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## *At the Bedside*

# When Adolescents May Die

*Edmund G. Howe*

### ABSTRACT

In this article I will discuss how clinicians might best treat adolescents who may die. I initially discuss these patients' cognition, emotional tendencies, and sensitivity to interpersonal cues. I next discuss their parents' feelings of loss and guilt and their clinicians' risk of imposing their own moral views without knowing this. I then address the practical concerns of helping these patients gain or regain resilience and to identify strengths they have had in the past. I finally explore who, among staff, might be best able to do this. I highlight as the main goal that patients, their parents, and ideally also their clinicians are able to come to agree on the best course the patients should take.

In this issue of *The Journal of Clinical Ethics (JCE)*, in "Physicians' Perspectives on Adolescent and Young Adult Advance Care Planning: The Fallacy of Informed Decision Making," Jennifer Needle, Cynthia Peden-McAlpine, and Joan Liaschenko<sup>1</sup> discuss an extremely painful

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and difficult ethical dilemma: when adolescents have a fatal illness, and someone—the patients, their parents, and/or their clinicians—singly or together, must decide whether life-sustaining treatment should stop, and if so, when.<sup>2</sup> These decisions are incredibly difficult because these adolescents do not yet have full decision-making capacity and have not been able to live a full life, and this is excruciating for their parents to consider. These patients may think as proficiently as many adults, and I will discuss what this may imply. Due to their ability to make decisions, and yet their cognitive limitations relative to most adults, there are huge discrepancies between the decisions that patients in this age group are allowed to make for themselves throughout the world—from the age of 18 years, as it generally is in the United States, to much younger, as it is in European countries.<sup>3</sup>

In this article I will discuss how clinicians might best help adolescents who face making life-or-death decisions. I will do this in two sections. In the first, I will highlight key considerations involving these patients, their parents, and their clinicians that we may want to take into account. I will highlight a characteristic that adolescents have that is little recognized at present, but that may affect what they choose to do medically, more than anything else does.<sup>4</sup>

In the second section, I will discuss practical approaches that clinicians may want to take when they treat these patients. Clinicians may

want to help patients gain emotional resilience, even as they are dying, and help them recall their coping strengths. I will suggest that the greatest source of anguish for these patients, other than their imminent death, may be when they are at odds with their parents or their clinicians. We might therefore give highest priority to helping these parties feel as one with each other. Hospices accomplish this on a regular basis.

### ADOLESCENTS, PARENTS, AND CLINICIANS

An example of the ethical challenges that adolescent patients may confront is Cassandra C., a 17-year-old girl with Hodgkin's lymphoma.<sup>5</sup> With chemotherapy, there was an 85 percent chance of survival; without it, she would likely die in two years. She was aware that the chemo would cause organ damage and infertility; she declined it. Her parents supported her. Her doctor filed a petition of neglect with the Connecticut Department of Children and Families, stating that Cassandra C. was not sufficiently mature to make this decision. The state supreme court did not support Cassandra C.'s decision and forced her to accept chemo; further, the court denied her parents custody after it determined they were not acting in her best interests. This case exemplifies the pain and difficulties adolescent patients may face. Cassandra C.'s doctor could have responded differently. For example, he could have taken a different tack, considered Cassandra C.'s reasons for refusal, and tried to find a way to preserve her fertility. At present, 14 U.S. states have mature minor doctrines recognizing that unemancipated adolescents may have the maturity to accept or reject medical treatment, with or without parents' agreement. Clinicians in these states may be required to offer their opinion in these difficult determinations, and may need to decide, as Cassandra C.'s doctor did, whether they should go to the state against their patient. What physicians should do when these situations arise remains most controversial. I will now look at some important factors affecting parties in such controversies: adolescent patients, their parents, and clinicians.

#### Adolescents

Adolescents mature as they age, and the part of the brain that enables them to make decisions, the frontal cortex, continues to develop. It is principally for this reason that adolescents are

treated less harshly under the law when they commit a crime than adults are, as it is unclear whether adolescents have sufficient "street savvy" to know what they are doing is wrong.

In general, adolescents tend to differ emotionally in ways that affect their behavior, and, relative to adults, they have a higher capacity for hypnosis that may greatly affect how they respond to others' views. Depending on their capacity, they may be more susceptible to psychosocial influences from others, without knowing it. Since each of these differences can most significantly affect their decisions when they are terminally ill, I will consider each separately.

#### Cognition

The frontal part of our brain gives us the capacity to think and choose. This capacity may be greatly disrupted by emotional turmoil. When we are upset, the feelings that we need to act quickly may take control, and then we usually cannot think as well as we might if we were not under stress. Later, I will address the importance of clinicians' doing what we can to help our patients feel calmer, as doing this may improve patients' decision making.

