Psychological Distress in Long-term Survivors of Adult-Onset Cancer

Results From a National Survey

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Background: As advances in cancer screening and treatment increase the number of long-term cancer survivors, it is important to understand the long-term psychological sequelae of the cancer experience.

Methods: The 4636 respondents who identified themselves as survivors of adult-onset cancer of 5 years or more and 122 220 respondents who were never diagnosed as having cancer were identified in the 2002 to 2006 National Health Interview Survey. The primary outcome in this population-based study was serious psychological distress (SPD) defined as a K6 scale (a validated screening tool for mental illness) score of 13 or more.

Results: Among survivors, the median age at diagnosis was 50 years, the age at interview was 66 years, and the time since diagnosis was 12 years. The prevalence of SPD was significantly higher among long-term cancer survivors than among respondents who were never diagnosed as having cancer (5.6% vs 3.0%; P < .001). After adjustment for clinical and sociodemographic variables (age, sex, race, relationship status, educational attainment, insurance status, comorbidities, smoking history, and ability to perform instrumental activities of daily living), survivors remained significantly more likely to experience SPD (adjusted odds ratio, 1.4; 95% confidence interval, 1.2-1.7). After adjustment for other clinical and sociodemographic variables, long-term survivors who were younger, were unmarried, had less than a high school education, were uninsured, had more comorbidities, or had difficulty performing instrumental activities of daily living were more likely to experience SPD.

Conclusions: Long-term survivors of adult-onset cancer are at increased risk for psychological distress. This study identifies several clinical and sociodemographic factors associated with SPD that may help target high-risk survivors for psychological screening and support.

THERE ARE AN ESTIMATED 12 million cancer survivors in the United States, representing 4% of the population.1,2 The number of cancer survivors has steadily increased over the last 3 decades and is expected to continue to increase with the implementation of improved cancer screening, the adoption of more efficacious cancer treatment, and the aging of the population. Currently two-thirds of adults diagnosed as having cancer are expected to survive 5 years or more after diagnosis.3

As more individuals survive cancer, it is important to understand how cancer and cancer therapies affect long-term quality of life and psychological adjustment.4 Recent Institute of Medicine reports call for attention to the potential psychological sequelae of the cancer experience.5-6 Although most long-term cancer survivors successfully adapt to life after cancer and may even experience positive psychological effects from coping with their cancer,7,9 it is now recognized that some cancer survivors develop significant and lasting psychological sequelae.8,10-16 A cancer diagnosis and subsequent treatment can cause both physical and psychosocial effects. Cancer treatment can create immediate physical deficits as well as delayed physical effects that emerge many years after the completion of therapy, such as infertility, cardiac dysfunction, and a second malignant neoplasm.17-19 A history of cancer can also have an impact on social adaptation by limiting employment opportunities and the ability to obtain health insurance coverage.20,21 As a result of their cancer experience, many cancer survivors develop a fear of recurrence, health worries, a heightened sense of vulnerability, a sense of loss for what might have been, and alterations in social support.6,6 It is important to study the psychological sequelae of the cancer experience because such mental distress is
likely treatable, and early detection and intervention may improve the overall well-being and quality of life of cancer survivors. Given the challenges that cancer survivors face, it is not surprising that several studies have suggested that long-term cancer survivors may be at risk for a variety of psychological symptoms, including anxiety, depression, and fatigue.\textsuperscript{22-40} The extent of psychological symptoms varies among these studies owing to differences in patient characteristics, survey timing, and study design. Ensuring a representative sample is difficult, as most persons with adult-onset cancer are treated outside of clinical trials and outside of the specialized cancer centers where these studies are often conducted. As a consequence, it is difficult to accurately assess the prevalence of psychological distress in the cancer-survivor population at large.

Therefore, we used a nationally representative sample of adults in the United States to determine the prevalence of serious psychological distress (SPD) among long-term survivors of adult-onset cancer and to examine whether the prevalence of SPD was higher among long-term survivors than among adults without cancer. We studied long-term survivors to describe and explore sociodemographic and clinical factors associated with experiencing SPD and to ascertain survivors’ utilization of mental health services.

