



"I LEARNED TO LIVE WITH IT" IS NOT GOOD ENOUGH: CHALLENGES REPORTED  
BY POST-TREATMENT CANCER SURVIVORS IN THE LIVESTRONG SURVEYS

A LIVESTRONG REPORT, 2010

## ACKNOWLEDGEMENTS

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- American Cancer Society®
- American Society of Clinical Oncology®
- Centers for Disease Control and Prevention®
- George Washington University Cancer Institute
- University of Pittsburgh
- Global Health Council
- University of Texas MD Anderson Cancer Center

And members of the LIVESTRONG Survivorship Center of Excellence Network:

- Dana-Farber Cancer Institute
- Fred Hutchinson Cancer Research Center
- Memorial Sloan-Kettering Cancer Center
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## EXECUTIVE SUMMARY

Recognizing the growing number of cancer survivors in the United States, LIVESTRONG launched the LIVESTRONG Survey for Post-Treatment Cancer Survivors in 2006. Cancer survivor respondents in that survey experienced significant concerns, which for many were not addressed. To further understand post-treatment cancer survivorship and examine trends over time, LIVESTRONG launched a similar survey in 2010. This report reviews the results from the post-treatment cancer survivors in the 2010 LIVESTRONG Survey and compares them with the 2006 LIVESTRONG Survey for Post-Treatment Cancer Survivors.

Cancer survivors who responded to these surveys experienced a variety of physical, emotional and practical concerns. While respondents had varied experiences in terms of type of cancer, type of treatment, time since treatment ended and a number of other characteristics, for these survivors, life after a cancer diagnosis continued to bring changes and challenges. An overwhelming number of cancer survivors (98 percent) experienced continued physical, emotional and practical concerns. Yet many did not receive help for their needs. While more than half of 2010 survey respondents who had experienced at least one physical concern did receive care (58 percent), only half of those who experienced emotional concerns received help (50 percent) and only 20 percent of those with practical concerns received help. Alarming, the receipt of care for physical, emotional or practical concerns decreased between 2006 and 2010.

The results from this survey are derived from 3,129 cancer survivors in the 2010 iteration and 2,307 cancer survivors in the 2006 iteration who voluntarily participated, primarily online. The majority of respondents were Caucasian/white, female, under the age of 55, insured and employed. While the results of this survey may not represent the experiences of all post-treatment cancer survivors due to its voluntary nature, the findings make an important contribution to the scientific understanding of the needs of this group.

After analyzing this information, we believe more should be done to address the needs of cancer survivors. These results highlight the gap between who reports concerns and who receives care for those concerns as a critical breakdown in post-treatment survivorship. This breakdown needs to be addressed.

We have identified three key steps that we believe can help to address the gaps between what cancer survivors are experiencing and what we are able to provide. We must...

- **Connect people to the resources they need.**

When care exists for — and helps to ameliorate — post-treatment survivors' concerns, connecting more survivors to this care is an actionable means to improve post-treatment cancer survivorship.

- **Identify and disseminate the essential elements of survivorship care delivery that can help to ensure cancer survivors' needs are met.**

To address the multifaceted experience of surviving cancer, we need systems of care that incorporate a variety of disciplines which are positioned to address the physical, emotional and practical concerns of post-treatment survivors. The cancer community should identify the minimal requirements for survivorship care that address the most common physical, emotional and practical concerns experienced by survivors and leverage resources, such as Health IT platforms, to coordinate good care.

- **Conduct continued surveillance of the concerns of cancer survivors and disseminate research to better understand the experience of post-treatment survivorship.**

Surveillance at the national and local levels should occur on a regular basis to measure the needs of and receipt of care by cancer survivors, including survivors in the post-treatment period. Continued research and attention to this unique piece of the cancer continuum — life after treatment — is vital as the number of survivors increases steadily.

# 1

## INTRODUCTION



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One in two men and one in three women will be diagnosed with cancer during their lifetimes, and more than 1.5 million new cancer cases are diagnosed each year in the United States (Horner et al., 2009). In the last few decades the number of cancer survivors has risen dramatically, and in the U.S. today, there are nearly 12 million cancer survivors (Ries, Melbert, Krapcho, Stincomb, Howlander, Horner et al., 2008; U.S. Cancer Statistics Working Group, 2010). The large increase in the number of people surviving cancer is due to advances in detection, prevention and treatment, and these advances have made it possible for a cancer survivor to have an overall 64 percent chance of surviving five years (Hewitt, Greenfield, & Stovall, 2006).

However, as the number of cancer survivors has increased, the late effects caused by cancer and its treatment have become increasingly prominent (U.S. Department of Health and Human Services [HHS], 2004). Treatment for cancer varies based on type of cancer, age at diagnosis, stage of cancer and a number of other factors, and as a result, the impact of cancer and its treatment on a person can vary greatly. The aftereffects of cancer and its treatment may be medical or physical concerns as well as non-medical or practical concerns (Hoffman, McCarthy, Recklitis, & Ng, 2009). Examples of physical

late effects include sexual dysfunction, infertility, impaired organ function and limitations in mobility and cognition (Hewitt et al., 2006). Examples of practical late effects include issues such as employment discrimination, debt and loss of insurance (Wolff et al., 2005).

Several reports to date have indicated the importance of addressing cancer survivors' needs (Adler & Page, 2007; Hewitt & Ganz, 2007; Hewitt et al., 2006). The Institute of Medicine (IOM) 2006 Report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, provided a critical look at the

issues experienced by survivors and recommended next steps to improve outcomes for them. The report recommends establishing post-treatment survivorship as a distinct phase of the cancer continuum for all survivors and their families. In recent years, a movement to embrace this challenge and provide effective care for the growing survivor population has taken shape.

In 2007, the IOM released additional information on cancer survivorship issues. First, the IOM released the report *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Second, a workshop and related summary were released: *Implementing Cancer Survivorship Care Planning*. Both the report and the workshop summary made important recommendations for addressing the needs of cancer survivors during and after cancer treatment, including attending to the non-medical needs of survivors (Adler & Page, 2007; Hewitt & Ganz, 2007). These reports have all highlighted the fact that as the number of cancer survivors continues to increase, surveillance of the impact of cancer on long-term survivorship has never been a more relevant topic to address.

#### LIVESTRONG SURVEY FOR PEOPLE AFFECTED BY CANCER

**LIVESTRONG** is a nonprofit organization and a leader in the area of cancer survivorship. Our mission is to inspire and empower people affected by cancer. We do this by serving people affected by cancer and empowering them to take action against the world's leading cause of death.

The 2006 IOM report recommended that nonprofit organizations increase their support of survivorship research and expand mechanisms for conducting such research (Hewitt et al., 2006). In response, **LIVESTRONG** launched a survey in 2006 aimed at providing insight into the needs of post-treatment cancer survivors. The **LIVESTRONG** Survey for Post-Treatment Cancer Survivors was designed as a self-report survey to comprehensively assess the physical (i.e., pain), emotional (i.e., emotional distress) and practical (e.g., financial) concerns of post-treatment survivorship. Further, the survey gathered information about whether or not survivors received care for their concerns and, if they did receive care, who provided the care (e.g., health care providers, family, self). The survey also gathered information on why some post-treatment survivors did not receive care.

It is tough regaining confidence in your health...but time heals everything. I have experienced a lot of fear and grief, but then comes appreciation for the little things that before were irrelevant.

—Survey respondent

Through the 2006 survey, **LIVESTRONG** learned that almost all (99 percent) of the 2,307 respondents experienced at least one physical, emotional or practical concern after cancer treatment ended. While 75 percent of respondents received care for their physical concerns, many emotional and practical concerns remained unaddressed. Only 55 percent of 2006 respondents received help for emotional needs and only 40 percent received assistance with practical concerns. Interestingly, for the four most common types of physical concerns—energy, concentration, sexual functioning and neuropathy—the majority of respondents had also not received care. The primary reason reported by individuals for not receiving help across all concerns was that they had learned to live with a concern on their own. The fact that many respondents chose to live with a concern instead of seeking help emphasizes the need for support during the post-treatment survivorship experience and illustrates the importance of research in cancer survivorship.

Since the closing of the inaugural survey in early 2007, **LIVESTRONG** has presented the results of the survey at national conferences and online at **LIVESTRONG.org**. **LIVESTRONG** has also used the results of this survey to inform the creation of educational materials and programs for cancer survivors. Finally, in June 2010 **LIVESTRONG** released *How Cancer Has Affected Post-Treatment Survivors: A LIVESTRONG Report* (Rechis, Boerner, Nutt, & Shaw, 2010), available on **LIVESTRONG.org**.

On June 20, 2010, in conjunction with the release of *Parade* magazine's first issue entirely devoted to survivorship, **LIVESTRONG** launched the 2010 **LIVESTRONG** Survey for People Affected by Cancer. The 2010 survey is similar to the 2006 version and again was designed to assess the physical, emotional and practical needs of post-treatment cancer survivors as well as survivors' perspectives on seeking health information and making sense of the cancer experience. However, the 2010 survey also incorporates additional questions that examine the impact of cancer on family members, caregivers and loved ones.

The intent of this report is to give voice to the more than 5,400 post-treatment cancer survivors who participated in the 2006 and 2010 surveys and shared their cancer experiences. While these survey respondents do not represent the entire post-treatment survivor population, they can provide important insight into the experience of life after cancer treatment.

