Inspiring Hope in Our Rehabilitation Patients, Their Families, and Ourselves

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When confronted with a devastating disability or chronic illness, rehabilitation nurses play a key role in inspiring hope for patients and their families. This article examines strategies nurses can implement in everyday practice: creating an environment of hope in a rehabilitation unit; assisting patients to manage their negative feelings about their disability; relieving chronic neuropathic pain; sustaining patient relationships with staff and family; helping patients to forgive themselves and others; enhancing patient intimacy with others; using literature to promote hope; acknowledging a patient’s belief that nothing is impossible; using humor therapeutically; and maintaining hope for the moment. It is the moment—the time we spend with our patients—that is essential. In that moment, we are promoting hope.

Judith Fitzgerald Miller (2000) defines hope as “a state of being characterized by an anticipation of a continued good state, an improved state, or a release from a perceived entrapment.” She also characterizes hope as “an anticipation of a future that is good and is based upon: relationships with others, purpose and meaning in life, as well as [a] sense of the possible” (pp. 253–254). Miller makes a clear distinction between nursing actions that can lead a patient to despair and those that can lead a patient to hope. For example, if a nurse helps a patient develop and revise goals, the patient is led to hope. If the nurse fails to help the patient set goals, the patient is led to despair. This article outlines several actions nurses can take to lead patients toward hope. When nurses implement these interventions they also find renewal in what they do.

When a person has an upsetting or terrifying experience, their friends and family members typically respond by saying “It will all be okay.” Rehabilitation nurses, however, should not automatically assure people that everything will be fine. It is not “okay” to have chronic pain, a head injury, a stroke, or a spinal cord injury. Nurses need to promote hope without using clichés.

Nurses also need to remind patients’ friends and family members to avoid saying “It will be okay” or “Get well soon.” Promises of recovery are not useful when it is clear a patient will not recover. A patient with a spinal cord injury explained how he was tired of receiving “get well” cards from well-intentioned friends: “They know I am not going to get well,” he said. This patient would have preferred a card with a message like: “I am so sorry this happened to you. I just wanted you to know I am thinking of you, and hoping you are learning all you need so you can come home soon.”

Inspiring Hope

Miller (2000) and other researchers suggest many ways in which nurses can inspire hope. Some of the strategies discussed in this article were recommended by Miller, others were gathered from the literature and the author’s personal experience as a rehabilitation nurse. Some of these interventions are research based, others are not. Rehabilitation nurses can conduct research to test some of these interventions; however, studying others may be impractical and even unethical because patients cannot be randomly assigned to groups nor can nurses withhold interventions such as listening or providing privacy from some patients and families (Kautz & Van Horn, 2008). These strategies include creating an environment of hope in a rehabilitation unit; assisting patients to manage negative feelings about their disability; relieving chronic, neuropathic pain; sustaining patient relationships with staff and family; helping patients to forgive themselves and others; enhancing patient intimacy with others; using literature to promote hope; acknowledging a patient’s belief that nothing is impossible; using humor therapeutically; and maintaining hope for the moment.

Creating an Environment of Hope

New rehabilitation nurses may be surprised when patients lose hope. As time passes, however, these same nurses may begin to wonder why all patients do not lose hope. How can some patients get up every day and accept that being disabled is part of their daily lives? Patients—even early on—remain hopeful and believe they are going to do well because of the way rehabilitation is structured. A chapter on rehabilitation nursing in an older trauma nursing text, Rehabilitation:
A Therapeutic Escape from Reality, presents the idea that a therapeutic escape often is preferable to reality. In a rehabilitation unit (unlike in the real world), staff ensure everything is wheelchair-accessible and they are knowledgeable about disabilities. Rehabilitation nurses and staff also do not regard disability as anything unusual; they help ensure patients can perform basic hygiene and are dressed in their own clothes every day, which gives them hope. These essential tasks remain the same for any person—regardless of disability—who is trying to maintain hope. Amie Smith, RN, (Smith & Kautz, 2007) tells the story of a patient who was hospitalized with small bowel obstruction; this person returned to Smith’s unit 9 months after being discharged. The patient said to her, “You were the only one who washed my hair.” By performing this simple task but often-ignored task, Smith made a lasting impression on her patient. Rehabilitation nurses must not underestimate the power of the moments spent with patients.

