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Reconceptualizing Cancer Survivorship Through Veterans' Lived Experiences

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Abstract

This study assessed the biopsychosocial impact of cancer on Veteran older adult survivors by garnering their accounts of their illness experiences. A narrative analysis of 73 cancer diagnosis and treatment stories reveals five “paths” Veterans are taking 18 months postdiagnosis. These paths indicate that cancer survivorship cannot be conceptualized as a one-size-fits-all experience but rather is a process of Veterans understanding and making sense of the effects of cancer on their lives. Our future goal is to develop a screening tool to help clinicians identify a patient's “path” to tailor survivorship care to meet specific needs.

Keywords

cancer survivorship; cancer care; older adults; Veterans; illness narratives; qualitative; quality of life

Introduction

The number of aging cancer survivors in the United States is expected to multiply in the next decade, well surpassing the roughly 13 million approximated today (Siegel et al., 2012). Yet these promising statistics do not reveal the full story behind survival. Cancer

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treatment protocols have the potential to cause significant late and long-term side effects that continually affect patients psychologically, functionally, and socially for years after the cessation of active treatment (Aziz & Rowland, 2003; Institute of Medicine, 2005). The recurrence of primary cancer, development of new cancers or diseases, and the onset of chronic pain, depression, and fear of recurrence are just a few of the many complications that have the potential to affect the lives of survivors, and those closest to them (Institute of Medicine, 2005). Older adult Veterans, much like non-Veteran older adults, are predisposed to late and long-term complications from cancer, and both groups have a high incidence of multiple preexisting conditions that can potentially complicate their illness experience (Avis & Deimling, 2008; Bellizzi, Mustian, Palesh, & Diefenbach, 2008; Hewitt, Rowland, & Yancik, 2003; Hilgeman et al., 2012; Moye, Schuster, Latini, & Naik, 2010; Rao & Denmark-Wahnefried, 2006).

Although more patients are surviving cancer (i.e., the physiological “disease”), the impact of cancer upon patients' individual and social lives (i.e., the subjective “illness” experience) continues on for many well after active treatment ends (Kleinman, 1973; Rowland, 2008, p. 362). Health care services that address the specific needs of survivors are severely lacking, and this issue is compounded by the variability of cancer illness experiences (Institute of Medicine, 2005; Khan, Rose, & Evans, 2012). For example, patients may need mental health interventions to help them cope with fears that their cancer may someday return (Herschbach et al., 2010; Humphris & Ozakinci, 2008) or psychoeducational interventions to learn skills to manage fatigue (Stanton et al., 2005) and changes to one's sexual health (Brotto et al., 2008). Survivorship research emerged to better articulate this experience and offer appropriate care to meet patients' individual needs (Aziz & Rowland, 2003). However, there remain ongoing debates concerning how to accurately conceptualize cancer survival (Bell & Ristovski-Slijepcevic, 2013; Feuerstein, 2007; Khan et al., 2012). Often these differences boil down to issues concerning terminology: who are cancer *survivors* and what is *survivorship*? Multiple conceptual models and definitions have endured such as Mullan's (1985) seasonal transitions or phases model (i.e., acute survival—diagnosis and treatment, extended survival—cessation of active treatment/remission, and permanent survival), and the National Coalition of Cancer Survivorship definition of *cancer survivors*. This organization “defines someone as a cancer survivor from the time of diagnosis and for the balance of life” (National Coalition for Cancer Survivorship, 2013).

Yet there are many challenges when labeling this experience. First, the term *survivor* is often used interchangeably with the term *survivorship* although they are conceptually different (Bell & Ristovski-Slijepcevic, 2013). *Survivorship* is conceptualized as a phase from “post-treatment until the end of life” (National Cancer Institute, 2013) whereas *survivors* are individual persons experiencing the illness (Bell & Ristovski-Slijepcevic, 2013). Second, disagreements remain about when the actual survivorship phase begins complicated by the changing nature of cancer diagnosis and treatment (Khan et al., 2012). Third, not everyone who survives cancer considers themselves *survivors* as the term implies (Jagielski, Hawley, Corbin, Weiss, & Griggs, 2012; Kaiser, 2008; Pieters & Heilemann, 2011). Frank (2003) noted how some survivors of cancer feel as though their illness is

ongoing—that they have not survived anything—so they are unable to identify with this term.

