

Information needs and preferences among rural cancer survivors in Queensland, Australia: a qualitative examination

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Cancer is a significant public health issue in Australia, as it is a leading cause of mortality and morbidity.¹ The provision of health information and the degree to which individuals can understand basic health information is an integral component of quality cancer care and can have a significant impact on a patient's understanding of the disease as well as their ability to manage their physical and emotional health.^{2,3} Cancer survivors want to know what to expect and how they could minimise the impact of treatment side effects.^{4,5} When equipped with appropriate and relevant information regarding their disease and treatment, survivors have greater capacity to be involved in decision-making and self-management, report less anxiety, and are more likely to adhere to treatment and medical follow-up.^{6,7} Thus, it is critical for cancer survivors to receive high-quality and comprehensive information.

Health information needs among cancer survivors are likely to be highest during diagnosis and treatment⁷; however, information needs continue throughout the cancer journey^{2,8} and for many years beyond, varying over time.⁹ To support ongoing wellbeing, information needs in the post-treatment period may shift to self-management of late and long-term effects, as well as resources for coping and transitioning

Abstract

Objective: This study aimed to understand how cancer survivors in rural Queensland seek and receive information, as well as their preferences regarding the content and delivery of health-related information.

Methods: This study explored cancer survivors' experiences in seeking and comprehending health information using a qualitative descriptive approach. Semi-structured interviews were conducted with 24 participants. Data were analysed using reflexive thematic analysis.

Results: Two major themes and six sub-themes were identified including 1) information content and gaps – a) information about diagnosis and treatment, b) survivorship information gaps and c) practical support needs and 2) delivery and acceptance of information – a) sources of information, b) personalised information needs and c) information seeking or avoidance. Findings suggested that health information provision was inconsistent; survivors' attitudes towards seeking information varied greatly; and survivors' had difficulty processing information due to emotional distress.

Conclusion: The role of the health professional is critical in providing information and support to rural cancer survivors. Information provided should be tailored to meet the needs and preferences of individuals taking into consideration demographic factors and attitudes.

Implications for public health: The current findings imply that quality information provision after cancer treatment would facilitate improvements in satisfaction among rural cancer survivors.

Key words: oncology, health information, rural health, cancer survivorship, qualitative

back to daily life.^{2,9} Thus, survivorship care guidelines endorse the provision of post-treatment support including evidence-based healthy lifestyle information that is tailored to cancer survivors' needs and preferences.¹⁰⁻¹² In addition, cancer survivors' recall of information can be poor and impacted by cognitive side effects of treatment, which

may further impact on their ability to make informed decisions and manage their disease effectively.¹³ This may be particularly important in rural areas where there is reduced access to services and supportive care, and extensive travel is required for specialist appointments.^{14,15}

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Individuals diagnosed with cancer residing in rural locations are known to experience higher distress, lower quality of life, and higher levels of unmet needs than cancer patients in metropolitan areas,^{16,17} and thus may have different experiences of survivorship care and information. Investigations into the experiences of rural breast cancer survivors in the United States have demonstrated a need for more information and emotional support after diagnosis, with over 50% requiring further information on side effects, symptoms and health promotion.^{18,19} In Australia, rural cancer survivors have also reported lacking clear post-treatment care and information, and have reported receiving limited information about the strategies they can use to manage their own care and maximise quality of life.²⁰ A greater proportion of the Indigenous population live in rural areas, with rural communities also tending to have lower socioeconomic status and lower levels of education than major cities, demographic characteristics that are known to have different cancer survivorship care and information needs.^{4,18} Thus, a better understanding of the unique preferences and needs of rural cancer survivors is needed to ensure future service delivery models provide optimal care and survivorship information for this population. Accordingly, this study explored how cancer survivors in rural areas of Queensland seek and receive information, as well as their preferences regarding the content and delivery of information.

Methods

Procedure

Ethical approval was granted by the University Human Research Ethics Committee (H17REA152). Participants were recruited through a larger longitudinal research project, with recruitment methods described elsewhere.²³ A sub-sample of participants enrolled in the larger project who had indicated consent to be contacted about future research studies were approached and invited to participate. The participants were recruited from Cancer Council Queensland subsidised accommodation services and had to be over 18 years of age and speak fluent English. The participants selected for interviews were purposively sampled to include a mix of genders, ages, cancer types, and geographic remoteness categories as it is recommended in qualitative descriptive

research to utilise maximum variation sampling in order to acknowledge the range of experiences that exist.²² Participant's residential postcode was geocoded and classified by Remoteness Area according to the Australian Statistical Geography Standard (ASGS) classifications.²⁴ The Consolidated Criteria for Reporting Qualitative Research guidelines were used to assist in the reporting of the study.²⁵

Data collection

Individual semi-structured telephone interviews were conducted by two female psycho-oncology researchers (FC, PhD and MF, Honours) who had experience conducting interviews with cancer patients and did not have an established relationship with participants. Interview questions focused on the cancer survivors' needs and preferences for information in the period following their cancer diagnosis. Probes were used when necessary to explore the specific aspects of information which may have been lacking, and the levels of trust and credibility in information sources. The interviews ranged from 32 to 76 minutes and were audio-recorded and then transcribed verbatim in preparation for analysis.

