

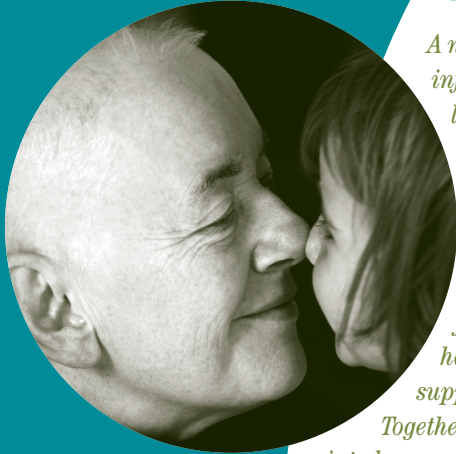


ResearchLink

volume 2, number 4

<http://McClellandInstitute.arizona.edu>

How Families Cope with Cancer



A new book provides families with information to understand and help loved ones diagnosed with cancer. Blending research and stories from cancer survivors, family caregivers, and social workers, the book shows how diverse families have coped with and found meaning from the illness. It also provides help finding financial assistance, support groups, and counseling.

Together, the book's authors offer insight into how a cancer diagnosis affects co-survivors and hope for managing the treatment process within families.

The Changing Face of Cancer

Until recently, cancer had been treated like a terminal illness: people who were diagnosed with the disease were expected to die. With advances in science and new medicines, many people survive cancer. Cancer is now seen as a chronic illness that people may cope with over long periods of time. As a result of these changes, research and intervention have focused on quality of life and survivorship. Given the family's important role in the patient's well-being, it is essential to understand the impact of cancer on family life.

How does a diagnosis of cancer affect the family? Family members must deal with many questions about their loved one's illness. Will he or she survive and regain their health? What treatment should be chosen, and can the family afford it? Yet too often family members are left out of formal, readily available services and cancer treatment systems. They do not get needed information and support that could help them deal with a cancer diagnosis. This situation may be

particularly true for family members from low income and diverse populations.

Cancer and the Family System

In helping families to deal with a cancer diagnosis, it is important to know:

1. Who belongs in the family?

"Family" refers to close relatives, spouses, life partners, primary caregivers, and important others. Families may have opposite or same-sex partnerships and exist with or without children. They are composed of people who have a shared history, lineage, future, and emotional life. In many ways, family members are co-survivors with the person struggling with cancer.

2. Where is the family in its developmental stage?

"Developmental stage" refers to where the family is in the life cycle. Are they a young couple starting to build a life together and who must now deal with a lengthy course of treatment? Are they a recently retired couple facing a diagnosis of advanced cancer? Looking at the course of treatment alongside the family's developmental stage provides a framework for understanding:

- what the impact of cancer might be
- how the family may cope
- how professionals in the healthcare system might be of service to the patient and family

3. What stage has the family reached in the cancer journey?

"Stage of cancer journey" refers to the clinical paths that follow a cancer diagnosis. For instance:

- (1) Primary treatment, restore to good health, long-term survival, cure.
- (2) Treatment, symptoms lessen, cancer comes back, another course of treatment.



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(3) When treatment fails for a return of cancer, efforts to relieve or soothe symptoms are taken.

Family Functioning

During the crisis of cancer, stress levels are high. But that may be when the family is called on to function at its best. A cancer diagnosis may:

- **Change future plans** – Family members may experience a sense of helplessness and loss of control. The family's functioning may become unstable as members try to adapt to changed lives. Their standard of living may decrease due to economic burdens from direct or hidden costs of cancer.
- **Upset the usual patterns of communication within the family** – Parents may be less available to their children, and their roles may change (e.g., a daughter may take her father to the doctor).

Family History and Beliefs

A family's beliefs about cancer, and the meanings attached to those beliefs, affect how a family may respond to a cancer diagnosis. For example:

- Some families believe that illness is an emotional or mental weakness. This belief may prevent the family members from being able to support one another.
- If cancer led to death in a family over generations, the family may believe that cancer always leads to death.
- Some families believe that if their family member with cancer is optimistic and positive, the cancer may be cured; cancer will return if that member is pessimistic. This belief can place a huge burden on the patient.
- Unresolved family issues (e.g., blame, shame, or guilt) can also strongly affect views of cancer's cause or cure.

