Published in final edited form as:

Support Care Cancer. 2014 January ; 22(1): 163–172. doi:10.1007/s00520-013-1961-x.

The importance of symptom surveillance during follow-up care of leukemia, bladder, and colorectal cancer survivors

Erin E. Kent,

Outcomes Research Branch, Applied Research Program, Division of Cancer Control and Population Science, National Cancer Institute, 9609 Medical Center Drive, Rockville, MD 20850, USA

Sandra A. Mitchell,

Outcomes Research Branch, Applied Research Program, Division of Cancer Control and Population Science, National Cancer Institute, 9609 Medical Center Drive, Rockville, MD 20850, USA

Ingrid Oakley-Girvan, and

Cancer Prevention Institute of California, 2201 Walnut Avenue Suite 300, Fremont, CA 94538, USA

Neeraj K. Arora

Outcomes Research Branch, Applied Research Program, Division of Cancer Control and Population Science, National Cancer Institute, 9609 Medical Center Drive, Rockville, MD 20850, USA

Erin E. Kent: erin.kent@nih.gov

Abstract

Purpose—We examined cancer survivors' experience of bothersome symptoms, association of symptom bother with health-related quality of life (HRQOL), survivors' perception of symptom care, and their symptom-related information needs.

Methods—Using self-report survey measures, survivors of leukemia, bladder, or colorectal cancer who were 2–5 years post-diagnosis and received follow-up care in the past year ($N = 623$) provided information about the presence of bothersome symptoms, symptom-related information needs, adequacy of symptom-related care, and their physical and mental HRQOL. Multivariable statistical analyses were conducted to identify correlates of symptom bother, inadequate care, and symptom information needs and to examine the association between symptom bother and HRQOL.

Results—Twenty-eight percent of the 606 respondents experienced symptom bother in the past year (46 % of leukemia, 24 % of bladder, and 26 % of colorectal cancer survivors). Younger

Correspondence to: Erin E. Kent, erin.kent@nih.gov.

Disclaimer Findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the National Cancer Institute. There are no financial disclosures.

Electronic supplementary material The online version of this article (doi:10.1007/s00520-013-1961-x) contains supplementary material, which is available to authorized users.

survivors, those of Hispanic ethnicity, with low income, those with recurrent cancer, and chemotherapy recipients were more likely to report symptom bother (all $p < 0.05$). Symptom bother was associated with lower physical and mental HRQOL ($p < 0.001$). While 92 % of survivors with symptoms discussed them with their follow-up care physician, 52 % of these reported receiving inadequate symptom care. Survivors reporting inadequate symptom care were 2.5 times as likely to identify symptom information needs compared to those who received adequate care ($p < 0.05$).

Conclusions—One in four cancer survivors report symptoms 2–5 years post-diagnosis, and only half of these survivors receive adequate care to address those symptoms. Research that refines and tests symptom care interventions for this population is warranted.

Keywords

Cancer survivorship; Symptom burden; Symptom management; Late effects; Health-related quality of life

Introduction

Advances in cancer treatment have led to a growing number of individuals surviving well beyond diagnosis. However, many survivors experience significant psychological distress as well as an array of long-term and late physical effects of treatment [12, 17, 39]. Prevalence estimates of bothersome symptoms among survivors vary depending upon cancer site, time from diagnosis, and the symptom measures used, making it challenging to gauge the scope of the problem. Symptoms also vary in terms of type, frequency, severity, associated interference and distress, and patterns of co-occurrence [6, 15].

Survivors reporting symptoms may be ill-equipped to manage these symptoms, in part due to sub-optimal communication with or low perceived quality of care received from healthcare providers [40]. Effective symptom management is critical to reduce the emotional distress and interference with usual function that often accompanies the symptom experience [17]. Most research has focused on symptom care during or shortly after the conclusion of treatment [8, 15, 34]; very little research has examined a longer survivorship period [37]. Furthermore, most research on the symptom experience in survivors has focused predominantly on breast cancer [32].

The aim of this analysis was to examine the prevalence of bothersome symptoms and the adequacy of symptom care in a population of adult survivors who had been treated for leukemia, bladder, or colorectal cancer. These three cancer subpopulations have been understudied with respect to the symptom experience, and there is a critical gap in our understanding of their symptom management needs. We first modeled factors hypothesized to be associated with survivors' experience of bothersome symptoms. We then described the symptoms most commonly reported and examined the association between symptom experience and survivors' health-related quality of life (HRQOL). To identify areas for intervention, we evaluated factors associated with receipt of inadequate symptom care from physicians and whether inadequate symptom care was associated with higher symptom information needs.

Methods

Study design

We analyzed cross-sectional survey data collected in 2003–2004 as part of the Assessment of Patients' Experience of Cancer Care (APECC) study of cancer survivors diagnosed with leukemia, bladder, or colorectal cancer 2–5 years prior to the study [2]. The APECC study recruited survivors from the Greater Bay Area Cancer Registry in northern California, which is part of the national Surveillance, Epidemiology, and End Results (SEER) program. Eligible participants (a) were diagnosed with a first primary malignancy (leukemia, bladder, or colorectal cancer) between June 1, 1999 and May 31, 2001, (b) were at least 20 years old at diagnosis and able to read English, (c) had not received an additional cancer diagnoses between their initial diagnosis and the beginning of the study, and (d) had no contraindications to participation identified by their treating physician [2].

