

Cancer-Related Cognitive Impairment: A Mixed-Methods Evaluation of A Standard Factsheet

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Abstract

Purpose: To understand the impact of cancer survivors accessing a standard factsheet regarding cancer-related cognitive impairment (CRCI), publicly available to the Australian public via Cancer Council Australia's websites.

Methods: Twenty-three cancer survivors completed a questionnaire assessing pre-factsheet knowledge of CRCI. Semi-structured interviews were conducted to explore participants' experiences of CRCI and perceptions of the factsheet. Interviews were analysed via thematic analysis using a framework approach. Finally, participants completed another questionnaire assessing post-factsheet change in knowledge of CRCI.

Results: Pre- and post-factsheet questionnaire change scores indicated increased knowledge and greater confidence about CRCI. Interview data resulted in five themes: generally positive perceptions of the factsheet's layout and wording; survivors, regardless of treatments received, experienced CRCI symptoms, with some having strong negative emotional responses to their symptoms; perceptions of the factsheet's strategies to manage CRCI ranged from relevant and useful, to impractical or unrealistic if symptoms were too severe; interactions with healthcare system influenced survivors' perceptions of help-seeking, with negative healthcare experiences a major barrier; and, generally positive impacts of the factsheet, with survivors praising the factsheet's ability to validate the CRCI experience, increase CRCI knowledge, influence health beliefs, and prompt help-seeking.

Conclusion: The factsheet presentation and wording were acceptable to participants. Its ability to normalise and raise awareness for CRCI validated participants' symptoms. The factsheet's potential as a first-line intervention in a stepped-care approach was identified, with participants finding the suggested self-management strategies practical. The factsheet may overcome barriers to self-reporting by encouraging patients to talk with HCPs about CRCI.

Background

Cancer-related cognitive impairment (CRCI) is a deterioration in cognitive functioning (e.g., memory, attention, information processing, executive functioning) reported by some people with cancer, including those with non-central nervous system (CNS) tumours [1, 2]. CRCI affects 24–75% of patients before, during or after chemotherapy [2–9]. Use of the term *chemo-brain* has shifted towards *CRCI* to signify the cancer itself, and not only chemotherapy, may cause cognitive impairment.

In 2018, Cancer Council Australia released an online CRCI factsheet [10] explaining CRCI, its causes, symptoms, and strategies to manage CRCI. Written information about CRCI is important as it is not commonly discussed prior to treatment [11], and recall of information provided during cancer diagnosis is limited [12–14].

Within a stepped-care model, information may provide an initial, low-intensity, low-risk intervention, ameliorating concerns of those with low-level CRCI. For people with more severe CRCI, information may facilitate self-report of symptoms to healthcare professionals (HCPs), increasing access to effective intervention (e.g., cognitive rehabilitation programs) [15]. Overall, through provision of health information and services, the factsheet should reduce distress and symptoms in people with cancer.

This study's theoretical background was informed by Andersen's Behavioural Model of Health Services Use [16], which states help-seeking behaviour is influenced by environment, predisposing characteristics, health beliefs [17], availability of enabling resources, perceived and actual need, health behaviours, and health outcomes.

Understanding the CRCI factsheet as an enabling resource encouraging patient health behaviours such as personal health practices (i.e., self-management) and help-seeking (i.e., health services use) is important.

This study evaluated the Cancer Council Australia's CRCI factsheet [10] from a patient perspective. It aimed to understand the impact of accessing CRCI-related information on cancer survivors.

Methods

Design

A mixed methods design was used, comprising baseline and follow-up knowledge questionnaires, factsheet presentation, and qualitative interviews with cancer survivors.

Participants

Participants were Australian residents over 18 years who could read and speak English, were diagnosed with early-stage non-CNS cancers, and had completed primary treatment at least six months earlier. Participants were recruited regardless of experience or knowledge of CRCI.

Materials

Factsheet.

The three-page factsheet was developed by Cancer Council Australia [10] following a standard process [18], describing CRCI and its symptoms, causes, prevalence, and management.

Questionnaires.

An online questionnaire was developed to obtain participants' demographic and disease data, health literacy [19], and assess knowledge of CRCI. Knowledge questions were multiple-choice and adapted from the factsheet content. Higher scores indicated greater knowledge. Knowledge questions were repeated after the interview.

Semi-structured interview guide.

A semi-structured interview guide (Supplementary file A) was developed to explore perceptions of the factsheet. Questions were guided by the Behavioural Model of Health Services Use [16] and the Linguistic Framework for Evaluating Healthcare Text [20]. Topics included: accessibility and utility, CRCI-related health beliefs and help-seeking behaviours, post-factsheet CRCI knowledge and attitude, and self-management strategies.

Procedure

Recruitment.

Participants were recruited through social media; passive snowballing; or their treatment team, via brief introductory flyers. Purposive sampling prioritised recruitment of diverse demographics. Participants self-referred via weblinks, providing informed consent before completing baseline questionnaires.

