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Stories and the Longitudinal Patient Relationship: What Can Clinical Ethics Consultants Learn from Palliative Care?

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ABSTRACT

A case of conflict in pediatric end-of-life decision making is presented to compare the complementary roles of clinical ethics consultants and palliative care specialists. The progression of the case illustrates the differing structures, goals, and methods of the majority of such teams. The strengths of each of consultation are emphasized. Particularly in centers where palliative care services are not available, it can be important for careproviders and clinical ethics consultants to focus on alliance-building and a longitudinal relationship with patients and families.

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Sharon is a 14-month-old child who never learned to crawl, never picked up a Cheerio between index finger and thumb, never babbled, and never looked curiously at a toy. She weighed just under five pounds at birth, even though she was born only two weeks before her mother's due date. She was brought to the neonatal intensive care unit (NICU), where the team noticed she had unusually wide-spaced eyes and low-set ears. Her breathing would also slow ominously when she slept, and so she was placed on "continuous positive airway pressure"—a thick prong placed into each nostril, blowing air under enough pressure to keep her airways open and stimulate her breathing.

A geneticist determined that Sharon had a chromosomal translocation, meaning that a piece of one chromosome was misplaced on the end of another chromosome, most likely having lost some important genetic material in the switch. It is possible that the abnormality was inherited from a parent with a "balanced translocation," such that one parent might also have a shifted bit of DNA, but in such a way that all

the required genes are present. Someone with a balanced translocation would be completely healthy, and no problem would be apparent until his or her chromosomes split and mixed with another person's as egg and sperm join to make a new individual. As is often the case with such abnormalities, the team was unable to tell Sharon's parents exactly what the future held, but they anticipated that she would be significantly delayed in her motor, verbal, and cognitive development compared to other children.

Sharon never fed well, and eventually had a feeding tube surgically implanted through her abdominal wall into her stomach. Her parents struggled with deciding how aggressive to be with medical procedures, realizing she would likely not have a long life and might have a very poor quality of life. In talking with the medical team, they decided to place a "do-not-attempt-resuscitation" (DNAR) order.¹ Because of her complex medical needs, she was eventually discharged to medical foster care, although her parents retained full custody and full medical decision-making rights, and visited her often.

One year following her NICU discharge, Sharon was readmitted to the intensive care unit (ICU) with aspiration pneumonia. Her foster mother accompanied her to the hospital and her father arrived shortly thereafter. The team in the emergency department talked to her father about her respiratory status, explaining that she would likely die without intubation, and asked to confirm her prior "do-not-intubate" order and the family's desire to focus on her comfort without invasive measures. Her father hesitated, "She's a happy kid, even though she can't do much. I don't think it's her time to go yet. We want you to put in the tube. Try to get her through this."

The next day her mother arrived and was surprised to find that Sharon had been intubated. She realized that her husband asked to have the DNAR order reversed, but angrily stated that, "You had to have both parents put that DNAR on in the first place, you should have to have both sign to take it away!" The ICU physicians decided to call both the ethics committee and the palliative care team for help.

Both ethics committees and palliative care teams often address issues that arise when dif-

ficult decisions need to be made about end-of-life care or life-threatening illness. In some cases, an ethical quandary is apparent and the ethics committee is called, while in other cases there are no conflicts, but only concerns about symptom management, so palliative care is the obvious resource. But in many cases, such as this one, both issues arise.²

The format of clinical ethics consultations may vary at different institutions or even within institutions due to the requirements of specific cases. Some consults involve an individual consultant investigating an issue and rendering an opinion. Others use a small team approach, in which a handful of people meet with the various stakeholders and make recommendations. Others use a "full committee" model, in which a large group attempts to gather any who might have opinions related to the case (family, physicians, nurses, clergy, other staff, administration, and members of the ethics committee itself) in a room at the same time to hash out a solution.³ Most ethics committees do a good job of trying to listen to all opinions and gathering enough information to understand the differing perspectives that are causing conflict, whether the conflict arises between the team and patient or family, between team members, or within the family. The goal is usually to gather enough information to understand the ethical issues involved, ponder a range of potentially acceptable solutions, and work with the health-care team, patient, and family to build consensus and choose a mutually acceptable course of action. Sometimes ethics committees have to exclude certain courses of action as morally unacceptable or even illegal, but otherwise most try to avoid issuing mandates or ultimatums.⁴

