May 17, 2017
Volume 14 No. 5

Consent for Spiritual Care in Pediatric Hospitals

Jenny, a 16-year-old A-student, varsity athlete and leader in her school community with a seemingly limitless future, lay alone in her hospital room after a failed suicide attempt—perhaps the first thing she had failed at in her life. As I listened to her nurse’s report and the team discussion in patient care rounds, it seemed plausible, if not inevitable, that Jenny was experiencing intense spiritual and/or emotional distress. I resolved to stop by her room after rounds to see if I could be of service.

I peeked into her darkened room—the lights were off and the window blinds were drawn. Jenny was awake, but she lay motionless in her bed, her arm covering her eyes. Other than the “sitter” assigned to stay with Jenny at all times (hospital protocol for all suicide attempts), she was alone. I spoke briefly with her nurse, who was now seated at the computer terminal outside the room. The nurse explained that Jenny’s parents had at first been tearful and terrified. But, as Jenny stabilized and it became clear that she would survive, her parents seemed to become increasingly angry and even hostile toward her. At some point, the parents decided to leave and had not yet returned.

I paused at the door. I had experience working with patients who had attempted to take their lives, both on medical floors as well as in an inpatient behavioral health unit. But all of my experience was in the setting of an adult hospital. I was new to pediatric chaplaincy, and this was my first encounter with a suicide attempt by an adolescent.

If Jenny had been an adult, I would not have hesitated. I would have knocked on the door, introduced myself to Jenny, explained my role and asked her if I could be of service to her. Had she said yes, I would have pulled up a chair. If the answer were no, I would have respected her choice, made sure she knew she could change her mind at any time and taken my leave.

But Jenny is only 16. And her parents were not present. Whose decision is it whether to make use of available spiritual care services in the pediatric setting? Is
it the patient’s choice? Is it up to the child’s parent(s) or guardian(s)? In the absence of a referral, is it appropriate for a chaplain to initiate a visit with a child when his or her parents are not present? Does the age of the child make a difference? Does the reason for hospitalization make a difference? Is obtaining parental consent necessary? If not necessary, is it nevertheless a good idea?

I struggled with the decision. Neither Jenny nor her parents had requested the services of a chaplain. I was acutely aware from my experience in the adult setting that many people have pre-conceived ideas about why chaplains visit and what they do in a visit, often assuming that the chaplain is there either to prepare the patient for frightening medical news or to proselytize. I have found this latter assumption to be especially common in situations involving patients of either minority faiths or no religious tradition, as was the case with Jenny and her family. I, of course, hoped that I had something healing to offer Jenny, but, in these circumstances, I felt uncertain about dropping in unannounced and uninvited at such an intense and vulnerable time for this patient and her family.

I inquired internally within our department about how such decisions are made and learned only that “we have never been consent-based.” This understanding appeared to be offered not as a consciously-made decision but rather a statement of practical reality. Intuitively, though, it seemed to me that it might be troubling for at least some parents to find out that a chaplain conversed with their child without their knowledge or permission. Given the sensitivity I had experienced around chaplain encounters in the adult setting, I could imagine some parents being particularly wary when it comes to vulnerable children.

I solicited the opinions of other chaplains with more pediatric experience by posting my dilemma on a pediatric chaplains’ list serve: what consent process if any, do you use before visiting with children? Is your process grounded in hospital or department policy or protocol? What thinking underlies your approach?

Many colleagues responded quickly and helpfully. Their answers varied widely: some chaplains do not ever meet with children without parents present, some wait until parents are present for the first meeting but then will meet with the child alone after that, some contact absent parents by phone first to introduce spiritual care resources and offer to be of service, some meet with children regardless of whether/when parents are present but do so with certain safeguards in place. Predictably, the age of the child appears to be an important consideration, though chaplains do not approach/address the age factor uniformly.

Chaplain responses also varied widely in their explanation for their particular approach. Those who do not visit with children alone explained that they feel it is important to wait until a family member is present in order to explain the chaplain role before proceeding. Even after that introductory conversation, some chaplains only meet with a pediatric patient when the family is present. Another chaplain
shared that she became sensitized to the issue by a physician from a minority faith tradition who expressed concern that the chaplain was praying over babies in the NICU without their parents’ permission. She has modified her practice as a result.

