Today, the CAHPS survey often doesn't capture the entire picture when it comes to customer satisfaction. To meaningfully improve the patient experience, an organizationwide, proactive approach to patient-centered care is needed.

Beyond CAHPS: A Guide for Achieving Patient- and Family-Centered Care gives healthcare providers the knowledge to construct a top-notch patient experience.

This book will help you:

• Understand how patient satisfaction has evolved into patient experience and patient-centered care
• Set up an effective patient-centered care structure throughout your organization
• Use data to effectively illustrate current progress and identify improvements and goals
• Work with staff and leadership to provide the best patient-centered care possible
Beyond CAHPS

A Guide for Achieving Patient- and Family-Centered Care

Janiece Gray, MHA, BSW, CPXP
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Dedication

For Betty, who told me to “Go downstairs and write” and encouraged me throughout!
About the Author

Janiece Gray, MHA, BSW, CPXP, is a gifted communicator and consultant who is passionate about improving care by helping caregivers and healthcare professionals do a better job of understanding, connecting and engaging with patients. She is a cofounder and CEO of DTA Associates Inc., a healthcare consulting firm focused on helping providers achieve patient-centered improvement goals. Janiece and her team are uniquely positioned to partner with clinical care teams and operations leadership to develop custom solutions to enhance patient experience, improve clinical outcomes, and streamline processes. Janiece has more than 20 years of experience in patient care, healthcare administration and operations, performance improvement, and patient experience. She earned a bachelor’s of science in social work from Bethel University and a master’s in healthcare administration from the University of Minnesota. Janiece worked in a variety of progressive leadership roles at Allina Health in Minneapolis, developing new prevention programs as well as new care environments. Using her Lean training and her Black Belt in Six Sigma, she has developed and led service and performance improvement training programs to create more efficiencies and opportunities for better patient care. Additionally, Janiece has not only led performance improvement and patient experience departments but has also developed and leads empathy, patient experience, and quality improvement training programs. She loves to shadow and coach physicians and other care team members on ways they can enhance their patient communication.
One of my earliest memories was when I was 3 years old and my mom and her friend and I went to the mall in Harrisburg, Pennsylvania. We spent the evening shopping, and as we went back to our car (a light blue Ford Pinto) at the end of the night, my mom’s friend, Cheryl, looked at my mom and asked, “Does she always talk this much?” My mom politely smiled and nodded. Later that evening back at our house, I looked at my mom and said, “I know I talk a lot … it’s just because I have so much to say!”

I love that story because it’s very true of me, even today. When I was asked to write a book about one of my passions—patient experience and patient- and family-centered care—I couldn’t believe it! Not only was it a dream come true, but as always, I realized I had so much to say.

When I was in junior high, they had us do one of those career exploration exercises to help us figure out what we wanted to be when we grew up. For a while I wanted to be an interior designer, then a financial planner. But somehow I never really had a clear vision for what I wanted to be when I grew up. Now, as an adult, I realize it’s because many of the jobs I’ve held and careers I’ve been fortunate enough to be in didn’t exist back then. Almost every position I’ve been in has been a newly created one for the organization: social worker and outreach coordinator for a Parkinson’s specialty clinic and nonprofit fundraising association; wellness intern focused on building a medical fitness center for a large senior housing company; director of operations
who designed and built a medical specialty center with clinics, lab, radiology, and a surgery center; performance improvement consultant within a newly formed Lean/Six Sigma division for a healthcare organization; director of patient experience for systemwide improvements; founding partner of a consulting firm; and leader of a patient experience practice.

There’s a theme there, and it made me realize that so many of us are in jobs and roles that didn’t exist 15, 10, or even five years ago. When I first took on my role leading patient experience at Allina Health, it wasn’t as popular as it is now. My resources for improvement and mentoring were not as robust as they are today. However, I am so fortunate for the many people and connections that helped to teach me what I was able to learn and lead. I’m unbelievably grateful to Carrie Brady, Esther Burlingame, Lynn Ehrmantraut, Colleen Feldhausen, David Medvedeff, and Dale Shaller for their friendship and leadership.

