ChiPPS Pediatric Palliative Care Newsletter
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Edited by Charles A. Corr, PhD, Christy Torkildson, RN, PHN, MSN,
and Maureen Horgan, LICSW

Issue Topic: Ethical Issues in Pediatric Palliative and Hospice Care

Welcome to the twenty-second issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some ethical issues in pediatric palliative and hospice care. These are, of course, merely a limited number of the vast assortment of ethical issues that arise in this field. Nevertheless, we hope this sampler will help to bring out some useful discussions and guidelines for readers of this issue.

This newsletter is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s Communications Work Group, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpc.org/pediatrics.

Comments about the activities of ChiPPS, its Communications Work Group, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at torkc@sbcglobal.net or Maureen at Maureen.Horgan@providence.org.

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Issue #21: Ethical Issues in Pediatric Palliative and Hospice Care

(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

A Perspective on Moral and Ethical Challenges of Everyday Health Care  p. 4
David M. Browning, MSW, BCD
David Browning, Senior Scholar at Children’s Hospital Boston & Harvard Medical School, shares an overview of his recent article focused on the ethics of intention and caring in the healthcare setting. He provides a link to a recent journal on Pediatric Ethics sponsored by the AMA.

Telling Him  p. 5
Mark Nassutti
Mark reflects upon his experience of telling his teenage son Andrew that there are no more curative treatment options for his brain tumor and that he will die. Mark’s poignant writing captures a father’s internal struggle to assure they are both as “ready” as possible for the unthinkable – Andrew’s death.

Whose Definition of “Right or Wrong” Are We Talking About Here?  p. 10
Ann Fitzsimons BS, MBA
“What’s best for my child?” Unfortunately there is no “right” answer to this question, especially when parents are faced with the likelihood of their child’s death. Ann weaves together the thoughts and reflections of several parents who have a seriously ill child or a child who has died. The article provides directives from parents to medical providers about how to “be with” them and respond to their inquiries without judgment so together the best possible care is provided.

Everyday Ethics in the PICU; Living and Dying in the “Gray Area”  p. 13
Kristin Meade, MD, and Sarah Friebert, MD
The numbers of children living with complex medical conditions have increased with the advancement of medical technology. The authors highlight potential conflicts that can arise in caring for medically complex children. Medical assessments, particularly when medically complex children are in crisis, are subjective and can under estimate the quality of life and baseline functioning of the patient. These assessments can lead to moral distress for the practitioner and the family. Various strategies for coping with this moral distress and conflict are discussed.

A Dying Child and Truth Telling  p. 17
Christy Torkildson, RN, PHN, MSN
The members of a pediatric hospice team work together to assure a child participates in legacy building and has the opportunity to explore the meaning of her death, while honoring her grandmother’s uncertainties and fear. Crystal’s story provides a framework for exploration of the ethical principles of autonomy and beneficence as we learn about this young girl’s preparation for death.

The Role of the Child in Decision Making  p. 22
Suzanne S. Toce, MD
Dr. Toce, Neonatologist at Gundersen Lutheran Medical Center, illustrates through a case study and examples the importance of encouraging children to participate in health care decisions based upon their developmental capacity. Her article provides an overview of “components of decision making capacity” that can be assessed by the health care team.
Decisions Related to Artificial Hydration and Nutrition  
Kelly Komatz, MD
Dr. Komatz focuses on the importance of recognizing artificial hydration and nutrition as a medical intervention that requires intensive supportive discussion with the medical team should a family consider discontinuing medical nutrition and hydration. Acknowledging the risks and benefits of the intervention and taking the time to fully understand a family’s perspective are essential to providing compassionate quality care for the entire family faced with such a dilemma.

Thoughts on Teaching About the Ethics of Pediatric Palliative Care  
O.J. Sahler, MD, and Jenni Linebarger, MD, MPH
Doctors Sahler and Linebarger reflect upon the question, “Where is the operating room in palliative care teaching?” They challenge readers to consider the importance of assuring students have the opportunity to learn “by example” by witnessing difficult conversations and then supporting the students as they practice. It’s a gentle balance of assuring best care for the patient and family and assuring future care givers are taught and experience “moral discourse.”

Sneak Peak: Module 3: Ethics, Decision-Making and Advance Care Planning  
In the Pediatric Palliative Care Training Series  
Suzanne S. Toce, MD
Dr. Toce, content expert for the "Ethics, decision-making, and advance care planning" module in NHPCO's Education and Training Curriculum for Pediatric Palliative Care, provides a brief summary of the Pediatric Ethics module, one of 10 modules of the soon-to-be released online learning pediatric palliative care educational series. She also provides a comprehensive list of resources on the topic of pediatric ethics.

Reader's Corner  
Suzanne S. Toce, MD
Dr. Toce provides a summary of a recent article in the AMA’s Journal of Ethics. The article provides a case study about a teenager’s role in decision making and how palliative medicine and oncology care can be integrated to assure compassionate patient-centered care.

Items of Interest
A PERSPECTIVE ON MORAL AND ETHICAL CHALLENGES
OF EVERYDAY HEALTH CARE

David M. Browning, MSW, BCD
Senior Scholar and Co-Director of Patient Safety and Quality Initiatives
Institute for Professionalism and Ethical Practice
Children's Hospital Boston & Harvard Medical School
david.browning@childrens.harvard.edu

If we want to address the moral and ethical challenges of everyday health care, we will need to expand our vision beyond a narrowly constructed medical lens and adopt a wider and more lucid perspective, one that honors the mind but also encompasses the heart, the spirit, and the relational world in which we all live. In order to see the right things and not lose our focus, we will need to learn differently together than we have heretofore. The first step in unraveling many of our wicked “macro” problems will be to discern the “micro” ethics that will help to solve them—things like treating people respectfully, telling the truth, listening to oft-silenced voices, and valuing the knowledge of patients, family members, and health care workers who are lower on the totem pole of power.

“Microethical and Relational Insights from Pediatric Palliative Care”

Good practice in pediatric hospice and palliative care requires a grounded sense of connectedness with children and families who are going through some of the most difficult experiences life has to offer. When we practice well in this domain, we bring an everyday ethical sensibility to our relationships with patients, families, and our fellow professionals. Doing this work gives us knowledge and insights that are applicable to many of the more challenging problems in mainstream health care facing us in the twenty-first century.

The excerpt above is from a commentary I wrote for the July 2010 edition of Virtual Mentor, the ethics journal for the American Medical Association. If you would like to read the entire article, it is available online to download at http://virtualmentor.ama-assn.org/2010/07/pdf/medu1-1007.pdf.
Someone has to tell him. Right? Someone?

It’s early October, 2001. My son Andrew, 16, has been fighting brain cancer for more than two years.

The cancer has won.

I’m walking away from a tearful conversation with Andrew’s high school homeroom class. At Andrew’s request, I’ve invited them for a visit. But now I have a problem.

At yesterday’s medical conference, the doctors said what amounts to “there’s nothing else we can do.” Andrew wasn’t in the room. I’m not sure how it happened that way, because he was almost always in the room, but this particular day he was down the hall channel surfing in the teen room at Seattle Children’s Hospital.

As we walk away from that homeroom, Bev, my hospice case manager, wonders aloud. “Does Andrew know as much, in concrete terms, about his situation as his friends now know?”

I have to consciously restart my breathing.

“He never got briefed after the last MRI,” she says, “and the decision to stop treatments. He was in another room, remember? We agreed Dr. Geyer would tell him, but he got called away. They never connected.” I came to this homeroom meeting assuming he’d been told. That’s my problem.

She doesn’t have to say it out loud. I already know who it will be, but I don’t like the idea. I’m scheduled to pick him up this afternoon from his mother’s house and have him for the weekend. The class will visit Sunday.

I know that if I ask Dr. Geyer to do it, he’ll just tell me it should come from a parent.

I know Andrew’s mother can’t do it.

But if I do it, she’ll hate me for it. We’ve been divorced seven years, pretty amicable until Andrew was diagnosed. Then, she pretty much shut down. She refuses to speak to me. She rolls her eyes whenever I ask questions in medical meetings, almost as impatient to get out as Andrew is. Key information like new meds or an ER visit for a seizure doesn’t get passed along to me. Our parenting plan means I sometimes have to endure up to 12 days without seeing Andrew, so I’m constantly blindsided. And on top of that, Andrew and my daughter Claire both tell me I’m constantly getting dissed by their mother and her new husband, no matter what I do.

I admit, I’m no angel. I’ve done my share of stupid things that made matters worse. But even if none of those things had happened, telling Andrew would be like throwing gasoline on a fire.
But he has to know.

He knows things aren’t good. Until yesterday, he’d seen every MRI and discussed every treatment, the potential benefits, the risks, the side effects. He’d been the decision-maker.

Until now, there’s always been something else to try.

He has to know. He has to have time to get ready. I swore 18 months ago that if he had to die, he would not die in ignorance, he would not die in fear.

