



## HEALTH, CULTURE and SOCIETY

### Beyond Patienthood:

Integrative Medicine, healing environments and the journey toward new selfhood

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## Abstract

The purpose of this study was to learn about the relationship between participation in an integrative medicine program and the impact upon the social identities of seven individuals with cancer. Data were collected via semi-structured, face-to-face interviews and observations in the clinic space, and analyzed using a constant comparison method. All of the participants reported a change in their social identities as they transitioned between illness and wellness. The sub-themes that emerged included: the use of complementary and alternative medicine (CAM) as a means of fighting cancer after chemotherapy ended, maintaining health becoming a main occupation, and the “cancer filter” through which all other experiences are viewed, shaping the post-treatment phase of life. Overall, findings suggest that seeking CAM played a role in the participants’ transitions from selves defined by patient status, to new selves, with new perspectives.

*Keywords: Personhood; CAM; integrative medicine*

## Beyond Patienthood:

Integrative Medicine, healing environments and the journey toward new selfhood

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### 1. Introduction

The challenges of experiencing a significant life course disruption (Adler 2011; Becker 1994; Manderson 2011) including living with cancer have been well documented in the medical literature as well as the social science literature (Carpenter 1997; Carpenter et al., 1999; Drew and Schoenberg 2011; Frank 1995; Lampic 1999; Lawton 2000; Taylor 2000; Drisko et al, 2003). The last decade has seen an increasing amount of attention paid to the environment in which care is delivered across the health care spectrum. This spectrum ranges from the medical spas of Europe and middle class America, designed for stress reduction and relaxation (Frost 2004) to the resource deprived communities of central Appalachia, where fatalistic attitudes serve as a coping mechanism for socially and economically marginalized cancer patients (Drew and Schoenberg 2011). One response to, and recognition of, the various challenges associated with living with cancer is reflected in the trend toward delivering care in a healing space. This trend has culminated in the Optimal Healing Environment (OHE) concept.

OHEs have become part of the integrative medicine trend, as facilities that were once dedicated to natural or “holistic healing” must now compete with or be replaced by facilities that offer biomedical treatment in conjunction with alternative therapies (Baer 2004). These newer integrative medicine facilities offer the combination of biomedical and alternative therapies delivered under the supervision of physicians and registered nurses, in a physical environment specifically designed to promote healing and relaxation. This attention paid to the environment in which care is delivered served historically as the gateway for the OHE concept to take hold. Since their inception, OHEs have carried the expectation to “...build positive, resilient relationships among participants, using qualities and resources of those relationships to enhance health” (Frankel Sung and Hsu 2005). OHEs are based on a holistic model of care that acknowledges the limitations of cure-focused, depersonalized medicine (Jonas et al., 2003). Healing environments have existed in multiple forms dating back to antiquity; however, the type of healing environment being discussed here emerged in the 1990s and took its place among the leading treatment and research centers in the United States (Frost 2004).

Much has been written about the philosophy and ethos of the OHE trend, yet sources of information regarding the administrative, and research aspects of these environments are scarce, if not somewhat vague (Findlay and Verhoef 2004). Cancer care healing environments have cropped up alongside numerous other specialties in recent years. Studies have recently been carried out investigating the role of OHEs in cardiovascular disease and hypertension, substance abuse, end-of-life care, pediatric rehabilitation, diabetes and cancer (Block, Block and Gyllenhaal 2004; Geller and Warren 2004; Kligler 2004; Marshall et al., 2004; Wesa and Culliton 2004; Wesa and Grimm 2004; Silver 2004). The practical concerns actually required for a health care facility to be considered a

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healing environment were examined in a systematic review of the environmental stimuli shown to impact upon the well-being of patients (Dijkstra et al., 2006). Of the 4075 papers Dijkstra's team found, only 30 ultimately contained data on effects of the physical environment on the well-being of patients and lacked overall specificity. The results included the requirements of sunlight, pleasant odor, specifically orange oil, and a spatial layout that allowed for patient privacy (2006).

