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January 2005

Working Paper 05-01

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Running head: Risks to Quality of Life

Abstract: 250 words

Text: 4485 words

This article is based upon work supported by the National Cancer Institute, U.S. Department of Health and Human Services under grant RO1 CA82619. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the NCI. The authors gratefully acknowledge the contributions of Margaret Davitt (Milton S. Hershey Medical Center), James Evans and Sharon Reeder (Geisinger Medical Center), Andrea Geshan (Lehigh Valley Hospital and Health Network), and Barbara Abdullah (The Johns Hopkins Hospital) in recruiting subjects at their sites. CODA, Inc. of Silver Spring, MD conducted the interviews. We are also indebted to the study's Patient Advisory Committee and to Frank Lawrence, Terry Hartman, Maria Hewitt, and Carol Weisman for suggestions about the manuscript.

Abstract

Purpose: To make a multi-dimensional assessment of health-related quality of life (QoL) in a recent, heterogeneous cohort of adult cancer survivors. To identify risk factors predicting differences in QoL, including socioeconomic status and cancer site.

Patients and Methods: The sample included 1763 working-age survivors diagnosed with different cancers from 1997 to 1999. A telephone interview asked retrospectively about life circumstances before diagnosis and measured QoL at interview. Age/sex-adjusted QoL for survivors was compared to population norms. Multivariate analyses predicted SF-12 physical and mental health, BSI-18 psychological distress, work disability, and labor force participation from demographic, socioeconomic, and clinical characteristics. Participation biases were modeled and assessed.

Results: The adjusted mean of physical health for survivors was 0.23 ± 0.07 standard deviations below the population mean. Mental health and psychological distress were similar to population averages. Labor force participation dropped 12 percentage points from cancer diagnosis to follow up. Nineteen percent of survivors reported cancer-related limitations in ability to work. Twenty-three percent had problems getting insurance to pay for cancer care. Twenty-seven percent of policyholders remained in a job because of health insurance concerns. Higher socioeconomic status was associated with better QoL. Differences in QoL by cancer site generally followed differences in survival rates.

Conclusions: Quality of life, measured 2-3 years after diagnosis for most subjects, was generally high. However, QoL varied with a number of factors. These risk factors

should be considered in screening for QoL deficits, deploying clinical and psychosocial services for survivors, and modifying treatments to produce even better QoL outcomes.

As the number of Americans surviving cancer approaches 10 million, oncology is being asked increasingly to look beyond initial treatment to the care and quality of life (QoL) of cancer survivors.¹⁻² Recent surveys of the field have called for more studies of differences in QoL by socioeconomic status and cancer site among cancer survivors³⁻⁴ Most survivor studies have focused on a particular type of cancer or treatment procedure, often with samples too small to discern many statistically significant differences between subgroups and with subjects recruited from a single facility.

This article examines multiple dimensions of health-related QoL in a large and heterogeneous cohort of cancer survivors. They were diagnosed from 1997 through 1999 with a variety of cancers at four medical centers in the Eastern U.S. The study identifies clinical, demographic, and socioeconomic risk factors associated with differences in QoL. Economic and work-related aspects of cancer survival are given special attention, as these topics have also been identified as a priority for additional research.³

Previous research indicates that demographic and socioeconomic differences in QoL among adult cancer survivors often parallel differences in the general population.⁵⁻⁶ For example, survivor studies have shown that increasing age is associated with lower physical health and reduced employment among adult cancer survivors. Also in keeping with general population patterns, male survivors report better physical and mental health than females, and male survivors have greater attachment to the workforce.⁷⁻¹¹ Psychological distress and mental health problems are more prevalent among younger adult survivors, a pattern that is also evident in the general population.^{7,9,10,12-20} Despite generally similar physical health, married survivors seem to enjoy better emotional or psychological health than survivors with no spouse or partner.^{10,21-25} Although a number

of survivor studies have not found statistically significant differences by socioeconomic status,^{11,13,14,20,26-29} others have reported lower QoL for survivors from racial or ethnic minorities or with less income and education.^{12,14,21,22,25,30-33} Small sample sizes have likely contributed to the ambiguity of findings related to socioeconomic disparities.

Systematic comparisons of QoL by cancer site are useful in targeting services for survivors and identifying the need for modifications in treatment. Such comparisons also set a broader context for site-specific studies of survivors. Previous research has associated head and neck cancers, as well as lung cancer, with poorer health and employment outcomes.^{5,18,29,34,35} Comparisons of breast and prostate cancer, the two sites accounting for the largest numbers of survivors by gender,³⁶ have identified few significant differences; these usually suggest better QoL for prostate cancer.^{5,9,26,27,35}

Patients and Methods

Sample

The sample was recruited from a conceptually well-defined population of cancer survivors, the surviving members of a recent cohort of incident cases. The cohort included people first diagnosed with cancer from January 1997 through December 1999. Given the interest in employment consequences of adult-onset cancers, eligibility was restricted to adults of working age at diagnosis (25 to 62 years old). Several well-known organizations concerned with survivorship have embraced a common definition of “cancer survivor” that encompasses all patients from the time of diagnosis to the end of their lives.³⁷⁻³⁹ Accordingly, this study recruited all surviving patients in the tumor registries of The Johns Hopkins Hospital (Baltimore MD), Milton S. Hershey Medical

Center (Hershey PA), Geisinger Medical Center (Danville PA), and Lehigh Valley Hospital (Allentown PA) who met the criteria for age and date of diagnosis, except as noted below.

There were three additional exclusions by cancer site and stage. First, skin cancers other than melanoma were excluded. Second, most patients with Stage 4 cancers at diagnosis were excluded, because of the small probability of surviving to the end of a multi-year study.⁴⁰ Leukemias, plasma cell cancers, and lymphomas that were classified as Stage 4 at diagnosis, but have relatively favorable survival rates, were included. Third, because urological cancers were not under the administrative control of the registry at Johns Hopkins, prostate and testicular cancers were excluded there. As shown in Table 1, 5150 cases were targeted for recruiting, including about 3000 from the Pennsylvania hospitals and 2000 from Johns Hopkins.

Human subjects committees at the four hospitals and Penn State's University Park campus approved the research protocol. Each hospital obtained informed consent, with support and training from the research team, before subjects were identified to the research team. Consent was obtained in writing at Hershey and verbally elsewhere. The recruiters discovered that 340 patients were ineligible because of age at diagnosis, a prior cancer diagnosis, or death. Consent was obtained from 2076 subjects (43% of eligible cases). Those who did not consent included 347 cases still being recruited at Johns Hopkins when intake ended at the start of the second round of interviewing. Recruiting was delayed at Johns Hopkins when federal authorities temporarily suspended all human subject research there.

This article is based on the first of four annual interviews with the cohort. Initial interviews were conducted with 1763 subjects from October 2000 to December 2001, 1 to nearly 5 years after their initial cancer diagnosis. Accounting for deaths and other ineligible cases discovered by the interviewers, the survey response rate (conditioned on consent) was 88%.

