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I'm Still Me: Inspiration and Instruction from Individuals with Brain Cancer

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Individuals with brain cancer face many challenges, including threats to cognition, personality, and sensory and motor functioning. These can alter one's sense of identity and result in despair. Chaplain-led spiritual interviews were conducted with 19 patients with brain cancer as part of a larger spiritual legacy intervention called "Hear My Voice." The majority was female (58%), married (68%) and had aggressive/advanced tumors (63%). Participants were 22–68 years of age and expressed the following religious affiliations: Protestant (42%), Catholic (21%), Muslim (5%), and none (32%). Framework analysis was applied to reduce and understand the interview data. Primary codes were relationships with: God or the spiritual, others, and self. Brain cancer was reported to deepen and enrich patients' commitment to these relationships. Struggle and grief were also revealed. Results suggest the continued vitality, growth and generativity of these participants and provide insight for chaplains and others on the medical team.

KEYWORDS *brain cancer, chaplains, legacy, qualitative research, spirituality*

We are fortunate today that the treatment of those with brain cancers is informed by objective, evidence-based science (Gu et al., 2015; S. Y. Kim et al., 2015; S. S. Kim, Harford, Pirollo, & Chang, 2015). Research has led to precision in the surgical procedures, chemotherapy, and radiation used to combat these uninvited and often deadly tumors (S. Y. Kim et al., 2015). Numerical odds, based on large groups of people with similar disease presentations, are used to prescribe treatment and predict outcomes (De Ieso, Schick, Rosenfelder, Mohammed, & Ross, 2015). Such information is an invaluable and indispensable rudder that steers medical professionals towards their goal of providing the best of care. However, there is a different aspect of the rudder to consider: the voices of patients (Ingram, 2014).

Narrative medicine is an approach to medical care that seeks to understand the unique and subjective discourse of each patient. It trusts that an equation of $n=1$ provides valid and vital guidance for a patient's medical course. It is informed by the stories of each patient and efforts to understand their critical significance and meaning in the midst of illness (Kleinman, 1988). Narrative medicine does not deny the importance of science, but emphasizes the role of the lived experience of the patient (Charon, 2000).

Patients' personal narratives may be deeply affected and even halted by internalized cultural and societal expectations of what it means to be a person of worth. Such expectations may lead patients to the assumption that diminished ability in their productivity and independence means that they

lack value. Such beliefs can push them toward profound suffering, despair, and narrative foreclosure (Lange, 2011; Newberry et al., 2013).

Research with a variety of patient populations suggests that attention to personal stories can foster openness to the experience of illness that helps bolster meaning, dignity, hope, and agency (Chochinov, 2002; Chochinov et al., 2011; Fitchett, Emanuel, Handzo, Boyken, & Wilkie, 2015; Frank, 2009). This outcome provides encouragement for chaplains and others on the health care team to find effective ways to support patients' sharing of their developing narratives in the midst of illness. Unfortunately, there is a paucity of spiritually-focused interventions in the narrative medicine literature, but they are considered important to pursue because of the contribution that spirituality makes to the well-being of many with serious illnesses (Dose, Leonard, McAlpine, & Kreitzer, 2014; Piderman, Kung, et al., 2015; Puchalski et al., 2009).

The Present Study

This qualitative investigation is part of a pilot study developed for patients with brain cancers and other neurologic illnesses (Piderman, Radecki Breitkopf, Jenkins, Euerle, et al., 2015; Piderman, Radecki Breitkopf, Jenkins, Lapid, et al., 2015; Piderman, Radecki Breitkopf, Jenkins, Lovejoy, et al., 2015). The project was designed to examine the feasibility of and provide preliminary efficacy data for a chaplain-led intervention on patients' spiritual well-being and quality of life in the midst of illness. Analysis of process and outcome data from 27 participants and their nominated support persons suggested that the intervention was feasible in a setting where health care chaplains were available and that it promoted spiritual well-being, inner peace, and positive religious coping in patients and support persons (Piderman, Radecki Breitkopf, Jenkins, Lapid, et al., 2015).

