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Examining cancer survivorship trajectories: Exploring the intersection between qualitative illness narratives and quantitative screening instruments

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Abstract

Objective—This article examines the associations of quantitatively refined trajectories of adjustment to cancer survivorship determined by previously published qualitative narrative analysis.

Method—Patients completed measures of cancer-related worry (Cancer Related Worries Scale), depression (Patient Health Questionnaire-9), posttraumatic growth (Benefit Finding Scale), and open-ended survey questions 6, 12, and 18 months postdiagnosis of head and neck, esophageal, gastric, or colorectal cancer. Previously published narrative analysis revealed five distinct survivorship “paths,” which were combined into four paths in the present article: Moving On, Seeing the World Differently, Taking One Day at a Time, and Never the Same. To determine the association of qualitatively determined paths with quantitatively assessed adjustment (i.e., Cancer Related Worries Scale, Patient Health Questionnaire-9, Benefit Finding Scale), we used linear multilevel modeling to regress the adjustment variables on time, path, the time-by-path interaction, and relevant covariates (age, stage, cancer site, ethnicity, and Deyo score).

Results—There was a significant main effect of path on cancer worry, depression, and post-traumatic growth ($p < 0.02$ for all). Patients in the Moving On group reported consistently low worry, depression, and growth compared to the other groups. Patients in the Seeing the World Differently and Taking One Day at a Time paths both reported moderate worry and depression; but those in the Seeing the World Differently path reported the highest post-traumatic growth, whereas

patients in the Taking One Day at a Time path reported little growth. Finally, patients in the Never the Same path reported the highest worry and depression but lowest posttraumatic growth.

Significance of results—This longitudinal study reinforces the notion that cancer survivorship is not a one-size-fits-all experience nor a dichotomized experience of “distress” or “no distress.” Additionally, this hypothesis-generating study suggests future directions for potential self-report measures to help clinicians identify cancer survivors’ trajectory to develop a more patient-centered survivorship care plan.

Keywords

Cancer survivorship; illness narrative; posttraumatic growth; cancer worry; depression

Introduction

Improvements in the detection and treatment of cancer over the past several decades have led to a dramatic increase in the number of cancer survivors in the United States; more than 60% of adults diagnosed with cancer survive longer than 10 years after diagnosis (Moryl et al., 2010). There are currently 14.5 million cancer survivors in the United States (DeSantis et al., 2014), a number that is almost quadruple the rate estimated four decades ago (Institute of Medicine, 2006). Cancer survivors experience a host of physical and psychological symptoms that can last decades after treatment concludes (Jacobsen & Andrykowski, 2015). In an effort to characterize cancer survivors’ experiences, a number of studies examined patients’ distress ratings (e.g., depression, anxiety) during the year following treatment. These studies were largely done with breast cancer survivors and generally indicate that 40%–70% report consistently low distress, 10%–20% initially report high distress but “recover,” and 20%–40% report consistently high distress more than a year posttreatment (Boyes et al., 2013; Bredart et al., 2016; Deshields et al., 2006; Dunn, 2011; Henselmans et al., 2010; Hou et al., 2010; Lam, 2010; Stanton et al., 2015).

However, for many patients, the experience of cancer survivorship is characterized not just by distress, but also by growth. Fifty to 80% of cancer survivors report positive growth or change following their diagnosis (Stanton et al., 2006; Wang et al., 2014). This “posttraumatic growth” likely occurs in the presence of more distressing posttraumatic symptoms, such as intrusive cancer-related thoughts; and some studies suggest that greater disruption from cancer may lead to greater growth (Carver & Antoni, 2004; Chandwani et al., 2010; Helgeson et al., 2006), in addition to greater distress. Thus, although some patients appear to have little difficulty adjusting to survivorship, others would likely benefit from improved care that acknowledges their distress as well as their experiences of personal growth during survivorship (Stanton, 2012; Stanton et al., 2015), whereas still others with high distress may benefit from behavioral health interventions.

