"I Love Pumpkins": The Role of Therapeutic Recreation in Oncology

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Abstract

The purpose of this narrative is to recount my personal journey with bile duct cancer, focusing on the experience during a 12 day in-patient stay on a surgical unit. The surgery, the Whipple procedure, consisted of the removal of the bile duct and gallbladder and small parts of the liver, pancreas, and stomach. Within this narrative I examine the role of recreation and leisure during the in-patient recovery process, with an emphasis on the role of casual leisure (Hutchinson & Kleiber, 2005). Casual leisure allowed for the buffering of stress and maintenance of aspects of my personal identity. Implications for CTRSs working in oncology are discussed.

KEYWORDS: *Oncology, Cancer, Therapeutic Recreation, Casual Leisure, Self-Protection, Self-Restoration*

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Introduction

The purpose of this narrative is to recount my personal journey with bile duct cancer, focusing on the experience during a 12 day in-patient stay on a surgical unit. Although I did not receive therapeutic recreation services during my hospitalization; in the months following my hospitalization and surgery I have wondered as to whether or not leisure impacted my experience during those in-patient days. And if leisure impacted my stay, then questions remain as to the implications for certified therapeutic recreation specialists (CTRSs) who may work in oncology. Therefore, I decided to examine my experience through the lens of recreation and leisure.

In the Content Section, I provide readers with information on the diagnostic phase of my illness as well as detailed information on my in-patient stay following surgery. In the Author's Comments Section, I examine my in-patient stay using the lens of recreation and leisure, as well as discuss implications for CTRSs working in oncology.

Content: "A View from the Inside"

Initial Symptoms and Diagnosis

In September of 2007 I traveled to Milwaukee, Wisconsin to attend the Annual Board Meetings and Conference of the American Therapeutic Recreation Association. During my weeklong stay, I developed abdominal cramps and diarrhea, and vomited on several occasions. Although I attended the board meetings and presented a continuing education session, I would return to my hotel room and rest during unobligated times.

Upon returning to Clemson, South Carolina I went to Urgent Care on Sunday, September 16th, 2007. Over the course of the following week, physicians ruled out giardia and hepatitis; although they informed me that my liver enzymes were extremely elevated. On Friday I saw my primary care physician and she scheduled a gastrointestinal ultrasound for the next day. The radiologist reading the ultrasound informed me that my gallbladder was blocked and this was causing the bile to back up into my liver. He could not see what was causing the blockage. Following the gastrointestinal ultrasound, the radiology staff took me over to the Emergency Room. An Emergency Room physician ordered a CT scan, wrote a referral for a gastroenterologist, and then discharged me to home.

On Sunday, September 23rd, the gastroenterologist called me to let me know he had received copies of the tests and that his office would call me on Monday to schedule an appointment. Throughout the day, I became increasingly sick and I called the gastroenterologist who then decided to admit me to the hospital on Sunday evening. On Monday morning the gastroenterologist came into my room and talked with me about the various explanations for why my gallbladder might be blocked. One possibility was a cancerous tumor. I remember thinking that was just not a plausible explanation; there was no way I had cancer. Cancer did not run in my family. Over the course of my hospital stay, the gastroenterologist continued to very gently discuss the probability of cancer as the diagnosis. During my stay he conducted several procedures that allowed him to biopsy my bile duct and pancreas, as well as insert a stint in the bile duct to allow the bile to drain. Pathology reports on the biopsies indicated abnormal cells. The diagnosis was cancer of the bile duct or pancreas. I was referred to a surgical oncologist affiliated with a major cancer institute in the southeast.

The day prior to my initial hospitalization I sent out an email to friends and family to share with them my possible surgery. At that point in time, I thought that I would most likely have gallbladder surgery. A friend, Gina, was on the list and she promptly began sending updates to everyone on the list. The list grew in number of recipients over the weeks of my care. Gina fielded concerns and questions from my friends. Her generosity in sending out updates allowed friends to feel a sense of connection to me and resulted in people sending many cards, flowers, and gifts as I underwent surgery and subsequent treatments.

I was discharged from the hospital on Friday, September 28th. I remember leaving the hospital and being struck by the beauty and sunlight of the day. Tears filled my eyes as I felt this incredible contrast between a life threatening illness and the beauty of the day. In the days following discharge from the hospital, there was an unreal quality to the diagnosis and I found it hard to believe that I had cancer. At one point I went on the American Can-

cer Society's website to read about bile duct cancer (http://www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=69). I quickly realized the serious nature of this type of cancer and the high mortality rate. Overall, I felt somewhat removed from my emotions and found myself focusing on working with my doctors to fully understand the prognosis and treatment for this type of cancer.

