2.5.2 Conflicts with Patients' Families in the Neonatal Intensive Care Unit

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Educational Objectives

1. To understand the concept of the best interest standard of judgment in end-of-life (EOL) decision-making for newborn infants.
2. To appreciate the potential for conflict between the best interests of the young infant and those of the family.
3. To appreciate how a procedural framework may help physicians to navigate EOL ethical conflicts in the neonatal intensive care unit (NICU).

Case

Clark was born at 26 weeks' gestational age to a 27-year-old G3P2 mother. His birth weight was 800 g. His admitting diagnosis was severe respiratory distress syndrome. He received surfactant and required high ventilator rates and pressures to maintain adequate oxygenation and ventilation. Cranial ultrasounds performed on his third, seventh and 14th days of life revealed the presence of bilateral, grade 2–3, intraventricular hemorrhages. In addition, the early ultrasounds raised concerns about increased peri-ventricular echogenicity, suggestive of ischemia in that region. His health was also complicated by a patent ductus arteriosus, which required medical treatment with indomethacin.

Clark's parents were kept informed of their son's progress. They were informed of the need to follow the ultrasound findings to see the evolution of the findings. They were assured that important decisions would be made only when consensus was reached between them and the health care team.

It is now day 23. Clark's lung disease has deteriorated and he is requiring significant respiratory support measures. Furthermore, the latest cranial ultrasound on day 21 showed signs of increasing ventricular size and evidence of bilateral peri-ventricular cysts in the frontal and parietal cortex. Based on this evidence of cystic peri-ventricular leukomalacia (PVL) and his deteriorating respiratory status, the medical team feel it is not in Clark's best interests to continue life-sustaining treatment (LST).

On day 23, a meeting is scheduled between the parents, a staff neonatologist, a social worker and a neonatal fellow. After being informed of the most recent clinical and ultrasound findings, both parents say they understand the gravity of the situation. The mother says that she cannot think about her son dying. This is the mother's third visit to the NICU; she has only managed to visit when parent meetings have been scheduled. Physical fatigue, caretaking responsibilities for her other children and long-distance travel have limited her ability to visit more frequently.

During the meeting, the neonatologist recommends withdrawing ventilatory assistance and embarking on a comfort care course. The mother feels that it is inherently contrary to her beliefs to discontinue therapy. She does not articulate her reasons for this view; she seems to be a very private, introspective person. Clark's father indicates that he is comfortable with a decision to withdraw ventilatory support; he feels it is wrong to prolong his son's suffering. In fact, he says he would have difficulty visiting his son if treatment is not withdrawn and he continues to suffer. Clark's mother refuses to continue the discussion and leaves the conference room.

Questions

1. What should be done immediately?
2. What is in Clark's best interests?
3. Is Clark suffering?
4. By continuing LST, at least in the short term, are the best interests of the family overriding those of the child?
5. How should the health care team respond to the mother's beliefs if she will not or cannot explain these beliefs?
6. Is it morally and legally acceptable to proceed with the consent of one parent?
7. Are there ethical conflicts between the neonatologist/health care team and the mother or between the father and the mother?

Medical background

This child has a very low probability of survival and, if he were to survive, a high probability of a very poor outcome. It is difficult to predict the respiratory outcome precisely, but the clinical picture is one of severe lung involvement with bronchopulmonary dysplasia (BPD). If the pulmonary status stabilizes then he is likely to require months of ventilatory assistance, and oxygen supplementation for many more months or years after that. In addition, he would be prone to episodes of bronchospasm and right-sided heart failure (cor pulmonale), and could develop upper airway compromise. BPD is also associated with a poor neurodevelopmental outcome.

The major brain injury likely to affect neurodevelopmental outcome is the PVL: this is likely to result in both motor and cognitive deficits, with probable overt spastic quadriplegic cerebral palsy or motor handicap of a slightly lesser degree. Cognitive outcomes are very likely to include visual, hearing, behavioural and attentional deficits. Although the severity of these handicaps may vary, it can be stated with certainty that, were he to survive, Clark would have neurodevelopmental problems in the moderate to severe range. In addition to BPD and PVL, other complications of prolonged hospitalization are likely. For example, episodes of infection or oxygen damage to the retina will make him vulnerable to a prolonged hospital stay and retinopathy of prematurity, with limited visual acuity or even blindness.