The three cancer sites were selected to represent common cancers applicable to men and women across a broad age range. A total of 774 survivors provided data, and of those, 623 (80 %) received follow-up care in the past 12 months and reported on the presence of bothersome symptoms, the adequacy of symptom-related care they received from their physicians, perceived symptom-related information needs, and perceptions of health-related quality of life (HRQOL). Of the 623 participants who reported follow-up care, 17 individuals had data missing on covariates and were thus excluded from analyses. Participant consent was included as part of the survey, and the study was approved by the Institutional Review Board of the Cancer Prevention Institute of California. Additional details on the APECC study are reported elsewhere [2].

Measures

We collected self-reported information on survivors' sociodemographic characteristics: gender, age at diagnosis, race/ethnicity, education, employment status, income, marital status, health insurance status, and residence in a medically underserved area (based on whether participants had been treated at a county hospital and/or yes to at least one of the following two census block variables: >25 % of the population living below the poverty line or 75 % of the adult population without a high school degree). The following clinical characteristics were also collected: cancer site, number of comorbidities, years since diagnosis, type of treatments received and cancer status, and follow-up care related variables (receipt of follow-up care in the previous 12 months, number of physician visits in the past 12 months, the specialty of the physician who provided the majority of their follow-up care, and length of relationship with the follow-up care physician).

Symptom bother—The survey contained a single item about the presence of symptom bother, asking, “In the last 12 months, were you bothered by symptoms or treatment-related side effects?” Participants could respond yes or no, and if yes, they were asked to describe one or more of the symptoms/side effects they had been experiencing.

Symptom care—Of those who reported symptoms, participants were asked two additional questions regarding the quality of symptom care they received from their follow-up care

doctor. They were asked how often in the last 12 months their follow-up care doctor gave the help they wanted to take care of their symptoms or side effects and how often the doctor gave clear instructions on what to do if symptoms or side effects recurred or worsened. Both items employed a four-point response scale ranging from “never,” “sometimes,” “usually,” or “always.” Cronbach’s alpha revealed good internal consistency between these two items ($\alpha=0.80$). We considered symptom care to be adequate if participants indicated that they *usually* or *always* received the help they wanted, and *always* received clear instructions about what to do if symptoms recurred or worsened. Since our aim was to examine predictors and consequences of inadequate symptom care, consistent with other investigations [3], we reasoned that if respondents experiencing symptoms never or only sometimes received help with symptoms and did not always receive symptom information, that this evaluation reflected significant unmet need with regard to symptoms and thus suboptimal care.

Symptom-related information needs—The presence of symptom-related information needs was determined with the following question: “at this time, do you feel you need more information about any of the following cancer-related topics?” Symptom topics included needing information on: symptoms that should prompt a call to the doctor, long-term and late effects of cancer treatment that might be expected, and dealing with long-term and late effects of treatment. Cronbach’s alpha among these three items was high ($\alpha=0.82$). Response choices items included needing no more information, some more information, and much more information [5, 25]. Symptom information needs were considered unmet if respondents indicated they needed “much more information” about at least one of the three topics.

Health-related quality of life (HRQOL)—HRQOL was measured using version 2 of the Short-Form-36 (SF-36 v2®) health survey [41], Physical and mental component summary scores (PCS and MCS) are normed on a T-score metric based on 1999 norms such that a score of 50 and standard deviation of 10 represents an average score for the general US population. Higher scores reflect better HRQOL [42]. Minimally important differences for the PCS and MCS were considered to be least a 2-point difference [21].

Data analyses

We utilized multivariable logistic regression to examine sociodemographic and clinical factors associated with survivors’ experience of bothersome symptoms. Next, we used multivariable linear regression to determine if being bothered by symptoms was associated with lower PCS and MCS scores, after adjusting for sociodemographic, clinical, and follow-up care related factors. Finally, we conducted two additional multivariable logistic regression models to examine, among survivors reporting symptoms, sociodemographic, clinical, and follow-up care related factors associated with inadequate symptom care as well as unmet symptom information needs. The latter model also examined the association between inadequate symptom care and unmet information needs, after adjusting for covariates. Given their association with cancer patients’ care and treatment experiences documented in prior studies, we included age at diagnosis, sex, race/ethnicity, cancer site, and comorbidities. We also included as a predictor whether participants had experienced a

cancer recurrence, since it is increasingly recognized that disease recurrence/progression is an important concern as survivors live longer following the successful completion of initial treatment. In addition, having recently received anticancer treatment was associated with the disease recurrence ($r=0.45$), and thus, disease recurrence was also included to account for the anticipated effects that it might have on symptom experience and symptom management needs. Multicollinearity between other independent variables was assessed further by examining spearman rank correlations, which revealed no other correlations above 0.4. For other covariates, we included a parsimonious set of additional sociodemographic, clinical, and follow-up care related variables if they were associated with the dependent variable at $p < 0.20$ in the univariate analyses.