Data

Many of the questions in the computer-assisted telephone interview were drawn from the Health and Retirement Study (HRS).⁴¹ HRS is an ongoing national cohort study of older Americans, originally ages 51 to 61, that began in 1992. HRS is conducted by the University of Michigan and funded primarily by the National Institute on Aging. In addition to asking about each subject at the time of interview, the cancer questionnaire asked retrospectively about employment, health insurance, and marital status at diagnosis. Subjects who could not be interviewed in English were excluded.

To compare health-related QoL for cancer survivors to norms for the general population, the survivor survey included two QoL instruments developed in the general population. The SF-12 is a 12-item version of the widely used SF-36 that yields separate summary measures of physical health (PCS-12) and mental health (MCS-12).⁴² Norm-based scores for each domain are standardized to a mean of 50 and standard deviation of 10 in the general U.S. population. The Brief Symptom Inventory-18 measures psychological distress.⁴³ Cut-off scores for the BSI-18 identify patients with high levels of distress, defined as the 90th population percentile by gender.⁴⁴

As in HRS, work disability was ascertained by asking subjects if they had impairments or health problems at the time of interview that limited the kind or amount of paid work they could do. If so, they were asked if the problem was related to their cancer and if they were able to work at all. Survivors who were working for pay, on lay-off, or unemployed and looking for work were considered labor force participants. To facilitate comparison of income across married and single survivors, the 1999 income of each survivor (and spouse, if applicable) was divided by the federal poverty line (FPL). The FPL is adjusted for family size and was approximately \$8700 for a single individual and \$11,200 for a couple in 1999.

The questionnaire asked about enrollment in different types of health insurance and two insurance concerns. Policyholders with insurance from their jobs were asked if the fear of losing health insurance ever kept them from looking for another job. Everyone insured at the time of interview was asked about problems getting the plan to pay for special doctors or care for cancer that they thought they needed.

Clinical details regarding the type and stage of cancer and the date of diagnosis were obtained from the registries. The date of diagnosis was reviewed and sometimes revised in the interview. Cancer status, treatment status, and the prevalence of a small number of physician-diagnosed chronic conditions (diabetes, chronic lung disease, heart problems, stroke, or arthritis or rheumatism) were self-reported at follow up.

Analysis

Unadjusted means (or percentages) and confidence intervals for the following measures were computed for the entire sample and by gender: PCS-12, MCS-12, BSI-18

indicator of distress, divorce or separation (for survivors married at diagnosis), work disability at follow up, labor force participation at diagnosis and follow up, health insurance at diagnosis and follow up, insurance-related concerns about changing jobs, and problems getting insurance to pay for cancer care. Means and percentages for the survivor cohort were adjusted by age and sex for comparison to the general adult population under age 65, which was younger and less female.⁴⁵ Only significant differences (in a two-tailed test with $p < .05$) are discussed in the text, except as noted.

Multivariate logit analyses identified risk factors associated with differences in QoL as measured by the variables just described. Only results for the PCS-12, MCS-12, BSI-18, work disability, and labor force participation are reported, as there was little systematic variation in other measures. Labor force participation and work disability were analyzed separately by gender after likelihood ratio tests (with alpha conservatively set at .10 to reduce Type II error) rejected combined analyses of those two measures ($p = 0.059$ and $p = 0.067$, respectively).

All QoL measures were analyzed as rates to allow comparisons of odds ratios for each risk factor with respect to different outcomes. Continuous health scores from the SF-12 were converted to rates by categorizing survivors as above or below the standardized population mean of 50. Clinical, demographic, and socioeconomic variables (including labor force participation at diagnosis) were included as predictors. Family income in 1999 was included in analyses of physical and mental health. However, because the earnings of some survivors in 1999 could have been reduced by disability and changes in labor force participation reported at follow up, 1999 income was not included as an exogenous predictor of disability or labor force participation.

An important goal of the multivariate analysis was to compare adjusted odds ratios by cancer site. Sites were defined by topological groups of ICD-O-2 diagnostic codes assigned by the registries. Colorectal cancer, the most prevalent cancer that was well distributed across genders, was chosen as the reference site. Odds ratios and their confidence intervals were graphed to show the relative magnitudes by site, on a logarithmic scale to make the confidence intervals symmetric. Sites with risks significantly different from colorectal cancer were identified by confidence intervals above or below 1 in the graphs. Significant differences between other pairs of sites could not be identified from non-overlapping confidence intervals in the graphs, because the logit estimates were not statistically independent. A Wald chi-square (with one degree of freedom) was used to test other pair-wise differences between sites.

Because Stage 4 diagnoses were associated only with blood and lymph cancers, survivors of stage 4 cancers were identified by the interaction of stage and site. Separate indicators were assigned to Stage 4 blood cancers, Stage 4 lymph cancers, and other lymph cancers. A few blood cancers not diagnosed as Stage 4 were assigned to “other cancers.”

To assess potential biases associated with the relatively low rate of participation in the study, a logit model of participation was estimated for the 4735 eligible survivors with patient characteristics from the registries. This model included year of diagnosis, age at diagnosis, gender, race, cancer site, stage at diagnosis, and facility. As in the QoL analyses, the differences between all pairs of subgroups were tested for statistical significance. Predicted probabilities of participation, derived by applying the coefficients from the participation model to the characteristics of each study participant, were

included in the QoL logits to test for biases involving correlations of QoL outcomes with the propensity to participate. Because the inverse of each individual's estimated probability of participation was the expected ratio of eligible subjects to participants in a group with like characteristics, weighting the characteristics of the study population by the inverse probabilities approximated the distribution of characteristics in the eligible population. Mean QoL measures for study participants were recalculated with these weights and compared to unweighted means.

Results

Sample characteristics

Table 2 describes the sample. Thirty-one percent of the subjects, and nearly half of the females, were female breast cancer survivors. Fourteen percent of the sample reported a new cancer or metastases. Sixty-five percent of the interviews were conducted from 1.5 to 3.5 years after diagnosis, with 81% of the survivors no longer in treatment for their first cancer. Of the remaining survivors who reported that they were still in treatment for their first cancer, 62% said that the cancer was inactive. Forty-five percent of the cohort reported a chronic illness other than cancer.

The median age of the subjects at the time of interview was 52.5. Fifty-nine percent had attended college, and 58% had family incomes at or above 400% of the federal poverty line. The sample included 124 nonwhites, including 94 African Americans.

Average measures of quality of life for the sample

Even after age- and sex-adjustment, the mean SF-12 physical health score for the cancer survivors (49.0 ± 0.7 , Table 3) was significantly below the general mean for adults under age 65 (51.3). Although unadjusted mental health scores for the cancer survivors exceeded the general population mean, the adjusted mean (50.4 ± 0.7) for the cancer survivors was not significantly different from the general average. The rate of psychological distress from the BSI-18 was not significantly different from the 10-percent rate implied by defining high distress at the 90th population percentile.

Adverse effects on the employment of the cancer survivors were evident from self-reported disability and changes in labor force participation from diagnosis to follow up. Nearly 1 out of 5 survivors reported cancer-related limitations in ability to work, including 9% percent who were unable to work at all. Just before diagnosis, age- and sex-adjusted labor force participation in the survivor cohort was well above the national rate (87.6% compared to 80.1%). However, at follow-up, the age- and sex-adjusted rate in the survivor cohort had dropped to the national rate. About two-thirds of survivors who quit working attributed the change to cancer (data not shown).

