Published in final edited form as:

J Psychosoc Oncol. 2015 ; 33(2): 124–141. doi:10.1080/07347332.2014.992085.

Prevalence and Predictors of Distress in Post-Treatment Adult Leukemia and Lymphoma Survivors

Whitney C. Jones, PhD, MSPA¹, Carla Parry, PhD, MSW², Sharon Devine, JD, PhD³, Deborah S. Main, PhD³, Sonia Okuyama Sasaki, MD⁴, and Zung Vu Tran, PhD¹

¹ Colorado School of Public Health, University of Colorado Denver, Denver, Colorado, USA

² Health Services Research and Implementation Science, Southern California Permanente Medical Group, Pasadena, California, USA

³ Department of Health and Behavioral Sciences, University of Colorado Denver, Denver, Colorado, USA

⁴ University of Colorado Anschutz Medical Campus, Division of Medical Oncology, Aurora, Colorado, USA

Abstract

This paper examines predictors of cancer-specific distress among post-treatment adult Leukemia and Lymphoma Survivors (LLS). Using a survey mailed to LLS in the Colorado Central Cancer Registry ($n=477$), the authors developed a multivariable risk profile for distress. 31% of LLS reported indicators of distress. Significantly higher distress was associated with younger age ($p<0.001$) in bivariate analyses. The risk profile included fear of recurrence, financial burden and younger age. Distress did not attenuate based on time since treatment completion and may persist up to four years post-treatment, suggesting a need for intervention, particularly among high risk LLS.

Keywords

hematologic malignancies; cancer survivorship; psychosocial; distress; cancer; fear of recurrence; age factors; quality of life

INTRODUCTION

Composing roughly four percent of the nation's population, 13.7 million Americans live with a history of cancer, a figure projected to reach 20 million by 2020 (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007; Parry, Kent, Mariotto, Alfano, & Rowland, 2011). As the number of cancer survivors grows, so does the need for evidence-based interventions to meet survivors' psychosocial needs (Stanton, 2012). The Institute of Medicine (IOM) has identified the post-treatment phase as a time when survivors remain a vulnerable population who often find themselves in need of information, guidance, and psychological support, yet

that phase remains under-represented in research (Hewitt, Greenfield, Stovall, & National Cancer Policy Board (U.S.). Committee on Cancer Survivorship: Improving Care and Quality of Life., 2006; “Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement,” 2008; Adler, Page, & National Institute of Medicine (U.S.). Committee on Psychosocial Services to Cancer Patients / Families in a Community Setting., 2008). As defined by the IOM, the post-treatment phase follows the end of treatment and extends to the long-term survivorship phase, beginning five years post-diagnosis (Hewitt et al., 2006; Stanton, 2012).

Literature on the post-treatment phase overwhelmingly focuses on breast cancer survivors, a narrow demographic of women typically over age 50, whose experiences may not be generalizable to other cancer sites or individuals outside this age/gender demographic (Stanton, 2012; Stanton, Ganz, Rowland, et al., 2005). This study focused on *adult* leukemia and lymphoma survivors (LLS) during the post-treatment phase, with both hematologic malignancies and the *post-treatment phase* of survivorship remaining understudied areas (Lobb et al., 2009; Parry, Lomax, Morningstar, & Fairclough, 2012; Parry, Morningstar, Kendall, & Coleman, 2011). Hematologic malignancies occur roughly equally in men and women (55 percent versus 45 percent) and cross the lifespan (Aziz, 2007; Finch & Arend, 2009; Jemal, Siegel, Xu, & Ward, 2010). Thus, studying the prevalence and predictors of distress in the LLS population, with its diverse age and gender profile, afforded unique opportunities to explore survivors at highest risk for distress across the lifecourse and across genders.

The National Comprehensive Cancer Network (NCCN) defines distress as “an unpleasant experience of an emotional, psychological, social, or spiritual nature that...extends along a continuum, from common normal feelings of vulnerability, sadness, and fears to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis” (National Coalition for Cancer Survivorship, 1999). Distress is associated with poor outcomes including increased morbidity and mortality, decreased health related quality of life, and low adherence to provider recommendations (Adler et al., 2008; Kaiser, Hartoonian, & Owen, 2010). Rates of distress in cancer survivors nearly universally exceed norms for the general population (Hoffman, McCarthy, Recklitis, & Ng, 2009; Kaiser et al., 2010; Stanton, 2006). A large-scale study of cancer survivors (n=4496) found elevated levels of distress in 35.1 percent of survivors (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), with other studies reporting a range from five to 35 percent (Kaiser et al., 2010; Norton et al., 2004; Zabora et al., 1997; Zabora et al., 2001).

