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CANCER-RELATED HEALTH WORRIES AND PSYCHOLOGICAL DISTRESS AMONG OLDER ADULT, LONG-TERM CANCER SURVIVORS

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SUMMARY

While long-term survivors (5 years+) do not face the stressors of diagnosis and treatment, they continue to face the uncertainties that survivorship brings: recurrence, other cancers, late effects of treatment, and the potential of a shortened life expectancy. This research focuses on the cancer-related health worries of older adult, long-term cancer survivors, the factors that predict these worries, and their link to traditional measures of psychological distress. Specifically, a model is proposed that identifies the personal (including race and gender) and illness/treatment characteristics of survivors that are significantly associated with cancer-related health worries and their effects on anxiety and depression. Descriptive and multivariate analyses of a random sample of 321 long-term survivors in a major cancer center tumor registry are used to address these issues. About one-third of survivors continue to report worries about recurrence, worries about a second cancer, and worries that symptoms they experience may be from cancer. The regression analyses show that cancer-related health worries is a significant predictor of both depression (beta = 0.36) and anxiety (beta = 0.21). Race is a significant predictor; being African American is related to fewer cancer-related health worries (beta = −0.22). Having more symptoms during treatment is also a predictor of having more cancer-related health worries (beta = 0.20). The most consistent predictor of psychosocial distress is dispositional optimism/pessimism, with more optimistic individuals reporting fewer cancer-related health worries (beta = −0.27), lower levels of both anxiety (beta = −0.16) and depression (beta = −0.23). Overall, for many older adult, long-term survivors, the legacy of cancer continues in terms of cancer-related health worries. In spite of these, for most survivors, their quality of life is not dramatically compromised either physically or psychologically.

KEY WORDS: cancer; health worries; psychological distress; older adults; long-term survivorship

INTRODUCTION

This research examines the cancer-related health worries of older adult, long-term cancer survivors, and the factors associated with these worries. We also examine the role that these worries among long-term survivors play in predicting two global measures of psychological distress, anxiety and depression. This is accomplished by analyzing data from in-person interviews with a tumor registry sample of older adults who have survived breast, colorectal, or prostate cancer for five or more years.

Cancer survivorship and distress

Relatively little attention has been given to cancer as a chronic stressor that affects quality of life (QOL) over the life course. Instead, most research has, and continues to focus on the immediate and short-term effects of cancer, primarily at diagnosis, during treatment, or during the first years after treatment (Stanton *et al.*, 2002). Therefore, much of what we know about the psychological distress associated with cancer is from research in the 'acute' rather than the

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'chronic' stage of survivorship. Bloom (2002) indicates that one reason for the relatively little attention to the QOL of long-term cancer survivors is due to the recency of improvement in cancer survival rates. The research that does exist documents that cancer survivors continue to experience health problems, psychological distress, and social life disruption, even decades after diagnosis and initial treatment (Bloom, 2002).

The stressors that persist among long-term survivors are likely to be different from those faced by patients in treatment or in the period immediately following. After diagnosis, cancer patients' concerns are most likely to focus on the treatability of the disease, and prognosis for survival. But once treatment begins, patients' concerns may shift to the potential risks of invasive procedures and the often noxious effects of treatment. After treatment, concerns about recurrence are likely to be most prominent (Ferrell *et al.*, 1998).

With the passage of time, worries about recurrence may be reduced to some degree, while other cancer-related health worries, such as concerns about another cancer resulting from radiation or chemotherapy, may take their place. For example, Mullens *et al.* (2004) found that survivors of colorectal cancer worried more about a new primary cancer than they worried about a recurrence or any other health condition. Concerns about a new or different type of cancer may be compounded by perceptions that whatever predisposition 'caused' the initial cancer may yet produce another. Furthermore, survivors may recognize that even in the general population, the possibility of getting cancer increases with advancing age, making them increasingly vulnerable to another cancer.

Research has also found that distress is associated with continued testing and monitoring (Burish *et al.*, 1992; Glanz and Lerman, 1992). This may continue for years, if not decades, into the chronic survivorship phase. Given this long temporal reach of cancer, it is not surprising that Benyamini *et al.* (2003) found that individuals with a history of cancer were more likely to express cancer-related health worries than a comparison group of individuals who had not had cancer, but lived with a family member who did. Cancer survivors were also more likely to express vulnerability to cancer than either family members of cancer survivors or individuals who did not have a cancer experience.

Cancer-related health worries, anxiety and depression

The above discussion suggests that cancer-related health worries may persist into the chronic stage of survivorship. While some research has shown that these may diminish over time (Mullens *et al.*, 2004), if these worries translate into more general forms of psychological distress such as depression or anxiety, they may be significant in terms of the overall QOL for survivors. A number of studies have documented the prevalence of anxiety and depression among cancer survivors (Thomas *et al.*, 1997; Gotay and Muraoka, 1998; Grassi and Rosti, 1996; Deimling *et al.*, 2002). However, we know of no study that has examined the impact of cancer-relates health worries on survivors' levels of these more general forms of distress. Also, research on distress among long-term survivors has generally not controlled for the effects of other important health stressors, such as co-morbidities, functional difficulties, or dispositional traits such as optimism/pessimism. Finally, prior research on cancer-related health worries has not examined the range of cancer/treatment factors that may play a role in generating these worries and more general forms of distress.

Aging and cancer survivorship

Our research focuses on older adult survivors for a number of reasons. First, as Ferrell (1999) points out, cancer has always been a disease of greater incidence and morbidity in the elderly population, and 'the experience of cancer, superimposed on the normal problems of aging, creates significant burden (p. 239).' Over half of all cancers occur in individuals over 65 years of age and the incidence rate for all sites triples in the 60–79 year age group, compared to individuals age 40–59 (American Cancer Society, 2002). Furthermore, the incidence of the most common forms of cancers (lung, colorectal, breast and prostate) increases dramatically after age 60. The proportion of the population aged 65 and older who are cancer survivors is already substantial and estimated at 16% (Hewitt *et al.*, 2003).