Ninety-eight percent of the survivor cohort had health insurance at diagnosis (Table 4), much higher than the national rate (83.9% in 1998).⁴⁶ There was little change from diagnosis to follow up in the overall rate insured, but private insurance decreased slightly and Medicare enrollment increased. Four percent of survivors under age 65 at follow-up entered Medicare after diagnosis, presumably through Medicare's disability provisions. Nearly a quarter of insured survivors reported problems getting plans to pay

for cancer care. More than a quarter with insurance from their own employers said they had not changed jobs for fear of losing coverage.

Rates of marital dissolution were comparable in the survivor cohort and the general population. About 2 percent of survivors married at the time of diagnosis were divorced or separated at follow up. This was similar to the national percentage of married individuals who divorced or separated over two years.

Average quality-of-life measures by gender

Several quality-of-life measures differed by gender. On average, male cancer survivors scored better on both the PCS-12 and MCS-12 than female survivors. A higher percentage of females reported work-related disabilities, and female policyholders were more likely to say that they stayed in a job because of health insurance concerns. Although labor force participation at follow up was higher for males than females, the decline in labor force participation from diagnosis to follow up was not significantly different.

Adjusted odds ratios by cancer site

Multivariate analyses of the PCS-12 identified two groups of cancer sites at opposite extremes in terms of physical health, controlling for other factors shown in Table 5. The least healthy group included cancers of the urinary, respiratory, and central nervous system (Figure 1). The most healthy group included cancers of the prostate, thyroid, skin (i.e., melanoma), and female breast. All pair-wise comparisons of adjusted odds-ratios between sites in these two groups were significant at $p < .05$, except that

differences involving melanoma were significant only at $p < .10$. The health of prostate cancer survivors was significantly better in comparison to survivors of all other cancers except thyroid, melanoma, and female breast cancer.

Melanoma and stage 4 lymphoma were associated with the best mental health as measured by the MCS-12, significantly better than central nervous system and colorectal cancers at the other extreme. The only significant differences in the BSI-18 (Figure 3) involved head and neck cancers, which were associated with more distress than all sites except urinary, respiratory, colorectal, and central nervous system cancers.

Work-related outcomes were significantly worse for cancers of the central nervous system compared to most other cancers, regardless of gender (Figure 4 - Figure 7). The male disability rate was significantly lower for prostate cancer compared to all sites except melanoma, head and neck, and thyroid cancers. Blood and central nervous system cancers were associated with the lowest rates of male labor force participation, while stage 1-3 lymph cancer, prostate, melanoma, and colorectal cancer were associated with the highest rates of male labor force participation. Among females, uterine, melanoma, breast, stage 1-3 lymph, and thyroid cancers were associated with lower disability rates compared to central nervous system, stage 4 lymph, blood cancers, and head and neck cancers. Colorectal, breast, and uterine cancers were associated with higher rates of female labor force participation compared to central nervous system, stage 1-3 lymph, and head and neck cancers.

Adjusted odd-ratios for other clinical risk factors

Treatment status and cancer status at interview were the clinical factors most often associated with significant differences across QoL domains (Table 5). For survivors who were still in treatment for an active cancer, QoL was lower in all domains except psychological distress and male labor force participation. Survivors who were still in treatment, but with inactive cancer, were similar in all but one domain to survivors who were no longer in treatment. The mental health of survivors who continued to receive treatment for inactive cancer was significantly worse in comparison to survivors who were not in treatment. Recurrences or second cancers were associated with poorer physical health and, only among males, increased disability and reduced labor force participation. Outcomes were not significantly better for survivors diagnosed at early stages, except for disability and female labor force participation. The only significant difference by length of follow up (i.e., the time from diagnosis to interview) was in the male disability rate. Co-morbidities were associated with significantly worse outcomes in all domains except the MCS-12 and female labor force participation.

Adjusted odds-ratios for demographic and socioeconomic risk factors

Younger cancer survivors were at greater risk for mental health problems than older survivors according to both the MCS-12 and the BSI-18. Controlling for the prevalence of co-morbidities, there was no consistent relationship between age and physical health. As in the general population, labor force participation declined at older ages among cancer survivors. As noted earlier, specification tests rejected combined analyses of male and female cancer survivors with respect to work disability and labor

force participation. In analyses of the SF-12 and the BSI-18 that combined genders, females had significantly lower physical health but were similar to males on both mental health measures. The rate of psychological distress was significantly lower for survivors who were married at diagnosis.

Most of the socioeconomic variables were associated with significant differences in multiple domains. High school drop-outs were disadvantaged in terms of every outcome except work disability. Survivors with post-graduate education had a lower risk of psychological distress than any other education group. Labor force participation at diagnosis not only predicted labor force participation at follow up, but was associated with better mental health, less psychological distress, and (marginally) better physical health at follow up. Survivors in the top income category had better physical health than those below the poverty line. Income was marginally significant in models of the MCS-12 and BSI-18 that included education and labor force participation at diagnosis, as shown in Table 5, but was highly significant in alternative specifications that omitted either of these variables ($p < .01$ without education, $p < .02$ without labor force participation).

Assessment of participation biases

The logit model of study participation is shown in Table 6. The participation rate was significantly higher for women than men, and for whites compared to nonwhites. Rank order differences between the facilities were all statistically significant, with the highest participation at Geisinger and the lowest at Hershey. All differences between the four cancer sites with the highest participation rates (breast, stage 4 lymph, blood, and

prostate) and the four sites with the lowest participation rates (central nervous system, head and neck, melanoma, and uterus) were significant. Because there were no significant differences by year of diagnosis, that variable was omitted from the table. Predicted probabilities of participation from the model ranged from .1342 to .6512 among study participants. However, these propensity scores were not significant in any of the QoL logits; the significance levels ranged from .2125 to .8158. Furthermore, weighted means that adjusted for the differences between study participants and the target population were well within the confidence intervals for the unweighted means of the QoL measures (47.5 for the PCS-12, 51.1 for the MCS-12, 9.6% for BSI distress, 70.8% for labor force participation at follow-up, and 20.3 % for cancer-related disability).

Discussion

In a large and heterogeneous cohort of cancer survivors, average mental health was better than average physical health when standardized against population norms. Average physical health scores from the SF-12 for cancer survivors were similar to scores of adult patients with “minor medical conditions” (uncomplicated hypertension, diabetes, chronic heart failure, and history of heart attack) assessed in the development of the SF-12.⁴⁷ This study’s positive findings regarding the average mental health of cancer survivors are consistent with prior research, which has generally shown few differences in psychological health between cancer survivors and the general population and sometimes suggested positive psychological benefits of survivorship.^{4,48-49}

However, in keeping with findings reported previously, survivors in this study who were diagnosed at younger adult ages had more psychological problems than those diagnosed at older ages.³⁴

The evidence that cancer survival adversely affects employment is important because of its potential economic implications, namely, loss of income and access to health insurance. However, the psychosocial implications are also potentially important, because of the connections of work to social relationships and personal identity.⁵⁰⁻⁵² Despite the decline in labor force participation among the cancer survivors in this study, enrollment in health insurance remained high. Most survivors who quit working after diagnosis retained private insurance, apparently through spouses or former employers. In other instances, private insurance was replaced by Medicare. Even when insured, significant percentages of survivors reported problems getting plans to pay for needed care and reluctance to change jobs because of insurance concerns.

