When health care professionals say "more" and parents say "enough"

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The aim of the present article is to provide an overview of the myriad bioethical issues faced when a family believes that interventions are not in the child's best interest, but the clinician believes otherwise. The present article will illustrate how an analysis of the ethical issues can provide a way forward.

CASE PRESENTATION

JD is a two-year-old boy with a history of hypoxic ischemic encephalopathy who subsequently developed severe cerebral palsy. Although he is wheelchair-bound, his family believes that his quality of life is good. He is able to communicate through sounds and gestures, enjoys movies and books – especially cartoons – and loves to interact with their dog.

However, over the course of the past year, JD has not been growing well and has experienced significant reflux despite maximizing anti-reflux medications. He has experienced two episodes of aspiration pneumonia, which were managed with oral antibiotics, and has fallen off his growth curve for weight despite optimization of his diet. He continues to be exclusively orally fed. JD's physician has repeatedly recommended a gastrostomy tube (G-tube), which may help with many of JD's issues (ie, weight gain, aspiration pneumonia); however, his parents have consistently declined this option. Both the physician and JD's parents are becoming increasingly frustrated with this topic of conversation because they do not fully appreciate one another's point of view.

A common pitfall in situations such as this can occur when one party assumes that they know the other's intentions (1). Misperceptions about motivation and goals can be easily resolved through open communication. Therefore, in the present analysis, we will explore the perspectives of the parents and clinician and their intentions.

THE FAMILY'S PERSPECTIVE

JD's parents do understand that, for some children like JD, a G-tube would be the next step. However, they do not believe that for their family – and, importantly, for JD –this would be the 'right' option. Their rationale is multifaceted and includes consideration of their goals of care, which focus on quality of life and being good parents. Additionally, the ethical principles of autonomy, beneficence and nonmaleficence support the family's wishes.

Parents' desire to maintain good quality of life

JD's parents have always felt that they would do whatever they could to keep JD's quality of life high. To them, this means having more good days than bad, maintaining a level of interactivity with JD (ie, JD being able to respond to stimuli in a meaningful way) and, most of all, enjoying one another's company. Despite each feed taking 90 min, they believe that their time together during feeds is quality time. JD appears to enjoy it – both the taste of the food and the time together. They do not feel that his poor weight gain is significantly impacting his quality of life. Furthermore, research has shown that feeding tubes do not necessarily improve quality of life. A recent study assessing the quality of life of neurologically impaired children before and after G-tube and gastrostomy-jejunostomy tube insertion found that quality of life, as rated by caregivers, did not improve significantly one year postinsertion (2).

Being a good parent

JD's parents feel that by declining the G-tube they are parenting in a meaningful way by making decisions that will support what they believe is a good quality of life with minimal harm. At the heart of their decision is their desire to be good parents. Multiple studies have examined the concept of a 'good parent' (3,4). One study found that parents of children who have serious illness often describe themselves as trying to be a "good parent" by making care decisions in the child's best interest (4). In another study, parents described several themes that reflected what it means to be a good parent; these included "being there for my child," "conveying love to my child," "being an advocate for my child" and "not allowing suffering" (3). JD's parents want nothing more than to be good parents by loving JD, advocating for him and not permitting suffering. They truly believe that their decision to forego the G-tube is consistent with their definition of being good parents and, as such, they are sure that their choice is the 'right' one.

Respect for autonomy concerning parents

Autonomy can be defined as the right to self-govern, in this case exercised through a surrogate (5,6). JD's parents believe that maintaining a good quality of life is important. They believe that this is their autonomous decision to make, being JD's parents, and that it is in their son's best interest to maintain his quality of life, despite the consequences of a suboptimal weight. JD's parents would argue that the decision to forego a G-tube is theirs to make, even if it is controversial. They are JD's surrogate decision makers (SDMs) and have given no reason to question their ability to make decisions in JD's best interest.

Beneficence

The principle of beneficence can be defined as providing benefit(s) to the patient, but also should consider the net benefit and

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possible harms of an action (5,6). In the present case, JD's parents have weighed the potential benefits of a G-tube (ie, weight gain) against the harms of the surgery. They have also considered the risks and potential benefits of continuing to only feed JD orally. They have determined surgical intervention would not provide benefit at this time and only stand to decrease his quality of life.

Do no harm – nonmaleficence

JD's parents understand that while G-tube insertion may help their son's nutritional status, there are significant risks associated with its insertion and maintenance. The concerns that are greatest on insertion are peritonitis, pain, bleeding, infection and sedation from the procedure. In addition, there are concerns with ongoing infection risk, tube care and intussusception postinsertion (7). JD's parents also understand that JD's life expectancy will be shorter than his age-matched peers based on his medical condition. However, they do not believe that, at this point, his poor weight gain is having an impact on his longevity. As such, they have difficulty seeing the G-tube as anything other than a potential harm. Consistent with the ethical principle of nonmaleficence – to do no harm – as his parents, they cannot support the intervention because they view it as harmful.

