Lessons Learned From Two Decades of Patient- and Family-Centered Care in Radiology, Part 1: Getting Started

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Abstract

Patient- and family-centered care has a long history, but the application of these principles to radiology is limited by infrequent direct patient contact for many radiologists; scarce peer-reviewed data in the radiology literature; and sparse access to implementation strategies, tools, and best practices. In a series of two articles, the authors share two decades of lessons learned from implementing patient- and family-centered care in a radiology department.

Key Words: Patient- and family-centered care, patient-centered design, patient experience, patient satisfaction, radiology, Imaging 3.0

INTRODUCTION

Patient- and family-centered care (PFCC) is a model of delivering care in which patients are partners in the design of their care [1] (see Table 1). Principles of patient engagement and PFCC are entering all aspects of health care, from shared decision making to reimbursement. The changes are due in part to the linkage of patient experience to reimbursement for hospitals through the Medicare Value-Based Purchasing Program and physicians through alternative payment programs and the Merit-Based Incentive Payment System. PFCC is particularly criticized for the limited availability of data showing quantifiable results of this approach to care. Some results have been published in the peer-reviewed literature [2]. Other data are often not published in peer-reviewed journals commonly read by physicians or may not even be found in the peer-reviewed literature [3-6]. The lack of a common nomenclature or formal taxonomy further limits the successful dissemination and identification of effective strategies and tactics to transform care. For hospitals and physicians who are just starting to explore this space, it is helpful to look at lessons learned and best practices from organizations that have already begun this journey and achieved demonstrable success.

Radiology has unique challenges because not every encounter includes a direct interaction between a patient or family and a radiologist. Although radiologists seldom experience PFCC in current imaging workflows, when interaction with patients does occur, it can have measurable impact. In our experience at our own and at other institutions, limited direct interaction between radiologists and patients does not diminish the impact radiologists can have on other aspects of the radiology experience, such as ensuring that appropriate imaging occurs and delivering a high-quality, actionable report that informs care. We contend that PFCC can occur in all aspects of the imaging value chain, regardless of whether patient and radiologist interaction actually occurs [7].

In a two-part series, we review two decades of experiences with implementing PFCC principles in a radiology department at an academic medical center. We highlight factors that are enablers and accelerators as well as potential barriers and obstacles encountered. We present a
series of real-world projects that engaged patients and families, along with the trade-offs, lessons learned, and actual outcomes. Because the hospitals in our health system changed names over the past two decades, we refer to the institution as “our institution.” In this first article, we focus on the beginnings of PFCC at our institution through two case studies. We study the design of a new children’s hospital (including the creation of a pediatric radiology department) and the renovation of a mammography suite. In the second article, we will study a series of smaller renovations in a radiology department and the lessons learned from each project. We believe that this approach will demonstrate that it is possible to implement PFCC in radiology. It will also encourage additional experimentation and the development of a larger body of evidence to propel PFCC adoption forward in radiology.

BUILDING A HOSPITAL WITH CHILDREN AND PARENTS

It is important to understand the time period when our institution began its PFCC journey. Angelica Thieriot formed Planetree in 1978, after a series of traumatic personal health experiences [8]. Planetree was named for the tree under which Socrates taught medicine to his students and was focused on a holistic and patient-centered view of medicine. Every aspect of health care was to be reevaluated from the patient perspective. In the 1990s, the pediatric community was exploring ways to include families in the care of chronically ill children [9-11]. It was in this environment that planning for a new children’s hospital began. The process was led by the medical center’s executive director, Patricia Sodomka [12], and was unprecedented. Sodomka was a hospital administrator but had a clinical background as a physical therapist. In 1993, the Family-Centered Care Steering Committee was formed at our institution [5]. Several parents of young children with chronic conditions were identified by nursing staff members to participate. As a first step, both staff members and families were trained to learn how to collaborate effectively. Three critical planning elements were identified; the first element was defining core values (Table 2). In the first year, hospital leaders convened a retreat at which administrators, clinical staff members, families, and both community and faculty physicians developed a philosophy and value statement for the new hospital. A second critical element was the expanded involvement of families. After the retreat, family members were appointed to all design committees for the new hospital. The Family-Centered Care Committee was appointed and charged with exploring ways to integrate family-centered care into all aspects of the new hospital.

Through these progressive interactions and collaborations, the hospital planners recognized the opportunity to move beyond naming patients to committees; by

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### Table 1. Patient- and family-centered care principles

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<th>Principle</th>
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<td>Dignity and respect</td>
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<td>Participation</td>
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<td>Collaboration</td>
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Source: Johnson [1].

