Health promotion and psychological interventions for adolescent and young adult cancer survivors: a systematic literature review

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Abstract

Background

The effects of cancer and treatment have severe and long lasting negative impacts on quality of life. Adolescents and Young Adults (AYA) have high survival rates but may not reach their full life potential because of these consequences. This review aims to identify, appraise and synthesise the effects of health promotion and psychological interventions for AYA after cancer treatment.

Methods

The review was undertaken using the preferred reporting items for systematic reviews and meta-analyses guidelines. Included studies were identified though a range of electronic databases through to May 2016. Studies were critically appraised using the Cochrane Risk of Bias tool.

Results

Seventeen studies, comprising a total of 2314 participants aged 13-39 years were included in this review. Participants in 15 studies were survivors of childhood cancer, with only two studies specifically recruiting survivors of cancer diagnosed during young adulthood. Ten studies were randomised controlled trials (RCTs); the remaining seven were before and after studies. The quality of studies was variable across all appraised domains; risk of bias was evident in regards to recruitment, measures of exposure and outcomes, confounding factors, attrition and lost-to follow-up. Studies evaluated a range of health promotion and psychological interventions to improve health related and process outcomes. Eleven studies reported modest positive outcomes, with psychological and physical activity interventions achieving greater success compared to general health promotion interventions.

Conclusion

This review highlights the lack of high-quality studies for optimising the health and well-being of AYA cancer survivors. No conclusive evidence favouring specific interventions were identified,
although recommendations for future studies are made. Interventions delivered face-to-face and those that facilitate peer-to-peer support hold promise. Harnessing social media and technology to deliver interventions is likely to increase and these modes of delivery require further investigations.

**Keywords**

Adolescent and Young Adult; Cancer; Survivorship; Quality of life; Health and Well-being; Interventions
Introduction

When active cancer treatment ends, patients describe feelings of contradiction and uncertainty about their future. Survivorship is understood to be a process of living with, through and beyond a cancer diagnosis, and as such has been described as a process of liminality, or a series of passages one takes to move through life events. The concept of liminality proposes the transitional phase between one passage and another—the liminal phase—is often associated with feelings of ambiguity and paradox, when one doesn’t quite fit or belong to any group. Thus patients who have completed treatment for cancer, may not return to their previous sense of self, nor quite see themselves as ‘survivors’ as the threat of the return of cancer remains prominent.

Adolescence and Young Adults (AYAs) who have completed treatment for cancer face additional challenges to their sense of self. The time period between childhood and adulthood, recognised variably as the years between 10-39, is when important cognitive, psychosocial and emotional developments occur. Cognitively, the ability to think abstractly and to reflect upon one’s thoughts and ideas ensue. Psychosocially, a sense of personal identity develops, peer group relationships become increasingly important along with independence from parents. Emotionally, this time period can be characterised by feelings of anxiety and self-consciousness, and is recognised as a time when there may be less control over emotions. The impact of a cancer diagnosis and subsequent treatment during this period is understood to pose further challenges to the developing individual. AYA patients report altered sense of identity; changed relationships; challenges to body image and sexuality; impacts on education and employment with financial consequences; concerns about cancer recurrence; a pre-occupation with death and dying, and generally a less positive outlook on life.

In Australia, disease-free five-year survival for AYAs aged 15-29 years has reached 88%. However, survivors are at risk of long-term health problems; up to 70% report at least one chronic health problem and up to 40% have severe problems and need ongoing medical intervention or surveillance. This is significantly different to AYAs with no history of cancer. Compared with their counterparts, AYA cancer survivors have more disability, chronic disease, and poorer mental and physical health.

Evidence suggest there are modifiable risk behaviours, such as diet, smoking and alcohol intake, that are associated with this increased incidence of chronic health conditions and also for secondary malignancies. As AYAs represent the future workforce, prospective parents and community members of a society, investing in
their health needs is warranted. Indeed not meeting their health needs is likely to increase costs to the health and social welfare systems.[13] With increasing pressures on health budgets, there is a need to ensure interventions to address health needs are both effective and economical. Interventions in this population may be broadly categorised into those that promote health or those that address psychological issues. Health promotion interventions are defined as combinations of educational, organisational or environmental actions that support behaviour modification conducive to health.[14] Psychological interventions are defined as evidence-based formalised strategies that aim to alter self-re-informing processes and improve individuals outcomes.[15]

