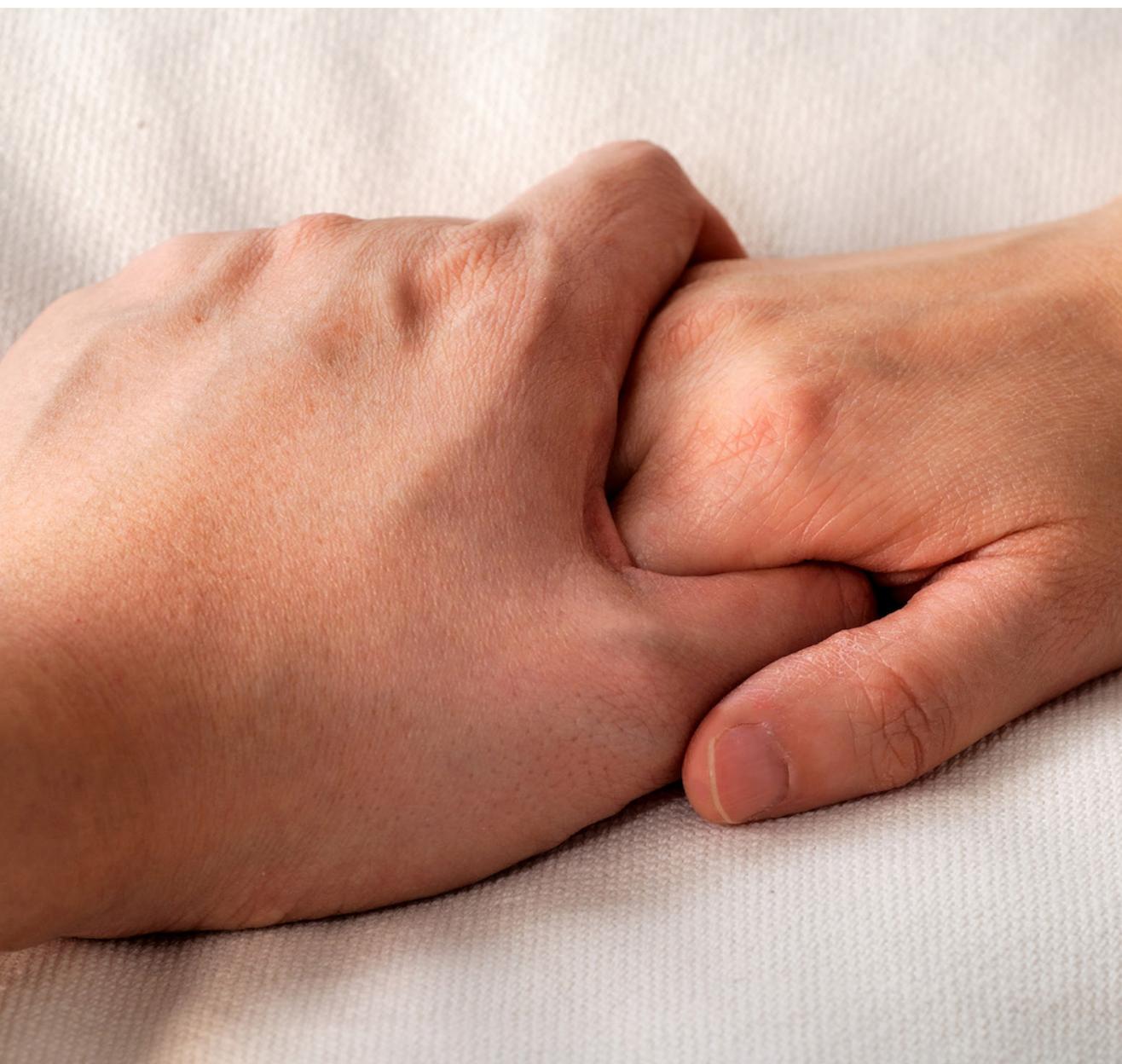




**HEALING  
HEALTHCARE  
SYSTEMS®**

Creating  
Environments  
that Heal



**IMPROVING THE  
PATIENT EXPERIENCE,  
ONE PERSON AT A TIME**

SUSAN E. MAZER, PH.D.

Improving the Patient Experience, One Person at a Time

Susan E. Mazer, Ph.D.

Copyright ©2015 Susan E. Mazer, Healing HealthCare Systems, all rights reserved.

This eBook or any portion thereof may not be reproduced or used in any manner whatsoever without the express written permission of the author/publisher except for the use of brief quotations in a book review.

The information contained in this guide is for informational purposes only.

I am not a lawyer or an accountant. Any legal or financial advice that I give is my opinion based on my own experience. You should always seek the advice of a professional before acting on something that I have published or recommended. Any amount of earnings disclosed in this guide should not be considered average.

The material in this eBook may include information, products or services by third parties. Third Party Materials comprise of the products and opinions expressed by their owners. As such, I do not assume responsibility or liability for any Third Party material or opinions.

The publication of such Third Party Materials does not constitute my guarantee of any information, instruction, opinion, products or services contained within the Third Party Material. The use of recommended Third Party Material does not guarantee any success and or earnings related to you or your business. Publication of such Third Party Material is simply a recommendation and an expression of my own opinion of that material.

No part of this publication shall be reproduced, transmitted, or sold in whole or in part in any form, without the prior written consent of the author. All trademarks and registered trademarks appearing in this guide are the property of their respective owners.

Users of this eBook are advised to do their own due diligence when it comes to making business decisions and all information, products, services that have been provided should be independently verified by your own qualified professionals. By reading this eBook, you agree that myself and my company is not responsible for the success or failure of your business decisions relating to any information presented in this eBook.

Editing by Sara Marberry, [www.samarberry.com](http://www.samarberry.com)

Cover design and formatting by Troy Elizares

Digital book formatting by Booknook.biz, [www.booknook.biz](http://www.booknook.biz)

## Table of Contents

About Susan E. Mazer

Preface

Introduction

Today's Noise is Tomorrow's HCAHPS Score

I Witness: My Under the Cover Patient Experience

HCAHPS Scores and Curry

HCAHPS Version of Jeopardy: Coming Soon to a Hospital Near You

Everything Teaches: How Patients Learn

PTSD: When Memories Live in the Present

How Do We Add Mission to Admission?

The Patient Experience: What Matters?

5 Steps to Optimize the Patient Experience

Aging, the Aged, and the Generic Patient Experience

Healing Into a New Future for the Patient Experience

Keeping Time With the Patient Experience

ICU-Acquired Weakness: Powerless in Recovery

Creating a Healing Relationship Between Patient and Physician

5 Questions to Add to the HCAHPS Survey

HCAHPS Survey Questions Not Really About the Patient

All HCAHPS Scores Being Equal: Caregiver as Patient

HCAHPS Scores: Mind the Gap Between the Survey and the Answers

What Happens to Patients When the Lights Go Out

Setting the Stage for the Patient Experience

The Waiting Room: Where Suffering Begins

The ROI on Human Caring in Healthcare

How Hospital Television Impacts Acute Care Patients

Compassionate Care: Who Have We Become?

The 5-Star Patient Experience: What do Stars Have to Do With It?

Thank You

## About Susan E. Mazer, Ph.D.



Hi. I'm Susan E. Mazer, President and CEO of Healing HealthCare Systems, producer of The C.A.R.E. Channel relaxation programming for patients.

I've been working in healthcare for more than 25 years, but like you, have also been a life-long patient and caregiver. I've written many articles and whitepapers and spoken at conferences around the country on noise in hospitals, speech privacy, patient experience, patient safety, elder care, and other related topics.

A few years ago, I earned a Ph.D. in Human and Organizational Development from Fielding Graduate University, where I also hold a Master of Arts degree. As a young musician, I was awarded a graduate fellowship to Stanford University where I completed a Master of Arts in Musicology.

Born in Detroit, Michigan, I got my undergraduate degree from Wayne State University.

Prior to my work in healthcare, I had a full-time career as a jazz harpist, performing with my husband Dallas Smith, and such notables as Ahmad Jamal, Frank Sinatra, and Julio Iglesias.

Our music has been featured on NPR, the Discovery Channel, NOVA, and, of course, The C.A.R.E. Channel. Together, we also are the founders and sponsors of the Elder Care Concert Series in Reno, Nevada, which is administered by the Sierra Arts Foundation.

## Preface

I have never thought of writing a memoir. However, if I were to write about my work and its pull on my mission and accountability to improve the human condition, my blog comes the closest to doing just that. It has allowed me to document what grabs my attention and become a focus of concern.

My interest in blogging began with a desire to share observations and experiences working in healthcare -- both directly and indirectly in the world of nurses, physicians, patients, and families. I describe this world in ways that make it clear I am an advocate. But I have not lived all the experiences, nor have I been subject to the many organizational and regulatory requirements that define clinical practice today.

So, this book is a compilation of some of my best and most read posts on the patient experience.

Why do I write so much about the patient experience? Because it is complex. And, it really matters.

The patient experience is, at its core, both universal and individual. That patients experience discomfort, fear, frustration, anxiety, and everything else that goes with being acutely ill, is universal. However, how they each process these feelings; how they interpret the culture of the hospital and the values of those who care for them; and how they manage their expectations, is totally unique.

I have been writing about the human side of patienthood for years. In the U.S., so often the battle is between our economy and our humanity. In many ways, this still remains the challenge. However, the scales of healthcare are weighed each day. And, it is at the bedside that the human story plays out.

In compiling this first book of blog posts, I looked at a thematic structure, rather than one that is wholly chronological. So, some of the posts that follow each other may have been written several years apart.

What will you get from reading this book? I hope you'll come away with a better understanding of what matters to patients and how you can contribute to a better patient experience.