It is that commitment, to him, for his sake, no matter what happens to me, that drives my decision.

I must tell him. Tonight.

At dinnertime, it’s just the two of us at my rough-hewn Mexican table. The house is silent. He’s rolled up in his wheelchair. I sit next to him. As I help him eat, he’s lucid and wide awake despite the potpourri of meds that manage his symptoms but sometimes rob him of speech. Conversation flows. Inside, I feel hollow but calm.

Now.

“Andrew. Has anyone told you the results of your last MRI?”

“No.” He locks his eyes on mine and won’t let go.

I can’t tell him unless I have his permission. “Do you want to know the results?”

“Yes.”

“It’s not good.” I take his hand. “There’s new tumor growth, in other parts of your brain.” His eyes tell me to go on. “The doctors can’t get at it with surgery, and the chemo appears to have stopped working.” I take a long breath. “I know, it seemed to help for a little while, but not anymore.”

“So I’m fucked.” Dry, straight to the point, no sign of emotion, just a hint of anger, his eyes still locked onto mine.

I look down, and shake my head. “Yeah, I’m afraid so, Andrew.” I meet his eyes again, search for something to say, something that will make it easier for him. Something that will break this increasingly awful silence. I resort to more facts.

“In the meeting, the doctors tell us there’s nothing more they can do. I didn’t like what they said so I phoned Dr. Geyer that afternoon, to ask him again if there was anything else we might try.” Andrew’s grip tightens on my hand. “He said there isn’t. We’re out of options. He said even if there was something, we probably couldn’t get you into the trial because they have certain requirements that you don’t meet anymore.”

“So I’m fucked.”
“Yeah.” I shake my head again. “Do you have any questions, or anything you want to say?”

“No.”

“Okay.” More silence. I remember something Bev had said was often helpful in this situation. “You should know that we asked, well, when it happens, how will it happen. He told us. Would you like to know that?”

“You mean, how I’ll die?”

“Yes.”

“When will I die?” So matter of fact.

“Nobody knows for sure. Dr. Geyer said it’s very unlikely it would be less than two weeks, and it’s very unlikely it would be more than six months.”

He rests, releases my hand to scratch an itch, then takes my hand again. “Okay, how?”

I feel calm now, a bit surprised about that. “You know the tumor has already affected your mobility. You’ve seen how it’s made it tougher for you to talk. That’s happening because the tumor is putting pressure on the parts of the brain that control those functions. What’ll happen next is you’ll get sleepier and sleepier. Eventually you’ll fall into a deep sleep called a coma. Then sometime after that, the tumor will put pressure on the bottom of the brain, the part that controls breathing. Your breathing will get more erratic, and then one day you’ll just stop breathing.”

“Will it hurt?”

“You won’t feel any pain.”

“How long?”

“I don’t know, Andrew.” After a moment, I ask again, “Do you have any questions? Anything you want to say?”

“No.” His eyes still hold mine.

“Are you scared?”

“Yeah.”

The silence feels unbearable. I have to say something. “Of what?”

He gives me that look that he always gives me when he’s about to say “you are such a dork.”

“Of dying.”

“What do you think it’s going to be like?”

“Scary.” The look.
I feel like I’m in a fog. “Do you think you’ll see anything or feel anything as you go through this?”

I hear a hint of wise-guy. “Scared.”

I look away, but he still holds my hand. After another long silence, I start to tell him about my beliefs. We talk about ancestors, about cultural traditions, about friends and family. Still holding his hand, my other arm wrapped around him over the top of the wheelchair, I tell him I believe my ancestors will be there on the other side, waiting to greet him. I tell him what I believe about souls choosing each life for what they will learn and what they will teach.

When I’ve run out of words, I kiss him on the forehead. I clear the table and do the dishes, he watches some TV. At bedtime, after I’ve tucked him in, I say, just as I’ve said nearly 6,000 times, “Good night Andrew. I love you. See you in the morning.”

Saturday is a normal day of television, video games and dinner at his favorite Mexican restaurant. On Sunday morning, it’s just the two of us for breakfast. I find him looking at me with those beautiful brown eyes of his.

“Andrew, you’re looking to me as if you’re looking, searching for something.”

“Uh-huh,” with that you-are-such-a-dork tone.

“So what is it?”

“The answer.”

“The answer to what?”

“Why?”

“Why what?”

“Why am I going to die before you? This is bullshit. The father is supposed to die before the son.”

Some tears come, and I yield to them, but feel thankful that he can talk about it.

That afternoon, his homeroom visits. This, too, was a controversial decision. Bev was an ambassador of sorts, visiting both households. She had told me she spent much less time there than here and pretty much was only asked to help with hygiene techniques, like the bed bath I’d given Andrew that morning (he thanked me for making him look great). I’d asked her if his friends had visited there, and she said Andrew’s mother “wants his friends to remember him the way he was.” Fair enough.

But to Andrew, to probably any 16-year-old, especially a popular one like him, friends are everything. I asked him if he’d like a visit. He lit up.

When I see the boys, I’m shocked. Only four months have passed since I saw them last, but they have all grown. They look healthy and tan and vibrant, and the contrast hits me in the gut.
But Andrew looks both elated and wistful when the visit ends. When I roll him out of the wheelchair van at his mother’s house that evening, a Sunday, I kiss him on the top of his head and say “I love you, Andrew.”

“I love you too.”

On Wednesday, my wife gets a call from the stepdad. It’s a crazed rant about how I’ve killed Andrew, that he broke down crying that morning and when they asked him what was wrong he said, “Dad told me I’m going to die,” that this is all my fault and that if I hadn’t interfered, Andrew would be fine.

I just wish I could have been there when Andrew’s tears came.

On a Wednesday two weeks later, my wife and I take Andrew to his favorite Mexican restaurant again. He can no longer hold his head up, or feed himself. Between bites of honey-drenched sopapillas, he tries to say something, but I can’t understand him. He tries again and again, and I shake my head in desperation.

As I drive him back to his mother’s in the wheelchair van, I hold his hand. The electric fuzzy dice he gave me for my birthday a month ago glow red under the rearview mirror. At his mother’s driveway, I roll the wheelchair out of the van and stop. Cradling Andrew’s head in my hands, I kiss him on the forehead. “I love you, Andrew.”

“Love you too.”

“See you Monday.”

What had he been trying to tell me? More fajitas? Pass the guacamole? Or, “I think I’m done.”

Two days later, Bev visits me at home. She had seen Andrew the night before at his mother’s and tells me that, based on the way he looked, spoke, and breathed, he’s getting close. Hours, maybe. She asks me if he’s ready.

“Yes,” I say, “yes. He’s ready.”
WHOSE DEFINITION OF "RIGHT OR WRONG" ARE WE TALKING ABOUT HERE?

Ann Fitzsimons BS, MBA
Pediatric Palliative/Hospice Care Family Advocate
AnnCompassion@aol.com

Webster defines ethics as: (1) the study of standards or conduct and moral judgment, and (2) the system of morals of a particular person, religion, group, etc. To go further, "moral" is then defined as "dealing with, or capable of distinguishing between right and wrong."

As parents of a seriously or dying child, we don’t think of the word “ethics” as we try to make decisions regarding our child’s care, but instead, about “what’s best for my child,” be it right or wrong. This whole topic is so loaded for parents, that it’s hard to know where to begin to share with you what it’s like to be us and to have to make the kinds of decisions that we often do regarding the life…and yes, even death, of our children. To start (or stop) feeding and hydration…to start/continue/stop treatments, to do/not do another surgery or procedure…to transition to or from palliative care…to sign on for hospice care…to decide that we’re done…and that it’s over.

At every twist and turn in our child’s journey toward death, we’re faced with countless “ethical” decisions that have no easy answers or solutions. Our mind and emotions are a tangled mess from which it’s hard to stand back and take an objective look at where we’re at in this journey, and make informed, rational decisions. This is our child—we can’t separate anything out to make the decisions clear, so we struggle, or we make decisions we have to live with for the rest of our lives, which nearly always have some kind of consequence. While this may be commonplace for you as a medical professional working in pediatric palliative or hospice care, this is probably (hopefully) just a once-in-a-lifetime situation for us for which there is no “Parent Guide” like “What to Expect in Baby’s First Year” that we can refer to for help finding the answers. We have to dig deep, or just react from our gut, or heart, or head, to be able to move forward and make the decisions you need us to make for our child as they arise.

You try to support us, help us, but in the end, the decisions are not yours to make…or to live with for the rest of your lives. And when we make them, you’re there, but we sometimes wonder and worry, “Are you judging us?” and “Did I do the wrong thing?” Yes, even with all we face, we sometimes (selfishly and stupidly) worry about “What you and others will think of us” for withdrawing nutrition from our child, for not doing surgery if there’s even a .00001% chance it could help, for not continuing with chemo or some other treatment, and all the other decisions we have to make in the course of our seriously-ill or dying child’s care.