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# 2

METHODOLOGY  
AND DEMOGRAPHICS

## Survey Design and Characteristics

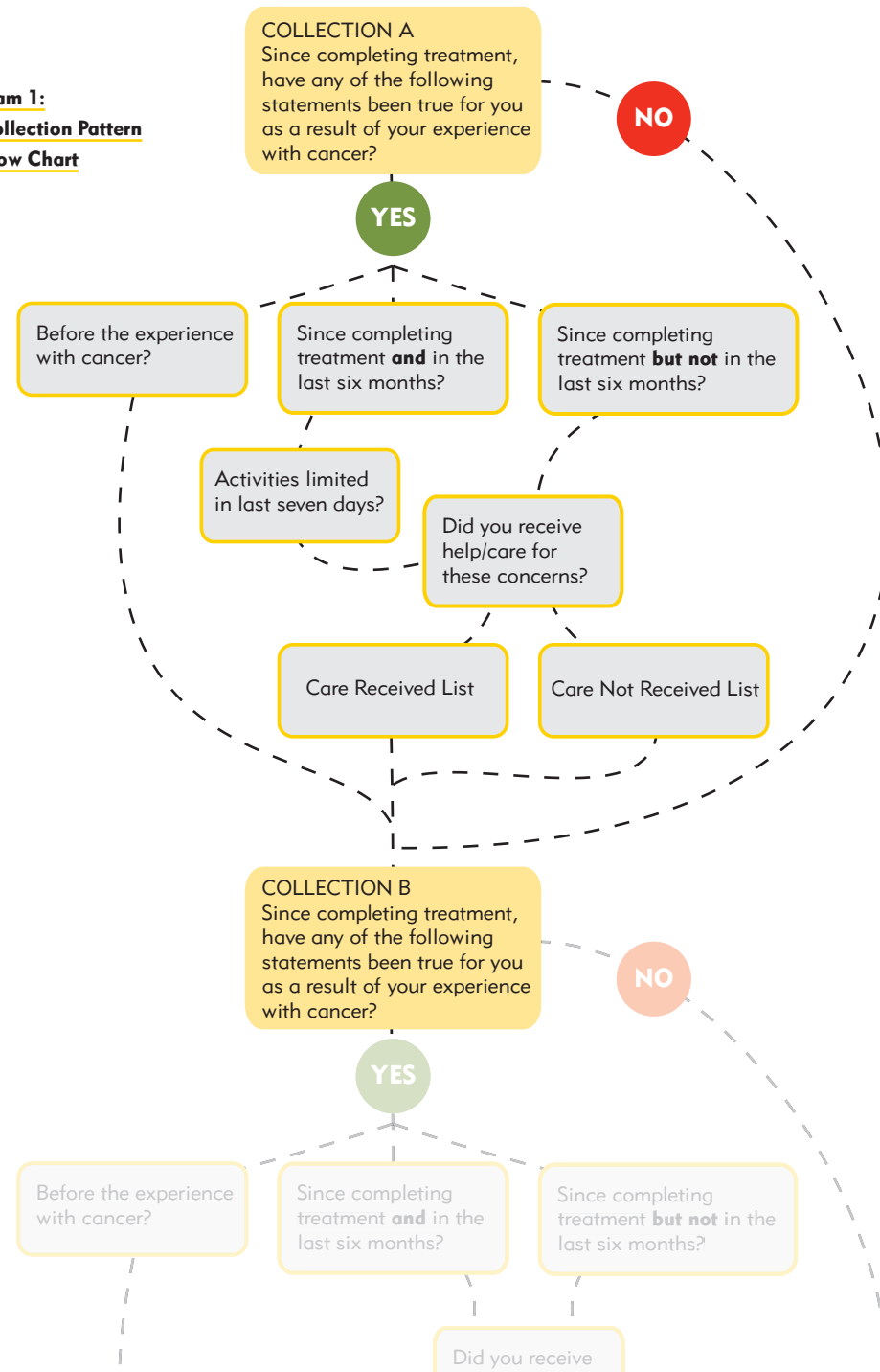
The 2010 LIVESTRONG Survey for People Affected by Cancer built upon the previous survey, the LIVESTRONG Survey for Post-Treatment Cancer Survivors. The 2006 survey instrument was designed through a process that engaged both cancer survivors and experts in the field of survey methodology and oncology with peer review, focus groups and a pilot test. For the pilot test, cancer survivors participated in the survey and provided feedback on the content and the length of the survey in an interview with the principal investigator of this study.

An analysis of survey content conducted by the RAND Corporation examined the response patterns of survey participants and the content covered in the 2006 survey. In general, the analysis showed that most of the items performed well and would be worth retaining in the 2010 survey instrument. Further, the results of a review of other large-scale studies of cancer survivors (Baker et al., 2005; Beckjord et al., 2008; Zebrack et al., 2006) suggested that there were no notable gaps with respect to the areas covered by these studies and the 2006 survey. In fact, LIVESTRONG's emphasis on a wide variety of medical issues and the survey's inclusion of employment and education-related concerns were noted as relative strengths.

Therefore, the content of the 2010 survey intended for post-treatment cancer survivors was largely consistent with the 2006 instrument, with minor modifications and additions noted in this section and the Results section (chapter 3).

The 2010 survey instrument was divided into five sections. The first three sections focused on physical, emotional and practical concerns encountered by cancer survivors after the end of cancer treatment. The two remaining sections included questions for both post-treatment survivors and others affected by cancer, including family members, loved ones and individuals currently undergoing cancer treatment. This report includes the results of only the first three sections

**Diagram 1:**  
**Collection Pattern**  
**Flow Chart**





of the survey and is focused on post-treatment cancer survivors. Later in 2011, **LIVESTRONG** will release additional publications and briefs that will focus on the remaining survey content.

Post-treatment cancer survivors included individuals who had been diagnosed with cancer and were currently finished with treatment, or those who were managing cancer as a chronic condition. The sections of the survey intended for post-treatment cancer survivors included questions about: 1) physical concerns, 2) emotional concerns and 3) practical concerns. The physical, emotional and practical concern sections of the 2006 and 2010 surveys were organized into groups of related items, which will be referred to as “collections” throughout the rest of this report. For example, one physical concern collection contained four items related to energy and fatigue (e.g., “I have felt tired a lot.”) and one emotional concern collection contained four items related to sadness and depression (e.g., “I have felt blue or depressed.”) There were a total of 28 collections addressing a broad range of concerns such as heart problems, insurance issues and spirituality. See Appendix A for a list of the collections and individual concerns included in this survey.

For each collection of concerns, respondents first indicated whether or not any of the concerns applied to them. According to their responses, they were asked a series of follow-up questions. This process is outlined in Diagram 1: Collection Pattern Flow Chart on the previous page.

For each collection, participants were asked the following question: “Since completing treatment, have any of the following statements been true for you as a result of your experience with cancer?”

For almost all collections, the statements that followed included both a non-technical description of the concern and a selection related to a doctor having told the survivor that he or she had a particular condition. Participants were then provided with a list of one or more options that were relevant to a particular collection.

- If individuals selected any of the concerns within the collection, they were then asked to answer if the concern had occurred before their experience with cancer, since their cancer diagnosis and within the last six months or since their cancer diagnosis but not within the last six months.
  - If respondents had experienced the concern(s) before cancer, they were directed to the next collection. This was done to try to ensure that responses were related to the post-treatment cancer experience.
  - If respondents had experienced any of the concerns since their cancer diagnosis and within the last six months or since their cancer diagnosis but not within the last six months, they completed follow-up questions related to these concerns.
- New to the 2010 version, if individuals experienced any of the concerns within a collection, they were asked if their day-to-day functioning in the last seven days was limited a lot, a little or not at all by the concern(s) selected.
- Depending on whether an individual received care, the respondent was sent down one of two paths: care received or care not received.
- If individuals did not select any concerns within a collection, they were directed to the next collection.

## CARE RECEIVED

### Question 1

If an individual received care, he or she was first asked to select from a list of 18 options (which were consistent throughout the survey) to determine who provided the care. While there was a lengthy list of individual options, the consistency of options across the long survey was reported to be a helpful tool by the pilot test group. Individuals could select more than one option. It should be noted that the care provider options were not all from the medical field.

The list of care provider options included the following:

- Primary care physician
- Oncologist
- Medical specialist (for example, an ophthalmologist)
- Other medical personnel (for example, a nurse)
- Psychiatrist or psychologist
- Social worker, counselor or child life specialist
- Complementary, alternative or unconventional practitioner
- Support group
- Self (for example, the Internet or a book)
- Partner
- Family member
- Friend or friends
- Other cancer survivors
- Cancer organization or other nonprofit organization
- Religious leader (for example, a pastor or rabbi)
- Government agency (for example, a National Cancer Institute)
- Insurance company
- Other

### Question 2

Once an individual reported that they had received care, they were prompted to report on how well the care met their needs. Respondents could select from the following five options:

- All of my needs
- Many of my needs
- Some of my needs
- Very few of my needs
- None of my needs

## CARE NOT RECEIVED

If respondents did not receive care, they were asked to characterize why they did not receive care by selecting one or more choices from a list of 22 options. This list was consistent throughout the survey and included:

- I plan to receive care in the future
- I tried to receive care but was unsuccessful
- I was told it was a side effect that would go away with time
- I have learned to live with this concern
- I was told nothing could be done
- I have given up on trying to find care
- I am afraid of finding out what is wrong
- I did not want to bother anyone
- I have not had time
- I was unsure of where to go
- I was unsure of who to see
- My doctor did not refer me for help
- My insurance would not pay the costs
- Medicare/Medicaid would not pay the costs
- I could not pay for the services
- There were no services in my area
- I did not have transportation to get to services
- I did not know help was available
- I have addressed this on my own
- I did not want to receive care
- I do not know
- Other

## Methodology

The 2010 survey opened on June 20, 2010, in conjunction with the release of *Parade* magazine's issue devoted to cancer survivorship and the results of the 2006 survey. The Spanish version of the survey launched in February 2011. The responses of individuals who were post-treatment cancer survivors and completed the survey on or before February 28, 2010, are included in the current report.

The survey was available on **LIVESTRONG.org** as well as **LIVESTRONGespanol.org**. **LIVESTRONG** constituents, including cancer patients and survivors, were notified about the survey by email and through Twitter and Facebook. Additionally, **LIVESTRONG** reached out to many of its community, national and international partner organizations and all state cancer coalitions to provide information about the survey

and to assist these organizations in reaching potential respondents. **LIVESTRONG** also collaborated with comprehensive cancer centers, such as members of the **LIVESTRONG** Survivorship Center of Excellence Network, to share the survey with their constituents (Rechis & Nutt, 2011). **LIVESTRONG** provided partner organizations with a toolkit that included content for a newsletter, an email, a flyer, a Tweet and a Facebook post about the survey and the need for participants. See the Acknowledgements for a list of partner organizations and institutions.

All respondents completed the survey online. The study was reviewed and approved by the Western Institutional Review Board.

## Data Analysis

Summary statistics (frequencies and percentages) are used to report the frequency with which each of the physical, emotional and practical concerns within each collection were reported by the 2010 sample, and where possible, to compare these findings to the results of the 2006 survey. Among the respondents who reported any concern within a collection, we show the percentage who received care and the degree to which the care received met the survivors' needs. Additionally, for physical and emotional

collections, we report the degree of functional impairment. The top five sources of care for each of the physical, emotional and practical collections are shown for the 2010 data, and in side-by-side comparisons with the 2006 results. Similarly, we report the top five reasons for not receiving care for each of the collections in the 2010 survey, and compare results with the 2006 report.

Regression models (linear and logistic) were used to look at whether there were changes from 2006 to 2010 for the following outcomes: 1) the average number of physical concern collections endorsed; 2) the average number of emotional concern collections endorsed; 3) the likelihood of having received care for physical concerns; and 4) the likelihood of having received care for emotional concerns. Because there were some differences in the sociodemographic and medical characteristics of the samples between 2006 and 2010, these analyses are statistically adjusted for these.

## Sample Size, Demographics and Medical Characteristics

Data from 3,129 post-treatment cancer survivors are included in the current report. To meet the criteria for inclusion, survivors had to have completed at least 75 percent of the items indicating their experience of physical, emotional and practical concerns. Only participants living in the United States are included in the current report.