Ethical concepts relevant to this case

Best interests of the newborn

This is the basis of judgment in young infants. It is a moral and legal (see below) standard of judgment that helps to establish the primacy of duties to the newborn. Pursuing a course in the best interests of an infant implies determining the course that has a more favourable benefit/harm ratio than the other possible options. Best interests acts both as a threshold for judgment and also for possible intervention, if it is perceived that the infant's best interests are not being served by a particular course of action. Most importantly in Clark's case, it also raises the question of whether death may be in his best interests, as opposed to a prolonged and uncertain period of hospitalization with a very poor predicted quality of (potential) survival. It must be appreciated that the assessment of best interests is being made by surrogates and physicians, because infants are clearly not able to express their own value system.

The legal aspects of best interests

In Ontario's Health Care Consent Act of 1996, best interests considers the following factors:

1. Whether the treatment is likely to,
   - improve the incapable person's condition or well-being,
   - prevent the incapable person's condition or well-being from deteriorating, or
   - reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.
2. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.
3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.
4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.

Health care providers who believe that a surrogate's decisions are not in the child's best interests can appeal to the provincial child welfare authorities. The courts have the authority to assume a parentalistic or protective role in treatment decisions if the child is deemed to be in need of protection.

Quality of life

Determination of best interests requires an assessment of what the child's quality of life (QOL) would be, were he
to survive. QOL considerations encompass the predicted cognitive and neurodevelopmental potential of the infant, the potential for motor disability or other physical handicaps (e.g., vision, hearing) and longer-term concerns such as behavioural and learning difficulties or school problems. It also considers the potential requirements for repeated or prolonged hospitalization, surgery or medication, and the potential for pain and suffering endured throughout. QOL considerations may also include less concrete medical states such as the capacity for meaningful and potentially enjoyable interaction with other people and the environment. The subjective nature of a QOL assessment, as well as the fact that this assessment is being done by a substitute decision-maker, must always be recognized.

**The moral and legal authority of parents**

Society grants parents the right and the responsibility to make health care decisions for their young children, the assumption being that the child's interests are central to parental concerns. Therefore, respecting parental authority implies that the NICU team should incorporate parents' values, preferences and religious beliefs into decisions, remove barriers that inhibit parents from exercising their moral authority (e.g., by ensuring parents are informed, removing language barriers, and facilitating access to visiting and interaction with the infant and team) and not allow medical/technical expertise to dominate value considerations. Parental authority, however, is not absolute and can and should be challenged when conflicting assessments of the child's best interests arise. Parental *authority* is often used synonymously with *autonomy*; however, the latter refers to a competent adult making decisions about his/her own medical care.

**Parent–physician/team relationships**

The development of a mutually trusting relationship between the parents and the physician/health care team requires that parents have trust in the competence and commitment of the physician/team to their infant. From the physician/team's perspective, they need to recognize the uneven power relationship and parents' vulnerability due to stress, anxiety and "medical uncertainty." The physician/team is responsible for developing the relationship, elucidating parental concerns and demonstrating caring and compassion regardless of the parents' attitude.

**Family-centred care**

Family-centred care is a basic tenet of NICU care. It emphasizes the concept of the newborn infant being part of a family. It acknowledges that the family status directly affects the infant's interests and well-being. It also considers the effects of a decision on all family members, their responsibilities towards one another and the burdens/benefits for each family member.

**Consensual decision-making**

Consensual decision-making implies that both the parents and the physician/team are involved in the decision-making process; that they share relevant information with each other, they express their treatment preferences and, when a final decision is made, both parties are in agreement. The ideal consensual decision is one in which neither party feels individually responsible for that decision.

Parents normally want to be informed and involved in decision-making, but may feel burdened by what they perceive as their responsibility for the decision. When the consensual shared decision-making process is handled well by the physician/health care team, the "burden" of the decision's consequences is shared. The final responsibility does, however, rest with the parents, and no decision to withdraw treatment would be made without their agreement.

**Summary**

The key ethical principles that underlie EOL decision-making in the NICU

- Decisions must serve the best interests of the infant.
- Parents must be fully informed.
- Parents' values, cultural beliefs and religious beliefs must be respected whenever possible.
- A family-centred care approach must be utilized.
- Whenever possible, consensus must be derived between the parents and the physician/health care team directly involved in the care of that infant.

