The perceptions of Australian oncologists about cognitive changes in cancer survivors

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Abstract

Objective- Cancer-related cognitive changes (CRCC) can have a profound impact on a cancer survivor’s quality of life. However, cancer survivors frequently report receiving limited information about their experience of CRCC from their oncology specialists. This qualitative study aimed to explore the perceptions of oncology specialists regarding CRCC and the potential for their views to influence their decisions about patient care.

Methods- Thirteen medical oncologists and five radiation oncologists currently practising in Australia participated in this study. Data collection involved individual semi-structured interviews via telephone. Data were audio-recorded, transcribed verbatim and analysed using a thematic approach.

Results- Four key themes emerged: (1) beliefs about the impact of priming on cancer survivors’ perceived cognitive function, (2) perceptions of who is more likely to raise concerns of cognitive change, (3) uncertainty of how to best manage CRCC, and (4) the perceived role of oncologists in the management of CRCC.

Conclusions- CRCC and its impact on the cancer survivor’s journey have been under-addressed by oncology specialists, and they are uncertain of potential management strategies. With cancer survival rates increasing, there is a need for specific interventions and management guidelines addressing CRCC and their effects on cancer survivors. Future exploration should focus on the survivor as central to their care and holistic approaches to CRCC management involving all members of the multidisciplinary team.

Keywords- Cancer Oncology Cognition Survivorship Clinical practice Qualitative

Background

One in two Australians will be diagnosed with cancer during their lifetime, and both cancer prevalence and 5-year survival rates for people diagnosed with cancer have increased in Australia [1]. Survivorship is increasingly recognised as a distinct phase of cancer care, yet uncertainty has emerged regarding the roles and responsibilities of those caring for cancer survivors [2–4]. In a study by Cheung et al. [2], cancer survivors were found to have higher expectations than oncologists regarding the role of oncologists in survivorship care, and oncologists and general practitioners (GPs) overlapped in providing follow-up, screening for other cancers and preventive healthcare [2]. The gaps in survivorship care have previously led to cancer survivors being ill-informed of the potential challenges associated with the survivorship phase [5].

Subtle changes to cognition are widely acknowledged as an issue present during cancer survivorship [6], and these can impact daily functioning and quality of life (QOL) [7]. Changes in the cognitive domains of information and processing speed, attention, memory retrieval and executive function are commonly reported by cancer survivors [6]. While this phenomenon has received growing attention in the literature, the explicit cause of cognitive changes remains unknown [8]. ‘Chemobrain’ or ‘chemofog’ are common terms used to describe these subtle cognitive changes and are often attributed to chemotherapy treatment [9], although cognitive changes may be due to hormonal imbalances and the toxic effects that chemotherapeutic agents can have on the brain [10], or factors relating to the disease itself such as the production of pro-inflammatory cytokine levels in the brain [11, 12]. Various personal factors may also influence a cancer survivor’s cognitive function, including age, education, genetics and treatment-induced menopause [10, 13]. Additionally, psychological and physical implications as a
result of a cancer diagnosis and the burden of treatment, such as anxiety, depression and fatigue can influence a cancer survivor’s cognitive function [10, 13–15].

Despite the impacts of cancer-related cognitive changes (CRCC), cancer survivors receive limited information about the possibility of cognitive changes following cancer diagnosis and treatment [16]. Boykoff et al. reported that cancer survivors may have their cognitive concerns dismissed by oncologists [17]. Amongst oncologists, nurses, and pharmacists practising in Asia, half of the oncologists in one study claimed that patients seldom raised the issue of cognitive changes [18]. This may explain why other studies suggest that oncologists do not specifically address the potential of cognitive side effects of a cancer diagnosis or treatment with their patients [17, 19].

Therefore, this research asks the following:

- How do oncologists perceive CRCC and the underlying cause(s) in cancer survivors?
- How do oncologists anticipate and address CRCC with their patients across the continuum of cancer care, including the survivorship phase?

