

SUPPORTING Family Caregivers

Communicating with Family Caregivers

Nurses can foster partnerships with patients and families during acute care hospitalizations.

Editor's note: This is the last article in a three-part series, *Supporting Family Caregivers*, in collaboration with the AARP Foundation and funded by the Jacob and Valeria Langeloth Foundation. The series is part of an initiative, Professional Partners Supporting Diverse Family Caregivers Across Settings, and builds on the work addressed in AJN's September 2008 State of the Science report, "Professional Partners Supporting Family Caregivers" (available at <http://bit.ly/o9GZOD>). Each article in the series has an accompanying video; the third video can be accessed at <http://links.lww.com/AJN/A27>.

“Disease interrupts a life, and illness then means living with perpetual interruption,” wrote Arthur W. Frank in 1995.¹ Acute care hospitalization is often a necessary, though stressful, interruption in a patient's life. Yet the family caregiver of that patient also faces an interruption in the daily routine, as hospital-based care providers assume authority and responsibility for care. Nurses might believe family caregivers consider this shift of care from home to hospital a respite. In truth, however, while it may provide relief from duties, new concerns will undoubtedly arise: Will the patient suffer a loss of function? Are we going to get bad news? Will she or he require more intensive or complex care after discharge?

A transformation is under way in acute care, at least in the United States, from provider-centered care to patient- and family-centered care.^{2,3} Providing an exceptional inpatient experience for both patients and families requires clinicians to practice in partnership with patients and their loved ones.³ Inpatient nurses, central to the quality of the inpatient experience of care, have been characterized as

being “in the middle”^{4,5} or “working the in-betweens.”⁶ The Institute of Medicine report *The Future of Nursing: Leading Change, Advancing Health* called for nurses to be system innovators, given the higher standards of care quality, the growing demands of an aging population, and the need to deliver more care in the community. Although nurses have educated patients, coordinated care, and collaborated with other clinicians for decades,

the extent and centrality of these roles is new,⁷ and the focus has shifted to the notion of partnership with patients and families. As Harrison and colleagues have written,⁸

Partnership is about working together to achieve something that would be impossible to do on your own, and it is characterized by the following:

- identification of a common goal to work toward and a joint evaluation of progress



Jill English and Marybeth O'Malley, nurses at the Hospital of the University of Pennsylvania in Philadelphia, listen as Walter Hunter and his daughter, Carmen Hunter-Anderson, discuss concerns about his care. Photo by Tom Upton.

- mutual respect about what each partner brings to the partnership
- open and honest communication and two-way sharing of information
- shared planning and decision making
- ongoing negotiation about the role that each partner can and wants to play over time

An understanding of the structures and processes that promote nurse–family caregiver partnerships during acute care hospitalizations is necessary for the provision of appropriate care in the transformation of the U.S. health care culture. These include the admission assessment, bedside rounds, family meetings, communication strategies, narrative approaches, discharge planning, and patient and family education.

Skills to Family Caregivers” [November].)

Discharge planning, which in the past focused on “discharge teaching” (injections, wound care, and medications, for example), must expand so that caring for the family caregiver is considered part of a safe transition to home. As the complexity of care increases, the population ages, and adequate home care resources become harder to obtain, the needs of family caregivers must be addressed. This work can start at the bedside when families are present and can be based on their preferences and needs, rather than on the schedule set forth by the hospital or the care staff.

ON ADMISSION

First impressions matter. If you are the greeting nurse, you have an

identified and addressed early on. Although patients and family caregivers with hearing, vision, or speech impairments may arrive with their own assistive devices, you should assess for the need for auxiliary aids or services that will facilitate the admission interview.

This is the time to determine the patient’s and family’s preferences for communication throughout the hospitalization, in order for you to know how best to prepare the patient and family caregiver for care after discharge.

Using the preferred language.

Given the complexity of the initial assessment, when a patient’s or caregiver’s English is limited, a trained medical interpreter is essential. Discussions about medications, symptom history, and care instructions pose a high risk of misunderstanding and error. An interpreter in the room (as opposed to on the telephone), enables participants to read nonverbal cues; for instance, if the interpreter reads confusion, frustration, or anger on the face of a patient, the caregiver, or a provider, she or he can stop the interpretation and ask for clarification or offer information on aspects of the patient’s culture. (If an interpreter isn’t available, use the organization’s phone system to access an off-site interpreter; note that a two-handset phone or speakerphone enables everyone to hear everything at the same time.)

