intima a journal of narrative medicine

FIELD NOTES | SPRING 2015

Narrative Mindfulness

By Charles Paccione

Throughout my three and a half years of working with cancer patients in the Bronx, New York, I have been consistently reminded of the important role storytelling plays in healing both mind and body when faced with a life-threatening illness. Listening to patient stories of remission and recurrence, of risky treatments and procedures, and of uncertainty for the future provides me with the landscape of their illness as it is experienced. If healthcare providers wish to understand how to optimally treat cancer, or any illness for that matter, I believe that they must not only look at a patient's lab values and test results, which correlate to diagnosis and drug prescription, but they must also look at how the patient is experiencing their illness- both in mind and in body. As a therapist and prospective psychiatrist wishing to gain intimacy with a patient's landscape of illness experience, I engage in what I like to call narrative mindfulness— the act of listening to a patient's illness narrative with a mindful (i.e. nonjudgmental, receptive, attentive, and unknowing) ear.

By mindfully listening to my patients' illness narratives I have acquired an understanding of their cancer that is not based on knowing but instead on recognizing. This is a recognition that I can never truly understand what is being told, a recognition that listening to a patient's illness narrative involves listening to the story instead of for things within that story, and a recognition that patient's may not tell stories in order to receive the "right answer", but instead, may tell stories in order to experience what it feels like to be witnessed and cradled in another's attention—simply to be listened to.

In this piece, I would like to describe how I have developed my notion of narrative mindfulness with cancer patients in the Bronx and how engaging in such a practice can cultivate a healing to take place even when a cure is not possible. By highlighting the illness narrative of one of my patients, whom I will be referring to as Sarah, I will show how the practice of mindful listening can have an important impact on how medicine is both practiced and received. This practice allows a caregiver to address a patient not as object but as subject and provides the patient with a new degree of intimacy and acknowledgment of that very thing which has weakened and changed their life, the illness itself. This type of mindful medicine can aide in bringing the mind back into biomedicine and can nurture a humble, tender, compassionate, and human relationship between both clinician and patient.

My notion of narrative mindfulness began in the summer of 2012 when I developed the

Contemplative Program for Cancer Care, a free psychophysiological therapy program designed for underserved cancer patients residing in the Bronx, New York. All of the patients whom I have seen for the past four and a half years have suffered from a broad spectrum of psychosomatic conditions ranging from chronic pain, anxiety, depression, post-traumatic stress and various other body-dysmorphic disorders. I wanted to use my knowledge and love of world literature and contemplative neuroscience to begin a program that utilizes poetry, prose, and the practice of meditation to facilitate a healing environment within a marginalized community of patients diagnosed with cancer of any type and stage. The Contemplative Program became an environment where patients from various cultural, religious, and ethnic backgrounds from the Bronx can come together to share their personal experiences, perspectives, and unique stories of what it is to live with a life- threatening illness.

Often times, many of my patients arrive to these sessions right after radiation treatments, appointments with doctors, and begin to share stories of their lives in terms of diagnostics, analytical information, and of a life composed merely of physical and physiological processes: the stories they were taught by doctors about their lives. These stories are of a cognitive nature that relate to cancer as an illness known merely through fact, terminology, and discursive analysis. Patients talk about appointments missed, unruly doctors, forgetful nurses, new medications, and events that surround their diagnosis that others can understand and reason out. These are the narratives that they are used to telling because it is these narratives that many clinicians expect to hear. But the narrative of cancer and how one lives that narrative is not only cognitive, quantitative, and one which can be discursively reasoned out—it is a narrative which is layered in contradictory suggestions for treatment, moments of insecurity and vulnerability, misunderstandings, losses and gains, and most of all, emotions. I believe that my job as a contemplative therapist has always been to shift the narrative that is often told by the mind to a narrative that is instead spoken by the body.

