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Ethics, Emotions, and the Skills of Talking About Progressing Disease With Terminally Ill Adolescents:

A Review

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Abstract

IMPORTANCE—For clinicians caring for adolescent patients living with progressive, life-threatening illness, discussions regarding prognosis, goals of care, and treatment options can be extremely challenging. While clinicians should respect and help to facilitate adolescents' emerging autonomy, they often must also work with parents' wishes to protect patients from the emotional distress of hearing bad news.

OBSERVATIONS—We reviewed the ethical justifications for and against truth-telling, and we considered the published ethical and practice guidance, as well as the perspectives of patients, parents, and clinicians involved in these cases. We also explored particular challenges with respect

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to the cultural context, timing, and content of conversations at the end of adolescents' lives. In most cases, clinicians should gently but persistently engage adolescents directly in conversations about their disease prognosis and corresponding hopes, worries, and goals. These conversations need to occur multiple times, allowing significant time in each discussion for exploration of patient and family values. While truth-telling does not cause the types of harm that parents and clinicians may fear, discussing this kind of difficult news is almost always emotionally distressing. We suggest some "phrases that help" when clinicians strive to deepen understanding and facilitate difficult conversations with adolescents, parents, and other family members.

CONCLUSIONS AND RELEVANCE—The pediatrician's opportunities to engage in difficult conversations about poor prognosis may be rare, but such conversations can be crucial. These discussions affect how patients live at the end of their lives, how they die, and how their families go on. Improved understanding of basic principles of communication, as well as augmented understanding of patient, family, and clinician perspectives may better enable us to navigate these important conversations.

In this case scenario, Carlos was 16 years old when he was diagnosed as having metastatic osteosarcoma. A varsity athlete and 1 of 4 children of Latino immigrant parents, he struggled not only with physical symptoms from his cancer and its treatment, but also with the emotional distress of being separated from his family and community and the uncertainty of his ultimate outcome. When his disease progressed and cure became exceedingly unlikely, his parents asked that Carlos not be told his prognosis. In response, members of the health care team became distressed over the nondisclosure and missed opportunities for advance care planning.

This hypothetical case scenario illustrates the challenges in talking with adolescents about poor prognosis, dying, and death. These discussions are difficult, both in terms of ethical considerations and emotional ramifications. Clinicians and parents navigate tensions between patient and parent control over information, coexisting principles of avoiding harm and enabling autonomy, and goals of avoiding patient-isolation while minimizing anxiety, sadness, and anger.

When done compassionately and respectfully, these conversations can have important implications for how patients live the end of their lives, how they die, and how their families and clinicians cope. In this review, we discuss the ethical reasoning and evidence supporting our view that, in most cases, clinicians should gently but persistently move toward engaging adolescents in conversations about the nature of their disease progression and prognosis. Although such conversations may hurt in the short term, they do not cause the types of harm that parents (and some clinicians) fear. Instead, they facilitate critical, ongoing discussions of goals and preferences, ultimately alleviating patient, family, and clinician suffering. While we know of no panacea to make divulging terminal disease emotionally pain free, we will offer some "phrases that help" clinicians better understand and navigate talking with adolescents, parents, and other family members.

Truth-Telling Standards and Why They Are Not Enough

Historically, concealing the truth to protect both adult and pediatric patients from the potential harm of hearing a specific diagnosis or grim prognosis was widespread. In the 1920s, the art of medicine was described as “skillfully mixing falsehood and truth.”[1] In 1961, most physicians avoided disclosing a diagnosis of cancer because the knowledge was overly distressing for patients and families.[2] By 1979, however, this paradigm had shifted, and 97% of physicians reported full disclosure of cancer diagnoses to their adult patients.