Palliative care teams are usually much less focused on conflict resolution and ethical analysis than ethics committees; instead, they pay close attention to pain and symptom management and psychosocial needs at the end of life. Yet most palliative care teams also spend a great deal of time helping patients and families make difficult decisions about how aggressive to be with medical care, many of the same types of decisions that prompt calls to the ethics committee. Palliative care and clinical ethics con-

sultations are certainly not interchangeable, and most of the time clinicians have very different goals in mind when calling these two teams. There may be some strategies used in palliative care consultation, however, that would be beneficial for clinical ethics consultants to consider and adapt, particularly in institutions where palliative care teams may not be available and ethics committee members take on more challenging end-of-life conflicts.

When a palliative care team meets a patient, the team members usually expect that they will be following the patient and family over time. It would be rare for a palliative care team to help a family make difficult decisions and not continue the relationship. A palliative care team also tends to spend a lot of time getting to know the patient and listening to the patient's and family members' stories about the illness or about life. They do this for several reasons. Getting to know the patient and family helps the team to better understand the patient's values, which is of crucial importance when helping the patient and family clarify their goals of care and sort through difficult decisions. It is also usually therapeutic for the patient and family to be able to tell the healthcare providers about the patient's life when the patient is faced with the prospect of death. Sharing such stories helps to honor the life that has been lived, acknowledge an individual's importance to others, consolidate memories, and recognize the shared humanity of all who are coming together at the time of this death.⁵ The team is more likely to build an alliance with the patient and family the better they know their history; such an alliance will help the team best ease the often times difficult process of dying.

The longitudinal relationship of the palliative care team can be very different than the relationship developed by members of an ethics committee. Some differences naturally arise from the different goals of the two teams: conflict resolution versus ongoing support and symptom management. The ethics consultant is usually brought in as an impartial third party to mediate a dispute or provide specialized knowledge about what options are acceptable. For the palliative care consultant, however,

impartiality is almost never the goal. Building an alliance is more important. Most clinical ethics consultants realize they are at a disadvantage in not having this longitudinal relationship and frequently make use of others who do, by bringing a primary care physician or a subspecialist caring for a chronic condition into a conversation to help resolve a conflict.

Some of the differences in approach arise from the structure of the teams themselves. Ethics committees are usually composed of individuals from multiple disciplines who all have other roles in the hospital.⁶ There may be an ethicist on the committee or a leader in the group whose job description includes a significant amount of time devoted to the activities of the committee, hopefully accompanied by some financial support of that person's salary. For all of the other members of the ethics committee, their committee work is squeezed into whatever time can be found amongst their other duties.

Most palliative care teams, by contrast, are run as a clinical service. There are team members assigned to take care of the patients on the service, whether in the hospital or at home, and their clinical income is usually predicated upon providing that service. The team expects that their day will be filled with duties involved in caring for patients at the end of life, including helping them to make difficult decisions.⁷ Such expectations facilitate being able to sit at the bedside with a patient and family, and spend the time that it takes to get to know them and to manage difficult symptoms.

Sharon's case illustrates the different processes followed by the two teams, and highlights some advantages of each. The ethics committee rounded up committee members to meet with the physicians, nurses, parents, and the medical foster mother. They found that the father and medical foster mother thought that Sharon was somewhat interactive with her environment, had been "doing very well," and that it was "worth it" to try to support her through this episode of pneumonia, as she would likely be able to return to her prior quality of life. Sharon's mother, on the other hand, felt that the right decision had been made to make her DNAR, did not want that decision reversed, felt

that the endotracheal tube and suctioning were causing her daughter to suffer, and thought she should be extubated and kept comfortable, even if that led to her death. The medical team was uneasy with the conflict that had arisen, especially when the mother was angry. They felt that Sharon's quality of life was such that a DNAR order was appropriate and that it would be acceptable to extubate her at this point and focus only on comfort measures, but only if the family was in agreement that this was what they wanted for their daughter. The bedside nurses and respiratory therapists did not like the thought of Sharon suffering unnecessarily, but they felt that she was being kept relatively comfortable with her current levels of sedation. They were willing to accept whatever decision was made, but were hoping to avoid feeling trapped when disagreements occurred at the bedside.

