Mindfulness in Oncology: Healing Through Relationship

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I met Stephen during my residency year before the completion of my PhD in clinical psychology in 1997. Stephen had recently received a diagnosis of stage 4 non-Hodgkins lymphoma. I had some training in health psychology, but it was my first introduction to working with cancer patients. I was seeing people preparing to undergo high-dose chemotherapy and stem-cell transplantation in the bone marrow transplant unit, and was learning a lot about the cancer experience and what it entailed both medically and psychologically. My job was to help people cope through this grueling procedure by applying principles of counseling and clinical psychology, providing support to patients and families in ways that fit with their resources, personalities, and values. We were learning to treat specific psychological reactions including anxiety and depression, as well as and symptoms, such as sleep disturbance, pain and fatigue, and existential concerns around death and dying.

Stephen was to be one person I saw through his entire intense medical journey, and well beyond, for over 10 years. We became very close, with the kind of familiarity and deep implicit knowing of one another that eventually results in understanding without the requirement of much speech. The relationship provided him comfort, familiarity, and a feeling of being seen, understood, and accepted. He also learned concrete tools for coping and integrating mindfulness practice into his everyday life. But how did we get there? There were considerable challenges to overcome, medically, and psychologically. I will first tell you about his medical treatments, my role at that time, and how we integrated mindfulness into our relationships and into his process of healing and recovery.

Autologous stem-cell transplantation (ASCT) is a procedure whereby people with systemic cancers, usually lymphomas, are subjected to extremely high-dose chemotherapy which depletes the immune system. Before the chemotherapy, the patients' own stem cells are harvested, cleaned, frozen, and stored for later reinfusion. This can only be done in cases where the cells themselves are thought to be relatively cancer free. In the case of most leukemias, donor marrow or peripheral stem cells are harvested and those are later reinfused, rather than the patient's own blood cells, which are tainted with cancer.

Regardless of whether the procedure involves later infusion of the patient's own cells or donor cells, after the harvest they are subjected to high-dose chemotherapy, much higher dosages than could normally be safely administered due to immune depletion. Then after the chemotherapy, the "clean" cells are reinfused into the patient with the hope that they will safely engraft and reestablish a healthy immune system. This process involves sometimes lengthy inpatient stays while the person is immunosuppressed and the process of rebuilding the cells is occurring. At the same time, terrible side effects of the chemotherapy are common, including painful mouth sores, diarrhea, hair loss, neuropathy, and overall extreme fatigue and nausea.

Stephen was not well suited for this kind of treatment. The cancer experience in general is fraught with uncertainty and loss of control. No one can tell you what your chances of survival are, or how your disease may progress. Death may be imminent. Oncologists cannot even tell you exactly what treatments you may need, or even, in some cases, definitively what the diagnosis is. They cannot tell you if or when it might recur. Stephen was 36 years old, and was physically fit and active. He was married but he and his wife had chosen not to have children; they had a full life with a small but active social circle, family ties, and travel. He was well read, intelligent, and a good conversationalist with a passion for politics and music, but he had his own mental health problems that predated the cancer.

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He grew up in a family with a history of depression, anxiety, alcoholism, and abuse, and had a long personal history of anxiety and depression himself. He has been diagnosed with obsessive–compulsive disorder (OCD), generalized anxiety disorder (GAD), and had also suffered from major depressive disorder (MDD) intermittently. While his anxiety symptoms had been quite constant throughout his life, depressive symptoms waxed and waned. Despite these challenges, he was resilient. He trained in technical school and, while he had periods of anxiety and self-doubt, became a licensed tradesman. After a few years in the field, however, the stress of trying to work in a job that required precision and focus, where the consequences of slipping up could be fatal to himself or others, had taken a toll. Escalating OCD symptoms had led to leaving his job and taking disability a year or so prior to his illness, as he was unable to function. He doubted his own mind's ability to complete the required tasks, was constantly second guessing himself and checking his work obsessively. This resulted in a high level of mental fatigue and depression which culminated in a suicide attempt and brief stay in a psychiatric unit within the 2 years previous to his cancer diagnosis. He had been treated with medication and supportive counseling and been recovering from this traumatic experience when he began experiencing symptoms of lymphoma. Stephen did not do well with uncertainty, and his obsessive personality style and chronic anxiety escalated once again as he entered the cancer treatment system.