The body of a patient can hold the narrative which is mysterious, contradictory, non-discursive, and affective about a diagnosis. During a cancer journey, patients often pull their bodies along through treatments and decisions that are made by their minds and suggested by the minds of others. After months or even years of radiation, surgery, and various other anti-cancer treatments, the body as well as the cancer may become mechanized and objectified from the minds of patients and their clinicians. Patients and doctors become used to knowing cancer by these mechanical means and are at a loss when it comes to explaining the random incidences of panic attacks or crippling anxiety that may arise from within the body. The corporeal narrative is lost beneath the storm of thought, decisions, stages, and numbers. Even successful treatments can cause a sense of relief for the mind but a sense of loss for the body. So often I work with cancer survivors who feel confused and at a loss after remission, as if their cancer took away everything (i.e. health, mobility, financial freedom) but at the same time offered them so much (i.e. spirituality, a sense of community, self-reflection). They can be left with a

mind feeling alienated from and alone with a body narrative that has accumulated so many layers of feelings, emotions, and stories.

How can patients acquire a relationship to their bodies, during or after a diagnosis, which allows them to listen to its narrative?; Once told, how can healthcare providers listen to this corporeal story in a way which allows the mystery and depth of a cancer to be valued and recognized? And what can healthcare providers do to nurture this connection between body and mind in order to better understand how to holistically treat cancer? The tool that can shift the storyteller of the mind to the storyteller of the body is meditation.

Every week before the start of each session, I arrive early to dim the ceiling lights and situate the black office chairs into a circle around a rectangular conference table. This transforms the business of curing into the field of healing. As each patient arrives I invite them to find their own seat and proximity to one another. Stories and conversations about their everyday lives and their cancer begin to emerge from the space and I listen carefully—it is these stories that make the space livable and sacred enough to heal, share, and listen for the rest of the morning.

When all of the patients have arrived, I introduce a meditation that I will be guiding them through for that morning as well as the title and author of the following literature that we will be reading and discussing after the practice. Usually either the meditation or the piece of literature has something to say or suggest about the practice of listening—for listening is one of the most powerful ways in which we can encounter ourselves, our condition, and the world around us.

Meditation is a form of listening to the memories, thoughts, sensations, and feelings that come and go in and out of our minds. For patients, meditation is a means of placing a life affirming attention onto that which is injured and difficult, the cancer itself. Through meditation, a patient is able to intentionally invite their cancer into their present life and cradle it in their awareness: this process takes cancer, which may have been objectified through months or even years of clinical treatment and psychological alienation, and makes it subject in the experience of a patient. A patient can finally recognize the psychophysiological presence of their cancer without judgment or criticism, and in so doing come into relationality with it.

Meditation changes the quality of attention for a patient so that when they come out of the practice, they look upon their life, and the lives of others in the room, with a new and fresher perspective- similar to how poets, novelists, and philosophers look upon the world and then bring that experience to language. Martin Heidegger, the famous German philosopher and arbiter of phenomenology describes how attention is how things come into presence for us. For if attention is how we gain access to anything at all in our lives, then staying with an entity, such as cancer, with a mindful attention, would unravel the story which is contained within the

layers of meaning, hope, gain and loss, praise and blame, and held in cancer. A patient can come out of meditation with a new sense of story not necessarily of understanding but of recognition—a recognition of how their cancer fits within the context of their life instead of how it is in opposition to that life.

One afternoon after a meditation, Sarah, a patient whom I see often, began to tell her illness narrative from her body by giving voice to the layers of meaning, circumstance, and events which all surrounds her cancer. She begins this narrative with a recognition of the losses she has experienced:

"After working with a company for 35 yrs I was let go. And in January of 2010, the following year, I lost my mother. And in August 2012, I was diagnosed with lung cancer… even though I never smoked, never drank and lived a clean life. And then in 2013, my husband served me with divorce… They told me it's not operable and it's not curable so I have to try and live with it; I have to live with this down in the valley… I went to work diligently. I would say a 'model employee', I couldn't understand why they fired me, but we figured it out afterwards."

