4.2.3 Abortion and Capacity to Consent

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Educational Objectives

1. To identify the ethical issues raised by abortion for a woman whose capacity to consent is questionable
2. To identify the legal issues raised by abortion for a woman whose capacity to consent is questionable

Case

Paula Robeson is a 24-year-old woman with mild to moderate intellectual disability and a tested full-scale IQ of 54 (Verbal 49, Performance 68). In addition to her intellectual disability, Paula has previously been treated for depression and self-injurious behaviour, but she has been doing well for the last year or two without medication. She lives with her mother and stepfather, and she works in a local grocery store bagging groceries. Her mother, Janet Robeson, brought Paula to her family physician because of bouts of nausea and vomiting. Physical examination and a pregnancy test revealed that she was approximately eight weeks pregnant. Her mother immediately indicated that her daughter should terminate the pregnancy. Paula Robeson told the doctor that whatever her mother wanted was okay with her, but when her mother was out of the room, she told the nurse that she wanted to keep her baby and take care of it. When the nurse asked Paula if she knew how to take care of a baby, Paula said she thought that she could learn and asked the nurse what she thought was the right thing to do. Paula smiles when she talks about having a boyfriend but does not reveal any details of the relationship. She seems frightened of her stepfather and refuses to say anything about him. The nurse who talked to Carla wonders if Carla may be the victim of sexual abuse, possibly by her stepfather, but there was no direct disclosure in their conversation. At this point, the circumstances of Paula's pregnancy remain unclear.

Janet Robeson gave a long list of reasons why terminating her daughter's pregnancy was the only reasonable option:

1. “Paula cannot take care of a baby. She still needs someone to take care of her.”
2. “Four years ago when Paula had appendicitis, I was appointed her guardian to make medical decisions on Paula's behalf because she was not considered competent to consent. Therefore, I am the person empowered to make this decision.”
3. “If Paula has this baby, I will be the one who ends up caring for it. Since I am the one who will have to care for the baby, I should have some control over its birth.”
4. “Paula has just gotten over some serious mental health and behavioural issues; pregnancy could set her back and cause major mental health issues.”
5. “We don't know what causes Paula's disability. How do we know her baby won't have the same problems or even worse?”
6. “Paula's stepfather will be furious if he finds out that Paula is going to have a baby. He may leave or throw Paula out of the house.”

Paula's mother believes that an abortion should be carried out as soon as possible. Since Paula has been previously determined to be incompetent to make another medical decision and her mother has been previously appointed as guardian and substitute decision-maker, her mother believes she has the authority to make this decision and feels comfortable authorizing the procedure. She knows that Paula has mixed emotions and wants the doctors and nurses to help convince Paula that terminating her pregnancy is the right thing to do.

Questions

1. Who should be involved in the decision to continue or terminate Paula's pregnancy?
2. What ethical and legal principles should be considered in making this decision?
3. Which, if any, of the six concerns raised by Paula's mother should be given consideration in addressing this issue, and what implications do these have for determining the course of action?
4. What additional information might be important in considering this matter?
5. Should the potential best interests of the child to be born be considered and, if so, how?
Discussion

**Q1. Who should be involved in the decision to continue or terminate Paula's pregnancy?**

It is prudent to involve Paula, her mother, and all her direct care-providers in the process of decision-making. Capacity is decision-specific; the starting point will be whether or not Paula has the capacity to make this particular decision or not. It is necessary to determine this before proceeding with this particular decision. A physician should first attempt to make an assessment; if necessary, a referral for further capacity assessment should be made.

If Paula lacks the legal capacity to make a competent decision independently, a substitute decision-maker must act on her behalf. It is still important, however, to involve Paula in the decision-making process to the extent possible. She may require individual counselling and support to assist her in doing so, and these services should not be misused to attempt to manipulate the expression of her wishes. Although adults with intellectual disabilities differ from children or adolescents in many respects, the general principles outlined by the Canadian Paediatric Society's position statement on involving children to the maximum extent possible in their own treatment decisions can be applied to this case. Paula's mental age is at least similar to that of a student in primary school, and these principles suggest that at this level children may participate in decision-making, that any strong dissent should be carefully considered and that, “before treatment is forced on an uncooperative child, consideration should be given to the potential harms of this course of action and all available alternatives.” The principles go on to say that some children do have the capacity to make their own decisions and that health care professionals must carefully examine when this is the case.

Involving Paula in the decision is essential for the stewardship of the therapeutic relationship that will hopefully continue long into the future. Forceful or non-consensual treatment may inflect psychological harm, may be associated with worse health outcomes, and may be injurious to the relationship between Paula and both her present and future caregivers.

