

# A Qualitative Study of Caregivers' Experiences With Newly Diagnosed Advanced Colorectal Cancer

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**Purpose/Objectives:** To report on a descriptive, qualitative study of 14 caregivers of patients newly diagnosed with advanced colorectal cancer.

**Research Approach:** Qualitative.

**Setting:** One urban ambulatory cancer center in the northeastern United States.

**Participants:** 14 identified caregivers of patients newly diagnosed with stage III or IV colorectal cancer.

**Methodologic Approach:** Semistructured interviews were taped recorded. Interviewers asked participants to describe their experiences caring for a loved one with colorectal cancer. Thematic content analysis with inductive coding was used to code the transcribed interview data. Throughout the data-coding process, emics in each category were compared within and between categories to maximize the fit of participants' data. Categories were reviewed in a final stage of analysis and further organized into domains from which the core category was derived.

**Main Research Variables:** Caregiver experiences of living with a person with colorectal cancer, effect on daily living, coping strategies used, and effect on children.

**Findings:** The coded interview data yielded three domains: Experiencing Total Disruption of My Life, Staying Positive, and Attempting to Keep Family and Children's Routines as Normal as Possible. The core category that explained study participants' caregiving experiences was "balancing caregiving activities and disruptions while dealing positively with daily demands and personal impact."

**Conclusions:** The dominant experiences of the participants focused on coming to terms with the disease's disruption in their lives, attempting to deal positively with the effect of the disease, and maintaining normalcy in family life.

**Interpretation:** Targeted assessment of caregivers' needs is important in the three dimensions of the study domains. Clinicians who work with caregivers of patients with cancer should offer direct support because caregivers cope with the care of their loved one and struggle with their own distress and with maintaining normal family life. Findings suggest the importance of offering psychosocial support to caregivers and providing guidance to caregivers for support of their children and families.

Colorectal carcinoma is the third most commonly diagnosed cancer among men and women in the United States and accounts for almost 10% of all cancer deaths annually. In 2007, an estimated 112,340 new cases of colon cancer and 41,420 new cases of rectal cancer will be diagnosed. Sixty-four percent of the individuals newly diagnosed across all stages will survive for at least five years (American Cancer Society, 2007). Cancer, particularly when diagnosed at advanced stages, is devastating, creating signifi-

## Key Points . . .

- ▶ A diagnosis of colorectal cancer can have a devastating effect on caregivers.
- ▶ Significant gaps exist in understanding of the effect of colorectal cancer from the perspective of caregivers.
- ▶ Caregivers struggle with caring for their loved one diagnosed with colorectal cancer; assume increased household, family, and financial responsibilities; and cope with the personal effects while attempting to meet their own needs and maintain a normal family routine.

cant distress throughout the entire family network (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Manne, 1998; Maughan, Heyman, & Matthews, 2002). Although work has been done to provide evidence of the concerns and challenges that affect caregivers, scant research exists of the impact of recently diagnosed advanced colorectal cancer on caregivers. This article reports on a descriptive qualitative study of 14 identified caregivers of patients newly diagnosed with advanced colorectal cancer.

## Literature Review

The PubMed, CINAHL<sup>®</sup>, PsycINFO, Social Work Abstracts, Sociological Abstracts, and Cochrane Database of Systematic Reviews databases were searched for research from 1995–2004 to capture the state of the science. Articles published prior to 1995 that were cited as seminal articles in the retrieved publications were included. Using the search phrase "colorectal neoplasms" as the major focus, the results were combined with searches using caregivers; family caregivers and spousal caregivers combined with cancer-psychosocial factors; social

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