I am not sure what my supervisor was thinking in assigning me this case. I had no idea how to help him through this experience, and certainly could not imagine trying to treat all his other psychiatric problems during the storm of cancer therapy. I got to know him and his wife gradually, through the first intake interview where I learned a little about his background, and more and more each time I visited his bedside during treatment. I was impressed by their bond, and her commitment to stick by his side through thick and thin. She was there most days and maintained an upbeat persona. They talked about everything and were very open with one another. They had already been through a lot, but she was his rock. She was stable, good-natured and while she shared some of his more minor obsessive personality traits, did not suffer any serious psychopathology. She worked full-time in a stable job, had many friends, maintained an exercise routine, and received a lot of support at the workplace. Stephen was fortunate to have such a caregiver and partner in his life. I wondered, as Stephen got sicker and sicker, whether I was doing any good. I felt helpless and overwhelmed by his problems; and his prognosis was poor. All I could do was sit by his bedside, sometimes I would help him relax by instructing him in the use of deep breathing techniques. I talked with his wife when he was sleeping or in too much pain; she was practical and worked hard to hold herself together. She kept busy with managing his needs.

During our sessions over a period of months, I learned more about Stephen's background; he liked to talk and was insightful about his childhood and how it formed him into the person he became. He had been in counseling before and appreciated its value; he clearly wanted me to understand him on a deep level. His father had been an alcoholic, distant, and both verbally and physically abusive. His mother suffered from anxiety and depression. As a child, he often shouldered the brunt of his father's rage to protect his mother. I felt like I was just doing a lot of listening, and that I had to do something more to help him. He was suffering awfully though the treatments, his anxiety was sky high and his side effects from the treatment were torturous. He had severe mouth and throat sores, and could not eat and barely could drink, but the worst for him was not knowing the prognosis and fearing death. Radiation therapy was administered; it burned his skin. The tumors did not respond the way the oncologists had hoped. The lymphoma refracted to under Stephen's left arm, and a mass of tumors rapidly developed there. He was informed that his odds were not good. To Stephen this was a death sentence. He prepared to die. Things were spiraling down and he felt out of control and in despair.

Through this all I continued to feel helpless, but faithfully remained by his side despite some days dreading the visits and fearing what I might encounter. I held his hand and listened to his fears. I do not even remember now what I said, but I was there. I accepted what I encountered, and I was present with the horror. After some time, my intention became just that: to be present, to witness this relentless calamity. At times, I felt repulsed by the state of him, the smell of the hospital room, but I soldiered on. I grew to respect him and his strength in facing not only this, but everything life had thrown at him, seemingly he had been dealt an unfair hand.

After that first transplant, because he was young and fit, miraculously his body recovered its strength, but the refractory lymphoma was relentless; his tumours grew again. The medical team decided to try something almost unprecedented; a second ASCT. Could he handle it psychologically? Could he handle it physically? We could do it together; Stephen, his wife, me, and his medical team. He decided to try; it was his only hope to survive. We discussed the irony; how he had tried to take his own life a short time previously and now was fighting with every fiber of his being to save it. He wanted to live. Desperately he wanted to live. He was surprised by this primal drive to maintain life at seemingly any cost. There was barely a reprieve and the preparations for the second transplant and another course of high-dose chemotherapy began.

Throughout all this time, which was about 4–6 months by then, I had been talking to him about mindfulness, showing him how to use breathing techniques to help manage the pain, to relax around pain, to see that this all was temporary.

