Voices of Patients and Families: Partners in Improving Patient Experience

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Improving the Patient Experience

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The Beryl Institute is the global community of practice and premier thought leader on improving the patient experience in healthcare. The Institute serves as a reliable resource for shared information and proven practices, a dynamic incubator of leading research and new ideas and an interactive connector of leaders and practitioners. The Institute is uniquely positioned to develop and publicize cutting-edge concepts focused on improving the patient experience, touching thousands of healthcare executives and patients.

The Institute defines the patient experience as the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care.

The Foundation: Patients as Partners

The Beryl Institute opened 2013 with a powerful series of papers touching on the wide range of voices impacting the patient experience. In creating this series, we have heard from numerous players-- doctors, nurses, executives, students and now patients themselves. A common theme across all the Voices papers has been that a crucial element of any healthcare worker's job is the ability to listen, to hear the voices of all involved in the patient experience, both their spoken and unspoken words. When it comes to providing excellent patient care, providers can't compensate for a deficit in the ability to hear and listen. More importantly they can't miss the opportunity they have to act.

The Beryl Institute presents this paper, *Voices of Patients and Families: Partners in Improving Patient Experience*, as part of its mission to raise awareness as to how those in healthcare can positively influence patient experience. This paper is a companion to earlier documents in the Voices series and acknowledges that patients and families are at the center of the entire healthcare conversation. At The Beryl Institute, we believe the voices of patients and families are the most important voices for health leaders and practitioners to hear. They inform and guide practice and provide vital feedback on and offer insights into the way in which healthcare organizations operate with impact in addressing quality, safety and service.

Through our research, we have learned that healthcare workers can lose their ability to hear patients and family members. Deficits in our ability to hear patients are often due to the busy schedules, the alarms, competing priorities, multiple patient responsibilities, business objectives, etc. These "noises" create both personal and organizational deafness for some hospitals.

Perhaps it is time for those of us in healthcare to realize that patients and families are no longer simply "receivers" of care offered by "providers." In fact, the trend of engaged patients has taken on increasing significance in the larger healthcare dialogue. This is not only realized in ways such as the February 2013 issue of *Health Affairs*, "The New Era of Patient Engagement," but in increasing discussions among patient advocates and others in healthcare. In his speeches, Dave deBronkart, known to many as e-Patient Dave (@ePatientDave on Twitter), and a contributor to this paper, shares with audiences his core foundational principle, "'Patient' is not a third-person word."
This statement sums up the essence of the insights gained in speaking with 18 courageous patients and family members, from healthcare practitioners to patient advocates, in creating this paper. The voices represented here, desperately want healthcare organizations to not only hear, but also acknowledge, engage and truly listen to the voice of the patient when it comes to devising efforts to improve patient experience.

For this paper we collected more than 450 pages of transcripts of our interviews with the contributors. The paper summarizes the key themes emerging from our dialogue around a set of central questions. It includes a broad selection of quotes, statement and stories – the patient and family voice itself. And while it is no means a presentation of every word shared, I believe it represents the essence of what was said. To provide context for these direct statements, it may be helpful to review the full bio for each of our contributors (pages 31-36). Each of these individuals brings a valuable story, a powerful perspective and critical insight into the heart of any effort to improve the patient experience.

As you read the comments shared, you may also sense the frustration these individuals experience with the healthcare system. I would challenge readers working hard to help improve healthcare not to take these ideas in offense, but rather see them as an opportunity to gain new insights on how you can consistently deliver the experience patients and family members expect. Our intention in sharing these comments is not to criticize, but rather to enlighten the conversation that often is grounded in talking to or at patients and families rather than with them.

Nearly all of our contributors have dealt with chronic or severe illnesses, even loss, and offer perspectives that arise from intense and long exposure to healthcare systems in the United States and around the world including Australia, England and New Zealand. They offered comments that stem not only from personal experience, but also from what they have observed in their ongoing work across the U.S. and around the world engaging in the causes that they have been moved to address as a result of their personal experience.

As the contributors demonstrate, patient experience challenges exist in every country, and no system of care has devised the ultimate way to address these challenges. Yet even with the diversity of these incredible individuals not only in background, but also in the situations they encountered or challenges they overcame, we find their comments reveal common ideas to address, opportunities to explore and strategies that can be applied to patient experience challenges.

To provide for a consistent measure across the entire *Voices* series, we asked our patient contributors a very similar set of questions to those of other audiences. The questions included: How do you define the patient/family experience?

- Why do you believe a focus on patient experience is (and should be) central to healthcare today?
- What are the most important efforts healthcare organizations can take on to address patient experience?
- What do you see as the role/responsibility of patients/families in supporting/informing patient experience efforts?
- What do you see as the greatest roadblocks to effectively addressing patient experience and what would you say are/would be some of the greatest supports of success?
- What advice do you have for healthcare leaders working to address the patient experience in their organization? Where should they focus, what actions should they take, etc. What should they avoid in their efforts.

All too often in addressing the patient and family experience, we approach this work from the intelligent, educated and caring perspective of those who work tirelessly in the healthcare industry. This is not at all negative, but as we are learning, it can be limiting. It is time for those in healthcare to engage patients and family members not just as individuals that complete surveys at the conclusion of their encounter, but also as viable partners in not only their own care experience, but also in those for patients to come.

It is here where patients and family members can be realized as partners, where their role can be shifted from that of passive recipient to active participant.

How patients and family members define patient experience

Over the last three years, one of the most consistent comments from members of The Beryl Institute has been how helpful it is to have a standard definition for patient experience. We have continued to study this issue, initially gathering input from patient experience leaders across the United States and continuing to synthesize feedback from interviews and conversations with people across the globe as we reinforce the need for a formalized definition of patient experience.

The Institute defines patient experience as *the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care*. We strongly suggest that organizations adopt or adapt this definition (or a definition of their own) to support their patient experience efforts. Interestingly enough, our research[1] on the state of patient experience shows that still less than half the hospitals in the United States have a formal definition they follow.

We believe the definition is central to any effort, for without definition you have little basis or clarity for action. A formal definition provides guidance to hospitals and other healthcare providers so they can fully address the many aspects of patient experience. The Institute's definition suggests healthcare organizations consider all the orchestrated touch-points of people, processes, policies, communications, actions, and environment. It acknowledges that the values of all the employees must be aligned toward meeting the spoken and unspoken needs of patients. It raises the importance of perception rather than the simple adherence to standardized practices, and it moves employees to look beyond their own areas of responsibilities to help shape a positive patient experience across the entire continuum well beyond the four walls of the clinical encounter.

However, as Kathy Torpie, one of the paper's contributors stated, patient experience is not only the sum of what happens; it must also be inclusive of what doesn't explicitly happen, but perhaps should have. This provides a powerful insight into the value of patient and family voices and reinforces the point raised above. That to plan for and implement actions on the patient experience without patient and family voice ensures there are parts of the equation an organization will miss. Many organizations reach out to the Institute with some frustration, saying they have implemented all the central actions or tactics they believe needed to address patient experience. Perhaps this is the very point they overlook. Through the conversations that framed this paper I too learned that the action items are not enough to impact outcomes if you do not know what the patients and families – the consumers of your healthcare services – desire and expect. By the time we ask them to fill out surveys post visit, it is simply too late. They must be partners from the very start. This begins with how they define the experience themselves.

The 18 contributors interviewed for this paper offered the following on how they define the patient and family experience and how caregivers can make patient experience clearer, more comprehensive and more impactful. They offer a broad view of patient experience well beyond, but clearly inclusive of the clinical context. This reinforces our perspective at the Institute that experience itself is the totality of all that is done to address quality, safety and service. While it may make operational sense to distinguish between these items in managing them internally for a healthcare organization, patients and their families do not draw this distinction, rather seeing experience in its entirety.

The power of defining patient experience, and the richness of perspective is exemplified in the words our contributors share in replying to how they define patient experience. You will see the broad view and critical nature of perspective in framing this issue for patients and families.

> It really comes down to whatever somebody has as a want or need in his or her mind, whether or not that person can articulate it or not. How does it go when he or she tries to get their needs satisfied? How easy is it to get somebody to understand what you want? Ordinary human decency is what people want. Listening skills are key. How prepared is the healthcare system to respond to what you want, to offer what you want, as opposed to saying to patients, 'Look, here's what we have to offer, and you'd better be glad that you have it? Because without it, you'd be in trouble.'
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> Dave deBronkart

> For those of us who are ill, in chronic terms, I'd say the support and treatment – the bulk of that support and treatment--is going to come from the staff around us, rather than contact with clinicians and specialists. So, I tend to look at patient experience from this sort of global overview, rather than strictly a practice delivery issue.
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> Zal Press

[1] *The State of Patient Experience*, The Beryl Institute, 2013.

It's an emotional connection between the healthcare staff and the individual. It addresses mental and medical needs. That was the key element in my background with consumer and clinical research. When the individual is involved, you're very vulnerable and there's a lot of emotion tied to it. For me that was when the connection that really made, or broken, and how the relationship that I formed with various clinical personnel was evaluated. I just decided, personally, that in healthcare they make it so complicated that if they forget one of the key elements it is just the human exchange of emotions.

Brooke Billingsley

It's a very broad and open term that encompasses not only what goes into the care relationship in the clinic or in the hospital, but really the continuum of care… how our healthcare team works together regardless of where the patient sits. That's part of the patient experience, or that really defines the patient experience for me.

Libby Hoy

The patient experience is the story of the hospital's interaction with the patient and the family, from the parking lot, to discharge and out the door, and everything in between. That includes every person, the equipment, the facility, food, and the patient and the family members' perception of the care, the concern, the compassion, the competence and the comfort that is provided.

Barbara Lewis

It is what you go through emotionally, physically and financially. It is how the healthcare process affects the family and the family dynamics and a patient's life.

Alicia Cole

First of all, quality and safety are givens. The experience of care addresses every aspect of the patient's life and family. Once I enter the parking deck, how easy is it to find the right entrance, to locate the wheelchair if needed, to find a cup of coffee, to receive the information on the medication I'm taking. But It goes deeper than this, and it is about providing patient- and family-centered care, which integrates the four concepts of dignity and respect, information sharing, participation, and collaboration.

Julie Moretz

Patient experience is about the details. It's about the details of the communication. It's about the details of the physical experience, the emotional experience, and the psychological experience of illness. The patient experience is the broad spectrum of the interaction with the person at the parking deck, to talking with the physician, to going home and trying to maintain some semblance of independence through illness, while also dealing with all of the psychosocial dynamics and the culture of the family and friends. All of that combined is the patient experience. It is life with illness. If providers don't understand that this is the perspective of patients, they will continue to just look at things (like) lighting and room noise.

Tiffany Christensen

Patient experience is the interactions, the respect, the information that is shared and how it's shared.

Naomi Williams

Patient experience is about more than the sum of the events that occur. It includes how the events take place. It includes events that don't occur and should have, from the patient's perspective. Importantly, it also includes the patient's perceptions of what happened and/or what didn't happen and the meaning and emotional reaction the patient has to those events. So it's a combination of subjective, as well as objective information. Although I think the objective information is so much easier to measure, it doesn't mean that it's the whole story. The importance of subjective factors often gets left out.

Kathy Torpie

Patient experience is how patients perceive how they're being dealt with and how they're being cared for.

David Festenstein

Why a focus on patient experience is (and should be) central to healthcare today

While all of the contributors responded to this question with the general sense that it is the right thing to do, most also displayed a solid understanding that there are business reasons for paying attention to patient experience. Some said paying attention to patient experience is a trend that re-emerged after decades of neglect. Others said it was a completely new thing that has emerged during the last five to ten years with the rise of value-based purchasing and payer incentive programs that focus on patient satisfaction.

Strictly from a business perspective, focusing on patient experience pays off in terms of survey scores, such as with HCAHPS in the United States. Furthermore, paying attention to patient experience usually facilitates engaging patients such that they take more active roles in their ongoing care and leads to better quality outcomes. A recent analysis by Press Ganey[2] validated this point. It showed that actively engaged patients and solid patient experience scores typically translate into lower 30-day readmission rates.

Why does improving patient experience have this positive impact? One contributor illustrated the point with a famous Chinese proverb: *"Tell me, I'll forget. Show me, I'll remember. Involve me, I'll understand."* In reinforcing this point, a different contributor offered a variation on that theme by quoting writer Maya Angelou, *"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."* If organizations work at empowering people to be partners in their healthcare, they will have the courage to try. If people are treated simply as dependents of the healthcare system, as passive individuals looking for someone to manage their illnesses, their voices are lost in the process, and opportunities to communicate and plan effectively will be missed.

