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# Characterizing the Psychological Distress Response Before and After a Cancer Diagnosis

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# Abstract

Psychological distress among cancer survivors is common. It is unknown if symptoms predate diagnosis or differ from patients without cancer because studies are limited to patient follow-up. Linked cohort (Wisconsin Longitudinal Study) and tumor registry records were used to assess the psychological distress response pre- to post-cancer diagnosis. Adjusted predicted probabilities of being in one of five categories of change for three psychological distress measures (depression, anxiety, well-being) were compared for participants diagnosed with cancer between 1993–1994 and 2004–2005 and participants without cancer (N=5,162). Cancer survivors were more likely to experience clinically significant increases (0.8 standard deviation) in depression (15%, 95%CI=12–18%) and anxiety (19%, CI=16–22%) compared to their no-cancer counterparts (10%, CI=10–11%; 11%, CI=11–12%). Cancer survivors <5 years from diagnosis were more likely to experience worsening depression. Survivors 5 years were more likely to experience worsening depression. Survivors 5 years were more likely to experience worsening depression. Survivors 5 years more likely to experience worsening depression. Survivors 5 years were more likely to experience worsening anxiety. No significant results were found for well-being. Characterizing the psychological distress response is a prerequisite for identifying at-risk patients and communicating expected symptoms, allowing for proactive resource provision.

### Keywords

cancer; oncology; depression; anxiety; quality of life; psychological well-being

As the cancer survivor population grows, so too does concern for the psychological adaptation of these patients (Hewitt et al. 2006, Institute of Medicine 2008), a significant proportion of whom exhibit high levels of psychological distress (depression and anxiety) (Zabora et al. 2001). The prevalence of psychological distress (e.g., post-traumatic stress, depression, anxiety) at the time of and up to 4 years following diagnosis has been estimated at 20–40% (Bleiker et al. 2000, Deimling et al. 2002, Zabora et al. 2001). Depressive

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symptoms in particular have been shown to be costly in terms of well-being and in increased health care use, estimated at approximately \$3,000 per patient (Druss and Rosenheck 1999). As a result, the Canadian Council of Health Services Accreditation has included psychological screening as a "sixth vital sign" in their cancer care standards (Accreditation Canada 2008).

Due to the limitations of prior studies, little is known about the psychological distress response (which can encompass both distress and well-being) following a cancer diagnosis. It is not known, for example, if the level of psychological distress among cancer patients predates the illness or whether it truly differs from people without cancer, as the majority of studies are limited to the follow-up of cancer survivors (Bowman et al. 2004, Deimling et al. 2002, Zabora et al. 2001). In addition, studies have emphasized immediate and short-term effects, primarily at diagnosis or initial treatment (Bloom et al. 2004, Deimling et al. 2007, Deimling et al. 2006b). Even the few studies that have included comparison groups (Andrykowski et al. 1996, Cella and Tross 1986, Tomich and Helgeson 2002), have been limited by relying on the recall of pre-cancer psychological distress in the cancer and comparison groups or have emphasized general quality of life changes within one year of diagnosis.(Baker et al. 2009, Reeve et al. 2009) One notable exception is a study by Trentham-Dietz et al. (2008) that demonstrated greater quality of life declines in breast cancer patients pre- to post-diagnosis than in age-matched controls over the same time period (Trentham-Dietz et al. 2008), though longitudinal information (2 years postdiagnosis) was available for only 26 women. The lack of information about the magnitude and long-term temporal course of the psychological distress response after a cancer diagnosis is a critical gap, as clinicians currently do not know what changes in psychological distress to expect in their patients or how to identify patients at risk.

Previous studies have primarily incorporated a narrow psychological distress definition that does not recognize the potential for a cancer diagnosis to evoke positive as well as negative psychological states. Qualitative and cross-sectional studies suggest there may be a subset of patients who report positive psychological changes at the time of diagnosis or months to years later (Andrykowski et al. 1996, Cella and Tross 1986, Ganz et al. 1996). It is unclear, however, whether these positive psychological changes are real or an artifact of study design (Sumalla et al. 2009).