Responses to the open-ended question about what symptoms were currently experienced as bothersome were summarized using content analysis and simple descriptive statistics. Symptom categories, generated inductively after review of the survey responses and guided by author expertise (SAM), were created by two of the study co-authors (EEK and SAM), and survey responses were independently coded. Inter-rater reliability between coders was high (Cohen's kappa=0.85) and remaining discrepancies were resolved by an additional blinded coauthor (NKA). Distributions of the most common symptoms were examined visually to look for a natural breakpoint in frequency and displayed by cancer site.

Results

A total of 606 survivors ($n=84$ leukemia, $n=161$ bladder, and $n=367$ colorectal cancer survivors) completed information on symptom bother. Sample characteristics are presented in Table 1. Twenty-eight percent of the sample ($n=171$, 46 % leukemia, 24 % bladder, and 26 % colorectal cancer survivors) reported experiencing bothersome symptoms in the past year. Of these, 158 (92.4 %) listed specific symptoms which were coded into 58 unique non-overlapping symptom categories. Figure 1 shows the distribution of the most commonly reported symptoms (reported by 10 or more respondents) by cancer site. The median number of symptoms per survivor was 1 (range 1–3) for bladder cancer, 1 (range 1–7) for colorectal cancer, and 2 (range 1–7) for leukemia survivors. The most commonly reported symptoms, by cancer site, were urinary symptoms and procedural pain for bladder cancer survivors, diarrhea and abdominal pain for colorectal cancer survivors, and fatigue and nausea for leukemia survivors.

Symptom bother

Table 2 presents results of the multivariable logistic regression model examining factors associated with symptom bother, which accounted for 20 % of the variance. Hispanic survivors were 2.8 times (OR=2.77, 95 % CI 1.35–5.66) more likely to report symptom bother than non-Hispanic white survivors. Survivors reporting extremely low household income (<\$20,000) were also more likely to report symptoms (OR=3.65, 95 % CI 1.67–8.01) than those in the highest income category (\$100,000+). Survivors who had experienced a recurrence were more likely to experience bothersome symptoms than those who had not had recurrence (OR=7.91, 95 % CI 4.57–13.69). Finally, those who had undergone a combination of radiation and/or chemotherapy vs. receiving surgery alone were

also more likely to report symptom bother (OR=3.82, 95 %CI 1.45–10.11). There was no significant difference in likelihood of reporting symptom bother by age, gender, education, living in a medically underserved area, cancer site, or number of comorbidities (all $p > 0.05$).

Symptom bother and health-related quality of life

Table 3 presents results of the multivariable linear regression model examining the association between symptom bother and survivors' physical and mental HRQOL. Survivors who experienced bothersome symptoms also reported lower PCS [β (SE)=-4.8 (1.1), $p < 0.0001$] and lower MCS [β (SE)=-3.0 (0.9), $p < 0.0001$] scores. These estimates of the differences in PCS and MCS scores between those experiencing and those not experiencing symptom bother are above the minimally important difference threshold to signify a clinically meaningful effect.

Inadequate symptom care

Of the 171 survivors who report being bothered by symptoms, (157) 92 % also discussed their symptoms with their follow-up doctor in the last 12 months. Of these, 82 (52 %) indicated that they received inadequate symptom care. Although the model accounted for 17 % of the variance explained, none of the examined factors in the multivariable logistic regression model (see Table 4) were significantly associated with inadequate care.

Symptom information needs

Survivors reporting inadequate symptom care were also more likely to report unmet symptom information needs, and the effect remained marginally significant after adjustment for other variables in the multivariable logistic regression model (OR=2.55, 95 % CI 1.00, 6.54; see Table 5). Other factors associated with higher likelihood of having unmet needs included female gender (OR=2.95, 95 % CI 1.21–7.16) and living in a medically underserved area (OR=2.83, 95 % CI 1.08–7.41). Survivors with a college education (vs. graduate education) (OR=0.15, 95 % CI 0.02–0.99) and those who experienced a cancer recurrence (OR=0.31, 95 % CI 0.10–0.93) were less likely to have unmet needs for symptom information. The model accounted for 34 % of the variation in symptom information needs.

Discussion

Symptom bother

More than one in four respondents in this population-based study of survivors of leukemia, bladder, and colorectal cancer reported experiencing symptom bother 2–5 years post-diagnosis. This prevalence is comparable to that noted in a previous study documenting symptom burden in survivors' 1-year post-diagnosis [37]. Our study results replicate those of other investigators in noting that younger survivors[8], Hispanic survivors [18], those with lower household income [37], and those who experienced a recurrence[18] were the most likely to report symptom bother.

A wide range of symptoms was reported by survivors in our study, and it is not clear whether these reflect disease-related symptoms, persistent effects of treatment, late

treatment effects, or comorbidities not related to cancer or its treatment. The prominence of distinct and clinically interpretable symptom profiles by cancer site in our sample is consistent with the observations of other investigators, who have noted fatigue in leukemia survivors [36], abdominal pain [22] and diarrhea [35] in colorectal cancer survivors, and urinary symptoms in bladder cancer survivors [23]. Procedural pain also emerged as a prominent symptom for several participants in our study, most notably bladder cancer survivors. At the same time, it is important to point out that many of the symptoms reported by our participants may be distinct to survivors of leukemia, colorectal or bladder cancer; survivors with other tumor sites may experience a different profile of symptoms. Consistent with prior studies, cancer survivors who experienced symptom bother also reported statistically and clinically worse HRQOL than those who did not [15, 23, 37].