Analyses of differences within the cohort revealed socioeconomic disparities in the QoL of survivors that extend beyond previously recognized differences in cancer survival rates.⁵³⁻⁵⁴ After controlling for differences in income and education, racial differences in QoL were not large enough to be statistically significant at conventional levels. However, the power to detect significant effects was limited by the number of nonwhites in the sample. We did not have measures of physical and mental health for the cohort before diagnosis; therefore, we cannot rule out the possibility that disparities preceded the onset of cancer. However, we can conclude that the care provided during cancer treatment and follow-up perpetuated or contributed to any existing disparities.

Quality-of-life was reassuringly high for survivors of prostate and female breast cancer, the two cancers that have been targeted most intensively for early detection and treatment. Most of the significant differences in QoL by cancer site in this study followed differences in survival rates. Sites associated with better QoL in multiple domains (including prostate, thyroid, uterus, breast, and melanoma) have 5-year relative survival rates above 90% when diagnosed at an early stage.⁵⁴ Sites associated with worse QoL in multiple domains (including central nervous system, head and neck, respiratory, urinary, and blood cancers) have lower survival rates. Cancers of the central nervous system were at or near the worst level of QoL in all domains, indicating that supportive services may be especially important for survivors of those cancers.

Extreme psychological distress was most prevalent for head and neck cancers, perhaps because of effects on facial appearance, eating, swallowing, and speaking. In addition, the incidence of head and neck cancers is closely linked to smoking and excessive alcohol consumption,⁵⁵ unhealthy behaviors that are also associated with psychological distress. Concerns about appearance might explain the higher rate of work disability for women surviving head and neck cancers compared to men.

The average QoL of the cancer survivors in this study may not generalize to the comparable national cohort of recent survivors for several reasons. The sample was regional and reflected the caseload of the four medical centers. The average socioeconomic status of the subjects was higher than for cancer survivors nationally.⁴⁵ Although statistical analyses suggested that any biases associated with non-participation were small, we cannot rule out unobservable biases that were uncorrelated with variables in the participation model. Finally, length of recall could be an issue for the reporting of

changes from diagnosis to follow up, although the research design assumed that receiving a cancer diagnosis was such a salient event that subjects would be able to recall the circumstances surrounding it. For within-sample comparisons, there was limited power to detect significant differences among small subgroups, such as by race or cancer site, despite a much larger total sample than is usual in the literature.

Recruiting subjects for population-based studies of cancer survivorship is challenging. Important human subject protections complicate the task of convincing unenthusiastic members of scientifically selected, representative samples to participate. With a targeted sample of 4735, this study had considerable statistical power to demonstrate that participation was not random. However, participation was not strongly associated with QoL either. Reweighting to account for systematic differences between participants and non-participants had little effect on QoL estimates.

By sampling from records with patient characteristics associated with study outcomes, by arranging for the results of recruiting to be entered on individuals' records, and by obtaining data for the entire eligible sample (which was completely de-identified for non-consenting individuals), we were able to assess and (if necessary) correct participation biases. None of the human subjects committees questioned our request for access to de-identified data for non-consenting patients, which allowed us to implement these analytic procedures. These procedures compensated for other committee requirements (such as written consent) that reduced participation and increased the potential for bias.

Because this study assessed QoL in a recent cohort of cancer survivors, its findings reflect the recent advances in cancer screening and treatment that have produced

marked improvements in survival rates and, in turn, attracted more attention to the well-being of cancer survivors^{1-2,53} Quality of life among the survivors in this cohort, measured approximately two to three years after diagnosis in most instances, was generally high. However, QoL varied by cancer site, treatment and cancer status, comorbidities, and demographic and socioeconomic characteristics. Knowledge of these risk factors can be used to screen survivors for deficits in health-related QoL, to deploy clinical and psychosocial services for survivors, and to set priorities for modifying treatments to achieve even better QoL outcomes.

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Table 1. Recruiting and Interviewing Outcomes

Selected for recruiting	5150
<i>Discovered ineligible for study (includes deaths)</i>	340
<i>Eligible, but no consent</i>	2734
Unable to locate or contact	230
Refusal	2157
Still being recruited when intake ended	347
Consent obtained	2076
<i>Ineligible for interview</i>	75
Discovered ineligible for study	71
Died before interview	4
<i>Eligible, but no interview</i>	238
Language problem	6
Physically incapacitated	11
Unable to locate or contact	103
Refusal	118
Interview completed	1763

Table 2. Sample Characteristics

Characteristic			Characteristic				
	Total	Male	Female		Total	Male	Female
<u>All</u>	1763	585	1178				
<u>Cancer site</u>				<u>Age at interview</u>			
Blood	86	43	43	25-44	401	109	292
Breast	552	2	550	45-52	463	130	333
Central nervous	50	21	29	53-57	369	128	233
Colorectal	112	63	49	58-61	263	88	167
Head and neck	69	40	29	62 and over	258	115	119
Lymph	96	53	43	Unknown	49	15	34
Prostate	144	144	0	<u>Race</u>			
Respiratory	69	21	48	White	1588	535	1053
Melanoma	66	30	36	Nonwhite	124	35	89
Thyroid	132	31	101	Unknown	51	15	36
Urinary tract	60	43	17	<u>Married (diagnosis)</u>			
Uterine	110	0	110	Married/partner	1409	497	912
Other	217	93	124	Single	354	88	266
<u>Stage (diagnosis)</u>				<u>Education</u>			
1	735	167	568	Less than high school	108	39	69
2	575	216	359	High school	566	180	386
3	273	111	162	Some college	373	101	272
4	131	70	61	College	349	133	216
Unstaged	49	21	28	Post college	319	118	201
<u>Follow up</u>				Unknown	48	14	34
LT 1.5 years	156	57	99	<u>Income (% FPL)</u>			
1.5 – 2.4 years	570	187	383	<100	66	15	51
2.5 – 3.4 years	576	192	384	100-199	120	32	88
3.5 - 5 years	414	135	279	200-299	162	43	119
Unknown	47	14	33	300-399	142	41	101
<u>Treatment Status</u>				400+	1017	373	644
Not in treatment	1429	488	941	Unknown	256	81	175
In treatment, active cancer	127	43	84	<u>Chronic Conditions</u>			
In treatment, inactive cancer	207	54	153	Yes	786	263	523
<u>Any new cancer</u>				No	971	322	649
Yes	242	83	159	Undetermined	6	0	6
No	1510	497	1113	<u>Medical Center</u>			
Undetermined	11	5	6	Geisinger	327	126	201
				Hershey	293	106	187
				Johns Hopkins	678	187	491
				Lehigh Valley	465	166	299

FPL is federal poverty line.