A second reason to focus on patient experience is that patients and families as consumers of care now have come to expect a focus on the overall experience of care. The conversation about patient experience has stretched across many consumer media channels and is well entrenched now in social media as seen in such efforts as "e-patients" and #Patients Included. Just a few years ago, many may have not have imagined that hospitals would be ranked not only in *U.S. News & World Report*, but also rated via such services as Angie's List (www.angieslist.com) or online through Yelp. This is the reality facing healthcare organizations today. The traditional framework of blindly accepted care relationships, deference to healthcare expertise and the idea of

Government and healthcare professionals have always thought the best way to design healthcare delivery is around efficiency and cost and the bottom line, without really taking into account the patient's world. I mean the patient's world is obviously included, but I think the main focus has been about costs and the bottom line. I think now the whole redesign of healthcare around the patient experience is showing you actually get a far more efficient and effective system in (focusing on the patient experience).

David Festenstein

So many hospitals are focused on improving patient experience and HCAHPS scores, but they do it in ways that are peripheral and not central. The central part of it is how you interact with patients. That's what it really comes down to. I think healthcare leaders are much more aware of that now than they ever were before.

Keith Boyle

Addressing patient experience has to be a top strategic priority. Before any new project is funded, the question ought to be asked, 'Did you meet with the patient-family council to discuss how this might impact the patient experience. Were they involved in planning?' I also think that whenever there is a leadership or senior management meeting, hospitals should always have a patient or family leader share a story before every meeting. I think that sets the stage for putting the patient and the family in the center. Healthcare organizations should even consider bringing patients and family members onto their boards of directors to help them tweak their mission and value statements to make them tangible and not just words. Patient and family advocates can also help mistake-proof things. Those are the reasons I think patient experience should be central.

Julie Moretz

I'm the younger version of the baby boomer, but the generations below me see themselves as equal with clinicians, versus generally just accepting the authoritative model that my elders saw. So I debate with my healthcare providers about the kind of care I'm getting and the decisions being made, because I can do more research on the Internet. I expect to be engaged.

Brooke Billingsley

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[2] The Relationship Between HCAHPS Performance and Readmission Penalties, Press Ganey, 2012.

If I were a hospital executive, I would start connecting with people who came through my doors to find out about their experience. I wouldn't do it just through a survey. I would personally find out whether people felt cared for. Did they feel like the people who worked there were taking care of them? And that's a whole separate issue from the technical excellence. Did they feel like they were listened to when they had a problem? And everybody knows that there are staffing problems and so on, but there's no reason on earth why people can't be doing what they can to take care of the patient.

Dave deBronkart

As hospitals understand the relevance of patient experience, that patients place a lot of value on it, they will reach out to the community differently. Unless you are the only doctor in the country offering a unique procedure, or you're the Cleveland Clinic or Mayo, patients want more than clinical care. If you have services that are similar to the services offered at two or three different facilities within a 20-mile radius, then the patient experience is what sells a person on coming back to your hospital. For me it was the kind of care I was going to get, versus the care I had received at another organization, which was the healthcare system closest to me. I elected to drive across town to a different healthcare system because of how I was made to feel by a front line staff person at another facility during my tenth mammogram. That one front line person cost that hospital $250,000 over the course of 16 months, which was the cost of the treatment I received at the second hospital.

Brooke Billingsley

To me, the last great asset that is still so completely underutilized in healthcare is input from the patients themselves. I think probably the largest challenge facing the whole system is engaging patients in order to improve outcomes. I keep coming back to a proverb from Confucius. "Tell me and I'll forget. Show me and I might remember. But involve me, and I will understand."

Zal Press

Organizations such as Leapfrog are ranking hospitals. Healthcare is a business. It becomes imperative for patient experience to improve because patients will end up not going to hospitals that are not highly ranked. Research shows that good patient experience helps healing. Finally, the Internet really has forced hospitals to listen to patients and to improve the patient experience. Because that experience is no longer carried simply by word-of-mouth, it's viral, and it affects a lot of people, and the bottom line is, it'll affect the number of people who end up going to the hospital.

Barbara Lewis

It is the right thing to do. It's learning how to make the healthcare experience better. But I also believe that it's a way to ensure continuity and consistency of care. For example, we want to make sure that communication is taking place at the bedside, in the boardroom, with the patient and the family leaders. We want to be sure that patients and families are listened to, respected, and that things are explained in ways they can understand. Again, it delves deep into the concept of patient- and family-centered care. That is why the patient experience is central to healthcare today. Because we know, in the long run, this is what provides safer outcomes and quality care.

Julie Moretz

The focus on the patient experience is essential because that's what patients already assume we're doing. This idea that this is a new concept is actually a little bit upsetting from a patient's perspective. We're just now thinking about this?! Most patients and families come into a health facility or into the healthcare environment assuming that our protocols are already designed around the patient experience, and assuming that our communication has already taken into consideration the patient experience. We have to catch up with the expectations, especially when we are looking at these competitive markets where people are becoming empowered and deciding whether to stay at a local hospital or somewhere else. You must have a please-the-customer kind of model, which we didn't have to think about years ago. As our patients become more savvy, the need to meet their expectations is going to become more and more essential, if we want to continue to treat those savvy patients rather than lose them to another hospital.

Tiffany Christensen

When you focus on the patient experience, when a patient is satisfied and able to take care of him or herself thanks to proper instructions, it reduces everyone's costs. It reduces the costs on the patient. It reduces the costs for the hospital, plus you have a patient or family member who is involved in the healthcare process. They're able to take care of themselves and hopefully, to better manage their care. So, it reduces that revolving door, whether to the ER or to doctor's office. It's just in everyone's best interest to focus on the patient experience. It can be a win-win for everyone. It equates to less gas being wasted driving to the doctor for unnecessary follow up. I don't have to leave work. The hospital doesn't have to expend additional resources, etc. But then again, you have to have a good patient experience in order to involve patients to where they're not so dependent, but learning self-sufficiency and developing the ability to manage their own healthcare, or like myself, better able to manage my child's care with limited assistance.

Naomi Williams

The traditional framework of blindly accepted care relationships, deference to healthcare expertise and the idea of individuals as passive participants in their healthcare situations has well passed.

What healthcare organizations can do to address patient experience

Based on the cumulative years of healthcare experience, the contributors spoke about various ways hospitals, physician practices, and other healthcare settings, can enhance patient experience effort. The comments coalesced around a few central themes: communication, training and patient and family engagement.

A common communications point raised by the contributors was that in healthcare we often tend to make the simple complex, infusing most situations with jargon and confusing clinical terms. The technical language barrier puts patients at a disadvantage when it comes to engaging them and opening the door to asking questions. It's intimidating, and intimidation doesn't produce dialogue and partnership. Several contributors even rebelled against the word "provider." They asserted that it transformed hospitals and clinical care teams into the only active agents in the care process, and turned patients into passive recipients of care. While none of the contributors thought the word should be abandoned, they encouraged the Institute to document that creating a positive patient experience requires a partnership and movement away from traditional provider-recipient language and roles.

Many of the contributors recognized that hospitals have applied checklist formulas toward improving patient experience. That's not surprising, given that measurement tools, such as the HCAHPS survey, require hospitals to perform certain activities consistently. However, all the contributors said that performing activities well is not the same as addressing patient experience. One contributor recalled how a hospital she worked with had encouraged nurses to ask patients, "Is there anything else I can do for you today?" before leaving each room. Surprisingly, patients didn't acknowledge being asked this question. Through her consulting engagement with the hospital, she learned that patients didn't recall the question or discounted it because they didn't feel the nurses really wanted an answer, since they looked like they were running out the door. In other words, it would have had a greater impact if the hospital had encouraged staff members to engage patients, not simply make a hollow inquiry. Checking a scripted question off of a required list of action clearly does not help the patient experience.

This simple story illustrates what all of the contributors said in one way or another. Hospitals are trying various process formulas to attack patient experience, but they are ignoring the one formula that works: connecting with people. Being in a hospital is a fear-inducing situation and generates a range of other emotions. It can impede peoples' abilities to think or relate clearly to their circumstances until the fear can be alleviated. If patients perceive they are surrounded by clinical team members who are too busy to really care about their emotions, or only trying to check boxes, then these emotions will often steer them in a negative direction.

The contributors saw the behaviors of caregivers to be central to the positive and effective delivery of the patient experience. They recommended a broader focus on communications training for staff at every level in the hospital. They also felt that empathy training, generational training and cross-cultural training would significantly impact patient experience efforts. The goal of the training would be to help staff step into the shoes of the patient, as well as the patient's family members. One contributor related a story of how her nurse saw how anxious her husband was prior to her surgery, and the nurse took his hand and reassured him. She didn't have to do that, but she recognized his emotional need and addressed it.

Because of the intense nature of the work being performed, the contributors acknowledged that initiatives like empathy training would likely need to be repeated over the course of any worker's career in order to counter potential burn out and desensitization. This is especially true if caregivers are asked to perform essential, but perhaps unpleasant tasks as part of the care process. One contributor told how an individual cleaning her open wound admitted that he had to view her as a piece of meat in order to keep from breaking down emotionally as he tended to her severe wounds day after day. She challenged his honesty in terms of how it made her feel as a patient ("I am a person, not an object") and he softened his approach, but it took sharp words from her to stimulate change. The contributors consistently recommended healthcare organizations focus as much time talking about emotionally-based medicine as they do evidenced-based medicine.

In addition to improving how clinical team members communicate, the contributors had a lot to say about the targets for communications. They recommended that hospitals and physician practices intensify their efforts to involve patients and family members, or other support partners in the care process. Because several of the contributors had been engaged in caring for sick children, they noted the distinct difference between pediatric hospitals and hospitals and physicians who only cared for adults with regard to family engagement. Pediatric hospitals and physicians naturally communicate with the adults in the room, as well as the patient, because they recognize that pediatric patients need team-focused care. One contributor was visiting a hospital that had both adult and children's wings, with each building connected by a long elevated glass breezeway. She noticed a distinct difference between the staff demeanor and the communications with the patients and families as she crossed from one side of the hospital to the other. "I left a fun circus-like environment and entered a cold, sterile place, and it wasn't just the lack of balloons on the walls on the adult side of the hospital, it was literally how I observed the staff behaving and communicating with patients that changed the atmosphere."

The contributors noted that engaging the patients and the families typically only happens if the clinicians invite and encourage patients to step forward and engage. If hospital staff members appear too busy or too closed to accept input or questions, patients may hesitate or even won't bother to connect, and the opportunity to engage can be lost. This means hospitals may miss out on the crucial input they need. Patients know their own bodies better than anyone, they understand their emotional needs even more, so unless they have the opportunity or are invited to share crucial details, clinicians may be hampered in making fully accurate assessments beyond what the diagnostic measures are telling them.

The contributors said that it can be especially difficult for older patients or older family members, who likely grew up with the viewpoint that doctors should never be questioned or bothered, especially to engage in dialogue. This same perspective can be found within certain demographic groups as well. Hospitals that want to involve patients in the care program must create open and friendly communication channels that patients will be willing to access. This advice comes with a warning to make sure staff members are willing and ready to hear input from patients. One hospital launched a "Speak Up" campaign before the staff members were fully engaged, and the nursing and physician staff was overwhelmed, scared and sometimes frustrated by the input and questions they received from patients. Communication is not simply listening to voices, it is knowing how to hear what is said and respond appropriately in each unique circumstance. This is not a core competency taught to new healthcare professionals, but one clearly more and more important every day.

Finally, the contributors recommend involving both current and former patients in efforts to improve patient experience, either by first-person interviews or by forming patient-family councils and holding regular meetings that create opportunities for management and medical staff team members to ask questions, review specific care challenges and assist with rewiring existing patient experience initiatives. This isn't necessarily news to most hospitals, but a new wrinkle is that some contributors recommended hospitals compensate patient-family care council members, or at least cover their child care costs to attend the meetings. Otherwise the hospital runs the risk of skewing the committee composition and the input they receive. Again they warned a council for the sake of having one does not address issues if it simply done to check off another box.

At the same time, another contributor cautioned against assuming that patient-family councils can solve all the problems. She said hospitals must instead structure their entire organization toward improving patient experience and not rest on the fact that a patient-family council exists.

In selecting our contributors for interviews, we were drawn to people whose extensive experience with healthcare had generated intense passion to improve healthcare. That said, readers might be tempted to discount some of the comments because the contributors also experienced medical errors and negative outcomes, etc. The question becomes, "How does a hospital or health system shape its approach to patient experience so that it works for patients who only come in once every few years, as well as for people who might be hospitalized often and for long stretches of time?" Patient experience efforts have to be effective for the one-and-done shopper and the frequent flier, the emergency department patient or the individual with chronic illnesses. This dilemma can be addressed by ensuring different types of training are offered for the diverse patient care teams.

The contributors' comments indicate a broader global awareness of the importance of improving patient experience as well.

