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# Living with long-term consequences: Experience of follow-up care and support needs among Asian long-term colorectal cancer survivors

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**Abstract**

**Objectives:** This study aimed to provide an in-depth exploration of follow-up care experiences and supportive care needs in long-term colorectal cancer (CRC) survivors within multiethnic Asian communities.

**Methods:** Semi-structured in-depth interviews were conducted on a purposive sample of 30 long-term CRC survivors who had completed all treatment without recurrence ranging 2 to 17 years in Singapore. Interviews were audio-recorded and transcribed verbatim. Thematic analysis was conducted following grounded theory approach.

**Results:** Four themes represented the experience of the Asian long-term CRC survivors: (a) living with long-term consequences, (b) dealing with unceasing adaptation demands, (c) navigating a healthcare journey with limited direction, (d) regaining mastery through adversity. CRC and its treatment had profound physical impacts on some long-term survivors and these effected their psychological well-being. A sense of abandonment and vulnerability following the cessation of a 5-year follow-up care was repeatedly expressed. Participants defined recovery from CRC as not merely surviving but also having high physical function and full independence. They often sought less conventional remedies and medicine based on cultural beliefs rather than current evidence. Participants noted pervasive social stigma associated with CRC that impeded their inclusion in the workforce.

**Conclusions:** Asian long-term CRC survivors experienced multiple challenges and needs relating to the care experience, information provision and workforce stigmatization, and several of which were unique to the Asian context. Future work will need to consider the implementation of culturally tailored cancer survivorship care plans that incorporate the specific needs of Asian CRC survivors.

**KEYWORDS**

adaptation, Asian, colorectal cancer, follow-up care, long-term survivors, oncology, psycho-oncology, qualitative, support need

## 1 | INTRODUCTION

Globally, colorectal cancer (CRC) is the third most common cancer, with nearly 1.8 million new cases diagnosed in 2018.<sup>1</sup> In Singapore, CRC remains the most frequently occurring cancer among males.<sup>2</sup> Along with South Korea and Japan, Singapore has one of the highest age-standardized incidence rates of CRC (36.8 per 100 000) in Asia and the world while the corresponding figures in Western Europe and North American are much lower, 28.8 and 26.2, respectively.<sup>3-4</sup> Despite this high incidence, Singapore has seen an increasing trend in the age-standardized relative survival of CRC from 45.96% in 2005-2009 to 50.77% in 2010-2014.<sup>5</sup> Improved medical treatment coupled with a recent national screening program to detect CRC at the earliest possible stage may have led to a considerable rise in the number of patients that are treated with curative intent.<sup>6</sup>

As more CRC patients survive, there is a growing recognition that patients need support after the treatment phase of their illness. This is of particular importance for people diagnosed with CRC given the physical challenges and restrictions that the disease (gastrointestinal obstruction, nausea, and fatigue) and treatment (stoma care, bowel functioning, neuropathy, and diarrhea) can pose in the short- and long-term.<sup>7-8</sup> While these physical consequences of CRC treatment are wide-ranging, the impact on other aspect of life is also considerable. Studies suggest that a cancer treatment and physical and functional symptoms can cause psychological dysfunction such as anxiety and depression.<sup>8-9</sup>

Unlike some countries such as US, UK, and Canada that have cancer survivorship care plans in place, there is a lack of a national standardized care pathway for the management of cancer survivors in Singapore.<sup>10</sup> Models of care in Singapore are disease-specific with limited coordination of care between specialist clinics and primary care.<sup>11</sup> Typically, CRC patients after primary treatment are followed up for up to 5 years by a surgeon-led program whose main focus is detection of recurrence and monitoring of treatment complications. Consequently, the follow-up visits may not necessarily address the CRC patients' multiple needs for supportive care. Furthermore, there is limited social and professional support to address care needs and treatment-related consequences that often persist beyond 5 years.

Several studies have explored experiences of cancer survivors mainly focusing on survivorship, follow-up care and unmet supportive care needs.<sup>10-13</sup> Although the existing studies provided an important insight into gaps in survivorship care, most studies were limited to breast cancer, and conducted predominantly in countries where survivorship care plans were well established. In addition, studies of survivors tended to focus on early survivorship, an experience immediately after the completion of treatment.<sup>14-16</sup> There has been less consideration of long-term cancer survivors' experiences. Further, few studies conducted on CRC survivorship reported mainly on the experience of Caucasian survivor groups in Europe, North America and Australia. Cross-cultural variations in cancer experience and care warrants caution in transferring existing evidence across sociocultural settings.

