Finding the heart of [hospital]ity
Patient satisfaction and the healthcare experience

Analytical insights from patient narratives
The next step for better patient experience

The REDE model of healthcare communication
Optimizing relationship as a therapeutic agent

Enhancing the empathic connection
Using action methods to understand conflicts in end of life care
Every challenge creates opportunity
Every relationship brings responsibility

Every patient is our inspiration

© Johnson & Johnson Health Care Systems Inc. 2014
A CLEANER CLEAN.

Imagine using fewer chemicals to keep hospitals even cleaner. If we can dream it, we can do it. Our state-of-the-art cleaning system uses electrically charged water for a reduced chemical footprint. Whether it's working with hospitals, universities, stadiums, or businesses, innovative customer service is at the heart of what we do.

WE DREAM. WE DO.

Find out more at www.aramark.com/innovations
© 2014 Aramark. All rights reserved.
WELCOME

Wow! A Journal of Patient Experience. What extraordinary times we are in. The fact that your eyes are dancing over these words is a culmination of a tremendous amount of effort by people like you.

I’m humbled by the intensity and fragility of this human life; the stories and perspectives herein are a testament to that and the authors’ vulnerability in sharing them is powerful. You’ll also read about several efforts ongoing to incorporate relationship-centered care, empathy, and patient perspectives into the care we provide.

We are a multi-disciplinary, peer-reviewed journal supported by the Association of Patient Experience. That being said, let’s break some molds! We started by making sure we put patients at the forefront — literally on the front cover as a means of honoring their stories. We recruited a wonderful, charismatic patient to join our distinguished Editorial Board, and as with all patients, she isn’t defined by that term. We also placed patient pieces in the beginning and end to highlight that they are paramount. Since we are so early in this process, we can do anything, and I am receptive to new ideas. So drop me a note…

I have several wishes for this journal moving forward. The first is that we create a space for best practices, lessons, research, arts, and reflections as relates to patient experience AND provider experience — in my mind, there is no patient experience without attending to the providers of it. My second wish is that together, we drive the field of patient experience forward with relentless enthusiasm, creativity, and rigor. And if I was really dreaming and shooting for the stars, that we knock the world’s socks off (as I like to say) by simply honoring the experience of being human.

Sincerely,

Adrienne Boissy, MD, MA
journal@patient-experience.org

ON THE COVER

Jason DaSilva, Producer/Director/Writer/Editor

In 2006, 25-year-old Jason DaSilva was on vacation at the beach with family when it all changed. A few months earlier, doctors had told him that he had multiple sclerosis. After a fall, Jason picked up the camera, turned it on his declining body, and set out on a worldwide journey in search of healing, self-discovery, and love. DaSilva’s documentary, WHEN I WALK, was an Official Selection of the 2013 Sundance Film Festival. It will air on PBS in 2014. For more info about Jason or WHEN I WALK, visit: http://wheniwalk.com

PHOTOGRAPHER

Annie Levy, Photographer/Writer and Creative Director of Photo ID Foundation

Annie began as a photographer/ writer and in turning her eye to the world of medicine, her work has expanded to creating/producing projects and forming the Photo ID Foundation. For more info about Annie’s work: www.annielevy.com and www.photoidfoundation.org. Annie is speaking at the 5th Annual Patient Experience: Empathy + Innovation Summit.

Thank you to Annie Levy for her generously donated picture of Jason.
CONTENTS

ISSUE 1 / VOLUME 1 / 2014

6 Family nonpresence during stabilization in the ER
   The front and the back

8 The REDE model of healthcare communication
   Optimizing relationship as a therapeutic agent

14 Enhancing the empathic connection
   Using action methods to understand conflicts in end of life care

22 Analytical insights from patient narratives
   The next step for better patient experience

25 Finding the heart of [hospital]ity
   Patient satisfaction and the healthcare experience

28 Caring behaviors
   Perceptions of acute care nurses and hospitalized patients with diabetes

BOARD OF DIRECTORS

Editor-in-Chief:
Adrienne Boissy, MD, MA
Director, Center for Excellence in Healthcare Communication
Staff, Neurological Institute and Bioethics
Cleveland Clinic

Patti Substelny
Patient

Geri Lynn Baumbiatt, MA
Editorial Director
Emmi Solutions, LLC

Richard Frankel, PhD
Professor of Medicine and Geriatrics
Indiana University School of Medicine

Mary Anne Hilliard, Esq, BSN, CPHRM
Chief Risk Counsel
VP Safety and Patient Experience
Children’s National Health System

Mohammadreza Hojat, PhD
Research Professor of Psychiatry and Human Behavior
Director of Jefferson Longitudinal Study
Center for Research in Medical Education and Health Care
Jefferson Medical College

Edward Krupat, PhD
Director, Center for Evaluation
Harvard Medical School

Kathy Leonhardt, MD, MPH
Vice President, Clinical Quality
Aurora Health Care

Deirdre E. Mylod, PhD
Executive Director, Institute for Innovation
SVP, Research & Analytics
Press Ganey Associates, Inc.

All rights reserved ©Association for Patient Experience, 2014, unless otherwise noted.
Family non-presence during stabilization in the ER: The front and the back

Lacey Colligan, MD

At 8:50 a.m. on a Friday in July, I found my 21-year-old daughter on the floor of her apartment. She was not breathing and did not have a pulse. I dialed 911. I started CPR. The police and EMS arrived. I could hear them say to each other “no pulse, no pulse.” I kept waiting for them to stop. Then, “radial pulse, 9:45 a.m.” EMS bundled her up and transported her two blocks to my own hospital, an academic medical center at my daughter’s university, where I was a fellow in neonatology.

My daughter and I were alone at school without my husband and three sons, who were all far away. I called my division chief, a friend, for help. He met me in the main waiting room, in the front of the ER.

“Please, please go back and tell them not to subject her to extraordinary measures. She didn’t have oxygen for an hour. She doesn’t want extraordinary measures; our family doesn’t want extraordinary measures.”

My chief disappeared, then returned quickly. He had found the doctors in charge and told them, “Her mother is a doctor. She doesn’t want extraordinary measures.” He relayed with assurance, “There’s a heart rate and a blood pressure. There is no choice to make now.” He sat with me in the quiet special waiting room. That’s the room you wait in when something bad is happening. My daughter was a student at the university and the police had notified the dean of students; the dean arrived and stayed with me quietly and respectfully. Her presence comforted me and made me feel that my daughter was important. Different members of my division came in rotation to sit with me. I called my husband but couldn’t speak. Someone took the phone, updated him, and told him he needed to come as fast as he could.

Two ER doctors came to the front to talk to me. They asked about my daughter’s medical history, medications and allergies. They told me she had a “wide QRS.” I take care of babies. Arrhythmias are not common in neonates, and I could not process the meaning of a wide QRS. I stared at them blankly and told them that I didn’t know what that meant.

The clock told me that three hours had passed. At last, a social worker took me back to see my daughter. My child lay naked in the treatment room, with only a sheet twisted around one ankle. Her eyes were closed, and she was intubated and ventilated. The bloody puncture marks over her right clavicle were too numerous to count. Her arms were outstretched, perpendicular to her body. Two nurses bent over the veins in her hands, trying to place IVs. They didn’t look up. A resident looked at me from the other side of the gurney, across her bare breasts.

I surveyed the room. Three code carts were open, with doors askew. Medication vials, gloves and debris littered an empty stretcher that served as a worktable. Plastic trays and wrappings from central line kits were strewn across the floor. A large trashcan propped the door open to the central work area, where house staff sat at their computers. They laughed as one of them regaled the crowd with a story of the “dirtiest central line I ever placed.” A transport attendant wheeled a teenaged boy by the door with a shiny new cast on his leg. His family trotted behind and curiously glanced in the room at my naked daughter. She would have been horrified to be seen this way.

This was just another day at my hospital.

As a pediatrician, I used to be uncomfortable with recommendations promoting family presence during resuscitations and painful procedures. When I performed procedures on infants and toddlers, I always asked parents to wait outside. I would get them “when it was done.” In healthcare, we sometimes have to do awkward and unpleasant things to our patients; I wanted to keep that part of medicine secret. I justified the separation of child and parent with the idea that I was sparing them. I justified the separation hoping I would perform better if the parents weren’t there. The truth is, separating parent and child made my job easier.

The option of family presence is standard of care at some hospitals. In these institutions, families are offered the choice to remain present with their child or loved one during procedures and resuscitations. They are also offered the choice to wait
separately until the medical team has done its work. If the family decides to remain present, a nurse stays with them to provide support and explanations. The nurse is also able to ensure the family does not interfere with medical care.

My ER did not offer me a choice. My regret supports research findings that families prefer to be offered a choice. Those who choose to be present understand that healthcare is often awkward, and even gruesome. They understand that the doctors and nurses are doing the best they can. The knowledge of what happened to their loved one during resuscitations supports healthy bereavement, especially when a child dies.

During the three hours that I waited, my daughter’s brain herniated. Her brain’s reaction to oxygen deprivation was to swell. Ultimately, it became so swollen that it squished down from her skull towards her spine. My deepest regret is that I wasn’t with my child at this terrible and precious time.

As I move into a future without her, I relive these three hours. The images of that time appear in frames and replay over and over again. I wish I could have protected her.

The image in the back contradicted my calm discussion with the doctors in the front. The back described a full-on code, with everyone prodding, pumping and ravaging a patient who is dead but should be alive. Didn’t the doctors understand that the patient, and the family, didn’t want extraordinary measures? Didn’t the doctors appreciate that she was deprived of oxygen and perfusion for 55 minutes?

The image of her lying naked in a crucifixion position makes me wonder if anyone else noticed this.

In my darker moments, I wonder if she was a body that they practiced on. It was July, and new interns had just arrived. Did the ER attendings line up the interns to learn central line placement? “Go ahead, try on this one, she can’t feel a thing.” Or, “this is a good one for your first, she’s got great landmarks.” Or, “everyone should take a try; if you can’t get it, it won’t matter.”

Did anyone know she was a scholar at the university? She was like them. She was like their own children. She was one of ours.

Did anyone know she was an accomplished ballet dancer? Did they notice the exquisite beauty of her white shoulders and arms? Did they recognize the gorgeous line of her long, elegant limbs?

I’ll never know what might have happened if I had been with her in the room where she died. I am left to wonder. Maybe I could have aborted the trajectory that futilely maintained my child for the next 30 hours. Maybe someone would have listened if I yelled, “Stop. Please!” Maybe I could have sat next to her and held her hand. Instead, I was in the front, and she was in the back.