When you go into the hospital, you basically become a completely different entity. You might go in as a respected teacher, a lawyer, or an expert in some field. But when you become a patient, all of that just kind of gets left at the hospital door, and you become a non-entity to your healthcare providers. They see you as someone who is completely uneducated about what's going on, and they relate to you in that way, and so you really don't become a part of the team. Hospitals need to do better.

Alicia Cole

Make sure your organization is designed around patients and not cost reduction or business objectives.

David Festenstein

Invite patients to help create surveys and go on rounds. Not every former patient would be equipped to do this. Some would be best at sitting in forums and having informal chats about their care. Some would and should be included in committees and on boards. I also think patients need to be reimbursed for their time because they are providing expertise that hospitals need, and I mean reimbursement beyond tea and biscuits. Find out what would make the patient experience satisfying to each patient and demonstrate partnership with patients by including the patient and family voice on multiple levels.

Kathy Torpie

Hospitals must find ways to generate collaboration and information sharing within the care pathway. I'm with my child all the time. I know his mannerisms. I know his quirks and not everybody responds to treatments in a textbook manner. Information shouldn't just come from the top down. 'I'm the doctor, or I'm the nurse and this is what you're going to do.' Have a conversation and listen to the concerns of the patient and/or the family member! Get on the same page so that they can manage their care at home. Share information both ways and build a collaborative model of care. That plays a big part in shaping patients' perceptions of their experience.

Naomi Williams

Getting the family members involved with the providers and not isolating them makes a difference.

Dale Ann Micalizzi

We may be experts in the work we do daily but, remember the healthcare world is very strange when we first enter into it. I dare a healthcare provider to come into my world, because it will be strange to them as well. Remember when we walk into your world, the smells are different, the sounds are different, the vocabulary is different which is all very intimidating to us.

Alice Gunderson

Hospitals are telling their staff members to improve patient experience. But are you giving them the tools to actually do it? Are you training them? Are you having patients come in to tell their stories? Are you asking them how to improve? Are you letting the staff hear that? That's happening sometimes, not consistently.

Linda Kenney

Pretend we've got a patient who's been instructed not to eat anything for 24 hours, and we're bumping that person's tests because there's been an emergency and somebody needs to have a CT scan. That patient and perhaps the family are feeling neglected. They're feeling disrespected. The patient is saying, 'Here I am, I'm starving. I haven't eaten in 24 hours, I'm very uncomfortable, I'm very sick. How can you do this to me?' Whereas the provider is looking at it from a larger perspective. 'We need to do this test on another patient. You're going to be okay. You'll be able to eat later today.' When the physician finally does come to the room, we often see the physician doesn't acknowledge how the patient has been inconvenienced. An appropriate response would be, 'I'm sorry; I was in the middle of an emergency.' But oftentimes the physician comes in agitated, in a hurry, and that just adds fuel to the frustration. So, again, it all comes back to having someone on the physician's team call the unit and say, 'Can you please tell this patient we haven't forgotten about him. We're just in the middle of a crisis right now?' That kind of communication can diffuse conflict and increase patient satisfaction and help the patient realize that they're on the radar screen. This can avoid the spiral effect of feeling neglected or feeling like nobody cares and nobody's taking me seriously.

Tiffany Christensen

Hospitals have to create environments where patients and families feel confident and comfortable asking questions and getting the information they need. Hospital may have kiosks with FAQs and handouts, but those don't always do the trick. It's like being forced to use a Phillips screwdriver when what you really want to insert is a flathead. Providing information to patients, but not supporting actual dialogue doesn't empower the staff to really address and engage patients and families.

Libby Hoy

There was a woman on www.e-patients.net recently who blogged about an experience she had with her sick husband. By the way, she was a nursing professor—a very qualified person. While her husband was undergoing some outpatient treatments, she was able to use the hospital's patient portal and keep track of his test results, tracking them over time, and so on. However, when he got admitted as an inpatient, she was shocked to discover that she was suddenly shut out from that information. Once he became an inpatient, she was no longer welcome to engage in his case. And she got nothing but grief as she attempted to do so. She was told that she could go to medical records and pay $1 per page, for example. I believe patients are the most underused resource in healthcare. Senior doctors at my hospital have been saying that since the 1970s. One way to improve the experience of the patient and family is to let them be as involved as they want to be, so that they can have the experience of being valued, listened to, trusted, and involved, rather than being shut out and told, 'You don't belong here.'

Dave deBronkart

I want that interaction first to be personal. I want them to connect with me. Then they can go about doing their business transaction. And then I want it to end with something personal, where they've acknowledged that I'm under stress, or that I'm in good hands. I also want healthcare organizations to understand that they have to appreciate their own employees in order for their employees to turn around and be kind to patients. I believe the C-suite needs to model the behaviors they're asking their employees to exhibit. So, if you're telling people they have to have a certain type of greeting, or be kind, or show eye contact, but yet you don't engage with your own employees while walking down the hall, then you're not really modeling anything that you say you want to be part of the organizational culture.

Brooke Billingsley

Healthcare organizations need to actually demonstrate and appreciate and recognize the value in the patient experience. And that begins by thinking that patients have value. For too long it's been my view that healthcare organizations, hospitals, clinics, etc., have believed that patients are cheap. I mean, they can buy them by the dozen, right? There's a lot of lip service to patient experience. People are put on patient advisory councils as honorary positions or as volunteer positions, with limited scope of power. In my view, that reinforces the idea that patients are cheap. But the reality is that the experience of these patients is valuable, and organizations should recognize that and pay the people who are involved in helping them improve. They need to invest in it.

Zal Press

I think hospitals understand now that if they're not hearing feedback in the hospitals, they're going to hear it on the surveys. They should hear it in the hospitals, though, because that's where change can be made, and that's where the patient experience can improve. I think part of the answer is just the encouragement. Patients and family members need to be encouraged to ask questions. 'How do you feel about this? Or, what are your thoughts?' Or constantly communicating, asking questions of the family member and the patients, so that there are no surprises and people aren't holding in what they really want to say. For example, analyses of the surveys has revealed that both young patients and highly educated, generally score the HCAHPS lower. If you know that kind of information, you can deal proactively with it by targeting those populations with additional efforts. Besides listening, I think constantly communicating with patients and family members is really important. And the compassion, walking in their slippers is critical.

Barbara Lewis

I think another huge step healthcare organizations can take is professional training as a priority with medical students and nurses.

Julie Moretz

A STORY FROM JULIE MORETZ

My son had heart disease, and sadly Daniel died seven years ago at the age of 14. But throughout his hospitalizations, and heart transplant, and 12 surgeries, and 150 blood transfusions, the one thing I remember early on was his cardiologist saying that I needed to take the reins and I needed to be his best advocate and take his healthcare by the reins. The surgeon said there was no one else who could do it better than me. I needed him to tell me that—to give me permission to be able to do that. Why? Because I trusted so much in the clinicians who were looking after him, and I expected them to know their jobs and to do the right things. But clearly, and sadly, you find that things don't always happen the way they're supposed to. Not everybody has that advocate, or has those family members to be their best advocate. So that's when, many times, as the patient we have to do it ourselves.

The most important thing healthcare providers can do is to start talking to patients. And I mean from the executive level down, from the C-Suite level, because they're often in a bubble. They talk to themselves and their peers all day, all week, and they go to conferences and lectures and summits where they are lectured by other doctors, and they never really hear from the patients. They have no clue… I believe patients don't start out angry. Patients don't get angry until they can't get answers.

Alicia Cole

A real missed opportunity to impact patient experience occurs just prior to discharge. When patients know they are going home, they will be most attentive to instructions, but also most anxious, so they may not hear things clearly. This is the perfect opportunity to engage with family and other caregivers to make sure the team is able to follow through on the home care instructions. It's the perfect time for staff to build the relationships with a patient and family members and to ascertain if any barriers exist to providing proper care in the home following discharge.

Libby Hoy

When I help hospitals set up patient-family advisory councils, we don't launch them until the structure is really sound within the organization. Until the organization decides upon its vision for the patient-family advisory council, in my opinion, it may not be fruitful to have one. That vision needs to come from the organization and the potential council members. What does the organization hope to get out of this group? Why are they putting the effort into creating the group? What kinds of priorities do they want this group to look at? The biggest way we lose patient-family advisors is when they sit in a room and review material and put their time and effort into it and then, and it never results in anything. They don't know what happened. Was that input integrated into the organization? They don't see the final product, so it's imperative that we set those structures up within the organization before we launch the advisory council to enable the council members to see the impact they are having. And finally, provide the patient-family advisors with some training. If we don't, we're going to end up with these token groups that may give you some feedback, but not much value.

Libby Hoy

We can do a lot of things that may be driven by patient feedback, like addressing noise, lighting and room temperature. If we get all those done really well that's great. But if we're still lacking the human compassion, it's really going to be empty, isn't it?

Stephanie Newell

It's really just about helping our providers to be better communicators, but also educating our patients and families on the nature of the business. And I think that unfortunately our culture has taught us that medicine is an exact science, and we expect to come in and have A, B and C happen in that order. If you've been in healthcare for more than five minutes you know that actually B sometimes happens before A and sometimes D gets thrown in the mix. Setting the right expectations helps create an environment that helps patients cope with surprises, so their experience isn't so shocking and upsetting.

Tiffany Christensen

When patients come into the hospital, the first thing we tell them is, 'Welcome, come in, take off your clothes.' We strip them of their identity. We strip them of everything, and now they're "the patient," not Keith Boyle, or my son. They're now "the patient." And that's the piece that healthcare personnel need to understand. We strip people of their identity. We've already set it up to be a bad experience. So, we've got to think about how we keep things human, to keep things personal and positive.

Keith Boyle

My husband, given my experience, has high anxiety every time I go in for surgery. And I'll need to go in for many more procedures. If people took the time beforehand to understand why he has that anxiety, it would be much easier for care team members to engage him, instead of looking at him like a one of those crazy family members. One nurse told him, 'Don't worry, Mr. Kenney. We're really going to take care of her.' Do you know what that meant to my husband? It meant the world to him. Somebody acknowledged that this was scary for him. And how much did that cost them? Not a thing.

Linda Kenney

As more and more care is delivered outside of the hospital, I think it's going to be crucial, especially when we have this whole national push around readmissions, for providers to make sure patients understand all the things they should be looking for as part of recovery. We hear from lots of patients who have said to us, 'I tried to tell them I wasn't ready to go home, or I was having problems at home, and no one listened.' How many readmissions could have been avoided if someone had listened to the patient?

Linda Kenney

If providers don't recognize the importance and the clear significance of the family unit, the community unit that surrounds this patient and attempt to understand it, the clinical outcomes might be limited. This includes understanding cultural differences. I think it's really important to step back and look at the patient within the context of his or her community, in order to be able to deliver care that's going to produce a positive health outcome. It's the community that responds to the illness experience, not the individual provider.

Libby Hoy

Hospitals have to become wellness centers. They have to become community places. I mean you should want to go to the cafeteria at the hospital because it rocks and has the best food in the town, right. The hospital should be a part of the community life, not just this evil place you go to when someone's sick. It's just a negative space, but it doesn't have to be. We've got to reevaluate how we have these spaces within our community. I'm part of the advisory council for the hospital in my community. We meet at night. The entire wing is empty. They could allow other groups to host meetings there. It is prime real estate in a major developed metropolitan area and nothing is going on. The hospital hasn't figured out like churches have figured out how to be a hub in the community. I think hospitals may help patient experience perceptions when they do that.

Regina Holliday

The role of patients and families in informing patient experience efforts

Healthcare has traditionally been a hierarchal expert system. The people at the top had the most knowledge, and they shared it with the people down below. The knowledge flowed one way. As we gathered input from patient contributors about how to improve patient experience, the common theme was that patients are the experts on their own bodies. They should be talking as much as the physicians and nurses during any exchange of information. This goes against the grain for many older patients, so they have to be trained to provide this feedback. Our contributors urged patients to move beyond timidness to finding a way to play a role in your own care. "Find your voice," was the advice offered to other patients.

The contributors also noted that communication is a two way street and while patients and families can best contribute to patient experience improvement through the willingness to speak up, they also urged that physicians and clinicians be trained to seek patient input more aggressively and to accept it. Our patient and family members recognized that simply making it safe for patients and family members to ask questions and become more engaged doesn't transform the hospital into Disneyland. One contributor noted, "As patients we are not there for fun. We most often enter the healthcare setting to deal with serious issues, so hospitals must seriously engage in efforts to make dialogue meaningful…and remember we are people who desire to be treated with dignity and respect."

In many ways the contributors offered their responsibility in improving experience is not only their willingness to speak up, but also serving as a reminder of patient and family voice in general. In a healthcare setting where engagement and outcomes, compliance and experience all now go hand in hand, creating a dialogue among all on the care team is key to this effort and the patients and family members recognize they have a role to play in this.

