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Psychosocial Issues in Post-treatment Cancer Survivors: Desire for Support and Challenges in Identifying Individuals in Need

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Abstract

Purpose—The ongoing and late effects of cancer treatment can interfere with quality of life and adoption of healthy behaviors, thus potentially impairing recovery and survival. Developing effective methods to identify individuals in need of support is crucial in providing comprehensive, ongoing care and ensuring optimal use of limited resources. The current study provides an examination of long-term survivors' reports of psychosocial issues, their desire for follow-up, and the role of widely-used distress screening measures for identifying survivors who desire help.

Method—317 cancer survivors (*M* age=62.98 years, female=70%, *Md* years since treatment=7.5 years, mixed diagnoses) completed measures of psychosocial adjustment and quality of life, as well as a checklist of psychosocial issues on which they indicated whether they would like to speak with a health professional regarding each issue.

Results—Participants reported an average of 1.7 psychosocial issues. Only a minority desired to speak to a health professional; however, those desiring follow-up reported significant impairments in adjustment and quality of life. Though far from adequate as a stand-alone measure, AUC and regression analysis suggested a combination of the Distress Thermometer and number of psychosocial issues may be the best assessment of those desiring follow-up assistance.

Conclusion—These results indicate that there is a need for a more sophisticated system of assisting survivors that takes into account issues, symptoms, and motivation for help. The current study is important in guiding the development of effective survivorship care and contributing to the growing literature describing the adjustment and care needs of survivors.

Keywords

Psychosocial distress; Cancer survivorship; Supportive care

Enhanced awareness, screening, and treatment have resulted in a growing number of patients expected to survive with cancer (ACS, 2015). These advances have led to a greater focus on long-term and late effects of treatment, quality of life, and the management of co-morbid disease states in this growing population. Thus, enhancing the provision of comprehensive

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care throughout the disease trajectory has become an important area of clinical research over the past decade (Adler & Page, 2007; Hewitt, Greenfield, & Stovall, 2005; Pirl et al., 2014; Salmon, Clark, McGrath, & Fisher, 2015), especially with respect to reaching survivors, assessing their needs, and understanding barriers to requesting services and service uptake.

The majority of cancer survivors will report successful adjustment in survivorship (A. W. Boyes, Girgis, Zucca, & Lecathelinais, 2009; Pirl, Greer, Temel, Yeap, & Gilman, 2009), however, a significant number of patients will experience clinically relevant psychosocial issues. Across cancer diagnoses, it has been estimated that between 20 to 30% of survivors will experience significant burden from psychological symptoms (Burkett & Cleeland, 2007; Foster, Wright, Hill, Hopkinson, & Roffe, 2009; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Philip, Merluzzi, Zhang, & Heitzmann, 2013; Shi et al., 2011), most notably depression and anxiety, as well as cognitive difficulties and impaired reengagement in personal, professional, and social roles. The screening and treatment of psychosocial issues in the context of cancer has important historical roots, including more than three decades of empirical investigation. Worden and Weisman (Weisman & Worden, 1976; Worden & Weisman, 1975, 1980, 1984) referred to the “existential plight”, which included shock and distress, for which they developed an intervention that included problem-solving skills training. Also, Holland and colleagues (Holland & Rowland, 1989), in a seminal edited volume were among the first to make a case for the clinical psychosocial aspects of cancer and interventions that remedy emotional disorders in cancer patients. However, the discussion of distress in survivorship was not a part of these earlier writings.

Importantly, these symptoms can interfere in survivors’ adoption of healthy behaviors, thus potentially jeopardizing long-term health outcomes (e.g., Artherholt & Fann, 2012; Hopko et al., 2008; Kjaer et al., 2011). It is important to emphasize that not all psychological symptoms will reach clinically diagnosable levels, though the cumulative effects of these symptoms can impair quality of life and disrupt the transition to a satisfactory post-treatment lifestyle. Despite this, there is evidence that few survivors will receive or even request care from a mental health professional (Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005) and connecting survivors to appropriate supportive care represents a complex and challenging clinical task. An enhanced understanding of survivors’ psychosocial experience and desire and motivation for supportive care follow-up is therefore critical in informing the development of care practices, especially with respect to the barriers and facilitators of engaging in supportive care, for those in need.