In this section I will focus on the relevance of adolescents' limited cognitive capacity, relative to that of most adults. Between the ages of eight and 11, children's reasoning ability improves significantly; the development of more complex reasoning takes longer.<sup>6</sup> A critical ethical question is at what age adolescents' reasoning ability should be considered sufficient to allow them to choose to die. Based on recent studies of adolescents' brain development, some researchers argue that there is no bright-line age marker for when adolescents can make treatment decisions for themselves. A recent study reports that, generally, children who are older than 11 may be competent to consent to participate in clinical research.<sup>7</sup> Double consent (that is, consent by a child and parent when the child is 12 to 18 years old) is required in many European countries for decisions regarding the child's medical treatment and participation in research.<sup>8</sup>

Views of the sufficiency of children's capacity to make decisions may be affected by what some adults can—or rather can't—do, even when these adults are deemed to have sufficient capacity to make medical decisions. The capacity of some adult patients (whose capacity has not been of clinical concern) may be no greater than that of even young adolescents. For example, some adults may not understand abstract con-

cepts such as the constancy of a volume of water when it is in a tall container versus when it is in a flat, shallow container.<sup>9</sup>

Research indicates that children's memory increases significantly between the ages of six and 12 and continues to increase during adolescence.<sup>10</sup> The recall ability of children aged 10 to 12 may be as good as adults'.<sup>11</sup> Needle and colleagues, in their article in this issue of *JCE*, emphasize that it is critically important for children to know how their illness and its treatment will affect them when they must make treatment decisions. These authors are the first to study the singular significance of children's prior experience with illness and treatment—which they call *embodied knowing*—and their parents' experiences as they witness what their children go through. Research indicates that 14-year-olds are as competent as adults in their ability to make decisions about their own medical treatment.<sup>12</sup>

There are highly disparate views on how adolescents' capacity to make decisions should best be determined. There is even doubt that age is a useful marker of capacity. Adolescents' less-than-complete brain growth may not warrant the moral weight it has been assigned. As Needle and colleagues write, children's past experiences of illness and treatment should be accorded greater moral weight in considerations of their competency to make decisions. Using an objective marker such as age may simplify making these determinations, and possibly render them more consistent. Still, these grounds for establishing adequate capacity to make decisions are hardly sufficient if deeper evaluation of patients' idiosyncratic capacity could do better. Lengthier discussions with patients and their parents may give them new insights and rationales for making decisions that they may not have considered. Emotions may be a substantial factor in competency to decide, and this may especially be the case for adolescents.

### *Emotions*

As I noted briefly above, emotional arousal may unhinge competent thinking. Adolescents' hormones are changing, and that may greatly affect their emotions and the degree to which they feel emotionally aroused at any given time. Their hormones are only one of the many changes they are experiencing. The precise effects of any of these changes are uncertain. Emotional arousal particularly can affect a person's judgment, as I will shortly discuss. The effect of hormonal changes on a person's moods and behavior was

brought home to me when I treated an adolescent whose pituitary gland became cancerous and was removed before he reached puberty. His hormonal changes couldn't occur progressively from within. Instead, his doctor had to administer them externally. The young man experienced these changes not gradually, but in spurts. His emotions responded accordingly. This made it apparent to the patient, and to me, how his hormones affected his emotions each time he received an injection. This anecdote illustrates the enormity of the effects that hormones may have. It points too to how difficult determinations of capacity can be to make.

There are three ways that changes in adolescents' emotions may affect their medical decision making: their willingness to take risks, the extent to which their emotional arousal may affect their risk taking, and their responsiveness to rewards. All of these affect adolescents more than they do adults.

*Risk taking.* A greater willingness to take risks in this age group is often seen as a liability. When an adolescent is dying, however, it may not be a liability, but a benefit. Increased willingness to accept risk may move these patients to accept a higher risk procedure, or be more willing to enroll in a research protocol, and they may have access to experimental treatments through research protocols that they otherwise wouldn't and couldn't have. While taking risks is ubiquitous and varies from person to person, that it is greater in adolescents suggests the need to especially take this into account.

Beyond that benefit, participation in a research protocol may enhance patients' emotional resilience and, given the patients' stage of illness, increased or regained resilience may be more important than anything else in their life at that point. Increased or regained resilience may allow patients to be able to cope well during these possibly last days or months of life.

These patients may be able to experience greater quality of life than they have previously. How could this be? When death may be days or weeks away, patients may be able to communicate more heartfelt truths and feelings with loved ones than ever before. This might not be what we would expect. After all, these patients are dying, and they know it. Some may not experience a short-lived higher quality of life, but others may experience it, due to a strong religious belief, or wanting to do so for their parents, or as an echo of their parents' capacity to remain upbeat, or some other factor. For this reason, ac-

quiring greater emotional resilience, if that is possible, may be the single most important goal at this time, and is a goal that clinicians should strive to help their patients to achieve.