We ask ourselves, others, and if we can find the courage and our voice in this process, we sometimes ask you, “What would you do if this were YOUR child?” Unfortunately, we sometimes ask after the fact as we live with our regrets, “What would you have done had this been your child?” Sometimes your answers are helpful, and sometimes not, but we nearly always appreciate you giving us an answer…telling us what you think, even if you don’t know or don’t have all the answers. In the long run, you have more of a perspective on this medically than we could ever hope to, so we need your advice, guidance, counsel. Some of us will hold you accountable for perhaps persuading us one direction or another after our child has died and we struggle with our grief and “What if’s,” but for others of us, we’re just thankful that you
chose to be a full-fledged partner with us in our child’s care, and in some life-changing decisions about that child’s future, or lack of one. We don’t want to walk this journey of waiting and watching them die alone, so we need you to help us make the little and big decisions about their care with us.

It would help if you could try to put yourselves in our shoes…to “be us” for a little while and imagine what it’s like for us to face what we’re staring down. Another surgery, another test/procedure, another treatment, more time in the hospital…the list goes on and on. We admit that we never really think about what impact this must have on you…to care for and invest so much of your professional and personal time in our child’s care…only to lose them in the end. We should, but we can’t and likely won’t, because we’re so wrapped up in our own worlds and worries about our and our child’s future…What will the side effects of a treatment/surgery be like? How long does he/she have left? How much will he/she suffer? What will the end look/be like?

However, as we are forced to make what could be life-threatening or life-ending decisions about our child’s care, try and see our side. Think about how it feels for us to withdraw life support and feel like you may be causing your own child’s death, or to stop feeding and hydration and feel that you’re starving your child. We hear what you say, that it’s the body’s way of starting to shut down, but that’s not how it feels to us. It feels like we’re killing or starving our child and what can possibly ever be “right” about that. As parents, it’s our job to love, protect, and nourish our children (among a million other things), but not continuing treatment/surgery, withdrawing life support, or withholding food or water is so counter to our basic parental responsibilities, that it can’t possibly seem like the “right” or “ethical” thing to do, so we may chose other options like continuing these therapies or treatments, even though they are of no benefit to the child.

We should be the people who know “what’s best” for our children, and in some cases, we are, but not always, because sometime “what’s best” is so counterintuitive to what should be best, that we simply can’t get our head wrapped around that stopping or withdrawing this kind of support, or not doing another treatment or surgery, is “what’s best.”

And when, or if, the time comes and we have to “let our child go”, well, how do you do that? How do you ever stop loving and hoping that this one time, that for this one kid, the result will be different. Our hope is a fragile thing and needs to be protected throughout this journey with our child, but it also needs to be given “reality checks” every once in a while to make sure we’re “checked in” and at least trying to be the best parents we can under the circumstances so we can make “good” care choices.

We’ll fight with you, we’ll scream at you, we’ll cry in front of you or with you, at times, we’ll even curse you, but it’s all part of the process of trying to partner with you to care for our child. To figure out what to do, to get some answers, or guidance, or even just hypotheses so we can make informed decisions with everything you know…so we can make a “good decision”…not necessarily one labeled “right or wrong.” When our child has died, there can be no “What If’s”, so help us turn over and examine every stone, so we don’t have those regrets as we deal with our grief and bereavement.

Ethics is a touchy topic when a child is seriously-ill or dying and also one that’s very subjective. We know you have a “Code of Ethics” you need to follow that essentially boils down to “Physician, do no harm.” However, if you turn the table on this, this is also the same unspoken “Code” many parents of dying children live by…”Parents, do no harm to your child.” In the slippery slope of what constitutes “harm” or
“no harm” and by whose definition, we will try to meet you, if you try to meet us. Please don’t judge us about what’s “right or wrong” (i.e., “what’s ethically advised”), but instead, help us to make “good” decisions that we can all live with during and after the death of our child, by:

- Educating us about our child's care plan and where this is all headed, and on what kind of timeline.
- Keeping us updated on changes in our child's condition or options to consider at critical junctures (e.g., treatments, surgeries, stopping, withdrawal, etc.) in clear, concise language we can understand and grasp.
- Not letting us be surprised about where we’re at with our child’s situation until it’s too late. You have to tell us when he/she is dying…it’s the “ethical/right” thing to do; be proactive about this and don’t make us keep questioning or begging for answers. And if we’re not asking (even though we should be), then tell us anyway.
- If you’re asked “What would you do if this were your child”, then answer the question. We value and respect your professional opinion. We know our children personally the best, but you know him/her medically the best. Let’s make an informed decision together. If you don’t know, then tell us that, but still providing even a personal opinion is better than leaving us to the wolves to sort this out on our own. Most of the time, we’re “drowning in sea of medical mayhem” and your opinion, professional and/or personal, may be our only life ring.

A physician once counseled a family member who had to make some medical decisions about her unborn baby’s care when a serious problem was discovered in utero. Despite all the tests, films, scans, etc., she could not tell my sister and her husband what to do. In this situation, it was not possible to make a medical recommendation as to “what course of action to take” given some unknowns that couldn’t be diagnostically tested for. But this Doctor didn’t leave it at that. She then gave them this advice, “In the end, the decision to make here is the one that six months or a year down the road, regardless of the outcome, when you’re shaving in the mirror or brushing your teeth, that you can look yourself in the face and live with the decisions you made here. The ‘right answer’ is the answer you and your family can live with when everything is said and done. Make decisions so that you have no ‘What if’s’ and you’re not second-guessing yourself for the rest of your lives.” This is “ethically-sound” advice from a Doctor who understood how hard it was for parents of a dying child to make the kind of decisions they were facing. May we all strive to do help parents of dying children make “ethically good decisions,” without our own label of whether it’s “right or wrong.” This journey for them is hard enough, let’s not make it any more difficult for them.

Contributor’s Note: This article was written as a compilation of thoughts and wishes shared by other families of seriously-ill or dying children, or who have had a child die, so it’s presented not as one family voice, but as many family voices weighing in on this topic.
EVERYDAY ETHICS IN THE PICU:
LIVING AND DYING IN THE “GRAY AREA”

Kristin Meade, MD
Haslinger Pediatric Palliative Care Division
kmeade@chmca.org

Sarah Friebert, MD
Director, A Palette of Care
Haslinger Pediatric Palliative Care Division
Akron Children’s Hospital
sfriebert@chmca.org

Jacob is a 14 year-old boy with cerebral palsy and intellectual disability due to a history of extreme prematurity and intraventricular hemorrhage. He suffers from recurrent seizures requiring multiple medications. He is wheelchair-bound and requires full assistance with all activities of daily living. He has a VP shunt for hydrocephalus, a baclofen pump for treatment of spasticity, and a G-tube and Nissen due to severe dysphagia and reflux. Because of worsening obstructive apnea and restrictive lung disease from scoliosis, he has required BiPAP at night for the last year. He is unable to speak, but can vocalize, smile, and recognize people. Four years ago Jacob was placed in an institution because the family was unable to take care of his multiple needs at home; however, his family remains actively involved in his care. Over the last 3 years, he has required 5 intensive care unit (ICU) admissions for respiratory distress attributed to aspiration pneumonia, each requiring prolonged intubation. After each illness, his baseline status deteriorated slightly, but he was ultimately able to return to his facility. During his most recent hospitalization, multiple staff members voiced their distress related to Jacob’s repeated admissions and the sense that the family was prolonging his suffering by choosing intubation and ICU-level care. On the other hand, the parents felt that his quality of life was still good enough between episodes to justify his admissions, and continued to pursue an aggressive plan of care. After a 4-week admission, Jacob was discharged back to his facility.

Cases like this one are ubiquitous in pediatric ICUs across the country. Each story has a different “flavor,” but the fundamental issues are the same; that is, what are the ethical principles related to the repeated use of aggressive, life-sustaining therapies in children with chronic, severe medical and/or developmental disabilities with a debatable baseline quality of life? While the extreme ethics cases capture the headlines and spur numerous contentious debates, cases like Jacob occur on such a regular basis as to feel almost routine. However, the ethical issues invoked can be some of the most difficult and distressing issues that medical providers face.

One of the unanticipated outcomes of the advancement of modern medicine is the dramatic increase in the prevalence of children with complex medical diseases and/or developmental disabilities over the last few decades, thanks in large part to the use of medical technology, complex multi-disciplinary care, and high-quality home nursing care. A subset of these children is considered medically fragile, meaning that they have complex chronic, multi-system diseases that require medical technology and intermittent-to-continual care to assure their safety and manage their complex needs. This population is often
characterized by their underlying medical instability and frequent utilization of acute medical care, ranging from clinic visits to inpatient admissions including ICU-level care. These patients often acquire the unfortunate label of “frequent fliers,” and their care is frequently a source of conflict within the ICU setting; disagreements are common, either between families and providers in relation to goals of care, or within the care team, in relation to the appropriateness of continuing or discontinuing aggressive care.

