Involving Patient and Family Advisors in the Patient and Family-Centered Care Model

Nancy Warren

Many health care organizations, including government and private agencies, have embraced the goal of providing patient- and family-centered care. The thrust of this model of care is to involve patients and families in their own health care decisions and treatments. The Institute of Medicine (2001) recognized the value of this model in identifying patient-centered care as one of six points for health care redesign and one way to provide care “that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (p. 40). Knapp (2006) subsequently suggested use of a patient- and family-centered care model can help hospitals raise their patient satisfaction scores as an indicator of how well a health care organization is serving its customers.

Planetree, Inc., and the Institute for Patient- and Family-Centered Care (IPFCC) have been two of the most prominent pioneers in developing and promoting patient- and family-centered health care (see Figure 1). To develop a more patient- and family-centered health care setting, both organizations promote the use of patient and family advisors. Planetree integrates patients and family members in focus groups and patient and family advisory councils (Frampton et al., 2008). IPFCC offers multiple publications addressing the importance of and strategies for incorporating patient and family advisors as well as advisory councils in health care settings.

For health care providers, implementing patient- and family-centered care involves a shift from “doing for” to “doing with.” Implementation also requires creating partnerships among physicians, nurses, patients, and families. The use of patient and family advisors in the health care setting can model “doing with.” These advising partnerships also educate providers about ways health care can work better for patients and families, as well as the facility as a whole.

Planetree and the Institute for Patient- and Family-Centered Care

According to its mission statement, “Planetree is a non-profit organization that provides education and information in a collaborative community of healthcare organizations, facilitating efforts to create patient-centered care in healing environments” (Planetree, 2012, para.15). The Planetree model was developed by Angelica Thieriot in 1978. Hospitalized with a rare viral infection, Thieriot found her hospital stay to be cold and frightening. Her inspiration was to create a more healing setting where loved ones could be with the patient in a warm and caring environment. Soft colors, lighting, home-like fabrics, and music are important in designing the Planetree rooms and common areas. In developing the model, Thieriot also wanted to assure ample opportunities for patients and families to learn about their illness in order to foster participation in their care. Planetree organizations are committed to providing understandable information to patients and to allowing them to make decisions that affect their well-being. The Planetree model focuses extensively on what patients and families want. In this regard, Planetree settings also are very open to alternative therapies, as patients may desire (Planetree, 2012).

Founded in 1992, the Institute for Patient- and Family-Centered Care (IPFCC) is a not-for-profit organization offering health care providers and institutions a wealth of information and practical guidance related to patient- and family-centered care. The IPFCC has developed core guiding concepts for patient- and family-centered care. IPFCC encourages an array of family-centered practices, including open visitation; family presence during all procedures; patient, family, and staff communication and collaboration in care plan development, multidisciplinary rounds, and bedside handoffs between nurses; information availability in patient and family resource centers; and the use of patient and family advisors in performance and safety improvement efforts (IPFCC, 2012).
Understanding the varied and useful roles of patient and family advisors in health care settings, as well as reviewing advisors’ successful contributions, can lead to implementing advisory roles for patients and families in any organization or institution.

What Is a Patient (or Family) Advisor?

Patient and family advisors are former clients of an organization or institution who have become re-engaged in a new, advisory capacity. Their experiential knowledge as a patient or family member receiving care in that setting offers the institution a unique and important perspective. They are able to relate their patient and family experiences in such a way that meaningful changes can be made to improve the next patient’s experience in the organization (IPFCC, 2012). Patient and family advisors serve in varied roles:

...[as] members of task forces, advisory board members, program evaluators, co-trainers for pre-service or in-service sessions, paid program staff, paid program or policy consultants, mentors for other families, grant reviewers, participants in a needs assessment process, reviewers of audio visual and written materials, group facilitators, witnesses at hearings, advocates, participants in focus groups, members of committees hiring new staff, fundraisers, members of boards of trustees, participants at conferences and working meetings, participants in quality improvement initiatives (Jeppson & Thomas, 1995, p. 3).