Data analysis

The current study applied a qualitative descriptive approach to provide direct descriptions of the phenomena from the survivors perspective.²² As the approach to analysis for qualitative descriptive research is dictated by the aims of the research, a reflexive thematic analysis method was selected to provide clear and compelling interpretation of the interviews, grounded in the data.²⁶ In this approach the interpretations were questioned and queried through reflective and thoughtful engagement with the data, and the themes were actively created by the researchers following a six-step process.²⁷ To gain a holistic understanding, one author familiarised herself with the data by listening to each recorded interview, studying the transcription several times before beginning line-by-line coding of relevant statements related to information needs and preferences. The codes were then used to generate and define themes. Coding and thematic grouping was then discussed with a second researcher so that differing interpretations could be explored. The final analysis presented is an interpretation of the original

interview data and representative quotes are presented to illustrate the major themes.

Results

Participant characteristics

Twenty-four participants were approached and agreed to participate in the interviews. Participants had a mean age of 63.8 years (range 44–85), 13 were female and 11 were male. The most common primary cancer diagnoses were breast, lung, skin, head and neck, and prostate (Table 1). The participants were interviewed at an average of 24 months post diagnosis.

In general, participants reported that health-related information provision was inconsistent and occasionally contradictory; cancer survivor's needs for information and attitudes towards seeking it varied greatly; and many survivors had difficulty processing and retaining information due to emotional distress. Analyses led to the emergence of two major themes and six sub-themes, which can be seen in Figure 1.

Theme one - Information content and gaps

Information received about diagnosis and treatment

Participants had received basic information about diagnosis, treatment and common side effects, however, this was generally described as limited or 'surface level'. Many participants knew what type of treatment they were undergoing but could not recall the specific pharmaceutical names, and while several patients described 'knowing enough' others were not provided with a comprehensive understanding of their cancer or how the treatment would work.

Well in the beginning I went in blind, you know, the drugs they give you, the steroids, basically what's happening is that you don't really have much of a memory for information. (ID #21 – Female lymphoma cancer survivor, outer regional)

I did get information on the pill, which I still have. Um and I kind of understand what it's doing. (ID #24 Male lung cancer survivor, outer regional)

Participants were generally aware of their ongoing treatment appointments and follow-up schedules, but this was often described as 'drip-fed' information with the next appointment arranged after the first.

No summary given. It's only verbal. No... they just said we'll give you a review every, around every quarter. No set... there's no set time, so what I have got is get a letter, to say when I'm gonna come down for a review. (ID #22 - male skin cancer survivor, inner regional)

Survivorship information gaps

Participants were rarely given information about maintaining a healthy lifestyle, signs of recurrence, or social and emotional support information. Information about healthy lifestyle behaviours was limited, however, this information was often seen as 'common sense' with survivors reporting that they knew they should be exercising or eating healthy food.

Oh well I just know. Cos, you know, in general, I should be keeping a bit more active I suppose... I eat healthy though, like we eat our veggies and fruit and... we are sort of healthy eaters... in that way I should be more fit, because I have put on weight. I mean I know I've gotta walk, you know? So I know I've got to exercise, so it's just something that I've gotta do. (ID #11 - Female bladder cancer survivor, inner regional)

Nutrition was discussed by health professionals more often than exercise, with some participants being referred to a dietician. When asked about the information they were given about diet, participants only reported advice regarding temporary measures to reduce treatment side-effects as opposed to ongoing nutrition advice. Several survivors reported being recommended nutritional supplements, with some (n=4) being told to eat high calorie foods in order to put weight on after significant weight loss during treatment, but it was unclear for those survivors whether this was healthy or necessary.

When we were going through my chemo and radiotherapy... I lost a lot of weight, and we were looking for healthy ways to put on weight, and the recommendation at the hospital from the doctor was just go to McDonalds and have a chocolate thick shake. There's no focus on quality nutrition. (ID #17 - Male lung cancer survivor, remote)

Several participants wanted to know as much as possible about staying healthy but perceived that the health system was 'siloe'd' and that health professionals were more inclined to provide medical and treatment information than healthy lifestyle information. It was reported that person-centred, integrated care was missing, which would include more information about healthy

Table 1: Demographic characteristics of the sample.