In addition to those connections and influences, there were so many amazing leaders and partners from within Allina, as well as other organizations, that helped to shape my experiences and helped form the basis for writing this book.

People like Dr. Tierza Stephan, Dr. Ben Bache-Wiig, Dr. Penny Wheeler, Dr. Steve Bergeson, Mary Jo Morrison, Tomi Ryba, Cheryl Reinking, RJ Salus, Tracy Laibson, Janet Wied, Amy Edwards, Jay Scott, Mike Wenzel, Tracy Kirby, Gretchen Leiterman, Richelle Jader, and Dr. Kurt Isenberger. I specifically want to highlight and thank contributing chapter authors Dr. Steve Bergeson, Tracy Laibson, Janet Wied, and RJ Salus, for the case studies that they took the time to write for me. I’m grateful for my partner Kevin Campbell, who not only authored several chapters but also proved to be an excellent editor and cheerleader for me in this process. I also want to thank those who graciously gave their time and shared their expertise to help research and fine-tune various aspects of this work: Lynn Ehrmantraut, Leslie Balbecki, Mike Wenzel, Jay Scott, Dr. Tierza Stephan, Nicole Braegelmann,
and Jennifer Schugel. There are a few others whose voices have impacted me as their words echoed in my writing—thanks to Doug Pagitt, Mark Dixon, and Jessica Anderson. And last but not least, thanks to my husband Jason and our three little ones who challenge, inspire, and support—Emma, Alyson, and Avery.

Since leaving Allina, I’ve had the privilege of working with several organizations helping and assisting them in their journey to improvement in striving for patient- and family-centered care and patient experience. What I’ve learned with them, building off of my journey at Allina, is that A) there’s so much to do in this space; B) anything is possible; and C) it’s always more of a journey than a destination. In some ways, that’s great job security for those working in this field.

And yet, there are frustrations. I’d be remiss if I didn’t admit that this is some of the more challenging work that I have ever encountered. This work is very personal, and so often the people that we’re trying to influence can be defensive. The data and measurement for outcomes are tricky at times and often directional at best. There’s a significant lag in the measurement between performance improvement activities and actual results. And there’s increasing pressure from the payment system and organizational leaders to go further, farther, faster.

That being said, this is truly some of the most rewarding work I’ve ever been a part of, and I truly feel that in this place, I’ve found my passion. My hope is that, by sharing some of the experiences, lessons learned, and ideas about how to avoid many of the potholes I’ve fallen into and helped others get out of, you too can experience greater success on your journey.
Section 1

Introduction
My first introduction to work in quality and performance improvement was at Allina Health under the direction of then–Chief Clinical Officer (CCO) Penny Wheeler, MD. As Penny assumed the CCO role, she had an approach to and a platform for her vision for quality deemed the 4 C’s: compulsories, connection, collaboration, and community. While it sounds like a simple model, realizing this to its fullest is both daunting and inspiring. Little did I know at the time, this model would become the basis of my approach not only to quality and performance improvement but also to patient experience, and ultimately to patient- and family-centered care.

Let’s look a little deeper at this approach:

- **Compulsories**
  
  Any time you’re working in an area with tons of rules and regulations, it’s easy to get bogged down in the “must do’s,” the “cans,” and the “cannots” of the work. These are the compulsories. Many people get lost and stuck in this place and focus only on the letter of the law, whether we are hitting the measure, and the resulting color on the scorecard. These are things we must do (hence “compulsories”); however, when you’re trying to engage care team members about quality,
focusing solely on the compulsories is not what will ultimately motivate them.

- **Connection**
  
  To look beyond the minimum requirements and regulations and to consider how we can make a difference and improve takes connection: connection with caregivers and the care team members providing the care, as well as with the patients and family members receiving the care. This means leaving our offices or cubicle land and getting out—to the sites, to the units, to the people, to the physicians, to the patients—and connecting with them about what is meaningful to them with regard to whatever quality metric is being considered.