The intervention provided an opportunity for each participant to discuss and preserve his/her core spiritual beliefs, practices, values, struggles, and life-learned wisdom in the context of a relationship with a board certified chaplain. Board certified chaplains were chosen as interviewers because they are trained listeners, seasoned in the art of attending to the nuances of communication, and most importantly, because they are familiar with the complexity and sensitivity of spiritual matters.

METHODS

After approval by the Institutional Review Board, eligible participants provided informed consent, demographic information, and completed baseline study questionnaires. Then, an interview with a chaplain was set up for the patient at his/her convenience.

The Interview

The patient's discussion with the chaplain was fostered by a semi-structured spiritual life review interview guide. The interview questions were based on published research, that is, the spiritual assessment tool known as FICA (Borneman, Ferrell, & Puchalski, 2010), Dignity Therapy (Chochinov et al., 2011), and research on spiritual struggle (Pargament, 2007). They were organized around nine themes: faith, importance, community, activity, call, contributions, changes, challenges, and communication. Sample questions include: "What would you consider to be God's call or your purpose in life?" and "Can you describe some experiences that changed you? Were there any that helped you grow spiritually or religiously?" The full interview guide is published elsewhere (Piderman, Radecki Breitkopf, Jenkins, Lovejoy, et al., 2015).

The interview was conducted by one of four chaplains who met together to review the interview guide and ensure uniformity in its use. The interview was intended to promote a thorough and respectful spiritual dialogue and spiritual care. Each interview was digitally audio-recorded and transcribed. Then, it was verified for accuracy and completeness by the interviewing chaplain. The verified transcription was edited by the study team and the patient and/or his/her support person into a unique booklet, called the Spiritual Legacy Document (SLD), and presented as a keepsake.

Analysis

A subset of 19 participants in the aforementioned larger study were chosen for in-depth qualitative analysis. All had a diagnosis of brain cancer. This sub-group was selected because of the immediate challenges they face, that is, threats to their cognition, personality, memory, expressive ability, and sensory and motor functioning, and the possibility of concomitant suffering (Lange, 2011; Newberry et al., 2013).

The majority was female (58%), married (68%), and had an advanced brain tumor. The mean age was 48 with a range of 22–68 years. Most identified themselves denominationally (Protestant, 42%; Catholic, 21%, Muslim, 5%), but 32% did not, indicating that they were agnostic, atheist, or not religiously affiliated. A total of 42% had achieved college graduation.

Framework analysis (FA) was used to understand and analyze the data provided in the transcripts. FA is a well-established, stepwise qualitative research method whose purpose is to reduce large amounts of data by paraphrasing and organizing it so as to be auditable and reproducible; it is ideal for multidisciplinary teams with varying degrees of exposure to qualitative methods and requires no specialized software (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie & Spencer, 1994; Srivastava & Thomson, 2009). To assure the qualitative rigor of the analysis and results reporting, this

project adhered to the Consolidated Criteria for Reporting Qualitative Studies, (COREQ) (Tong, Sainsbury, & Craig, 2007).

Study team members included two chaplains, both with a research background; a psychologist; a nurse-investigator; and a qualitative research analyst. The senior chaplain and the qualitative research analyst formed the primary coding team and independently read each verbatim transcript to gain an understanding of content and meaning. In discussion with the other study team members, an initial codebook was developed, comprised of a set of codes and related definitions that represented conceptual categories found in the content of the transcripts. Code naming was assisted by using the final interview guide, as well as an inductive grounded theory approach. This method enriched the codebook by constantly comparing themes that emerged from the transcripts (Glaser & Strauss, 2012).

The initial codebook was then individually applied to three transcripts by the primary coders who subsequently met with the full study team to discuss coding similarities and differences, and assess codebook adequacy. The codebook was then adapted using prevailing concepts from transformative illness literature (Ando, Morita, Lee, & Okamoto, 2008; Pargament, 2007) to produce the finalized codebook which is summarized in Table 1.