This evolution toward truth-telling may reflect the rise of the modern bioethical principles of autonomy, beneficence, nonmaleficence, and justice. Yet while autonomy is prioritized in Western medical systems,[3] truth-telling is not always the most important nor appropriate ethical guidepost. The injunction to “do no harm” may trump honesty, and respecting parental autonomy may sometimes supersede the needs of an adolescent minor.[4] Other ethical theories deliberately integrate the dynamics of interpersonal relationships and dependencies, including their influence on patient, parent, and clinician decisions.[5] This practice is highly relevant in adolescent health care settings where parents and adolescents each make decisions based on the needs of the other.[6]

Cultural and religious considerations also suggest different priorities and practices. In a systematic review describing the role of cultural context in pediatric end-of-life care, multiple studies under scored broad differences in acceptable practices, but none described cross-cultural similarities and differences in preferred parent-child end-of-life communication.[7] Whereas Western cultures recommend honest communication and respect for adolescent autonomy, others believe that immediate damage to the child’s emotional well-being can translate to poorer prognosis or even hastened death.[7] Further, role definitions are culturally determined and conditioned through professional training, family systems and values, religion, and lived experiences. Assumptions of Carlos’ cultural values and preferences may be in accurate and possibly harmful. Understanding and navigating these perspectives is a critical, but understudied, element of pediatric palliative care.

Different Perspectives

Hearing that cure is unlikely is always distressing and, when associated with the probability of death, perhaps devastating. Carlos’ parents may have more intense grief reactions because his impending death goes against the natural life order, subjects them to feelings of guilt or failure, and profoundly disrupts the family structure.[8–10] Carlos may feel his own distress for the same reasons. In cases like his, clinicians may believe that the kinder, more humane, and even more ethically appropriate course of action is to minimize the delivery of bad news or even tolie.[3] However, evidence suggests that most adolescent patients and parents prefer honest disclosure, and that this practice ultimately allows for appropriate decision-making and the alleviation of later suffering.[11–20]

Clinician Perspectives

Clinicians may avoid telling Carlos and his family the truth simply to avoid their own immediate feelings of discomfort. Nearly half of pediatric oncologists report a sense of failure at the prospect of a patients' death and a quarter believe delivering bad news is the "worst part of the job."[21] Additionally, patients' opinions about their clinicians may further disincentivize bad news truth-telling: adult patients perceive their physicians to be more compassionate immediately after hearing optimistic (albeit less realistic) compared with pessimistic (albeit more realistic) news.[22,23] Adults who rate their physicians' communication skills highly are twice as likely to falsely believe they will be cured.[24]

Clinicians should understand that these potential benefits of withholding bad news are short-lived. Most adult patients report a moral aversion to "false hope" and consider deliberately withholding the truth "unacceptable," even when done with compassionate intent.[17] Parents of children with cancer report greater trust in physicians who deliver complete and honest prognostic information.[11,12] Nearly 80% of pediatric oncologists retrospectively reported that advance care planning conversations, although difficult, were helpful.[25] In contrast, deliberate or inadvertent deception to mitigate the immediate pain associated with hearing the truth may be counterproductive; in Carlos' case, his family may request inappropriate, even harmful, medical treatments. Indeed, nearly half of medical oncologists provide treatments that they believe are unlikely to work.[26] This is important because most parents continue to look for and suggest treatment options until the time of their child's death.[27] When these searches are conducted without concurrent, progressive acceptance of the child's prognosis, patients and parents may lose opportunities to create meaningful legacies, say goodbye to each other, or find spiritual peace.[19,28] Parents also may ultimately regret their decisions; when 102 parents were asked retrospectively what their goals of care should have been when their child had no realistic chance of cure, only 12% still reported "to cure" the cancer and more than half reported "extending life" or "lessening suffering."[29] To make appropriate decisions, 91% of bereaved parents stated they wanted as much prognostic information as possible and one-third stated they did not receive enough.[13]