The aim of this study was to explore the perceptions of Australian oncologists regarding CRCC, and the potential for their views to influence their decisions about patient care.

Methods

Study approach

This study adopted a qualitative approach using thematic analysis, to identify values, perceptions and experiences [20], such as exploring oncology specialists’ perceptions of cognitive changes in cancer survivors. Ethics approval was obtained from the Human Research Ethics Committee at the University of Sydney, Australia (reference no. 2014/323).

Sampling and recruitment

Medical and radiation oncologists currently practising in Australia were eligible to participate in the study. Participants were recruited through advertisements distributed via e-mail by membership organisations within the oncology community. The advertisement invited members to complete an online Expression of Interest if willing to participate in the study. The purpose of the Expression of Interest was to collect participants’ demographic information to enable stratification of the sample if possible, information about availability for interview, and gaining informed consent. Snowballing was also used to maximise participation by a group with a known low response rate due to existing priorities in everyday practice [21].

Data collection

Data collection involved individual telephone interviews. Interviewing via telephone rather than face-to-face was selected due to likely constraints regarding time and location for participants. A semi-structured interview schedule was used for all interviews [22]. Prior to commencing interviews, participants provided verbal consent for interviews to be audio-recorded and transcribed verbatim. Interviews were conducted by the first author and lasted between 15 and 30 min.

Data analysis

Braun and Clarke’s guidelines for a rigorous thematic analysis were followed [20], and an inductive approach to coding was used so that the data drove the coding process as opposed to coding data using a pre-existing framework [20]. In addition to personally transcribing 13 of the 18 interviews, the first author repeatedly read each of the transcripts. Initial codes were then generated from the data and organised into potential broader themes that signified meaning and were relevant to the research questions.

Rigour
A number of strategies were employed to enhance the study rigour. The first author used a journal to document their thoughts and interactions during and directly after interviews. This enabled reflexivity and the ability to distinguish between personal values and assumptions and the true perspectives of participants [23]. Member checking was used to ensure accuracy of data [23]. Transcripts were sent to participants for the opportunity to edit responses. No participant requested any changes to be made. Throughout data analysis, consensus coding was conducted by three of the authors (Smidt, Mackenzie and Dhillon). Authors coded data separately then discussed similarities and differences between individual analyses and resolved any issues. Potential themes were then reviewed and refined before authors identified four key themes. Peer debriefing occurred throughout the research process. The second and third authors provided ongoing feedback to the first author, ensuring that the reported interpretations and conclusions were true representations of the dataset.

**Results**

**Participants**

Thirteen medical oncologists and five radiation oncologists participated in the study (Table 1). Most participants were aged 35–44, male and practised within the Australian public hospital system, across the Australian mainland states. Participants also specialised in a range of cancer groups. Codes contained within the interview transcripts began to repeat after 15 interviews had been conducted; therefore, we were confident that data saturation had occurred within this sample.

**Table 1**

Participant demographics

<table>
<thead>
<tr>
<th>Participant no.</th>
<th>Geographical location</th>
<th>Gender</th>
<th>Age range</th>
<th>Institution of primary practice</th>
<th>Oncology discipline</th>
<th>Sub-specialty</th>
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<tbody>
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<td>Breast</td>
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<td>Gastrointestinal, head and neck, brain</td>
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<tr>
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<td>45–54</td>
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<td>Breast, genitourinary, brain</td>
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<tr>
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<td>35–44</td>
<td>Public</td>
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<tr>
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<td>Public</td>
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<td>Breast, gastrointestinal, lung</td>
</tr>
<tr>
<td>6</td>
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<td>35–44</td>
<td>Public</td>
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<tr>
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<td>Private</td>
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<td>Genitourinary</td>
</tr>
<tr>
<td>8</td>
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<td>45–54</td>
<td>Public</td>
<td>Medical</td>
<td>Breast, genitourinary, lung</td>
</tr>
<tr>
<td>9</td>
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<tr>
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<tr>
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<tr>
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<td>Public</td>
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</tr>
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<tr>
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<td>Mixed</td>
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<td>Breast, gastrointestinal</td>
</tr>
</tbody>
</table>
While participants had varying perceptions of CRCC, four key themes emerged from the interview data: (1) beliefs about the impact of priming on cancer survivors' perceived cognitive function, (2) perceptions of who is more likely to raise concerns of cognitive change, (3) uncertainty of how to best manage CRCC, and (4) the perceived role of oncologists in the management of CRCC (Table 2).