Encouraging use of an interpreter. Ask patients about their need for an interpreter in a way that encourages, rather than discourages, interpreter use. The California Academy of Family Physicians Foundation has developed a guide to show what asking in an encouraging way looks like—and doesn’t look like (used with permission)¹⁰:

- **Poor wording.** “You (or the patient) won’t need an interpreter, will you?” Asking the question this way discourages the patient, or the [caregiver], from

The accuracy of the initial evaluation can be compromised if patient and family communication needs aren’t identified and addressed early on.

RELATIONSHIP-BASED CARE: INCLUDING THE FAMILY

The American Nurses Association’s *Code of Ethics for Nurses with Interpretive Statements* states that nurses’ primary commitment is to the recipient of nursing care, whether “an individual, a family, a group, or a community.”⁹ But the needs of the family caregiver haven’t been a primary focus of nursing attention in the inpatient acute care setting. Attention is (understandably) focused on the patient, and caregivers may feel invisible. (For more, see the first two articles in this three-part series, “The Hospital Nurse’s Assessment of Family Caregiver Needs” [October] and “Teaching Essential

opportunity to lay the foundation for mutual respect: greet the patient *and* the family. Perceptions that a bedside nurse is distracted, stressed, or disinterested set a negative tone. Despite the ever-present and competing demands of the acute care setting, give your full attention and sincerely demonstrate concern, being as fully present and mindful as possible. Let the family know what you’ll be doing when you need to leave the room and also when they can expect you to return.

Identifying communication needs. The accuracy and completeness of the initial evaluation can be compromised if patient and family communication needs aren’t

asking for the language assistance that [she or he] may need.

- **Basic wording.** “What language do you (or the patient) speak at home?” This question will get you information about the patient’s home language but ignores the possibility that the patient may [speak] English as well.

are few moments in our lives that call for greater compassion and companionship than when a loved one is admitted to the hospital.” As a result, recognition of the need for a support person is now embedded in regulatory and accreditation standards.^{11,12} In its 2010 report, *Advancing Effective Communication, Cultural Competence, and*

In accordance with Joint Commission standards, all patients are asked about advance directives on admission. It may be helpful to clarify the difference between a support person and a surrogate decision maker who’s authorized by the patient or law to give consent for treatment and surgery when the patient doesn’t

Establishing a formal program for preparing a family member to be a ‘care partner’ can promote patient satisfaction and positive responses from nurses and physicians.

- **Better wording.** “Do you need an interpreter for your visit? In what language?” This question may generate information on the need for an interpreter. On the other hand, many patients may reply in the negative, believing that they have to either bring their own interpreter or have a family member interpret. As a result, you will not get an accurate record of how many [patients with limited English] you are treating and from what language groups.
- **Best wording.** “In what language do you (or the person for whom [you’re acting]) prefer to receive your health care?” Asking the question this way will provide you information on the language the patient feels [she or he] needs to speak in a health-related conversation. If the answer is a language other than English, you can plan to have language assistance available for the patient, and you can add this information to the patient’s record.

Identifying a support person.

As president Barack Obama wrote in his April 15, 2010, memorandum on hospital visitation, “There

Patient- and Family-Centered Care: A Roadmap for Hospitals, the Joint Commission defines the support person as one who “should provide emotional support, give comfort, and alleviate fear during the course of the patient’s hospital stay.”¹² This new standard provides patients an opportunity to identify a person who can assist them throughout a hospitalization. Limitations to the caregiver’s presence are justified only when there would otherwise be an infringement on other patients’ rights, compromises to safety, or a medical or therapeutic contraindication. (For the purposes of this article, consider the family caregiver the identified support person.)

Establishing a formal program for preparing a family member to be a “care partner” who performs and documents routine personal care tasks and procedures can promote patient satisfaction and positive responses from nurses and physicians.¹³ Orient the support person to her or his role and the unit environment. Remember that the support person may or may not be the patient’s designated surrogate decision maker.

have the capacity to make a specific health care decision.

Consider the support person an ally in the quest for care quality and patient safety during the hospitalization. Ask whether she or he expects to provide care upon discharge home. Clarify with the patient whether there’s to be any restriction on sharing health information with the support person. Document the support person’s name in the medical record and indicate whether the patient gave permission to discuss protected health information during the hospitalization. Including information on how to reach the support person when she or he isn’t in the hospital will help with ongoing communication and care planning.