Lacey Colligan, MD MSc FAAP, is a pediatrician with research expertise in patient safety science, human factors and informatics. She can be reached at rlcolligan@mac.com.
The REDE model of healthcare communication: Optimizing relationship as a therapeutic agent

Amy K. Windover, Ph.D., a Adrienne Boissy, M.D., M.A., b Thomas W. Rice, M.D., c Timothy Gilligan, M.D., d Vicente J. Velez, M.D., e and James Merlino, M.D. f

Abstract

The REDE model is a conceptual framework for teaching relationship-centered healthcare communication. Based on the premise that genuine relationships are a vital therapeutic agent, use of the framework has the potential to positively influence both patient and provider. The REDE model applies effective communication skills to optimize personal connections in three primary phases of Relationship: Establishment, Development and Engagement (REDE). This paper describes the REDE model and its application to a typical provider-patient interaction.

Introduction

Effective communication is the foundation for any relationship in healthcare, and our ability to consistently deliver high-quality care requires that this relationship be strong and meaningful. A significant tradition of work on the therapeutic alliance, patient-centeredness and relationship-centered care has long recognized the healing potential of the healthcare relationship.1 In our experience teaching relationship-centered communication to thousands of seasoned clinicians, we nonetheless recognized that many providers did not intuitively view forming relationships with patients as their role, nor did they perceive benefits of this mode of communication. In addition, in a world intensely focused on patient experience, providers often feel left out. Subsequently, building upon the previous theoretical and empirical work, we constructed a model that put the concept of relationships in healthcare at the forefront. To further reinforce the concept, we directly correlated phases of the healthcare relationship to phases of the medical interview and communication skills therein. Emphasizing the premise that genuine relationships are a vital therapeutic agent,2 3 use of this framework has the potential to positively influence both patient and provider.

The REDE model

The REDE model of healthcare communication is a conceptual framework for teaching and evaluating relationship-centered communication. REDE harnesses the power of relationships by organizing the rich database of empirically validated communication skills into three primary phases of Relationship: Establishment, Development and

CASE STUDY AND BEST PRACTICES

Relevant disclosures: None
Engagement (see Figure 1). Many models of healthcare communication exist. In our experience, several considerations led to the design of REDE, its resonance with advanced clinicians and implications for teaching. First, REDE is informative and also transformative because it challenges users of the model to explore their own assumptions and beliefs about patients and their role as providers. Second, we recognized that seasoned clinicians have performed countless interviews and often developed an unconscious competence in communication. Our teaching of REDE appreciates the skills clinicians already have, intentionally models relationship-centered communication in our facilitation method and encourages reflective competence by providing a common language that allows providers to reflect and refine their own skills. Third, the REDE model characterizes communication skills as tools in a toolbox, to be applied as needed. For the healing power of a relationship to be optimized, the skills must be presented in a manner that is genuine and authentic. If every provider was encouraged to recite the same lines of welcome, patients would perceive them as rote and impersonal. At the same time, we acknowledge that in early stages of learning, most newly introduced behaviors can feel scripted or unnatural until they become automated from repetition and practice. For ease of recall and utility, REDE also includes a mnemonic for each relationship phase that further supports the principles of relationship-centered care, as we have found, not unexpectedly, that learners codify information differently, and some appreciate explicit verbiage. Fourth, the REDE model can be generalized to a variety of settings. Because adult learning theory has shown that anchoring new information in what is already known facilitates learning, REDE skills can easily be woven into the traditional medical interview (See Figure 2) in both outpatient and inpatient settings and used across settings in a variety of conversations.

**Phase 1: Establish the relationship**

Creating a safe and supportive atmosphere is essential for making a personal connection, fostering trust and collaboration. The emotion bank account is a concept originally proposed by psychologist and author John Gottman, Ph.D. It refers to a mental system for tracking the frequency with which we emotionally connect with other people. Each time an emotional connection is made, it is equivalent to making a deposit in the emotion account with that person. Building up the emotion account is important to sustain a personal connection. This way, when a withdrawal inevitably occurs, such as when a patient is forced to wait to see a provider, the emotion account does not automatically go into the red.

**Convey value and respect with the welcome.** In doing so, we are essentially building the emotion bank account with our patients and families. Given that people form first impressions very quickly and patients are discussing emotional and value-laden topics, how we set the stage for conversation matters, even if it feels irrelevant to the clinical problem(s) at hand. The skills outlined in Phase 1 are intended to create a climate conducive to the development of trust by demonstrating that the provider is receptive and interested in the person first, patient second.

**Collaboratively set the agenda.** Many providers fear this practice will sacrifice time necessary for assessing or treating the primary concern. However, research has shown that sharing in agenda setting not only facilitates partnership but also improves visit efficiency, diagnostic accuracy and patient satisfaction. Sharing in the agenda setting helps minimize our tendency to presume what a patient’s concerns are and in what order of priority.

**Introduce the computer.** The electronic health record is a reality for most healthcare providers. How we introduce and utilize the computer should be explained as a means of enhancing patient care rather than detracting from it.

**Demonstrate empathy.** Empathy is the ability to imagine oneself in another’s place and to understand that person’s thoughts and feelings. In his book, “Empathy and the Practice of Medicine,” Howard M. Spiro, M.D., described empathy as “I and you becomes I am you or I might be you (p. 9).” Substantial research has examined the importance of empathy. Human beings are hard-wired to be empathic toward one another. Unfortunately, we also know that, without intervention, empathy declines through medical training, over time in practice and with task pressure. Our experience is that most providers care about their patients, but not all recognize emotional cues or respond to them. Making verbal statements of empathy has been shown to reduce the length of both an outpatient surgery and primary care visit. In REDE, every opportunity to convey empathy is encouraged, and the mnemonic SAVE is introduced for outlining different types of empathic statements a provider can use.
CASE STUDY AND BEST PRACTICES

Figure 1: The REDE Model Skills Checklist

<table>
<thead>
<tr>
<th>Relationship:</th>
<th>Establishment Phase I</th>
<th>Development Phase II</th>
<th>Engagement Phase III</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Convey value &amp; respect with the welcome</strong></td>
<td>Review chart in advance &amp; comment on their history</td>
<td>Engage in reflective listening</td>
<td>Share diagnosis &amp; information</td>
</tr>
<tr>
<td>• Nonverbally – doing only that which feels natural &amp; authentic to you</td>
<td>Knock &amp; inquire before entering room</td>
<td>• Nonverbally – e.g., direct eye contact, forward lean, nodding</td>
<td>• Orient patient to the education &amp; planning portion of the visit</td>
</tr>
<tr>
<td>• Greet patient &amp; companions formally with smile &amp; handshake</td>
<td>Verbally using continuers such as “mm-hmm”, “I see”, “go on” or reflecting the underlying meaning or emotion of what is said – “What I hear you saying is…” or “Sounds like…”</td>
<td>• Avoid expressing judgment, getting distracted, or redirecting speaker</td>
<td>• Present a clear, concise diagnosis</td>
</tr>
<tr>
<td>• Introduce self &amp; team; clarify role(s)</td>
<td>• Recognize emotional cues &amp; respond “in the moment”</td>
<td>• Express appreciation for sharing</td>
<td>• Pause if necessary</td>
</tr>
<tr>
<td>• Position self at patient’s eye level</td>
<td>• Clarify the emotion if needed</td>
<td>• Collaboratively develop the plan</td>
<td>• Provide additional education, if desired &amp; helpful to the patient</td>
</tr>
<tr>
<td>• Recognize &amp; respond to signs of physical or emotional distress</td>
<td>• Validate – “Most people would feel the way you do.”</td>
<td>• Frame information in the context of the patient’s perspective</td>
<td>• Alert patient that the visit is ending</td>
</tr>
<tr>
<td>• Attend to patient’s privacy</td>
<td>• Emotion naming – “You seem sad.”</td>
<td>• Provide closure</td>
<td>• Affirm patient’s contributions &amp; collaboration during visit</td>
</tr>
<tr>
<td>• Make a brief patient-focused social comment, if appropriate</td>
<td>• Nonverbally - doing only that which feels natural &amp; authentic to you</td>
<td></td>
<td>• Arrange follow-up with patient &amp; consultation with other team members</td>
</tr>
<tr>
<td><strong>Collaboratively set the agenda</strong></td>
<td><strong>Demonstrate empathy using SAVE</strong></td>
<td><strong>Explore the patient’s perspective using VIEW</strong></td>
<td><strong>Dialogue throughout using ARIA</strong></td>
</tr>
<tr>
<td>• Orient patient to computer</td>
<td>• Recognize emotional cues &amp; respond “in the moment”</td>
<td>• Vital activities – “How does it disrupt your daily activity?” or “How does it impact your functioning?” or “What do you think is wrong?”</td>
<td>• Assess using open-ended questions</td>
</tr>
<tr>
<td>• Explain benefit to the patient</td>
<td>• Allow space to be with the patient &amp; their emotion without judgment</td>
<td>• Expectations – “What are you hoping I can do for you today?”</td>
<td>– What the patient knows about diagnosis &amp; treatment</td>
</tr>
<tr>
<td>• Include patient whenever possible (e.g., share labs or scans)</td>
<td>• Clarify the emotion if needed</td>
<td>• Worries – “What worries you most about it?”</td>
<td>– How much &amp; what type of education the patient desires/needs</td>
</tr>
<tr>
<td>• Maintain eye contact when possible</td>
<td>• Recognize emotion evoked in you &amp; refrain from trying to fix or reassure</td>
<td></td>
<td>– Patient treatment preferences</td>
</tr>
<tr>
<td>• Stop typing &amp; attend to patient when emotion arises</td>
<td>• Demonstrate verbally with SAVE – Support – “Let’s work together...” – Acknowledge – “This has been hard on you.” – Validate – “Most people would feel the way you do.” – Emotion naming – “You seem sad.”</td>
<td>• Health literacy</td>
<td>– Health literacy</td>
</tr>
<tr>
<td><strong>Introduce the computer, if applicable</strong></td>
<td><strong>Collaboratively develop the plan</strong></td>
<td><strong>Provide closure</strong></td>
<td><strong>Reflect patient meaning &amp; emotion</strong></td>
</tr>
<tr>
<td>• Orient patient to computer</td>
<td>• Describe treatment goals &amp; options including risks, benefits, &amp; alternatives</td>
<td>• Alert patient that the visit is ending</td>
<td><strong>Inform</strong></td>
</tr>
<tr>
<td>• Explain benefit to the patient</td>
<td>• Elicit patient’s preferences &amp; integrate into a mutually agreeable plan</td>
<td>• Affirm patient’s contributions &amp; collaboration during visit</td>
<td>– Tailor information to patient</td>
</tr>
<tr>
<td>• Include patient whenever possible (e.g., share labs or scans)</td>
<td>• Confirm patient’s commitment to plan</td>
<td>• Arrange follow-up with patient &amp; consultation with other team members</td>
<td>– Speak slow &amp; provide small chunks of information at a time</td>
</tr>
<tr>
<td>• Maintain eye contact when possible</td>
<td>• Identify potential treatment barriers &amp; need for additional resources</td>
<td>• Provide handshake &amp; a personal goodbye</td>
<td>– Use understandable language &amp; visual aids</td>
</tr>
<tr>
<td>• Stop typing &amp; attend to patient when emotion arises</td>
<td>• Summarize list of concerns to check accuracy</td>
<td></td>
<td><strong>Assess patient understanding &amp; emotional reaction to the information provided</strong></td>
</tr>
</tbody>
</table>

© 2013 The Cleveland Clinic Foundation. All Rights Reserved.
Phase 2: Develop the relationship

Genuine curiosity and interest are the necessary first steps in relationship building. However, once a safe and supportive environment has been created, the relationship needs to evolve and grow. Getting to know who the patient is as a person and understanding that person’s symptoms in a biopsychosocial context is the next step. Developing the relationship also requires continued deposits into the emotion bank account and, thus, ongoing use of empathy.

