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Coping with cancer: a qualitative study of adolescent and young adult perspectives

Running title: Coping with cancer: AYA perspectives

Abstract

Objectives:

Cancer can have long-term biopsychological impacts for young people that persist for years. To promote adjustment, it is essential to understand how young people cope, yet this is relatively understudied.

Methods:

This study explored the coping strategies using semi-structured interviews with 16 young people with cancer aged 15-24 years. Eligible participants were diagnosed within the previous 24 months and recruited through Australian Youth Cancer Services. Transcribed interviews were analysed using content analysis.

Results:

Coping strategies included: seeking support; controlling the focus; avoiding negatives and staying positive; meaning making and; changes with time. During treatment, seeking support, focussing on the present, distraction and avoidance were commonly applied.

Following treatment, planning for the future, avoidance of re-traumatising situations and meaning making were used.

Conclusion:

Findings support the concept of coping as a dynamic process where different strategies are used depending on the stressor, available resources and previous experiences.

Practice Implications:

Comprehensive, developmentally appropriate psychosocial assessments, open communication, education and information provision, as well as appropriate referral for support are essential, particularly for young cancer survivors identified at risk.

Keywords:

Adolescent; Young Adult; Cancer; Emotional adjustment; Attitude to health; health services;

Qualitative

1. Background

While cancer in young people is rare, the diagnosis, treatment, and interruption of the processes of typical adolescent development has long-term physical and psychological impacts which can be felt by the individual, family and society for many years [1]. Definitions for the age range of adolescents and young adults (AYA) vary around the world, but it is generally recognised that young people aged 15-19 years differ significantly to pre-pubertal children in terms of physical, physiological, cognitive and behavioural characteristics, and that most developmental milestones are reached by age 29 years [2]. In some nations, five-year disease free survival has now reached 89% for AYA aged 15-29 years [3, 4]. Compared to young people, with no history of cancer, these AYA survivors experience a higher prevalence of chronic disease, disability, and poorer mental and physical health across their life course [5]. To optimise outcomes, it is imperative that services address unmet needs and provide appropriate, developmentally tailored, individualised support throughout the continuum of care [6].

Despite the growing body of research into the biological, clinical, psychosocial and survivorship aspects of cancer in AYAs there is still much to be done to advance care for this

population [6-8]. Awareness of how young people cope is essential to understand how to enhance appropriate care that maximises the young person's individual coping styles and resources. However, to date, this has been relatively under examined.

Coping is defined as the 'constantly changing cognitive and behavioural efforts to manage specific internal or external stressors that are appraised as either taxing on, or exceeding the resources of the person' [9]. As such, coping is an intentional effort, and differentiated from reactive, automatic responses to a situation. Since the Transactional Theory of Stress and Coping was first described by Lazarus and Folkman in 1981 the literature has evolved, however continues to focus on the internal cognitive elements that are used to identify problems, gain insight, develop strategies and actively re-frame the problem. Theories continue to largely dichotomise strategies as either active or passive coping. Active coping strategies refers to those where an individual attempts to control either the stressor or responses. Passive coping strategies refers to those where control is relinquished to others [10]. Active coping is associated with resilience [11], which in turn is correlated with improved quality of life in adults with cancer [12]. In AYA with cancer, resilience is a demonstrated mediator quality of life, playing a protective factor against negative cancer related effects [11]. Thus, those with active coping styles and higher resilience, which commonly includes access social supports, lowers reliance on others at both institutional and individual levels. These person-centred coping strategies can enhance wellbeing, and are important for health care providers to promote as a core skill beyond the clinical environment [13].

The contemporary literature on how AYAs cope with cancer is largely focussed on particular time points such as at diagnosis [14] , during treatment [15] and in the transition to post-treatment survivorship [16]. Little is known about how coping strategies are applied by AYAs

or how they change from the time of diagnosis, through treatment and beyond.

