

ARTICLES

Salvaging Their Normal Lives: A Qualitative Study of Patients With Recently Diagnosed Advanced Colorectal Cancer

Arlene D. Houldin, PhD, APRN, BC, and Frances Marcus Lewis, PhD, MN, FAAN

Purpose/Objectives: To describe the experiences of patients living with newly diagnosed stage III or IV colorectal cancer.

Research Approach: Qualitative; inductive coding methods were used to identify open codes that were analyzed, compared, and grouped into categories.

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

Participants: 14 patients newly diagnosed with stage III or stage IV colorectal cancer.

Methodologic Approach: Semistructured interviews were recorded on audiotape. Interviewers asked participants to describe their experiences with the diagnosis and treatment of colorectal cancer. Content analysis with inductive coding was used to code the transcribed interview data. Categories were reviewed and organized into larger groupings, from which the core category was derived.

Main Research Variables: Experiences of living with a diagnosis of colorectal cancer, impact on daily living, quality of life, coping strategies used, level of preparedness, and impact on children.

Findings: The coded interview data yielded six domains: feeling life is disrupted, experiencing physicians, feeling unprepared for everything, rethinking parenting, wondering "why me?," and dealing with it. The core category that explained study participants' experiences with recently diagnosed colorectal cancer was "salvaging their normal lives."

Conclusions: The dominant experience of the study participants focused on four aspects of their illness experience: (a) framing it in ways that enabled them to recreate a semblance of normalcy or of their pre-illness state, (b) trying to tell children about the illness in stabilizing ways, (c) generating or maintaining a positive outlook no matter what, and (d) concretely managing the distress of the illness and its symptoms.

Interpretation: Targeted assessment is important in the six dimensions of the study domains. Clinicians who work with patients with cancer should offer support as patients search for meanings to explain this potentially devastating life event. Teaching active coping strategies as patients with advanced cancer struggle to come to terms with the demands of the disease while attempting to live their lives as fully and as normally as possible is important.

Colorectal carcinoma is the third most commonly diagnosed cancer among men and women in the United States and the second most common cause of cancer death (American Cancer Society, 2005). According to current estimates, colorectal cancer will develop in about 6% of people over their life span. When men and women are considered separately, colorectal cancer is the third-leading cause of cancer death in each gender (American Cancer Society).

Key Points . . .

- ▶ A diagnosis of colorectal cancer and its ensuing treatment can have a devastating impact on a person's quality of life.
- ▶ Significant gaps exist in the understanding of the disease's impact, particularly in its advanced state, from the perspective of patients, including the concerns, benefits, challenges, and burdens associated with diagnosis and treatment.
- ▶ Patient participants struggled with balancing living with the illness while attempting to rescue and protect some semblance of their routine lives.

Scant research exists on the impact of colorectal cancer for newly diagnosed patients with advanced disease. This article reports on a descriptive, qualitative study of 14 patients newly diagnosed with advanced colorectal cancer.

Literature Review

A diagnosis of colorectal cancer and its ensuing treatment can have a devastating impact on a person's quality of life (QOL). A number of studies have been completed since the 1970s to provide research evidence on QOL and health-related QOL (HRQOL) (Anderson & Palmer, 1998; Klemm, Miller, & Fernsler, 2000; Nordin & Glimelius, 1997; Ramsey et al., 2000; Sahay, Gray, & Fitch, 2000; Sprangers, te Velde, Aaronson, & Taal, 1993; Williams & Johnston, 1983).

Arlene D. Houldin, PhD, APRN, BC, is an associate professor of psychosocial oncology nursing in the School of Nursing and program director of the Adult Nurse Practitioner: Oncology Advanced Practice Nursing program at the University of Pennsylvania and the nursing director of palliative care services at Philadelphia Veterans' Affairs Medical Center, both in Philadelphia, PA; and Frances Marcus Lewis, PhD, MN, FAAN, is the Soule Professor of Family and Child Nursing in the School of Nursing at the University of Washington in Seattle. This research was supported by a 2003 ONS Foundation small research grant. (Submitted September 2005. Accepted for publication October 20, 2005.)