**Listen reflectively.** Shown to enhance the therapeutic nature of a relationship, increase openness and the disclosure of feelings and improve information recall, 28, 29, 30 reflective listening is vital for developing the relationship. Yet listening in such a way as to understand and acknowledge what is being said can be a deceptively complex and challenging skill.

**Elicit the patient narrative.** Obtaining the history of present illness (HPI) can quickly become a series of closed-ended questions that are of most interest to the provider. 31, 32 However, the goal of this skill is to better understand the patient’s perspective on his or her symptoms. This has been proven more efficient and effective than a provider-centered data gathering approach. 33

**Elicit the patient’s perspective.** Explanatory models are values, beliefs and experiences that shape a person. 34 Being curious to explore and open to learn are key to knowing the person, their illness that is a social response to disease and the disease itself. The REDE model suggests a simple mnemonic VIEW to explore the patient’s perspective.

Phase 3: Engage the relationship

The last step in relationship building aligns with the education and treatment portion of a patient encounter. Relationship engagement enhances health outcomes by improving patient comprehension and recall, 35, 36 capacity to give informed consent, 37 patient self-efficacy, 38, 39, 40 treatment adherence and self-management of chronic illness. 41, 42, 43

**Share diagnosis and information.** Telling a patient the medical facts and what he or she needs to know is not sufficient for effective care. We must also be sure the patient understands the information. Framing information in the context of the patient’s perspective and engaging in dialogue that allows the patient to register new information and ask clarifying questions facilitates patient understanding. 44, 45, 46, 47

**Collaboratively develop a plan.** Relationship engagement is designed to support patient understanding, decision making and consideration of potential treatment barriers. Treatment adherence and behavior change are more likely when the patient is an integral part of the planning process and agrees with the recommendations. 48

**Provide closure.** Ending a visit can easily be taken for granted. However, reviewing the time spent and demonstrating respect and appreciation for the patient provides closure and engenders continued partnership.

**Dialogue throughout.** Patients are unable to comprehend and accurately recall a considerable amount of information presented during a typical medical visit. 49, 50 Dialogue, as opposed to monologue, keeps the patient involved in the learning process 51 and, more important, reflects the importance of the patient’s role as head of his or her treatment team. In REDE, the sequence for engaging in this dialogue throughout the education and treatment portion of a patient visit is summarized by the mnemonic ARIA.
Summary
Effective communication is necessary to deliver safe, high-quality medical care. At the core of effective communication is the ability to develop meaningful relationships with patients. The REDE model builds on a significant research base including placebo, therapeutic alliance, communication skills and patient-centeredness that recognizes the healing potential of the healthcare relationship for not only patients but also providers. The REDE model helps frame the specific communication strategies that optimize their effect(s) on processes, outcomes of care and the patient-provider relationship itself. The REDE model also encapsulates evidence-based communication practices and our experience with seasoned clinicians, mostly staff physicians, within a large hospital system. It is hoped that such systemwide efforts will result in improved experience of care and self-efficacy for patients, and increased confidence, emotional connectedness and resiliency for providers. Future research will examine the generalizability of the REDE model for different contexts and provider types, as well as its potential to impact patient and provider outcomes.

References
26. Spiro et al., Empathy.
Introduction
In providing end-of-life care to patients with advanced disease, conversations around treatment failure, transition to palliative care, resuscitation and discontinuation of life support can evoke strong emotions in both the patient and family, as well as in the physician.\(^1\)\(^2\) Regarding the latter point, it can be daunting for the clinician to be present and know how to respond when patients and families are shocked by bad news, are in disbelief when told that their loved one may not recover from an illness or are intensely saddened when it is explained that there is no more effective treatment for a progressive disease.\(^3\)\(^4\) It may be even more of a challenge for the practitioner when patients and families respond to negative information with denial or anger or blaming of the medical team.\(^5\)

Empathy is a core feature of patient-centered care. It enables practitioners to better understand patient and family concerns that are key to satisfaction with care, prevention of anxiety and depression, and patient empowerment. Current methods of teaching communication skills do not specifically focus on enhancing the ability to “stand in the patient’s shoes” as a way of connecting with the patient and/or family experience and understanding feelings that may be a source of conflict with providers. In this paper, we present a model for deepening empathic understanding based upon action methods (role-reversal and doubling) derived from psychodrama and sociodrama. We describe these techniques and illustrate how they can be used to identify hidden emotions and attitudes and reveal that which the patient and family member may be thinking or feeling but be afraid to say. Finally, we present data showing that these methods were valuable to participants in enhancing their professional experience and skills.

Enhancing the empathic connection: Using action methods to understand conflicts in end-of-life care

Silvia Tanzi\(^a\), Guido Biasco\(^b\), Walter F. Baile\(^c\)

Abstract
Empathy is a core feature of patient-centered care. It enables practitioners to better understand patient and family concerns that are key to satisfaction with care, prevention of anxiety and depression, and patient empowerment. Current methods of teaching communication skills do not specifically focus on enhancing the ability to “stand in the patient’s shoes” as a way of connecting with the patient and/or family experience and understanding feelings that may be a source of conflict with providers. In this paper, we present a model for deepening empathic understanding based upon action methods (role-reversal and doubling) derived from psychodrama and sociodrama. We describe these techniques and illustrate how they can be used to identify hidden emotions and attitudes and reveal that which the patient and family member may be thinking or feeling but be afraid to say. Finally, we present data showing that these methods were valuable to participants in enhancing their professional experience and skills.
practitioners began in the ’70s and ’80s, when survival from serious diseases increased and ethical norms dictated that the patient be given truthful information and encouraged to participate in decision making. Despite this, evidence-based teaching methods have not yet completely caught on, both in Anglo and non-Anglo countries.7-10

In teaching communication skills, case presentations have been effectively used to illustrate key issues and challenges in patient care. This method is often accompanied by role-plays,11 in which learners are given the opportunity to try out different strategies, such as how to give bad news. Learners thus may interview a standardized patient or role-play among themselves to permit strategies for communication to be tried out in a safe way, where they can be coached to improve their skills. This type of experiential learning is considered the cornerstone of teaching communication and interpersonal skills.12-15

In this paper, we describe the use of advanced role-play techniques called “action methods” and how they are incorporated into dramatic enactments. Action methods are derived from the teachings of Jacob Moreno (1889-1974), a psychiatrist who used them to create scenarios in which challenging social situations were enacted so that participants could “see” rather than “hear about” problematic interactions.16

They are aptly named action methods because they are used in the setting of enactments that dramatically recreate problematic interactions often involving conflict in order to reveal the underlying complex social dynamics. These methods differ from standard role-play in that they are focused on having participants step into the shoes of the patient, thus creating empathy for him or her.

As previously mentioned action methods do not usually stand upon their own but are instead usually part of an enactment called psychodramas (an individual’s story) or sociodramas (a story created by the group), which strive to replicate the communication dilemma. They are meant to reveal the communication complexities with the goal of not only developing a deeper understanding of them but to enable participants to formulate and explore possible communication solutions. Action methods are designed not only to help recreate a scenario but to immerse the group participants in the life of the enactment and to stimulate an empathic connection to the feelings of the different characters participating in the drama and how they influence the action, potentially leading to insight into the communication

### Table 1. Examples of how painful emotions may be displaced by those that are easier to express

<table>
<thead>
<tr>
<th>Emotion</th>
<th>Thought/Feeling</th>
<th>What a person does/says/exhibits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear/Anxiety</td>
<td>My father’s going to die. I can’t handle this.</td>
<td>DEMANDING BEHAVIOR: “Don’t tell him his cancer has come back”</td>
</tr>
<tr>
<td>Helplessness</td>
<td>I just don’t want to make the wrong decision.</td>
<td>SEEKING REASSURANCE: “What would you do doctor?”</td>
</tr>
<tr>
<td>Loss of Control</td>
<td>I can’t stand not knowing what is going to happen.</td>
<td>ANGER: “The CT was done this morning. You mean you haven’t seen it?”</td>
</tr>
<tr>
<td>Confusion</td>
<td>They’re telling me I’m better but I don’t feel good.</td>
<td>DISTRUST: “I don’t think they’re telling me the truth”</td>
</tr>
<tr>
<td>Guilt/Shame</td>
<td>If I had been there for her maybe this would not have happened.</td>
<td>BLAMING OTHERS: “Why aren’t you doing more for him?”</td>
</tr>
<tr>
<td>Denial</td>
<td>It just can’t be true. I’m so scared.</td>
<td>UNREALISTIC EXPECTATIONS: “I just know there’s going to be a miracle”</td>
</tr>
<tr>
<td>Panic</td>
<td>I can’t handle this hospital confinement.</td>
<td>IMPULSIVENESS “I’m going to leave the hospital”</td>
</tr>
<tr>
<td>Discouragement/Hopelessness</td>
<td>I don’t think I’m going to make it.</td>
<td>VICTIMIZATION “Nothing good ever happens to me”</td>
</tr>
</tbody>
</table>

Fig 1. The Emotional Jug. Emotions which are too painful to face are displaced by ones that are easier to express.
in communication skills.

In this paper, we describe several action methods and illustrate how they were used in a workshop with learners who were participating in a communication skills workshop as part of a program awarding a master’s degree in palliative care. We explain how, through enacting a case of a difficult conversation, a debriefing of the learners and incorporation of didactic elements into the program, a simple case presentation can be transformed into a powerful vehicle for professional development in communication skills.

Table 2. “Action” Methods

| Warm up exercises, a form of “getting to know you.” | These enhance the spontaneity necessary for participants to enter into role-play and promote the working relationship among group members through sharing of information |
| Role-taking. | Participants enact characters from a case that they have selected. Case selection is learner-centered and reflects the priorities of the participants. The characters are invented by the group from their own experiences with similar cases. This enables participants to take on the role of characters in the scenario |
| Doubling. | Doubling encourages participants to speak for group members taking on roles to facilitate their immersion in their role and reveal unspoken or hidden emotions, thoughts and attitudes. In doubling, participants stand behind a role-player and speak for him or her, revealing attitudes, values and feelings that they imagine their character might have, based upon the challenge facing that person. Participants can also double themselves as characters. |
| Role-reversal. | A technique whereby the facilitator asks the main character to assume the role of other characters in their scenario to help set the scene. Role-reversal is also used to allow the main character to experience, in the role of others, the impact of that person’s own actions and communication. Thus, a main character who tells a patient that there is no hope would reverse roles with that patient and become that patient in order to experience what that statement feels like. |
| Processing. | This discussion that follows the enactment gives participants the opportunity to say how the enactment affected them personally or what it was like for them to be in the role of someone in the enactment. |
| Role-training. | A form of role-play in which participants practice the skills that can help them become more expert in their professional roles. |

Methods

The dramatic enactment we will discuss was conducted as a part of a two-day communication skills training workshop for 19 palliative care professionals attending the Master’s Program in Palliative Care at the University of Bologna, Italy. The learners who participated were nurses, palliative care physicians, oncologists, psychologists, physical therapists and a philosophy student. 