There are other possible benefits from joining a research protocol, even if the experimental medicine doesn't provide a direct benefit. First, it may give patients hope; second, participating in research may give patients a way to express altruism. In regard to hope, philosopher and psychiatrist Jodi Halpern writes that many dying patients participate in research not because they mistakenly believe that the purpose of the trial is to treat their illness (an error known as the therapeutic misconception), as is often feared, but because the patients, although realistic, remain optimistic.<sup>13</sup> Such hope, even when it is due to exceptional optimism, may spur and fuel resilience.<sup>14</sup> This emotionally profound gain flies in the face of our desire for patients to avoid any kind of therapeutic misconception. This is illustrated by a clinician quoted by Needle and colleagues, who said that patients' family members "take 5 percent chance of [a] great outcome, instead of thinking about the 95 percent chance of something terrible happening." We might choose to leave patients and families with their hopes once we have informed them accurately. Sometimes, as Halpern notes, offering hope may break our connection with patients and families because, in doing so, we may be responding to what we feel, rather than responding to them. Given this, it may be best for us to only spend time with them, and learn what they think.

A second source of resilience may come about even when patients enter a protocol and have little or no hope. Patients may gain resilience from knowing that their participation may help others. Altruism, even if not accompanied by hope, can fuel resilience.<sup>15</sup>

*Emotional arousal may increase risk taking.* Strong emotions may further increase adolescents' risk taking.<sup>16</sup> This can be a liability. This might have been what happened in the case described above, in which Cassandra C. declined possibly lifesaving chemo in order to pursue a goal that she imagined, of living and having children. This has a highly important implication for clinicians: we should do all we can to try to reduce our patients' becoming overly aroused emotionally, due to stress. This can help enable patients to make better decisions for themselves. To do this, we can try to find ways to regularly meet and talk with patients, to help reduce their fears regarding uncertainties. If there is enough

time to develop greater trust with patients, our very presence may have a calming effect, as it would with the presence of a beloved parent. Examples of this occurring with a nonparent are numerous. Therapists, for example, routinely find that patients who come to sessions frantic, saying they feel they are emotionally breaking apart, are able, within several minutes, to calm down and even laugh. Patients often state that they have barely held their breaking emotions together throughout the week, and believe they can do this because they know that once they see their therapist, they can vent their chaotic feelings and have their therapist's full support. While the relationships between therapists and patients differ from those between nontherapists and patients, nontherapists can form extremely trusting and meaningful relationships with patients. For example, medical students may become close to patients because the students have the time. I will consider how other clinicians may do this later in this article.

A second example of how staff can help reduce a patient's stress is that of a patient who had psychotic delusions who was acutely threatening another patient on a hospital ward. The ward staff surrounded the patient until a close family member arrived. That person was able to calm the patient instantly, when no one else could. Likewise, a patient who was bent on committing suicide did not respond to any attempted intervention. All clinicians in this circumstance should know that if the patient cares for someone who has not yet been involved, clinicians should contact this person. Due to having an emotional connection with the patient, that person may be able to move the patient from seeing only the option of suicide when no one else can.

A final example is the comfort that a companion animal can provide. I had a patient who lived alone and wrapped up pet toys for his dog as gifts on Christmas day. He said his dog loved to chew through the wrapping paper as much as he enjoyed the toy inside. This dog, I often thought—like so many patients' pets—may have enabled the patient to survive.

The critical element in providing this kind of comfort is spending time with patients. I will discuss how to accomplish this in my comments in the last section of this article.

*Rewards.* A third emotional response to which adolescents are especially prone is experiencing joy in response to receiving a reward.<sup>17</sup> This likely is due to their increased responsiveness to the brain chemical dopamine.<sup>18</sup> In other

contexts, increased dopamine has the same effect. Some antidepressants may, for example, work in this way. One of these medications is a drug sometimes used to help motivate people to give up smoking. A heightened sensitivity to rewards can have positive or negative effects.

A positive effect of a heightened sensitivity to rewards is that it may be able to enable patients, even as they are dying, to find joy and resilience in the time they have remaining. This is a core goal that clinicians can help patients achieve. I think in this regard of a colleague who was dying from cancer. He did not want to discuss his death. He did want to discuss his passion for art, and it was obvious how much he enjoyed it. This illustrates the extent to which dying patients can still find joy, even when they know—or because they know—that they have only a few days left.

On the other hand, a heightened sensitivity to reward may negatively move some patients to choose short-term rather than long-term goals. This might have been one reason that Cassandra C. chose to keep her fertility rather than have chemo, even though she would probably die as a consequence. She may have felt irresistibly rewarded by her imagining herself having and raising a baby. That positive feeling may have blocked out everything else. (Here I am imagining that Cassandra C. felt as *I* would have felt. But the task of her doctor would not be to imagine how *I* felt, but to learn how she actually felt.)