A number of reviews have synthesised either health promotion or psychological interventions for AYAs with cancer. A review examining the long-term and life-long psychological impacts of cancer in this population reported complex, challenging and nuanced problems and highlighted the need for specific interventions targeting finances, relationships, education, goals, body image and physical well-being [16]. Walker et al. undertook a critical review of psychosocial interventions finding the availability of psychosocial interventions were increasing and although higher quality studies are needed, the results suggest interventions are beneficial.[17] Pugh et al completed a systematic review of health behaviour change interventions and concluded further work is required to evaluate how best to promote health change behaviour in young people.[18] Wurz et al completed a systematic review of two controlled trials regarding the effects of physical activity on health related quality of life for adolescent cancer survivors; the authors found physical activity was safe, feasible and showed promise for improving health and quality of life.[19] To date, no systematic review has collated high level evidence (i.e. randomised controlled trials, controlled trials) of all health behaviour and psychological interventions for AYAs with cancer to identify the attributes associated with positive changes. Therefore, the aim of this systematic review was to identify, appraise and synthesize the effects and attributes of health behaviour and psychological interventions on health-related or process outcomes for AYA cancer survivors. Health related outcomes of interest included quality of life, symptom burden, unmet needs, rates of hospitalisation, or screening for new cancers. Process outcomes of interest included patient behavioural uptake, quality of care, training and education, satisfaction, costs and resource utilisation.
Methods

Randomised controlled trials (RCTs); quasi RCTs; controlled before and after studies, and before and after studies that examined the effects of health promotion and psychological interventions for AYA cancer survivors were included. The protocol for this review was registered with PROSPERO ref 42016036470.

Search Strategy

The search terms were devised by the study authors in consultation with a medical research librarian. Searches included combinations of the terms: (physical interventions, psychological intervention, physical therapy, psychological therapy, physical treatment, psychological treatment) AND (follow up, end of treatment, survivorship, cancer survivor) AND (cancer, neoplasm, oncology) AND (adolescent, teenager, young adult, youth, minor) AND (quality of life, value of life, quality assurance, distress, anxiety, outcome assessment, health outcome, healthcare economics). Databases searched included: Medline; CINAHL; Web of Science; PsycINFO; EMBASE and Cochrane CENTRAL. These databases were searched up to May 2016. Authors of studies were contacted for further information if required. Hand searching of referenced articles was also undertaken. Searches were restricted to humans and the English language. Studies were excluded if full text were not available.

Selection criteria

The population of interest for this review were adolescents and young adults, aged 15-25 years, who have completed treatment for cancer. We aimed to include studies where participants were potentially diagnosed during adolescents or young adulthood. The age range of 15 to 25 years was chosen as in Australia, AYA cancer services are limited to this group. Studies with participants beyond this age range were included if their study population included a substantial (25%) proportion of participants in this age range at the time of cancer diagnosis, or time of study. Articles were included if they reported any health promotion or psychological intervention or therapy during survivorship. All studies were required to have a comparator group or comparator measure. Outcomes of interests included any health-related outcomes (e.g. quality of life, symptom burden, unmet needs, rates of hospitalisation, screening for new cancers) or process outcomes (e.g. patient behavioural uptake; quality of care; training and education; satisfaction; costs and resource utilisation). Secondary outcomes included attributes of, and resources required, for the intervention, as well as benefits and shortfalls. The study
setting could be primary, secondary or tertiary level health facilities, or interventions delivered in community settings.

Data collection

All titles and abstracts were screened for eligibility independently by both authors (NB, RC). Full text articles were reviewed independently by the same two authors against the inclusion and exclusion criteria. Discrepancies were resolved by discussion. A summary of the selection process is presented in Figure 1. Data extraction were completed using pre-defined data extraction forms and included details regarding: authors; publication year; country; study design; study aim; characteristics of participants; content and intensity of the interventions; sample size; response rate; outcome measures; resources required; findings, and the level of evidence of the study (see Box 1). [20] The quality of all studies was appraised using the Cochrane Risk of Bias tool. As per the Cochrane handbook, non-randomised trials were also appraised for risk of selection bias and other potential confounding factors.[15] The Risk of Bias tool examines seven categories relating to the design, conduct, analysis and presentation of factors that may cause the effect of an intervention to be over or underestimated. Each category is rated as having either low, high or unclear levels of bias. Both study authors independently rated studies and reached consensus through discussion. The quality assessment did not influence inclusion of studies; all identified studies were included in the narrative synthesis regardless of their rating. [21] Data from each study were summarized and synthesized where possible. Where statistically significant findings were reported for continuous variables, the mean difference (MD) from baseline to last follow-up was calculated with 95% confidence intervals. For categorical data, odds ratios (OR), percentage comparisons, and simple descriptive statistics were used to summarize the data.

Results

Overview of included studies

A total of 17 articles were included in this review. Characteristics of included studies are summarized in Table 1. Authors of two included studies were contacted and provided further information regarding participant ages.[22, 23] Of the 17 included studies, 24% (n=4) [24-27] were before and after studies, 18% (n=3) [28-30] were controlled before and after studies, and 59% (n=10) [22, 23, 31-37] were RCTs comprising a total of 2314
participants across all studies. The smallest study recruited 10 participants and the largest 796. In 15 studies, participants were survivors of cancers diagnosed during childhood or adolescence. Two studies specifically focussed on recruiting survivors diagnosed during young adulthood. [37, 38] Ages of participants ranged 13-39 years, and mean time since diagnosis ranged 1.9-21.8 years. All studies included both males (N= 1087, 49%) and females (N= 1227, 53%). Caucasians were the most represented ethnic group across all studies, with the larger studies also recruiting small proportions of African Americans, Hispanic and Asian participants. All studies were conducted in developed nations; 11 were undertaken in the USA [22-24, 28, 31-37], one in Canada [38], two in the UK [25, 29], and three in Northern European countries [26, 27, 30]. Cancer survivor diagnoses commonly included acute lymphoblastic leukaemia as well as other childhood cancers and those seen in adolescence and young adulthood. Some studies excluded patients with brain tumours due to potential cognitive impairment.