The enactment followed sequential steps. (See appendices in the online version of Journal of Patient Experience at [www.patient-experience.org](http://www.patient-experience.org) for the entire story and accurate description of the psychodrama.)

- Warmups (described in references 17 and 18) and in Table 2
- Presentation of the story (See below.)
- Setting the scene (appendix 1)
- Preparation for learners and scenario-setting using some action techniques with the group mediated by the facilitator (role reversal, role immersion, doubling, asides, role training) (appendix 1)
- Enactment: Each character assumes the role that they learned. (appendix 2)
- Debriefing with arising benefits from the enactment (appendix 3)

About two months after the workshop, a questionnaire was submitted by email to all participants. The survey asked participants to evaluate the workshop along five dimensions: organization, usefulness of skills taught, effectiveness of the program, acquisition of skills and acquisition of knowledge.

Selecting a case for enactment

The first step of the workshop was to solicit a challenging case from the participants. Lidia, a hospice nurse, volunteered to present the two-part case of Angela, and Lidia’s conflict with Angela’s son and Lidia’s own supervisor. The facilitator (WB), trained in the use of action methods, guided Lidia in telling the following story to the group: Lidia was assigned to make a home visit to Angela, an 82-year-old woman who had recently been discharged from the hospital, where she had been admitted with abdominal pain. Angela was diagnosed with advanced pancreatic cancer. Angela’s disease was inoperable, and after diagnosis, she was discharged home on opioid analgesics and scheduled for a followup visit by the home hospice nurse, Lidia. However, keeping with the wishes of her son, Antonio, an engineer who lived at home with his mother, Angela was not told of her recent diagnosis, nor about the severity of her disease.
After the home visit, however, Lidia was abruptly taken off of Angela’s case with no explanation. Several days later, the medical director of the hospice called to tell her that the hospice coordinator had transferred her from the case because Angela’s son, Antonio, complained that, in talking to his mother, he noticed that Lidia acted very serious and a little sad, and he did not want this type of communication with his mother. The actual enactment is described in the appendices.

Appendix 1 describes how the role-play encounter was set up by using warm-ups.

Appendix 2 describes how the enactment played out in a sociodramatic fashion, with participants taking on the part of the characters.

Appendix 3 describes the debriefing of the scenario, whereby those involved in the enactment talk about how it felt to them being in the role of others and what insights they obtained. Group members also relate as to how the drama affected them personally.

Comments on the enactment
One of the important goals of psychodrama and sociodrama is to explore conflicts. In the story, Lidia had two emotionally laden conflicts: that with Antonio, and that with her coordinator. The goal of the planned enactment was to use action methods to recreate first the scenario of Lidia so that her interaction with Angela and Antonio could be examined and explored by the group and the social dynamics more deeply appreciated and understood. Then Lidia would have also the opportunity to enact a conversation with her supervisor over the actions that she had taken to remove Lidia from the case.

Results (see tables 3-4)
The median average of work experience of participants was nine years and ranged from the newly graduated to the most experienced learner, who had been employed for more than 30 years in the area. More than half of the group had been in their position for five years or longer. Ninety-four percent of participants rated the workshop as well organized (rating of 4-5) and that time was used effectively. Eighty-two percent said it was useful or very useful) to them in their professional lives. Eighty percent of participants rated the format as very effective and as providing them with important communication skills. To the question of, “Which aspects of the workshop did you like most?” half (nine) of the participants mentioned the applicability of the techniques taught and the realism of the scenarios. Six mentioned the methodology used, such as role-play or doubling, and three students underlined the skill of the facilitator in being clear, straightforward and spontaneous.

From the post-workshop questionnaire, it can be seen that all learners reported that they had implemented at least one skill learned from the workshop. The most frequent of these was the use of empathic statements.

Seventy percent of the learners expressed the desire to attend additional workshops, and several suggested they be focused on communication with family or children. Three proposed additional training by watching videos of difficult cases with discussion, or participating in other workshops with co-workers at their place of employment.

### Table 3. Demographic characteristics of participants

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Seniority (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>10</td>
</tr>
<tr>
<td>Palliative physician</td>
<td>12 (range 2-32)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>12 (range 3-20)</td>
</tr>
<tr>
<td>Philosopher</td>
<td>1</td>
</tr>
<tr>
<td>Oncologist</td>
<td>6</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>6</td>
</tr>
</tbody>
</table>

### Table 4. Questionnaire results regarding participant satisfaction with different dimensions of the program

<table>
<thead>
<tr>
<th>Rating scale 1-5</th>
<th>1 (Poor)</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 (Excellent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well organized</td>
<td>1</td>
<td>8</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time effectively used</td>
<td>1</td>
<td>7</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usefulness of skills</td>
<td>3</td>
<td>3</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effectiveness of the program</td>
<td>2</td>
<td>10</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skills acquisition</td>
<td>1</td>
<td>11</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge acquisition</td>
<td>3</td>
<td>11</td>
<td>5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 5. Frequency of communication skills taught in the workshop and used in daily work

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Sometimes</th>
<th>Often</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathic statements</td>
<td>8</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Wish statements</td>
<td>5</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Exploratory questions</td>
<td>7</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Six-seconds rule</td>
<td>8</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>Staying calm</td>
<td>6</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>
The participants uniformly rated the course highly and reported an increase in their technical communication skills, favorable changes in their attitudes toward communicating bad news and higher self-reported confidence in their ability to effectively communicate with patients and family.

Discussion

The simulation of cases is a technique of proven effectiveness for teaching communication and interpersonal skills in medicine. Role-play and dramatic techniques have been used in the medical field to improve basic communication, teach complex communication techniques, increase empathy and improve self-confidence. They have also been used in palliative care and end-of-life care.

In many countries, there is a lack of communication skills programs and information regarding how to effectively address difficult communications in patient care. This is especially true in Southern European countries, where a patient-centered model of care may still be unfamiliar. Workshops such as those described, which include formal teaching, role-play and small/large group exercise have been effective in this setting in teaching communication techniques. However, action methods have not routinely been incorporated into this teaching.

Advanced role-play enactments such as sociodrama and psychodrama that incorporate action methods put words into action and explore the substrate of human emotions behind the difficult communications and interactions. Revealing the hidden attitudes, emotions and values allows participants to respond to human problems and dilemmas.

In comparison with other methods of teaching, such as the discussion of cases and interviews with trained actors, sociodrama and psychodrama are similar to other dramatic teaching methods such as improvisation and theater. Unlike role-play and theatre, these techniques enhance the opportunity to increase empathy, and by putting directly in action scenarios they have established, the students can double and assume the role of characters on stage.

Doubling is a technique for revealing unspoken thoughts and feelings, thus broadening our understanding of the dynamics of the encounter and stimulating the group to reflect and observe on how the unspoken thoughts and feelings of the character might be motivating the character to act and speak in a certain way.

The doubling technique illustrated in the scenario described (see appendix 1 for details) serves to bring the group into the enactment by creating empathy for the characters by asking them for a moment to step into the shoes of Angela. The empathy immerses them in the drama in a deeper way. It is also a gateway to addressing patient emotions that were previously hidden and allows the facilitator to brainstorm with the group to formulate empathic responses to these emotions. Thus, during the workshop, the facilitator stopped the action occasionally to teach specific skills, such as how to make empathic statements to address patient emotions and their own emotions. This intervention can introduce a pedagogical element into a sociodramatic or psychodramatic enactment and expand its goals.

Conclusion

This paper illustrates how action methods used psychodramatically can reveal the personal and interpersonal dynamics often seen in complex patient and family encounters. These insights are particularly important because, in Southern European countries such as Italy, openness in discussing bad news is less common, and the paternalistic approach of protecting the patient is very strong. Some available data suggest that the climate is changing toward providing essential medical information to patients and families, but unpleasant communication such as disclosure of diagnosis and prognosis is often concealed.

Finally, the conclusions drawn from the evaluation of this project must be interpreted cautiously because of the small sample size of palliative care professionals. However, it does provide suggestive evidence that communication techniques such as those mentioned above could be learned using dramatic enactments such as the one described. This could be done perhaps at the same time, and also without increasing costs of standardized patients, by incorporating action methods into communication skills teachings using conventional role-play.

Appendix 1: Setting the scene

Lidia’s Conflict

Interviewed by the facilitator so that the group could understand her conflicts, Lidia presented the story of Angela and her son, Antonio, to the group. Specifically, she related that in making a home visit to Angela, which was scheduled by her hospice organization, she was met at the door by Antonio, who greeted her and related briefly the history of his mother, telling Lidia that his mother did not know her diagnosis and was not to be told. Lidia was bewilder by this request. After an introduction to his mother, Lidia sat and spoke to Angela for some minutes, conducting a review of symptoms. Lidia related to the group that she was concerned about Angela because she was having significant abdominal pain. During the meeting, Lidia asked Lidia what was wrong with her. As Lidia...
continued her interview with Angela, she was soon interrupted by Antonio, who said that his mother was too tired to go on and that it would be better to continue the conversation at another time. As he escorted her to the door, he reiterated that he did not want his mother to know about her disease and briefly stated, “The thought of mama being gone has been devastating. I'm not sure what I will do without her.” He then quickly ushered her out the door and would not discuss anything further, even though Lidia attempted to have further conversation. She was left feeling very ill at ease about being so abruptly dismissed and around Antonio’s brief display of distressing emotions.

Lidia was particularly dismayed because Angela seemed to want to know about her illness but was blocked by Antonio and she ruminated about it for some time. Several days later, the medical director of the hospice called to tell Lidia that the hospice coordinator had taken off the case because the patient’s son complained that, in talking to his mother, he noticed that Lidia acted very serious and a little sad, and he did not want this type of communication with his mother. Moreover, Antonio said he did not trust that Lidia would not tell his mother about her disease. Lidia was stunned by this and felt even more puzzled. Her feelings were hurt because she had always prided herself in being a good nurse, and her patients seemed to like her. However, she did not say anything, carrying the sting of this repudiation around for a year and never bringing it up with her coordinator.