Table 3. Means of quality of life measures for cancer survivor sample and general population

Measure	Cancer survivor sample				General adult population ages 25-64
	Unadjusted		Age and sex adjusted		
	Mean	95% CI	Mean	95% CI	
SF-12 physical health ^a	47.7	47.2, 48.2	49.0	48.3, 49.7	51.3
Male	49.1	48.3, 49.9			*51.2
Female	47.0	46.4, 47.7			*49.1
SF-12 mental health ^a	51.2	50.8, 51.7	50.4	49.7, 51.1	49.9
Male	52.3	51.6, 53.1			*50.7
Female	50.7	50.1, 51.2			*49.4
BSI-18 high distress (%) ^b	9.3	8.0, 10.8			*10
Male	7.5	5.5, 10.0			
Female	10.2	8.5, 12.1			
Limited in ability to work because of cancer (%) ^c	19.4	17.5, 21.3	18.3	15.7, 20.9	10.9
Male	16.8	13.8, 20.1			*12.2
Female	20.7	18.4, 23.1			*11.9
Labor force participation at diagnosis (%) ^d	84.0	82.1, 85.7	87.6	85.9, 89.3	80.1
Male	90.2	87.4, 92.5	93.4	91.1, 95.7	88.1
Female	80.8	78.4, 83.1	82.0	79.5, 84.6	72.4
Labor force participation at interview (%) ^d	72.2	70.0, 74.3	79.8	77.4, 82.2	79.8
Male	76.2	72.5, 79.6	85.9	81.4, 90.7	87.5
Female	70.2	67.5, 72.8	74.1	70.7, 77.4	72.4
Divorced or separated after diagnosis (%) ^f	2.4	1.7, 3.1			2.3
Male	1.5	0.5, 2.5			2.1
Female	2.9	1.9, 3.9			2.4

*Includes adults ages 65 and older. ^aGeneral population means of SF-12 for adults under age 65 were calculated from Ware J, Kosinski M, and Keller S, *How to score the SF-12 physical and mental health summary scales*, 2nd edition (Boston: The Health Institute, New England Medical Center, 1995). ^bHigh distress for the BSI-18 is defined as the 90th percentile in the general population. ^cGeneral population rates of limitations in activity due to chronic conditions in the 2001 National Health Interview Survey are from National Center for Health Statistics, *Health, United States*, 2003 (Hyattsville MD: 2003). NHIS asks respondents about limitations in ability to perform activities usual for their age group due to a physical, mental, or emotional problem lasting 3 months or more. ^dGeneral population labor force participation rates for 1998 (diagnosis) and 2001 (interview) are from U.S. Census Bureau, *Statistical Abstract of the United States*. ^fGeneral population rates for divorce and separation over two years were estimated by the authors from the 1996 panel of the Survey of Income and Program Participation. These rates were too low to adjust reliably by age and sex in the cancer survivor sample.

Table 4. Health insurance of cancer survivor sample and general population

Measure	Cancer survivor sample			General adult population ages 25-64
	Mean	95% confidence interval		
Any health insurance at diagnosis (%) ^a	97.9	97.1	98.5	83.9
Private	92.9	91.6	94.1	76.1
Medicaid	1.9	1.3	2.7	4.9
Medicare	3.0	2.3	3.9	
Any health insurance at interview (%) ^a	98.3	97.6	98.9	83.7
Private	88.3	86.6	89.8	76.1
Medicaid	1.7	1.2	2.5	5.2
Medicare	8.3	7.0	9.6	
Afraid to change jobs because of health insurance (%)	27.2	23.9	30.6	N/A
Male	18.2	13.9	23.2	N/A
Female	33.1	28.6	37.8	N/A
Problems getting cancer care (%)	23.2	21.1	25.3	N/A
Male	22.3	18.9	26.1	N/A
Female	23.6	21.1	26.3	N/A

^aGeneral population health insurance rates for 1998 (diagnosis) and 2001 (interview) in the National Health Interview Survey are from National Center for Health Statistics, *Health, United States, 2003*, Hyattsville MD: 2003.

Table 5. Adjusted odds ratios for variables other than cancer site in logit models for quality of life outcomes

	Above average PCS-12	Above average MCS-12	BSI-18 distress	Cancer-related work disability		Labor force participation	
				Male	Female	Male	Female
Stage 2	0.952	1.033	0.853	*1.970	***1.723	0.702	0.822
Stage 3	0.765	0.888	1.254	*1.926	***2.894	1.326 ^b	***0.348 ^b
Unstaged, unknown	1.137	0.865	0.589	0.932	1.188	0.564	1.123
1.5 – 2.4 years	1.002	0.958	0.928	0.567	0.987	1.836	1.069
2.5 – 3.4 years	1.078	0.893	1.129	**0.337	0.946	2.077	1.213
3.5 - 5 years	0.933	0.860	0.819	***0.288 ^a	1.212 ^a	1.847	1.150
In initial treatment, active cancer	***0.247	**0.564	1.449	***3.412	***3.934	0.717	***0.251
In initial treatment, inactive cancer	0.849	**0.673	1.337	1.746	1.445	0.539	1.043
Any new cancer	**0.670	*0.727	1.307	***4.021 ^b	1.446 ^b	***0.372	0.817
Any chronic conditions	***386	0.836	***2.024	**1.881	**1.487	**0.550	0.812
Female	**0.676	*0.770	1.179				
Age 45-52	*0.758	*1.304	0.674	**2.632	***1.885	0.417	0.763
Age 53-57	0.801	**1.520	*0.625	1.421	1.207	**0.268	**0.515
Age 58-61	0.810	***2.410	***0.348	1.266	1.408	***0.156	***0.279
Age 62 and over	1.348	***3.620	***0.337	1.987	0.570	***0.043 ^a	***0.168 ^a

	Above average PCS-12	Above average MCS-12	BSI-18 distress	Cancer-related work disability		Labor force participation	
				Male	Female	Male	Female
Nonwhite	*0.680	0.759	0.712	1.786	0.822	0.696	0.906
Married at diagnosis	0.895	1.170	**0.626	0.557 ^a	1.249 ^a	**2.438 ^b	0.930 ^b
High school	*1.565	**1.654	**0.478	0.890	0.724	1.742	***2.850
Some college	**1.935	1.362	*0.562	0.674	0.935	2.425	**2.334
College	***2.244	1.538	*0.504	0.494	0.852	*2.619	***2.843
Post college	***2.702	***2.225	***0.190	0.613	0.637	***7.122	***7.592
100-199% of poverty	1.318	0.965	1.416				
200-299% of poverty	1.341	1.440	1.017				
300-399% of poverty	***2.702	*1.865	0.885				
400+% of poverty	**2.250	*1.859	*0.473				
In labor force at diagnosis	*1.303	**1.437	***0.436	0.803	1.380	***18.528	***20.003
N	1645	1645	1674	562	1116	561	1114
Mean	0.557	0.667	0.093	0.169	0.208	0.767	0.709