Furthermore, the terms *survivor* and *survivorship* have been conceptualized so broadly that the diverse biopsychosocial variability of how patients' articulate their individual cancer experiences is noticeably absent (Bell & Ristovski-Slijepcevic, 2013; Khan et al., 2012). What then can we glean from such broad definitions that is truly clinically meaningful? Khan et al. (2012, p. 35) argued that the broad nature of these conceptualizations moves us away from providing truly patient-centered cancer care. They suggested “alternative definitions or frameworks” that draw attention to the nuances of cancer survival, and therefore have the potential to better meet patient needs (Khan et al., 2012, p. 35).

Widely utilized in the social sciences, illness narratives provide us with such an alternative in which to view survivorship (Frank, 2003, p. 248). Illness narratives are accounts of patients' individual lived experiences managing complex chronic conditions in the context of their daily lives (Frank, 1995; Good, 1994; Kleinman, 1988). Arthur Frank (1995) proposed a framework of three “narrative types” that help us interpret these experiences. The restitution narrative is the dominant “master narrative” of illness where individuals engage in health seeking with the ultimate goal of returning to their previously healthy selves (Frank, 1995, pp. 79–80). Not everyone who becomes ill returns to a state of health, according to Frank, but the cultural primacy of this narrative gives patients hope that health can be restored. Chaos narratives portray individuals as forever caught in a never ending cycle of illness as “its plot imagines life never getting better” (Frank, 1995, p. 77). The storyteller's actions are not told chronologically but rather are out of order (Frank, 1995, p. 97). Quest narratives describe the individuals as using their illness experience as a means of igniting positive transformation (Frank, 1995, p. 115).

Frank's (1995) narratives have been used to interpret patient's experiences with a variety of chronic conditions such as pain (Vroman, Warner, & Chamberlain, 2009; Zheng et al., 2013), chronic fatigue (Whitehead, 2006), cancer (Plough Hansen & Tjornhoj-Thomsen, 2008; Thomas-MacLean, 2004), and menopause (Nosek, Kennedy, & Gudmundsdottir, 2012). Frank (1995) believes narrative facilitates paying “closer attention to the stories ill persons tell” (p. 76). Becoming better listeners is an especially salient skill when working with those who have survived cancer, according to Rowland (2008, p. 367), who believes that truly patient-centered cancer care only emerges when survivors “voices” about their experiences are heard. Importantly, Frank (1995) fully believes that these narrative types are not mutually exclusive. Restitution narratives, for example, can be permeated by elements of the other two narrative types in its telling, and that there can be more than the three types he proposed (Frank, 1995, p. 76).

The purpose of this study was to better understand and identify the biopsychosocial impact and specific needs of Veteran older adult survivors of cancer by garnering their accounts about their illness experiences, and the effects of these experiences on their lives and identities. Drawing on a set of patient illness narratives from a large mixed methods study on cancer survivorship among aging Veterans, we identified five narrative types derived from patient's lived experiences that are similar in some respects, yet divergent from Frank's

(1995) model. These narratives represent particular “paths” Veterans are taking 18 months postdiagnosis.

Method

Study Design & Method

This article focuses on a set of 73 illness narratives from Veterans age 50 or older that were drawn from a large ($N = 170$) longitudinal oral-digestive cancer survivorship study, the Veterans Cancer Rehabilitation Study (VetCaRes), jointly conducted between the Boston Veterans Affairs (VA) Medical Center in Boston, Massachusetts and the Michael E. DeBakey VA Medical Center in Houston, Texas (November 2009–April 2013). We recruited participants utilizing the VA tumor registry. A confirmed diagnosis of esophageal, head and neck, colorectal or gastric cancer, and treatment in the form of surgery, chemotherapy, and/or radiation therapy were required for eligibility. Patients who were actively dying or in hospice, and patients with confirmed psychiatric disorders or a diagnosis of dementia were excluded as well as those with precancerous (in-situ) lesions. We first invited eligible participants to enroll by mailing a letter explaining that the purpose of this study was to better understand their experiences with cancer. This letter ensured the confidential and voluntary nature of this study, and noted compensation for the interviews (\$30 each). One week later we contacted eligible participants by phone to verify if they were interested in the study, and to begin the enrollment process.

Participants completed three mixed-methods interviews that contained a diverse set of psychometric scales assessing cancer-related biopsychosocial changes. Physical function was assessed through several means, including the Short Physical Performance Battery (Freire, Guerra, Alvarado, Guralnik, & Zunzunegui, 2012) and the Treatment Impact Scale (Syrjala et al., 2000) that measured sexual function. Psychological changes were measured via, for example, the Patient Health Questionnaire (PHQ-9) for depression (Kroenke, Spitzer, & Williams, 2001); post-traumatic growth was evaluated with the Benefit Finding Scale (BFS) (Tomich & Helgeson, 2004). We documented changes to Veterans' social lives through measures such as the Participation Assessment with Recombined Tools (PART) scale (Bogner et al., 2011). We also included several qualitative, open-ended questions that permitted Veterans to share their diagnosis and treatment experiences. Many of these questions formed the basis of our qualitative analyses described in detail below.

