

Cancer families

Psychologists' new interventions are helping families cope with what can be a devastating diagnosis.

BY REBECCA A. CLAY



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As traumatic as it can be to be diagnosed with cancer, it can be even more upsetting for the parent, spouse or other relative of the person who is ill, say psychologists.

Their research is leading to new information about families facing cancer and interventions for helping them cope. For parents of children with cancer, for example, the result can be post-traumatic stress symptoms even years after their children have recovered. For partners, cancer can mean the end of sex as they knew it as well as plans for having children together. And the relationship between cancer and family relationships also works the other way around, with marital status and long-term survivorship linked in surprising ways.

"Families know state-of-the-art medical care is important," says APA President Carol D. Goodheart, EdD, an independent practitioner in Princeton, N.J. "What they often do not realize is that state-of-the-art psychological care is also available to ease the impact of cancer fears, procedures, side effects and treatment sequelae."

When it's a parent who has cancer, the impact on children typically varies according to their age and gender, says Bruce E. Compas, PhD, professor of psychology and human development and professor of pediatrics at the Vanderbilt-Ingram Cancer Center in Nashville, Tenn. In a 1994 paper published in *Health Psychology* (Vol. 13, No. 6: 507-15), Compas found that teenagers — especially adolescent girls — experienced the greatest distress.

Now Compas focuses on children with cancer. Halfway through a five-year grant from the National Cancer Institute, he is studying how parents communicate with children with cancer.

"Parents are faced with two challenges when a child has cancer," he says. "One is to provide information, and the other is to provide emotional support at the same time they're dealing with their own emotional difficulties."

Through his research, he and his colleagues seek to identify effective communications strategies to help families cope.

The stress doesn't end when treatment does. In a 2009 functional neuroimaging study published online in *Pediatric Blood & Cancer*, for instance, Compas and colleagues found memory problems and other cognitive deficits in survivors of childhood acute lymphocytic leukemia.

"Children survive now where they didn't before, but they survive with long-term adverse effects," says Compas. "We have to look at cancer as a chronic condition and understand the stresses and strains it puts on families for the long haul."

Not surprisingly, the stress of a child's cancer can result in serious stress symptoms for both the child and the parents, says Anne E. Kazak, PhD, director of the psychology department at the Children's Hospital of Philadelphia. Immediately following a child's cancer diagnosis, most parents experience acute stress symptoms, Kazak and colleagues found in a 2007 study published in *Pediatric Blood & Cancer* (Vol. 50, No. 2: 289-92). Some develop acute stress disorder.

"To be told your child has a life-threatening illness evokes a

lot of feelings of helplessness, uncertainty and fear," she says.

And that stress continues, says Kazak. In a 2005 study of parents with children in treatment, published in the *Journal of Clinical Oncology* (Vol. 23, No. 30: 7405-10), Kazak and fellow researchers found that all but one of the 171 parents studied had post-traumatic stress symptoms, such as intrusive thoughts, physiological arousal and avoidance.

To treat those symptoms, Kazak and her colleagues developed a one-day intervention called the Surviving Cancer Competently Intervention Program, which combines cognitive-behavioral therapy with family therapy approaches. In a randomized clinical trial published in 2004 in the *Journal of Family Psychology* (Vol. 18, No. 3: 493-504), they found that the intervention reduced symptoms for adolescent cancer survivors and their parents.

Now the researchers are developing a similar intervention to help families prevent post-traumatic stress symptoms from developing in the first place. In an initial randomized trial, published in 2008 in the *Journal of Pediatric Psychology* (Vol. 34, No. 8: 803-16), the intervention failed to show a significant impact, although participating parents offered positive feedback. The main reason the study didn't go as well as hoped, the researchers believe, was the sheer difficulty in recruiting families into the study while they were coping with the shock of a new diagnosis. "We're continuing to work on some adaptations of the intervention model we hope will make it more effective," says Kazak, explaining that the researchers are now considering alternative research designs and changes to the timing of the intervention.

Sexuality and fertility

For couples, cancer treatment can bring sexual challenges, says Leslie R. Schover, PhD, a professor of behavioral science at the University of Texas's M.D. Anderson Cancer Center in Houston.

In a 2009 study in the *Journal of Sexual Medicine* (Vol. 6, No. 1: 149-63), she and colleagues surveyed patients who had been treated for cancer at the center about whether they were experiencing sexual dysfunction and related problems following their treatment. After treatment, 49 percent of male respondents reported new erection problems following their cancer treatment, while 45 percent of female respondents reported vaginal dryness and a loss of desire. In addition, a third of respondents under age 50 wished that they had had a fertility consultation before their treatment.

Cancer patients and their partners aren't getting the information they need about coping with these sex and fertility issues, says Schover.

"Oncologists are pushed more and more to spend less time with patients and already have so many things they have to explain," she says. "Even the advanced care nurses and physician's assistants in the clinics often don't feel comfortable talking about reproductive health topics."

Schover is working to close that gap. With funding from the National Cancer Institute, for example, she and a partner are developing a computerized education and counseling

tool for women with cancer. Designed for use from the initial diagnosis to long-term survivorship, the multimedia tool covers sexuality, fertility and pregnancy. A new grant will fund a version for male patients.

Schover's earlier research shows that this low-cost approach to helping couples cope with the physical problems that arise from cancer treatment is effective. An Internet-based prostate cancer program she helped develop significantly boosted couples' sexual functioning and satisfaction, according to her not-yet-published data. "The improvements were not only quite significant but lasted for up to a year without losing significance," she says.

Marital status's impact

While cancer can strain marriages and other committed relationships, marital status itself is tied to cancer survival rates, says neuropsychologist Gwen C. Sprehn, PhD, an assistant professor of neurology at the Indiana University School of Medicine in Indianapolis.

In a 2009 study published in *Cancer* (Vol. 115, No. 21: 5108-16), Sprehn and her colleagues found that married cancer patients have higher survival rates than the never-married or divorced. But their most striking finding, she says, was that people undergoing separation while they were diagnosed had the lowest survival rates.

Drawing on registry data on almost 3.8 million Americans with cancer, the researchers found that only 45 percent of separated cancer patients were alive five years after diagnosis and just 37 percent after 10 years. The rates for married patients were 63 percent and 57 percent respectively.

Although the researchers aren't sure of the mechanism, says Sprehn, they suspect that the stress of separation weakens the immune system. They suggest that patients try stress-relief strategies such as psychotherapy, social support exercise and sufficient sleep. "The last thing we would want is for people to feel like, 'Not only do I have cancer and my marriage is falling apart, but I'm probably going to die sooner,'" says Sprehn. "Rather than that being the take-home message, we'd much rather view it as, 'You may be more vulnerable, but there are things you can do to potentially reduce the impact of that vulnerability.'"

Rebecca A. Clay is a writer in Washington, D.C.

Further reading:

Woznick, L.A. and Goodheart, C.D. *Living With Childhood Cancer: A Practical Guide to Help Families Cope*. APA Books, 2001.



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