The purpose of the current investigation is to estimate the magnitude and long-term temporal course of the cancer psychological distress response, incorporating negative (depression and anxiety) and positive (psychological well-being) measures. We address the limitations of prior studies with the use of a longitudinal cohort study linked to tumor registry records. The availability of prospectively-collected information for participants with and without cancer, coupled with medical-record based cancer information, created an opportunity to compare changes in psychological distress in cancer survivors to changes in participants without cancer but who are likewise facing aging and increasing chronic disease risk.

#### Method

#### **Data Source and Participants**

Participants were from the Wisconsin Longitudinal Study, a cohort of a one-third random sample of people who graduated from Wisconsin high schools in 1957 (N= 10,317) and 8,778 randomly selected siblings of these graduates. Mail and telephone-administered surveys were collected from the original graduates in 1957, 1964, 1975, 1993, and 2004 and a sibling in 1977, 1994, and 2005. Extensive measures were included in the 1993–1994 (precancer) and 2004–2005 (post-cancer) surveys used in the current analysis. Among respondent survivors, the telephone and mail survey response rates in 1993–1994 were 93%

and 76% for graduates and 87% and 77% for siblings (N= 8,054). The sample was restricted to the 66% of Wisconsin Longitudinal Study participants who resided in Wisconsin from 1993–1994 to 2004–2005 (N= 5,317) to capture data on incident cancer cases in Wisconsin's tumor registry ("Wisconsin Cancer Reporting System"). Cancer survivors were restricted to participants diagnosed with cancer between the 1993–1994 and 2004–2005 surveys to allow for an assessment of pre- to post-cancer diagnosis change in psychological distress. The final sample size included 5,162 participants (3,578 graduates and 1,584 siblings).

**Cancer Case Identification**—The Wisconsin Longitudinal Study was linked to the Wisconsin Cancer Reporting System (Wisconsin Cancer Reporting System 2007) based on name(s), gender, street address(es), Social Security number, and day/month of birth. This linkage allowed for a medical records-based cancer assessment, including cancer site, Surveillance Epidemiology and End Results summary stage, and diagnosis year. Through the linkage, we identified 448 participants (8.7%) with one or more primary cancers diagnosed between 1993–1994 and 2004–2005. The participating University approved this study with verbal informed consent from participants.

#### Measures

Outcome Variables—The outcome variable of interest was change in psychological distress, as defined by depression, anxiety, and psychological well-being. Depressive symptoms were measured using the 20-item Center for Epidemiological Studies Depression Scale (Radloff 1977). Anxiety was assessed with a modified version of the 20-item Spielberger State Trait Anxiety Index that measures "state anxiety" (Spielberger et al. 1970). One modified version of the "state" component of the State-Trait Anxiety Scale is a 10-item self-report measure that includes the 10 symptoms assessed in the state anxiety component of the State-Trait Personality Inventory (extent participant feels calm, tense, nervous, at ease, steady, frightened, worried over possible misfortunes, or are jittery, relaxed, or worried) (Spielberger 1995). In the Wisconsin Longitudinal Study, participants were asked to report symptom frequency in the previous week, but only 7 of the 10 items were collected longitudinally (frightened, worried, and steady were excluded). Correlations between the 7 and 10 item versions of the State Trait Anxiety Index in the study were found to be high (r =0.98, p < 0.0001). A previous study has also utilized the anxiety measure in this way to assess change in symptoms longitudinally (Springer et al. 2003). Psychological well-being was assessed via a shortened version of the Psychological Well-Being scale (Ryff 1989, Rvff 1995). Longitudinal anxiety information was available for sibling respondents only (*n* = 1,584). A study that examined the relationship between the shortened and longer versions of the Psychological Well Being scale found that the reduced set of items were highly correlated with the full set of items and factor analysis confirmed that the items represented a common factor and could be used to assess psychological well-being (Springer et al. 2006, Springer et al. 2004). The internal consistency reliability of the summated scales as used in the current study were assessed with the calculation of Cronbach's alpha statistics, which suggested good reliability (>0.8) for both the 1992–1993 and 2003–2004 surveys.