Role negotiation. Throughout the hospitalization the role of the caregiver may change, and continuing assessment is therefore needed. Begin the collaboration—and negotiation—about the caregiver’s presence and participation on admission. Explain what resources and protocols are available. Does the family caregiver plan to stay overnight on the first night of admission? How is the caregiver

feeling now that the patient has been admitted? Would it help the caregiver to go home? (If so, get contact information.)

Ask about baseline home care, eliciting details and plans for care continuity, as appropriate. Family caregivers may not be able to give any more than a yes-or-no response to questions about participation in care at the time of admission. Revisit the topic and renegotiate throughout the hospitalization. The ability and need to participate may vary from day to day. Recognize that family caregivers may have had experiences with nurses who expected, required, or prohibited family-caregiver participation. Asking about past experiences may be informative and helpful as the new relationship is being established and may serve as an opportunity to bring the family member up to date on current attitudes toward family participation in care. (Remember that a caregiver's absence from a planned visit or meeting may be a result of any number of situations, including conflicting responsibilities, a lack of funds for transportation, or a fear of hearing bad news. Nurses need to be cautious about assigning a reason for a no-show without supporting facts.)

A caregiver's participation in treatment may reflect differing emotions or motives, such as a desire for control, distrust of a nurse's technique, or a desire to demonstrate love to the patient. Increasingly sophisticated research focusing on the family caregiving process reveals a complexity "that affects and is affected by gender, culture, socioeconomic status, and lifespan developmental processes."¹⁴ Appreciation of this complexity, with a recognition of the individual nature of each family, will enable you to assess and address patient- and family-specific needs.

BEDSIDE ROUNDS

Beginning care-planning discussions in the presence of the patient is a visible symbol of patient-centered care, and engaging the patient and family in these discussions can create care that is truly patient and family centered.

any errors in patient history or care. The Institute for Patient- and Family-Centered Care (www.ipfcc.org) offers numerous online resources for developing new approaches to bedside nursing rounds, including a bibliography, tip sheet, and film clip.

Nurses can explore with physicians and other providers how to efficiently engage patients and family in rounds.

As you do during the initial assessment, acknowledge the need to protect the patient's confidentiality (as well as the value of the caregiver's presence) by confirming that the patient authorizes the family caregiver to participate in these discussions.

The change-of-shift report. A caregiver's regular participation in nursing handovers ensures frequent updates. Patient and family caregivers will need to be apprised of the unit routine and hand-over times. Introductions with invitations to all to offer observations, clarify treatment goals, and ask questions will demonstrate mutual respect. If a more detailed conversation is needed, the nurse can return after the transfer of care is completed. Bidirectional exchange between the nurse and the patient and family is essential for rounds to be meaningful. The effectiveness of the family caregiver's participation will be limited if the nurse provides only a perfunctory "do you have any questions?" at the end of the nurses' information exchange. Not only does engaging the patient and family in this process create a partnership among patients, nurses, and the family, it also provides patient or family caregiver opportunities to correct

Physician and multidisciplinary rounds. In some settings, even ICUs, patients and family caregivers are beginning to be welcomed to participate in multidisciplinary rounds.³ Nurses can explore with physicians and other providers how to efficiently engage patients and family in rounds. Rounds provide routine assessment of care plans, progress toward goals, and symptom management. Patients and family caregivers may want to opt out of bedside rounds at times. Systems can be devised to ensure that patients and families can control when they participate and that their preference is communicated to the rounding teams. For example, the Lucile Packard Children's Hospital at Stanford University in Palo Alto, California, provides colored magnets that caregivers can place, indicating their desire for involvement in the rounds.

FAMILY MEETINGS

Family meetings are organized when important information needs to be discussed and decisions must be made. Attention to planning the content and who will participate is essential for productive meetings. Critically ill patients are often not in a position to express their preferences or values. As Curtis and

Douglas wrote in 2008, “clinician–family communication is a central component of good medical decision making in the ICU.”¹⁵ Although primarily focused on end-of-life care, approaches to communication in the ICU are relevant to other hospital settings. For example, one study found that using a proactive approach to communication provided family members with more opportunities to discuss the patient’s wishes, express emotions, and understand the goals of care. The approach involved the use of five study objectives for the provider, represented by the mnemonic VALUE: to value and appreciate what the family members say, to acknowledge the family members’ emotions, to listen, to ask questions that allow the caregiver to understand who the patient is as a person, and to elicit questions from the family members.¹⁶ This approach to communication has value for all interactions with family caregivers, whether in a conference room or at the bedside.