Over half (n=10, 58%) of the studies included in the review were Level II evidence from RCTs, potentially contributing high levels of evidence. However, there was significant variability in the quality appraisal of all studies; risk of bias was evident across multiple domains, and in particular with regards to recruitment, measures of exposure, confounding factors, attrition and follow up (see Table 2).

Target outcomes of included studies

The aims of studies were to examine feasibility of the intervention [24, 25, 33, 37], to establish the efficacy or impact of the intervention on outcomes [22, 23, 26-28, 30-32, 34, 36-38], and two studies were undertaken to confirm the results of earlier pilot studies [29, 35]. Studies were categorised into two groups depending on the primary objective of their intervention: health promotion or psychological well-being. Outcomes of interventions included:

- health related outcomes, e.g. quality of life, anxiety and depression, fatigue, perceived vulnerability and motivation
- process outcomes, e.g. behavioural uptake of physical activity or health practices, satisfaction and feasibility

Attributes of studies
Most interventions were delivered face-to-face in individual sessions (n=9, 53%) [22, 25, 28-32, 34, 35], with use of telephone and workbooks as ‘boosters’. The telephone (n=3, 18%) [26, 33, 36] and internet (n=3, 18%) [23, 27, 37] were also commonly used as the primary mode for delivering the interventions. One study used group sessions with peers, [24] and one population based study mailed guidebooks with worksheets to participants. [38] Table 2 summarises all studies by intervention group, attributes and mode of intervention delivery, outcome measures and summary effects of interventions. Response rates for studies varied widely; some studies contacted hundreds of potential participants only to recruit a relatively small number to the study. [30, 31, 38] Response rates ranged from 11- 87% with retention to studies also varying widely between 59-100%.

Outcomes

Health Promotion Interventions

Physical Activity

Five studies [24, 26, 30, 37, 38] examined interventions to promote physical activity and all reported positive outcomes. One study evaluated a home training program finding improved physical fitness and reduced peak oxygen uptake in 17 participants. [26] Similarly, group based exercise sessions improved physical activity and fitness for a small group of 10 participants [24], and counselling sessions with use of a pedometer decreased in fatigue in a study with 46 participants. [30] A study using Facebook to deliver cognitive theory-based intervention to 86 participants found significant increases in physical activity in both the control and intervention groups, with greater improvements seen in the intervention arm. [37] A printed guidebook targeting young adult cancer survivors was found to be superior to existing guidelines for a subset of 96 participants reporting less than 300 minutes/week of exercise. [38] All five studies reported the interventions were feasible and safe, with three studies reporting the interventions were economical requiring no special facilities. [30, 26, 37] Effect sizes were modest, with wide confidence intervals reducing precision; results were suggestive rather than conclusive in their findings.

Other health promotion interventions
There were six studies reporting effects of a range of interventions to improve diet, bone health, tobacco use, psychosexual development and knowledge of cancer risk factors. [22, 23, 29, 31, 32, 34] Unlike the reported success of physical activity, there were only two studies that reported success with these interventions [31, 34]

One of these successful studies was an RCT that tested the effect of educational sessions to enhance psychosexual development. While the study found significant improvement in cancer related sexual knowledge, confidence, body image and a decrease in emotion distress, the authors acknowledge that the sample is most likely biased with counselling being more attractive to those with problems. Of the several hundred participants contacted, only 24 were ultimately recruited. [31] The other study found skill building exercises were effective at improving dietary intake. The authors found their methodology was well received, relevant and understandable and that findings are potentially important for the long term health for AYA cancer survivors. [34]. Again, the precision of effect sizes was reduced by wide confidence interval, some encompassing the null; results were suggestive rather than conclusive of positive effects.

The other studies in this group attributed the lack of success of their interventions to a variety of factors: an information package aimed at improving readiness to change and self-efficacy was troubled by lost to follow-up participants [29]; a one month counselling interventions to promote health-protective behaviours was deemed not intensive enough [32]; a web portal with personalised information was found to in-effective with improving knowledge of risks of cancer treatment- few participants actually logged on and used the portal [23], and a single session with educational counselling (with periodic telephone re-enforcement) regarding the risks of smoking had no effect on participants who smoked. [22]