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### Table 2. Statement of values

The Children’s Medical Center honors each child and family as unique and respects their values, needs, environments, cultures, resources, and strengths. We recognize them as integral members of the health care team. Therefore, we believe:

- In empowering all employees to be family-centered, in an environment where education and employee development is valued;
- In providing a healing environment:
  - that offers access to friendly, natural environments appropriate to the development needs of children,
  - where the daily needs of families are met in a comfortable and nurturing way,
  - where procedures are performed with respect for the dignity of children and families as well as the privacy and psychological well-being of individuals, and
  - that promotes family-to-family support and networking;
- In education and research programs for students and professionals that incorporate family-centered values;
- In the participation of community-based physicians, health care professionals, community service providers, families, and other members of local communities in carrying out the mission of the Children’s Medical Center;
- That the exchange of information with families and across disciplines in the hospital and community is essential to promote the health and well-being of children;
- That policies based on family-centered care concepts promote efficiency, cost effectiveness, quality care, and flexibility.
actively seeking meaningful and powerful roles for patients and their family members, the PFCC philosophy was integrated into organizational workflows that would occur in the new hospital. This group subsequently evolved into the Family Advisory Council, with a more expanded scope beyond the new children’s hospital that encompassed the entire medical center. The final element for planning the children’s hospital was engaging children. In 1996 Sodomka created the Children’s Advisory Council, also known as the Kid’s Architectural and Recreational Team, with a membership of current and former pediatric patients. In addition to assisting with design, they helped select a hospital logo, raised money, and published their experiences as patients.

In 1996, the new children’s hospital opened in Augusta, Georgia. This hospital, including the radiology department, was designed with patients (children) and their parents at the design table. Before the opening of a separate department, most pediatric radiology examinations were performed in the same areas as the adult examinations, with the exception of pediatric fluoroscopy, which had its own dedicated room. The new pediatric radiology department concentrated pediatric x-ray, fluoroscopy, ultrasound, and CT in one area and had color schemes chosen by children and families. A separate pediatric radiology registration and waiting room was also created.

When the hospital opened, another significant change was made in “visiting hours.” Before opening the hospital, family visits were limited by time of day, number of people, visitor age, and whether care activities such as rounds were occurring on the units. When the hospital opened, there were no visiting hours because families were no longer guests or visitors but had become partners in the care process. More than 20 years later, we still do not have visiting hours.

The results for the new hospital with a PFCC focus were a staggering 40% market shift in favor of the new children’s hospital over the period from 1996 to 2003. With the clear return on investment from using PFCC to build a children’s hospital, leadership wanted to expand the application of this approach to other areas within the health system. In 1997, a strategic plan to implement PFCC in the adult hospital was written that included the creation of the Adult Family Forum, which eventually became the 35-member Partners Advisory Council. In 1998, Julie Moretz was hired as the first director of family services development. Progressive leaders in other parts of the hospital saw the impact of PFCC on pediatric care and began to work with Sodomka and Moretz to introduce these principles in their clinical environments.

The application of PFCC principles to the neuroscience service at our institution led to the redesign of the neuroscience inpatient service in 2003. Again, the results were positive [5]:

- Increased patient satisfaction from the 10th to the 95th percentile
- Decreased length of stay of neuroscience admissions by 50%
- Reduced medical error rate on the neuroscience inpatient service by 62%
- Reduced staff turnover rate from 7.5% to 0%, with a waiting list of staff members who wished to transfer to this unit

In 2006, our institution was featured in “Hand in Hand,” an episode of the PBS national series “Remaking American Medicine” [13]. In 2009, our institution (then Children’s Medical Center) was named a national model in PFCC by the Picker Institute [14].

Lessons Learned

- Leadership commitment and champions at the outset are essential.
- Bring patients and family members into the discussion early in the planning process.
- Train staff members and families to work together on projects; don’t assume that they know how to do it.
- Demonstrate and communicate early successes so that they can be replicated by others.
- Identify and quantify the return on investment of PFCC to encourage further adoption.
- PFCC is a process, not a destination.

WOMEN’S HEALTH DESIGNED BY WOMEN

In 2001, when screening mammography had backlogs nationwide, most hospitals approached this as a radiology problem and hired more staff members. Sodomka approached the problem in a unique manner. She asked the radiology chair’s permission to view this as a systems problem rather than a departmental one. This would require that radiology give up control of how to solve the problem and that other stakeholders be included in discussions. A work group was convened, but it was not called the Task Force on Mammography Backlog. It was named the Breast Health Work Group [15], and it consisted of a very diverse group (Table 3). By this time, there were many patient advisers who had been recruited and trained; patient advisers with interest in breast health were invited to participate. Counterintuitively, the group
studied breast health from puberty to the end of life, not mammography. By exploring how mammography fit into the institutional strategy for breast health, it was discovered that there was no strategy for breast health. By the time the design was completed, the Breast Health Work Group had evolved and was focused on more than just addressing a clinical backlog. The initial proposed renovations focused on high throughput and low cost to address the backlog and were centered on technologist and radiologist workflow. This design was rejected by the patients, staff members, and physicians because of its impersonal nature.

