



HOW CANCER HAS AFFECTED POST-TREATMENT SURVIVORS: A **LIVESTRONG** REPORT

FINAL REPORT

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EXECUTIVE SUMMARY

In the United States, the number of cancer survivors has more than tripled to 12 million people during the past 30 years. As the number of survivors has dramatically increased, so has the need for reliable information about the post-treatment cancer experience. To comprehensively assess the physical, practical and emotional needs of cancer survivors, **LIVESTRONG** launched a survey in 2006.

Created in collaboration with cancer survivors, the **LIVESTRONG** Survey for Post-Treatment Cancer Survivors (**LIVESTRONG** Survey) was conducted to contribute to the understanding of survivors' needs after completion of treatment. The survey instrument was divided into five sections which covered 1) physical concerns, 2) emotional concerns, 3) practical concerns, 4) positive experiences with cancer and 5) resources and information provided by **LIVESTRONG**. The extensive list of concerns included items related to late effects of cancer and its treatment such as lymphedema, fatigue, sadness and depression and issues with insurance.

The survey results show that almost all respondents (99 percent) experienced at least one concern after cancer treatment ended. Almost all experienced at least one physical concern (91 percent) and/or at least one emotional concern (96 percent). The majority of respondents (75 percent) also experienced practical concerns. For those experiencing emotional concerns, 55 percent received help for one or more concern; for those experiencing practical concerns, a minority — 40 percent — received help for one or more concern; and for those experiencing physical concerns, 75 percent indicated that they received care for one or more concern. However, for the four areas most frequently reported as physical concerns — energy, concentration, sexual functioning and neuropathy — the majority of respondents had 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 in lieu of receiving help highlights the critical need for more support during the post-treatment cancer survivorship experience. For these post-treatment survivors, emotional and practical concerns were the areas where post-treatment support was most needed. As one respondent noted, "The emotional effects were often harder than the physical ones for me, and this is where I felt the most lost and alone."

The results from this survey are derived from 2,307 cancer survivors who voluntarily participated in this primarily online survey. Of these, 85 percent were under the age of 55 when they were diagnosed. Further, the majority of respondents were white (92 percent), female (67 percent), one to five years post-treatment (61 percent) and college graduates (59 percent). Since the survey was administered almost entirely online, it can be assumed that most respondents were Internet savvy as well. While the results of this survey may not represent the experiences of all post-treatment cancer survivors due to the voluntary nature of the survey, the findings can make an important contribution to the scientific understanding of the needs of post-treatment cancer survivors, particularly for describing the experiences of adult survivors under the age of 55.

Due to advances in prevention, detection and treatment, people diagnosed with cancer are much more likely to survive at least five years. While this is exciting news, it is important for the cancer community to consider how we can best support people with the multifaceted experience of surviving cancer. Cancer survivors need research, information and access to services to help address their physical, emotional and practical concerns after treatment ends.

1

INTRODUCTION



One in two men and one in three women will be diagnosed with cancer during their lifetimes. More than a million new cases of cancer are diagnosed each year (American Cancer Society, 2009). Fortunately, due to advances in detection, prevention and treatment, cancer survivors have an estimated 64 percent chance of surviving five years, compared with a rate of 50 percent three decades ago (Hewitt, Greenfield, & Stovall, 2006). In fact, in the United States, the number of cancer survivors has more than tripled to nearly 12 million people during the past 30 years (Ries, Melbert, Krapcho, Stincomb, Howlander, Horner, et al., 2008). Cancer is a term used to describe a wide range of diseases. Treatment for cancer can vary based on type of cancer, age at diagnosis, stage of cancer and a number of other factors. As a result, the impact of cancer and its treatment on an individual can vary greatly.

As the number of cancer survivors has increased, the late effects caused by cancer and its treatment have come to the forefront (U.S. Department of Health and Human Services [HHS], 2004). These late effects can take many forms. Post-treatment, some cancer survivors will experience very few late effects, while others will face life-altering symptoms (National Cancer Institute, 2007). These effects can occur months or even years after treatment ends. Cancer survivors may face

medical as well as non-medical late effects (Hoffman, McCarthy, Reckiltis, & Ng, 2009). The medical late effects cancer survivors experience vary but may include psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes and limitations in communication, mobility and cognition (Hewitt et al., 2006). Non-medical late effects can include issues such as employment discrimination, debt and loss of insurance (Wolff, et al., 2005).

A poll conducted in 2004 on behalf of **LIVESTRONG** revealed that about half (49 percent) of the cancer survivors who responded felt that their non-medical needs were not being met. Further, of this group, 70 percent indicated that their oncologists did not offer support in dealing with their non-medical needs. The remaining 30 percent responded that their physicians were willing to talk about their needs but did not have the resources to address them (Wolff, et al., 2005).

Although post-treatment cancer survivors may have many needs, research on these needs and how they are met is limited (Hewitt et al., 2006; Rowland & Bellizzi, 2008). As the number of cancer survivors continues to increase, it is imperative that a system of care be developed to understand what the needs of cancer survivors are and how those needs are (and are not) being met (Rowland, Hewitt, & Ganz, 2006).

The Institute of Medicine (IOM) (Hewitt et al., 2006) released a report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, which focused on survivors of adult cancer during the phase of care that follows primary treatment. In this report, the IOM made recommendations for follow-up care for cancer

survivors and addressed those issues that need to be studied further to ensure better care for post-treatment survivors.

The IOM report (2006) noted that, “Too many survivors are lost in transition once they finish treatment. They move from an orderly system of care to a ‘non-system’ in which there are few guidelines to assist them through the next stage of their life or help them overcome the medical and psychosocial problems that may arise.” Often cancer survivors are unaware of the late effects that may be caused by their treatment, and even for those who are aware, their needs are often unmet.

Further, the IOM report recommended that private voluntary organizations, such as nonprofit organizations, need to increase their support of survivorship research and expand mechanisms for its conduct. Future research initiatives should include populations that represent the diversity of cancer survivors in terms of types of cancer and treatments as well as their sociodemographic and health care characteristics (Hewitt et al., 2006).

“Going into and during treatment, I had tremendous medical support, but I feel that my issues as a survivor have not been well-addressed by the medical community. I knew what to expect or possibly expect in treatment, but have muddled through as a survivor.”

—Survey respondent

LIVESTRONG Survey For Post-Treatment Cancer Survivors

In late 2006, in response to the IOM recommendations, **LIVESTRONG** launched a survey designed to capture data to provide insight into the needs of post-treatment cancer survivors.

LIVESTRONG is a nonprofit organization and a leader in the area of cancer survivorship. The mission of this organization is to inspire and empower people affected by cancer. To this end, **LIVESTRONG** provides people with resources and support they need to fight cancer head-on and finds innovative ways to raise awareness, fund research and end the stigma that many cancer survivors face. In addition, **LIVESTRONG** empowers people and communities to drive social change and calls for state, national and world leaders to help fight this disease.

The **LIVESTRONG** Survey for Post-Treatment Cancer Survivors (**LIVESTRONG** Survey) was designed to comprehensively assess the physical, emotional and practical needs of survivorship post-treatment. Further, the survey gathered information about why some post-treatment survivors did not receive care and, if they did receive care, who provided it.

4 Over the past two years (2007–2009), the results of the survey have been shared at national conferences and via **LIVESTRONG.org** as well as used internally to inform the development of educational materials and programs (Rechis, 2008; Rechis & Shaw, 2009). The intent of this report is to give voice to the more than 2,300 cancer survivors who participated in this survey and provided information about 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.



2

METHODOLOGY
AND DEMOGRAPHICS

Survey Design and Characteristics

The survey instrument was designed through a process that engaged both cancer survivors and experts in the field of survey methodology and oncology through peer review, three focus groups and a pilot test.

The concerns used in the survey were initially selected and included for the following reasons: 1) they had been used in other surveys, 2) they were concerns that had been identified by experts as known late effects of cancer and/or 3) they were areas of concern addressed by LIVESTRONG educational resources. Concerns and related answer choices were included in the final instrument only if they were recognized as effects known or options used by the participants in the cancer survivor focus group and pilot test. This was done intentionally to ensure that the survivor voice was the driving force behind all aspects of this survey.

The survey instrument was divided into five sections which covered 1) physical concerns, 2) emotional concerns, 3) practical concerns, 4) positive experiences with cancer and 5) resources and information provided by LIVESTRONG.