You don't have to read it all at once. Or in any particular order.

Hopefully, you'll find the posts interesting and provocative; that something you read (or re-read) will positively impact your practice.

Or maybe it will inspire you to write your own blog.

## Introduction

Those who know and love me often point to repetition in my blog posts. I'm proud to say that it's true.

Because the healthcare topics I write about are far from outdated or resolved. Rather they are pressing enough that I feel if I take a different approach, maybe those who do not yet engage in tackling the issues will become engaged.

Even in my home life, I tend to repeat and repeat because nothing happens. Sound familiar?

Then, there is the reality that there are only so many topics that are interesting. Well, maybe.

Hospital noise, for example, has been a focus for me for more than 20 years. It finally has some teeth because of HCAHPS and value-based purchasing.

But, still, there is a global desire for the magic bullet of quiet. A fixed solution that once mastered, removes the problem forever and a day. This exists in fantasy only, and fantasies of silence are often more frightening than they are worth.

Patient safety is another interesting healthcare topic. Again, still marginalized as if some patient issues skip the concern for safety. So, I continue to write and talk about it.

And, now the patient experience is at the top of the list. However, I see a craving for a menu of items and events that create the perfect patient experience -- ones that can be dealt with one at a time as if they do not inform each other or at least can move the HCAHPS dial on their own.

The experiences any of us have are like stews well cooked over many hours. Every little thing counts, but is so enmeshed into the wholeness of it all that we can only identify the chili in the soup because it is hot enough to cover up everything else.

I keep writing about how we each continue to repeat the same Google searches, meeting topics, newsletter themes over and over -- because few issues get permanently resolved or are out of date. After all, my Patroness Saint, Florence Nightingale, wrote Notes on Nursing 155 years ago, and she could write it again, and again, and again.

Human issues never go out of date. They are spoken of, written about, sung and rapped about, and studied over and over. And, repetition is part of our collective chant; it is the drone of stability.

We crave the familiar as we explore the unfamiliar. This is not to say that everything repeated is a good idea; but a good idea, when repeated, remains a good idea.

## Today's Noise is Tomorrow's HCAHPS Score

I am writing about noise. Again. It is still here. It seems to survive earthquakes, hurricanes, elections, the flu season, and taxes. What is so fascinating about the topic is that "noise" does not exist in the physical world. Sound exists -- it can be measured, qualitatively and quantitatively.

Noise only exists in the ear and mind of the listener. We hear something that is annoying; we declared the "sound" to be "noise." And, whatever sound it is prior to such a declaration is irrelevant. Once a noise, always a noise -- so our ears tell us.

So, what does this say about hospital noise? First, that all those beepers, buzzers, alarms, cellphone ring tones, and television commercials, can, at any time, be declared, "noise." Therefore, a patient whose acuity level is high may easily hear every sound as noise because his or her ability to interpret the sound is compromised.

Hospital noise is a cultural tolerance out of control, one that takes little responsibility for the experiences of its patients, staff, and visitors. Noise survives in a culture that permits sounds to become toxic to those within earshot. Further, noise thrives in a culture that tolerates annoyance, causes annoyance, and then spends years trying to do everything except deal with it.

***Hospital noise is a cultural tolerance out of control, one that takes little responsibility for the experiences of its patients, staff, and visitors.***

The HCAHPS question about "quiet at night" is very telling. First, nighttime is generally quieter. And, in its immutable way, noise shows up softer, clearer, and unrelenting. Second, if patients remember anything, they remember what they hear when they are not sleeping. Third, noise does not respect suffering, pain, or fear, it feeds on it. Many of us sleep delightfully in front of loud televisions. However, put us in a room alone, in the dark, and all of a sudden even the softest sounds alarms us.

So, the answer is to look honestly at what we permit to happen, acknowledge noise as an outcome rather than as a problem, and look and listen past the obvious and go to the source. I have written so many papers on noise. The question always comes up about research, which I think is awkward because all of the research in the past 40 years indicating the damage noise causes, its disruption to our daily lives, and the many symptoms related to noise for patients has not changed the din.

From what we do know, clearly today's noise is tomorrow's HCAHPS score. But maybe that time is now. How are you dealing with noise in your hospital?

## I Witness: My Under the Cover Patient Experience

Having just spent 10 days in the hospital with E. coli, enteritis, acute colitis, a urinary tract infection, and septicemia, I have great tales to tell about my patient experience.

Up until now, my only direct patient experiences, besides routine check-ups, have been outpatient surgery and a hysterectomy 20 years ago. At that time, all I noticed about the latter experience was that my uterus had been removed and I was admitted to a maternity room for an overnight stay.

Today, because I am deep into the implications of HCAHPS, patient's rights, nursing advancement, and the patient experience, I pay more attention.

While researching and writing about HCAHPS, I have found the all too brief questions vague and subject to too much inference, particularly when it came to how a patient was treated by the other numerous hospital staff members. Neither the questions nor answers reveal why a patient feels dis-respected, or what exactly causes even a single communication with a doctor or nurse to make a patient feel respected. Being treated with respect is decidedly different than being respected.

There are also no questions about CNAs, housekeepers, phlebotomists, lab technicians, ultrasound technicians, etc. Why are these healthcare professionals seemingly given a pass on being respectful and acknowledging, or kind and compassionate?

As a patient, each person who walked into my room with a name badge was a touch point to recovery -- however, most of the time, they were not interested in knowing who I was, what was happening to me, or what they might be able to do to help. Neither could they, or would they, provide any new information, even about how the hospital operated, leaving me frustrated and anxious. I am not talking about a CNA changing or administering medication. I am talking about the CNA as a patient advocate, even if just for a moment -- being able to decide that a patient is in enough observable pain and discomfort to put down what she is doing and go get the nurse.

Perhaps the primary key to a real human connection is spontaneity -- an authentic, engaged human response that is not scripted, contrived, or in want of anything. Our policy police have allowed HCAHPS and every other performance survey to rob healthcare of all of that.

What does remain are Rubik's stations of productivity, where each person can ever only be one color, one cube, and can only move in a singular direction. Simple tasks that serve basic needs are frustrated, delivered as if they are not involving anything human, and everyone avoids the obvious: The patient is really sick and there is not much more "they" can do. And yet, each person touches the patient, the same patient, in ways that beg for more compassion, for more inventiveness, and more sensitivity, that begs for human connectedness.

An example of this is the difference between the aide that takes vitals once an hour (which may try to pass as rounds) and the aide that makes up the bed. So, the person comes in, takes my vital signs, and announces my blood pressure is 168/85 -- not even acknowledging that I told her my normal BP is 104/70. I was upset. I finally turned down the offer for a vital sign check. Seriously, refused. I also complained about my arms, which were twice normal size, making the blood pressure band most painful. Nada. No response.

Then, the changing of the linen. No, not automatically done (Florence Nightingale would have had a fit!). In fact, I had to beg to have my soiled bed linens changed. If a pad could cover up the blood from a poor attempt to put in yet another IV, why change the sheet?

If I was all tangled in the sheets and blankets trying to navigate two IVs per arm, why bother trying to straighten all of this out? I hate unmade beds -- and slept in one for 10 days, with maybe three linen changes. On demand. Only if needed.

The housekeeper that removed the trash did not make eye contact long enough for me to thank her, and the nurse that collected a specimen paid more attention to the achievement of having a specimen than the person whose life seemed to be foretold in this vial of urine. Yes, different jobs. But, only one patient around whom is an army of people who talk to each other through laptops. It is this singular core experience that evaporates in a tornado of activity.

Now, in all fairness, I am describing this from the observation of being a patient, under the covers, in the bed, waiting to be helped to the commode, waiting for a med, waiting for ice chips -- waiting for this whole episode to end. I am also far from uninformed. I am an astute observer of people, places, and processes. And, I am old enough to pay attention.

I also know that if my husband Dallas was not able to be with me every moment during my hospital stay, I may not have survived. And, I'm grateful that he was noticed and appreciated by the staff. However, it was only his loving disposition and patience that held us together. His way of dealing with lack of responsiveness was to "do it himself." He knew where to find the hidden sheets and blankets -- he just nosed around and found what we needed. I doubt anyone noticed, or cared.

Nonetheless, there are moments when the slightest act of kindness and inventiveness is pure magic.

I called for the nurse. The CNA, an older Philippine woman who was the sweetest of them all, walked in and asked what I needed. She knew I had been clock watching, that every hour was one closer to pain relief or nausea relief.

"Could you call my nurse," I asked, "I need some Ativan." This was a query based on my looking at the only medication that was PRN -- on an as-needed basis.

This CNA had watched me suffer now for seven days. She had washed my back, changed my bedding, and thanked my husband for his gentleness in helping her. To me, she seemed to be the only real person walking around.

She looked at me and quickly responded, "You don't need an Ativan... you need a Popsicle!" She then scurried out of the room to return only moments later with a red Popsicle -- totally within my limited diet, and fully pungent to my "ice-chips-only" palate.

It was the only fun moment of my entire hospital stay. Laughing, I was reminded that I didn't want the Ativan; I wanted to be well again. It was the first time anyone had offered me a Popsicle, although it was my fifth day on NPO (nothing by mouth) except for ice chips. There was no reason I couldn't have one. It was totally delightful. And, I don't even like popsicles.

The work of Healing HealthCare Systems has been, and remains, tending to patients during those hours when suffering is all that is going on. When the rest of the world has shut down, but fear

***During the 10 days I was in the hospital, I was offered comfort through a single popsicle -- and not until the seventh day of my stay.***

and anxiety are just waking up. We do so through providing The C.A.R.E. Channel, which offers stunning nature and instrumental music. And, it is not offered as a competitor to American Idol, Fox News, or ESPN.