Data collection.

After completing baseline questionnaires, eligible participants were emailed the factsheet, prior to completing a telephone interview. Interviews were audio-recorded and transcribed verbatim. Post-interview, participants were emailed a weblink to the follow-up questionnaire (Fig. 1).

Analysis

Descriptive data.

SPSS and Microsoft Excel were used to analyse: demographic, disease and treatment data descriptively; and median pre- and post-factsheet knowledge change scores. Hypothesis testing was not conducted due to the qualitative focus and small sample size.

Thematic analysis.

Interview transcripts were analysed in Microsoft Word and Excel using thematic analysis [21]. Specifically, a five-stage framework approach was used [22, 23]: familiarisation with data, identifying a coding framework derived from the data, indexing data, charting data, and mapping data to identify relationships.

Analysis of transcripts occurred concurrently with interviews. Thematic saturation was achieved after 14 interviews. Three member checking interviews were done, and six further interviews were completed.

Methodological rigour.

Methodological rigour [24] was ensured through a range of strategies detailed in Supplementary files B and C [25].

Results

The sample comprised 23 cancer survivors (18 female), with a median age of 55 years (range 35–83). Most were breast cancer survivors (n = 11), all had received surgery, and most (n = 13) adjuvant chemotherapy (Table 1).

Table 1
Participant demographics

ID	Sex	Age	Education	Cancer	Stage	Years from diagnosis	Treatments	Hormone therapy	Returned 2nd survey?
P01	F	36	Tertiary	Breast	3	2.25	Surgery Chemotherapy Radiation	Yes	Yes
P02	F	46	High School	Breast	3	2.17	Surgery Chemotherapy Radiation	Yes	Yes
P03	F	49	Tertiary	Breast	1	1.50	Surgery Radiation	Yes	Yes
P04	F	54	Vocational	Ovarian	2	2.58	Surgery Chemotherapy	N	Yes
P05	F	60	Tertiary	Ovarian	3	1.00	Surgery Chemotherapy	Non	Yes
P06	F	45	High School	Bladder	2	2.58	Surgery Chemotherapy	Yes	Yes
P07	M	36	Vocational	Testicular	2	8.92	Surgery Chemotherapy	No	Yes
P08	F	54	Vocational	Ovarian	2	0.92	Surgery Chemotherapy Radiation	No	Yes
P09	F	68	High School	Breast	1	5.92	Surgery Radiation Hormone	No	Yes
P10	F	59	Tertiary	Breast	1	1.58	Surgery Radiation	Yes	No
P11	F	57	High School	Breast	1	5.08	Surgery Radiation	Yes	Yes
P12	F	52	Vocational	Ovarian	2	7.75	Surgery Chemotherapy	Yes	Yes

ID	Sex	Age	Education	Cancer	Stage	Years from diagnosis	Treatments	Hormone therapy	Returned 2nd survey?
P13	F	38	High School	Ovarian	1	1.17	Surgery Chemotherapy	No	Yes
P14	M	72	Tertiary	Prostate	2	7.50	Surgery	No	Yes
P15	F	35	Tertiary	Breast	2	2.08	Surgery Chemotherapy Radiation	Yes	Yes
P16	M	61	Tertiary	Bowel	2	11.25	Surgery Chemotherapy	No	Yes
P17	F	83	Tertiary	Breast	3	3.92	Surgery Radiation Targeted agents	No	Yes
P18	M	67	Tertiary	Prostate	1	11.67	Surgery	No	Yes
P19	F	57	Tertiary	Breast	2	2.33	Surgery Chemotherapy Radiation	Yes	Yes
P20	F	58	Vocational	Vulva	1	2.08	Surgery	No	Yes
P21	F	59	Tertiary	Breast	1	6.50	Surgery Chemotherapy Radiation	Yes	Yes
P22	F	55	Vocational	Breast	1	1.92	Surgery	Yes	Yes
P23	M	51	Vocational	Prostate	2	7.42	Surgery	No	Yes

CRCI knowledge

Prior to reading the factsheet, 78% of participants had heard of '*cancer fog*' or '*chemo-brain*' and 74% believed CRCI to be real. Knowledge scores increased from pre- to post-factsheet completion, with fewer participants uncertain about CRCI (Table 2).

