

## Personalized Health Information

*Patient-centered education includes the use of ‘patient pathways’ and tailored information.*

This is the second 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](http://www.planetree.org).

**P**atients entering the hospital encounter a foreign place where we providers are the insiders and only we understand the language. Visitors to our facilities often struggle to comprehend the meaning of test results and procedures, the significance of diagnoses or conditions, and most important, what’s required of them to live well after they leave us.

Angelica Thieriot founded the nonprofit Planetree organization after being hospitalized with a life-threatening illness and finding the facility where she was treated to be impersonal and unwelcoming. She decided that having access to meaningful, personalized health information—something she lacked during her hospitalization—was crucial for patients. This became one of the founding tenets of Planetree.

Illnesses present great challenges and result in significant personal growth for many patients. Life goals and values are reassessed; priorities become clear. Information and education are crucial components of this process, and nurses are often the ones providing them.

### THE NURSE AS EDUCATOR

According to the Institute of Medicine, “Stable, trusting rela-

tionships between a patient and the people providing care can be critical to healing or managing an illness.”<sup>1</sup> Time is central to such relationships. During the report given at every shift change, for example, a nurse learns about each patient’s needs and has an opportunity to clarify details of the care plan. Including patients in this conversation empowers them, and it also reinforces that they need to remain involved in their treatment.<sup>2</sup>

Patient education is a cornerstone of nursing care.<sup>3</sup> It’s essential to ensuring that patients follow their discharge plans and avoid subsequent hospitalizations. Many nurses find it to be one of the most satisfying parts of the job. The nurse’s role as educator is “a distinct, dominant, central and unifying focus” of the profession, according to Madeleine Leininger, the founder of the transcultural nursing movement.<sup>4</sup> Patient-centered teaching recognizes a patient’s cultural, spiritual, intellectual, biological, and socioeconomic individuality.

The nursing assessment conducted at admission—which is documented in the patient’s medical record—provides the first opportunity for the nurse and patient to frame the illness as something that might be

meaningful and manageable. This interview allows the nurse to identify the patient’s educational needs; the nurse then determines which type of education the patient would most benefit from and creates a plan. For example, a nurse who determines that a patient with diabetes isn’t monitoring her or his blood glucose levels regularly could demonstrate monitoring techniques during the hospital stay.

In the hospital, nurses typically employ one or several of the following educational tools and strategies:

- TV shows, DVDs, and Web sites such as the GetWellNetwork, which combines patient education and entertainment, or WiredMD, which provides resources and a forum in which health care professionals can discuss cases
  - return demonstrations, in which they ask patients to demonstrate what they’ve just seen
  - “teach back,” in which they ask patients to confirm their understanding by repeating the nurse’s instructions
  - written materials, such as booklets, handouts, and instruction sheets
  - conversation, in which the nurse and patient discuss what was taught
- These strategies all focus on a task, activity, or action designed to elicit behavioral changes that will help improve health.<sup>3</sup>

### EMPOWERING PATIENTS

Even in an institution dedicated to a patient-centered care approach, patient education presents many challenges. Language and literacy are obvious potential obstacles, but limited staffing or a lack of educational resources (such as DVDs, teaching models, booklets, charts, or diagrams) can also stymie education efforts. Some patients are simply too sick to learn or are in denial about their conditions; others are depressed or anxious. Educating patients requires flexibility and engaging the patient's family, if possible.

Patient-centered care encourages nurses to act as educators by using an open-chart policy, patient libraries, customized information packets, and "patient pathways." An open-chart policy enables patients to read and write in their medical records, thereby allowing them to participate in their own care. Health resource centers and satellite libraries provide both nurses and patients with a variety of materials that support educational goals. These resources may also be available to family and community members.