Another example is a tool kit developed for use in family meetings that comprises a family meeting planner, a guide for families, and a documentation template.¹⁷ The guide prompts users to reflect on their current knowledge, record questions they may have, and document areas of concern in preparation for the meeting. Evaluation of the meeting is based on attendees’ perception of the knowledge they’ve gained and the attention that was paid to emotions.¹⁷ Although the guide was developed for use by those with a high level of health literacy, it can be adapted for use with others. The authors consider the three tools to be prototypes and believe adaptation to the setting and available resources to be essential for integration of the tool kit into teams’ routines.

The open and two-way communication that are essential to

any partnership may make it necessary to schedule family meetings regularly, not just when major decisions need to be made. If patients and families are consistently involved in multidisciplinary rounds and change-of-shift report, such meetings may not need to be held as often. The progress toward achieving the goals of care will be visible to all participants on a daily basis, as families are welcomed at the bedside as partners in planning and evaluating care.

COMMUNICATION STRATEGIES

Given the diversity in caregivers’ values and experience, nurses cannot always accurately or completely anticipate their needs. Understanding how family caregivers see the patient’s problems and their beliefs about how best to respond should inform nursing care and teaching. Approaches to understanding the patient’s perspective can also be used to elicit the family caregiver’s perspective.

Kleinman referred to these informal descriptions of the illness through the patient’s (or caregiver’s) eyes as “explanatory models,” the “notions that patients, families, and practitioners have about a specific illness episode.” Because they’re “responses to urgent life circumstances,” they serve as “justifications for practical action.”¹⁸ Ask family caregivers how the patient’s illness has affected their own life and what they fear most about the illness. This provides an opening for assessment of learning needs in addition to showing care for and interest in them as individuals. Providing family caregivers an opportunity to talk about their experience has therapeutic value as well.¹⁸

An anthropologic approach published more than 30 years ago, known as Kleinman’s Questions, is still recognized as an effective strategy for understanding a patient’s health-related beliefs and

practices.¹⁹ The recent report on improving communication in hospital settings from the Joint Commission also recommends their use. Here they are as originally published and as they can be adapted (when necessary) for use with caregivers¹⁹:

1. What do you think has caused your problem? (What do you think has caused the patient’s problem?)
2. Why do you think it started when it did?
3. What do you think your sickness does to you? How does it work? (What do you think the patient’s sickness does to her or him? How does it work? How has the patient’s illness affected home life?)
4. How severe is your sickness? Will it have a short or a long course? (How severe is the patient’s sickness? Will it have a short or a long course?)
5. What kind of treatment do you think you should receive? (What kind of treatment do you think the patient should receive?)
6. What are the most important results you hope to receive from this treatment? (What are the most important results you hope the patient will receive from this treatment?)
7. What are the chief problems your sickness has caused for you? (What are the chief problems the sickness has caused for the patient? What are the chief problems the sickness has caused for you?)
8. What do you most fear from your sickness? (What does the patient most fear from this sickness? What do you most fear from this sickness?)

It’s important to ask about caregivers’ home experiences with care and about the kinds of help provided in the home and the hours

per week that are devoted to this care. Find out whether caregivers feel limited or prevented from doing things most people their age do.²⁰ This may reveal the need to identify community resources or focus on the health care of the family caregiver.

NARRATIVE APPROACHES

The role of narrative, or storytelling, is well recognized in clinical education and bioethics. Illness

other clinicians? If so, why? Did you offer emotional support?

One approach is to ask the family caregiver to describe a day in the life of the patient at home. Ethics consultants use this approach to gain an understanding of the quality of the patient's life before hospitalization. The answer may reveal opportunities for you to respond with admiration and encouragement and areas in which help is needed.

Forums in which patients and families can share their stories with hospital staff promote a patient- and family-centered culture.

occurs in the context of a person's life story, and stories are embedded in care processes: rounds and shift reports include stories. Forums in which patients and families can share their stories with hospital staff promote a patient- and family-centered culture.