Understanding this is important to inform the development of appropriate, tailored interventions to meet individual needs and match support with the young person's own resilience and coping resources. This is perhaps most important to understand among the AYA cohort who experience rapid development and evolving coping skills and styles over time. Knowing how best to support person-centred coping may limit the psychosocial distress that can ripple throughout a young person's life and promote adjustment to the cancer experience. As part of a larger study exploring supportive care needs, (reported elsewhere) this study explores individual AYAs perceptions of coping with a cancer diagnosis and treatment.

2. Methods

These methods are reported according to the Consolidate Criteria for Reporting Qualitative Research (COREQ) [17].

2.1 Setting

We undertook semi-structured interviews with AYAs aged 15-24 years as the recognised age for referral to dedicated Youth Cancer Services (YCS) in Australia. These services are funded through Commonwealth and state-based funding and are based in adult or paediatric public hospitals. In Queensland, the YCS operates as a partnership model across the five major tertiary cancer centres, one of which is a paediatric hospital [18]. The YCS provide evidence based best practice clinical care, psychosocial support, advocacy, education, and research, to support young people and families to achieve optimal outcomes [19].

2.2 Sampling procedure and participants

The study protocol was developed by NB, a nurse with PhD qualifications and experience in qualitative research. Eligible participants were identified through YCS data [20] and included those diagnosed with cancer between January 2016 and December 2017, and who were referred to YCS in Queensland. Participants had either completed treatment or were on maintenance therapy nearing the end of planned treatment. Participants who had a prognosis less than 12-months were excluded from the study. To maximise diversity, a purposive sample of eligible participants with different age ranges, diagnoses and treatment protocols were selected. The list of eligible participants was screened by YCS Nurses across five hospitals to assess suitability, before potential participants were approached to participate by telephone. The researcher explained the purpose of the study and provided a written information sheet via email to potential participants. In total, 34 potential participants were approached to participate.

2.3 Interview and Procedure

The question guiding this research was: What do AYA do to cope with a cancer diagnosis, cancer treatment and post-treatment survivorship? Interviews were undertaken between September and December 2018. Following the provision of informed verbal consent, 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. Interviews were undertaken by NB or CC, both female nurses with extensive oncology experience, but no clinical relationship with participants. Following re-confirmation of consent, each interview was conducted in a conversational style, using a guide as a structure. Questions were open-ended and addressed the participant's experiences of cancer care, their needs, ways of coping and use of support resources and services. So as not to lead participants, no

reference was made to coping strategies or theory of coping during the interviews.

Following introductory questions about diagnosis, and treatment the interview questions included:

‘What are some of the challenges you have had?’

‘How did you manage different feelings?’

‘What did you find useful or helpful?’

‘What was your greatest concern after cancer treatment?’

Additional questions were asked to expand the discussion. All interviews were audio-recorded and transcribed confidentially and verbatim by a professional transcription service. Field notes about the participant or interview were documented electronically within 24 hours. Interviews lasted between 25 and 70 minutes.

2.4 Analysis

Audio recordings of the interviews were listened to while transcripts were simultaneously read, to ensure accuracy of the transcription by one researcher (CC). Transcripts were then imported into NVivo™ to aid organisation of the analysis. Using a constant comparison technique, content analysis was used to organise and elicit latent and manifest themes, while seeking divergent experiences [21]. The process of moving between the original data and the analysis aided distancing and reflection of potential biases from the researchers. Two researchers (NB, CC) independently coded the first two transcripts and then discussed and compared coding structure. A preliminary coding structure was agreed upon and the remaining transcripts were openly coded, allowing for the identification of further emergent themes. Data within codes were then grouped into themes and higher concepts. Through discussion with a third researcher, LH, a social worker and researcher with experience in adolescent oncology and qualitative research, the coding structure was further refined.

Throughout the process, transcripts were re-read, and codes, themes and concepts were iteratively discussed. This enabled the identification of common themes and concepts as well as differences. Emerging findings were also discussed with peers to promote trustworthiness and reliability [21, 22]. Themes were then summarised narratively and are presented here with supporting quotations.