Survivorship care that is tailored to meet individual patients’ needs is often referred to as patient-centered care. It was the focus of the Institute of Medicine’s 2006 report, *From cancer patient to cancer survivor: Lost in transition*. This report recommends the use of individualized survivorship care plans to document survivors’ previous treatment, identify remaining physical and psychosocial needs, and outline a plan to address remaining needs

(e.g., referral to mental health providers). In line with this effort, the American College of Surgeons Commission on Cancer added distress screening at critical junctures in patients' treatment, including the conclusion of treatment, to its accreditation requirement (American College of Surgeons, 2015; Pirl et al., 2014). The American Society of Clinical Oncology and National Comprehensive Cancer Network also put forth guidelines for using the single-item Distress Thermometer or two-item Patient Health Questionnaire (PHQ-2) to routinely screen throughout patients' treatment course (Andersen et al., 2014; National Comprehensive Cancer Network, 2008). Although these efforts to identify survivors in need of psychosocial support represent positive steps in the direction of patient-centered care, they rely on blunt instruments, leading to a rough dichotomization of survivors (e.g., distressed vs. nondistressed) that is not aligned with more nuanced patient experience, including patients' experiences of posttraumatic growth and, thus, may hinder truly patient-centered care (Khan et al., 2012).

To more fully understand the multifaceted impact of a broad range of cancer diagnoses and treatment regimens on survivors, we conducted narrative analysis of survivors' cancer diagnosis and treatment stories collected at three intervals (6, 12, and 18 months postdiagnosis). The results of the narrative analyses revealed distinct "paths" that patients took over the 18 months postdiagnosis (Table 1; Martin et al., 2014). These distinct trajectories represent very different processes of integrating the sequelae of cancer diagnosis and treatment into their lives, and patients in each of these trajectories would likely benefit from very different survivorship care. Interestingly, four similar survivorship trajectories were identified in qualitative research done with 58 long-term cancer survivors (Foley, 2006). These studies suggest that cancer survivorship is not a one-size-fits-all experience or even a two-category ("distressed vs. nondistressed") experience, but rather a more nuanced process with multiple distinct trajectories, possibly falling along two dimensions of distress and growth. Exploring differences in quantitative measures among patients in each of the paths may inform future development of multifaceted screening tools to help clinicians tailor patients' survivorship care to meet their specific needs.

The purpose of this article is to examine the association of distress (worry, depression), growth, demographic, and physical health variables with the trajectories that emerged from the previously published narrative analysis (Martin et al., 2014), to elucidate the possible role of quantitative measures helping identify patients' survivorship pathway.

Methods

Participants and procedure

This study is part of a larger, longitudinal mixed-methods study in which 170 veterans diagnosed with head and neck, esophageal, gastric, or colorectal cancer at the Boston and Houston VA Medical Centers completed quantitative questionnaires and qualitative open-ended survey questions 6 (time 1), 12 (time 2), and 18 (time 3) months after pathology analysis confirmed malignancy. Patients were identified from the VA tumor registry and contacted if they were diagnosed within 6 months of the study's opening and had undergone chemotherapy, radiation therapy, and/or surgical treatment for cancer. Patients were excluded if their medical record indicated a diagnosis of dementia or psychotic disorders, or

if they were undergoing hospice care, considered actively dying, or had a precancerous (in situ) diagnosis. Questionnaires and open-ended survey questions were conducted in person, or, in rare cases, over the phone ($n = 7$) and lasted approximately 2 hours each. Veterans received compensation for their time after the completion of each interview (\$30 per interview) (Naik et al., 2013). Narrative analyses were completed on an additional 36 veterans after the initial publication, which included 73 veterans (Martin et al., 2014). This article includes all veterans ($n = 109$) with data at all three time points who were previously categorized into one of five pathways.

Measures

Demographics—Participants reported their age, gender, ethnicity (Hispanic/Latino or not), race, and level of education. Information about the cancer diagnosis, stage, and treatments was obtained from the medical record.