Perspectives on Cancer, Culture, and Diversity

The need to shift a treatment approach from patient-centered to family-focused becomes clearer when seen through the lenses of culture and diversity. Many of us have different cultural values about:

- how cancer is viewed
- the degree to which we keep information about the illness public or private
- the role of family members in decision-making about treatment

Healthcare providers need to educate themselves about differences in language, sexual orientation, and social customs. They need to build relationships with underserved populations, and use trained bilingual and bicultural

translators. In this way, they can prevent such differences from becoming barriers to communication and understanding.

African American Families and Cancer

For most cancers, African Americans have the highest death rate and shortest survival rate of any racial and ethnic group in the United States. Five key strengths of African American families can help them with a cancer diagnosis: strong kinship bond, work orientation, culture of achievement, religious views, and ability to change family roles.

Some recommendations:

- Understand that many African American women value being strong and independent. They may hide their illness to avoid admitting weakness and to protect their families from the burden of cancer. Family members can help them understand how much they, as co-survivors, need to be a part of the treatment process.
- Be creative in how you offer help. Bring over a meal, or see a movie together. Sometimes support means having to say, "I am going to do this" rather than asking "What can I do?"
- Recognize that these families often draw on prayer and other spiritual resources to help cope with the distress of cancer.

American Indian Families and Cancer

Cancer is the second leading cause of death among American Indians over the age of 45. A key to working with this population is to understand that great diversity exists among the many tribes' customs. The federal government recognizes more than 560 tribes; state governments combined recognize more than 100 tribes.

Some recommendations:

- Seek help from individuals that serve American Indians with cancer, such as reservation-based Community Health Representatives, and from organizations such as the Indian Health Service.
- Help an elder understand that she can control the cancer treatment process. For example, if she does not understand the doctor's explanations, she can get help from an advocate, a nurse, or even a teenager.

Latino American Families and Cancer

Cancer is the second leading cause of death for Latinos. Latinos also have a lower five-year survival rate from cancer compared to non-Latino whites. Fear and lack of health insurance are the top reasons why Latinos may delay seeking help. By the time they do, it is often too late and they may require intense or more complex treatment.

Some recommendations:

- Perceive the central role of family to Latinos. Honor customs that many Latinos may experience as therapeutic

and healing; for example, asking for *La Bendición* (a blessing) from elders when greeting them.

- Know how to interpret the deeper meaning of co-survivors' silence during talks with health professionals. Rather than lack of interest, silence often reflects a sign of lack of understanding, fear, frustration, and helplessness.
- Understand the fatalistic approach that many Latinos take toward diseases such as cancer. Many consider it a curse or a punishment; Latino men may become very depressed, feeling powerless because they cannot provide for their family.

Asian American Families and Cancer

Cancer has been the number-one killer of Asian American women since 1980. Lung cancer rates among Southeast Asians are 18% higher than among white Americans. Liver cancer rates in Chinese, Filipino, Japanese, Korean, and Vietnamese populations are 2 to 11 times higher than among white Americans.

Some recommendations:

- Know potential barriers to creating community resources for Asian Americans. For example, culturally, Asian Americans tend to emphasize keeping things private and being able to endure.
- Be aware that a cancer diagnosis may be seen as a disgrace to the family. Cancer patients may feel compelled to hide their diagnosis from their families.
- Understand Asian Americans' need for privacy about their illness. Help them find outlets to express their feelings, for example, through writing, painting, or music.

Sexual Orientation and Cancer

Lesbian, gay, bisexual, and transgender (LGBT) families cope with a cancer diagnosis like most families. But this group experiences unique issues that make living with the illness more intense. These issues include assumptions of heterosexuality in the healthcare system and the potential negative impact of "coming out" to providers.

- Many health professionals take for granted that a person is heterosexual. Many LGBT individuals may hesitate to seek healthcare or disclose their sexual orientation to providers and their families for fear of homophobic attitudes. Homophobia is the irrational fear of, intense dislike of, or discrimination against the LGBT population.
- Health professionals often do not recognize LGBT patients' partners. They may assume that LGBT individuals do not have family and lead unhealthy lifestyles. The patient then has reduced support to make important decisions about cancer treatment. Also, lack of acceptance for LGBT relationships and family can create legal hurdles, especially around end-of-life concerns.