Setting up the dramatic portrayal: the facilitator’s interventions

In order to explore Lidia’s dilemma, the facilitator used an action method called role-reversal to set up this dramatic portrayal. It consisted of several steps. In the first step, Lidia was asked to select someone from the group to help her in the portrayal by taking on the role of Angela. When a person was selected to be Angela, we will call her Maria, the facilitator (WB) helped Lidia prepare this person for the role of Angela by reversing roles with Maria and becoming Angela. This is necessary because only Lidia has a personal knowledge of Angela, and Maria, who will assume this role, must learn (and also the group must learn) the social particulars about Angela and what she is thinking and feeling. This is called role-immersion. Lidia was thus interviewed by the facilitator in the role of Angela. The facilitator asked social questions, such as how old she was, about her family and details of her medical illness. This revealed for the group that Angela was in distress from abdominal pain and troubled by the lack of knowledge about what was wrong with her. During the interview, when Angela talked about how bad she felt, the facilitator introduced the concept of doubling. The purpose of doubling is to explore Angela’s feelings and attitudes that are unspoken but that could contain important information about her current emotional state, wishes and thoughts. Doubling consists of two parts: in the first part of self-doubling, the character (in this case Angela) is asked to stand behind her own chair and take a step back from her standing position. The facilitator then asks, “Angela, can you tell us what you are thinking and feeling that you might not be saying?” Angela exclaimed that she was hurting, the medicine is not doing much good and she is worried. She also said that she was puzzled why her son sent the nurse away. This doubling provides the group with additional information that is important in understanding the dynamics of Angela’s illness and the reactions to it.

In the second half of doubling, members of the group were asked to come up and stand behind Angela to add their own empathic understanding of what Angela might be feeling. The facilitator started by asking, “Who can imagine what Angela might be feeling?” Group members who raised their hand then proceeded to stand behind Angela and speak as if they were Angela. In this situation, phrases that were expressed included, “I’m so confused.” “I’m afraid of what is wrong with me.” “I’m angry that they sent me home from the hospital still hurting.” In these situations, the facilitator might also double Angela, for example saying, “I’m not sure why Antonio is acting so strange. He wouldn’t let that nurse finish her visit with me.”

The selection of additional characters in the drama was guided by Lidia, who was then asked to choose someone to take the part of the son, Antonio. She reversed into (assumes) the role of Antonio and was interviewed by the facilitator.

Facilitator: “Antonio, tell us about yourself and about your mother.”

Antonio: “I have lived with my mother all of my life, and I can’t stand to see her in this state. She is the only one who understands me. The thought of losing her is devastating.”

Group members doubled for Antonio, and picking up on his last statement, further expanded on what he might be feeling “I just can’t think of losing my mother.” “I am really anxious about what is going to happen to her.” “I don’t know what will happen if she finds out she has cancer.” “What will I do without her?” Thus, the feelings of fear, anxiety, helplessness and anticipated loss emerged from the doubling, which helped deepen the group’s understanding of the very troubling situation that Antonio found himself in and helps the group member playing Antonio immerse himself into his role.

Appendix 2: The dramatic portrayal

Enacting the drama

Having set the important characters in the scenario, the facilitator moved the group into an enactment, and each character assumed the role that he or she learned from observing the role reversal. However, this is only the beginning of the use of role reversal, as we will see how the facilitator used it to help Lidia put together all the underlying components of the different personae that we have seen up to now — Angela’s desperation and confusion, Antonio’s fear and sense of helplessness, and Lidia’s puzzlement about what happened in that scenario.

Facilitator: “OK, Lidia, can you precede with the encounter?” At this point, Lidia describes the scene that she will enter, the kind of home that Antonio and Angela live in and other details that might lend realism to her visit and immerse the entire group in the scene.

Lidia meets Antonio at the door, he ushers her in and tells her that his mother does not know her diagnosis, so she should not bring this up with her. Lidia says nothing but enters Angela’s room.

Lidia: “Good morning, Angela. I’m Lidia, a nurse from the hospital. How are you feeling today?”

Angela: “I’m very tired and my stomach hurts. I am not sure what’s wrong.”

Lidia begins to explore the nature of Angela’s pain when Antonio interrupts. “We need to keep taking these pills, mother, so you feel better. You really look tired, and I think we need to let you rest now.”

Exploring the conflict

The enactment proceeded to the point where Antonio stopped the interview and asked Lidia to leave. At this point, the facilitator stopped the action and asked Lidia if she wants to try to discover what was happening to Antonio that he bullied her out the door. With agreement, the scenario was replayed. This time, however, the facilitator, with dramatic license,
allowed Lidia to have a conversation with Antonio, helped by the group, which made suggestions for tactics for her to use such as praising him for his care of his mother, empathizing with his distress and saying, "I’m sorry for your plight" to attempt to align with him. Lidia tried some of these approaches with Antonio, but they seemed to not get very far. The facilitator then suggested that she might explore more deeply what Antonio meant earlier when he said that he would feel “devastated” and that his mother was the only one who understands him. However, in order to allow Lidia to speak as Antonio, each time she asked him a question, she reversed roles with Antonio’s role in order to answer her own question because, on some level, only Lidia knew Antonio and, better than anyone else, could guess what Antonio might be thinking and feeling.

Thus, when Lidia was responding as Antonio to her own question as what the he meant when he said he would feel “devastated” if his mother died and that she was the only one who understood him, Antonio revealed that he was gay and had kept this secret from a lot of people, but this mother knew and always accepted him. This was unlike his deceased father, who was very critical and disapproving of his lifestyle. Although Antonio now had a partner, it was also a new relationship and he could not handle all of the stress of this and his mother’s illness. After revealing this in the role of Antonio, Lidia was reversed back into her own role. She was asked if she knew this information before and she said she had known it coming into the case presentation but had not considered an important determinant of Antonio’s behavior. This conversation led to a discussion of Antonio’s distress. The group at that point recognized the intensity of the bond between Antonio and his mother and speculated that Antonio’s complaint that Lidia was too serious and somber with his mother represented his underlying fear that his mother would come to understand from her conversation the seriousness of her own illness, which frightened him.

**Pursuing a second conflict**

In order for Lidia however to get complete closure on her situation it was also necessary for her to have a conversation with her coordinator, who had pulled her off Angela’s case, as her own feelings of anger and confusion about this issue had also been part of the dynamics of the presentation. She was invited to choose someone from the audience to play the role of the coordinator and subsequently told the group about her coordination through role reversal. Doubling of the coordinator by the group suggested that the coordinator might have been ill at ease in discussing the issue of Antonio with Lidia and that perhaps her motives for taking her off of the case had nothing to do with Lidia’s competence, given what had been previously revealed by the dramatic enactment. There followed a discussion of how, despite Lidia’s lingering anger after a year, Lidia could still have a discussion with her coordinator in a way that the coordinator could hear her concern. In this second half of the enactment, which is called role-training [11] Lidia tried out different strategies for talking to the supervisor without putting her on the defensive. A second conversation was then held, this time with the coordinator using “I” statements that would not make her defensive, with another group member playing the supervisor. This turned out to be successful when the person who was in the role of the supervisor, taking the cues from the doubling, was able to say to Lidia that it was not about her but about how difficult a job it was to make the patients’ families happy. And on the day that conversation with the son occurred, she was feeling overwhelmed. She reinforced the fact that Lidia was, in her eyes, an excellent hospice nurse. The facilitator ended by pointing out that when our feelings are hurt and we feel unfairly accused, it is really difficult to talk about it rather than getting angry.

**Appendix 3: Debriefing of the scenario**

**Processing the drama**

In a debriefing, Lidia was able to relate that she had, at some point, been told that Antonio was gay but had not related that to his distress. In fact, without the benefit of the actual Antonio, we do not know exactly why he was protecting his mother from the information. However, for Lidia, it was important for her to realize that Antonio’s asking her to leave did not likely have to do with her being an incompetent nurse but instead likely had to do with Antonio’s relationship with his mother. This was very relieving and therapeutic for her because, after a year, she liberated herself from the confusion she had been carrying regarding why Antonio might have sent her away and asked for someone else. As part of the debriefing, other actors in the scenario spoke about how it affected them to be in their role. Other members of the group shared how the drama affected them personally.

**References**


Analytical insights from patient narratives: The next step for better patient experience

Cheristi Cognetta-Rieke, DNP, a Senem Guney, PhD b

Introduction

As any person intersects with the current healthcare delivery system — in clinics, emergency departments or hospitals — care providers ask a series of questions to identify patients (name, age, date of birth) and take scientific measurements (height, weight, temperature, blood pressure, heart rate, etc.). These are necessary pieces of information to identify, understand, and begin to create an individualized plan of care for the patient who is seeking healthcare services. The unique aspects of patients as individuals are often not discussed, however, such as the patients’ preferences, culture and values and their expectations of the care experience. This creates significant gaps in the care interaction and in the care being provided. In this thought piece, we present a perspective on bridging these gaps by using patient narratives to provide more personalized care and create better care experiences.

Evidence-based practice

Healthcare organizations across the globe are working to implement an evidence-based practice culture. It has been widely recognized that evidence-based practice is instrumental in delivering the highest quality of healthcare and ensuring the best possible outcomes for patients.1 The U.S Department of Health & Human Services Agency for Healthcare Research and Quality defines evidence-based practice as “applying the best available research results (evidence) when making decisions about healthcare. Healthcare professionals who utilize evidence-based practice use research evidence along with clinical expertise and patient preferences.”2 Melnyk and Fineout-Overholt describe evidence based practice as the “synthesis of evidence from multiple studies and combines it with the expertise of the practitioner as well as patient preferences and values.”1

This shows us that providing the highest quality of care and achieving the best possible outcomes for patients require healthcare providers to inquire about the patients' individual preferences, values and concerns. This valuable information should be included into an evidence-based approach to decision making about the care provided to the patient as an individual. Within our current healthcare delivery system, this information is often overlooked, not recorded within the electronic health record, and most alarmingly, not even discussed with the patient.

We have the technology

We are in an age where technology is sophisticated enough to help us achieve better quality and safety outcomes in healthcare. The technological infrastructure within the healthcare setting allows clinicians to enter patient data at the point of care and allows interprofessional team members to access the data when caring for the same patient in various settings throughout the delivery system. Electronic health records allow patients to access their records remotely via the Internet. These technologies also enable online communication with providers for patients to ask questions or get updates on test results. While we currently have the capability to record patients’ first-hand accounts, this rich source of information is often excluded not only from the patients’ electronic health record, and consequently from the delivery of care, but also from the evaluation of care experiences.

The MyStory© project is an illustration of the existing technological capability to support the use of patient narratives in the delivery of care.3 This project was funded on an Always Event™ grant by the Picker Institute in 2011. The MyStory© tool was initially developed with and for the pediatric patient population and was later expanded to include the adult population. This tool was used as a method to capture the individual story of each patient in responses to questions about the patient’s values, preferences and expressed needs, such as,

Corresponding author

Senem Guney, PhD
Founder & CEO, NarrativeDx
701 Brazos Street
Suite 1601
Austin, Texas 78701

Relevant disclosures: None
“What is your normal routine for sleep, meals and activities?” or “What comforts or calms you?” This tool made it possible to document this information within the electronic health record. All healthcare team members could then view this valuable information and use it to involve the patients in care decisions and care planning. The use of this tool allowed the care to be personalized to each individual patient and positively impacted patient satisfaction scores for the pediatric population.

