

What cancer survivorship services do young people want?

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Abstract

Aim To identify experiences of young cancer survivors and their perception of optimal components of survivorship care and wellness programs.

Background Most young people survive their cancer diagnosis and are then at risk for long-term negative consequences. Survivorship care is important, but there is little evidence to inform optimal service models.

Methods Semi-structured interviews were conducted with adolescents and young adults (15–24 years). Content analysis was used to identify themes.

Results Sixteen young people participated. Three major themes are described: concerns after treatment; after treatment services; and perceptions of a wellness survivorship program. Within each theme, further subthemes highlighted the difficulties young people face when trying to return to normal life. Fear of cancer recurrence and a need for greater coordination of support and services were the highest concerns.

Conclusions: Findings highlight the need for an individualised approach to survivorship care that engages and empowers young people as partners in their own healthcare.

Introduction

Cancer survivorship is considered the next tsunami to affect health services, with an exponential number of people surviving treatment, many of whom have ongoing needs for healthcare related to their cancer¹. In Australia, up to 89% of adolescents and young adults (AYA) aged 15–24 years reach 5-year disease free survival^{2,3}.

Common to all cancer survivors, AYA experience a wide range of long-term negative effects after cancer treatment. Problems with mobility and limitations with usual activities are reported by up to 43% of all cancer survivors, and 12% report moderate to extreme levels of anxiety and depression⁴. The AYA population is more likely to also suffer psychosocial problems such as: altered sense of identity; changed relationships; challenges to body image, sexuality and fertility concerns; impacts on education

and employment with financial consequences; concerns about cancer recurrence which can manifest as a preoccupation with death and dying; and generally a less positive outlook on life⁴⁻⁶. Importantly, compared to AYAs with no history of cancer, AYA cancer survivors are also more likely to have a higher prevalence of chronic disease (14% vs 7%), disability (36% vs 18%), poor mental (20% vs 10%) and physical health (24% vs 10%)⁷, and lower quality of life⁸.

After completion of cancer treatment, ongoing routine surveillance and support in Australia is generally oncologist-led. This medical assessment includes risk of cancer recurrence or new cancer development, review of previous cancer therapies, and management of comorbid conditions⁹. This surveillance model of survivorship care, however, does not address all the after effects of cancer treatment. Attention to supportive care, lifestyle and health-related behaviours are also important to manage the physical and psychological effects of cancer and cancer treatment¹⁰.

The needs of AYAs during and after cancer treatment are further complicated by the need to simultaneously navigate the social and developmental transitions of adolescence. It is recognised that the biggest challenge for this population is the immediate time following completion of active cancer treatment, when the intensive support provided during this time ceases¹¹. When treatment ends, young people report feeling unprepared, concerned about managing their ongoing health needs, uncertain about relationships, education, employment, and lacking the confidence to plan for the future^{11,12}.

It is imperative we strive to improve outcomes for this group; however, little research has been undertaken to examine the effects of different models of care after cancer treatment, nor young people's preferences for post-treatment survivorship care¹³. Without this evidence, we don't know the best way to provide services and there is little impetus to change the way cancer services are delivered. Research and evaluation in this area is therefore critical to the successful design and delivery of sustainable, flexible and cost-effective survivorship care^{13,14}.

Well-designed models require an understanding of the clinical issues, the existing health system, and the processes required to integrate new systems^{15,16}. Importantly, new models of care should also be informed by AYAs themselves as partners in their own healthcare. As part of a larger project to develop a new survivorship model of care, the aim of this research was to identify experiences of young cancer survivors and their perception of the optimal components of survivorship care and wellness programs.

Methods

The study was informed through discussions with the Queensland Youth Cancer Service's (YCS) Youth Advisory Group (YAG)¹⁷. The YAG consists of young people whose lives are affected by cancer.

The role of the YAG is to advise on health service planning, delivery and evaluation. Through discussions with the YAG, survivorship care was identified as a priority area for research. The concept of a wellness program was discussed, where young people could access a range of resources and services to support recovery after cancer treatment. The YAG identified important issues to consider such as preferences for both group and individual services, and the need for equity of service in regional areas. These discussions informed development of a semi-structured interview guide which was endorsed by the YAG (Appendix 1). Qualitative methods were used to explore the perspectives of AYA regarding their experiences of cancer treatment and perceptions of wellness and survivorship needs after treatment.