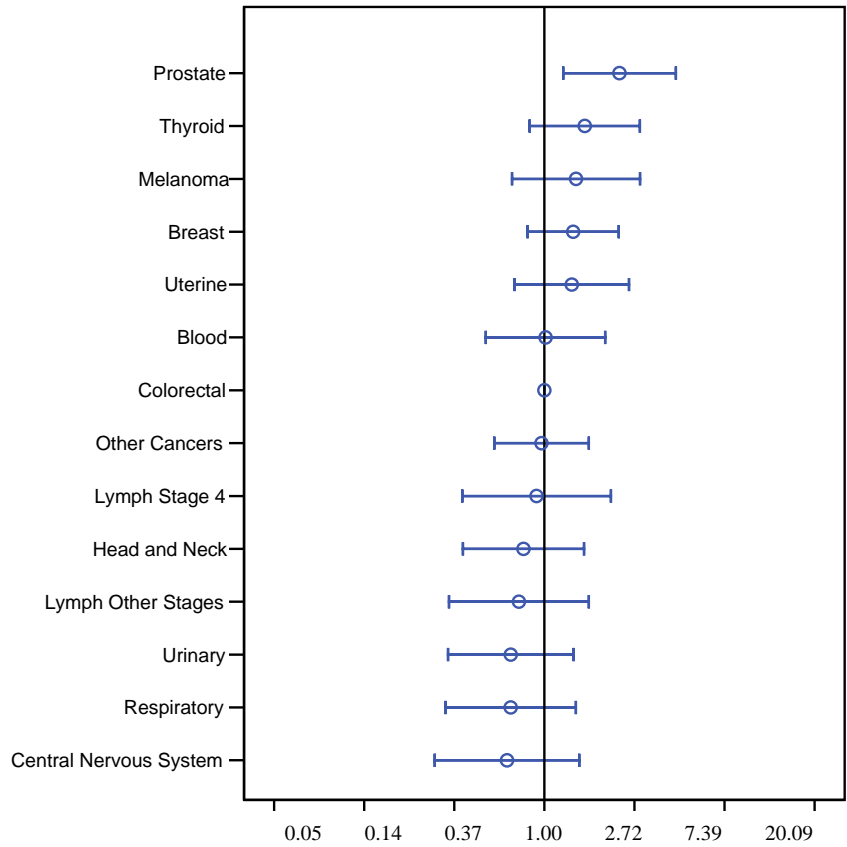
Odds ratio is significantly different from 1 at *p<.10, **p<.05, ***p<.01. ^aFemale > male, p<.05. ^bFemale < male, p<.05. The models also include indicators for the cancer sites shown in Figures 1-6. The reference categories are male, colorectal cancer, not employed at diagnosis, Stage 1 diagnosis, interviewed less than 1.5 years from diagnosis, not in treatment, no metastases or new cancer, under age 45, white, not married at diagnosis, less than high school, below poverty, no chronic conditions.

Table 6. Logit model of study participation by characteristics of eligible survivors (N=4735)

Characteristics	Eligible (N)	Adjusted Odds Ratio (95% confidence interval)	Rank by participation	Significant pairwise differences (by rank)
Gender				
Female	2927	1.291 (1.097, 1.521)	1	> 2
Male	1808	1.000	2	< 1
Age at diagnosis				
25-34	501	1.000	3	
35-44	1027	1.108 (.879, 1.397)	2	> 4
45-54	1655	1.206 (.967, 1.505)	1	> 4
55-62	1552	0.897 (.712, 1.128)	4	< 1, 2
Race				
White	4302	1.000	1	> 2
Nonwhite	344	0.680 (.528, .876)	2	< 1
Stage at diagnosis				
1	1986	1.000	2	
2	1398	1.096 (.939, 1.278)	1	
3	810	0.954 (.794, 1.146)	3	
Unstaged, unknown	213	0.556 (.393, .786)	4	< 1, 2, 3
Cancer site				
Breast	1149	1.460 (1.104, 1.930)	1	> 8-14
Lymph stage 4	109	1.349 (.850, 2.141)	2	> 11-14
Blood (Stage 4)	219	1.295 (.891, 1.883)	3	> 10-14
Prostate	375	1.232 (.882, 1.722)	4	> 11-14
Thyroid	332	1.150 (.823, 1.606)	5	> 11-14
Lymph other stage	143	1.141 (.748, 1.742)	6	> 13-14
Urinary	177	1.092 (.736, 1.618)	7	> 13-14
Other	651	1.070 (.801, 1.428)	8	> 13-14
Colorectal	331	1.000	9	< 1
Respiratory	223	0.849 (.586, 1.231)	10	< 1, 3
Melanoma	216	0.788 (.541, 1.150)	11	< 1-5
Uterus	350	0.761 (.540, 1.072)	12	< 1-5
Head & neck	262	0.711 (.494, 1.023)	13	< 1-8
Central nervous system	198	0.700 (.465, 1.053)	14	< 1-8
Facility				
Geisinger	700	2.291 (1.863, 2.818)	1	> 2-4
Lehigh Valley	1129	1.711 (1.422, 2.059)	2	> 3-4
Johns Hopkins	1870	1.384 (1.163, 1.647)	3	> 4
Hershey	1036	1.000	4	< 1-3

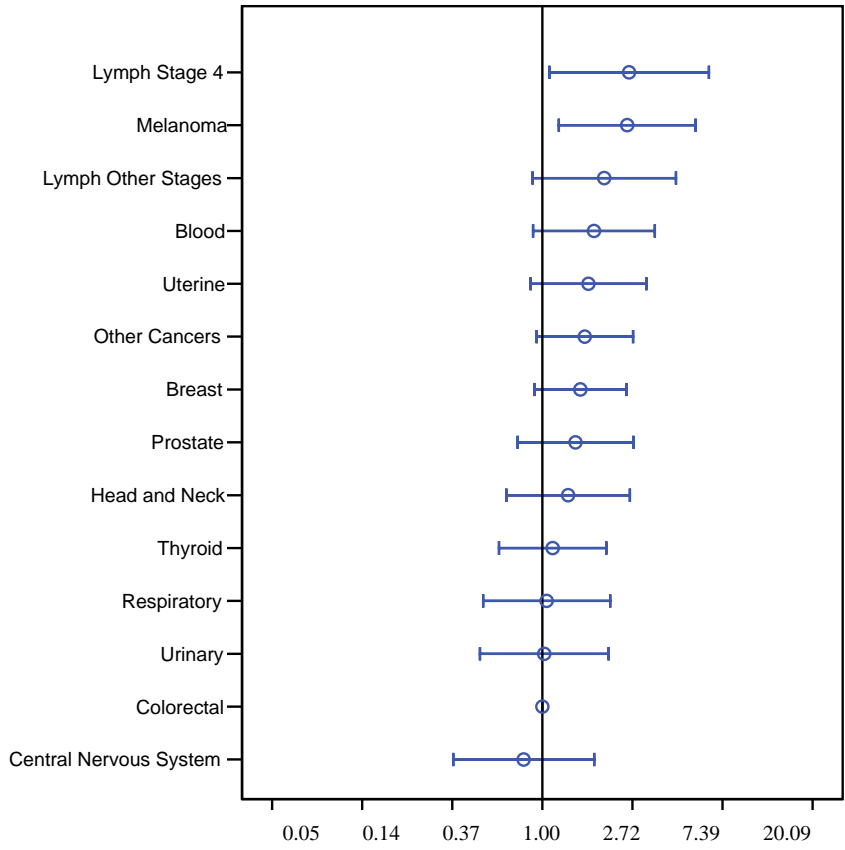
Model also included year of diagnosis, which was not significant.