**METHODS**

**DATA SOURCE**

The National Health Interview Survey (NHIS) is a cross-sectional in-person health survey that is administered annually by the US Census Bureau for the National Center for Health Statistics, Centers for Disease Control and Prevention.\textsuperscript{41} The survey is the principal source of information on the health of the civilian, noninstitutionalized US population. Households were randomly selected based on a multistage stratified sampling design. Hispanic and non-Hispanic black populations were oversampled. Face-to-face surveys were administered in English and/or Spanish. One randomly selected adult (age $\geq$18 years) from each family was asked to complete the Sample Adult Questionnaire; proxy respondents were not permitted. Our study sample was selected among respondents to the sample adult questionnaire. Respondents were asked to rate how frequently they experienced symptoms of psychological distress during the last 30 days (felt so sad that nothing could cheer them up; felt nervous; felt restless/fidgety; felt hopeless; felt that everything was an effort; or felt worthless) using a 5-point Likert scale (none of the time to all of the time). The items were summed to create a score ranging from 0 to 24, with higher scores indicating increasing symptoms of distress. As suggested by Kessler et al.,\textsuperscript{43} a score of 13 or above was used to indicate SPD. Because a 30-day reference period is used to ascertain symptoms, our results reflect 30-day prevalence rates. Fewer than 2% of respondents were excluded from the analysis owing to missing responses on K6 items (76 survivors and 2433 respondents never diagnosed as having cancer). The final study sample included 4636 long-term cancer survivors and 122,220 adults without a cancer diagnosis.

**STUDY SAMPLE**

We studied long-term cancer survivors and a noncancer comparison group composed of adults who had never been diagnosed as having cancer. Respondents were asked, “Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?” Those responding affirmatively were then asked about specific types of cancer and their age at diagnosis. We classified respondents as long-term survivors if they reported a diagnosis of cancer at age 18 years or older and if it had been at least 5 years since their cancer diagnosis. We excluded respondents with only nonmelanoma skin cancer (n=1452) because treatment for nonmelanoma skin cancer is considered relatively minor. Our comparison group, representing the general adult population of the United States that had never been diagnosed as having cancer, consisted of respondents 23 years or older who did not report a diagnosis of cancer. We excluded respondents who were younger than 23 years (n=10,736), respondents whose cancer status was not known (n=171), and respondents who had been diagnosed as having cancer less than 5 years before the interview (n=3044). We also excluded respondents 85 years and older (n=3421) because the NHIS does not report the actual ages in this group to protect their privacy. The initial study sample included 4712 long-term cancer survivors and 124,653 adults without a cancer diagnosis.

**PRIMARY OUTCOME**

The primary outcome was SPD as measured by the K6 scale, which is a validated, reliable, screening scale that is designed to assess nonspecific psychological distress.\textsuperscript{45} During our study years, the K6 items were included in the sample adult questionnaire. Respondents were asked to rate how frequently they experienced symptoms of psychological distress during the last 30 days (felt so sad that nothing could cheer them up; felt nervous; felt restless/fidgety; felt hopeless; felt that everything was an effort; or felt worthless) using a 5-point Likert scale (none of the time to all of the time). The items were summed to create a score ranging from 0 to 24, with higher scores indicating increasing symptoms of distress. As suggested by Kessler et al.,\textsuperscript{43} a score of 13 or above was used to indicate SPD. Because a 30-day reference period is used to ascertain symptoms, our results reflect 30-day prevalence rates. Fewer than 2% of respondents were excluded from the analysis owing to missing responses on K6 items (76 survivors and 2433 respondents never diagnosed as having cancer). The final study sample included 4636 long-term cancer survivors and 122,220 adults without a cancer diagnosis.

