

# 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®, 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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support; support, non-U.S. government; stress, psychological; and the key words caregivers and colorectal cancer.

Published evidence has been increasing about the devastating effect that cancer may have on caregivers, particularly at the end of life (Goldstein et al., 2004; Grunfeld et al., 2004), but little research exists regarding how patients and their caregivers adjust to colorectal cancer at the time of diagnosis. Two relevant studies of spousal caregivers were found comparing patients' and spouses' appraisal of the illness and patterns of adjustment over a one-year period after colorectal cancer surgery. Northouse, Mood, Templin, Mellon, and George (2000) found that women reported more distress, more role problems, and less marital satisfaction than men, regardless of whether they were patients or spouses. Baider, Perez, and De-Nour (1989) reported similar results for patients with colorectal cancer; adjustment to the illness was worse for female than for male patients. However, they found just the opposite in spouses—male spouses fared worse than female spouses. Northouse et al. found that both partners (patients and spouses) reported decreases in their family functioning and social support as well as in emotional distress over time. Few significant correlations were found between partners' emotional distress scores; however, partners' role adjustment problems were significantly related across all assessment times, suggesting that role problems were interpersonal in nature and significantly influenced by the partner's adjustment. The strongest predictors of patients' role adjustment problems were hopelessness and spouses' role problems, whereas the strongest predictors of spouses' role problems were spouses' own baseline role problems and level of marital satisfaction.

Maguire, Walsh, Jeacock, and Kingston (1999) compared the congruence of reports of symptom distress among patients with terminal colorectal cancer, caregivers, and physicians. Reasonable congruence was found between patients' and caregivers' reports for appetite loss, nausea or vomiting, and pain, but agreement was low between patients' and caregivers' perceptions of psychological concerns. Of interest, the rate of caregivers' false-positive reporting was high. The major concerns noted by the caregivers were patients' illness, the future, and their own emotional demands.

In a series of studies, Carter (2002, 2003) found that adult family caregivers experience sleep problems and depression while caring for patients with cancer. Furthermore, over time, significant changes were reported from week to week in sleep and depressive scores (Carter, 2003); the sleep loss affected emotions and caregiving ability (Carter, 2002). Carter and Acton (2006) recently compared the relationship of personality and coping in caregivers of patients with cancer with the published findings from caregivers of patients with dementia. Results suggest several similarities, including a higher risk for clinical depression, severe sleep problems, and less functional coping. The investigators concluded that caregiver personality and coping strategies appeared to be related to caregiver outcomes. In their qualitative study, Broughton, Bailey, and Linney (2004) examined 49 patients' and 8 caregivers' experiences with colon cancer after surgical intervention. Their findings indicated that patients and caregivers had unmet information needs and were unaware of the signs and symptoms of colon cancer.

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). Study findings indicated physical, mental, practical, and positive changes for patients and spouses. 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 spouses.

Research to date provides evidence that colorectal cancer and its treatment significantly affect caregivers. However, data are limited to describe the nuances of caregivers' experiences adjusting to a loved one's advanced cancer diagnosis. As a result, significant gaps exist in understanding about the effect of advanced-stage colorectal cancer from the perspective of caregivers at the time of a loved one's initial diagnosis.

## Methods

### Participants

Fourteen caregivers and patients recently diagnosed with advanced (stage III or IV) colorectal cancer participated in a larger interview study. This article will describe the qualitative results obtained from confidential face-to-face interviews with the identified caregivers (i.e., 12 spouses and 2 friends). After study approval by a human subjects committee, caregivers of patients who met eligibility requirements (i.e., patients diagnosed with stage III or IV colorectal cancer) 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 caregivers were invited to participate. A total of 18 patients were invited to participate, and 14 agreed to be interviewed. No differences existed in any treatment or background characteristics between patients refusing to participate and those agreeing to be interviewed. All of the patient-identified caregivers of the 14 patients who consented to participate in the study agreed to be interviewed.

### Procedure

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

Interviewers asked participants to describe their experiences with their loved ones' diagnoses and treatment of colorectal cancer. Initially, a broad question was asked: "What has it been like for you caring for your loved one who has just been diagnosed with colorectal cancer?" Specific prompts were given to invite elaboration about the effect on daily living, coping strategies used, and the effect on their families or children.