While predictors of distress vary across studies, fear of cancer recurrence regularly ranks among the greatest of psychosocial concerns reported by cancer survivors in the post-treatment phase (Antoni et al., 2006; Aziz, 2007; Stanton, 2006; Stanton, Ganz, Kwan, et al., 2005). Not surprisingly, fear of recurrence has been linked to serious psychological distress and decreased quality of life (Demierre, Tien, & Miller, 2005; Hoffman et al., 2009; Kaiser et al., 2010; Stanton, 2006; Stein, Syrjala, & Andrykowski, 2008). Younger age is a consistent predictor of distress among cancer survivors (Avis & Deimling, 2008; Enns et al., 2013; Greenberg et al., 1997; Hoffman et al., 2009; Kaiser et al., 2010). Conversely, older age and previous life experiences (that ostensibly allow more time to develop coping skills)

have been recognized as protective factors, as has marriage (Blank & Bellizzi, 2008; Kaiser et al., 2010; Weiss, 2004). Finally, financial burden is associated with higher levels of reported psychosocial needs, (Cella, 1987; Hodgkinson et al., 2007; Lobb et al., 2009) but the financial consequences of cancer remain understudied and the relationship between financial burden and distress has not been established (Hewitt et al., 2006; National Cancer Institute, 2011). Other sociodemographic predictors of distress frequently include female sex (Blank & Bellizzi, 2008; Enns et al., 2013; Hodgkinson et al., 2007; Lobb et al., 2009), being unmarried (Hodgkinson et al., 2007; Lobb et al., 2009; Weiss, 2004), and lower levels of education (Greenberg et al., 1997; Hoffman et al., 2009; Kaiser et al., 2010; Wenzel et al., 1999). While distress has been studied in a variety of cancer patient populations, a gap persists in the post-treatment phase, as the majority of extant studies focus on the active treatment phase. The unique contributions of the present study include the focus on *adult* LLS in the *post-treatment phase*, the use of a population-based (state cancer registry) sample, and the inclusion of perceived financial burden used to predict distress, which has rarely been done in this literature. Based on the extant literature, hypothesized predictors of distress in this inquiry include high fear of recurrence, younger age, high financial burden and interactions between age and financial burden and age and fear of recurrence. Other sociodemographic variables including female gender, lower education, relationship status (unmarried or not in a committed relationship), and lower income are also included in our model as hypothesized predictors.

Despite a large body of evidence on psychosocial outcomes in cancer survivors, critical gaps remain in our understanding, specifically that not a single study focuses exclusively on the post-treatment phase, despite continued emphasis by the IOM and other sources that post-treatment is a critical phase in adjustment, with important implications for health services delivery (Adler et al., 2008; Hewitt et al., 2006). Further, when limiting one's focus to leukemia and lymphoma, the bolus of research reflects the experiences of *childhood* survivors; not adults. Finally, the majority of studies use samples generated in one or two medical centers, often academic medical centers, which may not be representative of the majority of cancer survivors' experiences. The current study remains one of the largest studies to our knowledge of adult leukemia and lymphoma survivors, the only study using a population-based (state cancer registry) recruiting strategy and sample, and unique in its focus on the post-treatment phase in an adult LLS population.

METHOD

Participants

Recruitment—This study is derived from the quantitative component of a mixed methods study exploring psychosocial outcomes and service needs in the post-treatment adult LLS population. The present inquiry is a secondary analysis of a study that employed criterion sampling of all individuals listed in the Colorado Central Cancer Registry (CCCR) meeting the following inclusion criteria: diagnosed with leukemia or lymphoma between May 2002 and August 2006, age 18 to 85 at time of diagnosis, resided in Colorado, and completed primary treatment for cancer within the previous three to 48 months. The recruitment process is outlined in a prior publication (Parry et al., 2012; Parry, Morningstar, et al., 2011)

and depicted graphically in Figure 1. Of the initial sample of 1649 individuals, 1379 patients were contacted by mail, and 270 were unable to be reached. Of the 1379 participants to whom a survey was mailed, 810 responded: 187 returned the refusal postcard, and 623 returned completed questionnaires (45% response rate). Of those 623, 146 (18%) were deemed ineligible for the study because of active treatment status or not having completed treatment in the 3-48 month window (because the Colorado Central Cancer Registry does not record treatment cessation dates, eligibility status was determined by survivors' reports of treatment completion date in their surveys), yielding a sample of 477 participants (Parry et al., 2012). Participants who had completed primary treatment but were undergoing maintenance treatment were intentionally included in the parent study and the current study (Parry et al., 2012). The rationale for combining individuals with these differing hematologic malignancies stemmed from the finding that no statistically significant differences exist for the outcomes of interest (indicators of cancer-specific distress, financial burden or fear of recurrence) between those undergoing maintenance treatment and those who had completed treatment or between those with chronic versus acute diagnoses. Non-respondents were significantly more likely than respondents to live in areas with greater than 10% poverty, be non-Caucasian, have a comorbid condition, have Medicare or Medicaid (as opposed to private insurance). Despite these differences, response patterns across diagnoses remained relatively consistent (range: 30 to 53 percent), with slightly higher response rates among those with lymphomas and slightly lower rates among those with acute myelogenous leukemia (AML) and chronic myelogenous leukemia (CLL) (Parry et al., 2012). Study procedures complied with the Colorado Multiple Institutional Review Board and the CCCR Review Board.

Measures

Self-administered questionnaire—The self-report survey included questions that assess sociodemographic and clinical characteristics (e.g. age, income, diagnosis, treatment received, time since treatment cessation), and psychosocial outcomes, using the Impact of Event Scale (IES) and the Quality of Life in Cancer Survivors Scale (QOL-CS).

Impact of Event Scale: Indicators of cancer-specific distress were measured using the IES-Intrusion Subscale (IES-I), which captures unpleasant, intrusive and uncontrollable thoughts about an adverse life event. In this study the stressful event was defined as “your experience with cancer”, the NCCN definition of distress. A commonly-used distress indicator in cancer survivorship research, the IES serves as a validated measure of an individual's response to a specific trauma (in this case, after-effects of cancer) within the past seven days using a seven-item intrusion subscale ranging from 0 to 35 (Sundin & Horowitz, 2002; Wenzel et al., 2002). IES features high test-retest reliability, internal consistency (Cronbach's $\alpha=0.86$), and clinical validity (Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002). IES subscales are frequently analyzed separately, as in this study (Marcus et al., 2010; Wenzel et al., 1999).

