus that which is calculated and emotionless)
• That there is an emotional mind that is not as well developed in an adolescent compared to the cognitive mind. There is an imbalance
• Adolescents may be vulnerable to highly emotional states, charged states, and the influence of peers due to the salience of social rewards, particularly anticipated rewards. In these states their ability to access their cognitive abilities is less likely when compared to times when they are calm and have the time to be thoughtful
Adolescent Refusal of Lifesaving Treatment: Are We Asking the Right Questions?

“Adolescents and young adults are more likely than adults to engage in a variety of risky behaviors… The increased risky behavior seen among adolescents does not appear to be the result of deficits in logic or reasoning. Adolescents are similar to adults in terms of their ability to perceive risk, evaluate risk, and estimate their vulnerability to it. However, they may weigh risks and benefits differently under certain conditions and react more impulsively, perhaps ignoring the “little voice” warning them of danger. In addition, adolescents may consider some forms of risk in certain contexts to represent a positive thing (offering an immediate reward…), whereas an adult might perceive the same risk as a negative thing (focusing instead on the potential future losses).”

Dikema, Adolesc Med, 2011
So Who Can Consent or Refuse to Consent?

- Generally only adults can refuse treatment
- Exception is the emancipated minor
  - Children who are legally emancipated
  - Condition specific laws (again, for birth control, treatment of STD’s, etc)
- Through legal mechanism
What Happens When an Adult Refuses to Consent to Life-Saving Treatment?

- Allowing an adult to refuse medical treatment is based upon the previously noted 1st and 14th amendments in addition to the ethical principal of autonomy granted in those rights.
- Autonomy: allowing for self determination.
- The patient must demonstrate capacity.
- As long as you can demonstrate capacity, you have the right to refuse medical treatment even if the refusal results in death.
Capacity Evaluations in Adults: Common - A Psychosomatic Medicine Doc’s Bread & Butter

It is worth noting that for adults, capacity assessments to refuse treatment are straightforward. These assessments hinge on three “abilities” and four “standards.” The patient demonstrates the ability to **understand** the proposed treatment choice, can make a treatment choice, and communicate choice. The “standards” refer to fundamental mental capacities needed to be present which are: 1) communication of choice, 2) **understanding of information provided**, 3) **appreciation of options available**, 4) and **rational decision making** (4). Since it is reasonable that the threshold of capacity for an adolescent should not be higher than an adult, adolescents should also meet adult criteria.

Virginia Statute:

However, no child who in good faith is under treatment solely by spiritual means through prayer in accordance with tenets and practices of a recognized church or religious denomination shall for that reason alone be considered to be an abused or neglected child. Further, a decision by parents who have legal authority for the child or, in the absence of parents with legal authority for the child, any person with legal authority for the child, who refuses a particular medical treatment for a child with a life-threatening condition shall not be deemed a refusal to provide necessary care if (i) such decision is made jointly by the parents or other person with legal authority and the child; (ii) the child has reached 14 years of age and is sufficiently mature to have an informed opinion on the subject of his medical treatment; (iii) the parents or other person with legal authority and the child have considered alternative treatment options; and (iv) the parents or other person with legal authority and the child believe in good faith that such decision is in the child’s best interest.
Capacity in a Minor

It is not reassuring that the meaning of “maturity” is vague. To quote, “The main difficulty of the mature minor doctrine lies in assessing maturity; there are no firm guidelines for assessing maturity or decision making capacity” (3). Similarly, the legal standards for the assessment of capacity in an adolescent remain poorly defined. To quote again, “… standards of competence for providing informed consent are poorly specified by law (3)” Guidance provided by Kuther suggests “they generally are thought to encompass the following abilities: to understand the situation, factual issues, and vital information including possible outcomes; effectively consider the consequences of each alternative; compare alternatives based on one’s evaluation of the consequences and an understanding of how each fits within the framework of one’s values and goals; and make a voluntary and uncoerced decision” (3).

(3) Kuther, Tara L, “Medical Decision-Making and Minors: Issues of Consent and Assent”, Adolescence; Summer 2003, 38, 150
The Findings

Applying what was learned about D to his capacity to refuse medical treatment begins with an overview of D’s findings. D is an even-keeled, expressive, and thoughtful youth. His communication and expression did not appear inhibited and there was nothing from the assessment that would suggest that he suffers from a mental disorder either by interview or screening tools. Testing finds him solidly on grade and age level and if anything, the fact that he was raised in a Spanish speaking home would suggest at least for the K-BIT that his IQ is underestimated. Although his school grades have not been exemplary this year, these concerns are offset by his testing results, his interview, and the effect of an illness yet to be diagnosed. I would also suggest that D’s learning style leans to the meticulous. This was most evident in his approach to Trails A and Trails B. He performed poorer on the easier task due to neatness. Trails involves drawing lines and connecting consecutive circles and for B requires the ability to change set which is a frontal lobe or executive function. Rather than do it as quickly as possible, he made sure it was done neatly with each line touching just the outside edge of the circle even though the instruction was to do the test as quickly as possible. D’s future career goal of cabinet or furniture maker may pair nicely with this task style.
The Findings continued

As for D’s views on illness, his understanding was relatively thorough given he is a Freshman in high school. He reported a fair to good understanding of what cancer is, how it makes him ill and what would happen if untreated (death). I would further note that he was also aware of the “alternatives,” which were the non-blood related products that were being used to prevent the need for blood products. His view of death was gloomy and fatalistic and was not particularly religiously shaped. He understood that if he needed blood products and did not receive them he would die. His understanding of his religion’s role reflected the importance to adhere to religious beliefs.
The most difficult topic we discussed was what he would do if his choices differed from his parents’ choices. This was done to determine if coercion was present. It was very difficult for D to imagine his parents would ever agree to something not in his best interest and defying his parents left him disquieted. This is reflected in the discussion of loyalty and the wish to avoid discussion of what might happen until it does happen. It may be that D will not defy his parents or go against his religion and receive blood products. If so, this is based on his love for his parents and his closeness and belonging to his religion.
The Findings continued

Probably the most difficult aspect to assess is the role D’s parents have in his decision making. To defy his parents would be anathema. To say that this is coercion is unfair. On one hand, we have sage words from Donald Winnicott, “there is no such thing as a baby; there is a baby and someone.” In other words, when a loving relationship between child and parent is present, it is difficult to parse where the child’s wishes end and the parent’s wishes begin. Voluntariness is what is really being assessed here. For a younger child, it may be voluntariness is not possible. Quote, “Given their physical, emotional, and financial dependence as well as their relative inexperience with disease, pain, medicine, and making complex decisions, it is uncertain whether younger minors can ever provide truly voluntary and informed consent regarding medical treatment” (3). On the other hand, the Commonwealth has decided potential maturity begins at 14 and adults choose their loyalties and loves. As adults, we do choose to risk our lives for, and at times die, for loyalty and love.

(3) Kuther, Tara L, “Medical Decision-Making and Minors: Issues of Consent and Assent”, Adolescence; Summer 2003, 38, 150
What Do You Think?

• The only research conducted on the medical decision making of children was conducted as an *as if* experiment. Does emotional distance from the decision matter?

• Can an adolescent in an end of life situation remain calm or will emotion guide the decision – will we have a mature or immature mind?

• Can a child truly make a voluntary choice if she loves his family and his culture and community? Does it matter?

• How can voluntariness be demonstrated?
Last Prize Question

• Did I bill for this evaluation?
• What was said about conducting future evaluations like this one – would I agree to do more in the future?
• What will I say if testimony is needed?