Second, the degree to which cancer adds to the vulnerability of older adults is documented in the gerontological literature. For example, Hewitt *et al.* (2003) found that functional difficulties, in terms of ADL and IADL, and the number of chronic health conditions, increase with advancing age. They further report that among these older adults, functional difficulties and health problems were greater for cancer survivors when compared to individuals with no cancer history.

Third, symptom monitoring is an important part of cancer survivorship that is likely to have special significance for older adult survivors. With increased age, the symptoms of age-related co-morbidities may generate cancer-related health worries, especially if the symptoms are ambiguous. Furthermore, survivors are likely to experience a broad range of illness symptoms that could be perceived as serious threats, especially if they are similar to cancer symptoms previously experienced (Easterling and Leventhal, 1989).

Benyamini *et al.* (2003) found that cancer survivors were more likely than those with no history of cancer to contact their physician to check out ambiguous symptoms. For the breast cancer survivor, enlarged lymph nodes may signify a recurrence, a new cancer, or a simple infection. For colorectal survivors, digestive problems or abdominal discomfort may have ominous meaning, or be the result of a simple dietary problem. Most prostate survivors recognize the potential for their cancer to spread regionally and may interpret problems with urination or elimination as a possible spread of that cancer.

Research questions and conceptual model

Because of the limitations in prior research, we suggest that the following questions remain largely un-addressed:

1. What proportion of long-term survivors continue to express cancer-related health worries such as fears about recurrence, fears of new cancers, concerns that symptoms they experience may represent cancer, and concerns about diagnostic tests?
2. Do these cancer-related health worries and general measures of psychological distress, such as anxiety and depression, differ by cancer type and gender?
3. What are the factors that predict cancer-related health worries, anxiety, and depression among long-term, older adult survivors?
4. Are cancer-related health worries associated with global measures of psychological distress (anxiety and depression) among older adult, long-term survivors?

Our analysis is guided by the conceptual model portrayed in Figure 1 which is derived from the general stress paradigm as developed by Pearlin and colleagues (see Pearlin *et al.*, 1981; Pearlin, 1989). In this formulation, distress (i.e. cancer worries, anxiety and depression) can be viewed as the result of a range of specific stressors. Pearlin and colleagues identify demographic characteristics of individuals such as race, gender, and age as potential chronic stressors. As such, these need to be considered as both stressors and as important covariates in the cancer/distress relationship. Beyond these demographic characteristics, our model includes optimism as an additional predictor. Optimism is typically viewed as a dispositional, trait-like characteristic (Facione, 2002), and has been found to have an impact on distress outcomes in prior research (Schou, 2004). In this research, optimism is an important covariate, as low levels of optimism (i.e. pessimism) may be related to distress.

Of key importance in the model are the illness/treatment characteristics of the survivor, which represent potential primary stressors that may persist into the chronic phase of survivorship. These include cancer type, stage at diagnosis, years since diagnosis, total number of treatments, treatment type, and number of symptoms during treatment.

Pearlin's approach also identifies secondary stressors that arise out of initial stressors, as important in understanding distress. In his original formulation of the stress model, these secondary stressors are typically behavioral responses to illness such as role strain or compromised social relationships. In our adaptation of Pearlin's work, these are replaced by the more temporally proximate illness-related stressors that may have resulted from the initial illness stressors. Potential secondary stressors include the number of current symptoms attributed to cancer or its treatment, the number of current co-morbid health conditions and current functional difficulties. In this model, the primary stressors represented by the demographic/personal characteristics of the survivor, and cancer-related stressors along with secondary stressors represented by current health factors are seen as contributing to cancer-related worries. Cancer-related health worries are in turn seen as

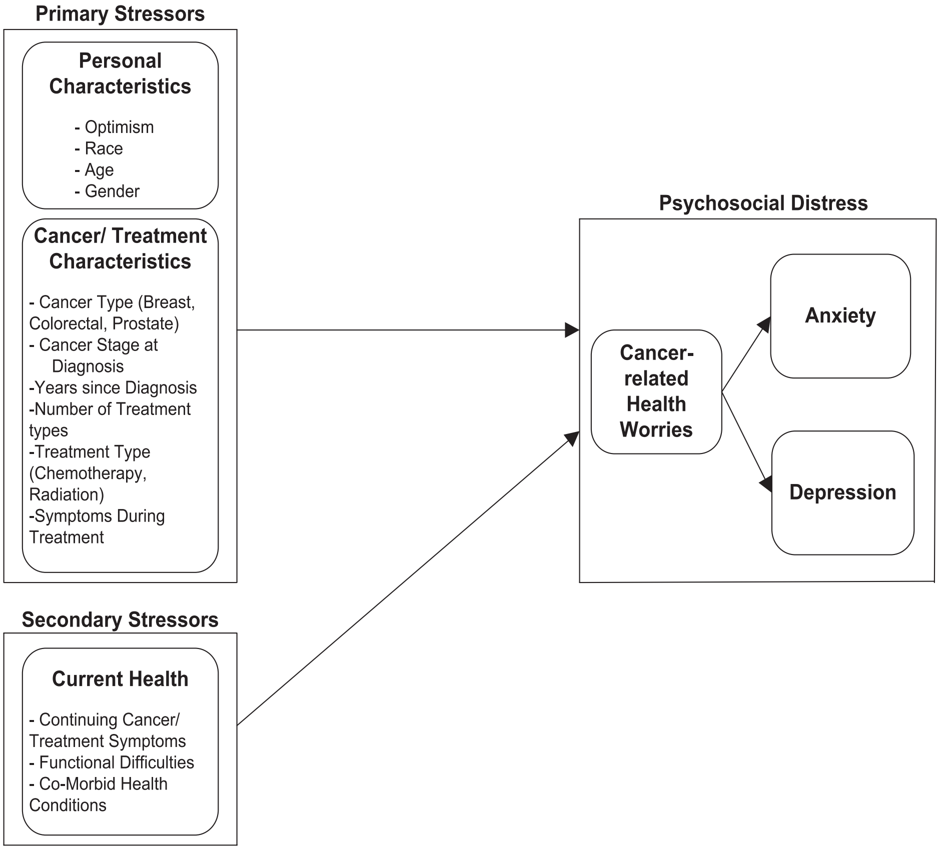

Figure 1. Model of cancer-related worries, depression and anxiety.

an important predictor of two global indicators of distress: anxiety and depression.