	N = 24
Sex	
Male	11
Female	13
ASGS^a remoteness classification	
Inner regional	9
Outer regional	9
Remote/ very remote	6
Cancer type	
Breast	6
Lung	6
Skin	3
Head and Neck	3
Prostate	2
Other (bladder, kidney, brain, lymphoma)	4

Note:
a: ASGS = Australian Statistical Geography Standard

lifestyle behaviours and self-care as well as the medical information on treatments.

It's very difficult to find somebody, because you go to a GP, they don't have the whole picture, because it is a speciality really... so it's very difficult to find somebody who can fill in, you know, I would much prefer a more holistic view. (#ID 7 - Female lung cancer survivor, remote)

Practical support needs

Participants described a lack of information about practical support specifically needed for rural cancer survivors, such as travel and accommodation resources external to the healthcare system. Information about these services was not provided by health professionals and was often learned much later than needed.

Nup didn't know anything about it. It wasn't until I got back here and I asked around and I found out there was a patient travel assistance scheme, which I'd never ever used ever. And it has been my lifeline - I wouldn't be able to do it without them. (ID #16 - Male oesophageal cancer survivor, remote)

Participants also reported that it seemed like health professionals may not be aware of their location and the need to travel for appointments, or the practical requirements associated with travelling for appointments, and that it was their responsibility to share this information with health professionals.

You have to make them realise also that you're not just around the corner when you have appointments in Brisbane. You're there for a certain time, you don't want to be called back the following week to have another appointment. (ID #13 - Female breast cancer survivor, very remote)

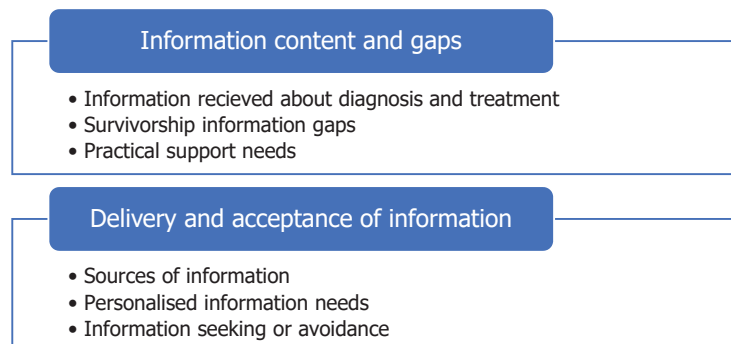
Theme two - Information preferences

Sources of information

Participants indicated three main sources of information: i) information provided by health professionals; ii) information provided by peers; and iii) alternative sources of information.

- i) Participants reported receiving the majority of information related to their cancer from oncologists and nurses, with verbal information provided more commonly than written information. The doctors' communication style had a significant impact on understanding of information, and participants indicated that the relationship with their healthcare team was more important than the information provided. A majority of participants had positive experiences dealing with health professionals, but a negative interaction with health professionals could have an impact on the participants overall satisfaction. *The radiation oncologist lady was excellent. She talked you through things, she explained things, she gave you, gave you space to have an opinion or to ask questions, but the medical oncologist at the [hospital] was disgusting. (ID #4 - Female lung cancer survivor, inner regional)*

Figure 1: Overview of major themes and sub-themes.



- ii) Information from other cancer survivors was also valuable as this could give insight into practical difficulties and lived experience and could fill a gap in the information provided by healthcare teams. *Even just speaking to other women that were just going through the same thing, that was very supportive too. Two women that I met ... they were very, well the three of us were helpful to each other I believe.* (ID #14 – Female breast cancer survivor, outer regional)
- iii) Alternative information sources included books and/or pamphlets sourced through hospitals, charities and online that were not provided through routine medical care. The internet was also utilised to search for information, more commonly to corroborate information provided by health professionals or to seek information on specific cancer types or treatments, rather than to search broadly for health information. *I think you can get confused with too much knowledge, and I don't know that the internet is always the best knowledge, I prefer to focus on the doctor.* (ID #1 – Male tongue cancer survivor, outer regional)

Personalised information needs

Participants emphasised a preference for individualised health information depending on: i) personal experience; and ii) timing of information

- i) Participants' need for health information varied according to their own health. Generally, participants who had experienced mild side-effects after treatment felt most comfortable with the information they had received, while individuals who had experienced a severe adverse event due to treatment felt that they were not prepared for that with the information they had been provided by their healthcare team. *I didn't realise that there would be that many symptoms. I mean, will I get them all, will I won't. It was like a wait and see game, you know. A bit like, they're letting you know what could happen.* (ID #19 – female breast cancer survivor, outer regional)
- ii) Many participants felt that there was not enough time for discussion with their healthcare team and this led to difficulties in processing and then retaining information. There were cases where information could be confronting, particularly early on after diagnosis and

participants felt that health professionals needed to be aware of this and the impact this could have on decision-making and information comprehension.