The contributors' comments illustrate these ideas best.

Rights and responsibilities are interconnected and interdependent. Equal measure must be given to each. For any enduring change to take place in the clinician/patient relationship all parties must change. Just as physicians must give up their God-like role (and the unrealistic expectations with come with that), patients must give up their passive role in the relationship and, with the guidance (rather than direction) of the physician, learn to take responsibility for ensuring that they have the information, understanding and support necessary to make decisions about their care in collaboration with their doctor AND that their doctor understands what is important to the patient in this collaboration

Kathy Torpie

As more diseases go from terminal to chronic, we need to learn more about how to manage the symptoms from YOU. The places we're going to learn is when we're at the bedside, either with our hospitalized loved one or when we're at the doctor's office. We look to doctors, nurses and therapists to teach us how to be engage in self-care. However, it's our responsibility and obligation to say when we don't understand. We together have to get the dialogue going.

Alice Gunderson

Try to inform yourself as much as possible. If you have a support system, try to inform them about what's going on as well.

Tifiro Cook

Remember, healthcare providers are facing a competitive environment. They need to know that we're going to be asking questions. Any doctor or hospital that gives you any grief for asking, needs to be treated the same way you would treat a store that gives you grief for asking questions. Ultimately, whether it's through your employer's insurance or the US government through your taxes, the money for those services comes out of your pocket, so act like it. Speak up for yourselves.

Dave deBronkart

Be informed, know your rights, get a second opinion, work with and not against your healthcare provider. Give as many compliments as you do complaints.

Brooke Billingsley

To be engaged in their own care, to feel confident in what they're doing because they are empowered, patients must be given "permission," because they feel like it's the right thing to be engaged, but may still be reluctant. Or they could be fearful about being looked down upon for not knowing enough already about their health status, if they do speak up. But patients must learn how to be their own best advocate, whether through opportunities within the hospital, or in a medical home setting.

Julie Moretz

Patient care needs to be a partnership and collaboration. That is what should happen in the hospital. And unfortunately, it's not happening. I think the hospital needs to set the tone and the framework for that collaboration.

Barbara Lewis

If you are a patient, if you have a condition, you've got to learn as much as possible about that condition and about your own healthcare, so that when a doctor is talking you can understand it. This is important because not all doctors are good at communicating and breaking things down to a layperson level. If you know you have a chronic condition, begin to learn the lingo of your condition so that you can understand what the doctor is saying. Plus, we've got to get over this fear of speaking up.

Alicia Cole

I think one of the biggest roadblocks is not educating yourself. You need to be your own advocate.
I have to fight for my life and I understand this. I have to keep the armor up. The armor is me educating myself. I would see people leave dialysis and just leave without asking questions about what's going on with them and things like that. You know, the doctor's only going to care as much as you care.

Tifiro Cook

Patients need to accept their role as partners in the equation. Partnerships are strong because the two sides bring something different and equally valuable to the table.

Stephanie Newell

Greatest roadblocks and supports of success in effectively addressing patient experience

The responses to this question flowed easily for the contributors, and they focused on many of the same topics. Despite the fact that their hospital experiences were diverse clinically and geographically, they were able to produce similar answers to this question. That should be viewed as good news. It means that focused attention on a small number of issues can produce significant benefit. Of course, that is like saying simply lift this boulder out of the way and we can move ahead with our journey.

In reviewing the responses to these two questions, we've synthesized the answers into these statements:

Roadblocks to success:

- Unengaged patient-family councils or failing to really engage former patients
- Failing to engage the family in the care process
- Organizational tolerance of arrogance
- Lack of communications training
- Organizational unreadiness to address patient experience or listen to patients
- Hurried clinical team members and support staff

Success factors:

- Breaking down communications barriers with patients
- Encouraging patient and family involvement
- Creating and truly using patient-family councils
- Making clinical information and patient records easily accessible to patients and family members
- Appreciating and encouraging employees so they in turn will encourage and engage with patients
- Pairing evidence-based medicine with emotionally-based medicine
- Looking at patient experience in the context of all the systems that interconnect to create it

Several of these topics are worthy of additional discussion.

Lack of communications training/breaking down communications barriers

The importance of communication has always been part of the conversation in our papers at The Beryl Institute, but its impact and role may resonate most clearly in this paper. The contributors said communications training, encompassing how to communicate in ways that patients understand, conveying compassion with words, and bridging cultural roadblocks, should be a central part of early medical education and an ongoing focus for continuing education. It also needs to be a part of the clinical experience, where communication is as important a skill as diagnosis. Yes, first and foremost these patients want to ensure they have positive outcomes, but they reinforced this was not at the expense of their humanity.

Unengaged patient-family councils/creating and truly using patient-family councils

Some hospitals we encounter through road shows and seminars have voiced concern about their inability to find people to serve on patient experience councils. One contributor recommended looking at people in the community who were already actively addressing this issue on their own, even from a negative view. If they are willing to be engaged as patient advocates on their own time, they might be willing to do it on behalf of the hospital, if the opportunity presents a legitimate chance to contribute.

For organizations that are struggling to maintain effective patient-family advocacy councils, a contributor suggested partnering with existing regional patient advocacy groups and offer to host their meetings, assigning staff to attend as guests so they can learn how to run or organize these meetings and glean ideas for improvement.

The bottom line is that our contributors suggest a formal means for communication in engaging patient and family voices is as equally important as the informal processes suggested above. Building the right structures, but more importantly the right processes for sharing ideas and putting actions in place is fundamental. Simply declaring you have a Patient Family Advisory Council and checking it off the list of "things to do" in addressing patient experience will not serve you well...it is the process and purpose that trumps the structure each and every time.

We pulled several comments from our contributors under each of our major headings.

Roadblocks to successfully addressing patient experience

Healthcare leaders have too many priorities that they have to deal with. I also think we see departments working in silos, not working together. Once we can get beyond those silos, then we can bring people together, shoulder to shoulder, to make things happen."

Julie Moretz

In my opinion, one of the roadblocks to the patient experience is when nurses or hospital staff don't seem to care. I've learned this is often due to what's known as compassion fatigue. Healthcare personnel learn to steel themselves against impending death and disappointment, and they wall off their hearts, which prevents compassion from shining through. What I'm hoping for is that one day hospitals have a perspective that death is a transition, and that the nurses who help patients in that transition feel honored.

Barbara Lewis

Not sharing information that patients need to become partners in the care process is a significant roadblock. If you, as the patient, only had the information that the doctor gives you, and the doctor decides only to tell you what he wants you to know so you will make the decision he wants you to make, and you're not allowed to ask a nurse what she thinks, or perhaps they aren't allowed to tell you anything, then you are at an information disadvantage.

Alicia Cole

Get rid of the hierarchical physician-centered culture. This tradition impedes the patient's ability to move forward and accept the role of partner. It impedes the physician's ability to get the important information he/she needs from the patient. Removing the other roadblocks involves removing the hierarchy. They are interconnected.

Kathy Torpie

A STORY FROM LINDA KENNEY

I had to go into surgery to get my ankle rotated and straightened out, so I could later have the ankle replacement I needed. When I woke up from surgery — now this was my 21st surgery at that time — I said, "Jeez. You know, my bladder's uncomfortable. I'm having some problems. They said, 'Oh, drink more water. You'll be fine.' Once I arrive on the floor, I tell the nurse I'm still having trouble urinating. I had a lot of pain in the pelvic region, but the surgeon had taken some bone from my hip as part of the ankle procedure. So again, I think they discounted my complaint. A couple of hours later I said, 'Look, I'm really having some problems.' The nurse said, 'You know, that's really normal after surgery.' She even looked at the other nurse in the room with the other patient and said, 'Isn't that normal after surgery?' So, now I'm tag-teamed, you know? Obviously, I'm the one who is wrong.... About five hours later, it was an hour before the shift change and I had been on the bedpan for an hour, unable to urinate, and in excruciating pain, and crying. Now I feel extremely vulnerable. Is it in my head? Am I crazy? Finally, I communicate with a doctor. He said, 'Oh, for God's sakes. Just put in a catheter.' It was a change of shift, so I had to wait for the nurse. Well, I finally got the catheter in and 1800 cc's came out. The nurse said, 'Oh, Mrs. Kenney, I'm so sorry.' By that time I couldn't even be mad, because I was just so happy I wasn't crazy. .... So, fast forward two years later. I'm on a different floor. And this floor was strictly orthopedic, versus the one that I was on before. I have the same problem. I was a little anxious because of that last experience, so I said to the nurse, 'I'm having problems urinating gain.' The nurse said, 'Here's what we can do. I can do an ultrasound. We can see how much fluid is in your bladder, and then we can make decisions.' I was like, 'Wow.' He comes back in and says, 'this is how much you have in there. What I can do is wait an hour and then put a catheter in and we can leave it in all night so that you don't have to worry about that.' I was on drugs, but I do remember thinking that he was the best nurse I had ever come in contact with. It wasn't until I got home and came down a little off the drugs when I realized, how sad that story was. My expectations of healthcare had fallen so low that a person simply doing his job and doing it correctly was rated as off-the-charts wonderful.

Children's hospitals and pediatric practices are way ahead of the adult facilities when it comes to engaging families. When it's a child and a parent or couple there from the very beginning, the clinical team shares all the information with the child and the family members. They engage everyone. In adult facilities, we might engage the patient, or a family member, but we might fail to do both. Pediatric hospitals don't do that. They talk to the kids in a way the kids can understand, and then they talk to the parents in a way the parents can understand, knowing the parents are going to have to reassure the child continually by sharing information at home. Maybe we should pretend all of our patients are pediatric patients and that will motivate us to fully engage the patient and family members in the care process.

Alice Gunderson

Surveys don't always give patients an opportunity to share their experience. It's too vague to be of real value to the organization's improvement efforts. Bring patients in and sit down over a conference room table or in a town hall forum with the CEO and the department heads. This should be a group of former patients who've had both positive and negative outcomes. The invitation to the patient should be, 'We would like to invite you to help us improve our facility and help us evaluate some of the things that we're trying to implement.'

Alicia Cole

The biggest roadblock is the perception of time. Clinical personnel, but especially nurses, believe that they haven't got enough time to attend to each patient. They dash about, presumably with an internal voice telling them, 'I'm too busy. I don't have time to do this.' So they are pushed to think about the next task. In contrast, I think the biggest support to successfully addressing patient experience is building a support system that allows each worker's intrinsic sense of compassion to emerge so they can focus totally on the patient they are dealing with at the moment.

David Festenstein

Some of the roadblocks to improving patient experience are embedded in the medical culture and medical education. They are really difficult to dislodge. The siloed system of specialists can create barriers to dealing with the whole person and dealing with all of the emotional aspects of the patient experience, too. Compound these problems with the issue of patient literacy. This can be due to patients being undereducated, as well as the simple imbalance of power on the information scale. Medical professionals start out having a 35,000-word vocabulary that they learn over many years. Patients don't have that. So, you come down with a serious illness, and all of a sudden you're faced with learning a huge vocabulary in about 30 seconds. You don't get six years or more to learn this sort of thing. And for a lot of patients, they enter into the equation with a fifth-grade literacy level. So, it's a huge roadblock. If hospital personnel want to create positive patient experience scenarios, they need to step out of the patterns they have ingrained in their work selves and reach out to where patients are.

Zal Press

The one-size-fits-all approach to medicine is not working. Individuals see their own care individually, like I saw my own process of going through breast cancer individually. Even though I might have been given a regimen that was standardized for my diagnosis, my goals and how I approached my disease and how I handled it were totally different than the average patient's. And sometimes when I see healthcare providers using a one-size-fits all approach, it's frustrating from the consumer side, because they don't see themselves the same as everyone else when they encounter various circumstances. Healthcare needs to be personal and personalized.

Brooke Billingsley

[In healthcare] we communicate in our language, not the patient's or family's language. We tend to have an expectation that they should just know our language. If you're not listening to what people are telling you, and you are just doing your tasks, you're not doing the job right. You can't really address the patient experience well. Avoid checkbox medicine

Keith Boyle

One of the roadblocks is the way we educate our healthcare professionals. It starts there. We are still educating in a very patriarchal manner, and that establishes the tone for our healthcare providers in the way they manage the clinical relationship. I think it's very threatening for healthcare as a whole to let down the drawbridge and accept a layperson's perspective of how to improve care of their loved one. It requires kind of a shift in power of the relationship to more of a shared power remembering we are all working toward best patient outcomes. It goes back to service delivery not 'to' and 'for' but the 'with'.

Alice Gunderson

Successfully addressing patient experience

One supporter of success would be to help staff members hone their emotional intelligence. Not everyone has an innate ability to excel at connecting with patients. For some, they have to reawaken that skill because it's not a muscle they've used in awhile. Having classes on empathy and listening in healthcare seems out of place, but it's not.

