9 Patients and Families

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I spent the large majority of my life not thinking about healthcare, let alone interacting with the institution. Growing up, my parents, siblings, and I were very healthy. I could count on one hand the number of times I've been to a specialist. I married a man who had a similar background. When we had our first child, the pregnancy was typical and uneventful. We had a home birth. I remember this peaceful and calm experience initially laboring while watching the snowfall in our backyard. Certainly, when labor heated up, no one would have described me as calm. Yet, our son Harrison was born healthy and without event after 18 hours of labor with two midwives and my husband at my side.

Shortly after, I was hired at a pediatric hospital in learning and development. This was a thrilling opportunity being a new mom and now working with the world's best and brightest in pediatrics. I spent a career designing and delivering training on leadership and team development but in non-healthcare business settings or with the federal government. Those organizational structures and environments can be very similar. Healthcare was a whole other universe for me. So much so, I initially struggled with the ubiquitous terms people steeped in the industry take for granted,

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like the difference between “inpatient” and “outpatient.” I kept thinking to myself, “Aren’t all patients in?” The meaning of those terms was not obvious to me. It took a solid 3 years for me to start to understand the experiences and challenges of this industry. My job was and still is to help healthcare employees work more effectively together.

When I became pregnant with our daughter Julia, everything changed.

At the 20-week ultrasound, Julia was diagnosed with myelomeningocele, or the most severe form of spina bifida. It was devastating. A neural tube defect, spina bifida occurs at the very initial stages when the baby’s spine is formed. In Julia’s case, her spine and nerves formed outside of her body as a result of an open lesion in her lower back. Julia also had hydrocephalus or a buildup of cerebral spinal fluid in her brain. We were terrified looking up information online and seeing the different ways our child’s life could be impacted. We learned after another round of testing about fetal surgery. A procedure to close Julia’s back while she was inside me – surgery on a human, inside a human. It seemed like science fiction. Our first birth, a home birth, involved the lowest level of technology possible. Our second birth went speeding to the opposite end of the spectrum.

When the nerves of the child’s spine are exposed to amniotic fluid during pregnancy, additional damage is caused to the child’s health. Fetal surgery closes the child’s back in utero. By doing so, the damage is stopped. There are countless benefits to having the surgery. There are risks too.

This kind of operation puts two lives at stake. Over the course of 2 days, my own health was intensively evaluated and so was the baby’s. In addition, my husband’s health history was scrutinized and even our marriage. We were interviewed with a psychologist who was clearly seeking to understand if there were any signs of abuse or trauma that in some way could adversely impact the outcome of the surgery. The two-day evaluation process made it clear that this surgery was not something to consider lightly. When we learned of qualifying, we made the tough choice to move forward.

Experiencing something like fetal surgery is a level on its own. There is the terrifying and emotional stress of making that deci-

sion to have surgery, and that decision could result in losing the baby. It is rare but possible. A parent's mind will spiral, "What if I am responsible for losing our child?" As we weighed our decisions about the surgery, we met with countless people: maternal and fetal medicine specialists, neurosurgeons, genetic counselors, radiologists, neonatologists, nurses, psychologists, and socials workers. The hospital we were at was out of network. The insurance paperwork was incredible. We had inches thick file folders to keep track of everything. Feeling overwhelmed was an understatement.

Looking back, I was in 100% patient mode. I did not see myself also as a healthcare professional in the midst of fetal surgery, during recovery, birth, or even the first 6 months of Julia's life. During that time, we could barely keep up with the number of appointments we had. I was and still am grateful now to be working at the same institution where Julia receives care. The care we received for fetal surgery was fantastic, and the care we receive now is excellent as well. We have received quality care and have felt that we were the center of those care strategies.

Yet, this is not the experience of many parents. We belong to parent groups on social media, an excellent venue for sharing information and stories (though it has its pitfalls too) and have learned about a wide variety of approaches to care. **As patients and families, it is clear: the more involved we are, the more included we feel, and the better the care we receive.** Putting patients and families at the center of care is a core tenant of quality improvement. Yet, it had become abundantly clear through my many interactions as a parent and professional that patients and families do not intuitively know how to be involved, know the right questions to ask, or have the means to navigate the healthcare field. In addition, healthcare teams do not always have the knowledge and skills to effectively work together, let alone bring patients and families into the team as well.