Quality of Life in Cancer Survivors Scale: Designed for post-treatment cancer survivors, the QOL-CS measures four dimensions of quality of life, and captures two hypothesized predictors of distress, perceived financial burden and fear of recurrence (Ferrell, Dow, &

Grant, 1995). The QOL-CS demonstrates high internal consistency: Cronbach's $\alpha=0.93$, test-retest reliability= 0.89 , and sufficient overall validity (Ferrell et al., 1995). Because no validated stand-alone scales currently assess financial burden, an individual item measuring financial burden and a parallel item for fear of recurrence, both from the QOL-CS, were used in the analyses reported herein. The financial burden item asks: "how much financial burden have you incurred as a result of your illness and treatment?" (0=none→10=great deal). The fear of recurrence item asks: "to what extent are you fearful of recurrence of your cancer?" (0=no fear→10=extreme fear).

Data Analysis/Procedures

Preliminary analyses included generation of descriptive statistics (means, standard deviations, frequencies). Pearson correlations were used to explore associations between variables. For purposes of intuitively reporting descriptive statistics for prevalence, distress was measured using three standard assessment ranges for the IES-I: low (IES-I score of 0-8.5), moderate (8.6-19) and high (20-35) (Joseph, 2000). Because both moderate and high distress warrant clinical intervention according to the ACOS CoC recommendations, these categories were combined and considered "elevated distress" in reporting prevalence of distress for descriptive purposes (Adler et al., 2008; Commission on Cancer, 2012). However, for multivariate analyses, continuous IES-I scores were used. Prevalence of distress was assessed in the sample as a whole and within subsamples of three lifespan development stages; ages 18-39 (young adulthood, approximating childbearing years), 40-64 (representing midlife), and 65-85 (coinciding with Medicare eligibility and retirement age). Mean levels of distress, perceived financial burden and fear of recurrence were assessed for the sample as a whole and by age, gender, education, income, marital status, and time since treatment completion.

Statistical significance of the differences in mean IES-I scores, financial burden and fear of recurrence was tested using ANOVA with post-hoc Bonferroni tests or t-tests as appropriate. Hierarchical multiple linear regression was used to determine the proportion of variance explained by the predictors of distress and to test for interactions between age and perceived financial burden, between age and fear of recurrence, and between gender and fear of recurrence (Agresti & Finlay, 2009). The study was adequately powered (exceeds 99 percent power) to detect differences using multiple linear regression with an effect size of 0.45 and an alpha of 0.05, as determined by G*Power, version 3.1 (Heinrich Heine Universitaat, Dusseldorf, Germany). All statistical analyses were conducted as two-tailed tests using STATA, version 13 (College Station, TX: StataCorp LP). The multivariable risk profile was composed of all variables contributing to an increased R^2 in the multivariable model. Adjusted R^2 was reported in lieu of an unadjusted R^2 because an adjusted R^2 is regarded as less biased and more useful in selecting a multivariable model (Agresti & Finlay, 2009).

RESULTS

Sample Description

The demographic, medical, and treatment characteristics of participants are presented in Table 1. The mean age of the sample is 56 years (s.d. 14.8). Approximately half the sample

(53.2 percent) is in the midlife category (ages 40-64), while young adult survivors (ages 18-39) composed 14.5 percent of the sample and older survivors (ages 65-85) accounted for the remaining 31.2 percent of LLS. Slightly more than half of LLS (53.9 percent) were male, and most (91.0 percent) were white. Over half the sample (52.8 percent) had completed an associate's degree, some college, or less, and 39 percent of LLS reported annual household income of \$50,000 or less. Most LLS (71.9 percent) were married and/or in a committed relationship. Diagnoses included Non-Hodgkin's lymphoma (59.6 percent), Hodgkin's lymphoma (19.1 percent), and the remainder included acute and chronic leukemias. The vast majority of the sample (94.5 percent) reported completion of definitive treatment, with 5.5 percent undergoing maintenance treatment after primary treatment completion (Parry et al., 2012). Median time since treatment completion was 2-4 years. Most LLS (94.1 percent) had received chemotherapy, while 5 percent had undergone a bone marrow transplant. Fifty-two (10.9 percent) had been treated for a cancer recurrence.

Descriptive Analyses

Prevalence of Elevated Distress—Prevalence of distress among study participants is organized in three categories: low, moderate and high distress (Table 2). As noted above, the moderate and high categories of distress were considered “elevated distress,” both of which meet the ACOS CoC's criteria for intervention. Nearly one-third (31.2 percent) of LLS in the sample reported elevated distress, up to four years after completion of treatment, operationalized as an IES-I score above 8.5 (capturing moderate and high distress) [34]. Over one-fourth (26.0 percent) experienced moderate distress (IES-I score between 8.6-19), and 5.2 percent reported high distress (IES-I between 20-35).

Chi-square tests revealed significant differences in prevalence of distress (low, moderate and high) by age ($p<0.001$), gender ($p=0.010$) and education ($p=0.019$).

