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The Post-Treatment Experience of Cancer Survivors with Pre-Existing Cardiopulmonary Disease

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Abstract

Purpose—The purpose of this study was to explore the cancer experience of survivors with pre-existing diagnoses of heart and/or lung disease following active treatment.

Method—The Lance Armstrong Foundation recruited cancer survivors throughout the United States to complete a web-based survey to provide insight into post-treatment supportive care needs. Experts in survey methodology and oncology, as well as cancer survivors, provided input into the survey.

Results—The 137 individuals whose physicians told them they had heart or lung problems were 50 years old on average, and most were more than five years past active treatment. Two-thirds of these respondents reported pain for long periods, and 20% of them agreed that they now need help with everyday tasks that they did not need help with before their cancer. Among those who were tired, had no energy, or had trouble sleeping and/or resting, less than half (47%) agreed that they had received help with this problem. One third of these respondents indicated that they had decreased their physical activity since their cancer diagnosis because of fatigue and 26% decreased their activities because of pain. More respondents indicated that their needs were met during their cancer treatment than afterwards.

Conclusions—Researchers and health care providers are urged to consider the unmet supportive care needs of cancer survivors with co-morbid conditions following active treatment, particularly the need for careful monitoring of their complex health conditions.

Keywords

comorbidities; long-term cancer survivorship; clinical trials

The negative impacts of co-morbidities on cancer diagnosis, treatment outcomes, and survival rates are now better understood than just a decade ago [1, 5, 8, 12, 14, 15, 17, 19, 23]. These effects vary by the type of cancer and associated treatment, as well as the nature of the co-morbid condition [9, 13, 16, 17, 26–27]. For example, concerns about the effects of anesthesia on underlying co-morbid conditions may reduce the surgical options; and drug

interactions may affect chemotherapy choices. While these studies underscore treatment complications and a worse prognosis for those with co-morbid conditions, they often do not indicate the timing of the co-morbidity or the long-term consequences other than survival following cancer treatment. Accurately assessing the impact of co-morbidities on the cancer experience, therefore, remains a challenge [10, 26].

As the body of literature on cancer survivorship has grown, we have come to recognize that long-time cancer survivors face numerous challenges [2, 4, 20, 24, 29]. However, we have limited understanding of the physiological, psychosocial, and economic supportive care needs from the perspective of those survivors who had a pre-existing co-morbid condition and who are now past the active treatment phase of their cancer. The purpose of this study, therefore, was to explore the cancer experience of survivors with a co-morbid condition that could present serious complications: pre-existing diagnoses of heart and/or lung disease.

Methods

This secondary analysis was from a survey launched by the Lance Armstrong Foundation (Austin, TX) in March 2006. Consistent with the organization's mission, the purpose of the LIVESTRONG Survey for Post-Treatment Cancer Survivors (LIVESTRONG Survey) was to provide insight into the post-cancer needs of survivors.

The survey instrument was developed with input from experts in the field of survey methodology and oncology, as well as cancer survivors. The content was also informed by previous survivorship research. The survey was then pilot-tested before being posted online. The survey consisted of six sections: background characteristics, physical concerns, emotional concerns, practical concerns (e.g., financial), the types of care received in each of these domains, attitudes toward cancer, and use of LIVESTRONG cancer resources.

Following Institutional Review Board approval, LIVESTRONG research staff notified their constituents about the survey in the LIVESTRONG newsletter and via e-mail. Additionally, LIVESTRONG informed its community and national partner organizations (140 organizations) and all state cancer coalitions about the survey. These groups were provided with an e-mail and a flyer that they could share with their constituents. Paper copies of the survey with postage-paid envelopes were also provided to these groups.

The survey was made available online from March 2006 through February 2007. Potential respondents were told that they were eligible to complete the survey if they were adult cancer survivors who had completed cancer treatment (i.e., not now receiving chemotherapy or radiation). Usable surveys were received from 2,307 survivors.