Among those chaplains who do visit with children alone, some see it as an issue of permissibility and parity with other members of the interdisciplinary care team. As one chaplain explained, "I visit children when no family is in the room. As part of the multidisciplinary team, I may provide care to patients under my care." [4] Another chaplain explained, “Our nurses, physicians, physical therapists, occupational therapists, social workers, and child life specialists do not wait for parents to come to the hospital to provide care. We are part of the medical team. . . From a legal standpoint, we are covered under the consent to treat that parents sign when the patient is admitted to the hospital.” And another, “In general, I agree with the belief that chaplains are an equal member of the care team and in that way would visit patients individually just as someone like a social worker, doctor, or child life specialist might.” [5]

Some chaplains focus on the potential benefit to the patient of the chaplain encounter in determining the course of action. For them, visiting patients without their parents’ presence, knowledge or consent can be justified and is even preferable in certain circumstances, including Jenny’s situation. As one chaplain offered, "In the example of the 16-year-old girl, I think that it is crucial for you to meet with her without her parents in the room. . . I personally believe that suicidal patients are experiencing spiritual distress. It is during these difficult times that people often need the spiritual support that chaplains can provide. . . I think most of us would agree that it would be appropriate to talk to a 16-year-old without seeking the permission of her parents.” Another chaplain agreed, “I visit often with patients who have attempted suicide or are admitted for psych-related diagnoses. I feel very comfortable visiting with them 1:1, even if I have not met their parents, as I believe chaplains have valuable roles to play in their care.”

While not a scientific or statistically valid study, my informal survey seems to demonstrate one important finding: chaplains are not relying on institutional policy or practice, but rather are making decisions about consent based on their individual experience, intuition, and goals. I asked in a follow-up question whether respondents felt this was an area in which professional pediatric chaplaincy should establish some guidelines or best practices. Some said yes, but several thought this was unattainable due to cultural variations within organizational systems.

In general, I am a strong believer in the role of intuition in the delivery of high-quality spiritual care. There is no question in my mind that effective use of intuition can be the difference between adequate spiritual care and excellent spiritual care.[6] With that said, I also believe that as we strive to professionalize our work, we need to analyze and understand our actions to ensure they meet basic
Standards for competent care, are grounded in an ethically appropriate framework and aspire toward best practices.

**Consent in the Pediatric Context**

It has long been understood that the issue of consent as it applies to the pediatric decision-making context is different from and considerably more complex than in the adult setting. The doctrine of informed consent, now a deeply entrenched and essential part of health care practice, has its roots in both law and ethics. Support for informed consent is grounded in the concept of autonomy, a word that derives from the Greek and literally means self-rule. Autonomy is the capacity to make choices based on a personal assessment and weighed in terms of one’s own value system.[7]

The complexity of consent in the pediatric setting arises as a result of several, often competing, considerations, all related to the concept of autonomy: the parents’ general right and responsibility to raise their children as they see fit and to make decisions on their behalf; the child’s evolving cognitive, social and emotional development in the process of becoming an autonomous individual capable of expressing preferences and, ultimately, assuming the rights and responsibilities for his or her own decision-making; the health-care provider’s fiduciary duty to meet the pediatric patient’s needs, which may not necessarily be what the parents desire or request; and the recognition that the family is often a child’s primary source of support and coping.

To address this unique complexity in the pediatric context, a variety of standards for pediatric decision-making have emerged in the literature and evolved over time. Most of these standards have attempted to strike a balance in the tug-of-war between parents’ and providers’ respective and sometimes conflicting rights and responsibilities around decision-making, along with efforts to include the child in the discussion as developmentally appropriate.[8] While acknowledging that legal parental rights in the area of pediatric decision-making are not absolute, the American Academy of Pediatrics (AAP) Committee on Bioethics nevertheless explains that “parents generally are better situated than others to understand the unique needs of their children and family and make appropriate, caring decisions regarding their children’s health care.”[9] In its most recent policy statement on *Informed Consent in Decision-Making in Pediatric Practice*, the AAP Committee on Bioethics recommends that:

- Parents should generally be recognized as the appropriate ethical and legal surrogate medical decision-makers for their children and adolescents. This recognition affirms parents’ intimate understanding of their children’s interests and respects the importance of family autonomy.
• Surrogate decision-making by parents or guardians for pediatric patients should seek to maximize benefits for the child by balancing health care needs with social and emotional needs within the context of overall family goals, religious and cultural beliefs and values.