Table 2
Themes and sample codes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sample codes</th>
</tr>
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</table>
| 1. Beliefs about the impact of priming on cancer survivors' perceived cognitive function | - Higher rates of self-reports by breast cancer survivors (BCS)  
- Online forums, support groups influence perceived cognitive deficits (PCD)  
- Informing patients of CRCC pre-treatment may contribute to increased self-reports  
- Hesitant to initiate discussion due to priming effect  
- More likely to initiate discussion with BCS due to priming effect  
- Dissociation between PCD and measurable cognitive impairment |
| 2. Perceptions of who is more likely to raise concerns of cognitive change | - Younger females  
- Older Adults  
- Cognitively demanding work roles  
- Cancer survivors receiving chemotherapy, radiotherapy to brain  
- Brain tumour, brain metastases  
- Fatigue  
- Anxiety  
- Depression |
| 3. Uncertainty of how to best manage CRCC                              | - No management guidelines  
- Lack of screening assessments  
- Hesitant to initiate discussion due to uncertainty |
| 4. The perceived role of oncologists in the management of CRCC         | - Management of physical side effects  
- Screening for cancer recurrence  
- Health promotion  
- Normalise CRCC  
- Recommend informal tips/coping strategies  
- Referral to GPs, psychologists, other Allied Health  
- Referral for neuropsychological assessment  
- Perceived barriers: lack of post-treatment clinics, financial constraints, limited time for follow-up appointments |

**Theme 1: Beliefs about the impact of priming on cancer survivors' perceived cognitive function**

Many oncology specialists perceived a difference in the frequency of reporting cognitive changes between survivors of breast cancer and other cancer groups. This difference was believed to be associated with the higher degree of supportive care provided to breast cancer survivors. Online forums, local support groups and information provided by not-for-profit organisations were believed to facilitate information sharing and raise awareness regarding the potential for cognitive changes as a result of a cancer experience.

*Participant 3: ...there’s so much more literature about it [cognitive change] for women out there with breast cancer and support groups... I think the women are more aware of this whole chemo fog thing and the effects of chemotherapy in general. [Medical oncologist]*

*Participant 14: I think in, in the breast cancer population this [cognitive change] is much more often discussed and I think there are more services that are tuned in to help people with breast cancer when they have this problem. But certainly in the other tumour streams it [cognitive changes] doesn’t seem to have the same degree of interest or reporting or, or recognition that this is a problem. [Medical oncologist]*

The previous experiences and perceptions of participants influenced how they anticipated and addressed cognitive changes with their patients. Some participants were hesitant to initiate discussions about possible cognitive changes, believing that patients were more likely to raise cognitive concerns if their oncologist informed them of this potential side effect.
Participant 1: I feel that priming is a key issue in all of this. You go into a room and give a talk to women then say, ‘who’s got some cognitive changes after chemotherapy?’ and everybody puts up their hands. I don’t believe the problem is that common...
[Medical oncologist]

In contrast, some participants felt it was important to lead a discussion with breast cancer survivors regarding the potential for cognitive changes as a result of chemotherapy. Oncologist-led discussions that focused specifically on cognitive issues aimed to ease the concerns of breast cancer survivors due to the heightened awareness within the breast cancer community.

Participant 12: So [for] the breast cancer population I would tend to talk about it more than I do in other groups up front, …to try and prevent some of the issues. [Medical oncologist]

Theme 2: Perceptions of who is more likely to raise concerns of cognitive change

Most participants perceived the underlying cause of cognitive changes as multifactorial. Factors thought to contribute to changes in cancer survivors’ cognition included method(s) of treatment, associated medications, emotional functioning and the level of support available to survivors across the continuum of cancer care.