Worry—The Cancer Related Worries Scale (CWS) (Moye et al., 2014) evaluated veterans' level of cancer-related worry in five domains—fear of recurrence, healthcare, family, existential, and recovery—they may have experienced over the 4 weeks before this interview. This measure has 15 items, scored 0–4, with a maximum score of 60.

Depression—The nine-item PHQ (PHQ-9) (Kroenke, et al., 2001) was used to assess depression. It corresponds directly to the *Diagnostic & Statistical Manual* criteria for major depression. This nine-item self-report measure assesses depression symptoms on a 0–3 scale, with a maximum score of 27. Higher scores indicate greater symptom severity.

Posttraumatic growth—The Benefit Finding Scale (BFS) (Tomich & Helgeson, 2004) was used to evaluate posttraumatic growth. We changed item stems and response categories to allow recording positive and negative change. Participants were asked whether each item had changed since cancer following response categories (0 = a lot less, 1 = less, 2 = the same, 3 = more, 4 = a lot more).

Survivorship pathways

Five survivorship pathways were determined via narrative analysis described previously (Martin et al., 2014). To determine whether any of the five qualitatively defined paths (i.e., Moving On, Seeing the World Differently Now, Taking One Day at a Time, Believing Life will Never be Cancer Free, and Losing Myself) could be combined to increase statistical power, given the small subgroup size, we conducted general linear mixed-model regression analysis (LMM) to regress the psychosocial variables (i.e., CWS, PHQ-9, BFS) on time, path, the time-by-path interaction, and relevant demographic or clinical information found to have an association with either psychosocial variable at the $p < 0.05$ level (i.e., age, stage, cancer site, ethnicity, and Deyo score). When pairwise comparisons revealed that paths did not significantly differ on either psychosocial variable, we combined those paths. This process resulted in a combining of the Believing Life will Never Be Cancer Free and Losing Myself pathways because these paths did not differ significantly on cancer worry, depression symptoms, or posttraumatic growth. Additionally, the narratives included in these two paths were conceptually similar, in that cancer and its treatment resulted in a predominantly

negative transformation of individuals' lives. Thus, the present article analyzes four paths: Moving On; Seeing the World Differently; Taking One Day at a Time; and a combined path titled Never the Same (Table 2).

Data analysis

Descriptive statistics were computed. We used general LMM to determine whether demographic or clinical variables were associated with psychosocial outcome variables (i.e., CWS, PHQ-9, BFS) and included variables associated at the $p < 0.05$ level in bivariate analyses as covariates. These analyses yielded age, stage, cancer site, ethnicity, and Deyo score as covariates. To determine the association of a patient's pathway with psychosocial factors (i.e., CWS, PHQ-9, BFS), we used LMM to regress the psychosocial variables on time, path, the time-by-path interaction, and covariates. LMM can take the dependent nature of nested longitudinal data (i.e., repeated measures nested within participants) into account and efficiently handles unbalanced designs and missing data without excluding participants or imputing values (Gibbons et al., 1988, 1993). The intercept was treated as random and the path effect was treated as a classification variable, using the class statement in SAS PROC MIXED. Where there was a significant path or path-by-time interaction effect, we conducted pairwise comparisons.

Results

Participant characteristics

Participants were mostly male (98%) and white (90%), with a diagnosis of colorectal (60%), head and neck (35%), esophageal (4%), or stomach (2%) cancer (Table 2). Participants had an average age of 65 (standard deviation [SD] = 9.35), had an average of three comorbid conditions (SD = 1.85), and represented a range of cancer stages. Age was the only demographic or clinical variable associated with path ($p = 0.006$). Patients in the Moving On path were older than those in the Seeing the World Differently and Never the Same paths.

Association of paths with psychosocial factors

Cancer worry—There was a significant main effect of path on cancer worry ($F_{(3, 93)} = 9.10$, $p < 0.0001$; Figure 1a). Specifically, patients in the Moving On path reported lower cancer worry than patients in the Seeing the World Differently ($p = 0.011$) and Never the Same paths ($p < 0.001$); patients in the Taking One Day at a Time path reported lower cancer worry than patients in the Never the Same path ($p < 0.001$).