**PREDICTORS OF INTEREST**

Explanatory variables evaluated for association with SPD and with being a cancer survivor included sociodemographic factors (age, sex, race, educational attainment, relationship status, and health insurance status) and clinical characteristics (comorbid illness, functional status, smoking status, and years since cancer diagnosis). To assess comorbid illness, respondents were asked if a health care professional told them that they had a certain disease. Diseases were categorized as heart disease (including coronary heart disease, angina pectoris, myocardial infarctions, and other heart conditions), stroke, diabetes mellitus, chronic obstructive pulmonary disease (including emphysema and chronic bronchitis), and kidney disease. Illness burden was defined by the presence of none, 1, or 2 or more of these chronic illnesses. Functional limitations were measured by a report of needing help with any of the following 4 instrumental activities of daily living (IADLs): everyday household chores, doing necessary business, shopping, or getting around for other purposes. Smoking history was grouped as never smokers vs former and current smokers. Fewer than 1% of the respondents were missing responses to questions about relationship status (n=356), educational attainment (n=1222), insurance status (n=416), smoking status (n=901), and/or functional status (n=31). For the respondents who had been diagnosed as having more than 1 cancer, age at first cancer diagnosis and years since last cancer diagnosis were used for the analysis. Respondents were also asked whether they had seen or talked to a mental health professional and whether they could afford mental health care during the prior 12 months.
Table 1. Characteristics of 4636 Long-term Cancer Survivors

<table>
<thead>
<tr>
<th>Variable</th>
<th>Survivors, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis, y</td>
<td></td>
</tr>
<tr>
<td>&lt;45</td>
<td>43.0</td>
</tr>
<tr>
<td>45-64</td>
<td>38.0</td>
</tr>
<tr>
<td>&gt;65</td>
<td>19.0</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td></td>
</tr>
<tr>
<td>5-10</td>
<td>45.8</td>
</tr>
<tr>
<td>11-15</td>
<td>19.8</td>
</tr>
<tr>
<td>&gt;15</td>
<td>34.5</td>
</tr>
<tr>
<td>Site or type of cancer</td>
<td></td>
</tr>
<tr>
<td>Cervix, uterus, or other female genital organs</td>
<td>25.2</td>
</tr>
<tr>
<td>Breast</td>
<td>22.9</td>
</tr>
<tr>
<td>Prostate or testes</td>
<td>13.9</td>
</tr>
<tr>
<td>Colorectal</td>
<td>9.6</td>
</tr>
<tr>
<td>Larynx, trachea, bronchus, or lung</td>
<td>4.6</td>
</tr>
<tr>
<td>Leukemia, lymphoma</td>
<td>5.9</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1.0</td>
</tr>
<tr>
<td>Bladder or kidney</td>
<td>5.6</td>
</tr>
<tr>
<td>Other</td>
<td>14.2</td>
</tr>
</tbody>
</table>

*Table 1.* Characteristics of 4636 Long-term Cancer Survivors

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LONG-TERM CANCER SURVIVORS’ USE
OF MENTAL HEALTH SERVICES

Overall, 9% of long-term survivors and 6% of respondents without cancer reported seeing or talking to a mental health professional during the previous 12 months. Of survivors with SPD, 33% reported having seen or talked to a mental health professional, and 18% reported they could not afford mental health care during the previous 12 months. Similarly, of respondents with SPD in the non-cancer comparison group, 33% reported contact with a mental health professional, and 19% reported an inability to afford mental health care during the prior 12 months.

A population-based sample of 4636 long-term survivors of adult-onset cancer, who represent an estimated 6.3 million long-term survivors residing in the United States annually, were more likely to experience SPD than were adults who had never been diagnosed as having cancer and remained significantly more likely to experience SPD after adjustment for sociodemographic and clinical characteristics. Several sociodemographic and clinical factors were associated with SPD among these survivors who had received their cancer diagnosis at least 5 years earlier.

