Coping with colorectal cancer: a qualitative exploration with patients and their family members

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Abstract

Background. Extensive family coping research has been conducted among breast cancer, prostate cancer and melanoma with lesser emphasis on the coping experiences of colorectal cancer (CRC) patients and their family members.

Objective. To examine ways in which patients and their family members cope with the diagnosis of CRC.

Methods. A total of 73 participants (21 patients, 52 family members) from 23 families described their experiences during and after a CRC diagnosis, including their coping experiences with the diagnosis. Data from semi-structured interviews were audio recorded and transcribed. The data were analyzed utilizing content analysis with inductive coding methods.

Results. Eight major themes were identified: positive reframing, holding on to a sense of normalcy, religion and spirituality, joining a group, creating awareness of CRC, lifestyle change, seeking information and alternative treatments. Maintaining an emotional sense of normalcy through positive thinking, engaging in activities to take one’s mind off the diagnosis and believing that there is a higher authority which has control over the diagnosis and life were vital for the patients and their family members. Patients and family members used similar coping strategies.

Conclusion. Findings from this study have implications for understanding how families blend emotion-based and problem-focused coping strategies in the face of a CRC diagnosis. Further developing evidence-based interventions that target coping and well-being in cancer patients and extending them to family members is necessary and holds great promise for providers who care for patients with familial cancers.

Key words: Cancer coping, colorectal cancer, family coping, family experience, qualitative methods.

Introduction

Colorectal cancer (CRC) is the third most commonly diagnosed carcinoma and the third leading cause of cancer-related deaths among women and men in the USA (1). It is expected to cause about 50,830 deaths in 2013 alone (1). Research shows that a cancer diagnosis impacts not only physical but also mental health (e.g. depression, distress and anxiety) and family relations [e.g. decreased communication and intimacy (2,3)]; particularly when cancer is diagnosed at advanced stages, it can be devastating and create significant strain in personal and family life (2,4,5). Familial cancers extend the burden and stress from a
patient’s diagnosis to the patient’s biological family members. For instance, individuals who have a first-degree relative with CRC are at two to three times higher risk of developing cancer (6). Also it is evident that cancer diagnosis may have a devastating effect on caregivers (7,8). Consequently, individual patients and their family members require persistent adaptation to the stress endured from the disease and treatment.

Extensive family coping research has been conducted among families dealing with a broad range of cancers (9,10), specifically lung cancer (11), prostate cancer (12,13), melanoma (14) and breast cancer (15). These studies have reported on both positive and negative changes emanating from the diagnosis of cancer, to its treatment and care. These changes range from patients and families adopting a more positive attitude towards life, to experiencing disruption within the family dynamic (16). As a result, findings from these studies have led to the development of interventions targeted to patients as well as caregivers dealing with a cancer diagnosis (17,18). As for CRC, the family literature, however, has mainly reported on the impact of the diagnosis on the psychological morbidity (19) and screening decisions (20,21) of patients and their family members, with few studies reporting on the coping experiences (2). Similar to other types of cancers that have high penetrance susceptibility, it is imperative to acknowledge the coping experiences of CRC patients and their family members. This will inform practitioners on how to develop effective CRC family-based coping interventions. Therefore, the aim of the present study is to explore ways in which patients and their family members cope with the diagnosis of CRC.

Methods

Research design

This research is part of a larger federally funded study that was conducted to document the experiences of patients with CRC and their family members and their receptivity towards family-based cancer prevention programs: The family cancer experience and CRC prevention study. The larger, mixed-methods study employed semi-structured interviews and survey methodology. Details of the methods are reported elsewhere (22). This paper reports on the results pertaining to qualitative interviews only.

Participants and setting

Patients were identified through the Mayo Clinic Biobank for Gastrointestinal Health Research. After the study was approved by the Mayo Clinic Institutional Review Board, patients and family members who met eligibility requirements were approached in person at a clinic appointment or received an invitation by mail to participate. The inclusion criteria for patients was a CRC diagnosis at least 1 year ago, 18 years of age or older, able to provide informed consent and able to nominate at least 2 adult family members who would be willing to be contacted about study participation. Family members were eligible if they were at least 18 years and had a first degree relative who was diagnosed with CRC. For this study, ‘family’ is defined broadly, to include a group of people who are related biologically and a group of intimates with strong emotional bonds (identification, attachment, loyalty, reciprocity and solidarity), with a history and future as group (23); thus family members were not limited to biologically-related kin, but could also include ‘social’ family members. Nominated family members were contacted about study participation subsequent to enrolling the patient.