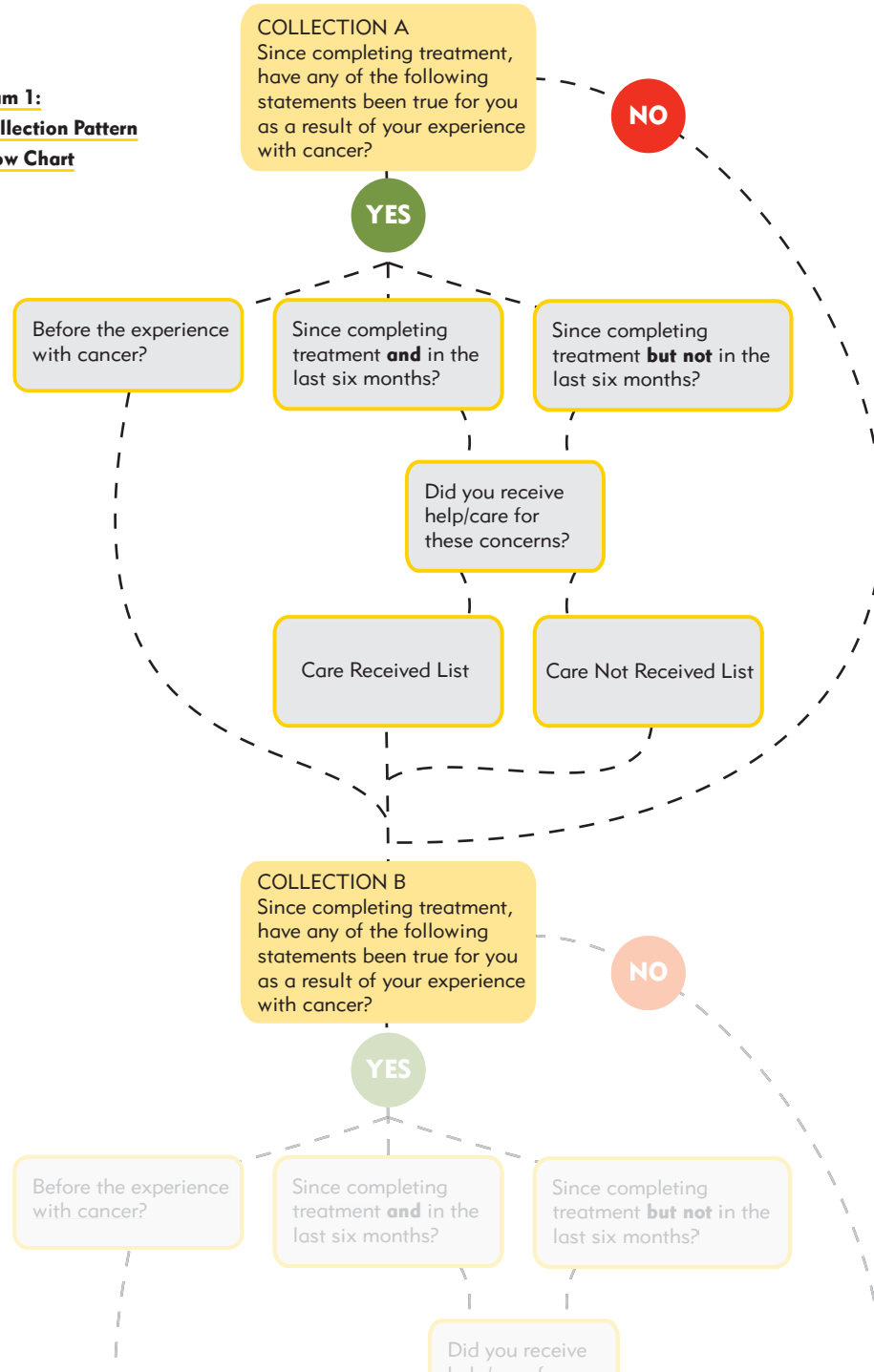
The positive experiences section and the resources and informa-

tion provided by LIVESTRONG section included dichotomous statements to which respondents indicated whether or not they agreed. (For example, "I have appreciated life more because of having had cancer.")

The other three sections of the survey (physical, emotional and practical concerns) were further organized into groups of related items, which will be referred to as "collections" throughout the rest of this report. For example, one collection contained four items related to energy and fatigue and another collection contained four items related to sadness and depression. There were a total of 27 collections addressing a broad range of concerns such as heart problems, insurance issues and spirituality. See Appendix A for a list of the concerns included in this survey.

As outlined in Diagram 1: Collection Pattern Flow Chart, for each collection participants were asked to respond to the following statement: "Since

Diagram 1:
Collection Pattern
Flow Chart



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 low-literacy 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 did not select "yes" for any concerns within a collection, they were directed to the next collection.

If individuals selected "yes" for 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 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 chose either of the latter answer choices, they were then asked to complete a statement about whether they had received care or help for these concerns. Depending on whether an individual received care, the respondent was sent down one of two paths: care received and care not received.

CARE RECEIVED

Question 1

If an individual received care, he or she was first asked to select from a list of 17 options (which were consistent throughout the survey) to determine who provided the care. While there was a lengthy list of individual choice 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, a dentist or fertility specialist)
- Other medical personnel (for example, a nurse)
- Psychiatrist or psychologist
- Social worker, counselor or child life specialist
- Support group
- Self (for example, the Internet or a book)
- Partner
- Family member
- Friend or friends
- Other cancer survivors
- Cancer or other nonprofit organization
- Religious leader (for example, a pastor or rabbi)
- Government agency
- Insurance company
- Other (please specify)

Question 2

Once an individual reported that they had received care, they were then 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 select one or more choices from a list of 21 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 whom to see
- My doctor did not refer me for care
- 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 _____ (with space to cite another option)

“I thought the survey’s questions were well-worded and I liked how in-depth some of them were. I really got a sense that they were written by those who understand what survivors are going through.”

— Survey respondent

Methodology

The survey was opened on March 30, 2006, following analysis of three focus groups and a pilot test. The survey remained open through February 2007, and was available both online and in paper form. The survey was intended for individuals who had been diagnosed with cancer who were currently finished with treatment or managing cancer as a chronic condition. This included those still taking medication, such as tamoxifen, to prevent a recurrence as well as those still seeing a doctor to check for new or returning cancers. The study was reviewed and approved by the University of Texas Institutional Review Board.

The survey instrument was available on **LIVESTRONG.org** to anyone who was interested in taking the survey. **LIVESTRONG** constituents were notified about the survey through the **LIVESTRONG** newsletter and emails. Additionally, **LIVESTRONG** reached out to all of its community and national partner organizations (140 organizations) and all state cancer coalitions to provide information about the survey. These organizations and coalitions were provided with an email and a flyer they could share with their constituents. They also were given the option of receiving paper copies of the survey with postage-paid envelopes to allow for no-cost return. Six of these organizations requested a total of 200 paper surveys and 41 surveys were returned to **LIVESTRONG**. Of note, just less than half of respondents (42 percent) reported having used an educational resource or being engaged with a **LIVESTRONG** program. Respondents were not asked about participating in events, such as the **LIVESTRONG** Challenge, or purchasing merchandise, such as **LIVESTRONG** wristbands.

Data Analysis

To assess the prevalence of physical, emotional and practical needs of post-treatment survivors, the mean percentages of those survey respondents who answered a particular question, or answered all reported questions in a particular collection were used. This number varied from question to question, and collection to collection. Additionally, respondents were often able to select more than one item; that is, they could have sought multiple sources for help, or experienced concerns both before treatment and since.

Most collections used a dichotomous selection to choose either a positive, "yes, I have experienced this concern," or a negative, "no, I have not experienced this concern." Once a selection was made whether a respondent experienced a particular physical, practical or emotional aspect of the cancer experience, follow-up questions were given.

Because not all respondents answered every question in a collection, averages for each section were estimated using the available data. Likewise, not all respondents answered all questions in each area of physical, emotional or practical needs and estimations were made using the available data. Additionally, all percentages were rounded to the nearest whole percent.

Sample Size, Demographics and Medical Characteristics

A total of 2,568 individuals accessed the survey. Of these, 261 participants were ineligible to continue because they were still on some form of treatment for cancer or were under the age of 18. A total of 2,307 individuals were included in the survey analysis.