Table 2
Change in knowledge after reading factsheet

Item	Pre-factsheet (N = 23)	Post-factsheet (N = 22)	Change score
Percentage of participants that:			
Heard of the terms “cancer fog” or “chemo-brain”	78%	96%	+ 18%
Think “cancer fog” or “chemo-brain” is real	74%	91%	+ 17%
	(22% NS)	(9% NS)	(-13% NS)
Median accuracy of knowledge of (range):			
CRCI symptoms (/12)	5	9.5	+ 4.5
	(0–12)	(2–12)	
Cognitive change causes (/8)	3	4	+ 1
	(1–6)	(1–8)	
Effects of the actual cancer (/10)	0	1	+ 1
	(0–8)	(0–10)	
Percentage of participants responding to the following:			
CRCI prevalence:	0%	9%	+ 9%
1 in 3 people before treatment <i>only</i>	13%	14%	+ 1%
1 in 3 people after treatment <i>only</i>	30%	27%	-3%
3 in 4 people during treatment <i>only</i>	17%	36%	+ 19%
All of the above	0%	0%	0%
None of the above	39%	14%	-25%
Don't know			
Strategies to manage cognitive changes:			
Adjusting daily routine	74%	77%	+ 3%
Maintaining a healthy lifestyle	48%	64%	+ 16%
Improving thinking and memory	61%	82%	+ 21%
Involving other people			
NS = not sure			

Qualitative data

Median interview length was 32 minutes (range 18 to 65). Interviews generated five themes: perceptions of factsheet, experience of CRCI, strategies to manage CRCI, interaction with the healthcare system, and impact of the

factsheet (Fig. 2). Exemplar quotes are presented, reflecting diverse participant perspectives. The themes were mapped to Andersen's Behavioural Model of Health Services Use [16] (Fig. 3).

1. Perceptions of the factsheet.

Participants discussed the *layout and presentation; wording; and, information* both positively and negatively, demonstrating varied perceptions. For example, P01 described the factsheet as *"easy to read... in language that somebody would be able to understand"*, while P10 stated, *"there's probably... far too many words and it's too long for people who have trouble with literacy."*

Information was divided into: *overall content; symptoms; and strategies and resources*. Overall, responses reflect the factsheet being *"very practical"* (P23), thus an enabling resource [16]. Some participants preferred more information, including what CRCI is and why it occurs. Additionally, P07 recommended including a severity chart to determine whether symptoms were severe enough to consult a HCP.

2. Experience of CRCI.

Participant experiences of CRCI included *symptoms and timing of changes*. Subthemes *symptoms experienced and impact* were identified. Many participants treated with chemotherapy experienced symptoms described in the factsheet, including feeling mentally 'foggy', difficulty following conversations or multitasking, and memory issues. Persistence of symptoms varied, some stopping *"immediately after I finished chemo"* (P05), while ongoing for others: *"definitely worse than before I had the chemo"* (P21).

A minority, mostly those not treated with chemotherapy, did not experience CRCI symptoms, although others reported CRCI:

I couldn't multitask... I can't think of the right word, and I haven't had chemo... so I wonder... I think when we call it "chemo-brain" that can negate some people's experience. P03

Experiencing CRCI impacted participants differently, related to differing health beliefs regarding the severity and consequences of cognitive change [17]. Some reported acceptance or positive reframing: *"if this is a side effect of the treatment, well, it just has to be"* (P07). Several expressed negative responses towards their symptoms:

The idea that I can't rely on my brain as much is actually super upsetting, emotionally, it goes to my sense of identity, my sense of self, it makes me worry about my future career prospects, and about whether I'm going to be able to continue to do my job, or get the promotions that I had hoped to. P15

There was variability in timing of CRCI symptom onset. For example, P12 realised: *"before I was diagnosed I noticed that I was starting to not cope"*. Others noticed changes after diagnosis or treatment: *"After the first week of chemo... things started to just blur"* (P07). Some took greater notice of symptoms after treatment ended: *"When you sort of think things should improve and you're actually still a bit brain fogged... maybe a year after [chemo]."* P04

3. Strategies to manage CRCI.

Participants identified strategies reflecting the four groups in the factsheet, indicating their 'personal health practices' [16]. Most adopted *"setting alarms on your diary, writing things down, to do lists, trying not to multitask"* (P21). Some found the strategies relatable, achievable, and informative:

I didn't really make the connection between nutrition and cognitive function, so that's good, that feels nice, 'cause it's a thing that I'm already doing. P15

However, the following quotes reflect some strategies are unrealistic, particularly where symptoms are more severe:

It was clearly written by someone who's never been through it... the bits about, you know, eating healthy, nutritious food, and going for a walk and getting fresh air... Some days, you know, just, getting out, having a shower, getting some breakfast, getting some clothes on, and I'm absolutely wiped out. P08

4. Interaction with healthcare system.

The theme *perceptions of healthcare system* encompassed positive and negative health beliefs regarding benefits and barriers to seeking professional help [17], influenced by 'use of health services' [16]. For example, P01 described hesitating to discuss symptoms with the doctor, who was "very good... but [doctor's] bedside manner isn't great... [they're] not super empathetic". On the other hand, P12 stated, "I had a fabulous, fabulous GP.. in Queensland and even though I'm down in Adelaide I still... consult with [them], because [they're] phenomenal."

Some believed there is a lack of access to healthcare resources, particularly outside major cities, rendering recommended resources inaccessible. Stigma was also associated with obtaining a Mental Health Care Plan.