Patient pathways, a term that's popular in the United Kingdom, are known in the United States as clinical practice guidelines. Planetree hospitals prefer the term "patient pathways" because it illustrates that the patient is the focus of the care plan. These can be described as "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances,"<sup>5</sup> but patient-centered care embraces an expanded definition. *Bandolier*, an independent journal on evidence-based care, describes a patient pathway as care designed "to help a patient with a specific condition or set of symptoms move progressively

through a clinical experience to positive outcomes."<sup>6</sup>

A pilot project at one Planetree affiliate hospital is studying patient outcomes associated with a four-day congestive heart failure (CHF) patient pathway designed to prepare and motivate a patient to assume personal responsibility for self-care.<sup>7</sup> Begun in the fall of 2007, the pilot study measured outcomes including readmission rates and patient adherence to medication regimens. Patient education is performed at each step of the hospitalization, which typically lasts four days. For example, the nurse assesses the patient's literacy level and readiness to learn and tailors the education plan accordingly. The pathway allows nurses to assess patients' levels of motivation to care for themselves and change their habits and lifestyles.

The pathway prompts nurses to evaluate different aspects of self-care for CHF. For example, Day 2, Item 1 says: "Patient understands the importance of daily weight monitoring." If that is untrue, the nurse is directed to review its importance with the patient. If the statement is true, she or he is to proceed to Item 2: "Patient knows importance of decreased salt intake." The pathway outlines an orderly education plan, and the nurse assesses a patient's readiness to learn at each step.

### HEALTH INFORMATION SPECIALISTS

Facilities are increasingly employing health information specialists. They are typically librarians or health educators who have master's degrees and training in evaluating patient health materials produced in multiple languages and literacy levels. These specialists work with nurses, visiting newly admitted patients on what are called "patient information rounds." During typical visits,

the health information specialist talks to the patient and identifies her or his need for information about the diagnosis. They approach patients with particular sensitivity to their conditions and ask about the illness, their age, and whether or not family members can help. In a short visit, the health information specialist can ascertain the patient's cognitive ability.

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A health information specialist offers additional educational resources, such as materials that more specifically address the patient's diagnosis and personal history. For example, the resources provided to a 35-year-old mother of two who is newly diagnosed with breast cancer will differ from those given to a newly diagnosed 75-year-old. The younger woman would receive materials such as books and lists of local support groups that will help her to discuss her illness with her children and keep her job while undergoing cancer treatment. Some patients may say they don't need additional information, but we've found that they soon see the benefit of information tailored to their needs.

The information is usually geared more toward the patient's life after discharge, but not always. Sometimes patients want more detailed information on a test or procedure they are to undergo in the hospital so they can better determine its risks and benefits. While the nurse may have a standard handout or DVD designed to prepare the patient for this procedure, the health infor-



Health information specialist Linda Stahl conducts bedside rounds at Mid-Columbia Medical Center in The Dalles, Oregon. Photo courtesy of Jim Semlor.

mation specialist would have a larger collection of resources to cull in responding to the patient's request. The health information specialist supports the nurse's educational role by providing resources in addition to—not instead of—the nurse's materials.

After completing rounds, the health information specialist documents the patient's request for information in the medical record and assembles a personalized packet of information that includes details about the diagnosis or condition, treatment, complementary therapies (if requested), nutrition, coping (such as stress reduction techniques or ways to discuss the diagnosis with children), local support groups, and relevant health education classes provided by the facility or other organizations in the community. Packets are typically delivered within

48 hours of the request, either directly to the patient in the hospital or at home. The information packets are designed to support, reinforce, and expand the teaching performed in the facility by the patient's nurse.

### PATIENT LIBRARIES

Providing access to information was a founding principle of the Planetree model beginning in 1981, as evidenced by the development of a consumer and patient library at Pacific Presbyterian Medical Center (now called California Pacific Medical Center) in San Francisco and the open-chart policy adopted by Planetree members. Patient libraries provide a safe place for patients, family members, and the public to acquire health care knowledge. An appropriately staffed library includes medical librarians,

whose skill at matching the patient's information needs with trusted resources makes them crucial to a health resource center's success. Appropriate health information has the power to help patients solve problems, make treatment decisions, gain confidence in their ability to care for themselves, communicate with providers, and reduce costs.<sup>8</sup>

If illness is to lead to transformation, having access to sound information and resources patients can trust helps to lay the foundation for the journey. Information welcomes patients into our world. ▼

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