Best Interest Standard

Unlike adult medicine, where the principles of autonomy and substituted judgment guide decision making, pediatrics relies almost solely on the principle of the best interest standard, which stipulates that all medical decisions made by surrogate decision makers reflect the best interest of that child. In almost all situations, this is a notoriously subjective decision. Decisions for patients like Jacob with severe, chronic medical and developmental disability, however, magnify this subjectivity. These are patients that often fill the “gray area” of decision making; two different, devoted, and loving caregivers could appropriately make opposite decisions in the same situation, as these decisions are based on a values judgment, taking into account quality of life, suffering, and moral obligations. Based on an inherent selection bias, patients in this “gray area” whose families choose to continue aggressive medical interventions are becoming an increasing presence in pediatric ICUs and inpatient units.

Ambivalence and Moral Distress

With the continued improvement in available medical technologies, ambivalence related to the use of these treatments is a common dilemma faced by medical providers. While they may see the potential benefit of sustaining life through aggressive therapies and the use of medical technology, providers may also see the potential harm and suffering that comes from the use of these same treatments. Ambivalence, itself, does not lead to distress, but there is often significant overlap with moral distress, which has been defined as the distress felt when one has the impression that he or she is required to act against a core personal or ethical obligation based on an external force.

Many studies of moral distress have documented that providers often feel tremendous anguish when providing care to children or adults in situations where they may feel that the treatment is overly aggressive, is merely prolonging suffering, and/or survival would lead to such a poor quality of life that death might be preferable. Few, if any, studies specifically address moral distress related to the repeated utilization of acute care for this specific population. Nevertheless, anecdotal evidence suggests that many medical providers feel significant distress when they feel obligated to provide aggressive care to children like Jacob repeatedly, even though the decision maker feels that this care is ethically and morally appropriate.

Added to the complexity of the decisions is the realization that, typically, ICU-level care is not fundamentally futile; that is, aggressive care will likely return that child to or close to his/her previous baseline. Conflicts, therefore, arise from a more nuanced ethical perspective: providers (or decision makers) may feel that the perceived suffering from an acute care admission is excessive given the patient’s baseline quality of life and overall prognosis, or the acknowledgment that even if this child survives this hospitalization, he or she will likely return for the same or similar acute illness in the future. The difficulty with this argument is that it places all of the weight on a subjective assessment of suffering and quality of life, risk and benefit. Who, then, defines quality of life? What degree of “quality” is worth
saving through aggressive therapies, and which is not? This issue is at the heart of most conflicts over goals of care related to this population.

**Defining Suffering; Defining Quality of Life.**

It goes without saying that there is no mutually agreed-upon definition of quality of life or suffering within the medical profession. Such subjective assessments are as varied as the staff themselves, having been shaped by moral beliefs and personal and professional experiences. Even within a person, assessments shift over time, altered by new experiences, both positive and negative. Variability in the subjective assessment of quality of life and suffering is expected and, in itself, is not a problem. However, an increasing body of literature suggests that these assessments do have a dramatic impact on the decisions surrogates will ultimately make. As most deaths in the ICU (both pediatric and adult) now involve the active forgoing or discontinuation of aggressive medical interventions, physicians need to be acutely aware that their assessments and recommendations carry great weight.

Added to this inherent variability, medical providers often underestimate the quality of life of patients or their baseline functioning. An understanding of both of these dimensions is of utmost importance when setting goals, assisting in decision making, and determining appropriateness of forgoing or discontinuing aggressive life-sustaining therapies. Like Jacob, children in the ICU, by the mere fact that they are critically ill in the ICU, will not be at or near their baseline. This leads to the concern that providers may have a biased perspective on the appropriateness of medical interventions based on inaccurate information about a patient's baseline quality of life.

While the recommendations of the physicians and other staff may carry great weight, the final decision ultimately lies in the hands of the designated medical decision maker. There are extreme and rare situations where treatment (or non-treatment) is deemed to be either ethically obligatory or forbidden and a specific decision can legally be forced upon the decision maker. In reality, though, most medical decisions related to children with complex, chronic medical and developmental disabilities lie in the ethical “gray area.” As long as medical decision makers can argue that a decision is ethically appropriate and is in the child’s best interest, and there is no clear conflict of interest, medical providers are generally obligated to follow those wishes, even if they may disagree. Situations such as these often lead to conflict: in some, providers may feel strongly that suffering clearly outweighs any benefits and discontinuing aggressive treatment would be humane and selfless; in other situations, providers may feel that a decision maker is “giving up” on a child prematurely. In such unique and challenging situations, ethically appropriate decisions can still lead to great amounts of moral distress and conflict.

**Coping with the Conflicts**

Knowing that children like Jacob will likely become an even greater presence in acute care medical settings, it is of utmost importance that the medical community takes thoughtful and deliberate steps to address the ethical issues that have and will continue to surface. Systems need to be set up to allow providers to cope with their ethical distress in a positive and proactive way, in order to be able to respect and honor the rights of medical decision makers. This would include methods to insure effective communication amongst providers, so that the subtleties of goals of care discussions are shared with those who may not be privy to these discussions (particularly bedside nurses). Providers must be aware
of their own biases and be as objective as possible when guiding families through complex decision making.

Lastly, we need to create support networks for patients and decision makers, so that they can work through these complex decisions in sensitive, non-judgmental ways over time, appreciating that their decisions may shift based on the circumstances. Ideally, these discussions should occur prior to an acute illness, providing families with anticipatory guidance and educating them about the decisions they may ultimately face. Goal-directed advance care planning should be included in these discussions between families and their primary medical team(s) to clarify the patient's and family's wishes, as a proactive approach will not only be more beneficial to patients, but may also help to minimize moral distress among staff. Despite the best-laid plans, however, circumstances may dictate that such discussions take place in the ICU. When this occurs, interdisciplinary team conversations with patients and families, including the primary care provider(s), involved subspecialists, palliative care team, and ICU staff can result in improved adherence to goal-directed interventions and reduced suffering for all, including the care team(s).

Caring for this unique population carries with it both great challenges and great rewards. By being aware of the complex ethical underpinnings of the care provided to this population and finding ways to cope with the inevitable conflicts, we can maximize the rewards and minimize the challenges, in order to create a work culture that is both sustainable and meaningful.

References

A DYING CHILD AND TRUTH TELLING

Christy Torkildson, RN, PHN, MSN
University of California, San Francisco
torkc@sbcglobal.net

Case Study

Crystal was a 7-year-old girl dying from a brain tumor, a brainstem glioma, the type that accounts for approximately 10% of all intracranial tumors in children. Brainstem gliomas are incurable; 90% of all affected children will die within two years of diagnosis. Crystal was a very bright little girl, having outlived her prognosis by 2 years. She had spent those four years undergoing radiation therapy, receiving massive doses of steroids, chemotherapy with frequent and lengthy hospitalizations for a variety of reasons including active treatment for severe infections requiring isolation and intravenous antibiotics. I met her when her tumor was showing signs of increasing in size despite aggressive treatment. She was an engaging, mischievous little girl, full of life and dying.

Crystal was wise beyond her years. Speak to any professional who works with cognitively intact children living with a chronic medical condition, and they will confirm that these children know much more than most would suspect. Crystal knew she had a brain tumor, she knew she was extremely large because of the steroids she had to take, she knew she was no longer receiving the same treatments, and she knew that her arms and legs no longer worked the way they had before. Crystal also knew other children who had tumors, including brain tumors, who had died, having lost a number of friends made on the oncology ward. Yet her primary caregiver and mother figure, her paternal grandmother, would not discuss her prognosis or her condition with members of the healthcare team or with Crystal. When approached she would start to wail and say over and over that she would not listen, her baby was going to get better. She refused to discuss Crystal’s condition. She also made sure all members of the healthcare team knew that she did not want us to discuss Crystal’s condition with her.

Crystal continued to decline and soon one of her greatest joys, coming to the dining room and sharing meals with staff, patients, and family members became more of a burden for her. She was having trouble swallowing and the possibility of aspiration became a fear for the clinical team. She could no longer walk and was incontinent, suffering one of her greatest humiliations, the need for diapers. She was restricted to her bed or wheelchair and yet she still maintained her engagement with staff and visitors, still maintained an active interest in those around her – during the day. At night Crystal was withdrawn, refused to let the nursing staff get her out of bed, refused to eat, and would often push things away if anyone tried to tempt her with food, books, or other activities. Crystal’s mood changes coincided with her grandmothers’ departure for the day.

Based on this case scenario to whom should we be true in considering our principles and truth telling? As staff, do we always tell the truth to everyone? As professionals caring for families, do we always follow
the wishes of those families? When caring for a child, should we respect the child’s needs and what we think would be best for her? What follows is a basic discussion on the different possible principles that might guide us and conclude with the how we resolved the situation for Crystal, her grandmother, and the staff.