Stephanie Newell

A good thing is when they engage patients and families on a regular basis, either through a town forum or by bringing someone in to get feedback, and not through just surveys, because surveys just provide metrics. It's just more numbers. There's no human touch with that. There's no bringing it back to real people. I think that by engaging real people in real conversations on a regular basis, it helps bring healthcare workers and providers back to the human side of healthcare, and that's really what I think is missing in all of this.

A STORY FROM ALICIA COLE

When the wound vac specialist was teaching the nurses how to do my wound vac dressing change, sometimes he'd stop and talk, and he would leave his hand sitting in my open wound and just kind of lean on my stomach. I would like take his hand and go, 'Okay, raw flesh, nerve endings, that hurts.' And sometimes he would be so rough. One day, I finally took his hand and I caressed it and I said, 'When you touch me, could you please touch me like I was your daughter?' The man burst into tears. He said, 'Oh, my God! How could you say that?' And I said, 'Because this is my mother right here. I'm somebody's daughter, too, and you are becoming more and more rough with my open flesh, and it hurts.' He said, 'I am so sorry, Alicia. Your wound is so just horrifying; I have to look at you just basically like a side of beef. I don't even see your face. I just see a piece of meat, and that's the only way I can get through this.' I said, 'Well, I understand that, and I appreciate it, but I am not a side of beef. I am human and what you are doing hurts. You're being rough because you just are thinking about me as a piece of meat. If you wouldn't touch your daughter this way, please don't touch me this way.' That changed the way he did my dressing from then on. I understand that a lot of times healthcare practitioners have to desensitize themselves just to get through the day and not internalize the suffering, but at the same time, they have to understand that horrific situations are attached to living persons with families, and jobs, etc. There is a full life attached to that condition. Successful hospitals understand how to train staff to still connect in a compassionate manner.

For me success is very concrete. When I see that the family's presence is welcomed in a healthcare system. When there are no visiting hours. When units include patients and families during rounds, and conversations are held in the room or at the bedside instead of in the hallway. When medical homes are truly collaborative and inclusive of patient and family participation. When an academic medical center practices what they teach by modeling patient- and family-centered approaches to care. Those are indications that the patient-family experience agenda is embedded.

Julie Moretz

Someone comes in and talks about ED. Is that person really talking about the emergency department or erectile dysfunction? Healthcare personnel need to use words that are easily understood by the patients and their families.

Naomi Williams

Active listening. Yes, the nurses are giving out the medications and checking blood pressure readings, etc., but are they slowing down to listen to the patient. How impactful is sitting down for two minutes listening?"

Linda Kenney

Sometime it's just the little things. I think I mentioned earlier about just placing the blanket back after you change the IV and then placing that blanket back on the patient after the x-ray is done, or straightening the sheets. You know, if you don't straighten the sheet, then it could cause a bedsore. If the care team members are simply checking off the things they are supposed to do, they can miss other necessary things. It's great if a patient is going to have a blood transfusion to have two people come in and read off and validate the name and blood type, but if they forget to put the blanket back on the patient and leave him shivering, all they have done is provide safe care, but not sensitive care.

Alice Gunderson

When you find workers who excel at engaging patients, interview them. What are their beliefs? What are their behaviors? What do they do when they get stuck? What's their internal voice? How do they check that internal voice when they feel frustrated? How do they reframe roadblocks? Copy some of their strategies and get other health professionals to adopt those patterns if they can.

David Festenstein

A STORY FROM REGINA HOLLIDAY

Belling Healthcare Systems in Green Bay, Wisconsin, is known for its Stroke Care, and the CEO was hosting a strategic planning meeting, which they do every 120 days to recalibrate and make sure they're on the right path. He asked the stroke team, 'How are the patients doing a year to a year and a half out?' The team just looked at him blankly, because they don't track their patients that long. He said, 'Well, find out.' So they started calling people. One of the people they called was Betty Bundy. She was 83 years old at the time, and she was hilarious. When they called her she told them that their services sucked and they almost killed her. This was due to the fact that they couldn't find her medical record and lost it between stays when she stayed three times in a four-day period. They didn't get the records together between those days. So she gave them honest feedback, and they actually embraced that and invited her to come present to the management team. Following that, they committed to implementing a new electronic medical record system, but instead of rolling out Epic system or McKesson or Cerner EMR, they called it Betty. And every time they talked about it they talked about this person, Betty. It was amazing how that changed the nature of the implementation. If they had problems with the system, they couldn't say, 'I hate Betty.' They were reminded constantly of why the system was important and that the new EMR system was created because a person almost died because of poor data access, poor medical record control. This IT story reminds us that we might avoid poor performance if we personalize it.

It seems to me that healthcare organizations tend to approach problems from a singular perspective, but problems don't get created singularly and they don't get solved singularly.

Libby Hoy

What does it look like when someone excels at providing a better patient experience? They don't just show you where the elevator is; they walk you to the elevator. They don't just say, 'Go down this hall.' They say, 'You already have a lost look on your face, let me walk you there.' Those extra elements that the hospitals and other providers are starting to put into place are contributing to them moving forward and creating more positive experiences, and making people feel cared for. It's extra mile behavior.

Brooke Billingsley

Some healthcare leaders are completely unaware of how their own people interact daily with patients. And they don't effectively handle the family or patient feedback when they do get it. There may be one key person in the hospital who receives it, and that person isn't empowered to do anything about it. I see that as a roadblock. Hospital leaders can create cultures of caring by demonstrating it toward their own employees. What does that look like? I've known administrators who shown up at midnight shift with a pizza for the Med Surg Unit. That says they appreciate what the employees are doing, and acknowledges them so they feel that somebody notices. That will motivate employees to follow through with their own small gestures as they engage with patients.

Brooke Billingsley

Up until a few years ago, I wouldn't have elected to be a nurse on a unit for all the tea in China, because of all of the demands on them. They had none of the authority to really provide the personal care they wanted to. Now the momentum toward patient experience puts the power back in the nurses' hands, giving them the authority to act and react to patients completely on their own. It gets to the heart of why they went into medicine. However, the support for this has to come from the top down. When we have real buy-in from the C-suite, philosophically, programmatically and financially, it undergirds all the efforts and supports the focus on patient experience. When that doesn't occur, that's obviously a big roadblock. Another support for the patient experience is a patient-family advisory council. I think it's important to have a structure where the patients and families can engage the organization as partners. In Massachusetts, it was legislated that hospitals have a patient-family advisor council, but the legislature didn't really give any tools or advice for how to do that well. So it became more of a token gesture instead of really being integrated into care teams.

Libby Hoy

It's a little bit sad that we have to teach our healthcare providers how to enter a room and introduce themselves, but if that's what we need to do, that's an important foundation. But the healthcare organizations benefit so much from the engagement that stems from that behavior that we must do it. The information they'll get back in response helps us meaningfully improve the patient experience.

Libby Hoy

Patients don't feel comfortable in asking questions of someone who is obviously rushed. Slow down.

Naomi Williams

If you want to successfully improve patient experience, give a former patient time to tell his or her story. What was that individual's experience? What has aftercare been like? I've got six years of concentrated experience with hospitals. My abdomen was open for three years. I was treated at a wound care center. I had five months of daily hyperbaric oxygen chamber treatments at UCLA. I had a year and a half of twice a day home healthcare nursing because my wound was so big. It took two people to do my dressing changes. I've got a lot of healthcare experience to share, don't patronize me by asking me to share that in just five minutes at a board meeting.

Alicia Cole

I see people comparing apples and oranges, I see people comparing a small community hospital to a major medical center and the difference in the feeling that they get when they're there. And I think that that's a lack of understanding of the different kind of places that you can go to get care. If you're going to a smaller community hospital, you are probably going to feel a little bit more of the hands-on love. It's a more nurturing environment because they aren't working with high acuity patients. Whereas if you go to a major academic medical center, you're not going to experience the same warm, fuzzy feeling because you're going there for a different reason. You're going there because you need to see specialists. I think that we have to start being honest about where we are and understand that it can be harder to create the patient family-center care model in some settings. It will look different in different locations.

Tiffany Christensen

I'm in the ER with my son, who is 3 ½. The nurse comes in to start and IV, and I'm watching her tape it to his hand. She tapes it to his hand like you would normally tape to an adult. I said, 'you can't leave it like that. You need to secure that more. He's going to knock that out.' She said, "Oh, he'll be fine," and she starts walking away, at which point my son closed his fist, I looked at the IV and before she even got from the gurney to the door, I said, 'Well, it's out.' JCAHO requires age-related competencies, and it's part of building a positive patient experience. Patients and family members need to sense that practitioners actually know how to take care of patients. Making sure staff members are trained is a patient experience building block.

Keith Boyle

Advice for healthcare leaders working to address the patient experience

In reviewing all our contributors shared, we asked them to sum up their thoughts in offering any advice they might have for healthcare leaders. The responses reinforced all they shared in their previous comments and the consistency is meaningful. In condensing over 450 pages of transcripts from interviews with our contributors, we were able to pull some common, concise and powerful words of advice.

- Create consistent experiences
- Open communications channels with patients and families
- Reignite a sense of compassion
- Evaluate with more than surveys

Create consistent experiences
Because patients don't stay in one place in a hospital, and throughout their lifetime they may connect with multiple points across a healthcare enterprise, contributors said one of the more important steps healthcare leaders should take was to address inconsistencies in an organization's patient experience outcomes and efforts. This might mean more standardized training for permanent and temporary staff, greater concentration on handoffs and transfers, better coordination with ER staff and ancillary service providers. It also reinforces the need for consistent hiring efforts and behavioral expectations that are shared throughout the organization. In healthcare, as elsewhere we don't get a second chance at a first impression, but we also need to ensure we have a consistent and lasting impression throughout a patient and family members' encounter.

Open communications channels with patients and families
It goes without saying that patients won't be happy if they feel their needs, questions or requests are ignored or pushed down the priority list. An equally unforgiveable sin is when patients and family members are told to keep calm and keep quiet. One of the best strategies to pursue in order to improve patient experience is to aggressively engage patients and family members while they are in the hospital. Don't limit these contacts just to the physicians and nurses in charge of care. Every employee should be trained to test the waters with patients and family members. Sometimes patients or family members who many not feel comfortable talking with doctors may easily talk to the nutrition aide who delivers meals. Obviously, the nutrition aide cannot answer serious clinical questions, but he or she can open the door for the patient or family member to talk with the nurse or doctor, or relay the message to the clinical team members.

All of the contributors noted that hospitals and physicians must make patients and family members feel comfortable in asking questions and engaging in their care plan. Care providers must encourage this dialogue. Patients either don't know where to begin, or they may feel that silence is safer based on past bad attempts to communicate with medical personnel in other facilities. In this case, silence is not golden; rather it could be the greatest impediment to quality care.

Reignite a sense of compassion
Another consistent message was the sense that healthcare has become so burdened by business priorities that hospital personnel don't have the patience or time to be kind to patients. When personnel do slow down and show human compassion and kindness, it is marked as a minor miracle. It stands out and is rated as a key to outstanding service.

Evaluate with more than surveys
As documented in earlier sections, the contributors understand that hospitals have to obtain patient survey data, but they don't view the survey data as a reliable guide for directing patient experience improvements. Talking directly to and listening to patients and patient advocates is deemed to be a better source for developing effective patient experience improvement strategies. Ask questions via rounding, establish informal and formal focus groups, gather data in real time and use patient and family advisory groups at system, facilities and at possible unit or department levels. Engaging your patients as close as possible to the actual encounter enables opportunities for rapid action, corrections or recovery and should lead to better scores later.

The smile test
Finally, the advice about smiling relates more to management's responsibility for shepherding employees. A person's ability to smile connects to an individual's level of stress, distraction, emotional health and the ability to engage with others. Front line managers need to pay attention to their team members. If a particular team

Silence is not golden; rather it could be the greatest impediment to quality care.

member has lost his or her ability to engage positively with patients, measured by the failure to show common emotions, that individual may need additional help or support. Employees cannot and will not be able to create a positive patient experience if they are emotionally burned out by the demands of the job or burdened by other life issues. As we have documented in our other white papers, healthcare personnel are human beings, too. They need management to create cultures that are supportive not just for patients, but for the employees who take care of patients.

As for strategies or tactics to avoid, that list was concise:

- Avoid the temptation to be satisfied with current patient experience improvement results or endeavors
- Avoid the temptation to circle the wagons at the first sign of criticism
- Don't be insulated from real patient feedback about what matters
- Don't neglect ongoing patient experience training

While these suggestions may seem like common sense, the key is to make them common actions. Criticism is hard to manage and complacency is hard to overcome, so having a system in place to check your response and reaction to feedback, positive and negative is critical. You also need to learn how to deal with success. I have all too often seen organizations feel they "achieved" their patient experience goals by hitting a certain score only to pull back on their efforts and seriously falter. Achievement is about consistent and constant effort, for there is no patient or family member that deserves less than the one that came before.