Attempts to further define essential characteristics of these environments have resulted in few objective standards beyond staffing requirements, organizational ethos, and marketing. Specifically, employing enough staff to adequately provide individualized attention to each client, an organizational ethos focused on holistic care, and an economic structure allowing customers to select from a menu of services to purchase, thus preserving the financial viability of the organization (Frost 2004). Each of these traits reflects the popular 'spa' environment with its emphasis on relaxation through the use of a neutral color palate, natural fibers, and an avoidance of institutional lighting or décor. In the United States, the term "spa" generally refers to a segment of the fitness and beauty industry, ranging from day spas, where customers purchase "pampering services" like massages and pedicures to medi-spas, offering cosmetic procedures supervised by a physician (Frost 2004).

Schweitzer et al (2004) reviewed existing literature on environmental factors that are thought to promote good health, but found too few to form any objective design guidelines for OHEs. In spite of the very little empirical evidence documenting specific benefits of healing spaces, the concept seems to be growing in popularity. The environment-well being relationship has been long established in occupational therapy with regard to the "...interaction between the skills of individuals and demands of health systems" as demonstrated by the PEOP conceptual model (Smith and Hudson 2011: 2). Current research suggests that OHEs focus on personal wellness and healthy life styles, as well as emotional support, and represent what has been called a paradigm shift in the delivery of medical care (Dijkstra et al, 2006; O'Malley 2005). On a consistent basis, the philosophy surrounding OHEs makes an important distinction between healing and curing. Furthermore, healing can take place in the absence of a cure and cure can take place in the absence of healing (Block, Block & Gyllenhal 2004). Such a distinction makes benchmarking success more complicated. Globally, the pursuit of healing expands the goals of these OHEs and opens the mission up to a vast spectrum of interpretation and expectation.

Halliburton's study of health systems in India emphasized the transformative impact made upon the social identity of the individual through the quest for healing (2009). The people Halliburton studied reported an experience of healing that was distinct from cure, or the eradication of an illness. They achieved a new orientation through the illness and treatment experience, described as "... an attainment of a state that is somehow higher and more vibrant than one's original pre-illness state" (2009: 126). Halliburton studied people seeking mental health care in biomedical, spiritual and traditional Ayurvedic contexts that challenged current notions of embodiment; extending experiences of suffering along a continuum from the most to least tangible, transcending what he calls the "Western mind-body phenomenology" (2009: 16). Care contexts continue to transition in the United States, exposing the expanding boundaries of what was once considered traditional biomedicine. The new boundaries now include therapies once considered 'alternative', gradually advancing through the growth of integrative medicine programs (Baer 2004).

Integrative medicine is currently taking the place of what was once called 'holistic health' and employs biomedicine along with complementary and alternative medicine, or CAM, comprising nutrition-based supplements, vitamin antioxidant infusions, meditation, yoga, aroma therapy and various other natural treatments (Baer 2004). Reports about the use of CAM by cancer patients range widely from 7% to 83% (Boon et al., 2000; Cassileth et al., 2004; Ernst and Cassileth 1998; Richardson et al, 2000). The rise of the holistic health movement was met with hostility by biomedicine although there have always been individual biomedical physicians interested in, or playing active roles in holistic practice (Baer 2004). The social stigma associated with CAM use, or fear of being negatively

judged by medical personnel is thought to be responsible for patient reluctance to openly discuss CAM use (Boon et al., 2000; Richardson et al., 2000). Regardless of the stigma, CAM expenditures are counted annually in the billions of dollars (Eisenberg et al., 1998). The use of complementary and alternative medicine in the United States is extensive, especially among those with chronic medical problems such as cancer (Monti et al., 2002). Many cancer patients combine some form of CAM therapy with conventional therapies (Boon et al., 2000; Richardson et al., 2000).