How Have Patient and Family Advisors Contributed in Different Settings?

Often busy health care providers cannot imagine fully the patient’s point of view. Former patients and their families now partner with health care staff in advisory groups to share their expertise as care recipients in order to address patient satisfaction, quality, and safety concerns. By sharing stories of real life experiences in the hospital and after discharge, patients and families are able to help health care professionals see those experiences from a different vantage point. As a consequence, providers’ sensitivity can be enhanced, and other patient- and family-centered improvements can be made (Callery, 2004). The following examples illustrate some roles of family advisors in developing plans related to a hospital’s physical environment; addressing clinical concerns; implementing family-centered care policies; serving as patient advocates and customer relations specialists; offering patient and family support; providing staff education and development; and participating meaningfully on multiple levels across an institution.

Patient and Family Advisors and a Hospital’s Physical Environment

At Bronson Methodist Hospital (Kalamazoo, MI), patient advisors have assisted in decisions such as whether to have curtains or glass doors between the nurses’ station and the neonatal intensive care beds (McCarthy 2007). Bronson Hospital leaders also convened multiple focus groups of patients and family members to provide input into the design plans (Morin, 2008). On a larger scale, administrators at Mid-Columbia Medical Center (The Dalles, OR) decided to renovate the whole facility using the Planetree model. The architect spent a night in a patient room to experience personally what it was like to stay there.

Patient and Family Advisors and Clinical Care

As one example from some cancer centers, patient and family advisors provide counseling to increase peers’ awareness of methods to manage pain and improve patients’ overall comfort. They also have improved pain management for patients through participation in quality improvement teams (Foley, 2001). According to Muething (2007), family advisors at Cincinnati Children’s Hospital suggested staff walk the path families take through the emergency department (ED). This exercise increased staff members’ understanding and sensitivity regarding the patient and family experience in the ED.

Patient and Family Advisors and Designing Family-Centered Care Policies

As one illustration of the importance of this role, a clinical nurse consultant from the Children Hospital (Westmead, New South Wales, Australia) described an exciting initiative to develop a collaborative care model for parents and nurses. Unfortunately, this initiative was not as successful as was hoped, in part because key stakeholders (parents) were not involved in the planning. Subsequently, leaders at the institution revised the plan with the input of patients and families. The resulting model is a better reflection of what is wanted by all parties (Kelly, 2007).

Similarly, at The University of Central Lancashire in the United Kingdom, a health care consumer group was formed to ask parents their perceptions of how family-centered care was practiced in the local trusts of the National Health Services. Many parents reported dissatisfaction about feeling obligated to provide a large part of the direct care for their children. Parenting in public also made many parents feel uncomfortable. As a result, policies were changed and parents now are asked about their preferred level of involvement. Additionally, each parent is invited to document observations regarding the child’s progress in the medical record. Because of the success of involving the consumer group in this project, some parents have been invited to the local university to teach nursing students about their experience as parents on a children’s ward. Parent input has been added to the curriculum in order to improve sensitivity in newer nurses (Sawley, 2002). Many limiting assumptions can be made by health care personnel, and obvious problems can be overlooked, if the
patient and family perspective is not represented in the planning process as demonstrated in this example. Clearly, including patients and families in the initial phases of planning family-centered programs and initiatives can be critical in assuring success.

**Patient and Family Advisors and Family Support**

A study using qualitative methodology found families with a loved one in the intensive care unit (ICU) rate support provided by former ICU family members high in importance during their stay (Sacco, Stapleton, & Ingersoll, 2009). Family advisors are able to share their experience from the ICU, when transferring to a rehabilitation setting, and then in the transition to ongoing care at home. This family-to-family advice and support help family members to cope better and participate more effectively in the care of a loved one. Findings also suggested a patient progresses better in these situations.