Demographics for the sample are reported below. Where possible, the demographics of the participants in this survey were compared to estimates of the demographics for all U.S. cancer survivors provided by the Surveillance Epidemiology and End Results (SEER) Program. SEER is a program of the National Cancer Institute that collects population-based data on cancer incidence and survival from state cancer registries in the United States. There are many notable differences between those who took this survey and the overall survivor population as captured by SEER.

Fig. 1 Gender of LIVESTRONG Survey Compared with SEER



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

GENDER

The majority of survey respondents were females. (See Fig. 1.)

AGE AT DIAGNOSIS

The majority of survey respondents were younger at the time of diagnosis when compared to the SEER incidence cases – with the majority diagnosed between ages 20 and 54. Most notably, the median age of the LIVESTRONG Survey at time of diagnosis is 43 while the median age of the SEER incidence cases is 67. (See Fig. 2.)

CANCER TYPE

Based on SEER data, in the U.S. the five most prevalent types of cancer, based on the total number of people living with cancer at any point in time, are breast, prostate, colorectal, gynecologic and hematologic. These five types of cancer were not the most often selected types among the LIVESTRONG Survey respondents. (See Figs. 3–4, types of cancer of LIVESTRONG Survey compared with SEER.)

RACE/ETHNICITY

The majority of respondents (92 percent) identified themselves as white. (See Fig. 5.)

Fig. 2 Age of Diagnosis of LIVESTRONG Survey Respondents Compared with SEER

Age Categories	LIVESTRONG Survey Respondents' Percentages	SEER Percentages
< 20	5%	1%
20 – 34	20%	3%
35 – 44	30%	6%
45 – 54	30%	13%
55 – 64	12%	21%
65 – 74	3%	26%
75 – 84	0.2%	23%
85+	0%	7%
Total	100%	100%

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

Fig. 3 Top Five Most Prevalent Cancers of LIVESTRONG Survey Respondents Compared with SEER

Type of Cancer	LIVESTRONG Survey Respondents' Percentages	SEER Percentages
Breast	32%	23%
Prostate	5%	20%
Colorectal	6%	10%
Gynecologic	7%	9%
Hematologic	14%	9%
Urinary Tract	2%	7%
Total	66%	7%

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

Fig. 4 Five Most Common Cancers Among LIVESTRONG Survey Respondents

Type of Cancer	LIVESTRONG Survey Respondents' Percentages
Breast	32%
Testicular	7%
Lymphoma, non-Hodgkin	6%
Colorectal	6%
Lymphoma, Hodgkin	5%
Total	56%

Fig. 5 Race and Ethnicity of LIVESTRONG Survey Respondents Compared with SEER

Race/Ethnicity	LIVESTRONG Survey Respondents' Percentages	SEER Percentages
Asian/Pacific Islander	2%	2%
Black or African American	1%	8%
Hispanic or Latino	3%	5%
Native American	1%	N/A
Other	1%	N/A
White	92%	84%

Source: Based on SEER Cancer Statistics Review 1975–2006; Horner et al. (2009).

ECONOMIC BACKGROUND

The majority of LIVESTRONG Survey respondents (56 percent) reported earning between \$41,000 and \$120,000 per year at the time that they took this survey. (See Fig. 6.)

EDUCATIONAL BACKGROUND

Most survey respondents (81 percent) had at least some college education and nearly 60 percent of respondents had earned either a Bachelor's or graduate degree at the time that they took this survey. (See Fig. 7.)

CURRENT EMPLOYMENT STATUS

At the time of the survey, the majority of respondents were employed full time and the fewest number of survey respondents were full-time students. (See Fig. 8.)

MARITAL STATUS/CHILDREN

At the time that they took this survey, the majority of respondents (70 percent) categorized themselves as either married or in a domestic partnership and 27 percent of the respondents were single. In addition to being married, the majority of respondents (66 percent) also had children.

Fig. 6 Income

Economic Category	Percentage	Number of Respondents
\$0 – \$40,000	14%	330
\$41,000 – \$60,000	15%	349
\$61,000 – \$80,000	16%	363
\$81,000 – \$100,000	12%	281
\$101,000 – \$120,000	12%	271
\$120,000 +	17%	394
Prefer not to answer	11%	262
Did not answer	3%	57
Total	100%	2,307

Fig. 7 Educational Background

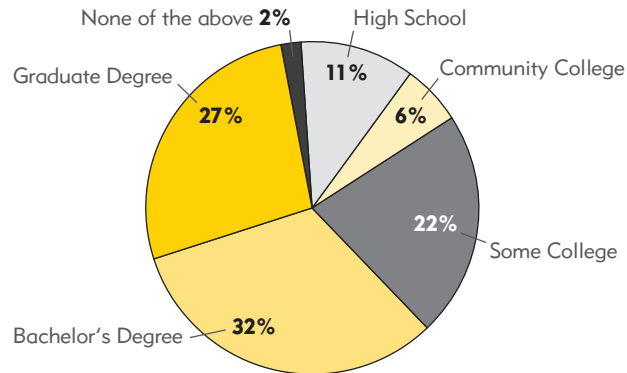


Fig. 8 Current Employment Status

Employment Status	Percentage	Number of Respondents
Full time	54%	1,235
Part time	9%	221
Full time college/university student	3%	64
Self-employed	8%	191
Not employed	6%	137
Retired	11%	260
Other	8%	182
Prefer not to answer	0.5%	11
Did not answer	0.3%	6
Total	99.8%	2,307

Cancer Experience

The following section includes information about the treatment experiences of the LIVESTRONG Survey respondents.

TIME SINCE LAST TREATMENT

While some respondents had not been treated for cancer for more than five or 10 years, the majority of respondents (73.4 percent) had received treatment within five years of taking the survey. (See Fig. 9.)

Fig. 9 Time Since Last Treatment

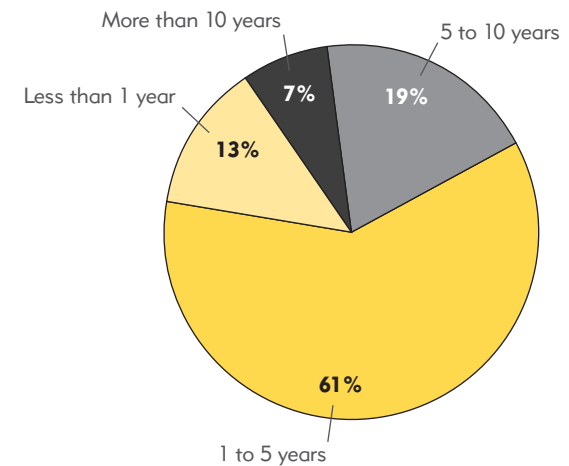


Fig. 10 Type of Treatment Received

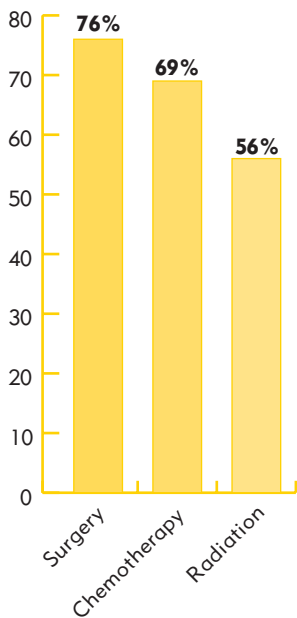


Fig. 12 Complementary or Alternative Medicine

Treatment	Percentage
Nutritional supplements	29%
Massage	27%
Meditation	23%
Special diet	19%
Herbs	17%
Other*	14%
Guided imagery	13%
Acupuncture	10%
Music therapy	8%
Traditional healer	5%
Art therapy	4%
Hypnosis	2%

*Other includes: Exercise program, Chiropractic care, Dance/movement therapy, Energy therapies/education, Green tea, Hands-on healing, Healing touch, Homeopathics, Hydrotherapy, Journaling, Laughing therapy, Naturopathic doctor, Prayer, Qigong, Reflexology, Reiki, Yoga

TYPE OF TREATMENT

The majority of respondents used traditional methods for treatment. (See Fig. 10.)