Discussion

This situation creates an untenable position for everyone involved in the care of a dying child, including the child, the family, and the healthcare providers. We know from earlier research that most children facing death are aware of their situation.iii As health professionals we often dance the fine line between truth and complying with the parents/guardians’ wishes, carefully choosing our words, giving vague responses, using euphemisms, or using techniques such as reflecting back when questioned.iv,v

Legally and ethically parents/guardians have full authority and responsibility for their children. Health professionals have a legal and ethical responsibility to be truthful. When faced with parents/guardians who feel as strongly as Crystal’s guardian did, the result is often strong moral distress and confusion as to the best course of action.vi-10

The issues about truth telling and the competent adult patient have been well described and commented upon in the literature. Debates center on truth telling continue, typically focused on specific adult populations, diagnoses, and cultural or religious issues, but the accepted tenet remains, as we learned in kindergarten, “honesty is the best policy.”vii,viii Fan and Li state, “Truth telling to competent patients is widely affirmed as a cardinal moral and biomedical obligation in contemporary Western medical practice.”ix It is important to note, for our purposes here, all topics under discussion relate to all healthcare providers and one can just as easily replace medicine with nursing, or any other discipline in healthcare.

There is little specific to pediatrics and truth telling in the current literature. However, there is a growing body of literature exploring informed consent with older school age children and adolescents. Until age 18 children do not have legal authority without specific exceptions. It is however, current standard of practice that if a child is cognitively intact that assent is ascertained, typically from age 7 to age 18 years.x

Pellegrino states, “human capability for autonomous choices cannot function if truth is withheld, falsified, or otherwise manipulated” (p. 472). O’Connor states, “The health professional is constantly faced with first defining truth, often no mean task, and then with communicating it appropriately to patients and families.”xi However, if children and adolescents do not have legal authority does it matter if they are told the truth? Whose autonomy are we serving? Are we debating truth telling with children simply based on a moral ideal? In revisiting our case study, it is clear that it is much more than just a moral ideal. It is a real and complicated dilemma seen all too often in pediatrics.

As a professional staff charged with caring for Crystal we “knew” that she must be having some thoughts and feelings about the changes in her body and her functional status. We were fairly certain that Crystal was not in pain as she consistently denied pain; but staff felt unable to delve into these possible fears/feelings because of the grandmother’s firm admonitions not to broach the subject of her prognosis with Crystal. How could we meet the needs of the staff, the grandmother, and Crystal? What were our ethical duties to our young patient, to her grandmother, to ourselves?

Beauchamp and Childress define a moral dilemma as a conflict between moral principles and rules, when a person must reconcile two or more alternatives yet cannot, while a practical dilemma is defined as a conflict between moral requirements and self-interests.xi A dilemma is “a situation in which conflicting principles allow no one answer to emerge as the right answer.”xii Ethical principles can guide health care professionals facing dilemmas to solutions that are considerate of all involved.
The ethical principles that may apply to this case include: a) respect for autonomy, b) beneficence, c) nonmaleficence, and d) ethics of caring. Miller states, “When treating adults, the norm of respect for autonomy has general priority… in pediatric contexts, in contrast, the norm of beneficence has general priority…”\textsuperscript{\textsuperscript{14}} Many take the emphasis on these principles as a good sign, indicating a movement towards a patient-centered care; however, in the world of pediatrics one could argue that our goal is family-centered care.\textsuperscript{\textsuperscript{15}}

One could argue that by abiding by the grandmother’s wishes we were emphasizing beneficence, we were respecting her authority and her position as the parent figure to Crystal. Some may also argue that it was nonmaleficient to not discuss Crystal’s impending death with her, that she was too young to have to deal with such terrible news, and that it was best to ”protect” her as her grandmother wished. Nonmaleficence is ‘to do no harm.”\textsuperscript{\textsuperscript{16}} Beneficence is defined as to do good for others. Positive beneficence requires balancing benefits vs. burdens to reach the best possible result.

Autonomy is the principle of self-direction and in order to be able to make the appropriate decisions for oneself there are two conditions that must agree must be met: a) freedom to make choices (liberty), and b) the knowledge and ability to make informed choices (agency).\textsuperscript{\textsuperscript{17,18}} Crystal is a seven-year-old little girl; many would argue that she did not need autonomy and that this principle did not apply to her or her situation. One could also argue that autonomy could be applied to the grandmother and the decisions she had made for her child. Although the grandmother would not discuss Crystal’s condition with any members of the healthcare team, there was no question that she knew that Crystal was in fact dying, that her brain tumor was progressing. To reach out a little further, one could also argue that we were denying the healthcare team autonomy in limiting their professional capacity and ability to talk to Crystal about her condition and pending death.

Ethics of caring emphasizes the relationship between the healthcare professional and the patient and family. The key is knowing the patient and family. As noted by Glass and Cluxton, “Sir William Osler captured the essence of the ethic of care when he said, ‘It’s more important to know what sort of patient has the disease, than what sort of disease the patient has”’ (p 236).\textsuperscript{\textsuperscript{30}} This can be a difficult principle for some to embrace as it veers from the traditional principle-based approach to ethics, which is based on rights, duties, reason, and objectivity. Ethic of care is based on relationships, emotions, and engagement with patient and families. “Caring …refers to care for, emotional commitment to, and willingness to act on behalf of persons with whom one has a significant relationship” (p. 369).\textsuperscript{\textsuperscript{24}}

A very real dilemma in ethic to care is the requirement and emphasis on relationship. This is a difficult dance in pediatrics as it is all too easy to blur professional boundaries with children. The emotional attachments can hinder objectivity, color decisions, and interfere with parent/child relationships. These relationships can also open the door to communication and enhance the parent/healthcare provider partnership in caring for the child. This relationship can help enlighten other members of the healthcare team to the needs and wishes of the child and family, as was the case with Crystal.

\textbf{Conclusion}

Interdisciplinary team meetings were held weekly and the subject of Crystal and her grandmother was always at the top of the list. How would we handle this, what was the best course of action, how could we meet everyone’s needs (Crystal, grandmother, and healthcare team)? The decision was to use the ethic of caring and work on building a relationship with Crystal’s grandmother. To date, the only interaction most had had with the grandmother was in the patient-family conference where she would cope by
starting to wail, literally bringing the meetings to an end. We were able to discern that the grandmother was overwhelmed and intimidated by the healthcare team. For Crystal, the special relationships with members of the healthcare team helped to identify her very real need to talk openly about her condition and pending death. This dialogue allowed us to demonstrate to the grandmother how much Crystal knew of her condition but was scared to talk about due to her fear of upsetting her grandmother.

The healthcare team was able to take this information and develop a plan to work with the grandmother and with Crystal. Two members of the healthcare team made a contract with the grandmother to meet with her twice a week and answer any questions she had. She in turn would allow us to answer any questions that Crystal posed. As long as we did not initiate questions, we could discuss whatever subjects Crystal broached. When Crystal started the discussion about why her body wasn’t working right anymore, we were able to have a wonderful, albeit gut-retching discussion about her brain tumor, her life, and pending death. We were able to discuss the fact that her grandmother could not talk to her about her condition because she loved her so much and it made her sad, but that she knew how important it was for Crystal to have her questions answered and to talk about whatever was bothering her. We reached the point where grandmother would stay in the room and hold Crystal’s hand on one side of the bed while we sat on the other talking with Crystal about her dreams and plans.

In the time she had left to live Crystal was able to have bake sales (courtesy of an Easy Bake Oven®) and a lemonade stand. Along with puzzles she and her child life therapist glued together, Crystal sold her wares at her “roadside stand” in the hallways. Crystal raised her own money to buy her sisters presents for birthdays and Christmases that would happen after her death. She was the princess at her “Hello Kitty” ball, complete with her “kings men” escorting her in full tuxedos. She dictated her will and decided which of her toys would go to her sisters and other friends she had made at the hospital. She was able to talk about her fears; the most pressing that she would be forgotten. Crystal was able to tell us how she wanted her funeral to be different than the ones she had been to, she only wanted pink flowers and she wanted happy music – which she chose. Crystal lived with us for 6 months from the time of her admission to her death and she has been one of my greatest teachers.

Any healthcare provider may face similar challenges when caring for any child with a life-threatening condition. As in this case, young children often know much more than what adults expect. The ability to acknowledge their fears and to provide a forum for expression and reassurance should be considered standard of care. Both the American Nurses Association’s Code of Ethics for Nurses and the American Medical Association’s Principles of Medical Ethics speak to the need to deal honestly with patients and families and to have their best interests at heart. Day and Benner note, “The nurse perceives herself as first caring about the family and primarily wanting to help them to understand the situation” (p. 78). It is important to note that this may mean, “adherence to moral absolutes (such as truth telling) in all cases and circumstances may do more harm than good” (p. 30).