Next the coders each applied the finalized codebook to each of the transcripts and established inter-coder reliability by generating a harmonization table, which listed all discrepant line numbers of passages for discussion, adjudication and consensus. The “gold standard” coded documents were

TABLE 1 Code book: Brain cancer as a transformative event

Code- Subcode	Description
	Relationship with God
Consolation	Experience of comfort, reassurance, peace, gratitude, hope, expectancy regarding the afterlife
Desolation	Spiritual struggle, may include pleading, bargaining, feelings of abandonment, fear
Continuity	Spiritual experiences/practices that have remained static
Change	Spiritual experiences/practices that have changed or deepened following the cancer diagnosis
	Relationship with Others
Positive	Personal inward experience of engagement, gratitude, peace, joy, fun
Challenges	Unresolved issues; unrest
Relationship Dynamic	Approach to relationships that remains the same, or deepens, or changes
Generative	Intention/action to make a difference in the lives of others; Closure; resolution; Words of Wisdom
	Relationship with Oneself
Gains	Focused approach to life; appreciation
Losses	Loss of faculties, or other loss because of brain cancer; loss of role(s); grieving; fatigue
Death Awareness	Mention of affairs planning or specific acknowledgement of their imminent passing

made available to the study team at large for perusal and comment. After agreement was reached, the single synthesized, coded transcript was generated for each participant, and the paraphrased and coded content was entered into a spreadsheet. Each paraphrase was placed on a respondent-by-code matrix, where rows represented unique patients and columns represented the codes. After distilling the data in this way, the investigators defined and described the framework as it emerged from patient narratives.

RESULTS

In the spiritual life review narratives, brain cancer was revealed to influence participants' relationships with God and/or the spiritual world, other people, and oneself. These relationships appeared to grow in importance for the participants in ways that were primarily positive and enriching. However, struggle and even anguish was also revealed. Sub-codes were developed to describe the qualities of participants' expressed experiences. "Consolation" and "desolation," words used frequently by spiritual directors, particularly those with Jesuit training (Gallagher, 2007), were the sub-codes used to describe relationship with God and/or the spiritual world. "Positive" and "challenges" were used to describe relationships with others, and "gains" and "losses" were used to describe a participant's relationship with him/herself. In some cases, the quality of participants' relationships since being diagnosed with brain cancer demonstrated consistency with past behaviors and attitudes, but in other cases, they changed quite dramatically. Thus, the sub-codes "continuity," "change," and "relationship dynamic" were employed to categorize these nuances. Participants' narratives also reflected their engagement in the latter stages of human development, that is, generativity versus stagnation and integrity versus despair (Erikson, 1982; Erikson, Erikson, & Kivnick, 1986; Piderman, Radecki Breitkopf, Jenkins, Euerle, et al., 2015). These experiences are specifically identified by the sub-codes "generativity" and "death awareness."

The sub-codes are underlined and defined more thoroughly in the following paragraphs. Representative quotations from the interviews are included throughout. Each is identified by participant number (P), gender, and age in years (y).

Relationship with God and/or the Spiritual World

Almost all of the participants spoke about having an intimate and dynamic relationship with a higher power, and most spontaneously used the term "God" to describe this relationship. Consolation in this relationship was defined as an experience of comfort, reassurance, peace, gratitude, hope or expectancy regarding a spiritual presence and/or the afterlife.

For many, consolation included trusting God's plan.

God has brought this to me to make me a better person. I do believe it is a part of my path. I think the biggest thing that I have learned throughout all of this is that I am guided in ways that I can't understand. ... Once I have accepted them, they become a part of me. [Now] I find all my happiness and all my joy daily dealing with cancer. (P31, female, 53y)

For some, being active in a religious denomination or religious practices contributed to consolation.