Data collection

Data were gathered via semi-structured, open-ended interviews. Although there were separate interview guides for patients and family members, the content areas were similar. Each guide utilized probes to explore the CRC diagnosis as a family experience and ways of coping with the diagnosis. Participants were asked to share how they maintain control over their day to day lives and to express their perception towards the notion that cancer diagnosis takes away the ability to have control over one’s life. All interviews were audio recorded and transcribed. Of 105 participants (42 patients and 63 family members) who initially consented to participate, 4 patients did not nominate any family members and were excluded. Fifteen participants were lost during the follow up process, one declined and 12 were unable to schedule an interview. Overall, a total of 73 participants (21 patients and 52 family members) completed an interview. The time frame between interviewing the patient and completing interviews with all subsequent family members was 2 months or less for three-quarters of the families. Each participant was offered a $25 gift card as remuneration for their time.

Data analysis

An analysis team (GBA and RWE) read the transcripts and performed content analysis to reduce the data. An inductive analysis method was adapted from methods described by Patton (24). The process included immersing in the details of the data and identifying important patterns, themes and categories. Open codes and themes were identified, analyzed and compared. Similar themes were combined and definitions for the categories of themes for coping strategies were developed and refined. Coding of transcripts was performed independently and harmonized through discussion. Representative participant quotations are included to inform the presentation of results. Data management and analysis was facilitated by Nvivo 10 (QSR International, Pty Ltd).
Results
A majority of the participants were female (n = 42) and of those who reported race/ethnicity, all self-identified as white, non-Hispanic. Participant’s age ranged from 19–80 years; M = 61 (SD = 16). More than half of the participants (n = 40) were employed and 22 had a college degree (Table 1). Of the 21 patients, 12 were diagnosed with Stage III CRC, 8 were Stage II and 1 person was diagnosed at Stage I. Tumour sites included the rectum (n = 11), right colon (n = 6) and left colon (n = 4). Three patients were interviewed within the first year of their diagnosis, a majority (n = 14) were interviewed 1–5 years post-diagnosis and 4 patients were interviewed 5 or more years post-diagnosis. Family members consisted of 14 spouses, 2 mothers, 7 sisters, 2 brothers, 16 daughters and 11 sons.

Data analysis resulted in eight main themes that identified primary strategies used by patients and their family members to cope with a CRC diagnosis. These strategies included, ‘positive reframing’, ‘holding on to sense of normalcy’, ‘religion and spirituality’, ‘joining a group’, ‘creating CRC awareness’, ‘lifestyle change’, ‘seeking information’ and ‘alternative treatments’. Out of the eight strategies, six (positive reframing, holding on to sense of normalcy, religion and spirituality, creating CRC awareness, lifestyle change and seeking information) were utilized by both patients and family members and two (joining a group and alternative treatments) were solely used by patients. Description of the themes and representative quotes are presented in Table 2.

Table 2

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients (n = 21)</th>
<th>Family members (n = 52)</th>
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<tr>
<td>Age (range 33–80; M = 61 ± 13; range 19–80; M = 47 ± 16)</td>
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<tr>
<td>Under 30</td>
<td>0 (9.5)</td>
<td>10 (19.2)</td>
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<tr>
<td>30–39</td>
<td>1 (4.8)</td>
<td>3 (5.8)</td>
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<tr>
<td>40–49</td>
<td>3 (14.3)</td>
<td>10 (19.2)</td>
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<tr>
<td>50–59</td>
<td>4 (19.0)</td>
<td>10 (19.2)</td>
</tr>
<tr>
<td>60–69</td>
<td>5 (23.8)</td>
<td>6 (11.5)</td>
</tr>
<tr>
<td>70+</td>
<td>6 (28.6)</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (9.5)</td>
<td>10 (19.2)</td>
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Positive reframing
This includes the use of cognitive processes to take away the burden of the diagnosis. In this category, participants focused on having a positive attitude. Irrespective of initial fear and shock, most patients eventually assumed a positive attitude regarding the CRC diagnosis. Family members also confirmed patients’ optimism and maintained a positive attitude in support of their relative’s diagnosis. Most importantly, family members relied on the optimism of patients to maintain their own positive attitude in order to support patients.

Holding on to a sense of normalcy
Most patients and their family members kept working and/or doing whatever they could around the house. They saw themselves as being fine, normal and courageous in the face of cancer. They articulated keeping a busy schedule and concentrating on activities and hobbies rather than on feelings about the diagnosis. Some also reported that nothing has changed in their lives despite the diagnosis of CRC.

One family reported that they cope by not making any plans for fear of not following through due to the patient’s ailment: thus living in the moment.

Religion and spirituality
This coping strategy focused on spirituality and the participants’ belief that they cannot control their diagnosis or their relative’s diagnosis but a higher power is in control. They reported that their faith in God was central to what kept them moving forward. This theme included both physical and spiritual activities such as praying, meditating, joining religious groups, relying on church for support and strengthening their faith in God.

Joining a support group
Strategies of joining a support group or identifying strongly with others who are cancer survivors were primarily used by patients. Seeing other survivors gave patients a sense of hope and consolation.

Creating awareness of CRC
Both patients and family members expressed how a CRC diagnosis inspired them to educate others and increase awareness of CRC through participation in fundraising activities (one family describes an annual golf tournament). Fundraising was to primarily support CRC research, which provided hope and comfort for participants. Also, creating awareness was focused on helping other people get screened and prevent CRC.
Lifestyle change

The diagnosis of CRC rendered most patients to change their lifestyle to adopt healthier behaviours and many, but not all family members to engage in CRC screening. Through family communication, most family members became aware of their vulnerability and increased familial risk; they became proactive by initiating or planning to initiate lifestyle change to stay healthy and prevent the disease. Lifestyle change included getting screened regularly for CRC and other diseases, increasing physical activity, keeping a healthy weight and eating healthy foods.

Seeking Information

Some participants actively sought information to understand the diagnosis and the available treatments as a means of coping. Patients sought information through the Internet, relied on other family members and reported asking more questions during doctors’ appointments. Although the Internet was the primary and the first place to look for information about CRC, participants expressed that sometimes information on the Internet can be harmful. Many patients also relied on other family members who have medical backgrounds to acquire more information and available treatment for CRC.

<table>
<thead>
<tr>
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<th>Definition and summary</th>
<th>Representative quote (patient)</th>
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<tbody>
<tr>
<td>Positive reframing</td>
<td>The use of cognitive processes to take away the burden of the diagnosis. Family members fall back on the patient’s optimism to maintain their own positive attitude in order to support patients</td>
<td>...and I don’t know if we will or not, but I still think positive rather than get scared….. I don’t really think that I can probably get rid of it totally, but possibly we can.</td>
<td>And I have had tough things that have happened to me and I will always feel that I’m incredibly blessed with the things that we are dealing with and other things that every person and every family have to deal with.</td>
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<tr>
<td>Holding on to a sense of Normalcy</td>
<td>Most participants expressed how they try to lead a normal life by keeping a busy schedule and taking their minds off of the CRC diagnosis</td>
<td>I still keep doing those trips to see what I can do. I go up and see the grandkids … we [patient and spouse] go down there and we got great-grandkids down there, so we try and get down and visit them and enjoy them, and they come and stay with us once in a while. So I still stay and do whatever I can as much as possible. I don’t try to let the cancer take over and prevent me from doing things outside.</td>
<td>I don’t think anybody is behaving any differently from when she was in the cancer treatment as to now.</td>
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<td>Well, I guess I’m still trying to keep control of my life, doing what I want and hopefully I can keep doing whatever I would like to do… … but I still try and do everything I can. We do gardening and take care of the yard and we went out East in the Spring and …. I’m going up to Canada for a week fishing.</td>
<td>But you just keep doing your everyday thing. You have to keep your mind busy with other things…keep your mind on other things, too. You know, do the health things you are supposed to do, but keep your mind on other things.</td>
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<td>Religion and Spirituality</td>
<td>This theme reflects both physical and spiritual activities such as praying, meditation, joining religious groups, relying on the church for support and strengthening their faith in God. Also, believing that there is a higher power which is charge.</td>
<td>I pray a lot…when you have conversations with yourself. I think that's kind of where my philosophy background comes in. That's helpful… kind of have to reassess the nature of things. You know, there's always a cause-and-effect relationship.</td>
<td>Male Every morning I get up, the house is quiet before we go to work and I'll watch the news for a little bit and have some coffee. And then I turn off the TV and I have a meditation book – just a daily meditation and I read that. And then I pray a little bit, pretty much the same stuff every morning – pray for my family and everyone around me – the kids and stuff. And then I read like a little chapter in my Bible.</td>
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<td>Male I pray a lot…when you have conversations with yourself. I think that's kind of where my philosophy background comes in. That's helpful… kind of have to reassess the nature of things. You know, there's always a cause-and-effect relationship.</td>
<td>Male There are things that you can control and can handle. And those that you have no control over you do what you can do and that is it. We are not in charge.</td>
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<td>Joining a group</td>
<td>Used primarily by patients for support and inspiration</td>
<td>I keep going and, we had a day last Fall here called 'get your rear in gear'. It is a …cancer awareness. You actually got to see a whole bunch of cancer survivors. But I think I'm the longest one around...It goes back to the get your rear in gear promotion. We have the stability of people that had it and the stories of people that didn't make it and the people that did make it. Those are great.</td>
<td>Male There is nothing that I can really do…with all the cancer going around I look at it as some guys say, why me, God? And I say, well why not me? So that is the way I felt, it is something that happens and it happened. We are not exceptional. That is the way I accepted it and we have great faith and great strength throughout the family.</td>
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<td>Creating awareness of CRC</td>
<td>Patients and family members actively create the awareness of CRC by organizing events, talking about cancer and supporting research through fund raising.</td>
<td>And then we have a family golf tournament. I mean, you know, they're [family members] very proactive on it.</td>
<td>Male After the surgery it was pretty easy, I think. Yah, if he [patient] sees kids now smoking he will give them…he will show him his chest and say, hey, this could happen to you! A lecture and then some.</td>
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<td>Female Every time I socialized, I would sort of put that into the same you know…talk about cancer all the time.</td>
<td>Male It was after my brother’s cancer we started the family golf tournament to not only raise money for colon cancer, we kicked in a little money and we play golf and make t-shirts and it is our private little fund raiser and I manage the money and send it off to the Cancer Society.</td>
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<tr>
<td><strong>Lifestyle change</strong></td>
<td>This theme included proactive behaviours (diet, exercise) to improve overall health, prevent CRC, or detect it early. Activities were commonly shared with family members.</td>
<td>So I still exercise and take it more seriously.</td>
<td>I think at the point she [patient] was diagnosed everybody in my family has [had colonoscopies] through the years just to be safe.</td>
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<td></td>
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<td>Female</td>
<td>Male</td>
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<td>Oh, yah, we go out walking together and we do the yard work and everything pretty much together</td>
<td>It definitely made me more aware of my own risk, and I have seen a doctor in the last week and a got a referral to get a colonoscopy</td>
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<td>Yah, I am always trying to eat more fruits and vegetables than I used to.</td>
<td>Once my dad had the colon cancer we started going, I think it was every 5 years we go for a colonoscopy, and then I go faithfully, every year, for a physical</td>
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<td>And I eat a lot of fresh fruit now, and I didn’t before. I bought an extractor ... I do a lot of extracting, and drink fresh vegetable juice.</td>
<td>So I work out a little more often than I [used to] do.</td>
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| **Seeking Information** | Participants sought to understand CRC diagnosis and treatment. This was done through the Internet, relied on other family members who have medical backgrounds. Ironically the same Internet mediums are the same medium that scared some participants about the CRC diagnosis. | You know, we were reading…and research and looking on the Internet and so forth. That was tough. | There were times you would look online, you know, and see what the diagnosis means and how they’re going to do the surgery. | Male |
|                        |                                                                                        | Female                         | Female                                |
|                        |                                                                                        | I went [to] the Internet quickly. But I quickly stopped doing that because – you know, I was curious about living with this...blogs, it just tears you down, obviously...I don’t think that’s good. | I try to read up to see what the medical arena has to say about cancer and try to stay on top of it and be educated about this particular type of cancer. | Female |
|                        |                                                                                        | Male                           | Male                                  |
|                        |                                                                                        | ...we’ve got two other people that are doctors in the family and, you know, we make sure that everything is passed around...you know, poor [name of family member who is a doctor], I mean, he’s got all of us calling him and saying, “What about this? What about this?” And, yeah, then he checks it out, and – you know...he sends us anything he finds in the medical journals or online, and we all check it out. And I’ve got a brother who’s a newspaperman, and he sends us anything he happens to come across. |                                | Female |
Alternative treatments

The search for alternative treatments was primarily utilized by patients as a way of coping with their diagnosis and CRC treatment. These alternatives included clinical trials and nutritional supplements. While family members were not actively using this strategy for themselves, they helped patients identify and research alternative treatments.

Discussion

This study provides evidence of mutuality of experiences among patients and their family members as they cope with CRC. Overall, the participants recognized that there is nothing they can do to modify the CRC diagnosis and its treatment. The dominant experiences of the patients and family members reported in this paper focused on attempting to deal positively with the diagnosis of CRC and trying to maintain a sense of normalcy while finding solutions to the CRC diagnosis and its related stress. Thus there was a strong desire for participants to contain their fear and worry as well as avoid thoughts that reflected ‘worst-case scenarios’. Patients and family members alike tried to manage their emotions through positive thinking, living their normal lives, engaging in activities to take their minds off the diagnosis and believing that there is a higher authority which has control over the diagnosis and their lives. Similar to the findings of Winterling and colleagues (25), a number of study participants noted positive changes emanating from the CRC diagnosis. Also, as in Teleghani et al. (26), participants in our study described that a positive relationship with and full reliance on God gave hope. Although alternative treatments were utilized solely by patients, family members rendered their support by searching for information regarding these treatments. For example, family members were involved in finding patient resources such as cancer centres for trial opportunities and information regarding nutritional supplements.

Patients and their family members described several strategies to actively cope with a CRC diagnosis including joining a support group, educating others about the disease and supporting CRC research, information gathering, changing lifestyle patterns and seeking alternative treatment options. While patients strategized to optimize their outcomes, many family members used their relatives’ diagnosis as a teachable moment to develop new patterns of behaviour. These behaviours included, being more physically active, eating healthy foods and attending regular screening programs. Our findings suggest that strategies used by family members to cope with a family member’s CRC diagnosis are not very different from strategies used by patients. As cancer support programs are being developed and implemented, it is

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**Table 2. Continued**

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<tbody>
<tr>
<td>Alternative</td>
<td>Primarily used by patients this includes clinical trials, alternative nutrition and supplements.</td>
<td>I’m on a study from up there, too, on I think it was bands, different strength bands; it is an exercise for colorectal patients, they are doing a study on it and I’m doing that, and I do most anything. It helps, it gets your mind occupied on other things besides sitting and thinking about your cancer. That, to me, that is the biggest thing – trying to think of other things and you don’t think about our cancer.</td>
<td>Male I had heard a lot about asparagus and… you put it in the blender and puree it and it doesn’t matter even if its canned – the person who found out is a biologist and said it doesn’t matter, just puree it and four tablespoons in the morning and 4 tablespoons at night. So I’ve been doing that for the last couple of months. And then, another one is the… supplements…which is an antacid for heartburn and taking an active ingredient and… I take four of those every night before I go to bed. And that is supposed to retard the cancer from the metastasizing.</td>
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<tr>
<td>treatments</td>
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<td>Female</td>
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important to fully consider the needs of the family members and how they cope with the diagnosis. In an earlier analysis of these data with regard to program development (22), we learned that patients and family members are receptive towards family-based programs for CRC. In the analyses reported here, we learned that patients and families share a number of coping strategies. Taken together, these findings suggest that interventions that introduce patients to new activities to enhance coping strategies and promote quality of life in light of a cancer diagnosis may also be beneficial for family members. For instance, interventions for cancer patients involving meditative movement (27,28) and multi-component interventions for caregiving adults (29) to improve coping and quality of life/well-being are emerging in the literature. Our data suggest general receptivity towards such interventions and support the need for rigorous testing of these interventions, particularly when delivered in the family context.

Although not explicitly defined, the themes that emerged from our study could be categorized into emotion-focused and problem-focused strategies as described by Lazarus and Folkman (30) in their Transaction Model of Stress and Coping. According to Lazarus and Folkman, the function of emotion-focused coping is to change either (a) the way the stressful relationship with the environment is attended to (as in vigilance or avoidance) or (b) the relational meaning of what is happening, which mitigates the stress even though the actual conditions of the relationship have not changed. The function of problem focused coping is to change the troubled person-environment relationship by acting on the environment or oneself. Lazarus and Folkman’s coping theory has been used as a conceptual basis for previous coping studies for patients with breast cancer (31,32) and prostate cancer (33). The themes ‘positive reframing’, ‘holding on to a sense of normalcy’ and ‘religion and spirituality’ reflect emotion-focused coping strategies that attempt to regulate distress and maintain a positive outlook while facing the reality of the diagnosis. The findings are consistent with those of Houldin and colleagues’ (2) earlier report on family members experiences with newly diagnosed advanced CRC. The other five strategies are certainly strategies used by participants in ‘actively’ addressing the stress that is associated with CRC diagnosis more directly or engaging with others to adjust the source of the stress strategies that demonstrated a problem-solving approach of coping with CRC. Future studies could formally test the strategies outlined by the theory to compare their effectiveness in facilitating coping among patients and their family members in the context of CRC and other cancer diagnoses.

In addition, our findings suggest that both patients and their family members may see a CRC diagnosis as a teachable moment and attempt lifestyle changes. Therefore, as in other familial cancers, diagnosis of CRC in one individual should prompt discussions and interventions with relatives, recognizing that nonbiologically related family members can be an important part of family support and coping. It is imperative that at every point of care, General Practitioners have an opportunity to provide counselling and screening to patients and their family members who are dealing with a CRC diagnosis.

The findings of the current study are based on conducting 73 semi-structured individual interviews; nevertheless, they should be interpreted cautiously. For instance, the study population was relatively homogeneous, including educated individuals who self-identified as Caucasian or white, non-Hispanic. It is possible that some of the coping strategies that were described would be less appealing or accessible to more diverse populations. In addition, qualitative inquiry is subject to a respondent’s willingness and capability of sharing their experience and to potential bias in interpretation of that experience on the part of investigators. In many cases, stories or examples ‘repeated’ within families despite the fact that family members were interviewed individually rather than as a family group. Episodes of repetition could be interpreted to lend credibility to the subjective nature of the data. However, family members and patients were interviewed individually and patients were generally interviewed first, thus ‘repetition’ or corroboration could also support the interpretation that patients were priming their family members on what was discussed in their interviews.

With regard to interpretive bias, coding was performed independently by two of the authors (GBA, RWE) and adjudicated by a third (CRB). The coping strategies were well-described by the Transaction Model of Stress and Coping, however, additional interpretations may be supported. Despite these limitations, this study is an important step towards the development of family-based coping interventions for patients with CRC. Moreover, the study has implications for further research to gain a more complete picture of the family members of CRC patients with regard to experiences and coping strategies from a more diverse socio-cultural context.

Declaration

Funding: National Cancer Institute (5R03CA142065).

Ethical approval: Study procedures and interview guide were approved by the Institutional Review Board at Mayo Clinic under expedited procedures appropriate for minimal risk research, and all ethical principles related to research involving human subjects were upheld in the conduct of this study.

Conflict of interest: none.

References