Resources in Healthcare Systems

When a family member faces a cancer diagnosis, many resources exist to support the family. Counselors, patient navigators, and social workers often give the best help for learning about resources and getting financial assistance.

Counselors: One of the first challenges for people with cancer is to accept the diagnosis. Family members are encouraged to talk with a professional counselor soon after the diagnosis. In this way they can avoid self-destructive ways of coping and learn healthy methods. Counselors can:

- Help families manage a range of emotions, and address expectant grief issues.
- Serve as a consultant to other professionals on the healthcare team.
- Help families tap into their strengths; sort out realistic versus unrealistic fears; and explore strategies to best take advantage of the time they have left.
- Encourage families to include trusted members of the extended family or cultural and spiritual communities in their support system.
- Help tell children about the cancer, and help children work through feelings and concerns.

Patient Navigators and Social Workers: Nearly all major cancer centers throughout the United States have patient navigators. They help people manage the maze of clinics, doctors' offices, hospitals, outpatient centers, and insurance and payment systems. Ideally, navigators speak the preferred language of the patient and her family. Cancer centers without navigators have social workers who can assist patients.

Financial Assistance Programs: Typically, medications used for chemotherapy are the most expensive part of cancer treatment. Many pharmaceutical companies have patient assistance programs that provide medication support. Federal programs such as Medicare, Medicaid, and Social Security may also be available. U.S. Oncology, CancerCare, the American Cancer Society, and other programs can also help families secure financial support for patients.

“A cancer diagnosis can be stressful for a person’s entire network of family and friends. In order to support co-survivors, it is time that family-focused intervention be made available to families facing cancer,” says Dr. Catherine Marshall, Ph.D., CRC, NCC, and associate research professor in the Frances McClelland Institute of Children, Youth, and Families at The University of Arizona.

Implications

- Evidence shows that families play a central role in a cancer patient’s diagnosis, treatment, and recovery. Yet most health systems that provide cancer care still do not focus on families. Efforts among providers to ensure that a family perspective is reflected in all systems that provide care and support need to be encouraged.
- Cancer research that looks at family-based intervention across low-income and ethnically diverse groups is needed. Such research would identify ways to prepare family members to support a cancer patient and assist co-survivors.
- Cancer care also needs to be culturally appropriate; a family’s cultural values as well as their economic status need to be considered.

Funding:

Dr. Marshall acknowledges the development of her understanding and thinking about cancer as a result of her participation in the Cancer, Culture and Literacy Institute; H. Lee Moffitt Cancer Center and Research Institute, University of South Florida, January–December, 2002. The work was also informed and supported in part by a Ruth L. Kirschstein National Research Service Award for Individual Senior Fellowship (Grant Number F33CA117704), the Department of Health and Human Services, National Institutes of Health, National Cancer Institute, awarded to Dr. Marshall and administered by The University of Arizona Center of Excellence in Women’s Health. The author also acknowledges support from the Frances McClelland Institute for Children, Youth, and Families. The content is solely the responsibility of the authors, and does not necessarily represent the official views of the National Cancer Institute or the National Institutes of Health.

This ResearchLink summarizes the following book: Marshall, C. A. (Ed.). (2010). *Surviving cancer as a family and helping co-survivors thrive*. Westport, CT: Praeger.

Acknowledgements:

The ResearchLink also acknowledges the book’s chapter authors: Alice F. Chang, Mark Clark, Dierdre Cobb-Roberts, Joyce A. DeVoss, Paul Donnelly, Maria C. Figueroa, Alma E. Flores, Lena R. Gaddis, Rose Gordon, Sharon R. Johnson, Lorraine Johnston, Claudia X. Aguado Loi, Anne Mallett, Mika Niemelä, Rebecca Paradies, Monica R. Robinson, Ilkka Saarnio, Sarah Sample, Gloria I. San Miguel, Dinorah Martinez Tyson, and Leena Väisänen.

Suggested citation for this ResearchLink:

Van Campen, K. S., & Marshall, C. A. (2010). *How Families Cope with Cancer* (Frances McClelland Institute for Children, Youth, and Families *ResearchLink*, Vol. 2, No.4). Tucson, AZ: The University of Arizona.