[Before the brain tumor,] I was just living on easy street ... I just had this ideal life. ... Now the ideal has been re-defined. I get up in the morning. I make sure I say my rosary before I have breakfast. That was kind of one of those things that if it got done [it was OK and if I didn't it was OK]. Now I have re-ordered it. (P6, female, 59y)

I'm reading my Bible ... and praying and just seeking God in every situation and just reaching out to Him and knowing throughout this whole time, He's been comforting me and just helping me through it all. (P9, male, 22y)

At least as often, participants indicated that being a spiritual person and finding consolation was possible without a denominational focus.

I don't need to go to a house of God to know that there's a God. Personally, I know in my heart right from wrong. Just listen to it and it will tell you what to do. ... I consider deep breathing to be a part of myself, which is the whole. It helps to ground me. ... Most people winging around so fast so much goes by. (P21, male, 43y)

I appreciate hymns and lots of different rituals. ... Of course, I don't follow them, but I do appreciate them, and ... I can sit in a cathedral for many hours, but it's all part of the beauty. (P16, female, 48y)

I consider myself to be an agnostic For me, God is everywhere. In fact, I don't necessarily consider Him to be an individual like an old man in the sky. I consider Him to kind of be in the wind and around everywhere and flowing with you and almost like a spirit. ... I feel like He is everywhere and anywhere that you need him to be. He is there whenever you need Him. (P27, female, 25y)

Additionally, many spoke of their belief in an afterlife as a source of consolation.

When you think about [heaven], it looks like it is going to be very peaceful. Very, very, and you can see it coming, you can feel it. I ... know that when the time [comes, I'll be] fine and God is going to hold me. (P32, female, 68y)

It's the different things that I see on Earth that I think are beautiful - the fields, the trees, the animals ... just to get a glimpse of something that's pretty amazing and then just knowing that heaven is going to be unfathomable. ... The key is giving your heart to the Lord, and trusting in Him is the complete resolution ... that you will be sharing eternity with Him. (P2, male, 53y)

Spiritual consolation included a sense of peace, comfort, and reassurance.

[Faith is] a blessing. A sweetness. A kindness. A force that makes me say, "I can do this" if I'm aching. I can get through the pain. I can get to the other side. (P31, female, 53y)

I feel better because I can now not cry so much because I don't need to because ... God did something ... He said He was going to take care of me. He is going to take care of me. [It is] a new relationship. And it feels good. (P32, female, 68y)

My spirituality comforts me every day. ... I have made peace with my God ... I am ready to go any time He wants to take me home. (P26, female, 44y)

Desolation in relationship with God or the spiritual was defined as spiritual struggle that may include pleading, bargaining and feelings of abandonment or fear. Desolation was reported by many in their experience of God's plan as something that was hard to understand or accept. For example, the pastor of one of the participants told him that he needed to pray that God's will be done. The participant's response to this advice was:

I can't do that. I've got a wife. I've got two little girls ... I was just fearful that - what if His will for me is to take me and be gone? (P8, male, 45y)

Others struggled with their regret for not living a good or "good enough" spiritual life. Some had actively sought forgiveness from God and felt that the past was resolved.

[It] does not mean I am a perfect person by any means ... I don't feel that way at all, but realizing that and giving that to the Lord, I feel it gives me the ability to cope with life and the world and different things, and it just gives me a peace in my heart, peace in my mind, and peace in my soul. (P2, male, 53y)

Others continued to worry about whether they had done enough to merit God's forgiveness, but continued to hope in God's mercy.

I wasn't always a perfect person, and so it is like I know I kind of pulled away, and I think once I found out that I had this terminal cancer, I felt

like I wasn't faithful enough or good enough to try to come back and, you know, step into the church and say [to God], "Hey, I am not ready yet... I need you now," kind of thing. But I have asked forgiveness for the things that I have done in the past, and I have told myself that is all I can do, and He is going to take me in His hands. ... So, I am putting my faith in Him and as best I can, as best as I know how.... Just getting back on track is what's important for me right now... and trying to keep it real. (P5, female, 45y)

Feelings of consolation often came alongside or in spite of feelings of desolation. In other words, desolation did not obscure or eliminate consolation in the spiritual relationship. Statements of desolation were often interwoven with statements of consolation and in other cases, statements of desolation were followed by “but” and statements of consolation.