Digital Object Identifier: 10.1188/06.ONF.719-725

Studies identified a range of physical problems for patients with colorectal cancer, including pain, fatigue, decreased functional status, frequent bowel movements, flatus, diarrhea, constipation, incontinence, disturbed sleep, appetite and weight loss, and digestive problems (Maguire, Walsh, Jeacock, & Kingston, 1999; Padilla et al., 1992; Whynes & Neilson, 1997). Furthermore, a number of psychosocial issues have been identified among patients treated for colorectal cancer, including depression, uncertainty, anxiety, worry, body image changes, social embarrassment, dietary concerns, coping difficulties, and impaired sexual functioning, more so among patients with a resulting colostomy than among patients who did not have a colostomy (Grant et al., 1998; Klemm et al., 2000; Maguire et al.; Sprangers, Taal, Aaronson, & te Velde, 1995; Whynes & Neilson). Finally, general consensus indicates that social adjustment may be a serious problem for patients with colorectal cancer and that poor relationships with family and friends, social isolation, and restrictions in social activities may occur more frequently (Northouse, Mood, Templin, Mellon, & George, 2000; Sahay et al., 2000; Sprangers et al., 1995; Whynes & Neilson).

In a review of literature specific to older patients with colorectal cancer (those older than 65 years), examination of surgical outcomes revealed elevated levels of postoperative morbidity and mortality, higher prevalence of comorbidities, more advanced stages of disease at initial diagnosis, and higher rates of emergent presentation compared to referent populations ("Surgery for Colorectal Cancer," 2000). More specifically, in a study of predictors of depressive symptomatology for older adults with colorectal cancer, Kurtz, Kurtz, Stommel, Given, and Given (2002) found that female patients, African American patients, and patients with two or more comorbid conditions exhibited more depressive symptoms than other subsets of patients, as did patients with more disease-related symptoms and increased restrictions on physical and social functioning. Among the important findings drawn from the study, the psychological status of older adults with cancer was tied closely to their symptom experience.

In other work, greater impairment of psychological functioning was noted for younger patients than for older patients and for female patients than for male patients (Baider, Perez, & De-Nour, 1989; Klemm et al., 2000; Kurtz et al., 2002; Northouse et al., 2000). Studies examining illness demands in patients with colorectal cancer indicated that the greatest demand burdens were psychosocial and existential concerns reported by patients in the youngest age group (age 26–45) compared to middle (age 46–65) and older age (66 and older) groups (Fernsler, Klemm, & Miller, 1999; Klemm et al.). Specifically, younger patients with colorectal cancer reported concerns about the personal meaning of the disease and issues related to their own mortality, the future of their family, and the worry that their children may face the same disease (Klemm et al.). Fernsler et al. hypothesized that the developmental tasks associated with the younger age group (e.g., marital adjustment, child rearing, career development) coupled with more aggressive disease may explain, in part, younger adults' greater susceptibility to disruption by the illness and treatment. Despite the documented morbidity, in general, patients with colorectal cancer have reported satisfaction with their medical treatment. A cohort of patients did express dissatisfaction with information concerning disease management and sexual dysfunction, and many patients acknowledge difficulty coping with the side effects of treatment

(Sahay et al., 2000). Additionally, some evidence indicates that patients who report higher levels of spiritual well-being may experience lower symptom distress (Fernsler et al.).

Health-Related Quality of Life

Despite the burden of illness-related demands for patients with colorectal cancer, very few studies have examined their HRQOL. HRQOL is defined as the sum of a patient's sense of well-being, framed in the context of past and present disease and treatment (Anthony, Jones, Antoine, Sivess-Franks, & Turnage, 2001).

A survey of 173 patients with colorectal cancer examined how HRQOL varied according to disease stage. Findings indicated that, for all stages, the impact of colorectal cancer was greatest in the first two to three years after diagnosis and that HRQOL for patients with colorectal cancer likely was affected by the burden of the disease and treatment regimens (Ramsey et al., 2000). Moreover, Ramsey et al. (2000) reported poorer outcomes on emotional and pain HRQOL dimensions for colorectal cancer survivors with low-income status. Other research has indicated that performance status, disease-related symptoms, and incidence of toxicity may be the most important indicators of patients' QOL (Anderson & Palmer, 1998). Additionally, some evidence has indicated improvement in overall QOL for patients with colorectal cancer with longer survival times (Schag, Ganz, Wing, Sim, & Lee, 1994).

Whynes and Neilson (1997) studied differences in symptom distress before and three months after surgery for colorectal cancer. Results indicated that, from the presurgery to postsurgery period, significant decreases resulted in some physical and psychological symptoms. However, other symptoms, including tiredness, decreased sexual interest, and difficulty concentrating and sleeping, persisted during the follow-up period. In a study of 20 patients with colostomies, Grant et al. (1998) described patient concerns in all four QOL domains: physical, psychological, social, and spiritual.