Symptom care

One in two survivors reporting symptom bother also reported inadequate symptom care. However, we did not find significant correlates of inadequate care, suggesting that provision of suboptimal symptom management during the post-treatment phase may be a systemic issue that is likely to have an impact on survivors of different sociodemographic backgrounds and clinical characteristics. In a study of advanced cancer patients in Europe, one of the factors associated with inadequate symptom management was provider underestimation of symptom intensity [26]. Given an understandable focus on primary disease and treatment, providers may under-prioritize comprehensive symptom assessment [17] or may not be fully aware of available treatment options [9]. Evidence suggests, however, that electronic data collection of patient-reported outcomes is feasible and adds value to the clinical consultation [38]; it has also been shown to have a positive effect on symptom management among cancer survivors [7].

Survivors in our study who received inadequate symptom care were also more likely to report unmet symptoms-related information needs, suggesting that in part, providing resources and plans for survivors to help self-manage their symptoms could improve outcomes. Effective management of symptoms and side effects can be achieved through engaged communication with follow-up care providers and evidence-based symptom management [13]. Problem-solving approaches, based on cognitive-behavioral therapy to help reframe symptoms as challenges, may aid survivors in reducing anxiety and distress that often accompany symptom onset as well as in engaging survivors in a plan to reduce the toll that symptoms take [28]. Evidence from clinical trials conducted with cancer survivors using mindfulness-based stress reduction [29], cognitive-behavioral therapy to reduce memory impairment [31], and exercise to manage cancer-related fatigue [33], demonstrate that improvements in symptom control are attainable for many survivors. In addition, strategies to improve symptom care through lifestyle modification including changes in diet and exercise have been shown to be effective [34].

The lack of systematic screening for symptoms among cancer survivors in clinical settings limits our understanding of the prevalence of particular symptoms, restricts exploration of the relationship between patient and clinical characteristics and symptom burden, and impedes appropriate triage and effective interdisciplinary symptom management [15, 17].

Several approaches have been proposed [43], including the Patient-Reported Outcomes Measurement Information System (PROMIS) [11] and the Patient-Reported Common Terminology for Clinical Adverse Events (PRO-CTCAE) [4], but not yet integrated into routine clinical practice.

Most of the research-tested interventions to improve outcomes for survivors have focused on women with breast cancer, and our results suggest that research to develop and refine interventions for survivors of other solid tumor sites and for leukemia survivors is warranted [19]. Our results also suggest that there is also a need to develop and refine targeted interventions for urinary and bowel symptoms, and abdominal pain. These are symptoms for which fewer intervention approaches have been tested in cancer survivors, and the results of a recent survey further emphasize the need to develop and disseminate resources for bladder cancer survivors [27]. Our observation that some symptom distress is procedurally related also appears to be a novel finding that warrants focused study. Our study adds evidence that inadequate patient-provider communication about symptoms is likely to be a significant barrier to effective symptom management [45]. Survivorship-based programs and clinics, survivorship care planning, as well as navigation services, supportive care, and case management can help improve patient-provider communication as well as communication between providers, particularly during the transition from active treatment to survivorship [14, 16, 30]. Of note, only 8.9 % of participants in our sample reported seeing a primary care physician as their follow-up care provider, which may reflect preferences to receive follow-up from cancer specialists [24] rather than primary care providers, and suggests the need to strengthen communication and care coordination between primary and oncology care [20].

Several caveats should be considered in interpreting our study results. While our sample was population-based and drawn from an ethnically diverse region, the sample size for Asians, Pacific-Islanders, and African Americans was small (although proportionate to the population), making it difficult to draw conclusions specific to these subgroups of survivors. The cross-sectional nature of our study limits our ability to make causal inferences about our findings. The ability of some survivors to recall their symptom experience over the past 12 months (the typical duration for many patient experience studies) may be limited. Considering the variability in symptom prevalence and characteristics across cancer sites, as evidenced by our results and those of other investigators, our findings may not generalize to survivors of other cancers. Our observations that there may be unique symptom management needs associated with differing cancer sites and the breadth of the symptoms reported by our participants underscore the importance of a sitespecific approach to symptom screening, evaluation and management and suggest that focused and comprehensive study of the symptom experience in survivors of leukemia, bladder, and colorectal cancers is warranted. Although our study utilized a single-item measure for assessing symptom bother, three arguments support our assumption that our item captured symptom bother well: (a) the inclusion of the phrase “bothered by symptoms” in the question, (b) the high percentage (92 %) of participants who both reported bothersome symptoms and who discussed their symptoms with their follow-up care doctor, and (c) the high percentage (92.4 %) who also described specific symptoms. Future research should make use of now-available tools to measure symptom bother that have well-validated psychometric properties.

