

Not Just Young at Heart

Ethical Issues in Caring for Young Adults

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Overview

- Setting the context
 - Three cases
- Typical approach to adolescent/young adult decision-making
- Adding complexity
 - The developing brain, capacity

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Overview cont'd

- Implications
 - Respect for autonomy
 - Transitioning to adult renal clinics
- Questions & discussion



Case 1

- Josephine - 20-year-old transplant recipient
- Attends clinic erratically after graduating to adult care
- A year after transfer she presents to emergency, weak and vomiting
- Her creatinine is 900 $\mu\text{mol/l}$ and she's 4 months pregnant
- She admits to stopping all her immunosuppressants because 'they're toxic to my baby'
- She loses not only her kidney but also the pregnancy

Case 2

- Ryan - 19 year old transplant recipient
- On honour role at university and a medal winner at the transplant games
- Participates in mentoring program & peer support group for teenagers with renal failure
- A year earlier, when he transitioned to adult care, he was fully responsible for his medical follow-up, knowledgeable about his disease, and communicated with his nurses and physicians

Case 3

- Simon - an 18-year-old college student on hemodialysis is transferred to an adult unit
- He fails to appear for treatment
- Phone calls home go unanswered
- Ten days later, it is learned he died of renal failure

(Cases from Bell, 2007)

Questions

- These cases raise questions about:
 - Understanding and “application” of respect for autonomy
 - The nature of capacity for youth/young adults
 - Attending to potential, particular vulnerabilities of youth with chronic illness

Typical approach

- Often focus primarily on respect for autonomy
 - Further narrowed down to determining whether patient has capacity
 - Ethical and legal basis
 - BC Infants Act

- What tends to be left out?
 - Developing capacity
 - Changing nature of best interests
 - Context of decision-making



Capacity: cognitive assessment

A reasonable understanding of:

- The nature of the health problem
- Treatment and non-treatment options
- The potential burdens and benefits of each option
- The consequences of each option

Capacity cont'd

And an ability to:

- Think about options and reach a conclusion that reflects one's values
- Communicate the decision to others (either verbally or non-verbally)



Adding complexity

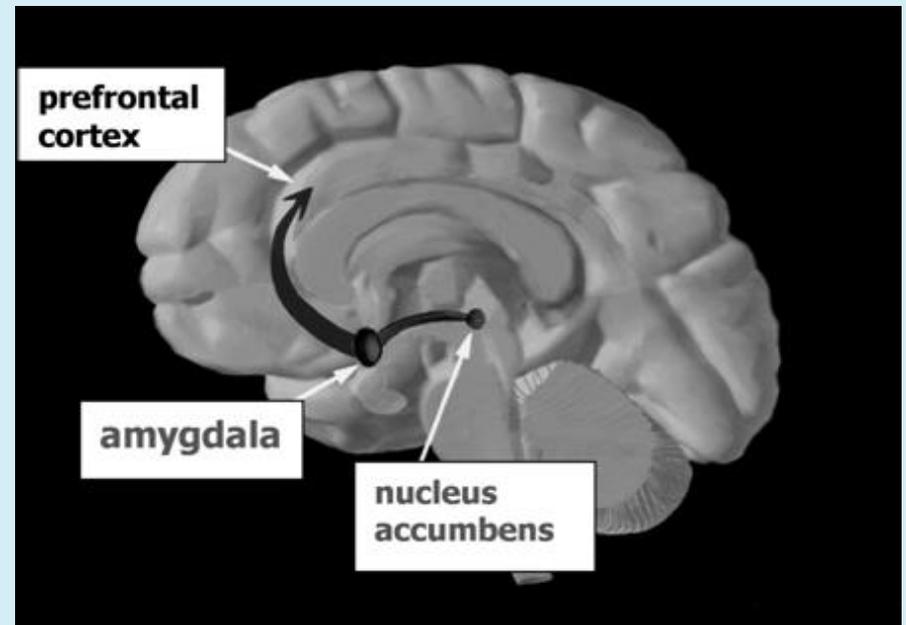
- Cognitive assessments of capacity do not take into account emotional and psychological contributors to decision-making - factors that play a significant role in adolescent/young adult decision making
- Data examining adolescent/young adult decision-making are based on situations that lack the emotional context in which decisions are made