Setting and sample

Eligible participants were those aged 15–25 years at the time of a diagnosis for any cancer. We chose this age range as this is the range for referral to YCS in Australia. Participants were identified through a database managed by the Queensland YCS network which links five major tertiary cancer centres in the state and provides specialised services to AYA. We excluded patients who were not expected to survive the next 12 months. To maximise clinical and demographic diversity, purposive sampling was used to recruit patients with different diagnoses, ages, and those who had received treatment across both metropolitan and regional areas. The list of eligible patients was screened by YCS cancer care coordinators in each cancer facility before being approached by the researchers; cancer facilities included those located in Townsville Hospital, the Gold Coast University Hospital, Royal Brisbane and Women's Hospital, Princess Alexandra Hospital, and the Queensland Children's Hospital. The researchers then explained the purpose of the study and obtained informed consent. In all, 30 participants were approached.

Interview procedure

The interview was scheduled for a mutually agreeable time and undertaken either face-to-face, or via telephone, depending upon the participant's location and preference. Each interview was conducted in a conversational style, using the interview guide as a structure. Questions were open-ended and addressed the participant's experiences of cancer treatment, their needs, ways of coping, and use of support resources and services. Participants were also asked about their perceptions of survivorship services, what they thought was needed, and if they would access a wellness program. The interviews were undertaken between September and December 2018. Interviews were audio-recorded and then transcribed verbatim by a professional transcription service.

Analysis

Audio recordings of the interviews were listened to whilst simultaneously reading the transcripts to ensure accuracy of

the transcription. Transcripts were then imported into NVivo™ software to aid organisation of the analysis. Content analysis was used to organise and elicit the latent and manifest themes within the data¹⁸. A preliminary coding structure was agreed upon by NB and CC which included deductive codes from interview questions. Transcripts were then openly coded by both researchers allowing for further emergent themes. The final coding structure was agreed upon through discussion, and data within codes were grouped into a hierarchy of themes¹⁹. Matrices were developed to enable coded data to be compared across the sample. Manifest data were subjected to counts and are presented as proportions of participants reporting a particular experience or perception. The latent (hidden or unsaid) meanings and divergent experiences were identified through immersion in the text²⁰. Throughout the process, transcripts were re-read, and codes, themes and concepts were iteratively discussed.

Ethical considerations

All participants voluntarily participated and were assured their privacy and confidentiality would be respected. The study protocol was approved by the local Human Research Ethics Committee (HREC/18/QRCH/104).

Results

Of the 30 potential participants approached, 10 declined an interview and we were unable to find a suitable time for four. Thus 16 participated in the interview. Reasons for declining to participate included being “too busy”, “just not keen” to “I don’t want to re-visit that very difficult period”. Demographics of participants are presented in Table 1.

In this report, we present the results regarding three major themes: concerns after treatment; a wish list for after treatment services; and thoughts about a wellness survivorship program. A summary of counts for each subtheme are presented in Table 2. Subthemes that were described by four (25%) or more participants are further discussed and presented with supporting quotes.

Concerns after treatment

Integrating back to normal life with a changed identity

The difficulties integrating back into normal life were of high concern for nine (56%) participants. This appears to be complicated by a changed sense of identify after cancer treatment that AYA were unsure of how to process. Some were unsure about disclosing their cancer diagnosis. There was fear of rejection from potential partners, others didn’t know how or if they should tell new employers. They reported feeling different from others and unsure about fitting back in with their peers. One participant likened his experience to that of a prisoner leaving jail:

I’ve never been to prison but [you could liken it to] a chemotherapy-type thing. You’re in hospital. You’re not in a

Table 1. Characteristics of participants (n=16)

Characteristics	n	%
Gender		
Male	10	63%
Female	6	38%
Age at time of study		
15–19	3	19%
20–25	13	81%
Cancer type		
Leukaemia	7	44%
Lymphoma	3	19%
Pituitary germ cell	1	6%
Brain cancer	2	13%
Carcinoma	1	6%
Ewing’s sarcoma	1	6%
Rhabdomyosarcoma	1	6%
Treatment*		
Chemotherapy	16	100%
Surgery	5	31%
Radiotherapy	5	31%
Immunotherapy	2	13%
Haematopoietic stem cell transplant	5	31%
Type of hospital		
Public adult hospital	8	50%
Children’s hospital	8	50%
Location of residence		
City	8	50%
Regional or rural	8	50%
Currently working or studying		
Attending school/university	6	38%
Working and university	2	13%
Working	5	31%
Not currently working or studying	3	19%

*Does not total as multiple treatment modalities received

comfortable environment. You’re constantly being threatened or you’re not eating nice food. Once you get out, people see you a bit differently, you know? You’re seen a bit as a criminal is, – ‘are they going to hurt me?’ You see a cancer patient, ‘okay, if I touch them, is their arm going to fall off?’ – #9, male, 22 years.