The contributors' comments provide additional insights regarding these thoughtful recommendations.

I think consistency in general is the greatest gift that you can give to patients and families and that's very difficult to do in some settings. But the more that we can be all on the same page and the more the patient is going to feel safe and calm because their care is actually not just being made up on the spot, but it's something that's been thought out.

Tiffany Christensen

One hospital I'm familiar with has a substantial, consumer medical library, with annexes on every floor. And it's not buried in the basement, where most hospitals' medical libraries are located. It's right off the lobby. They view engagement with information to be an essential part of the patient experience.

Dave deBronkart

I wrote the hospital about my first admission, which wasn't bad, but enough went wrong that I was having a difficult time recommending them. For example, I read the patient guide while I was hospitalized, and it said they were committed to doing hourly rounding. It didn't happen. They were communicating a wish list, but it's not what's actually happening. It didn't make me confident in the care.

Keith Boyle

I had two different experiences in the same hospital. I was on two different floors, and the care delivery was very different. That's something hospital leaders have to bridge. Inconsistencies in service delivery must disappear. Why does one floor do a wonderful job in addressing patient experience and another floor doesn't do so well?

Linda Kenney

A STORY FROM BROOKE BILLINGSLEY

I had had the opportunity to nominate three of my nurses for an award the hospital gives. In my mind I'm thinking it would be a simple paper award, end of story. But they asked if I wanted to present it. I said that would be awesome. A month after I'd been out of the hospital, they held this event, and it was a big deal. There were 30 people there, including the president of the hospital. The three nurses got a pin and they got a certificate, and I got to share some comments. I said their kindness helped me heal faster. One of the nurses, when I was in pre-op, sat down next to me because she could see I was anxious. I don't like shots -- I have tiny veins--so I pass out easily. I had already endured probably 60 shots by that time. The nurse was going to start the IV—the dreaded IV—on the top of my hand. I'd already had those black and blue marks. She sat next to me on a stool and she looked at me and she patted my hand. She said, 'I think you've got a good vein, and I think I can take care of this.' And she started to talk to me in this kind way, and started this little needle of lidocaine. And I didn't even know she had started the IV. Her kindness meant so much to me at that time. Because I was so full of anxiety, anticipating what was ahead. I just so appreciated her gesture that I nominated her. She was 60 years old. She had been a nurse, she said, for 35 years. She wasn't burnt out. She was still kind. She still knew what it took. We all know there are a lot of things that aren't working in healthcare, but human kindness always works.

I would encourage everyone, no matter what level they're at, to truly talk to some patients. Don't send out another stupid paper survey. Get on the phone. Top management needs to get on the phone. Call some randomly selected patient families and have an authentic conversation. Not five minutes conversations. Try 30 minutes. Explore the patient's story. See where it goes. Find out whether people felt they were cared for. I'm sure that everybody has some people who do, but if you want to know how to improve, find out from the front lines, not through intermediaries, and find out directly from patients.

Dave deBronkart

If you have had experience with multiple providers, each of those experiences stays with you, kind of like old relationships. We all know that sometimes you take baggage from one relationship into another. The same thing happens with patient experience, so if you have a wonderful patient experience, then that helps to bridge the gap with the next provider and sets a tone for what you're looking for. If you've had a negative experience, you're taking that with you. It would help providers to learn about other hospitalization experiences so the staff can compensate and not be penalized for something another facility did poorly.

Naomi Williams

A STORY FROM LIBBY HOY

Just four years ago (Stephen) was diagnosed with really severe scoliosis and needed to have a spinal fusion of eight vertebrae. We went for a second opinion. I'm as empowered as they come, so we were prepared with a list of questions, and we walked in and this surgeon looked at me and my 15-year-old son and said to me, 'Turn around and bend over.' I said, 'Excuse me?' He said, 'Turn around and bend over.' I said, 'I don't understand.' He said, 'Scoliosis is hereditary so I need to see what your back looks like.' He hadn't really even introduced himself. That was the first thing out of his mouth. You can bet I couldn't remember a single question that I had on my list after that. It was humiliating for my son. It was humiliating for me. He went on to say, "It says here this kid has mitochondrial disease." There's no way he has mitochondrial disease, he looks so healthy. The physician didn't engage properly and he wasn't ready to hear our input. It was so defeating. It closed our communication channel.

Here in Australia we've had a program going in one of the states called "Patient First," where peer consumer ambassadors frequent different parts of the hospital, mainly the out-patient clinics. The Ambassadors have an identifying t-shirt on that says 'Patient Ambassador.' They provide people with information on aspects of patient safety such as medications and other aspects of their care while patients are sitting waiting for their appointments. It's a very approachable set up. Because the patient ambassadors are there on a consistent basis, people may get to know their role. It provides another avenue for people to engage in their own health care and with patient safety aspects of their health care and connect in a peer to peer situation.

Stephanie Newell

The reason the intimidation piece is so important to me is because I was one of those parents who used to be intimidated by the clinicians. I was totally unfamiliar with the hospital scene. As my little boy lay in the hospital, I was afraid to ask them to wash their hands. I thought, shouldn't they know to wash their hands? Why should I have to remind a physician or a nurse to wash their hands? But clearly, as we were in the hospital for months and months, and after surgery after surgery, I began to speak up. Whereas I used to secretly take a napkins out of the towel dispensers and find a magic marker and write, 'Wash Your Hands' on it and tape it over Daniel's little bassinet, because I was too intimidated to say anything, I eventually found my voice. Clearly this is an issue nowadays, and I think this is one of the things that we have to learn to teach families, because they don't just know how to do this. Healthcare professionals... physicians... nurses... all go to school to learn how to be clinicians. But patients and families—we don't go to school to learn how to do this. We have to learn, unfortunately, by trial and error many, many times. Let's open the door so we can eliminate the error part of the equation.

Julie Moretz

My son came up with a solution to make shots not so bad, at least he thought it worked. He asked the nurse to put a blood pressure cuff on his opposite arm, the arm that wasn't getting the shot to give him deep pressure while he got a shot in the other arm. That was the solution he came up with. And prior to that, the only answer was to have five strong people hold him down. It was amazing. It was one of the best appointments we ever had because they talked to him and listened to him. They asked him what he would like to do. He came up with the solution. Even though it was out of their normal workflow, they did it, and it was great! That would be the kind of encounter I'd love to see more of in healthcare. It started with listening to the patient.

Regina Holliday

People complain, and things go wrong, and adverse events happen. In healthcare we tend to shy away from that. In fact, the negative episodes are pieces of gold that we need to really be exploring with the patients, because they're shining a light on areas we actually need to be reconfiguring.

Stephanie Newell

If you have an adverse event, approach the family and ask them to help you improve. This is what we did in Vermont. They went to the people who had filed complaints, and even lawsuits, and brought them onboard to help fix the problem, because they already had that passion behind them.

Dale Ann Micalizzi

When I was in the hospital getting this really arduous, physically brutal treatment for my cancer, people would holler down the hall at two in the morning to each other. My mother would smack our face if we did that in our home. Well you don't have to be a genius to know you shouldn't do that. So yes, the room quiet standards are great; however, some hospitals don't realize that it could be just as important to oil the wheels of the carts they push down the hall at 2 a.m. I would encourage them to ask patients if they are doing all the right things.

Dave deBronkart

Doctors are freaking out about HCAHPS. They're like, 'What kind of crazy world is it that you're using these simple measures to judge us?' Yes, they are just simple measures. But those simple measures mean so much. And they lead to so much. So if you screw up these simple measures, you likely can't get the harder ones right either.

Regina Holliday

Had they listened to me, I could have saved the taxpayers millions of dollars. My son spent five months in the NICU. Had they just listened and considered that something could actually be wrong, he may not have stayed in the hospital that long. He may not have had the infections that he had. He may not have had to stay on the ventilator for that amount of time. And we may not have the long-term effects that we're dealing with. They are not dealing with them. I am dealing with that. My son is dealing with that.

Naomi Williams

I would say make an organizational commitment to training. Get your board engaged in this topic. Because when the money has to be spent, you have to make it a priority. Sometimes, with the financial constraints, it's really hard to think about training, to treat it as a priority, when there seem to be so many other things fighting for attention. But if you're thinking about being competitive in this market, how can you afford not to focus on patient experience?

Linda Kenney

While the temptation is to focus on the negative, the organization's culture must also get equally excited about the positive. When people do something exemplary, praise them to the skies; publicize them. There's no reason why you can't have an internal YouTube channel or equivalent to broadcast three-minute vignettes about wonderful patient experience stories.

Dave deBronkart

Only one time did I mention to my radiologist/oncologist that I had switched from another healthcare organization because of a very rude exchange with a front line person at the other facility during a mammogram. I said, "You also have a front line person here who is just as rude." He looked at me and made some excuse for her. I said, "That experience cost the other health system $250,000." And he says, "Well put." When we came out of his office he steered me to the other front line person. The next time I came in, the front line person who was originally rude was exceptionally kind. The lesson is that hospitals shouldn't let patient experience problems linger. They don't get better if they aren't addressed.

Brooke Billingsley

Don't make isolated decisions that really don't have an impact on that patient or that consumer. And don't insult your employees by creating another acronym with another code of something people that have to memorize. There's a disconnect between that actual clinical staff person on the site and what the patient's going through, versus the administrative team that is making some of these decisions. So, I would tell healthcare leaders to get in touch with frontline workers. Managers need to be observing their employees and following that with coaching, and recognizing exceptional outcomes. It's not that they're trying to catch them doing something wrong, but that they're continually reinforcing the behaviors they want to see more of and providing training when needed. I think employees already know what their organization doesn't want. I don't think they're always clear on what they want more of. Management and the senior management can't always assume that the message is reaching the front line, and therefore reaching the patients. If a manager is really interacting with his or her employees and observing, coaching and supporting, you'll start to see that connection to the patient experience.

Brooke Billingsley

I was at a very good hospital, and I very much liked the primary physician I had. But one day I reported to the front desk at the practice in the hospital that I had heard a mistake in their voicemail announcement. And the woman at the desk just shook her head said there's nothing we can do about it. And I thought, you know, as good as the individual doctor might be, if that's the environment in this place, where people are powerless to fix a mistake on a voicemail recording, then I don't want to be around here when something more serious hits the fan. My point is that the things that constitute the fabric of your customer experience are pervasive, whether they're glorious or horrible.

Dave deBronkhart

We had a nurse that had an adverse event that has left her with medical problems for the rest of her life. It was the housekeeper who actually put her hand on her hand and asked, "Are you okay?" Not her fellow nurses. Not the doctor. It was the housekeeper. It's human contact that people remember in their worst times.

Linda Kenney

I was in a private hospital that was trying very hard to use the hotel kind of customer service approach. They treated me like a welcome guest when I came in. This was for a surgery. Everything was concierge-like, and great. After my 12-hour operation, I woke up in the middle of the night very nauseous. The surgeon had forgotten to draw away blood from my face, which was being reconstructed. The blood went down into my stomach, and I woke up vomiting copious amounts of blood. I was very noisy, and the nurse shushed me because I was disturbing the other patients. Thinking about that in retrospect… in treating me like a customer, it failed to register on the nurse that I was a patient, a very sick patient, so the "treat patients as customers" mentality has its shortcomings.

Kathy Torpie

Honoring the voices of patients and families

Our contributors remind us that the patient experience is universal and simultaneously unique. That is the challenge healthcare organizations and physicians face. How do you consistently implement protocols that must be perceived as customized to the individual in front of you?

One contributor used an analogy that differentiated the type of care patients want and what they sometimes experience by highlighting the customer service one might expect from a generic clothing outlet with what a shopper experiences in Nordstrom's. It was a useful analogy, and healthcare leaders could bring that to life by reading *The Nordstrom Way: The Insider Story of America's #1 Customer Service Company,* a book published in 1995, but still worthy of attention. In the book you will run across terms like *accountability, decentralized decision making, commitment, follow through*, and the *super service challenge*. The book also rejects the "It's not my department" mentality. Will reading the book solve an ER throughput problem or help nurses address slow lab results? At the very least it could provide a fresh perspective on common service industry challenges. Perhaps it could provide insights as to how to modify and adopt solutions that other service industries have successfully implemented in their attempts to build lasting, positive relationships with their customers.