The purpose of this chapter is to offer strategies to draw patients and families into the team-based approach to care, leveraging my experience as a parent of a medically complex child and as a team development professional. A framework for team-based care will first be introduced. Then, there will be brief discussion

of just some of the obstacles that get in the way of teams working effectively together. The chapter concludes by elevating the framework to align with a list of questions to engage patients and families. The value of this framework is it can be used outside of patient care. Any team, regardless of industry, will benefit from this approach to working together.

When Julia was 16 months old she needed two surgeries. They were relatively minor but both required anesthesia and recovery time. We were nervous about both surgeries occurring within a short timeframe. During a conversation with her first surgeon, we mentioned Julia's need for the second surgery and described it to him. He then offered to team up with the other surgeon to perform both surgeries under the same sedation. It was a scheduling struggle at first. Finding operating room time and scheduling pre-op appointments while balancing surgeon availability with our own schedules was a challenge at best. Yet, we worked together to make it happen. Experiencing doctors and nurses working with us heightened the trust and confidence in our daughter's care.

"Team-based care" has been around for some time in medicine. Generally speaking, the goal of it is to best meet the needs of the patient as well as the family by making the patient a part of the team, not the object of the team.

I have learned through numerous conversations with healthcare providers that when people come together effectively as a team, those members are more engaged, overall satisfaction is improved, and those members want to remain on the team. They do not quit. Loyalty and commitment are fostered, and creativity is nurtured. Not only is team-based care an approach that provides better outcomes for patients and families but also for the team members.

To do this, it is important to know what working in an effective team looks like. There are fundamental principles that make teams high performing. I've spent a 20-year career in this field, and in some ways the basics are repeated over and over again in leadership and team development books. My intention here is not to recite the research in team development. Rather, there are basics that we all can list as being important to working together with

others. These basic components are easily identified by just reflecting on our own experiences of working with others on a team.

Generally speaking, high-performing teams possess the following: clear goals, defined roles, conflict resolution, and feedback. The thread that ties it all together is communication: really good communication, not just reporting information back and forth but meaningful dialogue made up of asking questions and listening.

Here is a breakdown of what is involved in each component. This is not all inclusive. It is a general review of basic concepts.

Goals Everyone on the team knows what they are trying to achieve, in a specific way. The goals are aspirational and provide members a sense of connection to what they are working toward. As a parent I want to experience a group of people rally around the well-being of my child and my family. In order to rally, there has to be a goal. It describes or paints a picture of what is different as a result of working together.

Defined Roles Each member on the team is not only clear on their own role and what is expected but also the roles and expectations of each other. Assumptions fill the gaps if the team has not made these definitions obvious. Setting expectations early on with patients and families about their role and what it looks like is paramount in team-based care. Patients or parents will not naturally see themselves as having a part on the team at all. Discussing this and how the care team sees the patients contributing to the decisions will help draw them into the team in a more productive way.

Conflict Resolution No team has ever existed without conflict or disagreement. The teams that perform best are those that navigate it productively and talk about conflict before it comes up. They have a plan to resolve it before anyone disagrees. An important component of conflict resolution is empathy. Can the physician or nurse or technician step into the shoes of that parent and feel what they are feeling? It's emotional and, for some, uncomfortable ground. However, empathy shifts teams out of judgment and into

understanding. When people understand each other, they work more effectively together, and they certainly resolve conflict faster.

Feedback Feedback is about improvement and most effective when it is expected and routine. Teams may dedicate certain time to discuss performance and use a format to do so such as Plus/Delta, a Lean methodology. The Plus side reveals what is going well. Delta or Δ refers to a symbol for change. This means the team discusses changes that can be made. These conversations are free of personality or gossip. These feedback conversations are centered on the care and are focused on improvement.

Communication This is the thread that ties it all together. Yet, it is probably the most difficult. Entire postdoctoral programs are dedicated to the study of communication, so clearly we will not discuss it all here. What I tend to advise the teams I work with and also try to model in my own interactions with Julia's providers are two basic communication tactics: ask questions and listen. When talking about goals, ask questions and listen. When defining roles, ask questions and listen. The crux of resolving conflict relies on asking questions and listening. The same goes for feedback. Clearly, at some point everyone on the team will need to state an opinion or make a decision. Do that. Then, pause, ask questions, and listen.

I would be remiss to not mention the role of a leader. It is well documented that leadership of the team is critical to its success. What gets tricky in healthcare is that team leadership and membership changes frequently. As a parent and employee, I quickly noticed how residents and fellows come and go. There are rotating shifts of nurses and other support staff, which often results in a different team in almost every appointment.