This is the worst possible news [brain cancer]. But there was, almost every day, just a little Spirit – I call them spiritual pats on the back – that would say, “I got it. It's in My [God's] hands. I got it.” – which would kind of keep me going. (P8, male, 45y)

There are times where I questioned why God did certain things, and now when I get to my prayers, I thank God for being who He is and how He is and you know, where He is. I had to move out of the way. ... It's not all about me, you know. Much of what it takes is just simply having faith and belief that these things [having cancer and seizures] were done for us, and moving out of the way and letting God do it. But it's... hard to move out of the way, as we think we can do it [ourselves, but]... we can't. ... Those are some challenges, and that's been going on as I try and make this connection more solid. (P3, male, 55y)

Despite struggling with brain cancer, some patients mentioned continuity in their spiritual perspectives, i.e., they continued with spiritual or religious beliefs or practices that they had held prior to diagnosis.

Meditation and trying to clear my mind... I will do that to a chant “om”... I started doing it maybe 10 or 15 years ago. (P12, female, 58y)

Several continued to experience consolation in their relationship with God or people of faith through social media.

Just ever since I had the brain tumor and had to not be at church for like half a month to a month, I would constantly be getting messages—whether it would be text messages or Facebook messages—because people lifted me up in prayer, fasting for me, and just—it was a very beneficial encouraging experience for me, so I would say my church as a whole has been a big part of that. (P9, male, 22y)

Others focused on a long-standing practice of maintaining a positive attitude.

I am a very positive person. I always have been. When I was diagnosed with this brain tumor, I remember one of the very first things that I thought was, "I can deal with this two ways, I can either be really, really mad, angry, upset, sad, or whatever, or I can continue to be happy and joyful," and I mean, don't get me wrong I have my moments ... (P10, female, 37y)

Several retained a belief in God's providence and saw evidence in the circumstances of their lives that God had prepared them for brain cancer.

I have always known that I have a purpose. There is a reason I am here and stay on the path and pray to stay on the path. ... Everybody tells me, "You are dealing with this so phenomenally." ... I am still me. ... I got this tumor because I can take it. (P21, male, 43y)

Many reported that their spiritual life had changed for the better because of brain cancer. Most participants stated that their spiritual life and relationship with God had grown through a greater connection to church, traditions, prayer, scripture, spiritual leaders, and friends. Some mentioned traveling and growing in appreciation of the world, and renewing spiritual commitments as key contributions to this growth.

I'd say it [my faith] even got strengthened because of this time with cancer. (P9, male, 22y)

If I did not grow my faith during this period of time and [was] dealing with my illness as the person I was before, I would have torn into pieces from the inside. I would have ended in depression. I would have ended up in anger. I would have had a different personality than what I think I should be. I just like me now. (P24, female, 34y)

Others had to limit participation in church or spiritual activities due to their illness and limitations. One person explained that singing in the church choir had been an important part of his spiritual life since the death of his young son (many years prior), but stated that since the diagnosis of his brain tumor, music "hurts my head" (P1, male, 66y). Another was not able to participate in yoga as she had previously because of disability related to her cancer (P16, female, 48y).

Relationship with Others

The experience of having brain cancer triggered changes in interpersonal relationships for all of the participants and this was coded as relationship dynamic. Most claimed a positive deepening of relationships with others, stating that brain cancer made them better with others and able to focus

on what they value most. Specifically, most reported more quality time and communication with friends and family.

You don't always think about [relationships] and now you do. Now it is really something. [You don't want to waste] even a minute. (P32, female, 68y)

Others reported that they had become more spontaneous and expressive.

I am a fun-loving, joke-telling guy, but even more so than I was. I am not shy about that. I have a brain tumor. I can say and do anything! (P21, male, 43y)

Participants also expressed a greater appreciation for the goodness of others in their lives, including family, friends, colleagues, and even “strangers” whom they had met during the course of their cancer experience. Many expressed a desire to be compassionate and generous in return.

