



Beyond Bedside Manner

Supporting the Emotional Needs of Patients Receiving Alternate-Site Infusion Therapy

By Jeannie Counce

It's human nature—when we're sick, we'd rather be at home. Fortunately, home infusion allows many patients to receive IV therapies without having to stay in the hospital. We all know from experience that this option is more comfortable for them, is associated with better overall clinical outcomes, and is highly cost-effective. But that doesn't mean that it's anxiety-free for patients and their families.

IV therapy is a complex medical service that requires a team of highly skilled clinicians. Often, patients are on medications designed to treat serious conditions, such as infection, cancer, pain, and nutritional deficiencies. Despite being home, these patients can be very sick, which is a significant stressor to them and their families. Illness—and everything in its wake, including issues related to employment status, finances, and family dynamics—can trigger a host of emotions that dramatically affect patients' and caregivers' ability to cope.

While the ability to receive infusion therapy at home may offer the greatest opportunity for a patient, and their family/support system, to return to pre-illness levels of functioning, it also adds a layer of complexity to what used to be their way of life. Infusion providers

realize that when we walk through the front door, we are impacting everyone who lives in that home, including the family pets. And, we need to be keenly aware that the patient's needs may extend beyond the medical realm that we have been called to specifically treat. Although attention to a patient's mental health is not a core infusion service, it is a critical need with implications for how a patient will accept responsibility for their care, participate actively in their treatment, and ultimately respond to the therapy.

By becoming more self-aware when providing the everyday aspects of care—patient assessments, communication skills, and care planning, for example—infusion professionals can improve upon their own delivery of core services, and ultimately enhance overall clinical outcomes in the process. Help in this regard is available from those who specialize in mental health—the trick is recognizing when and how to reach outside the scope of our own expertise to ensure patients receive the support they need (see box, p. 13 for more on infusion professionals). A well-adjusted patient is more likely to have a supportive network of care that includes an infusion provider who puts all the pieces of the puzzle together.

TREATING THE WHOLE PATIENT

Like most forward-thinking clinicians, alternate-site infusion providers are aware that medical care does not occur in a vacuum. In fact, this discipline, built on a collaborative approach to individualized care, has always taken a holistic view of the patient. “We’re not just treating a disease, we’re treating a whole person,” explains Nelda Perry, B.S.N., R.N., Clinical and Operations Consultant with Vital Care, Inc., in Meridian, Mississippi.

“All the psychosocial aspects of care are addressed by the home infusion team,” adds Kathy Puglise, M.S.N./E.D., B.S.N., R.N., CRNI®, Vice President of Patient Care at HomeChoice Partners, Inc. “Part of the intake process involves screening for emotional issues.” For example, use of anti-depressants show up on a medication history, or references to life stress appear in the chart notes from a referring physician, she explains. This serves as a prompt for pharmacists and nurses to offer a listening ear and remain vigilant for signs of a growing problem. “Many emotional issues can be addressed simply by listening,” observes Puglise, noting that the “one-on-one time with patients during visits and periodic check-in calls is an excellent opportunity for a troubled patient to open up.”

Nurses and other team members who detect strong emotional needs should bring them up at regular case conferences, where the team can discuss and modify the care plan. “Each patient has a dynamic, comprehensive plan of care,” says Perry. “There are tools in place to make sure that it’s responsive to patient needs.”

Perry recalls treating a PN patient who was terminal, but not emotionally ready to enter hospice. “He was very concerned with the ingredients in his mixture and would read the labels and question the prescriptions,” she explains. “At one point, he was sure we were giving him too many calories.” Although the calories were clinically appropriate for his disease state, Perry says that the patient became more and more agitated over his prescribed therapy.

“The care team consulted with his physician and decided that, given his prognosis, it would not significantly affect his health if we modified his formula,” Perry recalls. “So, we got a revised order, and changed the mixture. It made him feel more comfortable, and ultimately, we recognized that it satisfied his need to feel like he was part of his own care.” In this example, the home infusion team’s holistic awareness enabled them to observe and respond to this patient’s emotional cues, giving the patient a “sense of control” amid a terminal medical condition that can make one often feel quite “out of control.”