5. Impact of the factsheet.

The theme *knowledge about CRCI* was identified, comprising *general knowledge, causes, and prevalence and trajectory*. Additionally, participants expressed varying perspectives concerning *effect, optimal timing, and sharing of the factsheet*.

Most participants knew of CRCI from other people with cancer, others from HCPs. Some learnt about CRCI through their own information-seeking, while a minority had no prior knowledge of it.

Causal attributions influenced participants' health beliefs of perceived CRCI susceptibility [17]. Many attributed cognitive changes to chemotherapy and ageing. Those not chemotherapy-exposed and experiencing CRCI expressed confusion about their cognitive changes and praised the factsheet on clarifying causes of CRCI's causes:

I thought, "I'm not having chemo why is this happening to me," ...I thought... it'd only happened if you had chemotherapy. P03

Participants' health beliefs surrounding severity and persistence of CRCI influenced perceived benefits and/or risks of using the healthcare system [17]. For example, some participants described fearing CRCI symptoms were permanent or without solution: "I didn't feel like it was worth discussing it with anyone because I didn't think there was any... solution to it" P01. The factsheet informed participants of CRCI's trajectory and prevalence, helping some understand it is common and recovery possible:

It's actually quite comforting to think that it might go away one day if it ... could possibly be stress or emotional... there's light at the end of the tunnel. P13

All participants stated the factsheet would not influence their treatment decision-making. This was linked to positive *perceptions of healthcare system*, particularly getting the right treatment being important, and the belief

“you’ve got to do what [HCPs] say because they know better than you,” (P17)

‘Consumer satisfaction’ [16] was identified in the factsheet’s ability to normalise, validate, raise awareness and prepare for CRCI. These effects were influenced by *impact of symptoms* on participants and *knowledge about CRCI*:

‘What’s nice about this factsheet is it just recognises that [CRCI’s] a thing’. P15

Some participants were indifferent towards the factsheet, recognising it may cause additional worry: *“Maybe it would have frightened me a bit more, I don’t know” (P06)*. However, most felt it would be useful to refer to, prompting adoption of personal health practices:

Anticipating that this might happen I think would have been useful... And then if it didn’t happen that’s fine, but if it did... You know you would have had some strategies... P18

For some, the factsheet would prompt use of health services:

[If I had the factsheet] I would have asked each of my [HCPs] at the time, “Is there anything else that I can do?” P21

Perception of optimal timing to receive the factsheet was informed by whether participants experienced CRCI, *timing of changes*, and *effect of the factsheet*. Perceptions varied, ranging from being most useful at diagnosis, prior to or during treatment, or during recovery. A minority questioned whether the factsheet should be provided at all, while others believed all patients should receive it:

It’s about giving them the factsheet, it’s not about... mandating that they read it... it’s there if you want to have a look at it. P06

Some participants believed providing the factsheet should be at the discretion of HCPs, either *“...if people are actually having trouble, then perhaps giving them some information” (P10)*, or during a discussion about cancer, treatment, and side-effects in *“a subsequent appointment... a couple of weeks [after diagnosis] perhaps to process that” (P18)*. Another participant, P03, suggested providing the factsheet at multiple timepoints, such as *“upfront, and then again”* and *“by different [HCPs]”,* to reinforce the information.

The positive *effect of the factsheet* meant most participants were open to sharing the factsheet with others. Attitudes towards discussing the factsheet with HCPs were influenced by *perceptions of healthcare system*. Prior positive experiences with their HCPs rendered some open to discussing the factsheet. Others perceived no benefits in discussion with HCPs, reflecting health beliefs surrounding benefits and barriers health service use [17]:

I probably wouldn’t discuss it with a doctor, to be honest. I might mention it, but doctors don’t always have time for these... side issues, I guess. They’re more concerned about cutting it out or making you well, as opposed to how you cope with life. P05

Discussion

We evaluated a CRCI factsheet [10], exploring cancer survivors’ perceptions of CRCI and the factsheet using a mixed-methods approach. In mapping our themes to Andersen’s model [16] (Fig. 3) we hypothesise how the factsheet may influence survivors’ experiences. While most participants had beliefs about ‘chemo-brain’, the factsheet increased knowledge about the nature, causes, prevalence, and trajectory of CRCI, demonstrated by

knowledge scores and interviews. Participants were generally pleased with their increased knowledge, supporting previous findings linking information provision to greater patient satisfaction [26]. Most participants were positive about the factsheet's layout and readability, with minor criticisms regarding visual presentation.

CRCI was experienced by participants who both did/did not receive chemotherapy, reflecting CRCI occurrence independent of chemotherapy [7, 8, 27]. Many who experienced CRCI reported negative emotional responses to its impacts on daily functioning, reinforcing CRCI's distressing nature [28]. Participants acknowledged the factsheet's role in normalising and validating CRCI, and its ability to increase confidence in patients, supporting the notion that education, awareness, and preparation maximise cancer survivors' quality of life [29].