Previous studies addressing psychological distress among long-term survivors largely focused on childhood cancer survivors, and many of the studies that did evaluate psychological distress in survivors of adult-onset cancer included patients who were within the immediate post-diagnosis or posttreatment period. Several single-institution studies did evaluate the mental well-being of specific groups of long-term survivors of adult-onset cancer, with most data available for long-term survivors of breast cancer, Hodgkin lymphoma, and bone marrow transplantation. In the majority of these studies, socially disadvantaged and ethnic minority groups are underrepresented, and these groups are also underrepresented in the long-term-survivor quality-of-life literature. A strength of this study is that the NHIS was designed to produce a nationally representative sample that reflects ethnic and socioeconomic diversity.

This study found a modest but real increase in SPD among cancer survivors, as measured by the K6 scale. Further research at the individual patient level is needed to fully clarify the clinical meaning of this increased distress. In general, mental illness can decrease quality of life, increase medical visits, and create an economic burden. The K6 is a screening scale that has been validated against an in-person Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition) interview diagnosis. It is designed to capture mental health problems that are severe enough to cause moderate to serious impairment in social, occupational, or school functioning and to require treatment. In a study comparing 3 screening scales, the K6 was found to be the most efficient scale to screen for serious mental illness, with a sensitivity of 0.36, a specificity of 0.96, and an overall accuracy of 0.92. However, the K6 does not identify a particular mental health diagnosis. Based on the symptoms included in the K6, it likely identifies severe, disabling mood and anxiety disorders.

There are several reasons why a remote cancer history can affect current psychological health. Cancer diagnosis and treatment can produce delayed detrimental effects on physical health and functioning such as secondary cancers, cardiac dysfunction, lung dysfunction, infertility, neurological complications, and neurocognitive dysfunction. A cancer history can also affect social adaptation, employment opportunities, and insurance coverage. Adjusting to these functional and life limitations may create long-term psychological stress. We found that survivors with more comorbid illnesses, difficulty performing IADLs, lower educational attainment, and no spouse or no health insurance were more likely to report SPD. The link between SPD and these sociodemographic factors in cancer survivors is disquieting and highlights the importance of developing accessible and affordable mental health services for cancer survivors.

### Table 2. Characteristics of 4636 Long-term Cancer Survivors and 122,220 Respondents in the Noncancer Comparison Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>Survivors, %a</th>
<th>Comparison Group, %a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serious psychological distressb</td>
<td>No</td>
<td>94.5</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>5.6</td>
</tr>
<tr>
<td>Age, yb</td>
<td>&lt;45</td>
<td>13.5</td>
</tr>
<tr>
<td></td>
<td>45-64</td>
<td>37.9</td>
</tr>
<tr>
<td></td>
<td>≥65</td>
<td>48.6</td>
</tr>
<tr>
<td>Sexb</td>
<td>Male</td>
<td>34.6</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>65.4</td>
</tr>
<tr>
<td>Raceb</td>
<td>White</td>
<td>90.5</td>
</tr>
<tr>
<td></td>
<td>Black</td>
<td>6.2</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>3.3</td>
</tr>
<tr>
<td>Relationship statusb</td>
<td>Married or living with partner</td>
<td>64.9</td>
</tr>
<tr>
<td></td>
<td>Not married or living with partner</td>
<td>35.1</td>
</tr>
<tr>
<td>Educational attainmentc</td>
<td>≥High school</td>
<td>82.6</td>
</tr>
<tr>
<td></td>
<td>&lt;High school</td>
<td>17.4</td>
</tr>
<tr>
<td>Insurance statusb</td>
<td>Insured</td>
<td>93.0</td>
</tr>
<tr>
<td></td>
<td>Uninsured</td>
<td>7.0</td>
</tr>
<tr>
<td>IADLsb</td>
<td>No difficulty</td>
<td>91.0</td>
</tr>
<tr>
<td></td>
<td>Difficulty</td>
<td>9.0</td>
</tr>
<tr>
<td>Comorbid illnessesb</td>
<td>0</td>
<td>55.6</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>28.6</td>
</tr>
<tr>
<td></td>
<td>≥2</td>
<td>15.8</td>
</tr>
<tr>
<td>Smoking statusb</td>
<td>Never</td>
<td>42.5</td>
</tr>
<tr>
<td></td>
<td>Former or current</td>
<td>57.5</td>
</tr>
</tbody>
</table>