Generally speaking, the physician is almost always looked to as the leader of the team, regardless of reporting structure. This puts a greater expectation on the part of the physician to model the behaviors needed in the team. As a parent, I also look to the physician as the leader and hold an expectation for them to take that

leadership role. But I also realized it's a tough spot to be in because of the lack of authority a physician has on overall team performance. In so many institutions, nurses report up to nursing, administration reports to administration, and physicians report up through other physicians. Yet, everyone is expected to work as a team despite many having different bosses and fighting institutionalized silos. The physician, who many look to as the leader, has very little authority over others.

This means everyone on the team is responsible for its success. This framework is designed to inform every person on the team what to do and how to do it. It is not dependent on a single leader. Teams certainly benefit from single leaders, but it's not always realistic or feasible in healthcare. So, healthcare teams all need to be equally informed on what actions to take for quality teamwork.

The purpose of this section is to describe team-based care and what the components of it look like: goals, defined roles, conflict resolution, and feedback with consistent communication threaded throughout the interactions. Team-based care yields better results, and we experienced that when Julia's surgeons teamed up for us to perform two surgeries under one sedation. However, it is not easy, and there are countless challenges and obstacles that hinder teams working together. The next section will address just that.

Julia regularly sees four to six different specialists. Thankfully, all six are in the same location, and the ideal is to see everyone in one visit every 6 months. All of her doctors and nurses recommend we group appointments into 1 day. This makes great sense and is ideal, especially for the parent. Yet, weekday clinics, appointment availability, more emergent cases, unexpected conflicts, sibling care, school activities, work schedules, available time off, and everyone's fortitude and attitude have to sync up to make it happen. It rarely does. For example, I spent at least 3 hours trying to schedule an ultrasound plus two clinic appointments for the same day. We got it done, and I received emailed confirmations for all three appointments. Yet, something happened with the ultrasound. We weren't on the schedule, and the rest of the timeslots were booked. It had something to do with one system not talking to another. I don't know. What I do know is that I had to waste 2

hours at the hospital with an 18 months old before the first clinic appointment. We also had to return the following week for the ultrasound.

There are countless obstacles in the way of creating a team-based care model. The example above is generally centered on scheduling and that is just one obstacle. Other challenges include complex health insurance, overwhelming medical information, paperwork and signatures needed – not to mention the constant stress and worry of being unwell or having an unwell or atypical child. Patients and families may very well be the most important members of the care team but also may be the ones most difficult to draw into that role.

The healthcare environment can be very intimidating, and as a parent, it is hard not to see yourself as anything other than an outsider. Even as a team development professional, I did not see myself as having a role on my daughter's care team. Both my husband and I were oblivious to it, especially when she was first born.

Very early in Julia's life, she was hospitalized. During rounds, the physicians and nurses would gather, stand in a circle, and talk without asking us any questions. They might smile and nod toward us, but that was it. We were literally outside their circle. We would eavesdrop but rarely understood the language and acronyms used. They were the experts, we were mere parents. In some ways, we conjured up this perception ourselves. If we had an urgent question, I believe we would have spoken up. But behaviors and posture, such as standing in a circle with backs and shoulders facing us, reinforced this impression of being excluded.

Certainly, there are instances where clinical providers may need to hold discussions without the patient or parent. We do not need to be involved in every discussion. Rather, if the parents are present, include them. Make a point to translate acronyms and complex medical terms into plain language to the parent. This might require identifying someone in rounds to take this role as well as carving out the time to do it.

Yet, this leads to another barrier, time. Never have we been more pressed for time in appointments than now. The pressure physicians and healthcare staff are under to create profitable clinics and drive productivity is significant. As an employee, I see it

firsthand in meetings and financial report outs. What's today's census? Is it up? Is it down?

I have lunch with stressed colleagues who feel they are losing or have lost the joy of what brought them to medicine in the first place, the time and interaction with patients. A colleague of mine recently said, "I didn't become a doctor to spend my day arguing with insurance companies." Layer all the other stress on healthcare professionals – such as frustrations with the electronic health record, online reviews, administrative duties, regulatory and organizational change, scorecards, and reimbursements – and it's no wonder the patient and family interaction is decreased and in some instances even lost.