The first interview took place at 6 months after diagnosis (Time 1), and again at 12 months (Time 2), and 18 months (Time 3) postdiagnosis. The vast majority of the interviews was conducted in-person by trained research staff and lasted approximately 2 hours each. Interviewers recorded participant's responses by hand and entered them into a database following the interview. The study team met weekly via teleconference to discuss recruitment, to hear detailed case study reports of completed interviews, and to assess data completeness (see also Naik et al., 2013).

Analyses

Two members of the study team with diverse experiences and training in the study of health, disease and illness conducted the qualitative data analyses. One team member (LM), a medical anthropologist, reviewed the three interview protocols in depth, and identified a set of qualitative questions that elicited Veterans' lived illness experiences over the 18-month time period (see Table 1). Participants' responses were extrapolated from the master data set in aggregate and a preliminary qualitative analysis was performed that was purely inductive, meaning it was free of any a priori theoretical frameworks (Bernard, 2002, pp. 464–465). This preliminary analysis familiarized this team member with the breadth and scope of participant's responses and was utilized to identify if any major themes and patterns emerged in the data while in its aggregate form (Luborsky, 1994). Although this preliminary analysis revealed the tremendous biopsychosocial impact of oral-digestive cancer on Veterans' lives, we realized that to truly understand the magnitude of cancer's impact, a deeper and more nuanced understanding of patient's individual lived experiences was required.

The second phase of our analysis was informed by a narrative approach, a methodological style that elicits individuals lived experiences through, for example, the collection of life histories and illness narratives (e.g., Good, 1994; Kleinman, 1988; Luborsky, 1987, 1990, 1993). To conduct this analysis we first had to build a set of longitudinal illness narratives for each Veteran in our sample by using their responses to the interview questions, which gave us a more contextualized understanding of their experiences over the 18 months. One member of the study team (LM) then conducted a narrative analysis of this data set (Bernard, 2002, pp. 451–455), and five types of narratives or survivorship “paths” emerged. Each individual narrative was thematically categorized into one of these five narrative types by “pile sorting” the data set (Bernard, 2002; Saldana, 2009, pp. 188–189). A codebook was constructed that contained code names for each type of narrative as well as a detailed description (Bernard & Ryan, 2010). Codenames and their corresponding descriptions were derived from patient's most salient experiences, and our codebook was continually refined throughout analysis (Bernard & Ryan, 2010, p. 79). This iterative process resulted in the recategorization of some narratives, and the identification of a small number of narratives ($N = 9$) where a clear type had yet to emerge.

To guard against any potential researcher biases, another member of the study team (AN), a medical doctor specializing in geriatric medicine with experience caring for the biopsychosocial symptoms and complications that arise following cancer treatment, analyzed the narrative types and either agreed or disagreed with their placement within this framework. This team member then independently developed codenames and descriptions based on his analysis. Both team members (LM and AN) then worked together until thematic saturation of the narratives had been reached, consensus was achieved regarding placement of the narratives in the framework, and mutual agreement on the codenames and descriptions had been attained. Codenames and narrative descriptions were then rewritten for greater clarity and definition based on this consensus process. Both team members reappraised the uncategorized transcripts using the finalized codenames until reaching agreement on their placement in the narrative framework. Two additional members of the study team also reviewed these emerging narrative types. A health communications scholar

(RS) independently reviewed the narrative framework, codenames, and descriptions for salience and coherence. We also discussed our findings via interdisciplinary teleconferences with another team member who is a clinical psychologist and principal investigator of the overall VetCares study (JM).

Research Ethics

This study received Institutional Review Board (IRB) approval from the Boston and Houston VA Medical Centers (Houston IRB# 25446, Boston IRB# 2317), Baylor College of Medicine, and Harvard Medical School. A Health Insurance Portability and Accountability Act (HIPAA) waiver was secured to utilize the VA tumor registry during the recruitment process. Written consent forms were used. Code numbers and pseudonyms are used to protect the confidentiality of our participants.