- **Collaboration**
  
  Making lasting changes and sustaining true process improvement is rarely achieved in silos. Whether within units or between sites within a larger organization, breaking down those silos and finding ways to collaborate and learn from one another is the key to success. Systemic change can only occur when we work together to understand why some areas can achieve success while others struggle, and when we creatively problem solve together.

- **Community**
  
  Historically in healthcare, we’ve been pretty siloed and myopic to only think about what goes on within the walls of our organization. This wasn’t selfishly derived so much as it was congruent with how we were paid. In a fee-for-service world, we competed on volumes with our rival health systems and were paid accordingly. With the shift to value-based payments and ultimately to accountability for an entire population, it’s no longer enough to think only within our organizations. To truly achieve this requires partnerships within the community and for the good of the community.
Before we take a look at how the 4 C’s relate to the realm of patient experience and patient- and family-centered care, it may be helpful to start with some definitions.

**Definitions**

Healthcare organizations are infamous for cooking up heaping mounds of alphabet soup: jargon and acronyms that mean something to some but not to most. My first job out of grad school was as an administrative fellow at a large tertiary hospital in Minneapolis. I’ll never forget when the then-president of the foundation handed me a document that he’d found particularly helpful when he arrived. It was lovingly titled the “Abbott Northwestern Bible.” In this document I found an alphabetical listing of all of the terms, acronyms, and words that meant something to those within that great institution but that could be baffling for those just entering it. That “bible” was one of the most helpful parts of my early orientation at Abbott Northwestern Hospital.

The patient satisfaction/patient experience/patient- and family-centered care space is no different. When I first got involved with work in this emerging area, it was called “patient satisfaction.” Within only a few years, that term seemed outdated and was becoming more often referred to as “patient experience.” According to the Centers for Medicare & Medicaid Services (CMS), from a survey perspective “patient experience surveys focus on how patients experienced or perceived key aspects of their care, not how satisfied they were with their care. Patient experience surveys focus on asking patients whether or how often they experienced critical aspects of healthcare, including communication with their doctors, understanding their medication instructions, and the coordination of their healthcare needs. They do not focus on amenities” (CMS, 2016).

In his post on the Hospital Impact blog in July 2014, Jason Wolfe, president of the Beryl Institute, wrote: “Satisfaction, the idea of how positive someone
feels about an encounter, is an important metric, but experience encompasses more than just a sense of satisfaction. Satisfaction is in the moment, but experience is the lasting story. It is defined in all that is perceived, understood and remembered. And patient experience encompasses much more than creating happy patients. It is about ensuring the best in quality, safety and service outcomes.”

I love the work of the Beryl Institute and have supported them and participated in their movement over the years. They define the patient experience as: “The sum of all of the interactions, shaped by the organization’s culture, that influence patient perceptions across the continuum of care” (n.d.).

However, I think the Beryl Institute’s definition misses a key point: When I share this definition with teams and in workshops, I change it to include “patient and family perceptions across the continuum of care.” Families are a significant factor in how patients experience their care, and therefore how they rate their care. We are increasingly hearing from patients that their family members are just as much a part of and impacted by their experiences as patients as the staff and physicians who care for them.
While the movement toward a focus on patient- and family-centered care might seem recent, the reality is that children's hospitals, perhaps the first to use the term “patient- and family-centered,” have been using the term for years. The Institute for Patient- and Family-Centered Care (IFPCC) has been in existence for more than 20 years.

According to IFPCC, “Patient- and family-centered care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families. It redefines the relationships in healthcare.

Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of healthcare. They promote the health and well-being of individuals and families and restore dignity and control to them.

Patient- and family-centered care is an approach to healthcare that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction” (n.d.).