Practices such as Tai Chi, among other holistic approaches to health, are thought to counter the negative side-effects of treatment, bolster participant sense of well-being and improve quality of life (Drisko et al, 2003a, Reid-Arndt, et al 2011). Continued medical advancements have resulted in earlier cancer detection and treatment; therefore the number of individuals living years beyond a cancer diagnosis is increasing to approximately 5 years (American Cancer Society 2003; Aziz et al., 2003). Due to an increase in longevity, cancer patients coping with long-term consequences of cancer diagnosis often report increase in levels of stress, poor health-related quality of life, and unfulfilled psychosocial needs (Monti et al., 2005). Antioxidant therapies are among the most popular, yet still controversial CAM therapies used by cancer patients and survivors.

Vitamin ‘cocktails’ and antioxidant infusions are often used by alternative-leaning cancer patients seeking to improve their immune systems, extend length of remission and prolong their lives (Drisko, Chapman and Hunter 2003). These antioxidant vitamin infusions are a key component and a major expense for the cancer patients seeking care as part of an integrative medicine/CAM program. Antioxidant use, especially the use of high-dose vitamin C during chemotherapy has been the source of ongoing controversy, rooted in the divide between research findings that either support or refute the evidence about antioxidants decreasing the effectiveness of chemotherapy and vitamin C specifically contributing to tumor growth (Grober 2009). The clinicians working with participants in this study supported the evidence claiming antioxidant infusions boosted immune responses, increasing the survival time for cancer patients. Patients managing cancer may never be considered ‘cured’ or cancer-free, stranding them in the socially and emotionally vulnerable space between illness and wellness (Frank 1995). The fact that people are now able to live longer with cancer, and are attempting to manage it like a chronic condition, raises the profile of the illness narrative. The illness narrative concept (Frank 1995; Kleinman 1988) and its power to shape how individuals make sense of their illnesses will be discussed next.

The disruption created by a life-threatening illness, such as cancer can often result in a reexamination of life goals, priorities, and the culturally embedded meaning contained within (Becker 1994). In “The Illness Narratives”, Kleinman discussed the “culturally shaped” ways of communicating about life course disruption and illness experiences and contrasts them with the concept of “disease” which privileges the health care practitioner’s perspective (1988: 5). Frank’s work on illness as a “call for stories” echoes the sentiment that the illness narrative is not merely a telling, or a retelling, but a significant part of the journey one undertakes in the face of serious illness or injury (1995: 53). Social and historical circumstances have created a shift from the more passive societal roles once assumed by recipients of health care, toward a more active voicing of one’s own experience, articulated by Frank as an “act of reclaiming” (1995: 69). Frank uses the “wreckage” metaphor to illustrate this process, for example, “narrative wreckage” takes place when, due to illness or injury, “...the present is not where the past was supposed to lead” (Frank 1995: 55). This narrative, giving voice to the experience of illness from the patient perspective, makes sense of the suffering and brings about the transformation that can result from suffering.

According to Frank the ‘wreckage’ is circumvented through narrative, and the sharing of narratives is a necessity of the identity process, the making and re-making of the social self (1995). One of the narrative types outlined by Frank is the Quest Narrative, which employs the ‘illness experience as a journey’ metaphor that is carried out to parallel the stages of a ‘hero’s journey’ in the famous work of Joseph Campbell, including: departure, initiation and return (Campbell 1949; Frank 1995: 117-119). Through suffering the quest results in a personal

transformation and a rejection of the former self, due to the new perspectives gained; The new perspectives include a “dual citizenship” or mastery of two worlds [the sick and the well] (Sontag 1978). Frank’s “remission society” is another example of that dual citizenship, where “sickness and wellness shift definitively as to which is foreground and which is background at any given moment” (1995: 9).

The participants in this study each experienced their own life course disruptions and had glimpses into the realm of the ‘remission society’ as they journeyed along the continuum between illness and wellness. The purpose of this study was to use narratives to explore these transformations, and the role that seeking CAM in a healing environment played in the lives of seven individuals, as they ventured out on a journey beyond patienthood.