• Physicians should recognize that some pediatric patients, especially older adolescents and those with medical experience because of chronic illness, may possess the adequate capacity, cognitive ability, and judgment to engage effectively in the informed consent or refusal process for proposed goals of care. [10]

In an effort to move away from more legalistic and potentially confrontational approaches and even further enhance the role of parents and families in medical decision-making, an increasingly-embraced process is that of shared, family-centered decision-making. According to the Technical Report accompanying the AAP Informed Consent Policy Statement, shared, family-centered decision-making permits “a more nuanced approach, incorporating respect for the pediatric patient’s medical experience, for family dynamics, and for emerging data on adolescent cognitive development and decision-making.” [11] This process “builds on collaborative communication between families and clinicians.” [12] In other words, this model of decision-making focuses on relationship and consensus-building.

Family-centered care is defined and described in a Policy Statement issued in September 2003 by the AAP Institute for Family-Centered Care:

In pediatrics, family-centered care is based on the understanding that the family is the child’s primary source of support and strength. . . . Health care professionals who practice family-centered care recognize the vital role that families play in ensuring the health and well-being of children and family members of all ages. These practitioners acknowledge that emotional, social, and developmental support are integral components of health care. They respect each child and family’s innate strengths and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Family-centered care approaches lead to better health outcomes and wiser allocation of resources as well as greater patient and family satisfaction. [13]

The emphasis on constructive collaboration is articulated in the Committee’s statement of core principles:

Family-centered care is grounded in collaboration among patients, families, physicians, nurses and other professionals for the planning, delivery, and evaluation of health care as well as in the education of health care professionals. These collaborative relationships are guided by the following principles:
• Respecting each child and his or her family

• Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family’s experience and perception of care

• Recognizing and building on the strengths of each child and family, even in difficult and challenging situations

• Supporting and facilitating choice for the child and family about approaches to care and support

• Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family

• Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health.[14]

The Policy Statement recommends, among other things, that “pediatricians should actively consider how they can ensure that the core concepts of family-centered care are incorporated into all aspects of their professional practice,” and that:

Pediatricians should unequivocally convey respect for parents’ or guardians’ unique insight into and understanding of their child’s behavior and needs, should actively seek out their observations, and should appropriately incorporate family preferences into the care plan. Decisions on a patient’s plan of care should be made only after such consultation has been made.[15]

Consent for Spiritual Care

It seems to me these policy statements together provide a framework for decision-making in the context of consent for medical care that can be used helpfully by chaplains to inform their practice around obtaining consent for spiritual care. The AAP Informed Consent Policy Statement recommends that parents be presumed to be the appropriate decision-makers for their children and adolescents. The recommendations further recognize that parents do not have unfettered autonomy in this domain and offer guidance on evaluating the multiplicity of considerations in the overall context of the family structure as well as the child’s own ability to participate in decision-making in certain circumstances. The AAP Family-Centered Care Policy Statement articulates a process by which these recommendations can be implemented. Notably, the Policy Statement includes a strong admonition to health care providers to refrain from creating a care plan until after the parents or guardians have been consulted.
The shared, family-centered model’s core principles are strikingly similar to those of spiritual care: uniqueness of the individual, respect, dignity, identifying and building upon existing strengths, personal empowerment. The framework also evidences outcomes that mirror those of spiritual care: improve patient and family outcomes, increase patient and family satisfaction, build on child and family strengths, increase professional satisfaction, decrease health care costs and lead to more effective use of health care dollars.