Abbreviation: IADLs, instrumental activities of daily living.

a Percentages are weighted to reflect population estimates, were computed for respondents with complete data, and may not add up to 100% because of rounding. Some respondents were missing responses to questions about relationship status (n=556), educational attainment (n=1222), insurance status (n=416), smoking status (n=901), and or functional status (n=31).

b P<.001, χ² test.

c P<.01, χ² test.
affordable support systems that include psychiatric care for this vulnerable population. The influence of various socioeconomic factors and physical health on the extent of psychological distress has been explored in the general population and in specific groups of cancer survivors. Similar to our findings among long-term survivors, studies have shown an association between increased psychological symptoms and comorbid illness, functional impairment, lack of health insurance, decreased social support, lower educational attainment, and smoking. Our finding of a persistently increased risk of SPD among long-term survivors as compared with those without a history of cancer, after adjustment for sociodemographic and health status, suggests that survivors have increased vulnerability to psychological distress through additional mechanisms that were not captured by the survey. Perhaps survivors are more likely to report SPD because of treatment-related fatigue, an underlying sense of loss for what might have been, or an underlying fear of recurrence and death. An increased frequency of SPD, as measured by the K6 scale, has also been reported in studies of psychological reactions to catastrophic disasters. Ten percent of survivors who were in collapsed or damaged buildings during the September 11, 2001, World Trade Center attacks reported SPD 2 to 3 years after the attacks. It is noteworthy that these studies examined SPD within 1 to 3 years after a catastrophic event, compared with the much longer follow-up period in our cancer survivor cohort.

The combination of younger age and comorbid illness placed cancer survivors at particularly high risk, with one-fourth of survivors younger than 45 years with co-morbid illness reporting distress. Young age as a risk factor for poor psychological quality of life has also been demonstrated in survivors of breast cancer. This find-

### Table 3. Adjusted Odds Ratio (OR) of Serious Psychological Distress (SPD) Among Long-term Cancer Survivors Compared With Respondents Never Diagnosed as Having Cancer

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample Size</th>
<th>SPD, %</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noncancer comparison group</td>
<td>122,220</td>
<td>3.0</td>
<td>1.0 [Reference]</td>
</tr>
<tr>
<td>Long-term cancer survivors</td>
<td>4636</td>
<td>5.6</td>
<td>1.9 (1.7-2.3)</td>
</tr>
</tbody>
</table>

Abbreviation: CI, confidence interval.

*Percentages are weighted to reflect population estimates.

### Table 4. Adjusted Odds Ratio (OR) of Serious Psychological Distress (SPD) for Each Clinical and Sociodemographic Characteristic Among the Long-term Survivors of Adult-Onset Cancer

