

Existential challenges experienced by lymphoma survivors: Results from the 2010 LIVESTRONG Survey

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Abstract

We sought to examine the existential challenges that cancer survivors may experience as they strive to make meaning, regain their self-identity, cope with fear of recurrence, and experience feelings of grief and guilt. Lymphoma survivors ($n=429$) completed the 2010 LIVESTRONG survey and provided responses about meaning, cancer worry, security, identity, grief, guilt, and perceived functional impairment due to these concerns. Most survivors (73%–86%) endorsed existential concerns, with 30–39 percent reporting related perceived functional impairment. Concerns were associated with being female, younger, unmarried, and having undergone stem cell transplantation. Lymphoma survivors experience existential challenges that impact their life even years after diagnosis.

Keywords

existential, lymphoma, meaning, survivorship, worry

Background

Nearly 80,000 adults are diagnosed with lymphoma in the United States each year (American Cancer Society, 2014). Adult-onset lymphoma can carry a generally favorable prognosis, reflected in the growing population of lymphoma survivors (Baxi and Matasar, 2010); nevertheless, a lymphoma diagnosis exerts a substantial psychological impact due to the daunting challenges of treatment and transition to survivorship. A cancer diagnosis can lead not only to psychological distress but may have a more fundamental effect on core aspects of a person's identity and their perceptions about the meaning of life and what the future might

hold. Furthermore, as survivorship progresses, patients are faced with the task of returning to their daily life that generally reflects a reordering of their life priorities (Little et al., 2002; Pascal and Endacott, 2010).

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Several studies have documented the emotional impact of cancer diagnosis and its effects on health-related quality of life in lymphoma survivors (Jensen et al., 2013; Mols et al., 2007; Roper et al., 2009; Smith et al., 2010), but less is known about the existential aspects of this experience. Existential aspects, generally taken to include the meaning and purpose of life and the awareness of values in life, are important because they impact one's sense of well-being and emotional distress levels (Henoch and Danielson, 2009; Vehling et al., 2012) and could affect decision making about current or future cancer care and health maintenance behaviors (Lee and Loiselle, 2012). Awareness of one's potential death may spur the examination of one's life (Lee, 2008; Willig, 2009). Equally important within the domain of existential concerns, personal identity can become altered due to illness, and one task of survivorship is to restore, preserve, or incorporate new aspects of identity into one's sense of self (Little et al., 2002; Neimeyer et al., 2006). Existential challenges also include the experience of cancer-related anxiety and uncertainty about possible recurrence and metastatic disease (Pascal and Endacott, 2010).

A cancer diagnosis offers an opportunity for self-examination as well as potential changes in self-identity (Jim and Jacobsen, 2008; Zebrack, 2000). Zebrack's (2000) model of cancer survivorship suggests that the experience of cancer leads to identity changes for the survivor, resulting in changes in self-concept. Cancer survivors may continuously experience cancer threat and the related potential for additional change and restructuring in their lives (Zebrack, 2000). Indeed, when people are faced with a highly stressful life event, such as cancer, most undertake efforts to make meaning, or some type of cognitive readjustment, so that the stressful experience can be integrated into one's larger belief system about their life and the world (Park, 2010); their coping style may affect their meaning making (Schmidt et al., 2011). The extent to which lymphoma survivors experience these existential processes of identity restructuring and meaning making and what factors

(sociodemographic or clinical) are associated with these concerns are unknown. We examined the prevalence of existential concerns (loss of meaning, worry about cancer recurrence and death, perceptions of a lost sense of security in the future and a lost sense of identity, and grief and guilt about seeing other cancer patients die) using data from the 2010 LIVESTRONG Survey (Rechis et al., 2011). We also evaluated respondents' perceptions of the impact of these concerns on their current daily lives as survivors. We expected that lymphoma survivors would experience existential concerns. We also expected, based on prior studies in lymphoma populations (Jensen et al., 2013; Smith et al., 2010), that younger survivors would report the most concerns. Finally, we anticipated that women would be more likely than men to report concerns, based on findings that women tend to experience more distress in response to cancer diagnosis (Hagedoorn et al., 2008).

Method

Participants

A total of 4286 post-treatment cancer survivors responded to the 2010 LIVESTRONG survey; this study is focused on the 429 respondents who indicated that they were post-treatment adult-onset lymphoma survivors. Of them, 43 percent were Hodgkin lymphoma (HL) survivors and 57 percent were non-Hodgkin lymphoma (NHL) survivors.