It's so interesting that we come right to the core. Just in the kitchen (of an American Cancer Society sponsored residence), I have the most amazing conversations. [They are] strangers... total strangers.... And it's so very important. We are all just trying to figure it out. (P16, female, 48y)

How did I ever end up staying with this family and getting to have this relationship with them when I had a need in my time, a financial need, that for five weeks it had been pretty tough for us to try to financially survive?... They just fulfilled a need that I had at the time, and now maybe blessings have gone both ways – that I was a blessing for them in a time (referring to his ability to offer support when one of the family was diagnosed with cancer), and they've been a blessing for me. (P2, male, 53y)

Some also reported feeling comforted by memories and thoughts of loved ones who had died, for example, a son who died as a child, a grandparent, and friends. A woman who had had several miscarriages stated:

I have all these little children waiting for me in heaven. ... [I have a sense of them] every day. (P31, female, 53y)

The cancer experience also brought up relationship challenges, particularly an urgency about making amends and tying up loose ends with people, especially family.

I want to get all my children together... and I want to talk about it, then I want to tell them that I love them and then I want to be done. ... I just want them to know that I love them. (P32, female, 68y)

I have a son that I do not know. ... I met him once. I made a poor decision, and I want him found. (P21, male, 43y)

Most participants were sad about “leaving” family members and wished they could spare them or at least usher them through the pain of losing them in death.

I find myself praying every night that I live 15 more years because then my youngest daughter will be 18. And not that it is okay to be 18 years old and not have a mom, but at least then she is an adult. (P10, female, 37y)

I don't want everybody to grieve for a long time. You know, life is too short. Grieve, go on, have a good time. My daughters have kids of their own now. It's like I want them to move on and, you know, yeah think of me every now and then and maybe have a sad day, but I don't want them to totally forget me, but I want them to enjoy each and every day with their family and their kids and my husband and make happy memories. (P5, female, 45y)

Several also were challenged by the collective fatigue, worry and anxiety around illness and the resulting lack of energy to engage with others.

It sounds almost like I am bragging, but I have a phenomenal amount of friends and family. I mean, phenomenal—and I am so grateful ... so I am trying to, like, make time for everybody, and it is really hard because I also want just quality time with my own husband and my kids and my grandkids. And then to try to get my weekends to get all my friends in, it's really hard. But I want everybody to be able to tell me what they need to tell me, and some have ... told me exactly what I have meant to them in their lives, and it makes me cry, but then they apologize. ... I feel wonderful that they got to tell me that, you know, for them this is part of their closure. They needed to do that. (P5, female, 45y)

I am really good at making sure that [setting the boundary] happens, because I need it. (P31, female, 53y)

Patients spoke at great length about generativity in the midst of brain cancer. Generativity was defined as an intention, action or words aimed at making a difference in the lives of others. This almost unanimously included being an example of strength, faith, and goodness in adversity, teaching and sharing scripture, tenets of religious tradition and personal values, and enjoying hobbies and activities with others. Some were religiously focused and some were not.

[I want] to leave this legacy for my children and grandchildren, that they can see what's important in life. And it's not getting to the finish line with the most or the best, it's just how you finish. It's how you finish and how

you finish. Not first place but to finish at your final breath, that you'll meet the Lord Jesus Christ. (P2, male, 53y)

Right here in this room and speaking about the change is, I think, the best thing I've done so far [in my life]... I've felt how the peacefulness that it (dealing with brain cancer) brought into my life. So probably if someone reads or listens to what I'm saying, it might ring a bell somewhere. It might be a wakeup call for others. (P24, female, 34y)

They can propose to extend things. I just think that sometimes that can be wasted time grasping at what could be when in reality, you become very at peace with where you are at and help other people do that, too. That is important to pass that along. (P11, female, 44y)

A person who identified himself as an atheist found consolation in the possibility that he'd find a way to help his family from "the other side" after he died.