While always available, The C.A.R.E. Channel specifically comes into play when none of those programs can any longer please, distract, or relieve. In producing C.A.R.E., we think about the patient who does not lie in his or her bed with their glasses or contact lenses on, the patient for whom moving color is but a blur, and the patient who cannot tell whether it is day or night.

During the 10 days I was in the hospital, I was offered comfort through a single popsicle -- and not until the seventh day of my stay. The flat screen television in my room was so bright that I covered it with a sheet. The only instrumental music was a loop on the opening screen, which, if I ever hear again, I am sure I will do something I will regret.

It was a new hospital building with lots of posters with smiling faces, and promises. I do not doubt the sincerity of these commitments; nor do I doubt that they are meaningful to everyone who walks in the facility. However, I now doubt the translation of all the pictures and words into a lived patient experience.

I further wonder whether the same caring promised to patients is offered to the staff. At this point, I question whether the best medical care in the world actually assumes responsibility for the unnecessary suffering of the moment, for the isolation of an illness, or for healing as well as curing.

## HCAHPS Scores and Curry

In Indian cooking, curry is a generic word for “stew” -- many spices put together in mysterious ways that result in a taste that is a combination of sweet and hot.

The relationship I see between HCAHPS scores and curry is that the questions are the spices and the outcomes are as mysterious as the final taste of a fine curry.

Those of us who love Indian cuisine know that every curry -- even with the same name -- has a unique taste. And, every patient experience is unique in ways we only wish we could understand.

The HCAHPS questions are somewhat simplistic. They are storefronts for events that only patients experience and tell a story that is much more complex than the questions.

For example, the questions on pain are twofold: was the pain well managed (whatever that means) and was “everything possible” done to mitigate discomfort? These two questions could not be more misleading.

What does everything possible mean? When a hospital patient is in pain that cannot neither be avoided nor fully resolved, what can be reasonably expected in terms of relief? Everything possible?

During my own hospitalization last month, the pain was unresolvable. Meds were provided every 8 hours, but my pain never followed that schedule. In fact, even when I complained about it and then the nurse called the doctor, the change to every 6 hours was insufficient to deal with my very in-the-moment suffering.

It would have been easier if I was on a morphine drip, but it was not that kind of pain. It was that gray area when pain and suffering are indistinguishable.

The room I was in was small and private. It had one wooden chair for my husband to sit by me 12 hours a day. The television was agitating when it was on -- it was useless to me. And, trust me, I love watching mindless television, giving my brain much needed respite from all that I am demanding of it. But this time, I couldn't watch anything.

I have said this before but I'm saying it again: the environment in which patients are confined 24 hours a day is the primary caregiver; it is in the “everything possible” column of what to do.

I was trapped in my hospital room. The bed was a mess, bathroom too complex to get to, the window too high and glaring, the overhead light was harsh, and the sounds I heard varied from erratic to nothing. “Nothing” is a sound: it is the chatter in my head that wonders if I will ever recover, that focuses on how awful I feel, that reminds me that I am alone with this misery.

We have been asked so many times if there is a relationship between HCAHPS scores and The C.A.R.E. Channel. There definitely is, which I've written about in a white paper posted on the Healing HealthCare Systems website.

In the paper, I suggest that HCAHPS magic is in the human factors of delivering care -- in the ways in which one person can offer compassion and empathy to another to just hold their burden

for a little while. The magic is in making the clock move faster on an experiential level if not on a real-time level. The magic is in taking care of the physiology of pain while fully addressing the spiritual and mental anguish that comes with it.

As a patient, time and place -- how long and where you are -- is a quality as well as a reality. And, curry is not curry if it has no taste. The environment must have the "spice of life" to support a life worth living.

## HCAHPS Version of Jeopardy: Coming Soon to a Hospital Near You

Welcome to the game of "Jeopardy 2," the HCAHPS version of the most popular quiz game on television! Today, we are going to provide some online clues and you have to guess the appropriate HCAHPS question to match the clue.

For instance, if we say, "45 minutes", you would ask, "How long was your wait for assistance?" Here is the first clue:

1. "Sleepless in ICU." Answer: "How often was your room quiet at night?"
2. "What did they say?" Answer: "Did you fully understand your discharge instructions?"
3. "Wait a minute." Answer: "How often did feel your physician treated you with respect?"
4. "I could not wait." Answer: "Did you get help when you needed it to go to the bathroom?"
5. "The towels are still wet." Answer: "How often was your bathroom cleaned?"
6. "How long?" Answer: "Was your pain managed well?"
7. "How much longer?" Answer: "Was everything possible done to control your pain?"
8. "I already told you." Answer: "How often did you feel you were listened to?"
9. "You have to change the bed again." Answer: "How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted?"
10. "What was that?" Answer: "Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?"
11. "Only in an emergency." Answer: "Would you recommend this hospital to your family and friends?"

While clearly these clues came from total frustration, lower HCAHPS scores reflect frustration of patients whose experience is far from what they feel they deserve or have a right to expect.

In some ways, backing into the HCAHPS survey from the symptoms may be more revealing than going from the results to action. The symptoms are always obvious: the patient who cannot sleep, the patient who is suffering, the physician or nurse who cannot remember the patient's name, the bathroom is still wet from the last shower. Somehow, we just know the obvious.

Jeopardy is a great model for HCAHPS. If only the real risks were not laid on patients first.

## Everything Teaches: How Patients Learn

I learned to be afraid of shots following a shocking injection of penicillin on my behind when I was six years old. I had scarlet fever (was I the last one?) and the doctor came to our house. At that time, house calls were normal!

After examining me with his cold hands, he told me to turn over and that "it would not hurt." He lied. Thus, I learned and subsequently responded in terror in anticipating a shot until I learned that they do not all hurt.

Everyone learns just the way I did. They observe, experience, and conclude. And, patients today are not as innocent as I was. They enter a hospital or exam room with lots of experience, information, and fear.

When I think about the challenge of imparting the correct information, telling an "evidence-based truth," explaining why a surgery or drug is not appropriate in spite of the benefits claimed on television, I think that we do not have the luxury of starting over with a clean slate. And, the

***Health literacy does not describe or account for the power of the teachable moment and the therapeutic relationship.***

environment and circumstances in which the information is given make it even more difficult.

Still, some clinicians -- both physicians and nurses, men and women -- just naturally teach, explain, engage with patients on an intimate level -- so intimate that they wait until they are reassured that their patient fully understands what is happening. Health literacy does not describe or account for the power of the teachable moment and the therapeutic relationship.

Fully understanding the power of the words spoken to patients and families requires understanding that a health crisis creates a teachable moment when the most difficult of subjects can be understood and dealt with. Whoever is with them at that very time does best to take wise advantage of it. The only resources needed are compassion, caring, and presence.

What do you know about healthcare that you were never taught?

## PTSD: When Memories Live in the Present

When I was a child, I had bad dreams -- dreams that would wake me up. I'd go into my Mom's room and she would walk me back to bed.

Sometimes the dreams haunted me for days. One time, I had to come home from school because I was so distraught. I had a great childhood. Just bad dreams.

Post-traumatic stress disorder (PTSD) is about haunting memories, real or made-up events -- hallucinations that never leave. They show up anew for reasons sometimes unknown, but often as the result of environmental triggers, such as sounds, that bring us back to moments and thoughts, fears, and sometimes, horrific events.

Studies have shown that critical care patients can suffer from PTSD. Being restrained, intubated, and entrapped by technologies that may be life saving is very frightening. The revisiting, reliving can show up years later. Hallucinations can be relived in the same ways my childhood nightmares survived daylight -- and years.

I have always known that what happens today, if I am conscious, remains with me for a lifetime. In fact, much of my life has been reduced to a series of extraordinary moments -- running the gamut from poignant, scary, thrilling, sad, and joyful -- the full span of emotions that life delivers. For most of us, this is probably true.

If we want patients to move forward in healthful living, then we must design the memories that they take away with them from the hospital. We must be aware of the power of their perception and proactively create positive, nurturing, comforting experiences of who we are to them.

Creating a healing environment at the bedside, providing compassionate care is not an option -- it's a necessity. And, the patient's perception of what is happening to them informs his or her emotional future.

In a previous post, I described my own experience as a patient in a hospital for 10 days. Since then, much has faded for me -- except for extraordinary moments that, when I think of them or speak about them, become as real for me as if I was back in that hospital bed.

Fortunately, I am fine. So many other patients are not.

What patients see and hear informs how they make sense of what is happening to them. That is why we developed and continue to provide The C.A.R.E. Channel -- to offer beauty amidst suffering, fear, and anxiety. To create different memories.

What kind of memories are you designing for your patients and families?

## How Do We Add Mission to Admission?

Great question. Great pun, too. However, in the current period of HCAHPS, patient engagement, employee engagement, and patient satisfaction, without a mission, how can you ever reasonably expect to provide quality healthcare?

And, I am not referring to the mission that is well framed and mounted in your administration office or hung in the lobby. I mean what really matters to each of us, at our core -- why we get up in the morning, and what guides our actions and decisions.

So, adding a mission to an admission implies that for each admitted patient, whether to the ER or the hospital, a mission must accompany every event, intervention, protocol, test -- everything. If not, the respect patients deserve, as individuals, will be lost.

As a musician, playing an instrument without mission means that one is a mechanic with technical prowess. I've read that it takes an IQ of only 40 to play an instrument. However, to be a musician and stir the hearts of your listeners is hardly mechanical.

Treating a patient with compassion and empathy, being sensitive to his or her situation and integrating your humanity with your skills is hardly mechanical either.

So, mission -- what really matters? What are you bringing to this situation that only you can bring because who you are is unique to you?