Depression symptoms—There were significant path ($F_{(3, 93)} = 3.58$, $p < 0.017$) and path-by-time effects ($F_{(6, 202)} = 2.40$, $p = 0.029$) on depression symptoms (Figure 1b). Specifically, patients in the Moving On path reported lower depression symptoms at every time point than patients in the Never the Same path ($p < .04$ for all). At time 3, patients in the Seeing the World Differently and Taking 1 Day at a Time paths reported lower depression symptoms than patients in the Never the Same path ($p < 0.03$).

Posttraumatic growth—There was a significant main effect of path on posttraumatic growth ($F_{(3, 93)} = 3.72$, $p = 0.014$; Figure 1c). Specifically, patients in the Seeing the World

Differently path reported higher posttraumatic growth than patients in all other paths ($p < 0.05$ for all).

Discussion

This longitudinal study of patients with diverse cancer sites found that quantitatively assessed worry, depression, and posttraumatic growth were associated with qualitatively determined trajectories of survivorship (Martin et al., 2014). These findings reinforce the notion that cancer survivorship is not a one-size-fits-all experience, and neither is it possible to dichotomize it into experiences of “distress” or “no distress.” Additionally, these findings suggest directions for future research on brief self-report measures to help clinicians identify cancer survivors’ trajectory to develop a more patient-centered survivorship care plan.

Specifically, the present study found that patients whose qualitative illness narratives prioritized Moving On with little distress or change following their cancer diagnosis and treatment did indeed report low cancer-related worry, depression, and growth on quantitative measures across all time points. Additionally, patients who framed their survivorship experience as one of considerable hardship as well as personal growth that led them to Seeing the World Differently reported relatively high cancer-related worry, depression, and posttraumatic growth. Patients who acknowledged Taking One Day at a Time because of continued side effects and concerns about the future reported moderately high cancer-related worry and depression, and little posttraumatic growth. Finally, patients who indicated that they were Never the Same, primarily in a negative way, because of near-constant worry about recurrence and frustration with residual side effects, reported the highest cancer-related worry and depression but only a mild amount of posttraumatic growth.

The concordance of quantitative measures of distress and growth with survivors’ qualitative description of their experience points to the possible utility of brief self-report measures to predict patients’ survivorship paths. Although current guidelines recommend screening for distress, using a single-item distress thermometer or the two-item Patient Health Questionnaire (PHQ-2), there is no recommended scale to assess the important constructs of cancer-related worry or posttraumatic growth.

The present study found that the extent of cancer-related worry differed considerably among the four qualitatively defined survivorship paths. Patients in the Never the Same path (38% of the sample) reported cancer-related worry half a standard deviation above the sample’s mean, patients in the Seeing the World Differently and Taking One Day at a Time paths (11% and 29% of the sample, respectively) reported a moderate amount of worry, and those in the Moving On path (22% of the sample) reported cancer-related worry half a standard deviation below the sample’s mean. These findings echo those of other studies, which report that the majority of cancer survivors experience moderate cancer-related worry (Koch et al., 2013), whereas 10%–30% of survivors report high cancer-related worry or fear of recurrence many years after diagnosis (Avis et al., 2005; Martin et al., 2014; Mehnert et al., 2009; Skaali, et al., 2009). Furthermore, cancer-related worry is among the most important needs reported by survivors during the years postdiagnosis (Harrison et al., 2011; Koch et al., 2013), likely because of its association with anxiety and depression (Deimling et al., 2006)

and reduced quality of life (Avis et al., 2005). Despite the prevalence and consequences of cancer-related worry, there are no standardized measures or established cutoff scores to indicate clinical significance (Simard & Savard, 2009; Stanton, et al., 2015; Thewes et al. 2011). Inclusion of cancer-related worry in screening and discussions of survivorship care plans may be an important step to identify and more adequately meet the needs of patients embarking on diverse survivorship trajectories.