Despite growing acknowledgement and documentation of the challenges faced by survivors of cancer, there are a number of barriers to the provision of supportive care to this population. During the diagnosis and treatment phase, patients have consistent and regular engagement with their care team. However, once treatment is complete patients will typically engage in less frequent contact with their oncology team, which can create difficulties in identification of survivors who may be experiencing significant psychosocial issues. Further, survivors who do experience long-term or late psychosocial issues may feel unsure about the most appropriate contact regarding their symptomatology, while others may hesitate to report persistent or new symptoms if they do not possess insurance coverage for supportive or specialist services. Finally, whereas not all patients with symptomatology will desire supportive care, stigma surrounding engagement with mental health services still exists (Thornicroft, 2008), and may therefore deter those who do want help from seeking support.

The psychometric properties of current symptom screening measures can also represent barriers to the effective provision of supportive care. This is perhaps most evident in the identification of clinically significant psychological distress. Current clinical screening measures, such as the Distress Thermometer (Roth et al., 1998) and Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), have demonstrated moderate to good validity and reliability in regard to identifying diagnosable disorders; however, the clinical utility of such measures as screening instruments has been questioned (Mitchell, 2007). This may be particularly pertinent amongst the survivor population (Merport, Bober, Grose, & Recklitis, 2012) where the critical factor may be individuals' desire for help and motivation to seek it, rather than their reported distress level. False positive findings, or the identification of non-distressed individuals as distressed, can result in undue patient and clinic burden, which combined with limited resources, can restrict the widespread adoption of screening protocols. Moreover, there exists a paucity of information regarding the relationship between distress and an individuals' desire for supportive care or their ultimate uptake of services. Given that not all survivors who possess symptomatology will desire supportive care, the ability to identify those who do becomes an important first step in the provision of services and will lead to a more complete understanding about how to utilize limited health resources.

The current study will seek to contribute to the growing literature and address the paucity of research pertaining to help seeking in survivorship through three primary goals: (1) document psychosocial issues and desire to speak with a health professional in a convenience sample of community-based post-treatment cancer survivors, (2) describe characteristics, screening scores, and functioning of those survivors who report a desire for support and compare and contrast them to those not desiring support, and (3) provide a preliminary examination of the capacity of validated screening measures to identify those seeking contact with a health professional. This important information will help further our understanding of the complex relationship between cancer survivors' distress and consequent desire to speak with a health professional, and thus help supportive care services provide effective care for this growing population.

Method

Participants

Participants ($N = 317$) were recruited by mail from the Research Participant Database of the Laboratory for Psycho-Oncology Research at a midwestern university. This database includes individuals who had been recruited through various efforts from 2006 to 2009 and who consented to further involvement in future studies conducted by the research team. Initial recruitment efforts ($N=681$) included contact at the time of treatment through partnerships with local hospitals, print advertising in major cities and contact with a number of support groups throughout the Midwestern, Western, and Southern United States. Therefore, the initial database included patients in treatment as well as off-treatment survivors from most geographical regions of the United States except the northeast where recruitment efforts were minimal. As part of the larger study, 530 individuals recruited early in the study, who were no longer in treatment were invited to participate; 317 survivors returned the completed questionnaire packet for a response rate of 60%. Physician offices were contacted to augment the self-reported data by participants; 52% of offices returned completed forms. This study received approval from all relevant Institutional Review Boards, and all participants were treated in accordance with the Ethical Standards of the American Psychological Association. The authors have no conflicts of interest to report with regard to the conduct of this research project.