Maisey et al. (2002) reported that baseline QOL was a significant independent predictor of survival in patients with advanced colorectal cancer. Findings from two studies indicate that pretreatment HRQOL scores predicted length of stay after colorectal cancer surgery (Holloway et al., 2002) and HRQOL scores at diagnosis and the occurrence of perioperative complications were significantly associated with HRQOL 12 months postdiagnosis (Anthony et al., 2003). Ramsey, Berry, Moinpour, Giedzinska, and Andersen (2002) found that long-term (those who survived at least five years from diagnosis) survivors of colorectal cancer reported relatively high HRQOL scores, although depression and diarrhea were continuing problems.

Taken together, patient, disease, and treatment factors have complex interactions that are important determinants of QOL. Work to date provides evidence that colorectal disease and its treatment may have a substantial impact on the physical, psychological, social, and sexual functioning of patients across all ages and stages of the disease, particularly in the first five years after diagnosis.

A phenomenologic study added to the understanding of patients' and spouses' perceptions of life changes after a diagnosis of advanced gastrointestinal cancer (Winterling, Wasteson, Glimelius, Sjoden, & Nordin, 2004). Findings indicated physical, mental, practical, and positive changes for patients and spouses. Physical changes included fatigue, pain, diarrhea, and nausea. In addition, three subcategories

of mental changes were identified for patients and spouses: despair, why, and uncertainty. Practical changes, such as those affecting role, were identified. Positive changes included improved marital relationships and obtaining peace in life. Study participants reported using various techniques to cope with the diagnosis, including reconciling themselves with the diagnosis, making the best of it, seeking support, and maintaining hope. The investigators concluded that patients seemed to accept the diagnosis to a greater extent than did spouses, prepared themselves for death, and exhibited less use of avoidance strategies than did spouses.

Summary

Research to date provides evidence that both colorectal cancer and its treatment affect patients significantly on every functional domain across all stages of the disease. Limited data are available to describe patients' lived experiences and HRQOL issues. As a result, significant gaps exist in the understanding of the impact of the disease from the perspective of patients, including the concerns, benefits, challenges, and burdens associated with diagnosis and treatment. Least is known about patients whose initial diagnosis is at the advanced stage of the disease.

Methods

Fourteen patients recently diagnosed with advanced colorectal cancer (stages III or IV) and their identified caregivers participated in a larger interview study. This article describes the qualitative results obtained from confidential face-to-face interviews with the patients. After study approval by the human subjects committee, patients meeting eligibility requirements were approached by a member of the study team in the outpatient hematology-oncology clinic at a major cancer center in the northeastern United States. The project was described, questions were answered, and patients were invited to participate in the study. A total of 18 patients were invited, and 14 agreed to be interviewed. The reasons given for nonparticipation included being "too sick to participate" and "too busy to be interviewed." Patients refusing to participate did not have any different treatment or background characteristics than patients agreeing to be interviewed.

Procedure

After signed consent was obtained, two advanced practice nurses, trained in interview techniques by the study investigators, conducted the patient interviews. Semistructured interviews took place largely in an outpatient clinic, and four interviews were conducted in patients' homes. Interviews lasted an average of 45–60 minutes and were recorded on audiotape. The tapes were transcribed verbatim. Five transcripts were randomly selected and reviewed for accuracy.

Interviewers asked participants to describe their experiences with the diagnosis and treatment of colorectal cancer. Initially, a broad question was asked: "What has it been like for you living with a diagnosis of colorectal cancer?" Specific prompts were used to invite elaboration about impact on daily living, coping strategies used, level of preparedness, and impact on children.

Data Analysis

Content analysis with inductive coding was used to code the transcribed interview data. Inductive coding methods

were adapted from methods initially described by Glaser and Strauss (1967), Krippendorff (1980), Spradley (1979, 1980), Strauss (1987), and Strauss and Corbin (1990) and extended by Lewis and Deal (1995). During the initial phase of coding, transcripts were read multiple times with the intent of identifying participants' concerns, distress, coping strategies, and impact on daily life. Open codes were analyzed, compared, and grouped into categories (Strauss & Corbin) according to some common element. Categories were based on the manifest, not latent, meaning of the verbatim-transcribed text and labeled with emic, not etic, words (Lewis, Haberman, & Wallhagen, 1986). That is, the category names themselves reflected the words of the participants. During the process of categorizing the open codes, definitions for the categories were developed and refined. Throughout the coding process, emics in each category were compared in and between categories to maximize the fit of patient data with the category. Finally, all categories were compared to maximize their unique and nonoverlapping quality. This process involved constant comparative analysis (Corbin & Strauss, 1984).