Such a propensity among teenagers to intensely experience the joy of rewards may bring about an outcome so feared in research: the therapeutic misconception. Perhaps Cassandra C.'s desire to retain her fertility is instructive: when adolescent patients will receive chemo or any other measure that may impair their capacity to later reproduce, we should explore with them what they want and what may be possible. They may survive, and they may want their eggs or sperm to be preserved.<sup>19</sup>

### *Hypnotic Capacity*

Adolescents are thought to be exceptionally influenced by others. Their peers are seen as likely to affect them most. A reason this may be true is that adolescents, relative to adults, have a greater capacity to be hypnotized. This capacity in teenagers is less than that of younger children, but still significantly greater than that of adults. Decades of research indicate that 80 to 85 percent of children younger than 12 are highly hypnotizable, whereas only 10 to 15 percent of adults have this same capacity.<sup>20</sup> This does not

mean, however, that those with a high capacity for hypnosis are more vulnerable to being controlled by others. This isn't true.<sup>21</sup> Some have come to believe this, perhaps through fictional literature or some other source.<sup>22</sup>

Those with higher hypnotic capacity can alter their sensory experience in ways those who lack the capacity can't; for example, they can undergo some surgical procedures without anesthesia, while those without the capacity cannot. Higher hypnotic capacity may have other effects. In this context, adolescents are particularly likely to be influenced—although not controlled—by interpersonal cues and feelings that they see in others.<sup>23</sup> This additional, heightened tendency has profound importance when we want to give the best possible care to adolescents as they are dying. I will discuss this below.

A first clinical consideration is that adolescent patients are prone to being influenced by what their parents want for them. (Of course parents are also influenced by their children, as are all of those in close and caring relationships, including siblings.) Patients may choose what others want without even knowing that they are doing it. Ethically, this may be good, although it goes against some understandings of autonomy-based ethics. For example, clinicians may find it important to separate adolescents who are Jehovah's Witnesses from their families, to be more certain that patients are making a decision to refuse blood transfusion on their own.<sup>24</sup>

Jehovah's Witnesses patients may accord priority to so-called relational autonomy, which values "the relatedness, interdependency, and embeddedness of patients."<sup>25</sup> In the same way, what adolescent patients may want most is to please their parents.<sup>26</sup> Since this is likely to be the case, clinicians should strive to foster agreement between adolescent patients and their parents, to the degree that they can. As Peter I. Osuji notes, "Practically, a child's decision is rarely made independent of his parents. To varying degrees, a child's decision is an amalgam, simultaneously an expression of preference infused with parental purpose. Failure to recognize the interrelated nature of child-parent decision making is a failure to appreciate how most families function."<sup>27</sup> At the same time, individuals and families differ. Providing optimal care requires bringing out these differences so they can be better addressed and resolved.

Clinicians may want to consider going outside what they would usually do to help severely ill adolescent patients and their parents achieve

such felt cohesiveness, as it may be most important to them—over the short run, perhaps, for patients, and for the rest of their lives for their parents, if their child doesn't survive. This may include providing life-extending interventions that patients and parents want, even interventions that might usually be seen as futile.

There are additional implications for clinicians, because adolescent patients may have exceptional sensitivity to cues from their clinicians. We should be especially careful to not convey cues that may have unintended connotations, as what is connoted may override what is said. An example is provided by Needle and colleagues. A clinician in their study describes the "clinical cascade" that very ill adolescent patients may experience: " 'a complex bone marrow transplant patient comes to the PICU [pediatric intensive care unit]. . . . We intubate this patient, and then she develops renal failure, and then she's on dialysis, and then her cardiac function starts going downhill, so then she's on pressors, and then she can't tolerate feeds, so we're on TPN [total parenteral nutrition], and then we have liver issues.' " Such a dire clinical cascade is a possibility for very ill adolescent patients, and, to inform patients and their parents fully, we might want to describe it. But what might be the effect? Patients and parents might feel terrorized. Realizing this possibility, we might want to disclose the possible clinical cascade as well as the feelings that hearing about it may evoke. Perhaps something like this affected Cassandra C. when she decided forgo chemo: a connotative comment may have helped move her to decline this lifesaving treatment.

That some patients have higher hypnotic capacity, to cite a final example, might suggest how best to share statistical information with them. How information is presented may influence what patients choose to do. For example, telling a patient there is a 50 percent likelihood of surviving surgery—rather than saying there is a 50 percent likelihood of dying—may affect what the patient decides. This may be more likely in adolescent patients. Thus, with adolescent patients, clinicians might want to share statistical information in both of these ways.

### Parents

As noted above, children's decisions may be greatly influenced by their parents' views. For similar reasons, parents' decisions may be

greatly influenced by the views of their child's clinicians. At the same time, some parents may respond in the opposite way when we try to impose our own views;<sup>28</sup> parents may reflexively oppose our views. We must try to prevent this response. This may be achieved by not intervening and opposing parents directly, even when that seems to be what is required. Logically, confrontation may seem necessary, but we may be more successful when we validate an aspect of a parent's position that is valid, and even celebrate a virtue that is shown in the parent's position. This virtue might be, for example, that the parent loves the child so much that the parent wants to have complete control. We might acknowledge how painful this is for all of the parties involved. This response should be genuine. After hearing this, a parent may be able to be more receptive to our raising treatment questions that may be harder to hear, and that a parent may find challenging.