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample Size</th>
<th>SPD, %</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at interview, y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 45</td>
<td>578</td>
<td>10.7</td>
<td>7.8 (5.4-10.9)</td>
</tr>
<tr>
<td>45-64</td>
<td>1629</td>
<td>6.7</td>
<td>2.7 (1.8-4.0)</td>
</tr>
<tr>
<td>≥65</td>
<td>2429</td>
<td>3.2</td>
<td>1.0 [Reference]</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-10</td>
<td>2052</td>
<td>4.6</td>
<td>1.0 [Reference]</td>
</tr>
<tr>
<td>11-15</td>
<td>936</td>
<td>6.0</td>
<td>1.3 (0.9-1.9)</td>
</tr>
<tr>
<td>≥15</td>
<td>1648</td>
<td>6.6</td>
<td>1.2 (0.9-1.8)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
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<tr>
<td>Male</td>
<td>1463</td>
<td>4.0</td>
<td>1.0 [Reference]</td>
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<tr>
<td>Female</td>
<td>3173</td>
<td>6.4</td>
<td>1.2 (0.8-1.8)</td>
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<tr>
<td>Race</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>4974</td>
<td>5.2</td>
<td>1.0 [Reference]</td>
</tr>
<tr>
<td>Black</td>
<td>398</td>
<td>8.2</td>
<td>1.3 (0.8-2.1)</td>
</tr>
<tr>
<td>Other</td>
<td>164</td>
<td>9.4</td>
<td>1.1 (0.6-2.1)</td>
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<tr>
<td>Relationship status</td>
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<tr>
<td>Married or living with partner</td>
<td>2233</td>
<td>4.2</td>
<td>1.0 [Reference]</td>
</tr>
<tr>
<td>Not married or living with partner</td>
<td>2336</td>
<td>8.0</td>
<td>2.2 (1.2-4.4)</td>
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<td>Educational attainment</td>
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<tr>
<td>≥High school</td>
<td>3719</td>
<td>4.6</td>
<td>1.0 [Reference]</td>
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<td>&lt;High school</td>
<td>890</td>
<td>10.4</td>
<td>2.1 (1.5-3.0)</td>
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<td>Insured</td>
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<td>Uninsured</td>
<td>337</td>
<td>15.3</td>
<td>2.4 (1.6-3.7)</td>
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<td>Comorbid illnesses</td>
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<td></td>
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<tr>
<td>0</td>
<td>2536</td>
<td>3.7</td>
<td>1.0 [Reference]</td>
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<tr>
<td>≥2</td>
<td>1350</td>
<td>5.5</td>
<td>1.7 (1.1-2.6)</td>
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<tr>
<td>Smoking history</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>2011</td>
<td>3.5</td>
<td>1.0 [Reference]</td>
</tr>
<tr>
<td>Current or former</td>
<td>2608</td>
<td>7.1</td>
<td>1.7 (1.2-2.5)</td>
</tr>
<tr>
<td>IADLs</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No difficulty</td>
<td>4147</td>
<td>4.4</td>
<td>1.0 [Reference]</td>
</tr>
<tr>
<td>Difficulty</td>
<td>487</td>
<td>17.4</td>
<td>3.6 (2.5-6.3)</td>
</tr>
</tbody>
</table>

Abbreviations: CI, confidence interval; IADLs, instrumental activities of daily living.

*Sample size may not add up to 4636 because of missing responses.

### Table 5. Proportion of Long-term Survivors With Serious Psychological Distress Grouped by Age and Comorbid Illnesses

<table>
<thead>
<tr>
<th>Variable</th>
<th>Comorbid Illnesses, %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Age at interview, y</td>
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</tr>
<tr>
<td>≥65</td>
<td>2.0</td>
</tr>
<tr>
<td>(n=1117)</td>
<td>(n=824)</td>
</tr>
<tr>
<td>45-64</td>
<td>4.6</td>
</tr>
<tr>
<td>(n=987)</td>
<td>(n=416)</td>
</tr>
<tr>
<td>≤45</td>
<td>7.4</td>
</tr>
<tr>
<td>(n=432)</td>
<td>(n=110)</td>
</tr>
</tbody>
</table>

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ing highlights the potentially disruptive effect of a history of cancer diagnosis and treatment on young survivors, who may be in critical life stages, such as starting a family or embarking on a career. Although younger survivors were more likely to report SPD, there was no association observed between SPD and the number of years since cancer diagnosis. Findings on the impact of time since cancer diagnosis on psychological health have been variable. In a longitudinal study of women with breast cancer, the 36-Item Short-Form Health Survey mental health, emotional role, and social role scores improved considerably from initial diagnosis to 5 years after initial diagnosis. In contrast, a report on 10-year survivors of head and neck cancer found that 9% of them had increased psychological distress compared with baseline scores obtained before treatment. A higher level of distress with longer time from treatment was similarly observed in a Norwegian study of long-term survivors of Hodgkin lymphoma that determined that longer time from initial diagnosis (>7 years) was independently associated with increased anxiety. The increase in the level of distress over time among survivors of head and neck cancers and Hodgkin lymphoma may be related to the emergence of late effects of treatment, which can adversely affect physical and mental health even many years after the completion of therapy. In our study, which included survivors of a wide range of cancers, time since diagnosis was not significantly associated with SPD after adjustment. Because our study excluded respondents within the first 5 years of a cancer diagnosis, the respondents had additional time to adapt to the cancer diagnosis and to recuperate from the initial cancer treatment. The continued adjustment from the initial cancer diagnosis, recovery from treatment, and reduction in fear of recurrence over time may potentially be offset by late effects of cancer therapy. Indeed, in a study examining the risk of significant depressive symptoms over an 8-year period after a cancer diagnosis, patients with cancer continued to have significant depressive symptoms beyond 4 to 8 years.