Patients, family members, and staff benefit from the use of family advisors. At Strong Memorial Hospital, University of Rochester Medical Center (Rochester, NY), family-to-family support is given in meetings which include a nurse manager, staff nurses caring for the patient, a social worker, a chaplain, and the family advisor. Meetings focus not on disease-specific or technical information but only on the family’s experience. Support also is given in one-to-one telephone conversations between family members and advisors. By participating in these family support meetings, staff members learn about the patient and family’s experience of the ICU and the transition to other levels of care. Participation has been found especially helpful for new nurses who may have less time to focus on a family’s needs when they are learning clinical and technical aspects of their roles (Sacco et al., 2009).

Additionally, the Parent Support Program at the Center for Children with Special Needs at Children’s Hospital and Regional Medical Center (Seattle, WA) employs a family member, currently the mother of two girls with health concerns, in a paid support role. This employee organizes other parent volunteers to mentor parents caring for children with special needs (Williams, 2007). Another family advisor from the Washington, DC, area began her involvement as one of several parents from the neonatal intensive care unit who created a parent-to-parent support group. That participation led to other important advisory roles, including membership in the hospital ethics committee. She has participated in efforts to educate clinicians about family-centered care, including pediatric end-of-life care, through publications, consulting, and program development. She is now co-editor of a column on family issues in the journal Pediatric Nursing. In addition, she has served on the U.S. Food and Drug Administration’s Pediatric Advisory Committee (Dokken & Ahmann, 2006). At the University of Utah, the neonatal family advisor also began as a volunteer and is now a paid staff member whose role is to coordinate family support services throughout the children’s hospital. Becky Hatfield has received awards and recognition for this role, which she began over 20 years ago (National Perinatal Association, 2010).

**Patient and Family Advisors and Staff Education and Development**

Bronson Methodist Hospital (Kalamazoo, MI) received the 2005 Malcolm Baldrige Quality Award for promoting patient- and family-centered care. Staff at this institution have benefited from a variety of patient and family input. Hospitalized patients are asked about care preferences, and patient and family advisory meetings are held monthly. These forums have led to implementation of four staff behavioral expectations: information sharing, dignity and respect, collaboration, and participation. The hospital’s staff report feeling more empowered to do their jobs because of receiving patient input (McCarthy, 2007). At the Medical College of Georgia (Augusta, GA), patient and family advisors serve as faculty to medical students. Discussing with medical students their experiences as parents of gravity ill children helps facilitate honest communication between parents and physicians about children who may die. Based on their experiences, family faculty members also are able to teach staff how to talk to parents in these situations (Dokken, Moretz, Black, & Ahmann, 2007).

**Patient and Family Advisors and Multiple Levels of Involvement**

Partnerships exist between doctors and nurses. A very important partnership also exists between patients and families and a hospital. At Children’s Hospitals and Clinics of Minnesota, patients and family members are involved on many levels and in many activities system-wide. For example, a family advisory council fields recommendations and concerns raised by patients and family members. Council members also assist in developing, implementing, and evaluating services and facilities of the entire hospital system, and all major initiatives and policies are contributed to or reviewed by the council. The council has created safety guidelines for a play area, helped improve family access to post-anesthesia areas, made meals available to visiting family members, raised funds, and gave input to the design of a new hospital tower. Additionally, council members have been involved in educational activities for hospital leaders, staff, managers, students, and new employees (Landis, 2007).

Another institution involving patient and family advisors on multiple levels is the Dana-Farber Cancer Institute (Boston, MA). Shortly after two sentinel events involving medication errors, leaders at the institute decided to merge with Brigham and Women’s Hospital. However, the proposed merger caused an outcry from the public. After several patients were invited to participate in the planning process, the public was convinced of the benefits of the merger. A permanent patient advisory system developed as a result of this experience, including adult and pediatric patient and family advisory ...
Professional Practice

councils. Leaders at the Dana-Farber Cancer Institute have used advice from IPFCC in recruiting and selecting council members who participate in work groups, performance improvement projects, planning committees, and quality and risk committees. They also help design education for the hospital staff. Patient and family advisors have become so integrated into the hospital's structure that patients, families, and staff now consider each other equal collaborators in care planning (Ponte et al., 2003). This experience offers a good example of response to the Institute of Medicine's (2001) call for patients to be in control of their own health care.