2.5 Ethical Considerations

All participants voluntarily participated, were assured their privacy and confidentiality would be respected, and provided informed consent. To protect participant's privacy, pseudonyms are used to report the findings. The study protocol was approved by the local Human Research Ethics Committee (redacted). The datasets generated or analysed during the current study are available from the corresponding author on reasonable request.

3. Results

Of the 34 potential participants approached, 14 declined an interview, and we were unable to find a suitable time for four. A total of 16 participated. The sample included representation across genders, the AYA age group, diagnosis and location of residence and care. Reasons for declining to participate ranged from being "too busy", "just not keen" to "I don't want to re-visit that difficult period". In three interviews, the patient and their significant other were interviewed; two interviews of participants with brain tumours included the patient's mother, and one interview of a participant with leukaemia included the patient's wife. Interview questions were directed only towards patient participants. Most (n=14) had completed planned treatment with the remaining two on maintenance oral chemotherapy for leukaemia. Demographic information and the characteristics of all participants are presented in Table 1. Participants reported the use of several active coping

strategies which were grouped into four themes: seeking and accepting support; controlling the focus; avoiding negatives and seeking positives; making meaning and making it matter. A fifth theme, changes with time is also discussed. These themes are summarised in Figure 1.

Insert Table 1 about here

Insert Figure 1 about here

3.1 Seeking and accepting support

Overall, most respondents acknowledged that the psychological aspects of a cancer diagnosis were the most difficult to deal with both at diagnosis and over time. Participants spoke about seeking and accepting support as a useful strategy. For some, support from family was preferred as a source of coping available from trusted people close to them, opposed to a more distant or unfamiliar professional.

“I did see a psychologist, but I didn’t really connect with her. She was older and didn’t really help me. I more connected with my family if I need to talk to someone. Yeah, pretty much my friends and family are my main contact. They make me feel better” (P8, Female, 22 years, Leukaemia).

“All the social workers always said if I needed to talk to someone, there was someone there, but we’re pretty close as a family so we never really took that up” (P11, Male, 18 years, Pituitary Germ Cell Tumour)..

For others, support was sought from healthcare professionals within, or external to the hospital setting. Young people described feeling vulnerable and that seeking support and opening up supported their coping.

“Now, I have got that trusting relationship with her (my psychologist), I can open up. If I can’t open up, then I’m not really helping myself. I have to be fully vulnerable to be able to accept any of the help that’s going on” (P10, Male, 22 years, Leukaemia).

However, the willingness to seek and access support as a coping mechanism varied according to the availability of other coping strategies and supports (i.e. family members), the intensity of stressors on the day (i.e. a change in health status) and mood changes.

“We kind of booked appointments, but it’s really finicky of how you feel... There’s those days that you feel terrible, you don’t want to talk to anybody, and then there’s the days that you’re feeling fantastic, and don’t want to talk to the psychologist because you don’t want to get down” (P10, Male, 22 years, Leukaemia).

While this participant recognises that psychological support will ultimately help him, there appears to be a tension where accepting support requires vulnerability and exposure of his thoughts and feelings, which might ‘bring him down’.

3.2 Controlling the focus

There were two approaches that young people identified in terms of changing the focus or stressor to cope. The first was focussing on the day to day, present moment and not thinking too far in advance. During treatment, some respondents were pragmatic when it came to accepting the diagnosis and treatment. Here, they focused on managing present stressors, one at a time. One young man described being on auto pilot, and others described the self-talk that helped to maintain this focus.

“It was like autopilot. It was like, okay, we need to get this done, just put my mind on it. It never came into my mind, like, I’m going to die. This is deadly. It was like, okay, this isn’t going to be fun, but we will get through it. I think it was, sort of, like, this is a battle we are going to win. We’re going to win” (P9, Male, 22 years, Hodgkin’s Lymphoma).