Results

Sample characteristics

LIVESTRONG survey respondents were asked to indicate if they had experienced a variety of medical conditions or symptoms before or after their cancer experience. Because previous research had shown that cardiopulmonary disease affects cancer treatment decisions [14, 15, 22, 28], we analyzed data from the 137 survey respondents who indicated that a physician told them they had heart problems and/or damage to their lungs before their cancer experience. This subsample was two-thirds female. Fifty-two percent were working part or full time, and 24% were retired. The group was highly educated; 41% have at least a Bachelors degree. Eighty-nine percent were non-Hispanic Whites. Their average age was 50.5 years, and they were residents of 36 different states.

Cancer history

While a variety of cancers were reported, the most common was breast cancer (28%) followed by lung cancer (17%). Other types of cancers were reported by less than 10% of the respondents. For the majority of respondents, it had been more than five years since their last cancer treatment. Eighteen percent of the sample ($n = 24$) reported a recurrence or additional cancer diagnoses. Half this group experienced the recurrence within the past 5 years. Post-treatment physical symptoms

Figure 1 shows the percentage of respondents experiencing various symptoms since completing treatment and as a result of their cancer experience. Two-thirds of respondents reported pain for long periods, and 51% agreed that pain had kept them from participating in activities. Sixty-eight percent of those with pain indicated that they received care for their pain, and 59% rated the help that they received as meeting many or all of their needs. Respondents were most likely to report that they had received help for these symptoms from a primary care physician ($n = 25$) or a medical specialist in pain management ($n = 21$). Among the 52 respondents who indicated reasons for not receiving care for their pain, 10 indicated that they were told that the side effect would go away with time and another 10 indicated that they had just learned to live with this concern. Fourteen others reported they were unable to get care, were not referred, or were told there was nothing that could be done.

Among those who were tired, had no energy, or had trouble sleeping and/or resting, less than half (47%) agreed that they had received help with this problem. Only 20 individuals indicated that many or all of their needs had been met, although 32 individuals indicated that they had received help from a primary care physician for these problems. Health-promoting behaviors

Figure 2 shows the percent of individuals indicating that they were or were not participating in various health-promoting behaviors following their cancer diagnosis. Fifty-three percent of respondents affirmed that they participated in some type of physical activities two to three times per week. While 44% increased their physical activity, one third of these respondents indicated that they had decreased their physical activity since their cancer diagnosis because of fatigue and 26% decreased their activities because of pain. By contrast, only 21% of respondents in the larger LIVESTRONG survey sample reduced their physical activity because of fatigue and 13% because of pain. In addition, 22% of the survivors with co-morbid conditions agreed that they now need help with everyday tasks that they did not need help with before their cancer, and 22% did not attend events that they used to enjoy. On a more positive note, only 6% of the sample reported they continue to smoke. Attitudes toward cancer

Many respondents endorsed positive statements about their cancer experience (Figure 3). For example, 88% agreed that they now recognized what was important in life, 61% experienced a renewed sense of spirituality because of their cancer diagnosis, and 90% now spoke up more about cancer screening. However, 91% were also concerned that their cancer might return and 55% were worried about dying from cancer.

Employment effects

Although this was a largely middle-aged sample, only 58% of the respondents were currently working part or full time or were self-employed. Seventy percent had been working when they were diagnosed with cancer. Thirty individuals indicated that their employment had not been affected negatively by their cancer. However, 48 respondents reported that they were unable to work or were unable to work in the same way as they had before their cancer, and 13 individuals had left their jobs. Twenty-three respondents

indicated that they had experienced problems at work, such as receiving a pay decrease or not getting a job because of their cancer. At the same time, many respondents cited positive experiences at work, such as receiving support from co-workers ($n = 48$), and 49 individuals reported they received medical leave from their employers.

Financial concerns

Ninety-three percent of respondents indicated that they had health insurance. Twelve of those with insurance indicated that they had problems with their insurance. Thirty-two percent indicated that they had encountered financial problems because of their cancer, its treatment, or late effects; 36% indicated they had gone into debt because of their cancer diagnosis. Unmet supportive care needs

Fewer respondents indicated that their needs were met following cancer than during their cancer treatment (Figure 4). At both time points in the cancer experience, physical needs were more likely to be met than either emotional or practical needs, both of which were unmet for the majority of respondents. Fifty-four percent of respondents indicated they would have liked more follow-up support after completing treatment. Approximately one third left their doctor's office with unanswered questions and 25% reported that the health care team did not seem open to discussing their questions or problems.