If it's possible, I'll find it [a way] and I'll help, I'll do it. ... I'll leave indicators that I got the message and that I'm operating. ... They're going to watch for them. (P15, male, 63y)

Participants also offered personal "life wisdom" that they wanted to share with others:

Life's too short, life's too precious. Really pay attention to what you are doing. Don't take it for granted. Go out there and have a good time and enjoy life and make happy, fun memories, but don't take it for granted. Don't live it stupidly. (P5, female, 45y)

Don't make every decision all deep and long. Sometimes you just have to say, "I am following God," and just jump into His arms. (P26, female, 44y)

Don't worry about yesterday. You are about today. (P20, male, 55y)

Relationship with Oneself

At the time of interview, the experience of brain cancer had often caused losses in physical and cognitive functioning, including speech, sight, dexterity, movement, and memory. This, in turn, forced many to leave careers and activities they enjoyed and meant a progressive loss of independence. There was grief and frustration with these losses, but an amazing determination to do what was possible.

[You] realize that you are losing your mind. You are aware of it, and it is very frustrating. ... I would not have worked all the late nights ... [I would have] taken more time to coach the soccer team. (P11, female, 44y)

Some days it's like I can't button my pants or I can't tie my shoes. I just tell myself, "Challenge yourself. Keep fighting. Keep trying to do these little things. They're just little things. Just keep trying." (P5, female, 45y)

Additionally, some participants spoke about grief related to the loss of treasured roles.

I think it's just the part of me that's a provider, and making sure [that] what I have in place from now until I die will provide for her well-being and spiritually and stuff, you know, my wife and my kids... they'll be fine. They'll all be fine, but still, it's those things back in my mind because of this macho-ness back there that [I have] to take care of the family and take care of this, to make sure they are provided for. That probably weighs on me, and I should probably let go, but I have a hard time letting go of that. (P2, male, 53y).

However, in the midst of the losses they experienced, patients reported certain gains, including opportunities to be humble, give thanks, be hopeful, and ask forgiveness, to make positive changes, and deepen spiritual and religious practices. One stated simply

I'm better because of this stinkin' tumor. (P26, female, 44y)

Ultimately, participants spoke with a candid awareness of death, particularly, its inevitability and its being part of a greater plan. They appeared to be "tying up loose ends" and integrating the reality of their disease into their lives.

People can't believe that I have [come to peace]. They don't understand why I am not mad ... I just am [at peace], I can't do anything about it ... you know, when it is time, it is time. (P31, female, 53y)

I think I live my life—I live everyday like it is my last. ... I try to live it to its fullest—that is why I say there is no time to be sad every day. I don't want to be. I want to be positive and have a good day. (P27, female, 25y)

They also spoke of knowing it was time to make arrangements and say goodbyes. There was a poignancy and grief evident in these comments. Many also reported acceptance and some even an eagerness to be united with God and their deceased loved ones.

Humor did not escape some of the participants as they spoke about their death. For example, when speaking of her tombstone, one participant indicated that her husband suggested that it read, "This too was on sale!" to reflect her love for shopping.

DISCUSSION

There is a compelling quality to the voices of the participants in this study. They invite those who hear them to understand that they have not been defeated by brain cancer. On the contrary, their words indicate that they are very much alive and are deeply engaged with God, others, and themselves. They are willing and able to name what blesses them and what challenges them, and they do not shy away from expressing complexity, ambiguity, or struggle. They mourn losses, but also proclaim gains and state a direct awareness of anticipated diminishment and death. Their expressed views seem closely aligned with those of “quest narratives,” as they describe their perspectives on how they have grown through illness and what they want to pass on to others (Frank, 1998). They have impressively retained the capacity for Erikson’s last developmental stages (Erikson, 1982; Erikson, Erikson, & Kivnick, 1986), generativity and integrity, and model them with profound generosity and honesty. In essence, they remain themselves, with the human capacity for introspection, intentionality, and growth.