## II. Method

A convenience sample of seven participants was recruited through flyers posted in the clinic space, within an academic medical center. Participants were consented and interviewed in private, at a time and location convenient to the participant; in all cases, participants chose to be interviewed inside the care facility. The Human Subject Committee approved research protocol for recruitment and data collection. Ethical considerations were prioritized given this potentially vulnerable population and all research related activities were conducted with the approval of the local Institutional Review Board.

Study eligibility was determined as interested persons voluntarily responded to the recruitment flyers, typically via telephone. Volunteers were excluded if they reported any condition that would limit their ability to participate in a face-to-face interviews lasting approximately one hour. Volunteers were also excluded if they revealed any signs of cognitive impairment or English speaking difficulties while enquiring about the study.

In-depth, face-to-face interviews were conducted with each participant and lasted approximately one hour each. Interviews were tape recorded to ensure accuracy and composed of mostly open ended questions about participant experiences living with cancer and receiving treatment at the infusion clinic. Data were also collected on demographic and social variables and life experiences. Analysis was conducted via constant comparison, or grounded theory approach (Glazer and Strauss 1967). Emerging themes were coded and indexed for interpretation. Because data collection was limited to the clinic space there was no opportunity to observe the “nested contexts” of home life or community relationships (Nichter 2002; 82).

A coding dictionary was developed and used to cross-code each interview, resulting in stronger validity to better document the lived experience of patients receiving care at the intersection of holistic and traditional medicine. I familiarized myself with these data by reading and re-reading the transcribed interviews and in a series of steps, identified, described and then confirmed patterns and themes of meaning. This technique allowed the narratives of identity-making to be derived from the interviews.

The findings presented in this article are based on all of the interview data gathered from participants, but focus mostly on the participants’ responses to core questions designed to explore the role that participation in an integrative medicine program played in the lives of these participants; specifically, what kind of impact has it made on their ability to renegotiate their post-treatment identities. These questions were: (1) “*What does this program require of you?*” and the follow-up, “*What is the toughest part of participating in this program?*” (2) “*Is it difficult to feel like yourself?*” Many probes and follow-up prompts were used to obtain as complete and descriptive responses to these questions as possible. These questions were asked along with other sets of questions which provided insight into the history, daily and leisure activities engaged in by these participants. See appendix for complete interview guide.

### III. The Infusion Clinic at Mid-Western University

The integrative medicine facility discussed in this article will be referred to as the Infusion Clinic. The Infusion Clinic space was decorated like a day spa, with a gentle water fountain in the entrance and a calm color palate of soft yellow and lavender. Furniture made of woven banana leaf or leather supported the relaxing atmosphere. The décor and absence of fluorescent lighting distinguished the space from the rest of the medical center. The patient lifestyle guidelines were another distinguishing feature and will be discussed next.

Before infusions began, clients had to undergo extensive blood work at an outpatient laboratory, at a cost of approximately U.S. \$4000 out-of-pocket expenses. Clients were instructed to stop smoking and limit their exposure to second hand smoke. They were also encouraged to read a book called *Beating Cancer with Nutrition* (Quillin 2005). Food sensitivities were tested and dietary recommendations were given. The dietary restrictions allow for [unless a food sensitivity had been detected] organic eggs and dairy in moderation, poultry and meat, pork in moderation, fish, nuts and seeds, beans and legumes and whey protein powder. All vegetables except white potatoes and corn were allowed, with carrots in moderation. High fructose corn syrup was forbidden, along with diet soda, alcohol, decaffeinated beverages, artificial sweeteners, white flour, simple carbohydrates and high glycemic-index fruits such as grapes, melon and bananas.

Clients were encouraged to have protein at each meal, green vegetables twice per day, and fruits on the approved list, plus approved carbohydrates such as barley, whole wheat, millet, and quinoa. Following the above described diet required a lifestyle make over for most people receiving care at the Infusion Clinic. Several study participants reported learning to ‘shop the perimeter’ of the grocery store to find the organic items, and cook everything from scratch. One of the Infusion clients created a cookbook which became so popular that the facility staff posted it on their website. A ‘teaching kitchen’ was under construction inside the facility at the time of data collection.