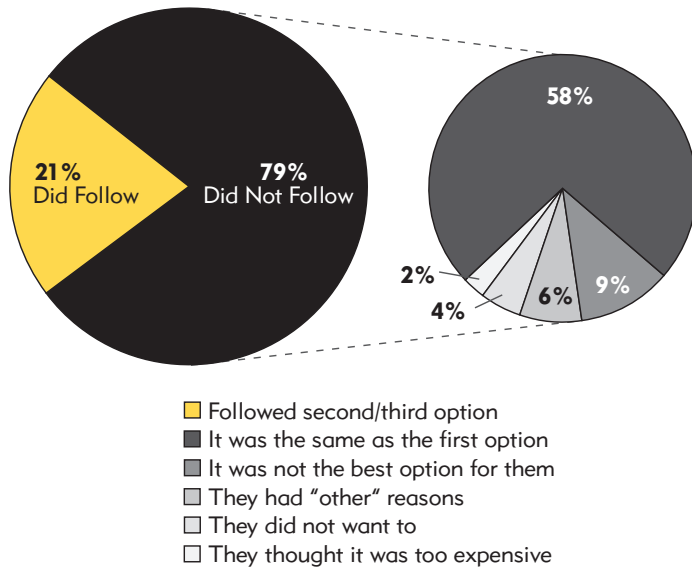
Additionally, 830 respondents (36 percent) reported receiving a second or third opinion for cancer, cancer treatment or late effects of cancer. Of this group, 21 percent of respondents followed the second or third opinion, but 79 percent did not. The reasons for not following the second or third opinion varied. (See Fig. 11.)

COMPLEMENTARY OR ALTERNATIVE MEDICINE

The majority of respondents (62 percent) also used at least one type of alternative or complementary therapy for cancer or late effects of cancer. (See Fig. 12.)

While the results of this survey cannot be generalized to the experiences of all post-treatment cancer survivors, the findings remain important and help to build the body of literature on the needs of post-treatment cancer survivors. The results of this survey also provide insight about a less-studied population of cancer survivors—those diagnosed under the age of 55.

Fig. 11 Percentage of Respondents Who Did and Did Not Follow a Second/Third Opinion and Reasons for Not Following the Second Opinion



“Your cancer treatment is over and all the focus that was on you during the treatment is over now. You are left with many side effects and no support or answers.”

—Survey respondent

3

RESULTS



Results are presented below for four of the five sections of the survey: 1) physical concerns, 2) emotional concerns, 3) practical concerns and 4) positive experiences. The fifth section of the survey, resources and information provided by **LIVESTRONG**, was conducted for internal purposes only and is not included in this report. See Appendix A for a list of all concerns in the survey.

Results were calculated from mean percentages of survey respondents who answered a particular question and are presented in the following way.

First, the results of the physical, emotional and practical concerns sections are provided in the following order:

1. Description of the collections addressed in that section of the survey
2. Summary of the total percentage of survey respondents reporting that they experienced at least one concern related to that collection post-treatment
3. Summary of the total percentage of survey

respondents reporting that they had not received care for concerns they experienced

4. Summary of reasons selected for why help was not received (respondents could select more than one choice)
5. Summary of who provided help when it was received (respondents could select more than one choice)

Second, the positive experiences section results are summarized.

Third, an overview of results across all collections is presented.

Physical Concerns Findings

The **LIVESTRONG** Survey provided valuable insights about what these post-treatment cancer survivors reported experiencing and how they dealt with the following survey collections:

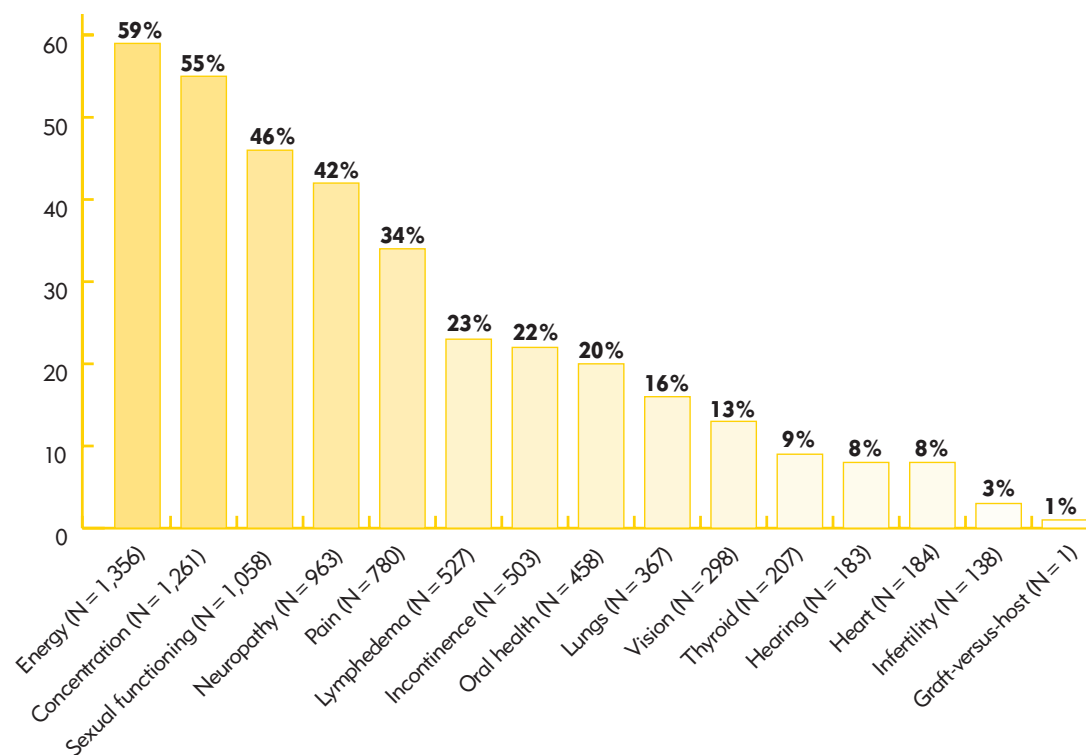
1. Concentration
2. Energy and rest
3. Graft-versus-host disease
4. Hearing
5. Heart problems
6. Infertility
7. Lungs and breathing
8. Lymphedema
9. Neuropathy
10. Oral health

11. Pain
12. Sexual functioning and satisfaction
13. Thyroid condition
14. Urinary incontinence
15. Vision

See Appendix A for the concerns in these collections.

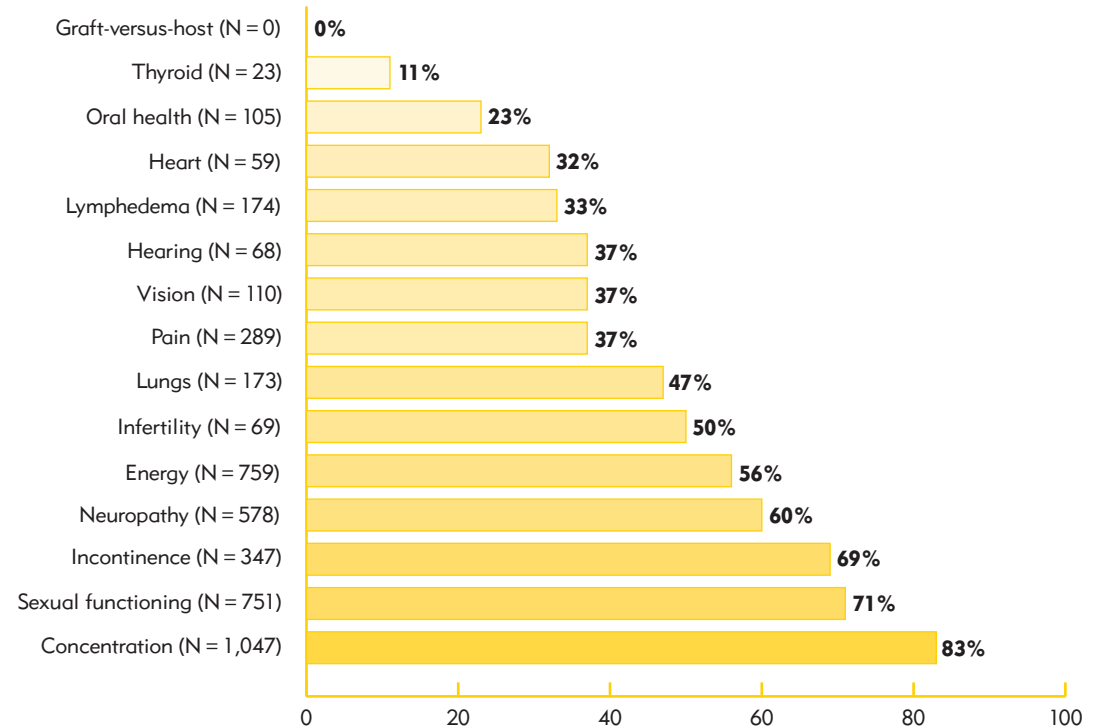
Overall, 91 percent of the survey respondents (2,099) indicated that they had experienced one or more physical concerns since their cancer treatment was completed. The three most frequently selected collections were: 1) energy and rest, 2) concentration and 3) sexual functioning and satisfaction. (See Fig. 13.)