Procedure

From June 2010 through March 2011, LIVESTRONG fielded the online LIVESTRONG Survey for Post-Treatment Cancer Survivors (see Rechis et al. (2011) for details on administration and a copy of the survey instrument). The survey was available on LIVESTRONG.org, and LIVESTRONG constituents (e.g. those who either received LIVESTRONG services or who participated in a prior LIVESTRONG event) were notified about the survey through emails, Twitter, and Facebook

posts. Additionally, **LIVESTRONG** reached out to partner organizations (e.g. the American Cancer Society) and state cancer coalitions who shared information about the survey with their constituents. Finally, **LIVESTRONG** worked with National Cancer Institute Comprehensive Cancer Centers to share the survey with patients.

Measures

Existential challenges. Three sets of variables from the 2010 **LIVESTRONG** dataset were used to examine six existential challenges.

First, the survey included seven items from the Constructed Meaning Scale, a previously validated scale used in other cancer populations (Fife, 1995). These items were *I feel cancer is something I will never recover from; I feel cancer is serious but I will be able to return to life as it was before my illness; I feel cancer has changed my life permanently so it will never be as good again; I feel that I have made a complete recovery from my illness; I feel that I am the same person I was before my illness; I feel that my experience with cancer has made me a better person; I feel that having cancer has interfered with my achievement of the most important goals I have set for myself*. Respondents rated each item on a 1 (strongly disagree) to 4 (strongly agree) scale. Several of the statements were reverse-scored and the total score for all statements was summed where higher scores indicate more constructed meaning. The scale had adequate internal consistency in this sample ($\alpha=0.73$), given our goals of examining prevalence and correlates of respondent concerns (Graham and Naglieri, 2003). The original Constructed Meaning Scale has eight items (Fife, 1995); as only seven were included in the **LIVESTRONG** survey (missing item: *I feel that my relationships with other people have not been negatively affected by my illness*), we prorated scores to examine the equivalent of an eight-item scale so as to allow for better comparison of our results to other studies.

The second existential issue examined in the survey was *cancer worry*, assessed with three items: I have (a) been preoccupied with

concerns about cancer; (b) worried about dying from cancer; and (c) worried about cancer coming back. For each statement, respondents selected “yes” (coded as 1), “no” (coded as 0), and “don’t know.” For purposes of analysis, “don’t know” was coded as “no” (0). A summed scale score was created wherein higher scores meant more cancer worry ($\alpha=0.65$).

Finally, four items addressed existential issues related to *security, identity, grief, and guilt*. Respondents reported whether each of the following statements was true for them as a result of their experience with cancer: *I have (a) lost a sense of security in my future; (b) felt that I have lost a sense of my identity; (c) felt grief about the death of other cancer patients; and (d) felt guilt over the death of other cancer patients*. Because these items each examine a distinct existential experience, they were considered individually. For each statement, respondents selected “yes” (coded as 1), “no” (coded as 0), and “don’t know.” “Don’t know” was coded as “no” (0). These items are derived from several years of work by the **LIVESTRONG** Foundation during which experts and survivors were consulted in a process of formative research to develop items that reflected the challenges people affected by cancer were facing when they presented to **LIVESTRONG** for services (Rechis et al., 2011).

Functional impairment. The degree to which the existential concerns of cancer worry, security, identity, grief, and guilt impacted respondents was assessed by asking respondents to what degree their activities were limited by these concerns in the past week (“a lot,” “a little,” “not at all,” and “I don’t know”). This impairment question was asked with regard to cancer worry only if a respondent endorsed “yes” on at least one of the three cancer worry items. A second impairment question was asked whether respondents endorsed at least one concern among those of security, identity, grief, or guilt. This impairment question was not asked in reference to items on the Constructed Meaning Scale.

Sociodemographic characteristics. Gender, age, education level, marital status, and race/ethnicity were included in analyses.

Clinical characteristics. We examined respondents' answers to questions regarding type of lymphoma (Hodgkin or non-Hodgkin); time since diagnosis; type of treatment received (radiation or chemotherapy alone or combined); and whether they received a stem cell transplant.