IT’S NOT JUST A NURSING THING

While nurses are on the frontline of this issue, the information in this article holds true for every team member at the provider organization. Intake and patient care liaisons are a first point of contact, working through a variety of insurance, financial, and logistical issues. Pharmacists and customer service representatives interact with patients and caregivers regularly over the phone and via secure e-mail. And, delivery personnel have a vital window into the home environment on usually a weekly basis.

NHIA has heard countless stories of people in these roles forging close bonds with patients and their families, and offering support that goes well beyond their job description. Sending birthday cards with a delivery, taking time to listen to someone “vent,” and checking back in to make sure things are OK are all par for the course. Patients and caregivers appreciate the extra effort—they all report that the little things really do make a difference (see the patient roundtable story on p. 28 for more patient insights).

But, perhaps even more critical than boosting morale, regular contact provides an opportunity to observe. If you notice changes in a patient’s health status, pick up on problems within the family, or have reason to be concerned about anyone’s safety, bring it up with another member of the care team so it can be addressed. Remember, it takes a whole team to treat the whole patient.

Still, there are times when the infusion team cannot resolve an emotionally related challenge on its own. At this point, the options depend on how the provider’s nursing component is set up. “If you’re providing your own nursing services and don’t have access to mental health professionals, your choices are to consult with the physician or refer the patient to resources in the community,” explains Perry. Accredited organizations are familiar with this last step, typically referred to as “community resources,” a requirement that they have in place a plan to connect patients with outside resources should they be needed.

For the nearly 20 percent of NHIA members using contracted nursing, turning to their partner Home Health Agencies (HHAs)—where additional resources, such as social workers, psychiatric nurses, and/or hospice workers, are readily available—is a logical and seamless step. “If something is beyond our scope of expertise, we work with our HHAs to pull in additional help,” explains Puglise. “We also maintain a list of local support groups and agencies that offer assistance with issues like grief, caregiver burnout, respite care, and so on,” she adds.



ACTIVE ASSESSMENTS

What can we learn from others in terms of identifying emotional distress and supporting patient needs? We talked with veteran nurses and mental health experts to find out.

“When you go into a patient’s home, you never know what you are going to find,” observes Nancy Preston, R.N., B.S.N., CRNI®, Clinical Specialist for Infusion and Homecare with Trinity Home Health Services in Livonia, Michigan. “Today, patients are in much more acute stages of illness at discharge, which often means a caregiver must be closely involved. On top of that, you have fewer professional visits in which to work,” she says.

Nursing assessments are key to evaluating the myriad factors that play into positive outcomes. Preston contends that, thanks to the home health Outcome and Assessment Information Set (OASIS), nurses working for HHAs are trained to assess the whole patient. “We are being held accountable for outcomes that affect the whole person. So, we screen for all kinds of issues, including depression and pain control,” she explains. “It’s part of a head-to-toe assessment that’s done on every visit.” Even if an HHA nurse is on an infusion visit, he or she is likely to be using the same assessment criteria.

Assessments are not only a time to gauge how patients are progressing toward therapy goals, but are also an excellent opportunity to appraise how everyone in the family is coping. “It’s important to take a minute to be present with the patient and really listen to them,” asserts Carole Rumsey, R.N., CRNI®, Home Infusion Program Manager for Sutter Care at Home and Sutter Infusion and

Pharmacy Services in northern California. “So often we are busy, thinking of all the other things we need to do that day. It’s important, and valuable, to offer a listening ear.”

It’s also important to touch base with caregivers on their needs, adds Rumsey, whose organization trains nurses in advanced illness management, hospice, and chronic care management programs, all of which deal with emotional components of care. “Communication among family members is different in every case and can cause issues.”

There is great value in listening, and picking up on cues, according to Preston. “You really need to learn how to actively listen, which is different than hearing,” she contends. “When you acknowledge what you hear, you open the door for further conversation,” she adds.

