TEN THOUSAND JOYS TEN THOUSAND SORROWS:

STORYTELLING AND STORYLISTENING FOR HEALTHCARE PROFESSIONALS

Slide 1 Title: Thank you for inviting me to participate in this wonderful conference. I will be talking with you this morning about the spectrum of emotions we experience in healthcare, and how storytelling and storylistening can be ways of reducing our stress, gaining new insights, and building community.

Since I'll be talking about storytelling, I'd like to share a small fragment of my story with you. I know this is a perinatal palliative care conference, but my story comes from the other end of life. In the last 18 months of his life, when my father was becoming significantly sicker and frailer, he lived with my sister and her husband in Northern California. I visited as often as I could, to help care for him and just to be with him. One night, or rather very early morning around 4:00 a.m., which many of you recognize as that porous border between life and the passing from life, I heard a noise downstairs in my father's room. I couldn't make it out. Was it the death rattle? Should I call 911? Instead I crept downstairs. My father, a stalwart Jew, but a great lover of Bach, was singing one of his most beloved hymns, Ein Feste Berg, a Might Fortress is Our God. What could I do? My father had taught me this song when I was 9 or 10 years old. I sat down on his bed and began singing. Together we watched the darkness recede and the sun rise. I remembered all the words. He died 3 days later.

This was a very small moment in the relationship between my father and me. It was the kind of moment that never makes it into the medical record. As you may imagine, it was full of emotion for me – joy, sorrow, loss, fear, grief, more joy – and perhaps for my father as well. This moment had a profound effect on how I understood life and death, and it had a similarly profound effect on the discussions I have with medical students and residents on this topic. When I share this story with colleagues, sometimes I see a glint of recognition in their eyes; and sometimes they share a story back. Sharing this story and many others has helped me accept my feelings, altered my teaching, and deepened my relationship with colleagues.

Slide 2 Buddha: The Buddha once said: "To open our hearts, we must embrace the ten thousand joys and the ten thousand sorrows." Ten thousand joys, I can get on board with that… the more joy the better. But embracing ten thousand sorrows? Way too many. Yet I suspect over the course of a lifetime in healthcare, we witness ten thousand sorrows and more. As for embracing them? Really? Maybe tolerate, ignore… but embrace? Further, do we even want to open our hearts to the suffering of others? Isn't that just opening ourselves to more pain?

Yet the Buddha was supposed to be a wise man, so we are going to consider what he might have meant, and why it might be surprisingly good advice for health professionals.

Slide 3 Emotions in Health Professionals: We all know that, as a result of being exposed to especially the ten thousand sorrows in healthcare, all of us who work in this field experience many emotions in response, often very intensely and often over short periods of time. A baby is still-born after an uneventful pregnancy. A patient hurls his food tray at you when you walk into the room. A 92 year old woman with CHF and COPD confides that she has made her peace and is ready sign the DNR that her children violently oppose. No one comes to visit the sickest kid on the floor. A perfect little boy is born to parents whose two daughters perished in a fire while they were having a date night. Frustration, sorrow, anger, grief, guilt and many other feelings fill our daily lives to overflowing.

Slide 4: Vicarious Trauma: Like all emotions, these eventually fade and pass away, but the negative ones can leave a residue of secondary or vicarious trauma. Vicarious trauma refers to how we are changed physically, psychologically, even spiritually by our commitment to helping others in situations of great suffering. Vicarious trauma may negatively influence the ways we interact with patients, family members, and colleagues. So, experiencing these difficult emotions can be overwhelming, exhausting, and scary.

Slide 5: Emotions are Scary. From working with physicians, medical students, and other health professionals for decades, it seems to me that many of us have two competing fears. One is that we will become detached from our emotions, and feel nothing, no matter how terrible or traumatic the event we are witnessing. The other, and even bigger, fear is that our emotions are dangerous. If we allow ourselves to feel them, they will impair our judgment and make it impossible for us to function professionally. We fear our emotions will lead to burn-out, perhaps worse. Further, our emotions remind us of our personal vulnerability and mortality. They remind us that the suffering of the patient and family is something we too can experience at any moment.

Slide 6: Emotions are Complicated. So, the emotions evoked by witnessing the ten thousand sorrows in the health professions are complicated, unpredictable, confusing, and distressing. It is also the case that in general we do not do a very good job of preparing ourselves and each other to deal with these emotions. Instead, we often conclude that experiencing the emotion is the problem, and suppression/detachment from the emotion is the solution. We look for that emotional off switch, plaster a smile on our faces, and try to carry on as though nothing momentous is happening.

