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In Focus:

**Moving Toward
Patient Autonomy:
A Case Study
of Communication
in Adolescent
Cystic Fibrosis Care**

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Child Life Focus



ABSTRACT

As life expectancy for patients with cystic fibrosis (CF) and other life-impacting chronic illnesses continues to increase, more pediatric patients will transition to adult care. As part of the complex shift in this transition, patients become legally, institutionally, and socially expected to assume a larger role in their own healthcare, which requires more sophisticated communication skills. This article reports a single case study in which two interview participants, a child life specialist and a 16-year-old CF patient, report the same incident through their independent perspectives. In responding to a question about failed communication, both participants independently related the story of the patient trying to persuade doctors to remove her gastric feeding tube. We analyzed their narrative of this series of events using a model called collaborative interpretation (CI), which posits that both patients and providers are experts and joint problem solvers. Our conclusions indicate that child life specialists can serve as models and educators to help adolescent patients master key communication skills as they become co-agents in managing their healthcare.

Moving Toward Patient Autonomy:

A Case Study of Communication in Adolescent Cystic Fibrosis Care

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Child life specialists fill an integral role in the care of children and adolescents with cystic fibrosis (CF), the most common life-limiting genetic disorder among Caucasians (Schraufnagel, 2010). CF, which affects mostly the lungs and pancreas, demands rigorous, daily medical intervention, and sometimes requires patients to be hospitalized for several days to weeks at a time. Through the use of relational, educational, and communication tools, child life specialists can bridge the gap between the biomedical demands of the disease and the psychosocial needs that arise for patients and their families.

These efforts significantly contribute to trust building between patients, families, and healthcare providers (Cary, Lin, & Anbar, 2013) and foster independent decision making as adolescents begin the transition to adult care.

Communication is a core skill for healthcare providers and is especially vital in caring for adolescents with chronic illness (Beresford & Sloper, 2003), yet few health communication training texts address patient/provider interactions in an adolescent setting, and none

that we found include child life specialists in discussions of team/patient communication. Child life specialists, however, are in an ideal position to build communicative bridges among all stakeholders in an adolescent care setting. In a policy statement published in

Pediatrics, the role of the child life specialist in communication includes “establish[ing] therapeutic relationships with children and parents to support family involvement in each child’s care, with continuity across the care continuum” (Child Life Council & American Academy of Pediatrics Committee on Hospital Care, 2006, p. 1757).

In this qualitative case study of communication practices and barriers between adolescent CF patients and their providers, we found a child life specialist who, through excellent communication skills, unknowingly demonstrated a model of healthcare communication called collaborative interpretation (CI; Young & Flower, 2002), which positions patients and providers as partners in addressing clinical and health-related problems. As the child life specialist described her interactions with one particular patient, two ideas emerged. First, these interactions needed to be analyzed as a case study, and secondly, child life specialists are ideally suited for formal communication training that would enable them to help young patients develop their own communication skills as they move toward independent decision making.

This article reports on a single case study in which two interview participants, a child life specialist and Helen*, a 16-year-old CF patient, report the same incident through their independent perspectives. The patient tells the story of wanting her gastric feeding tube (G-tube) removed, and the child life specialist describes her intervention in helping the patient communicate more successfully with her doctors about the issue. Their narratives illustrate the complex relationship between communication and patient agency, where, we believe, patient autonomy can eventually be enacted. Specifically, both participants told of the patient’s struggle to convince her doctors to remove her G-tube and, afterward, to surgically repair the remaining hole, which had failed to heal on its own. In these accounts of her struggle, the patient first tries to convince her doctors to allow her to manage her own calorie intake instead of relying on the G-tube, and by doing so, tries to exercise independent decision making. This effort is unsuccessful at first, for a variety of reasons. Eventually, though, the tube is removed. The transcripts then reflect her frustration when she needs some surgical repair, and ultimately, they show the patient’s and child life specialist’s collaborative efforts in designing

a communication strategy to solve what appeared to be an intractable problem.

Background

CF affects about 30,000 people in the U.S., with 1,000 new diagnoses each year (Cystic Fibrosis Foundation, 2016). It is an autosomal, recessive disorder passed to the child by both parents. Because of the thick, sticky mucus CF causes throughout the organ systems of the body, patients suffer from digestive insufficiencies, liver disorders, and, ultimately, recurrent lung infections which result in ever-worsening respiratory problems. Almost all CF patients must take supplemental enzymes that assist in digesting their food. In addition, many must have G-tubes surgically implanted to ensure they achieve and maintain a healthy weight. Respiratory treatments require daily, hours-long medical and physical therapies to relieve the patient’s lungs of their continual accumulation of thick mucus (Jain & McColley, 2010; Melnyk, Feinstein, Moldenhouer, & Small, 2001). Many CF patients experience positive outcomes through daily medical regimens, chest percussion, and respiratory therapies; others need frequent rounds of antibiotics to treat respiratory infections. Those who are the sickest need to be hospitalized, often for 10 to 14 days at a time, sometimes several times a year.