In regard to a child who does not want treatment, we might say, "It's hard for me to hear anyone say, 'I want to end it all,' especially when it is an adolescent or child." This is intentionally not worded as a suggestion. By sharing our own feelings, we may place an adolescent's having said this on the parents' table, so to speak, and help them to recognize it and talk about it, if they want to. If we instead make a suggestion on how to proceed, parents may become oppositional. If, though, the observation is just "out there," parents may be more likely to respond.<sup>29</sup>

After all, the parents may rightfully feel they have authority concerning their child that should be acknowledged. Rather than make *suggestions* to parents, we might *ask* them questions, such as whether they think going against what their child wants could add to their child's pain. We could even add that, from what we have seen, this occurs all too often.<sup>30</sup>

It is always a danger to over respond emotionally in these situations. If we do over respond, what we connote to parents, even non-verbally, may wholly overshadow what we do and say. Our best hope may be to understand, as well as we can, why parents are reacting as they are. This may help us to avoid responding in the ways that we hope to avoid.

For this reason I will now consider two feelings that parents are likely to experience and find overwhelming: loss and guilt. There is a specific intervention that may help parents fare better. It illustrates a host of other possible in-

terventions. Even though an intervention is difficult, it may be important. Our goal is to increase communication to better enable patients and parents to feel as close as they can.

#### *Loss*

Parents may exert exceptional and even harmful control over their adolescent child when the child is dying, because they so fear the loss. The pain that occurs with the loss of a child cannot be overstated. Those of us who have not experienced it may be not able to accurately imagine it. One parent, after losing a child, slept during the day and stayed awake every night. She said this helped her to avoid the pain she experienced when she saw children and parents playing together during the day. Even so, it is essential for parents to hear their child's views, even when their child says that there is too much pain, and the child wants to die. Ethically, it is essential that a child be able to share his or her views and not have them be ignored.

We must help these views not be ignored. Children and parents may need our help to discuss treatment decisions, and before these discussions begin, we must make it clear to all parties how difficult the discussions may be.<sup>31</sup> Facilitating an outcome that satisfies a patient and parents may be one of the most challenging tasks we can perform. Some approaches used by mediators may be most likely to succeed. These involve listening to and respecting the views of all of the parties in the discussion, and then asking all of them to "dig deeper," that is, asking what fears, hopes, or concerns may underlie what they just said. Descriptions of this approach have been previously presented in this journal.

Clinically, beyond this, we must appreciate fully the extent to which parents may value having every last possible minute with their child, even though we may see helping them to have this extra time as being complicit in providing care that is futile. Such questions also arise for adult patients, but, for children, departing from standard practices may be warranted because parents' feelings for their children can surpass everything else for them. Many parents would substitute their life for their child's, if they could. Seeing this, we may want to consider stretching our usual limits. The example of the mother who wouldn't go out during the day after her child died may help us when we are deciding what to do. Put ethically, we may want to reconceive what we consider to be futile treatment.

#### *Guilt*

In these situations, we may find it useful to inform parents that they may feel ambivalence about their child's illness and treatment. If they have not imagined that they could experience feelings of ambivalence, they may think it is abnormal. For example, parents may find themselves wishing that their child, after so much suffering, would soon die, and this may cause emotional havoc for them. Of course it is possible too that their child wants to die. If the child is at home and suddenly gets worse, parents may understandably call an ambulance to keep the child alive. The child may then be angry. There are few experiences parents go through in which they feel worse. This may be a source of feelings of guilt. Accordingly, if it is possible that this scenario might occur, we might want to discuss it with parents and children ahead of time.

There are any number of similar outcomes we might anticipate, and surely we can't cover all of them, or many of them, or even some of them. Thus, this example is primarily illustrative. As Needle and colleagues illustrate, guilt may be one of the worst insidious feelings parents can experience. The authors quote a clinician who shows how such second-guessing and guilt may be lifelong. The clinician took an adolescent patient off a ventilator at the patient's request, and the patient died. The clinician relates that the patient's mom "called me for years, saying maybe we should have put him back on the ventilator, because maybe we could have done something." Knowing this, we may take the initiative to tell patients and parents, while they are together, that it is common to feel ambivalence, and we can invite them to share with each other what they feel, if they want. Discussing this together may be extremely painful for them at first. But afterwards, since they do not have to continue to hide their feelings, they may be able to relate with each other more intimately.

We might even encourage parents, when they are with their child, to tell the child what they expect to feel if the child dies, after the child's death. They might say, for example, that although they will feel sad, even empty as though they had a bottomless pit inside, they will get on. Something like this may be most important for the child to hear. It is better for parents to believe what they say to their child, but, if they can't do this, they can still share. That might be better for the parents and the child than parents' bearing these feelings alone.

