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# Challenges in Cancer Survivorship

BY KATHY LATOUR

*Researchers confirm survivorship issues at biennial meeting.*

When Julia Rowland, PhD, director of the Office of Cancer Survivorship at the National Cancer Institute, took the stage in Atlanta at the fourth biennial cancer survivorship research conference in June, she welcomed the more than 450 participants on behalf of the estimated 12 million cancer survivors in the country today.

The 12 million, Rowland explained, represent the estimated number of individuals alive as of January 2007 with a history of cancer, “regardless of where they are in the illness trajectory—newly diagnosed, in treatment, post-treatment, suffering a recurrence, living with or dying of progressing illness.”

For the next two days, the 12 million would be the central focus as researchers presented the latest results of studies on the unique physical, psychosocial, behavioral, and economic outcomes associated with having cancer to the assembled cancer professionals, researchers, and public health professionals.

Also present were 20 patient/survivor advocates, attending as part of the Lance Armstrong Foundation’s Survivor-Researcher Mentor Program, which funded their attendance at the meeting so they could interact with researchers with the help of an assigned scientist-mentor.

Rowland complimented the range of findings presented by the growing number of researchers in what is still a very new field of research, telling the assembled group that meeting organizers selected 12 abstracts for podium presentations from a record 220 submissions, revealing a wealth of new data and directions for future research.

The conference, a collaboration of the NCI, LAF, and American Cancer Society, focused on interventions that explore the interrelationship among psychosocial, behavioral, and biological aspects of being a cancer survivor. Attendees also heard research presentations on follow-up care, caregivers, and the translation and dissemination of survivorship research.

Noreen Aziz, MD, PhD, senior program director in the OCS, explains that cancer survivorship is a very young research area, and this year's topics built on research presented at previous conferences. The goals of the meeting, she says, were to review and confirm existing research and identify new research directions with the ultimate intent being to create a body of empirical evidence that can be used to understand the challenges and special care needs of survivors post-treatment.

"This meeting highlighted the multifaceted aspect of survivorship research," Aziz says. "It is a rich research area with multiple domains that include psychosocial and medical outcomes as well as models of care." Aziz adds that among the challenges is the need to be sure that a study's findings are true and replicable, which says they will hold up over time, before moving toward the creation of truly effective interventions and application.

"Creating an intervention or changing treatment practice cannot happen based solely on one study," she explains. "You confirm findings by conducting additional studies until there is a critical mass of knowledge. This way one can make sure that a finding is not spurious. It is important to do this prior to disseminating research results."

Both Rowland and Aziz point to one study as an example of what could be a major finding when the results are repeated in larger studies. The research explored how chronic inflammation may be linked to fatigue, one of the most persistent side effects of cancer therapy—and one that has few treatments. Should these findings hold up in other studies, they could provide important insights into who is at risk for fatigue and ways to reduce its debilitating effect.

The meeting also included numerous presentations around issues of family dynamics and communication, while underscoring, Rowland says, the heightened attention being given to the role and impact of cancer on caregivers. For example, findings from one study indicate caregivers suffer from a greater fear of recurrence than patients in some circumstances, and that they are often more worried and suffer more stress than the patient. Rowland says the cancer research community has only recently begun to understand the physical, psychological, and economic costs associated with caregiving, and the importance of providing interventions for these family and friends who provide the majority of patients' care.

## Hearing From Survivors

The ACS reported findings from its nationwide cancer survivorship survey, the Studies of Cancer Survivors (SCS) conducted by its Behavioral Research Center, which was created in 1995 to conduct psychosocial and behavioral research on survivors and to facilitate the translation of that research into policy and programs.

Kevin Stein, PhD, director of the Quality of Life and Survivorship Research program for the Center, reported the first major findings from what he describes as one of the largest, most diverse investigations of long-term cancer survivors ever conducted.

The SCS includes two studies totaling more than 15,000 cancer survivors who were one, three, six, or 11 years post-diagnosis at the time of enrollment. Stein explains that the studies compare not only quality of life among survivors at three, six, and 11 years, but also follow the one-year survivors for up to 10 years to explore their psychosocial functioning as they move through the survivorship continuum.

One of the findings, Stein says, is that the majority of survivors in the SCS are doing quite well with respect to their overall quality of life by a few years post-treatment—and they continue to improve over time.

However, Stein says a subset of around 30 percent of survivors continue to struggle with a number of emotional and physical problems and have a poorer quality of life. “And, if you think about the almost 12 million cancer survivors in this country, that 30 percent adds up to a lot of people.”

The survivors suffer from a wide range of long-term or late effects, such as pain, fatigue, and fear of recurrence of their disease, and in these survivors the issues don’t go away, even at 11 years post-diagnosis, Stein explains.

Stein has been directing the SCS since shortly after the creation of the Center, and explains that the studies comprising the SCS were designed to improve on previous survivorship research by using the cancer registries of 21 states to enroll a large and diverse sample in terms of type of cancer, time since diagnosis, race, ethnicity, socioeconomic status, and geographic location.

Stein says that by studying survivors both at a given point in time (cross-sectional) and across a period of time (longitudinal), the SCS allows not only for the investigation of the issues of long-term survivors at a set time after treatment, but also provides the opportunity to follow a single group of survivors for up to 10 years after their initial diagnosis. The SCS also tracks the experiences of primary family caregivers, who were identified by survivors in the longitudinal study.

Few of the SCS findings have caused surprise, Stein says. “These studies were meant to corroborate a lot of what we thought we knew but couldn’t be sure of because previous studies of long-term survivors included small samples,” he says, adding there is now more evidence to understand what sorts of problems survivors face after the completion of treatment.

“For example, our data indicate that the top psychosocial problems survivors face include fear of recurrence, fatigue, fear of the future, and sleep difficulties,” he says. According to the SCS, fear of recurrence affects around 65 percent of survivors at one year post-diagnosis, but drops to less than 50 percent at three years, just over 40 percent at six years, and to 36 percent at 11 years. Fatigue and sleep difficulties affect just over 62 percent and 50 percent, respectively, of survivors at one year compared with just over 40 percent for each condition at three years—but they remain an issue for most of that 40 percent up to at least 11 years.

[View Graphic: Top Cancer-Related Problems](#)

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Stein says the ACS is creating interventions targeted to these issues, such as telephone-based and online stress management to help survivors deal with anxiety related to fear of recurrence, fatigue, and sleep issues.

Rowland says the conference served as a starting point for future research and clinical directions in understanding and meeting the unique needs of the growing population of survivors who are surviving second (third and fourth) cancers, those experiencing recurrence, and those living long-term with cancer as a chronic or slowly progressing illness.

The information from research on post-treatment issues allows for more informed decisions by patients and doctors at the day of diagnosis, when the benefits of some cancer treatments will be weighed against the short- and long-term side effects. To see presentations from the 2008 meeting, go to [www.cancer.org/survivorshipconference](http://www.cancer.org/survivorshipconference).