Not all needs could be met through nutrition, however and many of the clients used supplements. Supplements in pill form, are an important of the care protocol at the Infusion clinic. The type and amount of supplement are determined for each patient by Infusion Clinic doctors [one MD and one Naturopath at the time of data collection]. Participants used pill schedules to keep track of medication and supplements. Some had to be used on an empty stomach, while others were required to be taken with food. Issues surrounding the management of these pill schedules will be discussed later in more detail. Intravenous vitamin C therapy was introduced in small doses by a nurse, and gradually increased to the level believed to be therapeutic by the clinic doctors. As discussed earlier, the controversy associated with these and other antioxidant infusions remained unresolved at the time of data collection. Antioxidant use, especially the use of high-dose vitamin C during chemotherapy was the root of the divide between research findings that either support or refute the evidence about antioxidants decreasing the effectiveness of chemotherapy, and vitamin C specifically contributing to tumor growth (Grober 2009).

One nurse tended to the clients in the infusion room and socialized with each of them. Clients seemed to recognize one another and greeted each other when they entered the infusion room. Participants indicated that the previous clinic location was much smaller, forcing their infusion chairs together elbow-to-elbow in the treatment space. This forced closeness reportedly made it easier to establish and maintain friendships with other clients. In the clinic observed for this study, clients received infusions in sight of one another, inside the facility infusion room, for approximately 2 hours at a time. They watched television or read in leather recliners while attached to an I. V. stand by a drip line. A privacy screen blocked the view of people receiving care from the lobby of the facility, but there were no screens separating patients from one another. The information gathered from these interviews yielded three key themes which can be summarized metaphorically as fighting, working and filtering. Each of these themes will be thoroughly described, with examples provided from the interview transcripts.

## Fight however you can

When asked why she sought-out the Infusion Clinic program, Rose, a retired accounting manager facing her second diagnosis with colon cancer, said “I just want to do everything possible to defeat this cancer”. The metaphor of ‘fighting’ was used by several of the participants to describe their choice to seek treatment at this particular clinic. Participating in the program; receiving vitamin C infusions, following the strict diet and lifestyle changes gave a sense of continuing the ‘fight’ against their illness after surgeries and chemotherapy treatments ended. Another participant, Daisy shared that she imagines herself beating cancer and dancing at her granddaughter’s wedding. Fighting the cancer by participating in the Infusion Clinic’s program is her way of working toward that dream of being an active participant in her granddaughter’s wedding celebration.

Violet, an education specialist in her 30s believed that participation in the program continued the process she researched and began on her own to battle ovarian cancer, “In general, as I get further from treatment, I have been trying to exercise more and try to pick-up things like yoga and meditation, so those [are] lifestyle changes”. She began making dietary changes when she was first diagnosed, and was enthusiastic about following the Infusion Clinic guidelines, although the food sensitivity testing caused her to exclude many of her favorites:

I had done a lot of adjustments already, so if anything, it was just exciting to meet with [Oncologist name] and she talked about diet being such a big piece, and recommended working with [clinic doctor]... It has been difficult in the sense because we do the sensitivities and allergy testing here, and I think there are about 19 items, and about 17 of which I came back sensitive to, so that’s been a little challenging. Even though I was already working on the diet, of course when you have sensitivities, you need to stay away from those things for at least a little while. We’ll get to re-test here after a bit and see if we can start to re-integrate some of those things back-in.

Violet reflected on her fears and concerns about entering the post-treatment phase of her life:

You do have that feeling of like, ‘ok, the chemo is ending, and nothing’s going in to fight it’ [cancer]. So that was something that crossed my mind, and I think I am still adjusting to. For example, I got my blood counts back this week and they actually went up for the tumor marker, so you want it [the count] to be going down. It may be nothing, and [doctor name] said she is not worried about it, and we can compare it to the scans with the oncologist tomorrow. But certainly, when you go ‘the chemo is not going in anymore’, you wonder, are they [the blood counts] going to keep going up? But a number of us talked about it here, and we feel like we have vitamin C going in us, we are making diet changes, we are exercising, so even though we are not doing the chemo part [anymore] there are so many other things going on to fight the cancer, so to speak.