Parent Perspectives

When asked to select the single most important attribute of being a "good parent," more than half of parents of seriously ill children reported "focusing on my child's health," "making informed medical decisions," or "advocating for my child."[14] Fulfilling any of these roles requires honest and complete information. Indeed, without full understanding of the seriousness of Carlos' disease and the potential benefits and burdens of treatment, he (and his parents) may suffer more. Parents of children with advanced cancer who understand their child's prognosis are more likely to endorse goals of pain and symptom management, in turn minimizing in effective and toxic chemotherapies while maximizing the child's (and family's) quality of life.[30,31] In contrast, those who are unaware of their child's prognosis are up to 4.1 times more likely to pursue aggressive "curative" chemotherapy and their children are up to 4.6 times more likely to die in the intensive care unit.[15]

Although parents may want to protect their children from difficult conversations, engaging in them enables parents to better meet their child's needs, alleviate the child's fears, and ultimately protect the child in unanticipated ways. Bereaved parents who believed their child was afraid or anxious at the end of life were more likely to report their own distress or poor quality of life years later.[32] In a study of 429 bereaved parents, none of those who talked to their child about the child's impending death regretting having done so; however, 27% of those who avoided the topic regretted the missed opportunity. If the child was a teenager or if parents sensed the child was aware of the imminence of death, parents were more than 3 times more likely to report regrets.[33]

Importantly, parental goals of curative therapy are not necessarily inappropriate. For many parents, the decision to "leave no stone unturned" may be critical to their self-definition of good parenting. Effective communication and partnerships with families require that we align with and respect their priorities and goals of care. From there, we can navigate their evolving decisions.[16] Regardless of how parents choose to proceed, their simple understanding of prognosis may facilitate their preferred end-of-life care and enable them to direct how they spend time with their child.[34]

Delivering bad news neither lessens parental hope nor causes lasting parental distress.[35,36] Rather, clear prognostic understanding is associated with peace of mind and increased trust in the physician.[11,12] Physician truth-telling alleviates long-term parent distress, especially if it facilitates prognostic understanding and appropriate goals of care.[13,15,37] Sufficient parental awareness of the child's impending death also minimizes parents' risks of anxiety, depression, and sleep disturbance after the death of the child.[15,31]

Adolescent Patient Perspectives

While Carlos' parents may attempt to protect him from painful information by withholding the truth, most children and adolescents with advanced cancer understand what is happening, regardless of what their parents have told them.[38] Because many patients have high burdens of distressing physical and emotional symptoms,[39,40] not having opportunities to talk about these experiences can be frightening or disempowering. While consideration should be given to the degree to which younger adolescents are cognitive and emotionally "ready" to receive bad news and participate in decision making,[19,41,42] when presented with a hypothetical scenario about a patient with terminal cancer, 90% of teen cancer survivors reported a "non treatment" decision with consequential death would be okay, and 96% reported the patient has a right to be informed.[43]

Studies of teens with advanced cancer suggest they are not only capable of participating in complex decision making, but that nearly all understand the consequences of their decisions and care about how they affect surviving friends and family.[6] Nearly all report that their participation in advance care planning regarding medical treatments and goals of care would be helpful to them.[18,44] Doing so may alleviate their own distress about future uncertainty and enable them to identify realistic priorities for their medical care and quality of life.[45] In a pilot study of a structured advance care planning program for adolescents with cancer, 24% reported that early conversations about possible poor outcomes made them feel sad, but 71% said the conversations were also worthwhile and 91% said they were helpful.[45]

Although most teens are aware of more than their parents suspect,[38] some may choose not to ask questions they believe are painful for their parents to answer; just as parents are trying to protect the teen, so too are teens trying to protect the parents.[46] For other teens, the lack of parental disclosure can create emotional distance and suspicion at a time when closeness and trust are most needed. Teens may want to be involved in decision making, but to varying degrees; some may request filtered information and others fully defer decisional authority to their parents. Across this range of scenarios, balancing the developmental autonomy of the teen with the rights of parents to protect their children as they see fit can be challenging.

Skills and Words That May Help

Standard and successful approaches to difficult conversations all highlight the need to tailor approaches for individual families, assess prognostic understanding, reframe expectations, and attend to the emotions of parents, patients, and clinicians.[16,46–50] Here we present a few examples of perceived barriers and some words that may help facilitate effective communication.