Results

Our sample ($N = 73$) comprised mostly older ($M = 65.66 \pm 8.82$ years) males, the majority of whom were White (76.71%). Only 20.55% of our sample was identified as Black or African American and 2.74% were identified as “more than one race.” Just more than one half (53.42%) had attended at least some college or higher. We had a fairly equal distribution across all cancer stages (24.66% Stage I, 30.14% Stage II, 20.55% Stage III, and 24.66% Stage IV) based on American Joint Committee on Cancer (AJCC) classifications. Slightly more than one half of our sample had a diagnosis of colorectal cancer (52.05%), with the remaining sample having a diagnosis of head and neck cancer (43.84%) or esophageal cancer (4.11%). Our inductive analysis revealed five types of cancer narratives. These narratives present a holistic view of patient's most salient experiences with cancer over the study period and represent the various “paths” patients are taking 18 months since diagnosis (see Figure 1). Some describe leaving their cancer behind (Moving On) whereas others express a process of transformation (Seeing the World Differently Now). Some patients tell a story of dealing with treatment side effects day by day (Taking One Day at a Time). Yet others worry their cancer will never truly leave them (Believing Life will Never be Cancer Free) or describe a negative transformation that occurs as they lose a sense of their former selves and associated identities (Losing Myself). The paths' key characteristics, supporting quotes, and patient case studies are described in detail below.

Moving On

Nineteen (26%) participants out of our total sample describe Moving On after the completion of their active treatment. These participants represent the oldest group ($M = 70.74 \pm 9.88$ years) of the five paths. Twelve (63.16%) were diagnosed with early-stage cancers (Stage I and II) and 7 (36.85%) with late-stage cancers (Stage III and IV). Participants in this path conceptualize cancer as one of the many disruptions that can occur in daily life: “Cancer is one of life's illness[es] and the survival rate has improved” (2064). One participant emphatically states, “When they told me I had cancer ... What am I gonna do? I ain't going to cry!” (1008). Despite having faced mortality, our participants fully expect their posttreatment life to return to “normal.” “I haven't changed,” one says, “I still do the things I used to” (2081). Yet another fervently exclaims, “Stop thinking about this

shit [cancer] and move on!” (1044). Posttreatment health actually improved for one participant, “To tell you the truth, I think I feel better! My appetite hasn’t been the best, but I can eat anything sweet!” (1011). The importance of keeping a positive attitude and having strong existing social support systems like their family or faith that “will carry me through” (2074) are characteristic of this path.

“William” (1045)

William is in his mideighties and was diagnosed with “lousy” Stage II colorectal cancer. He says he knew something was wrong before his diagnosis because “I had trouble going to the bathroom. I felt constipated.” When William’s doctor requested a follow-up appointment after an X-ray, he “knew right away” it was cancer. William had to cope with 30 days of diarrhea and incontinence. His chemotherapy and radiation treatments left William having to change “diapers 3–4 times per day” while leaking feces every time he passed gas, making him “afraid to go out.”

Yet William had innate determination and a positive attitude, qualities he attributes to his military experiences: “At the beginning [of my cancer], I worried a little bit, but after I recuperated, I began to feel positive. I’ve always been a para-trooper at heart. Winner’s never quit, and quitters never win!” He expresses numerous times how he believed these qualities helped him cope. William’s “diarrhea-like symptoms” subsided, enabling him to resume his daily activities such as laundry and chores. Other than monitoring the type of food he eats so nothing will “go wrong in my stomach” and maintaining his follow-up appointments so “if there’s anything wrong, I can get treatment,” William’s life returned to normal. “I have a lot to accomplish in 100 years,” he says.

Seeing the World Differently Now

Eight (11%) participants out of our total sample describe Seeing the World Differently Now, and represent the youngest group ($M = 58.75 \pm 6.07$ years) of the five paths. Five (62.50%) were diagnosed with early-stage cancers whereas 3 (37.50%) with late stage. Cancer caused participants to see the world through new eyes:

My outlook on life got a whole lot better. Now I have plans. I look at the world a lot different now. Before the things that were important are not important now. You have to almost die to really appreciate life. (2056)

Another notes, “I have a different outlook on life. I don’t feel I have a lot of time to do the things I want to do. There is a sense of urgency that I didn’t have before” (2012). Participants describe transforming themselves in some positive way by developing new personal strengths such as adopting “better eating habits” (2030), and they “take things more serious now, live right, don’t smoke, or drink as much” (2070). Others convey becoming much closer to their families and developing “a closer connection with my God” (2014).

“Charles” (2024)

Charles was diagnosed with stage IV head and neck cancer in his early fifties that was discovered after an on-the-job injury. He learned that his disease was confined and “not spreading,” but that “surgery was not an option” for his type of cancer. Rather, Charles

needed an intense treatment regimen of chemotherapy and radiation. Charles felt that his cancer was “a death sentence,” a realistic response given that his father had died from late-stage cancer 2 years prior to his own diagnosis. He says the most difficult part of his cancer was “surviving chemotherapy” and credits a local restaurant for helping him endure his “very strong” treatments: “The ... lady who cooked red beans and rice at a nearby restaurant saved my life. I couldn't keep anything down except red beans and rice.”