Again, the thrust of this process is its emphasis on consensus-building through quality relationship-building. It recognizes the responsibility to care for the entire family, not just the patient. And it recognizes the responsibility to care for all dimensions of the human person, not just the physical. It is a model that places everyone on the same team, working toward the same goals. It builds a spirit of caring, trust, collaboration and cooperation that maximizes the dignity, respect, and satisfaction of all participants.

Somewhat ironically, where much has been written about the need for chaplains to “medicalize” in order to integrate more fully into the health care system, this appears to be an example of medicine attempting to “humanize” by emulating the foundations and values of professional spiritual care. I have written elsewhere about the need for the modern health care system to recover its historical understanding of health as encompassing the totality of human experience—mind, body and spirit, and the opportunity and responsibility of chaplains to model holistic, person-centered care for our colleagues on the interdisciplinary care team.[16] We can celebrate this evolution in the medical context,[17] and we can also take the opportunity to learn from it.

One important thing we can learn from the shared, family-centered process of decision-making is that consent is an important issue, with real implications for patient/family experience and outcomes. We may not all agree about how to approach it; regardless, it is an issue that demands thoughtful, conscious consideration on our part.

Another important thing we can learn is that there are, in fact, some aspects of our practice that are amenable to guidelines and/or frameworks. Unlike some other calls for chaplains to integrate into the health care system by standardizing our practice in ways that potentially threaten the essence of who we are and what we do, embracing this approach to obtaining consent for medical care is actually one very authentic way in which professional chaplaincy can align itself with the practices of other disciplines on the health care team without jeopardizing the integrity of spiritual care and its reason for being.

At a minimum, the shared, family-centered model helps to clarify that the chaplain’s desire to be viewed and treated as an “equal” member on the care team is not an appropriate justification on which to base a decision about providing
spiritual care without parental knowledge and consent. On the contrary, if we want to be viewed as respected professionals, then we must, like all other health care professionals, make decisions that reflect our commitment to place the needs of those we serve above our own.\[18\] The fact is, cold (i.e., unsolicited) visits to children by chaplains without the knowledge or consent of parents pose greater risks to patient/family well-being than encounters with others on the care team. Physicians, nurses, therapists and other clinicians attend to the child’s illness; this is the reason parents brought their child to the hospital and the involvement of these team members is implicit, understood, expected and welcomed. The role of child life specialists is less clearly medical in its orientation, but the risk of objection to a child life specialist bringing a child a toy to combat boredom or engaging a child in a distraction technique during a medical procedure would appear to be low. By contrast, the situation presented by an uninvited conversation with a chaplain without parental awareness and consent is more fraught, and the risk of upset for parents is higher.

A murkier area involves the dilemma of what to do when we really believe we can help the patient, but the parents aren’t available to give consent or have affirmatively declined spiritual care. Several of my colleagues said I should “definitely” see Jenny, regardless of her parents’ presence or wishes because “she needs a chaplain.”

The AAP Policy Statements on informed consent and family-centered care inform my process. If Jenny, as an older adolescent, had requested a chaplain, I likely would have met with her, even in her parents’ absence, and possibly even over their objections, though I would have worked hard to earn their trust and at least their acquiescence before doing that. But should I visit on my own initiative? Did I, as some chaplains urged, actually have an obligation to do a cold visit with Jenny on the grounds that she “needs a chaplain?”

At the risk of raising some hackles, I think the question must be asked: is there ever really a time that the patient “needs” a chaplain? People do not come to hospitals to meet with chaplains. They certainly may benefit from such encounters and it is essential to person-centered care that such support be available and offered, but how far can we—logically and ethically—push the “need” argument? The days of paternalism in health care are long gone, even in the context of medical decision-making.\[19\] In the context of spiritual care, the “need” for a chaplain is, intrinsically, defined by the patient/family.

Giving people the opportunity to say no to us meets an important need as well—the need to feel empowered in an environment that is inherently disempowering. The need to feel in control of some aspect of a situation that otherwise feels completely out of control. We need to remember that, unlike others on the care team, we are not there not to do things to the patient; we are there to be with the patient—to enter into a sacred and healing relationship that alleviates suffering in
the context of this health care experience. One cannot impose healing relationship on another out of our own sense of need for it; the healing nature of the relationship emanates out of the sense of need for it from those we serve.