***So, adding a mission to an admission implies that for each admitted patient, whether to the ER or the hospital, a mission must accompany every event, intervention, protocol, test -- everything.***

I have zero tolerance for doing something that has no meaning for me. That's probably why I performed for 25 years and then had to manifest the music in another way by creating The C.A.R.E. Channel. Because what mattered to me was more than my skill as a musician and what brought meaning to my life was far more relevant than a standing ovation.

Those of you who know me have heard me say this. For those of you who don't, both my husband Dallas and I needed more than musical perfection. We wanted more than could be offered by the pursuit of recording contracts, managers, and all else that cloaks the music industry.

And, each of The C.A.R.E. Channel artists has come to us with the same goals: to move beyond success to meaning. We specifically don't put artist/composer credits on The C.A.R.E. Channel so as not to burden or distract patients and families. So, all of us C.A.R.E. Artists have had to rearrange our professional goals to make room for our individual missions.

What matters? To feel alive, the stakes have to be electric; and to be electric, some connection must be made between who you are and what you are doing. Once made, the connection brings to life what matters.

Do you add mission to your admissions?

## The Patient Experience: What Matters?

In all of the writings about the patient experience, few ask the foundational question, "What matters?" While ambiguous and global, this question is primary to any experience as it defines our focus and our bottom line concerns in ways that details often miss.

If we asked ourselves what matters to us when we go to see the doctor, we might come up with the following list:

1. The office is clean.
2. The staff knows who I am. I am treated as a person, not a number.
3. I really get that what happens to me matters to the doctor.
4. The experience is not humiliating or cumbersome. Do I really have to take everything off?
5. I leave feeling better than when I walked in.

These hypothetical responses are far from hypothetical. We have all thought about them. Having an identity to the person to whom we are entrusting our health is not only reasonable, but also vital.

One by one, what do these statements mean?

### **1. Clean Office**

A clean office indicates intent to heal and treat. It reflects competence, expertise, and just about everything else about the skills of the clinician. What does an unclean office mean?

### **2. Who You Are**

The staff knowing who you are means that you are not invisible, that they have a better shot at getting the correct medical records, and they care enough to know that coming to the doctor is hardly an everyday event for you.

### **3. You Matter**

Having what happens to you matter to the doctor makes it personal. It says that you are not part of a generic patient population or just a billing number.

And, again, if what happens to you does not have value to the person taking care of you, what ultimately does that say about the kind of care you will receive?

### **4. Not Humiliating**

Taking off your clothes -- all of them -- in the doctor's office has never been easy. Feeling vulnerable at the same time that you are feeling unwell, or fear being unwell, is a double-layered hit to your own security.

Putting on a cold paper gown makes it worse. Waiting for the doctor with the door closed and

hearing all the other activities makes us even more nervous.

### **5. Better or Worse?**

The other side of an office visit, treatment, or medical intervention tells the tale that foretells the future. No, immediate relief may not happen. But, if you don't feel hopeful or have an understanding of why you feel the way you feel, and are in control of how you process the experience, then you are going to be worse.

This is because once you see a doctor there is no other place to go, other than to another doctor.

So, the experience of being a patient is more than just being examined and treated. It is intimate and private; it yields us helpless to people we have never met before.

What's called for is hardly clinical babble. We need acknowledgement, authentic concern, and consideration. And, above all, we need to know that we matter and that what happens to us matters.

## 5 Steps to Optimize the Patient Experience

It's time that we move from hypothesizing about the ideal patient experience to actually taking personal responsibility for making it happen. But how do you start? Here are five simple steps:

### 1. Get Honest

This is not easy. Our capacity as human beings to rationalize and right a sinking ship is stunning. What I mean by honest is no less than the rigorous honesty called for in the 12 steps of Alcoholics Anonymous.

Look around and become literal in your description of what you see. Listen without trying not to hear, but listen with the intention of owning what floats around in the auditory environment that no one wants to or should hear.

By doing this, you can begin to understand what patients and their families hear and see. And, then be compassionate with your staff if they have not seen or heard what you've heard and seen - after all, it took you until now to do so.

### 2. Get Honest With You

The level of rationalization that we master is matched only by the level of fibs we tell ourselves. Self-honesty is foundational to organizational integrity.

Patients and families know a cover-up or a "story" when they hear it. Many of us tend to lie to ourselves before we rationalize to anyone else. We accept the unacceptable by telling ourselves "it is not that bad" or "we have not gotten a complaint about this yet."

By getting honest with ourselves, what we tolerate becomes intolerable because what we "put up with" is very different than that we are proud of. If we are not willing to hear someone else's truth, how do we accept and come to our own?

It's also critical is to accept and encourage honesty in others. Again, be compassionate with your staff and help lead them through the process.

### 3. Be Urgent: Fix What is Broken

While I was doing a staff-development program on creating healing environments at a hospital that shall be unnamed, the staff complained all day about the doors on nurse servers that made noise when they closed. An annoying click.

They determined that when the doors were open (which was the expedient solution to avoiding the annoying click), these servers, which were part of a firewall, amplified every discussion that took place next to them, not only to the patient's room, but also to other rooms. Further, nurse reporting was done next to the open nurse server.

I asked how long this situation had existed. "About 20 years," was the response. When I asked

what was required to close them, the answer was "Using one's thumb to close it very carefully to make the least noise."

I must have looked surprised. Later that day when we toured the units, all the nurse servers were closed. Every one of them.

It only took a couple of decades to have an open, honest discussion about an ongoing annoying noise and subsequent breach of speech privacy and then only a couple of hours to take find and implement a solution.

The cart that squeaks, the sounds of inconsiderate laughter or conversations, the not quite clean enough public bathrooms that visitors try to ignore but never forget -- all of these or any of them can contribute to the angst and anxiety that can contaminate the whole unit.

Wheelchairs and gurneys that border corridors are also an accident waiting to happen. Clutter equals risk; tolerated and avoidable risk is intolerable.

Do everything possible to urgently deal with what is clearly not acceptable -- no delay, no forms to fill out. Just fix it. If you do this, risks that are often easily resolved can be eliminated.

#### **4. Celebrate the Heroes**

"Ordinary people who do extraordinary things." There are clearly people in our hospitals in every department who carry the burden of the patient experience in their hearts. They do intentional acts of kindness.

They would not think of passing a lost visitor, sad child, lonely patient sitting by a window, or co-worker who appears distraught without acknowledging them, without offering some kind of support. Acknowledgment is undervalued. It is saying, "I see you" without judgment or need for explanation.

It is about being human together. It is about being present while entrusted with the health of another. Heroism in this sense can be contagious.

Model intentional acts of kindness, compassion, and empathy. If you don't, what kind of expectations can you reasonably have of others? Be a hero among heroes.

#### **5. Appreciate What is Right**

Appreciative inquiry is a model of transformation that begins from strength and ends with stronger. It begins by taking stock of all that is working and what is the best in our organizations and its individual members.

It says that being strength-based is far better than investing in weaknesses. This is not a conflict with acknowledging what can immediately be improved or remedied.

It is our strengths that allow us to make sure changes with confidence and expedience. And, it demands that we have high expectations of others and ourselves when anything else puts someone's life on the line.

It says that strength comes from honesty and integrity. Commitment is what pulls us to the other side of brokenness. It's not about being perfect, but celebrating what is possible and happening every day.

**Final Thoughts:**

These steps are my steps. Far from original, they borrow from lots of other lists, experiences, and expertise. And, they are not absolute. But neither is the patient experience.

Also, they are contingent upon each other. Missing a step sacrifices them all.

Each step demonstrates our proactive commitment to our patients and those who care for them in a different way. They each call for simplicity, not a myriad of complexities that often hide the obvious and paralyze all action.

Make your own list. Borrow from whatever or whoever has influenced you positively, and, of course, from your own experience. But keep to no more than 5 steps. Any more and we may not hold on to any of them.

And remember, it's not about specialization. The more details you add, the less opportunity for success. Make each step totally simple and totally doable.

Then, work your 5 steps every day, in all of your affairs. Make the list public to make yourself accountable. Make changes as you learn what works.

Your experience becomes the patient experience, which becomes the organizational and community experience. Model the best and the best is what you shall achieve. And, the best is what all patients deserve.

## Aging, the Aged, and the Generic Patient Experience

Ageism is alive and well in healthcare. In fact, as a "boomer," many journalists have made great efforts to tell me how I am going to age, how much money I will have to spend or not spend, what kind of issues I might have, and at what age I will probably elect to leave my home for a long-term care facility.

There's danger in assuming that the Boomer Generation is a single mass of humanity.

When I was in hospital in June 2013 for E Coli septicemia, I suddenly became a female of a specific age that, when written on my chart, was no longer me. The entire 10 days I was there, no one asked me about who I was or why I was in a hospital 400 miles from home -- even though my address was on the chart.

Loss of identity is the journey to learned helplessness, loss of motivation, and depression. Even if temporary, when in the hospital your entire life is at stake, and those who are in charge of treatment become seriously significant in ways that override the fact that you have no idea who they are. The question becomes whether the person who is a patient is more important than the patient whose personhood may be secondary to their diagnosis.

Here's a patient experience story that brings this to the forefront.

A nurse at a hospital in San Francisco reported that she had an Asian patient, a man in his late 60s, who had had a serious heart attack. He was in ICU, intubated. He had not always needed a ventilator and so he had read books when he was able.

***Loss of identity is the journey to learned helplessness, loss of motivation, and depression.***

The nurse came into his room and saw a book on his nightstand. She picked it up and realized that this man was a scholar and the author of this book on complicated mathematics. He was a professor in Japan.

She looked at him and said, "Good Morning, Professor Ogawa!" With his eyes closed, a tear flowed down his cheek. From that moment, that nurse made sure that every staff member used his name and title to address him. He became a person that mattered more than a patient.