Patients and families feel it and see it. Brenda, a friend of mine who also has a child with spina bifida, talks about a physician they see who quadruple books her 8:00 AM appointments with less complex cases. Her strategy is to compensate for patients who are "no-show" as well as to move quickly through more cases in a short time. However, on the days everyone shows up to the 8:00 AM slot, it backs up the schedule. Clinic staffs mumble about it, and the frustration of other patients and families mounts throughout the day. The worst appointment to have is the 4:00 PM appointment. Everyone is tired, frustrated, abrupt, and running really, really late.

Brenda inevitably vents about the lack of time with the physician. She knows she only has 5 minutes before the doc is onto the next appointment, and often Brenda complains that if she just had another 5–10 minutes, she might have thought of the questions that came to her in the car ride home. I also believe that her physician, in many ways, feels the same. She would love to spend another 5–10 minutes with all of her patients. Doing so would reinforce who she truly is and why she became a pediatric physician in the first place.

Another major obstacle is racial, socioeconomic, and cultural disparities. My husband and I are white, well-educated, have insurance, and live in close proximity to the hospital. The large majority of our physicians and care providers look just like us. We have great privilege which makes getting the care we need for our daughter just plain easier. If a family is non-white, lives hours

away, and has low income, inconsistent transportation, no insurance, limited education, multiple children to care for, jobs without leave, and/or language and cultural barriers, the obstacles to get any healthcare are great. Layer on a complex diagnosis, and it can feel impossible.

Team-based care is even more important to quality care given the very real disparities and biases that are at play. The fundamentals of communication in the framework (ask questions and listen) cannot be underestimated. An intensive care doctor I know well, Tamar, tells a story of witnessing biases at play in the care setting. Three residents were discussing a child who had not been visited by parents in 2 days. They were talking in pitying and judgmental tones regarding the lack of presence of a parent. Tamar, the attending and an exceptional teacher, approached them and asked, in a pleasant tone, "What do you know about this family?" They responded by speaking clinically of the child's diagnosis which wasn't her question. Tamar, who knew the family well, explained that the parent was single and working an hourly job and had very little leave time. In addition, she had two other school-age children to care for and support. The patient's siblings missed him terribly, and this mother was heartbroken to not be at the hospital with her child. "Yet, this mother entrusts us to care for her child and support her in every way we can."

As a parent, a logical next question is, what kind of care does a child receive if a parent is not at bedside? How are providers judging me, and how are decisions made if I can't be present with my child? Who's got my back? This is why a team-based approach is so important. Teams build relationships with each other and empathize. This model lends a structure and guide to providing the best possible care. Creating space to discuss the goals of working together, the roles everyone plays, and how to support each other, especially the parent.

The final challenge to be addressed is intended to call out the obvious: working in teams is hard, especially in healthcare. The dynamic nature of the environment with shifting staff, schedules, and patients along with ever-changing rules and regulations makes it a very complex environment. Hospital employees could find themselves working on a different team month to month, day

to day, and even patient to patient. The members of the various teams could include a host of players – doctors, nurses, therapists, technicians, researchers, schedulers, specialists, social workers, and volunteers – and those players may have varying levels of training and education on how to actually work as a team. These are learned behaviors. Factor in varying personalities, egos, age groups, and stress, and it is no wonder we have teams that struggle.

Acknowledging the difficulty of working as a team is important. It means if we are on a team that is struggling, we are not alone. Each person bears a responsibility for making it successful, and the next section provides a framework to do just that.

Julia had a physical therapist that employed a team-based approach and set remarkable goals for her development. The therapist would ask us, "What do you want to see Julia doing in 6 months? Here are some options…" Many of those options I found unbelievable, such as independently crawling. Julia's head size was very large due to her hydrocephalus. She struggled to hold her head up to crawl, and her mobility from the waist down was so limited due to the L2 lesion on her back. I truly thought she would never crawl. The PT was optimistic and challenging. She not only pushed Julia but pushed us to think big for her. This meant we also pushed ourselves to maintain therapy at home, which supported and maybe at times accelerated her development. Julia became a speedy crawler by age two.

There is a wealth of research that describes what high-performing teams do. The question is how to engage patients and families knowing that if they are active members of the team, the care may very well be improved. From a parent's perspective, it is really quite simple: ask for our perspective, understand our circumstances, give us choices, and include us in the decisions. These needs are well in line with the framework offered in this chapter and support the tenants of patient-focused excellence. High-performing teams have clear goals, defined roles, conflict resolution, and feedback as well as strong communication (made up of asking questions and listening) woven throughout each component. Communication is that thread tying it all together.