METHODS

Data source

The data are derived from an ongoing longitudinal project funded by the National Cancer Institute that will ultimately collect six waves of data over a 10 year period (1998–2008). The sample was selected from the cancer tumor registry of the Ireland Cancer Center (ICC) at University Hospitals Health System (UHHS) in Cleveland, OH using a stratified random sample design. Because the ICC is geographically located in the center of a large metropolitan area, its tumor registry provided a unique opportunity to include a substantial sample of African American cancer survivors. By over-sampling this group, African Americans constitute nearly 40% of the final sample. The sample was further stratified by gender and cancer type with the three most survivable types of cancer among older adults: breast, colorectal, and prostate. Lung cancer was excluded because of the generally poor survival rates that limited the number of long-term survivors in the registry. The results reported here are derived from the analysis of data obtained from the initial in-person interviews with 321 older adult (over 60 years of age), long-term survivors (5–34 years post-diagnosis).

Sample eligibility/acquisition

The sample acquisition for the study began in March 1999. Based on the study's inclusion criteria, the tumor registry selected only persons who: (1) were 60 years of age or older, (2) had been treated for breast, colorectal, or prostate cancer, (3) were 5 years or more from diagnosis and (4) were African American or Caucasian. The resulting sampling frame consisted of 2129 cancer survivors, including 255 (12%) who were African Americans. The study randomly selected from among these individuals to fill the study cells related to race, gender, and cancer type as discussed above. The study also mandated that individuals in the tumor registry who became eligible during sample accrual (having reached age 60 or the 5 year period from diagnosis) would be included. These two groups, those randomly selected and those achieving eligibility during sample accrual, were comprised of 799 survivors. Of these, 46 (6%) were ineligible because they reported not meeting one or more of the study's four eligibility criteria.

Of the remaining 753 persons, the study was unable to contact 118 (16%), 273 (36%) refused to participate, and 362 (48%) agreed to participate. Of the 362 individuals initially agreeing to participate, 41 (11%) did not complete interviews (the study was unable to contact 11 individuals, two died before interviewer contact; four were physically or cognitively unable to do the interview, and 24 refused when the interviewer arrived). The remaining 321 (89%) completed the initial wave one interview upon which the current research is based.

Interviewing procedures

The project hired interviewers who were experienced in talking with and obtaining information from older adults with health problems. They participated in a 6 hours training session with the project's co-principal investigator/project director. Three training modules covered general interviewing techniques, procedures specific to potential risks when interviewing older adults and question-by-question review of the project's structured survey instrument. Manuals containing these protocols were distributed to interviewers and were updated as the study progressed.

After the study was reviewed by an ICC research review committee and approval obtained from the University Hospitals' IRB, letters were sent to prospective respondents from the cancer center's director. Letters included mailback cards indicating willingness to be contacted by the research project. Names and contact information of interested individuals were passed to research staff that called, explained the project, and obtained verbal consent. Names and contact information of those verbally consenting were forwarded to the interviewing staff. Before beginning the face-to-face interviews, all respondents read and signed written informed consents.

Sample characteristics

The personal and cancer-related characteristics of the sample are provided in Tables 1 and 2. Nearly 60% of the sample is female, and African Americans comprised approximately 38% of the sample. In terms of cancer type, the proportion of the total sample with breast cancer was slightly over 41%, prostate cancer survivors comprised approximately 29% of the sample, and colorectal survivors comprised nearly 30%. The mean age of the survivors was 72.3 years with a standard deviation (S.D.) of 7.5, and the mean age at diagnosis was 61.9 with an S.D. of 8.9. The average period of time since diagnosis was 10.4 years with an S.D. of 5.5.

With regard to the cancer/treatment characteristics, the tumor registry provided information on the stage of the cancer at diagnosis. Most survivors in the sample had '*in situ*' (6.5%) or localized cancer (56.7%) at diagnosis. However, nearly 30% had more advanced disease, either regional (27.7%) or distal (1.9%). The average number of types of treatment received was 1.6. Slightly more than 40% of the sample received surgery as the only type of treatment, reflecting the localized nature of the disease. The remainder of the sample received combined therapies, including radiation, chemotherapy, and hormone therapy. Approximately 12% received both surgery and radiation therapy and about 10% had surgery and chemotherapy. Only 5% of the sample was treated with a combination of surgery, radiation, and chemotherapy, however nearly 30% had other combined therapies.

Instrumentation and measures

In-person interviews were conducted with older adult cancer survivors using a structured interview instrument. On average, it took approximately

Table 1. Personal characteristics ($N = 321$)

	N	%
Age (M = 72.3, S.D. = 7.5)		
<60	5	1.6
60–64	45	14.0
65–74	145	45.2
75+	126	39.3
Gender		
Female	190	59.2
Male	131	40.8
Race		
Black/African-American	121	37.7
White/Caucasian	200	62.3
Marital status		
Married	179	55.8
Widowed	83	25.8
Divorced	34	10.6
Separated	2	0.6
Never married	22	6.9
Unknown	1	0.3
Education (M = 13.9, S.D. = 3.5)		
0–11 years	59	18.4
12 years	74	23.1
13–16 years	124	38.6
17+ years	62	19.3
Unknown	2	0.6
Functional difficulties (M = 3.9, S.D. = 3.3)		
0	54	17.1
1	54	17.1
2	32	10.2
3+	175	55.6
Number of co-morbid health conditions (M = 3.7, S.D. = 2.4)		
0	22	6.9
1	32	10.0
2	52	16.2
3	58	18.1
4	49	15.3
5+	108	33.6
Self-rated health (for past year) (M = 3.9, S.D. = 0.8)		
Excellent	71	22.3
Good	166	52.0
Fair	69	21.6
Poor/very poor	13	4.1

Table 2. Cancer/treatment characteristics ($N = 321$)