Long-term cancer survivors were more likely to report using mental health services in the prior year than adults who had never been diagnosed as having cancer, supporting our finding that cancer survivors were more likely to experience SPD. However, it is disconcerting that two-thirds of the long-term survivors with SPD had not seen or talked to a mental health professional during the year before the survey, although these rates were similar to rates among adults with SPD who had never been diagnosed as having cancer, and survivors may have received mental health support elsewhere. Eighteen percent of survivors with SPD reported that they could not afford mental health care, highlighting the importance of improving mental health resources for patients with cancer.

We acknowledge that this study has several limitations. It is cross-sectional, so we cannot determine causation. A longitudinal study would better assess causation and impact of time since diagnosis. We propose a plausible mechanism for why cancer survivors may have an increased rate of SPD. Alternatively, mental illness may place individuals at increased risk for cancer through psychiatric medications, lower socioeconomic status, health habits, or other mechanisms. We do not know prior individual or family mental health history. Health status and disease history, including the type of cancer and when it was diagnosed, were self-reported. The NHIS may underreport cancer cases, compared with cancer registry data, because it does not include individuals in hospice, nursing homes, or hospitals who are under treatment for cancer. In one study, the survey’s estimate of overall cancer prevalence was 20.2% and 2.9% lower than the cancer registry estimate for men and women, respectively. The NHIS also does not collect broader health status data that would indicate whether a survivor was cured or in active therapy and does not contain the details of cancer treatment. Therefore, this study could not assess the impact of these factors. However, a subset analysis of respondents who had not seen a medical specialist in the prior 6 months, and presumably were not under active treatment for cancer, demonstrated similar findings. Also, many individuals with the most serious mental illnesses are either homeless or institutionalized, and these individuals are not captured in the NHIS. At the other extreme, survivors whose SPD was successfully treated were not captured by the K6 scale. Finally, the K6 scale has not been validated specifically for cancer survivors.

This nationally representative study found an increased risk of SPD among long-term survivors of adult-onset cancer. Approximately 1 in 18 noninstitutionalized long-term survivors of adult-onset cancer who reside in the United States reported SPD based on a general screening instrument. After adjustment for clinical and demographic factors, long-term cancer survivors remain more likely to have SPD than adults who have never been diagnosed as having cancer. This study identified several clinical and sociodemographic factors associated with SPD that may help in targeting high-risk survivors for screening and mental health support. Prompt diagnosis and treatment of mental distress can have a positive impact on the functioning, quality of life, and overall well-being of survivors. Studies have demonstrated that routine psychological screening can be successfully integrated into the cancer survivor clinic and that several quick, low-cost screening methods are available. Because long-term survivors may not be seen by oncologists as frequently as they were during treatment, or at all, the increased risk of SPD and the need to screen for SPD should be communicated to primary care physicians and other care providers. Given that cancer survivors with more chronic medical conditions tended to be those most at risk for psychological distress in this study, the findings also underscore the need to integrate medical and behavioral health care for survivors. Specifically, cancer survivorship clinics may benefit from having mental health providers on staff for a multidisciplinary approach to the care of these patients. Further research is needed to clarify why individual long-term survivors experience distress and to develop effective interventions to detect, prevent, and alleviate this distress.

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