The dependent variable included five categories of change in psychological distress from 1993–1994 to 2004–2005. The cut-points used to define the categories were based on the standard deviation (*SD*) of the psychological distress measures in 1993–1994: two categories of improving symptoms (0.5–0.8 *SD* or 0.8 *SD* change), two categories of worsening symptoms (0.5–0.8 *SD* or 0.8 *SD* change), and a "no change" category (< 0.5 *SD* change). These distribution-based cut-points reflect moderate (0.5–0.8 *SD* change from 1993–1994 to 2004–2005) to large (0.8 *SD* change) effect sizes (Norman et al. 2003). In the Wisconsin Longitudinal Study, a 0.5 *SD* change in depression and anxiety symptoms (5

points for the Center for Epidemiological Studies Depression Scale and State Trait Anxiety Index) reflects minimally clinically relevant changes (Green et al.), while a 0.8 *SD* change (7 points for the Center for Epidemiological Studies Depression Scale and State Trait Anxiety Index) has been shown to reflect clinically meaningful changes for the Center for Epidemiological Studies Depression Scale (De Beurs et al. 2001, Schulz et al. 2002b) and State Trait Anxiety Index (Fisher and Durham 1999) measures. No clinical standard for change has been established for the Psychological Well Being Scale (0.5 *SD* = 6 points, 0.8 *SD* = 9 points in this sample).

**Primary Explanatory Variable**—The primary explanatory variable was the receipt of a cancer diagnosis between 1993–1994 and 2004–2005 (yes/no). A secondary explanatory variable was constructed to assess the relation between the time that had elapsed between a respondent's most recent cancer diagnosis and the 2004–2005 survey (no cancer, < 5 years,

5 years) and changes in psychological distress over time. Groups were selected a priori based on the clinical importance placed on five-year survival rates, which was hypothesized to translate to psychological distress response variation (Deimling et al. 2006a). For each new primary cancer, hospitals report diagnosis stage to the Wisconsin Tumor Registry using Surveillance Epidemiology and End Results Summary Staging (Young Jr. et al. 2001). These stages were categorized into four groups: in situ, localized, regional (direct extension and lymph nodes alone or in combination, or not otherwise specified), and distant spread (Wisconsin Cancer Reporting System 2008).

#### **Pre-Cancer Diagnosis Control Variables**

A comprehensive set of pre-cancer diagnosis control variables was selected based on a comprehensive stress process model described by Pearlin, and expanded by Israel et al. (Israel et al. 1994, Schulz et al. 2002a) and Deimling et al in their cancer survivorship stress process model (Bowman et al. 2004, Deimling et al. 2002). These models posit that an emotional and behavioral response to a cancer diagnosis is contingent on the extent to which the psychological and physiological demands of the experience exceed available individual (e.g., financial) or situational (e.g., environmental conditions, social support) resources (Becker et al. 2005, Israel et al. 1996, Lazarus and Folkman 1991). As the objective of the study was to isolate the effect of a cancer diagnosis on psychological distress symptom change, it was critical to control for pre-cancer factors known to be associated with changes in psychological distress over time.

**Sociodemographic and Health**—Sociodemographic measures included age, gender, education, household income, and employment status (*yes/no*). Health measures included self-reported diagnosed conditions occurring at a prevalence rate over 10% and included as indicator variables (hypertension, heart disease (heart trouble, circulation problems), respiratory conditions (asthma, bronchitis, emphysema), and arthritis/rheumatism). An indicator variable encompassing all other queried chronic conditions was included (diabetes, stroke, irritable bowel syndrome, colitis, kidney/bladder problems, multiple sclerosis, ulcer, anemia, chronic liver trouble). Functional status assessed whether a participant had a long-term condition/illness/disability that limited activities they do now or is likely to in the future. A self-rated health question assessed current health status (*excellent, good, fair, poor, very poor*). Cancer family history (*yes/no*) was constructed from questions that asked whether biological parents or siblings had ever been diagnosed with cancer.

**Psychological Measures**—Personality measures included standardized modified measures of the NEO five-factor personality inventory: extraversion, openness to experience, conscientiousness, neuroticism, and agreeableness (Briggs 1992, Costa and McCrae 1992). Pre-cancer diagnosis measures of psychological distress were also included.