Statistical analysis

Descriptive statistics were used to characterize the presence of existential challenges, as well as the sample's sociodemographic and clinical characteristics. A log-transformed version of time since diagnosis was used in all analyses in order to normalize its skewed distribution prior to performing any statistical tests. Bivariate statistics descriptively characterized relationships between existential challenges and each of the sociodemographic and clinical characteristics, as well as the degree to which the three categories of existential challenges were interrelated. Finally, multivariate linear regression (for constructed meaning and cancer worry) and multivariate logistic regression (for the four grief or identity challenge items) were used to examine the unique associations of each of the sociodemographic and clinical characteristics with the existential challenges.

Results

Descriptive statistics

Table 1 shows the descriptive and bivariate statistics for the study sample. Respondents averaged 44 years old and about 7 years post-diagnosis. Just over half (55.9%) of the sample was female, most were married or partnered (64%), White (87.1%), and had a college education. Nearly half (45.7%) received both chemotherapy and radiation while the remainder had just one of the two

(205 had chemotherapy with no radiation and 28 had radiation with no chemotherapy); 12.4 percent had undergone a stem cell transplant.

Regarding existential challenges, the average score on the Constructed Meaning Scale was 22.8, which is in the upper half of the range, indicating notable concerns. The average score on the Cancer Worry scale was 1.7, reflecting endorsement of more than one of three cancer worry items. More than half of respondents endorsed *I have lost a sense of security in my future* (51.7%) and *I have felt grief about the death of other cancer patients* (70.4%). About one-quarter endorsed *I have felt that I have lost a sense of my identity* and 38.7 percent endorsed *I have felt guilt over the death of other cancer patients*.

Bivariate associations between Constructed Meaning, cancer worry, and sociodemographic and clinical characteristics are also shown in Table 1. Figure 1 shows bivariate relationships between sociodemographic and clinical characteristics with issues related to security, identity, grief, and guilt. Age, gender, marital status, time since diagnosis, and receipt of a stem cell transplant were all associated with existential challenges in bivariate analyses (all $p < 0.05$). Specifically, younger respondents reported more cancer worry and were more likely to report identity challenges, though older respondents were more likely to report grief, and survivors further from time of diagnosis reported less cancer worry, were less likely to report challenges with respect to their sense of security, but were more likely to report experiencing grief and guilt over the loss of other cancer survivors (data not shown). Married respondents had higher Constructed Meaning scores than unmarried respondents and survivors who underwent a stem cell transplant had lower Constructed Meaning scores than those who did not.

Table 1 also shows the bivariate relationships among Constructed Meaning, cancer worry, and the remaining existential challenges, which were all moderately related in expected ways: higher Constructed Meaning was associated

Table I. Descriptive and bivariate statistics ($n=429$).

Variable		Mean (SD) or %	Constructed Meaning [†] (mean score or r)	Cancer Worry [†] (mean count or r)
Sociodemographic and clinical variables				
Age ^a	(years)	44.2 (12.7); range = 18–78	-0.01	-0.17**
Gender	Male	44.1	23.0	1.7
	Female	55.9	22.6	1.8
Marital status ^b	Married/partnered	64.0	23.1*	1.7
	Unmarried	36.0	22.2	1.7
Education ^c	Less than college	18.1	21.8	1.7
	Some college	25.1	22.9	1.8
	College degree	32.2	22.9	1.7
	Graduate degree	24.6	23.1	1.7
Race/ethnicity ^c	White	87.1	22.8	1.7
	Non-White	12.9	23.1	1.9
Type of lymphoma	Hodgkin	47.3	22.8	1.7
	Non-Hodgkin	52.7	22.7	1.7
Treatment	Solo treatment	54.3	22.9	1.7
	Combined treatment	45.7	22.6	1.8
Stem cell transplant	Yes	12.4	21.5*	1.9
	No	87.6	22.9	1.7
Time since diagnosis ^d	(years)	7.0 (7.4)	0.07	-0.15*
Existential challenges				
Constructed Meaning total score ^a	(mean score)	22.8 (4.1); range = 9.1–32.0		
Cancer worry count ^c	(mean count)	1.7 (1.0); range = 0–3	-0.38**	
Lost sense of security	% “yes”	51.7	-0.45**	0.46**
Lost sense of identity ^e	% “yes”	25.6	-0.36**	0.23**
Grief over others’ deaths ^e	% “yes”	70.4	-0.10*	0.23**
Guilt over others’ deaths ^f	% “yes”	38.7	-0.23**	0.27**

^aMissing for 1 respondent.^bMissing for 7 respondents.^cMissing for 10 respondents.^dMissing for 22 respondents.^eMissing for 3 respondents.^fMissing for 5 respondents.[†]Higher scores meaning more constructed meaning or more cancer worry.* $p < 0.05$; ** $p < 0.01$.

with lower cancer worry and lower probability of endorsing security, identity, grief, or guilt challenges; higher cancer worry was associated with a higher probability of endorsing security, identity, grief, or guilt challenges; and endorsing any of security, identity, grief, or guilt challenges was associated with a higher likelihood

of endorsing the others, except that identity challenges were not associated with grief.

