

Adolescents and young adult cancer survivors: exercise habits, quality of life and physical activity preferences

A. Murnane · K. Gough · K. Thompson · L. Holland · R. Conyers

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Abstract

Introduction Given the decades of survivorship for adolescent and young adult (AYA) cancer survivors, it is important to promote behaviours that enhance physical and mental well-being and quality of life (QoL). The purpose of this study was to explore the exercise programming preferences and information needs of AYA survivors and to examine the impact of a cancer diagnosis on physical activity behavior and QoL.

Methods Participants aged 15–25 years at time of diagnosis and referred to a specialist AYA cancer service between January 2008 and February 2012 were recruited. Eligible participants were mailed a self-administered questionnaire assessing demographic and disease-related information, physical activity levels over time and exercise information preferences. QoL was measured using the Assessment of Quality of Life-6D (AQoL-6D).

Results Seventy-four (response rate 52 %) participants completed the questionnaire. The mean age was 23 years with 54 % female, with prevalent diagnoses included hematological malignancy (45 %) and sarcoma (24 %). Results indicated a significant reduction in the average minutes of physical activity post diagnosis ($p < 0.001$) and during treatment ($p =$

< 0.001). AYA who met public health physical activity guidelines ($n = 36$) at questionnaire completion had significantly higher QoL than those not meeting the guidelines ($n = 38$) (median (Mdn) = 0.87, interquartile range (IQR) = 0.73 to 0.98 and Mdn = 0.81, IQR = 0.57 to 0.93, respectively; $p = 0.034$). Most participants wanted exercise information at some point after diagnosis (85 %) but many did not receive any information (45 %).

Conclusions Findings suggest that AYA with cancer experience a significant impact on physical activity levels and QoL. Moreover, survivors experience considerable difficulty returning to pre-morbid levels of activity. Our study suggests that interventions promoting physical activity and healthy lifestyle behaviours would be well accepted within this population and may be essential to improve their long-term health and QoL during survivorship.

Keywords Adolescent and young adult · Exercise · Quality of life · Survivorship

Introduction

Each year, in Australia, approximately 1,000 adolescents and young adults (AYAs) (15–25-year olds) are diagnosed with cancer [1]. The past decade has seen an overall improvement in survival outcomes, in some tumour groups, across this population, resulting in a growing number of patients surviving for decades with the long-term physical, psychological and social consequences of a cancer diagnosis and its treatments [2]. As a result, attention is now being directed towards age-specific services, and targeted interventions, in the survivorship period. Survivorship infrastructure will aim to support young people's healthy growth, development and QoL throughout treatment and beyond. To date, little exploration of the benefits of exercise, within the AYA patient

A. Murnane (✉) · K. Thompson · L. Holland · R. Conyers
ONTrac at Peter Mac Victorian Adolescent and Young Adult Cancer
Service Peter MacCallum Cancer Centre, Locked Bag 1 A'Beckett
St, Melbourne, VIC 8006, Australia
e-mail: Andrew.Murnane@petermac.org

K. Gough
Department of Cancer Experiences Research, Peter MacCallum
Cancer Centre, Melbourne, VIC, Australia

R. Conyers
The University of Melbourne, Grattan Street, Parkville, VIC,
Australia

R. Conyers
The Royal Children's Hospital, Parkville, VIC, Australia

population, has been undertaken. This is despite the research in the paediatric and older adult setting demonstrating an association between physical activity and improved QoL health-related fitness and improved survival outcomes [3–7]. Exercise during and post-treatment has proven to be an effective intervention within the adult oncology setting, improving cardiorespiratory fitness, providing treatment for side effects such as fatigue and improving quality of life, including psychological well-being [8–11]. Significantly, for some tumour groups, in particular breast and colorectal cancer, it has been linked to improved disease-free survival and overall survival [12–14].

There are very few studies that have reported the benefits of exercise within the AYA population, or ascertained their activity preferences or motivation to exercise post-treatment [15–18]. It has been found that AYA are less physically active than non-diagnosed siblings or peers and that their unmet need for exercise information is greater than that reported for older cancer survivors [19, 20]. Three studies have included this patient cohort, and all describe a high level of interest of AYA in participating in, and receiving information on, exercise and physical activity [15, 17, 18]. However, the desire for information has been reported to be unmet in 40–50 % of patients [18]. This lack of information provision and uncertainty around exercise ability may explain why only 50 % of AYA patients meet public health exercise guidelines post-cancer treatment [17]. Known benefits of activity for cancer survivors indicate the need for a targeted approach to address this modifiable risk factor for young people who may live for many years with the implications of their diagnosis and treatment.