THE CLINICIAN'S PERSPECTIVE

JD's physician has believed for some time that his nutritional status is suboptimal. Although, for many clinicians, this alone would be sufficient to recommend a G-tube, in the present case there are multiple additional reasons underlying this recommendation. Interestingly, they are similar to those of JD's parents and include beneficence, nonmaleficence and medical obligation.

Beneficence

The principle of beneficence is also relevant for the clinician. However, in the present case, the clinician believes that optimizing nutrition via a G-tube would very much be in JD's best interest. She believes that JD is at risk for aspiration with oral feeds, would benefit from optimized enteral feeding (eg, prevention of mucosal atrophy and preservation of the enteral immune system) and could live longer in his current state with G-tube feeds (5). Specifically regarding prognosis, she believes that by avoiding malnutrition, medical complications, such as bed sores, could also be prevented, thus minimizing harm.

Do no harm – nonmaleficence

The principle of nonmaleficence (doing no harm to the patient) plays an important role in the physician's argument (6). In addition to reducing the risk of malnutrition and aspiration, the clinician believes that JD could have a better quality of life if he did not require 90 min for each feed. She believes that the longer the feeds take, the higher likelihood of JD fatiguing and developing an aversion to feeds altogether. Finally, the physician does not have the same concerns as the parents regarding the risks of the procedure itself and, therefore, believes that it does not pose significant risk to JD.

Medical obligation

JD's parents' decision has created significant moral distress for the physician. Moral distress can be defined as the feeling "when there is incoherence between what one sincerely believes to be right, what one actually does, and what eventually transpires" (8). In the present case, she believes that it is her obligation to advocate for JD through the insertion of a G-tube. She also refers to the Canadian Paediatric Society (CPS) position statement regarding nutrition in neurologically impaired children. This article states that "[p]roviding adequate nutrition should be a priority when taking care of neurologically impaired children" (9). She believes that it is her fiduciary obligation to provide such treatment to JD.

Finally, she argues that the medical field has been charged with the responsibility to put the child's best interest ahead of the parents' interests. The physician believes the statement that "[a]ll infants, children and adolescents – regardless of physical or mental disability – have dignity, intrinsic value, and a claim to respect, protection, and medical treatment that serves their best interests", as stated in another CPS statement, 'Treatment decisions regarding infants, children and adolescents', supports her views (10). This same statement continues: "Although family issues are important and must be considered, the primary concern of health professionals who care for children and adolescents must be the best interests of individual children and adolescents." Therefore, she firmly believes that her recommendation of a G-tube for JD is the 'right' one.

MOVING FORWARD

The above examination does not offer any easy solutions, which is often the case when parents and health care providers disagree about what is in the best interest of the child. Below, we offer recommendations for moving toward a resolution of what can appear to be polarizing approaches. The role of a bioethicist will also be explored to provide insight into a position that could offer guidance and assistance for ethically challenging cases.

Clarifying the role of SDMs and 'best interest' standard

The role of SDMs is prescribed in provincial legislation (11). Parents are presumed to be the most appropriate decision makers for their children because of their special relationship and commitment; to act as decision makers for their children is also the parents' legal right.

Although SDMs must make medical decisions for children using the best interest standard, parents and health care practitioners alike may not be aware of how best interests are determined. Some may wrongly assume that SDMs are to make decisions based solely on what they understand to be the best medical option (eg, a combination of the highest chance of success and the least risky). The concept of best interest is a core ethical principle in paediatrics in Canada and internationally (12), and used as a legal construct for which SDMs are to make health care decisions (11). This concept requires considering a child and his/her interest broadly and not focusing exclusively on biomedical facts. It also must consider that children are embedded in family and that other family members have interests as well – this is the rationale for family-centred care, and is a concept that guides paediatric health care in many jurisdictions. Factors that should be considered include weighing the harms and benefits of various treatment options, including the potential for discomfort or pain and the complications associated with the treatment, any impairments that may result from treatment and the degree of and potential for benefit. As such, 'best interest' can be a broad and subjective concept. For decisions in which best interests are clear – where most rational people of goodwill would choose the same option – less focus is on the values and beliefs of the family (eg, a child who requires an emergent appendectomy). However, when a decision is unclear – rational people may disagree because the decision requires subjectivity – greater deference should be given to the parental decisional authority (eg, decisions pertaining to quality of life). In these instances, increased emphasis should be placed on the values and beliefs of the family and child. Best interests are often unclear due to uncertainty about outcomes or when subjectivity is a large part of assessing the consequences of a decision or lack thereof.

The ethical ideal for decision making in paediatrics is that health care providers and SDMs collaborate in the process, with health care practitioners generally contributing specialized knowledge of children and parents (and, when appropriate, the child) contributing knowledge of their child in this context. When available, a bioethicist is well situated to assist with this process. Their role includes working with stakeholders to find an ethically justifiable resolution to ethical dilemmas, facilitate discussion, and educate and clarify the roles and responsibilities of SDMs for both parents and health care teams.