Measures

Psychosocial Issues—A list of psychosocial issues relevant to long-term cancer survivors was adapted from existing measures for the current study. Existing measures examined included the Memorial Symptom Assessment Scale (Portenoy et al., 1994) and NCCN Distress Thermometer (National Comprehensive Cancer Network, 2013); further survivorship items were added based on consultation with clinical and radiation oncologists, oncology nurses, and mental health professionals. The final list of 15 psychosocial issues included, for example, emotional issues, financial issues, memory-concentration issues and role issues and relationship issues. Participants were asked to endorse whether a psychosocial issue was currently a problem for them, and whether they would like to speak to a health professional regarding this problem.

Quality of Life—The Functional Assessment of Cancer Therapy (FACT, Cella et al., 1993) is a 27-item measure of quality of life that contains four subscales: Physical Well Being, Social/Family Well Being, Emotional Well-Being, and Functional Well-Being. Individuals with cancer respond to a variety of questions by indicating on a five-point scale (‘not at all’ to ‘very much’) how the items apply to their lives. The authors reported subscale alphas of between .69 and .82 and a total score alpha of .89 in a large heterogeneous sample of cancer patients (Cella et al., 1993).

Anxiety and Depression—The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) is a 14-item self-report measure that has been designed specifically to assess depression and anxiety in persons with physical illness. Individuals respond to each item on a four-point Likert-type scale, including seven items that assess depression and seven that assess anxiety. Respondents are asked to report the degree to which they agree with each statement in considering the previous week. In the original scale development, probable cases of clinically relevant psychological distress are indicated by scores at or above 8 on a single subscale (Bjelland, Dahl, Haug, & Neckelmann, 2002; Zigmond & Snaith). Adequate scale sensitivity and specificity have been reported, however there remains debate as to the most appropriate cutoff score for screening cancer patients (Bjelland et al., 2002; Vodermaier & Millman, 2011) and survivors. A recent meta-analysis reported cut-off scores for detecting mental disorders in cancer patients as greater than or equal to 6 on the depression scale and greater than or equal to 8 on the anxiety scale (Vodermaier & Millman, 2011). Internal consistency values for the current study were .85 for the depression scale, .83 for the anxiety scale, and .89 for the total scale.

The Distress Thermometer (DT, Roth et al., 1998) is a visual analog scale in which participants rate their level of distress on an 11-point scale ranging from 0 (none) to 10 (extreme). The DT can be completed rapidly, has been used widely, and possesses moderate to good sensitivity and specificity for detecting depression in cancer patients (Mitchell, 2007). Follow-up based on a cut-off score of 4 or above has been recommended in the cancer literature (Roth et al., 1998) but cut scores have not been established for cancer survivors.

Social Support—The short form of the Interpersonal Support Evaluation List (ISEL, Cohen, Mermelstein, Kamarck, & Hoberman, 1985) consists of 12 statements concerning the perceived availability of potential social resources. The items relate to four categories of support: tangible support, appraisal support, self-esteem support, and belonging support. The total score indicates the amount of support the person perceives as available. Internal consistency estimates have ranged from .77 to .86 for the total scale (Cohen et al.) and was .90 in the current study.

Self-efficacy for Coping—The Cancer Behavior Inventory-Brief is a 14-item measure of self-efficacy expectations about coping with cancer (Heitzmann et al., 2011), which is based on the longer 33-item measure (Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001). Participants report their level of confidence to perform each coping behavior on a 9-point Likert-type scale (‘not at all confident’ to ‘totally confident’); item scores were summed to form a total score. Alpha for this scale was .94 in the current study.

Demographic and health information—Information regarding participants’ age, employment status, income, education, religious preference, race, diagnosis, treatments, marital status, and health behaviors was obtained based on self-report.

Procedure

Participants who met the inclusion criteria (18 years old, able to read English, and off active treatment) were selected from the larger database (described above) and mailed a letter inviting them to participate in the current study. Individuals who consented to participate received a packet of materials by mail, were asked to complete each questionnaire and return the materials using the postage paid envelope provided. The questionnaires took approximately forty minutes to complete and participants who completed and returned the questionnaire were compensated $20 for their effort. Participants were provided with a phone number to contact the research co-coordinator should they like any further information. In addition, those who endorsed a desire to speak with a health professional were contacted by a trained member of the research team to offer referrals to local resources. All information was handled with the utmost care and in accordance with the Health Insurance Portability and Accountability Act (HIPAA) regulations. For those for whom this information was available, the date of diagnosis, the course of treatments, and, if applicable, the ending date of treatment was verified.