Mean Distress Levels—For the entire sample, mean cancer-specific distress (IES-I score) was 6.4 (s.d. 6.7) (Table 3). Statistically significant differences in mean distress level were found between the three age groups ($p<0.001$). Post-hoc analyses revealed significantly higher mean distress observed among young adult LLS compared to midlife LLS ($p=0.044$) and older LLS ($p<0.001$). Midlife LLS also had significantly higher mean distress than older LLS ($p<0.02$). Non-significant differences in distress were found for gender, income, education, marital status and treatment status (maintenance treatment versus treatment completion).

Prevalence of Perceived Financial Burden—Statistically significant differences in perceived financial burden were found by age ($p<0.001$), income ($p<0.001$), marital status ($p=0.024$) and time since treatment ($p=0.038$). Post-hoc tests revealed that younger LLS had significantly higher financial burden compared to both midlife LLS ($p=0.008$), and older LLS ($p<0.001$), while midlife LLS had significantly higher financial burden than older LLS ($p<0.001$). Not surprisingly, those with higher household incomes (\$51,000-\$75,000, \$76,000-\$100,000, and over \$100,000 reported significantly less financial burden than those living in households earning less than \$25,000 ($p=0.011$, $p<0.001$, and $p<0.001$ respectively). However, there were no significant differences between those earning

between \$26,000 and \$50,000 and those earning slightly more or less (\$51,000 to \$75,000 and less than \$25,000 respectively). Significant differences, however, were found between those earning \$26,000 to \$50,000 and those earning \$76,000 to \$100,000 ($p=0.006$) as well as those earning over \$100,000 ($p<0.001$). LLS who were not married or in a committed relationship reported higher financial burden ($p=0.024$), as did LLS that had completed treatment in the past two years ($p=0.045$), compared with those undergoing maintenance treatment and those who had completed treatment more than two years prior. No significant differences were found by gender.

Prevalence of Fear of Recurrence—Statistically significant differences in fear of recurrence were found by age ($p<0.001$) and gender ($p<0.001$), with females reporting higher fear of recurrence. Post-hoc tests revealed that mean fear of recurrence was significantly higher in young adult LLS compared to both midlife LLS ($p=0.009$) and older LLS ($p<0.001$). Mean fear of recurrence in midlife LLS was significantly higher than older LLS ($p=0.01$). Non-significant differences in fear of recurrence were found by education, income, marital status and time since treatment.

Multivariable Risk Profile—A risk profile was developed to determine which LLS may be at highest risk of distress (Table 4). The multivariable model includes three variables: fear of recurrence ($p<0.001$), perceived financial burden ($p<0.001$), and age (NS) and explains 31.1 percent of the variance in distress. While not statistically significant in the multivariate model, age was statistically significant in the bivariate model ($p<0.001$) and contributes to the variance explained, as measured by adjusted R^2 . There were no significant interactions between age and financial burden, age and fear of recurrence or gender and fear of recurrence. Interestingly, most of the traditional predictors of distress (gender, education, income, marital status, and time since treatment completion) did not become part of the multivariable risk profile.

DISCUSSION

The findings provide insight into the prevalence and predictors of distress in adult LLS in the post-treatment phase of cancer survivorship. Young adult LLS experienced a disproportionate burden of distress, with nearly half of LLS aged 18-39 reporting elevated levels of distress compared with roughly one-third of midlife survivors and one-fifth of older survivors. This result echoes findings of higher distress among younger survivors of other cancer types (Avis & Deimling, 2008; Enns et al., 2013; Hoffman et al., 2009; Kaiser et al., 2010; Zabora et al., 2001). The inverse patterns between age and the two variables of interest (perceived financial burden, fear of recurrence) highlight the importance of future research seeking to better understand the unique psychosocial needs of young adult survivors in order to develop interventions to address those needs.

When examining predictors of distress in a multivariable model, traditional predictors of distress in other cancer populations (time since treatment, education, income, marital status and gender) did not emerge as predictors in this study. A possible explanation for this finding is that the effect of demographic and medical variables is minimized in the presence of fear of recurrence. This result underscores existing literature suggesting fear of recurrence

is a relatively powerful predictor of distress (Black & White, 2005; Wenzel et al., 2002). It is also important to note that cancer survivors may not see their experience with cancer as a single trauma, but as a series of traumas, which may impact the way they experience, describe and report distress.

The finding that time since treatment did not influence distress levels is particularly salient. Research in other cancer sites suggests that distress remits for most survivors approximately two years after treatment cessation (Stanton, 2006). One would expect to see a decline in distress levels for those survivors furthest from treatment completion, especially because this study includes LLS up to four years post-treatment. However, the results suggest the experience of distress may be more pervasive or qualitatively different among LLS than among survivors of solid tumors. More research is needed to replicate this finding and to understand the factors influencing the observed longer duration of distress in this post-treatment LLS population.

The findings highlight the prevalence and patterns of distress in LLS in the post-treatment phase, with nearly one-third of all LLS and nearly half of young adult LLS experiencing elevated distress up to four years post-treatment. The multivariable risk profile including fear of recurrence, perceived financial burden, and age offers a means to predict which patients are likely to experience elevated distress. Future research should seek to better understand the reasons for prolonged distress in this population, to develop and test interventions to mitigate distress, and to explore the best processes and models of care for delivering and coordinating distress detection and management activities across the survivorship continuum.