“As soon as I was told the treatment plan, I had this switch go off in my mind, that just like right: Well there’s no point thinking about why because that won’t change anything. I’ve got it and I’ve got to deal with it. So that actually helped me a lot in just putting up with what I had to do. And to my surprise my body responded really well to the treatment” (P6, Male, 20 years, Lung Carcinoma).

“I had more of a, ‘just let me do it’[attitude]. And, you’d get yourself down a bit because, well, I can’t do the thing I’d planned for, in the future. So, it was more about thinking, ‘let’s just get through this, take one day at a time’, and then when I’m a bit better, we’ll go forward” (P12, Male, 20 years, Leukaemia).

The second approach was to focus on what could be controlled in planning for the future. After treatment, young people were eager to regain former physical strength. They spoke about the importance of focussing on factors that they could control including nutrition and exercise to support physical recovery and as a way to regain control over their lives:

"I wanted to forget that it ever happened, and I didn't want people to look at me as, like, a cancer patient. So, I tried to make my hair grow back fast and exercise, so I didn't look so skinny and sick anymore. I ate really healthy" (P16, Female 21 years Leukaemia).

Like, I really have been good on exercise physio at the moment, which is great. So, it's slowly improving. I'm slowly getting back to a normal life... sort of" (P9, Male, 22 years, Hodgkin's Lymphoma).

After treatment, fear of recurrence became a new concern. To cope, respondents spoke about trying to rationalise worrying thoughts while at the same time recognising the reality that cancer can recur. The following quotes illustrate how this worry and fear permeate everyday life and the self-talk that accompanies the worry and aims to rationalise the associated thoughts.

Even in the car now, I put the wrong setting on my air conditioning, and the aircon 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 prior symptoms. Or, it's like, the other night, it was really hot, and I had two blankets on. I woke up and I was a bit sweaty. I'm like, oh crap. It's back. Actually, hang on a minute I've got two blankets on. What am I doing? (P9, Male, 22 years Hodgkin's Lymphoma)

The prognosis isn't too bad but 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. When to worry. So, I've seen a lot of days where if I have a headache or something that's only trivial, I do worry, where I know I shouldn't be. (P6, Male, 20 years, Lung Carcinoma)

Distraction was used, and valued, by many respondents to steer away from negative thoughts as well as the boredom associated with hospitalisation and treatment. Mindfulness

techniques were also reported as useful ways to apply distraction and cope with specific stressors, especially during treatment.

“(I needed) actual practical things to do, regulating my breathing and sort of like I go into like a corner of my mind that’s not like focused on the needle. It’s like, it doesn’t make me not scared but stops me from thrashing about and screaming. So that’s really good” (P16, Female, 21 years, Leukaemia).

Others spoke about the value of distraction to avoid negative thoughts. However, one respondent identified that this meant he was likely suppressing, rather than dealing with negative emotions. This exemplifies the dynamic process of coping where one strategy is not necessarily preferred, but each offer a way to manage different stressors at different times. In this quote, the participant reveals he has ‘things’ he is worried about. Here he uses distraction to purposefully avoid these worrying thoughts.

“I’ve been really involved at work, I’ve been really involved in my extra-curricular and things like that, and it makes me sort of forget. But at the same time, I’m not dealing with the things that I have been thinking about. The things that are in the back of my mind. So, it is definitely good to do things, but I keep wanting to use the word distract, distract myself” (P10, Male, 22 years, Leukaemia).

Some respondents also identified challenges associated with a lack of structured, developmentally appropriate distraction options at the hospital for young people and the impact of this on coping.

“So, I feel like the adolescents were sort of, not left to the side, but... I guess [I needed] coping mechanisms, like mental coping mechanisms for the treatment that you’re going through. So maybe someone to talk to. And then like activities that could distract you from your treatment, so I guess getting your mind off it would help” (P13, Female, 22 years, Rhabdomyosarcoma).