The ethics committee arranged for a group meeting to have all sides hear each others' opinion. They met in a large conference room with Sharon's parents, eight representatives of the medical and nursing teams, and five members of the ethics committee present. After the above positions were delineated, the committee members felt that both of Sharon's parents were appropriate surrogates and that each was acting in what they saw as her best interests, with each parent's desired goal being a morally acceptable one. Since they were decision makers with equal authority, neither parent's opinion could automatically take precedence over the other. For the time being, the committee explained to Sharon's mother that reversing a DNAR order was not the same as writing one, in that consensus from both parents was not required to rescind it—if one parent felt life-sustaining measures were indicated, the team was obligated to “err on the side of life” until circumstances changed or a consensus was reached. The committee therefore recommended continuing mechanical ventilation and reconvening as a group in a week to see if there was any change in the prognosis, clinical course, or family's opinions at that point. Even though Sharon's mother's wishes were not immediately honored, she felt reassured that her voice had been heard and a reasonable plan was in place.

The palliative care team came by to introduce themselves. The nurse on the team had briefly met the mother during her neonatal stay. Sharon's mother remembered a conversation, more than a year past, when the palliative care nurse asked her how she was coping, whether she was eating and sleeping and taking care of herself. A physician, nurse, social worker, or chaplain from the team stopped by every day, singly or in groups, to talk with the family.

Every day the palliative care team asked whether Sharon was comfortable, and made recommendations for medication adjustments if she was not. They discovered that Sharon's mother was the sole breadwinner for the family. She had difficulty working full time and dealing with Sharon's condition, but she could not cut back at work because they were dependent on her health benefits. In fact, she had recently turned down a promotion because it would have increased her salary to a point that they might have lost the secondary state medical assistance that helped them cover Sharon's needs. She had bonded with one of the doctors in the NICU who had told her it wasn't necessary to prolong Sharon's life with invasive, aggressive measures, but she sometimes worried that she was being selfish when she expressed this view. She got to see Sharon only once or twice a week due to her work schedule.

Sharon's father had lost his job shortly before her birth. He felt guilty for not being able to provide for his family, but without having to go to work, he was able to visit Sharon at her foster home almost every day. He had enrolled in classes to try to become a licensed practical nurse in order to be able to better care for Sharon, and he hoped to bring her to live in their home one day in the near future. He had also reconnected with his childhood religious community since her birth and was now attending services at least twice a week and reading spiritual texts extensively.

Sharon's medical foster mother had cared for her every day for over a year and took great pride in how well Sharon had been doing. She felt that with stimulation Sharon was becoming much more interactive. She accepted that Sharon's parents were the decision makers for

their daughter, but hoped fervently that they would try everything possible to get her back to her base line health status. She lived closer to the hospital than Sharon's parents, and would rush to her side immediately for any change in her condition.

The palliative care team talked to both parents and the medical foster mother about how obvious it was that they were devoted to Sharon and were trying to make the best decisions possible for her. They also spoke with her parents about how trying a child's life-threatening illness can be for a marriage, and encouraged them to be patient with each other until they could reach a mutually agreeable solution that they could both accept and live with years into the future.

The resident physician on the team was frustrated. When he had been told by the father in the emergency department that "we" wanted Sharon intubated, he had assumed the father meant himself and the child's mother, and that Sharon's mother had been informed of the situation. By "we," the father had actually been referring to himself and the medical foster mother, who was present in the emergency department at the time, and he had not yet spoken with his wife. The resident was indignant when Sharon's mother angrily accused the team of not talking to her about rescinding the DNAR and not informing her of Sharon's condition, as the resident felt that the team had been misled by the father. The resident wanted to tell the mother his perception of the conversation so that she would no longer be angry with him. The palliative care physician convinced the resident that it was best not to split the parents by pitting them against each other, and that it was far preferable to continue to let the mother's anger be directed at the team for the misunderstanding.

The ethics committee intervention in this case was helpful to everyone; the process was a fairly standard application of an ethical analysis to a problem at hand, with planned follow up to see if the issue had been brought to resolution. The committee included all stakeholders in the information-gathering process, and also mediated between the mother and father in a way that was beneficial. The committee

reached enough of an understanding of the background of each member of the family to inform the decision-making process, but were unable to achieve the depth of understanding that is usually only possible after building trust through repeated interactions over time.

