

Family caregiving challenges in advanced colorectal cancer: patient and caregiver perspectives

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Abstract

Purpose Family caregivers of advanced colorectal cancer patients may be at increased risk for psychological distress. Yet their key challenges in coping with the patient’s illness are not well understood. Soliciting both patient and caregiver perspectives on these challenges would broaden our understanding of the caregiving experience. Thus, the purpose of this research was to identify caregivers’ key challenges in coping with their family member’s advanced colorectal cancer from the perspective of patients and caregivers.

Methods Individual, semi-structured qualitative interviews were conducted with 23 advanced colorectal cancer patients and 23 primary family caregivers. Interview data were analyzed via thematic analysis.

Results In nearly all cases, patient and caregiver reports of the caregiver’s key challenge were discrepant. Across patient and caregiver reports, caregivers’ key challenges included processing emotions surrounding the patient’s initial diagnosis or recurrence and addressing the patient’s practical and emotional needs. Other challenges included coping with continual

uncertainty regarding the patient’s potential functional decline and prognosis and observing the patient suffer from various physical symptoms.

Conclusions Findings suggest that eliciting the perspectives of both patients and caregivers regarding caregivers’ challenges provides a more comprehensive understanding of their experience. Results also point to the need to assist caregivers with the emotional and practical aspects of caregiving.

Keywords Colorectal cancer · Family caregivers · Distress · Psychological · Coping · Qualitative

Introduction

In the USA, family caregivers provide over half of the care needed by cancer patients [1], with an estimated 4.6 million people caring for a family member with cancer at home [2]. Family caregivers often face a range of stressors, including occupational and financial strain, family role changes, disrupted household routines, and their own mental and physical health problems [3–7]. Indeed, among family caregivers of cancer patients, up to half report significant anxiety or depressive symptoms [8–11], and these symptoms often persist during the initial months and years following the cancer diagnosis [12, 13].

Little research has examined the experiences and distress of family caregivers of colorectal cancer patients, despite the high prevalence of this cancer [14] and extensive involvement of family members in patient care [3, 15]. A study found that approximately one fourth of colorectal cancer patients’ caregivers showed moderate to severe depressive symptoms during the initial months following the diagnosis [16]. Higher levels of caregiving stress have predicted more depressive symptoms in caregivers of colorectal cancer patients [17].

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This caregiving stress may be related to unmet needs for training in caregiving tasks, inadequate financial or social resources, or difficulty balancing multiple roles [3, 15].

Although research has provided an initial understanding of caregivers' reactions to the patient's colorectal cancer diagnosis, this research has not focused on key caregiving challenges. It is important to identify aspects of the cancer caregiving experience that are especially challenging for caregivers in order to develop interventions that may mitigate distress. At advanced stages, colorectal cancer may be especially distressing for caregivers as they cope with the patient's high physical symptom burden [18] and uncertain or poor prognosis [14]. Indeed, awareness of the inevitability of disease progression and death may contribute to caregivers' depressive and anxiety symptoms. Therefore, the goal of this qualitative study was to identify caregivers' key challenges in coping with their family member's advanced colorectal cancer. We used a qualitative approach that elicited both patient and caregiver perspectives on caregiving challenges in order to capture their range and complexity.

Methods

Sample

Following institutional review board approval, advanced colorectal cancer patients were recruited from the oncology clinic at an academic cancer center in the Midwestern US between September and December 2014. Patient eligibility criteria were as follows: (1) at least 8 weeks post-diagnosis of advanced (stage III or IV) colorectal cancer, (2) English fluency, (3) 18 years of age or older, and (4) presence of a primary family caregiver (i.e., a person who provided the majority of their unpaid, informal care). Eligibility criteria 1 through 3 were assessed via medical record review and consultation with oncologists. A trained research assistant then asked patients to identify a primary family caregiver and obtained written informed consent during a clinic visit. Consenting patients provided permission to contact their primary family caregiver. The research assistant evaluated family caregivers for eligibility (i.e., English fluency and age \geq 18 years) and obtained their informed consent in clinic or via telephone.

Of the 32 advanced colorectal cancer patients who were approached regarding this study, all patients were found to be eligible and six patients declined study participation. Primary reasons for declining study participation were lack of interest in the study and privacy concerns. Thus, 26 patients (87 %) consented to participate in the study and allowed the research assistant to contact their primary family caregiver. Ninety-six percent of caregivers (25/26) consented to participate in this study; one caregiver could not be reached via phone for the consent process. In addition, two caregivers and one patient

could not be reached via phone for the telephone interview, and one patient did not participate due to hospice enrollment. Interview data from one patient could not be analyzed because the recording was not audible. After data from 23 patients and 23 caregivers had been analyzed, the researchers determined that thematic saturation had been reached. Demographic and medical characteristics of the sample appear in Table 1.