Researchers who study language have noted a change in the way clinicians and support staff speak. Instead of saying “I hope,” rehabilitation nurses often say “hopefully”; in a conversation with a patient, for example, a rehabilitation nurse might say “Hopefully, at the end of your rehabilitation stay you will be able to live independently at home” rather than “I hope that at the end of your rehabilitation stay you will be able to live independently at home.” Notice the difference in these statements. When “hopefully” is used, the rehabilitation nurse is not making any promises to the patient, but he or she is acknowledging the uncertainty of the situation. Patients may go home; they may not. Using the phrase “I hope” implies the nurse is saying, “It is my goal, and I will do everything I can to ensure you go home.”

Rehabilitation teams are successful when they set goals, believe in accomplishing them, and focus the expertise and efforts of a diverse team on each patient’s goals. Every week, rehabilitation nurses document a patient’s progress toward specific objectives; achieving these goals is the focus of the patient’s life. Setting and achieving weekly goals, treating a disability as if it is normal, and having patients get up and get dressed every day are key principles for any inpatient rehabilitation unit (Booth & Jester, 2007; Pryor, 2002). This is why rehabilitation patients are less likely to lose hope. They have an entire team working with them every day.

Managing Patients’ Negative Feelings About Their Disability

The article “Common Psychological Challenges for Patients with Newly Acquired Disability” (Larner, 2005) is an excellent resource of information about the psychological challenges faced by patients with new disabilities. Nurses may overhear upsetting conversations similar to the following one I heard between a man with quadriplegia who was in his late sixties and a new 17-year-old quadriplegic. The older quadriplegic said: “We should have died, we’d be better off dead—especially you. I am old. You are young. What do you have to look forward to? You should die.” Patients may be anxious and worried all the time; they may have posttraumatic stress disorder, constantly reexperiencing life-threatening situations. They also may experience memory loss, pessimism about the future, and feelings of worthlessness and powerlessness. Patients may be frightened by how angry they have become. All of these overwhelming feelings are likely to cause fatigue.

Patients need to be referred for counseling, and counselors should be a part of every rehabilitation team. Nurses also can play a major role in helping patients manage negative feelings through “activity scheduling” (i.e., trying several activities until finding one that works best for a patient). Being with someone they love or care about, having a cup of coffee with friends, listening to the radio, thinking about a positive upcoming event, sitting in the sun, attending a religious service, watching animals, and reading all are activities patients can incorporate into their daily routines (Larner). Encourage patients to try at least one of these activities every day to escape the mindset of being disabled.

Relieving Chronic Neuropathic Pain

Most, if not all, patients in rehabilitation experience some type of chronic, unrelenting pain—not the type of pain from a serious cut that will heal and go away. These patients will have chronic pain that likely will never diminish or stop. It is likely that in the acute stage of rehabilitation, patients will experience either one type of pain or a combination of somatic, visceral, neuropathic, muscle, inflammatory, mechanical, or compressive pain (Institute for Clinical Systems Improvement [ICSI], 2006, 2007). All neurological insults—whether a stroke, head injury, spinal cord injury, peripheral nerve injury, amputation, or a severe multiple fracture (without neurological injury)—result in some type of chronic nerve dysfunction. In rehabilitation texts, the terminology describing chronic nerve dysfunction includes burning, numbness, or paresthesias. Paresthesias hurt, and most of them hurt all the time. In addition, many rehabilitation patients have had recent surgery, which leads to low-level muscular and inflammatory pain that lasts for weeks to months. Functional limitations, which all rehabilitation patients face, also result in pain. These functional limitations can cause stiffness or aching; joints that do not move regularly or do not have...
normal muscle support because of disuse, atrophy, or paralysis cause chronic low-level pain. Most patients older than 40 years of age also have arthritis and previous joint injuries that lead to pain. The only sensations new quadriplegics experience in a halo brace or cervical traction are painful ones, unless they are sitting up in a wheelchair; then patients experience dizziness and nausea in addition to pain.

Evidence shows that even though healthcare professionals know how to treat pain, pain remains largely undertreated in hospitals (O'Malley, 2005) and it is likely pain is undertreated in rehabilitation facilities, as well. Unrelenting, exhausting pain certainly may destroy hope. In fact, pain is one of the major reasons patients lose their hope, self-esteem, and the will to live. Often, when rehabilitation nurses start working with new quadriplegic patients, they resist therapy. Rehabilitation nurses commonly blame patients for this reluctance—“they are unmotivated and difficult” is a common complaint. Most rehabilitation nurses quickly learn, however, that patients often resist participating in therapy because they are in pain. Bruno (1995) found that chronic pain is a common reason for rehabilitation therapy noncompliance.