It was hard for him to apply these ideas in the midst of the whirlwind of treatments, tests, fear, and misery. I think he shifted a little, but OCD is a powerful master. Stephen's obsessions were largely mental, games he played in his head, questioning even the processes of his own mind: was what he perceived reality, or a trick his mind was playing? It was hard to get him out of his head and into his body, which is what we often do in mindfulness training; his body was not a refuge either during those times due to unrelenting pain and discomfort. So mostly I just listened, remained calm, and tried to understand, breathed with him.

Miraculously, the second round of high-dose chemotherapy worked, and the transplant was deemed successful; Stephen's immune system began to rebuild itself. There were many serious medical problems encountered and overcome during this second ASCT, but eventually, Stephen's immune system and overall health began to rebound. Stephen was then reassigned to radiation oncology for 40 more radiation treatments to his torso. Now he also had to rebuild himself in so many other ways. As is often the case, the terror and despair really hit him after the treatments were completed; then the fear of recurrence loomed large. Ultimately, Stephen was informed that his remission would likely be brief, between 2 and 6 months. This was a very real threat; it had come back quickly and aggressively before, and the initial onset was also a swift blow. It was at this point he began attending our 8-week Mindfulness Cancer Recovery Program. We had been offering it only a year or so at that time, and were still refining the content, but it was an adaptation of Kabat-Zinn's mindfulness-Based stress reduction, with more of a focus on cancer and the uncertainty it brings. Stephen attended the program and practiced the meditation and yoga exercises we prescribe faithfully—his obsessiveness and conscientiousness made him a good student. He attended all the classes, participated, shared his experience, and did his homework (45 min of practice a day). But he struggled with his mind still. Some question the utility of meditation for people with mental obsessions; would this just become the next obsession? Was self-reflection in the form of mindfully watching the mind advisable for someone already obsessed with an unreliable mind? I tried to assist Stephen, to move his focus into the body—this was a bit difficult too, though, as he could become obsessed with analyzing minor sensations from his chest, where the tumors had been. Were they growing back? What did that little tug mean?

We persisted nonetheless. I thought it would be useful for him to become familiar with what it felt like in the body to be anxious, versus tired, versus depressed, or actually physically sick. Through this work, he did learn to distinguish anxiety in his body from physical symptoms, which he had been confusing. The typical pattern went like this, "I feel something funny in my chest, could this be the cancer coming back? Oh my God, if it's back I'll be dead, there is no more treatment for me. What will happen to my wife? How will I die? Will I suffer? How long is this going to take? I don't want to die! I'm terrified!" Like a merry-go-round from Hell, on and on it would go. Of course then the symptoms would escalate with the fear—"It is cancer! I'm sure of it! Why else would I feel this way?" He would poke and prod his body constantly and further exacerbate symptoms.

We persisted with individual sessions after the group program, and practiced mindfully observing, identifying, and responding to stress-related symptoms, rather than automatically assuming that he was on the path to his inevitable death. Stephen was able to arrest the process over time. He did a really good job of this—he surprised me somewhat. We instituted a rule: If you feel what you think might be a symptom, note it, then immediately let it go, do your meditation or breathing exercises, leave it for a week, and if it is still there in a week, call the doctor. The symptoms almost always went away. This practice reinforced the idea that stress can manifest as physical symptoms that mimic his cancer symptoms. This practice was immensely helpful and he has continued to apply it for years.

I would like to report that my work with Stephen was a miraculous success story. However, despite some progress, he was still symptomatic 10 years later. I think given his history it would be miraculous was he not, but he has certainly made gains. A year or so after treatment we discovered something else; every year on the anniversary of his diagnosis, he became depressed and anxious. He had vivid nightmares of the hospital room he spent so much time in; the doctor telling him he was not doing well and his time might be limited. I diagnosed him with post-traumatic stress disorder (PTSD). He had all the symptoms. Now what would we do? I favor exposure therapy for PTSD, and in fact, mindfulness training is just that: gradual controlled exposure to the full range of content of the mind. This included flashbacks and memories of the trauma of his diagnosis and treatment. We reviewed it again and again; how one day he felt a lump in his chest, he fainted due to a syncopal episode, and eventually was taken to the Emergency Room; the swift diagnosis, the brutal treatments; seeing his roommates at the hospital deteriorate until eventually two of them died. We went over it again and again, hoping the memories would fade in their potency. Over time eventually they did, but even as our sessions became less frequent, every year at the anniversary I would get a call from him for a few sessions. He would tell the whole story to me yet again. I knew it so well I could tell it myself, but nonetheless I would try to apply beginner's mind and listen as if for the first time—I would even add in bits if he missed them.