When I was in the hospital last June, no one knew that I had just come from a six-week trip to Jordan, Israel, Sweden, and Orlando, FL, where I had spoken to various healthcare organizations. They did not know that I have four degrees, including a Ph.D., and have played the harp for over 50 years.

They did not know that my husband, Dallas, and I were married for 27 years and had started a company that now produces The C.A.R.E. Channel that is broadcast in more than 750 hospitals nationwide. I was just a 60-something female patient with E Coli suffering from colitis and other various conditions related to the serious infection.

It was awful. And, I do not want to die without a sense of myself in a broad community of people I love, respect, mentor, and follow. The term "generic" means "without a brand name or registered

trademark." It means, related to a person, without a name, without character, without unique talents or skills. It means an "anybody" rather than "somebody."

How do ageism and the tendency to create generic patient profiles play out in your organization? How do you deal with maintaining your own personhood in your work? How do we ensure that our role in an organization does not make us, or those around us an "anybody" rather than a "somebody"?

## Healing Into a New Future for the Patient Experience

Coming from the rich experience at the Beryl Institute Patient Experience Conference, I want to share some of my own takeaways. We heard from so many wonderful speakers, but more importantly, we heard from each other.

And, we listened carefully, consciously -- in ways often passed over for the sake of the tasks in front of each of us. Bearing witness to another's suffering and vulnerability is the key to healing the wounds of isolation that comes from acute illness.

The nature of patienthood is one that is lived a person at a time, each unique in his or her story, and each unique in the ways illness can change the future. Nonetheless, the patient experience movement forces us all to look at the human conditions of suffering and healing in ways that evidence-based medicine has tried to avoid.

Evidence-based medicine originally included more than just scientific outcomes. It included the patient's unique circumstances, values, and preferences. This has been set aside for the sake of standardization of practice.

However, none of us are "standard," nor do we want to be considered so.

I was moved by Brian Boyle's story, where he so precisely described his two months in a medically-induced coma after a catastrophic auto accident that left him able to hear and remember, but unable to respond. He talked about the spirit-saving value of those who spoke to him and included him in their discussions with each other, even when he could not respond.

Brian shared his confusion in only hearing bits and pieces about what had happened to him and his narrow hope of survival while his young 18-year-old life had come to an immediate halt.

Sometimes I think we live in a world of people who are in socially induced comas, unable to respond, hidden from view, and often ignored.

I was also moved by the commitment of those at the conference to step in the world of our shared humanity and begin valuing our ability to connect -- one person to another -- to heal the suffering that is inherent to the patient experience.

As a former patient, my experience is now part of the mosaic of my life. My recollection of my hospitalization last June, while now more integrated into a larger perspective, has become more meaningful with time.

Every aspect of what happened to me is not as clear as the people, the endless lonely nights, and the day-to-day angst I lived with while in the hospital. I remain grateful and humbled by the profound service provided by those who care for the ill.

The patient experience lives in each of us, one person at a time, one story at a time, one life at a time.

## ICU-Acquired Weakness: Powerless in Recovery

Recently, The *New England Journal of Medicine* published an article about ICU-acquired weakness. The authors explore the physiological (neurological) outcomes of having a critical illness, being administered strong medications, being intubated, and otherwise being unable to move.

Nerves atrophy and fail to function normally. The condition is identified as critical illness polyneuropathy.

Some of the symptoms resolve themselves and others are irreversible. What is most stunning, however, is the lack of interest or comment about the patient's mental, emotional, a psychological outcome from being in the ICU, powerless, weak, and most likely headed for yet more complications.

There is no reference to how immobility impacts the mind or life of the patient.

Earlier this year, I wrote a post about ICU-induced PTSD occurring in patients whose stay in the ICU included intubation and painful procedures. Studies show that up to 35% of ICU patients have symptoms of post traumatic stress disorder (PTSD) -- including nightmares and phobias -- for as long as two years after discharge.

***If you think about the physical environment of care and its impact on the patient experience, you can see how it might contribute to disorders like ICU-acquired weakness and ICU-induced PTSD.***

There is no question that ICU-induced PTSD is about the mental, emotional, psychological scars of a traumatic illness and being in the ICU. Now, we have ICU-acquired weakness.

When a person becomes a patient, his or her life changes. However, the change begins long before entering the hospital and continues long after discharge.

It begins when an individual is notified that he or she might have a physical condition over which he or she has little if any control. Then, he or she is subjected to the whim of medical science, the hospital staff, and his or her condition.

Just thinking about it changes a patient's sense of self -- the identity from which everything else flows.

If you think about the physical environment of care and its impact on the patient experience, you can see how it might contribute to disorders like ICU-acquired weakness and ICU-induced PTSD. For example, what if we put premature infants in a cardboard box?

Frail infants need softness and swaddling to feel secure. The sensory deprivation of a cardboard box would surely create developmental challenges by risking the infant's failure to thrive.

When I read about ICU-acquired weakness and ICU-induced PTSD, I feel that we are compelled to create and design memories for patients. Even intubated patients can hear, and what they hear

while in that hospital bed becomes whom they are while they are there and long after.

Using patients' hearing to tell them what is happening we can provide auditory swaddling. We can comfort and engage with life beyond the breathing tube down their throats.

Healing HealthCare Systems often gets phone calls, emails, and letters from ICU patients who tell us how much The C.A.R.E. Channel meant to them while in the hospital. They tell us that seeing the best of nature gave them something to hold on to and the music comforted them.

These communications are sometimes right from the bed or during the first days following discharge. Or one year or more later as they relive what happened to them.

The person in the room -- whoever it may be -- is the one to do the swaddling, comforting, and reassuring. To patients, the people working in the hospital that enter their room are assumed to carry the mantle of healing. Florence Nightingale was relentless in her demand that anyone to whom the health of another is entrusted exercise his or her own capacity to provide comfort.

Creating memories and designing experiences and environments that relieve emotional, as well as physical suffering can dramatically change how patients recall and relive what happened to them in the hospital.

I look forward to a study that identifies ICU-acquired HOPE.

## Keeping Time with the Patient Experience

As a musician for many years, the idea of “keeping time” was never mysterious -- even as a young child. Keeping time meant staying in rhythm, in tempo.

In some ways, when I was trying to play faster, it meant arriving at “ONE,” the downbeat, on time. Any hesitation was an obvious and embarrassing mistake.

As an adult, the idea of “keeping time” means something quite different. And, from my own patient experience last summer, I know that a patient’s time is not always kind.

I also realized that the rhythm of the hospital staff, the physicians, and the medication was not in sync with my condition or my pain.

Everything in healthcare is measured in time. On the hospital side, it is about length of stay, billing cycles, and staffing schedules. On the patient side, it begins with being left on hold while trying to make a doctor’s appointment, waiting rooms, and waiting in the examination room.

All of this continues with time spent waiting for results of a test or waiting for a pain med to work. Then, when we deal with the real stuff when it is a prognosis, the question is always, “how long?” Time is the currency of all things healthcare, all things life.

We bargain with time, but it does not bargain with us. Rather, time moves along no matter what, in many ways like the metronome that ticks and ticks and ticks. Clock time never stops, either.

Lived time, however, is another story. Experienced minute to minute, it is difficult to harness or predict. In some ways, the downbeat, ONE, can happen any time.

Lived time speeds up and slows down -- it can drag on forever, and then speed up to the point that we have to look back to know it has passed. If we accept that our experience of time is more elastic than being simply measured in hours and minutes, then we can do a better job of keeping time, being sensitive to the rhythm of our patients.

One thing music does is order time. It parallels the lived experience. It provides emotional character to an otherwise painfully indifferent blankness of an unfamiliar hospital room. It moves along in a temporal world and takes everyone with it.

Music can speed up our time or slow it down. We entrain to it, literally tapping our foot or finger unconsciously.

In the hospital, music breaks through the isolation that is often felt by patients whose lives are defined by the edges of a hospital bed or the walls of their rooms. It makes the pace of their life world easier. It fills the space and the time, especially when no one is with them.

If you’re stressed out, listen to the music you love and let it carry you to another place. Frightened? Listen to music you know so that the unfamiliar becomes familiar.

If you need a break, listen to what will take you away, to another place and time. It will allow you to return refreshed.

Every week, we get phone calls, emails, or letters from patients and family members who tell us how The C.A.R.E. Channel helped them endure their lonely hours in the hospital. The combination of music and nature is clearly restorative and supportive for all involved in a hospital stay.

Transforming time, smoothing it out, softening the ways it passes -- this is why music is so important at the bedside. And, keeping time with our patients, being in rhythm with them, is critical to optimizing their experience.

## Creating a Healing Relationship Between Patient and Physician

2 + 2 will always = 4. But, two people who are dealing with cancer, one a doctor and the other a patient, what do they equal?

A healing relationship is more than just two people. It is about an assumption that at the core of the relationship is the wellbeing of the patient. It creates an expanded wellness and hope factor. It is about trust where there was fear. It is more than simple arithmetic.

While for many years scientific objectivity has ruled the basis for medical science, the lack of understanding of how a person lives through an illness has become more evident in today's world of trying to optimize the patient experience.

The first mountain to climb is the belief that the "experience" has no medical relevance. The *Meaning Response*, so well defined by Moerman and Jonas as "the physiologic or psychological effects of meaning in the origins or treatment of illness," which has been shown to include everything from how the physician looks and acts, the tone of voice during examination, and, of course, the prognosis. Meaning drives health, let alone recovery.

How patients perceive their situation and engage with their recovery absolutely matters. So, why wouldn't the "how are you, really?" be part of a medical history?

Next, the misinformation found so easily on the Internet is setting up patients to already be engaged, but without the information that really matters. Can direct physician/patient dialogue be fully informative, with complete acknowledgement of the confusion? Like a real medical "fact check?"