Although some patients require narcotic pain medication for their entire lives, most can live tolerably without narcotic medication. However, patients should have access to medications that will treat their pain (ICSI, 2006, 2007). The Core Curriculum for Rehabilitation Nursing (Mauk, 2007) outlines several effective approaches for managing pain. These methods recognize patients may need several classes of medications, including either acetaminophen or a nonsteroidal anti-inflammatory drug around the clock, and that other drug options should be used as needed for breakthrough pain. Continuous medication intake is just the beginning. Ice packs, massage, hot tubs, distraction, and other alternative methods also are valuable for relieving pain. Every patient in rehabilitation should be treated with a combination of these methods every day. ICSI has published evidence-based practice guidelines for treating acute pain (2006) and chronic pain (2007), as well as patient education materials (available at www.icsi.org). The guidelines include recommendations for combination therapies to treat neuropathic, muscular, inflammatory, mechanical, and compressive pain. In addition, the American Pain Society (www.ampainsoc.org) regularly publishes guidelines and helpful resources for nurses who want to learn more about managing pain.

**Sustaining Patient Relationships**

Another way to inspire hope among patients is to help them sustain relationships with their family, friends, and rehabilitation staff. A professional boundary must remain intact between rehabilitation nurses and their patients, however.

The first step toward building relationships with patients is getting to know them. Learn about their likes and dislikes. What were they doing before they came to the rehabilitation unit? Who is important to them? Write this information down and pass it on from shift to shift. Document bits of conversation or personal information about patients in their charts so that during subsequent visits nurses can resume these conversations. Taking this extra step tells patients their caregivers care about them—not just as people with a diagnosis, but as people who have a life and interests outside of the rehabilitation unit. Also keep track of the people who have called or visited each patient and pass this information to the next shift. When nurses work with the same patients for consecutive days, they can start their conversations with “Yesterday when I saw you … and now today….” These details go a long way toward building meaningful relationships with patients.

When patients can maintain their identities, this sustains their relationships. Christopher Reeve credits his wife, Dana, for saving his life, explaining that she wanted him to live “because you’re still you. And I love you” (1998, p. 28). Rehabilitation nurses must encourage patients to express who they are. When caregivers know their patients as people, outcomes are much better. Knowing patients on a personal level makes it easier to individualize care; this allows patients to improve more quickly. When caregivers can recognize subtle changes in their patients, they can intervene before these changes become major complications.

Individualized care results in a variety of positive effects for patients. In one example, a woman who was in a coma following a head injury was placed in an intensive care unit (ICU). A nurse who was assigned to the ICU temporarily for 1 week cared for the patient every day. Even though the woman was either completely unresponsive or only minimally responsive to external stimuli (i.e., Rancho Level I or II), the nurse talked to the patient throughout the day, explaining her actions or talking about more general topics. On the nurse’s last day of working in the ICU, she told the patient it was her final day and that she had enjoyed caring for her. Years later, the nurse was riding the subway talking to another nurse. A woman with a noticeable limp approached them. She mentioned her name and said “You were my window to the world. When you left, I thought I had lost touch with reality forever.”

In another case, a young mother had sustained a serious head injury and was placed on an ICU ventilator and was not expected to survive. The doctors were going to wean her off the ventilator, and decided
it was time to have her young daughter come in to say goodbye. In the ICU, the daughter squirmed out of her father’s arms and climbed onto the bed. She crawled up to her mother’s face, grabbed her gown, and screamed, “Mommy, you get better, I need you.” Incredibly, the mother did get better. This scenario further illustrates the importance of maintaining relationships with patients even if they cannot respond.

Working with families can be one of the most challenging aspects of rehabilitation nursing; families can be too demanding, too uninvolved, or dysfunctional. Many nurses leave rehabilitation because they tire of dealing with families. Rehabilitation nurses must remind themselves each day that dysfunctional family members may be the only relatives patients have, and sustaining these relationships may help encourage and rehabilitate them.

