

Informed Consent for Patients with Special Needs

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Introduction

Informed consent is a conversation between the provider and a patient. The proposed treatment should be discussed including a specific diagnosis, intended procedure, risks and benefits and treatment alternatives, including no treatment. Obtaining consent is the legal and ethical obligation of the provider. This report reviews requirements for informed consent and case scenarios for patients with special needs where obtaining informed consent proves challenging.

Consent Scenarios

- 1. “Ashley” – Adult female with mild intellectual disability** Ashley is her own guardian who presents with her mother for a root canal procedure. She uses an alphabet communication board. Ashley requested a papoose board for her comfort (not due to movements or cooperative ability). After initiation of treatment, Ashley started moving her head away. Treatment was paused and Ashley’s mother stated problem was anxiety due to noise of handpiece. Patient nodded in agreement that she would like to continue treatment. Mom covered Ashley’s ears which helped patient momentarily during treatment. She again moved her head and the tooth was temporized and treatment discontinued. Treatment options further discussed.
- 2. “Brian” – Adult male with moderate intellectual disability:** Brian is his own guardian who presents with caregiver for exam and “cleaning.” He had a history of using a papoose board due to movement/not cooperating. He had signed a consent form for this. Attempted to examine without immobilization and the patient ran out of the operatory. Caregiver insisted patient could make his own decisions AND that he could sign form for immobilization. It did not appear Brian understood treatment options. Treatment discontinued and discussed surrogate decision making.
- 3. “Charlie” – Adult male with mild intellectual disability** Charlie is his own guardian who presents with caregiver for a root canal procedure. He requested a papoose board for his comfort (not due to movements or cooperative ability). During treatment a retained root was discovered and extraction recommended. It did not appear he understood risks for extraction although he agreed to procedure. Asked if he had someone that helped him make treatment decisions, he indicated his father and gave permission to contact father. Father and patient agreed to treatment and procedure continued.
- 4. “Donald” – Adult male with severe intellectual disability** Donald presented with a caregiver for an emergency appointment due to facial swelling. Donald has a guardian who consented to extraction and limited immobilization (excluding papoose). It was unclear if treatment could be successfully completed without a papoose due to previous history of body movement, sitting up and arm movement. Treatment continued and was successful without papoose.

Informed Consent Basics

Evaluating Capacity

Ability to Give Consent

- Understand the medical information
- Understand the progression of disease
- Understand the recommended treatment
- Understand the consequences of treatment or refusal of treatment
- Understand alternative treatment options

Evaluating Capacity

- Ability to make consistent choice
- Ability to understand information provided
- Ability to comprehend the nature of treatment and related consequences
- Ability to manipulate information rationally

Different procedures require different levels of capacity

Informed Refusal

- Patient’s refusal of treatment requires a discussion about risks of delayed treatment and no treatment
- Unusual beliefs, refusal of treatment or specific material does not necessarily mean that the patient lacks capacity
- Document refusal, discussion of risks and obtain patient’s signature
- Document if a patient leave without understanding risks or refuse an explanation

Surrogate Decision Making

Patient as Decision Maker

- Age of majority (18 year old in most US states)
- Competency: Legal definition of ability to consent, determined by legal system
- Capacity: Medical definition of ability to consent, can vary depending on complexity of procedure

Surrogate Decision Maker:

- Legal Guardian: Person declared by court system to make legal decisions on behalf of patient
 - General guardian
 - Limited guardian
 - Guardian of estate
- Medical Power of Attorney: Person chosen by patient when patient is competent to make medical decisions on patient’s behalf (enforced when patient is incompetent)
- Hierarchy of consent: Many states have a designated order of hierarchy which include guardian, Medical Power of Attorney, next of kin

How to Obtain:

- In person: Ideal, although guardians not always present for procedures
- Over phone: May be acceptable alternative
 - Provider unable to interpret body language, facial expressions
 - Guardian unable to visualize radiographs and dental condition (email of images a possibility)

The Ethical Dilemma

Informed Consent Conversation

- Explanation of treatment
 - Lay terms
 - Language the patient can understand
- Reasonable foreseeable risks
- Anticipated outcome
- Benefits
- Costs
- Alternative treatment options including the option of no treatment
- Opportunity to ask questions
- Time to consult others (friends, family)
- Other providers that will be involved in treatment, such as anesthesiologists
 - This is especially important for teaching institutions in which students, residents participate in treatment

Treatment without Consent

- Provider can be legally charge with battery or assault
 - Treatment meets standard of care or results in complications
- Procedures that go beyond the patient’s expectation or the expectation of the average reasonable patient
- It is the provider’s legal burden to prove the treatment was permitted by the patient or guardian of the patient

Withdrawal of Consent

- Consent can be withdrawn at any time
- Is it safe point to stop procedure or temporization
- Stabilize treatment and inform of risks and consequences of delay, no treatment

Consequence of Failure to Treat

- Undiagnosed disease
- Progression of disease
- Loss of teeth
- Swelling and acute infection
- Death

Who is responsible?

Conclusions

It is the provider’s legal and ethical obligation to obtain informed consent. Although there are many regulations in place to aid in obtaining and documenting consent the provider must use discretion in situations in which the law and ethics are unclear. A competent person may lack capacity to consent for some procedures and not others. This ethical dilemma leaves the provider to interpret the patient’s ability to participate in the decision-making process and the patient’s understanding of the treatment, risks and benefits. When patients seems to lack capacity, the provider should make recommendations for evaluation by physician, psychiatrist and guardianship proceedings.

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