

PedsCases Podcast Scripts

This is a text version of a podcast from PedsCases.com on “**Medical Decision Making**.” These podcasts are designed to give medical students an overview of key topics in pediatrics. The audio versions are accessible on iTunes or at www.pedscases.com/podcasts.

Medical Decision Making

Developed by Dr. Allyson Shorkey and Dr. Kevin Coughlin for PedsCases.com.
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Introduction:

Hello everyone, my name is Allyson Shorkey and I am a first year pediatrics resident from the Hospital for Sick Children and the University of Toronto. This podcast was made in conjunction with PedsCases and the Canadian Pediatrics Society. It was developed with Dr. Kevin Coughlin, a Neonatologist and Bioethicist, from Children’s Hospital at London Health Sciences and the University of Western Ontario. Dr. Coughlin is the lead author of the CPS statement we will be reviewing today. For additional information and to view the complete CPS statement, please visit www.cps.ca. The script for this podcast can be viewed at www.pedscases.com.

The goal of this podcast is to review the recently published CPS position statement on medical decision making in pediatrics. Using cases, we will discuss the following:

1. The complexities of decision making in pediatrics, including the wide variation in physical and psychological development of children as they progress from infancy to adolescence.
2. The role of health care providers in medical decision making in pediatrics.
3. The concepts of informed consent, capacity, assent and dissent and how these concepts are applicable to pediatric patients and their families.
4. Dealing with situations of conflict in regards to medical decision making.

Let’s begin with three different cases.

In the first case, you are working in a community pediatrician’s office. You are seeing a 5-year-old male who is here for his regular vaccinations. He tells you that he does not want his vaccine because it hurt a lot last time! He is kicking and screaming, and is very clear about his decision.

In the second case, you are seeing a 17-year-old female patient in your office who is requesting the oral contraceptive pill. She asks that you do not tell her parents about the prescription.

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In the third case, you are seeing a 16-year-old female patient who you recently diagnosed with a relapse of her leukemia. She vividly remembers what it was like to undergo chemotherapy when she was first diagnosed. As her physician, you have informed the family that her prognosis is poor, even with treatment. She is adamant that she does not want to undergo treatment a second time, but her parents are demanding to start treatment immediately.

Let's start by reviewing the concept of capacity in the pediatric population, as well as the concepts of assent and dissent.

To begin, let's review the concept of informed consent. In general, informed consent requires that (1) a decision maker has capacity to make decisions, (2) is adequately informed and has been given all relevant information that a reasonable person would want in order to make a decision, and (3) the decision must be voluntary and free of coercion. It is important to note that in Canada, there is no legally defined age for consent, which can make consent in the pediatric population very complex. You can refer to the full CPS position statement for a helpful chart outlining the laws related to consent and advanced directives in each province.

The first step in the process of informed consent is the determination of capacity. Capacity is the patient's ability to understand information relevant to a treatment decision and to appreciate the reasonably foreseeable consequences of a decision or lack of decision. In pediatrics, the capacity of a paediatric patient to consent to a proposed treatment varies with age, development, maturity and the specific situation. It must be determined on a case-by-case basis. For example, in some situations capacity is more straightforward like in infants and toddlers. We will discuss this in more details in a few moments. In this case, parents are usually the most appropriate substitute decision makers (SDMs).

The second requirement in this process requires that a capable decision-maker is given all the relevant information that a reasonable person would require to make an informed choice regarding their health care.

The final step is ensuring that the final decision is voluntary and free of coercion. The voluntariness of the paediatric patient's decision often comes into question because of their relatively limited life experience, their dependence on their parents and their emerging sense of self. When involved in treatment decisions for an incapable paediatric patient, the primary concerns of health care providers (HCPs) and SDMs should be to preserve the best-interests of the child, maximize benefits and minimize harms.

The participation of children and adolescents in medical decision-making should always be sought, and their degree of involvement should be developmentally appropriate. Their consent, assent and dissent should be respected. Assent ensures that children are provided with developmentally appropriate information and options and can participate, in a developmentally appropriate way, in their own care. Dissent, or strong objections to a proposed treatment, should always be given serious consideration.

Next, let's discuss capacity in pediatrics in more detail:

The first step in determining capacity is the assessment of a child's or adolescent's ability to understand the circumstances relevant to their illness and medical treatment. Infants and preschool children do not meet even a limited definition of capacity. In school-aged children, a developing self-awareness should be acknowledged. Assent should be sought and strong indicators of dissent should be considered. In situations where capacity is not demonstrated, the process of obtaining informed consent must involve the patient's legal guardian(s) in a family-centered, shared decision-making process. Healthcare providers must clearly communicate all essential treatment-related information to both the child and the substitute decision makers. It is our responsibility as healthcare providers to ensure the best interests of the child are being met in any decision being made.

Medical decision-making in adolescents is more complicated. While adolescents may demonstrate comparable decision-making capacity to adults, their ability to make decisions is affected by different psychosocial factors, such as peer pressure, impulsivity and acceptance of risk-seeking behaviours. In this population, HCPs must determine individual patient capacity on a case-by-case basis. If the youth is deemed capable and requirements for informed consent are met, consent from a substitute decision maker is not legally required. When an adolescent's capacity is less certain, a family-centered, shared decision-making approach is most appropriate.

It is also important to note that common law recognizes the special status of emancipated and mature minors. Emancipated minors are adolescents who live independently from parent(s) or guardian(s), or who are parents themselves. Mature minors are adolescents who have demonstrated decision-making abilities in other areas of life or have received this designation in a court of law.