As I reflected on the voices of our contributors and stories they relayed, I ran across a news story of how an employee at a chain restaurant addressed one diner's experience. A woman and her younger autistic sister were dining at Chili's, and the waiter served the autistic woman her cheeseburger, sliced in two pieces, which is the restaurant's usual practice. But the autistic woman didn't eat the cheeseburger, stating that it was "broken" and that she wanted one that was "fixed." Rather than ignoring the autistic woman's odd complaint, the waiter removed the cheeseburger and returned with a whole one. The manager also visited the table and apologized for serving a "broken" cheeseburger and even delivered extra French fries. The autistic women's sister used Facebook to applaud the sensitive approach the Chili's staff took to a potentially awkward situation. Nearly one million people have viewed the story.

Change the setting to a hospital. Patients can be just as emotionally compromised as the autistic girl. The care team can deliver care that is appropriate for the medical condition, and yet the patient could perceive something as "broken." Rather than labeling it as an inaccurate assessment, the nurse, or administrator could jump in and implement whatever service recovery steps are deemed necessary. The outcome might be the same, a family member applauding the hospital on Facebook. Will that change the organization's overall Press Ganey scores or HCAHPS ratings? Not likely, but the willingness of the organization to bend to meet the desires of its patients, even after delivering flawless care, is what is often required to meet the broad and diverse range of patient experience expectations.

What this story illustrates is that there has to be active and intentional engagement from the organization's standpoint to ensure that patient feedback and perceptions are considered, heard, and incorporated into their overall care delivery efforts. Challenging? Yes. Essential? Absolutely!

But I'm encouraged by the movement that I've seen across healthcare over just the last three years. There is a slow but growing commitment from the front line providers of care and the emerging crop of healthcare leaders to concentrate on patient experience. This is exciting, because we are building critical mass around the conversation about patient experience. I like the metaphor of an iceberg melting. When icebergs melt, they often melt from the bottom up, and at some point they become very top heavy and there is this sudden flip. It can be very dramatic. Some organizations might experience this sudden flip to the other side as they slowly break down barriers to improving patient experience and move toward where they want to be. They slowly build the team that supports that mission, and then at some dramatic moment, the entire enterprise embraces the goal. Sometimes this flip is precipitated by a tremendous example of what superior patient experience should be. Even so, there is, however, no real endpoint in this journey. Resistance keeps melting as the environment acts on the organization's systems, and the new levels of patient experience excellence can appear.

The central themes in many of The Beryl Institute white papers on the patient experience, especially the papers featuring interviews with healthcare leaders, have been: leadership, training, organizational commitment, rewarding and recognizing superior patient experience performance, etc. This paper certainly elevates those same themes. The one distinction in this paper is the importance of engaging patients and families and opening the door for them to take active roles in building a positive patient experience. They are not to be passive recipients of the patient experience, but active participants in the delivery and process of care. Patients must be empowered and invited to participate in the patient experience, and they have to learn that skill over time, but our current system isn't set up to activate that learning process. Some patients want to participate, but we make them climb uphill at times just to have their voices in the conversation. Patients can come and go quickly, and if they aren't encouraged to speak up and speak into their care environment, the value of that engagement never materializes.

Someone asked me what my vision was for this paper, and clearly my goal was to share the voices and stories of patients, and to promote the great work and the experiences in a way that people haven't probably looked at before. I also wanted to, "unsubjectize" patients (don't bother looking it up, it's not in the dictionary), meaning remove the sense that we are studying some sort of animal in the wild when we talk about the patient experience. Patients have to be part of the conversation. Finally, I'm hoping that as we share this white paper with patient audiences in various venues it will inspire others to speak up.

Contributor Keith Boyle reminded me of an important truth, that every patient is vulnerable, and vulnerable people are more sensitive than people who are feeling no vulnerabilities, and those sensitivities mean that seemingly minor acts can have dramatic impact, either positively or negatively. While patient experience improvement efforts have tended to focus on committees and checklists, this paper reminds healthcare providers that minor acts make a difference.

Our contributors provided an incredible gift in offering their insights, their raw perspectives, their challenging comments and their supportive encouragement as the healthcare community in general works to address the critical issue of patient experience. I offered in revising the power of patients and families as partners we must:

- Acknowledge patients are not subjects in the healthcare process or "something" you should talk about or plan for in third person. They are partners in the healthcare experience.
- Recognize patients are not necessarily wired to actively engage in the healthcare process, due both to the complexity of healthcare and the nature of the system itself (that potentially diminishes the role of the patient in an unspoken hierarchy of expertise). You must ask, encourage, and act on the patient's voice.
- Consider coordinating efforts to identify and incorporate patient perceptions into the overall planning of care.

In concluding the article and summing up what we discovered through the generous insights of our contributors I noted:

> One contributor to the paper offered, "All too often in healthcare, the conversation about what should happen to or with patients, is done by the people that are delivering, not by the people that are receiving." The reality this represents and what was reinforced by the patient and family voices with whom I spoke is that if you don't understand expectations and then actually make those explicit, you may already be on course to miss your target: fulfilling the needs of patients and families. In taking the time to listen with compassion and to establish productive partnerships, you create a space where true patient and family perceptions can be addressed and the overall experience positively impacted.
>
> Barbara Lewis summed this up in a powerful way, offering, "Patient care needs to be a partnership and a collaboration. The hospital needs to set the tone and the framework for that collaboration. The collaboration first has to start among the staff members, the doctors, and the nurses, and then between and among the doctors, the nurses, the patients, and the family members; encouraging them—everyone—to speak up, and to speak their mind."
>
> The ability to listen in the moment and act on what is invited or shared may be one of the greatest gifts in healthcare. This partnership of listening represents the gift of dignity and respect patients and family members ultimately desire in the healthcare setting. Once they feel it, their experience—all that is remembered of their encounter with your organization—will be positive and strong. Doing this not *for*, but *with* patients, should leave your organization with a sense of greater purpose and well-deserved pride.

I know our contributors wish those of you on this journey great strength, commitment and speed in achieving your objectives. In ensuring patients and families are true partners in the patient experience movement we all can continue this journey to the greatest of outcomes for all in our care.

CONTRIBUTORS

Brooke L. Billingsley

As a keynote speaker and consultant, Brooke Billingsley provides thought provoking insight as she shares her trifecta of knowledge as a cancer patient, 250,000 healthcare consumer reports, 100's of clinical employee interviews and ethnography studies on low performing hospital units. If you can't define patient experience, you can't provide it and you can't measure your success in delivering it. Brooke shares her emotional journey as she continues to navigate her way through the healthcare system on the path to healing. Her unique perspective as healthcare consultant, human behavioral expert and now as a patient provide her audiences and clients with strategies to access low hanging fruit, maximize marketing efforts and convey a message of truth. Brooke is co-founder and CEO of Perception Strategies, Inc., a national healthcare mystery shopping and customer service company since 1998. Brooke co-authored *Turn Your Customer On: 23 Ways to Motivate Employees and Make Your Customers Love You.* This book is a guide for companies who want to create a never-ending commitment to customer excellence. Brooke has been featured on Good Morning America, and in The Wall Street Journal and several professional healthcare magazines.

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Keith Boyle

Currently the Director of Service Excellence at Henry Mayo Newhall Memorial Hospital in Valencia, CA, Keith Boyle's career in healthcare has spanned 41 years that includes a broad variety of clinical, operational and management development positions including serving as the Care Management Specialist for Service Excellence at Catholic Healthcare West. A Registered Nurse since 1977, he completed his master's degree in Oriental Medicine and became a Licensed Acupuncturist in 1986. In 1999 he completed post-graduate work at University of California, Berkeley and was certified in Human Resource Development and Performance Technology.

Tiffany Christensen

Tiffany Christensen was born with cystic fibrosis; a life limiting genetic disease that primarily effects the lungs and digestive system. In 1995, at the age of 21, Tiffany was given the bad news that her lung disease had progressed to the point that she need a lung transplant to survive. Tiffany sadly left the NC School of the Arts where she was studying to be an actress and began to look for ways to cope with illness during the long wait for organs. In 2000, Tiffany got "the call," got her lung transplant and enjoyed the best health of her life for two years. It was this point Tiffany was diagnosed with a difficult-to-treat complication some transplant recipients face: chronic rejection. Tiffany's health declined rapidly and a second transplant was not an option.

Today Tiffany is a patient advocate at Duke Hospital, a national public speaker and the author of "Sick Girl Speaks!" (2007) and "We are the Change: Transforming the Healthcare Experience through Partnership" (2010). Tiffany is a grateful recipient of the Heroes of Hope award from Cystic Fibrosis Research Institute in Redwood City, CA.

www.sickgirlspeaks.com

Alicia Cole

Prior to 2006, Alicia Cole was a successful working actress whose only experience with healthcare was playing doctors on TV. All of that changed however when she entered the hospital for a routine procedure to remove two small fibroids. Alicia left the operating room with a fever, nausea and pain. She declined from there. Five days later, during a dressing check, Alicia's mother noticed a small black dot near the incision. In just over an hour the dot morphed into a quarter-sized pustule. Immediately Alicia's doctor assisted by her mother performed a bedside surgery cutting open her abdomen and draining the toxic fluid.

So began the nightmare of sepsis, pseudomonas- Zyvox, Zosyn and seven other powerful antibiotics along with nine blood transfusions as Necrotizing Fasciitis ate away at her abdomen. Suddenly a two-day hospital stay turned into; two months, six additional surgeries, near amputation of her leg, a year and two months of twice-a-day home health care for dressing changes, five months of daily hyperbaric oxygen chamber treatments and three years of treatment at a wound care center for an open abdomen.

Alicia Co-Sponsored and lobbied successfully for passage of two California Laws for Patient Safety and Public Reporting of infection rates and is a member of the State HAI Advisory Committee. This year she also became a member of the Wyoming HAI Advisory Group. From her experience Alicia has become a tireless advocate for patient safety. Today she shares her story with healthcare professionals and patients everywhere, so they might learn from her case. Alicia is also currently a Graduate Certificate Candidate in the Healthcare Management & Leadership Program at UCLA.

www.aliciacole.com

Tifiro Cook

As an 18-year-old freshman college football player Tifiro was living his dream, when in a split second his life changed forever. A fitness enthusiast, when Tifiro experienced heart-pounding pain during a practice session, he knew something was terribly wrong. Two days later and 22 pounds heavier, Tifiro was diagnosed with Glomerulonephritis, a kidney disease.

Returning to his hometown of Columbus, Ohio—far from the sunny football practice fields he so enjoyed in California—Tifiro underwent treatment and a kidney transplant. Four years later, his body rejected his sister's donated kidney and Tifiro entered the world of peritoneal dialysis. Not letting his condition weather his spirits, he continued to perform self-administered peritoneal dialysis 5 times per day for 6 years, and hemo dialysis 3 times per week for 5 years. For some, this grueling schedule would thwart any sense of normalcy, but not for Tifiro.

An inspiration to all who know him, he has shared his optimism and motivation with people around the nation. Featured in a National Geographic documentary, Tifiro's message has reached many, and he continues to share his moment, his journey, and his life with diverse audiences.

www.tifirocook.com

Dave deBronkart

Dave deBronkart, widely known as "e-Patient Dave," is a cancer patient and blogger who has become a noted activist for healthcare transformation through participatory medicine and personal health data rights. The term "e-Patient" was coined by "Doc Tom" Ferguson MD and is the subject of his seminal paper, "e-Patients: How They Can Help Us Heal Healthcare," funded by Robert Wood Johnson's Pioneer Portfolio. In 2009 Dave's blogging about health IT put him on the front page of the Boston Globe and thrust him into DC policy discussions about patient access to medical records under Meaningful Use. He's appeared in *Time, Wired, U.S. News*, and the *HealthLeaders* cover story "Patient of the Future." In 2009 *HealthLeaders* named him and his doctor to their annual list of "20 People Who Make Healthcare Better" for their role as founding co-chairs of the Society for Participatory Medicine, bringing official recognition to the importance of the e-patient movement. In 2011 his TEDx talk On.TED.com/Dave went viral globally, rising into the top half of the most-viewed TED talks of all time; volunteers have added subtitles in 26 languages. Its tagline is his appeal: "Let Patients Help."

www.epatientdave.com

David Festenstein

David Festenstein is a Communication Specialist, Coach and Professional Speaker, who suffered a stroke in 2008, that left him paralyzed on his right side and unable to walk.
David used a lot of his communication expertise to help him deal with the event and then subsequently to support and drive his recovery process.

In fact his Stroke Consultant said, “It was one of the best recoveries he had ever seen”.
David kept an extensive diary and Journal that reflected his “Language of Recovery”. When he reviewed his story and observations, he realized that he had used 7 distinct steps to his recovery. His Stroke Consultant encouraged him to speak at Medical Conferences where he got excellent feedback. On the basis of this success, he set up workshops, training and coaching health professionals in his “7 steps to recovery model”. The Stroke Association also made a podcast of his story.