In the work group, there were many discussions about the mammography experience, including the pain and discomfort of breast compression. The second proposed design concept attempted to make a bad experience more tolerable. The architect completed the design and then “tested” her design by walking through mammography as a patient would. Through this process, she saw the benefits of the changes being proposed. Her journey in the patients’ steps included changing into a gown and sitting at the mammography unit. Through the planning meetings, she had learned that she met age criteria to undergo screening mammography and could refer herself, so she underwent an examination as part of her walkthrough. After dressing and leaving mammography, she felt that her design failed to capture her experience. She had done something good for herself, and her design simply minimized a bad experience.

In the third major proposed design, a patient-centered approach was reflected in a concept that put the patient in the role of a visitor to a high-end spa, and mammography was a service that made patients feel as if they had done something good for themselves. The Breast Health Work Group continued to evolve and developed new terminology. “Cocooning” describes how a patient should feel at every step in the care process, starting with the greeting at registration and the walk to the dressing room. By the time the patient reached the mammography unit to be imaged, she should feel safe, with less anxiety about the procedure. Mammography should be a “sacred space” where women felt safe and protected, not exposed. The Breast Health Work Group did not recommend the replacement of any costly imaging equipment, but the clinical space was remodeled and the workflow redesigned to reflect this patient-centered culture change.

This design process was long and required patience as new designs that incorporated feedback replaced previous versions. This was an iterative process, and we had to be willing to not accept a first design or subsequent designs we were not happy with. It was the third major redesign that was implemented. Changes in mammography included the following:

- More doors were installed to seal off hallways and create a “sacred space.”
- Changing rooms included mirrors and counters.
- Changing rooms were redesigned to allow better storage of clothes on hangers.
- New workflow was created for male spouses to get to biopsy rooms while protecting the privacy of other patients.
- A bathroom was installed off of the waiting room to remove the need for nonpatients to use restrooms inside of mammography.
- A dedicated educational space was created, which also served as a room for radiologists and other physicians to talk with patients and families.

At the systems level, this new approach resulted in the elimination of the backlog, offering of same-day or walk-in mammography service, and an increase in patient satisfaction from the 40th percentile to the 74th percentile initially and later to better than the 90th percentile [5]. The mammography renovation did not include all of the recommended changes. Over several years, some additional changes that had been recommended by the Breast Health Work Group were made. Not all of the group’s recommendation have been implemented. By leveraging human-centered design principles used in other industries in health care, radiology departments can reap the return on investment of this business approach [16].

**Lessons Learned**

- Ask patients what is important to them and try to address that in the design change.
- It is important to actually start making changes, even if they are not perfect or the project will not accomplish everything that is wanted at that time.
Every renovation or upgrade is an opportunity to ask patients and families what matters most to them and reinforces culture change for all members of the care team.

Being more inclusive and taking more time at the beginning of the process may yield more satisfactory results at the end of it.

CONCLUSIONS

PFCC is a long journey; it is part of a successful strategy that incorporates inclusive management, fiscal responsibility, and process improvement. Using PFCC principles required us to accept that the physicians, technologists, nurses, and other staff members were not the experts in the patient experience. To learn how to improve the patient experience, we had to lower our guard and expose our imperfections and flaws to people outside of the radiology family. Expertise in patient experience is a patient core competency. We had to invite all of our customers to the design table: referring physicians, patients, families, hospital administrators, staff members, and so on. The ultimate value was not the destination of a new facility or a renovated space. The real value was the lowering of barriers and breaking down of silos that occurred during the journey. The value was in the relationships formed as part of the process. This resulted in the creation of larger and stronger teams that worked together and communicated often. These “microsystems” occurred in many environments, including on inpatient units and surgical teams in the children’s hospital. In radiology, we saw teams work together around a specialty (pediatric radiology) and a modality (mammography). These teams did not meet at regular, scheduled intervals; they worked together and communicated often.

Critical ingredients to a successful project included leadership willing to constructively expose weakness in open forums and the early involvement of patients, families, and other stakeholders, including staff members. None of these critical precursors required a particular governance structure, facilities, or governance. It meant placing patients’ interest above our own egos.

By viewing each project as a step in a long journey, the project does not have to fix all problems or meet all needs. All journeys begin with a first step, and the first step is the hardest one to take. Yet this must be balanced with the ability to not settle for something that will not work.

It is important to create an environment in which anyone can look at a proposal and say that we can do better and provide constructive feedback.

It will be hard to put patients at the center of health care if we are standing there ourselves.

TAKE-HOME POINTS

- If you want to know what is important to patients and their families, ask them. Building patients into operations ensures that their voices are continually heard.

REFERENCES

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