Participant 4: …the factors that go in to neurocognitive decline are psychological, spiritual, physical, disease-related, treatment-related, environmental. So it’s not something that we can say is one particular thing. It’s a number of things. [Radiation oncologist]

Participants distinguished between objective cognitive deficits and patients’ self-perceived cognitive changes. Cancer survivors’ self-reports of subtle cognitive changes were often thought to be strongly linked to other confounding factors, such as fatigue, anxiety and/or depression.

Participant 10: But if a patient has got a background history of psychological issues like depression and anxiety, and particularly those patients who have less psychosocial support, I feel that these patients... their cancer significantly impacts their cognition. [Medical oncologist]

Participant 9: It [cognitive change] tends to go hand in hand with fatigue, so people who get tiredness also get cognitive impairment. People who report no tiredness seem to be relatively unimpaired...

Age and gender of cancer survivors were believed to influence reporting of cognitive changes. Of the participants who felt these demographics contributed to perceived changes in cognition, the majority believed that younger women were more likely to report cognitive changes.

Participant 8: …I have had very little complaint about it [cognitive change] from men. It’s been largely women... I think that those patients under fifty and around that age, I would say, notice it [cognitive change] more. [Medical oncologist]

Additionally, participants discussed employment as a contributing factor to self-perceived cognitive changes.

Participant 9: So people in higher end jobs are more likely to notice it. If you’re not doing a job that requires a high degree of cognitive function, then you’re less likely to notice it. [Medical oncologist]

As cognitive changes were perceived by some oncologists as downstream effects of the cancer experience, they recommended screening for anxiety, depression and fatigue to ensure treatable symptoms were not missed.

Theme 3: Uncertainty of how to best manage cancer-related cognitive changes

While participants felt cognitive changes had received growing attention as a survivorship issue, many expressed uncertainty regarding the management of CRCC, because they believed there were few options available to intervene. This uncertainty impeded the likelihood of oncologist-led discussions regarding CRCC.

Participant 13: But the difficulty is, is that I don’t really know what to do about it, and it’s hard to ask a question that you don’t know the answer to or you don’t know the solution to. [Medical oncologist]

Participant 14: ... you can’t really fix it [cognitive changes] for them, and you don’t even know how bad it is and you don’t know where to go or anything, so most of the time you just end up just sitting on it. [Medical oncologist]

Participants attributed their uncertainty to the absence of management guidelines. Additionally, participants discussed the challenge of accurately assessing the cognitive concerns of patients due to the lack of screening tools designed to measure subtle cognitive changes. In the absence of evidence-based guidelines, the management of patients’ cognitive concerns differed amongst participants. Many acknowledged the need for...
ongoing research for the development and provision of specific interventions and management guidelines addressing CRCC and their effects on cancer survivors.

Participant 5: ...guidelines for clinicians would be useful as well, to sort of base what I’m doing on best practice and what evidence is out there... [Medical oncologist]

Theme 4: The perceived role of oncologists in the management of CRCC

Participants emphasised their curative role across the continuum of cancer care, in addition to the management of physical side effects as a result of cancer and its treatments. Screening for cancer recurrence was perceived as an important aspect of an oncologist’s role within the survivorship phase. Additionally, some participants discussed health promotion as a key responsibility of oncologists during the survivorship phase.

While discussions were often patient-led, some participants raised the potential for cognitive changes with their patients as part of the consenting process to treatment.

Participant 9: It’s part of consenting a patient to treatment. If you’re going to give chemo you need to know everything it may do, all the things that may happen, commonly at least. [Medical oncologist]

The management of patients’ perceived cognitive changes varied amongst participants. When addressing cognitive concerns, many participants normalised this phenomenon and provided informal strategies to cope with the daily impact of cognitive changes.