IMPLICATIONS FOR CLINICAL PRACTICE

Championed by the NCCN, several regulatory bodies have mandated implementation of distress detection and management for all cancer survivors, including the American College of Surgeons Commission on Cancer (ACOS CoC), which accredits more than 15,000 hospitals nationwide (Carlson, Waller, & Mitchell, 2012; Commission on Cancer, 2012; Holland & Bultz, 2007; Jacobsen & Wagner, 2012). The CoC standards call for implementation of distress screening in member institutions by January 2015, occurring at minimum at one critical juncture in the cancer continuum (e.g. time of diagnosis, transition off treatment), with referrals to psychosocial services for patients with “moderate or severe distress” (Commission on Cancer, 2012). As distress detection and management protocols become a standard of care for cancer survivors, the number of survivors identified for psychosocial referral may increase and a better understanding of the sources of distress (such as fear of recurrence and perceived financial burden) will be critical for distress management interventions to effectively target and address distress etiology. Additionally, understanding which individuals are most likely to experience elevated distress (such as young adult survivors), can be useful in targeting interventions to potential participants.

LIMITATIONS

The generalizability of these results to survivors of other cancer types, regions of the United States, or more diverse populations is unknown (Parry, Morningstar, et al., 2011). The

sample is representative of Colorado's LLS population in terms of gender and age but does not necessarily reflect the racial and ethnic diversity of the U.S. cancer survivor population, a byproduct of collecting data in a predominantly Caucasian state. The results provide impetus for future research to explore whether these findings are replicable and generalizable to other populations of LLS. Additionally, individuals with comorbid conditions are under-represented in this sample because of their statistically significantly higher non-response rate. While the distress burden is high in this study population, it could potentially be higher among less healthy individuals, as presence of comorbidities have been shown as predictors of distress (Avis & Deimling, 2008; Blank & Bellizzi, 2008; Hoffman et al., 2009; Kaiser et al., 2010; Mols et al., 2007; Zebrack, Yi, Petersen, & Ganz, 2008). Finally, while the use of single item measures for financial burden and fear of recurrence could be interpreted as a limitation of the study, it also underscores the importance of measurement development for more in-depth exploration of these constructs in subsequent research, particularly with respect to financial burden.

CONCLUSION

Many adult LLS experience elevated distress persisting up to four years post-treatment, suggesting the need for interventions to reduce cancer-specific distress, particularly among young adult LLS, those with high fear of recurrence and/or high perceived financial burden. Future research should seek a more comprehensive understanding of fear of recurrence and the financial burden of cancer (including development of tools) and to develop more nuanced measurement and intervention strategies to assess and address psychosocial morbidity after treatment. While the IES is a useful scientific tool for understanding elevated levels of anxiety and indicators of distress, other validated tools exist. Development of consensus about best measures for use in research and practice is an important next step in distress management (Parry, Morningstar, et al., 2011). Research is needed to develop and test the efficacy of interventions to reduce distress in LLS after primary treatment for cancer, and ultimately reduce the psychosocial burden associated with survivorship.

Acknowledgements

Support: Grant 5K07CA108565, National Cancer Institute (PI: Dr. Parry) No financial disclosures.

The views expressed herein are those of the authors and do not necessarily represent the views of the National Cancer Institute.

The authors are grateful to Al Marcus, PhD for his contribution to the manuscript.

REFERENCES

- Adler, NE.; Page, A.; National Institute of Medicine (U.S.). Committee on Psychosocial Services to Cancer Patients / Families in a Community Setting. Cancer care for the whole patient : meeting psychosocial health needs. National Academies Press; Washington, D.C.: 2008.
- Agresti, A.; Finlay, B. Statistical methods for the social sciences. 4th ed.. Pearson Prentice Hall; Upper Saddle River, N.J.: 2009.
- Antoni MH, Wimberly SR, Lechner SC, Kazi A, Sifre T, Urcuyo KR, Guellati S. Reduction of cancer-specific thought intrusions and anxiety symptoms with a stress management intervention among women undergoing treatment for breast cancer. *American Journal of Psychiatry*. 2006; 163(10): 1791. [PubMed: 17012691]