Results

Sample

There were 317 individuals who participated in the current study, the majority of whom were female (69.9%), married (62.5%) and Caucasian (72.8%). A concerted effort was made to recruit African Americans who constituted 21.5% of the sample. The mean age of the participants was 62.99 years (SD = 12.25) with ages ranging from 20 to 89 years old. The majority of participants had been diagnosed with cancer of the breast (48.3%) or prostate (14.2%). Participants were an average of 10.09 years post-treatment, with a median of seven years (Table 1). In recognition of the oversampling of breast cancer survivors in the current study, preliminary analyses were conducted to examine demographic characteristics and primary study outcomes between breast cancer survivors and non-breast cancer survivors. With the exception of marital status, there were no significant differences between these groups across study variables, and thus the full sample was retained for further analyses.

In terms of the scores on traditional screening measures the following was found with the measures used in this study: 23% scored 4 or above on the Distress Thermometer, 15.8% scored above the cutoff (greater than or equal to 8) on the depression scale and 36% on the anxiety scale of the HADS measure. Utilizing the alternative HADS cutoffs for those diagnosed with cancer provided by Vodermaier and colleagues (Vodermaier & Millman, 2011), 27.5% scored above the cutoff (greater than or equal to 6) on the depression scale (the anxiety scale cutoff remains the same). Thus, generally speaking, our data conform to other studies (Foster et al., 2009) in terms of the percent described as meeting the criterion for “caseness.” However, in the next sections we present additional analyses regarding help seeking, which represents the thrust of the current study.

Psychosocial Issues

Participants reported an average of 1.71 psychosocial issues, with the most prevalent being memory or concentration difficulties (reported by 35.6% of the sample), financial issues (26.5%), emotional issues (25.9%) and sexual issues (23.0%). Desire to speak to a health professional (13.6% of the sample overall) was most frequently associated with reports of memory/concentration difficulties (6.0%; 16.8% of endorsers), emotional issues (5.4%; 20.7% of endorsers) and financial issues (4.7%; 17.9% of endorsers) (Table 2). Examination of demographic characteristics revealed that female participants endorsed a significantly greater number of issues ($t(263) = 4.4$, $p<.001$), as well as heightened distress ($t(197) = 3.5$, $p<.001$), anxiety ($t(314) = 4.5$, $p<.001$) and depression ($t(242) = 4.2$, $p<.001$) compared to male participants. There was no gender-based difference in desire for support. Being younger was associated with heightened distress ($r=-.17$, $p<.01$) and anxiety ($r=-.22$, $p<.01$), but not depression. Individuals who endorsed emotional issues also reported significantly higher levels of anxiety and depression (all p’s<0.001) compared to those who did not endorse emotional stress. There were no differences based on time since treatment.

Group Comparison based on Desire for Follow-up

As noted above and consistent with our hypothesis, a small percentage of the sample (13.6%) requested help, with a number of significant differences emerging across demographic characteristics between those who expressed desire to speak with a health professional regarding any issue (n=43) and the rest of the sample (n=274). Individuals reporting a lower income ($\chi^2(6) = 15.83$, $p<.05$), being unemployed (vs. employed or retired, $\chi^2(1) = 9.0$, $p<.01$) or unmarried, separated or widowed (vs. married, $\chi^2(1) = 7.8$, $p<.01$) were more likely to report a desire to speak with a health professional. There were no differences by age, gender, education, or time since treatment between groups. Those expressing a desire to speak with someone reported a significantly greater number of psychosocial issues and symptoms of depression and anxiety, as well as lower quality of life, social support and coping self-efficacy (p's<.01) (Table 3) compared to those who did not. Thus, there may be a constellation of comorbidity that is accompanied by distress and compromised coping.