**Environment and Social Support**—Stressful life events included a count of 18 life events/problems (e.g., witnessed severe injury/death, experienced deep debt/financial loss). Social participation represented a count of memberships or participation in 16 types of social networks (e.g., church-connected groups, labor unions). Social relationships reflected a count of get-togethers with friends/relatives in the prior month. Marital status and number of children were also included.

**Health Behaviors**—Body mass index, physical activity, cigarette smoking (never, former, current), and hazardous chemical exposure in the work place (*yes/no*) were included. Body mass index categories were based on CDC guidelines reflecting underweight/normal (< 18.5–24.9 kg/m<sup>2</sup>) (combined because 0.82% of sample was underweight), overweight (25.0–29.9 kg/m<sup>2</sup>), and obese ( 30 kg/m<sup>2</sup>) categories. Physical activity groups included "sedentary," "light," "moderate," or "vigorous" based on reported physical activity frequency (Østbye et al. 2002).

#### **Statistical Analysis**

Multiple imputation accounted for missing data at the item level. Item non-response averaged across items was low (2.4%) and there were no statistically significant differences in predictor or outcome variable means or percentages between the imputed and nonimputed data. We imputed five data sets, averaged predictions, and adjusted standard errors for uncertainty due to imputation (Royston 2004). Initial analyses included the comparison of means and percentages of all pre-cancer explanatory variables by the cancer and no cancer groups. Multivariable multinomial logistic regression models were used with categories of change in psychological distress (improve by 0.8 SD, improve by 0.5–0.8 SD, stay the same (reference), worsen by 0.5–0.8 SD, or worsen by 0.8 SD) as the dependent variable and all other explanatory variables. The effect of clustering of graduate and sibling respondents was accounted for by calculating robust standard error estimates, clustering family explicitly. Statistical significance was determined by examining the pvalues associated with the beta coefficients of interest. Models predicting changes in depressive symptoms and psychological well-being included pre-cancer depression and well-being and were fit to graduate and sibling respondents (n = 5, 162). Models predicting changes in anxiety included pre-cancer depression, anxiety, and psychological well-being, and were fit to sibling respondents (n = 1,584). An ordinal outcome variable was not selected because results were not suggestive of a response continuum.

To give the regression results a meaningful interpretation, average predicted probabilities of being in each of the five categories of change in psychological distress were estimated for the cancer and no cancer groups adjusted to the overall distribution of covariates. Covariate values for a given participant (female, employed, etc.) were used to determine the probability of being in each of the categories of psychological distress change, having or not having cancer under actual and counterfactual scenarios. This was accomplished by first setting all participants' cancer status measure values to 1 (indicating that they had cancer), while maintaining each participant's unique set of other characteristics (e.g., gender, level of education), and averaging individual probabilities across the sample for each level of the outcome variable. Cancer status measure values were then set to 0 (indicating no cancer), and the above procedure was repeated. The difference in these two sets of probabilities can be interpreted as the difference in the probabilities of the outcome associated with cancer, for a population with the mix of other characteristics actually present in the sample. This approach allowed for the control of all explanatory variables in the model, while isolating the effect of a cancer diagnosis on psychological distress change. A similar approach was followed for the 3 "time since diagnosis" groups. In order to obtain standard errors, the average predicted probabilities were bootstrapped 200 times. The sample drawn during each

replication represented a bootstrap sample of clusters. The cluster samples either included an individual graduate participant if the participant did not have a sibling in the sample or a graduate/sibling pair in the case where both a graduate and sibling were interviewed. Analyses were performed using Stata version 10.0 (StataCorp 2007). Models were re-estimated excluding participants diagnosed with cancer at a distant stage to examine the sensitivity of study findings to diagnosis stage.

# Results

Participants at the pre-cancer survey (1993–1994) were 53 years old on average, with relatively high levels of income and education (Table 1). The majority of respondents (89%) reported good to excellent health. Participants who were subsequently diagnosed with cancer were significantly more likely in 1993–1994 to be older, male, have a higher educational level, and to have had a cancer family history than were participants without cancer.

The most frequently diagnosed cancers in the Wisconsin Longitudinal Study sample were prostate, breast, and colorectal cancers, which on average were diagnosed at a local stage (62%) (Table 2). Fifty-eight percent of cancers were diagnosed within five years of the 2004–2005 survey.