Next, let's review the roles and responsibilities of substitute decision makers, including the concept of best interest.

Most preadolescent children need an SDM to act on their behalf, and parents are usually the appropriate SDMs. In most jurisdictions, their decision-making authority is limited to medically necessary interventions. In cases where medical necessity has not been established or a proposed treatment involves personal preference, intervention should be deferred until individuals are capable of making their own choice. SDMs are obligated to act in accordance with the previously expressed wishes of a prior capable patient or, in the patient's 'Best Interests' if those wishes are unknown or nonexistent.

When making any treatment decision for an incapable child, the decision maker must weigh the benefits versus the potential burdens of a proposed treatment in the context of the patient's values, beliefs, and culture. In summary, we must act in the patient's best interest. The use of the Best Interests Standard requires three necessary factors: 1) using the best possible information to assess and maximize an incapable patient's long-term benefits and to minimize any corresponding burdens; 2) choices made using this standard must meet a

minimum acceptable threshold of care, as judged by the Reasonable Person Standard; and 3) SDMs must act in accordance with accepted moral and legal duties to their ward. When significant uncertainty surrounds a treatment, the focus should be on minimizing associated harms. For example, when a cure for a particular condition is unlikely and the treatment is associated with significant harms, providing palliative care may be an appropriate course.

At some point, it may be appropriate to withhold or withdraw life-sustaining interventions. For example, when progression to death is imminent, when a proposed intervention is ineffective or likely to result in greater harms than benefits, or when interventions would only prolong the dying process. These decisions are always difficult, however, patients, families and HCPs will benefit from family-centered, shared decision-making.

Inevitably, conflicts and disagreements may arise in the medical decision making process.

In pediatrics, it's important to remember that family centered care and shared-decision making is the standard of care. In this model, the patient and family's values, as well as the knowledge and experience of HCPs should be used to determine the best possible treatment for an incapable patient.

Occasionally however, situations arise where SDMs and HCPs experience competing interests. For example, a disagreement between parents with joint custody or the desire of parents to continue life-sustaining interventions when there is little hope of reasonable recovery. In cases of serious disagreement, the physician's primary responsibility is to the patient and his/her best interests.

Some strategies for resolving such conflicts include open communication and the consultation of other individuals with additional areas of expertise, including additional subspecialists, spiritual care leaders, social workers, patient relations experts, bioethicists, institutional legal counsel or occasionally, child welfare organizations when appropriate.

In true medical emergencies though, the ethical principles of beneficence and non-maleficence, as well as laws under the emergency doctrine, permit the provision of emergent life-sustaining interventions. Regardless, HCPs should continue to be truthful and transparent with the family in order to maintain trusting relationships.

Now that we've spent some time reviewing the complexities of medical decision making in pediatrics, let's go back to the cases:

In the first case, a 5 year old does not have the capacity to make his own medical decisions. However, assent should still be sought. In this case, it would be developmentally appropriate to ask the patient which arm he would like the injection in, enlist his parent to help support his needs during the procedure. Vaccination should proceed with the SDMs consent and the patient's guidance.

In the second case, it would be reasonable to determine the patient's capacity to make her own medical decisions, based on your past experiences with this patient. If she is deemed capable and is able to understand the risks and benefits of an oral contraceptive pill, it would be reasonable to prescribe the birth control pill without any parental knowledge.

The third case is much more complex and a decision would need to take into account the patient's capacity, the patient and family's values, as well as the medical considerations of the case. This is a case where it would be appropriate to consult other experts, including other healthcare specialists, hospital bioethicists and the hospital's legal team. A determination of the patient's capacity is essential, as well as a careful review of the patient's values. You ensure the family and patient are aware of the risks and benefits of treatment, as well as have an accurate understanding of her disease and prognosis. You meet with the family and the patient to discuss the patient's values and wishes. You encourage open communication between all team members, and ultimately, the family also feels the most appropriate course of action is to decline treatment and pursue a palliative approach. As her physician, you feel we are acting in the patient's best interests.

Now that we've applied some of the concepts we reviewed, let us finish with some key take-home messages:

- Children's and adolescents' participation in medical decision-making should be sought in proportion to their developmental capacity to understand the nature and consequences of their medical problem as well as the reasonably foreseeable risks and benefits of the treatment proposed.
- Healthcare professionals and substitute decision makers should be informed about, and act in accordance with, laws and regulations governing consent to treatment within their jurisdiction.
- Healthcare professionals must provide patients and their substitute decision makers with all the information they need to participate effectively in the decision-making process.
- Assent or dissent should both be respected whenever possible; it is also recognized that in the absence of capacity, minimizing harms and maximizing the patient's best interests is the priority.
- Healthcare professionals, patients and families should work together to reach medical decisions based on the patient's best interests or outcomes.
- In cases of serious disagreement or competing interests, the healthcare professional's primary responsibility is to the patient.
- In complex social situations, a collaborative process should be agreed upon to clearly identify the substitute decision makers(s) in a timely fashion.
- Healthcare professionals should be aware of the conflict resolution process in place in their practice environment.
- In situations of conflict, healthcare professionals have an obligation to seek and access resources to help resolve that conflict and to facilitate patient and family access to such assistance as well.

That concludes our podcast on medical decision making in pediatrics, brought to you by PedsCases and the Canadian Pediatric Society. Thanks for listening!