The coder-authors sought consensus on the categories and their definitions. Discussions resulted in refining a category's definition, recoding data in a different category, or identifying a new category. A final stage of analysis further organized the categories into larger groupings called domains, from which the core category was derived (Corbin & Strauss, 1984; Lewis & Deal, 1995).

Results

Study participants ranged in age from 27–67 years ($SD = 11.8$). Male patients were an average of 49.5 years old, and female patients were an average of 49 years old.

Nine men and five women were interviewed, and the sample consisted of 12 Caucasians, 1 Asian, and 1 African American. Ten participants had children ranging in age from 2–25 years. Patients had a mix of professional and technical employment; education ranged from some high school to a doctorate. Participants were middle to upper-middle class, based on income. Twelve participants were married; two were single.

All participants were recruited in the first three months following diagnosis of either stage III or IV colorectal cancer. Patients had completed surgical interventions; only one patient had an ileostomy. At the time of the interview, participants were in their first chemotherapy treatment cycle.

The coded interview data yielded six domains (see Table 1). The core category that explained study participants' experiences with recently diagnosed colorectal cancer was "salvaging their normal lives."

Patient participants struggled with dealing with the illness and concurrently maintaining their routine daily lives. The presence of symptoms and altered routines and bodily functions meant that they could not merely adjust or manage what was happening but rather had to try to identify and salvage visages of their premorbid life.

Domain 1: Feeling Life Is Disrupted

Participants reported that their lives were disrupted by the impact of the disease. Symptoms were not experienced merely as symptoms; they represented losses. For example, participants reported losing control over their bowels, weight, flatus,

Table 1. Study Domains and Related Categories

Domain	Related Categories
Feeling life is disrupted	—
Experiencing physicians	Feeling hope, experiencing noncompassion, being angry, receiving upsetting information
Feeling unprepared for everything	—
Rethinking parenting	—
Wondering “why me?”	Wondering about the implications of the disease, coming to terms with the uncertainty of the disease, engaging in a life review, drawing on faith, confronting one’s mortality
Dealing with it	Staying positive, accepting help, actively adjusting

sexuality, prior sleep patterns, and so forth. In addition, symptoms were unique to the type of treatment participants were receiving. They reported that even their tears were annoying and painful. The words of one male participant expressed it best. “My eyes are a little bit worse. . . . Some people . . . tend to secrete the chemo through the tear ducts and . . . that has been a real annoyance. . . . It affects your vision, and it’s painful in some cases, and it’s irritating.”

Study participants struggled with severe fatigue or sleep disruptions. The disruption was sometimes related to their chemotherapy cycle. For example, one woman noted, “I have a lot of fatigue. It’s a very sort of profound, sort of deep fatigue.”

Daily routines were affected negatively by physical symptoms. Patient participants were not even able to go to the refrigerator or write simple messages because of their responses to cold temperatures and inability to feel with their fingers. A male participant said, “I can’t go out and have a cold drink. . . . I can’t go in the refrigerator or freezer.” A woman said, “[The neuropathy] feels a little bit like I am wearing latex gloves all the time.”

As part of having their lives disrupted, participants talked as if they were standing still and their future was on hold. One man put it this way: “I basically feel like my career is kind of on hold.” A woman shared, “The world goes along, and I am just sort of spinning in this one little place.” Another woman said, “Everyone else is going on with their lives, and I am just trying to get a shower and do the dishes.”

Two individuals reported limited symptoms and limited impact. One person said, “I don’t think it has affected me that much other than reorganizing our lives around that schedule.” Another person shared, “I don’t feel any of the physical symptoms that I think I should be or that people are telling or that I have read about.”

Domain 2: Experiencing Physicians

Interacting with physicians was distressing for many of the participants and comforting for some. This domain had four categories: feeling hope, experiencing noncompassion, being angry, and receiving upsetting information. Participants had disparate responses to physicians. Participants reported feeling hopeful and experiencing a lack of compassion from physicians. For example, one participant noted, “[The doctors] did promise some hope in the future, medications that are a lot more promising than the ones that are used

now. That was helpful.” Noncompassion was reflected in another person’s words: “The way my doctors treated me didn’t make me feel like a person, just a patient.” Other participants spoke about anger and disappointment. One man expressed, “I am angry at my doctors in the past for not saying you should have this kind of test, colonoscopy.” Moreover, some participants expressed upset at the manner in which information was delivered. In the words of one participant, “A lot of the stress that I experienced . . . was . . . due to . . . either a faulty diagnosis . . . or some information that probably could have just been kept from me until somebody was ready to give me a more definite explanation of my circumstances.”