	N	%
Type of cancer		
Breast	133	41.4
Colorectal	96	29.9
Prostate	92	28.7
Age at diagnosis (M = 61.9, S.D. = 8.9)		
<50	33	10.3
51–60	104	32.4
61–70	126	39.3
71–80	48	15.0
80+	7	2.2
Unknown	3	0.9
Years since diagnosis (M = 10.4, S.D. = 5.5)		
3–10	197	61.4
11–15	71	22.1
16–20	31	9.7
21+	19	5.9
Unknown	3	0.9
Cancer stage at diagnosis		
In situ	21	6.5
Local	182	56.7
Regional	89	27.7
Distal	6	1.9
Not available	23	7.2
Number of current cancer/treatment related symptoms (M = 0.8, S.D. = 1.5)		
0	200	62.3
1	58	18.1
2	33	10.3
3+	30	9.3
Number of treatment types (M = 1.6, S.D. = 0.8)		
0	2	0.6
1	168	52.4
2	100	31.2
3	42	13.1
4+	4	1.2
Unknown	5	1.5
Treatment types		
Surgery only	141	43.9
Surgery and radiation only	39	12.1
Surgery and chemotherapy only	31	9.7
Surgery, chemotherapy, and radiation	16	5.0
Surgery, hormone, and other	45	14.0
Other co-morbid therapies	49	14.0

2 hours to conduct each interview. The questionnaire covered a range of issues related to the illness experience, such as disease and treatment characteristics, health perceptions, and psychosocial sequelae (see Deimling *et al*., 2002). The analyses reported here utilize selected measures in the

following categories: the personal characteristics of the survivor (age, race, gender, and optimism), their cancer/treatment characteristics (cancer type, stage at diagnosis, years since diagnosis, number of treatment types, types of treatment, symptoms during treatment), current cancer/treatment symptoms, current number of co-morbid health conditions, current functional difficulties and measures of psychological distress (cancer-related health worries, anxiety and depression).

Personal characteristics. The *age*, *gender*, *and race* of the respondent were based on tumor registry information and confirmed at the time of interview. Gender and race were used in the correlation and regression analyses and coded as dichotomous variables (0 = male and 1 = female; 0 = Caucasian and 1 = African American, respectively).

Optimism was measured using a subscale of the Life Orientation Test (LOT) (Scheier and Carver, 1985). Optimism, generally viewed as a stable dispositional characteristic of the individual (Scheier *et al*., 1986), was used as a covariate and predictor of the psychosocial outcomes. This eight-item scale included items such as, ‘In uncertain times, I usually expect the best,’ with responses coded on a five-point continuum ranging from ‘strongly disagree’ to ‘strongly agree.’ Scores on this index had a potential range of 8–40 and the scale had an alpha reliability of 0.78. The mean level of optimism in this sample was 30.2, with an S.D. of 4.4.

Cancer/treatment characteristics. The *type of cancer* and *stage at diagnosis* were derived from information in the tumor registry at the Ireland Cancer Center. The *types of treatment* was based on respondents’ self-reports of having received any or all of the following treatments: surgery, radiation, chemotherapy, hormone therapy, and/or other. For correlation and regression analyses, each type was coded as a dichotomous variable (0 = did not receive, 1 = received). Based on this information, a *total number of types of treatment* score was created as were specific combinations of treatment types described previously in the sample description.

A list of 22 possible symptoms including nausea, vomiting, weakness, pain, swelling, impaired immunity, loss of balance, numbness, and burns was used to elicit respondents’ self-report on the presence of these cancer/treatment effects. This list of symptoms was constructed based on focus groups conducted with long-term cancer survivors and was reviewed by three physicians, including a surgical oncologist and two family practice physicians. Using this list, respondents were asked to recall which of these symptoms they had experienced during treatment. This information was used to construct an index of *symptoms during treatment*. The mean number of symptoms reported by survivors as being experienced during treatment was 1.5, (S.D. = 2.0), with an actual range from 0 to 22.

Cancer/health stressors. Three measures are included in the model that represents the current cancer and health stressors of respondents. The list of 22 possible symptoms described above was also used to construct the measure of *current cancer/treatment-related symptoms*. Even though many of these symptoms are unlikely to occur after treatment, using the list of symptoms allows us to assess changes in the level of symptoms from the treatment period compared to those currently being experienced. The average number of symptoms reported as currently experienced was 0.8 (S.D. = 1.5), with an actual range of 0–22.

A list of 28 possible current co-morbid health conditions was used to assess the current health problems reported by the survivors. This list was based on the Older American Resources Survey-OARS (George and Fillenbaum, 1985), an instrument widely used in the fields of gerontology and geriatrics. The resulting co-morbid *health conditions* index was a sum of the number of current health conditions that respondents reported being diagnosed by a physician. In this sample of long-term survivors, the mean number of conditions reported was 3.7 (S.D. = 2.4), with an actual range of 0–28. In our sample only 7% had no other chronic conditions (besides cancer), 10% had one chronic health condition, and 83% had two or more. Utilizing data from the National Health Interview Survey, Hewitt *et al.* (2003) found that among individuals 65 or older with a self-reported cancer history, 48% had no other chronic conditions, 36% had one, and 16% had two or more conditions. They also found that among individuals who did not report a history of cancer, 56% had no other chronic medical condition, 32% had one, and 12% had two or more. While a strict comparison of our sample with these data is not possible, it is clear that our sample reports a substantially greater number of co-morbid health conditions.

The measure of functional difficulties used in this research was developed by Nagi (1976). This *functional difficulties index* assesses the problems survivors had with 11 specific motions or movements, such as standing, lifting or carrying objects, moving limbs, stooping/bending, or kneeling. Responses were scored on a four point continuum from '0 = no difficulty' to '3 = unable to perform'. Unlike traditional measures of functioning (ADL and IADL), this measure is not contaminated by the social support or sources of assistance that play a role in a survivor's ability or inability to perform daily activities. Moreover, the kind of motions and movements included in this index are relevant to the problems that cancer survivors might experience, such as breast cancer survivors inability to reach or stretch as the result of a mastectomy and associated lymph edema. Scores on the scale could range from 0 to 33. Survivors in this sample had mean scores of 5.2 (S.D. = 5.4), indicating relatively low levels of functional difficulty.