### Data Analysis

Content analysis with inductive coding was used to evaluate 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) that were extended by Lewis and Deal (1995). During the initial phase of coding, transcripts were read multiple times with the intent of identifying caregivers' concerns, distress, and coping strategies

as well as how their daily life was affected. Open codes were identified, analyzed, compared, and grouped into categories (Strauss & Corbin). Similar codes were grouped together according to a common element. Categories were based on the manifest, not latent, meaning of the verbatim, transcribed text and labeled with emic words (i.e., names reflecting the words of the caregivers) (Lewis, Haberman, & Wallhagen, 1986). Definitions for the categories were developed and refined. During the coding process, emics in each category were compared within and between categories to maximize the fit of the caregiver data with the category. All categories were compared with the other categories to maximize their unique and nonoverlapping qualities; the process involved constant comparative analysis (Corbin & Strauss, 1990). Discussions between two members of the research team resulted in refining the category's definition, recoding the data into a different category, or identifying a new category. Categories were reviewed in a final stage of analysis and organized into larger groupings called domains from which the core category was derived (Corbin & Strauss; Lewis & Deal).

## Results

Caregiver participants ranged in age from 26–64 years ( $\bar{X}$  age = 44.92, SD = 10.8). Male caregivers averaged 42 years, and female caregivers averaged 46 years. Four men and 10 women were interviewed: 12 Caucasians, 1 Asian, and 1 African American. Ten participants had children ranging in age from 2–25 years. Education ranged from some high school to a graduate degree. Participants were middle to upper-middle class based on their income. Twelve participants were married, and two were single. All participants were recruited within the first three months following their loved ones' diagnosis of stage III or IV colorectal cancer. All study patients had completed surgical interventions; only one patient had an ileostomy. At the time of the interview, the patients were in their first chemotherapy treatment cycle.

The coded interview data yielded three domains (see Table 1): 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 disruptions and personal impact." Caregiver participants struggled with the disruption of the disease in their lives and

attempted to cope positively while maintaining a semblance of normalcy in family life.

### Experiencing Total Disruption of My Life

Participants reported that their lives were completely disrupted by their loved ones' illnesses, which resulted in increased responsibilities, altered priorities, and an inability to plan. Significant personal, relational, and work impact was reported as well as the struggle to determine a balance. Some caregivers tended to minimize the disruption (e.g., "It's been a little bit stressful." "The diagnosis was a little bit of a shock."), whereas others did not (e.g., "This cancer has been a total disruption of my life." "Your whole life changes in 24 hours." "Now I just don't have a future. The statistics—they're just not positive for a much longer life.").

Participants reported struggling with the change in daily routine and the dramatic increase in responsibilities. As one female caregiver noted, "It's changed my daily routine. I don't have a routine anymore." A male caregiver related, "I have to tell you that paying the bills was the most stressful thing . . . because I am the primary breadwinner and have been for years, but I haven't paid the bills since we got married." Other types of disruptions were noted. One spousal caregiver stated, "His cancer diagnosis means I have to worry about . . . simple things like getting my son to his lessons, getting him to practices, getting him to [religion classes], making sure he gets his homework done, dropping off and picking up my daughter . . . doing all the grocery shopping."

A male caregiver stated, "I have to manage the whole house, earn all the money, pay all the bills." Another spousal caregiver noted, "I would take care of more personal stuff for her now . . . doctor's appointments, making sure things are done." Others reported that priorities shifted significantly. A male caregiver noted, "You get your priorities . . . you have totally different priorities now, what's important and what's not important."

Planning for the future was significantly affected by cancer. As one spousal caregiver said, "I'm reluctant to make vacation plans. I'm reluctant to accept social invitations. I'm reluctant to do a lot of things 'cause I just don't know, like, how he is going to respond to the treatment." A young caregiver noted the following.

He's gonna have trouble getting life insurance. Chemotherapy can make you go sterile, so he had to go to a sperm bank. We don't know if the treatment's gonna work, and if it does work, is it gonna come back 10 years from now when we do have kids? Am I gonna be a widow?

All participants spoke in great detail about the personal effect of the cancer diagnosis. A number of caregivers indicated their feelings of helplessness. A male participant stated, "I mean, like, I feel helpless. Like you feel like, if I could give her my strength for just that hour or so, I would give it to her." A female participant said,

Well, Jim and I just had a discussion about it because . . . he kind of said to me that he felt like he's done it himself, which kind of upset me because I feel like I've been trying to do as much as I can. But the truth is he's the one who's been going through the treatments, he's the one having the nausea, so that's hard.