If Janet's guardianship order grants her the authority to make health care decisions on behalf of Paula (health care professionals should always read the order to verify who the guardian is and what authority they have been granted), Janet will ultimately make this decision. She must do so in accordance with the principles outlined in the legislation she is acting under. These principles most likely revolve around Paula's best interests, as well as exercising Janet's authority in the least restrictive manner possible.

One of the complexities of the case revolves around the conflict between the interests of Paula and her family, and the fact that they may not easily be distinguishable from one another. However, in making decisions in Paula's best interests, the interests of family members or the family unit as a whole may only be considered if they coincide with the best interests of Paula.

The family physician providing care for Paula should also be involved, and it may be advisable to recommend consultation with other health care professionals and others in determining what course of action would be in the best interests of Paula. For example, Paula's psychiatrist may be able to provide helpful information as to the likely effects on Paula of proceeding with the pregnancy versus proceeding with the termination of the pregnancy.

**Q2. What ethical and legal principles should be considered in making this decision?**

The ethical principle of autonomy and its articulation in both informed consent and surrogate decision-making is a key principle when discussing consent to treatment. However, in cases where the individual lacks the legal capacity to give or withhold consent, it plays a much lesser role and must be balanced against the ethical principle of beneficence (doing good).

The principle of beneficence is essential. This means trying to determine what decision will be most likely to be in Paula's best interests, taking into account all relevant factors. Both Paula's guardian and her physician owe her a legal duty to act in her best interests. Given the Supreme Court of Canada's decision in *E. (Mrs.) v. Eve* (a case involving the requested non-therapeutic sterilization of a mentally disabled woman by her mother), it is likely that an abortion could be carried out on the authority of the guardian if the procedure is seen as therapeutic. This is particularly so if legislation is in place that authorizes substitute decision-making in the health care context. When *E. (Mrs.) v. Eve* was decided (in 1986), no such legislation was in place. Unless the abortion is considered to be therapeutically indicated, the guardian's consent may not be legally sufficient.

The principle of non-maleficence, avoidance of doing harm, is also important. Given the importance that individuals place on the ability to make their own reproductive decisions, due care should be taken to avoid depriving Paula of
this opportunity unless there are sound reasons for doing so. Paula's disability should not be used as a reason to unnecessarily compromise her rights.

Q3. Which, if any, of the six concerns raised by Paula's mother should be given consideration in addressing this issue, and what implications do these have for determining the course of action?

"Paula cannot take care of a baby. She still needs someone to take care of her."

Paula's ability to care for a child should be considered in relation to her own best interests. Most women do not have to prove that they will be good mothers before being allowed to have a child. However, when making a decision that will be in Paula's best interests, whether or not she can ultimately care for a child is an important consideration. The likely effects and consequences of giving birth to a child she is unable to care for need to be addressed.

"Four years ago when Paula had appendicitis, I was appointed her guardian to make medical decisions on Paula's behalf because she was not considered competent to consent. Therefore, I am the person empowered to make this decision."

Paula's mother's role as guardian to give consent to an appendectomy may have limited application here. The physician must read the guardianship order to confirm guardianship and whether it is still in effect. As all guardianship orders are different, the physician must also determine whether the authority granted is limited to certain health care decisions, or whether it is broad and covers all health care decisions.

There is no indication that Paula opposed the appendectomy. In this case, she has expressed a wish to continue with the pregnancy, and her wishes are important to consider. In addition, while abortion, sterilization and other reproductive health procedures are medical decisions, they have commonly been addressed as a special category in law and in ethics because they involve reproductive rights as well as individual health. An appendectomy can be presumed to be strongly medically indicated, but in this case there is no medical requirement for an abortion. For these reasons, a court order may be required, even if guardianship is in place.

"If Paula has this baby, I will be the one who ends up caring for it. Since I am the one who will have to care for the baby, I should have some control over its birth."

The effect of the birth of a child on Janet is not a directly relevant factor given the E. (Mrs.)v. Eve decision. The Supreme Court of Canada said that, when making a decision based on the best interests of an individual, at least one based on the inherent jurisdiction of the court (rather than under legislation), the decision cannot be made considering what is best for others but only what is best for the individual in question. However, as this decision is being made under legislation and not under the inherent jurisdiction of the court to protect vulnerable members of our society, factors such as what is best taking into account the larger picture of Paula's home setting and the repercussions upon it of a particular decision may or may not be seen as forming part of the consideration.