***How patients perceive their situation and engage with their recovery absolutely matters.***

Then, and perhaps the most important, is the ongoing empathetic patient-physician dialogue that prioritizes the "check in" before the "check up." A doctor intently gazing at the computer instead of the patient does not equal or come close to eye-to-eye contact.

"Right now, you matter more than your medical records," is what eye-to-eye contact says to patients.

A recent meta-analysis funded by the Arnold Gold Foundation found that the patient-clinician relationship affects medical outcomes. The results showed that "general empathy in a meaningful patient-clinician relationship appears to improve patient's well being, both emotionally, and now, physically."

Physician burnout can easily be traced to a lack of human connection that has defined the role of the healer long before the crowning of the M.D. removed it. If I am handing my life over to you, doctor, I need to know that the person that I am, my experience of what is happening to me, and the risks, as I perceive them matter to YOU.

In her book, *Kitchen Table Wisdom: Stories That Heal*, Naomi Rachel Remen observes:

"People who are physicians have been trained to believe, that it is a scientific objectivity that makes them most effective in their efforts to understand and resolve the pain that others bring them, and a mental distance that protects them from becoming wounded from this difficult work."

She goes on to write, "Objectivity, empathy, and global thinking, are not incompatible with a degree of dissociation, sufficient to protect oneself, from the patient's suffering. This has been my personal experience."

Suffering, isolation, and defensive detachment plague our society and are most clearly expressed in our healthcare system. The healing of healthcare is critical to healing our relationships, our communities, and ourselves.

## 5 Questions to Add to the HCAHPS Survey

The word "flourish" is relatively new as a humanistic goal for healthcare -- for patients, staff, and our communities. It is an easy word to say but so difficult to define, particularly in this era of HCAHPS surveys.

I'm not sure of the difference between thriving and flourishing.

However, I know that when we talk about someone thriving, it is generally circumstantial, as in "Bill thrives in his current job." Or, "Sara thrives in the middle of stress."

The word "flourish," as I have heard it used, is a broader sense of wellness -- a state of joy along with the state of well being.

What if our life and health goals were not circumstantially based? What if the patient experience was not limited to what happened during the hospitalization as the current HCAHPS survey evaluates, but rather was measured by how it informed health and life futures?

There's a disconnect between life outcomes and patient experience outcomes. How about adding these questions to the HCAHPS survey:

1. As you look to your recovery, how do you measure your hope?
2. As you think about who you are, following this health crisis, do you see yourself as stronger or weaker?
3. Are you more determined to be well or resigned to the status quo?
4. Do you think it is worth your time and effort to go through the tedious medications and exercises to stay well?
5. How do you feel about your future?

In truth, for all of us, every time we just don't feel well, we know we'll either get well or it may be a symptom of something more serious. Whatever we feel, the interaction between our physical self and our sense of self can be challenging.

At some point, as we get older, we may wonder what happened to our "spry self" given it has been replaced with our "pooped self." In the hospital, however, patients continuously wonder what happened to them and struggle to create an identity that can survive the hospital experience.

We already know that patients can slip into learned helplessness as a result of needing assistance to do what they have done for themselves since they were potty trained and not being able to affect their own situation. Their loss of independence, even if temporary, is not only sudden, but goes without comment or acknowledgment.

Yes, for most patients, this is short term. However, is the goal really only to get them to be able to go to the bathroom on their own? Do we set the goal as just "getting out of the hospital," or do we set the life goal of our patients at "flourishing"?

If patients do not have a sense that caregivers are invested in their vitality; their forward movement into a better future, why would they adhere or try to understand the complexities of

their discharge instructions?

Chronic conditions are even more difficult than acute conditions. Some chronic conditions are not fully resolved until life is over. How can caregivers help these patients flourish?

How can everyone who works in a hospital invest in their co-workers so that *they* can flourish as they do their work at the bedside every day and still have vitality for life?

Florence Nightingale put it on the nurse to help patients live. She wrote, “Being well is using well the powers we have.”

Caring for patients, in her vision, was not only about treatment. It was about encouragement, about respect, about compassion and empathy. Yes, it was about human flourishing.

## HCAHPS Survey Questions Not Really About the Patient

Healthcare providers ask patients lots of questions to find out if caregivers did their jobs right. And, from my own experience as a patient in a hospital last year, I don't think the main question has never been asked.

In fact, if we lump all the HCAHPS survey questions together, none of them are actually about the patient.

*During this hospital stay, how often did doctors treat you with courtesy and respect?*

The focus of this question is on the doctor, not the patient. And, providers will never know what happened to generate any particular answer.

Also, someone can treat you with courtesy and some kind of respect and still not give any indication that they actually care about what happens to you.

That was my experience. On the one hand, being in the hospital is never voluntary and staying in the hospital is even less so. On the other hand, making it clear that what happens to the patient matters -- not just the outcome -- is rare.

Then, to make it worse, follow-up calls are made by people who have never met you and don't know anything about you.

Nurses care by practice and tradition. Physicians care when they start, but the caring is "scinded" out of them. Then, over time, nurses become more medicalized, responding to a dehumanized system.

Patients and families adjust to their behavior, thinking, "It is what it is." However, everyone loses.

The healing relationship is one that bonds patients and caregiver -- where both experience a transformative relationship that is glued together by the goal of healing. A caring moment happens when the magic of the human connection becomes obvious to both parties.

Dr. Jean Watson speaks of it in her 10 Caritas Processes, the first of which calls caregivers to "embrace altruistic values and practice loving kindness with self and others." If caregivers do this, there is never a question that what happens to them matters to someone else. They are in it together with their patients.

Empathy, caring, and compassion require that we admit our own vulnerability in order to be close to another. In treating an ill patient, the healing occurs first in the mind and spirit when the connection, one heart to another, is palpable.

Coming back to the HCAHPS survey questions, the "how often" is meaningless. "Courtesy and respect" are seriously not enough. And, the main question has never been asked:

*Do you think that what happened to you during your hospitalization mattered to those who took care of you?*

## All HCAHPS Scores Being Equal: Caregiver as Patient

"The only difference between the patient and the caregiver is acuity." So said hospital CEO Pat Linton so many years ago. And, nothing has changed.

Being human puts us at parity with each other more than we may realize. We all want pretty much the same things: respect, safety, community, comfort -- and to be healthy, happy, and loved.

Then, something happens that puts us in the hospital, and regardless of who we were immediately before, our identity changes to that of "PATIENT." This now makes us equal to all other patients, or at least with that title, we are treated like we are like all other patients.

Once we become a patient, we temporarily forget or set aside who we were prior to entering the hospital or clinic. And, once a person becomes a nurse or a physician, they become a caregiver or provider.

The result is that "PATIENT" and "CAREGIVER" forgets how similar they are. This results in dispassionate treatment based on a kind of science that has also tried purposefully to forget all things human -- those that are impacted by our consciousness and personality.

***The moment the patient and nurse start caring for each other and sharing a vital relationship, healing happens for both of them.***

Objective science wants numbers rather than persons. And, even the person who reads the data must forget he or she is a person, and finds a kind of objectivity that can be considered absolute. This is a world that knows few absolutes.

The moment the patient and nurse start caring for each other and sharing a vital relationship, healing happens for both of them. Dr. Jean Watson's 10 Caritas Processes begins with, "Embrace altruistic values and practice loving kindness with self and others."

So, let's now enter the world of HCAHPS scores and patient satisfaction that are determined by surveys and have come to own the psyche of organizations.

"Do more! Do different! Hurry! Improve! PANIC!"

Since value-based purchasing was born, every healthcare organization has been put in the position best described by these exclamatory demands. Hospitals are now on a class-curve where, as in high school, test scores are based on a comparative mean that includes all the other similar hospitals.

Every year, hospitals must measurably improve, again scored according to the comparative improvement of other similar organizations. What does this do to our organizational health?

Without question the pressure is on. And, without question, every member of the organization is feeling it. The result of continued demands coupled with few demonstrable remedies is transformation fatigue.

All of us are susceptible to learned helplessness, a sense that no matter what we do, we have little

or no effect on outcomes. Given that the situation shared by both patient and caregiver is one in which they are sharing the same space (hospital room), time (admission period), and objectives (to get well enough to leave the hospital), it's no surprise that their experiences are more symbiotic than is currently acknowledged.

What to do? First, the same consideration, concerns, and care must be offered to everyone. In fact, this is the first, second, and all other steps.

If there is not parity of worth between patients and caregivers (including everyone), learned helplessness will set in and the whole organization will become symptomatic.

These symptoms are disengagement, lack of empathy and compassion for each other, and loss of the "edge" that fuels us because we have no sense that we are making a difference or that we matter.

If patients visibly see the collaboration, respect, and camaraderie between all the members of the team that are involved in their care, it reinforces their trust in what is happening to them. The opposite is, of course, lack of trust, and often patients and family members pick up attitudes and mimic them.

Somehow, teaming up with others to face the challenge, make changes, and share accomplishments cuts through all the other pressures that are so very difficult when faced alone.

You cannot give away what you don't have. So, start every day -- at every meeting and every encounter -- with an appreciation for who has chosen to work in your organization, on your unit, or in your department.

Random acts of respect and caring are the first symptom of a healthy, vital, and engaged individual and organization.

## HCAHPS Scores: Mind the Gap Between the Survey and the Answers

In thinking about the history of regulatory accountability, HCAHPS has no precedent. As a measurement tool, it has many gaps, including a gap between intention and outcomes, and a gap between the culture of the hospital and the culture of the patient.

There are also gaps between what the HCAHPS questions ask, what they really want to know, and what patients answer. The biggest gap, though, is between the survey and the interpretation of the answers.