On Friday, October 5th, I had a 2-hour consultation with a surgical oncologist at a major cancer institute. I brought copies of all tests, pathology slides, and my medical chart. The surgeon first conducted a physical exam and then met with me to discuss surgery. He explained that the extent of the mass made it difficult to determine if the cancer originated in the bile duct or the pancreas and that the extensiveness of the mass indicated the need for a Whipple Procedure (also known as a pancreatoduodenectomy; see http://www.mayoclinic.org/pancreatic-cancer/whippleprocedure.html or http://www.pancan.org/Patient/Pancreatic/whipple.htm). The Whipple Procedure involves removal of the bile duct and gallbladder and small parts of the pancreas and stomach. The intent is to remove the entire tumor rather than cut through the mass. The length of hospitalization ranges from 7 to 14 days. The surgery was scheduled for Thursday, October 11th.

Surgery and Hospitalization

My sister Cynthia, my friend Gina, and I arrived at the hospital at 7:30 am on Thursday, October 11th. The first person we saw was my surgeon. After we spoke briefly about my pre-op tests, Cynthia, Gina, and I went to sit in the waiting area. I felt somewhat anxious, but overwhelmingly, I felt the need to get this surgery over with. At approximately 9:30 am, I was called to the surgery prep area. After donning a gown, I was transported to the operating room and met by the Pain Management Team. There was discussion as to whether I would have a morphine pump or an epidural. I chose the epidural, my surgeon's preference. My friend Gina recounted my surgery in the following way:

> The surgery lasted five and half hours. As planned, the surgeon removed the gallbladder, the duodenum, the bile duct, and small parts of the liver, stomach and pancreas. Two things occurred that were not planned. First, the doctor spotted a suspicious area of tissue behind the bile duct and immediately sent a sample for biopsy. It came back identified as fibrous tissue, not cancer—good news. Then he discovered that the mass he had planned to remove had grown into a vein leading to the liver and into a bit of the stomach. The stomach was not a problem since he was already removing a part of it. The vein was a problem, so he did a vein resection effectively removing the affected part of the vein. This was the primary reason that the surgery went 2 to 3 hours beyond the normal time for this procedure. She [Judi] was in recovery until after 7:00 tonight and was then moved to the ICU to be monitored overnight. (G. McLellan, personal communication, October 11, 2007)

Although I remember many aspects of my 24 hours in ICU, I slept during much of this time. During the night I asked for something to drink and was allowed a sponge swab to wet my teeth and gums. At one point in the night the nurse told me I was doing fine and she needed to spend her time with her other patient. She assured me that her colleagues would check on me. Towards morning my mouth was parched and no nursing staff came in my room to swab my mouth. I remember calling out any time someone would pass the doorway. Unfortunately, until my nurse happened to walk by my room, no one responded to my calls. My sister arrived mid-morning and she made sure I had the dampened swab available. My surgeon came in during the late afternoon and we talked about the surgery. He told me that I may need to stay in ICU another night due to no beds being available on a surgical unit. Fortunately, a bed did open up and by early evening I was transferred from the ICU to a surgical unit.

When I arrived on the surgical unit, I remember the staff getting ready to transfer me from the gurney to the bed. I did not know any of the staff and was terrified of having them transfer me given the number of stitches in my mid-section. I asked if I could move my-

self. Staff immediately told me that I could not transfer myself. I held onto my sister's hand as they moved me. The staff first shoved a board below me, lifted me to the bed and then pulled out the board. The sense of being so dependent on people I did not know was a frightening experience.

Saturday was a blur due to a severe headache and nausea. The Pain Management Team worked to get my discomfort under control. I slept a lot and would wake up with various friends in the room. Sunday marked more adjustment to my pain medication. In the late afternoon a nursing staff member came in to ask me to sit up in a chair. My response was "I don't want to do this but I will." A physical therapist (PT) came by to assist me in walking using a walker. When I saw that walker, I really wondered why I would need to use one, but realized as I walked from the chair to the door just how unsteady I was. These early days were marked by sleep and a general blurriness.