Domain 3: Feeling Unprepared for Everything

Some participants reported feeling unprepared for all aspects of the colorectal cancer experience. The level of unpreparedness was quite significant in its magnitude, scope, and intensity. Being unprepared spanned everything from time of diagnosis to current treatment to anticipated outcomes. Representative quotes from two participants included, “I’ve felt unprepared for basically everything” and “I can’t really say I’ve been prepared for any of it, really,” and another participant felt unprepared for “the whole sort of mortality aspect to this.” On the other hand, two participants reported that they felt prepared: “I didn’t feel unprepared for the treatment. They told me everything that was gonna go, as [it was] gonna happen and that’s the way it did”; “Cancer runs in my family, so there’s not much, there’s nothing that I’ve seen that I haven’t seen before.”

Domain 4: Rethinking Parenting

Many participants struggled with multiple aspects of parenting children of all ages, particularly the youngest children. Parents struggled with how to tell their children about their cancer. “[My kids] really don’t know anything about [the cancer] at this point, and I kind of struggle over how and when and if [to tell them].” Some had not discussed it yet, and others hesitated to talk about it, worrying that too many details about the cancer would negatively affect their children. One participant said the illness had not affected her parenting of school-aged children at all.

Participants expressed that they did not know how to talk about the cancer without worrying their children. One participant shared, “I don’t want to affect them with too many details about the cancer . . . they’re going to school. Why would they want to be . . . worried and . . . lose out on their education or . . . their interactions with their friends?”

Some parents tried to spend more time with their children and wanted to reassure their children of positive outcomes. One participant noted, “I am trying to spend more time with my children, I guess, because of the circumstances. They were left out and worried when I was sick in the hospital, so I’m trying to build up, you know, their confidence and their trust that I’m still going to be around.”

Some parents attempted to do things differently with their children. It made them rethink what to do, including perhaps listening to them more. One parent reported watching his son’s school grades drop when he was in the hospital. The same parent worked to spend more time with his child, including taking him to his music lessons and soccer games and watching baseball games together.

Domain 5: Wondering “Why Me?”

The majority of participants attempted to make existential sense of their illness. Making sense of the cancer involved six categories: searching for reasons with some participants asking, “Why me?”; worrying about implications of the disease for self and family; coming to terms with the uncertainty of the disease; engaging in a life review; drawing on faith; and confronting one’s mortality. Some salient quotes from participants representing categories of existential concern follow.

I may die and never get a chance to do a lot of things that I wanted to do in my lifetime.

There’s some disappointment there in not reaching all my goals.

I think . . . what things I ought to have arranged. So, if I’m gonna be dead in five years . . . what should I be doing now.

I don’t worry, especially for me . . . but I’m worried for my close ones.

I worry about my kids.

And the first day I wondered, “Why me? Why me, you know, or why not Joe next door or somebody else?”

I never felt like shocked or anything. . . . Mostly I just feel like, you know, I’ve had bad luck.

I think if it escapes into the lymph system, it’s very questionable where it goes from there, and it can spread very easily. So, I had some concerns about that.

I probe deeply into my faith.

Finally, one participant reported engaging in a life review. “Then you begin to look back over your life and say, maybe I should have done something different somehow—the food I ate or the chemicals I hung around with or worked with all the years.”

Domain 6: Dealing With It

This domain includes three major categories encompassing an array of approaches participants used to deal with their colorectal cancer: staying positive, accepting help from others, and actively adjusting strategies. The patterns of “positive coping” and “fighting mentality” predominated the coping approaches used by the participants.

Participants tried to maintain a positive outlook despite the diagnosis and treatment. One participant shared, “I’m an extremely positive person. I have a lot of confidence in myself.” Others noted,

You deal with it with humor and a positive attitude.

But I feel like it’s something that I can deal with and I can beat.

I am feeling optimistic about the future.

I refuse to accept failure.

Benefit finding was used frequently by participants as another way to remain positive. One woman noted, “We’ve [my family and I] been drawn closer together.” A male participant stated, “I’ve had phone calls from brothers and sisters that I haven’t heard from in years, expressing their concern.”

Many participants discussed the importance of accepting help from others. Some examples follow.

You don’t want to feel like you have to do it all yourself, either. Have to be willing to accept help.

My wife had to assume all the responsibility for all of those things, and as well as trying to handle . . . phone calls to and from the doctors, and . . . she’s been very supportive and very helpful.

People approaching me said, “Look, I’m a cancer survivor.” . . . They were very helpful . . . and they told me about the whole chemotherapy scheme that they’d gone through. That made me feel better because they would relate family experiences with cancer, or perhaps their own experiences with cancer or heart disease or some other serious medical woe.