Multivariate analyses

Table 2 shows the multivariate linear regression models, and Table 3 shows the logistic models.

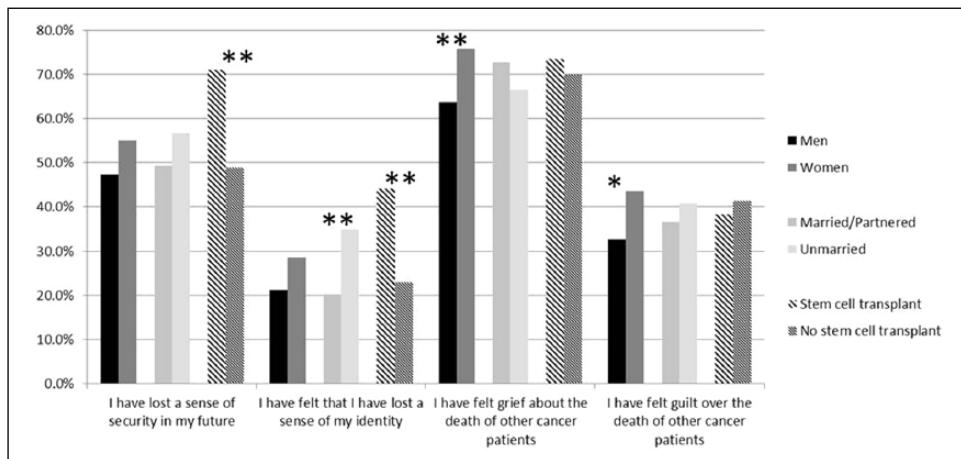


Figure 1. The percentage of respondents who endorsed existential challenges by sociodemographic and clinical variables.

* $p < 0.05$; ** $p < 0.01$.

Table 2. Multivariate linear regressions of constructed meaning and cancer worry.

		Constructed meaning (model adjusted $R = 0.23$); $F(11, 372) = 1.90$; $p = 0.04$		Cancer worry (model adjusted $R = 0.25$); $F(11,$ $381) = 2.26$; $p = 0.01$	
		Standardized β	p	Standardized β	p
Age	(years)	-0.04	0.47	-0.13	0.04
Gender	Male	Reference	0.51	Reference	0.45
	Female	-0.03		0.04	
Marital status	Married/partnered	Reference	0.01	Reference	0.40
	Unmarried	-0.14		-0.04	
Education	Less than college	-0.15	0.02	-0.02	0.81
	Some college	-0.05	0.46	-0.03	0.61
	College degree	-0.05	0.49	-0.05	0.43
	Graduate degree	Reference		Reference	
Race/ethnicity	White	Reference	0.86	Reference	0.11
	Non-white	-0.01		0.08	
Type of lymphoma	Hodgkin	Reference	0.93	Reference	1.0
	Non-Hodgkin	-0.01		0.00	
Treatment	Solo treatment	Reference	0.64	Reference	0.56
	Combined treatment	-0.03		0.03	
Stem cell transplant	Yes	-0.13	0.01	0.06	0.27
	No	Reference		Reference	
Time since diagnosis	(years)	0.06	0.31	-0.16	0.01

In the multivariate linear regression model of Constructed Meaning, marital status and having had a stem cell transplant had significant

unique associations with Constructed Meaning. Specifically, unmarried respondents (standardized $\beta = -0.14$; $p = 0.01$) and respondents who

Table 3. Logistic regression models of security, identity, grief, and guilt challenges.

