


RESEARCH UPDATES

The Next Module

As you know, each year we have a research module that runs for a year which supplements the core survey that changes every five years. This year, we are focusing on fatigue, vaccines and bone health. We previously asked you about fatigue and showed that rates of fatigue are about 2.5 times higher than the general population. In this year’s module, we are asking what you have tried to improve your fatigue, and whether you found what you used helpful. We apologize for the redundancy in the fatigue questions – we need to ask these questions exactly as they are worded so that we can compare your answers with the general population and other people who have received aggressive treatments or are living with challenging health conditions.

Some of you are more than 40 years after your transplants. We admit that most of our questions focus on issues that are most prominent in the decade after transplant. However, we still hope to hear from as many people as possible, even if your health hasn’t changed recently, or if it is better or worse than last year. This information helps us understand the health of the entire population.

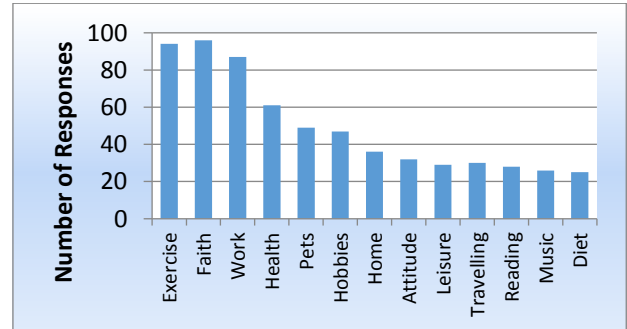
This summer we will be analyzing the results of the sexual functioning survey and the PTSD (post-traumatic stress disorder) surveys (the PTSD survey only ran for 6 months so you might not have been sent it). We selected these modules because so many of you mentioned you were experiencing sexual issues or symptoms you thought were PTSD. Some of the best ideas for research topics have come from you, so please send us ideas if you would like to see a particular topic addressed in future surveys.

Quality of Life

For part of last year, we asked people on their annual surveys both what enhances their lives and disrupts their quality of life. Results from the 779 responses are shown in the Figures.

The Positive:

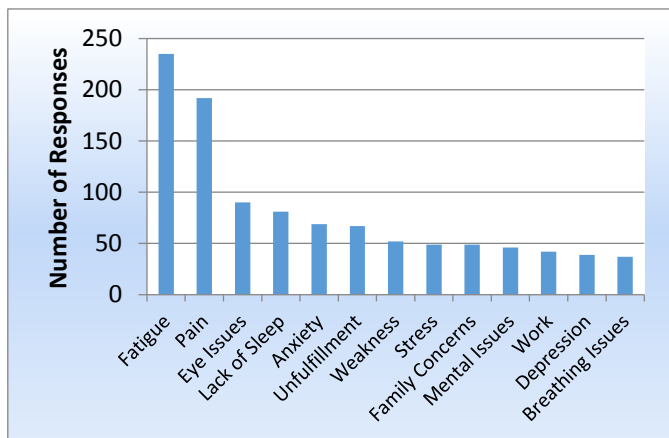
Some of the responses as to what enhances a survivor’s life are not surprising; however it’s good to highlight common trends so that more focus/emphasis is given to these areas of life post-transplant. By far, Family/Friends is the most commonly reported factor that enhances a survivor’s life, whether the response was from men/women or from any of the four age groups (under 21, 21-40, 41-60, 61+). Approximately 484 people (58% of total responses) mentioned family/friends. This probably doesn’t come as a surprise. Whether it’s getting through the day or enjoying an outing, sharing the journey with others can greatly enhance the experience. The other response categories are shown below:


The Negative:

On the flipside there were many factors that you told us negatively affected your quality of life, but other than fatigue (16.7%) and pain (15.5%), the responses varied quite a bit and were very specific to individual situations. Some of you have wondered whether these problems are due to the transplant or to just getting older. Looking at your survey responses, there is a clear worsening in physical functioning as people get older; however, this is matched by better mental functioning. These trends are what we see in the general population. Factors you told us worsen quality of life are shown on the graph on the following page.

(Continued)

LONG-TERM FOLLOW-UP NEWS



In Closing:

The data that are derived from these comments, while useful, only represent a very small fraction of the data we are able to obtain from the questionnaires. By taking the time out of your day to fill out these questionnaires year after year you are providing us with invaluable data that are utilized in multiple studies, as well as helping to solve individual medical issues. While filling out the questionnaires every year may feel redundant, especially if your health has not changed, it is extremely helpful to us since we can then be confident about our results. We are very thankful that many of you decide to do so. You are a large part of what makes Fred Hutchinson one of the most successful long-term follow-up programs in the world.

Giving Back to You

We are also thinking about how we can give back to all of you, especially those of you who continue to give us your time and energy by completing our surveys each year. One of the things we have been contemplating for many years is how to report back the information you have provided from your surveys. As you can imagine, this is very complicated for us, from a technological, safety, and ethical perspective. This is because we are unsure how the results might affect you. However, we are

committed to collaborating with you to maximize your health and quality of life, as well as giving you the knowledge of how your answers compare with others. Stay tuned next year- we are hoping to be able to send you some of your personal results in the future.

Positive Psychology

Many of our patients report that their physical and emotional health is pretty good. Many of you are even thriving after your transplant and report BETTER scores than the general public. Others experience daily struggles and your quality of life is not what you wish. Next year we will be inviting some of you to participate in a study of positive psychology to try to improve quality of life, whatever your current quality of life may be.

What is positive psychology? This is a branch of psychology that tries to use short exercises to help people experience better quality of life through focusing on and appreciating the positive aspects of our lives. These exercises have been tested in both the general population and in people who are acutely or chronically ill. We are currently thinking about an 8 week program that involves about 20 minutes a week of a positive exercise, and then a 30 minute group phone call to debrief the previous exercise and introduce the next week's exercise. We will be inviting participation, but if you know that you are interested, you can let us know by writing that on your survey, emailing us at replyltfu@fredhutch.org, or calling us at (206) 667-4415 and we'll add your name to the list. Telling us you are potentially interested does not guarantee that you'll be invited to participate nor does it commit you to participate.

Finally, as always, we are grateful to all our patients for sharing your journey with us and for helping identify better ways to manage health issues after hematopoietic stem cell transplant.

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