[Healthcare professionals] didn’t treat me [like an invalid]. And I appreciated that tremendously. And they tried to look at it objectively and . . . ask me how I’m doing.

Study participants described, often in great detail, ways in which they actively worked to manage their illness, how they maintained their routines to keep their day moving forward, and ways in which they dealt with the challenges confronting them. They talked about keeping a “correct” perspective on their illness. They distinguished between doing activities and tasks to deal with their days and the mental “battle” they experienced. One male participant put it this way: “I have to try to adjust and be more active and . . . push through the pain and weakness.” A female participant noted, “A lot of your success in battling something like this is in your head. . . . It’s very much a mental fight as much as it is a medical fight. Positive thinking and attitude is important.”

Living in the moment and “staying with today” were important for some participants. One participant stated, “Perhaps in some ways it’s better off for you to focus on . . . what you need and what’s best for you and, you know, worry about everything else at some later date.” Attempting to “control the disease” by gathering information, being prepared, and taking prescribed medications were some additional active strategies used by many of the participants.

Discussion

The dominant experience of the study participants, regardless of gender or age, focused on four aspects of their illness experience: framing it in ways that enabled them to recreate a semblance of normalcy or of their preillness state, trying to tell children about the illness in stabilizing ways, generating or maintaining a positive outlook no matter what, and concretely managing the distress of the illness, including symptoms. “Salvaging their normal lives” emerged as the dominant theme.

Participants attempted to contain and control their physical and psychological distress to live life as usual. The majority of the conceptual domains contained evidence of substantial distress from the illness in the lives of the study participants. Even when study participants attempted to be hopeful and describe the benefits of the illness in their lives (e.g., enhanced closeness among family members), they concurrently talked about their struggle to manage intrusive

and sometimes immobilizing symptoms, their struggle with existential concerns, and their deep worry about how to tell their children about and support them during the illness.

Although study participants identified ways that they kept their lives moving forward, even when they appeared to be standing still, reported symptoms and other sources of distress often were described in terms that delimited or bound the distress. In other words, when reporting physical symptoms, participants used words that minimized the magnitude, frequency, or intensity of the symptoms. For example, when reporting diarrhea, instead of describing the diarrhea as voluminous, odiferous, socially embarrassing, difficult to control, or horrific and omnipresent, participants chose words that circumscribed the nature of the diarrhea. One participant's words provided an example: "Sometimes the diarrhea is sort of, like, painful." Note the choice of words, "sort of, like, painful." Even the resection of a part of the colon was described in terms that minimized patients' symptoms. One man shared his experience: "I've had to learn to move my bowels all over again . . . because they took out a section of my colon and that's not been easy to adjust to. I haven't quite adjusted perfectly yet, but I'm getting there." The only symptom that participants described in noncircumscribed terms was being tired all of the time. The fatigue they reported was "profound" and "very deep."

Not only did participants downplay the scope, intensity, and magnitude of their symptoms, they also conditionalized them. Note one person's words: "I really felt that I was pardoned. I really had anticipated that the news was going to be bad. I really feel as if my circumstances are not much different than somebody who was condemned and been on death row and had been pardoned."

Participants focused on their symptoms but did not discuss the gravity of their diagnoses. Even when they were told the stage of their cancer, it was not always clear that they had heard the information or had integrated it. For example, the consent form for the study was modified after a participant expressed astonishment that her cancer was diagnosed at stage IV, despite the fact that the oncologist had carefully explained the diagnostic stage.

Interview data, especially in the domain "Why me?," reflect the existential struggle participants experienced at the time of diagnosis. As Weisman and Worden (1976) explained, the existential plight in cancer is a poorly recognized but significant period. It starts with the definite diagnosis and continues for two to three months into the illness, approximately 100 days. The chief signs of the plight are the predominance of life and death concerns and worries about health or physical symptoms.

Taylor (1998) and Taylor, Kemeny, Reed, Bower, and Gruenewald (2000) suggested that maintaining illusions of a positive nature about illness events such as cancer may enhance coping. In other words, maintaining positive illusions, believing that individuals can keep the cancer from worsening or coming back by maintaining a positive attitude, helps patients with cancer gain a sense of mastery and control over their illness situation. The illusions can be powerful coping strategies in a time of devastating stress. Evidence of this type of coping can be found in the study domains, specifically the dealing with it domain. Participants acknowledged the importance of gaining control and maintaining positive attitudes about their illness.

The findings in the rethinking parenting domain are congruent with the work of Lewis (1999, 2004). Patients with cancer often have worries about how to talk to their children about cancer and about their ability to support them. Results in the current study demonstrated that parental worries extended to adult children as well as toddlers, school-aged children, and adolescents.