Over 70% of respondents had psychological distress that remained the same (< 0.5 SD change) or improved from 1993–1994 to 2004–2005, with few differences in the depression, anxiety, or psychological well-being measures (data not shown). The percentage of respondents who experienced worsening of depression, psychological well-being, or anxiety 0.5 *SD* was 17%, 27%, and 16%.

Participants with cancer were significantly more likely to experience worsening depression and anxiety symptoms pre- to post-cancer than were participants without cancer over the same time period (Table 3). However, this effect differed by how long the participant had cancer. Within the first five years following diagnosis, 16% of cancer survivors as compared to 11% of participants without cancer experienced worsening depressive symptoms (0.8*SD*) (Table 4). Twenty-two percent of long-term survivors (5 years) experienced worsening anxiety symptoms (0.8 *SD*), compared to 11% of participants without cancer. There were no statistically significant differences for psychological well-being. When cancer survivors diagnosed at the "distant spread" stage were excluded (n = 33), long-term survivors remained more likely to experience clinically significant worsening (0.8 *SD*) of anxiety symptoms relative to no-cancer controls. However, short-term survivors (< 5 years) were also more likely to experience worsening anxiety symptoms (0.5-0.8 *SD*) than were participants without cancer. There were no other differences in the direction or significance of study findings when survivors diagnosed at a distant stage were excluded.

### Discussion

To our knowledge, this study is the first to document the magnitude and long-term temporal course of positive and negative psychological distress pre- to post-cancer diagnosis. We found that depression and anxiety symptoms worsened for cancer survivors relative to those without cancer, though this relation differed for short and longer-term cancer survivors. Cancer survivors within 5 years of diagnosis were more likely to experience clinically significant worsening of depressive symptoms relative to those without cancer. Long-term cancer survivors (5 years) were significant results were found for psychological well-being.

These findings address the apparent inconsistencies in the literature that have previously demonstrated worsening (Baker et al. 2009, Reeve et al. 2009, Trentham-Dietz et al. 2003) or no significant changes (Cella and Tross 1986, Ganz et al. 1998) in psychological distress in cancer survivors relative to a comparison group. The percentage of cancer survivors that did not have just a minimum degree of worsening, but a clinically significant worsening of depression and anxiety symptoms, was 5-11 percentage points higher than was evident for study participants without cancer. Importantly, however, the current findings suggest that the relation between a cancer diagnosis and psychological distress may change with time. Adverse depressive symptom changes predominately occurred within five years of diagnosis, consistent with prior research (Bleiker et al. 2000). This finding underscores the need to identify high-risk patients through psychological screening to facilitate early intervention. This research also demonstrated increased anxiety for long-term cancer survivors relative to respondents without cancer. This finding is consistent with survivor follow-up studies that have demonstrated higher prevalence of anxiety and lower quality of life months to years after diagnosis and treatment (Gil et al. 2004, Holzner et al. 2001). The increase in anxiety may relate to continued concerns voiced by cancer survivors (Ganz 2001) about the chronic physical effects of treatment or the fear of recurrence (Cordova et al. 1995). These anxiety symptoms may be magnified in this sample, as the majority of cancer survivors have cancers with follow-up guidelines that include continued surveillance for recurrence and new primary cancers. Screening and follow-up physician visits have been shown to elicit increased psychological distress in cancer survivors, including fear and anxiety (Mehnert et al. 2009) and physiological stress (cortisol) (Porter et al. 2003). It is important to consider that while the between cancer-group differences in worsening psychological distress are notable, in this population-based cohort study, the subset of people without cancer but who also experienced worsening psychological distress symptoms over time minimized between-group differences.

Though 24–36 percent of cancer survivors experienced positive changes in psychological symptoms over time, this study was not able to demonstrate significant differences in positive psychological change between people with and without cancer for any of the measures. This finding is consistent with some previous research (Andrykowski et al. 1993), though it is inconsistent with other qualitative and cross-sectional studies that have found increased positive psychological symptoms in cancer patients (Andrykowski et al. 1996, Cella and Tross 1986, Ganz et al. 1996). Some of the inconsistency in the literature may be attributed to the lack of prospective studies that include a comparison group (Sumalla et al. 2009), a limitation addressed by the current study. Further, most studies do not report methods for handling missing variables (Fairclough and Cella 1996). Prior research suggests that excluding cancer survivors with incomplete data removes from the analysis those survivors at greatest risk of adverse psychological/physiological outcomes as they are often the least likely to respond to all questions (Fairclough and Cella 1996).