The aim of this study was to explore the exercise levels and activity preferences within the Victorian AYA population at a specialist AYA cancer service in more detail. The specific objectives of the study were to describe physical activity over time (before diagnosis, during primary treatment and after primary treatment), examine the association between physical activity and QoL, identify exercise programming preferences and identify information needs of AYA patients.

Method

Design and setting

A cross-sectional survey was undertaken at a large specialist oncology facility in Melbourne, Australia. The study was approved by the local Human Research Ethics Committee (12/104L).

Patient population

Eligibility criteria included aged 15 to 25 years at diagnosis, being diagnosed in Victoria and Tasmania (Australia) with a primary or secondary cancer and referred to ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service, a specialist multidisciplinary state-wide cancer service that provides support to AYA with cancer, their families and health-care professionals who provide their care, between January 2008 and February 2012. Patients who were within the first 6 months following primary treatment completion (chemotherapy, radiotherapy or surgery), were unable to understand or read English, had a life expectancy less than 6 months, had no contact with the service within the past 5 years or had previously indicated that they did not wish to be contacted for research purposes were excluded.

Recruitment and assessment procedures

Eligible participants were identified via hospital databases; then, the total design method was used to maximise recruitment/response rates [21]. In this case, all eligible participants were mailed a personalised cover letter and questionnaire package. The latter comprised detailed participant information, study measures and a reply-paid envelope. Fourteen days after the initial mail-out, non-responders were sent a reminder letter. A further 14 days after the reminder letter, non-responders were mailed another cover letter and questionnaire package. Recruitment was undertaken between August 2012 and October 2012.

Measures

Physical activity, exercise programming preferences and information needs were assessed with a customised exercise-scoping questionnaire. A customised questionnaire was used due to the absence of a validated tool designed for this purpose. Constituent items were modelled on previous work in this area. Together, items provided a subjective measure of physical activity (frequency, duration and types) before diagnosis, during primary treatment and at questionnaire completion (i.e. after primary treatment) [23–25] and assessed the impact of a cancer diagnosis and treatment on participants' ability to exercise, whether participants had received exercise information and their interest in receiving such information. Items also assessed preferences regarding the timing of commencement of a potential exercise intervention (before, during or after treatment), the type of programme participants would like to undertake and the preferred location of the programme. QoL was assessed with the Assessment of Quality of Life-6D (AQoL-6D) [22]. The AQoL-6D has been validated for use with adolescents in health-care settings [22].

Participants also provided basic demographic and medical information.

Statistical analysis

Descriptive statistics were used to summarise patient characteristics and responses to the exercise-scoping questionnaire. Recruitment bias was assessed by comparing study participants with study decliners on age, sex, residential location and cancer diagnosis with Pearson's χ^2 , Fisher's exact or independent samples *t* tests as appropriate. McNemar's test was used to test differences between paired proportions (before diagnosis with during and after primary treatment) for AYA exercising, meeting exercise guidelines and engaging in various forms of exercise. An SPSS macro created by Garcia-Granero was used to perform this test with Yates' continuity correction [26]. Confidence intervals generated by this macro are based on methods developed by Newcombe [27]. A linear mixed model was used to estimate and test differences in self-reported minutes exercising per week (before diagnosis with during and after primary treatment). This model was estimated by maximum likelihood, and an unstructured variance-covariance matrix was used to model the covariance structure among repeated measures [28]. The Mann-Whitney *U* test was used to compare AQOL-6D utility scores in AYAs currently meeting exercise guidelines with those not meeting guidelines at questionnaire completion. Analysis was conducted using SPSS version 20 (SPSS, Chicago, IL, USA). Alpha was set at 0.05 (two-tailed) for all analyses. Given the exploratory nature of the study, no adjustments were made for multiplicity [29].

Results

Study profile

From the initial screen of 418 potential participants, 148 (35 %) met the inclusion criteria and were mailed the questionnaire package. Six packages (4 %) were returned undelivered. Of the 142 AYA presumed to have received the package, 74 (52 %) returned a completed questionnaire (Fig. 1). There were no significant differences between study participants and AYA who did not return a completed questionnaire in terms of age, sex or cancer diagnosis (all $p > 0.05$, Table 1). Study participants, however, were more likely to reside outside metropolitan Melbourne than non-participants ($p = 0.014$).