**Table 1. Domains and Related Categories**

Domain	Related Categories
Experiencing Total Disruption of My Life	Changing priorities, increasing responsibilities, struggling with an inability to plan, dealing with personal effects, experiencing relationship change, affecting work, and figuring out a balance
Staying Positive	Trying to go on living, dealing with things as they come, controlling emotions, using faith, and talking to friends
Attempting to Keep Family and Children's Routines as Normal as Possible	Worrying about the effect on children, struggling to know the right thing to do, giving children the positive side, and dealing with extended family



Several participants spoke about multiple worries and concerns. One caregiver noted, “Your whole future and every plan you have changes in the blink of an eye. So, immediately I look at our future as far as marriage, children, income, being together, life insurance. . . . All these things are affected now.” Another caregiver expressed concern about the relationship with the children: “I think the hardest thing for me is to see him be cranky with the kids, because, God forbid, anything happen a year or two from now, I wouldn’t want them to remember him being this cranky guy because he’s not.” Another worried about finances.

Now it’s all the more important for me to go to school and finish school and make sure I have a good income because now I feel like I have to make sure in the future, if something happens with him, I’ll be able to pay bills and I’m not gonna struggle. I’m not gonna be out in the street; I’m not gonna suffer.

Finally, a spousal caregiver spoke about his need to be an expert. “Well, I need to learn as much as I can, and with this treatment, there will be times that I have to look for the right paper, read the instructions, and make the right call perhaps. And I need to know. I have to have the intelligence about it so at least I know what I’m describing.”

In general, younger caregivers reported more distress.

I think the biggest thing would be our children are young. The other thing is that we’re still sort of, we’re at sort of the peak part of our careers or the fastest-moving parts of our careers, whereas a lot of the people I see in the infusion room, they’re retired, so, so it’s a problem. . . . I’m just kind of on pause, and the universe will basically stop the clock for a year.

Participants complained about a variety of symptoms resulting from the burden of dealing with their loved ones’ cancer, including anxiety, depression, poor sleeping, diminished appetite, guilt, and “being angry at the world.” Many participants indicated that the distress was worse at diagnosis and diminished somewhat when the chemotherapy treatments began.

I’ve found the most, the most anxiety was the period from the time she had her surgery and we knew what she had until we got her into treatment because we went through several hospitals. . . . It was not much unlike anything else in your life when something’s not complete and it’s naggin’ on your mind. . . . But once she got on the treatment . . . things started to get back to normal a little bit.

It seems like this picture of a shared future is disappearing. Like I said to my best friend, “I don’t see a reason for living anymore.” I always loved him very much. I hope for the best. But you never know. . . . You have to be realistic.

I’m a real easy-going [person], but I find that I can lose my temper faster now.

Kind of mad at the world a little bit.

Sleepwise . . . [you] know, [I] can’t sleep too good.

I think the fact that I could’ve . . . I didn’t do more to make sure she got the colonoscopy. Because if she did, they probably would’ve caught it sooner rather than later.

Some caregivers tried to avoid thinking about the course of the disease.

I guess [I’m] trying not to think about it too much. Because if I spend a lot of time thinking about it, I get very depressed over it, and initially I thought if I went out to the Web site, these different Web sites, and do some research, like if you know something, you feel like you can control it better, but all it did was frighten me so I just stopped looking. . . . The statistics are pretty grim.

Another male caregiver noted, “It comes into my head all the time. Since she got [cancer,] every 10 minutes it comes into your head whether you want to think about it or not.”

A few participants characterized cancer’s effect as being at war.

We are at war. . . . We’re a team and we’re at war right now, so that’s where we are, and it’s gonna take past December 31st, last chemo treatment, before we can start thinking about regrouping and reorganizing and rediscovering a different way of being in the world. And all the other roles in our life have been pushed to the fore and life as a couple seems like, where does that go.

A male caregiver indicated what was most difficult for him.

I guess initially, maybe the prospect of maybe not havin’ her. You know if she doesn’t survive it, but like I said, in the last four weeks, we’ve kind of started to get back to normal. I’m startin’ to think about other things now, where initially, like hobbies and stuff, that first six weeks we just stopped doin’ everything. We started to go away again, finally. We have a trailer up in New York, and we started to go up again.