**Psychological interventions**

Six studies reported the results of psychological interventions and five found sustained positive effects on outcomes including anxiety or depression, decision making, motivation and health practices. [25, 27, 33, 28, 36] Metacognitive therapy was used in one study [25] with positive effects in reducing anxiety, depression and post-traumatic symptoms in AYAs experiencing clinically significant distress related to their cancer. Internet-based cognitive behavioural therapy was used in another study [27], and found significant reduction in anxiety with clinical improvements that were sustained in those who completed and were followed up. However this study
had a large number of withdrawals and lost-to-follow ups; the authors concluded strategies were needed to better engage with younger participants for online interventions. [27] Hollen et al tested the effect of a decision making workshop on risk reduction behaviours and found short term effects for smoking. The authors acknowledge that participants may have self-selected and have been more motivated [28]. The study was repeated with a larger, more diverse sample, and found some immediate change in substance use motivation. Feasibility of the program was established, however the overall effects were modest and not sustained at 12 month follow up.[35] The telephone was used to deliver coping skills training to reduce anxiety and uncertainty in one study [33] and found modest improvements; there were significant delays with obtaining outcome measures that may have biased results. The most significant results were found in Emmons et al study where counsellors, who were survivors of childhood cancer themselves, provided motivational interviewing to cease smoking. [36] The intervention improved the likelihood of efforts to cease smoking. However, in this study, the intervention arm also had access to free nicotine patches whereas the control arm needed to purchase their own. This may account for the higher quit rate in the intervention arm. Aside from the findings in Emmons et al, the other four studies reporting positive effects from their interventions reported modest effect sizes, again with wide confidence intervals reducing the precision of the effect; results were largely suggestive rather than conclusive.

Discussion

The findings of this review highlight the lack of robust evidence to support interventions to promote health and well-being for AYAs after cancer treatment. While 11 of the 17 included studies reported positive effects of their intervention on outcomes, studies were all beset with methodological weaknesses that diminish the certainty of the effects of interventions. Additionally, given the heterogeneity of the included studies, it is not possible to draw firm conclusions regarding the most effective attributes of interventions, and few studies reported the resources required. The majority of interventions deemed effective were delivered in individual face-to-face sessions with a clinician and supplemented with workbooks or phone calls during the study period. One study found Facebook to be an acceptable, feasible and effective platform to promote physical activity.[37] This study found both groups participated in peer support chat on group walls and had improved levels of
physical activity, with the group that received the more intensive and directed cognitive theory-based intervention reporting higher increases of physical activity. Of interest however, is the otherwise lack of success with Internet based interventions; two other studies that used this strategy both had large numbers of withdrawals, lost to follow ups, or participants that did not even log on to the intervention.[27, 23] This is somewhat counter-intuitive as AYAs are generally high users of the Internet and technology based applications. This phenomenon is not limited to the studies included in this review; other studies have also found the Internet not useful for delivering interventions to young survivors.[39, 40] It is possible some young people view the Internet as a personal space where interactions with clinicians are not welcome. Conversely however, in other studies of cancer survivors aged to 39 years the Internet has been found useful. Physical activity was examined in two RCTs by Rabin et al. One study used a website designed to promote activity in sedentary adults that was adapted for young adult cancer survivors; the study demonstrated improvement in activity and participants reported high satisfaction with using the website. [41] A second study assessed a 12 week home-based program that included an online forum to connect with peers and found significant increases in physical activity and fitness as well as high satisfaction rates.[42] Further research is needed to understand the potential of harnessing the Internet to deliver interventions for this population.

It is well recognised cancer and cancer treatment has an immense psychological and physical impact on young people. The numbers of AYA surviving cancer treatment are exponentially increasing, and as young people, they have the most years to live with the consequences of cancer. Identifying and understanding interventions that improve outcomes of AYAs after cancer treatment should therefore be a priority for researchers. The paucity of evidence available to support AYAs after cancer treatment highlights the lack of research in this area. This is not surprising as relatively little attention has been paid to the specific needs of this population compared with that of children of older adults with cancer.[43] In fact, the vast majority of studies included in this review recruited participants who were survivors of childhood cancers, only two studies focussed solely on participants whose cancer was diagnosed during young adulthood. This is an area that requires further attention; it is highly likely the needs of a childhood cancer survivor differ significantly to that of one diagnosed during adolescence or young adulthood.[16] Additionally, it is important to identify strategies to engage this population in research and interventions that improve health and well-being.
If we consider the AYAs experience of cancer, and reflect upon the liminal processes that occur through the transition from healthy individual, a cancer diagnosis, cancer treatment and end of treatment, we can appreciate that the passage is turbulent. While a focus on the treatment is necessary for survival, there is also a need to consider what life beyond treatment will look like. Much like palliative care is advocated to be considered at diagnosis with certain cancers [44], so too should we consider survivorship at the beginning of treatment or soon after diagnosis? It is clear that survivorship issues such as fertility must be considered early in the disease trajectory. However, the lack of consensus regarding when survivorship care should commence requires further investigation to establish, from both the patient and clinicians perspectives, the optimal time to plan for life beyond cancer treatment.[45] Additionally, to provide such care over time, the capacity for cancer programs to deliver services must be considered. [46]

Balancing the finite healthcare resources with the needs of AYA cancer survivors needs to occur in a way that will maximise the benefits to patients and provide value to health system. Value based healthcare is increasingly important and future research should take into account resources and cost benefits of interventions to patients, the healthcare system and the wider community.