The thing is that even the best doctors, and even some of the nurses, they deal with this on a day-to-day basis, and if you go there and it's your first time, or your second time, you're still like a duck out of water. You're feeling your way the whole time ... and you don't know what questions to ask, what information you should have ... But, those doctors could be a lot more forthcoming, in relation to, "this is what's going to happen, this is the effect it is going to have on you" ... A lot more explanation needs to be done in relation to those initial visits. (ID #16 – Male oesophageal cancer survivor, remote)

There were distinct differences among the participants in the preference for timing of information delivery as some participants reported that the initial time of diagnosis was overwhelming and there was an overload of information at this time, while others preferred to know as much as possible early on in order to feel prepared.

Like I said a lot of information was given to me, but you sort of, it's hard to take it on board all at once. (ID #19 – Female breast cancer survivor, outer regional)

Some participants had little knowledge of how long the treatments (for trial patients and those on targeted therapies) or follow-up surveillance might last for, and this was a particular issue for participants who preferred to know more.

Our kind of problem ... we would have liked to have known, how long are we going to have to do this. How long? Does it ever get to the stage "well it's working for you, I'll see you once every 3 months" ... Most people are on it for 2 years and we've been on it for 15 months. I think it is an on-going thing if it is succeeding. He says if you are going good, you just stay on it. (ID #23 – Male kidney cancer survivor, inner regional)

Information seeking or avoidance

There was a clear divide in the way participants sought information, with several participants actively seeking out further information, while the remainder tended to avoid seeking information outside of that offered by health professionals. Survivors with an active information-seeking strategy generally had previous experience with the health system, tertiary education and reported knowing how to ask questions (or which questions to ask). These participants

showed concern for others with lower health literacy levels who may have difficulty getting the information they needed.

I'm sure that helped we're both well-educated and curious people. We encountered people at the cancer lodge who were on similar treatment, and they didn't have a clue, what drugs they were on, they didn't know what the prognosis was. (ID #18 - Male melanoma cancer survivor, outer regional)

Other participants with a passive information-seeking style reported trusting the information given by the health professionals and not being willing to seek further information for fear of learning something unwanted. In particular, these participants were hesitant to use the internet to search for cancer-related information.

Oh no I don't go and look for em'. I don't wanna read any words as to what might be and find something that's worse. (ID #12 – Male melanoma cancer survivor, inner regional)

Not necessarily. I don't like to scare myself too much because some things can be a bit misleading but while [this chemo] is working, I'm tolerating it, I don't have any reason to [look for information] really. (ID #13 – female breast cancers survivor, very remote)

Discussion

This study offers an understanding of the importance of survivorship care information for rural cancer survivors and provides insight into their preferences for information. The current findings align with existing evidence suggesting that cancer patients in rural areas have considerable information and support needs, particularly those who are required to travel for treatment and leave the support of their family and local community.^{14,16,18} Health professionals were noted as a key source of information and gaps were reported in the provision of holistic care information. Additionally, the provision of support for patients to cope with emotional distress may enable them to better understand information, and information should be tailored to individual preferences and attitudes.

The most common sources of information for cancer survivors are healthcare professionals, other cancer survivors and written material.²⁸⁻³⁰ This pattern of information preference is to be expected as survivors perceive health professionals to possess the expert knowledge and be most

reliable, while peers can give insights into the lived experience of treatment and side effects that cannot be provided by health professionals. If cancer survivors appreciate the perspectives of both health professionals and fellow survivors, it is important to find ways that these two sources of support can work synergistically. The internet is also becoming increasingly relied upon for cancer-related health information,^{29,31} but is concerning given evidence that online information regarding diet and exercise for cancer survivors is limited in detail, scope and credibility.³² This highlights a need to adapt to changes in care delivery, for instance through healthcare professionals directing survivors to sources of high-quality information on the internet or encouraging them to engage with peer supports.^{30,33} As health professionals are a trusted source of information for cancer survivors, it is important to ensure adequate cancer training for primary care providers and nurses to assist in the provision of survivorship care and information,³⁴⁻³⁶ particularly in rural areas where access to specialists is limited.³⁷