Amongst those who reported a desire for follow-up, 37.7% scored 4 or above on the DT, 20.9% scored above the cutoff (greater than or equal to 8) on the depression scale and 46.5% on the anxiety scale of the HADS measure. In addition, 44.2% of the sample was above the revised cutoff for the depression scale (greater than or equal to 6)(Vodermaier, Linden, & Siu, 2009).

Identification of Follow-up Seekers

If symptoms and help-seeking represent critical factors in the assessment of cancer survivors needs, then screening of survivors might be best accomplished by taking into account not only distress but also symptom burden and desire for help. The following analysis explored this idea by investigating the utility of symptoms and traditional distress screening for detecting help seeking. Area under Curve (AUC) analysis provided an indication as to the accuracy of a measure in predicting a dichotomous outcome (desire for follow-up vs. no desire). In these analyses the number of psychosocial issues reported by participants was the most predictive measure of desire to speak to a health professional. The AUC for this measure was 0.76, indicating that 76% of individuals would be identified correctly as ‘desiring follow-up’ based on this measure. The AUC for all five measures ranged from 0.65 to 0.76, with overlapping confidence intervals, and thus there was no clear advantage demonstrated by a single measure. However, assuming there is some unique variance in each measure, in order to determine the best combination of these variables to predict help-seeking, forward stepwise logistic regression analysis was used, controlling for demographic variables (income, employment, marital status). The best model ($\chi(3) = 27.66$, $p<.000$; Nagelkerke R^2=.202) in terms of fit included the number of psychosocial issues endorsed (β=0.23, Wald=6.3, $p<.05$) in conjunction with the Distress Thermometer (β=0.17, Wald=6.1, $p<.05$).

Sensitivity and specificity analysis provides an indication of a measure’s accuracy, which in the context of the current study includes the proportion of participants identified as distressed who reported a desire to speak with a health professional (sensitivity) and those identified as not distressed who reported not wanting to speak with a health professional (specificity). As noted, the number of psychosocial issues possessed the highest AUC, with further analysis revealing that the endorsement of two or more issues would provide an optimal balance of sensitivity (0.78) and specificity (0.64). Preliminary analysis of the DT measure revealed that if one were to use the recommended cutoff of 4, the sensitivity of this measure among survivors would be 0.50, with a specificity of 0.78, while a cut-off of 2 or more would provide the most balanced trade-off, with a sensitivity of 0.65 and specificity of 0.62. A similar, less-than-optimal pattern of sensitivity also emerged when considering the HADS. Both original cutoff scores and those proposed in the recent meta-analysis resulted in low sensitivity, while specificity ranged from 0.67 to .86 (Table 4).

Despite the DT emerging as one of the more accurate predictors of distress, if the current cut-off scores for follow-up were employed with a survivorship population, approximately half of those individuals who would like to speak with a health professional would be missed. Thus, there are those for whom symptoms are endorsed but are not accompanied by clinically relevant distress; while the absence of distress is not necessarily synonymous with an absence of desire for help. To illustrate this point we provide a more concrete example of the relationship between distress screening and desire for follow-up. The widely implemented DT was used to distinguish four groups based on distress and desire for follow-up (Table 5). As can be observed, a significant number of participants (*n*=73, 26%) are either identified as “cases” by screening but do not desire follow-up (*n*=53), or the inverse, are missed by screening and yet desired follow-up (*n*=20).