The figures below show the sociodemographic and medical characteristics of the 2010 sample (n = 3,129) compared to the respondents of the 2006 survey (n = 2,307) and cancer data from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, which collects population-based data on cancer incidence and survival from state cancer registries in the United States. Please note in some cases percentages may total more than 100 percent due to rounding or because respondents were allowed to select more than one answer.

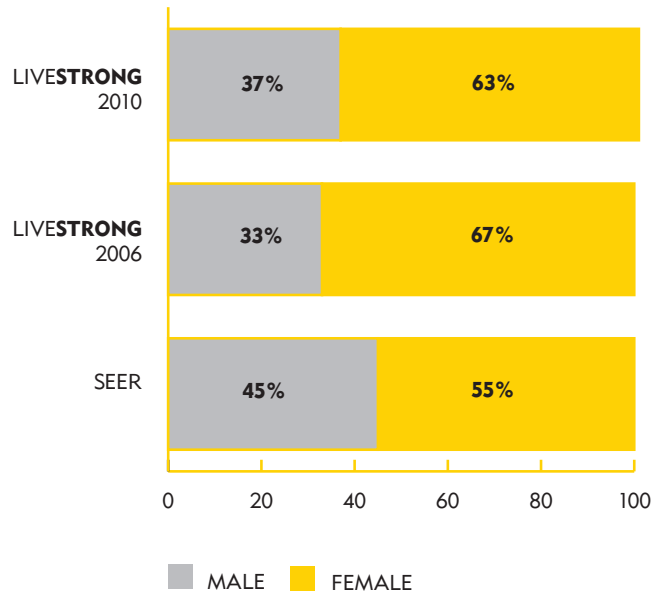
## GENDER

The majority of survey respondents in the 2010 and 2006 iterations were females. (See Fig. 1.)

## RACE/ETHNICITY

The majority of respondents in the 2010 and 2006 iterations identified themselves as Caucasian/white. (See Fig. 2.)

**Fig. 1 Gender of LIVESTRONG Survey 2006 and 2010 Respondents Compared with SEER**



Based on U.S. Prevalence Counts for 2006; Horner et al. (2009).

**Fig. 2 Race and Ethnicity of LIVESTRONG Survey Respondents Compared with SEER**

Race/Ethnicity	LIVESTRONG Survey Respondents' Percentages (2010)	LIVESTRONG Survey Respondents' Percentages (2006)	SEER Percentages
Asian/Pacific Islander	2	2	7
Black or African American	2	1	12
Hispanic or Latino	4	3	18
Native American	2	1	1
Other	2	1	9
Caucasian/white	90	92	67

**Fig. 3 Economic Background**

Economic Category	2010 Percentage	2006 Percentage
\$0-\$40,000	13	14
\$41,000-\$60,000	12	15
\$61,000-\$80,000	12	16
\$81,000-\$100,000	11	12
\$101,000-\$120,000	8	12
\$120,000+	17	17
Prefer not to answer	18	11
Did not answer	9	3

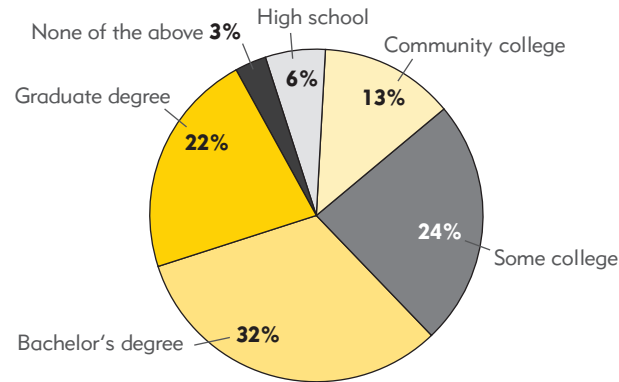
**ECONOMIC BACKGROUND**

Respondents in both the 2010 and 2006 iterations varied in their economic backgrounds. (See Fig. 3.)

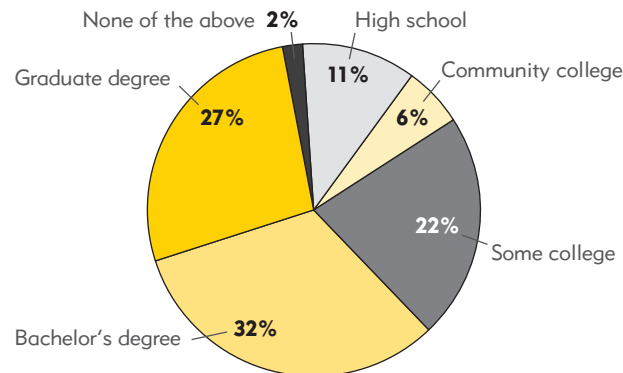
**EDUCATIONAL BACKGROUND**

Most survey respondents had at least some college education at the time that they took this survey in the 2010 and the 2006 iterations. (See Figs. 4-5.)

**Fig. 4 Educational Background of 2010 Respondents**



**Fig. 5 Educational Background of 2006 Respondents**



**Fig. 6 Current Employment Status**

Current Employment Status	2010 Percentage	2006 Percentage
Full time	45	54
Part time	10	9
Full time college/university student	2	3
Full-time caregiver*	3	N/A
Self-employed	8	8
Not employed	9	6
Retired	11	11
Other	4	8
Prefer not to answer	1	1
Did not answer	9	< 1

\* This option was not provided in 2006.

**Fig. 7 Health Insurance**

Health Insurance Status*	2010 Percentage
Employer (myself or family member)	72
Private insurance purchased individually by me or my family	12
A government program (Medicare or Medicaid)	14
Military	3
I don't know	1
None	3
Other	5

\* Respondents may have more than one type of insurance.

## CURRENT EMPLOYMENT STATUS

At the time of the survey, in both the 2010 and 2006 iterations, the majority of respondents were employed full time and the fewest number of survey respondents were full-time students. (See Fig. 6.)

## HEALTH INSURANCE

At the time of the 2010 survey, the majority of respondents were insured. (See Fig. 7.)

## MARITAL STATUS/CHILDREN

In 2010, the majority of respondents (68 percent) categorized themselves as either married or in a domestic partnership (18 percent were single) and most had children (66 percent). Respondents from 2006 were very similar: 70 percent were married or in a domestic partnership and 66 percent had children.

## SUMMARY AND COMPARISON

Overall, the sociodemographic characteristics of the 2010 sample were comparable to the characteristics of respondents in 2006, despite the fact that only 5 percent of the 2010 sample reported having taken the 2006 survey. Overall, the **LIVESTRONG** respondents in 2010 and 2006 differed from individuals tracked by SEER. With respect to gender and

race/ethnicity, the **LIVESTRONG** samples included higher proportions of women and Caucasian/white survivors than the SEER percentages. The 2010 respondents represent a varied range of annual incomes and are well-educated (more than 50 percent have a college or graduate degree). About half are employed full time and very few reported to be without health insurance.

## Cancer Experience

The following section includes information about the treatment and diagnosis experiences of the **LIVESTRONG** Survey respondents, compared with national cancer data from the SEER Program when possible.

## AGE AT DIAGNOSIS

The majority of survey respondents in 2010 and 2006 were younger at the time of diagnosis when compared to the SEER incidence cases – the majority were diagnosed between ages 20 and 54. Most notably, the median age of the **LIVESTRONG** Survey respondents at the time of diagnosis is 44 while the median age of the SEER incidence cases is 67. (See Fig. 8.)

**Fig. 8 Age of Diagnosis of LIVESTRONG Survey Respondents Compared with SEER**

Age Categories	LIVESTRONG Survey Respondents' Percentages (2010)	LIVESTRONG Survey Respondents' Percentages (2006)	SEER Percentages
< 20	7	5	1
20–34	20	20	3
35–44	23	30	6
45–54	30	30	13
55–64	16	12	21
65–74	4	3	26
75–84	< 1	< 1	23
85+	< 1	0	7

Source: SEER Age Distribution of Incidence Cases 2000–2004 All Races, Both Sexes. Ries et al. (2007).

## CANCER TYPE

Based on SEER data, the three most prevalent types of cancer in the U.S., based on the total number of people living with cancer at any point in time, are breast, prostate and colorectal. These three types of cancer were the most often selected types among the LIVESTRONG Survey respondents. (See Figs. 9–10.)

**Fig. 9 Cancer Type, Compared to the Top Three Most Prevalent Cancers in SEER**

Type of Cancer	LIVESTRONG Survey Respondents' Percentages (2010)	LIVESTRONG Survey Respondents' Percentages (2006)	SEER Percentages
Breast	24	32	22
Prostate	7	5	19
Colorectal	7	6	9

Source: Prevalence by Cancer Site, 2006; Ries et al. (2008).

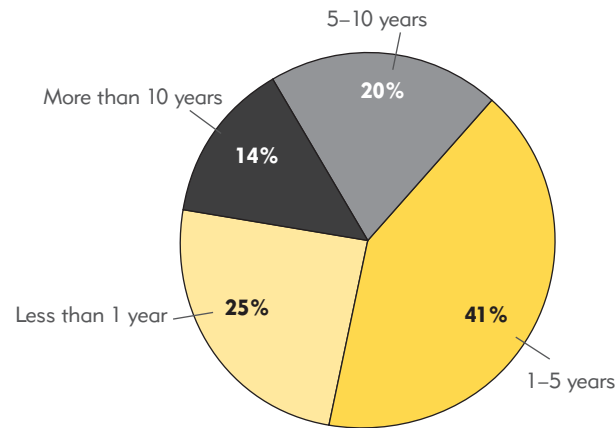
**Fig. 10 Cancer Type, Top Five Most Common in the LIVESTRONG Samples**

Type of Cancer	LIVESTRONG Survey Respondents' Percentages (2010)	LIVESTRONG Survey Respondents' Percentages (2006)
Breast	24	32
Colorectal	7	7
Prostate	7	5
Testicular	7	5
Lymphoma, non-Hodgkin	6	6
Total	51	55

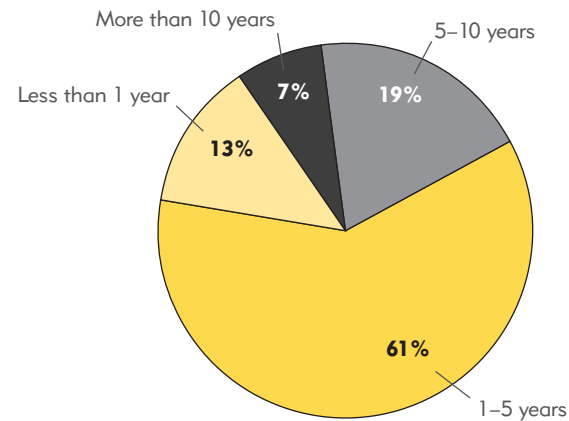
## TIME SINCE LAST TREATMENT

In 2006, the majority of respondents (61 percent) had finished their last treatment between one and five years; the 2010 iteration varied from 2006. (See Figs. 11–12.)