The perspective we present here is that a similar narrative approach should be used to gain analytical insights into patient experiences and improve satisfaction survey data. The narrative approach in the area of patient experience should concentrate on collecting short, first-hand narratives of specific incidents in the patients’ care experiences. Patient narratives contain valuable information about the patient experience that numerical ratings from standard patient satisfaction surveys do not capture. A recent review of Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS™) survey (http://www.hcahpsonline.org/surveyinstrument.aspx) responses from 589 patients at two hospitals showed that rating scales do not completely assess people’s care experiences. While relatively few people give negative ratings, they can be more dissatisfied than their responses to survey questions indicate. The information about why an individual had a negative experience is in the patient’s story and is not reflected in Likert scale-type responses to questions in standard satisfaction surveys.

Thought leaders in the field of patient experience acknowledge the importance of getting the patient’s perspective to truly improve the patient experience. If a patient answered the HCAHPS™ question, “How often did nurses listen carefully to you?” by marking two responses, the system would recognize it as a “no response.” What if those two responses indicated “Day — Never, Night — Always”? This discarded response would contain very valuable information. When patient stories are collected and analyzed properly to provide the necessary context for quantitative data, they can reveal such subtle yet significant differences between a positive and a negative experience. Analytical capability to process both qualitative and quantitative data rigorously and at large scales is critical for identifying significant trends in patient experience to take focused action for improvement.

Call to action and implications for practice
Patient narratives need to be part of the evidence base that healthcare providers use to achieve the best outcomes for quality, safety and patient experience. It is at this moment in time that healthcare organizations are called to action to employ their patient experience representatives, along with their patient advisers and patient advisory boards, to implement tools and methods that enable the analysis of narratives from patients and their families and create actionable knowledge for the improvement of the patient’s care.

According to the Institute of Patient and Family-Centered Care, “Patient- and family-centered care is an approach to healthcare that shapes policies, programs, facility design and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.”

Patient- and family-centered care (PFCC) will be more effectively achieved and patient experience will be significantly improved by including patient narratives into the evidence base that informs the delivery of care. The most valuable patient experience initiative should focus on 1) hearing and understanding our patients’ stories that reflect their needs and preferences and 2) holding this information as valid as the quantitative data we have on our patients — from lab test results to the scores from patient satisfaction surveys.

Patient experience initiatives focused on patient stories would require us to build scientific rigor into the analysis of narrative data that describe care experiences in the patient’s own words. If caregivers need to better understand their patients’ experiences by “paying attention to anecdotal comments and complaints,” these anecdotal comments and complaints should be collected and analyzed through procedures that are as scientifically rigorous as those in place for the collection and analysis of quantitative data.

Patient narratives provide more valuable insights into patient experience than check-box responses to standard questions on patient satisfaction surveys. People make sense of their experiences in narratives that they construct out of “what actually happened” from their perspective. Asking patients to share short narratives on specific incidents that take place during clinical encounters would provide a robust source of qualitative data. These data can then be analyzed to show the type, frequency or emotional content of incidents that correlate with particular scores on surveyed areas of patient experience. This mixed methods approach would allow hospital administrators and clinicians 1) to know “why” they are being rated with particular scores and understand the drivers behind patient experience and 2) to know “how” to design the most effective patient experience initiatives for improved outcomes.
Application of mixed methods analysis to understanding patient experience

The mixed methods approach to understanding and improving patient experience requires the concurrent triangulation of qualitative and quantitative data collection and analysis. In this approach, equal emphasis is given to both sources of data, where one is used to offset the weaknesses and add to the strengths of the other. Qualitative patient feedback, preferably in narrative form, should be analyzed to show categorical representations for comparisons with quantitative data. Currently, about 20 percent of HCAHPS™ surveys collected contain at least one written comment, and 58.6 percent of those who write comments make more than one comment. When surveys are administered on the phone, patients might provide narrative context to the option they choose on a scale from “always” to “never” for a particular survey question. Currently, contextual information such as “my nurse never remembered my name” is not recorded for analysis and is reduced to a low ranking in nurse courtesy and respect. Even with limited attention to qualitative feedback, patients want to share their experiences in their own words. When patients are asked to tell their story, they will provide invaluable incident-based insights into their care experiences. The integration of narratives with survey results will allow care providers to dig deeper into and learn from their patients’ experiences and will enrich the evidence base of clinical decision making for PFCC.

Conclusion

Within the healthcare delivery system, we have become quite proficient at collecting data from patients and families to inform their care. Most often, these data are objective and quantitative — heart rate, blood pressure, temperature, lab values, etc. In order to provide holistic care to patients and families, all members of the interprofessional healthcare team need to be proficient in collecting information about the whole person — on the patient’s body, mind and social environment. Healthcare providers need the capability to collect and process subjective and narrative, yet no less important, data to ensure that the care plan developed with the patient meets the patient’s identified needs. Also, healthcare executives, leaders and providers need to advocate for the use of research solutions that help capture and probe into the patient’s perspective in his or her own words.

We must get to know our patients in order to provide the highest quality and safest care and improve their care experiences. We need to think beyond satisfaction surveys to systematically collect and analyze our patients’ stories. We should work on what questions we need to ask and when we need to ask these questions of our patients’ experiences so that we get real-time insights into the care we provide. Regulatory changes and financial pressures are aligning with the movement of patient-centered care. Now is the time to develop new methods of learning from the stories of our patients and their families and build a new relationship with them in order to improve their care.

References

Finding the heart of [hospital]ity: Patient satisfaction and the healthcare experience

Micah Solomon

Let’s consider surgeon No. 1. She rolls her eyes at her patients, insults their family members and breeds terror among her colleagues and subordinates. She has, however, stunning knife skills.

Next, let’s look at surgeon No. 2. He’s sweet as cherry pie, but his hands shake during surgery (from Jack Daniel’s or nerves, it doesn’t matter). The question I have for you: As a patient, would you want the surgeon with the life-saving skills, or the one with the great bedside manner — the one who provides a better “patient experience?”

I didn’t pose this question because I actually want you to answer it, or even think about it for long. It’s a nonsense question, really. If the choice is between bad bedside manner and life-threatening clinical incompetence, it’s obvious which option a patient would choose. Of course you’d want to live long enough to be able to complain about the customer service in a hospital, rather than getting killed with incompetent kindness. I bring the question up, rather, because I feel that this imaginary choice lurks in the back of the minds of professionals when thinking about where the customer experience fits in the healthcare mix. I wanted to move it to the foreground, so we could look at it directly.

And now, let’s dispense with this artificial either/or. Real choices in healthcare don’t often resemble the choice between a friendly, clumsy surgeon and a barbarian with magic hands. The choices you run into, if looked at properly, tend to be more “consider this one positive, and another positive may hitch a ride with it, as well.” Or, just as often, they’re doubly negative choices. Factors that are negative in the patient experience can undermine clinical outcomes as well, as the institution gets sabotaged over time by rebelling staff and noncompliant patients alike.

Healthcare: hospitality with healing

The way I see it, healthcare is hospitality with healing, a combination of two positives. Or it’s healing with hospitality. The emphasis one way or the other probably does actually matter, and should be chosen depending on the patient, the ailment and other factors. But either way, I see healing and hospitality both as positives.

Because we all agree that clinical outcomes (the healing part of the equation) matter, I’ll leave that aside right now and discuss hospitality, the customer experience side of the equation. One of the best things to do to improve the patient experience is to consider the world your oysterbed of inspiration, to open your thinking to include models outside, as well as inside, healthcare.

Stop only benchmarking other hospitals

An obstacle to improving patient satisfaction in healthcare is the industry’s insular nature, which makes the status quo self-reinforcing. In other words, healthcare providers and institutions compare themselves to each other — to the hospital in the next town, the surgeon in the next O.R. — and benchmark their customer service accordingly. But to do so is to set the bar in the wrong place.

It’s not as if patients stop being consumers — customers — when they put on a hospital gown. And it’s not as if their loved ones surrender their identities as businesspeople and users of Twitter and Facebook, either, when they enter your institution. So it’s time to benchmark the healthcare customer experience against the best across all service-intensive industries, because that’s what your patients and their loved ones will do.

Every patient’s interaction with healthcare is judged in part on the basis of expectations set by the best organizations in retail, foodservice, the hospitality industry, financial services and other areas where expert players have made a science and an art of customer service.

However: nurses aren’t waiters, doctors aren’t baristas

I don’t want to overstate the case. I know consultants who take such things to an extreme. I’ve run in to (and competed with) consultants who make it sound like staying at the Ritz-Carlton...
and staying at a community hospital should be equivalent. Or that ordering a latte at Starbucks and getting an outpatient procedure are, in concept, more are less the same. And I argue back using the letter a nurse wrote to me recently. “Healthcare is a calling, and we don’t treat it like working in fast food. If we had wanted to be waitresses, we would be working as waitresses — and we’re not.” I think that’s absolutely correct, and that the analogy to other service-intensive industries is also strained by the fact that your patient didn’t, all things being equal, choose to “check in” with you either. Healthcare is enforced hospitality. Involuntary hospitality. Which makes things a bit, or more than a bit, different.

But there’s so much to be learned from the powerful, tested practices of organizations across many industries — and these do include Starbucks and Ritz-Carlton, in spite of my disclaimer. Here are a half-dozen valuable principles that will get you started.

1. Purpose vs. function
You can only build a foundation for great patient service if you work to ensure, from the first day of orientation onward, that every employee understands what his or her underlying purpose is in your organization. An employee has both a function — day-to-day job responsibilities — and a purpose: the reason why the job exists. For example, “To create successful medical outcomes and hospitable human experiences for our patients” is a purpose. “To change linens” is a function. A properly trained and managed employee will know to — and will be empowered to — stop changing linens if creating successful medical outcomes or being hospitable requires a different action at the moment. And afterward, management will celebrate the employee for his or her purpose-driven decision, not scold the employee for being a few short in the number of linens changed.

2. First things first: Fix your service beginnings and endings
Because of how human memory works, the first and last items in any list are the ones most easily remembered. In the customer experience, the same principle holds true: The first and last moments of a customer interaction are what customers are likely to hold in memory as permanent snapshots that represent the whole event for them in memory.

This means it can be hard to recover the goodwill of a patient or family member whose first impression is:

- Spending a long, tense time finding a parking space. And when patients do find it, the space is a six-minute walk to the front door — and they are on crutches.
- Signage in the building that is confusing — once they finally do manage to hobble the six minutes to the front door.

As far as goodbyes, your goodbye needs to be better than just a chilly invoice sent through the mail by your billing service. (Why do veterinarians universally follow up to see how Rover is doing, but physicians rather rarely do the same with their human patients? It could make all the difference.)