The symbolic action of fighting for these women meant a focus on diet and wellness, and extending the duration of remission as long as possible for some, and a hope to overcome cancer or be considered cancer free for others. Rose fought the cancer by taking the mega-dose vitamin infusions, taking the recommended supplements, and following the strict diet- a process she did not enjoy and struggled to afford:

That’s the worst part, the low-sugar diet. It is hard to stick with, especially for me, I have a sweet tooth. It is hard to find something appetizing. Everything is so flat and flavorless, the food is not appealing. So that is kind of a problem, getting enough protein and stuff to eat. They supply it [a cookbook] and we add to it every now and then... Whenever I cook things out of the recipe book, they [family] don’t think it is too appetizing. When you shop at the [organic food market] it is twice as expensive as a normal grocery store, the organic stuff is really high [priced]. So I haven’t been shopping there as much as usual, because my daughter and her little boy are living with me now. We have three to feed instead of one.



Fighting cancer was not inexpensive, as evidenced by the financial sacrifices made to make participation at the Infusion Clinic possible. These financial sacrifices were a common theme expressed by the participants. For Myrtle, a woman in her late 50's, her husband's 'un-retirement' was necessary to afford the expensive treatment at the Infusion Clinic, and allow her to continue to fight her cancer after the portion covered by medical insurance finished. Myrtle admitted that seeking care at the Infusion Clinic has caused financial strain to her family:

My husband's gone back to work [come out of retirement] and I've gone back to work part-time. But, what now-a-days, hasn't caused financial strain with the economy situation? I can't say this is 100% the reason why I went back to work and why he went back to work, it's not 100, but it is part of the reason. We believe in the program. It is a good program and we want to continue it.

Myrtle attributed Infusion Clinic diet and vitamins with her ability to cope and adapt to all the obstacles cancer has thrown her way. She reported a favorable quality of life, which reinforced her devotion to the Infusion Clinic program:

On the diet, I have a lot more energy. I did have forgetfulness sometimes due to the chemotherapy, but think the diet has enhanced my thinking. Some things I can pick-up quicker...I knew I would have to return to work part time. I owned my own business [before cancer diagnosis]. I went back to work, not self-employed, but working for a dentist. I had to totally learn a whole new [job] concept, program, way to react, way to do things, and at my age, 57, I thought it would be harder, but I think with the diet and treatment, things seem to click at lot quicker, easier. It is easier for me to learn, I feel better. I have more energy.

### **Working: staying healthy is a full-time Job**

Keeping a schedule of the numerous pills, diet supplements, and appointments, in addition to managing the diet and life style changes take up the majority of the participants' energy and time, but can be empowering, as one participant, Sabrina shared "Survival is my hobby now". Sabrina's cancer was discovered while she was going through a divorce. She shared the agony of lying in bed, recovering from her biomedical treatment sessions and overhearing her husband talking on the phone to his lover. Surviving, recovering and rebuilding her life included the dream of returning to work and moving on from past pain and disappointment. Daisy, a former school teacher in her 60s shared that living with cancer required an increased amount of self-care. The experience both tested and transformed her sense of herself: "I found a new me. It took a while; it felt like I was lost [at first]. It takes a lot just to take care of me."

The participants in this study reported taking an active role in adopting what they believed to be healthy lifestyles and habits. There did not seem to be a 'passive' way to participate in the program, considering the substantial time and financial requirement for organic food shopping, meal planning and preparation. Sabrina happily reported a significant weight loss of over 50 lbs due to following the Infusion Clinic diet. The diet called for the avoidance of commercially prepared foods, so cooking from scratch was typically required. Spending an entire day once per week, usually Sundays, preparing meals for the week ahead was not uncommon among the participants. Medication diaries or pill schedules were used to keep track of which pills they needed to take and when they needed to take them. Rose shared that she relied heavily on her pill schedule due to the fact that she took a combination of prescription medication and nutritional supplements that totaled approximately 30 pills per day:

Well, between watching the pill schedule, watching the diet and going to doctor appointments, it is pretty much a full-time job. It is so easy to get off schedule, like this morning I missed my pills. I am going to try to catch-up at lunch if I can... I have to write down what time I take my pills, [and] which ones.