The studies included in this review were categorised into health promotion and psychological groups by their interventions. Studies in the health promotion group focussed on promoting health and well-being to potentially prevent or minimise risks of developing secondary cancers or late effects of cancer treatment. Studies in this group typically aimed to encourage healthy lifestyles through diet, exercise and risk reduction behaviours, by fostering an understanding of the risks of sedentary lifestyles, smoking, alcohol and diet. While these studies focused on improving the AYAs awareness, self-efficacy and competence with decision making, they did not typically address actual ill health, or late effects associated with after cancer treatment. Similarly in the psychological group most studies focussed on interventions to promote health behaviours for a healthy lifestyle. There were only two studies in this group recruited patients with clinically significant distress that examined interventions for psychological support. [25, 27] One could argue resources and research efforts should focus on identified problems as well as preventative measures.

Our review has a number of strengths; we have collated the highest level of evidence available for health promotion and psychological interventions in this population group and provided and assessment of the current
state of the evidence. We conformed to established principles for the conduct of this review [47] and identified a number of key areas that warrant further investigation. More studies are required with participants diagnosed during adolescence and young adulthood; understanding how to engage this population group is important. Given it is well documented that AYAs following cancer treatment are burdened with long-term consequences of cancer treatment [16], the lack of robust research to inform how best to meet the needs of patients with clinical problems post-treatment is concerning. While late effects may be managed by a medical treating team, the undesirable psychological effects such as changed sense of identity, body image, cancer recurrence concerns and pre-occupation with death and dying, and poorer outlook on life appear to be largely neglected.

Our study has notable limitations. Only a small number of studies met our eligibility criteria. Our focus on participants aged 15-25 years means we have not included studies of participants aged to 39 years who are considered young adults in other nations. However, for nations where funding of services is limited to those aged 15-25 years, this review provides important information regarding the feasibility and effects of interventions. There are few studies in our review that include minority groups from different cultural backgrounds; AYAs in these groups are underrepresented in studies and there is a paucity of evidence to inform their health needs after cancer treatment. Whilst we sought to include studies providing high level evidence, many of the included studies had small sample sizes, biases and short follow-up duration. Variations in study methodologies, focus of interventions, outcome measures and study quality meant we were not able to conclusively identify attributes of studies that were effective.

**Conclusion**

This review identified interventions focussed on supporting AYA cancer survivors is a developing area; the included studies were generally small with methodological limitations that reduce generalizability of findings and preclude the ability to make conclusive recommendations. There is a strong need to undertake studies for patients who are diagnosed during adolescence and young adulthood rather than survivors of childhood cancer. High quality, well powered RCTs incorporating cost-effectiveness analysis should be conducted in this population, with the priority given to interventions that hold promise. Interventions delivered face-to-face and those that facilitate peer-to-peer support have potential to achieve positive outcomes; harnessing social media
and technology to deliver interventions is likely to increase and these modes of delivery require further investigations.

Conflict of interest statement

None declared

Acknowledgments

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<th>Level</th>
<th>Description</th>
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<td>Level I</td>
<td>Systematic review of RCTs, or evidence based guidelines based on systematic reviews of RCTs</td>
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<td>Evidence from RCTs</td>
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<td>Level III</td>
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<td>Evidence from case-control, cohort or before and after studies</td>
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<td>Level VII</td>
<td>Evidence from opinion of authorities or expert committees</td>
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Figure 1 Flow chart of literature searches

PRISMA Flow Diagram

Records identified through database searching
(n = 1123)

Additional records identified through other sources
(n = 19)

Total record titles screened after duplicates removed (828)

Records screened
(n = 828)

Excluded based on title
(n = 768)
Excluded based on abstract
(n = 30)

Full-text articles assessed for eligibility
(n = 30)

Full-text articles excluded, with reasons n = 13
(full text not available n = 1)
(age range not AYA focused n = 7)
(Intervention not evaluated n = 3)
(no comparator group n = 2)

Studies included in qualitative synthesis
(n = 17)

Studies included in quantitative synthesis
(meta-analysis)
(n = 0)
Table 1 Characteristics of included studies