“Listeners listen—they don’t tell you what to do,” continues Preston. “Sometimes the patient will want to take action; other times, it feels good just to get it off their chest,” she observes. “We aren’t (always) there to advise them, but we can initiate a thought process by asking, ‘What do you want do about it?’” continues Preston.

“If a patient shares that they are having challenges, I’ll offer them services, such as a patient support group or bereavement group,” continues Rumsey. “It can be very beneficial for them to know that others are going through the same thing.” Rumsey’s agency also has social workers on staff, so she offers their services too.

Both Rumsey and Preston note that regular care conferences are an ideal place to share information about patients and strategize about concerns. “If someone on the care team is picking up on problems, we talk about it as a group,” says Rumsey. “It’s very helpful because you get different perspectives, experiences, and ideas.”



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It's important to note that concerns—and solutions—can come from any member of team, even for independent patients who rarely interact with a nurse. In our patient roundtable article (p. 28), a young PN patient relays the emotional turmoil she experienced transitioning from the working world to being at home on Medicare disability. “It was a real blow to me,” recalls Jenn, who sought counseling for her depression. “My pharmacist knew what was going on and called me a lot to check in and see how I was. Eventually, I took up photography, and when I had a gallery opening he and several team members from the branch came to support me.”

“Collaboration brings more tools to the table,” agrees Preston, who emphasizes that it can only be effective if members of the care team share their observations. “I tell my nurses, ‘your assessment can’t live in your laptop.’ You have to connect what you see to the bigger picture.” That’s true for pharmacists and other team members as well. “The nurse’s assessment may contradict what the patient is reporting to the pharmacist over the phone,” says Preston. “You need to have all the information together to provide the best, most comprehensive care.”

The goal, say Preston and Rumsey, is to build a relationship with the patient and caregiver(s) that is based on trust and marked by open, honest communication. That “therapeutic relationship” is the foundation for many aspects of care—patient education, health literacy, and compliance, to name a few. But it is also essential to supporting emotional needs, especially if they become more pressing.

THERAPEUTIC ALLIANCE

“I enter the picture when patients are showing signs of being in crisis, which typically means feeling overwhelmed,” explains Karen Hellwig, M.N., R.N.-B.C., P.H.N., Psychiatric Case Manager for Physicians Choice Home Health in Torrance, California, and professor emerita of Nursing at El Camino College. “They can be depressed or grieving—patients grieve about their diagnosis, their treatment, a permanent change in health status, loss of lifestyle, loss of financial independence—or the stress of the illness can bring family issues to a head,” she observes.

The feelings manifest themselves in behaviors, she explains, which is typically what draws the attention of the team. “I see patients who show signs of depression: having

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a flat affect, appearing anxious, withdrawing, or expressing signs of hopelessness. I also see patients who are non-compliant, manipulative, demanding, or exhibit anger—which can be displaced onto the nurses,” she says.

Almost all of these behaviors stem from the patient feeling out of control, explains Hellwig. “They don’t have control over their body when they are sick; they may need to feel like they are in control of the medical process,” she reasons.

When treating patients like this, it’s essential to build a “therapeutic alliance,” advises Hellwig. “You’re always on their side, even if their behavior is hard to deal with,” she says. “Don’t argue with them. Don’t give advice about personal or family issues. And, educate them on medical issues whenever you get the chance.”

This is made easier when the patient’s goals are clearly stated. “Ask them what they want to get out of the medical experience,” advises Hellwig. Sometimes their answers are not in line with reality—or those of a family member—and that can be a source of stress.

“Empower them whenever possible,” she adds. “Patients need to retain power over what’s happening to them,” she explains. Ask how you can help. Offer them choices like what time of day to take medications or schedule visits—fostering some degree of control, even over basic choices like these, can often go a long way towards enhancing the patient’s emotional condition and crucial sense of autonomy.

LISTEN, LISTEN, LISTEN

As mentioned previously, good communication is the lubricant that makes the therapeutic relationship function. “My three rules to therapeutic communication are: listen, listen, listen,” asserts Hellwig. “It really is a skill.”