**Fig. 11 Time Since Last Treatment, 2010**



**Fig. 12 Time Since Last Treatment, 2006**



## TYPE OF TREATMENT

The majority of survey respondents in the 2010 and 2006 iterations used traditional methods for treatment. (See Fig. 13.)

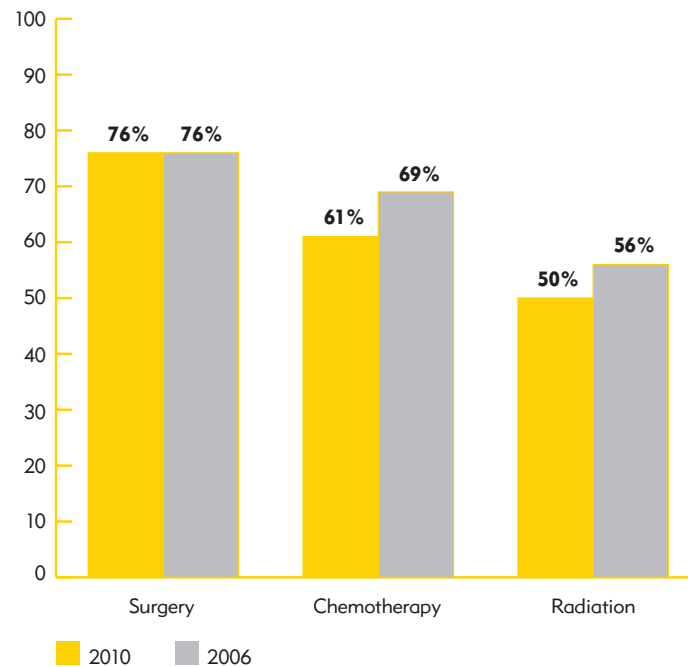
## COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

The majority of survey respondents in the 2010 and 2006 iterations also used at least one CAM for cancer or late effects of cancer. (See Fig. 14.)

## SUMMARY AND COMPARISON

The medical characteristics of the 2010 respondents were largely comparable to the sample from 2006. Both **LIVESTRONG** samples had average ages of diagnosis that were younger than the average in the SEER data. It is worth noting that SEER represents all cancer diagnoses, regardless of treatment or survivorship outcomes, whereas the **LIVESTRONG** surveys include participants who have completed treatment and have entered the survivorship period. This difference

**Fig. 13 Type of Treatment Received, 2010 and 2006**



in focus may account for some of the disparity in age of sample and type of cancer. Nonetheless, the top three cancers with the highest prevalence recorded by SEER are represented in the **LIVESTRONG** sample. In 2010, there was a more equitable distribution of cancer type compared to 2006, when breast cancer survivors made up nearly one-third of the sample. For most survivors in the 2010 sample, less than five years had passed since their most recent treatment for cancer. Slightly fewer respondents in 2010 received chemotherapy or radiation as part of their treatment regimens compared to 2006, but substantial numbers of respondents in both surveys reported to use some form of complementary or alternative medicine.

**Fig. 14 Complementary and Alternative Medicine**

Treatment	2010 Percentage	2006 Percentage
Exercise*	55	N/A
Nutritional supplements	38	29
Massage	27	27
Meditation	23	23
Special diet	23	19
Herbs	13	17
Other*	9	14
Guided imagery	10	13
Acupuncture	12	10
Alternative practitioner*	9	N/A
Music therapy	8	8
Traditional healer	5	5
Art therapy	4	4
Hypnosis	2	2

\* In 2006, exercise was commonly reported by respondents who chose "Other" so this was added as a separate category in 2010. A separate category was also included for "Alternative practitioner" in 2010.

\* Across the 2006 and 2010 surveys, a wide variety of activities were identified by respondents who selected "Other." These included aromatherapy, biofeedback, chiropractic care, dance/movement therapy, energy therapies/education, green tea, hands-on healing, homeopathics, hydrotherapy, journaling, laughing therapy, naturopathic doctor, pet therapy, prayer, qigong, reflexology, Reiki and yoga among others.



3

RESULTS

Results are presented below for the sections of the survey that related specifically to post-treatment cancer survivors: 1) physical collections, 2) emotional collections and 3) practical collections. See Appendix A for a list of all concerns in the survey. Results are presented in the following order:

1. Description of the collections addressed in that section of the survey
2. Total percentage of respondents reporting that they had experienced one or more concern
3. Summary of functional impairment reported for the collection
4. Total percentage of survey respondents reporting that they had received care for concerns they experienced
5. Summary of top-rated sources of care by collection
6. Ratings of care received by collection
7. Summary of reasons selected for why care was not received
8. Trends in results from 2006 to 2010

### Physical Concerns Findings

The 2010 LIVESTRONG Survey asked about physical concerns in 15 collections, or groups of related items. For a list of the individual concerns in each collection, see Appendix A.

1. Concentration
2. Energy and rest
3. Hearing
4. Heart problems
5. Infertility\*
6. Lungs and breathing
7. Lymphedema
8. Neuropathy
9. Oral health
10. Pain
11. Sexual functioning and satisfaction
12. Thyroid condition
13. Feeding/swallowing
14. Urinary incontinence
15. Vision

\* Because infertility issues only affect those individuals who are attempting to start a family and/or conceive a child, infertility is addressed in a separate sidebar (see page 21).

It must be noted that the 2006 survey included a physical concern collection on graft-versus-host (GVHD) disease. Due to the extremely low frequency of concerns about GVHD in the 2006 results, GVHD was not included in the 2010 survey. A collection about concerns related to feeding and swallowing was added in 2010 as these important symptoms were not addressed in the 2006 iteration.

Overall, 86 percent of the 2010 survey respondents (n = 3,129) indicated that they had experienced one or more physical

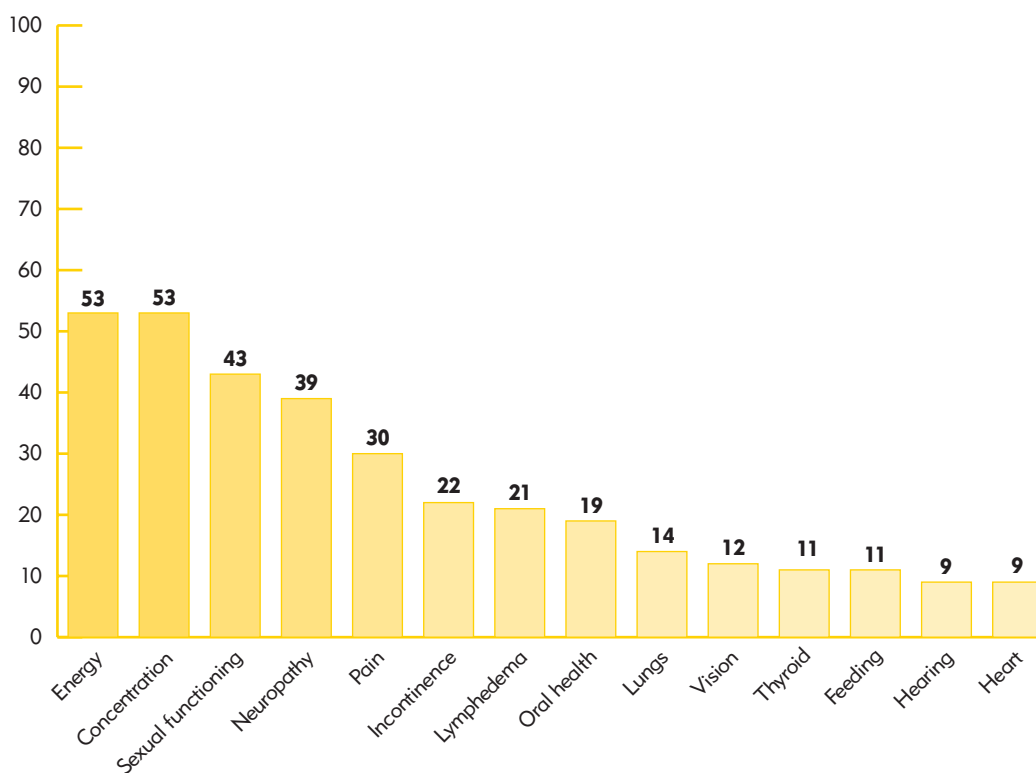
concerns since their cancer treatment was completed. The three most frequently selected collections were: 1) energy and rest, 2) concentration and 3) sexual functioning and satisfaction. (See Fig. 15).

These physical concerns caused significant functional impairment in survey respondents. Fig. 16 shows how much impairment was reported for each physical collection in the past seven days for those respondents who had indicated that the concern had been present at some point in the past six months. Some concerns

were reported as having less of an impact on daily functioning (e.g., oral health), whereas other concerns were typically more problematic (e.g., pain and sexual functioning and satisfaction).

The percentage of respondents who received care for physical concerns varied by collection. For example, almost all respondents who indicated thyroid problems were receiving care to address the issue. However, less than half of respondents who indicated having concerns with the four most prevalent collections (energy, concentration, sexual functioning

**Fig. 15 Physical Collections: Percentage of Respondents Who Experienced Physical Concerns, 2010**





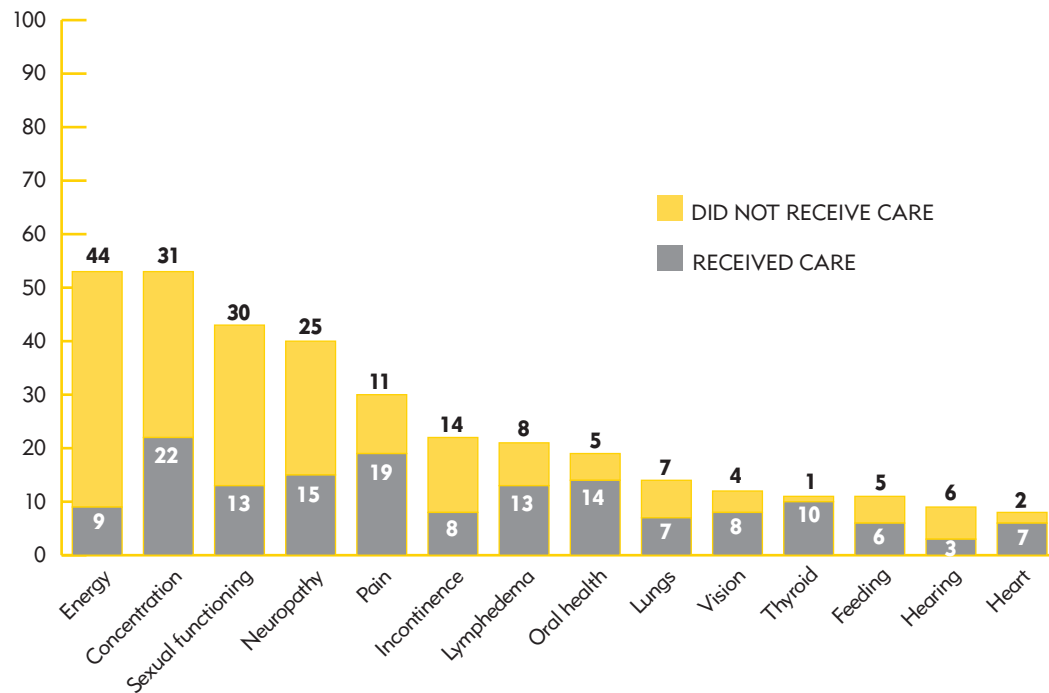
and satisfaction, and neuropathy) reported having received care to address the issue. (See Fig. 17.)