Charles exudes a much more positive and upbeat tone in his follow-up interviews. He considers himself “cured,” and believes he has “a chance to fight back” if cancer ever recurred. Charles is in continued surveillance, and repeated positron emission tomography scans show no evidence of his disease. Although he lost full range of motion in his neck due to scar tissue that developed from his radiation treatments, Charles feels his “entire life has changed” in a positive way because of his cancer: “It [cancer] brings you a lot closer to God. You are thankful for every day of life.... It makes you appreciate what you have.” In the past he focused too much on business and not enough on family, “It [cancer] pushes you away from just trying to be better in business it makes you want to be closer to your family.” This transformation helped Charles redirect his life in a positive way, unlike his father: “My dad died of cancer and he had pushed himself away from the family.”

Taking One Day at a Time

Seventeen (23.3%) participants out of our total sample describe Taking One Day at a Time since their cancer diagnosis and have an average age of 67 (+/- 7.58) years. Seven (41.17%) were diagnosed with early-stage cancers and 10 (58.82%) with late stage. Participants deal with physical and psychosocial side effects on a day-by-day basis: “The chemo was devastating ... I thought I would bounce back, but it's taken a long time. ... I take things as they come.” (1005). One participant vividly describes integrating these side effects into his everyday life: “My throat is still a little raspy, but I'm feeling good. It's still a little difficult to swallow bread, and meat. I have to be aware to have fluids when I'm eating, and not to panic when something gets stuck” (1026). Despite struggling with treatment related side effects, participants are generally accepting of their cancer and their own mortality: “Acceptance, coming to terms that I had cancer. I wasn't in denial, but I did have to think about it and accept it” (2039). Importantly, they try not to worry excessively about what the future may bring: “I don't think about it [cancer]. It's a fact that I'm going to die. Why think about it? I'm going to take it day by day” (1046).

“Albert” (1010)

Albert is in his midseventies and describes himself as “the kind of person that just deals with things. If it happens, it happens.” Albert was visiting his pulmonary doctor for a “regular appointment” when his doctor became concerned over his sore throat. A biopsy confirmed Albert's diagnosis of Stage II head and neck cancer, which he took in stride. He was treated with chemotherapy and radiation but only found the radiation treatments stressful. Albert's cancer treatment and long-term side effects curtailed certain aspects of his usually “active” life, “I've always been active, always doing something” but “I've slowed down a little bit. I can't do a lot of the stuff that I used to be able to do.” Yet some of Albert's activities such as

vacuuming his home and running the dishwasher are still within the scope of his physical abilities, so he feels “in that way I am basically the same as I always was.”

A year after his diagnosis Albert says his cancer is “gone” but notes that he must undergo repeated biopsies to check for recurrence. Despite this continuous surveillance, Albert is not too concerned over his future as a survivor of cancer. He already made the decision not to treat his cancer if it recurs, citing his advanced age, “I’ve lived a good life.” Albert is adamant that he wants no life-sustaining measures to avoid being “a burden to anyone” and will donate his body to science because he wants no funeral costs. Looking back at his entire cancer experience, Albert reflects: “I just didn’t care [that I got cancer]. I got it, I got it, why worry about it? One day at a time is all we got coming to us.”

Believing Life Will Never Be Cancer Free

Sixteen (21.9%) participants out of our total sample describe Believing Life Will Never Be Cancer Free and have an average age of 63.94 (+/- 6.9) years. Twelve (75%) were diagnosed with early-stage cancers and four (25%) with late stage. Participants describe how cancer touches many aspects of their present lives and possible futures, which they express in discourse about functional declines and worries over recurrence: “I always worry about the cancer coming back and spreading” (2082), says one participant, while another laments, “They didn’t find anything on the last scan, but I don’t feel like it’s [cancer] over” (2032). One participant explains the hesitation among clinicians to deem them “cancer free”: “I think I’m fine now. ... They [the doctors] can’t tell you if you’re cancer free. All they can tell you is things look good” (1006). Another participant expresses worry not only about cancer recurrence, but that “the treatment options start going down” if the cancer returns (2026).

Compounding their worry about recurrence, participants express frustration and worry over their continued side effects, “I don’t sleep well and I am always tired. I am in constant pain 24/7. Feeling normal is gone” (2007) notes one participant, whereas another comments, “I just want some weight back on. I’m tired man” (1051). One participant conveys how he feels better in some respects, but worse in others, “Better shape, feel healthy. That is the positive things; the negative things are that I cannot deal with the stress. My memory loss is driving me crazy” (2009).