The fact that depression and anxiety worsened without significant changes in well-being is consistent with research that suggests that well-being and distress are not simply a continuum of emotional states (Ruini et al. 2003). These findings are also consistent with a recent study that likewise demonstrated no significant differences in well-being between respondents with and without breast cancer (Heidrich et al. 2006). However in this study, survivors who attributed their adverse physical symptoms to cancer, rather than aging, reported reduced well-being relative to respondents without cancer (Heidrich et al. 2006), suggesting other potential mechanisms through which cancer may influence well-being.

The current analysis has several limitations. First, the study population lacks diversity. Though homogeneity facilitated statistical control, there may be an issue with the extent to which findings are generalizable to more socioeconomically diverse populations. The study

sample however, is broadly representative of non-Hispanic white men and women in the U.S. with at least a high school education (among the same age cohort in the U.S., approximately two-thirds are non-Hispanic white, with 12 or more years of education) (U.S. Bureau of the Census 2000) and represents an age cohort for which cancer is an increasingly relevant health concern.

Second, the cancer sites found in the Wisconsin Longitudinal Study were primarily those associated with screening and higher survival rates and tended to be diagnosed at an early stage. This is not surprising given the restriction of the study sample to survivors who responded to both surveys. It is important to note that cancer site-specific prevalence rates, with the exception of an over-representation of prostate cancer in the sample, are consistent with national cancer survivor rates (Aziz and Rowland 2003). The larger proportion of prostate cancer survivors in the Wisconsin Longitudinal Study is a likely consequence of the rapid increase in Prostate Specific Antigen screening between the two survey time periods (Greenlee et al. 2001). Third, due to sample size limitations, we were unable to explore relationships between other cancer characteristics (e.g., cancer site and treatment type) and psychological distress. Fourth, though recurrence information was not available in the Wisconsin Longitudinal Study, the availability of a longitudinal cohort, linked to a tumor registry allows for analyses that add significantly to our understanding of the changes in psychological distress that people experience following a cancer diagnosis. Last, there were a few significant differences between the cancer and no cancer groups at the time of the precancer survey. Differences are not surprising given the strong association, for example, between older age or a cancer family history and developing cancer and higher educational attainment and cancer screening. These differences highlight the importance of controlling for pre-cancer characteristics even in a relatively homogeneous sample. However, there were no significant between-cancer group differences in pre-cancer psychological distress.

Despite these limitations, our primary finding-that relative to people without cancer, cancer survivors experience significant worsening of depressive symptoms, particularly within five years of diagnosis, while longer-term survivors experience significant worsening of anxiety—has important clinical implications. Clinicians should be proactive in their provision of information about the psychological changes a patient may experience. Our findings provide evidence that a cancer diagnosis has the potential to evoke adverse psychological consequences that are persistent and do not necessarily diminish with time. This is an important finding in light of the rapidly increasing population of longer-term cancer survivors. This information could be used to facilitate self-care to the extent that resources can be proactively provided (before adverse psychological symptoms occur). These findings should inform psychosocial intervention development and future research on cancer-related psychological distress. Cancer patients continue to rate physician communication of expected symptoms as poor (Fitch et al. 2000) and physicians tend to underestimate adverse psychological symptoms (Fallowfield et al. 2001, Ford et al. 1994), referring fewer than 10% of patients with significant distress to mental health services (Sharpe et al. 2004). This underscores a need to provide this information to clinicians, who currently have little guidance with which to make proactive decisions about the psychological care of their patients.