The University of Pittsburgh Medical Center also has experienced exciting outcomes as a result of involving patients and family members more fully in all aspects of its health care system. A complete methodology for implementing patient- and family-centered care using lean concepts has been employed at the center (DiGioia, DiGioia, DiGioia, & The Innovation Center, 2010). One effort involves following a patient from parking lot entry through the entire hospitalization to discharge. Patient and family observations and feedback are recorded and compared to staff and advisors' perceptions of an ideal experience. Any differences between actual and ideal are subjected to a performance improvement process. A full description of their efforts and successes, including practical guides and tools for involving patients and families, can be found online (www.pfcc.org).

Testing the Concept with a Patient and Family Advisory Council

While it may appear to be easy for health care providers to make changes and implement patient- and family-centered care on their own, something is missing until the process becomes a collaboration with patients and families. Inviting patients and families to help in the implementation of the care model requires a new way of thinking. Partnering with patients and family advisors may be a very different approach for many health care providers.

Initial work with patient and family advisors may be uncomfortable because health care providers are demonstrating their vulnerability and potential fallibility by asking for input or help. There may be hesitation to initiate open discussion of approaches to care with patients and family members. Fear of litigation and poor public reports may be factors, and they may be concerned about potentially losing some control of the care experience.

Inviting patients and family members to be involved in process improvement at an organization may be uncomfortable for some staff members. As demonstrated earlier, some institutions have made changes without patient input and found they were not what were wanted by the customer. Even though some vulnerability may be demonstrated to patients and families by asking for help, this type of collaboration will create a more successful patient- and family-centered care model.

Several strategies can help health care providers work effectively with patient and family advisors despite any initial discomfort. Talking with staff in settings that already have a patient and family advisory council can demystify the process. In addition, observation of another patient advisory council in action may offer concrete ideas about how a council functions (Halm, Sabo, & Rudiger, 2006).

Another way to test the effects of a patient and family advisory body is to form a work group. This relatively informal arrangement can involve just a short commitment period for the staff and advisors, and can offer vital feedback about possible effectiveness. Beginning collaboration as a work group may be aided by undertaking a specific, time-limited project with clearly articulated, measurable goals. Starting with a well-defined project focused in a selected inpatient or outpatient setting can reduce potential roadblocks to success. In addition, use of a specific method or process for problem solving, such as Plan, Do, Study, Act (PDSA), can facilitate success. Initial projects for a patient and family advisory council might include input on relevant issues, such as patient safety, quality, and patient satisfaction (Leonhardt, Bonin, & Pagel, 2008).

The group may work on only one or two specific tasks and then be done. In the process, some discoveries might be made about the effectiveness and rewards of working together. In addition, patient and family leaders may emerge who could become chairs of future patient and family advisory councils (IPFCC, 2010b). Individual staff members also may demonstrate a particular gift for working collaboratively with patients and family members and/or advocating for continued joint efforts.

After work group activities have been completed, a more formal patient and family advisory council may be formed. The IPFCC has published materials detailing how to plan for, recruit, train, and then provide ongoing support to patient and family advisors. Many of their forms and materials can be customized for use in an organization. Key steps to consider in starting a patient and family advisory council are listed in the IPFCC's publication Patient and Family Advisory Council: A Checklist for Getting Started (IPFCC, 2010b) (see Figure 2).

Developing a Formal Patient and Family Advisory Council

When leaders of a health care institution are ready to develop a formal patient and family advisory council, a number of factors should be considered related to recruiting and training advisors, running successful meetings, and celebrating success. Ethical and risk concerns also must be addressed.