Cultural Humility

Culture shapes but does not strictly define people's preferences. For example, common values among Latino communities, such as that of Carlos, include the role of family, maintained closeness within the family, and the preference of most families that children die at home rather than in the hospital.[7] However, findings from studies of end-of-life care preferences, such as hospice, are mixed. While some suggest that hospice is rarely used,[7] others have described no differences[51] or higher hospice enrollment among Latino compared with non-Latino children with cancer.[52] Explanations for these discrepancies include community- and individual-level differences in perceptions of hospice services, language, and other sociodemographic variables, such as financial hardship, geographic separation, and intensity of medical needs.[53]

Cultural humility involves asking patients and families about their religious and cultural beliefs, spirituality, and preferences for integrating these constructs into their care. A helpful practice in any difficult conversation is to rely on simple techniques such as "ask-tell-ask."[54] Here, we deliberately obtain permission to explore family experiences, expectations, or information needs ("ask"), compassionately deliver manageable pieces of honest prognostic information ("tell"), and allow opportunities for questions ("ask"). In cases of cultural humility, this may begin with questions about how families like to receive medical information, how they make decisions, and how parents define their roles (Table 1). Some words used frequently in medical settings (eg, *hospice*, *palliative care*, and *morphine*) can have negative connotations for patients and families.[55] Focusing on the services provided can facilitate the introduction and exploring a family's prior beliefs can help identify barriers. This simple, respectful, and parent-oriented approach enables a partnership that may, in turn, facilitate ongoing conversation as Carlos' disease progresses.

Timing

Physicians are notoriously poor predictors of survival time.[56,57] In pediatric settings, this uncertainty is well-founded. Children with life-limiting illnesses have unpredictable and prolonged courses of waxing and waning symptoms before their deaths,[58,59] and treatment alternatives have variable success.[57] Consequently, physicians may be vague, overly optimistic, and focus on treatment options rather than their outcomes.[12,60,61] Clinical experience suggests that acceptance of poor prognosis takes time. On average, physicians know a child will die 100 days before the child's parents are able to accept the same reality.[31] The sooner the truth is heard, the sooner a family can begin the processes of grieving, regoaling, and, ideally, accepting. Taken together with the evidence of benefit to patients and families who are able to make informed decisions, it follows that physicians are obligated to fully tell the truth as soon as they know it.[46]

An early commitment of honesty can facilitate later difficult conversations. For example, clinicians can initiate their relationships with patients and parents with a contract for honesty (Table 1). This may establish a standard practice of open communication and ongoing discussion of patient and family expectations and worries. Later, when delivery of bad news is warranted, clinicians can provide both a warning shot and affirm their clinical role as a consistently honest and dependable partner in the child's care. This practice may feel less jarring to families ("this is how our doctor always talks to us"), and may also reassure patients and families that they are hearing all pertinent information.

Content

Some have argued that patients and families cannot possibly comprehend all of the medical information their physicians provide. Clinicians should deliver difficult news in digestable pieces to facilitate understanding,[62] and some degree of filtering will unavoidably occur. Others argue clinicians are not in positions to know a priori what patients and families can or cannot handle nor when their capacity for information changes.[63] The fact that most parents retrospectively wish they had received more information than they received emphasizes this point.[13]

These different viewpoints regarding the volume of delivered information can be reconciled with thoughtful preparation and ongoing opportunities for discussion. "Ask-tell-ask" or any other communication process should be repeated as often as necessary. We expect Carlos' family to need (and take) time to integrate new knowledge. Pieces of information may be delivered multiple times and in multiple ways. Over time, family understanding and corresponding needs may shift. Involving a multidisciplinary team can be helpful because different team members can attend subsequent meetings, provide additional insights and language for framing the circumstances, engage in follow-up, and help families process their feelings. Finally, although time constraints and family requests may encourage discussion of prognosis, goals, and next steps in a single sitting, these topics should ideally be separated. For example, discussions of goals may be more productive after a family has had time to process their new prognostic understanding.

