

A BRIEF UPDATE

From the Long-Term Follow-Up Study

June 2013

<http://ltfu.stjude.org>

Topic: POST-TRAUMATIC STRESS AND PERSONAL GROWTH

Why we studied post-traumatic responses:

Childhood cancer survivors sometimes develop symptoms of post-traumatic stress disorder (PTSD). Surprisingly though, some people find that their experience of cancer and treatment had a positive impact on their lives. We wanted to learn more about what leads to these different emotional responses.

Who we studied:

- The study of post-traumatic stress included 6542 adult survivors and 368 siblings of survivors
- The positive-impact study included 6425 survivors and 360 siblings

The participants in both studies were older than age 18 when they completed the study questionnaire.

What we studied:

1. PTSD in adult survivors study

We looked at things like age, gender, education level, and type of cancer diagnosis and treatment, to see if they influenced a person's chance of having PTSD.

2. Positive impact study

We asked the survivors and siblings some questions about how much they were influenced by their, or their brother's/sister's, childhood cancer and treatment. The questions were about:

- Seeing new possibilities in life after cancer
- Relating to others
- Personal strength
- Spiritual growth
- Appreciation of life

We found that . . .

- Even though the overall occurrence of PTSD was low, survivors were more than four times more likely to have PTSD than siblings.

- Intensive therapies that included radiation to the brain increased the risk of PTSD.
- Survivors were more likely to have PTSD if they:
 - Were female
 - Had lower incomes or educational levels
 - Were unmarried
 - Were unemployed
 - Were older than 30 when they completed the study questionnaire
- Survivors were more likely than siblings to report that the cancer experience had positively influenced their lives in all the areas we asked about.
- Bone cancer survivors were the most likely group to report a positive impact. Leukemia survivors were the next most likely group to do so.
- Survivors who had more intense therapies and those who had a cancer recurrence or a new second cancer were more likely to report a positive impact.
- Survivors who were diagnosed at older ages were more likely to report a positive impact than those diagnosed at younger ages.

Symptoms of post-traumatic stress include . . .

- Reliving the traumatic event through nightmares or flashbacks
- Being unable to feel or express emotions
- Avoiding reminders of the event
- Overreacting - being easily startled or irritated, or having outbursts of anger

In summary:

Most survivors are doing well. Many even feel that their experience with childhood cancer and treatment had a positive impact on their lives.

However, some survivors may need help to cope with negative emotional effects from their cancer experience. These effects may emerge later in life, as survivors reach their 30s and 40s.

References

1. Stuber ML, Meeske KA, Krull KR, Leisenring W, Stratton K, Kazak AE, Huber M, Zebrack B, Uijtdehaage SH, Mertens AC, Robison LL, Zeltzer LK. Prevalence and predictors of posttraumatic stress disorder in adult survivors of childhood cancer. *Pediatrics* 2010; 125(5):e1124-34.
2. Zebrack BJ, Stuber ML, Meeske KA, Phipps S, Krull KR, Liu Q, Yasui Y, Parry C, Hamilton R, Robison LL, Zeltzer LK. Perceived positive impact of cancer among long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *Psychooncology* 2012; 21(6):630-9.

Coping with Emotional Effects of Treatment

STRESS – It can be like a rubber band!

Everyone experiences stress. Stress is like a rubber band – too little makes you feel inactive or weak, but too much can make you feel stretched out of shape. A person who has too much stress may feel overwhelmed, out of control, or overly anxious and concerned – about things in general or something in particular. Most people experience four types of stress warning signs: feelings (emotions), sensations (physical symptoms), thoughts (which may be negative or unclear) and behaviors (for example, eating too quickly or smoking).

Post-traumatic stress symptoms such as those listed on the front of this newsletter are common responses among cancer survivors and their family members. These symptoms may persist for months or even years after treatment. A person who has experienced a traumatic event like cancer and whose stress symptoms are persistent and severe may meet the criteria for a diagnosis of Post-Traumatic Stress Disorder (PTSD). However, while many survivors live with occasional or ongoing stress in response to their cancer experience, few develop PTSD. Whatever your level of stress, it's important to be aware of when you are stressed and to have a plan to cope with it.

Personal growth can be another reaction to the stresses of survivorship. The Children's Oncology Group Health Link on survivors' emotional issues (see web address below) notes that :

“Some survivors and their family members may find that they have undergone meaningful and beneficial changes in themselves, their relationships with other people, and their values as a result of their experiences. It does not mean that these survivors would choose to have had cancer, but that they have been able to find some positive changes in their lives as a result of surviving that stressful experience. Experiencing these positive changes is sometimes referred to as post-traumatic growth.”

When to seek help for stress

If you have distress that lasts two weeks or more and/or interferes with your ability to do important tasks at home, work, or school, you should call your healthcare provider to discuss the need for a referral to a mental health professional. Some possible signs that help is needed can include:

- Changes in appetite and weight
- Crying easily or being unable to cry
- Constant tiredness and low energy level
- Sleeping a lot or not sleeping well
- Feeling hopeless; thoughts of death, escape, suicide
- Increased irritability
- Decreased interest in activities that had been satisfying in the past
- Unwanted recall of painful aspects of cancer
- Feeling extremely fearful, upset or angry when thinking about cancer
- Physical reactions (rapid heart rate, shortness of breath, nausea) when thinking about cancer
- Avoiding health care visits
- Having difficulty talking about cancer

From the LTFU Study Archives . . .

Worry about the risk of cancer recurrence or late treatment effects may be a significant cause of stress. A previous LTFU Study newsletter includes an article on “Understanding Risk” that may help clarify the concept of risk:

<http://ltfu.stjude.org/docs/ltfu/nwsltr-summer00.pdf>

The Fall 2002 newsletter contains a list of tips for finding and paying for community mental health services:

<http://ltfu.stjude.org/docs/ltfu/nwsltr-fall02.pdf>

Other Resources

<http://www.survivorshipguidelines.org/pdf/EmotionalIssues.pdf>
<http://www.ptsd.va.gov/public/pages/coping-traumatic-stress.asp>