In my work at the hospital, I regularly have staff coming to me with “Amy, I don’t know what to say. Can you just give me the words?” In the spirit of this frequent request, the following table takes this concept to the next level by offering suggestions for how to engage the parent in the care team through conversation. Certainly, this is not an exclusive or even novel approach. The steps and language offered are common place. However, hearing these words, said this way, might influence parents to engage differently than they had before.

Weaving communication throughout each component of the framework, the following table lists each element and provides guidance entitled the “teaching moment.” This creates context for the parent and provides an explanation for why these questions are asked. Being conscious of not sounding condescending is vital with teaching moments.

Then, after providing the instruction, there is a list of questions designed to draw the parent into the conversation. The point here is not to ask every single question. It is to provide a list of options to start a conversation and keep it going. Not all questions will be relevant or apply. Notice the questions are all open ended and the use of the pronouns “we” and “us.” This is intentional to foster a team-based dialogue (Table 9.1).

This model can be applied outside of engaging with parents too. All teams benefit from leveraging this framework to take time to discuss how they work together. Ideally, if there is a leader of the team, that leader is the one to take the initiative to start these conversations. Yet, again, each member of the team plays a role in its success, so anyone can start these conversations. What is essential is for teams to intentionally set aside time to ask questions and listen to each other about each of the components of the framework. Generally speaking, the teams that openly discuss and plan their work using a framework like this will perform better than those who do not.

The purpose of this chapter is to offer strategies to draw parents into the team-based approach to care, leveraging my experience as a parent of a medically complex child and as a team development professional. The focus has been on quality care knowing that the more patients and families are involved, the more they are included, and better care is received.

Table 9.1 Engaging patients and families through conversation using the team development framework

Component	Conversation starters
Clear goals: The purpose of these questions is to inform the care team of what is important to the parent. Goals can then be defined leveraging everyone's input.	**Teaching moment:** When we're all on the same page with a common goal, we know we will create better care options for your child. We want to hear from you what goals you have for your child so that we can all work together to achieve them. Conversation starters: What do you want us to accomplish as a team? What does success look like? What is holding you back now? What has been hard to manage? What is going well? What about it makes it a success? What are you learning about your child's diagnosis? What have you researched or talked about with others? Who else supports you and your child's well-being? Tell me about your family.
Defined roles: The purpose of these questions is to understand what role the parent wants to or can play. It will also set the stage to inform the role the care team wants or needs the parent to play.	**Teaching moment:** You play a critical role on our team and we want to hear your perspective. We think it's important to understand each other's expectations and roles. We see you as a vital partner in the development of care plans. Conversation starters: What are your expectations for how we'll make decisions as a team? What role do you want to play in decision-making? Who are the other decision-makers involved in the care of your child? How do you want to include your child in the decisions? How would you like us to interact and communicate with your child versus communicating only with you? Who else is providing care, and what role do they play?

(continued)

Table 9.1 (continued)

Component	Conversation starters
Conflict resolution: The purpose of these questions is to discuss and address disagreement before it comes up.	**Teaching moment:** We will inevitably disagree and that's ok. That means we will make better decisions and identify better solutions for your child. If we talk about disagreeing before it comes up, we'll handle it together more effectively. When we disagree, we'll go back to our goals. Conversation starters: What experience do you have disagreeing with a nurse or a doctor? What is it like for you when you disagree? How should we handle disagreement? How do you prefer to share your opinions? In person or via email or text? What ideas do you have for us to handle disagreement effectively?
Feedback: The purpose of these questions is to invite feedback and set the context of improvement rather than criticism.	**Teaching moment:** Your opinion matters, and we want to hear how we're doing as a team. We will always be looking for ways to improve, and we'll routinely check in with you on progress. We also provide surveys, and we'd appreciate you sharing your feedback there as well. Conversation starters: What is going well with our work together? What can we improve? What should we start doing, stop doing, and continue doing? How well-informed do you feel about the care you're receiving? How would you evaluate our performance toward the goals we set? What aspects of our goals need to change in order to improve the care we provide?

The basic components of a successful team were presented: clear goals, defined roles, conflict resolution, and feedback with communication woven throughout each one. That communication is demonstrated by asking questions and listening. Certainly, there are plenty of obstacles that get in the way. The overwhelming nature of healthcare; an overall lack of time; racial, socioeconomic, and/or cultural disparities; or just the simple fact that working in teams is hard are all valid reasons to turn away from a team-based approach. Yet, as healthcare professionals we know that when the patients and families are engaged and involved, the outcomes are better.