The meditation has not only allowed Sarah to speak from her body, deep down in the "valley" in which she finds herself, but also has allowed me to listen with a new quality of attention, openness, and patience. As a contemplative therapist I begin to mindfully listen to Sarah speaking from the landscape of her illness experience (i.e. her "valley"). Sarah speaks with a voice that is simply open, aware, and true to what has occurred. She then looks upon the subject of her life with a reflective gaze, a gaze that is not searching for an answer but recognizing a condition:

"You're old now and it's time that you need medical attention and all that, and it just so happened then that's when I got the worst diagnosis in my life and just didn't see that coming. So you have four catastrophic things happening to one person… So why is all this happening to me?"

Sarah's question may be seen by some mental healthcare professionals as a heroic chance to give the right answer, an answer that would make Sarah feel content as to the reason why she lost her mother, was diagnosed with lung cancer, fired from her job, and divorced by her husband. But I instead hear this as an invitation to breath with uncertainty, be in the unknowing with Sarah, and to sit with the question—to allow it to open into the room and have space among the others sitting there before her. By sitting with the question and allowing the uncertainty of her narrative to have its space within the room Sarah can begin to feel that she is not alone in recognizing this life of challenges and losses. By giving her question an answer, or even a follow up question of my own, I would change the natural progression Sarah's narrative is taking on.

So often we listen to patient accounts with the following conscious or subconscious thoughts running through our minds: “Am I understanding this story?; Does that make sense to me?; What should I say after she is done talking?; I have to pay attention; This is confusing to me; That makes sense to me; Oh, I have been through that too”. All of these self-centered thoughts guard us from ever encountering the narrative that patients may be presenting to us. The narrative of uncertainty, that so many patients like Sarah share, must be heard with ears that are comfortable to being open to uncertainty. Too often we allocate our attention to sounds and forms that are consonant rather than dissonant, intentional rather than unintentional, and clear rather than unclear. But the very nature of cancer is uncertain and unclear—a therapist must learn how to cultivate meaning and healing within that uncertainty. This can be done by mindful listening.

Sarah continues, and gives word to how her condition, her life, and her emotions have come into presence before her and through her:

“When somebody first invited me to a program they said it was for breast cancer and I said 'but I don't have breast cancer', but I went anyway. And showing up, they were talking about cancer. Period. So I just inject myself and I said, ‘Well I don't have breast cancer…’-- I was crying at the drop of a hat; I didn't know I had so much emotion bottled up.”

Sarah’s narrative begins to recognize not the information but the feelings that her body knows. Through her cancer journey Sarah’s body has held on to the pain, loss, and sense of uncertainty for so long yet has not had a chance to recognize it. Here she acknowledges the emotions and experiences that have been held within her body for so long. She recognizes that her body is a place where life’s challenges and graces can be held and released. Speaking from the body as Sarah does can initiate a response of release and acknowledgment through crying. By using the spoken work to tend that which is weak inside of her, Sarah soon begins to find meaning and stability in her life among others. She realizes that her weakness is unique yet something which can bind her to the conditions of others:

“So I came to the group sessions and I heard what everybody else was saying-- that I'm not alone, everybody has a different form of cancer, but we have one common denominator, the C word. So I went and I have been coming for 2 years now… And I tell you this program has helped me tremendously because I thought I was a private person, didn't share my personal life, whether it be my marriage, my children, my-... Because it's one thing I learnt, everybody's cancer is individual as your DNA. People are gonna tell you 'I did this, I did that and it worked for me, blah blah blah' but you come and get all the help you can get because you cannot do this alone. Nobody can tell you I did it alone, no. You have to tap into your spirituality, your faith if you have one, and everything else. And the doctors - what they tell you, the chemicals, everything has to work in unison. You can't just take just any one part of it

except for your faith of course, to hope and pray…"