Figure 1. Adjusted Odds Ratios (and 95% Confidence Intervals) for Above-Average SF-12 Physical Health by Cancer Site



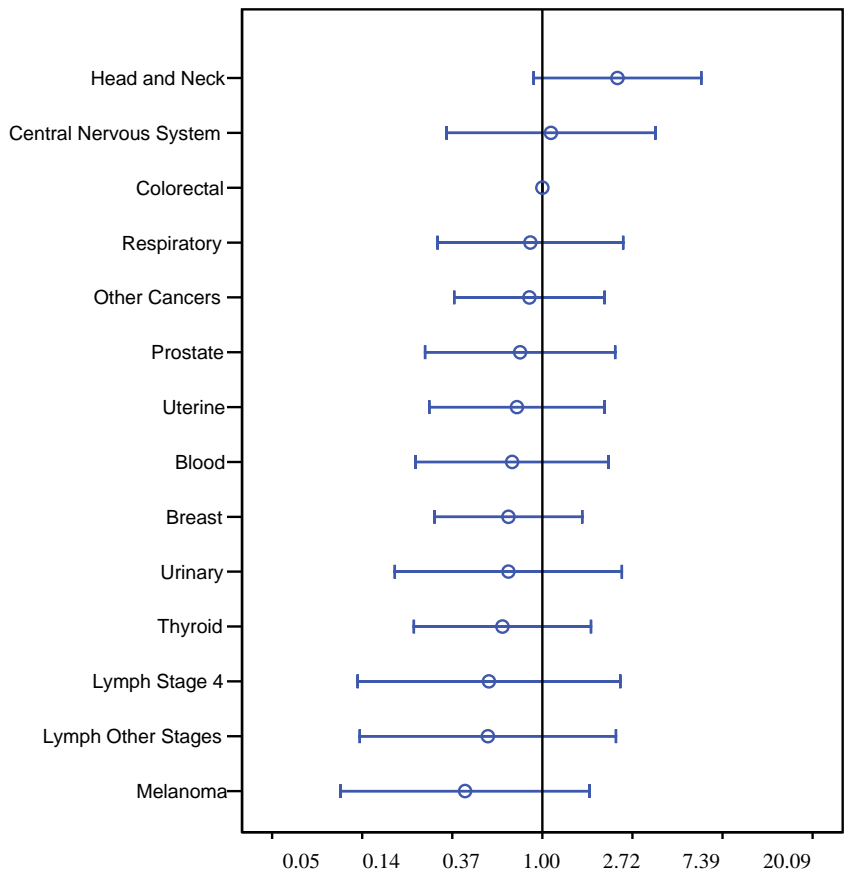
Odd ratios are adjusted for all of the variables shown in Table 5.

Figure 2. Adjusted Odds Ratios (and 95% Confidence Intervals) for Above-Average SF-12 Mental Health by Cancer Site



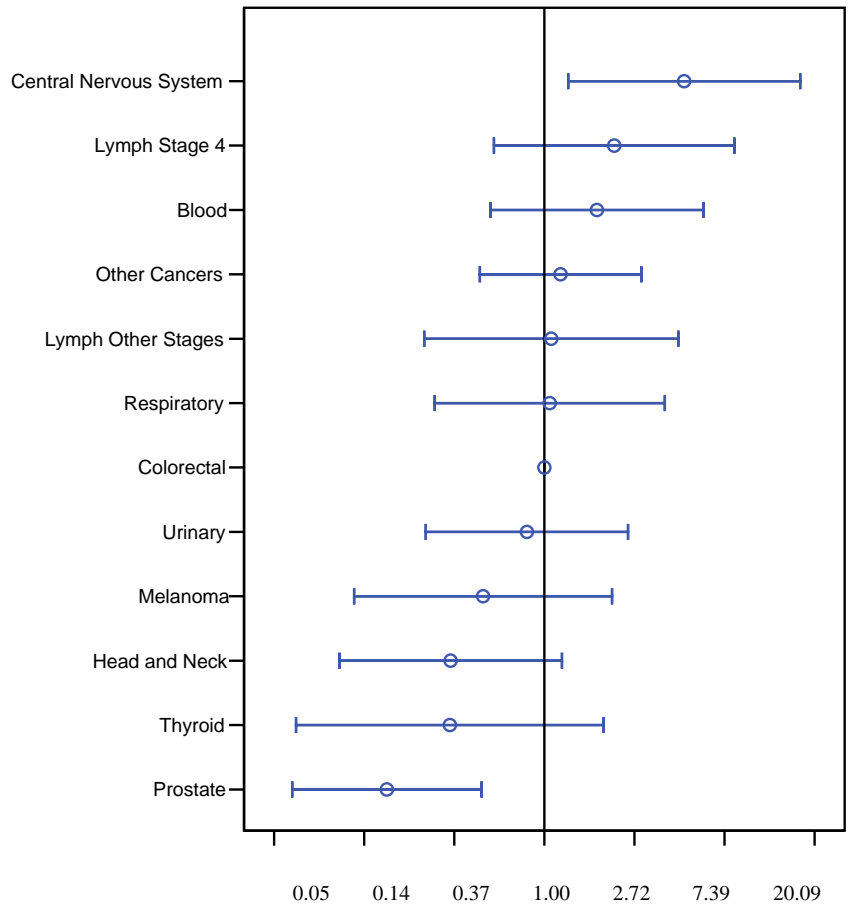
Odd ratios are adjusted for all of the variables shown in Table 5.

Figure 3. Adjusted Odds Ratios (and 95% Confidence Intervals) for BSI-18 Distress by Cancer Site



