Who decides when adolescents and parents don’t agree?

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WHEN YOU TELL
THE TEENAGERS NO

AND THEY SKIP SCHOOL TO
OVERTHROW THE GOVERNMENT ANYWAY
1. Understand the Mature Minor Doctrine and its legal implications
2. Explore the current understanding of neurocognitive development from late childhood to adulthood
3. Review the definition of Capacity and practice application of capacity tool
4. Explore avenues for compromise when adolescents with capacity and their parents do not agree
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1967 Smith v Seibly in Washington State
   - Young man consented to vasectomy due to concern for future with Muscular Dystrophy
   - Sued physician that he did not have capacity to consent
   - Court found for Seibly (physician) as Albert Smith was emancipated, held a job, was married and was caring for a child

Mature Minor Doctrine now used in most states to help determine if minor able to make medical decision on own
   - Court decided in case by case basis
<table>
<thead>
<tr>
<th>State</th>
<th>Minor Consent</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Alabama: Statute</td>
<td>≥14 have consent authority</td>
<td>Maine: Judicial Decision</td>
<td>Mature minor can say if don’t want to be kept alive in PVS</td>
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<tr>
<td>Alaska: Statute</td>
<td>Any minor who are capable can consent when parent is unable or unwilling</td>
<td>Massachusetts: Judicial Decision</td>
<td>Meet informed consent standard only when “best interest” will be served by not notifying parent, also allowed in religious reason</td>
</tr>
<tr>
<td>Arkansas: Statute</td>
<td>Minors who met informed consent standard</td>
<td>Montana: Statue</td>
<td>Who have graduated from high school</td>
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<tr>
<td>Delaware: Statute</td>
<td>Can consent if reasonable effort to reach parent first</td>
<td>Nevada: Statute</td>
<td>Meeting informed consent and would suffer a serious health hazard</td>
</tr>
<tr>
<td>Idaho: Statue</td>
<td>Minors who met informed consent standard</td>
<td>Oregon: Statute</td>
<td>≥15 can consent, may not apply to refuse treatment</td>
</tr>
<tr>
<td>Illinois: Judicial Decision</td>
<td>Met informed consent standard can accept and refuse treatment, court requires “clear and convincing evidence” of maturity, may be ignored if refusal</td>
<td>Pennsylvania: Statue</td>
<td>≥18 and high school graduates have consenting rights</td>
</tr>
<tr>
<td>Kansas: Statute</td>
<td>≥16 consent authority, case by case eval of maturity</td>
<td>S. Carolina: Statute</td>
<td>≥16 can consent to medical treatment- not operations</td>
</tr>
<tr>
<td>Louisiana: Statute</td>
<td>Allow any minor to consent of s/he believes necessary</td>
<td>Tennessee: Judicial Decision</td>
<td>If meet consent standard 14-18 can be mature</td>
</tr>
</tbody>
</table>
Our Patients

**Mateo***
- 14 ½ year old young man
- SMA type 2 with G tube dependence
- S/P intubation in PICU; now Bipap 18 hrs. per day
- Trach/Vent? Re-intubation?

**Fatima***
- 16 year old young woman
- Multiply relapsed ALL s/p BMT now with relapse
- Hx PICU stay for VOD and CVVHD x 2 weeks- continued renal insufficiency
- Phase 2 trial KYTE T cells to second BMT?