The time devoted by the palliative care team did not necessarily alter any of the decisions made in this case. Yet they put in the day-to-day, relationship-building work at the bedside that may have helped to ease the process of the hospitalization for the family. They also helped to assure that Sharon was not suffering. They were able to come to a better understanding of each individual's values than would be possible from an isolated meeting. The connection was facilitated because many of the conversations with the parents were one-on-one or with two people at the most, rather than in a conference room with more than a dozen people at the table. The ongoing discussions also helped each parent come to a better understanding of the other's point of view. Allowing this understanding to develop over time avoided emphasizing the "conflict" between the parents and let the team focus more on affirming that each parent wanted what was best for their daughter.

Is there anything that ethics committees can learn from the different model used by most palliative care teams? The majority of ethics committee members do a great job of listening to patients and families; such skills often lead to an individual being asked to be on the committee in the first place. They want to know the patient's and family members' stories. Yet it may take time and repeated interactions to build trust and develop a greater understanding. "Narrative competence" is easier to achieve when time and resources are available to focus on a patient and family.⁸

The importance of the longitudinal relationship is one reason for the ongoing crusade to integrate palliative care early in the disease process. Palliative care professionals find they can be most effective when they begin working with a patient and family before death is imminent, preferably from the time that an incurable disease is diagnosed. As palliative careproviders develop trusting relationships with the patient

and family, discussions about the goals of care can unfold naturally over time, alleviating or even completely avoiding conflicts about decision making.⁹ This anticipatory approach may also be useful to ethics committees. A few studies have described use of a proactive model for ethics consultation in the ICU setting, reporting shorter ICU lengths of stay, fewer life-sustaining technologies in the last days of life, and improved communication between healthcare teams and family members.¹⁰

The goal is not, of course, for clinical ethics consultants to become palliative care practitioners. The interactions are different precisely because each team has a different agenda.¹¹ Some authors have even debated whether clinical ethics consultants need to avoid behaving like clinicians, in order to maintain objectivity or neutrality, while others argue that some degree of clinical knowledge is invaluable to a clinical ethics consultant.¹² Yet perhaps ethics committees have something to learn from the palliative care model. They could better understand families if they follow up group meetings with frequent, individual interactions. Such longitudinal interactions will help them come to a more granular understanding of the problem at hand, rather than settling for an overly simplified breakdown into conflicting principles. Perhaps a longitudinal relationship could also demonstrate that supporting a family and winning trust often does more to resolve conflict than ethical analysis and logical persuasion.

Although it is not a component of a straightforward ethical decision-making process, some attention to preserving the psychological well-being and relationships of the key stakeholders could be an important consideration for clinical ethics consultants. The use of triggers for consultation and a more proactive approach might prevent many potential conflicts from ever reaching a crisis point. Hospitals should consider funding the time of ethics committee members so they can do a thorough job of building relationships and mediating conflict. Many ethics committees are experimenting with consultation models that involve mediation, for which listening and deliberation over time are essential skills. Many clinical ethics consultants

routinely perform all of these tasks with grace and insight on a nearly daily basis. Yet such practices are rarely considered standard operating procedure for ethics consultations.

Two weeks into Sharon's hospitalization, her parents agreed that they would not escalate care further. They asked the team not to resuscitate if her heart stopped, but wanted to wean her from the ventilator if she seemed ready to extubate. She would then not be reintubated, even if she decompensated. The ethics consultants talked with the physician and nursing teams to make sure that all agreed that this was a morally acceptable choice. The palliative care team sat with the parents and talked about how things might go once the tube was out, and what it might look like if, in fact, Sharon did die. Over the next few days the ventilator was weaned and the breathing tube was removed. Sharon struggled to breathe, and was supported with medications for dyspnea. One night her oxygen saturations began to inexorably drift downwards. Her nurse called her parents and suggested they come in, as she might be dying. They had a long drive, so the parents called the foster mother and asked if she could make it there to be at Sharon's side while they were on the way. Sharon died that night with all three "parents" at her bedside, taking turns holding her. She was comfortable, and her parents were grateful for all that had been done to help both her and them.

Sharon's medical team—and her parents—benefitted from the complementary services of both an ethics committee and a palliative care team. Many hospitals are not so fortunate, and their ethics consultants might find themselves the only resource for resolving conflicts. Incorporating aspects of the sustained narrative approach used by palliative care teams may, although time-intensive, allow for greater understanding, readier healing for both family and staff, and a smoother path towards resolution.

PRIVACY STATEMENT

The conflict described in the above essay was based on a real case, however, the clinical details of the case have been altered sufficiently

to protect the identity of the family and staff involved.

NOTES

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