Fig. 13 Physical Collections: Percentage of Respondents Who Experienced Physical Concerns



For many of these collections, respondents indicated that they did receive care for their physical concerns. However, for the four collections most frequently reported as physical concerns—energy and rest, concentration, sexual functioning and satisfaction and neuropathy—the majority of respondents had not received care. (See Fig. 14.)

Fig. 14 Lack of Care: Percentage of Respondents Who Did Not Receive Care for the Physical Concerns They Experienced



Of those respondents who reported reasons for not getting post-treatment care for physical concerns, the most common reasons cited were: 1) I have learned to live with this concern, 2) I was told it was a side effect that would go away with time and 3) I have addressed this on my own.

Respondents also were asked to indicate all types of providers from whom they received treatment for physical concerns. They were allowed to select more than one type of provider. The three most frequently selected providers across all of the physical collections were: 1) medical specialists, 2) primary care physicians and 3) oncologists. A majority of these respondents (65 percent) reported that all or many of their needs were met by those from whom they received help.

“Many of the symptoms I experienced were not addressed because no one told me they were side effects of treatment.”

—Survey respondent

Emotional Concerns Findings

The LIVESTRONG Survey provided valuable insights about what these cancer survivors reported experiencing and how they dealt with the following survey collections:

1. Faith and spirituality
2. Family risk
3. Fear of recurrence
4. Grief and identity
5. Personal appearance
6. Personal relationships
7. Sadness and depression
8. Social relationships

See Appendix A for the concerns in these collections.

Overall, 96 percent of the survey respondents (2,214) indicated that they had experienced one or more emotional concerns since their cancer treatment was completed. The three most frequently selected areas of emotional concerns were: 1) fear of recurrence of cancer, 2) grief and identity issues and 3) concerns about personal appearance. (See Fig. 15.)

For all eight of the emotional

collections, the majority of respondents did not receive help for their concerns. For five of these collections, 70 percent or more of respondents did not receive help when they experienced concerns. (See Fig. 16.)

Responses to a number of collections related to post-treatment emotional concerns suggested the need for more help and support around concerns such as recurrence of cancer, grief and identity, self-image, sadness and depression and concerns about risk to family members.

Of those respondents who reported reasons for not getting post-treatment help for emotional concerns, the most common reasons cited were:

1) I have learned to live with this concern, 2) I have addressed this on my own and 3) I did not want to receive help.

Survey respondents also were asked to indicate all types of help or support they received, if they indicated they received help with emotional concerns. They were allowed to select more than one type of provider. The three most frequently selected providers across all of the emotional collections were: 1) friends, 2) family members and 3) psychiatrists. Interestingly, the top two choices were not from the medical field. A majority of these respondents (68 percent) reported that all or many of their needs were met by those from whom they received help.

Fig. 15 Emotional Collections: Percentage of

Respondents Who Experienced Emotional Concerns

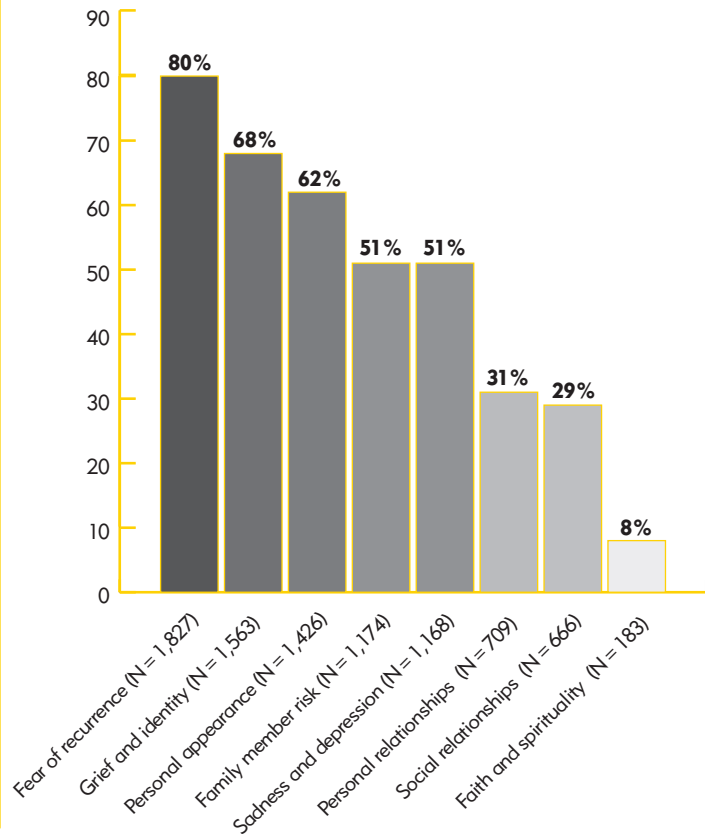
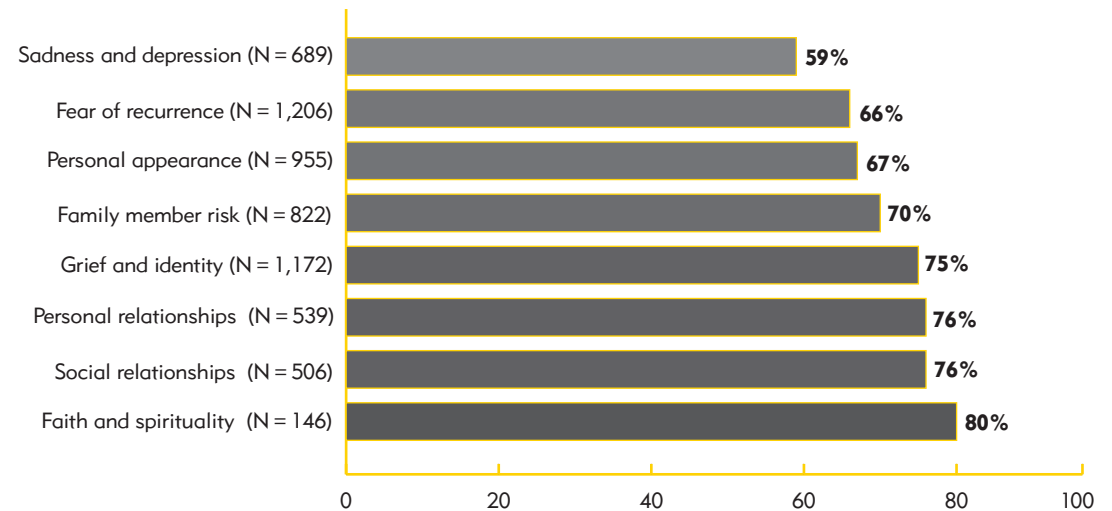


Fig. 16 Lack of Care: Percentage of Respondents Who Did Not Receive Help for the Emotional Concerns They Experienced



Practical Concerns Findings

The LIVESTRONG Survey provided valuable insights about what these post-treatment cancer survivors reported experiencing and how they dealt with the following survey collections:

1. Debt
2. Insurance
3. Employment issues
4. School issues

See Appendix A for the concerns

in these collections.

Overall, 75 percent of these cancer survivors (1,719) indicated that they had experienced one or more practical concerns since their cancer treatment was completed. (See Fig. 17.) It is important to note that not all respondents who answered the practical concerns collections were in school or employed during their experiences with cancer. If a respondent was not

in school or working during their experience with cancer they did not receive questions related to those topics.

- The majority of respondents were not in school when diagnosed with cancer; 251 respondents were in school. Of those who were in school almost all experienced issues.
- The majority of respondents (1,897) were working when they were diagnosed with cancer.

For all four of the practical collections, the majority of respondents did not receive help for their concerns. Compared to overall ratings of physical and emotional concerns, fewer respondents reported having practical concerns. However, when practical concerns were experienced, generally help was not received. (See Fig. 18.)

Of those respondents who reported reasons for not getting post-treatment help for practical concerns, the most common

reasons cited were: 1) I have learned to live with this concern, 2) I have addressed this on my own and 3) I did not know where to go for help.