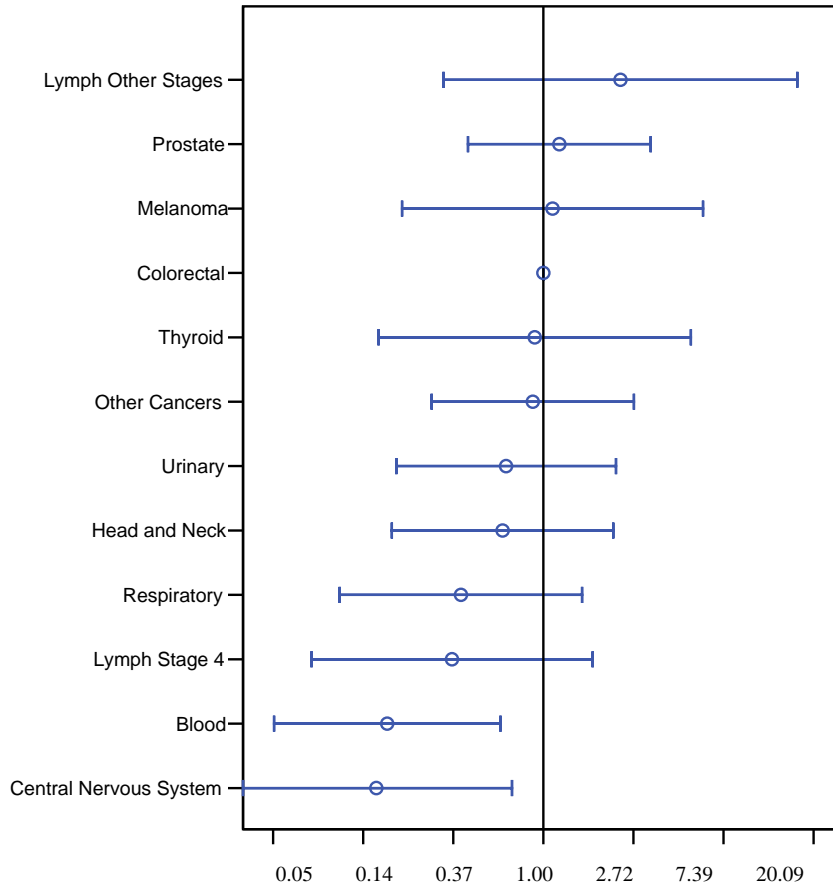
Odd ratios are adjusted for all of the variables shown in Table 5.

Figure 4. Adjusted Odds Ratios (and 95% Confidence Intervals) for Male Work Disability by Cancer Site



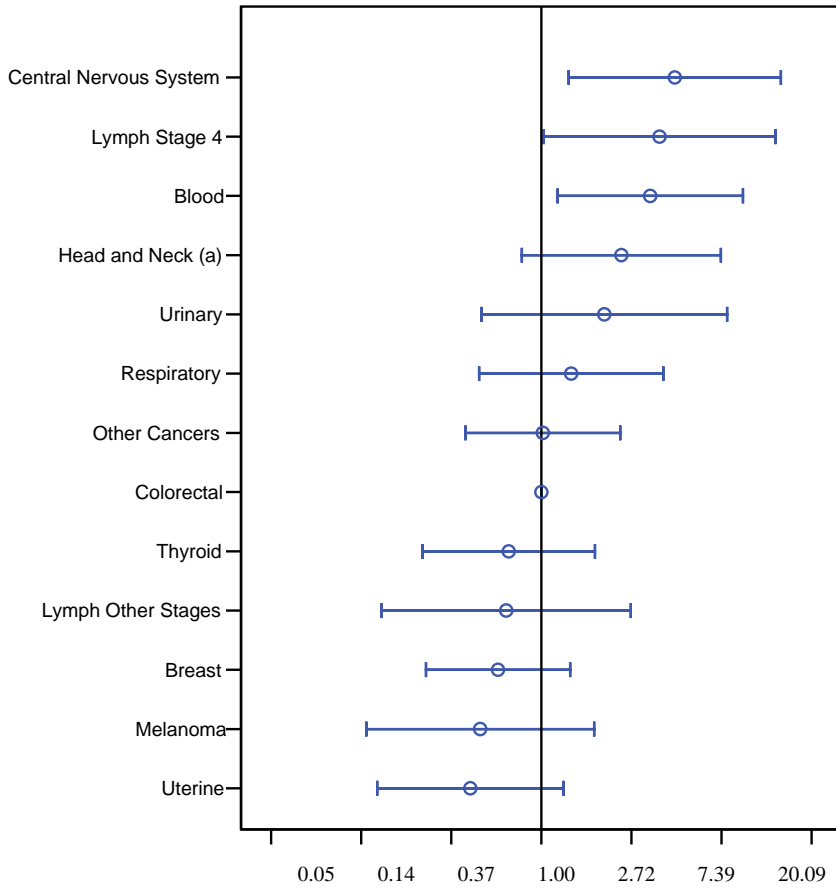
Odd ratios are adjusted for all of the variables shown in Table 5.

Figure 5. Adjusted Odds Ratios (and 95% Confidence Intervals) for Male Labor Force Participation by Cancer Site



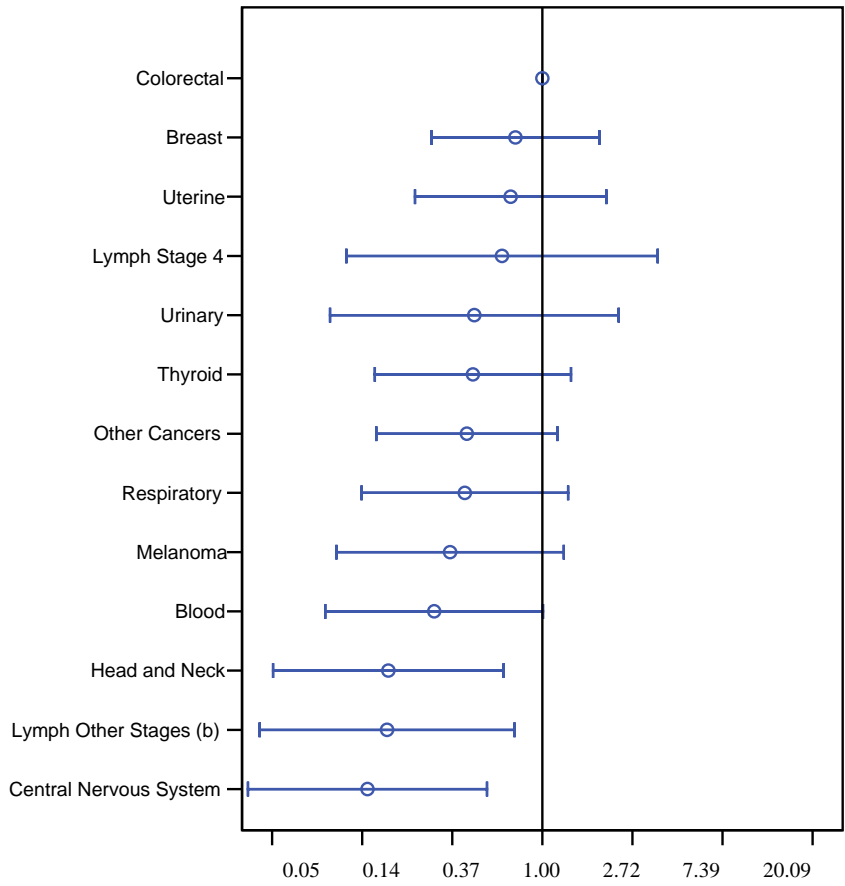
Odd ratios are adjusted for all of the variables shown in Table 5.

Figure 6. Adjusted Odds Ratios (and 95% Confidence Intervals) for Female Work Disability by Cancer Site



Odd ratios are adjusted for all of the variables shown in Table 5. ^aFemale>male, p<.05. ^bFemale<male, p<.05

Figure 7. Adjusted Odds Ratios (and 95% Confidence Intervals) for Female Labor Force Participation by Cancer Site



Odd ratios are adjusted for all of the variables shown in Table 5. ^aFemale>male, P<.05. ^bFemale<male, P<.05