Participants reported a significant effect, both positive and negative, on relationships with their loved ones. “My husband was nasty to me. He was just so rotten to me during that whole time. . . . He’s angry at the world and angry at the situation, and he took it all out on me. It was like walking on eggshells all the time.” Another female caregiver said, “On some level, [our relationship is] more business-like . . . because certain things have got to get done and things have to be scheduled.” A wife caregiver noted, “I go out of my way to make sure he’s not stressed out. I try to do everything I can to keep him peaceful and relaxed, and that puts more of a responsibility on me.”

A spousal caregiver noted problems in communication.

So, what he does is he bottles it up or keeps the information inside and feels that he protects people by not telling them. But what’s important is to tell them so they understand why you’re in a bad mood that day, why you don’t feel well, why you’re upset. But another problem is expressing these feelings because he, himself, he’s very sensitive, so, as a man, he doesn’t want me to see him cry, so he’ll intentionally not tell me because he doesn’t know how to talk about it without getting upset.

Several participants pointed out the positive aspects of dealing with colorectal cancer. One female caregiver stated, “We don’t argue. We used to badger each other a little bit, but we don’t do that so much now. He’s been kinder to me.” A male caregiver reported, “[The cancer diagnosis] definitely makes you bond because you talk to each other more personally and have to tell each other more personal things as far

your body and how you're feeling, things that you normally would just keep to yourself." Another caregiver stated, "I think we've grown closer because he's been forced to tell me things he normally wouldn't share with me, as far as how he feels."

Finally, a male caregiver described illness benefits.

Only in the respect that you kind of reprioritize what's important and the idea that you just don't know how much time you have. Before something like this, you tend to think, "Well, we're both reasonably healthy," and you assume that, chances are that you're gonna live a reasonably long life. Now it's kinda like different and you say to yourself, "I gotta stop, stop letting things, small things that used to bother me before, and pay attention to the more important things."

Several participants noted cancer's positive and negative effects on sexuality. A female caregiver said, "There's not a whole lot of desire on my part either, just from my own stress levels being so over the top, too." Another caregiver stated, "I guess sex is over, I guess. To put it bluntly." One female caregiver worried about the effect of sexual activity on the health of her husband.

I am not less interested in intimate relationships. But I just worry, not to give him, at the moment, when he has the chemo. He needs to be careful about maybe infections and because his immunity will be running lower. I don't want to give him any, any additional risks. God forbid he would run out, run out with some infection or something. I would probably be blaming myself and maybe because of me, maybe because his immunity was too low.

A female caregiver reported a positive impact on sexuality.

For some reason, our sexual relationship has gotten stronger and more often, and we do work around his treatment because we can't do it during treatment, not while the chemo is in his system, but, I mean, yeah, I think, as a result of us bonding more, being closer together, more personal, it's brought us together a little bit more intimately.

Caregivers reported a constriction in their social life that had positive and negative consequences. For example, one caregiver noted the negative implications, "I mean as far as going out over the weekends, we don't go out with our friends nearly as often." Another caregiver reported benefits: "We do stay home more and do what I would like to think of more quality. . . . I think healthier, nicer things like renting a movie or going out to the movies or just laying around watching TV or cooking at home."

Participants discussed the effect of their loved ones' cancer diagnoses on work. A male participant stated, "You know, I haven't been there that much. I took some time off [from work], days like today. That's so not important as this." A female caregiver said, "It's tough in my case to keep working. I mean I need to work and I should work, but when people ask me at work . . . I just don't want to have to answer all the time that he's fine."

A number of caregiver participants struggled with maintaining balance with caregiving demands and life demands. One caregiver characterized the tension in the following way: "I try not to wait on him hand and foot as I was. I'm trying to find a balance, but that's not always so easy because I think he's in

pain and I don't think he has the energy and so I don't want him to exert himself, but then, I guess, that's not necessarily the answer." A spousal caregiver noted,

I'm schlepping the kids on the weekends. I'm doing all the errands because, you know, on a chemo weekend, he's knocked, and either the kids are coming with me or they know they have to take care of themselves and I'm off doing grocery shopping and going out to do whatever has to be done, to get everything done. So, that's how it's affected me, the administration of life.

Another caregiver spoke about her experiences negotiating daily demands.

We don't get to spend as much quality time just talking about things that aren't health related. I realized that I hadn't had a chance to even talk to him about his doctor's appointment yesterday afternoon because of the whirl of coming home and making dinner and talking to the kids about each of their camp experiences.