Psychological distress. Cancer-related health worries were conceptualized and measured based on the work of Gotay and Muraoka (1999) and previously used by Bowman *et al*. (2004) to study appraisal of the cancer experience by older adults. Four items that tap this domain were included in this research: 'I worry about my cancer coming back,' 'I am sometimes concerned that symptoms I experience may indicate the recurrence of cancer,' 'I worry about future diagnostic tests,' and, 'I worry about another type of cancer.' Responses were scored on a five-point continuum from '1 = Strongly agree' to '5 = Strongly disagree.' In the descriptive and correlational analyses, these four items were used individually as single item indicators.

These four items were then totaled to construct a *cancer-related health worries scale* in regression analyses**.** The mean score of this indicator was 11.2 (S.D. = 3.4), with a potential range of 4–20. The alpha reliability for this scale was 0.84. Because cancer-related health worries might be considered an alternative measure of general distress, exploratory factor analysis was conducted to determine whether these worries are empirically distinct from anxiety and depression. The results of that analysis indicated that the cancer-related health worries items do not cross-load significantly with items from either the anxiety or depression scales, suggesting that they are empirically distinct (analysis not shown, available from authors upon request).

Two measures of general psychological distress were used: anxiety and depression. The *anxiety* measure was derived from The Profile of Mood States (POMS; McNair *et al*., 1971). Respondents were asked the degree to which statements described how they had been feeling during the past week including the interview date. Responses ranged from '0 = not at all' to '4 = extremely.' The anxiety sub-scale contains nine items such as shaky, tense, on edge, and panicky. The mean score on the scale for this sample, which had a potential range of 0–36, was 4.9 (S.D. = 4.8), with the higher score indicating more anxiety. The alpha reliability coefficient was 0.86.

The second measure of general psychological distress was a widely used measure of *depression*, the CES-D (Radloff, 1977). This scale consists of 20 items asking respondents the frequency during the past year that they have felt depressed, happy, lonely, sad, and fearful. Answer categories ranged from '0 = never/rarely' to '4 = all of the time.' The mean score on the scale for this sample, which had a potential range of 0–80, was 12.5 (S.D. = 9.2), with higher scores indicating more depression. The depression scale had an alpha reliability of 0.87.

Analysis plan

Descriptive data on cancer-related health worries are presented as a prelude to the correlation and regression analyses. Information on the specific worry items is presented by cancer type and gender. Correlation analysis is presented that describes the strength and directions of the association between the survivors' personal characteristics, cancer/treatment measures, current health indicators, and the distress outcomes. This bivariate analysis identifies the most important predictors of cancer-related health worries, anxiety, and depression that are included in the regression analyses.

Based on the conceptual model, a series of regression equations are estimated that provide the coefficients to examine the relative strength of personal, cancer-related and general health stressors on cancer-related health worries, anxiety, and depression. The coefficients provided are the standardized regression coefficients (beta) and the unstandardized regression coefficient (*b*) that identify the net effects of each predictor on the respective outcome. The regression analysis also provides basic goodness-of-fit information (R^2, F, and p-values) for the respective equations.

FINDINGS

Specific cancer-related health worries

Figure 2 displays the percentage of survivors who report specific types of cancer-related health worries. This descriptive information is provided by cancer type and gender. It is clear from this data that long-term survivors continue to express concerns about their health related to cancer. With regard to concerns about recurrence, depending on cancer type, 27% to nearly 40% of survivors continue to have these concerns. These concerns are most prominent among prostate and male colorectal cancer survivors. The data also indicate that many long-term survivors continue to worry that a current symptom they experience may indicate a cancer recurrence. Depending on the type of cancer, 34–41% report these worries, which are most prominent among male colorectal cancer survivors.

Long-term survivors also expressed concerns about getting another form of cancer at levels similar to concerns about recurrence, ranging from 26 to 36%, with prostate cancer survivors among those most likely to have this concern. Potentially related to both worries about recurrence and getting another type of cancer, are worries about future diagnostic tests, which may discover either a recurrent cancer or a new cancer. Worries about testing continue to be expressed by 36–44% of survivors, with colorectal cancer survivors most likely to express this concern.

Table 3 provides the means and S.D. on the three distress indices (i.e. the cancer-related health worries, POMS anxiety, and CES-Depression scales) displayed by cancer type and gender. The