### Respite

An additional question, meant as a paradigm for other painful issues we might raise with parents, is whether parents have a need for respite. If we don't raise the question, parents most likely won't. They may feel that they should be with their child every hour of every day. They may take shifts around the clock, day and night. This may be optimal, but, especially over time, may become harmful. To all parties.

Having respite may be best for all, despite any harms that may come about. Patients may want this for their parents, but too afraid to raise this themselves. They may, for example, fear that if they say this, their parents might feel rejected, or at least that the children don't cherish their parents' company. At these times, fears of emotional vulnerabilities run high. If we take the lead and raise this issue (and similar issues), it may free all of the parties to better support each other in ways they otherwise couldn't.<sup>32</sup> On the other hand, we may want to ask patients and parents if they want to talk about such things, because it may be too much for one or all of them to bear. Should this be the case, we must respect it.

### Clinicians

We may experience profound pain when we treat a dying adolescent. A clinician quoted by Needle and colleagues said, "I think until you have seen the things that we have seen, you can't even comprehend what kind of situations we are talking about, what kind of end points we are talking about." We may fear discussing with adolescents their possible or inevitable death for many reasons. We may want to protect them from knowing of this possibility. We may not want to destroy their hope. We may dread seeing pain on their face. Needle and colleagues note: "Even in the face of patients making decisions that are truly informed by previous medical experience, participants [in the study] felt distress over decisions to withhold life-sustaining treatment that led to patients' death."

We may feel distress at not being able to carry out our own moral views. As one clinician who was interviewed by Needle and colleagues said: "But when you're face-to-face in front of a parent who desperately will shoot for anything other than death, even if it is futile, we have to have a position and I think it's hard for people to be put in that position." Clinicians' pain may break through or threaten to break through their

emotional defenses. We may unknowingly respond in ways that primarily protect ourselves, and that may be harmful to patients. For example, we may become angry because feelings of anger may be less hard to bear than feelings of sadness or helplessness. Helplessness, in this regard, is viewed by some as the most painful emotion a person can experience. As one clinician in the study conducted by Needle and colleagues states: "You find out later that the parents want you to do things because they think it's going to help and it's not . . . it's usually very distressing because that's when things start to break down. That's when we get frustrated with the parents and that's when parents get frustrated with us." "

We may then seek to justify the anger we feel by rationalizing it. This may take the form of making unjustifiable, blaming judgments. For example, we may judge, with almost contempt, parents whom we feel do not visit enough. Parents may not visit more frequently for many reasons, including finding that watching their child die is too painful. This may be because they love their child so much. Is this a reason for "almost contempt"? Is there ever a reason for such a feeling?

We may also "act out" our feelings without being aware that we are doing so. If we do this, we may not feel painful emotions so intensely. Such acting out may take the form of pressuring patients or parents to do what we think is best.<sup>33</sup> Acting out may also take the form of all-or-none decisions that leave no openness for exception when a patient is "at the margins."

An example of this, although in a different context, is patients who are bedridden and have dementia, when the time comes that their loved ones can no longer feed them by mouth. Patients may forget how to swallow, and aspirate food into their lungs. We may unilaterally *decline* to surgically place feeding tubes for the patients to prevent aspiration. This may make sense for various reasons, for example it may prolong patients' lives after their lives have lost their quality. Still, there are some patients who live with a feeding tube for months or years, with much quality of life. The analogy to adolescent patients is the same I mentioned before: patients and their parents may want patients to live longer, by a means that is different from what is usually done.

What would be an ideal outcome for such patients and their parents? I recall one. The child had cystic fibrosis. His bouts of pneumonia in-

creased in frequency as he grew older, and became worse, causing him greater pain each time. Finally he and his parents agreed that his struggle should end. They had difficulty getting his clinicians to agree, but finally did. He died with his parents present, and they continue to share the most meaningful memories of him.<sup>34</sup>

To do best, adolescent patients and their parents may need to have their clinicians totally “with” them, as opposed to being rankled by what the patients and parents choose to do, or not do. This is the overall goal. I now will discuss some more-specific practical goals that clinicians may strive to achieve.

### PRACTICAL INTERVENTIONS

As noted above, adolescent patients are likely to be especially sensitive to their clinicians’ emotional cues. Negative cues may result from clinicians’ moral distress. Needle and colleagues provide such an example. A clinician says: “ ‘We tend to respect [what patients and parents want] as long as it agrees with our pathway. The minute patients say they don’t want it, then we’re not able to live up to the principles that we stated we would. So in the beginning, we say patients’ autonomy is of primary importance, yet when patients disagree, then oh, it’s not the greater good, or patients don’t fully understand.’ ” The clinician follows this observation with two additionally informative examples: “ ‘Sometimes they make decisions based on religious beliefs, sometimes they make decisions based on the idea of hope.’ ”

If clinicians are able to transcend any moral distress we may feel, and not show our distress, we may be able to provide patients a single, great, nonmedical benefit: we can confer a sense of calmness merely by our presence.<sup>35</sup> This calmness is of the utmost importance because it may free patients to better problem solve. As I shall discuss shortly, we may help patients utilize the strengths they already have, and in this way cope and fare better, and experience their maximal resilience. This may allow patients to have, even at this time, great quality in their life.