Measures of posttraumatic growth may also help distinguish patients' survivorship trajectories and tailor their care. For example, though patients in both the Seeing the World Differently and Taking One Day at a Time paths reported moderate cancer-related worry and depression, their scores on the measure of posttraumatic growth starkly diverged. This is reflective of the qualitative data, which revealed that, among patients who described continued concern about side effects and possible recurrence, some framed their experience as one of considerable positive personal growth (i.e., Seeing the World Differently) and some indicated little personal change (i.e., Taking One Day at a Time). Alternately, some patients (Never the Same) reported significant worry, depression, and change, although they perceived this change as largely negative. Finally, some patients consistently denied cancer-related worry, depression, or growth and held an expectation that life would soon return to "normal" (i.e., Moving On), which is evidenced in their low posttraumatic growth scores. These findings echo previous studies' assertions that posttraumatic growth takes place in the presence of perceived threat and cancer-related life disruption (Carver & Antoni, 2004; Helgeson et al., 2006), but distress does not necessarily lead to perceived growth. Relatedly, the present study suggests that patients who report high posttraumatic growth are not necessarily protected from also experiencing persistent distress during the survivorship period (e.g., high cancer-related worry, depression). Thus, posttraumatic growth appears to be an important factor in differentiating survivors' adjustment trajectories and may be a valuable consideration when developing survivorship psychosocial care plans.

Qualitative and quantitative data examined in the present study suggest that patients in each path have different psychosocial needs for providers to consider when creating survivorship care plans. If these paths and findings are replicated, future research might consider treatment approaches specific to their needs. Here we provide speculation as to which evidence-based therapies might be appropriate for each trajectory. For example, patients experiencing distress in the presence of considerable personal growth (e.g., patients in the Seeing the World Differently path) may derive the greatest benefit from interventions that build on their positive growth and assist them in fully integrating the disruptive cancer experience into their lives, such as acceptance and commitment therapy. This therapy encourages patients to accept internal experiences, such as unwanted thoughts and emotions, and commit to living in a way consistent with their values. It has been shown to reduce distress and improve quality of life for patients with cancer (Feros et al., 2013; Mojtabaie & Gholamhosseini, 2014; Paez et al., 2007). In contrast, patients experiencing moderate distress with little or no perceived growth following diagnosis (i.e., patients in the Taking One Day at a Time path) may benefit from traditional behavioral activation strategies, which encourage patients to engage in pleasant or meaningful activities to improve mood (Hopko et al., 2008), as well as potential pharmacological treatment for depression. Finally, patients experiencing relatively high distress who perceive little positive change (e.g., patients in the

Never the Same path) may benefit most from an intervention approach that fosters posttraumatic growth and meaning-making related to the cancer experience, such as meaning-centered group psychotherapy for patients with advanced cancer (Greenstein & Breitbart, 2000), supportive-expressive group therapy (Classen et al., 2001), or mindfulness-based cancer recovery (Carlson et al., 2013). Patients in the Never the Same path may also benefit from therapy that directly facilitates cognitive processing of their cancer experience (Salsman et al., 2009), such as cognitive processing therapy (Resick et al., 2016) along with medications for depression. However, it is important to note that current literature on which therapeutic approaches work best for which types of patients is in its infancy and that the most consistent findings simply indicate that patients with greater distress benefit most from any intervention (Hart et al., 2012; Pots et al., 2016; Ratcliff et al, 2015; Schneider et al, 2010). Thus, more work is needed to determine whether certain treatment approaches may be optimal for certain survivorship paths.