- Avis NE, Deimling GT. Cancer survivorship and aging. *Cancer*. 2008; 113(12 Suppl):3519–3529. doi: 10.1002/cncr.23941. [PubMed: 19058151]
- Aziz NM. Cancer survivorship research: state of knowledge, challenges and opportunities. *Acta Oncologica*. 2007; 46(4):417–432. [PubMed: 17497308]
- Black EK, White CA. Fear of recurrence, sense of coherence and posttraumatic stress disorder in haematological cancer survivors. *Psycho Oncology*. 2005; 14(6):510–515. [PubMed: 15669018]
- Blank TO, Bellizzi KM. A gerontologic perspective on cancer and aging. [Review]. *Cancer*. 2008; 112(11 Suppl):2569–2576. doi: 10.1002/cncr.23444. [PubMed: 18428204]
- Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: Review and recommendations. *Journal of Clinical Oncology*. 2012; 30(11):1160–1177. [PubMed: 22412146]
- Cella DF. Cancer survival: psychosocial and public issues. *Cancer Investigation*. 1987; 5(1):59. [PubMed: 3580947]
- Commission on Cancer. American College of Surgeons Commission on Cancer, 2012. *Cancer Program Standards 2012: Ensuring Patient-Centered Care*. 2012
- Demierre M-F, Tien A, Miller D. Health-related quality-of-life assessment in patients with cutaneous T-cell lymphoma. *Archives of Dermatology*. 2005; 141(3):325–330. [PubMed: 15781673]
- Enns A, Waller A, Groff SL, Bultz BD, Fung T, Carlson LE. Risk factors for continuous distress over a 12-month period in newly diagnosed cancer outpatients. *Journal of psychosocial oncology*. 2013; 31(5):489–506. [PubMed: 24010528]
- Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists : challenges to assuring access to oncology services. *Journal of Oncology Practice*. 2007; 3(2):79–86. doi: 10.1200/JOP.0723601. [PubMed: 20859376]
- Ferrell BR, Dow KH, Grant M. Measurement of the Quality of Life in Cancer Survivors. *Quality of Life Research*. 1995; 4(6):523–531. [PubMed: 8556012]
- Greenberg DB, Kornblith AB, Herndon JE, Zuckerman E, Schiffer CA, Weiss RB, Holland JC. Quality of life for adult leukemia survivors treated on clinical trials of Cancer and Leukemia Group B during the period 1971–1988: predictors for later psychologic distress. *Cancer*. 1997; 80(10):1936–1944. doi: 10.1002/(SICI)1097-0142(19971115)80:10<1936::AID-CNCR10>3.0.CO;2-Z [pii]. [PubMed: 9366296]
- Hewitt, ME.; Greenfield, S.; Stovall, E.; National Cancer Policy Board (U.S.). Committee on Cancer Survivorship: Improving Care and Quality of Life. From cancer patient to cancer survivor : lost in transition. The National Academies Press; Washington, DC: 2006.
- Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, Wain G. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology*. 2007; 16(9):796–804. doi: 10.1002/pon.1137. [PubMed: 17177268]
- Hoffman KE, McCarthy EP, Recklitis CJ, Ng AK. Psychological distress in long-term survivors of adult-onset cancer: results from a national survey. *Archives of Internal Medicine*. 2009; 169(14):1274–1281. doi: 10.1001/archinternmed.2009.179. [PubMed: 19636028]
- Holland JC, Bultz BD. The NCCN guideline for distress management: a case for making distress the sixth vital sign. *Journal of the National Comprehensive Cancer Network*. 2007; 5(1):3–7. [PubMed: 17323529]
- Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosomatic Medicine*. 1979; 41(3):209–218. [PubMed: 472086]
- Jacobsen PB, Wagner LI. A new quality standard: The integration of psychosocial care into routine cancer care. *Journal of Clinical Oncology*. 2012; 30(11):1154–1159. [PubMed: 22412134]
- Joseph S. Psychometric evaluation of Horowitz's Impact of Event Scale: a review. *Journal of Traumatic Stress*. 2000; 13(1):101–113. [PubMed: 10761177]
- Kaiser NC, Hartoonian N, Owen JE. Toward a cancer-specific model of psychological distress: population data from the 2003–2005 National Health Interview Surveys. *Journal of Cancer Survivorship*. 2010:1–12.
- Lobb EA, Joske D, Butow P, Kristjanson LJ, Cannell P, Cull G, Augustson B. When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for

haematological malignancies. *Patient Education and Counseling*. 2009; 77(1):103–108. doi: 10.1016/j.pec.2009.02.005. [PubMed: 19272749]

Marcus AC, Garrett KM, Cella D, Wenzel L, Brady MJ, Fairclough D, Kluhsman BC. Can telephone counseling post treatment improve psychosocial outcomes among early stage breast cancer survivors? *Psycho Oncology*. 2010; 19(9):923–932. [PubMed: 19941285]

Mols F, Aaronson NK, Vingerhoets AJJM, Coebergh J-WW, Vreugdenhil G, Lybeert MLM, van de Poll-Franse LV. Quality of life among long-term non-Hodgkin lymphoma survivors. *Cancer*. 2007; 109(8):1659–1667. doi: 10.1002/cncr.22581. [PubMed: 17330853]

National Cancer Institute. Office of Cancer Survivorship Overview. 2011

National Coalition for Cancer Survivorship. Practice guidelines for the management of psychosocial distress. *Oncology (Williston Park)*. 1999; 13(5a):113–147. [PubMed: 10370925]

Norton TR, Manne SL, Rubin S, Carlson J, Hernandez E, Edelson MI, Bergman C. Prevalence and predictors of psychological distress among women with ovarian cancer. *Journal of Clinical Oncology*. 2004; 22(5):919. [PubMed: 14990648]

Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. Cancer survivors: a booming population. *Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology*. 2011; 20(10):1996–2005. doi: 10.1158/1055-9965.EPI-11-0729.