Others found it difficult after treatment completion with the change in priorities; their own health was no longer a great concern to either their healthcare team or the others around them. For one young adult, whose treatment spanned over 5 years, this was difficult; their identify was caught up in being a patient.

Table 2. Counts of categorised themes and subthemes (n=16)

	n	%
Concern after treatment*		
Integrating back to normal life	9	56%
Fear of recurrence	6	37%
Physical health, fitness and nutrition	3	19%
Education and work	3	19%
Regain control of life	3	19%
Relationships and fertility	2	13%
'Wish list' for after treatment services		
Co-ordinated support and information	7	44%
Psychological support to find the new normal	3	19%
Survivorship plan for follow-up	1	6%
Education and vocation support	1	6%
Fertility services	1	6%
Thoughts about a wellness survivorship program		
Not needed/wouldn't access	7	44%
Would access if one-on-one services provided	3	19%
Would depend on what is offered	4	25%
Would definitely access	2	13%

*Does not total as some participants nominated discussed multiple items

I've found in my last two transplants, one of the hardest times is getting back into normal life. It's the after effect because everything is sort of provided for you, you're the number one priority, you're this, you're that, and you go back into what is classified as the 'real world'. Normality, and it's not the case, it's not the same. You're not the primary focus anymore, you need to think about other people and at the same time, think about what you want – #10, male, 22 years.

Integrating to normal life was also difficult for some because of the physical after effects of treatment. While they may no longer look unwell, with their hair re-grown and their weight improved, they didn't feel like their former selves, nor were they sure how to go about recovering. Fatigue and 'chemo brain' in particular were reported as an enduring concern after treatment.

Chemo foggy brain, well it feels like that lingers for about I would say 12 months after as well. So, you sort of, you're trying to get well but then you're not sure what to do or how to get well – #11, male, 18 years.

Even for those who didn't have physical or emotional difficulties, integrating back to a normal life was not straight forward:

It felt like we were just, like, left, like they'd cared for us so much, like, from diagnosis to, like, end of treatment, that I feel like we were left on our own. We didn't really know what to do. Like, how do you transition back to normal life? Because it was so long. Just, like mum and dad both stopped working

and were looking after me. And it was just hard to go back to what we used to live like – #14, female, 21 years.

Fear of recurrence

Another frequently reported concern after treatment was fear of recurrence. In our sample, six (37%) AYA reported this as a high concern. Some tried to rationalise this fear, and all acknowledged that this fear was what made the mental aspect of a cancer diagnosis more difficult than the physical:

It's torturous on the old mind... thinking, has it gone? Is it going to be better? What's going on? Even in the car now, I put the wrong setting on my air conditioning. I put the foot one or the face one on, instead of just the air con that blows on your face, and the air con starts blowing on my leg, and I thought, oh, crap. My leg's itchy. It's back. You know what I mean? Because, that was one of the symptoms – #9, male, 22 years.

I guess your biggest concern is getting sick again... because you're actually not getting treatment... – #13, female, 22 years.

So that's definitely always on my mind, that's definitely been the toughest thing to deal with at the moment, is thinking of what if it comes back. Yes – #6, male, 20 years.

Wish list for after treatment services

Co-ordinated support and information

Regaining strength and fitness was a high priority for AYA, and an area where more support was wanted. While services may be available, either the cost or the processes required to access services was seen as a barrier:

I think for me I would really love to get a good routine with a physio. Because since I've been sick like my back's gone, it's really weak in my bones because of steroids. Yes, I struggle with that... that's a big one for me. Because I used to be a very healthy person, so not being able to do squats or lunges really... brings me down. But I have to request it through my doctors. I feel like if I had an appointment once a week or once every two weeks it would just help me get back on my feet a bit better – #6, male, 20 years.