The factsheet as the first line of stepped care

Our results demonstrate the factsheet's potential as a low-intensity, low-risk first-line intervention within a stepped-care model [30]. The factsheet has the capacity to empower patients to engage in 'health behaviours' [16]: 'personal health practices' for less severe symptoms and 'use of health services' for those requiring more intense treatment.

However, this factsheet can only effectively encourage 'use of health services' if the perceived need to seek help is sufficiently large. Perceived need to seek help was influenced by participants' health beliefs of CRCI's severity and consequences, which were influenced by impact of symptoms. Thus, participants with severe and persistent CRCI intended to speak to HCPs about these symptoms.

Barriers to help-seeking

Barriers to help-seeking were influenced by CRCI-related health beliefs, informed by CRCI knowledge. For example, attributing CRCI to chemotherapy meant non-chemotherapy participants had reduced perceived susceptibility to CRCI, reducing their perceived need to discuss symptoms with HCPs. If CRCI was thought unmanageable, participants perceived no benefit to help-seeking. For the factsheet to foster positive health behaviours, it must influence CRCI-related knowledge and health beliefs. Our data revealed participants' perceptions changed after reading the factsheet, thus it appears to encourage help-seeking.

Health beliefs regarding use of health services can create barriers to help-seeking. Many participants expressed negative perspectives of the healthcare system due to prior experiences, making them hesitant to discuss CRCI symptoms with HCPs. Lack of discussion around CRCI within the hospital setting was a barrier, with several participants hearing about CRCI through other patients. If CRCI were discussed, patients sometimes perceived it a low priority to HCPs. These findings reflect HCPs' decisions to provide little CRCI-related information due to uncertainty about CRCI symptoms and management [11].

Clinical implications

A useful first-line intervention must encourage patients to seek help and is only possible if patients believe help-seeking is beneficial. While participants' knowledge of CRCI seemed to increase, many still attributed CRCI to chemotherapy. We recommend greater emphasis on cancer as a cause of CRCI, to overcome knowledge barriers.

HCPs need training about CRCI to facilitate proactive patient care, regardless of treatment or patient-reported symptoms. As HCPs indicate low confidence in managing CRCI [11], education of management and rehabilitation options may prepare HCPs for discussing CRCI with patients. Future research should explore whether CRCI

education for HCPs increases confidence in treating patients' symptoms and/or impacts patient self-reports. Andersen's behavioural model [16] highlights the healthcare system as an environmental factor not influenced by any other factor, meaning change within the healthcare system is needed to trigger health behaviours to improve patient outcomes.

A lack of shared experience limited cancer survivors' willingness to share the factsheet with others. More supportive environments may increase patient help-seeking. This is only achievable through more resources for the general community, to increase knowledge and understanding of the cancer experience.

Policy implications

To ensure allocation of resources, it is important to standardise the timing of factsheet provision. We have identified the importance of giving the factsheet to all cancer patients regardless of treatment or symptoms. Disseminating the factsheet during cancer consultations is feasible. Many participants preferred to receive the factsheet before or during treatment to prepare for CRCI; others only if CRCI symptoms emerged. These views were tempered by concerns about patients being overwhelmed with information during diagnosis and treatment decision-making, reflecting findings that timing and emotional arousal impacts information recall [31]. While acknowledging the overwhelming experience, participants stated that physically having the factsheet meant having control over timing of information, as they could choose when to read it.

The importance of HCP involvement was highlighted, with participants suggesting either nurses regularly monitor patients for CRCI symptoms, or provide the factsheet several times to reinforce the information. Repeating information is recommended to increase the amount of information recalled [14].

Factsheet provision seems unlikely to affect treatment decisions, as participants indicated receiving the factsheet before treatment would not change their treatment decision. However, one was concerned the factsheet could prime cognitive impairment, a concern shared by HCPs [11]. To counteract negative priming effects, Schagen [32] recommends CRCI information include management and cognitive rehabilitation strategies. Given many participants indicated memorable, positive perceptions of the factsheets' strategies, it possibly provides balanced CRCI information. Further research is needed to assess the factsheet's priming impact.

Importantly, factsheet provision alone is insufficient. Participants indicated the need for routine and holistic care from HCPs. Thus, we recommend HCPs include CRCI when discussing treatment options, regardless of whether treatment includes chemotherapy. To facilitate patient recall of CRCI information, we recommend providing a copy of the factsheet to reinforce the discussion, since written information is better recalled than verbal [33, 34]. The factsheet may be presented alone or incorporated into other materials, such as patient information booklets discussing treatment side effects, which participants have recalled receiving.

Early discussion of the factsheet aligns with the Clinical Oncology Society of Australia's Model of Survivorship Care [35], which highlights the importance of providing holistic patient-centred care at all time points. Multiple timepoints where the factsheet could be helpful have been identified, and we recommend it be provided at each stage (e.g., chemotherapy education, end of adjuvant therapy follow-up) [35].