Discussion

The current study examined the role of psychosocial issues and desire for follow-up in a community-based sample of cancer survivors six to ten years post-treatment and not currently engaged in active treatment. As hypothesized, many survivors reported symptoms consistent with late and long-term effects of cancer and its treatments; however only a minority of individuals reported a subsequent desire to speak with a health professional. Importantly, those who did desire follow-up reported significantly more impairment across several psychosocial domains compared to the remainder of the sample, as well as notable differences in demographic characteristics. Subsequent analyses revealed that the combination of the number of psychosocial issues and a widely used screening measure, the Distress Thermometer (DT), were the best predictors of an individual’s desire to speak with a health professional. Importantly however, utilizing this widely-used screening tool resulted in one in four individuals being either identified as distressed but did not desire any follow-up, or inversely, identified as non-distressed but desired follow-up. For survivors, where the emerging issue is help seeking (or not seeking help), traditional distress screening alone may not be optimal in identifying those for whom some effort should be made to provide referral for follow-up care. Thus current screening practices do not address those who want help for symptoms but are not distressed nor provide any model for those who are distressed and do not want help. The current study illustrates the importance of considering full spectrum of survivors in follow-up care. This reinforces the notion that distress alone may not be enough to address the complex clinical task of effectively identifying individuals in need and desiring of support in the context of survivorship.

Psychosocial Issues

Endorsement of psychosocial issues ranged from 15% and 36% of the sample depending on the issue. Previous studies of cancer survivors, most notably breast cancer survivors (which constituted nearly 50% of the current sample), reported that most survivors adjust well after treatment, with only a minority reporting ongoing and persistent psychological distress, depression or anxiety (Casso, Buist, & Taplin, 2004; Ganz et al., 2002; Mitchell, 2007; Pirl et al., 2009; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Whereas it is encouraging that most survivors appear to adjust well post-treatment, it is important that the challenge of providing supportive services to those who do experience long-term or late effects of treatment be rigorously addressed among this growing population.

Participants endorsed an average of nearly 2 psychosocial issues, most frequently memory and concentration difficulties, financial issues, emotional issues and sexual issues. This pattern of endorsement is consistent with past findings and represents a number of often-persistent long-term difficulties faced by survivors in the post-treatment phase (e.g., Alfano & Rowland, 2006; Hewitt et al., 2005). Despite endorsement of some of these issues by as many as 36% of the sample, very few individuals indicated a desire to speak with a health professional, with the highest rates associated with memory and concentration difficulties and emotional issues. Importantly, in spite of relatively few survivors endorsing issues associated with role functioning or relationships, a relatively high number of endorsers desired follow-up. This may be suggestive of the way in which role and relationship issues are perceived; perhaps they are less personal than discussing sexual functioning or more manageable than addressing changes in appearance. Patterns of help-seeking may therefore be associated with certain types of psychosocial issues, and upon further investigation, could assist in targeting screening and follow-up services.

A number of findings are notable in the context of supportive care in cancer survivorship. Sexual issues were reported by nearly one fifth of the survivors surveyed, which is often a function of both physiological changes through treatment (e.g., prostatectomy) and significant psychological changes in such domains as body image. Despite this, sexual issues are rarely discussed with health providers, and few survivors are referred to specialists for medical and psychological services (Flynn et al., 2012; Park, Norris, & Bober, 2009).

As a group, those desiring follow-up with a health care professional were substantively different from those not desiring follow-up across demographic and psychosocial variables. This included significant impairment across measures of depression, anxiety, and quality of life, as well as lower coping self-efficacy and social support. Importantly, survivors reporting lower annual income, being unemployed, or unmarried, widowed or divorced, were more likely to report a desire to speak with a health professional compared to those of higher income brackets, employed or married. These preliminary findings may be suggestive of groups who are not only at-risk for distress and impaired quality of life, but may also report less confidence in managing their distress and fewer resources.

Identification of Follow-up Seekers

The task of identifying individuals in need and desiring of assistance is both challenging and complex, but may represent a new paradigm for follow-up care of cancer survivors, who exist within a variety of post-treatment care models (Ganz, 2009). The relationship between issue endorsement, screening measures, and patient desire for follow-up services, remains largely unknown in the context of survivorship, yet represents a critical step in the long-term management of this growing population.

In an attempt to explore this complex relationship, regression analyses suggested that the number of psychosocial issues endorsed by survivors and the DT emerged as the most accurate predictors of desire for follow-up, though clearly lacking acceptable levels of sensitivity and specificity for broader implementation. Interestingly, the screening measure currently endorsed by the National Comprehensive Cancer Network (NCCN, 2007) includes the DT and a list of symptoms and psychosocial issues, thus aligning with the preliminary findings of this study. This information may help guide the further development of a new screening paradigm that includes patient stratification guidelines to identify survivors who may be in most need and desiring of support.