Data collection

In-depth, semi-structured telephone interviews were conducted by a doctoral student in clinical psychology with experience interviewing cancer populations. Patients and caregivers were interviewed separately to minimize response biases. Interviews ranged from 45 to 60 min and were digitally recorded. Patients and caregivers were asked to provide a detailed narrative of the illness, including treatments received and the caregiver's role in assisting the patient. The present analysis focused on caregivers' responses to the following questions: "Can you think of a particular moment that proved to be challenging when dealing with the illness? What has been the most challenging aspect of dealing with your [e.g., husband's/wife's] illness?" Caregivers were then asked to "describe the challenge and the steps that you took to deal with the challenge." The present analysis also focused on patients' responses to parallel questions: "Can you think of a particular moment that proved to be challenging for your [e.g., husband/wife] when dealing with the illness? What has been the most challenging aspect of dealing with your illness for your [e.g., husband/wife]?" Patients were then asked to describe the challenge and steps that the caregiver or they took to deal with the challenge. Throughout the interview, follow-up questions were asked to obtain a detailed narrative. The interviewer was trained to respond to distress by making appropriate referrals. Patient medical information was collected from medical records. Each person received \$25 for study participation.

Qualitative data analysis

Following transcription, interviews were imported into Atlas.ti software for thematic analysis [19]. Thematic analysis is a method of qualitative analysis that involves identifying, analyzing, and reporting patterns or themes across a dataset [19]. We chose an inductive approach to thematic analysis rather than a theoretical one, as the study was descriptive and exploratory [19]. A clinical psychology doctoral student and a clinical psychologist who both specialized in psycho-oncology read all transcripts and generated initial codes. The researchers then independently coded the transcripts in Atlas.ti and met regularly (i.e., after the first two sets of interviews completed by patients and caregivers and then every three sets of interviews after that) to review the codes and reconcile differences in coding [20]. At each of these meetings, the

Table 1 *Sample characteristics* (*N*_s=23 colorectal cancer patients and 23 family caregivers)

Variable	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	Range
Caregiver's relationship to the patient			
Spouse/partner	18 (78)		
Other family member	5 (22)		
Patient sex—female	9 (39)		
Caregiver sex—female	20 (87)		
Patient race/ethnicity			
Non-Hispanic White	21 (91)		
Black or Asian	2 (9)		
Caregiver race/ethnicity			
Non-Hispanic White	21 (91)		
Black	2 (9)		
Patient marital status			
Married or marriage equivalent	20 (87)		
Single, divorced, or widowed	3 (13)		
Caregiver marital status			
Married or marriage equivalent	22 (96)		
Single	1 (4)		
Patient age (years)		58 (11)	40 to 82
Caregiver age (years)		56 (12)	35 to 76
Patient education (years)		16 (3)	12 to 21
Caregiver education (years)		16 (3)	12 to 21
Patient annual household income (median)		>\$100,000	>\$10,000 to > \$100,000
Caregiver annual household income (median)		>\$50,000	>\$30,000 to > \$100,000
Months since the patient's colorectal cancer diagnosis		25 (21)	2 to 75
Cancer type and stage			
Stage III colon cancer	3 (13)		
Stage IV colon cancer	17 (74)		
Stage III rectal cancer	1 (4)		
Stage IV rectal cancer	2 (9)		
Colorectal cancer treatment type			
Surgery	23 (100)		
Chemotherapy	23 (100)		
Radiation	20 (87)		
Chemoradiation	4 (17)		

M mean, *SD* standard deviation

researchers jointly assessed whether saturation had been reached (i.e., no new themes observed in the data) [21]. Next, the researchers sorted the codes into broader themes. These themes were compared between patients and caregivers and within patient-caregiver dyads. Finally, the researchers checked to ensure that data within themes were consistent, and that the themes were distinct from one another.

Results

Our thematic analysis identified four cancer-related challenges experienced by caregivers: emotionally processing

the initial diagnosis or recurrence, managing practical and emotional aspects of patient care, facing an uncertain future, and encountering symptom-related suffering. Approximately equal numbers of patients and caregivers reported each challenge. However, when comparing patient and caregiver reports of the caregiver's key challenge within each dyad, these reports were discrepant for nearly all dyads.

A representative sample of these within-dyad comparisons is found in Table 2. The most common within-dyad difference (*n*=6 dyads) was that one dyad member identified emotional processing of the initial diagnosis or recurrence as the greatest challenge, whereas the other dyad member identified a challenge in caring for the patient's practical or emotional needs.