Participant characteristics

Demographic and medical characteristics of study participants are summarised in Table 1. The mean age of

study participants was 22.9 years (SD=3.5 years, range 16–31 years); 54 % were female; 59 % were attending, or had completed, university; and 76 % were single. Most participants had a haematological malignancy (45 %) or sarcoma (24 %). Approximately two-thirds (68 %) underwent chemotherapy, 58 % had surgery and 46 % underwent radiotherapy as part of their primary treatment. Mean time since diagnosis was 37.4 months (SD=31.6 months) and, at the time of questionnaire completion, 78 % of participants were disease free. Mean BMI was 23.8 kg/m² (SD=4.5 kg/m²); 34 % of participants were classed as overweight or obese [30].

Many AYAs thought their current health was either 'not as good' (36 %) or 'much worse' (8 %) than others their age. A majority thought their current fitness levels were 'not quite as good' (32 %) or 'much worse' (27 %) than their fitness levels prior to diagnosis (Table 1). Many (61 %) participants felt that treatment had affected their ability to exercise 'a lot' or 'a great deal' with the main contributing factors being fatigue (41 %), pain (21 %) or change in functional abilities (20 %).

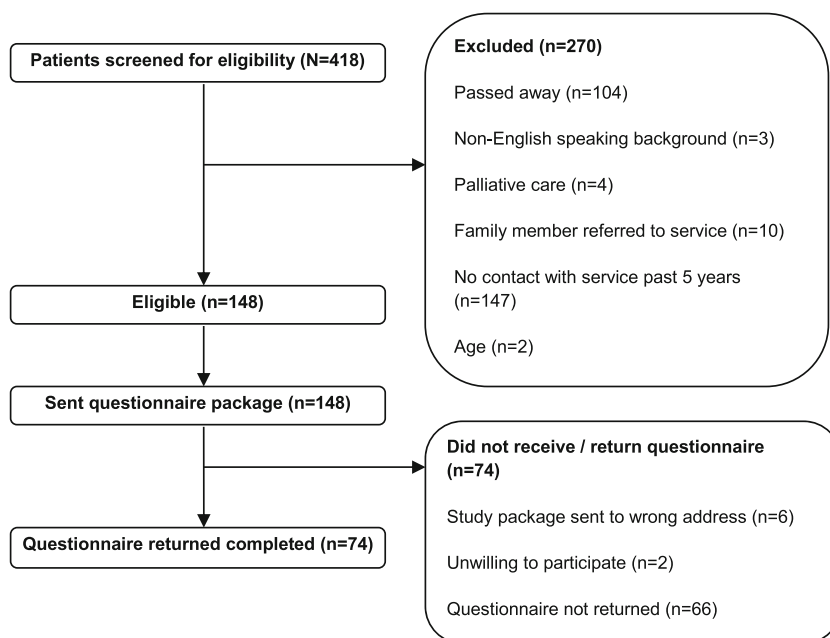
Physical activity

Estimates of physical activity before diagnosis, during primary treatment and at questionnaire completion (i.e. after primary treatment) are shown in Table 2. Results of tests of differences (during and after primary treatment with before diagnosis) are also provided in Table 2.

Fewer AYAs were exercising during primary treatment compared with before diagnosis (difference 43 %, 95 %CI 28 to 55 %, $p < 0.0005$). Correspondingly, significantly less time was spent exercising per week during primary treatment compared with before diagnosis (difference 173 min, 95 %CI 134 to 212 min, $p < 0.0005$; box plots of time spent exercising per week in each time period are provided in Fig. 2). While similar percentages of AYA were exercising before diagnosis and after primary treatment (difference 1 %, 95 %CI 11 to 9 %, $p = 1.0$), AYAs were still spending significantly less time exercising per week after treatment (difference 71 min, 95 %CI 33 to 109 min, $p < 0.0005$).

Compared with before diagnosis, fewer AYA were meeting current national exercise guidelines [31] during (difference 61 %, 95 %CI 47 to 71 %, $p < 0.0005$) and after (difference 22 %, 95 %CI 6 to 35 %, $p < 0.0005$) primary treatment. On average, AYA meeting exercise guidelines at questionnaire completion obtained significantly higher AQOL-6D utility scores than those not meeting exercise guidelines (median=0.87, interquartile range (IQR)=0.73–0.98 and median=0.81, IQR=0.57–0.93, respectively, $p = 0.034$; see Fig. 3).

