Soapbox: Do Patients Have a RIGHT to Be Difficult?

By Wendy Leebov, Ed.D., Partner; Language of Caring

I hope you’ll discuss this powerful question with your coworkers.

Last month, I shared my sister Linda’s story and my feelings about labeling people “difficult patients.” I was hoping to encourage all of us, including me, to find within ourselves the groundswell of patience and compassion that enables us to extend extraordinary lovingkindness to patients whom we find challenging. Who knew the flood of responses I would receive to that article. And who knew that my stance was actually CONTROVERSIAL!

Look at this:
“I do not agree that a person with chronic health care issues has the “right” to be rude, miserable and mean. You missed the point with this last newsletter. I have a daughter with chronic healthcare needs. I have taught her that’s it’s ok to be scared, in pain, tired, etc. - but it is never ok to verbally abuse another. As a healthcare provider- I do indeed empathize with the experiences of the chronically ill and I am kind, willing to communicate and problem-solve. Offering people a “pass” that promotes violence is unacceptable- no matter how they are suffering.”

In contrast: From Mary Koloroutis, VP, Creative Health Care Management

“I am not surprised but always disappointed to hear the perspective that patients must behave in a way that is acceptable to us -- that expressions of anger, frustration, difficulty coping with their suffering is an affront to the caregivers (abuse?) and needs to be managed and confronted. When a person is experiencing pain, is afraid for their very survival, is weakened and vulnerable from the chronicity of their situation, they are simply not at their best. Depending upon their lifelong ways of coping, some will have less capacity to “behave appropriately” than others. Our job is to meet people where they are and to love them through this difficult time in their lives. We cannot know their back story, or why they cope as they do -- but now is not the time to “set them straight” for goodness sake.
Our compassion and kindness at the end of their lives will not only enhance the chances that their suffering will be eased, but it will also help their families cope with the circumstances and will facilitate the grief process — because they know their loved one was cared for with dignity and kindness. That is what we signed up for when we took on the responsibility and license to care. I believe we are strong enough and capable enough to not take offense at a sick person’s expressions of distress. Our responsibility as licensed professionals is to understand the complexity of illness and the manifestations of distress. I appreciate your ability to accept Linda, to lift up the determination she had for independence and control in her life as something that is admirable, and seek to understand her distress rather than judging her. That is often much more difficult for a sister than it would be for her professional caregivers. It also sounds to me as though her “amazing personal physician” Dr. Caroline Ellis, along with many other caregivers, did not personalize Linda’s struggle and was a sturdy and consistent presence in her care. That gives me great hope for our work and our capacity for knowledgeable compassion.”

And this: From Marney Prouse, Quality and Governance Lead at West Herts NHS Trust

“I share concern that the patient who is trying to maintain a modicum of control in an otherwise catastrophic life is labeled “difficult”. Where is the psychological support for patients to help them to navigate through these waters? Your sister sounded like she was trying to be the captain of her own ship. Her comments were a cry for empathy and understanding. Which brings me to my next point: Why are we not educating our caring staff, providing support for them so that they can off-load their negative feelings and providing coping mechanisms for them? People are not born knowing how to do this- they need to have tools. The good news from Linda’s story is that there clearly were people who “got it”, whether by design or default -- they need to be the standard bearers for more empathic care.”

Initiate this very important conversation with your team: Do patients have a RIGHT to be difficult?

I think every healthcare professional should come to terms with this question. By achieving clarity, we can resolve our mixed feelings and develop a personal decision-rule that will inform our responses to patients’ and families’ challenging words and behavior.

- If you conclude that patients do NOT have a “right” to behave in challenging ways, then work together to find words to say that in a compassionate way. For instance, “I realize you’re very distressed, and I want to support you in every way I can. Still, those words hurt my feelings, and I’m sure you didn’t mean to do that.”
- And if you choose to accept people’s challenging words and actions, then help each other develop the self-talk and skills to avoid taking these words and actions personally and instead use them to trigger even more lovingkindness.”
Our Gift to You in Celebration of the New Year

On behalf of the entire Language of Caring team, we thank you for being powerful, positive change agents and champions in health care. And we wish you and your loved ones health, joy and fulfillment during the coming year.