Both in the outpatient clinic and hospital, CF patients work with a team of providers that includes pulmonologists, nurses, physical therapists, respiratory therapists, social workers, dietitians, and child life specialists. Because many CF patients are hospitalized frequently, they develop significant relationships with providers. With their knowledge and skills, child life specialists foster collaboration and communication among all stakeholders in a child’s care, which can contribute to the adolescent patient’s decision-making capabilities. Thoughtful, consistent, and strategic communication practices between CF patients and their providers can enhance their immediate well-being, as well as their journey toward adult care (Schlucter, 2014).

Adolescent Chronic Illness and Patient Autonomy

Beauchamp and Childress (2009) define autonomy as a patient’s or research participant’s right to self-determination and

independent decision making, arguing that the ethical imperative is to deconstruct any barriers to making informed decisions about treatment or participation. In this project, we are interested in understanding how communication can support an adolescent patient as she attempts to make an independent decision about her healthcare, which would move her closer to what Sakalys (2010) and Schneider (2006) might see as clinical autonomy. Sakalys states that patient autonomy is a “moral ideal in the patient-provider relationship, displacing the tradition of benevolent paternalism” (2010, p. 15). She emphasizes that autonomy is “conceptually and clinically complex” (Sakalys, 2010, p. 15). Schneider agrees that as an ethical construct, patient autonomy is often complicated and even impossible to achieve in practice. Yet “at the heart of bioethics and bioethical policy” (Schneider, 2006, p. 415), there has been a consistent effort to entrust patients with decision making and to “equip

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patients to make [decisions] competently” (Schneider, 2006, p. 415).

Adding to the complexity of achieving the “moral ideal” of autonomy is the inherently unequal nature of the patient-provider relationship, especially for children and adolescent patients. In spite of widespread acceptance that minor patients should have a voice in what happens to them (Coyne, 2008; Tierney et al., 2013; Tierney, Kirk, & Deaton, 2015), Coyne (2008) finds that chronically ill children and adolescents exhibit low participation in clinic visits for a variety of reasons, including parental demands, lack of physician training in communicating with children and teens, a traditionally paternalistic healthcare system, and a culture of children “being seen and not heard.” In echoing calls for autonomy, Coyne cites the United Nations General Assembly from 2002:

Children, including adolescents, must be enabled to exercise their right to express their views freely, according to their evolving capacity, and build self-esteem, acquire knowledge and skills, such as those for conflict resolution, decision-making and communication, to meet the challenges of life. (Coyne, 2008, p. 1683)

In the context of healthcare, Coyne reminds us of “the right of every child to self-determination, respect, non-interference, and the right to make informed decisions” (2008, p. 1683). In this case study, we view autonomy as a motivating factor that can be approached through communicative strategies, where self-determination is negotiated in each unique interaction and enacted in the context of shared information and collaborative decision making.

In an analysis of published adult patient narratives, Sakalys (2010) identifies factors that problematize autonomy, all of which are also applicable to adolescents: differing levels of comfort with decision making, lack of information, differing levels of education and social class, and previous healthcare experiences. She presents the central paradox of patient autonomy: “If disease and the subjective experience of illness are sources of diminished autonomy, then how is it possible for patients to be autonomous at times when they are vulnerable, suffering, conserving energy, coping, or getting through each day?” (Sakalys, 2010, p. 17). Communication re-

search shows a negative relationship between illness or other stressful situations and an individual’s capacity for comprehension and engagement, which are vital for enacting autonomy (Cappelletti, Kreuter, Boyum, and Thompson, 2015). Sakalys argues that a dialogic process is essential in helping us to “understand how perceptions, values, and beliefs of each participant in the relationship impinge on patient autonomy” (2010, p. 16).

Adolescents with CF inhabit a particularly unstable space in terms of seeking control of their healthcare decisions. They are in what Tierney and colleagues (2013) call a liminal space, in which they are transitioning between pediatric and adult philosophies and models of care. While Helen, the participant in this study, was not yet actively transitioning to an adult hospital at the time of the interview, she was in a space of growing expectations where both she and her pediatric physicians were unable to engage in a dialogic process that would foster collaborative decision making and move her toward more fully participating as an agent in her own healthcare. We argue that this shift from a paternalistic relationship to a collaborative one is a significant transition that advances the chronically ill adolescent toward increased clinical autonomy. Except for a decision to absolutely reject care, few, if any, medical decisions are truly autonomous simply because the options available are identified, designed, and presented to patients by medical authorities, which necessarily limits the range of possibilities. We argue that if patients and providers acquire effective dialogic communication skills, they will come together as partners, and patients can become stronger agents in determining their own paths. One model of dialogic communication that could be useful in healthcare is CI (Young and Flower, 2002).

