**Resilience is a person’s ability to maintain physical and emotional well-being when faced with a challenging circumstance.**

For cancer survivors, one of the biggest tests of resilience is staying mentally and physically healthy in between long rounds of tests and treatments and hospital stays. If a person feels resilient, are they more likely to report a higher quality of life after treatment? A recent study done by researchers at the Fred Hutchinson Cancer Research Center suggests this may be the case.

If you happen to have been a bone-marrow or stem-cell transplant patient enrolled in the LTFU (Long-Term Follow-Up) study during the period between July 2013 and June 2014, you may remember that year’s supplemental questionnaire. Patients were asked a series of questions about their resilience — here, defined as the ability to handle adverse situations on a mental and physical level — and then rate themselves on their capacity to adapt to these circumstances.

Some typical questions used to assess resilience:

“I believe I can achieve my goals, even if there are obstacles.”

“I tend to bounce back after illness, injury, or other hardships.”

The Fred Hutch investigators collected responses to these questions at the same time that they measured patients’ emotional and physical state, and whether it felt like life had returned to normal. In addition, some questions addressed the amount of personal growth that for some was a positive benefit of overcoming or learning to live with the disease.

The findings? People who reported having more optimistic and flexible strategies to handle adversity also felt they had an easier time coping with the issues surrounding their treatment.

“Individual resilience enables patients to harness the resources needed to maintain well-being during and after cancer therapy, to move beyond their experience with hope and insight.”

Not all patients enrolled in the LTFU study returned the supplement; the response rate was 39%. Some interesting demographics on people who did choose to respond: The mean age of respondents was 59 (as opposed to the mean age of 48 for all patients enrolled in the LTFU study). More men than women responded. GVHD (graft-versus-host disease) was also more common among people who returned the questionnaire.

Older patients (those over 70) had a significantly higher resilience score than those younger than 40 (but older than 17 — pediatric patients did not receive a supplement). Patients who worked full-time also had higher scores than those who were unemployed.

Some of these findings may strike you as just common sense. The feeling that your ability to overcome obstacles may have a positive impact on your physical well-being is not necessarily a new idea; nor is it always an easy thing to do, especially if you’re someone who has survived cancer and the challenges that surround recovery. It’s also important to note that the severity of the disease and treatment differs widely among cancer patients, independent of how the struggle is perceived. So how are the findings of this study useful?

As cancer treatment gets better and better, we have more survivors living longer and longer lives. Having a means of assessing which patients may need help allows for early intervention; ideally before the problems become chronic. Now that instruments such as questionnaires and interviews are being developed to detect low resilience (and possible future struggle with mental and physical health after a transplant), interventions can happen proactively. Whether it’s a social worker, therapist, or religious leader who steps in, patients can be taught coping and goal-setting strategies, along with other techniques to improve their quality of life.

When asked how she talks to her patients about resilience, Dr. Rosenberg, one of the authors, said she generally suggests people think about the following: How have they overcome adversity in the past? Who supports them? What good things have they learned/gained from their experience?

This wasn’t the first study to look at the relationship between resilience and health, but it is one of a few to focus solely on cancer survivors; specifically, those that have undergone bone-marrow or stem-cell transplants. Along with concrete measures such as proper nutrition and exercise, factors as intangible as resilience may become part of the treatment palette for cancer survivors in the not-too-distant future.

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FEATURED BIO

Kevin Bray

Kevin is the Data Supervisor of the Research branch at Long-Term Follow-Up (LTFU). He started as a part-timer in 2006, and worked his way up to his current position as head of the data team. When he first started the group had just moved away from painstakingly writing down patient and doctor contact info on 3x5 index cards, to the more robust computerized database that is used today. Instead of a rolodex and Wite-Out, the system now exists side by side with the databases at UWMC and Children’s Hospital.

“Our job is to try to makes sense of all the data” before it is handed over to the researchers. The Research team – the data technicians and coordinators – does the behind-the-scenes work, while the nurses and patient care coordinators who field phone calls and email on the Clinical side are the “face of LTFU.”

One of Kevin’s more recent accomplishments is the online version of the patient questionnaire (PRQ). “My goal is to make the questionnaire as user-friendly as possible, so that patients can complete it in the least amount of time possible.” Each year there is also a new supplement, covering a new research topic. (See the article on the Resilience study in this newsletter, based on patient responses to a previous year’s supplement.)

For patients who asked for a paperless PRQ, your wish is now here! If you completed your previous questionnaire online, and indicated that in the future you’d prefer an online PRQ rather than a packet in the mail, on your next transplant anniversary you will receive an email with the online web address and access code. If you didn’t indicate “online-only” on your previous PRQ but you’d still rather complete the questionnaire online, just send us an email at replyltfu@fredhutch.org with your full name and your request, and we’ll make those changes. This is also a good way to update your email address if you haven’t in a while.

The online version of the questionnaire is now over two years old. According to Kevin there has been a good response to the online option so far. With the onset of email prompts it will be even easier to just click on a link and arrive at the login for your PRQ. This greatly reduces the time it takes to get data into the system; when patients fill out a PRQ online they are doing their own data entry. A packet in the mail is still an option for those who prefer pen and paper.

Kevin is the father of two girls, aged 1 ½ and 4, who keep him quite busy. He balances out his family life and data work with hikes and backpacking trips in all kinds of weather. A multi-instrumentalist (drums are first), Kevin plays and listens to a wide variety of music and styles.

HAIKUS

In all this cool
is the moon also sleeping?
There, in the pool?

-- Ryusui

A lightning flash:
between the forest trees
I have seen water

-- Masaoka Shiki

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