Evidence in the dealing with it domain revealed a powerful pattern of active coping to fight the disease and limit its impact on QOL. Participants worked to remain hopeful and optimistic despite the gravity of their diagnoses. In contrast to the findings of Winterling et al. (2004), who studied patients with advanced-stage colorectal cancer, participants in the current study did not exhibit despair nor were they resigned to die. The findings were quite the contrary: Participants' coping processes were very active. They focused on living with their disease with an emphasis on the controllable—not the uncontrollable—aspects (Lewis et al., 1986).

The findings of the current study should be interpreted with caution. The sample size was small and the population was relatively homogeneous, most being Caucasian, middle- to upper-middle-class income, and largely well educated. Additional research is needed to gain a fuller picture of the experiences of patients with advanced colorectal cancer. Further research also is needed to develop and test evidence-based interventions that articulate participants' experiences reported in the current study.

Clinical Implications

Study findings suggest a need to carefully assess the impact of advanced colorectal cancer that explains participants' experiences in the core category of salvaging their normal lives. Many patients acknowledged the importance of maintaining their daily routine. Effective symptom management is necessary to reduce the daily disruption of the disease and treatment.

Furthermore, targeted assessment is important in the six study domains: feeling life is disrupted, experiencing physicians, feeling unprepared for everything, rethinking parenting, wondering "why me?," and dealing with it. Asking questions such as "How has this disease affected your life?" and "Do you ever ask why the cancer happened to you?" can help elicit the lived experiences of cancer.

Additionally, findings indicate that clinicians who work with patients with cancer should offer support as patients search for ways to explain this potentially devastating life event. Moreover, study findings suggest the importance of teaching active coping strategies as patients with advanced cancer struggle to come to terms with the demands of the disease while attempting to live their lives as fully and as normally as possible.

The authors wish to acknowledge the invaluable assistance of research team members Genevieve Hollis, MSN, CRNP, AOCN®, Barbara Boland, MSN, CRNP, Barbara Reville, MSN, CRNP, AOCN®, BC, and Mark Houldin, BA, JD.

Author Contact: Arlene D. Houldin, PhD, APRN, BC, can be reached at houldin@nursing.upenn.edu, with copy to editor at ONFEditor@ons.org.

