Psychological Distress in Long-term Survivors of Adult-onset Cancer: Results from a National Survey

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Background

- The number of cancer survivors has increased steadily over the past four decades, and an estimated 12 million cancer survivors are living in the United States currently (MMWR, 2004).
- About two-thirds of these patients are expected to survive for at least 5 years following their cancer treatment, and many of them will live significantly longer.
- Cancer survivors have been demonstrated to be at increased risk for receiving inadequate healthcare (Earle CC, Cancer, 2004), in addition to remaining at risk for cancer recurrence and late effects associated with cancer treatment.
- Cancer survivors may be at risk for psychosocial stressors, including difficulty having and maintaining insurance and employment (Short PF, JCO, 2006; Chen A, ASTRO, 2008), and a decreased sense of well-being (Stanton AL, JCO, 2006).
- Survivors have also been demonstrated to be at risk for developing persistent fatigue (Savarrd, 2001). Cancer-related fatigue has been demonstrated to persist in some cases for years after treatment has been completed (Lindley, 1998). Although fatigue after cancer is in all likelihood multifactorial, depression and psychological distress may contribute to its presence and severity.
- Although many aspects of quality of life after cancer have been studied in the past, the presence of psychological distress and depression in the general population of adult cancer survivors has not been specifically documented. The study described here was undertaken in order to evaluate the prevalence of severe psychological distress (SPD) among long-term survivors of adult-onset cancer, as well as to identify socioeconomic, demographic, and clinical factors that may impact the development of SPD.

Materials and Methods
The National Health Interview Survey (NHIS) served as the data source for this study.

- The NHIS is a continuous, nationwide survey that is conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC).
- The survey addresses approximately 40,000 households (100,000 persons) in the non-institutionalized, civilian population.
- The NHIS has been active since 1957, and is one of the most prominent population-based general health surveys conducted within the United States. In 1987, a Cancer Control Supplement addressing questions specifically having to do with cancer was added to the NHIS, and is co-sponsored by the CDC and the National Cancer Institute.

The study presented here utilized data gathered via the NHIS from 2002 – 2006. During this period, 87 – 89% of selected households responded to NHIS survey questions.

The study population was identified by being asked the following: “Have you ever been told by a health professional that you had cancer or any type of malignant disease?” Respondents answering "yes" to the above question were considered in this study, providing that they were adults (over 18 years), and five or more years had passed since their cancer diagnosis.

The primary outcome measure of this study was the presence of severe psychological distress (SPD) as measured by a K6 scale, which has been previously validated as an assessment for mental illness.

- The K6 scale poses the following questions:
  - During the past 30 days, how often did you feel:
    - So sad that nothing could cheer you up?
    - Nervous?
    - Restless or fidgety?
    - Hopeless?
    - That everything was an effort?
    - Worthless?

- Each question is scored on a scale of 0 – 4, with 0 indicating "none of the time," and 4 indicating "all of the time." Answers are summed, and a score of 13 or greater indicates SPD.

Multivariate logistic regression was utilized to examine the independent association of being a cancer survivor and presence of SPD, as well as to identify factors associated with SPD.

- Age, sex, race/ethnicity, relationship status, education attainment, insurance status, co morbidities, smoking history, and ability to perform independent activities of daily living were all considered in this analysis.
- Because the sampling design was quite complex, all analyses were conducted using SUDAAN, and were weighted to reflect national estimates.

Results

- Through the NHIS, 4,712 five-year survivors of adult-onset cancer were identified. They were compared to 126,841 adults with no previous history of cancer.
- The mean age at cancer diagnosis was 47 years, and mean age at the time of interview was 62 years.
- The most common primary cancer diagnoses were breast cancer (20%), gynecologic cancer (19%), male genitourinary cancer (12%), and colorectal cancer (8%).
Severe psychological distress as measured by the K6 was present in 5.6% of cancer survivors as opposed to 3% of responders with no cancer history (p < 0.0001).

After adjustment for demographic factors, survivors remained more likely to experience SPD, with an adjusted odds ratio (aOR) of 1.4.

Several factors were identified on multivariate analysis to contribute to development of SPD among survivors:

- Younger survivors were more likely to experience SPD than older survivors (aOR 2.7 for survivors age 45 – 65 years and 5.6 for survivors < 45 years, as compared to those over 65 years).
- Compared to survivors without co morbidities, those with one and two or more comorbidities were more likely to experience SPD (aOR 1.7 and 3.5, respectively).
- Survivors not married or living with a partner were more likely to develop SPD (aOR1.7).
- Survivors with less than a high school education were more likely to develop SPD than those with more education (aOR 2.1).
- Lack of insurance coverage was associated with increased presence of SPD (aOR 2.4).
- Survivors currently or formerly using tobacco were more likely to experience SPD (aOR 2.7).
- Those survivors with difficulty completing independent activities of daily living were also more likely to experience SPD (aOR 3.6).

Author’s Conclusions

- The authors conclude that SPD is present in 1/18 long-term survivors of adult cancer living in the United States, and that this risk is increased above that of the general population.
- They note that certain factors, including young age, comorbidities, lack of long-term relationships, less education, lack of insurance, tobacco use, and disability limiting function were associated with the development of SPD. They recommend that screening and education regarding SPD be focused on these higher-risk groups, as well as cancer survivors in general.
- They describe limitations of this study, including the fact that data is self-reported, and that details of cancer diagnosis and treatment are not available through the NHIS. They also note that homeless and institutionalized persons are not included in this study, which limits its generalizability to these specific populations.

Clinical/Scientific Implications

- As the number of cancer survivors living in the United States increases, issues regarding the care of this population are continually increasing in importance.
- Cancer survivors may face unique stressors, including fear of recurrent disease, complications from cancer and its treatments, and difficulty obtaining insurance and employment. Additionally, survivors have been demonstrated to have increased risk of persistent fatigue, anxiety, and depression.
- The study presented here demonstrates that cancer survivors are at increased risk for severe psychological distress when compared to the general adult population.
- This study focuses on long-term survivors, diagnosed with cancer at least 5 years prior to being surveyed. This is of interest in that it demonstrates that SPD may persist for many years after a cancer diagnosis, and is not associated only with the acute stress of diagnosis and treatment.
- The authors have identified certain groups within the survivor population who may be at increased risk for SPD.
Based on the results of this and other studies, practitioners within the oncology community should be aware that all survivors may be at increased risk for SPD, and that certain survivors, namely those who are young or have other health issues, less education, and/ or difficulty obtaining insurance and completing activities of daily living, may be at particular risk. Cognizance of increased evidence of SPD within these groups will help practitioners to focus screening and patient education.

As the authors point out, the study conducted here is somewhat limited in that details of cancer diagnosis are not available. Certainly, further studies identifying factors associated with diagnosis and treatment that may contribute to SPD would be of interest.

The authors also note that their study is not generalizable to the homeless or institutionalized populations, and this point is important; however, this study does represent a population similar to many patients cared for in cancer centers in the United States.

The results presented here are important, and clinicians and survivors alike should be aware of the increased risk of SPD demonstrated within this study.