3. Great customer service — true hospitality — is best delivered on the schedule of the customer. Strive to deliver service on a patient-centered timetable, not just a schedule that happens to be convenient for your institution.

For example:
Avoid unnecessarily long waits for/batching of lab results to be distributed; this practice is disrespectful and even cruel.

Consider implementing something along the lines of the Vocera Communications Badge, with which the patient speaks the name of the nurse and is directly in communication with him or her instead of waiting on a response to a call light.

Look at the Cleveland Clinic’s same-day appointment model. Do you really need to surrender your patients-in-a-hurry to a chain drugstore clinic — or is it possible that you could reorganize your operations to see them right away?

When reviewing your standards and approaches in the area of timely, patient-centered scheduling, always keep in mind that expectations of speed have changed. Your patients are not as patient as they used to be. Today’s patients and their families live in a world in which Android devices and iPhones, laptops and iPads, can connect them — instantly — to vetted advice from the Mayo Clinic, where Amazon.com can get them a book of expert advice instantly in electronic form, or within 11 hours in hardcover. So getting back to patients with information at the same sluggish pace at which you’ve always responded isn’t going to cut it. Patients don’t want you to shoot from the hip, but they need to be kept informed, frequently and speedily.

4. Every single employee needs know how to ...
- Handle a complaint or concern from a patient or family member. Even if handling the concern means “I’m finding
you someone right now who can address this,” that is far better than “I can’t help you, I’m the wrong person.”

• Apologize to a patient or a loved one. To resolve, and avoid escalating, an issue with a patient, you need to know how to apologize for service lapses that a patient or family member points out to you. It means getting rid of the defensiveness and legalistic responses that tend to mar the healthcare industry when confronted by upset patients or family members. Employees need to actively strive to share the patient’s outlook in these situations, immediately and with empathy, regardless of what the employee thinks the rational allocation of blame should be. Spread this approach throughout your staff through role-playing and other training devices, and it will serve you fully every time a patient goes through the roof.

5. Cues to quality matter — and everything you do as a healthcare professional gives off such cues, for better or for worse.

Don’t expect your patients to be nonjudgmental just because they’re at a disadvantage and in distress. Lipstick on your teeth implies incompetence in a healthcare setting, the same as it does in the outside world. While I sympathize that you just pulled a double, your patient won’t.

Many cues to quality are related to poor use of language and nonverbal snubs, such as hospital employees avoiding eye contact with civilians in the hospital and acting like they are “other.” (Speaking of which, employees need to understand that good customer service is their job from the time they get on the property to the time they leave the property: the negative cues that someone “not yet on duty” or “just off duty” can convey while traveling from the car down the hall to his or her station, or from the station down the hall back to the employee’s car, can ruin all of the effort his or her colleagues have invested.)

6. One more thing.

(And yes, I’ve intentionally asked you to wait this long to hear the first mention of HCAHPS™.) You’ll make the most progress on HCAHPS™ and as an institution by taking a broad approach to the subject. Being too selectively focused on the individual HCAHPS™ questions, while not bad as a once-in-a-while, all-hands project, can backfire if it becomes your day-to-day approach. A more effective and powerful goal is to create an organizationwide halo effect that raises your scores as well as your actual rate of referral — not just the hypothetical “willingness to recommend.”
Creating an optimal patient experience is a priority for healthcare executives. It is a worthy endeavor, yet it may be daunting given the lack of universal definition for patient experience. In the Patient Experience Leadership Survey conducted in 2009, 34.5 percent of respondents reported that patient experience equals patient-centered care, 29 percent agreed that providing care organized around the unique needs of each patient represented a positive patient experience and 23 percent identified excellent customer service as reflective of a memorable patient experience.

Cleveland Clinic defines the patient experience as “care that addresses every aspect of patients’ encounters, including their physical comfort, as well as their educational, emotional and spiritual needs.” Another definition, by the Beryl Institute, describes the patient experience as “the sum of all interactions shaped by an organization’s culture that influence patient perceptions across the continuum of care.” According to Press Ganey CEO Patrick Ryan, the patient experience is “not about happiness. It’s about patients being respected, being communicated with and having their care coordinated in such a way that they can get the best possible clinical outcome for whatever their circumstances are.” The common thread to these definitions is that each one encompasses an aspect of caring. A fundamental component of nursing caring is defined as “the work or practice of looking after those that cannot do it for themselves.”

**Abstract**

**Purpose:** The purpose of this study was to examine the perceptions of caring behaviors that influence the patient experience in acute care nurses and hospitalized patients with diabetes.

**Background:** Nurses are the caregivers who render most of the direct care patients receive while they are hospitalized. Understanding what patients perceive as caring behaviors is essential in tailoring nursing interventions to meet patient needs.

**Data sources:** Data collection occurred at a 1,200 bed, nonprofit academic medical center located in the Midwest.

**Description:** Sixty-four nurses and 54 patients with diabetes were queried about their experience with diabetes caring behaviors.

**Conclusion:** Nurses consistently reported providing caring behaviors more frequently than patients reported receiving them.

**Implications:** This study has implications for understanding the patient experience in the hospital setting specifically related to patient education. Providing patient education is an important caring intervention that directly affects the patient experience. However, none of the patients in this study identified this as a caring behavior used by nurses.

**Corresponding author:**
Mary Beth Modic, DNP, RN, CDE
Clinical Nurse Specialist
Cleveland Clinic – P32
9500 Euclid Ave
Cleveland, Ohio 44195
E-mail: modicm@ccf.org
Office: (216) 444-9005
Cell: (440) 823-5274
Fax: (216) 445-0455

**Relevant disclosures:** None
Behaviors associated with caring also serve the role of linking nursing interactions to the patient experience.

When patients are hospitalized, they have expectations about the care they will receive. Nurses are the caregivers who render the most direct care and have the most contact with patients while they are hospitalized. Understanding what patients perceive as caring behaviors is essential in tailoring nursing interventions that meet individual patient needs and impact the patient experience.

**Background**

Demands on bedside nurses have never been greater as they struggle with competing time demands and priorities to enhance the patient experience. The hectic pace of the bedside nurse may be perceived by the patient as lack of caring or may result in a nurse's inability to demonstrate behaviors discernible by the patient as caring. Without conscious attention to the development of the caring relationship, the patient experience can be negatively affected. Identifying the behaviors that patients perceive as caring can help nurses design interventions that are patient centric, predicated on evidence and contribute to the overall patient experience.

**Patient perceptions of nurse caring behaviors**

Previous research on patient perceptions of caring behaviors indicated that nurses’ “professional knowledge and skills” were rated the most caring behavior by patients. In a grounded theory approach to understanding patient perceptions of nurse caring behaviors, Finch identified four themes: responding when needed and without being prompted, doing extra “little things,” following through and taking care of patient needs.

O’Connell and Landers compared the perceptions of nurses (n = 33) and family members (n = 19) of patients in three ICUs

| Table 1. Demographics of Patients (N = 54) |
|-----------------|-----|-----|
| **Variables**   | n   | %   |
| Gender          |     |     |
| Female          | 21  | 39.0|
| Male            | 33  | 61.0|
| Race            |     |     |
| African American| 23  | 42.6|
| Asian           | 1   | 1.8 |
| Asian Indian    | 2   | 3.7 |
| Caucasian       | 25  | 46.3|
| Hispanic/Latino | 3   | 5.6 |
| Marital Status  |     |     |
| Not Married     | 27  | 50.0|
| Married         | 19  | 35.2|
| Widowed         | 8   | 14.8|
| Education Completed | |     |
| <High School    | 6   | 11.0|
| High School Graduate | 19  | 35.2|
| Some College    | 14  | 26.0|
| College Graduate| 8   | 15.0|
| Graduate School | 6   | 11.0|
| Missing         | 1   | 1.8 |
| Employment Status|    |     |
| Employed Full Time | 11  | 20.3|
| Employed Part Time | 1   | 1.3 |
| Unemployed/Looking for work | 5   | 11.0|
| Student         | 1   | 1.3 |
| Retired         | 23  | 42.1|
| Disabled        | 13  | 24.0|

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of diabetes diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>3</td>
<td>6.0</td>
</tr>
<tr>
<td>1-5 years</td>
<td>14</td>
<td>26.0</td>
</tr>
<tr>
<td>6-10 years</td>
<td>17</td>
<td>31.0</td>
</tr>
<tr>
<td>11-15 years</td>
<td>8</td>
<td>15.0</td>
</tr>
<tr>
<td>16-20 years</td>
<td>6</td>
<td>11.0</td>
</tr>
<tr>
<td>21-25 years</td>
<td>2</td>
<td>4.0</td>
</tr>
<tr>
<td>&gt;25 years</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>Type of Diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 1</td>
<td>10</td>
<td>18.0</td>
</tr>
<tr>
<td>Type 2</td>
<td>43</td>
<td>80.0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Admitting Diagnosis/ System problem</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>12</td>
<td>22.2</td>
</tr>
<tr>
<td>Infection</td>
<td>10</td>
<td>18.6</td>
</tr>
<tr>
<td>Endocrine: DKA/Hypoglycemia</td>
<td>6</td>
<td>11.0</td>
</tr>
<tr>
<td>Cardiac</td>
<td>5</td>
<td>9.0</td>
</tr>
<tr>
<td>Renal</td>
<td>5</td>
<td>9.0</td>
</tr>
<tr>
<td>Respiratory</td>
<td>5</td>
<td>9.0</td>
</tr>
<tr>
<td>Cancer</td>
<td>4</td>
<td>7.1</td>
</tr>
<tr>
<td>Ortho/Neuro</td>
<td>3</td>
<td>6.2</td>
</tr>
<tr>
<td>Hematologic</td>
<td>3</td>
<td>6.2</td>
</tr>
<tr>
<td>Immunologic</td>
<td>1</td>
<td>1.7</td>
</tr>
</tbody>
</table>
in Ireland. The top five caring behaviors reported by relatives, in descending order, were treat the patient as an individual, know what you are doing, know how to give injections, IVs, etc., know how to handle equipment and give the patient medications and treatments on time. The nurses in this study identified the most important caring behaviors as know what you are doing, treat the patient with respect, treat the patient as an individual and be kind and considerate. In another study, patients from six European countries were surveyed to determine whether caring behaviors affect satisfaction. Study results from 1,565 patients revealed that “knowledge and skills” were rated the as the highest (most important caring behavior) and “positive connectedness” received the lowest rating.

Von Essen and Sjoden studied the perceptions of 81 patients and 105 nurses in Sweden and found significant differences between patients and nurses. The patients rated knowing when to call the doctor, how to give injections, being honest with the patient, putting the patient first no matter what else happens and speaking to the patient in understandable terms as the highest mean items. Nurses rated the top five caring behaviors as listening to the patient, putting the patient first no matter what else happens, touches the patient when comfort is needed, talks to the patient, and speaking to the patient in understandable terms.