Going back a few days, to when Gina and I traveled to the hospital for the surgery, we drove past a school yard full of pumpkins. I commented to Gina that "I love pumpkins." Well, that phrase influenced the care and attention given to me by so many friends over the course of my hospital stay. In an update Gina sent to my friends and family on the 11th of October, she wrote:

> She [Judi] has loved all the cards you have sent already, and we know she will appreciate more. Near the hospital, we saw a school yard full of pumpkins awaiting a fundraising sale; and Judi told me how much she loves pumpkins. With that in mind, we're planning to brighten her hospital room with pumpkins hanging around. If you want to mail a paper pumpkin of any kind, send it on and we'll add it to the patch. (G. McLellan, personal communication, October 11, 2007)

Gina and a staff member in the Department of Parks, Recreation and Tourism Management at Clemson University printed off numerous colored pictures of pumpkins and placed them in the main office of the department. Faculty, staff, and students were invited to pick out a picture and sign it with a get-well note. Soon these pictures decorated the walls of my hospital room. On the Monday following my surgery Gina sent out an email update and reported:

> Her room is now decorated in dozens of pumpkin pictures with notes from many people and all the cards that so many of you have sent. And of course her nephews, Leo and Owen, have contributed photographs and original artwork to the growing wall mural. She received a beautiful flower arrangement yesterday which is done in a beautiful purple ceramic pumpkin. There are also some little pumpkins with painted faces wearing cute Halloween hats and a big pumpkin for hospital staff and visitors to sign. She can see all the cards, flowers, and artwork from the bed and her chair. These greetings add so much cheer and Judi sends her heartfelt thanks to all of you. (G. McLellan, personal communication, October 16, 2007)

Several staff members commented on the liveliness of my room. For example, one of my favorite surgical residents asked me: "What is it about your room? It is so alive. Some rooms I go in there is nothing, they're bland."

Eileen, a dear friend from my adolescent days, flew down from Chicago on Sunday, October 14th, and stayed through Friday, October 19th. She came at the perfect time since I was feeling a bit more alert and needed assistance with daily tasks. Eileen assisted me with daily tasks that the nurses appeared to have little time for, such as brushing my teeth and helping me with bed baths. She was so adept at assisting me that many nurses asked her if she was a nurse! Eileen brought cheer to each day – rolling her eyes at some of the absurd things that occurred. The most memorable absurdity occurred when a nurse told me that I would have to change the sheets on the bed if the drains from surgery leaked numerous times a day. Eileen and I just looked at each other and I informed the nurse that I would not be changing the sheets after going through such major surgery. Eileen provided a sense of camaraderie as I moved through this very difficult recovery.

On Wednesday, October 17th, there was a knock on the door and an employee from the

mail room sailed into the room with a stack of boxes, padded envelopes, and regular envelopes. There must have been at least 15 items in her hands. She looked at me and said: "You have lots of mail. Just who are you?" Eileen and I started laughing. There was no answer to that question! After she left, Eileen and I began sorting through the various boxes and envelopes. My friends, many of whom are CTRSs, had sent me an array of toys and Halloween decorations. There were Halloween socks, a light-up pumpkin necklace, orange pumpkins decals for the windows, hand lotion, Happy Hank, drawings from a friend's children, a miniature Martini set, to name a few! Well these gifts, in particular the toys, intrigued the various surgical residents who came in and out of my room. One of the surgical residents was curious about Happy Hank. Good old Hank was one of those little toys that expand in size when emerged in water. The surgical resident promptly brought in a large container of water and we popped Hank in the container. Over the next few days, during rounds, this particular resident would inform the other physicians that she needed to check on Hank. Subsequently there was a great deal of laughter and many questions about all the 'goodies' on my bed tray.

The most important connection created was with my surgical oncologist. He was skilled not only as a surgeon but also as one who could create a meaningful physician-patient bond. Gina described him as "the one who is cute, personable, caring, charming, and always holds Judi's hand for a while when he visits" (G. McLellan, personal communication, October 16, 2007). The connection with my surgeon seemed to develop based on the extensiveness of the surgery as well as his attentiveness to my care, my family and friends, and his kindness in holding my hand when he would talk with me. That physician-patient connection resulted in me having a positive outlook on all that was happening during the hospital stay and the ability to connect more easily to other medical personnel.

Food provided another means of connecting to others. Although my surgery involved removing part of my stomach, a number of friends sent me food, including ginger candies and cookies for nausea and energy bars for maintaining my "get-up-and-go." I gave the ginger candies and cookies to the nurses and the energy bars to the surgical residents. The surgical residents were thrilled with the energy bars and talked about how hungry they became during some of their shifts.