The complex schedule was used insuring that doses were not missed, doubled, or pills requiring an empty stomach were not ingested with food. She had something to take approximately every half hour each day. Rose had been living with Parkinson's disease for over 20 years before her cancer diagnosis and had grown accustomed to symptom management as a lifestyle.

### **The Cancer Filter: cancer changes how you see things forever**

Patients reported that once one has experienced cancer, it can become a filter through which everything else is viewed; illuminating expectations and aspects of one's life that were once taken for granted. Sabrina commented on how her life course has been altered through illness by sharing the following:

Cancer has a way of changing the how you view things. For me, it has made me stop and re-evaluate my life, what I want out of life, and I no longer take for granted that I'm going to be living into my 90s the way my grandmothers did. It's kind of like... being a member in an exclusive club of people who pretty much know what they're going to die of and know they're going to die sooner than most people, and that's ok. You reach a point where you just deal with it.

Several participants reported that their friends and family struggled to accept their new life style and diet, although the participants themselves felt the new lifestyle is necessary to recover and thrive. Harvey appeared to be equally philosophical when he explained how participation in the program positively affected his sense of well-being: "The program has...allowed me to feel more like myself." Yet it becomes clear that his positive sentiments existed in the shadow of the debilitating illness and life disruption when he stated, "The illness can make you question who you are, whether or not you are the same person" and "I can't do the physical things I used to do, or keep my [former] work schedule. It has changed who I am". He acknowledged looking to the Infusion Clinic program to restore what the illness had damaged, but at the same time admitted the 'self' he longed for had been transformed by the illness experience.

## **IV. Discussion**

The participants in this study were in the process of transitioning from the status of 'full-time patient' receiving active cancer treatment, to a new phase of life that did not bring about an end to the patient status, but left them feeling in limbo, between sick and healthy, well and unwell. They sought out treatment at an OHE integrative medicine clinic for healing and wellness. For all of these participants, the present was not "...what the past was supposed to lead-up to" (Frank 1995: 55). Their chemotherapy treatments came to an end with no transition to post-treatment life, creating an opportunity for the Infusion Clinic program to serve as the transitional vehicle. Former patients could look forward to fewer medical appointments, but the ending of chemotherapy did not restore well-being or heal the "inner chaos and disruption to the fabric of their lives" (Becker 1994: 383). The changes they experienced could not be undone and they could not revert back to their pre-cancer selves.

Participation in the Infusion Clinic program as a metaphorical form of 'fighting' cancer, or fighting for wellness set the tone for much of the interview process. The metaphor of fighting in health-related settings is of course nothing new, however it is worth exploring the way these participants went to great lengths and expense to use nutrition in their 'fight'. For these participants, aggressively seeking wellness through nutrition was a way of continuing to fight their cancer after traditional treatments ended. In these instances, aggressively seeking wellness meant following through with the lifestyle changes demanded by the Infusion Clinic program, and "marshalling of material resources" (Nichter 2002; 82) to pay for it. This symbolic fighting was part of the larger goal of reestablishing an identity beyond that of a patient.

The continuation of treatment in a new setting, in order to feel less ‘like a patient’ seems counter-intuitive at first glance. After diagnosis, these participants’ personal schedule/calendars took a back seat to the medical calendar, appointments, treatment schedules, medication and supplement schedules, treatment side effects, and so forth. They experienced their status as ‘person’ transform into ‘full-time patient’ at diagnosis and during treatment. As treatment ended, they experienced a status void, or a status that was neither here nor there, leaving each of them vulnerable when treatment ended; No longer a patient, but not able to return to their former lives, fulfilling all the social roles they once held. The participants in this study may never return to their previous lives, as in the many narratives and “narrative wreckage” examples studied by Frank (1995: 68-69).