Conclusions

Although many cancer survivors report HRQOL comparable to individuals without a cancer history [44], in our study, a notable proportion of survivors of leukemia, bladder, and colorectal cancer reported symptom bother and unmet supportive care needs months or years beyond their cancer diagnosis. Effective screening, evaluation and management of symptoms, and patient-provider communication about symptoms are essential components of survivorship care quality. Our results support a conclusion that survivorship care planning for individuals with leukemia, bladder, and colorectal cancer is needed to address the symptom experience, and should include tailored, periodic symptom screening with aggressive interdisciplinary symptom management interventions offered as clinically indicated [1, 10, 37, 46]. Our study also suggests the need for directed and systematic studies of symptom experiences in post-treatment cancer survivors. An ongoing dialogue between survivors and their providers that both assess symptoms and updates management strategies to reduce symptom bother and improve HRQOL in cancer survivors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Funding Support for data collection was provided by the National Cancer Institute (Contract No. N01-PC-35136) as a contract to the Cancer Prevention Institute of California (formerly known as the Northern California Cancer Center).

References

1. Alvarez A, Walsh D. Symptom control in advanced cancer: twenty principles. *Am J Hosp Palliat Care*. 2011; 28:203–207. [PubMed: 21398267]
2. Arora NK, Reeve BB, Hays RD, Clauser SB, Oakley-Girvan I. Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. *J Clin Oncol*. 2011; 29:1280–1289. [PubMed: 21357781]
3. Ayanian JZ, Zaslavsky AM, Arora NK, Kahn KL, Malin JL, Ganz PA, van Ryn M, Hornbrook MC, Kiefe CI, He Y, Urmie JM, Weeks JC, Harrington DP. Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol*. 2010; 28:4154–4161. [PubMed: 20713876]
4. Basch EM, Reeve BB, Mitchell SA, Clauser SB, Minasian L, Sit L, Chilukuri R, Baumgartner P, Rogak L, Blauel E, Abernethy AP, Bruner D. Electronic toxicity monitoring and patient-reported outcomes. *Cancer J*. 2011; 17:231–234. [PubMed: 21799330]
5. Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton AS, Hesse BW. Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. *J Cancer Surviv*. 2008; 2:179–189. [PubMed: 18792791]
6. Berger AM, Visovsky C, Hertzog M, Holtz S, Loberiza FR Jr. Usual and worst symptom severity and interference with function in breast cancer survivors. *J Support Oncol*. 2012; 10:112–118. [PubMed: 22277573]
7. Bock M, Moore D, Hwang J, Shumay D, Lawson L, Hamolsky D, Esserman L, Rugo H, Chien AJ, Park J, Munster P, Melisko M. The impact of an electronic health questionnaire on symptom management and behavior reporting for breast cancer survivors. *Breast Cancer Res Treat*. 2012; 134:1327–1335. [PubMed: 22798157]

8. Brant JM, Beck S, Dudley WN, Cobb P, Pepper G, Miaskowski C. Symptom trajectories in posttreatment cancer survivors. *Cancer Nurs.* 2011; 34:67–77. [PubMed: 20885306]
9. Breuer B, Fleishman SB, Cruciani RA, Portenoy RK. Medical oncologists' attitudes and practice in cancer pain management: a national survey. *J Clin Oncol.* 2011; 29:4769–4775. [PubMed: 22084372]
10. Burkett VS, Cleeland CS. Symptom burden in cancer survivorship. *J Cancer Surviv.* 2007; 1:167–175. [PubMed: 18648958]
11. Cella D, Yount S, Rothrock N, Gershon R, Cook K, Reeve B, Ader D, Fries JF, Bruce B, Rose M, Group PC. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Med Care.* 2007; 45:S3–S11. [PubMed: 17443116]
12. Cheng KKF, Thompson DR, Ling WM, Chan CWH. Measuring symptom prevalence, severity and distress of cancer survivors. *Clin Eff Nurs.* 2005; 9:154–160.
13. Clayton MF, Dudley WN. Patient-centered communication during oncology follow-up visits for breast cancer survivors: content and temporal structure. *Oncol Nurs Forum.* 2009; 36:E68–E79. [PubMed: 19273396]
14. Davis MP, Kirkova J. Lifting symptom burden—how far off the ground are we? *Support Care Cancer.* 2008; 16:757–761. [PubMed: 18256858]
15. Deshields TL, Potter P, Olsen S, Liu J, Dye L. Documenting the symptom experience of cancer patients. *J Support Oncol.* 2011; 9:216–223. [PubMed: 22055891]
16. Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol.* 2006; 24:5112–5116. [PubMed: 17093272]
17. Feuerstein M, Bruns GL, Pollman C, Todd BL. Management of unexplained symptoms in survivors of cancer. *J Oncol Pract.* 2010; 6:308–311. [PubMed: 21358961]
18. Fu OS, Crew KD, Jacobson JS, Greenlee H, Yu G, Campbell J, Ortiz Y, Hershman DL. Ethnicity and persistent symptom burden in breast cancer survivors. *J Cancer Surviv.* 2009; 3:241–250. [PubMed: 19859813]
19. Griffiths J, Willard C, Burgess A, Amir Z, Luker K. Meeting the ongoing needs of survivors of rarer cancer. *Eur J Oncol Nurs.* 2007; 11:434–441. [PubMed: 18023615]
20. Grunfeld E, Earle CC. The interface between primary and oncology specialty care: treatment through survivorship. *J Natl Cancer Inst Monogr.* 2010; 2010:25–30. [PubMed: 20386051]
21. Hays RD, Farivar SS, Liu H. Approaches and recommendations for estimating minimally important differences for health-related quality of life measures. *COPD.* 2005; 2:63–67. [PubMed: 17136964]
22. Heins MJ, Korevaar JC, Rijken PM, Schellevis FG. For which health problems do cancer survivors visit their General Practitioner? *Eur J Cancer.* 2012
23. Henningsohn L, Wijkstrom H, Pedersen J, Ahlstrand C, Aus G, Bergmark K, Onelov E, Steineck G. Time after surgery, symptoms and well-being in survivors of urinary bladder cancer. *BJU Int.* 2003; 91:325–330. [PubMed: 12603405]
24. Hudson SV, Miller SM, Hemler J, Ferrante JM, Lyle J, Oeffinger KC, Dipaola RS. Adult cancer survivors discuss follow-up in primary care: 'not what i want, but maybe what i need'. *Ann Fam Med.* 2012; 10:418–427. [PubMed: 22966105]
25. Kent EE, Arora NK, Rowland JH, Bellizzi KM, Forsythe LP, Hamilton AS, Oakley-Girvan I, Beckjord EB, Aziz NM. Health information needs and health-related quality of life in a diverse population of long-term cancer survivors. *Patient Educ Couns.* 2012; 89:345–352. [PubMed: 23021856]
26. Laugsand EA, Jakobsen G, Kaasa S, Klepstad P. Inadequate symptom control in advanced cancer patients across Europe. *Support Care Cancer.* 2011; 19:2005–2014. [PubMed: 21116653]
27. Lee CT, Mei M, Ashley J, Breslow G, O'Donnell M, Gilbert S, Lemmy S, Saxton C, Sagalowsky A, Sangsri S, Latini DM. Patient resources available to bladder cancer patients: a pilot study of healthcare providers. *Urology.* 2012; 79:172–177. [PubMed: 21996109]
28. Lee YH, Chiou PY, Chang PH, Hayter M. A systematic review of the effectiveness of problem-solving approaches towards symptom management in cancer care. *J Clin Nurs.* 2011; 20:73–85. [PubMed: 21044188]