The aim of this study is to explore the evolving experience of follow-up care and supportive care needs among long-term CRC

survivors and how they navigate their ongoing care issues in a multi-cultural Asian context.

## 2 | METHODS

A grounded theory approach was chosen because it explores experiential aspects of follow-up care and the process by which long-term Asian CRC survivors dealt with recurrent and long-term adaptation demands. The grounded theory approach allowed emerging constructs and themes through iterations of data collection and analysis.

### 2.1 | Sample

Patients who had nonmetastatic CRC with definitive treatment aged 21 years or older were targeted. Patients were identified from a registered database of the Singapore General Hospital by a research team member (colorectal surgeon). They were approached at or prior to their follow-up appointments and the study purpose and scope of confidential and anonymous participation explained. Informed written consent was obtained. Patients were selected purposively to capture the richness of a broad range of views and experience. As the data collection and concurrent analyses progressed, the variation in emerging themes was explored by recruiting subsequent patients for interview based on age, gender, time since diagnosis and stage of CRC to improve our understanding of specific aspects of the studied phenomenon.<sup>17</sup> A total of 42 patients were approached and 30 individuals agreed to participate in the interviews. Major reasons for decline were disinterest and busy schedule.

### 2.2 | Data collection

We developed an interview guide with open-ended questions to solicit the participants' experience and perceptions of the survivorship. The guide was developed based on existing literature and the aim of the study.<sup>15,16</sup> It covered key topics on illness experience, long-term treatment consequences, unmet supportive needs, processes of coping and suggestions for care improvement. Patients were initially asked, "tell me what it was like for you to survive from CRC," which was followed by probes to elicit more in-depth responses. Interviews continued until data saturation occurred. Each interview lasted approximately 45 to 60 minutes and was audio-recorded. The study was approved by SingHealth Institutional Review Board (IRB 2016/3077).

### 2.3 | Data analysis

Each audio recording of the interview was transcribed verbatim. We used a constant comparative method using NVivo 12.<sup>18</sup> The analytic process involved immersion in the data, coding, repeated sorting and

comparison. Each transcript was open coded to create code components. Each component was compared with other components to ensure that they were mutually exclusive. Following iterative comparisons of components, emergent categories were identified in terms of range and variability and properties for the concepts were hierarchically derived.<sup>18</sup> Core categories were elaborated around the phenomena of follow-up care experience, ongoing adaptation demands and the process of dealing with unmet needs, thereby grounding theory in the data. Researchers' personal perceptions regarding cancer survivorship were documented to avoid imposing a priori assumptions on the data during analysis. Memos during interview facilitated subsequent description and analysis.<sup>17</sup>

### 3 | RESULTS

#### 3.1 | Demographic and clinical characteristics

We achieved thematic saturation after 26 interviews. The median age of the participants was 64 years (range 51-70 years). Approximately 57% participants had survived from CRC for more than 5 years at the time of interview (Table 1).

#### 3.2 | Living with long-term consequences

A recurring theme was the potentially distressing long-term effects of CRC treatment. For many, various aspects of the daily activities had to be modified after CRC treatment. Common physical symptoms included altered bowel habits such as constipation or diarrhea after stoma reversal or colorectal resection. For survivors who had undergone adjuvant chemotherapy, peripheral neuropathy and fatigue were commonly experienced. Skin changes were prominent for patients who had concurrent radiotherapy. For some, the treatment consequences appeared to limit certain daily activities—avoiding strenuous work was mentioned by many.

I have no problem going out, just don't lift heavy objects...because you have a history of operation, you will definitely lose to others who have not, so your body is affected. (Participant 7).

For some participants who had fluctuating levels of function and complications over time, physical symptoms resulting from CRC treatment had a considerable psychological impact. Responses included depression and mood swings. Minor symptoms at times created fear of recurrence, an emotional response resulting from perceived threat as opposed to a real cancer risk.

In some nights, I really feel sorry for myself and ask this question when all my family members are asleep. 'Why me?' Then I realize that there is no answer to it. (Participant 10).