Recruiting and Training Advisors

IPFCC (2010b) suggests 12-15 advisors as an appropriate number in many cases; having one staff member for every four advisors also is suggested. Several approaches can be
Involving Patient and Family Advisors in the Patient and Family-Centered Care Model

FIGURE 2.
Key Steps in Starting a Patient and Family Advisory Council

- Assure support from the senior team in the organization.
- Consider the following questions:
  - Who has an interest in forming the council?
  - What kind of supportive people or structures will be needed?
  - What financial backing is available?
- Determine which staff members from various disciplines should participate.
- Anticipate potential challenges or barriers and develop plans to address them.
- Gather potential projects for the first few meetings.
- Decide when to have the first meeting.
- With council members:
  - Define and record the purpose of the council.
  - Decide where and when the meetings will occur.
  - Agree on ground rules and other operational guidelines, including:
    - Attendance requirements.
    - Length of service for staff and advisors.
    - Plans for members to rotate off the council at various times rather than all at once.

In one hospital, staff facilitators interviewed and selected more advisors than they thought would be needed for the council in order to accommodate expected rotation and non-attendance. Advisors were offered 2-year terms. However, actual participation decreased and recruitment of more advisors was necessary after about a year (Halm et al., 2006).

Caution should be taken not to select as advisors individuals who have a single complaint or who are still too emotional to be able to participate comfortably in meetings. Also, depending on the roles they will perform, patient advisors may provide communication to and from patients, staff, and administrators. Therefore, they should be chosen for their ability to offer the generic patient voice within their area of experience with the hospital (IPFCC, 2002).

Once selected, advisors will need orientation to their specific roles as well as ongoing training for effective communication and work within a group (IPFCC, 2002). Roberson (2008) reported a criminal background check is performed for all potential advisors at the Medical College of Georgia. In addition, advisors who will be in patient areas undergo the employee physical examination.

If advisors are unpaid volunteers, assistance with expenses (e.g., child-care, transportation, parking) may be warranted. A small stipend may be provided for attending meetings. When there is representation from all socioeconomic classes served by the organization, it may be difficult for some to be able financially to participate unless some of the financial burdens and barriers are removed (IPFCC, 2012).

Running Effective Meetings

If working with patient and family advisors is a new encounter for staff members, orientation to the experience and the staff member role is needed. Additionally, training related to group communication methods is advised. Jeppson and Thomas (1995) suggested this as an orientation exercise to promote “elements of collaboration” (p. 11). These elements include mutual respect for skills and knowledge, honest and clear communication, understanding, and empathy. Consideration of meeting time and location should involve attention to transportation concerns and convenience for advisors. Meeting at the well-known health care setting may be more comfortable and accessible. Some councils have found that daytime hours work best for meetings, while others meet in the evenings to accommodate advisor work schedules. McCarthy (2007) identified several approaches to scheduling meetings; for example, one group schedules advisory meetings every 2 months early on a weekday, while another meets for 90 minutes every month. Simple refreshments of beverages and cookies often are provided.

Strategies to reduce feelings of intimidation between patient and family advisors and health care personnel are important to assure productive working relationships. Having council members use first names during meetings and avoiding the use of professional titles can help with this. Arranging tables and chairs in a circle symbolically suggests equality. Advance agreement on ground rules for meeting procedures can eliminate potential points of disagreement or confusion. For
example, one council is committed to starting and ending on time, limiting discussion to the current topic, and assuring only one person speaks at a time. As a practical strategy, Halm and colleagues (2006) suggested the group facilitator may need to request discussion be continued in another forum if one member dominates the conversation. Facilitators also will need special sensitivity to assure meetings do not become focused on one person’s experience. If advisors seem to need professional assistance, they can be referred to an appropriate resource outside the council (IPFCC, 2002).

In order to engage all members and validate their importance to the group, each participant can be given work to complete for the next meeting (Leonhardt et al., 2008). If needed, sub-committees can be formed to address items that need research outside the meeting. Positive recognition is particularly important in validating the contributions of patient and family advisors.

Meetings should be run formally with agendas, minutes, and bylaws (IPFCC, 2002). In one facility, the patient and family council meeting is chaired by three staff facilitators, but the meeting belongs to the members (Halm et al., 2006). The council facilitator role includes scheduling the meeting, inviting appropriate speakers, and mailing the agenda to all members 2 weeks before the meeting.