29. Lerman R, Jarski R, Rea H, Gellish R, Vicini F. Improving symptoms and quality of life of female cancer survivors: a randomized controlled study. *Ann Surg Oncol*. 2012; 19:373–378. [PubMed: 21913014]
30. 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 Educ Couns*. 2009; 77:103–108. [PubMed: 19272749]
31. McDougall GJ, Becker H, Acee TW, Vaughan PW, Delville CL. Symptom management of affective and cognitive disturbance with a group of cancer survivors. *Arch Psychiatr Nurs*. 2011; 25:24–35. [PubMed: 21251599]
32. Minasian LM, O'Mara AM, Reeve BB, Denicoff AM, Kelaghan J, Rowland JH, Trimble EL. Health-related quality of life and symptom management research sponsored by the National Cancer Institute. *J Clin Oncol*. 2007; 25:5128–5132. [PubMed: 17991932]
33. Mishra SI, Scherer RW, Geigle PM, Berlanstein DR, Topaloglu O, Gotay CC, Snyder C. Exercise interventions on health-related quality of life for cancer survivors. *Cochrane Database Syst Rev*. 2012; 8:CD007566. [PubMed: 22895961]
34. Pan LH, Tsai YF, Chen ML, Tang R, Chang CJ. Symptom distress and self-care strategies of colorectal cancer patients with diarrhea up to 3 months after surgery. *Cancer Nurs*. 2011; 34:E1–E9. [PubMed: 20697270]
35. Schneider EC, Malin JL, Kahn KL, Ko CY, Adams J, Epstein AM. Surviving colorectal cancer : patient-reported symptoms 4 years after diagnosis. *Cancer*. 2007; 110:2075–2082. [PubMed: 17849466]
36. Schumacher A, Wewers D, Heinecke A, Sauerland C, Koch OM, van de Loo J, Buchner T, Berdel WE. Fatigue as an important aspect of quality of life in patients with acute myeloid leukemia. *Leukemia Research*. 2002; 26:355–362. [PubMed: 11839378]
37. Shi Q, Smith TG, Michonski JD, Stein KD, Kaw C, Cleeland CS. Symptom burden in cancer survivors 1 year after diagnosis: a report from the American Cancer Society's Studies of Cancer Survivors. *Cancer*. 2011; 117:2779–2790. [PubMed: 21495026]
38. Snyder CF, Blackford AL, Wolff AC, Carducci MA, Herman JM, Wu AW. Feasibility and value of PatientViewpoint: a web system for patient-reported outcomes assessment in clinical practice. *Psychooncology*. 2012
39. Stein KD, Syrjala KL, Andrykowski MA. Physical and psycho-logical long-term and late effects of cancer. *Cancer*. 2008; 112:2577–2592. [PubMed: 18428205]
40. Thorne SE, Hislop TG, Armstrong EA, Oglov V. Cancer care communication: the power to harm and the power to heal? *Patient Educ Couns*. 2008; 71:34–40. [PubMed: 18096354]
41. Ware, JE., Jr; Kosinski, M.; Dewey, JE. How to Score Version Two of the SF-36 Health Survey. QualityMetric Incorporated; Lincoln, RI: 2000.
42. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care*. 1992; 30:473–483. [PubMed: 1593914]
43. Watanabe SM, Nikolaichuk CL, Beaumont C. The Edmonton Symptom Assessment System, a proposed tool for distress screening in cancer patients: development and refinement. *Psychooncology*. 2012; 21:977–985. [PubMed: 21671304]
44. Wikman A, Djarv T, Johar A, Lagergren L. Health-related quality of life does not differ between short-term, long-term and very long-term cancer survivors in the Swedish general population. *Psycho-Oncology*. 2012
45. Yeom HE, Heidrich SM. Effect of perceived barriers to symptom management on quality of life in older breast cancer survivors. *Cancer Nurs*. 2009; 32:309–316. [PubMed: 19444083]
46. Zucca AC, Boyes AW, Linden W, Girgis A. All's well that ends well? Quality of life and physical symptom clusters in long-term cancer survivors across cancer types. *J Pain Symptom Manage*. 2012; 43:720–731. [PubMed: 22277904]