**TABLE 1** Participant characteristics (N = 30)

	N (%)
Age (years)	64 ± 5.45
Sex	
Male	22 (73.3%)
Female	8 (26.7%)
Race	
Chinese	27 (90.0%)
Malay	1 (3.3%)
Indian	2 (6.7%)
Educational Level	
Primary School	8 (26.7%)
Secondary School	12 (40.0%)
Tertiary or above	10 (33.3%)
Marital status	
Single/Divorced	3 (10%)
Married	27 (90%)
Stoma (temporary or permanent)	
Yes	9 (30.0%)
No	21 (70.0%)
Stage of colorectal cancer	
0	1 (3.3%)
I	5 (16.7%)
II	10 (33.3%)
III	14 (46.7%)
Adjuvant chemotherapy	
Yes	17 (56.7%)
No	13 (43.3%)
Time since treatment (years)	
0-5	14 (43.3%)
6-10	12 (40.0%)
11-15	2 (10.0%)
>15	2 (6.7%)

The treatment consequences provided participants with a change in life perspective, such as being more appreciative of aspects of life. Some spoke of a re-evaluation of life priorities, resulting in early retirement and change in job scope to reduce work stress.

I kind of come to a moment...it was suddenly dawned on me that why am I working so hard? Why am I putting my health, what you call, in a backseat? Alright, I question my own priorities. (Participant 4).

#### 3.3 | Dealing with unceasing adaptation demands

Living with long-term treatment consequences means that there are evolving adaptation demands. Across interviews, a wide range of ongoing care needs was identified. One of the salient needs was addressing the financial burden—the cost of chemotherapy drugs, lack of subsidies for stoma appliances and inadequate coverage of medical insurance. Although some treatments did not require out-of-pocket payment, several participants mentioned that deduction from a Medicare account would eventually drain their employment savings.

It's regarding the drugs for chemo and night-time drugs. Both are not subsidized unless you are very poor. Not even a single cent of subsidy [is available]. (Participant 11).

It's financial. Treatment is very expensive. I think the cost comes to almost \$100. I can use Medisave, but for some people who lost their job, money in the [Medisave] accounts will continue to be depleted. (Participant 6).

Another important area was ongoing information needs during their long-term care. In particular, participants expressed a desire for dietary counseling. For nonstoma survivors, it was commonly felt that dietary information provided by clinicians were unclear. Strong cultural beliefs together with informal information influenced survivors' dietary habit. Experimenting with foods in an effort to determine a suitable dietary regimen was a common practice to grapple with altered bowel habits.

...because to me, food is very important. Whatever you eat affects all your body. But the doctor tells me I can eat everything. I liked to know more [about diet], but I didn't get enough information. (Participant 16).

We should not eat too 'poisonous' food like prawns, squids and beef. I came across this video on the internet, it's actually from China saying old folks like me should drink honey and vinegar water daily. (Participant 28).

Another theme running throughout the data was challenges relating to employment. Participants described how their work environment was unsympathetic, their inability to keep up with work demands and insufficient medical leave. Some participants feared stigmatization from their bosses or colleagues. In addition, increased bowel frequency and fatigue were common factors that hindered work efficiency.

Don't tell employers. Just deal with it. If you say you have cancer on your application form, they won't call you back. They are basically running a business for profit. (Participant 29).

My work performance has notably dropped. I told my boss I got this numbness. Then, he said no way [laugh]. They [company] know my condition, but they didn't understand. If you tell your boss you cannot do this and that, that means you will have to leave. (Participant 15).

### 3.4 | Navigating a healthcare journey with limited direction

Participants under the 5-year follow-up program appreciated the opportunity to do checkups to detect relapse. The regular checkups

were construed as "comfort" or "confidence" to bring about feelings of relief and security.

I am worried that cancer may recur. That's why I am very happy with the 6-monthly checkup. I am really concerned about spreading to other parts of the body. So I always ask for whole body CT although it's pricy. (Participant 3).

Some participants were apprehensive of the cessation of the follow-up appointments indicating that they wanted to have continued monitoring and assessment.

Who knows after 5 years [cancer] relapses? My blood test seemed to creep up and I got scared. If they [hospital] discharge me, then where do I go for testing? How am I going to keep track of whether my cancer relapses or not? (Participant 6).