Look for non-verbal communication as well, she adds—body language and behavior are very telling. “Look for inconsistencies,” Hellwig continues. “For example, the patient may say they are fine, but appear anxious and jittery.”

If you feel like something isn’t right, it’s probably not, according to Hellwig. “Go with your intuition every time,” she assures. By using some simple communication techniques you can draw out responses and discover more (see Exhibit 1).

Sometimes you don’t have to say anything, you can just sit with the patient, and they will bring up what’s on their mind, adds Hellwig. “Once I was just sitting with a patient because I sensed that she needed that, and she blurted out, ‘I’m feeling suicidal,’” she recalls. “Really profound things will come out when you have trust and give them

EXHIBIT 1 TIPS FOR COMMUNICATING WITH PATIENTS ABOUT EMOTIONAL ISSUES

DO

- ✓ Listen, listen, listen—be “fully present” when listening to your patient’s verbal and non-verbal communications
- ✓ Seek to understand and clarify by asking open-ended questions that can draw out a response (“Tell me more about...”) and/or sharing an observation (“You seem upset...”)
- ✓ Mirror back what the patient says to get feedback (“Sounds like you’re feeling...”)
- ✓ Look for non-verbal cues (body language) and inconsistencies (behavior contradicts patient report)
- ✓ Touch base with caregivers regarding their needs—and the needs of the patient
- ✓ Ask the patient about his or her goals for the therapy
- ✓ Empower the patient in realistic, meaningful ways
- ✓ Take time to sit without talking
- ✓ Reassure the patient that he/she is not alone
- ✓ Be positive (“It’s good to see you” or “I admire your determination”)
- ✓ Trust your intuition—if something doesn’t feel right, it’s probably not
- ✓ Get help when safety is a concern
- ✓ Educate whenever the opportunity arises

DON’T

- ✗ Assume to know something without clarifying
- ✗ Ask “yes” or “no” questions
- ✗ Give advice
- ✗ Argue
- ✗ Criticize or lecture
- ✗ Be unrealistic in your efforts to reassure patients

time.” Of course, Hellwig adds, if there is ever a safety concern about a patient, it must be reported immediately.

It’s not uncommon for patients with chronic or life-altering conditions to experience depression. “It affects all aspects of your life—social, sexual, religious beliefs—everything changes,” observes Gwenn Herman, LCSW-C, D.C.S.W., Executive Director of Pain Connection - Chronic Pain Outreach Center, Inc., in Rockville, Maryland. “It’s typical for patients to have black and white thinking. They see all the ‘can’ts’ in their life, and they feel helpless.”

“It’s important to let them know that what they are going through is normal for a chronic illness,” continues Herman. “Encourage them to pace themselves, set goals that are realistic, and move them forward. Living in the past is where the depression comes in.”

Home infusion clinicians can support these patients by letting them know they are not alone, she says. “There are a lot of support groups and resources out there that can help them begin living with their condition.”

You can also be supportive by being positive, Herman adds. “Smile and say, ‘It’s good to see you,’ or ‘I admire

your determination,” she says. “Don’t be unrealistic, but offer them hope when you can. An effective approach might be sharing your past experience—‘I’ve seen patients where you are now, and you don’t have to stay there.’”

HELPING THE PATIENT ASK FOR HELP

When social or emotional issues get in the way of the patient taking full advantage of his or her medical care, it’s time to ask for help. “Asking for help is not easy for people, especially older people,” observes Kathrine Starace, M.S.W., LCSW, a medical social worker with Health Connect at Home in Lincoln, Nebraska. “Admitting that they can’t do everything themselves is hard for patients and family members,” says Starace, who helps patients tap into community resources, from financial and home health aid to support groups and counseling.

Often patients are concerned about adding another member to the care team because they think it will add to their health care expenses and bring another person into their home. “Nurses are in a good position to encourage patients to accept help,” explains Starace. “They’ve seen these situations before. They’ve seen

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people get help and get better, so they can relate that experience,” she says.