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# Table 1

Key Characteristics of Non-Cancer Controls and Cancer Cases at Baseline Assessment (N = 5162)

Age 50 51–54 55 Female Education High school or less Some college College degree			
50 51–54 55 <b>Female</b> High school or less Some college College degree			
51-54 55 Female Education High school or less Some college College degree	11	12	ŝ
55 Female Education High school or less Some college College degree	74	73	76
<b>Female</b> Education High school or less Some college College degree	15	15	20
Education High school or less Some college College degree	55	55	47
High school or less Some college College degree			
Some college College degree	63	63	56
College degree	15	15	20
	12	12	13
Post graduate training	10	10	12
Household income			
< \$20,000	15	15	13
\$20,000-\$34,999	13	13	12
\$35,000-\$49,999	20	20	19
\$50,000-\$64,999	19	19	17
\$65,000	34	33	39
Percent employed	84	84	85
Chronic conditions			
Hypertension	23	23	26
Heart disease	10	10	13
Respiratory conditions	10	10	6
Arthritis	26	26	29
Other diagnoses	22	22	21
Functional limitation	17	17	16
Self-rated health			
Very poor/poor/fair	11	11	12
Good	63	63	64
Excellent	26	26	25

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Characteristic	<b>Overall</b> $(N = 5162)$	No Cancer $(n = 4714)$	Cancer $(n = 448)$
Former	36	35	41
Current	16	16	18
Physical activity			
Sedentary/light	43	43	43
Moderate	43	43	43
Vigorous	14	14	14
Body mass index (kg/m <sup>2</sup> )			
24.9	32	32	31
25–29	43	43	45
30	25	25	24
Work with hazardous chemicals	17	17	17
Family history of cancer	57	56	64
Marital status			
Widowed/divorced/never married	15	15	14
Married	85	85	86
Mean number of children	3.01 (1.72)	3.01 (1.72)	3.05 (1.73)
Mean stressful life event count	2.37 (1.82)	2.36 (1.81)	2.52 (1.82)
Mean social relationship count	7.61 (6.14)	7.61 (6.11)	7.57 (6.4)
Mean social participation count	3.56 (2.95)	3.55 (2.94)	3.66 (2.85)
Personality (mean)			
Openness to experience	21.23 (4.67)	21.2 (4.71)	21.5 (5.06)
Conscientiousness	29.00 (4.29)	29.01 (4.33)	28.97 (4.08)
Extraversion	22.72 (5.42)	22.73 (5.43)	22.63 (5.17)
Agreeableness	28.52 (4.44)	28.52 (4.48)	28.48 (4.13)
Neuroticism	16.34 (5.03)	16.36 (5.01)	16.12 (5.02)
Mean CES-D Score <sup>a</sup>	10.5 (8.44)	10.51 (8.47)	10.41 (7.97)
Mean STAI Score <sup>a</sup>	9.86 (8.62)	9.92 (8.66)	9.18 (8.09)
Mean PWB Score <sup>a</sup>	41.32 (11.14)	41.34 (11.13)	41.04 (10.73)

*Note.* Bolded values indicate statistically significant difference between respondents with and without cancer, p < 0.05.

Values represent percents unless specified otherwise; Parentheses indicate standard deviations; Percentages may not add to 100% due to rounding. The range of scores for the scales were: Openness to Experience (6–36); Conscientiousness (6–36); Extraversion (6–36); Agreeableness (6–36); Neuroticism (5–30); CES-D (0–60); STAI (0–49); PWB (18–108)

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Anxiety questions asked of sibling respondents only (overall n = 1584; cancer n = 117)

<sup>a</sup>CES-D = Center for Epidemiological Studies Depression Scale (CES-D); STAI = State Trait Anxiety Index; Scale

#### Table 2

Cancer in the Wisconsin Longitudinal Study by Site, Stage, and Time Since Diagnosis (N = 448)

Cancer characteristic	Percent	N
Time between diagnosis and survey		
0-4 years	58	258
5+ years	42	190
Cancer site at diagnosis		
Prostate	30	135
Breast	25	113
Colorectal	9	41
Lung	3	14
Bladder	3	14
Other	35	131
Cancer stage at diagnosis		
In situ	8	38
Local	62	277
Regional	19	83
Distant	7	33
Missing	4	17

# Table 3

Adjusted Average Predicted Probabilities (%) of Being in Each Category of Psychological Distress Symptom Change for Depression, Anxiety, and Psychological Well-Being Measures for Respondents with and without Cancer