**Conflict or potential for conflict**

Many ethical issues arise in the care of newborn infants in the NICU, particularly when there is little chance for
survival or if the infant's life is likely to be one of severe suffering, with virtually no expectation of a good QOL. Ethical conflicts with parents in EOL decision-making tend to arise in one or more of four areas:

- differences in the assessment of what is in the best interests of the infant
- differences in the belief of what constitutes an acceptable QOL
- conflict between the family's interests and those of the infant
- conflict in the locus of decision-making—who has the ultimate responsibility for the decision

Procedural format for EOL decision-making

In general, most EOL decisions can be negotiated with parents via a well-defined process that encompasses the key principles above and utilizes a procedural framework such as that suggested here.

The procedural framework requires that the physician/health care team:

- establish that the presenting issue is an ethical problem, one in which concepts such as the "good" of the patient and the infant's QOL require consideration
- identify the rightful decision-makers: the parents and the physician and members of the team who are directly involved in the care of the infant
- create an environment that encourages active parental participation in discussions
- schedule a formal meeting in a quiet area, free from interruption
- attempt to overcome communication barriers (e.g., provide professional interpreters where language or cultural differences arise)
- establish the relevant facts: the child's diagnosis and prognosis, past experience on the unit, relevant institutional policies and relevant professional guidelines
- determine the parents' appreciation of the clinical status of their infant
- determine any parental informational needs
- promote an open, honest and "transparent" process whereby the responsible physician's thinking is conveyed to the parents in understandable language, placing the emphasis on reasoning and not technical information
- facilitate the parents' role as partners in decision-making, not merely ratify a course of action that may have already been decided upon by the team
- give assurance to the parents that their views are fundamental to any decisions
- explore the options, with explicit discussion of their known and potential short- and long-term consequences
- weigh the consequences of each course of action
- provide a medical recommendation as to what the medical team considers appropriate
- explore parental views and concerns (some parents may not wish to participate in a process of exploration, but all attempts to clarify the values underpinning a parental view should be made)
- attempt to derive consensus
- continue negotiation over time until consensus is achieved

On rare occasions, when conflict appears irresolvable, physicians may seek the authority to make unilateral decisions via institutional or legal redress. Both of these options are generally unsatisfactory and are regarded by some not only as a clinical failure, but also as unjustified in principle. Involving the legal system increases the anguish for patients and families, destroys the parent–physician relationship and may create (or increase) conflict between members of the health care team. It can be extremely costly and time consuming for all parties involved.

Discussion

Q1. What should be done immediately?

With the mother walking out of the room, the decision-making process is in grave danger of failing. A trusting relationship between the parents and the responsible physician/team has not been developed. We do not know how much the mother really understands, how she is feeling and how much information has been absorbed, or if she is hearing much of the information (and with this degree of certainty) for the first time. It is important to develop a collaborative, deliberative, trusting relationship and to elucidate the parents' values and views. The parents will also need time to absorb the information, ask questions and seek support from family and friends. Without all of this, pursuing the conversation with the mother is not appropriate at this time.

The immediate response is to assure the father, who has remained in the room, that the team will continue to support Clark medically and will not act on one parent's authorization. The team also needs to ensure that the mother is not in any danger of harming herself and make available to her any support to which she is receptive. She needs more time, and both parents need to discuss their own differences, which may have only emerged at the meeting.
After an appropriate time lapse (two to three days) a further meeting should be scheduled, preferably at parents’ choosing. Only then can negotiation and exploration begin as to whether the parents have questions/views about Clark's predicted outcome and a divergent or unified view as to what they see as being in Clark's best interests.

It will also be important for the parents to understand what withdrawal of LST involves: how it will not lead to suffering or pain, and how it will afford them privacy and time with their infant, allow extended family to be present and enable religious rituals to be performed.

**Q2. What is in Clark’s best interests?**

The predicted QOL for Clark is very poor. The absolute certainty of this determination would increase over time (if ventilatory support were continued), because more lung damage would become evident and further ultrasound or MRI findings of PVL would appear, even discounting other complications that, thus far, have not been central to his QOL determination. From the known medical literature, it is the assessment of the responsible physician and medical team that it is in Clark’s best interests to withdraw LST and allow him to die.

The parents may ultimately come to appreciate the reality of Clark’s probable outcome, but the mother is not at this level of appreciation at this point. We do not know if, over time, the mother will hold to a perspective that Clark could still have a "good enough" outcome and that, despite multiple handicaps, he would have a sufficiently acceptable QOL. Parents often want very explicit discussion of issues, such as whether their child will be able to walk, talk, go to school and live independently.