3.3 Avoiding negatives and seeking positives

Avoidance was used in several ways. As above, sometimes distraction was used as a means of avoidant coping to control the focus of thoughts. Others avoided potential negative thoughts or situations that were anticipated to cause stress. This was identified as one of the main reasons young people did not want to access peer-peer support, online support or organised counselling sessions and it was a strategy utilised by young people throughout treatment and into post-treatment survivorship.

"I wasn't really too open to it all [receiving emotional support], so I just kind of, just was sheltering. I was kind of just like, come on, hurry up, let's get out of here" (P1, Male 20 years, Leukaemia).

"I was someone who wanted isolation. I didn't really want to be around other people at first. It wasn't until I really got my remission diagnosis that I was happy to be around other people and talk about things and stuff like that" (P2, Female, 24 years, Non-Hodgkin's Lymphoma).

"It could have been a room full of positivity [a peer support group]. I just didn't want to take the risk of it being a room full of negativity. That was just something I felt. That was a personal decision but some people, I've heard that they like that thing of talking to people about it and humanising it a bit more. But I was more of a, just let me do it on my own" (P9, Male, 22 years, Hodgkin's Lymphoma).

"I don't know. I don't like to bring up my whole story to different people. It's not the easiest thing, bringing everything up makes me a bit sad" (P8, Female, 22 years, Leukaemia).

Staying positive was identified as an essential way of dealing with difficult emotions or situations and protecting future mental health. This was achieved by focussing self-talk on helpful or encouraging thoughts and minimising negative self-talk. Some focussed on a positive mindset for their own benefit. Others identified the importance of appearing positive to protect family members, often parents.

"It was because of the people around me, not wanting to make them worry or anything, trying to make it seem as normal as... not normal, make it

seem like I was okay. My mindset is extremely important, and I tried my best throughout to always stay positive... and that certainly helped” (P6, Male, 20 years, Lung Carcinoma).

“Keeping a positive mental state was the most important thing, because physically, to be honest, it’s really, really hard but it’s doable. Because, there’s good medication to get over it, if that makes sense. It’s the mental side of it that picks away constantly” (P6, Male, 22 years, Hodgkin’s Lymphoma).

3.4 Making meaning and making it matter

In the post treatment phase, several young people described how their perspectives on life changed after cancer. For many, finding meaning in the experience helped to make sense of it and support their adjustment. For some, this involved changing study or careers. Three respondents changed their course of university study intending to work in cancer related areas in the future and support others, or be more involved in supportive care, rather than medical treatment.

“So, I’m wanting to help kids, teenagers, and adults go through what I went through. And, I felt that, not to put this experience to waste. I’ve had the experience” (P6, Male, 22 years, Hodgkin’s Lymphoma).

“I was loving med lab. but I didn’t want to diagnose kids with cancer anymore. So, I changed. I was loving med lab, but I just couldn’t bring myself to continue, so I changed to exercise physiology because you can do like rehab and stuff for cancer” (P16, Female, 21 years Leukaemia).

Other respondents discussed an increased sense of gratitude for life and relationships.

Optimism was also common, with the acknowledgement that one bad day was just one day.

There was a new appreciation for the small things in life.

“I definitely don’t take anything for granted. One day at a time and if you’re good one day, make the most of it. And if you have a shit day, hopefully tomorrow will be a better day” (P8, Female, 22 years, Leukaemia).

“I am more appreciative of everything. Like every time I can wake up and walk, I’m really thankful. I just appreciate everything so much more. And I

appreciate other people a lot more too, like, with the amount of help that I've had from nurses and stuff like that. Not that I was like unappreciative before, but like, I'm ultra-appreciative now!" (P16, Female, 21 years Leukaemia).