CI and Rhetorical Agency

In pediatric and adolescent medicine, studies on patient/provider communication have far outnumbered those focusing on actual communication training for adolescent patients or parents. A few researchers have studied the impact of varied communication strategies used by patients and minor patients’ parents or guardians (Cegala, 2003; Cegala, Chisolm, & Nwomeh, 2012, 2013; Jenerette & Mayer, 2016). In the case of CF patients, some of whom spend a significant amount of their

lives in the hospital, communication training might well enable them to exercise more collaborative decision making by teaching them the concepts of a rhetoric of agency, which is a central construct in CI (Young & Flower, 2002; Young et al., 2010). Developed through a year-long analysis of emergency department interactions, CI is a communication model that promotes rhetorical agency to position patients as problem solvers and decision makers, in partnership with their providers. CI is practiced through a series of communicative strategies that (1) recognizes patients’ expertise in dealing with their own illness, (2) draws on a shared pool of information, (3) builds a partnership among all the stakeholders, and (4) develops shared goals for illness management. Importantly, CI is both a tool that can be used to analyze a difficult conversation and a strategy to develop a solution. Though not specifically named in the model, all of these strategies include audience analysis, a bedrock analytical skill that is the process of assessing the intended listeners’ or readers’ values, goals, interests, previous knowledge, and perceived or real communication barriers in the context of the intended interaction (Ede & Lunsford, 1984; Terryberry, 2017). In a conversation between patients and providers, audience analysis can be achieved through the strategies of CI, as each stakeholder shares his or her goals, concerns, perspective, and perceived barriers. Figure 1 illustrates the process of CI.

Analyses of conversations in a variety of healthcare settings have shown that the goals of CI can be achieved when stakeholders engage in rhetorical agency, which is “a multifaceted discourse that supports patients in creating their own narratives about their health and their lives and then in making decisions and plans to play those narratives out in reality” (Young & Flower, 2002, p. 73). Specific discourse moves instantiate a rhetoric of agency and are particular to each unique context. These include:

- localizing discourse in a particular context of place and time,
- identifying short- and long-term goals within that context,
- collaborating with providers,
- articulating decisions, and
- making personal commitments.