For those respondents who received care for physical concerns, the most frequently utilized types of providers for post-treatment care across all of the collections were: 1) medical specialists, 2) physicians, 3) oncologists, 4) self (e.g., use of self-help books) and 5) other medical personnel. A majority of these respondents reported that all or many of their needs were met by those from whom they received help. (See Fig. 18.)

**Fig. 16 Percentage of Respondents Who Have Functional Impairment of Physical Concerns, 2010**

Physical Collection	A lot	A little	Not at all
Energy	23	60	16
Concentration	13	56	30
Sexual functioning	29	37	30
Neuropathy	9	37	54
Pain	26	56	18
Lymphedema	11	42	47
Incontinence	6	35	58
Oral health	10	30	60
Lungs	14	44	42
Vision	6	43	50
Thyroid	8	23	66
Feeding	18	46	36
Hearing	5	37	57
Heart	11	40	46

**Fig. 17 Receipt of Care: Percentage of Respondents Who Received Care for Physical Concerns, 2010**



**Fig. 18 Top Three Sources of Care Reported by Those Who Received Care for Physical Collections, 2010**

Physical Collection	Source of Care (1)	%	Source of Care (2)	%	Source of Care (3)	%
Energy	Physician	65	Oncologist	46	Self	29
Concentration	Physician	57	Oncologist	44	Medical specialist	38
Sexual functioning	Medical specialist	66	Physician	36	Oncologist	32
Neuropathy	Physician	51	Oncologist	49	Medical specialist	47
Pain	Physician	64	Medical specialist	45	Oncologist	43
Lymphedema	Medical specialist	51	Oncologist	44	Physician	41
Incontinence	Medical specialist	72	Physician	44	Oncologist	22
Oral health	Medical specialist	79	Oncologist	22	Physician	18
Lungs	Physician	72	Medical specialist	57	Oncologist	42
Vision	Medical specialist	88	Physician	21	Oncologist	13
Thyroid	Physician	67	Medical specialist	50	Oncologist	36
Feeding	Medical specialist	68	Oncologist	43	Physician	42
Hearing	Medical specialist	85	Physician	36	Oncologist	32
Heart	Medical specialist	83	Physician	69	Oncologist	32

\* Note that respondents could identify multiple sources of care.

**Fig. 19 Ratings of Care Received for Physical Concerns**

2010 Physical Collection	Percentage of respondents whose needs were met				
	None of my needs	Very few of my needs	Some of my needs	Many of my needs	All of my needs
Energy	1	8	36	41	14
Concentration	1	9	36	38	16
Sexual functioning	6	14	36	28	16
Neuropathy	1	9	31	37	23
Pain	2	10	37	39	12
Lymphedema	1	5	25	39	30
Incontinence	1	8	22	33	36
Oral health	1	7	21	35	36
Lungs	< 1	4	26	42	27
Vision	< 1	4	15	43	38
Thyroid	1	2	14	32	52
Feeding	1	9	27	42	21
Hearing	3	5	22	37	33
Heart	1	2	17	40	42

**Fig. 20 Top Five Reasons for Not Receiving Care in 2010**

Reason for Not Receiving Care	Percentage
Learned to live with it	55
Were told it was a side effect	37
Addressed it on their own	20
Were told nothing could be done	19
Expect to get care in the future	14

Survey respondents were positive about the care that they received for their physical concerns. For each physical collection, most survivors who received care said that the care met at least some of their needs (e.g., thyroid, incontinence, oral health and vision), and more than one-third who received care said that the care met all of their needs. (See Fig. 19.)

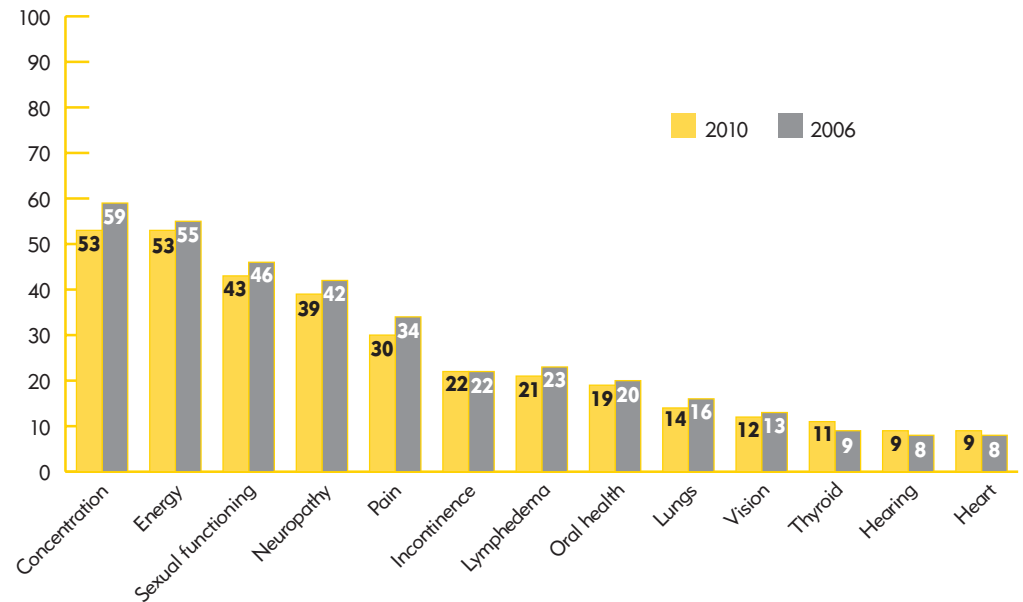
For those who did not receive care to address their concern(s), a variety of reasons were indicated. The most common reasons survivors did not receive care for physical concerns are listed in Fig. 20.

Trends in Physical Concerns

The prevalence of specific physical concerns in 2010 was similar to the prevalence reported in 2006. (See Fig. 21.)

After adjusting for the sociodemographic and medical differences between the samples (using linear regression), on average the respondents in the 2006 sample reported a slightly higher number of physical concerns (about 3.8) compared to respondents in 2010 (about 3.5). Despite this difference, most survivors in both surveys reported to be coping with multiple physical concerns in the post-treatment period. Receipt of care for physical concerns remained

**Fig. 21 Physical Collections: Percentage of Respondents Who Experienced Physical Concerns, 2006 and 2010**



My oncologist retired and my general practitioner acts like she does not believe me on these things. She has even gone as far to tell me she will not continue to fill my pain medications. Since the surgery for cancer, I have lost feeling in my left leg, a small amount at a time... I have asked doctors about it and they looked at me like I was crazy. So I gave up.

—Survey respondent

alarmingly low in 2010, similar to the results of the 2006 survey. For the four most prevalent physical concerns (energy, concentration, sexual functioning and neuropathy), less than half of survivors reported to have received care for the concern. After adjusting for sociodemographic and medical differences between the 2006 and 2010 samples (using logistic regression), results showed that significantly fewer respondents with physical concerns in 2010 received care for those concerns (59 percent) compared to the percentage who received care for physical concerns in 2006 (67 percent). The most common reasons for not receiving care in 2010 (e.g., “learning to live with it”) were comparable to the reasons reported by respondents in 2006.

**Emotional Concerns Findings**

The 2010 LIVESTRONG Survey asked about emotional concerns in eight collections, or groups of related items.

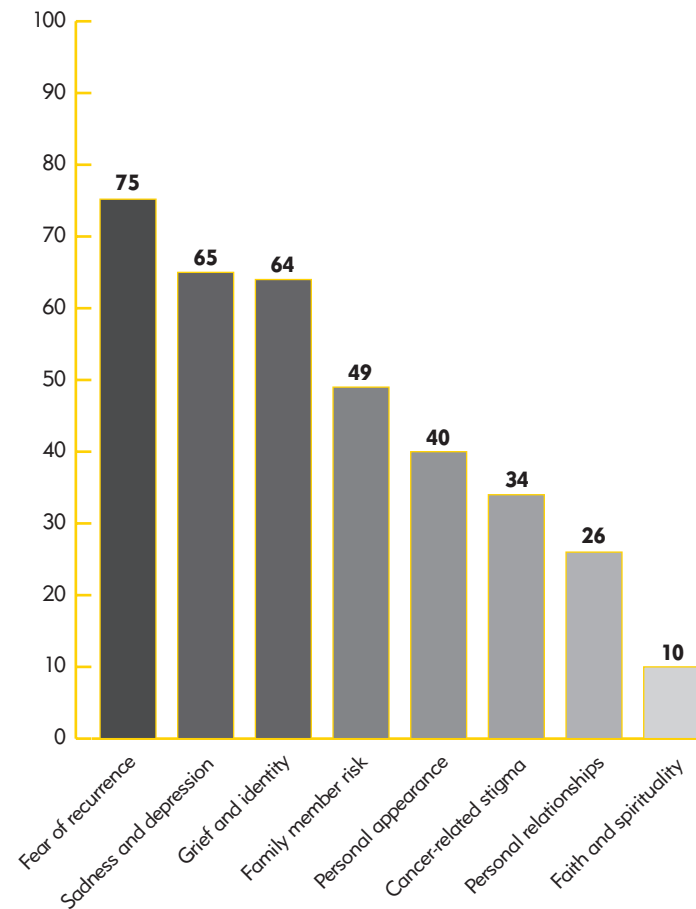
1. Personal appearance
2. Faith and spirituality
3. Family member risk of cancer
4. Grief and identity
5. Personal relationships impact
6. Fear of recurrence
7. Sadness and depression
8. Cancer-related stigma

For a list of the individual concerns in each collection, see Appendix A.

It must be noted that the 2006 survey included an emotional concern collection on social support; however, the 2006 survey gap analysis indicated that the items in the social support collection did not function well together as a scale and these items were not retained in the 2010 survey. A new collection on cancer-related stigma was included in the 2010 survey, as this important topic was not addressed in 2006.