Fig. 1 Flow of participants through the trial



Physical activity programming preferences and information needs

While most AYA (63 of 74, 85 %) indicated that they would have liked to receive exercise information at some point after their cancer diagnosis, only 41 of 74 (55 %) received such information (Table 3). Frequent providers of exercise information included medical practitioners (21 of 41), 53% physiotherapists (15 of 41), 38% family members (12 of 41), 30% and nurses (11 of 41), 28%. Nonetheless, most of the participants who would have liked to receive exercise information (57 of 63, 90 %) indicated that they would have liked to receive this information from an exercise physiologists (associated with the tertiary centre).

Of 74 participants, 50 (68 %) indicated that they would be interested in doing an exercise programme aimed at AYA. Of this group, a majority (31 of 50, 62 %) preferred programmes starting after treatment. Further, there was a clear preference for home exercise programmes (34 of 50, 69 %) and exercise programmes at local gyms (25 of 50, 50 %) among this group.

Discussion

Exercise has been linked to improvements in health and QoL after cancer treatment [9, 32, 33]; however, to date, little research has investigated physical activity levels and preferences of AYA patients following a cancer diagnosis [15–18]. These questions were examined in the present study utilising a sample of AYA patients referred to a specialist AYA cancer service.

The results of the study demonstrated the impact cancer treatment has on one's ability to participate in a regular physical activity during treatment. There was a significant reduction in the proportion of participants exercising during treatment, and these findings have been reported previously [23, 24]. Although physical activity increased post-treatment, the total time spent exercising remained significantly lower than prediagnosis activity for the sample involved in this study (Fig. 2). Post-treatment, almost half of the study participants were not meeting public health physical activity guidelines, and one in five were classified as sedentary [31]. Although these figures are similar to healthy Australian population-based data [34], they have specific and significant clinical importance in the AYA oncology population as AYA cancer survivors are known to experience a higher prevalence of all chronic conditions including cardiovascular disease, hypertension, diabetes, obesity and osteoporosis than healthy peers and siblings [2, 35–37]. Adoption and maintenance of physical activity is a difficult challenge pose by cancer diagnosis as evidenced by the decreases in physical activity observed in this study and others [38, 39] and highlights the importance of targeted programmes to address these issues.

One of the most provocative findings from this study was the finding that AYA patients meeting public health physical activity guidelines had significantly higher QoL scores than those not meeting recommendations [31]. It has been postulated that improvements in mental health may result from improved fitness [40] but may also arise from associated psychosocial factors including social interactions with others, improved body image, self-confidence and the impact of exercise outdoors [17, 32, 41]. Lack of physical activity may place AYA at increased risk for poor disease outcomes along

Table 1 Demographic and medical characteristics of study participants and decliners

	Participants		Decliners		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Age, years					
Mean (SD)	23 (4)		24 (3)		0.13
Range	16–31		17–30		
Gender					0.83
Male	34	46	30	44	
Female	40	54	38	56	
BMI					
Mean (SD)	24 (5)				
Range	14–40				
Marital status					
Single	56	76			
Married/de facto	13	18			
Other	5	7			
Residential location					0.014
Metro	46	62	55	81	
Rural	24	38	13	19	
Employment status					
Working	36	49			
Studying	20	27			
Work and study	8	11			
Not employed	10	14			
Education level					
Some high school	12	16			
Completed high school	15	20			
Attending university	24	32			
Completed university	20	27			
Other ^b	3	4			
Cancer diagnosis					0.84
Haematological	33	45	27	40	
Sarcoma	18	24	18	26	
Other ^b	23	31	23	34	
Disease status					
Disease-free	78				
Disease	22				
Treatment					
Radiotherapy	34	46			
Chemotherapy	50	68			
Surgery	43	58			
Other	2	3			
Months since diagnosis					
Mean (SD)	37 (32)				
How would you rate your health compared to others your age					
Much worse	6	8			
Not as good	27	36			
The same	28	38			
Better	6	8			

Table 1 (continued)

	Participants		Decliners		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Much better	4	5			
Not sure	3	4			
How would you compare your current fitness level compared to prediagnosis					
Much worse	20	27			
Not quite as good	24	32			
No difference	11	15			
Better	14	19			
A great deal better	5	7			

^aTrade, community or TAFE college

^bBrain, melanoma, prostate, colorectal, breast, cervix, parotid, ovarian

with other associated chronic diseases and may have a significant impact on overall QoL. This finding demonstrates the value of prioritising exercise interventions for AYA patients during and beyond treatment completion. Future work on the multifaceted benefits of exercise on QoL along with programmes that combine exercise and psychosocial training in the age group is warranted.