Whereas the current study did not seek to identify or validate a cutoff score, an examination of the most effective score on the DT for identifying individuals desiring follow-up was conducted. It was found that a rating of 3 or above on this 0 to 10 scale was associated with the greatest level of accuracy in predicting an individual’s desire to speak with a health professional. Similarly, a large survey study of Australian cancer survivors also identified a cutoff of ≥3 as possessing the greatest balance of sensitivity and specificity (A. Boyes, D'Este, Carey, Lecathelinais, & Girgis, 2013) in detecting individuals with depression and/or anxiety. This may be suggestive of a consensus evolving regarding DT cutoff scores for survivors, but does not address the challenge of identifying those who want help with symptoms and are not distressed.

The difficulty of identifying individuals in need and desiring of support was borne out in the fact that a substantial number (>50%) of those who desired follow-up scored below the cut point on routine psychological distress screening measures. This included 35% of individuals desiring support who would not have been identified by any screening measure. Using the DT as a concrete example further reinforces the complexity of this clinical task, with one in four individuals representing either missed opportunities (non-distressed but desiring follow-up) or decliners (distressed but not desiring follow-up). These findings suggest the need for further conceptual and empirical work to determine why those who are identified as clinically distressed do not desire support (so as to ensure effective use of resources), as well as how best to ensure that those who do not endorse distress can still access supportive services for problematic issues.

One possibility by which to address the issue may be to begin to untangle the complex relationship between distress and desire for follow-up. The most effective and sustainable method by which to conduct screening in the context of cancer care may be a two-stage assessment - including both survivors’ symptomatology and their desire or readiness for follow-up care. By enquiring across these dual domains, effective tailoring and prioritization of supportive care can be implemented in clinical care. For example, tactics for engaging those who are distressed and desiring of follow-up care would be different from those who, while not clinically distressed at present, reported a desire for additional services. In addition, individuals who endorse distress or symptomatology but decline follow-up care may represent a different clinical challenge and may benefit from an alternative approach.

The current study must be considered in light of study limitations. Most importantly, the goal of this study was not to estimate prevalence of psychosocial issues. Whereas significant efforts were made to recruit widely and across diverse populations, this sample was not intended to be nationally representative. Further to this point, and similar to other psychosocial research in oncology, breast cancer survivors were overrepresented in the current study. Although there were no substantive differences between participants with breast cancer and other cancers, caution should be used in generalizing results to other survivor populations. **Further caution is warranted given some questions were left unanswered by participants and thus there is missing data across some demographic domains.** Finally, the cross-sectional nature of the study did not allow for issues to be assessed at multiple time points, or causal relationships with outcome measures to be examined. It is acknowledged that this is important information and it is hoped future studies will enable greater insight into not only this, but also participants' reasons for not desiring follow-up with a health professional.

Future research might include an in-depth analysis of survivors' reasons for their lack of interest in follow-up care. It is possible that they may have previously sought assistance for endorsed psychosocial issues to no avail and, therefore, have no interest in further evaluation or follow-up. Moreover, given the ability of individuals to adjust over time to impairments, it is possible that individuals viewed such issues as a natural consequence of their cancer treatment (Homsi et al., 2006) or not a cause of sufficient distress to warrant further help seeking. The investigation of these issues, along with advanced statistical modeling, will help to contribute to a new model of follow-up care for survivors

Clinical Implications of the Study

The current paper provides an important first step in describing the experience of off-treatment cancer survivors, the potential support service needs of this growing population, and the complex nature of identifying those who desire follow-up care. Overall, this study suggests that many survivors are coping well; however, some survivors are experiencing burden and may be reluctant to seek help. Traditional screening measures may not be appropriate indicators of those individuals desiring follow-up amongst cancer survivors. Further research is needed to explore the relationship between psychosocial issues and desire for support services and inform the development of feasible and effective screening methods and interventions in the survivorship phase of care. Providing comprehensive supportive care to survivors is a challenging clinical task; this study provides insight into the complex relationship between psychosocial distress and desire for follow-up care and will help guide the development of effective support for this growing population.