The nurse's presence in the room provides opportunities for family caregivers to tell their stories. Nurses, as active and empathetic listeners, should ask themselves two questions: What is happening in the story? and What is happening here in the moment?²¹ Why has the family caregiver shared this information? In other words, is it a reflection of her or his knowledge, fear, family dynamics, or dissatisfaction with care? Is the caregiver asking for validation of her or his caregiving or revealing vulnerability? Reflect on the experience shared by the family caregiver: how does it inform your care of both the patient and the caregiver? What does it reveal about the knowledge and skills the caregiver has or still needs? Will the story be shared with

Incorporating storytelling into practice. Seeking to understand more about the caregiver's perspectives and needs promotes a collaborative relationship. When challenges arise, clinicians often expect patients and families to understand their perspective, and clinicians' responses may appear defensive rather than supportive. Kleinman's questions can be used to gain an understanding of the patient or family perspective. You can experiment with introducing one or two of them into bedside conversations. Understanding what the family sees as the cause of or solution to the patient's health problems can inform approaches to nursing care.

DISCHARGE PLANNING

Systems and structures for including staff nurses, patients, and family caregivers in the planning and education necessary for a smooth transition to home are needed. Nosbusch and colleagues suggested in 2010 that "ineffective communication and failure to involve patients and families in

discharge planning could be two important factors leading to the lack of congruence in nurses', patients' and families' perceptions of patient' [sic] postdischarge needs."²² Unit-based meetings to plan for discharge are typically held in conference rooms away from the bedside. Participants generally include physicians, social workers, nurses, and discharge planners. The patient's bedside nurse may not participate because the unit charge nurse often represents nursing at these meetings.

As part of discharge planning, begin to develop a 24-hour home schedule with the patient and caregiver, with estimates of the time tasks will take. Remember to include nonmedical aspects of a home routine. Does the patient like to take a walk every day? How long does a bath take? How and when are tube feedings prepared in the home? Include the cleaning of equipment. Estimated times may prompt a reevaluation of a home care regimen or provide justification for more resources or alternative plans.

EDUCATION

Teaching plans often identify one primary learner, but in reality others in the patient's support network are involved. In collaboration with the patient and the family caregiver (the support person), identify the learners and the concepts and skills to be learned. Offer opportunities for review and skill demonstration. Begin the discussion on admission and continue it throughout the hospitalization.

An educational principle called "ask-tell-ask" requires the teacher to know what the learner knows and then build on that knowledge.²³ It involves asking the patient (or caregiver) to describe her or his current understanding of the issue, telling the patient (or caregiver) in "straightforward language" what needs to be communicated ("the bad news, treatment

options, or other information”), and then asking the patient (or caregiver) questions to determine whether she or he understood the information. One study found an open-ended educational approach, called “tell back–collaborative inquiry,” to be effective and preferred by patients. This method acknowledges the teacher’s role in the educational process, but because it’s more patient centered, it may be more comfortable for the learner.²⁴ For example, you can lead with a gentle inquiry, such as “It would help me to know how clear my explanation was if you tell me what you found most helpful.”

Reading and health literacy will vary among and within families. Talk with the family caregiver to plan materials for home care. Use technology when possible. Digital photographs, for instance, rather than text may be the best way to illustrate the steps in a dressing change and can be especially helpful with a low level of literacy or a language barrier. Offer to audiotape explanations for care. If supportive materials aren’t available in the patient or caregiver’s language, offer to explain the information to an interpreter and record the discussion. Consider the range of learning styles and use a variety of approaches, keeping in mind that the learner in the hospital may be the teacher of family members in the home.

Hospitalization generates much information that typically resides in the medical record; access to the record may vary. Family caregivers can create a record of helpful facts for reference after discharge both at home and during ambulatory visits. Recommend creating a personal health record and help with its creation. A notebook kept at the patient’s bedside for notations by family and even staff may be helpful for caregivers. Some organizations have systems for electronic personal health records; ensure that families who want to

use such a system have the necessary information.

FINAL NOTES

Strumpf and Buhler-Wilkerson have written that “the centrality of expert and compassionate care, along with timely and honest communication, [are] crucial to the preservation of integrity, dignity, control, and hope in the face of serious illness.”²⁵ The experience of providing care for a loved one in the home may be both daunting and rewarding. Partnerships among family caregivers and bedside nurses can create a powerful force for the safety and quality of care in the hospital, provide for a smooth transition home, and enrich the lives of all participants. ▼

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