Table 2 Illustrative comparisons of patient and caregiver reports of caregivers' cancer-related challenges

Patient-caregiver relationship	Patient-reported challenge	Caregiver-reported challenge	Illustrative quote from patient and caregiver reporting caregiver's key challenge
Patient=husband Caregiver=wife	Initial diagnosis and recurrence	Practical and emotional aspects of patient care	<p>P: "Probably it's when we found out about the cancer was probably the biggest thing for her . . . One of the biggest and then we finally found out that it came back and . . . I think that was very challenging for her."</p> <p>C: "The most challenging thing . . . I really had to keep his children informed of any kind of tests that he was having done and how he was feeling . . . So I think that was the biggest challenge, just making sure his three kids and his two sisters and his parents, making sure all of them knew how he was doing . . . otherwise there wasn't really any big challenge."</p>
Patient=husband Caregiver=wife	Symptom-related suffering	Initial diagnosis	<p>P: "It would either be that one time where the pain was so bad in the hospital that I could hardly breathe. I don't think she was tolerating that as well as everything else. Also, I think that the nausea—when the nausea was real bad from the chemo—I think that bothered her a lot. Other than that, I didn't see anything that would jump out."</p> <p>C: "I think his very first diagnosis was the highest amount of emotion that I felt . . . feeling the most fear and regrets and despair. Leaving for the hospital the first time was extremely difficult where I felt like we were leaving our life behind us [crying]."</p>
Patient=mother Caregiver=daughter	Practical and emotional aspects of patient care	Initial diagnosis	<p>P: "The biggest challenge is that I live so far away and getting up there, and they [my daughters] work. They have to take off work. I don't like that they have to do that but they do it, and I am sure it could be stressful for them. Particularly stressful for [daughter who is primary caregiver]."</p> <p>C: "Being patient while we are waiting to hear results [of initial diagnostic tests] and then being patient to start chemo. She had surgery and even mom was like, 'Well let's just start the chemo.' And they were like, 'We need to give you a little bit,' and we are all just ready to keep moving forward, so a little bit of impatience on that."</p>
Patient=wife Caregiver=husband	Symptom-related suffering	Uncertain future	<p>P: "I'd say dealing with the sexual relations. That's hard because we were always really active before, so that is probably the biggest challenge . . . 'cause like I said, we were pretty active. Nothing stopped us. Now something's come in the way."</p> <p>C: "The helplessness that you can feel from the fact there's nothing I can do to make her better . . . there's no way I can make this go away unless I get some help from above or maybe that final cure will come through that we're all hoping for, for this disease."</p>
Patient=husband Caregiver=wife	Uncertain future	Practical and emotional aspects of patient care	<p>P: "it goes back to the kids . . . they can be a little exhausting. They can be a bit of a challenge and we . . . tag team on this, and I think every now and then she'll think about tackling that by herself and – and I think for her that can get a little overwhelming."</p> <p>C: ". . . providing everybody with his updates because you don't really want visitors And keep it together while keeping everybody in the loop and . . . having to actively try to stay positive and manage keeping track of everybody and keeping everybody updated. That was really difficult and having so much to do was really a challenge."</p>
Patient=husband Caregiver=wife	Initial diagnosis	Initial diagnosis	<p>P: "I think the most challenging thing that she's experienced is the night when I was first diagnosed she was very fearful for my life at that point in time, and she's explained it to me. So I think that it had a significant impact and was traumatic for her . . ."</p> <p>C: ". . . the shock of going from healthy, but knowing there's some strange things going on that we can't explain to 'Now you have stage III cancer' was quite – that was quite a shock."</p>

P patient, C Caregiver

The second most common within-dyad difference ($n=3$ dyads) was that one dyad member identified uncertainty about the future as the greatest challenge, whereas the other dyad member thought that encounters with symptom-related suffering were the most challenging. Other differences in caregiving challenges across dyad members were less frequent ($ns=1-2$ dyads), and, for two dyads, the caregiving challenges were identical across dyad members. Each challenge is described below.

Emotionally processing the initial diagnosis or recurrence

The initial diagnosis or recurrence was often characterized as a “shock” or “trauma” for caregivers. Feelings of fear, despair, and impatience with the lengthy diagnostic process were common. One patient whose sister was the primary caregiver described her sister’s and others’ reactions to her diagnosis:

they were all worried and scared and I told them don’t worry about it because I’m not. Most people broke down and cried when I got cancer [and thought that] I’m not going to live.