My roommate from college lives near the hospital and she came to spend the day with me on Saturday, October 20th. Just before she arrived I took my first shower, which was wonderful. Annette came into my room with a bag of goodies, including magazines and pictures from our early days of friendship. During my mid-morning nap, she went outside and later returned to say that we needed to spend some time out of doors. She rounded up nursing staff who then situated me, as well as my IV, in a wheelchair and then we headed out of doors. It was a sunny and warm afternoon. We sat and chatted for over an hour. I loved being outside and it provided a sense of normalcy. I felt renewed!

Medical personnel and friends related to me on various levels. One level being that I am a Buddhist. Prior to going into the hospital a friend had sent me a necklace with a Medicine Buddha medallion to wear. During my hospital stay another friend brought in a small Buddha statue for my bedside table. Through that necklace and the statue, the staff became aware that I was a Buddhist and related to me based on that very personal and meaningful identity. One morning, early in my stay, members of the Pain Management Team came in to talk with me. One of the physicians commented on my necklace and wanted to know if I was a Buddhist. When I said I was, he responded: "Cool. You know the Dali Lama is going to be here on campus this week." Several surgical residents asked me if I knew the Dali Lama was on campus.

Knowing that the Dali Lama was going to be on campus during the second weekend of my hospitalization my friend Gina contacted the Vice-President for Communications, who was coordinating his visit, to ask how I might be able to attend the Dali Lama's public talks. Well the Vice-President was ready to have me transported to the Dali Lama's talks, but unfortunately my medical condition prohibited me from being able to actually attend his talks. So, she then suggested that I have webcam access during the Dali Lama's talks. Gina brought my laptop computer to the hospital and one of the surgical residents came into my room to ensure that we were successful in linking to the webcam pre-

sentation. There was much conversation with various surgical residents as to how they were relating to the Dali Lama during his stay.

One afternoon, early in the week, my surgeon and one of my favorite surgical residents entered my room to share the findings from the pathology report. The report indicated that the specimen removed had cancer in the margins and that 16 of the 30 lymph nodes tested had cancer. Although I knew this was not a good report, somehow it just did not register. After the physicians left my room I turned to Eileen who had started to cry. The reality of the report started to sink in. Eileen shared the news of the report with my family and close friends, but I did not discuss it again until the last day of my hospitalization when my surgeon came into my room. After having several days to process the pathology report, I had questions for him and I asked him what it really meant to have cancer in the margins: "….[W]ere there millions of cancer cells or just a few cancer cells?" He told me that there were a miniscule number of cells. I looked at him and told him that I had decided to let go of the pathology report and just believe that I could survive this cancer.

I was discharged on Tuesday, October 23rd.

Authors Comments: "Through the Lens of Recreation and Leisure"

In this section I will address the following questions:

- What role, if any, did leisure play in aiding me to handle the inpatient experience?
- What do these experiences mean for the work of CTRSs in oncology?

Leisure: The Role and Benefits of Casual Leisure

The 12 day hospitalization was marked by stress and a constantly changing environment that included a shift from ICU to a surgical unit and interactions with numerous medical personnel. I was unsure of how I would come through the surgery or recover from such major surgery. During the 12 days, I also dealt with debilitating nausea and vomiting. And then there was the pathology report and learning that I had Stage IV cancer, which left me wondering if I could survive this cancer.

Although there was incredible stress and many challenges inherent in the hospitalization, there were moments of humor and enjoyment that helped me move through this difficult experience. One mechanism that allowed me to move through this stressful experience appeared to be casual leisure.[1] Casual leisure provides "…moments of pleasure in the midst of chronically busy or stressful lives, casual leisure may not only contribute to sustaining coping efforts in the short term, but to helping people to see themselves as capable of withstanding life's challenges over time" (Hutchinson & Kleiber, 2005, p. 5). Casual leisure consists of ordinary moments of activity engagement in daily life, including the simple pleasures such as reading, playing cards, taking a walk, talking with friends, or sharing a meal with family.

There were ordinary moments during my hospitalization that took me beyond the medical experience and allowed me to enjoy life. For instance, whenever I opened my eyes there were many pumpkin cards taped to the walls that reminded me of my love of pumpkins as well as my many connections with friends and family. Another example was the simple act of opening mail and packages, which provided me a psychological break from dealing with the physical discomfort of recovery. The morning when approximately 15 envelopes and packages were delivered to my room stands out as a time when I was able to enjoy the fun and care extended by my friends. Eileen and I spent time opening each package and laughing and appreciating the contents. We found Happy Hank, a pumpkin light-up necklace, a miniature martini set, to name a few. These toys provided a momentary break from the stress of the hospitalization. And this break from stress was relived as various medical personnel came in my room and looked over and laughed about the various toys. These moments of casual leisure provided a buffer from