Survey respondents also were asked to indicate all of the sources of help with their practical concerns. They were allowed to select more than one type of provider. Across all four areas of practical concerns, the three most frequently selected providers of help were 1) family members, 2) friends and 3) self-help by using information obtained from books, the Internet or other sources. None of these top three selected providers were from the medical field. In general, the majority of respondents (67 percent) reported that the help they received since completing treatment met many or some of their needs but not all.

The work section of this survey also included questions about the support individuals received from

colleagues and peers. Interestingly, a high majority (86 percent) of those who were employed when diagnosed with cancer had positive supportive experiences.

Specifically,

- 54 percent received medical leave from employer for treatment and recovery
- 49 percent had co-workers support them (for example, donated sick time)
- 37 percent raised funds or volunteered in the cancer field because of having had cancer
- 33 percent have earned increased respect at work
- 30 percent had an employer make reasonable changes or accommodations to help on the job
- 12 percent "other": "Clients supported me," "Happier to be at work," "I am a better at my job," "I was allowed to work at my own pace," "Job stresses are not as important as they used to be," "Positive perspective on work and life," "Work in the cancer field now."

Fig. 17 Practical Collections: Percentage of Respondents Who Experienced Practical Concerns

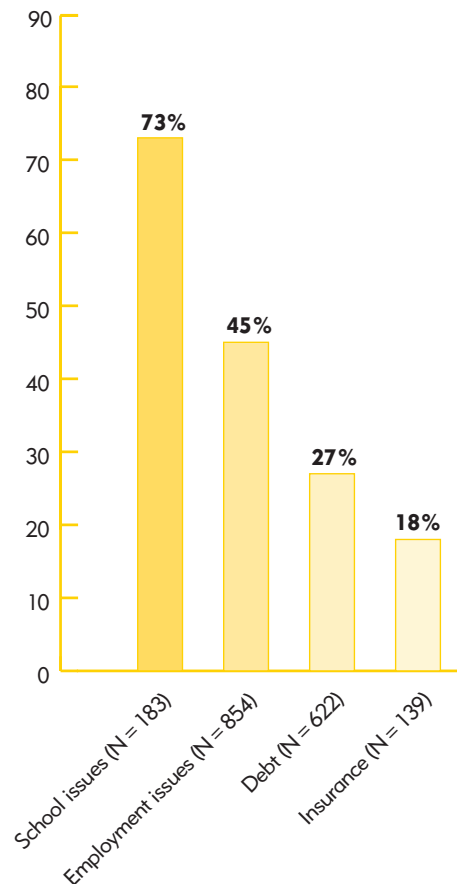
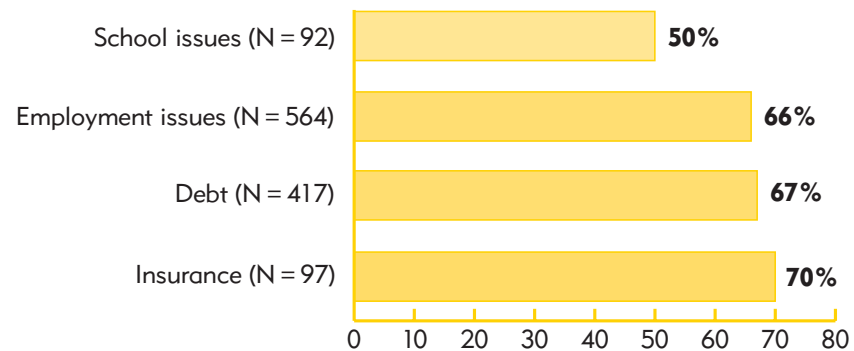


Fig. 18 Lack of Help: Percentage of Respondents Who Did Not Receive Help for the Practical Concerns They Experienced



DAILY ROUTINE

The practical section of the survey also included questions about positive and negative impact on healthy living behaviors. These questions did not follow the same format as the other questions. Instead, they were a series of questions that individuals could select if they were relevant to their experience.

A small percentage of survivors indicated that they led a less healthy lifestyle (four percent or 94), continued to smoke cigarettes (five percent or 106) or started to smoke (.57 percent or 13) after treatment.

The majority of all participants (85 percent) indicated they had changed the amount of physical activity in which they engaged. A total of 25 percent of those respondents indicated that they decreased their level of physical activity primarily because of fatigue and pain. (See Fig. 19.)

Individual respondents reported a variety of ways that cancer has

positively affected their daily lives in terms of physical activity and daily routine since a cancer diagnosis. These changes included reports of increased physical activity, a healthier lifestyle and a conscious effort to take care of their health through healthy living and medical care. (See Fig. 20.)

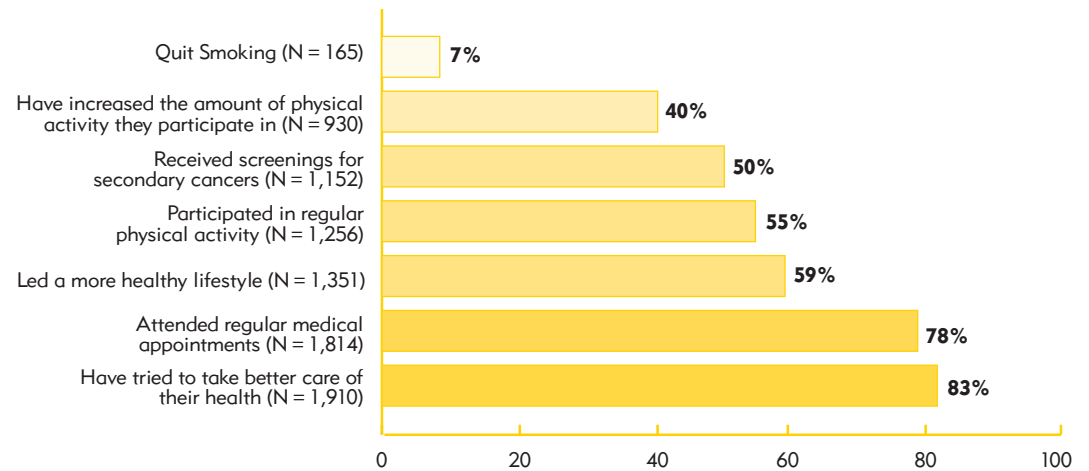
Positive Experiences Findings

In addition to questions focused on positive changes in daily living, the LIVESTRONG Survey provided valuable insights about how respondents have helped other survivors and how having had cancer may have positively influenced their lives more generally. Although many post-treatment cancer survivors identified the experience of cancer with the challenges it can bring, not all of the perceived effects of cancer were negative. Nearly all of the 2,307 respondents (99.7 percent) of the LIVESTRONG Survey selected

Fig. 19 Breakdown of the 25 Percent of Overall Respondents' Reasons for Decreasing Physical Activity

Percentage Decrease of Physical Activity	Reason
21% (N = 488)	Fatigue
13% (N = 291)	Pain
5% (N = 105)	They have no time
4% (N = 101)	Unsure what level of exercise is appropriate
4% (N = 92)	Worried about possible injury

Fig. 20 Respondents' Report of Positive Changes in Post-treatment Daily Routine as the Result of Having Had Cancer



at least one statement related to having had a positive experience.

For many respondents helping other survivors or other people was a part of their experience with cancer. (See Fig. 21.)

For almost all respondents, at least one statement related to a positive experience was true for them at the time of taking this survey. (See Fig. 22.) Further, individuals who indicated they had experienced one positive post-treatment effect were more likely to report on other positive effects as well. For example, 95 percent of those who indicated that they appreciate life more now also reported that they now recognize what is important in life.