		Odds of reporting security concern; * $R^2=0.07$; $\chi^2=26.00$; $p<0.01$		Odds of reporting identity concern; * $R^2=0.06$; $\chi^2=24.21$; $p=0.01$	
		OR (95% CI)	p	OR (95% CI)	p
Age	(years)	0.99 (0.97, 1.10)	0.25	0.99 (0.97, 1.01)	0.26
Gender	Male	Reference		Reference	
	Female	1.33 (0.87, 2.04)	0.19	1.29 (0.79, 2.12)	0.32
Marital status	Married/partnered	Reference		Reference	
	Unmarried	1.41 (0.90, 2.20)	0.14	2.01 (1.22, 3.30)	<0.01
Education	Less than college	0.83 (0.43, 1.59)	0.57	0.95 (0.46, 1.96)	0.90
	Some college	0.70 (0.38, 1.29)	0.26	0.72 (0.36–1.44)	0.35
	College degree	0.55 (0.31, 0.98)	0.04	0.71 (0.37, 1.36)	0.30
	Graduate degree	Reference		Reference	
Race/ethnicity	White	Reference		Reference	
	Non-White	1.02 (0.54, 1.98)	0.94	0.63 (0.28, 1.40)	0.26
Type of lymphoma	Hodgkin	Reference		Reference	
	Non-Hodgkin	1.48 (0.91, 2.4)	0.11	1.04 (0.60, 1.82)	0.90
Treatment	Solo treatment	Reference		Reference	
	Combined treatment	0.57 (0.57, 1.36)	0.88	0.90 (0.55, 1.49)	0.68
Stem cell transplant	Yes	3.09 (1.56, 6.13)	<0.01	2.6 (1.36, 4.97)	<0.01
	No	Reference		Reference	
Time since diagnosis	(years)	0.75 (0.42, 1.31)	0.31	0.85 (0.44, 1.62)	0.62
		Odds of reporting grief concern; * $R^2=0.05$; $\chi^2=21.12$; $p=0.03$		Odds of reporting guilt concern; * $R^2=0.05$; $\chi^2=19.91$; $p<0.05$	
		OR (95% CI)	p	OR (95% CI)	p
Age	(years)	1.10 (0.99, 1.04)	0.23	0.98 (0.96, 1.00)	0.06
Gender	Male	Reference		Reference	
	Female	2.03 (1.28, 3.23)	<0.01	1.77 (1.13, 2.78)	0.01
Marital status	Married/partnered	Reference		Reference	
	Unmarried	0.77 (0.48, 1.24)	0.28	1.04 (0.66, 1.65)	0.87
Education	Less than college	2.01 (0.97, 4.14)	0.06	1.39 (0.72, 2.70)	0.33
	Some college	1.71 (0.89, 3.28)	0.11	0.98 (0.57, 1.87)	0.95
	College degree	1.27 (0.69, 2.32)	0.44	1.03 (0.57, 1.87)	0.93
	Graduate degree	Reference		Reference	
Race/ethnicity	White	Reference		Reference	
	Non-White	1.03 (0.52, 2.02)	0.94	0.88 (0.45, 1.72)	0.71
Type of lymphoma	Hodgkin	Reference		Reference	
	Non-Hodgkin	1.10 (0.66, 1.85)	0.71	1.31 (0.79, 2.16)	0.3
Treatment	Solo treatment	Reference		Reference	
	Combined treatment	1.07 (0.67, 1.71)	0.79	1.35 (0.86, 2.11)	0.19
Stem cell transplant	Yes	1.16 (0.59, 2.28)	0.67	1.13 (0.60, 2.13)	0.71
	No	Reference		Reference	
Time since diagnosis	(years)	1.95 (1.06, 3.6)	0.03	2.26 (1.24, 4.11)	<0.01

*Cox and Snell.

had received a stem cell transplant (standardized $\beta=-0.13$; $p=0.01$) had lower Constructed Meaning Scale scores than married respondents or those who had not undergone transplant. For cancer worry, lower worry was significantly associated with being older (standardized $\beta=-0.13$; $p=0.04$) and being further from time of diagnosis (standardized $\beta=-0.16$; $p=0.01$).

In the logistic models of security, identity, grief, and guilt concerns, gender, marital status, having received a stem cell transplant, and time since diagnosis were each associated with significantly higher odds of reporting at least one of these existential challenges. Women had significantly higher odds of reporting challenges with grief (odds ratio (OR)=2.03; $p<0.01$) and guilt (OR=1.77; $p=0.01$). Unmarried respondents had significantly higher odds of reporting identity challenges (OR=2.01; $p<0.01$). For clinical variables, the odds of reporting security (OR=3.09; $p<0.01$) and identity (OR=2.60; $p<0.01$) concerns were significantly higher for those who underwent stem cell transplant, and the odds of reporting experiencing grief or guilt over the death of other cancer survivors was significantly increased as time since diagnosis increased (OR=1.95 for grief; $p<0.05$; OR=2.26 for guilt; $p<0.01$).