Using these discourse strategies moves the

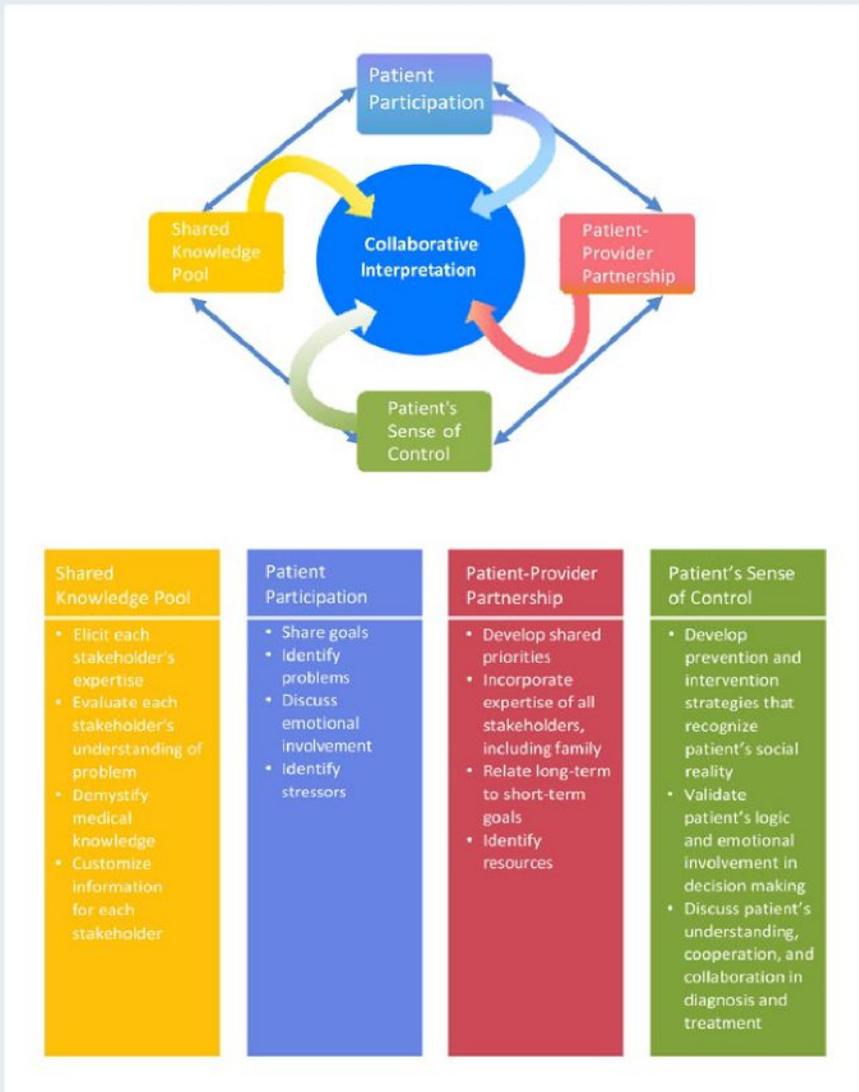


Figure 1. The Process of Collaborative Interpretation.

dialogue into the realm of CI, where collaboration and shared decision making enhance the patient's agency and allow all stakeholders to jointly manage an illness experience. In turn, power imbalances are mitigated, and each person's unique perspectives are honored. Communication, then, becomes the means to patient agency and is both the expression and enactment of a more autonomous healthcare interaction.

The interview with the CF patient, Helen, was part of a larger project that explored communication between adolescent CF patients and their healthcare providers through interviews conducted by one of the authors. Throughout the interview analysis, we found ourselves repeatedly returning to Helen's

G-tube experience. The incidents described by Helen and the child life specialist who participated in the study exemplified both communication failure and success, and the respective shortfall or achievement of Helen's goals. Through the lens of CI, we examined each participant's separate accounts of the incidents, observing the discursive moves that each described in the episodic journey toward reaching Helen's goals concerning the G-tube. We identified factors contributing to both ineffective and effective communication strategies that led to different results in Helen's quest to exercise control over her calorie intake and weight. In analyzing this single case study, the following research questions have been central:

Research Question 1: How does the framework of CI help us understand the communication barriers faced in this case?

Research Question 2: How do the strategies of CI help to overcome communication barriers?

Method

This case study is drawn from a larger, IRB-approved project in which we (the authors) interviewed 12 adolescent CF patients and 25 CF multidisciplinary healthcare providers, including a child life specialist. (The other providers interviewed were three physicians, two respiratory therapists, physical therapist, social worker, dietician, case manager, nurse educator, clinical director, and 13 floor nurses, all of whom were RNs.) The goal of the interviews was to learn about participants' experiences and perceptions of effective or problematic communication. The interview sites included the outpatient CF clinic and the unit in the adjacent children's hospital where CF patients are treated. The data for this case includes three 15-20 minute interviews with Helen, a 16-year-old CF patient, and one lengthy interview with a child life specialist who cared regularly for hospitalized adolescent CF patients. The first interview with the patient, Helen, took place while she was an outpatient at the CF clinic, and the other two occurred while she was hospitalized. This case was chosen because it is an exemplar of a patient and provider—a child life specialist—working together on a healthcare problem to develop a successful communication strategy.

Procedures

The first step of the study was for the research team to interact with healthcare providers in the clinic setting, making observations and shadowing patient/provider interactions. Formal interviews were arranged through the clinic nurse manager, as she introduced the research team to patients and parents. The first interview with Helen occurred in the clinic, after she completed all of her scheduled examinations and consultations. After receiving informed consent from her mother and assent from Helen, we interviewed her privately while she was waiting to be admitted to the hospital

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for IV antibiotic therapy. Following the study protocol, she was interviewed two more times over the next three days. Over the span of the three interviews, Helen responded to the following prompts:

1. Describe what you think “good communication” is and provide some examples.
2. Identify a time when communication with a healthcare provider went particularly well.
3. Describe a time when communication with a healthcare provider went poorly.
4. Think about and tell us how communication with your providers could be improved.

The interview with the child life specialist occurred after shadowing providers in the hospital unit where CF patients are cared for. All providers were asked the same four questions:

1. What unique communication challenges do you see in caring for adolescent CF patients?
2. How do you address those challenges?
3. How do you describe successful, effective communication?
4. What communication failures have you encountered and what has been their result?

All interviews were audio-recorded and transcribed. Helen’s interviews lasted for a total of 47 minutes, which resulted in 23 pages of transcript. The single interview with the child life specialist lasted 66 minutes, resulting in 37 pages of transcript.

Data Analysis

After several readings of the transcripts, a rich narrative emerged that gave differing perspectives on a particular series of events, all involving Helen’s G-tube. It was also clear in the transcripts that the child life specialist was implementing informal communication training in her efforts to support Helen. With that insight, we turned to CI as a lens through which to view the data because it evolved from a grounded theory analysis of many patient/provider interviews and it captures specific rhetorical strategies that stakeholders can use to construct shared meaning. A central question was whether or not the framework of CI was enacted in these

narratives. With that question in mind, the decision was made to use template analysis, a qualitative method that supports the use of a theoretically derived *a priori* set of themes in coding data (Crabtree & Miller, 1999; King, 2012). This analytic tool does not ask for frequency counts, as the number of times a theme occurs in a text does not necessarily reflect its salience (King, 2012).