Overall, 93 percent of the 2010 survey respondents (n = 3,129) indicated that they had experienced one or more emotional concerns since their cancer treatment had been completed. The three most frequently

**Fig. 22 Emotional Collections: Percentage of Respondents Who Experienced Emotional Concerns, 2010**



**Fig. 23 Percentage of Respondents Who Experienced Functional Impairment of Emotional Concerns**

Emotional Collection	A lot	A little	Not at all
Fear of recurrence	6	26	67
Sadness and depression	9	36	53
Grief and identity	7	34	57
Family member risk	3	19	77
Personal appearance	14	39	46
Cancer-related stigma	6	31	60
Personal relationships	15	56	27
Faith and spirituality	13	30	55

selected areas of emotional concerns were: 1) fear of recurrence of cancer, 2) sadness and depression and 3) grief and identity problems. (See Fig. 22.)

These emotional concerns caused some functional impairment in survey respondents. Fig. 23 shows how much impairment was reported for each emotional concern in the past seven days for those respondents who had indicated that the concern had been present at some point in the past six months. Some concerns were not associated with much impairment in daily activities (e.g., family member risk of cancer), whereas other concerns were associated with more impairment (e.g., personal appearance).

Very little help was given to me for the emotional problems of cancer. Any help I have received has been largely as a result of my own efforts.

—Survey respondent

It is sometimes difficult for those who have not had cancer to understand what a cancer survivor is going through. The fear of recurrence is illogical to them, but totally logical to the survivor.

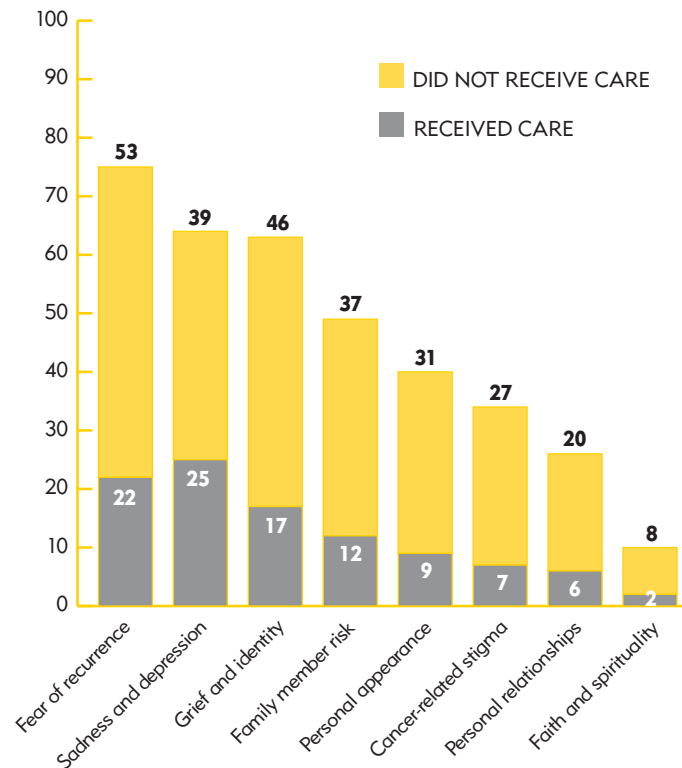
—Survey respondent

The percentage of respondents who received care for emotional concerns varied by specific concern. However, most emotional concerns remained unaddressed for survivors. (See Fig. 24.)

For those respondents who received care for emotional concerns, the most frequently utilized types of providers for post-treatment care across all of the emotional concerns collections were: 1) primary care providers, 2) oncologists, 3) friends, 4) self (e.g., use of self-help books) and 5) family. A majority of these respondents reported that all or many of their needs were met by those from whom they received help. (See Fig. 25.)

Survey respondents generally gave positive ratings on the care they received for their emotional concerns. For each emotional concern, most survivors who received care said that it met all or many of their needs. However, compared to the ratings of care for physical concerns, relatively fewer survivors said that the care they received for their emotional concerns met “all of their needs.” (See Fig. 26.)

**Fig. 24 Receipt of Care: Percentage of Respondents Who Received Care for Emotional Concerns**



**Fig. 25 Top Three Sources of Care for Each Emotional Collection**

Emotional Collection	Source of Care (1)	%	Source of Care (2)	%	Source of Care (3)	%
Fear of recurrence	Oncologist	43	Friend(s)	42	Other survivor(s)	38
Sadness and depression	Physician	51	Psychiatrist/psychologist	40	Friend(s)	35
Grief and identity	Psychiatrist/psychologist	44	Friend(s)	42	Self	37
Family member risk	Oncologist	49	Medical Specialist	40	Physician	27
Personal appearance	Friend(s)	40	Family member	34	Self/partner (tie)	33
Cancer-related stigma	Friend(s)	47	Psychiatrist/psychologist	46	Other survivor(s)	40
Personal relationships	Psychiatrist/psychologist	52	Friend(s)	42	Self	33
Faith and spirituality	Religious leader	51	Friend(s)	48	Self	43

**Fig. 26 Ratings of Care Received for Emotional Concerns**

2010 Emotional Collection	Percentage of respondents whose needs were met				
	None of my needs	Very few of my needs	Some of my needs	Many of my needs	All of my needs
Fear of recurrence	< 1	2	22	53	23
Sadness and depression	< 1	4	30	50	16
Grief and identity	< 1	4	27	52	17
Family member risk	< 1	3	20	44	33
Personal appearance	< 1	7	29	46	17
Cancer-related stigma	1	3	28	51	17
Personal relationships	1	8	34	43	15
Faith and spirituality	0	11	40	40	10

For the majority of respondents who experienced emotional concerns, no care was received for these issues. The most common reasons for not receiving care are shown in Fig. 27.

**Fig. 27 Reasons for Not Receiving Care**

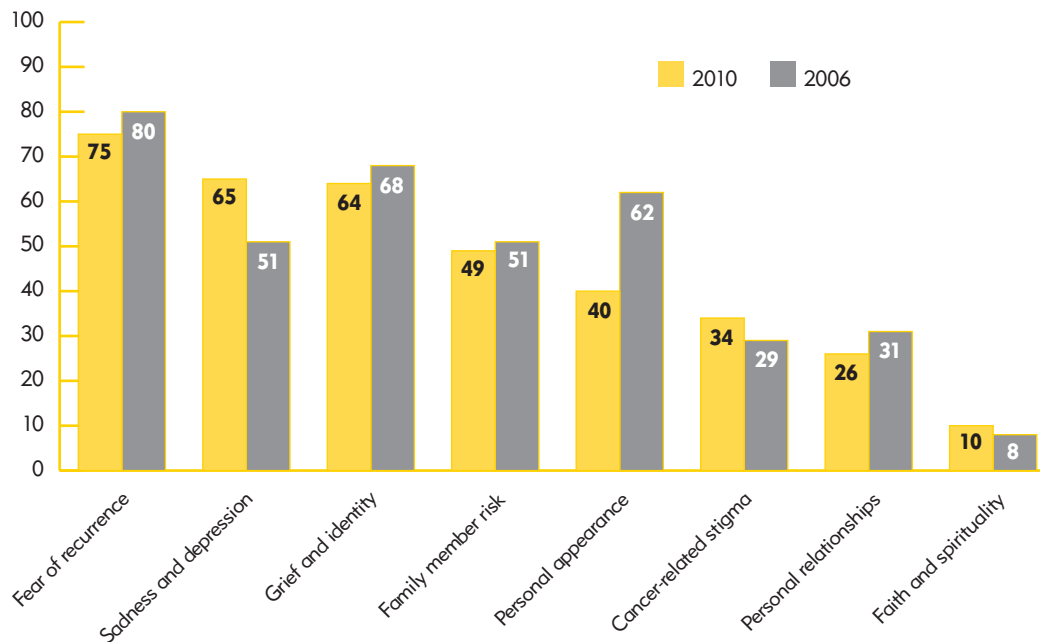
Reason for Not Receiving Care	Percentage
Learned to live with it	59
Addressed it on their own	41
Didn't want to receive care	19
Do not know	16
Was told it was a side effect	16

### Trends in Emotional Concerns

Emotional concerns in 2010 were reported at a similar prevalence as 2006. (See Fig. 28.)

After adjusting for sociodemographic and medical differences between the samples (using linear regression), on average, respondents in 2010 reported a slightly higher average number of emotional concerns (about 3.7) compared to respondents in 2006 (about 3.5). Similar to physical concerns, most survivors reported multiple emotional concerns in the post-treatment period, and receipt of care for emotional concerns was even lower in 2010 (49 percent of respondents received care for any emotional concern) than in 2006 (51 percent of respondents received care for any emotional concern). Only 40 percent of survivors who reported symptoms of depression (65 percent of the 2010 sample) received care. For all other emotional concerns, less than one-third of those who reported a concern received the help they needed. The most common reasons for not receiving care for emotional concerns in 2010 (e.g., learned to live with it) were comparable to the reasons reported by respondents in 2006.

**Fig. 28 Emotional Collections: Percentage of Respondents Who Experienced Emotional Concerns, 2010 and 2006**



### Practical Concerns Findings

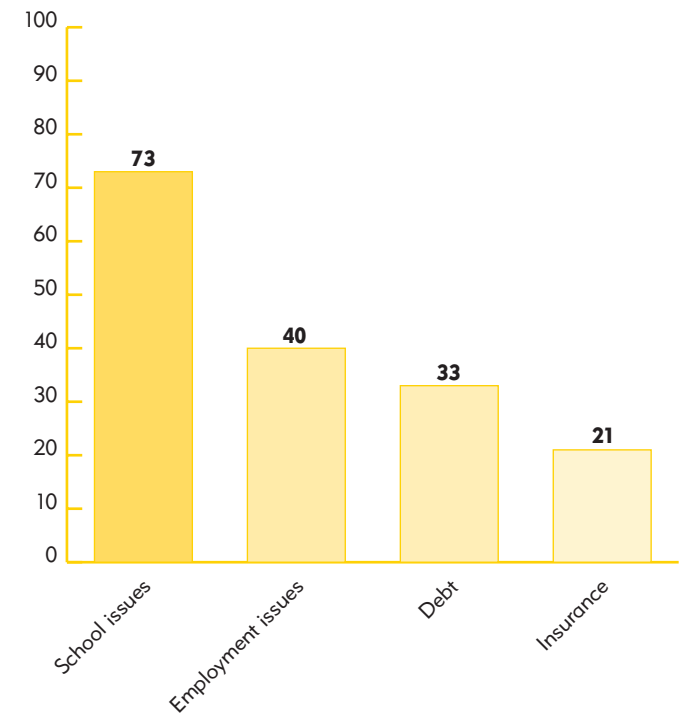
The 2010 LIVESTRONG Survey asked about practical concerns for the following collections, or groups of related items.

1. Debt
2. Health insurance
3. Employment issues
4. School issues

For a list of the individual concerns in each collection, see Appendix A.