Emphasising cognitive rehabilitation options may foster health beliefs surrounding recovery, increasing perceived benefits in using health services for more severe CRCI. Additional resources and information, such as cognitive-training programs, may alleviate HCPs' perceived burdens of administering cognitive rehabilitation [11]. We recommend further research regarding cognitive rehabilitation options (Box 1).

Box 1: Summary of recommendations

Factsheet:

- Increase accessibility by simplifying language to eighth-grade level
- Emphasise CRCI can occur without chemotherapy treatment
- Provide information on cognitive rehabilitation

Policy:

- Discuss CRCI as part of treatment option discussion; provide a copy of the factsheet
- Provide the factsheet by itself, or in other educational materials, such as pamphlets on treatment side effects
- Repeat CRCI discussion when patients consult treatment team; provide another copy of the factsheet
- Monitor CRCI symptoms regularly
- Improve access to healthcare resources for rural patients
- Develop online resources for patients to access information and services
- Develop brain-training apps for patients to use at their convenience

Limitations

This study is not without limitations. Despite all efforts to recruit a diverse sample, participants were mostly female, breast cancer survivors, with higher health literacy. Our results may not generalise to the broader Australian cancer population. The factsheet is only available in English, limiting the study to English-speaking participants. Self-selection bias may have skewed our participants to be more receptive to the factsheet than those not participating. Retrospective interviews necessitate caution in interpreting responses, e.g., recall of being informed about CRCI. Finally, it is possible the interview process increased CRCI knowledge. Future research is needed to explore the extent to which HCPs discuss CRCI and how patients manage CRCI information at different timepoints. This should be explored in diverse samples, including different tumour types and people with lower health or English literacy.

Conclusions

The factsheet's presentation and wording were acceptable to participants. Its ability to normalise and raise awareness for CRCI validated participants' symptoms. Its potential as a first-line intervention in a stepped-care approach was identified and may encourage patients to self-report CRCI, overcoming barriers. Policy change and educational interventions are recommended to inform patients, HCPs, and the community about CRCI to better support cancer survivors.

Declarations

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Conflicts of interest/Competing interests

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Availability of data and material

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

Code availability

Not applicable.

Authors' contributions

All authors contributed to the study conception and design, and material preparation. Data collection and analysis were performed by Chloe Lim, and Haryana Dhillon. The first draft of the manuscript was written by Chloe Lim and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics approval

Ethics approval was granted by The University of Sydney Human Research Ethics Committee (project 2018/302). This paper adheres to the COREQ checklist for reporting qualitative research (see Supplementary file C).

Consent to participate

All individual participants included in the study signed informed consent to participate in the study. Verbal informed consent was re-confirmed prior to the interview.

Consent for publication

All individual participants included in the study signed informed consent regarding publishing their data.