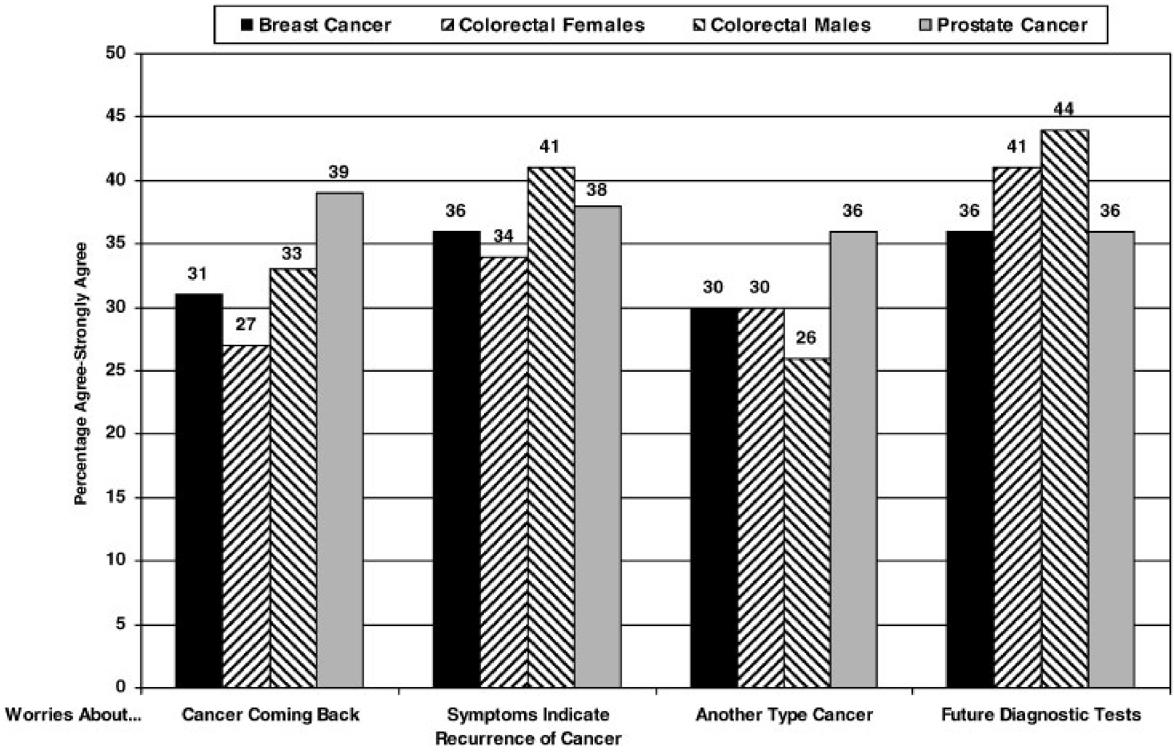

Figure 2. Cancer-related worries by cancer type and gender.

Table 3. Cancer-related health worries, depression and anxiety by cancer type and gender ($N = 321$)

	Breast ($N = 133$)		Colorectal				Prostate ($N = 92$)			
			Female ($N = 57$)		Male ($N = 39$)					
Psychosocial distress scales	Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.	F	p
Cancer-related health worries	10.9	3.6	10.9	3.2	11.7	3.1	11.4	3.3	0.73	0.53
Anxiety	5.3	5.3	5.8	5.2	4.0	3.4	4.2	4.3	2.05	0.11
Depression	13.8	10.0	14.1	8.7	11.0	9.2	10.2	7.9	3.35	0.02

data show that neither cancer-related health worries nor anxiety differs significantly by cancer type or gender, although a pattern was evident. While men reported more cancer-related health worries, they had lower anxiety scores than women, on average. Significant differences were found by cancer type and gender with regards to depression. Looking at the gender-unique cancers, breast and prostate, women had substantially higher average levels of depression than men (13.8 vs 10.2). Women also had greater average depression in terms of common cancer, i.e. colorectal (14.1 vs 11.0).

Bivariate correlation analysis

The analysis turns next to the correlation data provided in Table 4, in which the level of association between personal characteristics, cancer/treatment characteristics, and current health stressors of survivors, and the psychosocial outcomes (specific cancer-related health worries, the cancer-related health worries scale, POMS anxiety, and CES-D depression) are displayed. Looking first at the correlates of the individual variables that comprise the cancer-related health worries scale, a number of statistically significant, albeit modest, associations were found. Significant correlates of worry about recurrence ('cancer coming back') were optimism ($r = -0.22$), years since diagnosis ($r = -0.13$), having had radiation treatment ($r = 0.13$), number of symptoms reported as having occurred during treatment ($r = 0.22$) and current cancer symptoms ($r = 0.19$). Age ($r = -0.11$), number of types of treatment received ($r = 0.13$), and current cancer/treatment-related symptoms ($r = 0.19$) were statistically significant correlates of worries that current health symptoms might indicate a recurrence.

The correlation data also show that survivors who were less optimistic ($r = -0.27$), more temporally proximate to the cancer diagnosis ($r = -0.15$), had more symptoms during treatment ($r = 0.14$), and more current symptoms attributed to cancer/treatment ($r = 0.15$) were more likely to worry about diagnostic tests. Finally, African Americans, survivors who had higher scores on optimism, and older survivors were less likely to worry about another type of cancer ($r = -0.19$, -0.15, and -0.13, respectively). Also, survivors who reported fewer symptoms during treatment ($r = 0.19$), and those reporting fewer current cancer/treatment symptoms ($r = 0.14$) reported lower levels of worry about another cancer. Again, while these coefficients were statistically significant, they are modest in strength of the association they represent.

Looking next at the correlates of the cancer-related health worry scale, (a composite of the four cancer-related health worries items), age ($r = -0.11$) and optimism ($r = -0.27$) were statistically significant correlates, indicating that older survivors and those who had an optimistic disposition reported a lower level of cancer-related health worries. The next strongest correlate of cancer-related health worries was the number of symptoms that survivors reported as occurring during treatment ($r = 0.23$), with those reporting the most symptoms continuing to express the most cancer-related health worries. Similarly, the number of current cancer/treatment symptoms was also a statistically significant correlate ($r = 0.19$). Finally, the number of years since diagnosis was found to be weakly associated with cancer-related health worries, with the level of these worries diminishing over time ($r = -0.14$).

Table 4. Inter-item correlations ($N = 321$)[a]

	Specific cancer-related health worries				Psychosocial distress scales		
	Worry about cancer coming back	Worry that symptoms indicate recurrence	Worry about future diagnostic tests	Worry about another type of cancer	Cancer-related health worries	Anxiety	Depression
Personal characteristics							
Race (1 = African American)	−0.05	−0.09	−0.06	−0.19**	−0.11	−0.04	−0.02
Gender (1 = Female)	−0.07	−0.02	−0.02	−0.02	−0.08	0.14**	0.19**
Age	−0.10	−0.11*	−0.01	−0.13*	−0.11*	−0.09	−0.04
Optimism	−0.22**	−0.11	−0.27**	−0.15*	−0.27**	−0.26**	−0.35**
Cancer stressors							
Breast cancer	−0.03	0.01	−0.01	−0.01	−0.05	0.07	0.12*
Prostate cancer	0.06	0.00	−0.03	0.03	0.04	−0.09	−0.16**
Cancer stage at diagnosis	0.01	0.08	−0.02	−0.02	0.01	0.04	0.12*
Years since diagnosis	−0.13*	−0.10	−0.15**	−0.09	−0.14*	0.07	0.04
Number of treatment types	0.06	0.13*	0.10	0.06	0.08	0.01	0.05
Chemotherapy	0.01	0.04	0.09	0.01	0.05	0.06	0.13*
Radiation	0.13*	0.09	0.07	0.11	0.10	−0.06	−0.07
Symptoms during treatment	0.22**	0.16	0.14*	0.19**	0.23**	0.20**	0.22**
Current cancer/ health stressors							
Current cancer/treatment symptoms	0.19**	0.19**	0.15**	0.14**	0.19**	0.14*	0.16**
Health condition index	0.04	−0.02	−0.04	0.08	0.07	0.23**	0.09
Functional Difficulty	0.03	−0.01	−0.02	0.05	0.05	0.19**	0.26**

[a] N may vary for specific coefficients due to missing data.
*$p \leqslant 0.0.05$, **$p \leqslant 0.01$.