[1] Casual leisure is described as differing from serious leisure in terms of the intensity of involvement. At one point in the literature, serious leisure and deep engagement were viewed as the type of participation linked to optimal outcomes (Hutchinson & Kleiber, 2005). A growing body of literature documents the beneficial aspects of casual leisure (e.g., Hutchinson & Kleiber; Hutchinson, LeBlanc, & Booth, 2006).

the stress of hospitalization and allowed me to look forward to spending time once again with many of the people who care about me. These experiences provided *self-protection* from the stress of hospitalization and a life-threatening illness (Hutchinson & Kleiber, 2005; Kleiber, Hutchinson, & Williams, 2002).

There were also moments of *self-restoration* within the ordinary moments of leisure. Self-restoration, via casual leisure, allows one to preserve or restore their sense of self, their identity; thereby "…signify[ing] a sense of resiliency….providing a sense of normalcy" (Hutchinson & Kleiber, 2005, p. 8). The mere act of sitting outside in the sun provided me with a sense of renewal and normalcy that were in direct contrast to sitting in a hospital room and being faced with my illness via medical personnel, an IV, medications, etc. The act of sitting outside was a reminder that I could and would return to my home and normal daily activities that involve spending time out-of-doors. The recognition of my Buddhist practice was another means of self-restoration and remembrance that this important identity was still part of my being. My friends ensured that this identity was honored via markers of my faith (necklace and statue in my hospital room), thereby allowing staff to recognize this important identity.

My connections to medical personnel also provided a sense of self-restoration because relating to others has always been an important aspect of my leisure lifestyle and how I define myself. My surgeon's skill at creating a meaningful physician-patient bond certainly supported the preservation of this important aspect of my identity. The bond with my surgeon then allowed me to feel a connection to the surgical residents and other medical personnel. These relationships, although temporal in nature, reminded me of what is important in my life.

Sometimes, in retrospect, I marvel over the fact that at the end of my hospitalization I could say to my surgeon that I was letting go of the pathology report and was going to believe that I could survive this cancer. As I think about the entire experience, including the ordinary moments of casual leisure, I do believe that the ability to engage in leisure fostered self-protection and self-restoration, thereby allowing me to have hope for the future. Without these meaningful experiences, the hospitalization would have been marked by fear and the unknown, without any of the respite that allowed for a sense of hope for the future.

Implications for CTRSs Working in Oncology

As I consider the role of leisure in my hospitalization and illness, I realize how fortunate I am in my family and friends. They were active participants in my hospitalization. They shaped the environment so that I was able to handle and transcend the negativity of the experience. They ensured that I engaged in moments of ordinary casual leisure. I also realize that not all patients have family and friends who could do so for them, as was evident in the comment by one of the surgical residents: "What is it about your room? It is so alive. Some rooms I go in there is nothing, they're bland." This has led me to consider the role of therapeutic recreation in helping oncology patients create healing environments that buffer them from stress and affirm their personal identities.

Perhaps the most important role of the CTRS is partnering with patients and their family and friends to empower them to engage in interactions and activities that transport them from the medical environment to ordinary pleasures in daily life. For many patients the medical environment may preclude them from feeling as if they can engage in the ordinary. The role of the CTRS is to affirm their right to engage in meaningful casual leisure as well as support such engagement via resources and information.

Although patients in surgical oncology are frequently not ready for interventions that demand active engagement, a CTRS may play a key role in ensuring hospital rooms reflect the identity of specific patients. For instance, family and friends may be encouraged to bring in items that reflect meaningful leisure pursuits and identities, their personal histories with favorite activities and interests. These items may allow a patient to preserve his or her self-identity. Further, such items would allow medical personnel to relate to the patient in ways that go beyond the diagnosis and surgery, further honoring one's personal identity.

Most importantly, CTRSs may work with patients and their loved ones to identify the

casual leisure experiences that may fold into the day on a surgical unit. For example, casual leisure may also be supported via humor carts and short videos (http://www.dukehealth.org/Services/OncologyRecreationTherapy). These elements of treatment may allow the kinds of engagement and interaction that buffers patients and their families from the stress of their illness.

Conclusion

My personal journey with bile duct cancer has been transformative in so many ways. Of great importance has been the impact this journey has had on my understanding of and belief in leisure based interventions that support the growth and development of individuals with illnesses. It is my hope that, by sharing this journey, CTRSs will be empowered to advocate for the provision of therapeutic recreation services with oncology patients.

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