To code the data, we broke down the guidelines of CI into the segments illustrated in Table 1 to serve as a coding template. We then extracted every conversational turn in the transcripts that referred to Helen’s G-tube and assigned a code to each idea unit within them. An important aspect of this method includes the development of additional codes where the richest data—in relation to the research questions—are found (Brooks, McCluskey, Turley, & King, 2015). Using this process, two additional sub-codes emerged under the theme of “making decisions”: making decisions about communication strategy and making decisions about healthcare.

Each of us coded the transcripts independently and then came together to discuss our findings. Where we did not concur, we discussed the text until we came to agreement. In the end, we discovered enough exemplars for each theme to conclude that the child life specialist was, unknowingly, teaching Helen how to engage in CI.

Results

Both Helen and the child life specialist were asked to give examples of problematic communication, and independently, they

told the same story of Helen’s G-tube. Helen described being diagnosed with CF at age two, and shortly afterward having the G-tube inserted to enable her to gain weight. By the time she reached her early teen years, she had lived with the G-tube for over a decade, with her nutrition and weight goals managed by her healthcare providers. When she was 14 years old, she wanted to try maintaining her weight on her own and asked to stop the tube feedings. Her plan was to leave the tube in place but to demonstrate that she didn’t need it so that it could eventually be removed. For two years, the doctors refused. Then at age 16, they abruptly removed the G-tube. Unfortunately, the hole that was left in her abdomen did not close properly, and during the current hospital visit, Helen was adamant that surgeons repair it. From both Helen’s and the child life specialist’s viewpoints, it was clear that serious communication barriers existed and that Helen’s healthcare goal was not being met.

Template Analysis

Localizing conversations. Localizing the conversation refers to stakeholders speaking about events and goals within a specific context, including place, time, and means of communication. In her telling of the G-tube narrative, the child life specialist recounted one episode in which the context of the communication was problematic and one when the conversation was specifically localized to enhance communication. She described the context of the conversation between Helen and the surgeons when they were trying to talk to her during their 6:00 a.m. rounds:

Table 1.

Coding Themes and Subthemes Indicating Discourse Processes of Collaborative Interpretation

THEMES/SUBTHEMES	DESCRIPTION
Localizing Conversations	Specifying the conversation in context, including selecting the means of communication
Identifying Goals	Identifying short-term goals in the context of their current medical problem, as well as long-term goals for their lives
Collaboration	Collaborating with providers and naming institutions and individuals as resources for information and support
Articulating Decisions For Healthcare For Communication	Articulating decisions about medical care Articulating decisions about communication
Personal Commitment	Making a personal commitment to change or to follow through with a plan

But what was happening was when she, when the surgeons would come in the morning, she wouldn't talk to them because it was six in the morning and she was asleep, and she was grouching and "why are you in here?" because it's so early.

In this case, the context, or locality, of the conversation was early morning during physicians' rounds, when their time was short and Helen was sleepy and grouchy. Helen, typical of many CF patients, has a difficult time in the morning, waking up with excessive coughing and no inclination for conversation.

To address those early-morning communication challenges, the child life specialist suggested that they write Helen's questions on her room's whiteboard, using it as a memory aid to prime both Helen and the physicians for discussion.

So what we decided was, she and I wrote together questions on her whiteboard in her room, so when they came in at six in the morning and she was grouchy and tired and didn't want to talk to them and couldn't think of the right questions, the questions would be written out right there and she could say "I can't remember my questions but they are on the board. Can you sit down and let's talk about this?"

In specifying the context of place (hospital room) and venue (the whiteboard), she created a common space for discussion for both Helen and the physicians. In this strategy, Helen would wake up and talk with the doctors, and the doctors would sit down and discuss the questions on the whiteboard. In this example, the child life specialist used the tenets of CI to both analyze the problem and create a solution.

Identifying goals. The second marker of CI is identifying both short-term and long-term goals in the context of the medical issue. When Helen first spoke about the G-tube, she expressed her frustration that her physicians were not hearing her when she talked about her goal to maintain her weight on her own. The following is her response when asked to describe an example of communication that did not go well:

There's been plenty of times where I felt like I haven't been heard, I mean, like, when I had my G-tube and I first wanted it out they wouldn't listen to me, they



wouldn't let me try to not do it for a while or do the calorie counting or anything like that, and I was getting really frustrated and so they wouldn't listen and they wouldn't even let me try it.