## Domain 2: Staying Positive

Participants struggled to maintain a positive attitude and cope on a day-by-day basis for their loved ones' sake and for the sake of themselves and their family. Many caregivers struggled to maintain optimism. "So I take a step back and I think about [it]. I say, you know what? It's all gonna be good." Another caregiver noted that she had to train herself not to cry. "I would think about it and I would cry, and that wasn't helping him. So I had to try and train myself on my own, because I'm very sensitive, to learn how to suck it up when I was about to cry . . . clench my jaw, blink my eyes, turn away, go outside." Another female caregiver said,

I try to tell myself, well, you have to, you have to be positive. You have to be optimistic. You have to think positive. You have to pray and be positive, but then this is a theory. This is wisdom tells you this, but then, but then your realistic outlook, your knowledge also tells you it, you know, it can go any way.

A male caregiver stated,

I don't spend a lot of time thinking about the, the negative stuff. Initially when it first hit me, everything went through my head, from my health and what happens if something happens to both of us. Initially I was having some problems with my stomach and I was having pains and it turned out to be like my sympathy pains because I went and got it checked out. I was fine, but there was a lot of things going through my head. . . . If this turns out for the worst, I've gotta be there . . . and make sure the kids are fine.

Finally, a young male caregiver reported,

I like to look at it from a positive standpoint that she's more physically fit to be able to go through it and deal with it and beat it than if you got it when, you're 60 or 70 and you had another nagging illness and wear and tear of the chemo, making you sick, and you couldn't go through or couldn't go on with that. Other than having cancer, she's probably the most physically fit person. . . . She did all the right things, so I gotta . . . think that that counts for something.

Some participants reported the use of avoidance to preserve a positive focus. "I guess I try not to think about it too much because if I spend a lot of time thinking about it, I get very depressed over it." Another noted, "You know, you can't dwell on it. You can't think about it because it's not gonna go anywhere. I'm not gonna do anything. It's gonna kill ya. You gotta keep going." Others spoke about the importance of dealing with issues in the here and now. "I just feel like I need to sort of deal with what shows up on my plate every day as opposed to being able to look too far into the future."

A female caregiver emphasized the need to keep living. "When people say to me, 'Shouldn't you be home?' I say, 'No,' because I need to go on living, too. I need to go on living, too. We both need to go on living and doing what we want to do if that's possible." A few female caregivers noted that speaking to friends was helpful. "I've talked to some friends, and they are there for me. They talk to me. It's easier to get it out, to talk about how you're feeling with someone besides him and see how they come back about, what their point of view is."

A male caregiver believed that his positive outlook would help in dealing with the illness.

I'm probably the most prepared as you can be for something like this, having, you know, gone through it, with my brother and having gone through other adversities, having gone through the fact that when adversity happens people look to me and, and just the way that I approach life in my belief system. In fact, that's what I told [the patient]. You know, a lot of people say, "Why does this happen to them?" I wanna be able to tell people, "Why not happen to us?" You know, we're probably . . . and I speak more so for myself. We have the faith to sustain a positive outlook.

Some caregivers noted their faith helped them to deal positively with the illness.

Knowing that everyone's got their cross to bear and this is mine or this is my family's. So, from a faith standpoint, that's where my faith comes in. If I didn't believe that we're only here for a short period of time and that there's a better life after, when we pass away, I don't know if I'd be able to deal with things the way I deal with them now because I realize that this isn't the be-all, end-all. This is . . . okay, you know, everyone's gonna have these things to deal with. It's how you deal with them that's gonna determine, you know, how you're looked upon, when you pass away.

Other caregivers described their search for meaning.

Well, obviously when this happens, it changes your life. So, I think it's only appropriate . . . people do some soul searching and look at, where you've been, where you're goin', what you're gonna need to do and talk about that, how you're gonna do it. I mean are you, are you gonna face it head on . . . understand it, wanna know exactly what the diagnosis is and what you need to do, or are you gonna approach it on a need-to-know basis and just understand bits and pieces as you go?

Another caregiver described the importance of not placing blame in remaining positive.

We haven't, for one minute . . . never asked, why us and never, were we placing blame and spending a lot of time . . . even, even though, we probably have, if I were to go back over the records and what have you, a good case against doctors, that either they didn't do a test they should've done, it shouldn't be up to me to be telling my wife to go get a colonoscopy, with her seeing different doctors. But, the reason they probably didn't send her is because her age is, that's not the thing they look for at that age. But, I think that, I think that helps us in the long run that we don't dwell on the negatives and we don't get caught up in all that and we can use our energies in a more positive area, to fight the illness, to keep emotionally positive.