David’s 7 Step to recovery Model has given many health professionals insights on what they can do further to help their patients in their recovery process.

www.davidfestenstein.com

Alice Gunderson

Alice Gunderson is a Patient Family Advisor at St. Francis Medical Center (SFMC) in Los Angeles California. She comes to the healthcare world via a leadership and creative role in the fashion industry. She took an unexpected role as caregiver for her Mother diagnosed with vascular dementia and her Husband diagnosed with myotonic muscular dystrophy. Today she serves as an advisor in patient family centered care at SFMC where Alice sits on numerous hospital committees as a member of the hospital’s Quality, Patient Safety Committee (QPS).

Regina Holliday

Regina Holliday is an activist, artist, speaker and author in Washington DC. You might see her at a health conference painting the content she hears from the patient view. She is part the movement known as participatory medicine. She and others in this movement believe that the patient is a partner with their provider and both should work together as a team. Regina, like her friend Dave deBronkart, is also an e-patient. She utilizes the tools of technology and social media to better understand the patient condition and the landscape of medicine.

Regina is a mother and a widow; she speaks about the benefits of HIT and timely data access for patients due to her family loss. In 2009, she painted a series of murals depicting the need for clarity and transparency in medical records. This advocacy mission was inspired by her late husband Frederick Allen Holliday II and his struggle to get appropriate care during 11 weeks of continuous hospitalization at 5 facilities. Her paintings became part of the national debate on health care reform and helped guide public policy.

reginaholliday.blogspot.com

Libby Hoy

As the mother of three sons living with mitochondrial disease, Libby has over 20 years of experience navigating the health care system. Libby began volunteering as a Parent to Parent Mentor in 1995 and has been working to improve health systems and empower patients and families to be active partners in care ever since. In her role as the first Family Advocate at Miller Children’s Hospital, she developed the Parent to Parent Support Program, the Parent Advisory Board (Council) and created the structure for the long term integration of the Patient & Family voice within the organization. Libby has presented at multiple national and international conferences on subjects related to Patient & Family Centered Care and Family Empowerment.

In 2010, Libby founded PFCC Partners. The mission of PFCC Partners is to partner with patients, providers and organizations to improve the quality, safety, experience and delivery of health care. Libby has worked directly with more than 30 hospitals and healthcare organizations to design and implement patient & family engagement programs, which include Patient & Family Advisory Councils as well as support and empowerment programs. Libby lives in Long Beach, CA with her three sons and husband.

www.pfccpartners.com

Linda Kenney

Linda K. Kenney, Executive Director and President of MITSS (Medically Induced Trauma Support Services, Inc.), founded the organization in 2002 as the result of a personal experience with adverse medical event, when she identified the need for support services in cases of adverse events and outlined an agenda for change. Since that time, she has been a tireless activist for patient, family, and clinician rights. She has become a nationally and internationally recognized leader in the patient safety movement and speaks regularly at healthcare conferences and forums. In 2006, Linda was the first consumer graduate of the prestigious HRET/AHA Patient Leadership Fellowship. That same year, she was the recipient of the National Patient Safety Foundation's esteemed Socius Award, an annual award given in recognition of effective partnering in pursuit of patient safety. She has authored and contributed to a number of publications on topics including the emotional impact of adverse events on patients, families, and clinicians. Linda serves on the boards of the Massachusetts Coalition for the Prevention of Medical Errors, National Patient Safety Foundation and Planetree.

www.mitss.org

Barbara Lewis

Barbara Lewis' life took an unexpected turn in 2012 when her sister Joan spent two weeks in the ICU. When she saw her sister getting better, Barbara relied on her three decades as a successful marketing consultant to observe hospital personnel and jot down impressions of the patient and family member experience. Her plan was to meet with the head of the ICU the day Joan was released and share her observations.

However, Joan died unexpectedly of an unknown infection. Barbara decided to email the ICU, calling her message, Joan's Family Bill of Rights. The head of the ICU sent the document to the hospital's chief operating officer and he, in turn, sent it to the heads of the healthcare system. They asked Barbara to make three presentations at their facilities and videotaped the speeches as the "cornerstone" of their training program. At the hospitals, she spoke to a couple hundred people many of whom told her their stories, which had similar themes to the actions she had observed in the hospital. Barbara began to think that she had struck a nerve and she came away from that experience with a desire to help hospitals improve the patient and family member experience in her sister's name.

www.JoansFamilyBillofRights.com

Dale Ann Micalizzi

Dale Ann Micalizzi, Nationally known Advocate for Pediatric Patient Safety and Transparency in Medicine. Her eleven-year old son, Justin, died following a "simple" incision and drainage of an infected ankle in 2001. She has worked tirelessly in search of answers about her son's death, giving rise to a quest to improve pediatric patient safety and transparency in health care. Her efforts focus on compassion and support for grieving families, full disclosure of adverse events, and education and reform that will restore ethics and safety to medicine.

She has presented as a faculty member for the Institute for Healthcare Improvement beginning in 2005, IHI Forum Co-Chair in 2011 and Patient and Family Advisor. She has acted as a consultant, speaker and improvement advisor for numerous health care organizations, several medical schools and patient/family support programs. She is the founder and director of Justin's HOPE Project at The Task Force for Global Health (Child Survival and Development) which provides yearly healthcare scholarships to caregivers working with vulnerable pediatric populations, in partnership with the Institute for Healthcare Improvement.
Learning from Justin's tragedy, working with healthcare providers/students to make care safer and kinder and assisting families healing from harm are Dale Ann's goals.

www.taskforce.org/our-work/projects/justins-hope

Julie Moretz

Inspired by her son's battle with heart disease—his multiple heart surgeries and heart transplant—Julie Ginn Moretz, of Augusta, GA, has spent the better part of her career as a family leader to improve health care for patients and families. Julie was recently appointed associate Vice Chancellor for Patient- and Family-Centered Care at the University of Arkansas for Medical Sciences in Little Rock, where she has overall institution leadership responsibility for the development of clinical and academic programs related to patient- and family-centered care.

Julie initially served as the inaugural volunteer Chairman of the Family Advisory Council at the Medical College of Georgia and sat on numerous hospital committees, working with hospital administrators and clinicians to create a patient- and family-centered culture and to improve the experience of care. Expanding her role in the health system, Julie was named the Director of Family Services Development and oversaw six departments that supported both adult and pediatric services. She also managed the health system's patient and family advisory councils, which provided input in health system programs to enhance quality and safety. Julie developed the Family Faculty program to incorporate patient- and family-centered care concepts in medical education and was a faculty tutor for first-year medical students in Essentials of Clinical Medicine and Communication Skills Lab.

Most recently, Julie worked with the Institute for Patient- and Family-Centered Care, based in Bethesda, MD, as the Director of Special Projects for nearly seven years. She worked on a variety of projects to develop partnerships among health care professionals, patients, and families and also consulted with health care organizations throughout the country to advance the practice of patient- and family-centered care. Julie oversaw the Institute's nationally-acclaimed intensive training seminars, international conferences, and other educational programs.

Stephanie Newell

The death of Stephanie's son in hospital and the experience of receiving suboptimal care was the catalyst for Stephanie's involvement in health care design and delivery. Stephanie is passionate about ensuring the unique and valuable experience and knowledge of health consumers and patients informs, leads and activates change in health care policy and practice. Equally passionate that patients and health consumers are seen by all in health care as valued partners not only within their own health care but in system design also, Stephanie collaborates with health providers and health care organizations to embed partnerships principles in organizational systems and to facilitate collaboration with health consumers and patients.

Stephanie's commitment to advancing provider- patient collaboration and a "user led design approach" has included organizing and co-facilitating the landmark World Health Organization (WHO) Patients for Patient Safety 3 day workshop in Australia. In her role as a foundational member of WHO Patients for Patient Safety and Patient Safety Champion Stephanie assisted in bringing together health consumers and patients who had experienced harm in health care, health providers and policy makers to develop strategies and actions for working together in partnership to advance patient safety in Australia.

Stephanie has contributed her expertise in patient safety, quality improvement, population health, research, consumer advocacy and engagement, risk management, innovation and the client experience to health care policy and practice at state and federal levels in Australia and internationally as a health consumer advocate, health consumer representative and consultant on health consumer experience for the past 11 years.

Zal Press

Zal is the leading patient proponent of the use of patient narrative in medical education as an innovation tool to improve the practice of patient centred care. He founded Patient Commando Productions in 2010 as a social enterprise to produce authentic Patient Experience programming that informs and enriches our understanding of critical Health Care Issues. Patient Commando Productions is a CME provider of accredited continuing medical education programming focused exclusively on the patient experience.

For 25 years prior to founding Patient Commando Productions, Zal was the president of a contemporary wall décor manufacturer after a career as a marketing and communications professional. Throughout this period, he managed a chronic illness while developing his new career as a professional patient. His wife and 2 now-young adult children played pivotal roles in the 30 years it took him to move up the patient engagement ladder.

Patient Commando Productions produces Medutainment – health education informed by the patient experience using visual and performing arts. The company facilitates patient storytelling clinics with award winning, Second City alumnus, Brian G. Smith and presents live stage events such as the Canadian Comedy Award winner "Cancer Can't Dance Like This", a one man show starring Daniel Stolfi. The website is the most diverse collection of patient stories in any medium, with contributions from accomplished authors, filmmakers, educators, researchers and numerous internationally recognized patient advocates. Through innovative partnerships such as the collaboration with the Canadian Public Health Association, the site provides a platform for the unheard voice of remote, vulnerable, and marginalized health populations.

www.patientcommando.com

Kathy Torpie

Kathy was an active, independent woman in excellent health when she suffered life threatening, multi trauma injuries in a car accident. She woke up in intensive care on life support. Terrified, confused and feeling diminished, Kathy found herself trapped in a broken body in an alien environment that spoke in a language she didn't understand. She was totally dependent, even for her most personal needs, on strangers.

Kathy remained in a hospital bed, unable to stand for nearly four months. Following discharge, she had to coordinate dozens of surgeries, involving multiple disciplines over a period of seventeen years, as well as arrange home help, insurance and social services. She experienced some exemplary care over the course of her recovery, and some both physically and emotionally traumatic. Her overall patient experience, combined with her ability to "see the whole picture" provided Kathy with important insights about the nature of the patient experience and what constitutes quality healthcare. She has since shared her story and insights in inspirational keynote presentations in New Zealand, Australia, Europe, the United States and Canada. She was a steering committee member for a national project to optimize the patient experience in New Zealand and is currently a steering committee member for policy and advocacy with the Australasian College of Health Service Management (ACHSM)

Her book, "Losing Face; A Memoir of Lost Identity and Self Discovery" (Harper Colllins, N.Z) is an insightful narrative of her medical and personal journey of recovery that offers a deeply intimate view of the patient experience. She recently authored a chapter for a text book on patient stories.

www.kathytorpie.com

Naomi Williams

Naomi Williams has served as a patient advisor, on behalf of her son, with the Children's Hospital of Georgia since January 2010. In addition to serving on the Family Advisory, Neuroscience and OR quality control councils, she is a member of the Family Faculty program. Naomi holds a bachelor's of science degree in health and physical education from Augusta State University and in 2008 she earned a master's in public health from Walden University. Naomi is also a Certified Health Education Specialist (CHES) and Certified Intrinsic Coach (CIC).

Understanding the importance of meeting people where they are came natural for Naomi. Her years of working as a patient liaison and community outreach manager with high risk women and infants enrolled in the Enterprise Community Healthy Start program, became very real and personal when she became a high risk mother, just like the women and families she served; an experience which intensified her passion for patient advocacy.

As the parent of a special needs child, Naomi is passionate about helping families manage their decisions and navigate systems associated with special needs.

She is a trainer for Parent to Parent of Georgia, co-coordinator for the Children's Hospital of Georgia A-team (autism) support group, columnist for the Augusta Medical Examiner, and the Family Support Coordinator for the Children's Hospital of Georgia and Georgia Regents Cancer Center resource libraries.

About the Author

Jason A. Wolf , Ph.D., President, The Beryl Institute, is a passionate champion and recognized expert on organizational effectiveness, service excellence and high performance in healthcare. He is revolutionizing the Institute's services and outreach to position the organization as a globally recognized thought leader on improving the patient experience. Prior to joining the Institute, Wolf designed and led the Organization Change, Service and Leadership Development strategies for more than 45 facilities and 45,000 employees as the director of organization development for the Eastern Group of the Hospital Corporation of America (HCA). His 20-year career has spanned the healthcare and service industries in such roles as senior leader, internal and external consultant and entrepreneur. Wolf has authored numerous articles and publications on organization culture, change and performance in healthcare.

Also from The Beryl Institute

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Structuring the Patient Experience Effort: An Inquiry of Effective Practice

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Customer Experience: A Generational Perspective.

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