In line with past evidence, participants in the current study indicated that the provision of information on maintaining general health after a cancer diagnosis tended to be less common than that pertaining to diagnosis and treatment^{2,30,38} and cancer survivors commonly identified wanting information regarding healthy eating, physical activity and behaviour change support. Previous studies have suggested that rural cancer survivors desire specific advice on what health behaviours could aid recovery, as well as knowledge and information about how to resume and achieve a good quality of life post-treatment,^{4,19,38} but this information is often missing in traditional, specialist-led models of survivorship care and may be better addressed in shared care models.^{39,40} Health systems are known to already face resource and time barriers to developing and implementing cancer survivorship care, and this may be particularly problematic for cancer survivors living in rural areas.⁴¹ Thus, communication and collaboration between primary and secondary care is crucial to improving the delivery of holistic survivorship care information, particularly in rural areas.^{23,42} In addition, more research needs to be done to determine how community services and non-government organisations can be integrated into rural cancer care delivery to adequately meet the

holistic needs of cancer survivors and achieve equitable outcomes.⁴³

The current study aligns with existing evidence that not all survivors are alike in the amount of information that they desire, and that socioeconomic factors and information-seeking style can have a significant impact on information processing. For example, cancer survivors who are younger, more educated and female are more likely to have higher need for information;^{8,29} while disease status, health literacy and attitudes also play a role in preferences for information.^{4,9} Not all survivors desire a high volume of information, particularly if they do not want to receive bad news. The reasons for avoiding information are multifaceted;⁴⁴ however, avoidance can have the same consequence as a lack of necessary information, thus attention needs to be drawn to this issue and the experience of cancer survivors who are actively avoiding information should be investigated quantitatively in diverse population groups. Emotional distress can also impact on a patient's desire for information and ability to understand information, thus the provision of extra emotional support may improve cancer survivors information processing.⁴⁵ Consequently, it is important to assess information preferences and deliver tailored content, yet there is little guidance on how to do this effectively.^{13,45} Future research is urgently required on the specific mechanisms and cues that healthcare providers can use to assess information need in cancer survivors and tailor information accordingly.

Previous research suggests that rural cancer survivors need information on practical support, such as accommodation and transport options, which may not be routinely provided by healthcare providers.^{14,16,20}

While much of the information that rural cancer survivors require is similar to those in metropolitan cities, the need for information to assist with the practical and emotional issues caused by travelling for cancer care is something that urban survivors do not have to face. An increased use of telehealth services for routine check-ups may alleviate some of the challenges associated with travelling for healthcare services^{46,47} and avoid the barriers to accessing local survivorship care and support.¹⁹ Additionally, carefully designed rural-specific websites or peer-led YouTube videos have been shown to be an acceptable method of delivering rural specific information to cancer survivors.^{48,49} Insights from video storytelling suggested

that cancer survivors did not believe that disease-specific information needed to be rural-focused, but they valued the inclusion of rural-specific practical advice including what to pack when travelling to a major city for treatment, as well as information on the management of psychosocial issues in a rural context.⁴⁸ These creative and novel methods for enhancing survivorship care and meeting the unmet practical information needs for rural cancer survivors require further exploration.

Previous studies investigating unmet needs of rural cancer survivors have reported significant gaps in information provision yet have not addressed individual preferences for receiving or processing information, thus the current project addresses this gap. A key strength of the current study is the thorough exploration of specific information seeking behaviours and attitudes, which adds to the existing literature and can help inform the development of future survivorship care interventions for rural cancer survivors. However, the findings need to be interpreted within the context in which the study was undertaken. Participants were recruited through community accommodation facilities and as such may not reflect the views of cancer survivors who are not already engaged with charity services. These survivors are likely to have some of their information and practical needs met during their stay and be better informed than the average patient.⁵⁰ Thus, replication of this study in a community sample would be important to identify additional information and survivorship care needs.

Conclusion

Holistic survivorship information regarding long-term wellbeing is sub-optimal among rural cancer survivors and specific information regarding practical supports is desired. While rural cancer survivors may have similar information needs and preferences to those identified in metropolitan populations, communication and interactions with health care professionals may be more important as resources and support services are limited in these areas. Additionally, tailoring of information is needed on an individual level, as information needs to be delivered and adapted to the individuals' emotional state, attitudes, preferences and demographic characteristics. Future research is required to understand how to assess information

preferences in rural cancer survivors, and how to deliver tailored, practical health information through shared care survivorship models that incorporate peer support, online resources and local services.

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