Parry C, Lomax JB, Morningstar EA, Fairclough DL. Identification and Correlates of Unmet Service Needs in Adult Leukemia and Lymphoma Survivors After Treatment. *Journal of Oncology Practice*. 2012; 8(5):e135–e141. [PubMed: 23277776]

Parry C, Morningstar E, Kendall J, Coleman EA. Working Without a Net: Leukemia and Lymphoma Survivors' Perspectives on Care Delivery at End-of-Treatment and Beyond. *Journal of psychosocial oncology*. 2011; 29(2):175–198. [PubMed: 21391070]

Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*. 2008; 149(9):627–637. [PubMed: 18838716]

Stanton AL. Psychosocial concerns and interventions for cancer survivors. *Journal of Clinical Oncology*. 2006; 24(32):5132–5137. [PubMed: 17093275]

Stanton AL. What happens now? Psychosocial care for cancer survivors after medical treatment completion. *Journal of Clinical Oncology*. 2012; 30(11):1215–1220. [PubMed: 22412133]

Stanton AL, Ganz PA, Kwan L, Meyerowitz BE, Bower JE, Krupnick JL, Belin TR. Outcomes from the Moving Beyond Cancer psychoeducational, randomized, controlled trial with breast cancer patients. *Journal of Clinical Oncology*. 2005; 23(25):6009–6018. [PubMed: 16135469]

Stanton AL, Ganz PA, Rowland JH, Meyerowitz BE, Krupnick JL, Sears SR. Promoting adjustment after treatment for cancer. *Cancer*. 2005; 104(11 Suppl):2608–2613. [PubMed: 16247779]

Stein KD, Syrjala KL, Andrykowski MA. Physical and psychological long-term and late effects of cancer. *Cancer*. 2008; 112(11 Suppl):2577–2592. [PubMed: 18428205]

Sundin EC, Horowitz MJ. Impact of Event Scale: psychometric properties. *The British Journal of Psychiatry*. 2002; 180(3):205–209. doi: 10.1192/bjp.180.3.205. [PubMed: 11872511]

Weiss T. Correlates of Posttraumatic Growth in Married Breast Cancer Survivors. *Journal of Social and Clinical Psychology*. 2004 doi: 10.1521/jscp.23.5.733.50750.

Wenzel LB, Donnelly JP, Fowler JM, Habbal R, Taylor TH, Aziz N, Cella D. Resilience, reflection, and residual stress in ovarian cancer survivorship: a gynecologic oncology group study. *Psycho-Oncology*. 2002; 11(2):142–153. doi: 10.1002/pon.567 [pii]. [PubMed: 11921330]

Wenzel LB, Fairclough DL, Brady MJ, Cella D, Garrett KM, Kluhsman BC, Marcus AC. Age-related differences in the quality of life of breast carcinoma patients after treatment. *Cancer*. 1999; 86(9):1768–1774. doi: 10.1002/(SICI)1097-0142(19991101)86:9<1768::AID-CNCR19>3.0.CO;2-O [pii]. [PubMed: 10547550]

Zabora J, Blanchard CG, Smith ED, Roberts CS, Glajchen M, Sharp JW, Smith PM. Prevalence of psychological distress among cancer patients across the disease continuum. *Journal of psychosocial oncology*. 1997; 15(2):73–87.

Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psycho-Oncology*. 2001; 10(1):19–28. doi: 10.1002/1099-1611(200101/02)10:1<19::AID-PON501>3.0.CO;2-6 [pii]. [PubMed: 11180574]

Zebrack B, Yi J, Petersen L, Ganz PA. The impact of cancer and quality of life for long-term survivors. *Psycho-Oncology*. 2008; 17(9):891–900. [PubMed: 18050153]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Figure 1.
Recruitment Flow Chart

Table 1– Demographic, Medical and Treatment Variables for Study Participants ($n=477$)

	Categories	<i>n</i>	%
Age/Lifespan Development Stage	18-39	69	14.5%
	40-64	254	53.2%
	65-85	149	31.2%
	(Missing)	5	1.0%
Gender	Female	219	45.9%
	Male	257	53.9%
	(Missing)	1	0.2%
Race	White	434	91.0%
	Hispanic	25	5.2%
	African American	7	1.5%
	Other	8	1.7%
	(Missing)	3	0.6%
Education	Less than high school	17	3.5%
	High School or GED	72	15.1%
	Some college or associate's degree	163	34.2%
	College and/or graduate degree	223	46.8%
	(Missing)	2	0.4%
Income	<\$25,000	63	13.2%
	\$25,000-50,000	123	25.8%
	\$51,000-75,000	100	21.0%
	\$76,000-100,000	80	16.8%
	\$100,000+	88	18.4%
	(Missing)	23	4.8%
Marital Status	Married/committed relationship	343	71.9%
	Not married	133	27.9%
	(Missing)	1	0.2%
Diagnosis	Non-Hodgkin's Lymphoma	284	59.6%
	Hodgkin's Lymphoma	91	19.1%
	Acute Myelogenous Leukemia	24	5.0%
	Acute Lymphoblastic Leukemia	8	1.7%
	Chronic Myelogenous Leukemia	28	5.9%
	Chronic Lymphocytic Leukemia	37	7.7%
	Other	5	1.0%
Time Since Treatment Completion	Off Treatment		
	3-11 months	85	17.8%

	Categories	<i>n</i>	%
	12-24 months	124	26.0%
	25-36 months	113	23.7%
	37-48 months	129	27.0%
	Maintenance regimen	26	5.5%
Received Chemotherapy	Yes	449	94.1%
	No	26	5.5%
	Unknown	2	0.4%
Received Bone Marrow Transplant	Yes	25	5.0%
	No	452	95.0%
Recurrence	Yes	52	10.9%
	No	425	89.1%

Table 2Prevalence of Distress in Leukemia and Lymphoma Survivors in the Dataset ($n=477$)