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Figures

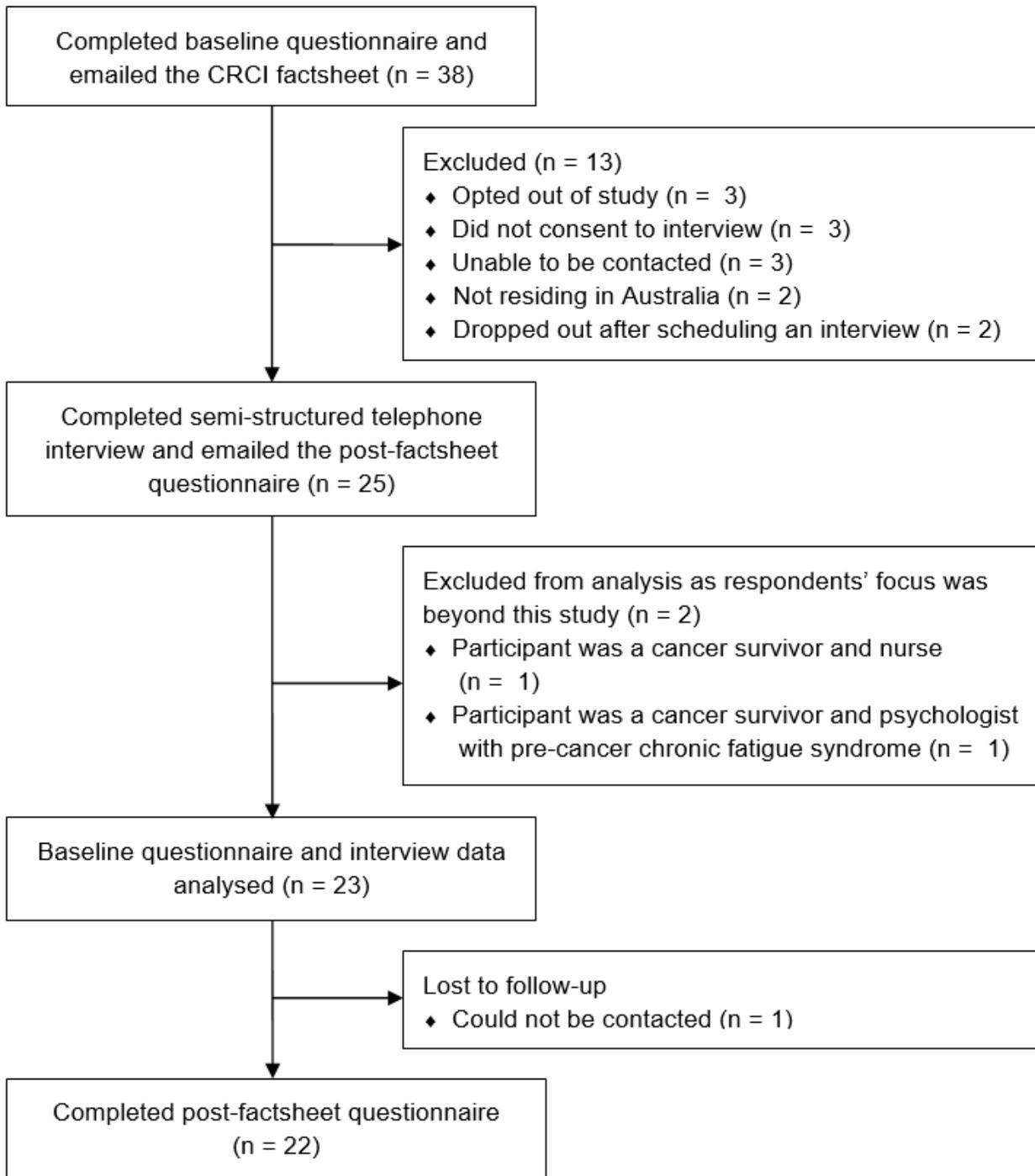


Figure 1

CONSORT flow diagram of study procedure and participant sampling

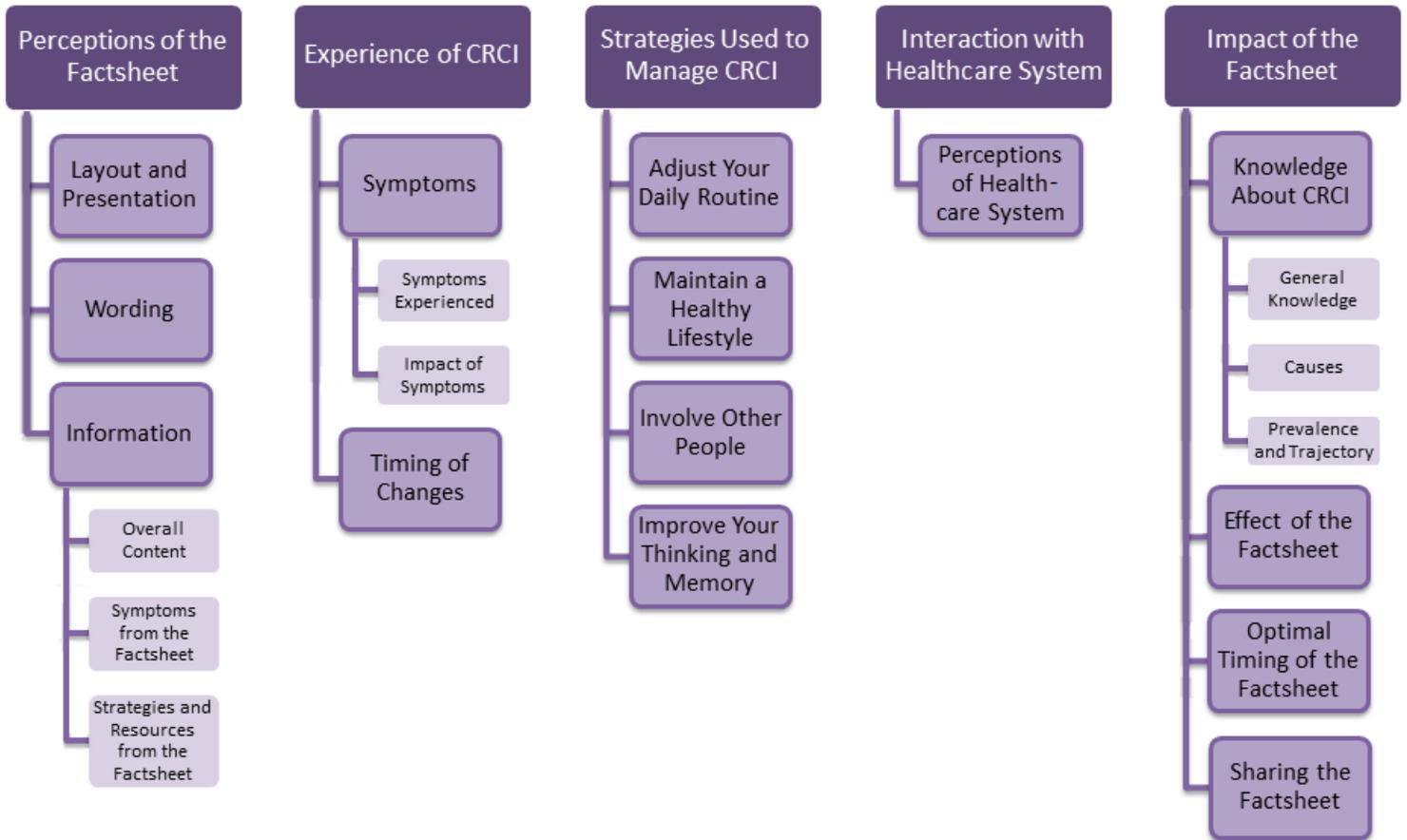


Figure 2

Themes and subthemes identified

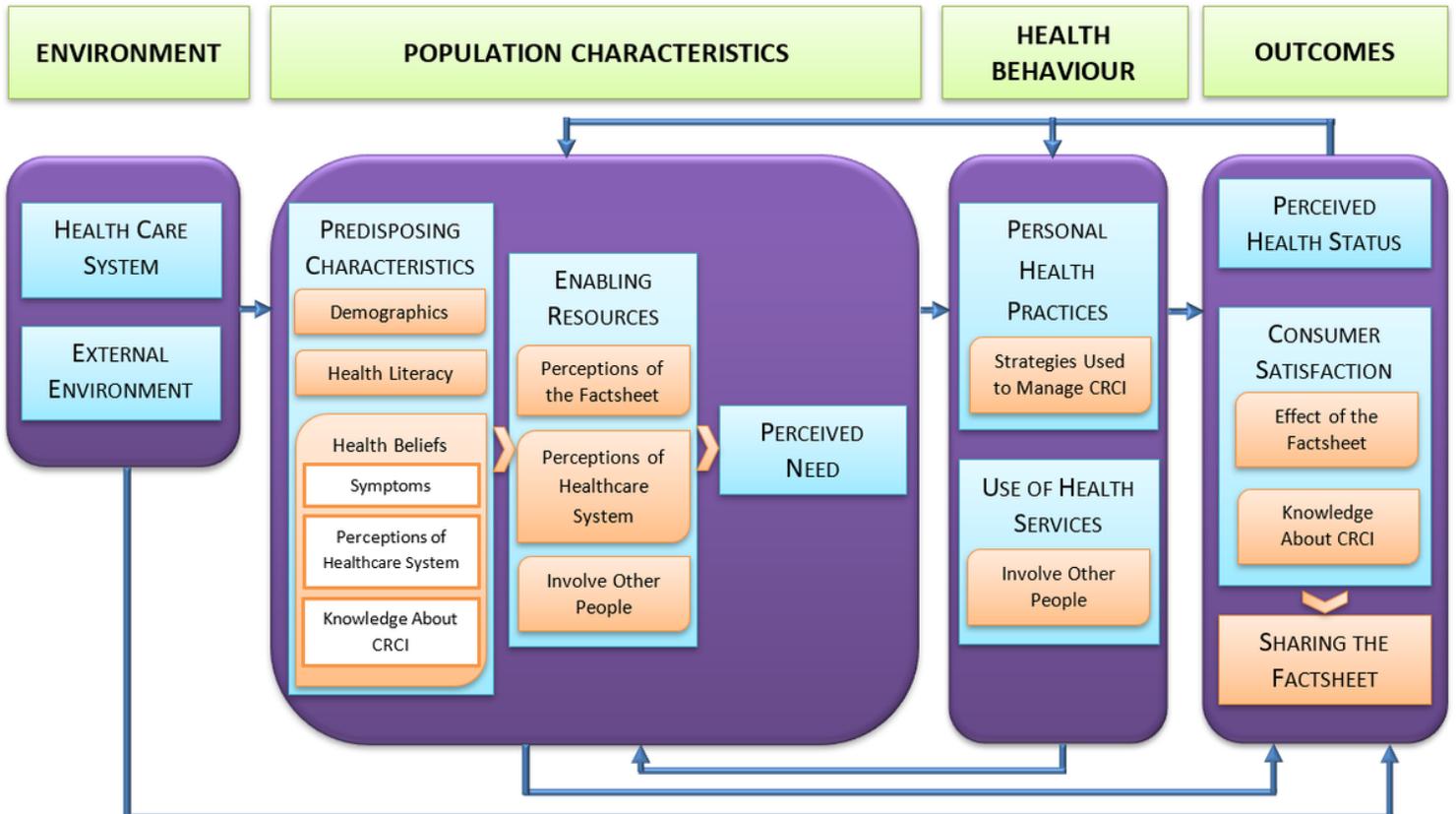


Figure 3

Themes mapped to Behavioural Model of Health Services Use [16]

Supplementary Files

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- [SupplementaryA.Semistructuredinterviewguide.pdf](#)
- [SupplementaryB.MethodologicalRigour.pdf](#)
- [SupplementaryC.COREQchecklist.pdf](#)