In terms of exercise programming preferences, 68 % of AYAs in this sample were interested in completing a targeted exercise programme, preferring to start the programme post-treatment (62 %) with a home-based exercise programme identified as the preferred type. This sentiment has been reported previously [23, 24]. Exercise programmes for oncology patients are often designed to be run in a group environment either during treatment or post-treatment because they are considered more cost- and time-effective. Within the AYA group, this may not be feasible due to the limited numbers of new cases diagnosed each year compared to the adult oncology population and the broad geographical spread of centres treating AYA patients, making it difficult to run AYA only exercise groups. For these reasons, tailored, individualised programmes for AYA may be required to engage them in a manner which promotes the development of autonomous skills for ongoing self-management within their own environment.

Given the potentially extensive years of post-treatment survivorship for AYA patients, preventative medicine plays an important role in supporting long-term mental and physical well-being. The time post-treatment completion, is critical for AYA patients as they adjust to a new version of normal [42]. Due to the developmental life stage of the young person, the cognitive processing of the cancer diagnosis, its treatment and the implications of this on ongoing health, well-being and identity often occur in the first year post-treatment. This time therefore provides an ideal opportunity to promote healthy

Table 2 Estimates of physical activity ($n=74$)

	Before diagnosis	During primary treatment			After primary treatment		
	%	%	Difference (95 %CI) ^a	<i>p</i>	%	Difference (95%CI) [‡]	<i>p</i>
Exercising	78.4	35.1	43.2 (28.3, 55.4)	<0.0005	79.7	-1.4 (-11.3, 8.7)	1.0
Type of exercise							
Walking	41.9	28.4	13.5 (0.01, 26.3)	0.08	53.4	-12.3 (-25.0, 1.1)	0.11
Sport	40.5	5.4	35.1 (23.7, 46.2)	<0.0005	24.7	16.4 (6.7, 25.9)	0.003
Running	36.5	4.1	32.4 (20.0, 44.2)	< 0.0005	27.0	9.5 (-3.9, 22.4)	0.23
Cycling	23.0	9.5	13.5 (4.5, 23.3)	0.009	23.0	0.0 (-12.1, 12.1)	0.82
Pilates/yoga	12.2	1.4	10.8 (3.2, 20.1)	0.01	9.5	2.7 (-7.3, 12.8)	0.77
Swimming	12.2	8.1	4.1 (-4.8, 13.3)	0.51	13.5	-1.4 (-11.7, 9.0)	1.0
Weight training	27.0	9.5	17.6 (6.2, 28.9)	0.005	39.2	-12.2 (-23.3, -0.6)	0.07
Meeting exercise guidelines	70.3	9.5	60.8 (46.6, 71.2)	<0.0005	48.7	21.6 (6.4, 35.5)	0.01
Minutes exercising per week ^b	219 (19)	46 (9)	173 (134, 212)	<0.0005	148 (13)	71 (33, 109)	<0.0005

^a Follow-up (during and after primary treatment) subtracted from before diagnosis

^b Data are maximum likelihood estimates and standard errors

behaviours such as exercise aimed at preventing chronic disease. In parallel, the sample reported this to the preferred time to implement a specific exercise programme. For these reasons, addressing barriers to exercise, such as side effects, during the treatment phase, to allow patients to engage in exercise along the treatment spectrum, combined with post-treatment interventions, may be proffered to be beneficial to improving long term health within this patient group.

Lack of information about the benefits of exercise during cancer treatment may also be a contributing factor to current exercise behaviour. A total of 85 % of participants expressed a desire for information regarding exercise; however, only half

reported receiving this information. When they did receive this information, it was often provided by a doctor or nurse, but participants indicated that they would prefer such information to be delivered by an exercise physiologist with experience in oncology care. This finding is similar to work undertaken by Zebrack [18] and Belanger et al. [15] where 86 % and 78 % of AYA participants retrospectively indicated that they wanted exercise information. In a similar study, AYA patients desired that the information be delivered from a fitness expert associated with the treating cancer centre [16]. This may reflect the fact that AYA cancer survivors perceive that their situation is unique and requires specialised exercise