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Table 1

Summary of Demographic and Health Information (N=317)

Demographic Information			Health Information		
Gender[*]			Cancer Diagnosis[*]		
	Male	30%		Breast	46%
	Female	70%		Prostate	14%
Age				Colon/Rectum	6%
	Range	20–89		Non-Hodgkin's Lymphoma	5%
	Mean	62.99			
Ethnicity			Time Since Diagnosis[*]		
	Caucasian	73%		Less than 5 years	21%
	African American	22%		5 – 10 Years	43%
Religious Preference				More than 10 Years	34%
	Christian Faith	87%		Mean (SD)	10.09 (8.3)
Annual Income[*]				Median	7.5
	$0–$14,999	12%	Treatment Type[**]		
	$15,000–$49,999	40%		Chemotherapy	57%
	Over $70,000	24%		Radiation	60%
Marital Status				Surgery	80%
	Married	63%			
	Divorced/Separated	16%			
	Widowed	11%			
Education[*]					
	Completed High School	93%			
	Completed Graduate Degree	19%[^]			
Employment[*]					
	Employed	35%			
	Retired	49%			

Note: This table presents the highest percentage entries. A complete list of all categories is available from the authors.

[^] Counted in both categories.

[*] Missing data, valid percentages reported

[**] Patients may have undergone more than one treatment modality.

Table 2

Most Frequently Endorsed Psychosocial Issues (N=317)

Issue	Endorsed	Desire to speak to HP (% of entire sample)	Desire to speak to HP (% of endorsers)
Memory/Concentration	35.6%	6.0%	16.8%
Financial Issues	26.5%	4.7%	17.9%
Emotional Issues	25.9%	5.4%	20.7%
Sexual Issues	23.0%	2.8%	12.3%
Role Issues	12.6%	2.8%	22.5%
Insurance Issues	10.4%	2.2%	21.2%
Relationship Issues	9.1%	2.5%	27.6%
Appearance Issues	6.6%	0.9%	14.3%
Transportation Issues	5.7%	0.9%	16.7%

[^] Endorsement ≥ 5% of total sample, HP = health professional

Table 3

Analysis of Those Desiring (N=43) or Not Desiring to Speak to a Health Professional (N=274)

Measure	Desire	No Desire
Depression (HADS) *	5.47 (4.7)	3.46 (3.4)
Anxiety (HADS) *	8.53 (4.9)	6.0 (3.8)
Distress Thermometer (DT)	3.9 (3.6)	1.87 (2.5)
Self-Efficacy *	108.3 (25.5)	119.32 (20.3)
Social Support *	36.43 (7.5)	40.48 (7.2)
Quality of Life *	100.5 (21.8)	112.99 (18.2)
Number of Problems *	3.19 (2.45)	1.48 (2.0)

* $p<.01$;

Table 4

Sensitivity and Specificity Scores for the Hospital Anxiety and Depression Scale

	Depression Sensitivity	**Depression Specificity**	**Anxiety Sensitivity**	**Anxiety Specificity**
Original Validation Sample (Zigmond & Snaith, 1983) *(Depression ≥8; Anxiety ≥8)*	0.20	0.86	0.45	0.67
Cancer Meta Analysis (Vodermaier & Millman, 2011) *(Depression ≥6; Anxiety ≥8)*	0.45	0.76	0.45	0.67
Cancer Survivors* *(Depression ≥3; Anxiety ≥7)*	0.70	0.54	0.70	0.57

*Current study sample

Table 5

Grouping Based on Distress and Desire for Follow-up (n=285)[*]

	Desire for Follow-up	
Distressed (DT≥4)	Yes	No
Yes	20	53
No	20	192

[*] DT scores not available for all participants