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CAPACITY TO CONSENT TO TREATMENT AND YOUTH

A Retrospective Lens

POGO an Integrated Approach to Relapse

2015 Multi-Disciplinary Symposium on Childhood Cancer

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WHEN DO ISSUES OF CAPACITY TO CONSENT TO TREATMENT OF A YOUNG PERSON ARISE?

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Actual clinical examples:

- **A 13 yr old girl with severe GI condition, an ileostomy, severe perianal disease refusing treatment**

- **16 yr old boy with Wilson's disease and neuropsychiatry symptoms (mania and delusional thinking) refusing treatment**

- **12 yr old boy with aplastic anemia Jehovah's witness requesting treatment without blood products**

- **16 yr old boy with chronic liver disease and several failed transplants refusing a transplant**

- **14 yr old girl with anorexia nervosa refusing fluids**

The right to autonomy with respect to health care decisions for the capable **individual**

MEDICAL (Evidence Based Health Care)

+

LEGAL (The Health Care Consent Act, 1996)

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Person must meet two criteria:

↗ **Person is able to <u>understand</u> the information that is relevant to making a decision about the treatment**

↗ **Person is able to <u>appreciate</u> the reasonably foreseeable consequences of a decision or lack of decision**

HCCA, Section 4 (1)

The Health Care Practitioner

proposing the treatment.

HCCA:
The Provision of Information

1. **The nature of the treatment**

2. **The expected benefits of the treatment**

3. **The material risks of the treatment**

4. **The material side effects of the treatment**

5. **Alternative courses of action**

6. **The likely consequences of not having the treatment**

HCCA, Section 11 (3)

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PROVISION OF INFORMATION

- Explain in detail the condition or diagnosis or its uncertainty.

- The proposed treatment or plan of treatment must be specific, and fully explained.

- Discussion of the risks, both common risks and serious infrequent risks, and benefits of accepting or refusing the treatment.

- Discussion of the alternatives to the treatment proposed and the consequences for this person of treatment or no treatment.

- Answer patient's questions.

- Document everything carefully.

THE ABILITY TO UNDERSTAND

- *"Person is <u>able to understand</u> the information that is relevant to making a decision about treatment"*

- Is the person is able to <u>comprehend</u> the information they have been given, namely that they are affected by a condition for which treatment is recommended

- Is the person is able to <u>grasp</u> the information they have been given about how the proposed treatment could affect their quality of life

→ failure to understand ≠ inability to understand

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1. Do you know why we are proposing treatment for you?

2. Do you understand the treatment we are proposing? Please tell me what you know about it?

3. What do you understand to be the expected benefits of the treatment?

4. Are you aware of any risks of the treatment?

5. Are you aware of any other types of treatment?

6. Can you tell me about the problem you are having with your health and how it is affecting you?

THE ABILITY TO APPRECIATE

- *"Person is <u>able to appreciate</u> the reasonably foreseeable consequences of a decision or lack of decision"*

- Whether person is able to <u>recognize</u> any symptoms or impairments which are the intended targets of the proposed treatment (ie do they appreciate how information applies to them)

- Whether person is able to <u>acknowledge</u> the therapeutic intent of the proposed treatment, as it applies to their situation

- Whether the person is able to <u>apply</u> information about potential risks/benefits of taking or abstaining from treatment, to their quality of life

→ inability to appreciate may be evident in words or actions

ABILITY TO APPRECIATE REASONABLY FORESEEABLE CONSEQUENCES OF A TREATMENT DECISION

1. Are you having any problems right now for which you might benefit from treatment?

2. How do you think the proposed treatment will affect you?

3. What will happen if you do not take the treatment?

4. Can you tell me how your illness or symptoms affect you?

5. Can tell me how your decisions will affect your future?

THE ABILITY TO APPRECIATE

- **Features of a <u>mental condition</u> which may preclude appreciation:**

  - **psychosis, delusions which provide an alternative explanation to the experiences which have been assessed as representing mental disorder (e.g. "I am not ill, I am God")**

  - **mood state which distorts perception of the experiences arising from mental disorder, such that the person cannot acknowledge any indication for treatment (e.g. "my guts are rotting, an antidepressant can't change that")**

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Information other than answers to questions is useful in assessing capacity:

Information about behaviour and relationships with parents may be gathered over time. Behaviour may be indicative of a young person's ability to appreciate the reasonably foreseeable consequences of a treatment decision. Relationships with parents may affect decision-making ability.

It is important to consider whether a young person is able to express a consistent choice about the treatment in question.

*All information considered in the assessment of capacity should be carefully and completely recorded.

- What is the nature of information to be given?
- What is autonomy in health care decision making for a youth with a serious illness?
- What does refusal of treatment mean?
- What does acceptance of treatment mean?
- What about the relationships if there is disagreement about treatment between the youth and the parent or the health care team?
- What about the biological maturation of the brain?

Thank You