Often listening to patients can assist them with “getting over the hump” of accepting help, according to Starace. “You can also encourage them to talk to their physician,” she adds, as the primary doctor may be able to help with antidepressants or anti-anxiety medications, when determined appropriate. “I also let patients know that there are other treatments for depression, such as counseling and ‘talk therapy,’ and I am willing to help them find a mental health counselor in the community who can work with them.” Even if a patient is receiving some type of medication for emotional distress, such a treatment regime is frequently made more productive by complementing it with counseling.

You want to help them see that their emotional stress is something that can be changed if they would get help, she encourages. “It’s like having a broken leg—you would get help to fix that.”

All our experts caution that home infusion team members shouldn’t forget to take care of themselves. “Boundaries are important. It’s so easy to be brought in, but there is a danger in taking on the role of a friend,” warns Starace. “In the end, it’s more difficult for patients to get the help they need, and they may also feel abandoned when you’re not there or their service ends.”

Sometimes nurses or other health care professionals get so involved with patients that they become “emotionally entangled,” observes Hellwig—especially if the patient is finding ways to pull the health care provider in. “If you are thinking or worrying about one patient too much, it’s time to talk to a supervisor, take a break, or rotate patients.”

“We want to care for people, want to make it better—that’s why we’re in this field,” Preston reflects. “But you have to take care of yourself too. Otherwise you aren’t able to do your job.”

MAKING SURE TO MAKE A MEANINGFUL DIFFERENCE!

Every alternate-site infusion professional, regardless of his or her position on the team, has a vital role to play in providing patients with the safest and most effective home infusion therapy possible—and a crucial part of that clinical picture is the fact that such patients require holistic care, including recognizing and supporting their emotional needs. Being “fully present” with our patients—truly listening and responding to their verbal and non-verbal emotional cues—will not only help enhance their emotional well-being, it will ultimately serve to promote better therapy outcomes, as well. Growing our self-awareness in this regard is sure to strengthen our overall positive impact on our patients’ lives...and that is what home infusion is all about! ❧

Jeannie Counce is the Editor of INFUSION. She can be reached at 406-522-7222 or jeannie.counce@earthlink.net.



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COMPASSION AS A HEALING

Allison Massari clearly understands health care intimately and is also familiar with infusion treatments, but she is not a provider, payer or a regulator. The award winning painter and sculptor—turned speaker and coach—experienced firsthand the critical value of health care delivered with empathy and support. Burned alive in a fire caused by a head-on auto collision 12 years ago, followed by a traumatic brain injury from a second high-speed car accident just two years later, Massari now delivers the message to providers that kindness and compassion have a direct impact on patient care and positive clinical outcomes.

Drawing on her personal experiences with empathic, devoted health care providers (including 40 days in a burn unit, followed by additional years recovering), Massari spoke to INFUSION about how alternate-site infusion providers can be more self-aware and person-centered in their interactions with patients in an effort to support their needs emotionally, as well as physically.



Allison Massari, award-winning artist and accident survivor, delivers the keynote address at the 2011 NHIA Annual Conference this past April in Orlando. The impact of her patient perspective “from the other side of the stethoscope” on attendees was palpable, and resulted in her being ranked in the top 10 percent of speakers from any NHIA conference.

Q. In your speaking work, whom do you typically address and what do your topics usually involve?

A. My primary audiences are health care workers, providers, and nonprofits. I am passionate about helping health care workers feel valued and motivated in the face of understaffing and fatigue. My mission is to inspire people to find success and happiness in tough times; and to refine a deeper understanding of the necessity for outstanding patient-centered care. Above all, my commitment is to alleviate human suffering.

Q. What about your story most opens your audiences’ eyes to something new? What do they seem to walk away with?

A. Again and again I’m told that my stories inspire people to reclaim their passion for their life’s work in health care. I’m told that they have a completely renewed willingness to keep giving even when a patient is non-responsive or unkind. I can’t tell you how many people run up to me after my keynotes jumping up and down with excitement. It’s awesome. They feel appreciated in such a deep way, and it gives them more energy for their work.