These studies exploring perceptions of caring behaviors have revealed a lack of congruence between what nurses and patients perceive as caring. Identifying these behaviors can help nurses design interventions that are patient centric and evidence based and that contribute to the overall patient experience. Additional research is needed to examine perceptions of patients and nurses.

Method
Setting: The setting for the study was conducted on four medical inpatient units of a nonprofit, 1,220-bed teaching hospital in the Midwest.

Sample: A convenience sample of hospitalized patients with diabetes was invited to participate in the study. Inclusion criteria consisted of English-speaking adults 18 years and older with a diagnosis of diabetes who were alert, oriented, able to verbally respond to questions and who agreed to participate in the study. A total of 68 patients were approached to complete the survey; five patients refused, and seven patients were deemed too ill to be interviewed. The nurse sample included bedside registered nurses who had completed new nurse hospital orientation and were assigned to one of the four medical units. This nurse sample also was one of convenience. Nurses in managerial or advanced practice roles, or were in new nurse hospital orientation, were excluded.

Each patient participant was asked to respond to the following open-ended question: “What actions did your nurses use during this hospitalization that reflected ‘caring’ in managing your diabetes?” Patients participated in an interview by the primary investigator, who was not involved in their care. Nurse participants were asked to respond to the following question via Survey Monkey: “What caring behaviors do you consistently use with patients who have diabetes to optimize their glucose control while in the hospital?”

Demographic information collected from patients included age, gender, race, marital status, education, employment status, reason for hospital admission, type of diabetes and length of time the patient had diabetes. Length of current hospitalization was abstracted from the participant’s medical record. Nursing background data included age, gender, race, educational background, years of nursing experience and employment status (full or part time).

Results
Patient sample: The patient sample (n = 56) included 33 males (61 percent) and 21 females (37.5 percent), ranging in age from 23 to 86 (M = 57.9 years; SD = 14.7). Ten patients had a diagnosis of diabetes mellitus (DM) Type 1, 45 patients had a diagnosis of DM Type 2 and one patient was diagnosed with latent autoimmune diabetes of adulthood, or Type 1.5. The duration of diabetes ranged from less than one year to more than 50 years. Three patients used insulin pumps to manage their diabetes and were not dependent upon the nursing staff to administer insulin. Digestive disorders and infections were the two most prevalent diagnoses. Diabetes-related complications were the third most prevalent diagnosis. Patients’ length of stay ranged from three to 25 days. (See Table 1).

Sixty-three registered nurses participated; 56 (89 percent) were female with an age range of 22 to 74 years (M = 36, SD = 13.9); 53 (83.4 percent) worked full time. On average, these nurses had worked 8.4 years as RNs and six years on the nursing unit. (See Table 2).
Patients verbalized positive caring examples, offered observations of when nurses tried to be caring and described situations when the interaction with the nurse was not perceived as caring. After the primary investigator reviewed the responses via content analysis, three categories were identified; these were confirmed by the other investigators. These categories included providing information, surveillance/monitoring and listening to patient concerns. Thirty-four patients (62 percent) described the caring behavior of providing information stating that they were informed of their blood sugar results and informed of upcoming tests and procedures. Regarding surveillance/monitoring, 13 patients indicated that nurses paid attention to and monitored them. Evidence of this category was the remark that six patients (11 percent) described experiencing a hypoglycemic event while in the hospital, stating that the nurses responded quickly. In terms of listening, one patient eloquently described his experience of nurse caring this way: “Since I am blind, I get a sense of how caring a nurse is going to be by the tone of her voice. ... I know they are busy, but you never hear it in their voice or in their footsteps as they walk away.”

The themes that emerged from the nurses’ responses included teaching, listening and supporting. Teaching was the most prevalent caring behavior described by the participants and was identified by 41 (76 percent) of nurses. One nurse wrote, “I find out what patients know about their diabetes and I learn from those that know themselves well. I teach those that need further instruction.” Another nurse said, “I assessed my patient’s level of knowledge regarding her diabetes, determining what she does at home and how well it works for her.”

Listening was a topic identified by 39 (67 percent) of nurses. In an illustration of listening, one nurse conveyed her practices in this way: “I strive to include patients in their care by listening when they are uncomfortable with a dosage or a medication that is prescribed.” Another nurse summed up listening this way: “Listening is the ultimate caring strategy. It conveys respect, acceptance and trust. It says to the patient, ‘I am with you, and I am here for you.’ It says to the family, ‘I think your loved one is important too.’”

The third most common intervention, supporting, was described by nurse participants as including praising behaviors, as described by one respondent: “I praise them when they are engaging in their care and asking questions, and I encourage them to ask me questions.” In describing her supporting role, one nurse wrote: “I always implement education in patients’ plan of care. I learn about the patients’ lifestyle and their strengths and weaknesses and develop a plan based on those observations.”

**Discussion**

Similar to the findings of previous research, the nurses and patients in our study perceived listening as reflective of caring. However, the promotion of teaching-learning that nurses in the present study identified as indicative of caring behaviors was not identified in previous studies examining caring or by the patients in this study. Patients did identify “keeping them informed” of their response to treatment or procedures for the day as reflective of nurse caring.

It was interesting to note that none of the patients identified formal teaching as a caring behavior used by nurses. Perhaps the disparity between nurses describing the teaching they provided and the patients identifying keeping them informed is the language and conversational tone used by nurses when providing teaching. It may be advantageous for nurses teaching patients about diabetes management to precede their instruction by stating that they are teaching the patient about preventing low blood sugars, or how to monitor their blood sugars because they care about them.

**Table 2. Demographics of Nurses (N = 64)**

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>57</td>
<td>89.0</td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>11.0</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>8</td>
<td>12.5</td>
</tr>
<tr>
<td>Asian</td>
<td>9</td>
<td>14.0</td>
</tr>
<tr>
<td>Asian Indian</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Caucasian</td>
<td>44</td>
<td>69.0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2</td>
<td>3.0</td>
</tr>
<tr>
<td>Highest Nursing Degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Associate Degree</td>
<td>19</td>
<td>30.0</td>
</tr>
<tr>
<td>Diploma</td>
<td>2</td>
<td>3.0</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>40</td>
<td>62.0</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Work Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full Time</td>
<td>53</td>
<td>83.0</td>
</tr>
<tr>
<td>Part Time</td>
<td>11</td>
<td>17.0</td>
</tr>
</tbody>
</table>
There are several limitations to this study. Specifically, data were collected from both patients and nurses at a single site, during one interview per participant. There is also a selection bias in the patients included for interviewing. It is recommended that future research focus on more extensive interviews over a period of the patients’ hospitalizations, in order to capture a more complete view of the patients’ experience with hospitalization and care.

The study results have implications for care of patients hospitalized with diabetes, such as disseminating specific behaviors patients think are caring in managing their diabetes and, conversely, behaviors nurses believe are caring. This information can be shared with nurses to refine the way they provide care to patients, or encourage nurses to ask patients about their expectations of care while in the hospital. This may result in more patient-centric care and improvement in the overall patient experience. Educational programs may be developed that highlight the caring expectations of patients. Further, this study may help nurses become aware of the importance of their caring interventions with patients.

References
The police arrive at your home unannounced at 11:30 p.m. They inform you in panicked voices that it appears you are facing an extremely serious offense, although they are not sure what it is, and you have to go with them.

Soon thereafter, you find yourself in an intake/booking area with numerous other individuals who do not appear to want to be there, look to be confused and seem to be in various degrees of stress and pain.

After being stripped-searched and required to wear ill-fitting unisex garb, you are escorted to a private room. The next day, a person who is apparently an employee, tells you to stay calm and not to worry, a lawyer will be with you as soon as possible. Later that day, an individual with the title “legal assistant” visits you and tells you that you have been charged with engaging in a pattern of corrupt activity. The assistant learns from you that you believe you have not done anything that would cause you to be confined, you do not understand the legal system and you are not even sure what the charge means, although it sounds serious. The assistant informs you that the sentence for this offense is 10 years in a maximum-security prison and that investigators are considering other charges that could include the death penalty, depending on how the facts (over which you have no control) turn out.

Your brother’s sister-in-law’s uncle knows a lawyer, but that lawyer is not permitted to practice in the county in which you are detained. You have a personal attorney, but that attorney knows very little about this area of law. Your spouse is allowed to talk to you through a screen, but you are not permitted to see anyone else in person.

Several days later, a lawyer comes to your cell. You have never seen this person before, but you are instructed that this lawyer’s firm will represent you and the lawyer assures you that “we” will do everything possible to get to the bottom of this “situation” and do whatever can be done to minimize the sentence.

About a week later, a law partner of the lawyer who previously saw you comes to your cell and says that the investigation has been completed, that “they” have examined all the documents (although you are not permitted to see them because they would simply confuse you) and that they recommend that you plead guilty. They say that they cannot predict what the sentence will be because this is all very complicated, especially to a nonlawyer; for example, you must consider the culpable mental state, mens rea, actus reus, allied offenses of similar import, organizational liability, the differences -- if any -- between racketeering activity and corrupt activity, and the potential necessity of establishing an “enterprise” as a structure separate and apart, or distinct from, any pattern that functioned as an ongoing unit, if that term is indeed ascertainable or merely redundant and potentially misleading.

The lawyer acknowledges that you may find this overwhelming but assures you that the alternatives are much worse. Therefore, “we” are going to go ahead and schedule your plea and sentencing. You are soon escorted, with numerous other detainees who seem very confused, resigned and depressed, to another area to await the results.

The lawyer tries to comfort you, saying that if this does not work out, you can try to appeal, if what happens is indeed a “final appealable order” as defined by the state or federal constitution and the statutes, ordinances, and regulations as they have been, to date, interpreted by other courts, agencies or administrative processes, and even then, you must be able to distinguish between sufficiency and weight of the evidence, and whether a de novo or abuse of discretion standard applies. The lawyer does confide that the odds of an appeal being accepted, let alone you prevailing, are not favorable, but you should relax and live your life, because there is not a lot you can do about the future.

You are then escorted back to your room, and later that evening are put by yourself (your spouse was told to go home and your lawyer is nowhere to be found), in chains, on a bus that drives with no lights into a very dark night.

Welcome to my world; how does a patient and family feel in yours?

Jeffrey E. Froelich, JD

The author has been a judge for more than 35 years; he and his wife met more than 50 years ago when she was 13 and he was 15. Marsha died of acute myeloid leukemia in November 2011, after 19 days in the hospital.
Listen to Every Voice, Learn from Every Experience.

Everyone Has a Voice in the Patient Experience

Press Ganey’s unique approach to improvement combines deep patient feedback with the voices of your clinicians and employees so you can see and understand thousand of daily touchpoints across the entire care experience.

Through advanced analytics and strategic advisory services, we help you drive targeted performance improvement to reduce patient suffering, improve the patient experience and achieve operational excellence.

Learn more at pressganey.com.