They [hospital] mentioned about this 5-year thing—after 5 years, you're safe. I must admit that I will have to be more conscious in future not only in exercise or diet, but watching my bowel movement, symptoms, abnormality in my faces and all that. (Participant 4).

Feedback of follow-up test from specialist physicians was felt to be insufficient as one participant noted,

the doctor says only two sentences. 'Is there blood in your stool?' I say no. Then 'everything is fine', telling me to come back a year later. Never say much else. (Participant 19).

Other common concerns included the need for better coordination of care from primary care to specialist hospitals. Many felt that GPs were not trained to provide a CRC-related care and therefore expressed a strong preference for speaking to their cancer specialists.

Polyclinic [public primary care clinic] is, I tell you last time when I had constipation, they just gave me the syrup which I couldn't take. It didn't help. Even the GP said, for constipation, there was nothing he could do about it. (Participant 24).

A minority of participants mentioned that the CRC peer support group, albeit helpful, disproportionately represented Chinese, requiring more support for survivors with Indian and Malay ethnic groups.

I think all these support activities are multi-racial kinds of thing, not just targeting Chinese. Right now, we have two non-Chinese patient ambassadors. One of them is quite busy and the other one is Indian. How about Malays? I feel that different ethnic groups need help. (Participant 26).

### 3.5 | Regaining mastery through adversity

Adaptive coping to regain mastery emerged as a key theme in participants' CRC survivorship journey. As described, anxiety-provoking thoughts on cancer recurrence surfaced from time to time even many years after the completion of treatment. Participants tended to dispel a sense of risk and initiate cognitive reinterpretation to enable a positive psychological state needed for peace of mind.<sup>19</sup> This prompted refocusing attention from the known peril of past illness to the redirection of long-term life goals.

Actually, I pray every day. One of the things I pray is that I won't have relapse. So I brainwash myself to get rid of that thought [laugh]. With this, I can eliminate the fear. (Participant 6).

I practice Buddhism. During my prayer, I try to refocus on positive ideas. So when my mind is filled with problems, I will get very tired right? So I try to use this positive thinking to help me. (Participant 25).

Some participants described how they become emotionally resilient as a result of their illness experience while others displayed fatalistic orientations. As one Malay survivor stated:

At times, I think of recurrence but after going through this experience, you must make peace with cancer. You must make a life adjustment like diet. Just be careful but if it [cancer] recurs, then I have no choice. This type of thing is *tikam* ['chance' in Malay]. It's fifty fifty. (Participant 28).

Maintaining independence and functionality were perceived to be the key to successful long-term CRC survivorship. Pragmatic use of less conventional interventions such as complementary and alternative medicine allowed moderation of long-term effects of treatment for many. Seeking complementary medicine typically involved traditional Chinese medicine, acupuncture and other forms of herbal supplements. Reasons for the use of complementary medicine included perceived increase in body's ability to reduce potential cancer recurrence, enhancing physical well-being and alleviating persistent side effects such as constipation or treating minor symptoms unrelated to CRC.

My friend recommended me I see a Chinese medicine doctor to adjust my body. They use traditional herbs so this will be good for your body when you eat. (Participant 19).

The cancer is due to the coldness. If we increase body temperature, many slow acting illness can be prevented. I think traditional Chinese medicine is beneficial to me...even though the western medication is good, its side effects are too much. (Participant 23).

Personal and cultural beliefs together with recommendations from friends and family were mentioned as major influences. Notably, most participants were reluctant to inform their primary care doctors of their use of complementary medicine, for fear of receiving negative responses.

## 4 | DISCUSSION

This study explored the experiences of follow-up care and supportive care needs among long-term Asian CRC survivors and how they navigate their ongoing healthcare issues. To our knowledge, our study represents the first that explored the specific needs and challenges of Asian long-term survivors from CRC.