One caregiver described the shock following her husband’s diagnosis:

It was horrible. We [my husband and I] could barely talk to each other because . . . we were still reeling with this diagnosis. And . . . when you try to talk, you’d have such a big lump in your throat, you couldn’t talk . . . we were like robots . . . we were numb . . . when you get through things like that, I always tell people, just go on autopilot. That’s all you can do.

Reports of cancer recurrence or metastases also were characterized as shocking. As one patient’s wife said:

we had found out that it [the cancer] went to the lungs and that it was no longer going to be a curable . . . And that kind of sucker punched all the hope out of us. So I think that was probably a big defining moment for us . . . it just switched things . . . meaning there are other treatment options but it was really a blow.

Managing practical and emotional aspects of patient care

Practical and emotional aspects of caring for the patient were also common challenges. Practical aspects of caregiving included balancing work, household chores, and the patient’s medical appointments and regularly informing others of the patient’s condition. Providing personal care to the patient,

such as managing an ostomy, was especially challenging for some caregivers. As one male patient said:

I think the most challenging was when I first came back from the hospital after the second surgery and . . . the ostomy device failed and we rushed back and [my wife was] having to nurse me through the problems initially . . . the device was failing multiple times . . . There are times where I think maybe if I had died earlier she could have picked up with things and by now her life might be far more normal.

Compared to patients’ focus on the practicalities of disease management, caregivers emphasized the challenges entailed in offering emotional support. Various efforts to improve the patient’s mood were described, such as statements of encouragement, humor, and gratitude. As one patient’s husband said:

the most challenging thing is keeping her positive when she gets down . . . it is a challenge to try to bring her back to seeing how blessed we really are.

Some caregivers described interconnected efforts to improve the patient’s mood and their own emotional states, as illustrated by a wife caregiver’s comment:

He [the patient] would say things like – “I’m done” . . . And I just felt like he had no hope, had given up. And that, I mean, it just took everything. I would say that zapped my energy . . . That made me just really, really down. And yet I tried not to show it and I tried to be [positive].

Facing an uncertain future

Continual uncertainty regarding the future was characterized as the greatest challenge for some caregivers. This uncertainty centered on the patient’s potential functional decline and prognosis. One patient’s sister expressed this uncertainty:

. . . just the day-to-day of not knowing. You know, what’s this test going to show, and what is the medicine going to—is it going to work, or is it going to make her so tired she can’t even walk? . . . Every day presents something different.

One patient’s wife expressed similar concerns:

I guess the most challenging is that fact that you realize that they might not get better, but you just take it one day at a time.

One patient made a similar statement regarding her husband:

The uncertainty of the future is probably the most challenging thing.

Encountering symptom-related suffering

Observing the patient suffer from various physical symptoms, such as pain, fatigue, diarrhea, weight loss, and sexual symptoms, proved to be challenging for some caregivers. Feelings of helplessness, frustration, and sadness were common responses to patients' symptoms. As the wife of one patient said:

When I had to watch him try to get from the bed to the bathroom and not make it . . . it just, it broke my heart to see him go through that part.

One patient believed that his weight loss was especially difficult for his wife to observe:

I think seeing me go from 196 pounds to 153 pounds was quite a challenge for her because it looked like I was wasting away. So seeing me go from being a really healthy guy to not being able to get up out of the bed, I think, was quite a feat for her to deal with. So I think that that's probably the bigger issue, just those kinds of changes.

Discussion

This study provides an initial examination of cancer-related challenges experienced by family caregivers of advanced colorectal cancer patients. Four key challenges were identified: emotionally processing the initial diagnosis or recurrence, managing practical and emotional aspects of patient care, facing an uncertain future, and encountering symptom-related suffering. Although about equal numbers of patients and caregivers reported each of the four challenges, reports of the caregiver's key challenge were discrepant within nearly all patient-caregiver dyads. The most common discrepancy was that one dyad member identified emotional processing of the initial diagnosis or recurrence as the greatest caregiving challenge, whereas the other dyad member thought that patient care was the most challenging. These findings underscore the importance of eliciting patient and caregiver perspectives on caregiver experiences to broaden our understanding of their challenges.

A number of factors may have contributed to discrepant reports of caregivers' challenges within patient-caregiver

dyads. First, in prior research, many cancer patients and caregivers have reported discomfort with illness-related discussions or avoidance of such discussions [22–25]. Thus, some caregivers in the current study may not have shared their greatest challenge with the patient in order to prevent further distress. Second, cancer often involves a number of caregiving challenges; thus, both patients and caregivers may have been reporting significant stressors. Third, recall and response biases may have affected patient and caregiver reports. For example, some caregivers may have been uncomfortable disclosing that certain caregiving tasks were difficult, as performing these tasks without complaint is a culturally expected role.