Fig. 1.
Percentages of symptom reports by respondents to the open-ended symptom question by cancer site

Table 1Sample description (*N*=606)

	<i>N</i>	%
Sociodemographic variables		
Age at diagnosis		
<50	98	16.2
50–64	229	37.8
65–74	158	26.1
75	121	20
Gender		
Male	341	56.3
Female	265	43.7
Race/ethnicity		
Non-Hispanic White	449	74.1
Hispanic	50	8.3
Non-Hispanic Asian	65	10.7
Other ^a	42	6.9
Marital status		
Married/living as married	434	71.6
Other	172	28.4
Education		
Some grad school/grad degree	169	27.9
College degree	124	20.5
Some college	189	31.2
High school or less	124	20.5
Employment status		
Working, full or part-time	243	40.1
Other	363	59.9
Income		
\$100,000+	151	24.9
\$60–100,000	154	25.4
\$40–60,000	84	13.9
\$20–40,000	90	14.9
<\$20,000	74	12.2
Missing	53	8.7
Residence in a medically underserved area		
No	408	67.3
Yes	198	32.7
Clinical variables		
Health insurance status		
Private	508	83.8
None/government only	98	16.2

	N	%
Cancer site		
Leukemia	84	13.9
Bladder cancer	161	26.6
Colorectal cancer	361	59.6
Number of comorbidities		
0	139	22.9
1	165	27.2
2	136	22.4
3	166	27.4
Recurrence		
No	499	82.3
Yes	107	17.7
Perceived health status		
Excellent/very good	288	47.5
Good	216	35.6
Fair/Poor	98	16.2
Missing	4	0.7
Treatment received (ever)		
Surgery only	226	37.3
Surgery plus chemotherapy or radiation	203	33.5
Chemotherapy with or without radiation but no surgery	81	13.4
Surgery plus chemotherapy and radiation	72	11.9
Missing	24	4
Follow-up care variables		
Received treatment in the past 12 months		
No	435	71.8
Yes	171	28.2
Years known primary follow-up care provider		
<2 years	121	20
2 years+	485	80
Number of visits to doctor in past 12 months		
1	141	23.3
2	175	28.9
3	90	14.9
4	92	15.2
5+	108	17.8
Physician specialty		
Primary care	54	8.9
Oncologist/hematologist	312	51.5
Other specialist	229	37.8
Missing	11	1.8
Setting of care		

	<i>N</i>	%
Doctor's office	288	47.5
Hospital clinic	178	29.4
HMO clinic	137	22.6
Missing	3	0.5
Bothered by symptoms	171	28.2

HMO health maintenance organization

^aThe Other category in race/ethnicity consists of Non-Hispanic Blacks (n=29), Non-Hispanic American Indians or Alaskan Natives (n=12), and Non-Hispanic Pacific Islanders (n=1), who were all grouped together because of small numbers

Table 2Factors associated with symptom bother ($N=606$)

Rescaled R -square=0.20	Adj OR (95 % CI) ^a
Sociodemographic variables	
Age at diagnosis	
<50	Ref
50–64	0.7 (0.39, 1.28)
65–74	0.42 (0.21, 0.84)
75	0.25 (0.11, 0.56)
Gender	
Male	Ref
Female	1.01 (0.66, 1.56)
Race/ethnicity	
Non-Hispanic White	Ref
Hispanic	2.77 (1.35, 5.66)
Non-Hispanic Asian	0.7 (0.34, 1.42)
Other	1.02 (0.45, 2.29)
Education	
Some grad school/grad degree	Ref
College degree	0.71 (0.38, 1.34)
Some college	0.96 (0.55, 1.68)
High school or less	0.71 (0.37, 1.35)
Income	
\$100,000+	Ref
\$60–100,000	1.11 (0.6, 2.05)
\$40–60,000	1.21 (0.59, 2.5)
\$20–40,000	2.16 (1.03, 4.54)
<\$20,000	3.65 (1.67, 8.01)
Residence in a medically underserved area	
No	Ref
Yes	0.91 (0.58, 1.45)
Clinical variables	
Cancer site	
Leukemia	Ref
Bladder cancer	0.64 (0.23, 1.74)
Colorectal cancer	1.1 (0.43, 2.82)
Number of comorbidities	
0	Ref
1	1.06 (0.58, 1.94)
2	1.24 (0.65, 2.37)
3	1.61 (0.87, 2.99)
Recurrence	