Helping Patients to Forgive Themselves and Others
Another integral facet of rehabilitation nursing (that sometimes is overlooked) is the need for rehabilitation nurses to help their patients forgive those responsible for their disability (this can mean the patient is struggling to forgive himself or herself). Many people sustain disabilities shortly after having major arguments with someone whom they love. Forgiveness is a crucial component of making progress in rehabilitation and for the duration of a patient’s life (Wohl, Kuiken, & Noels, 2006). Patients can learn forgiveness techniques with the help of a qualified mental health professional. I learned this lesson through personal experience. Some people were mistreating me and I was very angry. I even found myself thinking about hurting these people. After several weeks of feeling this way, I decided I needed to do something to remove the situation. I decided to see a therapist. After a couple of sessions he said, “Let me teach you how to forgive these people. Say to your self, ‘These people treated me wrong. They (spell out what they did). It was bad, they hurt me. And, I forgive them.’” He suggested I do this every time I thought about these people. I took his advice and it worked. Forgiveness would schedule himself as her 11 am “appointment.” She would drive home to find he had made her lunch; they enjoyed a relaxing bath and sexual intercourse. Sex and love are known to raise endorphin levels, which help to relieve pain (Paice, 2003). Consequently, the psychologist’s weekly “appointments” with her significant other helped her cut her pain medications by half that day and the next.

Nurses often do not talk to patients about intimacy because they are unsure of their role regarding the topic and they do not have printed resources. Internet resources are available, however; nurses can print Web pages and distribute them to patients (reprint permission must be received in some instances). To research the topic, nurses can type “sex and head injury,” “sex and stroke,” or “sex” and a term related to the patient’s specific condition into the “Google” search engine and find informative links to patient education handouts. The following Web sites provide reputable information on intimacy and disability: www.goodvibes.com, www.siecus.org, www.sexed.com, www.sexualhealth.com, and www.womenshealth.org. At the time of publication, these sites were checked for accuracy; however, please note that Web site text changes frequently. The key is to give patients and their partners information they need regardless of whether conversations have taken place. Kautz (2006, 2007) offers additional information about intimacy and sexuality with aging and chronic illness, and about love, sex, and intimacy after stroke.

Using Literature to Promote Hope
Creative use of readings, journals, and storytelling can help people cope with disability, sustain hope and comfort, and manage their life demands (Hobus, 2000). Nurses may need to tell their patients “I don’t know the answers. I don’t know what the outcome will be. I know that right now, everything seems hopeless. But I also know you need to get up and go to breakfast. You need to go on. Breakfast is cooked in the cafeteria; it smells good. I’m going to get you up now.” A Zen parable that Hobus quotes is both disturbing and comforting. In the story, a man falls over a cliff while trying to escape a tiger and clings tightly to a vine. “But, there is another tiger below him, snapping and snarling. All he can do then is with his free hand pluck a strawberry on that same vine and eat it, and enjoy its sweetness” (Hobus, p. 456). Hobus points out that as adults (and as rehabilitation nurses), we realize some problems just cannot be worked out; we might as well make the most of today.

Promoting Patient Intimacy with Others
Nurses can promote patient intimacy. A psychologist in her late 20s who grew up with juvenile diabetes had severe joint deformities and chronic pain. She found that having sexual intercourse in the middle of the day was best for her because this was when her pain was the least intense. Once a week, her partner...
Inspiring Hope in Our Rehabilitation Patients, Their Families, and Ourselves

is to gently prompt him or her onto the next stage of grieving. However, the following four patients changed my mind. They said:

“I am a truck driver. I have lived by my fists, and when I came to rehabilitation, I believed you all would beat me and I wouldn’t be able to do anything about it.”

“Every morning when I wake up, it takes me a few moments to realize that I am a quadriplegic and can’t walk. I have been a quadriplegic for 15 years, and every morning it is the same.”

“You are so mean. When you wake me up in the morning, I am almost always dreaming. And in my dreams, I am always walking. And then you wake me up, and I become a quadriplegic again.”

“Do you believe that I will be a quadriplegic forever? Do you believe that I will never walk? Do you believe I will be a quadriplegic in heaven? What does it matter to you what I believe?”

Patients’ denial and hope can serve as useful lessons for nurses. First, the word denial is used too loosely. Nothing Is Impossible by Christopher Reeve (2002) focuses in part on the value of denial. Believing in the seemingly impossible, as Christopher Reeve did until his death, does not necessarily mean a person is in denial about his or her present state. It is rare to hear a patient with paralysis say “I can walk right here, right now.” But many patients will say “I will walk.” Believing that nothing is impossible is a key element of survival.