Janet's concern that she will be required to care for her grandchild raises concerns about a conflict of interest. In her role as her daughter's guardian, she must act in her daughter's best interest. In raising this concern, Janet suggests that she believes that her own interests should play an important role. While she actually may not be legally or socially obligated to care for the grandchild, her internal sense of obligation raises conflicts with her obligation to act in her daughter's best interest. Therefore, someone who can be more objective about Paula's interests may need to be appointed to act on Paula's behalf in this case.

"Paula has just gotten over some serious mental health and behavioural issues; pregnancy could set her back and cause major mental health issues."

The possibility that the pregnancy and subsequent birth could have an adverse effect on Paula's health is a significant factor. If the medical and psychological evidence shows that it would be harmful to Paula and that the risks of continuing the pregnancy would outweigh those of terminating the pregnancy, then there is a strong argument in favour of terminating the pregnancy. The possible psychological risks of continuing the pregnancy would need to be carefully weighed against the potential psychological risks of terminating the pregnancy against Paula's wishes. Consultation with a counselling psychologist or psychiatrist would be very helpful in trying to assess the potential psychological consequences of both courses of action.

"We don't know what causes Paula's disability. How do we know her baby won't have the same problems or even worse?"
In the E. (Mrs.) v. Eve case, the court noted criticisms that have been levelled at justifying the sterilization of mentally disabled individuals in the past to prevent the births of future individuals with the disabilities of their parents. They expressed the opinion that there was a lack of evidence regarding many mental and physical disorders establishing them as hereditary. Without evidence of hereditary transmission, the presence of a disability does not substantially increase the risk to the baby.

"Paula's stepfather will be furious if he finds out that Paula is going to have a baby. He may leave or throw Paula out of the house."

The effects on Paula of her stepfather’s reaction to news of the pregnancy, or of the failure to terminate the pregnancy, may be considered as a factor only to the extent that it affects Paula's best interests. If the effects of proceeding with the pregnancy will mean that Paula loses a supportive family environment in which to live, this may indeed be relevant to the decision. It may also be important to explore this further in terms of whether or not her current living situation is indeed supportive. The mother's statement also raises the issue of whether her decision as guardian might be influenced by coercion.

Q4. What additional information might be important in considering this matter?

It is important to attempt to determine the circumstances that led to this pregnancy. Women with intellectual disabilities are frequently victims of sexual abuse or sexual exploitation. In addition, they often lack important information about birth control and sexually transmitted diseases. Her pregnancy clearly indicates that she is sexually active and could need support or assistance with this area of her life. Counselling may be useful to gather further information about the circumstances of the pregnancy. Depending upon further information that can be gathered, ongoing counselling or other referrals may be required.

Are Paula's hopes actual possibilities? Are her mother's fears surrounding her own situation realistic? Is there a possible third way involving the realization of Paula's hopes and the mitigation of her mother's concerns, such as birth and adoption with visitation, etc.?

Should Paula's willingness to defer the decision to her mother be considered assent? The concept of assent implies willingness or agreement as opposed to consent, which implies legal as well as ethical authorization to proceed. Although children and adults who are not legally competent to consent cannot provide legal authorization, their assent or lack of assent is ethically important. Subjecting an incompetent patient to surgical intervention that they do not want requires a compelling rationale based on the best interests of the individual. In this case, Paula's wishes are unclear. She has expressed a desire to continue her pregnancy but also indicated a willingness to let her mother make the decision. It would be important to clarify what Paula wants before determining how to proceed. If Paula does not clearly assent or clearly indicates her opposition to the abortion, she may wish to challenge her mother's guardianship, and she may be found competent to make her own decision.

Q5. Should the potential best interests of the child to be born be considered and, if so, how?

Ethically, there is no simple answer to this question. We may instinctively feel that this potential child may face a difficult life and, therefore, by preventing birth we are preventing harm. Any assumptions that we may hold that being born to such a parent leads to an unhappy life may reveal our own biases, since there is little evidence to support this notion.

Neither harm nor benefit can occur until a child exists, whether we envision the child as coming into existence before or after birth. If we assume that the child will exist in the future, we cannot simply avoid harm by preventing existence since doing so may also prevent benefit or do harm to the child by depriving her or him of this potential existence.

From a legal perspective, the interests of the fetus are not a relevant consideration in this decision. Children do not have legal rights until they are born.

The potential welfare of the fetus, Paula's mother or anyone else should be considered in this case only to the same extent that they would be considered in any other woman's decision to continue or terminate pregnancy.

Reference
1. Canadian Paediatric Society. Treatment decisions regarding infants, children and adolescents. [Position
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