

When parents and physicians disagree: What is the ethical pathway?

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A disagreement between a patient and her treating physician is a situation that both doctor and patient would likely rather avoid. Currently, a competent patient can make a treatment choice that is contrary to the advice of her treating physician, even if the choice results in death (1).

However, consider the situation where there is a disagreement in treatment choice between the parent of an ill child and the physician. These disagreements often occur in cases where the prognosis for the severely ill infant or child is that they will survive, but with a poor quality of life. The presumption is that the parent has authority to make treatment decisions for a child when the child does not have the capacity to do so. While this is true, the treatment choices of the parent on behalf of the child must be in the child's best interests.

What should the health care professional do when faced with the situation of a parent who disagrees with the recommended course of treatment? Like the parent, the physician believes the treatment recommendation is in the best interests of the child or patient. Should it be considered a 'problem' when a parent disagrees with her recommendation?

Like most issues in medical ethics, this 'problem' is often one of perception. Simply stated, both the parent and the physician feel that they are acting in the best interest of the child. After acknowledging this fundamental point, the physician should try to determine why there is a disagreement. As stated by the authors of *Bioethics in Canada* (2):

"Ethical dilemmas will be misconstrued, if the clinical situation is not understood in all its subtle medical and human complexity. The maxim of method in clinical ethics is: each case contains its own resolution. Understand the patient, body and biography as comprehensively as possible, and the balance of elements required to resolve an ethical uncertainty, conflict or dilemma will emerge".

In most cases, to achieve a resolution is often a matter of approach. Understanding the patient, in this case not only the ill infant or child but also the family and its dynamics, together with addressing certain basic ethical principles, will assist in achieving a resolution. First, the physician should assure the family that she too is acting in the best

interest of the child. The principle of beneficence, or acting in ways to promote the welfare of others, is at the core of medicine. Nonmaleficence, or acting so as not to cause needless harm to others, is also a fundamental principle of medicine (1,2). Something as simple as reassuring the parent that the physician is following these two principles, just as the parent is, will hopefully commence a dialogue.

Second, acknowledge that the decision to be made is one that may have lasting implications for the family and that the parents are the ones who are deferred to as the decision-makers for the child. This will hopefully also serve to reassure the parents. While these two points may seem self-evident and not worth repeating, they nevertheless are extremely important to hear from the parent's perspective. Often, we forget the self-evident. Restating, or stating in the first place, something that 'goes without saying', helps to break down barriers and also acts to stop barricades from being built.

A third point should be emphasized with the parents when addressing the disagreement. Much can be said to giving credence to the views of the physician. The physician can be said to be objective and have greater medical knowledge and experience on her side. In addition, she presumably would have consulted with other specialists and have reached a recommendation based on a number of factors. The physician, therefore, has the combined input of more than just the one discipline. It is important to point out that the health care professional's opinion is likely broader and, hopefully, objective.

By addressing these points, a collaborative approach between the parents and the physician will hopefully be achieved.

There have been few empirical studies conducted that look at disagreements between health care professionals and parents. One article examined the influence health care providers have on parents in these difficult decisions. The article looked at differences in preferences and the following quotation contains the authors' thesis (3):

"In critical care situations involving newborns, parents often assume responsibility for making important life sustaining decisions, along with neonatologists.

Obviously, the preferences of newborns are unknown, and it is assumed that parents will take the best interests of the infant and the family into consideration. But it is not clear whether parents are influenced by health care professionals, and if they are, to what extent those decisions are based on the preferences of the very individuals on who they rely for information and advice: neonatologists, neonatal nurses and their personal physicians. Thus, it is important to determine whether the preferences of medical personnel are similar to or differ systematically from patients who are extremely low-birth-weight (ELBW) infants or their parents and to measure the direction of these differences, if any”.

In this study, hypothetical fact situations were given to parents, health care providers and adolescents, one-half of whom had been ELBW infants. The participants were asked how they would rate the health-related quality of life for the hypothetical conditions of five children with varying degrees of disabilities. The authors found that the health care professionals and the parents viewed the mild to moderately disabled states similarly, but that parents were more accepting of the severely disabled health state than health care professionals. Furthermore, there was more of a consistency between adolescents and their parents for the severely disabled health state than between the adolescents and the health care professionals. The authors theorize that a health care professional’s clinical bias may affect that person’s decision making in terms of assessing the quality of life for others. They state: “This finding lends support to the concept that parents are the most appropriate agents when making decisions on behalf of their infants in the neonatal intensive care unit” (3).

A second study looked at the concept that parents are the most appropriate agents when making decisions on behalf of their infants in the neonatal intensive care unit (4). This study looked directly at the role of parents in end-of-life decisions in neonatology and found that disagreement was most likely to occur in cases of severely ill infants who were expected to survive with a very poor quality of life (4). Treatment decisions involving major medical interventions versus comfort care caused the most frequent disputes between parents and physicians on the medical course to be followed. They found that:

“The opinion of parents about which course of action is in the best interest of their child is apparently accepted by doctors in case it [sic] entails continuation of treatment. This may be the case for infants without chances of survival, as well as infants who may survive with, according to the pediatricians, an extremely poor quality of life. However, pediatricians frequently feel discontented about the course followed afterwards in such cases, especially about whether they sufficiently served the interests of the child. Acting in accordance with the principle of respecting the opinion of parents about which course of action is in the best interest of their child

may occasionally collide with the medical motive of avoiding any pointless suffering of the infant” (4).

This study identified the ethical dilemma that often presents in these situations as a conflict between the principle of nonmaleficence on the part of the physician, and the autonomy of the parents on behalf of the patient.

As indicated earlier, the resolution of the conflict between a parent and a physician can occur by approaching each case individually. In a study of parental roles in decision-making about paediatric cardiac transplantation, the author conducted a prospective ethnographic study of 24 parents of 15 children before their decision to accept or reject the transplant option for their children (5). The author comments that the parents’ desire to be considered a ‘good parent’ for the ill child was one of the strongest variables in influencing their choice. Examples of ‘good parenting’ included advocacy, unconditional love, presence and sacrifice. The health care practitioner who acknowledges his or her own belief system and values about treatment options, and also expresses a genuine respect for the personal differences in beliefs and values of the parent, will greatly assist the parent in the agonizing treatment choice that must be made.

The types of decision-making for parental involvement in deciding for their critically ill child has been categorized as collaborative, passive and active. Most parents prefer collaborative decision-making (52%) followed by passive (34%) (5). Should physicians be polled, it is likely that they too would prefer a collaborative effort in reaching a decision for treatment of a severely ill infant or child.

Although the presumption is that the parents are the ones to whom deference should be given when there is a disagreement concerning the treatment choice for an ill child, the health care professionals have an important role. The shared ethical dilemma facing the parents and the health care team must be resolved or the alternative is to seek the court’s intervention. As stated earlier, each ethical dilemma contains its own resolution. If the parties take the time to understand each other’s perspective as comprehensively as possible, then the balance of elements required to resolve the ethical uncertainty will emerge. The prospect of having a judge impose a treatment is an alternative that, it is safe to say, both parties would rather avoid.

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