We promote healing by exploring/identifying/strengthening the patient’s own inner coping resources. For children (even older ones), parents and family structure are often among the most vital of coping resources, and keeping these relationships intact is essential. Trust of the health care team is also essential. Parents who find out their children were visited by a chaplain without their knowledge or consent may well wonder what else is going on when they are not present. This can cause trust issues for other members of the care team that can materially and negatively affect the decision-making process and even the outcome.

As I reflect on Jenny’s case, I can see now that, as I wrestled with my decision, the priorities of safety, trust and relationship-building—cornerstones of the shared, family-centered model—were paramount for me. When I put myself in the shoes of the parents, I can imagine feeling distressed, uncomfortable, anxious to find out that my child was visited by a chaplain without my knowledge or consent (even more so if it happens against my wishes). The last thing I want to do is create more anxiety, suspicion, or distress when among my primary goals as a chaplain is to bring a sense of calm, comfort and reassurance.

Accordingly, even though I am a trained attorney, my concern here is not so much legal as ethical and spiritual. I suspect my colleagues are correct that it is “permissible” for me to meet with a 16-year-old without her parent’s permission. And, again, if she specifically requested it, I likely would have met with her, even in her parents’ absence. But dropping in unannounced and uninvited based on a gut feeling that I might be able to help when the parents are absent feels different to me. I did not feel obligated to do this; in fact, I think it is questionable whether an unsolicited visit from the chaplain in these circumstances is ethically defensible.

It is undoubtedly true, as some of my colleagues urged, that patients sometimes reveal things to the chaplain that they would never say in front of family, but absent evidence to the contrary, I am prepared to assume that Jenny’s parents and the health care team are on the same side in wanting what is best for her. [20] Perhaps they would prefer that their child speaks with her own clergy or at least someone of the same religious tradition. Or perhaps they would have agreed to my conversing privately with their child if only I had asked first, but now they feel betrayed and distrustful.[21]

It is conceivable that my self-imposed limitation means that there will be times when a patient will not derive the benefit he or she might have experienced from visiting with me. Of course, this is equally true in situations in which patients affirmatively decline to visit with me. Such is the nature of autonomy. As chaplains, we are trained to understand that our value is not determined by our
ability to “fix” the problem. Indeed, often it is precisely in our ability to enhance well-being in situations that cannot be fixed that we find our value. But in any event, our healing power is gifted to us by those we serve, not by our title or our training or a “right” to patient access conferred upon us by our organizations. We are trained to trust in people to know what they need in order to cope and to heal. Again, this is the fundamental meaning of autonomy.

Parental consent for spiritual care may not always technically be necessary, but, in general, I think it represents best practice. Parents are recognized in most cases to be the appropriate surrogate decision-makers for their children and adolescents. The shared, family-centered process of decision-making suggests that chaplains ought to start with a presumption that they will obtain at least parental acquiescence to the spiritual care visit and hopefully their outright support before meeting with their children. This process demonstrates a fundamental respect for parents and the critical support role they play in the child’s life. It promotes the goals of both family-centered and spiritual care in maximizing the patient’s own tools for coping. It fosters the establishment of healing relationship through trust-building and collaboration. It enhances a sense of safety for parents that extends beyond the spiritual care relationship to the rest of the care team and to the hospital as a whole. In short, it alleviates some of the sufferings that is implicit in the experience of a child’s hospitalization and it avoids the unintentional infliction of additional suffering.

To be sure, there will be situations in which this approach warrants modification and the model provides guidance for these situations. If parents simply cannot be reached (incarceration, restraining order, etc.) or there is another serious reason to believe parents cannot or will not act in the overall best interests of their children, the presumption recognizing parents as a support resource for their children may be rebutted, and chaplains will need to use their professional judgment and discretion in determining what is in the child’s best interests from a spiritual care perspective, just as others on the health care team do in such circumstances.[22] By utilizing a framework that is already in place for other pediatric health care professionals, chaplains demonstrate the alignment of spiritual care with the goals, practices, and outcomes of the rest of the interdisciplinary care team, as well as their commitment to providing care that meets professional standards and is both ethical and efficacious.