In this example, Helen recounted her immediate goal of maintaining her body weight without using the G-tube and her long-term goal of getting the tube removed, once she proved she could stay healthy without it. But those goals were not shared by her physicians; Helen believed that they intended for her to keep the tube indefinitely. In this example, CI is not practiced because from Helen's perspective, the doctors were not listening to her goals, and she was assuming what their goals were, though she never actually asked them. She saw an intractable difference.

In another example, the child life specialist recounted the short-term goal Helen had after the tube had been removed, which was to avoid the problems that were caused by the open hole in her abdomen:

So every time she eats or drinks, it is leaking out of her G-tube hole, which is painful, it's embarrassing, it's, you know, going to the school nurse's office multiple times a day to change her dressing, it's, you know, changing clothes, it's all of those things.

In naming these difficulties in the context of her goal to have the hole repaired, Helen had engaged her child life specialist as a collaborator in her effort to win her doctor's approval for reparative surgery. To our knowledge,

though, she had not shared these difficulties with the doctors themselves.

Identifying collaborators. After helping Helen to articulate her questions, the child life specialist then decided to seek further collaboration with the pulmonology fellow, a doctor who was completing her last year of specialized training under Helen's attending physician, who was ultimately in charge of her care. The fellow was at first unwilling to talk to Helen about the surgery because it was outside her area of expertise. Despite her reticence, however, she was able to explain to the child life specialist what the pros and cons were of the surgery and what the surgeon's concerns were. The child life specialist explained: "And all [of a] sudden my eyes were open to exactly why they weren't going to do the surgery at that point, why that wasn't their first go-to thing." Then she asked the pulmonology fellow to go to Helen's room and explain it to her:

Now, is there any way you can go to her and talk to her . . . about that and explain those things to her? And I said, honestly, 90% is just a communication issue. You all have your reasons why you don't think it's a great idea, the surgeons have their reason why they don't think it's a great idea. You know why those surgeons don't think it's a great idea, but Helen doesn't know these things. The surgeons haven't told her because she won't wake up. So it's a 50/50 thing going on here. They

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have their faults, she has her faults. We have got to get it together.

The fellow was reluctant to talk to Helen, feeling that it was the surgeon's responsibility to talk to the patient. But the child life specialist pushed, insisting that the fellow had provided answers that Helen needed. Eventually, the fellow did talk to Helen at length. In this case, the CI was in two stages, first between the child life specialist and the fellow, and then between the fellow and Helen. The result was that Helen's questions were answered to her satisfaction: "Yeah, when she came in, that helped me understand a lot as to why they couldn't do it. That answered a lot of my questions right there."

This episode also illustrates the complexity of CI within a culture of clearly defined areas of expertise and responsibility. CI can be either synchronous or asynchronous, and it often must cross disciplinary lines to be effective. In this case, the pulmonology fellow was initially unwilling to step outside the bounds of her pulmonology expertise into the purview of the surgeon. She was able to, however, because of the collaborative nature of the CF care team meetings, where all of the details of a case are discussed. And now, at the child life specialist's insistence, she talked to Helen about the medical reasons for not performing the surgery at that time, essentially extending the collaboration to include the patient. Her information allowed Helen to make the decision to accept the surgeon's delay.

Articulating decisions. In expanding the original model of CI, we have split the criterion of articulating decisions into two realms: decisions about communication and decisions about healthcare. While these overlap, we found that articulating collaborative decisions for communication often paved the way for collaborative healthcare decisions. In the example above, under the theme "localizing conversations," there is evidence of a communication plan being formed. The child life specialist told Helen: "So what you need to do is you need to start communicating with them like a 16-year-old should be communicating with them. Because they are not going to take you seriously and they are just going to think you are being a drama queen when that's not the case." This statement laid the foundation for the decision to write questions on the whiteboard and create a collaborative communication plan with the doctors.



In earlier stages of the story, however, the lack of a communication plan is apparent. The child life specialist described Helen's communication about wanting to get rid of the G-tube:

She has been begging for a long time for taking her G-tube out. Well, beg, beg, beg, beg, beg, beg, beg. Nobody is going for it. And finally about a month ago, a month and a half ago, when she was in clinic, they decided they would take her G-tube out.

While the G-tube was eventually removed, it was not the result of collaborative decision making. Helen spent months feeling that no one was listening to her. In fact, when asked to recount a time when communication failed, this was the story that she told. And when asked why the doctors decided to remove the tube, she said that she did not know.