**Q3. Is Clark suffering?**

It is not clear whether Clark is overtly suffering. Suffering in the form of pain and obvious discomfort can be managed via analgesics and sedatives. There is, however, "existential suffering" that cannot be quantified: we cannot know what life is like for an infant in the NICU on a ventilator. We therefore assume a level of existential suffering, or at least discomfort, from the tubes, lines and blood sampling that are constants for someone as critically ill as Clark in an intensive care setting. It must also be recognized that the parents are suffering through this process.

**Q4. By continuing LST, at least in the short term, are the best interests of the family overriding those of the child?**

Clark's interests should remain the central focus; the time allowed for further negotiation with the parents should be predicated on how much suffering he is enduring. On the other hand, if he is not overtly suffering then the interests of the family are extremely important and all efforts should be made to deal with their issues. It is clearly optimal to harmonize the family's and child's interests. It would be morally indefensible if Clark's LST was withdrawn prior to reconciling the parents' divergent views and the differences between the mother and the team. Thus, promoting understanding and acceptance of Clark's predicted outcome, with preservation of the integrity of the family, becomes the primary focus as long as Clark's suffering can be temporally and satisfactorily managed.

**Q5. How should the health care team respond to the mother's beliefs if she will not or cannot explain these beliefs?**

All we know is that Clark's mother is a private person—perhaps it is offensive to her to be asked these sorts of questions, or perhaps she is intimidated by the circumstances, the situation and the medical team. However, we need to know more about her understanding and reasoning. Therefore, all efforts must be made to find a member of the team who she will talk to. Alternatively, there might be someone within her extended family, moral circle or faith-based community who she would be willing to speak to (e.g., chaplain, patient representative, her parents), and who could then share this information with the team so that they may better understand the nature of her views.

**Q6. Is it morally and legally acceptable to proceed with the consent of one parent?**

It is common for parents to be at very different stages of appreciation of their infant's clinical situation and readiness to accept the recommendations of the physician/team. The father may have had more contact with the medical team, be less “bonded” than the mother and be less emotionally vulnerable. The mother has been through a pregnancy and delivery, has had a longer time bonding throughout her pregnancy, may be less familiar with the
medical information and is potentially more vulnerable to feelings of guilt about not fulfilling her role as the mother of the child or other societal expectations of her.

Under Ontario’s Health Care Consent Act\(^1\) parents have equal decision-making authority. As stated therein:

“If two or more persons who are described in the same paragraph of subsection (1) and who meet the requirements of subsection (2) disagree about whether to give or refuse consent, and if their claims rank ahead of all others, the Public Guardian and Trustee shall make the decision in their stead.”

Therefore, one cannot act with the consent of only one parent. Whatever the legal status, it is always best to help parents to agree and actively ameliorate any strain on their relationship over the decision-making process. Whatever happens (i.e., whether the child should survive or die), the parents will need each other for support.

Q7. Are there ethical conflicts between the neonatologist/health care team and the mother or between the father and the mother?

In this case, it is unclear if there is truly an intractable clash of values about what is in the child’s best interests. It may be that, because of the subjectivity of the best-interest determination, the parents and the physician/team have come to significantly different conclusions. However, many other issues need to be dealt before coming to this conclusion. These are not strictly ethical in nature, but encompass good compassionate practice such as dealing with the information gap and gap in trust, misperceptions about the baby and fears about the dying process, as well as any other as yet unexplored reasons for the mother’s reaction.

Conclusions

A unilateral decision by the responsible physician and medical team to withdraw LST against the wishes of one parent should not be undertaken, both out of respect for the mother’s wishes and convictions and as a means of maintaining the family’s integrity. Whenever consensus cannot be achieved or where sufficient medical uncertainty persists, care is continued until either consensus is achieved or clinical events intervene that subsume a negotiated decision-making process. Until such a time, the medical team would continue to support the child and his parents, and gently explore mother’s views and improve contact and opportunities for communication. At a subsequent meeting(s), and with increasing evidence of the infant’s worsening clinical status, it is likely that consensus between the parents would be achieved, with convergence on what is in the infant’s best interests.

On very rare occasions, differences may become intractable and the team may perceive that the infant’s best interests are not being served. After every creative means of resolving differences has been tried, the responsible physician may transfer the infant’s care to another accepting physician. Alternatively, the physician may seek legal recourse, in the full knowledge that this will lead to adversarial relationships that cannot be breached. The moral distress experienced by the team about continuing to provide interventions that are felt to be harming the infant would also require attention.

References


Further Reading