Ensure informed consent

Informed consent is often regarded as the cornerstone of health care decision making. It is a particularly important concept when the decisions being made are materially significant, such as in the aforementioned case. When making decisions about a treatment/intervention (ie, G-tube) it is imperative that parents have sufficient information to make decisions. Generally, the necessary information for decision-making will include, at a minimum, the potential harms and benefits of the proposed treatment, the consequences of withholding a treatment and its accompanied trajectory, and the alternative options and their associated trajectories. However, some parents may require more information. When there are concerns pertaining to the appropriateness of the decisions of parents, extra time should be taken to ensure that adequate information has been given to achieve informed consent. No assumptions should be made that parents have sufficient background information or may not be interested in the information. Without full information, consent may not be valid.

In all cases, and particularly in a case like JD's, it is important to note that consent is not a static concept. Consent is decision specific but also time specific. In other words, as the health and well-being of the child changes, so may the value of the proposed treatment as well as the associated risks and benefits. As such, it is important that consent for the treatment and alternative options be reassessed over time. In the case of JD, options such as a trial period of an NG-tube may be appropriate to explore. Depending on JD's trajectory of health and quality of life, the need for a G-tube may become more compelling and no longer be considered in a 'grey zone'; correspondingly, less deference may be given to family wishes.

Support staff

Supporting staff working with patients and families where there is disagreement about the ethically viable course of action is paramount. Participating in integrity-compromising situations (ie, when an individual compromises his/her values and his/her actions does not cohere with what is believed to be the right or desired course of action) can result in moral distress, which "has been shown to have negative consequences, contributing to emotional distress (eg, anger and frustration), withdrawal of self from patients, unsafe or poor quality of patient care, decreasing job satisfaction and even attrition" (13). Providing outlets to address moral dilemmas may help to reduce such distress.

The bioethicist can offer two interventions. Ethics debriefs, which provide staff the opportunity to work through their feelings toward ethical dilemmas and conflicts, provide a forum to validate and support one another. Debriefings can enhance communication among teams, improve patient care and reduce the burden on staff (14). Ethics consultations that provide staff, patients and families the opportunity to navigate ethics issues and develop a strategy to address the ethics problems have been shown to be supportive, informative and helpful in resolving ethical dilemmas. A study evaluating ethics consults found that even when staff and families have not been in agreement with the outcome of the ethics consultation, the majority would seek an ethics consultation again and recommend it to others (15).

Permit conscientious objection

At the current juncture of the aforementioned case, the degree to which practitioners may feel their integrity is compromised would likely not fit with conscientious objection. We explore this concept for guidance in other cases in which there is more uncertainty about the appropriateness of artificial nutrition and hydration.

Cases centred on decisions pertaining to the provision of artificial nutrition and hydration are heavily value laden. As such, some members of the health care team may find themselves feeling that their integrity will be unduly compromised by participating in the care of a child for whom artificial nutrition and hydration is withheld or withdrawn. Conscientious objection is the refusal to comply with a medically sanctioned request based on personal, moral or religious reasons (16). Institutions should offer support to these clinicians and develop policies to permit, in some circumstances, recusal and transfer of care to another practitioner. Bioethicists can also offer individual consultations for staff to address their moral distress and explore ethically viable ways forward.

If health care practitioners choose to recuse themselves from a plan of care, it is important to be cognizant of the possible consequences for the patient and family. Personal and professional views can heavily influence patients' and family members' decisions (17).

Health care practitioners should invoke conscientious objection in rare circumstances and, most importantly, should ensure that patients and families are not abandoned, and provide a thoughtful, sensitive explanation for the transfer of care. A case such as JD's, as it stands, is unlikely to be appropriate grounds for exercising conscientious objection.

Legal outlet

There may be rare circumstances in which the physician and health care team believe that the parental decisions are clearly not in the best interest of the child; such decisions have significant consequences. When all other supports have failed, pursuing resolution through the legal system may be a last resort. Some provinces have quasijudicial bodies whose mandate is to preside over cases for which SDMs' decisions are questioned by the physician or health care team. For provinces that do not have such bodies, concerns are brought directly to the provincial court. Because health care practitioners have a fiduciary responsibility to the patient to ensure decisions are made in their best interest, there may be occasions when it is appropriate and necessary to challenge the decisions of parents.

In cases in which the parents or SDMs refuse to provide consent for a medical treatment and, as a result, the child will experience physical harm or suffering, there may be grounds for health care practitioners to report the parents to the child welfare agency. As per provincial statues on child welfare, such reporting is warranted, with concerns that the lack of consent is akin to neglect and that the child requires medical treatment to cure, prevent or alleviate physical harm or suffering (18).

POSTSCRIPT

In addition to exploring the case using ethical principles, the physician and JD's parents also used a narrative approach to understand one another's point of view. Taking the time to share with each other their stories, perspectives, views and values, they all agreed that a G-tube was not essential at this time and that the family's goals would be best met by not inserting one. Instead, they worked together to establish a feeding and medication regimen that would minimize reflux and optimize calories. They all accepted that he would likely continue to experience poor growth; however, as long as his quality of life remained high, this was something they could all live with. They agreed to reassess the need for tube feeds over time, including nasogastric tube insertion as a possible time-limited trial in the future to determine the utility of supplemental enteral feeds.

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