Our findings suggest that CRC and its treatment had a profound physical and psychological impact on survivors and that these impacts can persist long after treatment completion. Issues surrounding altered bowel habits and persistent peripheral neuropathy were mentioned by many, which often had knock on effects on survivors' social activities and daily function. While these symptoms tended to improve over time, some survivors reported little improvement despite repeated follow-ups and medications. Persistent symptoms seemed to affect psychological well-being of the CRC survivors—feelings of vulnerability were not uncommon even for survivors who were at least 5 years beyond diagnosis. This is in contrast to the studies that intrusive thoughts dissipated over time among cancer survivors.<sup>20,21</sup> Hence, it seems clear that psychological well-being of survivors may be subject to the "experience" of survivors which could be highly personalized. Given the absence of optimal care pathways between specialist and primary care, a sense of "abandonment" primarily driven by the cessation of a 5-year follow-up care among long-term survivors is not surprising. The resultant tendency was deliberate seeking of information and techniques to alter certain aspects of survivors' lifestyle hoping to lower risk of recurrence and improve quality of life. Thus, considerations should be given to improving coordination of key care providers across the CRC survivors' long-term care journey and providing resources and supports to meet the specific needs of survivors.

Our study findings concur with existing studies that financial burden from CRC treatment and follow-up care was one of the key challenges influencing optimal long-term survivorship.<sup>22-24</sup> CRC survivors' unmet financial need was highly varied, ranging from insufficient personal coverage on medical claims and cost for colostomy bags and other accessories to having the responsibility to provide some degree of financial security for the family. This underscores the importance of involving clinicians as part of routine follow-up to briefly screen and refer patients to relevant services, as some might not be aware of financial subsidies and assistance that are available. Evidence suggests that survivors could benefit from a personalized nursing program that can aid in the assessment of ongoing concerns and needs of cancer survivors.<sup>25,26</sup> Such a nurse-led program can enhance patients' access to practical assistance services that they were previously unaware of and facilitate a timely intervention for CRC survivors.<sup>27</sup>

Another important support need in long-term survivors was the lack of dietary information. The low level of information provision on diet is not something new and resonates with earlier themes reported in the literature.<sup>28,29</sup> What is distinct from the existing studies is the strong influence of traditional cultural belief about food for health maintenance and nourishment.<sup>30–31</sup> Long-term survivors often adopted different dietary habits to ameliorate the unfavorable effects of CRC and its treatment. However, such dietary habits appeared to be based more on traditional dietary beliefs rather than current best evidence. Use of certain traditional Chinese medicines, remedies and herbal supplements was not uncommon. Further, this topic was rarely brought up to their clinicians. This finding indicates that amidst the abundance of dietary advice from various sources, there is an absence of advice that is tailored to the values and beliefs of Asian CRC survivors. Studies suggest that provision of evidence-based information on diet through telephone consultations improved symptom management and quality of life in CRC survivors.<sup>32,33</sup> Mobile health-supported counseling and education may further enable CRC survivors to address their ongoing dietary needs and adaptations.

Our participants described a lack of workplace accommodation to survivors' needs. Specific challenges noted in this study echo some earlier studies in which survivors noted that physical side effects could affect work productivity and that there is often a mismatch of the long-term effects of CRC and medical leave policies.<sup>34,35</sup> This study highlighted that in the local context, employers' lack of understanding and stigma attached with the CRC were pervasive and had a significant adverse impact on the survivors' prospects for employment or resumption of duties in the workplace. For some, employment changes were equated with not only a loss of income but it also meant a loss of normalcy. Since the retirement age is set to increase as a result of the extended life expectancy, a significant proportion of CRC survivors is expected to face similar challenges.<sup>36</sup> Introducing flexible workforce options may enhance return-to-work experience of CRC survivors. Yet, what would be more important is a cultural change through which difference and nonconformity are readily acknowledged and tolerated.<sup>37,38</sup> Future research should seek to explore how sociocultural factors facilitate and impede the inclusion of workforce among CRC survivors across different cultural settings.

#### 4.1 | Study limitations

This study has a few limitations. Despite numerous efforts made, the vast majority of recruited patients were Chinese (90.0%), with Malays and Indians representing 3.3% and 6.7%, respectively. As a result, we were unable to fully capture the survivorship experience and support needs of these two ethnic groups, which might differ from those of Chinese due to cultural and religious differences. A retrospective recollection of experiences may have inevitably resulted in interpretive bias. Although our participants represented a wide range of clinical and demographic characteristics of the Asian CRC survivors, a detailed subgroup analysis was not performed, which requires further investigation.

#### 4.2 | Clinical implications

This study provides intimate insight into the evolving care experience and supportive care needs of the long-term Asian CRC survivors. The key themes highlight the various ongoing challenges relating to successful survivorship. Current findings have the potential to guide the implementation of support services that are tailored to the specific needs of Asian long-term CRC survivors.

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#### CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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