<table>
<thead>
<tr>
<th>Author, Year, Country</th>
<th>Study design</th>
<th>Level of evidence</th>
<th>Aims</th>
<th>Characteristics of participants: sample size N; age at time of study (mean time since diagnosis in years); response rate; retention</th>
<th>Content and intensity of intervention (Follow up)</th>
<th>Outcome measures</th>
<th>Findings</th>
<th>Effect size (% change from baseline) mean difference, 95% CI (P value)</th>
<th>Resources required and other notes</th>
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<tr>
<td><strong>Health Promotion Interventions</strong></td>
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<td>Blauwbroek et al, 2009, Netherlands [30]</td>
<td>Controlled before and after III</td>
<td>To evaluate the effect of enhanced daily activity on fatigue in adult survivors of childhood cancer</td>
<td>Childhood cancer survivors N=46 Mean age 29.8 years (21.8) Response rate 56% Retention 38/46 (83%)</td>
<td>Intervention group (n=46) received counselling session re exercise program, pedometer and step diary. One face-face session. Control group (n=33) recruited by survivors from healthy siblings or peers. (9 months FU)</td>
<td>Fatigue, daily physical exercise</td>
<td>Intervention was effective in decreasing fatigue in adult survivors of childhood. Fatigue and daily steps walked improved. No differences in control group. High number of withdrawals suggest intervention may not be suitable for all patients</td>
<td>Fatigue levels decreased 21.8%: Mean Difference 17.75 (95%CI 1.12-1.48, p=&lt;0.005) Daily steps increased 53.2% Mean Difference -4.1 (95%CI 0.57 to 0.75, p=&lt;0.005)</td>
<td>No information provided for resources required. Stated to be an economical intervention that required no special facilities. Intervention developed and delivered by psychologist. Research assistant collected outcome measures. Small samples size and low response rate may have biased selection of participants; results suggestive rather than conclusive</td>
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<td>Belanger et al, 2014 Canada, [38]</td>
<td>Randomised controlled trial II</td>
<td>To determine the effects of a printed physical activity guidebook targeted to young adult cancer survivors on physical activity and quality of life</td>
<td>Young adult cancer survivors N=212 55 patients aged 18-29 years (26% of total N) Response rate 11% Retention 128/212 (60%)</td>
<td>Intervention group (n=106) received printed guidebook with planning sheet; developed on theory of planned behaviour, assessed and evaluated by experts and consumers. Control group (n=106) received Canadian Physical Activity Guidelines. (3 months FU)</td>
<td>Physical Activity, Quality of life</td>
<td>The guidebook did not increase physical activity compared to generic guidelines in highly active sample. In subsample of participants who reported less than 300 minutes/week of exercise at baseline, the intervention was effective</td>
<td>Increase in physical activity in subsample (n=96) of participants reporting less than 300 minutes/week of exercise Physical activity increased by 155% in intervention group compared to 68% in control group . Mean difference -82 (95% CI -155.07 to -8.93, p=0.028)</td>
<td>No stated information for resources required. Intervention developed by team and based on previous studies of young adult cancer survivors preferences and determinant of physical exercise. Participant self-selected and may be more motivated to exercise. High attrition rate, wide confidence intervals reduce the precision of effect size; results suggestive rather than conclusive</td>
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Jarvela et al, 2012, Finland [26]  
**Before and after study IV**  
To evaluate the effects of a simple, home-based exercise program on cardio-metabolic risk factors, peak oxygen uptake and muscle strength in AYA long-term survivors of childhood ALL  
Childhood cancer survivors N= 17  
Mean age 23 years (16.7)  
Response rate 22%  
Retention 17/17 (100%)  
Home muscle training program. Face-to-face instruction and Telephoned every 2 weeks for motivation. Matched controls recruited from larger study.  
(4 months FU)  
Peak oxygen uptake, muscle strength, metabolic factors  
Significant changes to fasting insulin, waist circumference, fat % and fitness in participants. Improved cardio-metabolic risk factors. Finding underline positive changes can be achieved with modest improvements in fitness.  
Volume oxygen (ml/kg/min) increased 5.4% Mean Difference -1.9 (95%CI -3.33 to -0.44, p<0.01)  
Homeostasis model assessment, insulin resistance decreased 33% Mean Difference 0.74 (95% CI 0.12 to 1.66, p<0.01),  
Fasting plasma insulin decreased 30.4% Mean Difference 3.06 (95% CI 0.83 to 6.95, p<0.01)  
No information provided for resources required.  
Intervention delivered by exercise physiologist. No information about existing exercise patterns. High missing values for some outcome measures  
Small sample size, low response rate and lack of control group may have biased results; results suggestive rather than conclusive

**Before and after study IV**  
Examine feasibility of conducting theory based physical activity intervention on QoL  
Childhood cancer survivors N=10  
Mean age 16.2 years (5.2)  
Response rate not determined  
Retention 10/11 (91%)  
Physical activity intervention-meeting once per week. Delivered face-face in group sessions over 16 weeks (12 month FU).  
Quality of life, total physical activity, fatigue, physical fitness, feasibility.  
Successful adherence attributed to safe and supervised environment, Improvements in Quality of life and fatigue at one year post intervention suggest physical activity and fitness positively influenced by intervention  
Quality of life (Total score) increase of 14% Mean Difference -9.9 (95% CI -23.46 to 3.67, p=0.05)  
1 mile walk/run (minutes) decrease 5.6% Mean Difference 0.7 (95% CI 3.56 to 4.96, p=0.01)  
No information provided for resources required.  
Intervention and assessment delivered by trained instructor. Small heterogeneous sample, no comparator group, possible self-selection bias; results suggestive rather than conclusive