Talking With Parents About Talking With the Adolescent

Carlos' parents are not alone in their hesitation to involve their child in end-of-life discussions. Parents' reasons are often well-intentioned and revolve around trying to protect the child and maintain advocacy. In such cases, a helpful approach is to explore hesitations while withholding judgment and to openly discuss worries, "good parent" beliefs, and family customs (Table 1).[14,19] To navigate if and how Carlos should participate in ensuing discussions, we might ask his parents what Carlos knows or is worried about. We might share some of the above-described evidence regarding lack of regret among parents who engage in these discussions,[33] and the fact that open, albeit difficult, conversations directly with the child have the potential to alleviate both child and parent distress.[64]

In the end, Carlos' parents may remain adamant that he not be told about disease progression or prognosis. Medical staff may struggle with how not to inadvertently disclose in formation or, more poignantly, how to respond if he asks for information his parents or primary physicians have yet to disclose. Both clinicians and parents should proactively explore what will be done if he asks directly. Managing such cases requires careful attention (Table 2). While we believe that honest and compassionate disclosure is typically best, such a disclosure may result in a breach of trust with the parents, thus jeopardizing the therapeutic alliance. Involving other health care professionals, such as social workers, psychologists, palliative care clinicians, or ethics consultants, may be helpful in maintaining acohesive commitment to the best possible care for the patient and family.

Talking With the Adolescent

Assuming his parents agree to direct communication, we suggest first assessing how much Carlos wants to be involved (Table 1). Regardless of his answer, gently and periodically reraising this question is important to ensure that evolving needs are met. Subsequent questions about prognostic understanding and corresponding goals of care should be concise and provide opportunities for the adolescent to direct the conversation.

Although most adolescents with long-term illness want to participate in medical decision making, when and how much they want to be involved are variable.[20] We and others have described standard approaches to adolescent palliative care, including how to assess patient readiness for end-of-life discussions, reframe goals, and engage teens in advance care planning.[18,19,41,42,45] The core attributes of successful communication with adolescents include (1) a systematic approach, including consistent time points for conversation and allowance of patient and family processing time[65]; (2) direct, compassionate, nonjudgmental, concrete, and developmentally appropriate language[66,67]; and (3) engagement of family, friends, and others who provide the patient with social support.[19] In addition, clinicians and family members must recognize the patient's own communication preferences. For example, teams may optimize success by identifying and including a trusted child-life specialist, chaplain, or psychosocial professional in difficult conversations.

Identifying Those Who Might Benefit From Truth-Telling and Addressing Their Fears

Although most parents and patients appear to benefit from truth-telling, a subset do not. If 27% of parents who avoid talking to their child about death end up regretting that decision, then the other 73% in the majority felt no regret.[33] Likewise, in retrospect, 12% of bereaved parents continue to report their goal of care should always have been curing their child's cancer, regardless of the final outcome.[29] How do we identify the parents and patients for whom truth-telling may cause more harm than good? We have found a framework of hopes and worries to be useful as a means to advance the conversation while remaining alert for red-flag signals. In Carlos' case, for example, clinicians may meet first with Carlos' parents to compassionately relay the bad news about his scans and then probe with questions about hopes and worries for the future (Table 1). Often, these types of questions open the door to shared perspectives about how to proceed, even if asking them does not include direct communication with the adolescent. If or when Carlos becomes involved, these same types of questions would work for him. By contrast, if the parents become agitated or hostile, then the clinician should consider shying away for the time being from a more explicit discussion or disclosure regarding prognosis.

Integrating Ethics, Emotions, and the Art of Truth-Telling

These conversations take time and need to unfold over time. The conversation where Carlos' family hears about his progressive disease may not be the same as the one in which they decide what to do next. Accordingly, were commend early and ongoing honest communication that is simple and compassionate. Building relationships over time is a necessary foundation for trusting and shared decision making. Although gently and persistently involving the adolescent in most cases is ideal, this pathway is not always open or optimal; however, compassionate exploration of patient-, parent-, and family-level values always is.