This study has several limitations. The relatively small sample size in each of the four identified pathways limits our ability to determine the utility of the measures in this study to predict patients' pathways. Additionally, the present study is limited to examining the association of three quantitative measures (cancer-related worry, depression, and posttraumatic growth) with patients' survivorship paths, although there may be other constructs important to consider, such as social support or comfort with treatment team. Finally, the present sample is mostly male, which may limit generalizability to women survivors. However, it is important to note that most studies examining psychosocial sequelae of cancer are conducted with breast cancer patients. Thus, the present study's sample of patients with diverse, understudied cancer sites, older age, and high comorbidities represents an important contribution to the survivorship literature. Additional study is needed of more racially and ethnically diverse samples to examine potential differences in illness experience in the context of the extensive literature on health disparities.

In conclusion, patients' qualitative descriptions of their survivorship experience revealed at least four different pathways of adjustment, corroborated by their responses to qualitative data. This hypothesis-generating study suggests that future work to examine the use of brief, multidimensional screeners to help identify patients' survivorship trajectory and psychosocial care needs is warranted. Continued work in this area is essential to improving patient-centered care for the growing population of cancer survivors.

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Fig. 1.

(a) Paths and cancer-related worry. (b) Paths and depression. (c) Paths and posttraumatic growth.

Table 1

Survivorship trajectories resulting from qualitative analysis of survivor's illness narratives

Survivorship trajectory	<i>n</i> (%)	Description	Case example
Moving On	24 (22)	Described cancer as 1 of the many disruptions that can occur in daily life, and fully expected posttreatment life to return to "normal"	"I got cancer, and I don't worry about it. It did not change my view of life. I just roll with the flow that's all." Stage II CRC, late 60s
Seeing the World Differently	12 (11)	Described seeing the world differently after their diagnosis, often in positive ways, such as having greater appreciation for life and increased closeness with family	"I stopped drinking, smoking, and started eating right.... I am more appreciative of life now. I am nicer to people." Stage I CRC, early 60s
Taking One Day at a Time	32 (29%)	Described a day-by-day approach to managing their side effects and concerns about the future, such as cancer recurrence	"It's a shock when you're diagnosed, but it doesn't turn the table upside down.... It doesn't inhibit what I want to do." Stage III HNC, late 60s
Never the Same	41 (38)	Described near-constant worry about recurrence and frustration with continued side effects, which has subsumed their identity	"My life and plans have been drastically altered. I must now completely readjust my daily routine and alter all plans I had for the future." Stage III CRC, mid-60s

CRC, colorectal cancer; HNC, head-and-neck cancer.

Table 2

Clinical, demographic, and psychosocial factors by path

	Total Sample <i>N</i> = 109 (100%)		Moving On <i>n</i> = 24 (22%)		Seeing the World Differently <i>n</i> = 12 (11%)		Taking One Day at a Time <i>n</i> = 32 (29%)		Never the Same <i>n</i> = 41 (38%)	
Male, <i>N</i> (%)	107	98	23	95.83	12	100	31	96.88	41	100
Age, <i>M</i> (<i>SD</i>)	65.27	9.35	70.33	9.87	61.50	6.52	66.06	10.44	62.78	7.59
White, <i>N</i> (%)	98	90	21	87.5	12	100	30	93.75	35	85.37
College education, <i>N</i> (%)	56	51	10	41.67	4	33.33	17	53.13	22	53.66
Deyo, <i>M</i> (<i>SD</i>)	3.34	1.85	3.19	1.69	2.50	1.62	3.50	1.93	3.54	1.90
Stage, <i>N</i> %										
I	28	26	6	25	4	33.33	6	18.75	12	29.27
II	33	30	10	41.67	5	41.67	6	18.75	12	29.27
III	26	24	6	25	1	8.33	13	40.63	6	14.63
IIII	22	20	2	8.33	2	16.67	7	21.88	11	26.83
Cancer site, <i>N</i> %										
Colorectal	65	60	15	62.5	9	75	20	62.5	21	51.22
Head and Neck	38	35	8	33.33	2	16.67	10	31.25	18	43.9
Esophageal	4	4	1	4.17	1	8.33	2	6.25	0	0
Stomach	2	2	0	0	0	0	0	0	2	4.88

SD, standard deviation.