Functional impairment

Of those respondents who had endorsed at least one worry concern (86% of sample), nearly a third (30%) indicated that their activities had been limited by this concern in the past week. Similarly, the majority of respondents (73%) endorsed at least one concern among security, identity, grief, and guilt. Of these respondents, 39 percent reported that their activities had been limited by this concern over the past week.

Discussion

The majority of lymphoma survivors reported having existential concerns due to their cancer diagnosis, even years later. Most survivors (86%) endorsed at least some cancer worry and

73 percent endorsed at least one concern related to identity, security, grief, or guilt. In terms of the real-life impact of such concerns, of those respondents who endorsed either worry or concern of identity, security, grief, or guilt, about a third (30%–39%) indicated that their current life was directly affected by that concern. These results suggest that existential concerns are not only common among lymphoma survivors, but have the potential to impact their daily lives for years afterward.

Lymphoma survivors reported an average score of 22.8 on the Constructed Meaning Scale which suggests that lymphoma survivors experience enhanced meaning in their lives, in the range reported for other types of cancer (e.g. mean of 24 in prostate cancer survivors (Steginga et al., 2004); mean of 21 in colorectal cancer survivors (Chambers et al., 2012); and mean of 19.6 in recurrent ovarian cancer survivors (Ponto et al., 2010)). It is possible that survivors gained a sense of resilience and strength due to having survived cancer (Chambers et al., 2012; Diemling et al., 2007).

We identified several sociodemographic and clinical characteristics related to our six existential concerns outcome variables. Women were more likely to report concerns of grief and guilt. Being married or partnered appeared to offer some protection against loss of identity and lower meaning, perhaps because being part of a committed couple may allow the maintenance of an important aspect of a survivor's identity (e.g. that of spouse or partner) after diagnosis. Furthermore, being part of a dyad may buffer against stress in general (Geise-Davis et al., 2012).

In terms of treatment, respondents receiving stem cell transplantation reported lower levels of meaning and were more likely to endorse both security and identity concerns; this is in line with other findings of existential concerns in stem cell transplant recipients (Rusiewicz et al., 2008; Somerfield et al., 1996). Stem cell transplantation is one of the most serious cancer treatments; complications (e.g. infections, cardiovascular disease) can be life threatening and disruptive and can occur long after transplantation (Gunasekaran

et al., 2012). It is therefore understandable that respondents receiving transplantation would struggle with existential concerns of security and identity as it is likely more difficult to preserve these due to this protracted experience. We found that older respondents worried less about cancer, similar to other cancer populations (Myers et al., 2013; Phillips et al., 2013). It may be that for older patients, cancer diagnosis is more developmentally normative than for younger persons (Zebrack and Butler, 2012). Finally, those who were further out from diagnosis reported less worry, perhaps due to knowledge about improved survival odds, which come with surviving cancer after the first few years. However, those further out from diagnosis also were more likely to report feeling grief and guilt over the deaths of other survivors. This may reflect simply that more time since diagnosis gives more time to lose people or could bring up a lingering question in lymphoma survivors of "why am I still here?"

The interpretation of these results is limited by several factors, including the cross-sectional nature of the survey which precludes ascertaining temporal relationships. We cannot determine the impact of disease stage on our outcomes as stage was not assessed. Furthermore, some of our outcome variables were single items, which introduce possible measurement concerns; multi-item measures were not available in the survey. Finally, given the voluntary, online nature of the 2010 LIVESTRONG survey, the lymphoma survivors completing this survey may not be necessarily representative of lymphoma survivors in general.

In conclusion, lymphoma survivors experience existential challenges which are impactful even years after diagnosis. Survivor characteristics most related to existential concerns (for example, being female and younger) could allow supportive services provided by pastoral care or mental health professionals to be targeted to these subgroups. It is important that health care providers become aware of these concerns, even in long-term survivors, so that they may be addressed (Leung and Espplen, 2010). Although often overlooked in psychological interventions for cancer patients

(Lindemalm et al., 2012), some evidence suggests that addressing existential concerns in cancer populations in general (Breitbart et al., 2012), and specifically in lymphoma survivor populations, would likely contribute to improved well-being and quality of life (Henoch and Danielson, 2009).

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