"You kind of get a step back and get to appreciate all the small things that you kind of take for granted, like just seeing your parents or seeing your siblings or seeing relatives, going to the beach, just sitting on the veranda having your tea. Like you kind of take more time to appreciate things that you kind of took for granted a lot before" (P11, Male, 18 years, Pituitary Germ Cell Tumour).

3.5 Changes with time

Participants described changes in coping strategies in response to different stressors overtime. Trying to navigate the new normal after treatment presented specific challenges. As the intensity of the past few months receded and participants returned to their old life, a new normal way of living needed to be found. For some, the emotional toll at this point was significant, feeling like life had so irrevocably altered, that it was not possible to get back to normality. This was a time where support was wanted.

"I found it hard sort of transitioning from the treatment like lifestyle in a way back into normality. It was sort of a bit of a shock and I didn't feel like I had anyone really to help me" (P13, Female, 22 years Rhabdomyosarcoma).

"It is, sort of, like prisoners. You can see that similarity of, how does an ex-con transition into it [normality]? If someone asks you, what do you say? How do you bring it up? When is a good time to bring it up? When is not a good time to bring it up?" (P9, Male, 22 years, Hodgkin's Lymphoma).

These statements illustrate the sustained effects of cancer on young people and the ongoing need to adapt coping strategies over time. As illustrated above, different coping strategies were observed during treatment and in the post-treatment survivorship phase. For many, avoidance and distraction, as well as positivity were applied to support coping throughout treatment. Meaning making was more routinely applied during survivorship, after some space from the experience.

One participant also described changes in coping as his resources and experience shifted over time. When he was first diagnosed, he was reluctant to discuss or share his thoughts. However, his relapse five years later was a very difficult and traumatic time. Facing the very real prospect of dying prompted a rushed wedding at the hospital, three days before his second transplant. This time, he was more open to accepting help.

“The first time, I was young, I was 16 and I didn’t think I needed it [help], and I learned my lesson. The second time it’s been, well, I know what to do this time. I know what can help, and what will be detrimental. Emotionally, this time was more difficult during, I guess, during treatment. I’m not going to say I handled it well afterwards, but I definitely handled it better than the last time. Last time was terrible. So, this time, knowing what to do, and that is immersing myself in everything else, in extra curriculums, in work, and talking to my psychologist. I’ve handled it a bit better this time. There is no way that I can just say that I’ve handled it well. This is not something that you can say you can handle well. Your emotional toughness would need to be the same as a bullet proof vest” (P10, Male, 22 years, Leukaemia).

Another respondent described a change in her coping approach and resources as these changed over time from having an internal focus questioning “why me” to holding an external view of the diagnosis and her situation, supporting her coping and acceptance.

“At the start it was really, really upsetting. But then, well, realised it could happen to anybody... Like, there’s no reason that it should be more bad for it to happen to me than like an eight-year-old or like a little baby. And I just feel like I have a different outlook on everything...” (P16, Female, 21 years, Leukaemia)

However, for this young woman, the end of treatment brought about thoughts and fears that she found difficult to manage. This illustrates that learning to cope with a specific concern at one time point, does not necessarily translate to coping at another point in time, and again highlights the challenge in managing fear of recurrence.

“[I have changed] for better and for worse I think. I don't worry about a lot of little issues anymore because I know that it could always be worse. But I also found recently that I can't enjoy things as much. I'm not really sure why. Something I didn't expect after treatment, is just how much it [the cancer experience] would be on my mind constantly. Which really has an effect on things. Which I'm still learning to cope with” (P16, Female, 21 years, Leukaemia).

4. Discussion and conclusion

4.1 Discussion

A cancer diagnosis with the associated treatment, hospitalisation and interruption to life impacts young people in profound ways [23]. Here we have described the coping tendencies of young people with cancer from diagnosis, throughout treatment and into the post-treatment phase. Within in this study, young people found the period immediately following diagnosis particularly challenging to cope with and described the use of numerous coping strategies at this time. However, the post-treatment phase was also a described as an especially challenging time of stress and confusion, as young people were faced with adjusting to a new normal, requiring different coping approaches and supports. Overall, the AYAs in this study used a variety of active and person-centred coping mechanisms that changed over time with changing stressors but also as their coping resources evolved.