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References

[1] Not her real name.
[2] A screening tool utilized by nursing staff at the time of admission alerts patients and families to the availability of spiritual care.
[3] Some chaplains focused more on how they conduct such visits than on whether they do so. For instance, several chaplains explained that they keep the door open and sit at the foot of the bed or at a safe distance from the patient. A few chaplains shared that they meet with children alone but avoid discussing specifically religious topics with them, an interesting self-imposed practice limitation that would seem to warrant further study. See notes 4 and 5, infra.
[4] Although this chaplain offered a seemingly categorical response, he also went on to offer a much longer set of qualifications:
However, I do take precautions to avoid any confusion or misconceptions about why I visited. First, I keep the patient’s door open and sit at a place nearer the foot of the bed so that passers-by can see me. And I spiritually assess the children but do not assess any religiosity—I avoid using religious words such as “prayer,” “blessing,” “God” or “church.” Before I end the visit, I write a note on a notecard “From the Chaplain” and explain to the patient that I’m leaving a note for Mommy or Daddy since I didn’t get to meet them that day . . . I write that ‘I stopped by just to see how [child’s name] is feeling today.’ And in the note I wish the parents well. Also on the notecards are brief instructions about how to reach a hospital chaplain. Before leaving the unit, I inform the nurse about the visit so if parents have questions, the nurse can explain the purpose of my visit and assuage any fears or concerns.
The chaplain thus states his practice but reflects the awareness that the practice has the potential to be misconstrued in a way that may be problematic and describes various actions designed to mitigate that risk.
[5] This chaplain, too, indicated that, at least for a younger child, she would avoid asking religious questions: “There is a lot that a chaplain can do supportively that doesn’t involve outright religious questions.”
[8] As described in a recent American Academy of Pediatrics Policy Statement:
Historically, medical decision-making in minors has centered on the best-interest standard, which directs the surrogate to maximize benefits and minimize harms to the minor. A broader approach for using the best-interest standard is to acknowledge the pediatric patient’s emotional, social, and medical concerns along with the interests of the child’s family in the process of medical decision-making.
The harm principle may be seen as a more realistic standard to apply in pediatric surrogate medical decision-making. The intent of the harm principle is not to identify a single course of action that is in the minor’s best interest or is the physician’s preferred approach, but to identify a harm threshold below which parental decisions will not be tolerated and outside intervention is indicated to protect the child.
The model of constrained parental autonomy allows parents, as surrogate decision-makers, to balance the “best interest” of the minor patient with his or her understanding of the family’s best interests as long as the child’s basic needs, medical and otherwise, are met. A parent’s authority is not absolute but constrained by respect for the child.
[14] Id. at p. 692.
[15] Id. At p. 693.

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[19] Id.; Pellegrino, supra note 7, at p. 369 (“Paternalism . . . violates the integrity of the person and can under no circumstances be a beneficent act.”).

[20] The pediatric system has a variety of built-in protocols to determine whether such evidence exists. Fortunately, these protocols do not involve the participation of chaplains, which permits spiritual care to remain a source of neutral support for everyone involved. We should assiduously guard this neutral status in order to be able to do our work effectively.

[21] The possibility that the relationship between Jenny and her parents is strained at the moment does not change my conclusion; on the contrary, it is in precisely such circumstances that the chaplain needs to tread carefully, lest s/he telegraph an unintended message of “taking sides” or a lack of trust in the parents’ willingness/ability to meet their child’s needs. Eventually, this adolescent will be returning home with her parents. It is vital that the chaplain avoid inadvertently “triangulating” that much-needed relationship and, instead, act in ways that promote its healing.

[22] This is the case in the adult setting as well, when the adult patient is not decisional and there is no available or appropriate surrogate decision-maker. It is important to stay clear that a determination that parents are not effective surrogates for their children cannot be made solely on the basis that the health care provider disagrees with their decision.