One of the earliest citations for support for patient- and family-centered care came out of the Institute of Medicine’s 2001 report Crossing the Quality Chasm: A New Health System for the 21st Century, which, among other things, called for healthcare systems that:

- Respect patients’ values, preferences, and expressed needs to be involved in their care

- Provide the information, communication, and education that people need and want
• Guarantee physical comfort, emotional support, and the involvement of family and friends

• Provide transformational change in healthcare

When my kids were younger, they liked to watch the PBS cartoon Martha Speaks. It’s about a dog who eats some of the family’s alphabet soup, and when she does, she can talk. To follow, let alone sort through and understand, the various definitions we’ve just covered feels like enough alphabet soup to keep Martha talking for a year. To understand and sift through it all, I asked a group of patient experience leaders about which terms they use in their organizations and how they would describe them. One of the best responses I received was from Brandon Parkhurst, MD, MBA, CPXP, medical director, patient experience, Marshfield Clinic (Beryl Institute Listserv):

*Patient experience is defined by those receiving care (patients, families, etc.), hence it is about perception; patient-/family-centered care is defined by the intention of those providing the care (and I include both individuals and systems in the word “those”), hence it is about prioritization. In short, patient/family-centered care is a promise and patient experience is the measured outcome.*

*I use both terms, and I suppose that at times it might seem like I’m using them as synonyms, but I’m not. As a rule of thumb, when speaking to providers, I’ll use the intention term and talk about patient-/family-centered care, as that is the primary motivation of providers … caring for patients. When speaking to organization leaders I use the outcome term, “patient experience,” as that’s how we reflect upon and judge our performance. I don’t see one as ever being used exclusively over the other. I see patient/family-centeredness as a business strategy and patient experience as the measure of success.*

Why should we discuss the terms within this facet of the industry, and do they even matter? Interestingly, the changes in terms have coincided with our evolving work and approach to improvement in this area. You can see on
this graph how the terms “patient satisfaction” and “patient experience” have basically flip-flopped in the past 10 years, at least in terms of what is searched for on Google.

Does it matter what you call it? I would say that it matters less what you call your work in the organization and more about how you define it. I encourage organizations to call their movement something that makes sense to the members leading it (and by members, I mean the staff and physicians as well as the executives involved with this work). I encourage organizations, whichever terms they use, to define their terms and come up with a definition that corresponds to what makes sense in their organization, similar to how you might develop a vision. For example, when working with a large Level 1 Trauma Center team at Regions Hospital in St. Paul, Minnesota, this was the definition that they created and then used throughout their training workshops with their staff:
The perceptions, thoughts and feelings that patients, families and visitors have about everyone they encounter and the care they receive during their unexpected visit; from the moment they arrive throughout their care and even after they leave.

It was this definition, developed from a frontline interdisciplinary team, that led the group to title its workshop “The Unexpected Experience.” This definition was useful to ask participants to identify which words stood out to them. The same words were heard over and over: “perceptions,” “everyone,” and “unexpected.”

Regardless of what you call your program, it’s important to have a definition of what you mean with the terms that you use and how you will know you are successful in your work. This shouldn’t feel like an overwhelming or arduous task. Some of the best work I have seen is when frontline staff and physicians are paired with patients and allowed to let their creativity run free.
It’s also okay to acknowledge that what your organization calls their efforts today may evolve over time. In some organizations, this seems to parallel the 4 C’s model mentioned previously.

I base this on what I see in the market and the organizations that we work with; the terms seem to evolve with the approach to improvement and the entrenchment in the organization. The reality is that the bulk of organizations across the country are somewhere in their journey related to patient experience, and that’s the term that seems to be most frequently used. Thus, for the balance of this book, we will use the terms “patient experience” or “patient- and family-centered care” to refer to the spectrum of these efforts, unless otherwise noted. We’ll also focus on the elements of the compulsories, connection, and collaboration. Further exploration into the community and the work of patient engagement will have to be the subject of another book. For now, we have plenty to cover, so let’s get started.

References


Parkhurst, B. (2016). Describing patient experience vs. patient- and family-centered care. PXLEADERS LISTSERV. Retrieved June 8, 2016, from PXLEADERS@LIST.THEBERYLINSTITUTE.ORG
Today, the CAHPS survey often doesn’t capture the entire picture when it comes to customer satisfaction. To meaningfully improve the patient experience, an organizationwide, proactive approach to patient-centered care is needed. *Beyond CAHPS: A Guide for Achieving Patient- and Family-Centered Care* gives healthcare providers the knowledge to construct a top-notch patient experience.

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