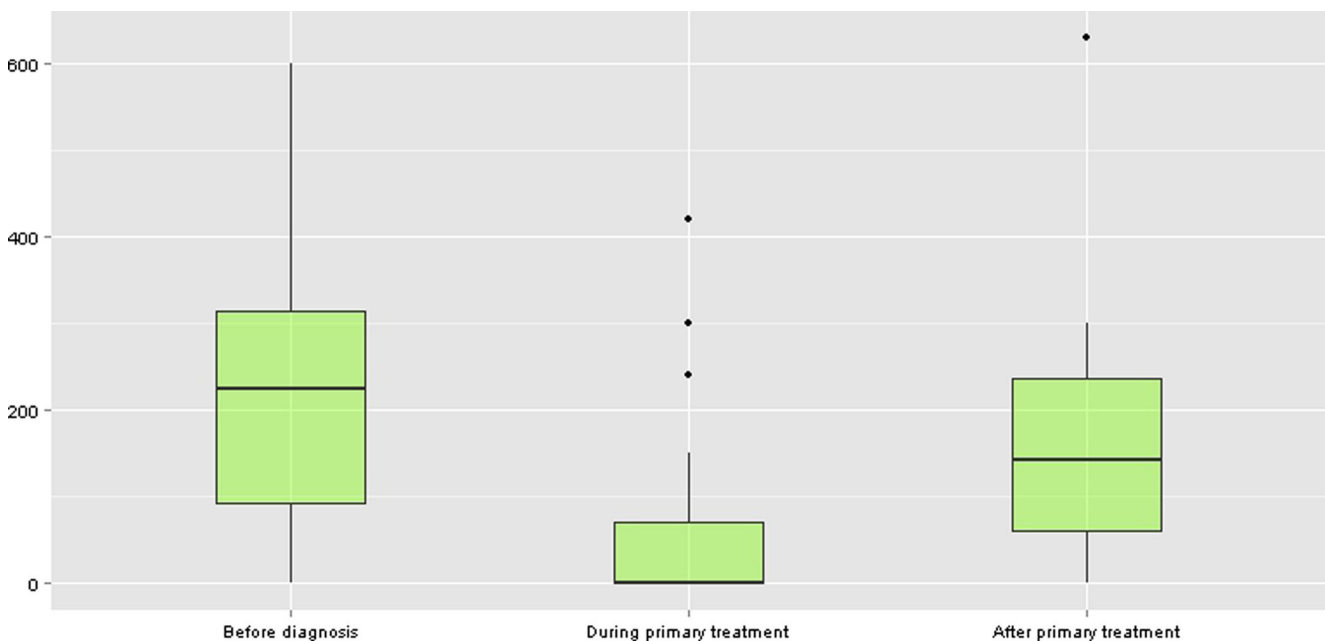


Fig. 2 Physical activity (minutes per week) before diagnosis, during primary treatment and after primary treatment