Personal commitment. In this case, both the child life specialist and Helen personally committed to a communication plan to address a specific problem. The child life specialist understood the root of the problem: "And I said honestly, 90% is just a communication issue." She was committed to helping Helen learn to "communicate like a 16-year-old," or in other words, to meet with the physicians when timing allowed, be clear with her questions, and be willing to listen to their answers. The child life specialist described how she and Helen enacted their commitment to better communication: "Helen and I sat and wrote down all the questions

that she had for the surgeons and so that was kind of our way of trying to get everybody on the same page and remedy the situation." The plan was that the questions would be on the whiteboard, and when the doctors came on their morning rounds, Helen would wake up and point them to her questions. Helen agreed to the plan but in the meantime, the child life specialist also talked to the pulmonology fellow, asking her to speak with Helen to explain the intricacies of the surgery and why the surgeons were reticent to do it. In the end, Helen explained that the fellow answered all her questions, so she was at peace with the surgeon's decision to not yet close the hole.

Discussion

In considering the first research question (how CI helps us understand communication barriers), Helen's story serves as an exemplar of both the challenges inherent in patient/provider interactions for chronically ill adolescents and also the potential of CI, especially when guided by a provider who has strong communication skills. Prior to the child life specialist's intervention, Helen was experiencing many of the typical communication problems that are often observed in medical settings, including power differentials (Formosa, 2015), fragmented information (Grant, 2015; Pham, Thornton, Engelberg, Jackson, & Curtis, 2008), unclear goals of care (Wocial et al., 2017) and the diminution of the patient's voice (Hopwood, 2012; Hargreaves, 2014). Of note, CI attributes

expertise to both patient and provider, and in Helen's story, the child life specialist focuses on each person's proficiency. She, of course, recognizes the expert knowledge that the surgeons bring, but she also highlights the expertise of the pulmonology fellow. Her unique contribution, though, is recognizing Helen's expertise in the day-to-day experience of having a G-tube implanted in her body over several years and then the aftermath of its removal. Her challenge is to bring all these voices together in conversation so that the stakeholders can make a joint decision that, in a more collaborative relationship, would further Helen's goals.

The child life specialist's intervention also highlights important reasons to teach communication skills to adolescents. Sakalys (2010) points out that patient autonomy is a moral ideal and that significant challenges exist to realizing patient autonomy in a clinical setting. Yet patient-centered care emphasizes the need to move intentionally toward patient autonomy in decision making, both in the medical settings and in day-to-day care (Chambers, 2017; Drisko, 2017; Epstein & Street, 2007; Lipstein, Dodds, & Britto, 2014; Truglio-Londrigan, 2017). Adolescents with CF are in unfamiliar territory as they gradually take more ownership of their healthcare and begin their transition to adult care. Schlucter (2014) recommends that adolescents be encouraged to be proactive in the decision-making process and that adult care providers understand that their adolescent patients bring a wealth of knowledge and expertise with them to the new relationship. These recommendations, though, are hard to implement without specific communication training, particularly when throughout their experience as pediatric patients, adolescents are accustomed to their parents or the doctors making all of the decisions. Additionally, an individual patient might have a strong, communicative relationship with a provider he or she has known for years. But as patients transition to adult care, their roles change and they need to understand how specific communication strategies work in redefining and building new relationships with providers who view them as adults. This recognition and application of skills is supported by CI.

In considering the second research question, which asks how CI can help to overcome

communication barriers, we see that the child life specialist unknowingly worked within the framework of CI to teach strategic rhetorical moves to Helen. First, she taught her to establish her credibility: "You need to start communicating with these doctors like a 16-year-old." She firmly but kindly instructed Helen to speak as a young adult, rather than "whining or refusing to communicate early in the morning." She encouraged her to analyze her audience by considering the physicians' expectations and needs, particularly in the context of early morning rounds in the hospital. She then worked on two fronts to help Helen choose a mode of communication: collaborating with another expert (the pulmonology fellow) and using the whiteboard in her hospital room as a memory aid in asking her questions. Through the child life specialist's coaching, Helen learned specific communication strategies that brought a resolution to her concerns. Even though she ultimately did not wake up to speak with the surgeons on their early morning rounds, she worked with the child life specialist and the pulmonology fellow to voice her concerns and to learn the intricacies of the proposed surgery. In Helen's iteration of the story, she said that she felt listened to: "When she [the pulmonology fellow] came in that helped me understand a lot as to why they couldn't do it. That answered a lot of my questions right there." Learning why her physicians were cautious helped Helen grasp the fuller picture of what was at stake in this decision. Once she understood, the changes in her attitude and behavior were dramatic and demonstrated one of the benefits of CI: the wider access to fully knowing the medical implications of an action.