This study is instructive for chaplains and others on the health care team for several reasons. First, the participants’ involvement indicates that they wanted to discuss their spirituality in the context of a spiritual care relationship, and they wanted their spiritual beliefs and experiences to be remembered. They willingly, and often eagerly, took time out of lives cluttered with medical appointments and treatments to reflect on and discuss key aspects of their spirituality with a chaplain, in order to develop a spiritual legacy that would one day succeed them and reveal their spiritual perspective to others. Spontaneous comments reveal their gratitude for the process and its meaning to them (Piderman, Radecki Breitkopf, Jenkins, Euerle, et al., 2015; Piderman, Radecki Breitkopf, Jenkins, Lovejoy, et al., 2015). Research is currently underway to determine whether or not patients with end stage renal disease and those with other advanced medical conditions will respond in a manner similar to those with brain cancer. The spiritual legacy interview may also be helpful for healthy elders, but it is not known whether, in the absence of the imperative brought about by a serious illness, the eagerness to participate would be the same.

Second, the questions in the interview guide seemed to open the door for the participants to engage in deep introspection and sharing with the chaplain-interviewers. Many stated that the process gave them a sense of peace and helped them understand and integrate aspects of their spiritual journey. The chaplain-interviewers described the interview as an effective means of pastoral ministry and indicated that it informed and enriched their ability to engage with the participants in an in-depth, thorough, and relational way.

The responses of the interviewees and feedback from the interviewers affirm the value of an active, focused approach to spiritual assessment (Grossoehme, 2013; Risk, 2013). They also suggest that a spiritual assessment

that includes the themes described in the interview guide may be helpful to patients and chaplains in a non-research outpatient setting. Though this has not been studied formally, it is likely that a chaplain's documentation of such a spiritual assessment would lead to greater respect and understanding of patients' spirituality by other members of the health care team.

Third, the participants interviewed in this study had all experienced upheaval and suffering in their lives because of brain cancer, but many reported that they chose to take part in this study because of the potential the research had to provide insight for others. Contributing to a project that might educate providers and enhance the care of those with brain cancer in the future was important to them. Additionally, all were able to identify in their experience, simple but profound wisdom they wanted to share with others. This wisdom is borne of their inherent dignity and ability to flourish in very difficult circumstances, and is consistent with literature on coping and positive reframing among cancer patients. It reminds us that each person, despite adverse circumstances, has a valuable contribution to offer to others and that opportunities for such sharing can be very fruitful (Risk, 2013). Their wisdom also invites chaplains and others on the health care team to remember that caring for cancer patients provides opportunities, not only to bless, but to be blessed.

The main limitation of this study is the potential selection bias within our sample. It is possible that our sample was comprised of those who were doing well spiritually, and that the results may be different for those who have marked spiritual distress or overt depression and other psychiatric difficulties that may have led them to decline participation. In addition, we selected patients with brain cancer for our in-depth qualitative analysis; it is possible that different patient populations will yield different conclusions. Another limitation worth noting is the time involved with delivering the intervention. Patients that may benefit most from a structured, chaplain-guided spiritual legacy interview often have fragile health and reduced life-expectancies. Preliminary attempts to provide the intervention clinically, that is, the interview and the development of the SLD, without the quantitative questionnaires, have shown promise for patients receiving hospice care (Piderman, unpublished data). This approach is less demanding of the patients and so may be more feasible for them. Also, by taking notes as the patient talks, the interviewing chaplain can reduce the time needed to prepare a draft of the SLD. This approach maintains the focus on spiritual assessment and spiritual care, which, we believe, is the core aspect of the intervention. Research comparing the benefit of the interview alone *vs.* the interview and development/delivery of the SLD is needed to further refine the intervention and balance use of available resources with effectiveness.

This qualitative study provided an opportunity for the participants to experience themselves and to have others experience them, not simply as "brain cancer patients," but as people—people with a sacred kaleidoscope

of spiritual experiences, relationships, and feelings. The intention of this article is to let their voices be heard by chaplains and others who care for and about them. Their voices provide an opportunity for those who listen to know and respect their spiritual side more deeply. They invite us all to consider our personal and professional lives with honesty and humility, and to choose to live wisely and well today.

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