Slide 7 Professional Alexithymia: The result may be a self-protective attitude that is a kind of professional alexithymia. As you know, alexithymia is a psychiatric diagnosis characterized by communication that focuses on facts and figures; discomfort with one's own and others' emotions; and a manner often perceived as cold or distant. Professional alexithymia (which by the way is NOT a diagnostic code) looks similar: Health professionals who focus on the

technicalities of treatment, who inundate patients and families with detailed information while avoiding the questions that matter most; who avoid or ignore the emotions of their patients, patients' families, and colleagues, as well as their own feelings; and who are perceived by patients and families as competent but lacking compassion and fellow feeling.

<u>Slide 8 Maria:</u> READ POEM. It is easy to see the casual racism and pervasive implicit biases in this resident. What is equally striking is how frightened he seems to be beneath his bravado; and how quickly he turns his patient into an object – to keep himself from facing his own fears, negative judgments and anxieties about ethnicity, immigration status, and language difference. It's hard to admit, but much as we don't ever want to be this person, many of us have experienced, in one form or another, this pushing away of a patient's suffering, this blaming of a patient for her sorrows.

<u>Slide 9 Dealing with Our Emotions – Embracing the Joys and Sorrows</u>: How can we "embrace the joys and sorrows" without being destroyed ourselves? We all have ways of coping with our emotions. Some of us go for a run, cook up a storm, or hug our kids. Sometimes we drink too much or cry or pound pillows. Sometimes we just go on to the next patient. Sometimes these strategies are helpful, sometimes they are ways of trying to avoid or suppress our feelings. Neuroscience research investigating the benefits and risks of empathy in healthcare providers points to the importance of emotional regulation, in the words of the Father of Modern Medicine William Osler, cultivating equinimitas, or a golden mean between indifference and over-identification. Other research has demonstrated the benefits of mindfulness meditation in calming emotions without, as the Buddha said, closing our hearts. These are both ways of "embracing" the thousand joys and sorrows.

I'd like to suggest that another way of both honoring and detoxifying our emotions is through story-telling and storylistening with colleagues, team members, and sometimes with patients as well.

<u>Slide 10 Everyone Has a Story to Tell:</u> Many philosophers, psychologists, and anthropologists have dubbed humans h*omo narratus* because of the centrality of storytelling in our lives.

These two quotes, both by individuals who make their living creating stories, may seem provocative to a healthcare audience. Stories are ALL that are holding us together??? What about Tamiflu? Stories are ALL we have to fight off illness and death??? What about our ever- evolving battery of medications and surgical interventions? Perhaps what these authors are trying to say is that without the stories to make sense of our experiences, the ten thousand joys, the ten thousand sorrows, the drugs and surgeries are not sufficient. They may sometimes cure, but they do not heal. Only our stories heal.

<u>Slide 11 Medical Stories</u>: Let's think for a moment about the stories we tell in medicine. Since I work mostly with residents and medical students, these remarks are based primarily on their stories; and nurses may tell somewhat different stories.

Nevertheless, it seems true to me that in medicine healthcare professionals are the ones doing most of the storytelling. True, the patient gets a chance to tell their own story, but it is usually quickly taken over by its medical translation. Further, the stories we tell are almost always stories about patients. Of course this is completely appropriate because medicine is about the care of patients and for medicine to exist, we need the patients' stories.

We also tell these stories in certain ways, focusing rather single-mindedly on the physical details of the patient sometimes to the detriment of the patient's life context.

And we ignore other important voices that need to be heard – the voices of the caregivers. This silence dehumanizes these health professionals and implies that their stories don't exist, or at least don't matter.

<u>Slide 12 Storytelling in Medicine</u>: Storytelling in medicine is something different than the medical story; it is something larger than recording the HPI in the EHR and conveying this information to team members and consultants. Storytelling in medicine keeps the patient's story at the center of care, albeit in a way than emphasizes the human context.

But storytelling in medicine also creates a space for the stories of healthcare providers. Making room for these stories – what we bear witness to on a daily basis - accomplishes two important things:

1) It helps us value our own unique personal voices and reminds us that our thoughts and feelings, our *experiences* matter and make us who we are.

2) Secondly, In telling our stories to each other, we other aspects our humanity to the listener, thus forging deeper connections with people whom we interact with every day. We see our stories are all different, yet all interconnected. When we don't share our stories, we miss the interconnections.

<u>Slide 13: Storytelling and Emotions:</u> Storytelling helps us take a pause from the onslaught of joys and sorrows. It helps us get a little distance on our feelings, so that we can step back from them, organize them, and understand them with more clarity and less judgment. Hmm, so maybe as a result of this infant's death, I'm really feeling grief, not rage. Or with this demanding family member, I'm feeling frustration, but I'm also feeling a kind of admiration for their tenacity.

When we share our stories, we realize that others have similar feelings. Once that happens, I think we are a little less afraid, a little less panicked by our emotions. We begin to have the courage to accept, normalize, and even embrace them.

<u>Slide 14: Medical Listening</u>: In healthcare, not only do we tell patients' stories in certain ways, we listen to their stories in very specific ways as well. (And again, these observations may apply more to the way some doctors listen than to the way nurses listen).