Some caregivers shared advice for others. One male caregiver said,

What I would tell somebody in the same situation, I'd just tell them . . . be a realist, try to understand exactly, you know, what you're up against. Get in the best doctors' hands, you know, stay positive. The other thing that we've done and I think it's been a source of strength . . . we've been very open and honest with everybody about her situation. So, I mean, even people that really don't know her know that she has cancer, know it's in the liver. . . . That helps us knowing, when you do that, everybody is a tremendous support system and they step up and they wanna do everything for you. So, we feel like we got so many people praying for us and, you know, helping us and supporting us, if we didn't take that approach and kept it secretive and it would just be us going through this alone, which would probably be a scary thing.

### **Domain 3: Attempting to Keep Family and Children's Routines as Normal as Possible**

The dominant theme was maintaining normalcy for the children. "I'm trying to keep my kids' lives, life, as normal as possible, and then part of me wondered if that is even reasonable. . . . I was so stressed about that." Another caregiver admitted, "I just don't know what the right thing is to do, and like I said, [the children] never ask. So . . . I haven't done anything directly. I just really don't know what to do." Another caregiver admitted uncertainty as to how to handle the children and the family. "[It's] hard to know [how] much to tell the kids. We have to watch what we say around them, as well as around my mother, and I'm more concerned about how my family responds through this than [the patient's] family. They seem to have a better feel." Others reported little confidence in their parenting ability: "No, I don't think that my confidence in parenting has changed. I think my confidence level's just as low as it was."

Some participants spoke about the importance of using faith to maintain normalcy of the cancer event for children within their belief system. A male caregiver said,

So we just try to keep their life as normal as possible, and they've looked at it like, Mom's gonna be sick some days and not feel well, but there'll be days that she's feeling good and she'll be able to do everything she's always done. So I guess we've instilled in them that the same thing in the way that I approach it, that, okay, we're all gonna die at one point and we're goin'



to heaven, but that's what we're here for. I mean they're sad when Mom's sick and she can't do different things, but at the same point in time, I think there's a comfort there knowing that, if things don't turn out and the worst happens, you know, that she's just gonna be up there, you know, with my uncle and my grandmother and everybody else.

Some participants spoke directly about the cancer to their children. "I sat down with [my son]. I explained what had happened. I explained [the] surgery. I explained what the doctor said. I told him that he would have to have chemo and stuff like that." Some participants decided not to tell their children about the diagnosis.

I have made it clear because a lot of people now know. He was in the hospital three times. He had two surgeries and so many people knew what was going on . . . but I make it clear that we are not using the cancer word in front of our children. They'll hear me talk about [the] therapy or because I don't think they understand that therapy necessarily means that. And my biggest fear is that my daughter who is nine would understand not what he has, but somebody else's grandmother might have died of cancer and then they'll associate, "Well, my dad has cancer and he's going to die." So we just don't use that word. They know he's still undergoing treatment . . . but it doesn't really alarm them anymore—like it alarmed them in the hospital. . . . But, no, they don't know, which has been good. So it really hasn't impacted them tremendously.

Other caregivers reported children's concerns about role changes. "But I'm really caring for him so much and the kids see it. It kind of bothers them [that] I care for him more and more, like he's becoming a baby. And he hates it, too. And at the same time they're also becoming little cops. Like, Dad, eat your vegetables."

Many caregivers attempted to maintain a positive point of view. "I try to give [my kids] the positive side. . . . I tell them the truth. I don't lie to 'em, but I try to give a positive spin on it." Other caregivers reported using a frank and factual approach with their children about the disease prognosis.

I talk to the kids on the side, and they have questions and I'm up front with them. And, initially they were both very concerned, "Well, what are the doctors saying? How much time?" And I just tell them, it's not about a matter of the time. She's getting treated and we just go from here. There's no guarantees. And there's nothing that is to say that she won't be able to survive and I leave it at that.

A female caregiver reported her reaction when her husband attempted to prepare the children for the worst. "The other thing that just made me burst into tears was when Bill told me that he decided he wanted to buy a digital movie camera so that we would have film of him with the kids in case he died off and so that they would remember."

A female caregiver created a story to help her children understand cancer treatment.