We actually came to laugh about Stephen's stories—we called them his "bird songs." I had read somewhere that once male birds of a certain species start their call; they cannot stop until it is done. There is no interrupting. Stephen had a

range of bird songs. I learned that interrupting to say "yes, yes, I know this one," was not very helpful. At times, I would notice myself getting really irritated when he would launch yet again into a story about his parents, or his diagnosis: Did he not know I had heard this many times? That is when my mindfulness practice played an important role. I would note the rising feeling of irritation in my belly and chest, the tightness of anger and feeling like we were wasting valuable time on this, the desire to control the encounter and move to whatever was on my particular agenda for the day. Then I would take a deep breath, look directly at Stephen, listen to the story and feel his pain. I would feel my body relax; subsequently I would usually see him relax a bit too. Then we could move on.

There were other successes too; after completion of treatment he was on a pharmacopeia of psychotropic medications: antidepressants (which he had been taking before cancer), benzodiazapines and barbiturates for sleep. He hated taking them all, but could not sleep or relax without them. Eventually, maybe 5 or 6 years after treatment, he decided to tackle this problem. He would wax and wane with formal meditation practice, but on one occasion he upped his home practice, started using our suggested sleep breathing exercises, and gradually decreased his dosages of one medication at a time. It took over a year, but eventually he was down to only his selective serotonin reuptake inhibitors (SSRI) antidepressant and the occasional Clonazepam as necessary. He was elated and I was impressed; Stephen was nothing if not persistent and committed.

Over the years, our visits fluctuated. Most years I would see him maybe every two months and we would review his progress, I would reinforce his mindfulness practice and we would tackle any ongoing or new problems. A few times he took longer breaks, but usually came back around his cancer anniversary date. Ten years after we met I had a child and left on maternity leave for a year. This was difficult for Stephen; I was like his security blanket. He did not always need me, but he really liked knowing I was there just in case. I referred him to another psychologist at our service; he saw her once and decided it was not worth the effort of starting over. When I came back we met again a few times and reconnected, then I went on another full year maternity leave; at this point, he was 12 years post diagnosis and doing as well as he ever had. He was still on disability from work; the anxiety disorder had never abated to the extent that he felt comfortable returning to his career. However, his cancer never recurred; his relationship with his wife survived and even thrived despite some ups and downs over the years. I have not seen him in 3 years now, but I would not be at all surprised to get a call from Stephen out of the blue. As much as I would like to see him, I hope I never do get that call.

This ongoing relationship I have had with Stephen has seen me through my entire career as a clinical psychologist working with cancer patients, researching the benefits of mindfulness training for people like Stephen. We both grew and changed and developed together through this relationship; each of us brought our own new learning and ideas and outside experiences to our encounters. Stephen was both one of my most challenging and rewarding clients. He taught me patience and the value of simple mindful presence: things I continue to value. He also taught me to let go of outcome. There was just no way I was going to "fix" him, so I did not really even try to. My intention changed from problem solving and fixing to being, connecting, understanding and sharing what I knew. It took the pressure off me as a junior psychotherapist; I could simply be myself in the encounter. I did not have to "pretend" to be an expert. Being me was good enough for Stephen; in fact it was just what he needed. Applying the attitudes of acceptance, non-judging and letting go to me, Stephen, and our relationship was liberating and ultimately healing for us both.

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