In closing, consider this quote from John Tyerman Williams in Pooh and the Philosophers, “his arms were so stiff from holding on to the string of the balloon all that time that they stayed up straight in the air for more than a week” (p. 15). What a brilliant picture of the way in which habit and emotion may cling to a belief that evidence and reason has rejected. This same paradox may give rise to many of the causes for moral distress. We need to continue to communicate and work as interdisciplinary teams not only to best care for our children and their families but to reinforce our own support network.

References


The role of the child in decision making: Suzanne S. Toce, MD

There is growing awareness that not only are children capable of participating in health related decision making, but they ought to be supported in this role. In 1968, Dr. Billy Andrews in his Children’s Bill of Rights noted:

“…That the personhood of each child be fully appreciated and that each be informed of all matters including health as they grow in intellect and in capability; and that they learn to be involved, as maturity allows, and to participate in all decisions concerning their well-being.”

It took over 20 years for the United Nations to catch up to this pediatrician in the UN Convention on the Rights of the Child in 1989:

“States parties shall assure to the child, who is capable of forming his or her own view, the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”

Not surprisingly there has been an evolution in thinking with respect to the role of the child in the family and in society. Prior to the 19th century, children were thought of as property and it wasn’t until the mid 20th century that the child’s interests were deemed important to society. With respect to decision making, for younger children, we think about assent (willingness to accept treatment) and for older children/adolescents we consider consent (agreement by an autonomous person). For all children, parental permission can be waived in emergencies and where child abuse/neglect is suspected. For many years, some states have allowed “mature” or “emancipated” minors such as those living independently, in the military, married, and who are mothers to legally consent for themselves. Adolescents over 15 years can provide consent with reproductive, STD, substance abuse, or communicable disease issues. In addition, new data have emerged showing that even young children who have chronic disease have developed the competence to participate to some extent in decision making.

The current model of shared decision making includes informed parental permission, child assent, and, for minors with decisional capacity, involvement and providing informed consent in making health care decisions. After assessing the child’s capacity, we as health care providers can support the child from whom we are seeking assent by helping her or him understand the condition, treatment, and consequences. We should offer only acceptable choices and solicit uncoerced willingness/assent for the treatment. Some examples where assent should be sought are:

- Venipuncture for a diagnostic study in a 9 year old
- Diagnostic testing for recurrent abdominal pain in a 10 year old
- Psychotropic medication for attention deficit disorder in a third grader
- Orthopedic device to manage scoliosis in an 11 year old
- Alarm system for enuresis in an 8 year old
- Cosmetic surgery for a malformed ear in a 12 year old

AAP Committee on Bioethics 1995
Some examples where informed consent should be sought include:

- Pelvic exam in a 16 year old
- Diagnostic evaluation of recurrent headache in an 18 year old
- Request for contraception in a 17 year old
- Long term antibiotics for acne in a 15 year old
- Surgical intervention for a bone tumor in a 19 year old

AAP Committee on Bioethics 1995

Remember that if a minor is deemed competent to provide informed consent, then dissent should be accepted as well.

But how do we know if a child is capable of providing assent or informed consent? After all, immaturity is characterized by changing values and goal, focus on the present rather than future, poor sense of identity, and focus on bodily appearance. **There are no tools to assess the child's competence to participate in decision making.** However the Midwest Bioethics Center has proposed components of decision making capacity that can be assessed by the health care provider:

- Cognitive capacity: Ability to comprehend information
- Emotional capacity: Voluntariness
- Reasoning: Ability to deliberate about choices in accordance with personal values and goals
- Social capacity: Degree of independence with respect to family and society
- Ability to communicate verbally or nonverbally to providers

Health care organizations have the responsibility to create an environment that respects the child as a person and supports child and family-centered decision making. Policies and procedures outlining the role of the child in decision making and conflict resolution will support the essential role of the child. As health care providers apply these principles, they should bear in mind that decisional capacity is not necessarily determined solely by age or developmental phase. Children with chronic illness have knowledge of their illness/condition that is greater than that expected by age. Cultural or religious traditions may influence the role of the child within the family and how decisions are made. Increasing treatment or non treatment risks will mandate increasing certainty about the capacity of the child to provide assent/consent. As with adults, neurologic injury, psychiatric illness, medication, and pain may impair decision making.

Clearly infants through preschool have no capacity, and parents guided by the health care team make decisions on the child’s behalf based on the child’s best interest. For children with developing capacity such as those in primary school, parents provide permission. The child should be provided with developmentally appropriate information, and should have assent sought. Dissent should be taken seriously. Most adolescents/senior high school young adults should work with their parents and health care providers to determine an appropriate course of treatment. They are capable of providing informed assent or dissent/treatment refusal and should participate in any conflict resolution.

**Case 1:** Jamal is an 8 year old with leukemia. He gets multiple blood draws that in the past have caused him great distress. The health care team working with the child life therapist gave him choices about site of venipuncture, direction of the antiseptic swab, where he would be when the blood was drawn, etc. Now, when his choices are respected, he is calm and in control. (But when a new nurse tried to draw blood not knowing his preferences he became inconsolable.)
Of course, children can’t participate in decision making concerning their health care if they are not informed of their disease state, prognosis, and treatment options. Some family members fear that disclosure will cause anxiety in their child, the child won’t be able to handle “the whole truth,” or the child doesn’t wish to know the truth. The fact is that children frequently know that they are ill and/or dying. Disclosure can frequently decrease the isolation and feeling of abandonment that occurs when the child knows that parents or health care providers are not being truthful. In fact, disclosure may actually relieve anxiety, foster trust, and restore control to the child. The child can better participate in important health care decisions, including those about palliative care. When asked, children with cancer wish information about diagnosis, prognosis, relapses, and treatment failures. They want to be actively involved in all phases of decision making including those involving palliative care and hospice.

Case 2: Amanda is a 15 year old with a recurrence of Ewing’s sarcoma, a bone cancer. Her friend who she met in the pediatric oncology clinic died from this same cancer a year ago. She knows that there are no more treatments that are likely to improve her survival. She is scared that she will die in the hospital far from her friends and her dog. But her parents will not talk about this. Amanda feels totally isolated. Her parents want the pediatric oncologist, Dr. Williams, to try an experimental drug that is being tested for safety. Furthermore they want the physician to promise that she will not tell Amanda that she is dying. Dr. Williams reminds the parents of their previous discussion when she emphasized the professional obligation for truth telling and that, when asked, she would provide Amanda with accurate information.

Dr. Williams suggests that she, the parents, and the team psychologist meet to assess what Amanda already knows. By asking open ended questions about what Amanda fears, it is clear to everyone that Amanda knows she is dying. This allows everyone to discuss how Amanda wants to spend her time remaining: Phase I drug trial in the hospital or home with hospice/palliative care services. As Amanda knows that her primary goals are to say goodbye to friends, family, and her dog, she chooses to go home. Parents are sad, but understand that Amanda is making a choice consistent with her own values and they agree with her choices.

In conclusion, all children should be encouraged to participate in decisions concerning their health care to the extent appropriate to their developing capacity. This capacity may be greater than expected based solely on the child’s age. While there are no tools to assess capacity to participate in decision making, there are components that can be evaluated. However, without disclosure of the diagnosis, prognosis, treatment options, and consequences, the child will be denied the basic human right of participating in decision making.

Resources


DECISIONS RELATED TO ARTIFICIAL HYDRATION AND NUTRITION

Kelly Komatz, MD, MPH, FAAP, FAHPM
Medical Director, Community PedsCare
Assistant Professor, Division of Community Pediatrics
University of Florida College of Medicine at Jacksonville
kelly.komatz@jax.ufl.edu

KC is a 12-year-old female with congenital toxoplasmosis who has spastic cerebral palsy, is minimally communicative, and receives gastrostomy tube feedings and supplemental oxygen at night. KC has been cared for at home by her family with the support of in-home nursing in the evenings. Over the past year, KC has experienced increasing symptoms due to progression of her disease including progressive scoliosis, increased contractures, and difficulties tolerating ADL’s. KC’s family is focused on comfort care, looking at quality of life, and not wanting to pursue surgical interventions. KC began to experience discomfort with her gastrostomy tube feedings with increased respiratory and heart rates, abdominal bloating, and at times frank vomiting. After many discussions with palliative care team members, the family agreed to discontinue her enteral feedings and focus on comfort measures with adjunct pharmacological interventions. KC died peacefully at home surrounded by her family, palliative care nurse, and home-care nurse several days later.

TK is a 10-year-old male who is admitted to the pediatric intensive care unit due to acute respiratory distress/decline. TK has Batten’s Disease and has experienced significant decline over the past few months. TK’s family does not want to pursue invasive pulmonary interventions including no intubation for ventilator support. TK’s family has decided to allow for natural death in the inpatient setting. The inpatient palliative care physician discusses with the attending physician comfort measures and removing the noninvasive positive pressure mask, using nasal cannula oxygen, and discontinuing the intravenous fluids. The PICU attending physician is not comfortable with turning off the intravenous fluids.