When I talk about compassionate patient-centered care, I illustrate through stories, what can go right and wrong when caring for a patient. It’s

powerful for the audience to hear the impact they can have (positive or negative) from a moment with someone. Many times audience members have expressed to me a deepened commitment to be more aware, and an eagerness to do more simple compassionate things like holding a patient’s hand. That warms my heart to no end. We cannot underestimate the role human connection plays in healing.

Q. What can alternate-site infusion clinicians (or others working in our field) do to support patients emotionally?

A. Love and compassion heal the places medicine cannot touch. That ability of being present fully with someone is powerful. It eases so much pain. You can shower someone with kindness and compassion in three seconds, for those times you are pressed on the job.

Just stopping to touch someone on the shoulder or arm and look at them lovingly is profound. These things calm the whole nervous system. Compassion is an absolute healing tool and heavily underestimated. I have never forgotten a single moment that was given to me like this by health care professionals—ever. It’s embedded into my memory.

—A Conversation with Allison Massari

Q. What should they never do (what is not supportive)?

A. This topic is so important, I could do a whole afternoon seminar on it. As difficult as it is to address, we all know that in every profession people sometimes struggle with how to approach others. Many times, bad things happen when health care workers are not aware, or not paying attention. It's critical to work hard to remove judgements of people or any assumptions. Always assume that you don't know someone's story. Give everyone the benefit of the doubt.

Quick tips: Don't make jokes about someone's weight or appearance. Be extremely compassionate with someone learning to use a bedpan. When a patient is coming out of anesthesia, they can still hear you.

People who are injured or sick are at their most vulnerable and are looking to health care professionals especially for care, respect, and kindness.

Q. How can health care professionals in alternate-site infusion, who are typically compassionate at-heart but not necessarily experts on mental health, be more sensitive to the needs of patients?

A. Anyone with a compassionate heart is already capable of being sensitive to the needs of patients. It's important to trust yourself. People feel your compassion and care even without you saying a word. You can communicate it with a kind look in your eyes, or in the gentleness you use to move a patient to get them ready for a procedure.

Let your heart be open and seen by your patients. It's not necessarily about saying the right words. Just love them. Listen to them. Ask what they need. They will never forget you.

Q. So many times, people don't act because they are unsure what to do, or afraid of upsetting the patient. How should they go about reaching out?

A. It's always healthy to monitor a situation or to pause before speaking if you are unsure of how

you will be received. Beyond that, remember that compassion never withholds itself. Compassion moves out and forward even at the risk of looking a bit foolish. I could always feel when health care workers were trying to be kind, even if they stumbled on their words a bit.

If you are afraid to reach out, just smile, touch their hand, offer them a glass of water or sit with them. The simple things work extremely well.

Q. What about family members? With so many things that could be going on with them (trying to be brave, fear, grief, anger, burnout), in your experience, when and how have good health care people supported them?

A. This is another big topic. Health care workers already have an awesome responsibility with the patient. In my situation, they were able to still be there for my family with kind words and moral support. However, I encourage people to learn more about compassion fatigue, or secondary traumatic stress. Both health care workers and families suffer from emotional and physical burdens embedded within a health care crisis. Over time, they may develop symptoms of depression, stress, and trauma.

Q. Throughout your experience, did you or your family ever find emotional support in an unexpected way—did anyone on your care team surprise you?

A. The most dramatic example was when my physical therapist took me out skiing on her day off. I was 10 months into my rehabilitation. I still had open wounds on my body and staples in my back. It was very difficult to move. I felt I had been assigned to a certain life and I was deeply depressed. The next thing I knew I was flying down the Vail Colorado mountaintop. That experience shifted my entire paradigm. I came alive that day. I will forever be grateful for her generosity.

Allison Massari was named the "2011 #1 Rising Star in Speaking by National Speakers Association." She can be reached through her website www.AllisonMassari.com.