References

- American Cancer Society. (2005). *Cancer facts and figures 2005*. Atlanta, GA: Author.
- Anderson, H., & Palmer, M.K. (1998). Measuring quality of life: Impact of chemotherapy for advanced colorectal cancer. Experience from two recent large phase III trials. *British Journal of Cancer*, 77(Suppl. 2), 9–14.
- Anthony, T., Jones, C., Antoine, J., Sivess-Franks, S., & Turnage, R. (2001). The effect of treatment for colorectal cancer on long-term health-related quality of life. *Annals of Surgical Oncology*, 8, 44–49.
- Anthony, T., Long, J., Hynan, L.S., Sarosi, G.A., Jr., Nwariaku, F., Huth, J., et al. (2003). Surgical complications exert a lasting effect on disease-specific health-related quality of life for patients with colorectal cancer. *Surgery*, 134, 119–125.
- Baider, L., Perez, T., & De-Nour, A.K. (1989). Gender and adjustment to chronic disease: A study of couples with colon cancer. *General Hospital Psychiatry*, 11, 1–8.
- Corbin, J.M., & Strauss, A.L. (1984). Collaboration: Couples working together to manage chronic illness. *Image—Journal of Nursing Scholarship*, 16, 109–115.
- Fernsler, J.I., Klemm, P., & Miller, M.A. (1999). Spiritual well-being and demands of illness in people with colorectal cancer. *Cancer Nursing*, 22, 134–140.
- Glaser, B.G., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Grant, M., Ferrell, B., Rivera, L., Dean, G., Chu, D., & Krouse, R. (1998). Quality of life for cancer patients with ostomies [Abstract]. *Quality of Life Research*, 7, 599–600.
- Holloway, S., Sarosi, G., Kim, L., Nwariaku, F., O'Keefe, G., Hynan, L., et al. (2002). Health-related quality of life and postoperative length of stay for patients with colorectal cancer. *Journal of Surgical Research*, 108, 273–278.
- Klemm, P., Miller, M.A., & Fernsler, J. (2000). Demands of illness in people treated for colorectal cancer. *Oncology Nursing Forum*, 27, 633–639.
- Krippendorff, K. (1980). *Content analysis: An introduction to its methodology*. Beverly Hills, CA: Sage.
- Kurtz, M.E., Kurtz, J.C., Stommel, M., Given, C.W., & Given, B. (2002). Predictors of depressive symptomatology of geriatric patients with colorectal cancer: A longitudinal view. *Supportive Care in Cancer*, 10, 494–501.
- Lewis, F.M. (1999). The relational model of functioning with cancer: A family focused framework for nursing practice. In C. Miaskowski & P. Buchsel (Eds.), *Oncology nursing: Assessment and clinical care* (pp. 319–331). St. Louis, MO: Mosby.
- Lewis, F.M. (2004). Shifting perspectives: Family-focused oncology nursing research. *Oncology Nursing Forum*, 31, 288–292.
- Lewis, F.M., & Deal, L.W. (1995). Balancing our lives: A study of the couples' experience with breast cancer recurrence. *Oncology Nursing Forum*, 22, 943–953.
- Lewis, F.M., Haberman, M.R., & Wallhagen, M.I. (1986). How adults with late-stage cancer experience personal control. *Journal of Psychosocial Oncology*, 4(4), 27–42.
- Maguire, P., Walsh, S., Jeacock, J., & Kingston, R. (1999). Physical and psychological needs of patients dying from colorectal cancer. *Palliative Medicine*, 13, 45–50.
- Maisey, N.R., Norman, A., Watson, M., Allen, M.J., Hill, M.E., & Cunningham, D. (2002). Baseline quality of life predicts survival in patients with advanced colorectal cancer. *European Journal of Cancer*, 38, 1351–1357.
- Nordin, K., & Glimelius, B. (1997). Psychological reactions in newly diagnosed gastrointestinal cancer patients. *Acta Oncologica*, 36, 803–810.
- Northouse, L.L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science and Medicine*, 50, 271–284.
- Padilla, G.V., Grant, M.M., Lipsett, J., Anderson, P.R., Rhiner, M., & Bogen, C. (1992). Health quality of life and colorectal cancer. *Cancer*, 70(5, Suppl.), 1450–1456.
- Ramsey, S.D., Anderson, M.R., Etzioni, R., Moynour, C., Peacock, S., Potosky, A., et al. (2000). Quality of life in survivors of colorectal carcinoma. *Cancer*, 88, 1294–1303.
- Ramsey, S.D., Berry, K., Moynour, C., Giedzinska, A., & Andersen, M.R. (2002). Quality of life in long term survivors of colorectal cancer. *American Journal of Gastroenterology*, 97, 1228–1234.
- Sahay, T.B., Gray, R.E., & Fitch, M. (2000). A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice*, 8, 38–44.
- Schag, C.A., Ganz, P.A., Wing, D.S., Sim, M.S., & Lee, J.J. (1994). Quality of life in adult survivors of lung, colon, and prostate cancer. *Quality of Life Research*, 3, 127–141.
- Spradley, J. (1979). *The ethnographic interview*. New York: Holt, Rinehart, and Winston.
- Spradley, J.P. (1980). *Participant observation*. Orlando, FL: Harcourt Brace Jovanovich College.
- Sprangers, M.A., Taal, B.G., Aaronson, N.K., & te Velde, A. (1995). Quality of life in colorectal cancer: Stoma vs. nonstoma patients. *Diseases of the Colon and Rectum*, 38, 361–369.
- Sprangers, M.A., te Velde, A., Aaronson, N.K., & Taal, B.G. (1993). Quality of life following surgery for colorectal cancer: A literature review. *Psycho-Oncology*, 2, 247–259.
- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Thousand Oaks, CA: Sage.
- Surgery for colorectal cancer in elderly patients: A systematic review. (2000). *Lancet*, 356, 968–974.
- Taylor, S.E. (1998). Positive illusions. In H. Friedman (Ed.), *Encyclopedia of mental health* (pp. 199–208). San Diego, CA: Academic Press.
- Taylor, S.E., Kemeny, M.E., Reed, G.M., Bower, J.E., & Gruenewald, T.L. (2000). Psychological resources, positive illusions, and health. *American Psychologist*, 55, 99–109.
- Weisman, A.D., & Worden, J.W. (1976). The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine*, 7, 1–15.
- Whynes, D.K., & Neilson, A.R. (1997). Symptoms before and after surgery for colorectal cancer. *Quality of Life Research*, 6, 61–66.
- Williams, N.S., & Johnston, D. (1983). The quality of life after rectal excision for low rectal cancer. *British Journal of Surgery*, 70, 460–462.
- Winterling, J., Wasteson, E., Glimelius, B., Sjoden, P.O., & Nordin, K. (2004). Substantial changes in life: Perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nursing*, 27, 381–388.