* Names have been changed
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“If you think of the teenage brain as a car, today’s adolescents acquire an accelerator a long time before they can steer and brake.” HARRY CAMPBELL

https://www.wsj.com/articles/SB10001424052970203806504577181351486558984
Two brain systems involved in risk-taking and sensation seeking
- Prefrontal cortex: which continues to develop into early adulthood
- Ventral striatum

Decrease in gray matter in early adolescence

Increase in white matter throughout adolescence

Increase in dopamine response

Grootens-Wiegars et al., 2017

• Self-regulation shows critical changes from ages 12-18 and continuing into early adulthood
• Changes in prefrontal cortex allow for increased performance in tasks that require control
• Communication between control and reward systems fully develop in early adulthood
  – Intellectual maturity ≠ social and emotional maturity
• Increase in dopamine response leads to higher value of small reward
• Abstract reasoning imperative:
  – Risks v benefits
  – Hypotheticals
  – Consideration of multiple variables
  – Taking future perspective

Grootens-Wiegers et al., 2017
Social/Emotional Development

- Level of autonomy
- Relationships with authority
- Identity development/Self-awareness
- Values related to family, religiosity, and culture
- Prior experience with decision making
- Emotional context
  - “hot” vs “cold” situations
  - Risky decisions more likely in hot situations
  - Level of stress

Grootens-Wiegers et al., 2017
APA and the Law (Hot vs Cold decision)

- Adolescents not responsible for capital crime (**HOT**)
  - Roper v Simmons (2005)
    - Abolish juvenile death penalty
  - Graham v Florida (2010)
    - Ban sentence of life without parole for juveniles convicted of non-homicides
  - Miller v Alabama, Jackson v Hobbs (2012)
    - Not constitutional of life without parole for sentence for juveniles convicted of homicide

- Adolescents responsible for medical decisions (**COLD**)
  - Hodgson v Minnesota (1990)
    - Minor right to obtain abortion without parental notification
    - Minor right to obtain abortion without parental notification only in emergency
Adolescent Factors and Decision Making

- Emotional/Mental state
  - i.e., anxiety, depression, delirium, etc.
- Physical state
  - i.e., pain, discomfort, medications impacting attention/concentration
- Preference/willingness to engage in decision making process
  - 4 distinct preference profiles for healthcare delivery and self management (van Staa, 2011)
    1. “Conscious and Compliant”
    2. “Backseat Patient”
    3. “Self-confident and Autonomous”
    4. “Worried and Insecure”
Objectives

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Competence/Capacity- I have a headache!

- **Competence**: Ability for individual to participate in legal proceedings or transactions and the mental condition to be responsible for his/her own actions
  - Legal and court defined

- **Capacity**: Ability to consent to a medical intervention
  - Understanding: the information given about disease or procedure
  - Appreciate: how this information is relevant to self
  - Reason: what your decision is based on and its rationale
  - Express: ability to share this information in conversation
• Understood he has a disease that “gets worse over time”
• Understood that doctors said he would likely live longer with trach/vent
• Mateo’s Goals and Values:
  – Always live at home (no facility)
  – Always be able to talk
  – Not live on machine
• Mom’s Goals
  – Be alive as long as possible
  – Be together as a family
• U/A: understand that he may die earlier without Trach/vent, understood his breathing will get worse and he has progressive disease
• R: Does not want to live in facility, does not want to be attached to machine or lose his voice—these things worse than dying
• E: Asked for us to protect him from re-intubation, tracheostomy placement, and cardiac resuscitation

• Mom: Did not agree
• Understood she had relapsed Leukemia again and would die without treatment and her kidneys remained damaged from VOD
• Understood Phase 2 trial goal is not to cure but to test the “medication”
• Fatima Goals and Values:
  – Be alive as long as possible; Try anything that is available
  – Better to die in PICU then be at home
  – Be comfortable
• Parent’s Goals
  – Be comfortable at home with family
  – No research on Fatima’s body
• U/A: Understood that cure was unlikely and had high side effect burden from KYTE T cells, Understood she would die from her disease
• R: would rather get some treatment and try with experiments than stop, every medication/treatment started as research and some work
• E: asked to be allowed to consent for treatment without parent approval

• Parents: Did not agree
Repetition is the mother of learning, the father of action, which makes it the architect of accomplishment.