Oral Historians Kathryn Anderson and Dana C. Jack describe how "Oral history interviews provide an invaluable means of generating new insights about women´s experiences of themselves in their worlds" (Gluck and Patai, 42). There is something about being a woman, being diagnosed with cancer, going through a divorce, living in the Bronx, and telling a story about one´s diagnosis – Sarah tells us a story as a means to come into relationality with her world, a world that has lost many relationships: professional, physical, spiritual, and familial. Stories can be a means to regain a sense of connection to that which moves onward and changes before a patient: a world that does not wait for them to "get better".

The oral exchange within the clinical environment offers possibilities of freedom and flexibility. For Sarah, her mindful narrative is an opportunity to tell her own story in her own terms, uncovering her unique perspectives and ideas about her illness. I believe that the expression of women´s unique experience as women diagnosed with cancer is often muted, particularly in situations where women´s interests and experiences are at variance with either those of doctors or their families. But by meditating Sarah is able to acquire a type of listening that can listen to both the muted and audible experiences, feelings, and sensations which all surround her diagnosis. Sarah is then able to come out of the meditation and tell her illness narrative from a body which has been listened to, acknowledged and given the time and space to open and receive her attention. This type of telling possesses a contemplative quality that is not searching for the right answers—it is simply a means of coming into relationality with questioning, uncertainty, and vulnerability. This relationship leads Sarah to acquire a sense of healing in the face of a cancer which she has been told is incurable. After Sarah gives an account of her illness the group has a chance to sit, reflect, and turn inward toward their own unique illness narrative. Many of the patients now feel safe to engage in such storytelling when their illness narratives are not being listened to with critical and analytical ears.

After one meditation and group discussion with the patients I handed out copies of an excerpt from Thomas Merton's work "Rain and the Rhinoceros". In this piece Merton, one of the most contemplative mystics and writers of the mid-20th century, describes listening to a rainstorm alone up in the mountains at his cabin where he was on retreat: "The rain surrounded the whole cabin with its enormous virginal myth, a whole world of meaning, of secrecy, of silence, of rumor. Think of it: all that speech pouring down, selling nothing, judging nobody… washing out the places where men have stripped the hillside! What a thing it is to sit absolutely alone, in the forest, at night, cherished by this wonderful, unintelligible, perfectly innocent speech, the most comforting speech in the world, the talk that rain makes by itself all over the ridges, and the talk of the watercourses everywhere in the hollows! Nobody started it, nobody is going to stop it. It will talk as long as it wants, this rain. As long as it talks I am going to listen" (Merton, 216).

As therapists we must listen as Merton does to the silences, meanings, and myths of a sound—especially if it is the sound of a patient speaking from the body and from a life stricken with illness. Like the rain, the cancer does not judge the body in which it is housed and will often continue as long as it wants to. Patients can sit in meditation and listen to the sound of their illness, the sound of their suffering, and begin to build a relationship to their bodies and to those who are treating it with openness and patience. And when they lift their heads to tell their story or place pen to paper to write about it, healthcare professionals should be ready to listen quietly, attentively, humbly, and hold it not with understanding but with recognition.

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Charles Ethan Paccione has always been interested in the strong bidirectional communication between the mind and the body. He performed contemplative neuroscience research at the University of Wisconsin-Madison where he took part in studies using meditation to express cognitive, emotional, and behavioral changes in toddlers. In New York he developed the Contemplative Therapy for Cancer Care program for cancer patients suffering from anxiety and depression at Albert Einstein College of Medicine. He has published several articles in various neuroscience journals and in April of 2013 gave a TEDx Talk titled *Mindful Medicine* about his research and work with patients. Paccione, M.S., Narrative Medicine, Columbia University, is studying for his second Master's Degree in the Spirituality Mind-Body Clinical Psychology Program at Columbia University´s Teachers College.