“James” (1047)

James is in his early seventies and was diagnosed with Stage II head and neck cancer after seeking an answer to his sore throat. He was treated with chemotherapy and radiation. James says he “took it very hard” when diagnosed and opted against surgery as it would have meant losing his ability to speak. He emphatically notes, “They said they could do surgery, but they’d have to cut out my voice box. I told them that if they cut out my voice box I don’t want to live and I meant it.”

James “never really thought about the future” until diagnosed with cancer. He found out about the long-term side effects of chemotherapy after his treatment ended and now worries about his future health,

I found out about what the side effects are all about. The cells that it [chemotherapy] kills take a long time to rejuvenate. I'm worried about the ... numbness in my extremities. It doesn't bother me mentally, but I'm worried the numbness won't go away.

James describes ongoing difficulties coping with his illness including difficulty eating because “the diameter of my throat shrunk,” which forces him to have an almost exclusively liquid diet. Although James says he is not bothered mentally by the side effects of chemotherapy, he blames his treatment for his loss of interest in much of life, “The side effects of chemo are killer. It stays with you. I don't want to do anything. I basically lay around all day. I don't really care anymore about things I use[d] to care about.” A new diagnosis of lung cancer has pushed him into a depressive state, and his life is overshadowed by a continuous fear of this disease, “Where is it [cancer] going to come up next? I read a lot of cancer books. A cancer gene can stay dormant for years without it coming up.”

Losing Myself

Eighteen months after diagnosis, 13 (17.8%) participants out of our total sample describe Losing Myself because of cancer. With an average of 62.85 (+/- 8.6) years, four were diagnosed with early-stage cancers (30.76%) and nine (69.23%) with late stage. Participants in this path report how their cancer and its treatment transformed their lives in a negative way: “One problem I have right now is my appetite is bad [and] I just don't feel like eating. My weight is low. I never was heavy but now I have lost 26 pounds ... and I have lost most of my strength” (2050). “What life?” says one participant, “I'm still on a liquid diet, occasionally I try to eat solid food. I don't have any taste for it” (1007). Another comments on their chemotherapy- induced memory loss: “I can't remember as well as I used to. Chemotherapy burned my brain up” (2006). “I don't do half of what I use to do. The inability to work [was] exacerbated by cancer—I have to use the bathroom every 5 minutes” (1027), comments one participant, whereas another emphatically says that their “entire life has been turned upside-down” (2023). Cancer subsumes participants' entire lives: “When you have cancer you have to think about it all the time day and night, no rest, never get a break. When you have cancer you feel terrible” (2062).

“John” (2063)

John is in his early sixties and describes experiencing symptoms such as a sore throat and tongue, and some neck swelling that affected his ability to speak. A biopsy confirmed a diagnosis of stage IV head and neck cancer, but John says “I pretty much knew I had a real problem when I went in [to the doctor].” John worried whether his doctors “were going to be able to cure it or not,” yet because of chemotherapy and radiation, John is now free of his disease 12 months after diagnosis. He reveres his independence and wants his family and doctors to know that “being able to do the things I need to do without help” is the most important thing to consider in any future decisions about his medical care.

Although John believes he is free from cancer, he feels damaged by his disease and describes how it has changed his life in a negative way. He struggles with treatment-related side effects such as “living on liquids” (i.e., a liquid diet) and communicating with others since the prophylactic removal of his teeth prior to treatment. He exclaims,

Losing my ability to eat and speak has ruined my life! I have received dentures to replace my full mouth extraction for cancer treatment, but they are not satisfactory. ... I would never have allowed my teeth to be removed had I known how I would struggle with my eating and talking.

Discussion

This study identified and described the physical, psychological, and social effects of oral-digestive cancer among aging Veterans. Our narrative analysis of a subsample of participants age 50 and older revealed five paths among these survivors (Moving On, Seeing the World Differently Now, Taking One Day at a Time, Believing Life will Never be Cancer Free, and Losing Myself). These paths offer a more patient-centered alternative framework for understanding cancer survivorship; they embody the patient's illness experience, highlighting individual, social and cultural expectations, norms, and values (Frank, 1995). Although it can be said that all survivors have unique individual experiences to some extent (Khan et al., 2012), our research shows how cancer survival, like other health conditions, can be categorized in significant ways, supporting the use of illness narrative frameworks like Frank's (1995).