Adding complexity

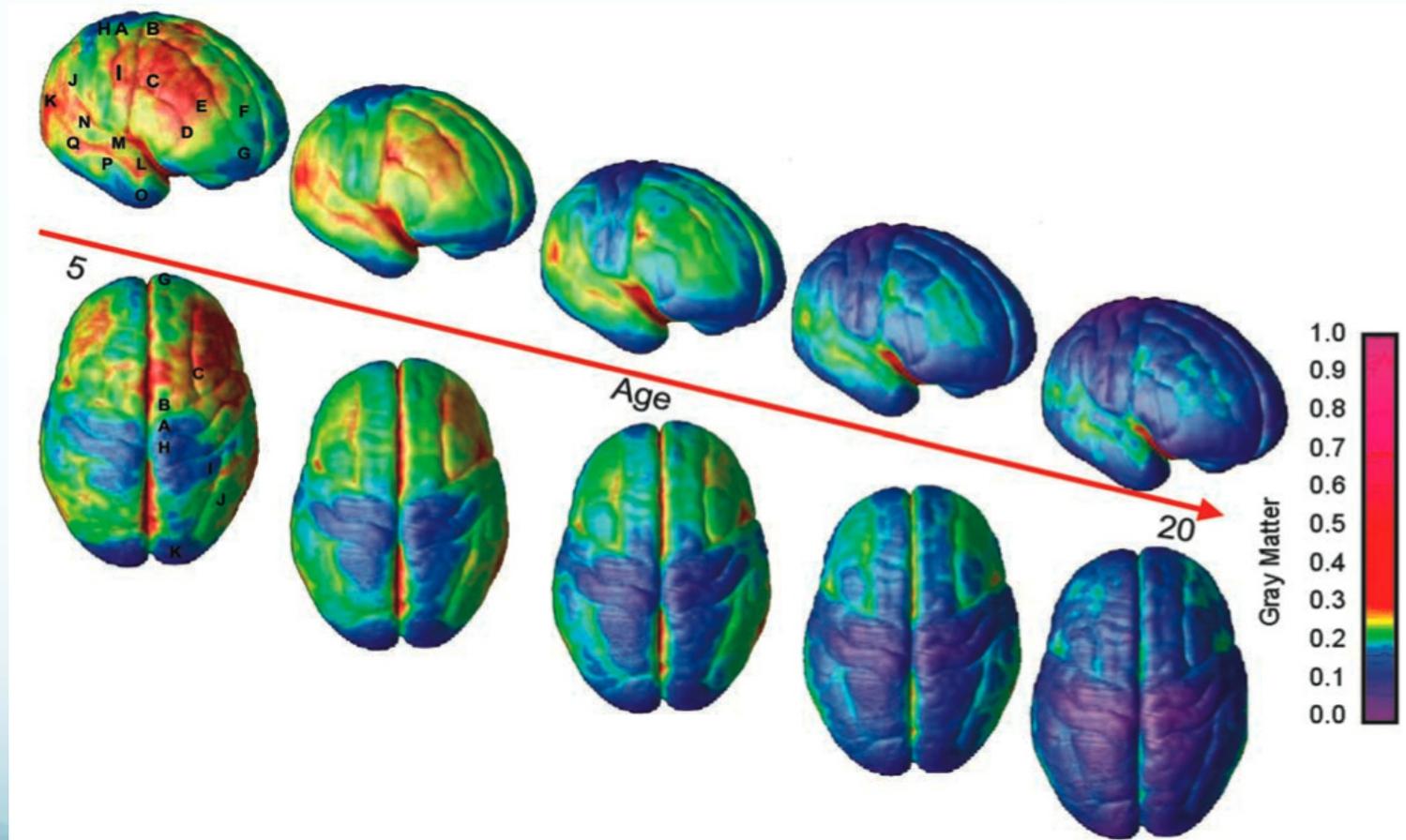
Dilemma: Adolescents/young adults have the cognitive ability to make adult level decisions (have capacity), but may not always use that ability

The Developing Brain

- Not fully matured until mid 20s
- Maturation occurs from back to front - prefrontal cortex is last to mature
- Imbalance between development pre-frontal cortex (later) and subcortical areas, i.e. amygdala (early)



Maturation of the brain



What does the pre-frontal cortex do?