In an integrative review of the literature on acceptance and denial, Telford, Kralik, and Koch (2006) concluded that when healthcare providers use labels and patients internalize them, the labels may obstruct the transition to living well with a chronic illness. It is far more important to listen to each patient’s unique story than to label a patient as being in acceptance or denial.

When a patient says “I am going to walk (or recover function in my...),” or asks “Will I walk (or recover)?” nurses can use one of the following responses: “Do you think today is the day?” “Wouldn’t that be wonderful?” “I’ve seen a miracle or two.” “No one knows,” or “Only God knows.” Or, to paraphrase Gulley in the movie “Harriet the Spy,” a potential response could sound like “Someday that may happen, but that day does not appear to be today. And today, we have to...” Another option is to simply give the patient a nod and a caring look and remain silent, or say “Okay” as in “Okay, I heard you.” Then proceed by saying “Now it’s time to get up for therapy.”

Therapeutic Humor
A closing speaker at an Association of Rehabilitation Nurses conference many years ago asked these questions of the audience:

• Is it fun where you work?
• Do other staff members like working with you?
• When you leave patients’ rooms (or when they leave you), are they smiling? If not, what have you allowed to happen?

Each of us is responsible for making sure our work is fun for us and for our coworkers, patients, and their families.

Jan Karon, a North Carolina author, offers examples of therapeutic humor in the Mitford Series. Karon created a fictional town, Mitford, which is the setting for her book series. In the first book of the series, At Home in Mitford (1998), the reader meets Uncle Billy, who always has a joke to tell. Uncle Billy has many lessons for rehabilitation nurses. By practicing his jokes, Uncle Billy inspired others to find joy in their lives. Uncle Billy was in love with (and married to) Miss Rose Watson, a woman with schizophrenia, believed by many of the townsfolk to be one of the most wicked people on earth. His legacy involved his love for Rose Watson and his jokes. In the last book of the Mitford Series, Light from Heaven (2005), Uncle Billy dies. At his funeral, the minister speaks about him:

Uncle Billy spent his life modeling a better way to live, a healthier way, really, by inviting us to share in a continued feast of laughter. When the tide seemed to turn against loving, he loved anyway. And when circumstances sought to prevail against laughter, he laughed anyway. Uncle Billy loved us with his jokes. And, oh, how he relished making us laugh, prayed to make us laugh. And we did (Karon, 2005, pp. 225–226).

One of Uncle Billy’s favorite jokes was:

An ol’ man and a ol’ woman was settin’ on th’ porch, don’t you know.
Th’ ol’ woman said, “You know what I’d like t’ have?”
Ol’ man said, “What’s at?”
She says “A big ol’ bowl of vaniller ice cream with choc’late sauce an’ nuts on top!”
He says, “By jing, I’ll jis’ go down t’ th’ store an’ git us some.”
She says, “You better write that down or you’ll forget it.”
Maintaining Hope for the Moment
The most important aspect of inspiring hope and preventing powerlessness in patients is the ability of the nurse to promote hope for the moment. Even without using any equipment or specialized knowledge—just by being with a patient or family—nurses can promote hope. When a patient has been incontinent with diarrhea in bed and is covered from waist to knees in diarrhea, the approaching nurse does not say, “Oh my God, look at you, that’s disgusting.” Instead, he or she says, “Oh, I see you’ve had an accident. Let me get you cleaned up. Then let’s talk about what we need to do to adjust your bowel program.” With this type of response, a nurse increases the patient’s control, makes the unimaginable manageable, focuses on sustaining the relationship with the patient, and uses a life-promoting framework. Synder, Brandt, and Tseng (2000) say that when nurses are present with their whole being and are attuned to their patients’ needs and concerns, they can transform a technical, potentially impersonal setting into a humane, healing place. The time nurses spend with their patients (the “right here, right now”) is what is essential. Every time a nurse tells a patient, “I will be your nurse today,” he or she is also saying, “You are worth my time, right here, right now.” In that moment, the nurse is promoting hope.

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References

continued on page 177
Environmental Issues in Patient Care Management: Proxemics, Personal Space, and Territoriality

continued from 147


Inspiring Hope in Our Rehabilitation Patients, Their Families, and Ourselves

continued from 153