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Table 1

Phrases That May Help Facilitate Difficult Conversations With Terminally Ill Adolescents and Their Families

Circumstance	Sample Conversation-Starting Phrases That May Help
Cultural Humility	
Understanding family values regarding direct communication with the child	"Your family has been through a lot. Could you please share with me how you prefer to [receive new information]/[make decisions]?
	"How would you like me to talk to [patient] about what is happening?"
	"Who does [patient] receive information from best?"
	"Would it be okay if we all talked to [patient] about [his/her] disease together?" If yes, then explore when and how the conversation might go. If no, then explore family hesitations and perspectives.
Introducing hospice	"Have you ever heard of something called hospice?" or "have you ever known anyone who received hospice at home?" If yes, then "can you tell me more about that?" and continue to explore how given case is similar or different. If no, then "there are providers who can come to your home to help take care of [patient]. Would it be helpful if I described what that might look like?" Then, as appropriate, describe home-based hospice support including spiritual, psychosocial, and ongoing pain and symptom management.
Timing and Content	
Contracting for honesty	Early in the relationship (eg, at diagnosis): "Something you should know about me is that I will always be straightforward and tell you the truth as best I know it." Then, later: "Remember when I told you how I'd be straightforward and tell you the truth? Well, now, I am afraid I have some difficult news…"
Introducing difficult news	"We have some stuff to discuss about the status of your cancer. How much do you want to know?"
	"Are there things you would rather I talk to your parents about first?"
Ascertaining prognostic understanding	Family members: "Can you tell me what you have heard about the status of [patient's] disease?" Adolescents: "What is your understanding of what is going on with your cancer right now?" Then, compassionately deliver manageable pieces of information, even if it is the same as the day before. Or say, "we have some new information about your disease. When would be a good time to talk about it?" Here, clinicians should make reasonable efforts to ensure key family members are present for discussions. Always close with an opportunity for family to ask questions and a schedule to continue the conversation.
Introducing goals of care	Whenever possible, discussions of goals should begin after a family has processed or articulated their new prognostic understanding. "We are in a different place now because we no longer know if cure is possible. Before we talk about other treatment options, I want to make sure I am considering what is important to you." "I'm worried your cancer will continue to progress. If that happens, I want to know what is most important to you. For example, some people say they want to be home with their family and others say it is really important to keep trying new medications. There is no wrong answer here, and we will support you no matter what you decide." "These are some really hard conversations to have. What do you think another person your age might want if he/she were in this situation?" Always suggest patients/families do not need to make a decision right away and close with an opportunity for questions and a schedule to continue the conversation.
Talking With Parents About Talking With the Adolescent	
Defining parenting roles	"What is most important to you in being a parent?"
	"What do you value most about your relationship with [patient]?"
	"Our goal is for [patient] to have the best life possible, while [he/she] has it. Sometimes that means having the opportunity to talk to you about [his/her] needs, hopes, and worries. What would it be like to share that with [patient]?"
Navigating the adolescent's involvement	"What do you think [patient] knows about the disease?"
	"What do you think [patient] is most worried about?"
	"Sometimes kids like [patient] try to protect their parents by not asking about or wanting to talk about their own death. Is this something [patient] might do?"

Circumstance	Sample Conversation-Starting Phrases That May Help
Setting expectations for honesty with patients	“Do you remember when I promised [patient] I’d always tell [him/her] the truth? It is really important that [he/she] knows he/she can still trust me, so I would like to answer him/her honestly if [he/she] asks me about [his/her] chances of cure.”
Identifying Those Who Might Benefit From Truth-Telling and Addressing Their Fears	
Probing hopes	“As you think about what is ahead, can you tell me what you are hoping for?” And then, “what else are you hoping for?” And even later, “would it be helpful to talk about what this might be like if things don’t go as we hope?”
Exploring worries	“As you think about what is ahead, what worries you most?” And then, “what else worries you?” And even later, “would it be helpful to talk about your concerns if things don’t go as we hope?”