All respondents were asked to indicate whether or not they experienced problems with debt and health insurance. Survivors who were employed at or after the time of diagnosis responded to questions about employment, and survivors who were in school at the time of diagnosis responded to questions about school. (See Fig. 29.)

**Fig. 29 Practical Collections: Percentage of Respondents Who Experienced Practical Concerns, 2010**



\* Note that the percentage of respondents with school and employment concerns were calculated using only respondents who indicated these issues were relevant.

- The majority of respondents (87 percent) were not in school when diagnosed with cancer; 415 respondents were in school.
- The majority of respondents (2,596) were working when they were diagnosed with cancer.

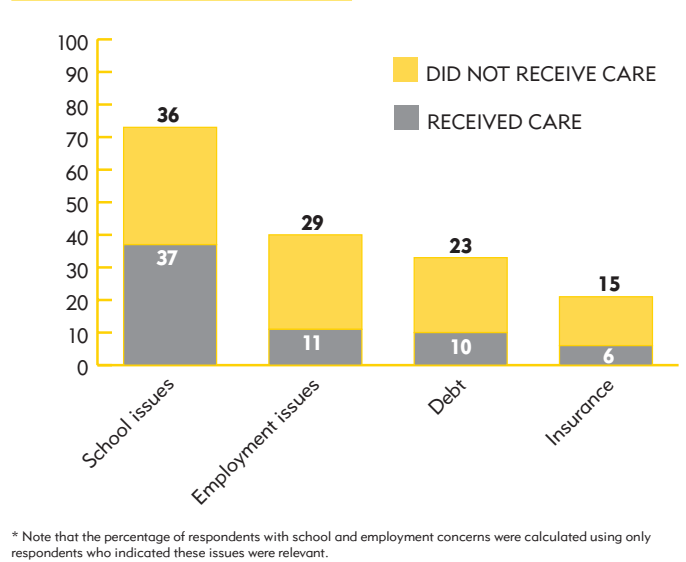
The percentage of respondents who received care for practical concerns varied according to the specific concern. Many respondents reported that they did not receive assistance in addressing their concerns. This lack of assistance was particularly pronounced for employment issues and debt. (See Fig. 30.)

The most frequently utilized types of providers for each of the practical concerns are shown in Fig. 31. Support from friends and family were particularly common across practical concerns.

Survey respondents generally gave positive ratings of the care they received for their practical concerns. For each practical concern, most survivors who received care said that the care met many or all of their needs. (See Fig. 32.)

However, most respondents indicated that they did not receive assistance with practical concerns. Of those respondents who reported that they had not received assistance with their practical concerns, the most common reasons are shown in Figure 33.

**Fig. 30 Receipt of Care: Percentage of Respondents Who Received Care for Practical Concerns, 2010**



Trends in Practical Concerns

Due to the differences between the 2006 and 2010 LIVESTRONG surveys (e.g., only respondents employed at the time of their diagnosis were asked about employment problems in 2006 whereas all respondents employed at or after the time of diagnosis were asked about employment problems in 2010), it is difficult to examine trends in practical concerns. Nonetheless, practical concerns were prevalent in 2010, and debt and insurance issues were reported by more 2010 respondents than 2006 respondents. Compared to the 2006 survey

**Fig. 31 Top Three Sources of Care for Each Practical Collection**

Practical Collection	Source of Care (1)	%	Source of Care (2)	%	Source of Care (3)	%
School issues	Other	42	Family member	41	Friends	36
Employment issues	Friends	45	Family member	34	Self	30
Debt	Family member	50	Friends	26	Other	20
Insurance	Insurance company	32	Other	27	Self	22

**Fig. 32 Ratings of Care Received for Practical Concerns**

2010 Practical Collection	Percentage of respondents whose needs were met				
	None of my needs	Very few of my needs	Some of my needs	Many of my needs	All of my needs
School issues	1	4	12	34	49
Employment issues	< 1	6	23	48	23
Debt	2	12	31	38	18
Insurance	2	5	28	39	27

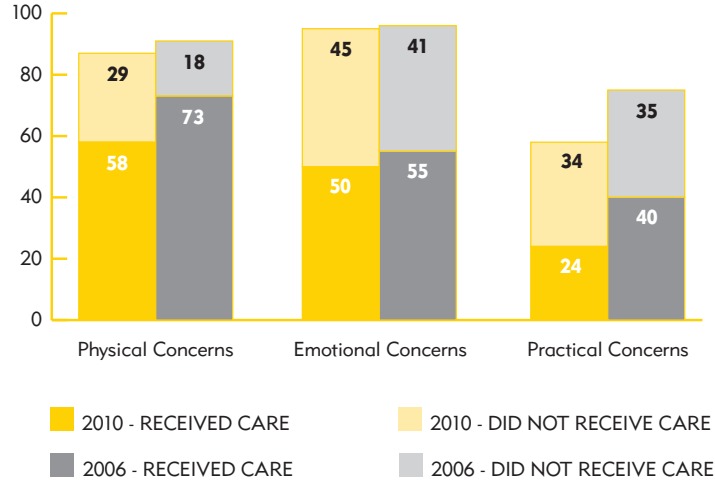
**Fig. 33 Reasons for Not Receiving Care**

Reason for Not Receiving Care	%
Learned to live with it	23
Addressed it on their own	18
Were unsure where to go	14
Tried but were unsuccessful	13
Didn't know help was available	12

The complexity of the financial roller-coaster cannot be over-emphasized, and the amount of energy required to connect with those resources is overwhelming. We need more support in this area!

—Survey respondent

**Fig. 34 Receipt of Care: Percentage of Respondents Who Experienced Concerns and Received Care for Those Concerns, 2006 and 2010**



results, a similar—and low—percentage of survivors in 2010 received care for practical concerns.

### Overview of All Collections

Cancer survivors who responded to this survey experienced a variety of physical, emotional and practical concerns. While respondents had varied experiences in terms of type of cancer, type of treatment, time since treatment ended and a number of other characteristics, for these survivors life after a cancer diagnosis continued to bring changes and challenges. Nearly all survey respondents—98 percent—experienced at least one post-treatment physical, emotional or practical concern. This section provides information across all of the collections about what these post-treatment cancer survivors reported experiencing and how they dealt with these concerns.

There were stark differences related to receiving help. While more than half of 2010 survey respondents who had experienced at least one physical concern did receive care (58 percent), only half of those who experienced emotional concerns received help (50 percent), and only 20 percent of those with practical concerns received help. Alarming, the receipt of care for physical, emotional or practical concerns decreased between 2006 and 2010. (See Fig. 34.)

### FERTILITY ISSUES

Fertility is an important issue for many cancer survivors, but not all medical teams routinely address this issue with patients. Of the 3,129 total respondents in the 2010 sample, 40 percent indicated that issues of fertility did not apply to their case. Of the remaining 1,872 respondents, 70 percent indicated that they did not receive information about options for preserving fertility before their cancer diagnosis, and an additional 3 percent were not sure if they had received this information or did not respond. Only 28 percent of respondents for whom fertility was relevant indicated that they had received any information about options for preserving it. The majority of those who received information about preserving fertility were male (65 percent). Of all respondents who received information, 77 percent indicated that the information met all or many of their needs.

In the 2010 survey, 303 participants tried to get pregnant or father a pregnancy after cancer treatment. Of these participants, 55 percent conceived a child without assisted reproduction, 8 percent conceived a child with assisted reproduction, (e.g., in vitro fertilization) and 38 percent were not able to conceive a child. (Note that some families may have used multiple techniques for different pregnancies.) For those who received infertility treatment, the most common sources of care were medical specialists (80 percent), oncologists (28 percent) and primary care physicians (24 percent). As shown in the table below, many respondents did not feel that their needs had been successfully met by the infertility care that they received. Few respondents (49 individuals) identified reasons that they had not received care for infertility, but those who did indicated that the most common reasons for not receiving care were: 1) I have learned to live with this concern (35 percent), 2) I was told nothing could be done (29 percent), 3) I plan to receive care in the future (18 percent), 4) Other reasons (18 percent) and 5) I could not pay for the services (12 percent).

2010 Collection	Percentage of respondents whose needs were met				
	None of my needs	Very few of my needs	Some of my needs	Many of my needs	All of my needs
Infertility	24	16	36	16	8

# 4

## CONCLUSIONS





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The 2006 **LIVESTRONG** Survey for Post-Treatment Cancer Survivors was fielded in the wake of the 2006 IOM report (Hewitt, Greenfield, & Stovall, 2006), calling for more attention to the post-treatment period of the cancer continuum. The results of the 2006 survey validated the IOM's call to action: most post-treatment cancer survivors reported experiencing a variety of physical, emotional and practical concerns, and too often they were not receiving care for those concerns. If the 2006 survey results offered validation, the results of the 2010 survey put forth a sense of urgency. Four years after the launch of the initial survey, the landscape of post-treatment survivorship in terms of what these cancer survivors experienced remains the same — and is quite concerning.

In 2010, more than half of post-treatment cancer survivors in this survey are still reporting problems with fatigue, concentration, fear of recurrence, grief and identity issues and emotional distress. More than 40 percent reported problems with sexual dysfunction and dissatisfaction, concerns about their family members' risk for cancer and personal appearance. Post-treatment survivors identify these issues as causing functional impairment in their day-to-day lives. Yet, despite this impairment, many with physical, emotional or practical concerns are not receiving help or care for those concerns, most commonly because they have "learned to live with it."

This is of particular concern when recognizing that the **LIVESTRONG** surveys are fielded online and the thousands of people who take part in contributing to this research do not necessarily represent all the characteristics of people affected by cancer. This sample lacks significant racial or ethnic diversity; is well-educated; is well-insured; and most have significant economic resources. Despite this, respondents in the survey sample reported a significant burden of physical, emotional and practical concerns, and alarmingly few received care for those concerns. One wonders, if this is the state of post-treatment survivorship for individuals

who may have adequate resources, how are the traditionally underserved faring?

#### NEXT STEPS

**LIVESTRONG** believes that we owe more to the men, women and children who have battled cancer than a scenario of "living with" significant physical, emotional or practical concerns. Based on the results of both iterations of the **LIVESTRONG** Survey, we have identified three critical areas of survivorship that require action. **LIVESTRONG** is committed to supporting cancer survivors to ensure these areas are addressed.

#### **1. Connect people to the resources they need.**

Cancer and its treatment often represent the fight of one's life. It may be unrealistic to assume that survivors will not encounter physical, emotional or practical concerns in the post-treatment period. However, when care exists for — and helps to ameliorate — post-treatment survivors' concerns, connecting more survivors to the care that they need is an actionable means for improving post-treatment cancer survivorship. The results of the 2010 **LIVESTRONG** Survey highlight the gap between who reports concerns and who receives care for those concerns as a critical breakdown in post-treatment survivorship. This breakdown needs to be addressed.