Rescaled <i>R</i> -square=0.20	Adj OR (95 % CI) ^a
No	Ref
Yes	7.91 (4.57, 13.69)
Treatment received (ever)	
Surgery only	Ref
Surgery plus chemotherapy or radiation	1.02 (0.59, 1.77)
Surgery plus chemotherapy and radiation	1.82 (0.88, 3.78)
Chemotherapy with or without radiation but no surgery	3.82 (1.45, 10.11)

^a Bolded values indicate statistical significance at $p < 0.05$

Table 3

Symptom bother and health-related quality of life (SF-36)

	Adjusted Mean (SE)	Estimate (SE)	<i>p</i> ^c
Physical Component Scale (PCS) ^a			
Bothered by symptoms			
No	40.5	Ref	
Yes	45.3	-4.8 (1.1)	<0.0001
Mental Component Scale (MCS) ^b			
Bothered by symptoms			
No	48.5	Ref	
Yes	45.5	-3.0 (0.9)	0.0009

^a Adjusted for age at diagnosis, gender, race/ethnicity, marital status, educational attainment, residence in a medically underserved area, health insurance status, cancer site, comorbidities, cancer recurrence, cancer treatment history, cancer care setting, length of relationship with follow-up care doctor, and time since diagnosis

^b Adjusted for age at diagnosis, gender, race/ethnicity, marital status, educational attainment, residence in a medically underserved area, health insurance status, cancer site, comorbidities, cancer recurrence, cancer treatment history, cancer care setting, and length of relationship with follow-up care doctor

^c Bolded values indicate statistical significance at *p* < 0.05

Table 4Factors associated with inadequate symptom care, $N=157^a$

Rescaled R -square=0.17	Adj OR (95 % CI)
Sociodemographic variables	
Age at diagnosis	
<50	Ref
50–64	1.81 (0.72, 4.53)
65–74	1.26 (0.4, 3.99)
75	2.74 (0.74, 10.06)
Gender	
Male	Ref
Female	0.55 (0.26, 1.14)
Race/ethnicity	
White	Ref
Non-White	1.07 (0.51, 2.27)
Marital status	
Married/living as married	Ref
Other	1.99 (0.89, 4.46)
Employment status	
Working, full or part-time	Ref
Other	0.69 (0.30, 1.60)
Residence in a medically underserved area	
No	Ref
Yes	0.72 (0.34, 1.49)
Clinical variables	
Health insurance status	
Private	Ref
None/government only	0.65 (0.23, 1.80)
Cancer site	
Leukemia	Ref
Bladder cancer	0.86 (0.28, 2.64)
Colorectal cancer	1.51 (0.60, 3.76)
Number of comorbidities	
0	Ref
1	1.38 (0.48, 3.95)
2	1.55 (0.51, 4.74)
3	0.69 (0.23, 2.09)
Recurrence	
No	Ref
Yes	0.66 (0.29, 1.47)
Follow-up care variables	
Number of visits to doctor in past 12 months	

Rescaled <i>R</i> -square=0.17	Adj OR (95 % CI)
Up to 3	Ref
More than three	0.71 (0.33, 1.55)

^aSample included survivors who reported bothersome symptoms and who discussed their symptoms with their follow-up care doctor in the last 12 months

Table 5Factors associated with symptom-related information needs, $N=157^a$

Rescaled R-square=0.34	
Sociodemographic variables	
Age at diagnosis	
<50	Ref
50–64	0.97 (0.30, 3.15)
65–74	3.60 (0.94, 13.78)
75	1.06 (0.20, 5.73)
Gender	
Male	Ref
Female	2.95 (1.21, 7.16)
Race/ethnicity	
White	Ref
Non-White	2.40 (0.96, 5.99)
Education	
Some grad school/grad degree	Ref
College degree	0.15 (0.02, 0.99)
Some college	0.99 (0.34, 2.88)
High school or less	0.55 (0.16, 1.9)
Residence in a medically underserved area	
No	Ref
Yes	2.83 (1.08, 7.41)
Clinical variables	
Cancer site	
Leukemia	Ref
Bladder cancer	1.06 (0.24, 4.76)
Colorectal cancer	1.32 (0.43, 4.03)
Number of comorbidities	
0	Ref
1	1.13 (0.34, 3.78)
2	0.31 (0.07, 1.35)
3	0.53 (0.15, 1.88)
Recurrence	
No	Ref
Yes	0.31 (0.10, 0.93)
Follow-up care variables	
Up to 3	Ref
More than three	0.65 (0.26, 1.63)
Years known primary follow-up care provider	
2 years+	Ref
<2 years	1.77 (0.70, 4.47)

Rescaled <i>R</i> -square=0.34	
Symptom communication	
Adequate	Ref
Inadequate	2.55 (1.00, 6.54)

^a Sample included survivors who reported bothersome symptoms and who discussed their symptoms with their follow-up care doctor in the last 12 months

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript