



Surviving Colorectal Cancer: More Than Treatment

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Abstract

Keywords

- colorectal cancer
- emotional distress
- personal experience
- psychosocial support

The main aim of this article is to contribute to a complete patient perspective on the psychosocial impact of colorectal cancer. The details included patient personal experience of being a colorectal cancer survivor and perception regarding psychosocial support during management of the illness. Health professionals should assume that patients may have difficulty in illness management and should encourage a discussion of patients' concerns.

Introduction

I began to experience significant fatigue around the start of this year 2022, as well as weight loss that was not alarmingly rapid. I also observed that I was leaner than usual. I assumed that it was due to administrative responsibilities I took at my workplace. But soon after, I decided to get blood tests, and I started seeing a drop in my hemoglobin level (7.7 gm/dL). This alarming change made me realize that I should get blood tests, and it gave me a bad feeling. My physician suggested going for the fecal occult blood test, as there were no other bleeding issues. Out of three samples, one test was found to be positive. I was referred to a gastroenterologist who suggested I go for upper and lower endoscopies.

As there was no history of cancer in my family, I did undergo mammography a few months back for a routine screening; I was confident that there is no possibility of having a cancer diagnosis. Shockingly, after my colonoscopy, everything changed. I awoke from the anesthesia and got to know that I need to go for a computed tomography (CT) scan. While I was getting ready without knowing the exact diagnosis (though the gastroenterologist informed my husband about my diagnosis and they withheld the information from me), another doctor who assumed I was informed about my diagnosis came to meet me to discuss the treatment options and revealed the bad news. "We have discovered a mass, and you will need surgery. Do you intend to have surgery here or

in South India?." I can still hear those frightening words. I felt like my blood was draining from my body and remember thinking, "This is cancer, and I could die, I am a mother of two young boys, how come this happened to me?." I was praying in my heart while I was prepared to go for a CT scan to look for metastasis. Thank God. There was no metastasis but there was the involvement of lymph nodes. The diagnosis was stage III colorectal cancer (CRC), and at that moment, I felt that was a dead end.

Four weeks after the colonoscopy, I went for an exploratory laparotomy. Though the postoperative period was uneventful, I was still going through a tough time as my biopsy report of resected colon mentioned that there were some abnormal genetic mutations. The oncologist I met with suggested that the mass in my colon is removed yet, I need to go for an adjuvant chemotherapy regimen of capecitabine and oxaliplatin for 6 months as I come under the high-risk group.

The emotional and physical struggles that I have gone through during my chemotherapy made me realize that psycho-oncological counseling in India is not much addressed as it is supposed to be. I began to realize the pain of having a cancer diagnosis. When you are uncertain about whether the rest of your life will be measured in months, years, or decades, you tend to concentrate more on what's happening right now and what matters in your life. I was aware that I wanted to repay the oncology community

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for everything that it had done for me. My personal experience with cancer has inspired me to seek out strategies for increasing public awareness of CRC, particularly in younger persons.

At first, I believed that “my close relatives and friends from the church community have been the key support.” Support from the medical personnel that was deemed appropriate and sensitive was extremely helpful, but I frequently preferred support from friends.

Cancer changes everything; “the longer the treatment goes, obviously, the more people sort of move on and don’t make contact anymore, so that sort of made me feel a little bit alone.”

Our lives were significantly impacted by the social isolation brought on by the disease. Social isolation and several treatments had a direct correlation, “I hardly ever go outside. It’s challenging when my life has been consumed by cancer. I was hesitant to ask for help because I didn’t want to burden others or because I didn’t want to seem weak.”

Though it seemed to be supportive in and of itself, seeing someone else going through a similar experience gave me the impression that I am not going through this alone. “Well, I always knew that other cancer survivors were having the same experience.... I knew they were going through the same as me,” “We can discuss topics that we probably won’t discuss with anyone else.” Even though it only lasted a short while, this shared experience opened the door to helpful relationships. I occasionally went out of my way to find people who had received the same diagnosis or therapy.

Much more crucial is the emotional support of our loved ones. In this way, “I had one [friend]...who was there the entire time, and I was in communication with him and, you know, he just listened and kept me updated and dropped in and, you know, that was a great support” (My husband’s). When talking about emotional support, it is more important to focus on the quality of your relationships than the quantity of sources you have. Here, I give some insight into my experiences receiving psychosocial care as a CRC patient, an area that has not yet been thoroughly studied.

Emotional Distress during the Breaking of Bad News

The most common initial responses when receiving a diagnosis of cancer were disbelief and shock. Likewise, many reported breaking down upon receiving the news of their cancer diagnoses.¹ I thought I have temporary mental incapacity in which I felt blank and lost upon knowing that I have cancer. I was unable to comprehend any information that was given to me. I was extremely distressed because of worries about my young children’s future in the event of my death.

Previous studies also reported having severe emotional distress experienced by people who had younger children. Yet, older participants coped better when informed of their cancer diagnoses because their children were independent and they were no longer the breadwinners of the family.

Evidence revealed that persons with a family history of cancer were also relatively less shocked by the news of a cancer diagnosis.^{2,3}

Psychosocial Support from Healthcare Workers

Patients and caregivers could benefit from support from having a good working relationship with the healthcare workers. In particular, it seems that the presence of this therapeutic relationship made the staff more approachable to patients and carers, promoting interaction and information-seeking. A noteworthy finding was the significance of both formal and informal communication with the treatment team. Notably, the findings showed how positive and respectful communication seems to affect patients’ and carers’ opinions of support.⁴

Existing literature proves that the use of active listening and empathy are the major elements of patient and provider communication in clinical settings.⁵ Besides, negative experiences included negative interactions (not communicating in a compassionate and caring manner), being treated disrespectfully, feeling pressured by time constraints, and helplessness due to physical infirmity, based on the results of a recent systematic study of patient and healthcare provider communication.^{4,6}

Due to the devastating nature of cancer, the stigma attached to it, and the sizeable psychosocial burden that can be brought on by the disease, positive communication may be even more important in the context of CRC oncology. It seems that in this situation, the healthcare professional-patient-caregiver interaction necessitates a high degree of compassion and trust, and as a result, effective communication is crucial.^{4,6}

Peer Support/Shared Experience

Peer support can be particularly beneficial for patients with cancer. The majority of participants talked about becoming friends with cancer survivors they had met, and half said that getting treatment at a cancer center opened up opportunities for casual and social engagement with other patients.^{1,7}

Emotional Support

It is widely documented in the literature that emotional support is important for both patients and carers; those who actively sought help had most of their needs met. Furthermore, it appears that the quality of support was crucial because even those who received less support indicated that it was worthwhile when they felt it was “appropriate.”^{1,7}

Overall, I was satisfied with the treatment, including the quality and timeliness of the information I received, the quality of their healthcare, and the level of involvement in decision-making. However, I was looking for psychological support for counseling to focus on a positive outlook on my illness experience. Despite the focus on positive change, I still have difficulty coping with the side effects of treatment.

In my opinion, I am still working on the ambiguity of my health, the need to accept the new normal, losing control and taking back control, experiencing positive and negative life changes, and the need to continually reframe my perspectives to focus on the positives.

Managing one's health after CRC may have specific challenges given long-term impacts on biopsychosocial functioning. Understanding experiences of managing one's health post-treatment is important to informing patient-centered supportive care.

Conflict of Interest

None declared.

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