Relevance for Cancer Survivorship

Three of our findings or paths, mirror Frank's (1995) narratives. The Moving On path most closely resembles the restitution narrative as patient's describe returning to (or an anticipated return to) health. Cancer was one of the many bumps in the road in life with smoother travels ahead, and William's story exemplifies this master narrative. Although chaotic in the beginning, William describes recuperation, returning to good health, and even a desire to reach centenarian status.

The Seeing the World Differently Now path most closely resembles the quest narrative where individuals find some life transformative meaning from their illness. Quest narratives embody three forms of storytelling, and our narratives are consistent with elements of two of these: memoir and automythology (Frank, 1995, pp. 119–126). Memoir quests iterate between the teller's life history and illness experiences, with transformation occurring in the form of “the incorporation ... of illness into the writer's life” (Frank, 1995, p. 120). Our participants saying, “I look at the world a lot different now,” “[t]here is a sense of urgency that I didn't have before,” and “I take things more serious now” convey the iterative and transformative process between pre- and postdiagnosis life indicative of memoirs. This iterative process illustrates the incorporation of the illness experience into participants' lives and a change in identity (Frank, 1995). Importantly, we also believe the Seeing the World Differently Now narratives have elements of the automythology quest. The automythology quest embodies reinvention; the individual emerges from illness changed in some significant way (Frank, 1995, pp. 122–123). Participants describe this reinvention by becoming more religious, eating better, giving up bad habits like smoking, and reconnecting with family as a result of their cancer. For example, Charles' narrative conveys his prediagnosis desire “to be better in business,” but once diagnosed with his disease, he reinvents himself by changing

life priorities and focusing on family. Charles' cancer triggered this reinvention as he saw himself following in the same footsteps as his father who disconnected from family life.

Participants who describe Losing Myself most closely resemble Frank's chaos narrative as they convey a sense of "life never getting better" (Frank, 1995, p. 77). Participants describe losing a sense of themselves and their various identities beyond cancer by losing their ability to work, or aspects of their physical appearance or bodily capabilities. John's narrative conveys this loss because he can no longer communicate the way he used to. An unsatisfactory attempt to remedy this loss—poorly fitting dentures—keeps him stuck on an ongoing cycle of illness that prevents him from returning to his former self. Unlike Frank's chaos narratives, our participants did not convey their experiences in an unordered way, perhaps due to the nature of our questions and the longitudinal study design.

Our findings confirm the presence of Frank's restitution, chaos, and quest narratives among those who have survived cancer (Thomas-MacLean, 2004). Yet other narratives exist among survivors of cancer that fall outside the realm of Frank's model. Thomas-MacLean's (2004) breast cancer "reconstruction" narrative captures the experiences of women who strongly desire restitution, but their breast prosthesis acts as a constant reminder "that their experiences also lie outside the domain of restitution" (p. 1651). Plough Hansen and Tjornhoj-Thomsen's (2008) "rehabilitation narrative" captures the experiences of survivors whose treatment-related side effects such as recurrence fears and bodily alterations prevents any sense of normalcy. These narratives are distinct from the restitution narrative because the illness continues to constitute an important facet of an individual's lived experience (Plough Hansen & Tjornhoj-Thomsen, 2008; Thomas-MacLean, 2004).

Similarly, we also found additional narratives among survivors of cancer. Although the rehabilitation and reconstruction narratives are distinct in their own right, our Taking One Day at a Time and Believing Life Will Never be Cancer Free narratives show a comparable process of illness integration into participants' lives that also make our two narratives types unique from the master narrative of restitution (Moving On). Those living by the mantra of taking life day-by-day have accepted cancer as an ongoing aspect of their lives but express little worry about what the future might bring. Albert eloquently states that there is no reason to worry about something you cannot control. This narrative describes a dynamic process of coping that integrates illness into one's life. In contrast, those who feel that they "will never be cancer free" are haunted by their illness and its impact on their life presently and in the possible future. Life is not chaotic per se, but overshadowed by worry—a nagging feeling of "what if" well-articulated by James who believes that cancer genes, although presently dormant, lay in wait somewhere inside his body. This narrative describes how the illness has become part of James' identity, but has not subsumed all aspects of it like the participants who describe the chaos of Losing Myself.