Valle et al, 2013, USA [37]  
**Randomised controlled trial II**  
To determine adherence to and acceptability of Facebook-based intervention approaches and to evaluate whether the approaches would produce differences in moderate-to-vigorous intensity physical activity  
Young adult cancer survivors N= 86  
Mean age 31 (4.9)  
Response rate not applicable; recruited till sample size achieved, 89% consent rate  
Retention 66/86 (77%)  
Intervention group (n= 45) received physical activity promotion through Facebook group delivered over Internet over 12 weeks (12 weeks FU)  
Control group (n= 41) had Facebook-based self-help as comparator  
Both groups used pedometer  
Physical activity, feasibility, body weight, quality of life  
Both groups reported increases in self-reported physical activity. Increases in light physical activity were greater in the intervention group who also achieved weight loss. No changes to quality of life.  
Self-report physical activity increase in both groups- 112% in intervention group vs 33% in control group  
No significant changes between groups: Mean Difference 131.8 (95% CI -119.34 to 382.94, p=0.08)  
Intervention group decreased body weight by 7.8%, Mean Difference 6.2 (95% CI -2.91 to 15.31, p=0.004)  
Facebook-based intervention approach demonstrated potential for increasing physical activity in young adult cancer survivors. Social networking sites may be a feasible way to promote health behaviours and distribute health information. Wide confidence intervals for physical activity results reduces the precision of the effect size; results suggestive rather than conclusive

Canada et al, Cross-over randomised  
To test an intervention  
Childhood cancer survivors  
Intervention group (n= 10) received education  
Body image, sexual  
Significant improvement in Body image inventory improved 13%: Mean Difference -0.4 (95% CI -0.04 to 0.39)  
No information provided for resources required.
### Controlled Trial

**2007, USA [31]**

**AIMS:** Aimed to enhance psychosexual development in adolescent and young adults with cancer.

**Participants:** N=24, Mean age 21yrs (1.9- some still on active treatment).

**Response rate:** No information.

**Retention:** 21/24 88%.

**Response to intervention:**
- Behavioural homework between sessions. Booster phone call at one month. Two face-face sessions, + phone calls (3 months FU).
- Comparator group (n=11) waitlisted to receive intervention.

**Outcome measures:**
- Concerns, cancer rehabilitation and brief symptom inventory of overall distress.
- Cancer related sexual knowledge, confidence about appearance, body perception, less dissatisfaction with body parts, decrease in sexual concerns, and decrease in emotional distress.

**Results:**
- Cancer related sexual knowledge improved 27%: Mean Difference -3.63 (95% CI -5.37 to -1.89, p=<0.001)
- Body competence scores improved 11%: Mean Difference -0.3 (95% CI -0.78 to 0.18, p=<0.05)
- Psychological distress decreased by 49%: Mean difference 11.53 (95% CI 3.18 to 19.88, p=<0.005)

**Authors:** Intervention developed and delivered by doctoral level psychologist. Authors acknowledge difficulties with recruitment, several hundred contacted, only 35 verbally agreed and only 24 participated. Treatment completed for 63% of participants. Sample most likely biased - counselling more attractive to those with problems. Intervention likely of interest only to those with significant problems.

**Sample:** Most likely biased, self-selected; results suggestive rather than conclusive.

---

### Before and After Study

**Eiser et al, 2000, UK [29]**

**AIMS:** To replicate previous findings from Blacklay 1998[48]. To assess effects following the intervention of survivors readiness for change; self-efficacy or competence; to determine the negative consequences of the intervention.

**Participants:** Childhood cancer survivors N=263, Mean age 21yrs (14.4)

**Response rate:** 87%.

**Retention:** 155/263 (59%).

**Response to intervention:**
- Information package including treatment summary and specific information sheets related to problems.
- Face-face instructions at clinic (2 weeks FU).

**Outcome measures:**
- Perceived importance of follow-up; readiness to change; self-efficacy; perceived vulnerability.
- Unable to replicate previous findings. Authors acknowledge those with least positive attitude were likely less likely to reply to follow-up questionnaires.
- Unable to target survivors who were not attending a clinic.

