Partnering with Patients’ Families

Three ways hospitals can enhance family members’ involvement in health care.

When patients can’t make their own health care decisions, hospitals and clinicians often rely on family members. But just as often they miss important opportunities to involve family members in routine, day-to-day care. As one patient put it:

I had a double mastectomy, and it would have been nice to know that my daughters could have learned to do the dressing changes while they were here and before I went home. We went home and it was trial and error.

Compare that with the experience of a man who was quite involved in his hospitalized wife’s care:

They showed me how to adjust things because they knew I would have to do this at home. They explained things to me. I was more comfortable during her recovery experience. They passed on their knowledge, they took the time.

Truly patient-centered care extends the role of family members beyond the bounds of visitation and support. (We use the term family members to refer to anyone, including friends, whom the patient considers family.) Patient-centered hospitals welcome family members not only by removing barriers such as restrictive visiting hours but also by engaging them at the bedside as members of the care team. The book Putting Patients First, which explains in detail the Planetree model of patient-centered care, describes patient and family involvement as “a complex, multifaceted, and dynamic concept, which evolves in the context of a true partnership.”

Many studies have shown the benefits of including family members in care in inpatient and outpatient settings, especially when there’s an emphasis on hands-on participation. Findings include an increase in patient satisfaction and better overall perceptions of care, a decrease in the number of patient complaints and the rates of medical error, and improved adherence to treatment and self-management. And while family members in no way replace nurses, anecdotal evidence suggests that family involvement might ease the demands on nurses.

In this article we’ll describe three ways in which “true partnerships” among patients, family members, and providers can be cultivated: care-partner programs, family-initiated rapid response teams, and family presence during resuscitation and other procedures.

CARE PARTNERS AT GOOD SAMARITAN HOSPITAL

One approach to engaging family members in a patient’s care is a “care PARTNER” program. In place at a number of hospitals and medical centers nationwide that have adopted the Planetree model, the program aims to enhance care by involving a person the patient chooses to participate in care during hospitalization. The care partner is much more than a consistent visitor; rather, she or he is a member of the care team and accepts agreed-upon responsibilities to help meet the patient’s needs—physically, psychosocially, and spiritually.

Such a program has been in place at Good Samaritan Hospital (GSH) in Kearney, Nebraska, since 2002, when a pilot test was launched on the inpatient orthopedic–neurosurgical unit. (It has since expanded to other medical–surgical and critical care units and is in development for

This is the sixth in a series of articles from Planetree, an international nonprofit organization founded in 1978 that’s “committed to improving medical care from the patient’s perspective.” For more information, go to www.planetree.org.

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well as the patient’s needs while hospitalized and after discharge. Using the Planetree framework, the nurse trains a family member in routine tasks: providing personal care (baths, massage, nail care, shaving), changing simple dressings, monitoring intake and output, helping with walks or wheelchair trips, ensuring comfort nonpharmacologically, offering therapeutic distractions (such as reading aloud and assisting with phone calls), planning discharge, acting as the spokesperson to visitors, and serving as the liaison between family and physician. Initially, the nurse and the care partner perform procedures together, but the nurse maintains responsibility for the patient’s care. The partner receives a journal to document the care she or he provides, and the primary nurse reviews and documents activities in the medical record, as appropriate, and a care partner’s involvement is noted in the care plan. The partner wears a badge so that all staff can include the partner in care and permit overnight visits. The partner also receives discounts in the cafeteria and gift shops and is considered a visitor with regard to hospital policies and liability.

Overcoming barriers with favorable outcomes. At first, the care-partner program at GSH was not universally embraced. Nurses feared that orienting and supporting care partners would increase demands on their time, and physicians expressed concern that patient outcomes could be compromised. Inconsistent approaches for communicating with patients about the program also hindered participation. One nurse might mention it to patients during the orientation process, while another might not mention it at all. In general, the organization didn’t have the experience needed to welcome family members to the care team. Several barriers would have to be overcome.

The nurses’ concerns about being overburdened were addressed with education, support, and validation; over time, nurses have found that as care partners become more adept at participating in care, their workload is lessened. (Patient assignments do not change for nurses who train and oversee care partners.) Developing a formal, standardized program with supporting tools and guidelines was essential. GSH has found that placing materials about the program in lobbies and gathering places, sharing them during admission, and including the program’s availability on the Patient Rx (the patient’s order sheet) as a reminder to nurses helps to ensure consistency. The nursing director’s support and monitoring of participation rates has been important, as well.

Providing space for care partners was another issue to be addressed. When the program started, GSH still had many use on the inpatient psychiatric unit.) The program was a response to family members’ statements that they felt “underutilized and inconsequential”; some said they wanted to provide more meaningful support. They also said they felt that they were “in the way” and “a bother to busy nurses” if they asked questions or requested care. Also, because physicians reported being frustrated by family members’ repeated questions and phone calls, the program sought to improve family–physician communications.

A “family care team,” a subcommittee of the hospital’s Planetree Steering Committee, oversaw the development and implementation of this model. First, the team developed materials inviting family members to participate in the program. These materials describe the program, list activities the partner might participate in, explain how the partner is trained, and provide a competency checklist.

A care partner is involved in care only according to her or his interests and abilities, as well as the patient’s needs while hospitalized and after discharge. Using the Planetree framework, the nurse trains a family member in routine tasks: providing personal care (baths, massage, nail care, shaving), changing simple dressings, monitoring intake and output, helping with walks or wheelchair trips, ensuring comfort nonpharmacologically, offering therapeutic distractions (such as reading aloud and assisting with phone calls), planning discharge, acting as the spokesperson to visitors, and serving as the liaison between family and physician. Initially, the nurse and the care partner perform procedures together, but the nurse maintains responsibility for the patient’s care. The partner receives a journal to document the care she or he provides, and the primary nurse reviews and documents activities in the medical record, as appropriate, and a care partner’s involvement is noted in the care plan. The partner wears a badge so that all staff can include the partner in care and permit overnight visits. The partner also receives discounts in the cafeteria and gift shops and is considered a visitor with regard to hospital policies and liability.