So there needs to be like a middleman to liaise with the doctor and then get the information from them and then they can maybe like contact any relevant people to get other information. Yes, and then like some, like classes about, nutrition and health advice would be useful after you've finished treatment and you're sort of wanting to improve your health after that, to get advice about that. And like someone to talk to about questions you might have after you've had treatment – #13, female, 22 years.

Some highlighted not having anyone to go to for advice or questions after completing treatment. For others, services were available, although only as part of a study or through strict referral criteria. These weren't flexible and, having just

completed cycles of schedule treatment, as a young person, more routine was not wanted:

I was offered a fitness programme for the end of this year, and that was just to resume sort of exercise rehabilitation. It's obviously the main thing that I was wanting, but my issue is that because it was part of a study, I had a fixed frame of, be there for the first week, the seventh week, and the twelfth week. Whereas now post-treatment, I'm sort of anticipating on travelling around the world now first for a year. So, whilst I would love to have done that, I would have preferred if there was just flexibility, just sort of me there at the end. Yes, because I'm just at this end of the phase I'm not going to be trying to get back to a scheduled life – #4, male, 21 years.

This highlights the complexity of balancing survivorship needs with normal life needs and the liminality an AYA with cancer faces.

Thoughts about a wellness survivorship program

Seven participants (44%) stated they would not access a survivorship program focussed on wellness. Some felt that while such a service may be beneficial for others, they said it would not suit them. Reasons included wanting to avoid potential group situations where negative experiences may be discussed, and that needs were already met by existing services, friends and family; others felt they had no need for such a survivorship program:

Yes, just because I've had my treatment for so long and like I've been lucky that [my treatment] has been kind of good, so I've been able to get back [to normal] and just, like all my sport and work. So just knowing me, even if it were available, I would have wanted to do it on my own anyway – #1, Male, 20 years.

Other participants suggested various combinations of services and factors that would make a service acceptable. There was great variation; some preferred one-on-one services, others group-based, some wanted to meet others who had been through treatment and others were not sure. Video conferencing was acceptable to most participants, although all agreed face-to-face was preferable. There was a difference of opinion on where a service should be located, e.g. hospital-based or community-based, what services should be available, and how long such a service should be offered for. These findings highlight the need for an individualised approach to survivorship care and that a one size fits all model is not appropriate nor acceptable.

Discussion

This study sought to identify the experiences of young people after cancer treatment and their perceptions of the optimal components of survivorship care and wellness programs. Our findings identified young cancer survivors were concerned with how to return to normal life, fears of recurrence and the desire to regain physical health. These findings are congruent with

research reported internationally^{5,21}. For these concerns to be addressed, the young people in this study discussed the need for a coordinated approach to survivorship care that is flexible and highly tailored to individual needs.

A significant proportion (44%) of AYA in our study stated they would not access a survivorship wellness program, despite agreeing that such a service would be beneficial for others. These young people were happy to continue oncologist-led medical follow-up but did not want their general health and wellbeing to be the concern of a cancer survivorship program. These findings highlight the complexity of developing services that not only meet the health needs of AYA cancer survivors, but that are also acceptable to young people. It is understandable that, following treatment, individuals may want to 'move on' and thus distance themselves from cancer services in an effort to return to their lives as they were before cancer. Reluctance to engage in survivorship services has also been described in adult cancer survivors and was attributed to patients downplaying problems, or not understanding that treatment is available²². Young people have the longest time to live with the consequences of cancer and cancer treatment, resulting in a higher long-term impact and known risks for treatment-related late effects²³. At this stage in life, a young person may not anticipate their future needs and consequently may not realise the importance of survivorship care. Transitional survivorship care that focusses on adjustment may be more preferable to programs focusing on physical or psychological health.

By the year 2040 in Australia, there will be an estimated 6000 children under 15 years living with or beyond cancer, 20,000 adolescents and 41,000 young adults aged under 40 years²⁴. While survival after cancer is increasingly likely, so too are the negative consequences of cancer that can limit the young person's ability to reach their full potential to contribute to society. Studies have identified four out of five young survivors experience at least one late effect and 50% experience significant sequelae; by the age of 40 years, most will have at least one chronic health condition^{25,26}. Additionally, the risk of secondary cancers in those diagnosed before age 25 years is high^{21,27}. Addressing the survivorship needs is therefore an imperative direction for health services and a public health concern. Indeed, there is an increased risk that instead of being active contributors to society, young survivors with unmet needs may continue to be reliant on the health and social systems²⁸. For these reasons it is important we address survivorship needs proactively and consider the ongoing consequences of cancer not just for the individual but also for the health system and the wider community.