The sort of medical listening I'm talking about involves being on the alert for pertinent findings, for relevant information that will lead to a differential diagnosis or guide us in caring for the body in front of us. Patient spiked a fever two days ago? That's important. Patient is lethargic, not eating? Could mean something. Patient's grandma died last week? Sad but tell me more about that fever.

<u>Slide 14 Storylistening in Medicine</u>: Just as storytelling in medicine is different than a medical story, storylistening in medicine differs from medical listening. In cultivating storylistening, both to patients' stories and each other's stories, and being interested in the emotions their stories contain, we are going beyond listening that has as its goal problem-solving, advising, educating, or "fixing."

Instead, we are working a different muscle, what Rachel Naomi Remen, a physician whose practice focuses on chronic illness and end-of-life care, calls "generous listening." In this kind of listening, we are witnessing the patient's and our colleagues' stories, rather than repairing them. We are fully present with these stories and their emotional depth; and they may prompt us to share our own stories in return, but we recognize that the person we are listening to does not need to be "fixed" so much as heard and recognized. Such storylistening encourages empathy and compassion for the joys and sorrows in others' lives.

<u>Slide 15 Schwartz Rounds:</u> It can feel a bit intimidating to think about sharing our stories. After all, our stories are not objective verifiable compilations of evidence, but profoundly intimate narratives. To encourage everyone to tell their stories and listen generously to the stories of others, I'd like to mention two more structured options.

The first is Schwartz Rounds. How many people here come from institutions that offer Schwartz Rounds? Most of you, and of course we have Schwartz Rounds at UCI. For those of you unfamiliar with the concept of Schwartz Rounds, Ken Schwartz was a young healthcare lawyer in Boston with a loving wife and small son. He was diagnosed with an aggressive lung cancer in 1994. Unfortunately, he passed away only 10 months later, but during his treatment he was impressed with the need for compassion and empathy in healthcare providers. Just days before his death, he endowed a foundation, the Schwartz Center for Compassionate Healthcare and Schwartz Rounds are an outgrowth of the Center.

In Schwartz Rounds, an interdisciplinary panel of healthcare providers assembles to talk about their own emotional responses to a particularly traumatic or distressing case. They tell their stories. The audience of their peers listens and in turn comments on these stories and shares their own as well.

Schwartz Rounds provide a place to openly and honestly discuss social and emotional issues that caregivers face in caring for patients and families.

They are based on the idea that caregivers are better able to make personal connections with patients and colleagues when they have greater insight into their own responses and feelings.

Slide 16 Schwartz Rounds Outcomes: Research conducted by the Schwartz Center has found that participation in the rounds results in

- **Increased insight into social and emotional aspects of patient care; increased feelings of compassion toward patients; increased readiness to respond to patients' and families' needs**
- **Improved teamwork, interdisciplinary communication, and appreciation for the roles and contributions of colleagues from different disciplines**
- **Decreased feelings of stress and isolation, and more openness to giving and receiving support**

In other words, telling our stories makes us better able to embrace the ten thousand sorrows we encounter in healthcare.

Slide 17 Finding Meaning in Medicine and Nursing: The Remen Institute for the Study of Health & Healing was founded in 1991 by the physician Rachel Naomi Remen. Its mission is help participants to:

- **Find deeper satisfaction/meaning in their work lives**
- **Remind them of their original sense of calling and renew commitment to healthcare**
- **Form community with colleagues**
- **Discover they are not alone in their emotional struggles and responses**

Slide 18 Finding Meaning in Medicine and Nursing: FMM & N is a more casual setting. It involves small groups of health professionals meeting informally to share stories from their own healthcare practice on topics such as grief, grace, healing, courage, mystery, intimacy, service. Research suggests that this kind of Storytelling and storylistening can deepen participants' connection to their day-to-day work and to their patients. In other words, by telling their stories, healthcare providers are better able to embrace the ten thousand sorrows and open their hearts.

<u>Slide 19 Take a Leap of Faith:</u> In addition to seeking out these resources, you can decide to be an agent of change in your own institution by simply telling your stories to colleagues, and coaxing them to share their stories with you.

<u>Slide 20: Poem NICU.</u> I'd like to close by sharing this short poem written by a nurse Dana Schuster. READ POEM

In a few compelling lines, Ms. Schuster tells a piece of her story. She captures the suffering of dying babies and the compassion she needs to journey with them in the dying process. This brief story shares this nurse's grief, distress, and love. Telling her story may have helped Ms. Schuster acknowledge and honor her sense of loss and her efforts to comfort and console to the point of death and beyond. In listening to this story, we recognize her anger, doubts and compassion. As a result of this storytelling and storylistening, we may feel just a little less overwhelmed by our own emotions in the face of an infant's death. Hearing her story may help us to be just a little more ready to embrace the devastating sorrow of this experience open-heartedly with love, as she has.