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When a family member hears about the care-partner program at GSH, she or he also learns about a recent innovation in patient safety at the hospital—the family-initiated rapid response team (FIRRT). It’s commonplace for hospital staff to initiate a rapid response team when they see a patient’s condition deteriorating, but the FIRRT enables those closest and most familiar with the patient to call for help. Patients and families were involved in the planning and piloting of Condition H (for “help”) at the University of Pittsburgh Medical Center.8 Traditional rapid response procedures such as Condition A (for “arrest”) or Condition C (for “critical”) are called by providers, but patients or family members call a Condition H when they believe immediate medical attention is needed.

Having such a process in place acknowledges that family members possess a singular expertise: they know the patient and just might notice changes before nursing or medical staff do. At GSH, FIRRT calls are rare because of frequent nursing rounds and strong relationships among family, patients, and staff. But when a call is made, a four-person team responds: the unit’s primary RN, an ICU nurse, a respiratory therapist, and a nursing supervisor. While the hospital hasn’t analyzed FIRRT data, evidence of the first five years of use at GSH suggests that the most common reasons calls are made include change in respirations, change in mental status, and insufficiently managed pain.

Other hospitals are using such teams as well. For example, the patient-safety implications of semiprivate rooms. The availability of private rooms has been a welcome change, but if private rooms aren’t available, nurses should ensure that care partners have enough room for activity and rest. A central gathering area can provide a spot for needed respite.

Patients and care partners have expressed satisfaction with the program. They appreciate the fact that patients often go home sooner because the family member receives training. Nurses have said that there are fewer call lights to answer, patients are less agitated and more alert, and there are fewer adverse events (such as falls and delays in care) when a care partner is present. And physicians have said the program has reduced the number of calls they receive from family members.

GSH has changed the way it conducts surveys in recent years, and so a before-and-after comparison of patient-satisfaction scores can’t be made. But a review of the hospital’s performance on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey suggests the positive impact that a care-partner program can have on outcomes. An analysis of GSH’s HCAHPS performance shows that on most outcomes measured the hospital exceeds national averages, especially on issues surrounding communication and discharge (areas possibly influenced by the care-partner program), as well as others. (See Figure 1.)

**FAMILY-INITIATED RAPID RESPONSE TEAMS**

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**Figure 1. Survey of Patients About Their Hospital Experiences: Good Samaritan Hospital vs. All U.S. Hospitals**

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Average for all U.S. reporting hospitals</th>
<th>Average for Good Samaritan Hospital, Kearney, NE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse communicates well with patient</td>
<td>75%</td>
<td>77%</td>
</tr>
<tr>
<td>Patients are told what to do after discharge</td>
<td>81%</td>
<td>86%</td>
</tr>
<tr>
<td>Patients get the hospital on a budget</td>
<td>65%</td>
<td>75%</td>
</tr>
<tr>
<td>Patients would recommend hospital</td>
<td>68%</td>
<td>68%</td>
</tr>
<tr>
<td>Patients give the hospital a rating of 9 or 10</td>
<td>79%</td>
<td>79%</td>
</tr>
</tbody>
</table>

FIRRTs were recognized in 2007 by the National Patient Safety Foundation; it gave its Socius Award to North Carolina Children’s Hospital for its Family Alert Initiative, which allows for a pediatric rapid response team on certain units. And to ensure awareness of its FIRRT program, Shands Jacksonville Medical Center in Jacksonville, Florida, provides information at the time of admission, signs are posted in patient rooms, brochures are available in public places, and phones are labeled with instructions for calling the “4CARE Hotline,” which immediately brings a team to the bedside.

**FAMILY PRESENCE DURING RESUSCITATION AND OTHER PROCEDURES**

As a complement to care-partner programs, FIRRTs, and 24-hour, patient-directed visitation,2 family-presence protocols give family members the option to remain with patients during invasive procedures, resuscitations, and other interventions. Usually, a staff member (such as a nurse, physician, chaplain, or social worker) acts as a “family facilitator” to explain the procedure, provide support, and ensure safety. After the procedure, the facilitator takes the family member to a comfortable place to respond to concerns and any other needs.

GSH doesn’t have a formal protocol permitting family presence, but because of the care-partner’s program, family members have been present during procedures on many occasions—especially when the end of life is imminent and the family has requested that “everything be done.”

Nurses increasingly have been advocates for family presence despite the challenge of caring for critically ill patients while also attending to family members and physicians. Faced with this conflict, nurses and nursing students might benefit from an analysis of a case study and a review of the extensive body of literature on this topic; discussion and debate could center on the perceived benefits and drawbacks for both the family and the provider.9 This topic has been extensively studied, and nurse researchers have been leading the way. In 1994 an Emergency Nurses Association (ENA) position statement was issued in support of formal policies on family presence during invasive procedures and resuscitation, as well as research and continuing education; the ENA’s white paper followed in 2005.10

A 2002 literature review suggests that family members want this option available to them and often will stay during an invasive procedure or a resuscitation attempt.10 Those who do stay often say that it’s beneficial to the patient and themselves.11-14 Among the benefits families report are feeling more in control, understanding the patient’s condition or status, being reassured that caregivers have done all they could to treat the patient, and assuaging grief if the patient has died.11-14 And although there is some disagreement among clinicians about the merits of family presence, many believe that it’s an important part of a patient-centered approach to care.11

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**REFERENCES**