Participant 2: ... if you keep doing crosswords and puzzles and things like that in the long term because that keeps your brain ticking over and stops this [cognitive changes], or slows down the effects that may come on as a result of treatment. [Radiation oncologist]

Participant 3: It usually boils down to just practical stuff like, make sure you get plenty of rest, don’t drink too much coffee, write lists all that sort of stuff. [Medical oncologist]

Referral to GPs and clinical psychologists was another common approach employed by participants in managing the cognitive concerns of patients, particularly if these changes were felt to be associated with anxiety or depression. A smaller number of participants referred patients to other members of the multidisciplinary team for supportive care, including nursing, occupational therapy and social work. Few participants informed patients of formal cognitive rehabilitation programs, such as memory clinics. Participants often discussed the role of clinical neuropsychologists in assessing measurable cognitive impairments. However, the time and resources required to administer neuropsychological assessments was perceived as a barrier to referring patients.

Participants spoke of the barriers to delivering holistic care. For example, one participant discussed the potential effectiveness of nurse-led posttreatment clinics for the continuing provision of support to cancer survivors. However, the reason such clinics were uncommon within the Australian public hospital system was attributed to financial constraints. Additionally, participants discussed the limited time dedicated to follow-up appointments, particularly in public hospitals. As a result, participants felt restricted in their ability to delve deeper into the challenges faced by cancer survivors.

Participant 15:... We get them [cancer survivors] back usually every three months. Our job then is to get their scans done and we say to them, look that’s good. Did you have any side-effects from the chemotherapy? No? Okay fine. Bye, see you in another three months. So we leave a lot of those things up to the general practitioner... I think we delegate some of that responsibility of that holistic aspect of their care to the community setting. [Medical oncologist]

Discussion

Findings from this study confirm that oncology specialists treat cancer survivors who experience long-lasting sequelae as a result of their cancer diagnosis and treatment. While the Australian healthcare system now regards many cancers as a chronic disease [24] requiring self-management [25], care offered by oncology specialists often reflects a medical approach and may not address chronic health concerns [26] or patient-centred cancer care [27]. Findings were consistent with other studies indicating that cancer survivors received little information from treating oncologists about CRCC [16, 19]. This may be due to uncertainty regarding the appropriate management of CRCC. The lack of clinical practice guidelines for the treatment of CRCC is a perceived barrier to best practice, and consequently, some participants were hesitant to discuss this potential side effect with patients. Indeed, there are issues with the informed consent process for chemotherapy treatment, as many people being treated demonstrate poor retention of information given to them, especially people with a level of
depression, and most rely on information given to them by their doctor, rather than the written information given to them [28]. There is the possibility that giving information about potential cognitive effects may induce anxiety. Therefore, it is recommended that attention be given to a patient’s emotional wellbeing and knowledge at the consent stage, so that they know what to expect during treatment and can take action after treatment [28].

As the sample consisted of predominantly male oncologists, it is possible that female patients may not generally be willing to discuss their concerns with them. This may especially be true of female breast cancer patients who often report cognitive changes [7, 8, 11]. Therefore, some oncologists may not be prompted to address cognitive issues in practice. However, there was no evidence from the data in this study that there were differences in the opinions of male and female oncologists which could contribute to differences in patient management. Irrespective of oncology management practices, findings indicated that usually it was patients’ role to initiate conversations about cognitive change. Patient education can foster health literacy and ultimately enable cancer survivors to assume a proactive role in addressing aspects of their long-term cancer care that may concern them [29]. To achieve this, cancer survivors need timely, balanced information regarding CRCC, its potential duration, cause(s) and recommendations for management.

Previous research suggests that the effects of priming and pre-existing knowledge may contribute to an increased reporting of cognitive concerns by cancer survivors [30]. This notion was supported by some participants in this study and may explain why some oncologists are hesitant to disclose information to patients regarding CRCC, although cancer survivors need to feel able to report symptoms that are troubling them. If oncologists do not inform patients of this potential side effect, cancer survivors may feel less inclined to raise cognitive concerns [18]. Oncology specialists in this study felt that information provided by cancer-related online forums, support groups and societies contributed to reports of cognitive changes amongst cancer survivors. Yet, if patients are not receiving information from their oncologists, this will be inevitable.