With regard to anxiety, optimism was again the strongest correlate ($r = -0.26$), with more optimistic survivors demonstrating lower levels of anxiety. Gender emerged as a correlate of anxiety ($r = 0.14$), with women reporting higher levels of anxiety as shown above in the descriptive data. Symptoms during treatment and current cancer/ treatment symptoms were also statistically significant, although modest correlates of anxiety ($r = 0.20$, 0.14). Other statistically significant correlates of this measure were the number of co-morbid health conditions ($r = 0.23$) and functional difficulties ($r = 0.19$).

With regard to depression, optimism continued to be the strongest correlate ($r = -0.35$). As with anxiety, women reported higher levels of this distress outcome than men ($r = 0.19$). Symptoms during treatment ($r = 0.22$) and current cancer/ treatment symptoms ($r = 0.16$) continued to be significant correlates. Having breast cancer was associated with higher levels of depression ($r = 0.12$) while having prostate cancer was associated with lower levels of this outcome ($r = -0.16$). Chemotherapy treatment was associated with greater depression ($r = 0.13$). The strongest current cancer/treatment stressors related to depression was functional difficulties ($r = 0.26$).

Regression analyses

While the correlation coefficients provide a preliminary picture of the factors that explain cancer-related health worries and general distress among long-term survivors, the multivariate approach that regression provides makes it possible to identify the net effects (i.e. controlling for other predictors/covariates) of each predictor. Since optimism, a dispositional or trait-like characteristic was a consistent predictor of the all of the outcome measures, it is especially important to control for its effects on the relationships between other model variables and to examine its unique effect on distress. Table 5 provides the standardized regression coefficients (beta), along with the

Table 5. Regression analyses of psycho-social distress characteristics ($N = 321$)

	Cancer-related health worries			Anxiety			Depression		
	Beta	b	p	Beta	b	p	Beta	b	p
Personal characteristics									
Race (1 = African American)	−0.22	−1.56	0.00	−0.10	−0.92	0.14	−0.08	−1.38	0.21
Gender (1 = Female)	−0.09	−0.61	0.44	0.15	1.33	0.21	0.09	1.58	0.39
Age	−0.08	−0.03	0.24	−0.08	−0.04	0.24	0.00	0.00	0.95
Optimism	−0.27	−0.20	0.00	−0.16	−0.17	0.01	−0.23	−0.45	0.00
Cancer/treatment characteristics									
Breast cancer	0.04	0.30	0.64	−0.07	−0.61	0.48	−0.04	−0.73	0.63
Prostate cancer	−0.01	−0.08	0.92	0.04	0.39	0.69	0.01	0.21	0.91
Cancer stage at diagnosis	−0.09	−0.50	0.21	−0.06	−0.45	0.41	−0.03	−0.42	0.67
Years since diagnosis	−0.05	−0.03	0.49	−0.03	−0.02	0.67	−0.05	−0.07	0.47
Number of treatments	0.05	0.23	0.58	0.00	−0.02	0.97	−0.04	−0.46	0.64
Chemotherapy	0.02	0.16	0.83	0.12	1.25	0.23	0.10	2.15	0.25
Radiation	0.07	0.48	0.40	−0.08	−0.72	0.35	−0.11	−1.41	0.16
Symptoms during treatment	0.20	0.33	0.03	−0.01	−0.01	0.96	0.09	0.34	0.32
Current cancer/health stressors									
Current cancer/treatment symptoms	0.01	0.02	0.93	0.03	0.09	0.73	−0.06	−0.29	0.50
Co-morbid health conditions	−0.03	−0.04	0.67	0.13	0.24	0.06	−0.07	−0.26	0.27
Functional difficulties	0.06	0.04	0.46	0.06	0.05	0.46	0.27	0.41	0.00
Psychosocial distress									
Cancer-related health worries	—	—	—	0.21	0.28	0.00	0.36	0.94	0.00
	$R = 0.44$			$R = 0.41$			$R = 0.60$		
	$R^2 = 0.19$			$R^2 = 0.17$			$R^2 = 0.36$		
	Adjusted $R^2 = 0.14$			Adjusted $R^2 = 0.11$			Adjusted $R^2 = 0.31$		
	$p < 0.000$			$p < 0.000$			$p < 0.000$		

unstandardized coefficients (b) and the related p-values for each of the three equations.

Looking first at the cancer-related health worries outcome, two of the personal characteristics of survivors had significant effects. Optimism (beta $= -0.27$) was the single strongest predictor of worries, and being African American was significantly related to lower levels of cancer-related health worries (beta $= -0.22$). The sole significant cancer/treatment characteristic predictor of cancer-related health worries was symptoms during treatment (beta $= 0.20$). The model explained 19% of the variance in this outcome.

Optimism was also an important predictor of the more general measures of distress, anxiety and depression (beta $= -0.16$ and -0.23). None of the cancer/treatment characteristics were significant predictors of these distress outcomes. However, cancer-related health worries were the single strongest predictor of both anxiety (beta $= 0.21$) and depression (beta $= 0.36$). Importantly, this relationship persists when the effects of optimism and the other personal and cancer characteristics are statistically controlled. The model explains 17% of the variance in anxiety, and 36% of the variance in depression.