During treatment, commonly applied strategies included seeking and accepting support from family and healthcare professionals as well as cognitive restructuring to focus on the present, rather than future worries. Distraction and avoidance were also commonly applied, although limitations to distraction options for young people in the hospital environment were noted as being detrimental to coping. Staying positive and avoidance of re-traumatising or stressful situations were also applied throughout the cancer trajectory.

Following treatment, cognitive restructuring was used to focus on planning for the future, along with making meaning of their experiences.

Within the literature it is debated whether problem based, active coping is more adaptive than passive, emotion based strategies such as distraction or avoidance. [24] Our findings support the concept that for young people with cancer, both types of coping can be adaptive depending on coping resources and the nature of the stressor. In this case, emotion-based coping can be particularly adaptive when the source of stress is beyond the locus of control.

The cancer experience is described as a mediating effect on health related quality of life, which subsequently impacts a young person's ability to re-establish identity, achieve life's goals and return to normality. [25] Our findings also support the dynamic process of coping where individuals use different coping strategies, whether intentionally or automatically, depending upon the stressor, the available coping resources and their previous experiences. As highlighted in this study, and others [26], young people may not always want to access recommended supports. One participant used the term '*sheltering*' to describes the sense of needing to internalise to cope with the reality of treatment and hospitalisation. It implies protecting oneself from potential harm. In this case, the young person (P9) wanted to get away from the hospital and the possibility of further stressors. This was regularly reported as a coping strategy for young people, especially in relation to coping during treatment. As another participant (P8) describes, it was only after treatment that she felt ready to talk to others. This may be typical for young people who are focussed on 'getting through' treatment. Once treatment has ended, there is more space and time to process the

enormity of the cancer diagnosis and the impact on their lives; this is a time when support can be helpful.

Several limitations **of this study** should be noted. As a qualitative study, these findings are not intended to be generalisable, but examine individual experiences. In addition, participants were all recruited from a single geographic region, although this region spans over 1.8 million square kilometres and included participants across metropolitan, regional and rural locations. While there were fewer teenagers in this sample than older AYAs, there was a diversity of cancer types represented. This is both a strength of the research and a weakness as coping may differ by cancer type. This requires future investigation. Three participants elected to have a significant other present during the interview which may have influenced participant responses and there were several AYA approached, who did not want to participate. The sample may therefore include AYAs with different coping strategies compared to those who declined participation. Furthermore, interviews were conducted at only one time point. A longitudinal study would enable further exploration of how changes in coping occur over time. Overall however, the findings support empirical evidence which adds to this study's transferability and trustworthiness [27].

These findings also add further data to the literature demonstrating the effects of the cancer experiences and the dynamic process of coping. Providing young people a voice to express their experiences not only acknowledges the significant impacts of cancer on their lives but can also act as a powerful message to policy makers, healthcare providers and health services about the unique needs of this population. Our findings provide a narrative voice for the psychologically adaptive coping strategies in young people, which are more

frequently measured in quantitative research approaches [28]. Open discussions about fears, worries or concerns can assist with processing the cancer experience in a way that contributes to positive adaptation, facilitating the developmental tasks of adolescence and young adulthood [28]. We found the young people who participated in this study were eager to share their story in an interview process despite several acknowledging they did not want to share their story in formalised support groups. This provides some insight into the uptake of supports available in a variety of formats.