X7	No Cancer $(n = 4714)$	a	Cancer $(n = 448)$	
v artable	Predicted Probability (%)	95% CI	Predicted Probability (%)	95% CI
Depression				
Worsen by 0.8 SD <sup>a</sup>	10	(10, 11)	15	(12, 18)
Worsen by 0.5 SD	9	(5, 6)	9	(4, 8)
Stay the same	55	(53, 56)	49	(43, 52)
Improve by 0.5 SD	10	(9, 11)	10	(8, 14)
Improve by 0.8 SD	20	(19, 21)	21	(18, 24)
Psychological Well-being	18			
Worsen by 0.8 SD	16	(15, 17)	17	(14, 20)
Worsen by 0.5 SD	11	(10, 12)	12	(10, 16)
Stay the same	51	(50, 53)	47	(43, 52)
Improve by 0.5 SD	6	(8, 10)	11	(8, 13)
Improve by 0.8 SD	13	(12, 14)	13	(10, 16)
Anxiety $b$				
Worsen by .8 SD	11	(11, 12)	19	(16, 22)
Worsen by .5 SD	4	(3, 4)	4	(3, 6)
Stay the same	51	(49, 52)	41	(37, 45)
Improve by .5 SD	8	(1,9)	6	(6, 11)
Improve by .8 SD	27	(25, 29)	27	(23, 31)

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Note. Models adjusted to the composition of the overall sample with respect to all variables shown in Table 1. Items in bold indicate comparisons that were significant in the multinomial logistic regression model (p < 0.05). Baseline anxiety included only in models that predict anxiety symptom change.

 $^{a}SD =$  Standard deviation

b Anxiety questions asked of sibling respondents only (n = 1584)

# Table 4

Adjusted Average Predicted Probabilities of Being in Each Category of Psychological Distress Symptom Change for Depression, Anxiety, and Psychological Well-Being Measures for Respondents with and without Cancer

	No Cancer $(n = 4/14)$	(	Cancer Diagnosed $< 5$ Years before Survey( $n = 258$ )	(0 < 7 = u) favore a	Cancer Diagnosed 5 Years before	S rears before survey $(n \equiv 190)$
Variable	Predicted Probability (%)	95% CI	Predicted Probability (%)	95% CI	Predicted Probability (%)	95% CI
Depression						
Worsen by $0.8 \ SD^{a}$	11	(10, 11)	16	(12, 21)	13	(8, 19)
Worsen by 0.5 SD	9	(5, 6)	9	(3, 9)	9	(3, 10)
Stay the same	55	(53, 56)	48	(42, 53)	50	(44, 57)
Improve by 0.5 SD	10	(9, 11)	10	(7, 15)	11	(6, 15)
Improve by 0.8 SD	20	(19, 21)	20	(17, 25)	21	(17, 26)
Psychological Well-being	18					
Worsen by 0.8 SD	16	(15, 17)	16	(12, 20)	18	(14, 23)
Worsen by 0.5 SD	11	(10, 12)	12	(8, 16)	13	(8, 17)
Stay the same	51	(50, 53)	49	(41, 55)	45	(39, 51)
Improve by 0.5 SD	6	(8, 10)	11	(7, 15)	10	(6, 14)
Improve by 0.8 SD	13	(12, 14)	12	(8, 16)	14	(9, 18)
Anxiety $b$						
Worsen by .8 SD	11	(10, 12)	15	(12, 19)	22	(18, 28)
Worsen by .5 SD	4	(3, 4)	6	(5, 12)	1	(1, 3)
Stay the same	51	(49, 52)	40	(33, 46)	41	(35, 47)
Improve by .5 SD	8	(7, 8)	12	(7, 15)	9	(3, 9)
Improve by .8 SD	27	(25, 29)	25	(21, 32)	29	(23, 34)

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Note. Models adjusted to the composition of the overall sample with respect to all variables shown in Table 1. Items in bold indicate comparisons that were significant in the multinomial logistic regression model (p < 0.05). Baseline anxiety included only in models that predict anxiety symptom change

 $^{a}SD=$  Standard deviation

b Anxiety questions asked of sibling respondents only (n = 1584)