Findings from this group of Australian clinicians have added to gathering evidence about the background causes of CRCC [6], including treatment modality, the side effects of associated medications and the psychological impact of a cancer experience. Consistent with previous studies [11, 31], participants perceived a dissociation between cancer survivors’ perceived cognitive changes and measurable cognitive impairment. Participants believed that perceived changes in cognitive functioning were strongly linked with fatigue, anxiety and/or depression. Previous research has demonstrated a correlation between perceived CRCC and negative emotional functioning [15], but a causal relationship remains unclear. Regardless of the causes of CRCC, cancer survivors want their cognitive concerns to be acknowledged and validated by treating oncologists in a timely and open manner [17].

Interestingly, a number of participants perceived a greater likelihood in the reporting of cognitive concerns amongst cancer survivors in work roles requiring a high level of cognitive functioning. While previous studies demonstrate the challenges faced by cancer survivors returning to work due to CRCC [32, 33], there is limited evidence to suggest that cancer survivors are more likely to report concerns to oncologists if they are in cognitively demanding positions. The functional implications of CRCC are commonly reported by survivors of varying backgrounds and experienced across a range of settings [34]. As a result, some cancer survivors are unable to satisfactorily participate in a range of everyday activities, including driving [35] and community engagement [36].

Findings from this study highlight the barriers to delivering survivorship care from the perspective of Australian oncologists. Participants commonly discussed time limitations in follow-up care particularly within the public healthcare system, and their focus on screening for cancer recurrence and the management of physical side effects. However, the survivorship phase should also include avenues for health promotion, education and addressing the long-term health concerns of patients, including CRCC [5]. While participants in this study referred patients to GPs and psychologists for the management of CRCC, particularly if thought to be linked with anxiety and depression, very few discussed the role of other multidisciplinary team members in managing the cognitive concerns of cancer survivors. As suggested in previous research [37], the limited understanding of specialist roles in cancer care may prevent oncologists referring patients, ultimately limiting the provision of high-quality survivorship care.

Cognitive rehabilitation is a growing area of interest in cancer care, and there is research to suggest that group-based programs may improve cognitive function and overall quality of life [38]. Allied health professionals have much to offer in cognitive rehabilitation and management of long-term functional and psychological implications of a cancer experience [24]. Particularly for CRCC, occupational therapists can apply a holistic approach and
foster participation in everyday activities through a range of coping skills and compensatory strategies [39]. However, oncology specialists tend not to refer for these services. Further research is needed to determine effective interventions in managing the cognitive concerns of cancer survivors across the continuum of cancer care.

Limitations

The study was limited by most participants being younger male practitioners and practicing within the Australian public hospital system in a metropolitan area. Thus, the results of this study may not be easily generalisable to other oncology disciplines, locations or service providers. As participants were volunteers, they may already have had an awareness of CRCC and had a particular interest in this area of cancer care. Many participants currently or previously specialised in breast cancer, and perceptions may reflect a bias towards this cancer group as research into CRCC has mainly focused on breast cancer populations. Future studies could benefit from recruiting a larger number of oncology specialists from a range of disciplines within the public and private hospital systems.

Conclusion

As cancer survival rates increase, CRCC has received growing attention as a survivorship issue because of its profound impact on a person's daily functioning and QOL [7]. However, research indicates a gap in information-sharing by oncologists [14, 16] and uncertainty of oncologists regarding the appropriate management of CRCC. As a result, this aspect of a cancer survivor’s journey may be under-addressed by oncology specialists [19]. Future research is needed to determine evidence-based interventions and clinical practice guidelines for the treatment of cancer survivors’ cognitive concerns across the continuum of cancer care. The survivorship phase should include avenues for health promotion and management of the long-term sequelae of the cancer experience [5] by involving all members of the multidisciplinary team.

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Conflict of interest - The authors have no conflict of interest to declare in relation to this study.

References


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