4.2 *Conclusion*

The young people participating in this study demonstrated positive and resourceful coping strategies, illustrating their inherent resilience and the resources they bring to cope with life and their cancer experience. However, despite this, cancer is a traumatic experience for anyone and many young people also described challenges in coping with diagnosis as well as persistent fear of cancer recurrence and difficulties with returning to normal life post treatment. This speaks to the importance of developmentally appropriate support for young people throughout the cancer trajectory that identifies and fosters resilience and coping resources as both the nature of stressors and their coping tools evolve over time. While aspects of post-treatment support are challenging for health services to manage, with a focus predominantly on acute cancer treatment and care, healthcare providers and services have a duty of care to ensure that the wellbeing of patients is supported in addition to focusing on clinical aspects of care. For young people with cancer, this must be done in a developmentally appropriate way and through partnership with young people to support individualised care planning and delivery, considering the whole cancer trajectory. In this way, available coping resources can be maximised, and adaptive coping strategies supported to promote long term health outcomes and adjustment to cancer for young people.

4.3 *Practice implications*

There are important implications for clinical practice and service development from this study, particularly when viewed across the future potential lifespan of young cancer survivor. The findings from this study highlight that resourceful strategies are used by young people to cope with cancer and cancer treatment, but also that these are unlikely to be promoted or discussed during interactions with their healthcare teams. Utilisation of a comprehensive, developmentally appropriate psychosocial assessment is central to understanding the inherent resilience of a young person, the stressors they experience, available coping resources and changes over time. The use of structured, validated assessments tools is recognised as gold-standard care in childhood and AYA cancer to identify distress [29, 30]. This is particularly important for young people as studies consistently report a higher prevalence of distress in AYAs compared with both children and older adults [1, 15, 30]. The use of such assessments is essential for holistic care planning and to support referral and access to allied health, education, financial and practical assistance, and community support throughout the cancer journey. Understanding levels of distress also supports the provision and tailoring of counselling and education at multiple different time-points across the cancer care continuum, depending on need [31]. However, as highlighted above, young people may not always be receptive to referral for support and offering and re-offering appropriate referral and information is an important aspect of quality AYA oncology care. This further supports partnering with young people in care planning to both maximise their available coping resources and foster resilience over time.

The young people in this study also emphasised their ongoing needs and concerns after cancer treatment, echoing findings from a large international study, which identified survivorship as the number one research priority in AYA cancer [32]. Despite this and the above practice recommendations, barriers in access to service remain and the availability of YCS tailored for young people is not ubiquitous. Services are not equitably available to all young people regardless of geographic location, location of treatment or into post-treatment survivorship [33, 34]. This means that currently, young people do not consistently receive routine, developmentally appropriate psychosocial assessment, or access to appropriate services, information and support [35-37]. Moreover, current models of psychosocial support do not reflect the contemporary approaches of participatory community-based care that aim to empower cancer survivors, without the need for ongoing services from healthcare providers [13]. The work of the YCS in Australia continues to advocate for the specific needs of young people with cancer, but further research and service development is required to promote and support positive adaption which facilitates a return to normal life and the ability to achieve life goals.

5. Conflicts of interest

The authors declare no conflicts of interest

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Table 1 Characteristics of participants N=16

Sex		N	%
	Male	10	62%
	Female	6	38%
Range of age at time of study (years)		Mean	SD
	15-24	21	2.13
Cancer Type [^]		N	%
	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%
	HCST	5	31%
Phase of treatment			
	Completed all planned treatment	14	88%
	Maintenance therapy for leukaemia	2	12%
Type of Hospital		33	
	Public adult hospital	8	50%
	Children's Hospital	8	50%
Location of residence			
	City	8	50%
	Regional or rural	8	50%
Level of education			
	Attending high school	3	19%
	Completed high school	6	38%
	Attending university	5	31%
	Completed university	2	13%
Employment status			
	Working full-time	5	31%
	Working part-time	2	13%
	Looking for work	1	6%
	Student, not looking for work	6	38%
	Not working or studying	2	13%

*Total exceed 100% as participants could receive more than one treatment

[^] Two participants with brain tumours both had mothers in attendance for the interviews, and one participant with leukaemia had his wife in attendance.

Figure Legend

Figure 1 Themes from interviews about coping