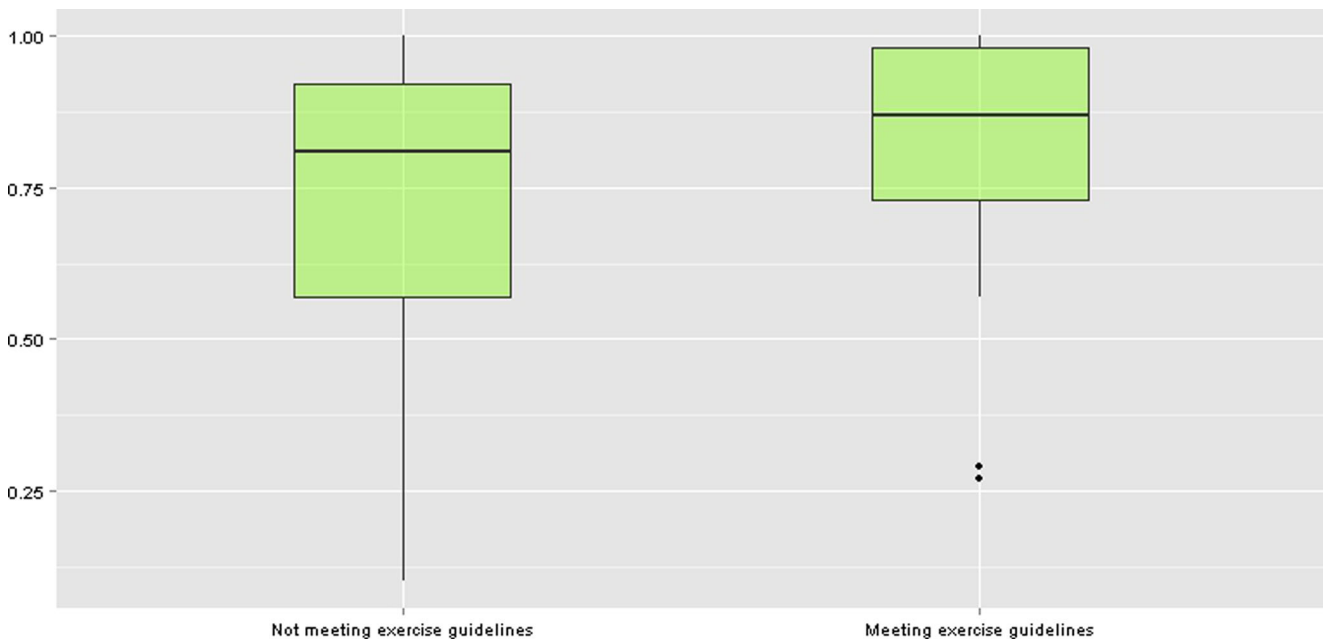


Fig. 3 AQoL-6D global utility score by level of physical activity after primary treatment. Meeting exercise guidelines defined as 150 min of exercise per week using the sum of walking, moderate activity and vigorous activity (weighted by two) [35]

information and advice rather than generalised information geared towards the healthy population.

Current exercise interventions and models of care have yet to target AYA patients. Previous research has highlighted that in order for exercise programmers for cancer patients to be successful, they need to be individualised and targeted to the needs and goals of the patient [9, 32]. Although receiving this type of information requires more resources than a handout or DVD, it is often required as many aspects of an exercise programme for medical patient populations should be supervised, at least initially, and demonstrated rather than simply described [9, 32]. For example, correct technique when performing resistance-type exercise, heart rate-training zones when undertaking aerobic activity and goal setting with the patient prior to programme development. The importance of the goal setting component along with a detailed medical history cannot be overstated in ensuring long-term adherence and safety for any new exercise programme. It ensures that exercise is appropriate for one's needs, allows for questions to be answered, alleviates fears and anxieties about exercise and can be targeted in a way that allows clients to not only meet short- and long-term goals but also enable behaviour change and motivation. Working in conjunction with the treating team, exercise physiologists (or exercise specialists) with oncology experience may be the most appropriate clinician to deliver such information to patients over other medical and allied health staff. Given their unique and specialist skill set, they are best placed to design a programme that is individualised and safe, which is inclusive of guidance, support and motivational cues which cannot be delivered or provided by a booklet, phone application or a generic website.

Side effects of long-term treatment also need to be addressed when considering models of care. Patients in this study cohort completed the questionnaire at a mean of 37 months post-treatment, and the majority reported that their ability to exercise was still impacted by fatigue, pain and change to functional ability and one in three were overweight or obese. The significant impact of these side effects and late effects on activity reduction for young people highlights the importance of providing advice, guidance and regular review to support young people to navigate through these issues, for example, how to adjust activity levels to compensate for treatment side effects such as fatigue. Without such support, patients appear to be at significant risk of stopping exercise altogether, for fear of making things worse, which is likely to have a significant impact on ongoing health and well-being [19, 43]. What is not quantified in this study that warrants further investigation is whether receiving specialist exercise information, administered in a therapeutic intervention during the treatment phase, would enable patients to stay engaged in regular physical activity and whether exercise could ameliorate side effects including fatigue, pain and change in functional ability.

This study had a number of important strengths and limitations. One of the greatest limitations of the study is selection bias where respondents may be more interested in receiving exercise information. Although the characteristics of respondents and non-respondents were synonymous, self-selection bias cannot be excluded. Recall bias is another limitation of this study with participants on average 3 years since diagnosis, therefore making judgements about physical activity behaviour and barriers to exercise during treatment problematic.