It may seem logically impossible to imagine helping patients in this way, at this time in the patients’ life. How could we possibly help patients to feel calm when they continue to fear impending death? The answer is counter-intuitive: people can feel calm at the same time that they feel fear. This has been shown empirically,

and may be partially biologically based. The center for calmness and the center for fear are in different places in the brain, and there is some space between them.<sup>36</sup> Recognizing that we can help patients feel calm is critically important. As a result of our efforts, we can help evoke the resilience that our patients need.

### Creating Resilience

Earlier in this article, I described two ways that patients may acquire additional resilience when they participate in a research protocol: they may acquire new hope, and they may feel more altruistic. A third way for very ill adolescent patients to become more emotionally resilient is to increase their engagement with others.<sup>37</sup> We may be able to model a continuing caring and vibrancy that can help convey to them that there still is joy in life to be experienced.

How might we model this? Here are two real examples. One was with a younger child. He was afraid of everyone and every clinician his parents introduced to him. Then, during his first appointment with a new clinician, he picked his nose. The clinician went wild. He exclaimed that the not-so-tiny bit of mucus on the child’s finger was by far the most beautiful form of mucus he had ever seen. The child at first didn’t know how to respond. It seemed to catch him wholly off guard. Regardless, he was tickled, and perhaps moved. He believed, it seems, that the clinician would not be judging him, and he opened up and spoke to the new clinician.

The other child was a teenager. He felt anger. He had been bullied. “Makes you feel like this,” his clinician said, and took a piece of chalk from his desk and threw it with force at a blackboard. The stick of chalk shattered. The boy seemed to feel understood. He had felt totally alone and helpless, but now he no longer felt alone, and shared with the clinician what he felt.

What might we take from these examples? That it is possible to help our patients make gains by being with them more than just a few times, and by encouraging them to be just as they are. Such candor could leave us feeling more vulnerable. Such shared hurt may be particularly needed by adolescents as they are dying. Like the two patients I just described, adolescents who are dying may feel not so alone. They may relate with us in a way that is more meaningful for them than they have ever experienced. Why? Dying, they know that they have limited time.

As a result, they may want and be able to tolerate only genuine interaction. Being adolescents, they may have had less time to expect and accept the less-than-wholly-genuine interactions we may have with others as we age, as we try to act in ways that are socially appropriate. These examples are offered as paradigms. There are myriad ways we can respond to patients from our heart. Over time, responding from the heart may be necessary, regardless of how we do it, to help patients regain the resilience within them.

### **Tapping their Strengths**

Without extensive extra training, we may additionally benefit these and other patients who feel disconsolate in a specific way. We may explore with our patients, if they are willing, the coping strengths that they have used in the past. We can do this in two steps. The first step is to ask patients if they can recall a time—or times—that were the worst they had ever experienced. The second step is to ask how they coped at those times. What strength did they have that enabled them to “get through”? There are several strategies we can use to cope when things are bad. Here are two that are representative. We may problem solve wholly on our own, or we may contact and rely on others, tapping their strengths to help us get through. How problem solving works is perhaps self-evident; our presence alone may help calm our patients, and then they may be in a good position to do their own problem solving. Contacting another is invaluable; it may be most helpful to all of us throughout our lives. First, we can note we lack a skill, and then we can look for someone who has that skill. This can enable us to succeed in innumerable contexts in which we otherwise would not.

This intervention was pioneered by James Griffith, a psychiatrist who teaches this approach to other clinicians. He reports that, not infrequently, when demoralized patients recall a strength that they have, they feel buoyed up almost at once.<sup>38</sup> Perhaps when they see that they have the capacity to help themselves, they feel renewed self-esteem. The experience seems like what psychotherapists call an “aha,” a sudden, exhilarating moment in which people make a connection between two parts of their life they didn’t see before.

I think of a patient who was greatly troubled because he didn’t find his partner’s nose to be sexually attractive. Yet the patient loved his partner and wanted to be with him his whole life. I

asked him to try to experience the feeling of being turned off, and then holding it, to see what came into his mind. He did. He then euphorically shouted, “I was mocked by my classmates in grade school for my nose!” His limited sexual attraction to his partner diminished from that moment.

When we can be ourselves with patients, we may be able to explore patients’ strengths with them. But even if we can do this, an absolute obstacle is still in the way: How can we possibly find the time? I will discuss this now.