Whereas patients emphasized the caregivers' practical challenges, caregivers tended to describe emotional aspects of caregiving as the greatest challenge. These emotional aspects included dealing with their own reactions to the patient's diagnosis or recurrence and symptom-related suffering as well as the continual threat of the patient's physical decline and mortality. Attending to the patient's emotions helped caregivers to manage their own fears regarding the future. Our results support a theory that considers "emotion work" to be a central aspect of family caregiving [26, 27]. In this study, emotion work was described as interconnected efforts to improve the patient's mood and their own feeling states, such as maintaining a positive or grateful demeanor. Similar emotional tasks were described in a qualitative study of caregivers of lung cancer patients [28]; thus, these tasks may be common across cancer types.

In this study, a minority of participants, most of whom were patients, considered practical aspects of patient care to be the greatest challenge. These practical aspects of caregiving included balancing a demanding schedule that involved accompanying the patient to medical appointments and frequently updating others regarding the patient's condition. Providing personal care to the patient, such as ostomy care, was particularly challenging for some caregivers. Perceiving practical tasks as stressful may be related to a lack of preparation for the caregiving role. Indeed, a prior study of caregivers of colorectal and lung cancer patients found that, depending on the clinical care task, half to one third of caregivers reported needing, but not receiving, training in these tasks, such as administering medicine, managing pain, and changing wound bandages [3]. Further research is needed to elucidate ways to support advanced colorectal cancer patients' caregivers in the management of patient symptoms and medical devices and enhance their self-confidence for care provision. Our findings show that practical aspects of caregiving were less salient for most participants than emotional aspects. However, as most participants were middle to upper class, they had access to financial and educational resources for managing practical matters.

Limitations of this research should be noted. Consistent with demographic trends for our cancer center, participants were primarily Caucasian and college-educated. In addition, although participants had a wide age range, older adults were underrepresented. Regarding gender, the majority of patients were male and most caregivers were female, which reflect the gender composition of these populations [2, 14]. Research is needed to assess the transferability of study findings across gender, racial, and socioeconomic groups. In addition, this cross-sectional study was intended as an overview of caregiving challenges to be explored further in future qualitative and quantitative research. We sampled patients who had received surgery and chemotherapy and their caregivers to obtain a retrospective account of caregiving challenges and primarily included patients with stage IV disease; thus, we could not compare challenges by treatment type or disease stage. A longitudinal design would help elucidate change in caregiving challenges at different phases of the disease and treatment process as well as factors contributing to these challenges.

Conclusions

The present findings have important implications for future research. First, our results suggest that eliciting the perspectives of both patients and caregivers regarding caregivers' challenges provides a more comprehensive understanding of their experience. In this study, patient and caregiver reports of caregivers' key challenges were almost always discrepant. Second, findings underscore the need for research addressing emotional aspects of caring for a relative with cancer. Although rates of significant distress are high among caregivers of colorectal and other cancer patients [8–11], their rates of mental health service use are generally low [10, 29]. Caregivers' underuse of mental health services may be related to their preoccupation with caregiving responsibilities, financial strain, and stigma associated with service use [30]. Research efforts are needed to increase distressed caregivers' engagement in mental health services. For example, researchers could test whether routine distress screening and referrals to mental health services is a better strategy for managing psychosocial issues than offering educational materials on distress management to all caregivers. Finally, as most intervention studies involving cancer patients' caregivers have primarily focused on the patient [31–33], research is needed to develop, evaluate, and disseminate interventions to address caregivers' needs. Our findings suggest that these interventions should include training in patient care in addition to addressing caregivers' mental health needs.

The present results also have implications for clinical practice. First, healthcare professionals may assess caregivers' psychosocial and practical needs and provide appropriate referrals. A checklist of potential concerns may help with the

referral process [34]. Obtaining both patient and caregiver perspectives on caregiver concerns may provide a more thorough assessment of these concerns. In addition, increasing patient and caregiver awareness of the other person's perspective may lead to improved communication and relational closeness. If divergent perspectives on caregiver concerns reflect underlying relational distress, a referral to counseling services may be warranted. Caregivers also may be referred to various informational and practical resources as well as mental health services such as stress management classes, support groups, and psychotherapy. Additionally, healthcare professionals may prepare caregivers for the practical and emotional aspects of caregiving. Meta-analytic evidence supports psychoeducation, skills training, and counseling as methods for reducing distress and enhancing quality of life among caregivers of cancer patients [32]. Such interventions may improve the health and well-being of both patients and caregivers.

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Compliance with ethical standards All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors declare that they have no competing interest.

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