Table 3 Descriptive statistics for physical activity programming preference in AYAs

Preference variable	Number responded	% of cases
Were you provided with exercise information at some point during your cancer treatment		
No	33	45
Yes	41	55
If yes, who provided the information ^a (<i>n</i> =81)		
Doctor	21	53
Physiotherapist	15	38
Family	12	30
Nurse	11	28
Friend	9	23
Exercise physiologist	6	15
Other	7	17
Would you have liked to receive exercise information at some point after diagnosis		
No	11	15
Yes	63	85
If yes, who would you have liked to receive this information from ^a (<i>n</i> =166)		
Exercise physiologist from cancer centre	57	91
Doctor	24	38
Personal trainer	23	37
Physiotherapist from cancer centre	16	25
Nurse	14	22
Community exercise physiologist	13	21
Cancer support group	11	18
Community physiotherapist	6	10
Other	2	3
How would you like to receive this information ^a (<i>n</i> =152)		
Face to face	54	79
Handout	37	54
Email	19	28
Application on a smart phone	16	24
Internet	15	22
DVD	7	10
Telephone call	4	6
Would you be interested in doing an exercise programme that was aimed at AYA		
No	24	32
Yes	50	68
When would you like to start a programme ^a (<i>n</i> =61)		
Before	9	18
During	21	42
After	31	62
If you would like to begin an exercise programme, what sort of programme would suit you best ^a (<i>n</i> =104)		
Home exercise program	45	71
Exercise program at local gym	29	46
Exercise programme at cancer centre	18	29

Table 3 (continued)

Preference variable	Number responded	% of cases
Community-based exercise programme	9	14
Other	3	5
Is there additional information you would like to assist you in returning to a healthy lifestyle ^a (<i>n</i> =84)		
Diet/nutrition advice	42	78
Support groups/networks	20	37
Return to work programmers	14	26
School	7	13
Other	1	1

^a Multiple response question

Research has also shown that cancer patients both under report and over report, depending on cancer type [44]. Future prospective studies are required to gain a better understanding of barriers to exercise. The study also solely reflects the perspectives of AYA patients referred to a specialist AYA cancer service and may not reflect the views or experiences of young people treated for cancer more broadly. In addition, the exercise-scoping questionnaire was a customised measure developed for this study and was not tested for reliability and only tested for face validity.

One identified deficit of the current study is that, due to study numbers, we were unable to look at burden of chemotherapy regimen versus exercise participation. Ideally, it would be useful to subclassify regimens into those expected to cause decline in performance status (ECOG), i.e. auto graft, higher dose therapies versus those that are less burdensome. In future studies, it may be possible to subdivide the groups further and risk-stratify according to disease stage and therapy burden so that targeted interventions can be implemented.

The response rate for this study (52 %) is also a concern for bias although this is comparable to similar studies involving AYA [15, 17, 39] and design methods where response rate have been reported as low as 15 % [16]. Finally, the finding that participants meeting public health physical activity guidelines have significantly better QoL than those not meeting guidelines, could have occurred by chance and a definitive answer requires an appropriately designed prospective study. Despite some of these limitations, to the best of our knowledge, this study is the first to focus on the physical activity preferences in AYAs across all tumour streams in Australia and comprises the largest total number of participants. The findings demonstrate that there is strong interest from AYA patients to receive exercise programming advice and this may be necessary to improve the health and well-being of a cohort that may live for a long period of time with the ramifications of a cancer diagnosis and its treatments.

Conclusion

There are a growing number of AYA cancer survivors, and as a result, there is the need to implement positive interventions that aid in easing the morbidity of the survivorship period. Given the associated health benefits of exercise, there is a need to examine physical function, exercise preferences and QoL across the treatment spectrum, to fully understand the relationship between these variables within the AYA oncology setting. This study highlighted three key issues: (1) the impact of a cancer diagnosis and its associated treatments on physical activity levels, (2) the unique and special needs of this group along with the need for tailored information and service provision, and (3) an association between physical activity and QoL.

AYA within our sample struggled to return to premorbid levels of activity with responders largely not meeting physical activity guidelines. Of concern, we showed that those not meeting physical activity guidelines demonstrated worse QoL. Additionally, one in three participants were overweight or obese, highlighting the potential for a number of long-term health implications within this group, if left unaddressed. The sample was heterogeneous with high motivation to exercise but low confidence in what physical activity could be undertaken. Furthermore, AYA patients want specialised exercise information and support at some point during their cancer experience and would like to be under the direction of an exercise physiologist/exercise specialist from the cancer centre, to be able to guide them through this process.

To date, health behaviour interventions developed for cancer survivors have yet to target or engage young people. The preliminary findings provide evidence that interventions promoting physical activity and healthy lifestyle behaviours would be well accepted within this cohort and may be essential to improve their long-term health and QoL during survivorship. Future, prospective intervention-based studies are required to validate these findings and assess the efficacy of exercise interventions in improving the physical function and quality of life for young people experiencing a diagnosis of cancer.

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Conflict of interest The authors have no conflict of interest to declare.

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