As a token of our appreciation, during this holiday season, we are making three contributions in your honor to causes close to our hearts. Click here to see our choices.

A GREAT Resource: Patient Experience Radio (And a 32-minute interview with Wendy!)

This is a gem! Pat Rullo offers an on-line audio forum for sharing patient experience tips, tools, products and services designed to enhance and support a positive patient experience. Pat is a recognized voice in the patient safety and patient experience world as the host of the nationally syndicated radio program Speak Up and Stay Alive Patient Safety Radio.

Recent broadcasts (all available for free on-line) feature Peter Pronovost, MD, James Merlino, MD and most recently an interview with Wendy Leebov.

For more info about Patient Experience Radio, go to http://www.patientexperienceradio.com


• Wendy Leebov is the only non-physician honored to serve on the Society of Hospital Medicine’s new “Patient Experience Committee,” chaired by Mark Rudolph, MD of Sound Physicians. Click here to see the Committee’s charge. Also, Wendy welcomes your insights and suggestions about the role of Hospitalists in achieving the exceptional patient, family and team experience. (Send to wleebov@languageofcaring.com).
AHRQ and the CAHPS Consortium are proposing to make some significant changes to the CG-CAHPS Survey and the Patient-Centered Medical Home (PCMH) question set. Revised surveys are expected in early 2015.

The proposed changes are designed to balance concerns over the length of the surveys and robust content, to improve the efficiency of the existing domains, to update wording to match current practice, and to maximize reliability and validity. For more detailed information, visit the AHRQ website.

Suggested Self-Development Books for the New Year

- *The Miracle Morning: The Not-So-Obvious Secret Guaranteed to Transform Your Life (Before 8AM)*, Hal Elrod
- *Essentialism: The Disciplined Pursuit of Less*, Greg McKeown
- *Mini Habits: Smaller Habits, Bigger Results*, Stephen Guise

**Take a Break from Tech!**

Unplug from your computer and cell phone, like this:

1. Stuck in a line? Instead of grabbing your phone, do some intense people watching. Examine people’s faces, their shoes, their hands.
2. Instead of checking e-mail while you wait for a meeting to start, take a few deep breaths, stare out the window, or sip and savor a nice-smelling tea.
3. While waiting for an appointment, give yourself a hand massage instead of texting.
In his book *The Heart Aroused*, David Whyte argued for a workplace where our souls feel at home enough to release the creative energy residing in the dark depths of our beings. People who work with soul apply their life energies to the mission of their job, to their everyday way of doing it, and to the challenge of doing it even better. Hear Wendy describe concrete strategies that help the wonderful people on our teams feel fully alive and fulfilled in their work.

**HIGHLIGHTS:**
- “The Three C’s” key to soulful work: Commitment, Craft and Community
- Practical positive strategies you can use to advance the 3 C’s

**WHO SHOULD ATTEND?**
- Executives, physician leaders, directors, managers, nurse managers, supervisors, human resource professionals

**WEBINAR FACULTY**
Presented by Wendy Leebov, Ed,D – Partner, Language of Caring, a passionate advocate, speaker and consultant for creating healing environments for patients, families, and the entire healthcare team for over 30 years and author of more than 12 books for healthcare.

**SPACE IS LIMITED**
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**INDIVIDUAL $49**
**GROUP (PER CALL-IN LINE) $199**

If your system wants to purchase several call-in lines, contact us.
Are Language of Caring Programs Right for Your Organization?
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– Learn how these programs work and their specific components
– Preview our awesome new Client Portal for easy access to videos, all materials and and sustainability resources
– Get to know our implementation services that help you jumpstart your strategy and accelerate your results
– Ask your questions!

Language of Caring
Achieving an unparalleled patient experience and a culture of caring through exceptional communication.

If you like this HeartBeat, please forward it to others. If someone else sent this to you, please subscribe at www.languageofcaring.com.

Join our LinkedIn Group “Quality Patient Experience and HCAHPS Improvement” and add to the rich discussions about the quality patient experience. AND please send us an INVITE so we can connect. Thank you!

Jill Golde, MA, Dorothy Sisneros, MS, MBA and Wendy Leebov, EdD—partners at Language of Caring.

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