So, there was one day I was just dropping them off and [my son] was talking about why I wanted to take a medicine that makes me so sick and so, he knows it's 'cause it helps cure the cancer. And so, I came up with a little

story . . . and [my son] asked me about it once or twice and I heard him explaining it to somebody else.

Another caregiver reported seeking a guidance counselor's assistance for her son. "I've asked the school to have the guidance counselor check in on him, but not to do it in a way that it would be obvious."

Some caregivers reported difficulty dealing with extended family.

The family didn't go to him because they didn't know how to face him. They were devastated. In Poland, cancer is a death sentence. They just write you off. It has been like that for a long time. So everybody's sort of brought up in that kind of frame of mind. You know, cancer means death. That's why a lot of the times nobody, people will even ignore the subject completely, not even mention, go around it, skirt around it, and you know that they know it, and you know, but they're afraid to, they're afraid to. . . . Well, we told everybody in the family to go get a colonoscopy and many already went.

Another caregiver said the following.

Well, first of all, all of his relatives wanted to come and although we didn't want to be negative about that. Like I said, he wanted to continue with his activities and so his sister did come for a week . . . and she was very helpful. But later, they all wanted to come and that would be . . . just a whole gang. And he felt that he wasn't ready for it psychologically, and so he told them that. I think I would have gone nuts had they all come at that time. But now if we get through the holidays and I do think he is deteriorating, then we'll have to reassess in January.

## Discussion

The dominant experiences of the study participants focused on coming to terms with the disruption of the disease in their lives, attempting to deal positively with the effect of the disease, and maintaining normalcy in family life. The core category that explained study participants' caregiving experiences was balancing caregiving activities and disruptions while dealing positively with daily demands and personal impact. The study findings show a relatively consistent and significant pattern of distress for male and female caregivers, which differs from previous work (Baider et al., 1989; Northouse et al., 2000), that is most intense after diagnosis and before adjuvant treatment begins. Some evidence indicates that the youngest caregivers experienced heightened distress. The caregivers struggled with the delicate balance of supporting their loved ones, maintaining their lives, and meeting the needs of their families. In the domain Experiencing Total Disruption of My Life, caregivers identified personal, relationship, and family burdens of the disease. Their familiar life patterns were upended. Their relationships were strained. As one participant noted, the cancer diagnosis affected "the administration of my life." Many caregivers suffered silently, worried that a shared future may not exist. Others struggled with role changes and financial and social disruptions, whereas some participants noted significant benefits. The domain Staying Positive illustrated the strong desire on the part of the caregivers to contain their distress and avoid thinking about the worst possible scenario. Many caregivers

appeared to have an urgency to hold on to a positive view of the disease and its prognosis to maintain normal living and meet the demands of caregiving.

In the domain Attempting to Keep Family and Children's Routines as Normal as Possible, caregivers focused on preserving normalcy in their daily routines. Caregivers assumed the role of protector for their children, extended family members, and loved ones with colorectal cancer. However, many caregivers expressed uncertainty about the most effective approaches to use, particularly with their children. Similar to the findings of Winterling et al. (2004), a number of study participants noted positive changes emanating from the colorectal cancer diagnosis.

The findings of the current study should be interpreted cautiously. The sample size was small, and the population was relatively homogeneous. Most participants were Caucasian, had a middle- to upper-middle class income, and were well educated. Additional research is needed to gain a more complete picture of the caregivers' experiences of patients with advanced colorectal cancer.

## Clinical Implications

Study findings suggest a need to carefully assess the effect of advanced colorectal cancer on caregivers within the core category of balancing caregiving activities and disruptions

while dealing positively with daily demands and personal affect. After a colorectal diagnosis, many caregivers put on a brave face while silently struggling with significant sources of distress and attempting to meet the needs of their loved ones with cancer and families.

To deeply understand caregivers' needs and concerns, a focused assessment is important in the three dimensions of the study domains. Some specific assessment questions include "How has this illness affected your daily life and your family life?" "Do you try to remain positive while dealing with the demands of the illness?" and "What have you told your children (family) about the cancer?"

Furthermore, study findings suggest the importance of offering psychosocial support directly to caregivers and providing guidance for support of their children and families. Clinicians should meet with caregivers separately and jointly with their loved ones with cancer to give permission to caregivers to acknowledge, validate, and normalize their concerns; encourage caregivers to care for themselves and seek personal support as needed; identify role and relationship issues; offer suggestions for meaningful personal and family support; and provide appropriate resources.

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