	Low		Moderate		High		Missing	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<u>Age</u>								
Whole sample	326	68.4%	124	26.0%	25	5.2%	2	0.4%
18-39 $p<0.001$ ***	38	55.1%	24	34.8%	7	10.1%	-	
40-64	166	65.4%	75	29.5%	13	5.1%	-	
65+	119	79.9%	23	15.4%	5	3.4%	2	1.3%
<u>Gender</u>								
Male $p=0.010$ *	189	73.5%	52	26.1%	15	26.1%	1	0.4%
Female	137	62.5%	71	32.4%	10	4.6%	1	0.5%
<u>Education</u>								
Less than high school	13	76.4%	1	5.9%	3	17.7%	-	
High School or GED $p=0.019$ *	49	68.0%	17	23.6%	6	8.4%	-	
Some college or associate's degree	103	63.2%	52	31.9%	8	4.9%	-	
College or more	167	74.9%	47	21.1%	7	3.1%	2	0.9%
<u>Income (Household)</u>								
<\$25,000	41	65.1%	13	20.6%	9	14.3%	-	
\$25,000-50,000	86	69.9%	31	25.2%	5	4.1%	1	0.8%
\$51,000-75,000	64	64.0%	31	31.0%	5	5.0%	-	
\$76,000-100,000	58	72.5%	20	25.0%	2	2.5%	-	
\$100,000+	62	70.4%	22	25.1%	4	2.5%	-	
<u>Marital Status</u>								
Married/Committed	240	70.0%	86	25.0%	15	4.4%	2	0.6%
Not married	86	64.7%	37	27.8%	10	7.5%	-	
<u>Time Since Treatment</u>								
Maintenance	20	76.9%	1	3.8%	5	19.3%	-	
3-24 months	146	69.9%	59	28.2%	4	1.9%	-	
25-48 months	165	68.1%	65	26.9%	10	4.2%	2	0.8%

** $p<0.01$

Test: Pearson's chi-square.

*
 $p<0.05$ ***
 $p<0.001$

Table 3

Mean Cancer Specific Distress, Mean Perceived Financial Burden and Mean Fear of Recurrence by Demographic Variables (n=477)

	Mean Cancer Specific Distress (0-35)	Mean Perceived Financial Burden (0-10)	Mean Fear of Recurrence (0-10)
Whole sample	6.4 (n=475, s.d.=6.7)	4.2 (n=471, s.d.=3.6)	4.8 (n=465, s.d.=3.3)
Age	p<0.001 ***	p<0.001 ***	p<0.001 ***
18-39	9.0 (69, 7.4)	6.1 (67, 3.5)	6.2 (69, 3.5)
40-64	6.8 (254, 6.8)	4.7 (252, 3.6)	4.9 (246, 3.2)
65+	4.5 (147, 4.5)	2.5 (148, 3.1)	3.9 (145, 3.0)
Gender			p<0.001 ***
Male	5.9 (256, 5.9)	4.0 (253, 3.6)	4.3 (251, 3.2)
Female	7.0 (218, 6.4)	4.3 (217, 3.7)	5.4 (213, 3.2)
Education			
Less than high school	6.4 (17, 9.5)	6.0 (16, 4.0)	3.4 (17, 3.6)
High school or GED	6.7 (72, 7.4)	5.5 (72, 4.0)	4.7 (68, 3.4)
Some college or associate's degree	6.7 (163, 6.6)	4.9 (162, 3.7)	4.4 (159, 3.2)
College or more	5.9 (221, 6.1)	4.5 (219, 3.4)	5.0 (219, 3.2)
Income		p<0.001 ***	
<\$25,000	7.5 (63, 8.9)	5.9 (62, 3.9)	4.8 (61, 3.8)
\$25,000-50,000	5.9 (122, 6.5)	5.2 (122, 3.7)	4.7 (122, 3.5)
\$51,000-75,000	6.8 (100, 6.7)	4.1 (99, 3.5)	4.7 (96, 3.1)
\$76,000-100,000	5.9 (80, 4.9)	3.4 (80, 3.2)	5.2 (76, 2.8)
\$100,000+	6.1 (88, 6.4)	2.8 (87, 3.0)	4.7 (87, 3.2)
Marital Status		p=0.024 **	
Married/committed relationship	6.1 (341, 6.5)	3.9 (339, 3.6)	4.7 (334, 3.2)
Not married	7.0 (133, 7.1)	4.8 (131, 3.8)	5.0 (130, 3.4)
Time Since Treatment		p=0.038 **	
Maintenance	5.2 (26, 5.3)	4.7 (26, 3.0)	4.4 (21, 3.4)
3-24 months	6.8 (209, 7.1)	4.6 (206, 3.8)	5.0 (206, 3.3)
25-48 months	6.2 (240, 6.5)	3.8 (239, 3.5)	4.6 (238, 3.2)

*p<0.05

Test: ANOVA (t-tests used for variables with two categories), post-hoc Bonferroni tests (post-hoc test results reported in the text).

**
p<0.01

p<0.001

Table 4

Risk Profile: Most Parsimonious Multiple Regression Model

Explanatory Variable	β Coefficient	95% Confidence Interval	p-value	Variance Explained	Adjusted R ²
Fear of Recurrence	0.94	0.77 – 1.11	p<0.001 ***	26.44	
Financial Burden	0.34	0.18 – 0.49	p<0.001 ***	4.21	0.311
Age (continuous)	−0.03	−0.07 – 0.00	p=0.084	0.43	
Constant	2.36	−0.28 – 4.99	p=0.079		

*p<0.05

Test: F test statistic

p<0.001