A facilitator will ensure the meeting runs smoothly and remains focused. Each topic of discussion should be allowed at least 15 minutes (see Figure 3 for possible agenda items). To allow time for all topics, more complicated issues should be placed at the end of the meeting. Sometimes guest subject matter experts are invited to meetings; for example, if food concerns arise, a diettian may be asked to attend. The council also may find it beneficial to allow time for discussion of members’ new concerns at the end of each meeting. A facilitator also takes minutes to document the council’s suggestions. One group found using informal, cartoon-embellished minutes to be less threatening to participants than more formal minutes (Sawley, 2002).

**Recognition of Accomplishments**

In most settings, an advisory council only makes recommendations and not binding decisions. Because decision making authority typically remains with hospital leaders (Halm et al., 2006), meeting minutes should be distributed to persons in authority. Widespread distribution of minutes across the organization also allows everyone to be informed about the council’s work; in addition, this exposure contributes to group credibility (IPFCC, 2002). The group also should be given feedback about any of its recommendations that are considered and implemented. This validates the group’s contributions and spurs further sharing of new ideas for improvement (Leonhardt et al., 2008).

**Ethical and Legal Concerns**

The Healthcare Information Portability and Accountability Act (HIPAA) must be observed in all dealings with patients and families. A common strategy is to have advisors receive instruction (written, verbal, or both) regarding the HIPAA rules, and then sign an agreement to follow these rules. In particular, advisors providing peer support should be trained in HIPAA compliance. Advisors who are members of risk, safety, and quality committees have a legitimate need to know about specific patient cases. As long as HIPAA training has been received, they can be considered fully functioning members of the committee for related discussions. Hospitals report patient and family advisors understand and comply with the intent of HIPAA (IPFCC, 2010a).

Regarding potential litigation arising out of revelations at meetings, one institution found that concerns about increased litigation were not justified. Johnson and colleagues (2008) reported that while many academic hospitals who do not have patient and family advisors reported annual increases in litigation expenses, the Medical College of Georgia Health System (Augusta, GA) actually experienced a decrease in such expenses from 2001 to 2006.

**Conclusion**

In health care settings around the globe, patients and family members share their unique perspectives to help organizations and institutions with improvements in honest, accurate, timely information sharing; shared decision making that respects patient wishes; and smooth transitions between levels of care, including the transition to self-care. Use of electronic communication and other communication and documentation improvements have been made with patient input. Improved pain management and other timely, tailored, expertly managed quality advances have occurred when physicians and nurses hear patient stories that bring urgency to a situation. When patients act as faculty to medical and nursing students, increased attention is placed on relieving fear and anxiety. Facilities that utilize patient and family advisors are experiencing decreased length of stay, and improved reimbursements and patient satisfaction. Patient and family advisors can continue to be strong allies in ongoing performance improvement efforts. Perhaps even more important-

---

**FIGURE 3.**
Common Topics Addressed in Patient and Family Advisory Councils

<table>
<thead>
<tr>
<th>Concerns addressed by the patient and family council typically address one of the following seven areas:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Philosophy of care</td>
</tr>
<tr>
<td>2. Environment and design</td>
</tr>
<tr>
<td>3. Personnel practices</td>
</tr>
<tr>
<td>4. Information and decision making</td>
</tr>
<tr>
<td>5. Patient-family support</td>
</tr>
<tr>
<td>6. Charting and documentation</td>
</tr>
<tr>
<td>7. Patients and families as advisors</td>
</tr>
</tbody>
</table>

Source: Halm et al., 2006
ly, involving advisors in health care systems encourages treatment of the whole patient as he or she would want to be treated. By involving patients and families in advisory roles, providers are able to modify care based on patient needs rather than make the patient accept one model of care (IOM, 2001). As Solomone (2007) noted, patient- and family-centered care is not a destination, but a journey. Patient and family advisors can teach health care providers that it is a journey most successful and rewarding when taken together.

REFERENCES