~Zig Ziglar
Capacity Testing: Vignettes

• Can use patients actual medical issue or vignette

• Our test Vignettes:
  – Phase 1 Trial for New Influenza vaccine
  – Amniocentesis during pregnancy
Domains of Assessment

1. Understanding: repeat back in own words
2. Voluntariness: own decision without external pressure
3. Orientation: oriented to person, place, time
4. Ability to communicate: in a form of communication, speech, signing, writing
5. Sustained attention: follow at least one verbal or written instruction
6. Distorted Reality: experiences hallucinations, delusions, paranoia
7. Appreciation: knows at risk of illness or has an illness
8. Reasoning: use information to either consent or refuse intervention
9. Expression of Choice: verbally or physically indicate choice
10. Decision making Demands: distracted by others or symptoms
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Lessons Learned

- Compromise
- Diplomacy
- Best Interest (yours or patients)
• Met with Mateo and Mother separately
• Discussed his goals and ideas of autonomy
• Mother agreed to support his decisions
  – “As your mother I can not sign this POLST but as your friend I will”

• Agreed for DNR/DNI protect from PICU unless reversible
Fatima explained how she knew she had difficulty in PICU previously but feels great now so anything is worth living.

Parents stated- “Fatima doesn’t remember that she was delirious and cried during most of the PICU stay.” They don’t believe this will work and don’t want their child to suffer.

Together agreed to try KYTE T cells- provision of DNR and Fatima to fill out a 5 wishes.

Goal to be at home with family as much as possible “Live now Not later”

If this works will discuss 2nd BMT.
Adolescent Strengths

Harry Potter has almost become their playbook: The Ones Who Lived fighting an “evil” force that has infiltrated the government...
• “Arguing for the sake of arguing” - experimenting with increased reasoning skills
• “Jumping to conclusions” - may be bravado or anxiety
• “Being self-centered” - increased self confidence
• “Finding fault with adult’s position” - experimenting with new reasoning abilities
• “Being overly dramatic” - may be bravado or anxiety
Unique AYA needs

• Transgender - who is ‘family’ to the pt?
• Substance using - implication on medical care - marijuana use?
• Emancipated - own decision maker
• Parenting - legacy and need for guardianship of children
• Mental illness - therapy and medications
Common responses to complex trauma

- Impulse control issues
- Moodiness
- Attentional problems
- Self perception issues/Feeling damaged
- Relationship and Trust problems/re-victimization by others
- Physical symptoms/chronic pain
- Hopelessness/aimlessness
The way youth respond to trauma often gets them in trouble...

- Gang involvement
- Homelessness
- Substance abuse/use
- High risk sexual activity
- Teen parenthood
- Depression/suicidal ideation/withdrawal
- Truancy/academic problems
- Heightened vigilance to perceived threat
- Low self esteem/helplessness/hopelessness
When can risk-taking become a problem?

- Very early risk taking (e.g. 8 – 9 years)
- Has multiple problem behaviors
- Major problem areas include –
  - Alcohol and drug abuse
  - Pregnancy and STI’s
  - School failure and dropping out
  - Delinquency, crime and violence
- Protective factors include –
  - Stable positive relationship with an adult
  - High realistic academic expectations
  - Positive family environment
  - Emotional intelligence and ability to cope with stress
  - Staying active – keep them moving
Warning Signs

- **Academic Red Flags**
  - Sudden drop in academic achievement
  - Cutting classes, tardiness, or truancy from school

- **Behavioral Red Flags**
  - Social
  - Personal

- **Emotional Red Flags**
  - Sudden mood swings
  - Feeling down, hopeless, worthless
  - Signs of frustration, anger or stress

- **Physical Red Flags**
  - Signs of self harm
  - Aches and Pains
  - Rapid weight loss or weight gain
• Ultimately, the AYA decides - mastery and ownership
• Respecting cultural differences
• Assess family ethics and values
• Discuss options with AYA from the beginning - tailor
• Assess readiness to no cure
• Team approach
• EoL plans - planning legacy


• [https://theconversationproject.org/](https://theconversationproject.org/)