- High-level reasoning and decision-making (such as considering multiple points of view when arriving at a decision)
- Thinking ahead
- Planning
- Comparing risks and rewards
- Estimating and understanding probabilities
- Impulse control

Implications: immature prefrontal cortex

- Emotionally volatile
- Impulsive
- Thrill seeking
- Likely to take risks
- Reactive to stress
- Vulnerable to peer pressure
- Respond to short-term rewards and underestimate long-term consequences of actions

(Dahl 2004; Diekema 2010)

Immature prefrontal cortex

- Psychologist Laurence Steinberg describes the adolescent's brain as an automobile with "a well-developed accelerator but only a partly developed brake" (2004)
- In other words, adolescents/young adults may give greater weight to current rewards and feelings at expense of future implications



Add in chronic illness

- Chronic illness can:
 - Interfere with normal maturation
 - Impair growth and cognitive development
 - Often associated with diminished self image & greater prevalence of behavioural problems such as anxiety, depression, social withdrawal and peer conflict
 - Missed school may lead to reduced educational and employment opportunities

(Bell 2007, 2010)

Transitioning: adult care

- Principle of respect for autonomy has significantly more moral weight for adults
- We do not initiate an assessment of capacity unless the risk-benefit ratio of a decision is extremely unfavorable
- The reason for this is that we consider decisions made by an adult to be '**authentic**' in the sense they are based on a well-established set of values or constitute a stable "**moral self**"

Authenticity -

But what about the young adult?

"There is no doubt that the normal adolescent [young adult] is capable of recognizing selfhood: a teenager has long since developed the ability to say ``I'' with meaning. However, it is not nearly so clear that or when the normal adolescent develops a moral self, so that he or she can say with meaning, ``I value this or that,'' so that a particular decision is authentic, an expression of who I am in a moral sense, of what kind of person I am, of what is really important to me.

Ethically valid consent?

When an adolescent [young adult] has not yet developed a moral self, his choices would not be his in the sense that demands respect as an expression of his autonomy. There might still be grounds for respecting his choices, but this would not be because his choices reflect values that are authentically his own."

Blustein (2009)

Implications for transitioning

- Turning 18 years does not of itself signify achievement of adult functioning
- World Health Organization has defined youth as the period between 15 and 24 years in recognition of the growing capacity for more mature adult functioning/social development beyond the age of legal majority



Reframing autonomy – Respect for persons

- Respect for persons:
 - Focuses on both autonomy and beneficence
 - Includes decision-making ability and recognizes adolescents/young adults have emerging capacity
 - Considers appropriate means for showing respect given emerging capacity

Respect for persons

- Asks us to consider the possibility that even at 20, decision-making may not reflect “mature” decision making
- Recognizes the kinds of situations in which decision making by youth/young adults may be flawed and where they may require additional supports

(Diekema 2010)

How?

- Make time to talk to the adolescent/young adult
 - Ask about feelings & concerns, discuss issues that are relevant to their lifestyle (sexuality, relationships, pregnancy, substance use, recreational activities, vocational and educational choices)
- Provide developmentally appropriate information
- Recognize that transitioning to adult care often occurs when risk taking behaviour peaks

Cont 'd

- Support young adult during times of emotional/physical distress
- Recognize potential role of family in continuing to assist young adult (e.g. medication adherence)
- Recognize youth alone, or from more emotionally chaotic backgrounds, will likely need more [directive?] support

(Bell 2010, 2007; Diekema 2010)

Transitioning: Breaking down the divide

- Adult and pediatric centres need to work together to prepare both patients and health care services for appropriate transfer
- Reciprocal trust and understanding may be enhanced by adult and pediatric trainees spending time in each others' centres
- Incorporation of transition training into both adult and pediatric residency programs

Breaking down the divide

- Formal transition program
- Other suggestions
 - Dedicated practitioner
 - nephrologist/nurse specialists
 - Joint adolescent/young adult clinic staffed with both pediatric and adult nephrologists, nurses



Summary

- Young adults have emerging capacity
 - The ability to make adult level decisions, but may not always use that ability
- Capacity is relative - determined by the complexity and context of the decision
- Transitioning young adults
 - Respect for persons vs. respect for autonomy

Reflections cont'd

- Adult care focuses on the individual patient, but for young adults need to look at the individual in relationship; environment is crucial
 - What supports are in place?



Transfer is an event; transition a process
(Watson 2005)

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Questions or comments?

Thank you!