Artificial Hydration and Nutrition (AHN) is one of the most distressing issues that come to light when working in palliative and hospice care. The decision about withholding or withdrawing AHN is not unique to pediatrics but is a heated discussion in the adult world as well. The American Academy of Pediatrics Committee on Bioethics released a Clinical Report in August 2009, “Clinical Report – Forgoing Medically Provided Nutrition and Hydration in Children (Pediatrics Vol 124, No 2, August 2009, pp. 813-822) that reviews in detail the issues at the heart of making this decision.

At the crux of the debate is whether or not medically provided nutrition and hydration is viewed as a life-sustaining medical treatment akin to continuation of a ventilator, dialysis, ECMO, etc. Further distress comes when making the decision between “forgoing” or never starting an intervention and the actual discontinuation of a medical intervention. Bioethics committees and experts see no ethical or legal distinction between not instituting a treatment and discontinuing a treatment already initiated. (Guidelines on Forgoing Life-Sustaining Medical Treatment, Pediatrics Vol 93 No 3, March 1994).

One of key points is in the understanding and acceptance of definitions and consistent use throughout the discussions with the family and caregivers. Starving to death is fraught with psychological and religious difficulties when a family is faced with that decision. But it is important to remember that delivering artificial nutrition via feeding tubes (nasogastric, gastrostomy tubes, etc.) and intravenous fluids is a
medical intervention similar to a ventilator and other medical interventions commonly found in the intensive care setting.

Palliative care personnel are essential team members when these discussions are being held with the family. If a hospital has access to consult a palliative care team, it should be done early on when such discussions are being had with the family. The perspective from a palliative care focus includes controlling pain and symptom relief. Pain and symptom relief is often viewed as prescribing medications including opioids and anxiolytics. But the focus of palliative care includes the domains of psychosocial and spiritual support as well.

At times, the continuation of artificial nutrition and fluids has been shown to increase suffering as the end of life draws near. Patients who are receiving tube feedings are at risk of having regurgitation and aspiration that can cause further respiratory compromise. Receiving intravenous fluids during the end-of-life process has been associated with increased respiratory distress and extremity swelling. Symptom relief from discontinuing artificial nutrition and fluids is usually a necessary part of allowing a comfortable and peaceful death.

There is a wonderful document, “Making decision about food and water at the end of life – A guide for patients, families and friends.” available by Froedtert Medical College Palliative Care Program (Medical College of Wisconsin) that provides a quick overview of artificial hydration and nutrition and defines terminology for families. It also includes a decision-making tree or questions for both families and physicians to consider when specifically discussing the benefits of discontinuing medical nutrition and hydration.

It is important to understand the family’s perspective of what they envision as a comfortable death and address their concerns and questions in detail to assist with this difficult decision. Part of the discussion is to ensure that the goals of therapies and the benefits/side effects are understood. Is this a child who is dying from or will die from his or her disease and the interventions are only prolonging the dying phase OR is this a child who is expected to make a recovery from the current acute medical condition and therefore should be sustained using life-prolonging interventions. In the situation where a child is dying from a progressive illness, the child might not be able to tolerate enteral feedings as this creates a physiologic burden in his or her body while it is in the process of “shutting down.” Also, intravenous fluids require maintaining a line and this can become cumbersome during end of life.

Decisions related to artificial hydration and nutrition need to be evaluated in the same manner as other decisions are made related to medical interventions. The risks and potential benefits need to be determined given the current state of the child, the goal of the proposed medical intervention, and the preference of the patient/family/caregiver. Medical personnel need to recognize that artificially provided nutrition and hydration is a medical intervention/treatment and should be discussed in the same way as they would approach withdrawal of a ventilator or allowing natural death order.

References
When considering teaching about the ethics of pediatric palliative care, many difficult issues come to mind. To approach these ethical complexities, it can be helpful to use a framework of moral reasoning. Four principles of common morality are frequently cited in the health care literature: autonomy, beneficence, nonmaleficence, and justice. The principle of autonomy underlies key decision-making issues: assent, mature minor status, shared decision-making, as well as surrogate decision-making for infants or children who never have and never will make their values known. The principles of beneficence (to do what is good and helpful) and nonmaleficence (to not inflict harm) play out at the bedside when questions of suffering and decisions about withholding or withdrawing ineffective or too burdensome interventions must be addressed. The principle of justice captures yet another set of issues that might be termed societal and involve matters such as cost – both to the population as a whole and to the family in particular – and the allocation of scarce resources. Justice, in this sense, is almost always easier to apply in the abstract than in the presence of the individual. Other issues which do not fall into the framework as easily, might be termed spiritual or existential and have to do with defining quality of life, the meaning of suffering, and the meaning of having lived and died.

A uniquely medical dilemma, because the physician writes the “orders,” stems from questions about the application – or not – of any treatment: If we can do it, should we do it? And if we should do it, to what end should we do it? And, finally, who decides?

While physicians may write the orders, and bear the responsibility for what that authority entails, these orders have an impact on those carrying them out and/or supporting the patient and family. Under the best of circumstances, decisions are made in concert with not just the patients and their families, but also the team members caring for them. When this process is not shared, the result can be a confrontation of conscience. To do or not to do what has been “ordered” becomes the dilemma. Without question, what is “right” to do is what is in the best interests of the patient. But how do we know what that is?

The question of whether or not to provide certain types of care has arisen from the major advances of medicine. We have become able to treat almost all infections, sustain neonates at 23 weeks gestation, and transplant virtually any organ of the body – in some cases, multiple times.

What has often been lacking in our education of physicians has been teaching about when to show restraint, how to define quality of life, how to communicate with patients and their families in such a way
that they not only know (have been informed) but also feel that they have choices in how their life will be lived, and ways to share this information amongst the treatment team.

There are many ways to teach about these issues: books, lectures, video clips, standardized patients, small group discussions, debates. These all have their place, and the literature shows changes in knowledge or attitude following one or another of these experiences, thus validating their usefulness. We would argue, however, that the best way to learn this aspect of the art of medicine is through apprenticeship, one of the oldest and most effective methods of sharing formal as well as tacit knowledge between "expert" and "novice" learners. At its most crude, it is "see one, do one, teach one." At its most refined, it is the senior surgeon guiding the sixth-year resident through a delicate hours-long neurosurgical procedure.

The first instance can be thoughtless mimicry. The second instance is a carefully planned approach with thoughtful contingencies, and constant attention to the patient's status and ability to endure. The procedure is fully orchestrated with layers of professionals supporting the surgical team and the patient. Problems are quickly identified and alternative solutions are weighed. Non-beneficial maneuvers are discarded in favor of those that seem most likely to produce the best possible outcome. Time is of the essence, but not at the expense of the patient's likelihood to survive the procedure. Patience, logic, and reason must prevail at each step.

Where is the operating room in palliative care teaching?

It is probably no surprise given this analogy that one of us (OJS) was taught how to talk with families by a cardiovascular surgeon. The time was 40 years ago when bypass surgery was in its infancy and the mortality rate approached 30% in the immediate post operative hours. A young adult man, father of two children with a pregnant wife, had chosen to undergo the procedure as the last hope for living more than a few months longer. He had done well for the first couple of hours in the recovery room, but then had a cardiac arrest. While resuscitation was being performed, the surgeon called the man's wife and asked her to come to the hospital because her husband "wasn't doing well." He recommended that someone drive her and suggested that they meet somewhere quiet, the chapel. After he finished the call, he ended the resuscitation. I asked if I could accompany him to the chapel and he immediately said no. I tried a couple of other times and then, finally, said, "If you don't teach me, who will?" Perhaps it was the recognition that he held a critical skill that swayed his decision as he let me join him with the stern admonition: "Sit in the corner and don't say a word."

I learned more about talking with families in crisis in those brief minutes than I had learned in all the preceding years of medical school. I learned that shock can be so great that no tears will come. I learned that it is vital to reaffirm the family's love for the one who has died and that the decisions that had been made were carefully considered and the best at the time and place. I learned that it is important to make a follow-up appointment for a week or so after the death as a sign, in this case to the wife, that she would get through the next few days and she would have a chance to reflect on her husband and his illness and his death. I learned that even a busy, intrepid surgeon doing pioneering procedures caught his breath when he talked about the death of his patient. I also learned that he had made the unilateral decision to stop resuscitation to spare the wife making the decision to withhold further treatment in what he deemed to be a futile effort that would extend, not living, but dying.
Students tell us all the time that they want to accompany the attending physician when he or she gives bad news, talks with a patient and family about goals of care, sits at the bedside while a child dies, attends calling hours or a funeral, or writes a letter of condolence. They want to watch, listen, and learn. Unfortunately, frequently they only hear an attending’s initial reaction: the “no” of the cardiovascular surgeon. Many give up their quest for knowledge in the face of rebuke. Yet, the responsibility lies with us to embrace our role of teacher, rather than our gut instinct to “protect” the patient and family from the learner…or to protect ourselves from betraying our own vulnerability to feelings of guilt? Inadequacy? Caring deeply?