In a recent newsletter, patient experience expert Wendy Leebov, Ed.D., shares a conversation with her sister about her recent hospitalization:

*I ask her, "How are people on the care team treating you?" And she says, "Fine, I guess." I ask her to elaborate. What does, "Fine, I guess" mean? And she says, "Every time I go home, I get these surveys, and they ask me how often people do different things. And I give good scores, because people do those things often. But I feel so alone -- anonymous, and no one seems to get what I'm going through. And they don't ask about that on the surveys."*

Dr. Leebov goes on to describe the same gap that I am describing here. In fact, she talks about HCAHPS scores going up and patient experiences not improving, but the persistent problems are invisible to the organization and caregivers.

Some compare HCAHPS to patient satisfaction surveys, but those are informational and if there are any consequences for low scores, they are internal to the organization. HCAHPS scores, on the other hand, are part of a national effort in the U.S. for transparency and public awareness of the performance of healthcare organizations beyond mortality.

It places the power of grading in the voice and hands of patients.

I have been critical of the questions included in the now 31-question survey because none of the questions inform actionable strategies that are clearly related to the patient responses. We just do not know what would generate an answer -- except the obvious.

But the obvious still may not be the whole story.

So, how do we evaluate the quality of the patient experience, the family experience, and the staff experience? We could set the experience up as being blatantly evidenced by a series of symptoms. For example:

1. Family members walk to nurses' station with concerns more than twice an hour.
2. Patient pushes call button 4-20 times a day.
3. Patient is agitated upon the nurse entering the room.
4. Physician complains that the patient and family members are difficult to deal with.
5. Patient demands to see the physician.

But what if this was the scenario:

1. Family member delivers box of candy to nurses' station and thanks the nurses regularly.
2. Patient is relatively quiet and is not in need of anything relative to his or her care.
3. Patient is happy to see the nurse and thanks nurse when entering and leaving the room.
4. Physician is in good mood and finds patient and family members to be engaged and active in understanding the patient's condition.
5. Family members, regardless of the seriousness of the patient's condition, treat the staff with deference to the complexity of the task of caring and gratitude for doing what they can.

I suggest you make your own list of symptoms of a good vs. a bad experience.

Then, look at your HCAHPS scores. Is there a mismatch? Does it matter if the HCAHPS questions do not address what you identified?

There clearly is a correlation between the actual lived patient experience and your honest observation and HCAHPS, even if there is no direct question. This is because the patient experience is a whole and complex experience that can hardly be detailed in 31 multiple-choice questions.

Taking responsibility for what you observe and do is much more critical than "teaching to the test."

The answers are in front of us every day, in every way, with every patient, with every interaction. If your HCAHPS scores do not match your patients' experiences, find out why.

## What Happens to Patients When the Lights Go Out

I found the term "nocturnal rumination" in a recent study on insomnia in palliative care patients in the ICU. Basically, it's obsessive thinking when the lights go out.

The study noted that many factors have been studied about ICU patients. However, insomnia has not been suspected or diagnosed.

Nonetheless, the fact that patients struggle with sleep deprivation is well known. What happens to patients whose cognition is sufficient to know their own diagnosis, know their own prognosis, and dream up what dying will be like?

The study points to environmental disturbances that led to interrupted sleep. Environmental factors were primary for 76% of the participants.

And, we know that noise is at the top of causes for sleep deprivation. However, the one that got my attention was nocturnal rumination -- thinking, contemplating one's situation when the lights go out and no one else is around to interrupt disturbing thoughts.

By far, this is the real suffering of patients.

Many of us suffer from nighttime loneliness and chatter. And, our lives are probably not in as much turmoil as our thinking. The terrifying thoughts -- these nocturnal ruminations -- are like reruns of fear that plague us emotionally and keep us from restful sleep.

***Neuroscience has long shown that thought is auditory -- that the volume of our internal screams can be intolerable to us but quiet to everyone else.***

Perhaps this is at the core of what is being asked in the sole question about noise on the HCHAPS survey addressing "quiet at night." Neuroscience has long shown that thought is auditory -- that the volume of our internal screams can be intolerable to us but quiet to everyone else.

When I was in the hospital last year, well enough to think, nights were the most dreaded part of each 24-hour day. They were long, lonely, and scary. Memorable for all the wrong reasons.

The C.A.R.E. Channel, from its inception, was designed to offer an environmental antidote to the silence that feeds patients' internal chaos over the 24-hour cycle. The kind of silence that leaves patients with nothing to do but think, because they have nothing else to focus on but the dark and unknown.

With a midnight starfield that is engaging to the eye, and music to calm the mind and attract the ear, The C.A.R.E. Channel can help ease nocturnal rumination. It can also help improve HCHAPS scores, as reported in this case study from Tuality Health.

Other ways to ease suffering in the nighttime hours are human in nature. Nurses and others who do nighttime rounds need to pay attention to the patients who are clearly in a state of unrest. Speak to them, cut through the isolation -- and offer them the security of knowing that they are not alone.

## Setting the Stage for the Patient Experience

I keep coming back to the patient experience as being elusive, difficult to nail down, and more difficult to actually make happen and control. Added to that is the role of the physical environment as it informs patients and families about the hospital culture, staff competency, and provides real-time "data" for their prognosis.

So, let's talk about setting the stage. How do you pre-empt opinions and reactions by anticipating the first impression of everyone who comes into the patient room?

When we set the stage for a romantic dinner, we carefully consider the needs and desires of the guest. We think about how the front door, front hall, even the walkway to our home looks. We take care to remove any incriminating or irrelevant stuff.

We clean everything that is accessible to the guest. And, most important, we add certain amenities to make that person comfortable and put him or her in a receptive mood.

When we get married, we may do this for guests, but we also become a bit more casual, less careful, and, if anything, accepting of the impossibility of keeping up the "front" all the time for our spouse.

Recovery from an illness is as uncertain as any relationship. Just like a budding romance, what patients really need is clear evidence that the hospital staff expects them; that they took great and detailed care to welcome them, and keep them safe and comfortable; and, most important, that they matter.

The hospital room tells its own story. Leftover dust and clutter betray lack of detail in care. Stains on the privacy curtain and the ceiling do the same.

So, it's important to remember that the environment of care is primary care. It cares for patients the way a cradle holds an infant. Your own commitment and compassion are represented in the kind of environment your patients experience 24-hours of each admission day.

This is an unending tale as patient after patient enters the same hospital room, one after another, and each needs to feel special, unique, and cared for. The equally critical challenge is for everyone else -- nurses, aides, housekeepers, etc. -- to have the same experience.

## The Waiting Room: Where Suffering Begins

In the waiting rooms of clinics, hospitals, emergency departments, urgent care clinics, humanity comes together as equal. And, for every minute that one waits, one also stops engaging in anything but the wait.

Having a health issue, whatever it is, even if there is no issue, brings us to the basic truth that we are each human, vulnerable to wear and tear, that our differences have been reduced to less than 1% of our genomic makeup.

So, how do we design the waiting room experience to minimize stress, anticipation, expectation, fear of surprise (to borrow from Florence Nightingale)?

Here are some assumptions:

1. No one wants to be there.
2. The seats are uncomfortable regardless of design.
3. No matter what, there is stress, fear.
4. That waiting is part of this appointment, treatment, is an insult to the process.
5. Everyone listens to everything.
6. Confidentiality and privacy are "afforded," but not a given.
7. Whatever happens after a long wait is worse for the wait.
8. Being put on hold is more annoying than annoying.
9. Being on hold and held hostage to hospital advertising (no matter what it is) makes things exponentially worse.

With these assumptions, how do we design a healing waiting experience?

First, let's build waiting into the treatment. Have tools, such as computer stations that can help patients and families make use of the time they have. And, let them know in advance.

Second, have seating arranged for small conversations, some privacy, and coziness. Avoid the Greyhound Bus station paradigm of rows of seats facing in the same direction.

Third, do not ignore the clock. Have a limit for waiting and personally report to those who are waiting what is happening.

Fourth, provide coffee, tea, and water. This goes a long way. Food and drink are nurturing.

Many of our hospitals put The C.A.R.E. Channel on in the waiting rooms as part of the design. Commercial television is upsetting, inciting, and controversial. It is everything we do not want in a healthcare setting.

With all of this, the gestalt of the waiting experience is a combination of many changeable factors, including how people are greeted, how long the wait, the acuity of the person waiting and the person waited for, the weather, the time of day, the mood of the office staff.

Do your own research. Sit in a waiting room for an hour (at least) without your badge. What is it like? What would make it better?

Immediately make the changes that can be done, like moving the furniture around, cleaning up tables and chairs, changing the television programming. And, have your reception staff do "Waiting Room Rounds" to keep them warm, clean, and intentional.

## The ROI on Human Caring in Healthcare

Return on investment (ROI) is what we get for what we pay. Making "human caring" a commodity may seem crass, but, these days, if we look at supply and demand, human caring in healthcare is in high demand and, relatively low supply.

I say this because we are approaching the time of year that calls upon us to be generous and forgiving, to be grateful and kind. In reality, human caring that expresses and makes obvious each of these qualities, knows no season.

Introducing The C.A.R.E. Channel to a hospital administrator sometimes generates a request for an ROI document. We don't always know how to respond to this, but we do have an ROI document.

We did the research about financial benefits for hospitals and arrived at a savings of at least \$158 per/patient per/day based on a reduction in the need for pharmacological intervention in some patients by as much as 15%-29%.

The cost of The C.A.R.E. Channel per bed per day ranges from a penny to a dime.

The ROI comes in the form of better patient experience, better HCAHPS scores, and higher patient satisfaction. How do you measure that in numbers?