Table 2

Navigating Circumstances Where Parents Forbid Direct Conversations With Dying Adolescents

Circumstance	Sample Scenarios	Tensions to Consider	Conversations That May Help
Parents forbid disclosure of poor prognosis to an adolescent patient.	Carlos’ parents explicitly ask that Carlos not be told his poor prognosis.	Patient autonomy: Honest and compassionate sharing of information respects Carlos’ autonomy, enables his participation in decision making, minimizes his isolation, and underscores trust between him and his medical team.	Exploring parenting roles, whether parents have differing views, whether other family members have influential opinions, as well as culture and expectations, may provide insight regarding the rationale for not including Carlos.
		Parent autonomy: Carlos’ parents understand his coping and information needs best. He may not be developmentally and cognitively ready for explicit information about death and dying. His parents worry full disclosure will be highly distressing and of no benefit.	Exploring what Carlos’ parents believe he knows or is worried about may provide opportunities to explain how health care staff can help fill knowledge gaps and/or alleviate fears.
			Exploring how Carlos has heard and processed difficult news in the past, and how he responded immediately and over time, may suggest ways to pave the road for future communication.
Health care staff anticipate questions directly from the adolescent.	Carlos’ nurse wonders how she will answer if he asks for confirmation that his cancer is back.	Staff needs: Not acknowledging what is happening feels dishonest and disregards Carlos’ personal autonomy.	Explaining it is important that Carlos knows he can trust his team to answer questions honestly, and requesting permission to do so if he asks directly, may take responsibility of disclosure off parents’ shoulders and open doors to communication.
		Patient needs: Carlos may know or suspect that his condition is deteriorating. The lack of open communication may contribute to his feeling isolated or afraid.	Exploring with parents ways that Carlos’ clinicians can respond may help all parties navigate the situation.
		Parent needs: Responding without prior agreement from Carlos’ parents may undermine their trust at a time when partnership with medical staff is critical.	Inviting ongoing dialogue with the family to provide support as Carlos’s health changes and guidance if they wish to share additional prognostic information may enable real-time resolution if conflicts arise.
The adolescent directly asks health care professionals questions about prognosis.	Carlos asks his psychosocial clinician, “am I dying?” She knows his parents have not yet discussed this with him directly.	Alleviation of distress: Answering Carlos honestly enables him to explore a frightening concept with someone he trusts. Speaking out loud about worries he has kept to himself may facilitate conversations both he and his parents have not yet been able to initiate.	Acknowledging the importance of Carlos’ questions and suggesting his family be invited to join the conversation may enable discussion, trust, and emotional support for all involved. This allows family members and other medical staff to prepare together and create a unified voice.
		Worsening of distress: Answering without the concurrent support and presence of the family may be more distressing if it conflicts with what Carlos has heard from others or if he has no outlet to continue to express and explore his hopes and worries.	Framing responses around Carlos being “very sick” enables continued conversation without overt dishonesty. Exploring his reason for asking the question may elucidate his worries and unmet needs, thereby facilitating ongoing conversations about goals and preferences of care.
The adolescent makes a provocative statement about his prognosis to his parents.	Carlos tells his mother, “I just want to go home.” She does not feel ready to “give up.”	Parent roles: Parents may have very strong notions that they must keep up Carlos’ spirits, and that if they fail to do so, they have failed him.	Asking parents what they feel is most important to them as parents may create opportunities for reframing their goals of care.
		Parent distress: Parents may feel emotionally overwhelmed by even the	Offering to talk with Carlos together and offering to take the lead in exploring what he meant by “just go

Circumstance	Sample Scenarios	Tensions to Consider	Conversations That May Help
		notion of having to tell their son of his progressive disease.	home" and/or in telling him the truth that his disease cannot be cured may alleviate parent distress and guilt while facilitating conversations about keeping Carlos comfortable, telling him he will not be alone, that his family and health care team will continue to work very hard to care for him, and that the choices he makes will be supported and honored.
		Patient wishes: Respecting Carlos' wishes to go home may limit ongoing medical interventions or introduce a goal of care that has not yet been discussed.	