Students seek to mimic the skills and techniques of the teacher, but eventually we must urge them to seek to develop their own unique style of caring. It is not our place to clone but to practice authentically and let them choose what they have seen that fits their personality and belief system. Ideally, after seeing the attending physician in these moments, students are given the opportunity to perform while being directly observed, just like the sixth-year neurosurgery resident, and then to receive constructive feedback that allows them to grow and perfect their skill.

In summary, then, how do we teach about the ethics of end-of-life care? Our answer is: by example. We must teach clinicians how to conduct moral discourse, but in the throes of caring for a sick, hurting, or dying child we should do our work in the most honest and timely fashion we can. We can arm ourselves with a moral framework to guide our initial deliberations, but the nuances of each person’s situation are unique and factors we do not and cannot anticipate can become the basis for a wholly unexpected ethical dilemma. Like the surgeon in the operating room, we must make the bedside and the conference room our spheres of expertise. We must learn to allow others to support us by helping us see the pitfalls ahead, to balance alternative strategies and choose what appears to be most beneficial, to step back if we have miscalculated, and to always aim for what is best for the patient. Primum non nocere has stood the tests of time and culture. It is a worthy guiding principle as we become increasingly capable of “doing everything.”
First of all, I should probably make a disclosure: I was the primary author of Module 3 which will be released by the National Hospice and Palliative Care Organization in their Online Learning area in 2011. But my only interest here is that interested pediatric palliative care providers should have access to a solid introduction to the topic and some very interesting case studies. This brief review should help you imagine how this information could impact care of your patients.

Our goal with this module was to describe the basis of decision making, define the role of the child in this process, explore communication styles that might facilitate decision making, and help providers collaborating with the child/family formulate an ethically and medically appropriate advance care plan consistent with the goals, values, and culture of the child and family. If you are interested in a more in-depth review of the role of the child in decision making, please see my article on this topic elsewhere in this issue.

The principles of ethics and decision making are important as we work with the child and family to develop a plan as the child moves through phases of illness and possibly death. It is understood that the plan will evolve as the illness and child’s needs change. Uncertainty is inherent in this process but should not be a barrier in providing excellent palliative care. One of my favorite quotes on this topic is from Betty Davies:

“We think that clinicians need to realize that uncertainty is not something to be avoided but rather is an inherent dimension of care. An uncertain prognosis should serve as a signal to initiate palliative care, rather than to avoid it, even when it is not yet appropriate to begin EOL care.” Davies, B. Pediatrics 2008;121:282-288

Some of the challenging issues addressed in this module include withdrawal/withholding of no longer beneficial treatment including artificial nutrition and hydration, managing conflicts, delivering bad news, and developing advance care plans.

Cases that the participant will interact with include:

- An 11 year old unconscious motor vehicle accident victim whose mother is a Jehovah’s Witness and refuses blood transfusion felt by the medical team to be life saving
- A 15 year old with recurrent Ewing’s sarcoma when decisions about amputation are being made
- A fetus with severe central nervous system abnormalities with no specific diagnosis but a grim prognosis for survival and neurologic development who needs an antenatal advance care plan
Practice examples include:

- A 7 year old with severe CP where the mother requests treatment deemed by the medical team to be overly burdensome relative to the benefit
- A newborn diagnosed antenatally with a condition with expected death in infancy
- An 18 year old with CP with frequent bowel obstructions and short bowel syndrome
- An 8 year old with cancer and multiple relapses who wishes to stay in school

I hope that I have tickled your interest and that you want to learn more. Furthermore I trust that you will find the online learning format meets your educational goals and that this effort will support you in your care of children and families.

Some additional resources for those eager to learn more about pediatric ethics, decision making, and advance care planning in children with life-limiting illnesses and conditions:

- Ian Anderson. Continuing Education Program in End-of Life Care: Module 12 End-of-Life Decision-Making in Pediatric Palliative Care http://www.cme.utoronto.ca/EndOfLife/Modules.htm
- Lang, F, Quill T. Making decisions with families at the end of life. *Am Fam Phys* 2004;70:719-723
• Royal College of Paediatrics and Child Health. Withholding or withdrawing life sustaining treatment in children: A framework for practice. 2004 http://www.rcpch.ac.uk/Publications/Publications-list-by-date
• Tools from SSM Cardinal Glennon Children’s Hospital and Seattle Children’s http://www.promotingexcellence.org/i4a/pages/Index.cfm?pageID=3310
• Way N. Withdrawing life support and resolution of conflict with families. *BMJ* 2002;325:1342-5
CLINICAL CASE: Nondisclosure and Emerging Autonomy in a Terminally Ill Teenager.

Commentary by Sarah Friebert, MD


(Yes; this article is free on the web, and there are several other good articles on pediatric palliative care, including one by Chris Feudtner, MD “What We Don’t Know about How We Decide”)

(No abstract available)

Dr. Friebert presents the case of Neil, now a teen with recurrent acute lymphoblastic leukemia no longer responsive to chemotherapy or other disease directed treatments. His mom wishes to pursue a phase I chemotherapy trial (to determine toxicity and maximum tolerated dose, not effectiveness). Neil expresses his past suffering from his treatment and his wish to not go through anything like that again. Parents request that the medical team not disclose his diagnosis/prognosis. Strategies to avoid and resolve nondisclosure conflicts are clearly presented. Information about Neil’s role in decision making and assess/dissent for participation in research is offered. There is a nice discussion about integrating palliative care into pediatric oncology care. Finally Dr. Friebert reviews the need for compassionate care for the healthcare providers who may be experiencing moral distress as they deal with these conflicts.

Who is the audience for this information? All pediatric healthcare providers. All children who are verbal have the right to be involved in health care decisions to the extent appropriate to their developing capacity. This would be particularly helpful for providers who are less experienced in having these difficult discussions with parents.

What is special about this article? Practical step by step suggestions for avoiding/resolving nondisclosure conflicts are presented. The rationale for integrating pediatric palliative care into the pediatric oncology care is very persuasive.

Where and how can I apply this information? This information can help the health care provider do good anticipatory guidance as they discuss the provider’s obligation for truth telling and disclosure, the role of the child in decision making, and strategies for conflict resolution. It is always preferable to avoid rather than have to resolve conflicts.
Items of Interest

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **Pediatric Intensive at 2011 Clinical Team Conference.** NHPCO is proud to offer the Pediatric Intensive as part of the 12th Annual Clinical Team Conference, to be held in San Diego, California from October 6 - 8, 2011. The conference theme is “leading and innovating quality throughout the care continuum.” In addition to the Pediatric Intensive session track, conference attendees may attend any of the other concurrent sessions offered as part of the CTC. The conference will offer opportunities for networking and sharing with your peers in the field. Learn more about the CTC and register online at [www.nhpco.org/ctc2011](http://www.nhpco.org/ctc2011).

2. **NBCHPN Pediatric Registered Nurse Exam Available in March 2011.** As announced in the previous ChiPPS newsletter, the National Board for Certification of Hospice and Palliative Nurses announced that the hospice and palliative pediatric registered nurse examination is available for the March 2011 testing window. The 2011 Candidate Handbook is available online and applications are accepted beginning December 1, 2010 for the pediatric registered nurse exam. For more information, visit the NBCHPN website at [www.nbchpn.org](http://www.nbchpn.org).

3. **Subjects and Contributors for Future Issues of This Newsletter.** In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, and examples of many programs offering this type of care in various parts of the world outside the United States. (Please note that you can visit archived issues of this newsletter at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).) For future issues, we are thinking about addressing subjects such as bereavement issues and perhaps developmental considerations. If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please contact any of the following: Christy Torkildson at [torkc@sbcglobal.net](mailto:torkc@sbcglobal.net); Maureen Horgan at [Maureen.Horgan@providence.org](mailto:Maureen.Horgan@providence.org); or Chuck Corr at [ccorr32@tampabay.rr.com](mailto:ccorr32@tampabay.rr.com). We will work with you!

4. **Reader's Corner.** Our Reader's Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader’s Corner, like the one in this issue (see page 34), include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at [torkc@sbcglobal.net](mailto:torkc@sbcglobal.net).

5. **Calendar of Events.** As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). ChiPPS is a program of the National Hospice and Palliative Care Organization. Please e-mail Christy Torkildson at [torkc@sbcglobal.net](mailto:torkc@sbcglobal.net) to have your pediatric palliative care educational offering listed.
Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or colleague, you can join the email distribution list by completing a simple online form at www.nhpco.org/chippssignup. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460.

Visit the ChiPPS Web page at www.nhpco.org/pediatrics for further materials and resources of interest.