Fig. 21 Respondents' Report of Positive Ways Cancer Can Affect One's Life

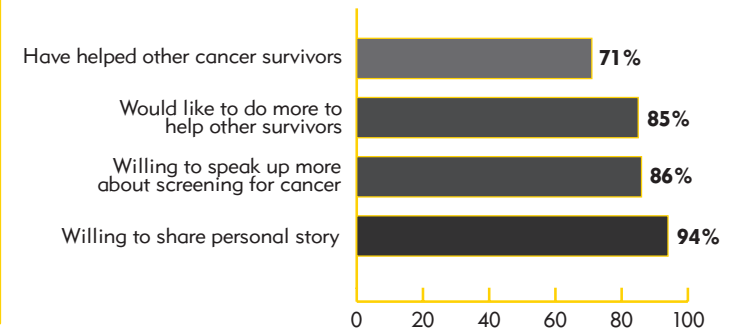
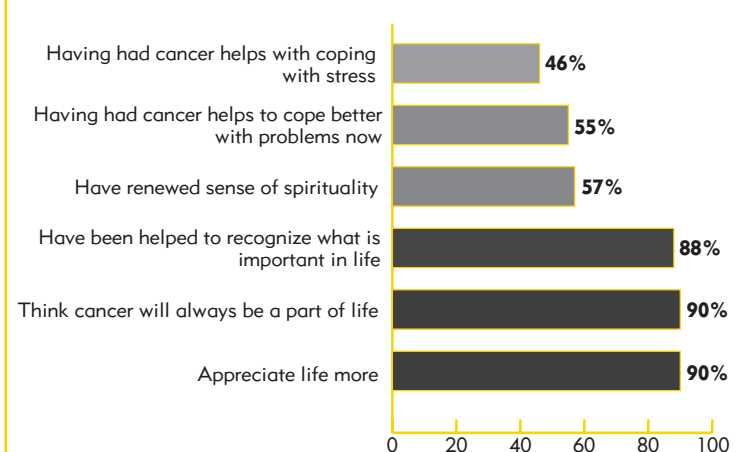


Fig. 22 Respondents' Report of Positive Ways Cancer Can Affect One's Life



Overview of All Collections

Cancer survivors who responded to this survey experienced effects in their lives that were multidimensional. While respondents had varied experiences in terms of type of cancer, type of treatment, time since treatment and a number of other characteristics, for these survivors life after a cancer diagnosis continued to bring changes and challenges. This section provides valuable insight across all of the collections globally about what these post-treatment cancer survivors

reported experiencing and how they dealt with these concerns.

Almost all respondents (99 percent) experienced at least one concern after cancer treatment ended. Overall, the emotional collections were selected the most, while the practical collections were selected the least. This may be due in part to the fact that most respondents were employed and insured during their experience with cancer.

Overall, there were stark differences related to receiving help. While the majority

Fig. 23 Percentage of Individuals Who Experienced Concerns and the Percentage Who Received Care for Those Concerns

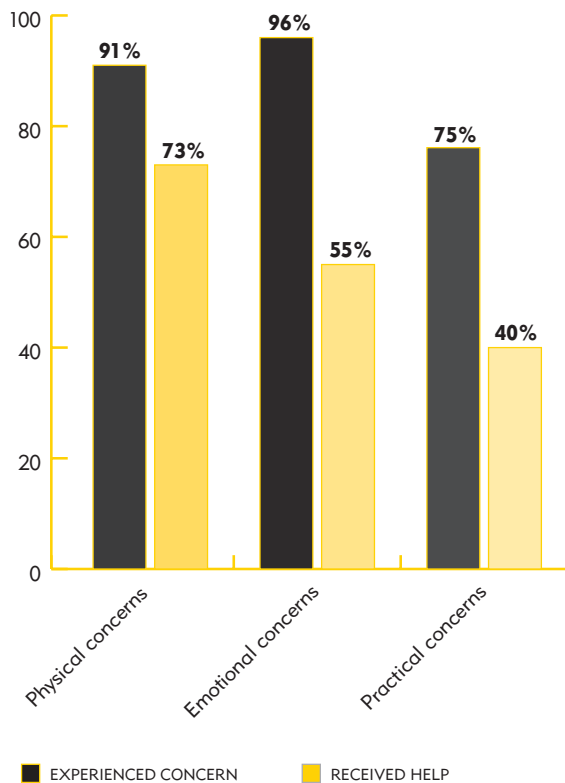


Fig. 24 Percentage of Post-treatment Cancer Survivors Who Received Help from the Medical Field

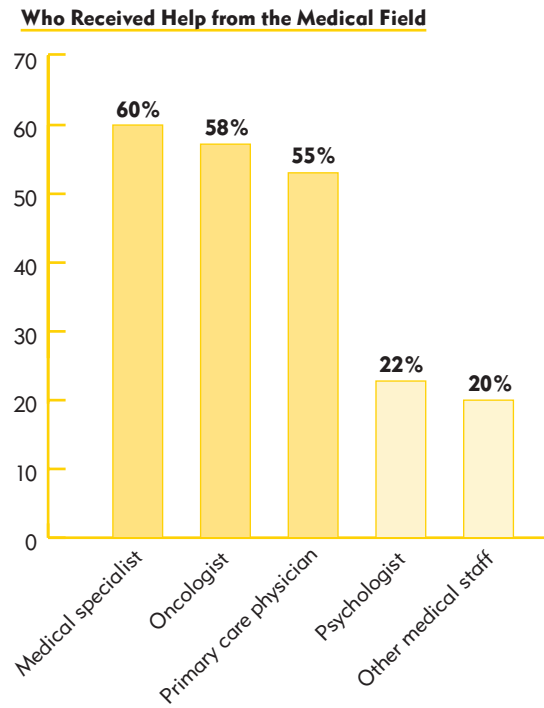
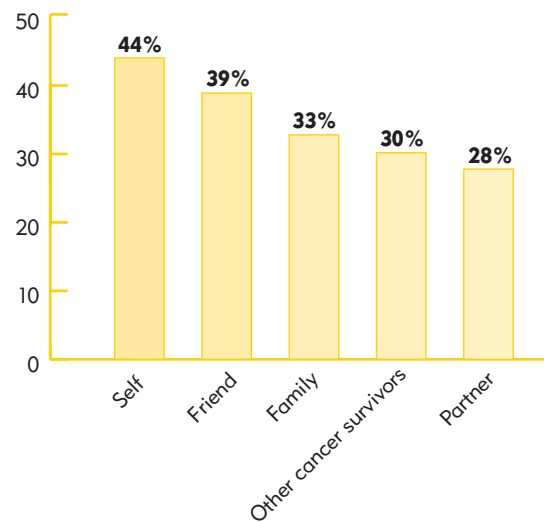


Fig. 25 Percentage of Post-treatment Cancer Survivors Who Received Help from Personal Sources



of survey respondents who had experienced at least one physical concern did receive care, just over half of those who experienced emotional concerns received help. Almost half, 45 percent (996), of those with post-treatment emotional concerns reported that they had not received help for any of their post-treatment emotional concerns. Likewise, the majority of those with practical concerns did not receive help. Of the respondents with practical concerns since treatment ended, only 40 percent (784) indicated they had received help with one or more practical concerns. (See Fig. 23.)

Those cancer survivors who did receive help indicated they received it from professionals, loved ones, other survivors and themselves. The most frequently selected providers across all collections were 1) medical specialists such as dentists or fertility specialists, 2) oncologists and 3) primary care physicians. (See Figs. 24–26.) Interestingly, the providers of care or help received varied greatly by collections. While medical professionals were most selected for the physical concerns, they were not for the emotional and practical concerns.

Across all of the collections, the majority of those who did receive help indicated that many of their needs were met. (See Fig. 27.)

Across all of the collections, the reasons cited for not receiving help varied but were primarily

related to the survivor's willingness to address the concern on their own. The top three reasons across collections for not getting help were: 1) I have learned to live with this concern, 2) I have addressed this on my own and 3) I was told this was a side effect that would go away with time.