### **Ethics Consultants**

I have raised many possibilities. When adolescent patients feel stressed, clinicians may be able to calm them down, and then patients should be able to make better decisions. This may be possible even when patients feel fear. With our ongoing presence, we may be able to further our patients’ emotional resilience, or even help them newly create it. Even without extensive special training, we may be able to help patients unearth their past coping strengths, and so help them revive their spirits, or, said differently, restore their resiliency.<sup>39</sup> Even assuming that some or all of this is possible, who has the time? Healthcare institutions could free up some time for this purpose. For example, some institutions especially task nurses with explaining the details of a procedure to patients, while another clinician performs the procedure. In some settings, chaplains have some time specifically roped off to visit and talk with patients.

My leading candidate for this would be ethics consultants. Many healthcare institutions, however, do not have enough ethics consultants to devote the time to patients that patients ideally need. Many patients would require daily visits to maximize their capacity to respond optimally as new problems arise, and to feel more secure. I would advocate that ethics consultants be numerous enough to provide patients with the ongoing consultations that patients need, and that, in the future, ethics consultants take on the role of meeting often with adolescents who may be dying and with their parents, as soon as possible. This presupposes that ethics consultants have these skills. There may be many clinical contexts in which patients’ clinicians need a medical background, but in this context, empathy and interviewing skills would be needed.

For this to happen, there is another need that may be unmet in many healthcare institutions.

This is that ethics consultants may feel just barely welcome in some places such as hospital wards. They are hesitant on their own to take on the kind of intimate and frequent interactions with other clinicians' patients that I have outlined here. Ethics consultants would need to be welcomed. For example, adolescent patients' primary clinicians would need to specifically request and invite an ethics consultant to work with the patients and parents in the ways I have described above. Clinicians should unequivocally indicate to ethics consultants that their assistance is wanted, and that the clinicians hope and expect that the consultants will pursue the intimate interactions some patients and their parents may need. Consultants may need inservice training on this, and supervision, which should be made available in advance.

### CONCLUSION

I have explored how to best help adolescents who are dying. I have suggested that the best outcomes may be possible only when adolescent patients and their parents can agree. Clinicians need to prioritize this outcome. I have reviewed pertinent aspects of adolescents' cognitive, emotional, and hypnotic capacities, and have offered some thoughts on how to best take these characteristics into account. I have discussed parents' loss and guilt and their possible need for respite, and that it may be ideal to discuss these issues with parents and children.

I have discussed clinicians' possible sense of loss and how important it is that we not unknowingly react in ways that are harmful to patients and their parents. I have outlined how we may be able to help maximize patients' emotional resilience and help them to unearth their own strengths, and that ethics consultants may be able to assist in these efforts.

The death of an adolescent is as profound a human loss as occurs. Notwithstanding this, we may be able to help patients find meaning and joy, even in the last days of life. We have learned this from hospice workers. Clinicians and ethics consultants in the future may be able to provide support for these patients and their parents that they have not had before.

### BLINDING OF THE CASES

Details of the cases in this article have been altered to protect patients and their family members.

### NOTES

I would like to thank Norman Quist for his most insightful comments on this article.

1. J.S. Needle, C. Peden-McAlpine, and J. Liaschenko, "Physicians' Perspectives on Adolescent and Young Adult Advance Care Planning: The Fallacy of Informed Decision Making," in this issue of *The Journal of Clinical Ethics* volume 30, number 2 (Summer 2019).

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3. P. Grootens-Wiegers, I.M. Heins, J.M. van den Broek, and M.C. de Vries, "Medical Decision-making in Children and Adolescents: Developmental and Neuroscientific Aspects," *BMC Pediatrics* 17, no 1 (8 May 2017): 120. See also I.M. Hein et al., "Informed Consent Instead of Assent is Appropriate in Children from the Age of Twelve: Policy Implications of New Findings on Children's Competence to Consent to Clinical Research," *BMC Medical Ethics* 16 (9 November 2015): 76; B. Partridge, "Adolescent Pediatric Decision-making: a Critical Reconsideration in Light of the Data," *HEC Forum* 26, no. 4 (December 2014): 299-308; and D.A. Sturman and B. Moghaddam, "The Neurobiology of Adolescence: Changes in Brain Architecture, Functional Dynamics, and Behavioral Tendencies," *Neuroscience & Biobehavioral Reviews* 35, no. 8 (August 2011): 1704-12.

4. This is their hypnotic capacity. This is not as pronounced in adolescents as it is in children, but it is still much greater than it is in adults.

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14. S.M. Southwick and D.M. Charney, *Resilience* (New York: Cambridge University Press, 2012), 32-43. See also G.M. Figueroa et al., “Balancing Hope and Risk Among Adolescent and Young Adult Cancer Patients with Late-Stage Cancer: A Qualitative Interview Study,” *Journal of Adolescent and Young Adult Oncology* 7, no. 6 (December 2018): 673-8.

15. Figueroa et al., “Balancing Hope and Risk,” see note 14 above, pp. 674-7.

16. Grootens-Wiegers, Heins, van den Broek, and de Vries, “Medical Decision-making in Children and Adolescents,” see note 3 above, p. 6.

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