DISCUSSION AND SUMMARY

The descriptive findings and the regression analyses provide a relatively clear picture of the role that the survivors' personal and cancer/treatment characteristics play in their continuing health worries related to cancer and how these in turn impact their broader mental health. First, survivors, even those whose cancer experience is decades in the past, continue to experience health worries related to that experience. That these cancer-related worries persist beyond the 5-year anniversary, the period often thought of by many as indicating a 'cure,' suggests that the cancer experience has a long temporal reach. Moreover, that these worries encompass not only fears of recurrence, but worries about other cancers and diagnostic testing, suggests the breadth of these concerns. It also suggests that most survivors realistically recognize that 5-year survival does not 'guarantee' a cancer-free future, and that there is the possibility of getting a new type of cancer from the carcinogenic effects of treatment. The data are consistent in showing that these worries, while present, do diminish with temporal distance from the diagnosis/treatment period, and also with advancing age.

The data presented also demonstrate that cancer-related health worries can be empirically linked to specific aspects of the illness experience (symptoms, type of treatment, etc.). Further, these worries are significant predictors of overall mental health, as measured by anxiety and depression. The fact that cancer-related health worries persist and are associated with anxiety and depression speaks to their potential to contribute to a reduced QOL. It is also important that the association between cancer-related health worries is strongest with depression, and that approximately 24% of our sample of survivors scored above the cut-off for clinical levels of depression (scores of 16 or higher on the CES-D). The gerontological literature shows that rates of clinical depression have been found to range from 8 to 17% in the population over age 65 (Blazer, 2003). As such, the cancer-related health worries reported by survivors should be an important consideration for oncologists, primary care practitioners, and mental health professionals treating older adult long-term survivors, as they may be linked to depression.

The correlational analysis also suggests that for older adults, co-morbidities and functional difficulties play a slightly greater role in the anxiety they experience than do current symptoms attributed to cancer or its treatment or cancer-related health worries. It should be noted that this sample clearly reports more co-morbidities than older adults with or without cancer in the NHIS sample (Hewitt, 2003). The regression analysis shows that functional difficulties also play a substantial role in the levels of depression survivors report. However, the fact that cancer-related health worries play a larger role than either co-morbidities or functional difficulties in explaining depression is an important finding for those who treat older patients.

Given the interest in health disparities related to gender and race, the findings are also instructive. In the general population, women consistently report more depression than men (Turner and Lloyd, 1999), and lower emotional well-being (Wan *et al.*, 1997). Therefore, it is not surprising that, in our analysis, being female is significantly, although weakly, correlated with both anxiety and depression. That relationship disappears, however, in the multivariate analyses when other factors such as co-morbidities and functioning are controlled. Moreover, being female is not associated with more cancer-related health worries in either the bivariate analyses or the multivariate regression where the effects of health factors are controlled. This is not to suggest that gender is not an important consideration in understanding the mental health of long-term survivors, but it is likely that other health factors, that is, those factors other than cancer, are likely to be more important.

With regard to race, the correlation analysis shows that compared to Whites, African American survivors report lower levels of cancer-related health worries, but do not report significantly different levels of either depression or anxiety. Further, as with gender, race may disadvantage the survivor in terms of more general aspects of health and functioning, but any racial health disparity is not necessarily due to the cancer experience. Other research points to the role that race plays in delayed diagnosis and poorer prognosis and survival (Clayton and Byrd, 1993). These disparities do not appear to translate into more health worries about cancer among minority survivors later in life. While this is a positive finding with regards to African Americans expressing less worry, there is a potential negative component. Survivors who have less concern about recurrence or another cancer may be less vigilant in monitoring cancer-indicative symptoms or may be less likely to contact their physician when such symptoms occur. As a result, healthcare practitioners may want to discuss specific aspects of symptom monitoring with minority survivors.

There are a number of important limitations and caveats that need to be considered in interpreting this research. First, data on symptoms during treatment were based on retrospective reports. These reports may be, in part, a function of the respondent's psycho-social characteristics at the time of the interview, with more anxious, depressed, or worried respondents reporting more symptoms. Similarly, reports of current health problems and symptoms may be the result of their current levels of distress as individuals who are likely to endorse symptom reports are also likely to endorse the distress measures. The cross-sectional nature of the analysis and the use of retrospective reports for past symptoms does not allow us to untangle the causal sequence of these factors, or examine reciprocal causality.

Another limitation is that cancer survivors in the tumor registry with severe co-morbidities may not have survived to be included in the study. As a result, the variance on co-morbidities may be limited, and make it difficult to fully address the role of other health problems relative to cancer. Untangling these effects requires a prospective, longitudinal design that follows cancer patients from the acute phase into the chronic phase of survivorship. To our knowledge, no such research currently exists, but such a design would be ideal for a more complete understanding of other health problems role in cancer survivorship.

A related limitation, one inherent in long-term survival research, is the fact that individuals who were initially diagnosed with advanced disease are less likely to have survived long-term, especially given the lower survival rates that were typical decades earlier when individuals in our sample were diagnosed. Furthermore, those with localized disease are likely to have received less extensive treatment, as is true for our sample where most received surgery as the only form of treatment. As a result our sample, like most long-term survivor samples, is inherently skewed toward lower levels of cancer-related stressors. However, it is important to note that a substantial number of survivors in our sample did have metastatic disease and many received radiation and/or chemotherapy. Further, in our analysis neither cancer stage nor treatment type were significant predictors of cancer-related health worries in the regression analysis. The fact that from one-third to one-half of survivors report cancer-related health worries, verifies that even early stage, survivable cancers that receive limited treatment continue to generate distress years, if not decades, after treatment for some.

Finally, it is important to note that, in spite of the relative prominence of continuing health worries related to cancer, most survivors report fairly few continuing symptoms, few functional difficulties, and low levels of distress. In general, our findings replicate other researchers' findings that most long-term cancer survivors do not experience serious psychological problems (Hewitt *et al.*, 2003). For most older adult long-term survivors, the legacy of cancer continues in terms of health worries, but does not dramatically compromise their physical or psychological QOL.

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