Participation in the Infusion Clinic program helped bridge the gap between patienthood and personhood, however, the decision to pursue post-treatment care in a healing environment is not without some measure of irony for these individuals. The OHE emphasis on healing stands in sharp contrast to the participant interpretation of ‘fighting’ for wellness. The social environment at the Infusion Clinic provided support for the lifestyle changes required to follow the protocol, which provided a means to ‘fight’ against illness. Receiving the infusions, following the strict nutrition plan and having their health closely monitored by the clinic staff were all tools, or ‘weapons’ in the fight and fighting became a primary occupation. These individuals undertaking a metaphorical journey could be considered ‘warriors’ in the fight for not only health and well-being, but for a restored social personhood.

Financial security, (for example, a spouse coming out of retirement to pay for infusion treatments) is a form of ‘ammunition’ for the ‘weapons’ in this fight because it provides the resource necessary to fight for wellbeing. Framed in Frank’s terms, these participants received a call that may have been ignored at first, reluctantly accepted, and lead on a transformative journey, achieving a type of “permanent visa status requiring periodic review”, anchoring them in the realms of both the sick and the well (Frank, 1995: 9). The irony of fighting and war metaphors used for a program designed around healing and a spa-like atmosphere is perhaps best accounted for by the postmodern context of illness, where “opposing tendencies happen simultaneously” Frank 1995: 69).

A life-threatening illness such as cancer provides a ‘filter’ through which most other things are viewed because the fear and insecurity over a once taken-for-granted health status become permanent fixtures in the survivor’s life, shaping his or her behavior. Beyond fear and insecurity, however, cancer filters potentially serve as tools of transformation. The lenses through which all other experiences and actions are viewed allow one to see one’s life choices differently. This new perspective may play a role in the transition toward ‘post-patient’ life and opportunities for meaningful engagement and a new selfhood.

## V. Conclusion

Fighting cancer through participation in the Infusion Clinic program is how these participants worked to reestablish personhood, pushing beyond patienthood, transitioning toward a new sense of self. Fighting for their own wellbeing was a form, if not a therapy, of healing for these participants. The ending of chemotherapy or radiation treatments offered no transition into post-treatment life, creating a void that the Infusion Clinic program helped to fill. The vitamin infusions, dietary guidelines and focus on wellness may have provided continuity or a sense of empowerment for the patient to keep fighting the illness on their own terms. For these participants, aggressively seeking wellness was part of the larger goal of reestablishing an identity beyond that of a patient, negotiating personhood and selfhood. Receiving the infusions to strengthen their immune systems, following the strict nutrition plan and having their health closely monitored by the clinic staff were all tools, or ‘weapons’ in the fight and fighting became a primary occupation. Cancer filters became the lens through which all other actions were viewed, influencing the approach to post-patient life. The cancer filter is a constant reminder of the journey

one has endured and may play a role in the transition toward meaningful engagement with the new self and new lifestyle.

It has been well established that Western biomedicine maintains its status as the leading health system even as it absorbs the holistic, alternative or complementary therapies that have gained widespread acceptance (Baer 2004; Yoshida 2002). In this sense, the integrative medicine trend is reinforcing the “dominance of biomedicine” rather than challenging it (Bear 2004: 115). It remains to be seen whether or not these CAM therapies will continue to serve as a vehicle for personal transformation and differentiation from the ‘patient status’ if they become fully integrated into the biomedical treatment spectrum. More research is needed on long-term attitudes and beliefs of people who gain entry into the ‘remission society’. Further research that included the family and social networks of cancer survivors would provide opportunities to observe the “nested contexts” of home life or community relationships (Nichter 2002; 82). Such expanded context would enrich current understanding of not only the healing experience, but also the culturally embedded aspects of identity building.

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