Fig. 26 Percentage of Post-treatment Cancer Survivors Who Received Help from Other Sources

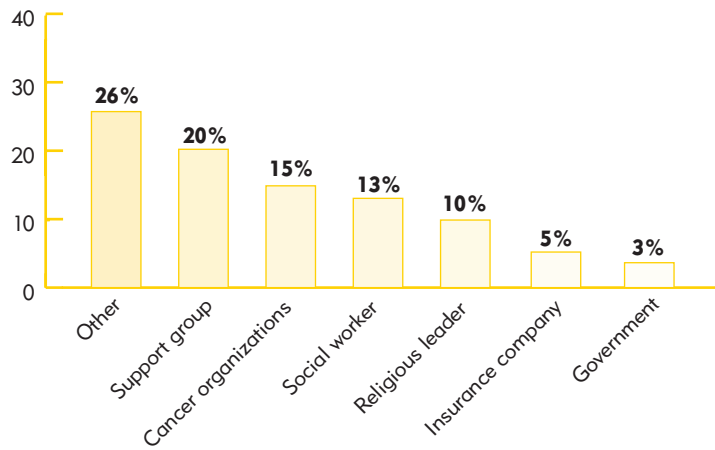
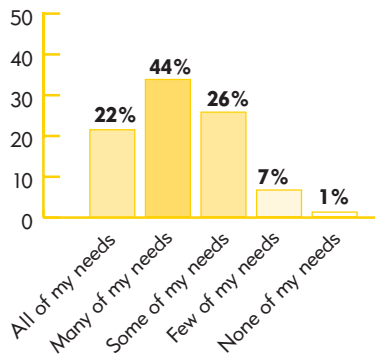


Fig. 27 Quality of Help Received



4

CONCLUSIONS



Understanding the impact of cancer on long-term survivorship has never been a more relevant topic to address. The **LIVESTRONG** Survey was created to better understand the experiences of cancer survivors after treatment is completed—specifically, the constituency of survivors who engage with **LIVESTRONG**. The findings of this survey indicate that cancer has impacted many facets of these 2,307 post-treatment cancer survivors’ lives. While the results of this survey may not represent the experiences of all post-treatment cancer survivors, the findings make an important contribution to the scientific understanding of the needs of post-treatment cancer survivors.

Based on the **LIVESTRONG** Survey results, we encourage the cancer community, including all of those who work with people with cancer, to consider the following:

1. Cancer survivors’ post-treatment concerns should be addressed and understood more fully.

For the survivors in this survey, in particular for emotional and practical concerns, many did not receive help for their post-treatment concerns. The survivors in this survey indicated most often that they chose not to receive

help because they had learned to live with their concerns. Even for those who received help, across the collections 78 percent indicated that not all of their needs were met.

Interestingly, in this survey, other cancer survivors were frequently selected (30 percent) as a support mechanism—oftentimes over medical professionals and family members. Additionally, many of these survivors reported that they either have helped or have the desire to help other cancer survivors.

Identifying ways to meet all of survivors’ post-treatment needs through effective existing or new evidence-based programs and resources, especially for emotional and practical concerns, is a critical step in ensuring positive outcomes for survivors. Further, understanding the role that all providers and support systems play in cancer survivors’ lives can provide insight in all aspects of survivorship care.

2. Health care providers should engage with their patients to understand the multifaceted nature of survivorship.

Cancer impacted almost all aspects of these survivors’ lives. Most survivors experienced at least one concern and many experienced physical, practical and emotional concerns. Across these concerns, survivors received help from as many as 17 different types of providers. For some receiving help from multiple providers was challenging. As one respondent noted, “Addressing difficulties following treatment is something none of us anticipated. Each physician I met was wonderful but they addressed the problem in their field. Period.”

Finding ways to understand and address the full scope of the survivors’ experiences with cancer, including both the negative and positive outcomes, could help to better meet the needs of cancer survivors. Survivors should be engaged as active partners in their care strategies and provided with sufficient information to make challenging decisions and to facilitate meaningful discussion with health care providers. Survivorship care plans can help health care providers and survivors to coordinate care and address the complexities of surviving cancer (Hewitt, et al., 2006).

3. Research should be conducted to better understand the survivorship experience, especially of underserved populations including adolescent and young adult (AYA) cancer survivors.

Further research is needed to more fully understand the post-treatment cancer experience, especially studies across the cancer continuum that engage cancer survivors in study design, implementation and dissemination of research results. Research should include minority and medically underserved populations as well as individuals who represent the diversity of cancer survivors in terms of type of cancer and treatment.

The results of this survey differ from other research in post-treatment survivorship in part because more than 30 percent of the **LIVESTRONG** Survey respondents were AYA cancer survivors, individuals diagnosed between 15–39 years of age. AYA cancer survivors represent an underserved and understudied population (Adolescent and Young Adult Oncology Progress Review Group, 2006).

By conducting further research, appropriate interventions and programs can be created to support these vulnerable populations. Survivors and their loved ones as well as health care providers need quality, evidence-based information to ensure the best quality of life and long-term outcomes for cancer survivors.

LIVESTRONG

“Thank you for giving me a voice! These are the questions that need to be asked and hopefully the responses will provide data to support changes in current practices, new programs and give cancer survivors better opportunities to address their issues.”

—Survey respondent



Survey Concerns

The full survey is available upon request at research@LIVESTRONG.org.

Physical Concerns

- I have had trouble with my heart.
- I have been told by a doctor that I have heart problems.
- I have had trouble breathing.
- I have been told by a doctor that I have damage to my lungs.
- I have had trouble seeing.
- I have been told by a doctor that I have problems with my vision or sight.
- I have had trouble hearing.
- I have been told by a doctor that I have problems with my hearing.
- I have had problems with my mouth.
- I have had problems with my teeth.
- I have been told by a doctor I have problems with my mouth.
- I have been told by a doctor I have problems with my teeth.
- I have been told by a doctor that I have graft-versus-host disease.
- 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.
- 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.
- I have been told by a doctor that I have a thyroid condition.
- 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.
- 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, I have been unable to get pregnant, maintain a pregnancy or father a pregnancy for more than a year.
 - No, because _____
- 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.
- 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.
- 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."
- 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

- 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.
- 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.
- I have been preoccupied with concerns about cancer.
- I have worried about dying from cancer.
- I have worried about cancer coming back.
- I have been reluctant to start new relationships.
- I have not wanted to participate in social gatherings.
- I have not wanted to be around people because I worried about germs.
- 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.
- I have received the support that I need from my partner.
- I have received the support that I need from my friends.
- I have received the support that I need from my children.
- I have received the support that I need from my family.
- I broke up with, separated from or divorced my partner.
- I have not wanted to tell others that I have had cancer.
- 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.
- 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.
- I was bothered by the amount of weight I lost.
- I was bothered by the amount of weight I gained.

Practical Concerns

- 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 _____

- 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 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 _____

- 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...

- No debt.
- Up to \$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.
- Debt, but I would prefer not to say how much.
- I don't know.

Due to a cancer diagnosis, I have spent, above and beyond insurance,

- Nothing.
- Up to \$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.
- I would prefer not to answer.
- I don't know.

Since completing treatment, I (or the primary policy holder of my insurance) have...(please check all that apply):

- Had problems with my health insurance.
- Had problems with my life insurance.
- Have not tried to obtain health insurance for the first time or in addition to what I already have.

- Have not tried to obtain life insurance for the first time or in addition to what I already have.
- Had adequate health insurance.
- Had adequate life insurance.

Since completing treatment, I (or the primary policy holder of my insurance) have...(please check all that apply):

- Lost my health insurance.
 - Have not been able to get health insurance for the first time.
 - Have not been able to get additional health insurance.
 - Reached the health insurance lifetime maximum.
 - Have problems with health insurance because of cancer as a pre-existing condition.
 - Have not been able to get the prescriptions that I needed because of my health insurance.
 - Have not been able to get the treatment that I wanted because of my insurance.
 - Have not been able to get the screenings that I wanted because of my health insurance.
 - Lost my life insurance.
 - Have not been able to get life insurance for the first time.
 - Have not been able to get additional life insurance.
 - Other _____
- Since my cancer diagnosis, I have: (Please check all that apply.)
- Led a healthier lifestyle.
 - Participated in regular physical activity (for example, you participate in some type of physical activity at least two–three times a week).
 - Increased the amount of physical activity I participate in.
 - Quit smoking.
 - Attended regular medical appointments.
 - Received screenings for secondary cancers.
 - Tried to take care of my health.
 - Other _____

- Led a less healthy lifestyle.
- Not changed the amount of physical activity I participate in.
- Decreased the amount of physical activity I participate in because of pain.
- Decreased the amount of physical activity I participate in because of I'm afraid of being injured.
- Decreased the amount of physical activity I participate in because I have no time.
- Decreased the amount of physical activity I participate in because I'm not sure what level of exercise is appropriate.
- Decreased the amount of physical activity I participate in because of fatigue.
- Continued to smoke cigarettes.
- Started to smoke cigarettes.
- Needed help with everyday tasks that I did not need help with before cancer.

Positive Experiences

- I have appreciated life more because of having had cancer.
- I have felt that cancer helped me to recognize what is important in life.
- I have a renewed sense of spirituality because of having had cancer.
- I am willing to share my story if it can help other cancer survivors.
- I have helped other cancer survivors through their cancer experience.
- I think that cancer will always be a part of my life.
- I speak up more now about screening for cancer.
- I would like to do more to help other cancer survivors.

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