Discussion

While this survey was not population-based, it provided some initial insights into the long-term cancer experience of survivors with pre-existing co-morbid heart and respiratory disease drawn from across the United States. Findings addressed the major categories outlined in the 2004 report of the President's Cancer Panel [21], including physiological, psychosocial, and economic supportive care needs.

Many of these survivors identified positive experiences, but they also reported a number of unmet needs following cancer. Although 44% increased their physical activity and 13% had quit smoking, the majority struggled with pain, lack of energy, or trouble sleeping because of their cancer experience. Over one-third had gone into debt because of their cancer, and many reported negative employment impacts. One in five required help with functional activities that they did not need help with before their cancer experience. Perhaps most striking was the finding that these survivors were more likely to report unmet needs *following* active treatment, as opposed to during the active treatment phase of their cancer. This finding, coupled with the fact that one-third of these respondents left their providers' offices with unanswered questions, points to the need for heightened focus on the supportive care needs of long-term cancer survivors. A 2009 Canadian study [7] found that primary care physicians are willing to provide routine long-term follow-up care of cancer survivors and in fact believe that they should be involved earlier in the process. However, these respondents expressed a need for patient-specific information from the oncology specialist, guidelines for patients in remission, and expedited referral mechanisms to oncology specialists.

Only six percent of these respondents reported they were still smoking. Other studies have found that cancer survivors smoke at about the same rates as the general population [3, 18]. The noticeably lower rate among these respondents may be due to their underlying cardiopulmonary co-morbidities.

A somewhat higher percentage of respondents in the survey (53%) indicated they participated in physical activities, compared with previous studies of cancer survivors [3, 18]. The variations among samples in age, recruitment methods, and activity questions, as

well as underlying medical conditions, may contribute to the differences in reports of physical activity.

Approximately one-third of these respondents decreased their physical activity after their cancer diagnosis because of fatigue or pain. A growing body of literature supports the benefits of physical activity for cancer survivors [6, 11, 25], although cancer treatment can certainly affect survivors' abilities to engage in physical activities [2]. Additional intervention research is needed to determine how best to support appropriate physical activity in this special population of cancer survivors.

Many of the symptoms listed here, such as fatigue and pain, are associated with cardiopulmonary disease as well as cancer. While the survey clearly asked the respondents to report if the symptoms were a result of their cancer experience, it was undoubtedly difficult for individuals with co-morbidities to distinguish between symptoms associated with cancer versus other diagnoses. The complexity surrounding the etiology of signs and symptoms for this group points to the need for careful follow-up and monitoring of individuals with multiple conditions. As the 2004 President's Cancer Panel report [21] stated, co-morbid conditions can obscure symptoms of recurrence or late effects of cancer treatment. Both patients and their providers may attribute these symptoms to aging and not investigate them as needed.

The general questions used to determine cardiopulmonary co-morbidity used in this study limited the interpretation of the findings. The nature and severity of the diagnosis and its degree of impact on functioning before the cancer diagnosis were unknown. This descriptive cross-sectional study does not allow the timing of the impacts of co-morbidity to be adequately determined. A carefully constructed case control study should be undertaken to elucidate the relationship between pre-existing co-morbid conditions and the long-term cancer experience. As previous researchers have pointed out [10, 26], the measurement of co-morbid conditions also needs further clarification and measures that are more valid are necessary.

In this study, the sample of survivors was relatively young at an average age of 50 years. The typical cancer survivor is over 60 years of age, and even more co-morbid conditions among older cancer survivors would be expected. In future studies, the experience of cancer survivors with co-morbidities should be examined in greater detail and with more representative samples. In addition, interventions targeting their supportive care needs should be designed and evaluated.

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Fig 1.
Percent of survivors reporting symptoms following cancer

Fig 2.
Percent of respondents' reported health behaviors

Fig 3.
Attitudes toward cancer

Fig 4.
Percentage of respondents indicating their needs were met