CI is not a rigid formula that requires lock-step adherence. Rather it is a framework for building collaboration and developing agency as patients journey toward autonomy, and it is particularly applicable for chronically ill teenagers transitioning to adult care. The child life specialist in this project is not a communication specialist, and she had not had specific communication training. Yet because she is grounded in a patient-centered model of care, she was acutely aware of the role that communication plays in identifying and meeting patients' and providers' goals. Helen was fortunate to interact with a child life specialist who had strong intuition about communication and a deep commitment to its value, two factors that enabled her to

effectively brainstorm and problem solve. We believe, therefore, that the training and role of the child life specialist could be expanded to include communication instruction for patients. As professionals whose scope of practice includes interactions with patients, families, and numerous providers, child life specialists are well positioned to receive and then promote communication training.

Conclusion

Although decades of prior research have identified the importance of improved communication between patients and providers, much of the focus has been on physician training (Cegala, 2003; Elder et al., 2008). Of course, communication training for physicians and other healthcare providers is essential. However, to strengthen a collaborative model of healthcare communication—perhaps especially for chronically ill patients who spend so much of their lives in the medical world—we argue that patients need communication training as well. As chronically ill children mature, a heightened communication ability might help ease the transition to adult care as they increasingly shoulder more of their healthcare responsibilities. Communicating more strategically with a strong knowledge base might help them become their own best advocates, and these skills could serve as scaffolding as they adjust to an adult model of care.

Much research in patient-provider communication focuses on the power differential between physicians and their patients, with most power credited to the physicians through professional status and expertise and in their institutionalized roles in the healthcare environment. However, in communicative exchanges, power can also be wielded by patients, sometimes in a negative manner. The child life specialist in this study described the physicians exhibiting hesitancy in talking with Helen to the point that they were dodging the patient during rounds: "So the surgeons would just kind of take a peek and then run back out because, I think they were a little nervous that she might lash back." As the child life specialist successfully brought these stakeholders together, she demonstrated facility in collaboration and communication. She modeled CI's ability to mitigate

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power structures and support patient agency through the identification and negotiation of shared and divergent goals for specific treatments as well as overall support in the illness experience. Sakalys (2010) notes that while patient autonomy has been established as a moral ideal in the patient-provider relationship, it is conceptually and clinically complex. This case shows that it is also rhetorically complex. Both participants' narratives about the feeding tube show the child life specialist rejecting a paternalistic model of "fixing the problem" and instead challenging Helen, the adolescent patient, to exercise empathic, respectful, and age-appropriate engagement with the surgeons with whom she is at odds.

Implications

This case study highlights a role of a child life specialist in CF care and her critical need for effective communication skills. It also demonstrates the need for communication training for patients, which we believe could be effectively delivered by child life specialists using the CI model. Such training could help patients convey to their healthcare providers a better understanding of an issue from their own perspective, but shaped to respond to the provider's concerns, too. This kind of audience analysis is widely promoted in writing and speaking strategies for communication professionals, but seldom is it explicitly taught to patients or providers as part of their communication skills. As demonstrated in this case study, patient/provider communication is greatly enhanced when each party considers the perspectives and goals of the other.

Limitations

This study is but one vignette in the life of an adolescent CF patient whose experience might not be typical of other CF patients in her age group. Nor is the experience of a CF patient necessarily typical of the illness experience in other chronic diseases. While a qualitative case study provides rich insight into a single event or circumstance, larger studies are needed before a communication curriculum could be designed and tested. Further analysis is necessary in other areas of adolescent healthcare, and pertinent attributes of successful adult patient/provider collaboration must be identified before an adequate communication tool for child life specialists could be developed. The CI model must also be tested in various cultural settings and adapted accordingly.

Future Research

In addition to continued analysis of the data from this project, future research should include more analyses of patient-provider interactions in adolescent CF care to develop training materials for young patients. Although long-term outcomes are not available from this study, the child life specialist's strategy to use the whiteboard in the patient's room (a low-tech memory aid) argues for further studies for asynchronous (not necessarily high-tech) conduits for communication between patients and providers. The need for patients and family members to communicate with physicians or other healthcare providers at unscheduled or inconvenient times provided motivation for prior studies conducted with

physicians, nurses, parents, and adolescent cancer patients at a children's research hospital (Kim, Young, Neimeyer, Barfield, & Baker, 2008; Young et al., 2010). Both studies, as well as this one, suggest that CI could be a productive framework for developing communication training materials for child life specialists and adolescent patients. Future work should also include longitudinal studies, both to develop and then test patient communication training materials.

This study is but the beginning of what could be a fruitful partnership between communication scholars and child life professionals. Understanding and addressing potential communication barriers is vital if adolescents with CF are going to develop agency and decision-making skills in their journey toward adulthood. This study suggests that learning the strategies of CI—localizing conversations, identifying goals, articulating decisions, and committing to a communication plan—could help adolescent patients become more effective partners in their healthcare. In so doing, they will be better prepared to engage in the self-determination that is at the center of bioethics and the competent, shared decision-making at the heart of patient-centered care. ✨

* Helen is a pseudonym.

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