This research confirms findings in the literature that conceptualizations of cancer survivorship can vary in their expression depending on the populations studied (Foley et al., 2006; Plough Hansen & Tjornhoj-Thomsen, 2008; Thomas-MacLean, 2004). Foley et al.'s (2006) qualitative study with longtime survivors of cancer (over 15 years) who were mostly female, White, and ranged in age from midtwenties to mideighties identified four themes

that are similar to our narratives. “Personal growth” (Foley et al., 2006), where cancer is life changing, resembles the kind of transformative process seen in our participants who report *Seeing the World Differently Now*. The authors also report how patients “let go and relinquish control of their lives” (Foley et al., 2006, p. 252), which is similar to our participants who describe *Taking One Day at a Time*. Others felt resentful of their cancer and its impact in their lives (Foley et al., 2006), indicative of our participants who describe *Losing Myself*. Although the themes vary to some extent, the similarities between our study and Foley et al.’s supports the notion that though there are different paths across surviving and living with cancer, there are common shared characteristics.

Frank (2003) describes cancer survival as “craftwork,” a kind of “work-in-progress” (pp. 250–253). Cancer survival cannot be definitively labeled as a one-size-fits-all experience or phase, but rather is a process of patients dealing with and understanding the impact of their illness on their lives and identities (Frank, 2003; Kaiser, 2008). Surviving cancer, especially for older adults, is a dynamic process drawing on one’s illness experiences and life histories (Towsley, Beck, & Watkins, 2007). Importantly, given how narrative types are not mutually exclusive categories (Frank, 1995) the possibility exists that our participants’ paths may change over time the further along they go in their recovery.

This study has several limitations. Our sample was comprised of mostly older male Veterans of the U.S. armed services who were 18 months postdiagnosis when the study was completed, so further research is needed to assess the generalizability of these narrative paths to other cancer populations. Additionally, our interviews were not tape-recorded that prevented verbatim transcription of participants’ words. Interviewers took hand written notes that were later entered into a database, which limits the scope of the responses. Also, we exemplified written responses to a subset of open-ended questions and formulated narratives out of these questions. We did not do lengthy qualitative interviews that were directed at uncovering patient’s free-flowing illness narratives. The answers we received were responses to specific questions, for example, “what was most stressful,” which does not allow us to form a full view of the narrative compared to if we would have conducted full open-ended interviews.

Implications For Clinical Practice

This study underscores the clinical importance of the patient’s experience in tailoring cancer survivorship care and determining interventions. Narrative provides an effective way to bring these experiences into the clinical encounter as it provides a framework for clinicians to listen to patients stories, positive and negative (Frank, 1995; Thomas-MacLean, 2004). Satisfaction with and engagement in comprehensive cancer care maybe improved through the use of patient-centered interventions (e.g., written diaries and patient-controlled web portals) that allow patients to share their personal narratives (Jenks, 2013). Unlike broader psychosocial approaches that propose tailoring survivorship care based on the level of physical and psychological sequelae (Holland & Reznik, 2005), a more holistic view of this experience drawn directly from patient’s “voices” could provide for interventions matched specifically to the individual’s greatest concerns (Hilgeman et al., 2012). Our paths show such promise by identifying those who need services the most (e.g., *Losing Myself*), as well

as make the process of screening and care planning less labor intensive on clinicians if not all patients need these services (e.g., Moving On).

As a next step, we hope to identify how various physical, psychological, social, and spiritual (Ferrell, Grant, & Hassey-Dow, 2004) quality of life needs emerge across our five narrative paths, including their different presentations and modifiable elements. We will take specific psychometric scales utilized in this study to assess whether patients in these paths have, for example, higher or lower levels of depression, post-traumatic stress, worry, community integration, and physical function. These future findings will help us develop validated scales to characterize the specific needs for each path, and to develop a screening tool to help clinicians determine when and how a patient fits into a given path to create more targeted cancer survivorship care plans that have the potential to improve quality of life.

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Figure 1.
Cancer narrative paths 18 months postdiagnosis.

Table 1
Interview Questions

6 Months
We would like to know the story of your diagnosis
What was most stressful about the diagnostic experience?
12 Months
What is happening with your cancer now?
Looking back at your cancer treatment, what was most stressful?
Now that you have had cancer, and may face ongoing decisions about medical care in the future, what would you want your family, friends, and/or doctors to know about you, in terms of what is most important to you in your life?
If your cancer were to recur, is there anything you'd want to be sure your loved ones knew about you and your goals of care?
18 Months
What is happening with your cancer now?
From your perspective, what has changed over the 18 months since you were diagnosed?
After you completed your initial cancer treatment, did you have to face a decision about continuing or restarting cancer treatment? [yes/no]
What was the decision before you?
What did you decide to do?
What factors did you consider in making a decision to have or not to have treatment?
In thinking about your whole cancer experience, what has been the hardest part of having cancer?
In thinking about the future of dealing with this illness, what is the hardest thing for you to face?
What helped you the most in facing the diagnosis and treatment of, and recovery from cancer?