Internationally, services are starting to focus on the survivorship needs of this population^{4,23,29,30}. There is a paradigm shift from measuring clinical outcomes to a greater focus on recovery and measuring experiences for survivors based on individual needs

and preferences³¹. A risk-based approach for after treatment care is advocated for, and wellness-centred approaches may offer a way to provide education and support self-management while also addressing the specific issues AYA face in regards to sexuality, body image, relationships, fertility and education/vocation²¹. Further research is required to develop and test risk stratified models of survivorship care that address health needs, engage and empower young people and, as highlighted here, are acceptable. Developing such responsive health services requires an understanding of the demand for services, and this study contributes to the limited evidence base.

Young people in this study made suggestions for various models of care, including the use of technology to connect survivors with each other and with healthcare professionals. The use of technology holds promise for both accessing specialised support from distant locations, and also connecting back to local communities from metropolitan areas³². Emerging novel examples include using online video-based cognitive behavioural therapy (CBT) for youth cancer patients³³. Further research could investigate the potential of using technology to connect patients, specialists and primary care teams. Other models of care that require further development and evaluation include nurse-led survivorship clinics and peer support models³⁴.

Limitations

There are several limitations to consider with this study. Our sample size was small, and there were a number of young people who did not want to participate who may have added further depth and understanding to this issue. We had equal numbers of adolescents and young adults, which reflects the population referred to Queensland YCS, but not the population of AYA diagnosed with cancer; there are more young adults diagnosed with cancer than adolescents, a substantial number of whom receive treatment in private hospitals which are not included here. We did, however, include young people from diverse locations, across multiple institutions, and with different experiences, and our sample size is typical of other qualitative studies^{35,36}.

Conclusion

We identified the experiences and concerns of young people following cancer treatment. There was a strong desire to return to normal life as quickly as possible. While some participants felt their needs were met, others needed greater information and coordinated support at this time. Given children and young people are the population with the most potential to contribute to the economic growth of a nation, a continued and sustained focus on improving services for this group is warranted. Not only will this have positive societal effects, services may ultimately also prove cost-effective.

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Conflict of Interest

The authors declare no conflicts of interest.

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Appendix 1. Semi-structured interview guide

ARCHWAY interview guide: interview question prompts

What has been your greatest concern after cancer treatment?

- Consider general physical and psychological health, education, finances and relationships.

What types of services are needed to support these needs?

Who should provide these?

- GP, cancer service, other community service, cancer survivorship centre?

What type of after cancer treatment or follow-up was provided to you?

- Hospital, GP, other?
- Have you tried to source information/services yourself to address this need?

Improving care in the future

Wellness program

There is recognition that cancer treatment focuses on illness and the things that are needed in life to be well are not always addressed. A focus on wellness rather than illness is an opportunity to reframe the experience, emphasise the future, and set realistic goals to attain optimal wellbeing.

If we were to develop a wellness program, what are the types of activities, information or services that you think would be important in the program?

Prompts:

- Managing worry.
- Information about treatment or side effects.
- Concerns with fertility.
- Getting back to work or school.
- Practical issues.
- Issues with relationships.
- Meeting other people the same age.
- Staying fit and active.
- Diet and nutrition.
- Complementary or alternative treatments.

How do you think an ideal program would be delivered?

- E.g. in a group setting?
- One-on-one regular consultations?
- Telephone?
- Written materials?
- A program delivered over a specified time period?
- Drop in centre?
- Online resources/chat?

- Opinions on use of apps, chat features, videoconference, text?

Where is the best place for a wellness program for young people with cancer to be run from?

- In the hospital where treatment was given?
- In the local community?
- In a GP practice?
- In a setting away from hospital services?
- In a dedicated cancer survivorship centre?

For people living in rural areas, is videoconferencing a suitable way to receive services?

How long do you think a wellness program should be available for, for people who have received cancer treatment?

Who should deliver the wellness program?

- Nurses, social workers, psychologists, leisure therapists, teams of multi-professionals with different skills?

What things should we consider to make a program acceptable for young people to attend?

Thinking back over your experiences, do you think you would have accessed support via a wellness program if it were offered to you?

Are there any other ideas or issues you would like to talk about today?