The good news is that respondents to the 2010 survey who *did* receive care for their concerns reported that it met some, many or in some cases, all of their needs. However, we need to ensure this is happening for more individuals. Cancer care providers should carefully evaluate whether there is a breakdown in the provision of cancer care between when a survivor finishes primary treatment and when a survivor enters the post-treatment period. If a breakdown is identified, survivorship-specific services are needed to address physical, emotional and practical concerns in the post-treatment period. Further, the role of patient navigators to address this breakdown should be better understood, and utilized when appropriate.

#### **2. Identify and disseminate the essential elements of survivorship care delivery that can help to ensure cancer survivors' needs are met.**

The most common concerns reported by survey respondents — energy, concentration, sexual functioning, emotional distress — are problems that likely require multidisciplinary solutions to resolve. Perhaps not surprisingly, survivors who received care for their concerns reported to use a variety of health care professionals, as well as informal sources of care (e.g., family and friends) to address their physical, emotional or

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”I think it's impossible for doctors to tell you all the possible side effects that may or may not occur, without frightening you witless. I found it a great consolation, when feeling ill at three in the morning, to read how other people felt/dealt with it.”

— Survey respondent

practical concerns. As models of survivorship care continue to evolve (Jacobs, Palmer, Schwartz, DeMichele, Mao, et al., 2009), the LIVESTRONG survey results highlight the need for systems of care which incorporate a variety of disciplines that are positioned to address the physical, emotional and practical concerns of post-treatment cancer survivors. This will be most successful when there is good care coordination between multiple providers involved in a survivor's care. Ongoing developments in electronic health information exchange (i.e., electronic health records, personal health records) may help to facilitate this kind of multi-disciplinary care, and other LIVESTRONG research (Rechis, Nutt, & Beckjord, 2010) suggests that cancer survivors believe that electronic health information exchange will help to improve coordination in cancer care.

The cancer community should identify the minimal requirements for survivorship care, and these requirements or essential elements should address the most common physical, emotional and practical concerns that have been expressed across both LIVESTRONG survey administrations. Further, survivorship care should leverage all available health information technology to facilitate care coordination, provision of patient education and patient empowerment to help post-treatment cancer survivors be active participants in their own care and symptom management. Specially, we need to better understand the key "ingredients" of care plans and the impact of having a care plan on post-treatment survivors' physical, emotional and practical concerns and on their ability to obtain care for those concerns.

### **3. Conduct continued surveillance on the concerns of cancer survivors and disseminate research to better understand the experience of post-treatment cancer survivorship.**

Surveillance at the national and local levels should occur on a regular basis to measure the needs of and receipt of care by cancer survivors, including survivors in the post-treatment period. In 2010, LIVESTRONG worked with key partners to distribute and disseminate information about this survey. In June 2012, we intend to release this survey again. Over the course of the next year, we will analyze this data further, sharing this data with partners, considering opportunities for the next version of the survey and identifying opportunities for engaging more survivors in the future. We humbly request that the research community consider how they might engage in this work and how we might be able to work collaboratively to understand the full scope of the more than 350 questions answered by more than 3,100 cancer survivors as well as as well as how to conduct upcoming surveys to engage even more people affected by cancer. Contact us at [research@LIVESTRONG.org](mailto:research@LIVESTRONG.org) to get involved.

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## Survey Concerns

The full survey is available upon request at [research@LIVESTRONG.org](mailto:research@LIVESTRONG.org).

### Physical Concerns

#### Heart collection of concerns

- I have had trouble with my heart.
- I have been told by a doctor that I have heart problems.

#### Lungs and breathing collection of concerns

- I have had trouble breathing.
- I have been told by a doctor that I have damage to my lungs.

#### Vision collection of concerns

- I have had trouble seeing.
- I have been told by a doctor that I have problems with my vision or sight.

#### Hearing trouble collection of concerns

- I have had trouble hearing.
- I have been told by a doctor that I have problems with my hearing.

#### Oral health collection of concerns

- I have had problems with my mouth.
- I have had problems with my teeth.
- I have been told by a doctor that I have problems with my mouth.
- I have been told by a doctor that I have problems with my teeth.

#### Lymphedema collection of concerns

- I have had swelling in my legs, arms or other areas of my body.
- I have been told by a doctor that I have lymphedema.

#### Swallowing and feeding collection of concerns

- I have had problems swallowing naturally and easily.
- I have had problems eating solid foods.

#### Neuropathy collection of concerns

- I have lost feeling or had strange sensations in my hands or feet.
- I have experienced dizziness, such as when getting up from a chair.
- I have been told by a doctor that I have neuropathy.

#### Thyroid collection of concerns

- I have been told by a doctor that I have a thyroid condition.

#### Urinary incontinence collection of concerns

- I have not been able to control when I urinate.
- I urinate more frequently than I used to.
- I have been told by a doctor that I have urinary incontinence.

#### Infertility collection of concerns

- I have been pregnant or fathered a pregnancy since cancer treatment ended...
  - No, because my partner is infertile or has fertility problems.
  - No, a doctor has told me that I am infertile because of my cancer diagnosis or cancer treatment.
  - No, but I plan to try to conceive a child at some point in the future.
  - No, I have been unable to get pregnant, maintain a pregnancy or father a pregnancy for more than a year.
  - No, because \_\_\_\_\_

#### Sexual functioning and satisfaction collection of concerns

- I have been bothered by difficulty or inability to function sexually.
- I have been dissatisfied with my sex life.
- I have avoided sexual activity or lacked interest in sex.
- I have had difficulties with impotence.

#### Pain collection of concerns

- I have had aches or pains for long periods of time.
- I have had pain that kept me from doing the things I wanted to do.

#### Concentration collection of concerns

- I have had difficulty doing activities that require concentration.
- I have been bothered by having a short attention span.
- I have had trouble remembering things.
- I have been bothered by forgetting what I started to do.
- I have had "chemo brain."

#### Energy and rest collection of concerns

- I have not had the energy to do the things I wanted to do.
- I have felt tired a lot.
- I have had trouble getting the rest that I need.
- I have had trouble sleeping for several nights in a row.

## Emotional Concerns

### Sadness and depression collection of concerns

- I have felt blue or depressed.
- I have been bothered by mood swings.
- I have felt anxious.
- I have felt a constant state of worry, tension or stress.
- I have been told by a doctor that I am suffering from depression.
- I have dates or events that make me think more about cancer. (For example, the date you were diagnosed or the date treatment ended.)
- I feel blue or depressed each time these dates or events occur.

### Grief and identity collection of concerns

- I have felt that I have lost a sense of security in my future.
- I have felt that I have lost a sense of my identity.
- I have felt grief about the death of other cancer patients.
- I have felt guilt over the death of other cancer patients.

### Faith and spirituality collection of concerns

- I have felt that I have lost a sense of my faith or spirituality.
- I have felt that my faith or spirituality has been negatively affected.

### Fear of recurrence collection of concerns

- I have been preoccupied with concerns about cancer.
- I have worried about dying from cancer.
- I have worried about cancer coming back.

### Personal relationships impact collection of concerns

- I have been reluctant to start new relationships.
- I have not wanted to participate in social gatherings.
- I have not wanted to be around my friends.
- I have been reluctant to meet new people.
- I do not go to events that I used to enjoy.

### Cancer-related stigma collection of concerns

- I have not wanted to tell others that I have had cancer.
- I have felt ashamed because I have had cancer.
- I am afraid others will judge me negatively if they know I have had cancer.
- I feel others have avoided me because I have had cancer.

### Family member risk of cancer collection of concerns

- I have worried about whether my family members should have genetic tests for cancer.
- I have worried that my family members were at risk of getting cancer.
- I have worried about whether my family members might have cancer-causing genes.

### Personal appearance collection of concerns

- I have felt unattractive.
- I have felt people have treated me differently because of changes to my appearance.
- I was bothered by hair loss from cancer treatment long after treatment ended.

## Practical Concerns

### Employment issues collection

- I have been affected at my job because of my cancer diagnosis in the following negative ways: (Please check all that apply.)
  - I lost my job.
  - I left my job.
  - I am unable to work at all now.
  - I am unable to work full time now.
  - I am unable to work in the same way I did before my cancer diagnosis.
  - I have been treated poorly on the job.
  - I have received a decrease in pay.
  - I have experienced employment discrimination.
  - I have felt that my employer would not make reasonable changes or accommodations in my job to help me.
  - I was passed over for a promotion.
  - I have returned to work at a lower level than I was at before my diagnosis.
  - I have stayed in my job because I did not want to lose my health insurance.
  - I have stayed in my job because I did not want to lose my life insurance.
  - I had difficulty with the return to work.
  - I had to take on a second job because of debt due to cancer.
  - I have felt that I did not get a job because of my cancer diagnosis.
  - Other \_\_\_\_\_

### School issues collection

- I have been affected at my school because of my cancer diagnosis in the following ways: (Please check all that apply.)
  - I left school.
  - I missed a large amount of school.
  - I felt my teachers did not know how to support me when I returned to school.

- I felt my classmates did not know how to support me when I returned to school.
- I have had difficulty keeping up with my school work.
- I have had trouble with my classmates since receiving a cancer diagnosis.
- I did not have any special accommodations while I was in school.
- I had to drop out of school because of debt.
- I was unable to attend college.
- Other \_\_\_\_\_

### Debt collection

- My loved ones or I have had financial problems because of cancer, treatment or late effects of cancer.
- Due to a cancer diagnosis, I have the following amount of debt. (Please select one.)
  - No debt
  - Up to \$5,000 in debt
  - Between \$5,001–\$10,000 in debt
  - Between \$10,001–\$24,999 in debt
  - Between \$25,000–\$49,999 in debt
  - Between \$50,000–\$74,999 in debt
  - Between \$75,000–\$99,999 in debt
  - \$100,000 or more in debt
- Due to a cancer diagnosis, I have spent the following, above and beyond insurance.
  - Nothing
  - Up to \$5,000
  - Between \$5,001–\$10,000
  - Between \$10,001–\$24,999
  - Between \$25,000–\$49,999
  - Between \$50,000–\$74,999
  - Between \$75,000–\$99,999
  - \$100,000 or more

Insurance concerns collection

- Since completing treatment, I have (or the primary policy holder of my insurance has)..
  - lost my health insurance.
  - been denied health insurance.
  - not been able to get health insurance for the first time.
  - not been able to get additional health insurance.
  - reached the health insurance lifetime maximum.
  - problems with health insurance because of cancer as a pre-existing condition.
  - not been able to get the prescriptions that I needed because of my health insurance.
  - not been able to get the treatment that I wanted because of my health insurance.
  - not been able to get the screenings that I wanted because of my health insurance.
  - not been able to get the follow-up care that I wanted because of my health insurance.
  - not been able to get the medical care I wanted because of the costs I would incur above and beyond what insurance covers.
  - Other\_\_\_\_\_

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