We do not yet know whether a satisfied patient is healthier or a healthier patient is more easily satisfied. We do not know why patients answer HCAHPS questions the way they do.

And, we do not know the human cost of dissatisfaction. We have trends, not absolutes.

Human caring matters. Dr. Jean Watson and the Watson Caring Science Institute have been tracking patients who have been cared by nurses using Caring Science as their nursing practice model.

***We do not yet know whether a satisfied patient is healthier or a healthier patient is more easily satisfied.***

The first question of a five-question survey is "Were you treated with loving-kindness?" We could debate the value of loving kindness over respect, but we do not experience loving kindness without respect -- because minus respect, loving kindness is patronizing, unauthentic, insulting.

The ROI for kindness has not been established. In fact, we often speak of kindness as a luxury, taking time that we cannot afford.

Making human caring a commodity is, indeed, crass. Nonetheless, human caring in healthcare is in high demand and can only be delivered, one heart to another.

If the patient experience is what matters, then we must demonstrate compassion and empathy, concern and respect. We must make the investment in human caring and let the return be its own reward.

## How Hospital Television Impacts Acute Care Patients

There are many theories about how the violent television programs influence teenagers and adults -- how they might desensitize us to horrific events. However, there is little discussion about the effect of violent news, programming, or commercials on an acute care patient.

A medicated or semi-conscious patient's perception is, at best, compromised. And, his or her sensory system is slower to respond or may be hypersensitive.

What looks too bright may be normal daylight; what sounds too loud may not be; what sounds violent might be a sitcom on the hospital television.

Words are not heard through normal ears. They are heard through pain, fear, and stress. In elderly patients, cognitive decline, hearing impairment, and any number of other issues may also precede them.

The role of hospital television in the patient experience is unique and fickle. During the day, it can be a welcome distraction for those who are well enough.

At night, the hospital television is hardly friendly, and worsens the long hours of darkness. To the most acute patient, the television programming that is not fully comprehended can be alarming, confusing, and agitating.

Also, a hospital room is not a hotel room. The patient is not on vacation. When it is on, the television can dominate the patient environment.

However, when a patient is not capable of choosing or understanding programs, the staff should ensure that the television is not hostile to recovery.

The potential negative impact of television programming and the need for a positive distraction and soothing environment is what inspired us to create The C.A.R.E. Channel. And, that is why it is a 24-hour, continuous play channel.

Patients can turn C.A.R.E. on and don't have to deal with the remote to find another program at the end of every hour. There are no commercials or interruptions. No disturbing Talk TV at night, just soothing music and a midnight starfield.

Florence Nightingale taught us that creating a healing environment is about both providing for the comfort of the patient and protecting the patient from distraction and intrusion.

And, yet, the hospital television seems out of bounds. Often, when family members come to visit patients, they take over the television as if they were in a hotel. They may turn up the volume for their own listening when the bed speakers are meant and designed for the patient.

We received an email recently from a woman whose mother was in a hospice that had The C.A.R.E. Channel. She wrote that it was very soothing to her and calming to her mother. She observed that when her kids came in and changed the channel to regular TV, her mother seemed restless.

What happens to the patient happens to the family.

It's good to include broadcast media as part of a healing environment. But it's also up to hospital administrators and staff to be aware of the impact of television content on the patient.

And, know that however it seems, that is how it is. The television is fickle, moving at any time from friend to foe.

## Compassionate Care: Who Have We Become?

According to a recent report from the Schwartz Center for Compassionate Healthcare, "Healthcare organizations that show a commitment to compassion enjoy a better bottom line as well as increased patient and caregiver satisfaction."

Is it really as simple as if we do THIS, we get THAT?

The incentivizing of empathy and compassion is yet another stunning example of how our healthcare system has hijacked patient-centered care. No, not 100%. But, when an organization is motivated by economic benefit rather than by a shared humanity and caring for the community it serves, it seems as if we have forgotten why healthcare is a calling; not just a job or a transaction. Who have we become?

The valuation of compassionate care is frustrating. Do we need an ROI to prove that kindness, concern, and genuine engagement with patients is good for business?

In an op-ed in the *New York Times*, Dhruv Khullar, M.D, a resident at Massachusetts General, shares his experiences of "efficiency-empathy trade-offs" that are resolved only in bartering the "time to care" for "tasks to do." Dr. Khullar writes eloquently about the pressures placed on new residents who cannot or do not prioritize spending time with patients in any meaningful way.

"We hide behind buzzwords like "patient-centeredness" and "shared decision-making" without being able to offer the time that gives these terms true weight," he writes.

***Do we need an ROI to prove that kindness, concern, and genuine engagement with patients is good for business?***

We often read about dying patients requesting a nurse or doctor stay with them for a few moments. The response is "I will be right back." And, the patient dies waiting; the nurse or doctor never forgets what they failed to do for one patient.

When I was in the hospital with my own serious crisis several years ago, I remember having dry heaves, panicking because I could barely breathe. The nurse standing outside of my room was apparently oblivious to my situation. Instead, she was checking on her laptop to see when my next meds were scheduled.

There was a disconnect between the nurse and her job to care for me.

HCAHPS scores have given us one more report card that follows the model of teaching to the test. And, the test, each time, is a human being whose life is at stake, being pitted against an operational manual that doesn't have "human caring" as part of its instructions.

If you've got one of those manuals, here's what I suggest you do.

### **1. Use a No One Dies Alone Program**

Started at Sacred Heart Medical Center in Eugene, OR, Sondra Clarke, RN, tells her story, which has now become a national movement to ensure that no patient is alone in the hospital at the end of their life.

### **2. Create a Nurturing Environment**

A physical environment that itself is nurturing is palliative by its very nature. Utilizing The C.A.R.E. Channel is one way to do this. Both patients and families tell us all the time how The C.A.R.E. Channel "held their hands" and comforted a dying parent to his/her last breath.

### **3. Establish Comfort Processes**

This will allow nurses to be with a patient, as needed, and still take care of their other patients. This could include brief, but frequent "drop ins" that may not each include measuring anything. It could also include informed CNA's coming in, speaking to the patient by name, and engaging in personal caring. I might include informing Spiritual Care as to the needs of patients and families. Partnering among nurses, so that patients experience their "care team" as more than one person allows for more flexibility. It will take more than one person, regardless of their role, to authentically care for a patient and families whose personal needs have reached the acuity level of their physical needs.

### **4. Be Creative and Flexible**

If there is a situation than requires special planning, such as a patient near death or approaching active dying process, then do it, one patient at a time.

Experiencing human intimacy through the sense of caring is the real bottom line benefit of compassionate care.

## The Five-Star Patient Experience: What Do Stars Have to Do With It?

In the beginning, there was only accreditation.

Then, there were surveys to measure patient satisfaction.

Then, there was a survey to measure the patient experience.

Now, there are 5 stars.

In April, the CMS instituted the 5-star rating, supposedly to make it easier for consumers to understand. However, this oversimplification has substantial risk of misunderstanding and misinformation.

How can we logically reduce the patient experience from 31 HCAHPS questions down to a single group of 5 stars when the questions themselves have implications as long as an encyclopedia?

The results are in for how our hospitals are doing. Modern Healthcare reports that of 3,500 hospitals that have received a star rating, only 251 have been given the top, 5-star rating.

Does that mean that most of us will not be going to the best hospital? What concerns me, though, is that hospitals are often not comparable to each other and certainly not to a hotel, which is where the rating system was first generated.

So, why isn't the commonly used 5-star rating system effective in picking a hospital?

### **1. Cost**

5-star hotels are more expensive. Healthcare insurance pays exactly the same, so cost isn't a factor that dictates the type of "clientele."

### **2. Comfort**

5-star hotels are luxurious and have lots of amenities. Providing comfort and choice has been shown to improve healthcare outcomes, but that is very different than offering well-appointed environments or extra nice features.

### **3. Safety & Security**

5-star hotels are expected to provide high levels of security and safety. The hospital 5-star rating does not even include issues such as morbidity and mortality, adverse events, or rate of infection.

### **4. Personalized Staff**

5-star hotels have lots of people 24-hours a day to respond to the bidding of every guest. And, the more money you pay, the better the service. Waiting time for room service or housekeeping or anything is expected to be minimal. Furthermore, in a 5-star hotel, no one is in a bad mood.

Hospitals are now consistently understaffed and, unless one is in ICU, the staff to patient ratio is challenging at best. Waiting times remain too long for the patient who calls. And, the moods of the staff are irrelevant to the work being done.

## **Key Take-Aways**

The patient experience is a human experience. CMS is trying to mandate an excellent experience when the experience is not just about the place or the person. It's about both.

Yes, there are hotel and hospitality service models that have come to support hospitals in achieving the best customer service model. However, a patient is not a hotel guest or a customer. A patient is someone whose health is in crisis and whose bargaining power is sacrificed for life-saving efforts of people they do not know.

The patient experience is informed by what precedes it and what follows. And, it includes every other healthcare event in the patient's and his or her family's life.

The 5-star hospital rating system is pushing patients to select hospitals according to a system that looks familiar, but is not the same at all.

## Thank You

I hope you enjoyed reading this eBook and can apply some of the thoughts and ideas to your own practice.

Please visit my website, [www.healinghealth.com](http://www.healinghealth.com), for more resources, news, and information on quality management.

Also, connect with me on LinkedIn at [www.linkedin.com/in/susanmazer/](http://www.linkedin.com/in/susanmazer/) and follow my blog at [www.healinghealth.com/susan-mazer-blog](http://www.healinghealth.com/susan-mazer-blog).

Or email me at [smazer@healinghealth.com](mailto:smazer@healinghealth.com).

Finally, I spent a lot of time and effort creating this eBook and I'd appreciate it if you wouldn't share or distribute it to anyone else without my permission.