**Results:**
- No change in ratings of importance of follow-up between two assessment times.

**Authors:** Unable to target survivors who were not attending a clinic.

**Sample:** Most likely biased, self-selected; results suggestive rather than conclusive.

---

**Note:** The table provides a summary of controlled trials and before and after studies focusing on the psychological and sexual well-being of childhood cancer survivors. The studies vary in design, sample size, and reported outcomes, highlighting the challenges in conducting research in this population.
<table>
<thead>
<tr>
<th>Study Authors, Year, Location</th>
<th>Study Design</th>
<th>Objective</th>
<th>Sample Size, Mean Age</th>
<th>Response Rate</th>
<th>Retention</th>
<th>Intervention Details</th>
<th>Health Outcomes</th>
<th>Findings</th>
<th>Resources Required</th>
<th>Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hudson et al, 2002, USA [32]</td>
<td>Randomised controlled trial II</td>
<td>To assess the impact of a multi-component behavioural health promotion study</td>
<td>Childhood cancer survivors N=266, Mean age 15.1 years (10.63)</td>
<td>86%</td>
<td>95%</td>
<td>Intervention group (n=131) received educational counselling intervention to increase practice of health-protective behaviours. One individual training module face-to-face, written materials, 2 telephone calls (12 months FU)</td>
<td>Health protective questionnaire, health knowledge, perceived susceptibility; seriousness; benefits; barriers, health practices</td>
<td>No significant difference at one year between groups. More intensive intervention is most likely needed.</td>
<td>No significant differences between groups</td>
<td>No information provided regarding resources required. Clinical assessments by physician, nurse practitioner or psychologist. Results suggestive rather than conclusive.</td>
</tr>
<tr>
<td>Kunin-Baston et al, 2015, USA [23]</td>
<td>Randomised controlled trial II</td>
<td>To measure cancer knowledge and understanding of late effects among AYA survivors and to develop and test a web based resource</td>
<td>Childhood cancer survivors N=52, Mean age 21yrs (12.2)</td>
<td>59%</td>
<td>73%</td>
<td>Intervention group (n=26) received access to a web portal with personalised information, journal, links to information and messaging to healthcare professionals. Face-to-face instructions and email instructions (12 months FU)</td>
<td>Cancer knowledge, state trait anxiety, computer knowledge, website use and satisfaction</td>
<td>No difference between groups, intervention had no effect. Offering educational information in person or by Web does not appear to be enough to close the gap.</td>
<td>No significant differences between groups</td>
<td>No information provided regarding resources required. Developed a web portal and personalised summary sheets for study- less than 50% of participants used this resource. High lost to follow-up (27%) Results do not support intervention, but identified need to education in this patient group; less than half of participants recognised the risk previous treatment for cancer posed.</td>
</tr>
<tr>
<td>Mays et al, 2011, USA [34]</td>
<td>Randomised controlled trial II</td>
<td>To examine the efficacy of survivor health and resilience education to immediately improve bone health</td>
<td>Childhood cancer survivors N=75, Mean age 14.2 years (3.4)</td>
<td>49%</td>
<td>Retention not reported</td>
<td>Intervention group (n=38) received skill building exercises addressing risk taking behaviour. Bone health education, and discussion of recommended dietary calcium intake, role laying, food tasting. One face-face session (1 month FU)</td>
<td>Bone health measured by calcium consumption and bone health behaviours</td>
<td>Study suggests intervention was well received, relevant, understandable, beneficial and acceptable. Potentially important for long term health of survivors</td>
<td>Milk consumption increase in intervention group at one month: Mean difference 0.43 (95% CI 0.05 to 0.81, p=0.03). Intervention group were 24.5 times as likely to take calcium supplement (p&lt;=0.001)</td>
<td>No information provided regarding resources required. Intervention delivered by dietician who was member of research team. Limited follow up, small sample size, self-report measures developed for this study; results suggestive rather than conclusive.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Aim</td>
<td>Population</td>
<td>Intervention</td>
<td>Outcome Measures</td>
<td>Results</td>
<td>Feasibility</td>
<td>Notes</td>
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<tr>
<td>Tyc et al, 2003, USA [22]</td>
<td>Randomised controlled trial II</td>
<td>To evaluate the efficacy of tobacco risk counselling intervention compared to standard care</td>
<td>Childhood cancer survivors N= 103, Mean age 15yrs (6.3)</td>
<td>Intervention group (n=53) received educational counselling, on late-effects and toxicities exacerbated by tobacco. Single educational session with periodic re-enforcement by telephone. (12 months FU) Control arm (n=50) received standard care</td>
<td>Self-reported knowledge, perceived vulnerability, intention to use tobacco and perceived positive effects of tobacco use</td>
<td>Results indicate tobacco related knowledge, perceived vulnerability and intention to use tobacco can be modified with risk counselling intervention. Feasibility of the program also established. Intervention did not have an effect on patients who used tobacco.</td>
<td>No significant group differences</td>
<td>No information provided regarding resources required. Intervention delivered by masters level psychologist. Outcomes collected by research nurse. Only 70% of patients provided data at 6 and 12 months. No differences in the smoking status across time; delayed effect of intervention at 12 months indicated modification takes time. Results suggestive rather than conclusive.</td>
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</table>
| Emmons et al, 2005, USA [36] | Randomised controlled trial II | To evaluate the impact of a peer-based telephone counselling intervention on smoking among childhood cancer survivors | Childhood cancer survivors N= 796, Mean age 31 (50% diagnosed before age 9 years) | Intervention group (n=398) assigned a counsellor who was also a childhood cancer survivor provided motivational interviewing to cease smoking. Written report, supplementary material sent. Telephone counselling average 6 calls (12 months FU) Control group (398) received self-help information | Quit rate-smoking status, number of quit attempts, nicotine replacement treatment, self-efficacy, perceived vulnerability, perceived medical outcomes | Intervention did not have an effect on efforts to quit, but rather the likelihood that those efforts would be successful. Predictors of cessation identified: short term and long term self-efficacy were related to smoking cessation. Individuals with high self-efficacy were 4 times more likely to quit than those with little or no self-efficacy. Quit rate for smoking was higher in the intervention group compared to self-help group: 15% vs 9%, Odds Ratio 1.7 (95%CI 1.05 to 2.63, p<0.05). Controlling for baseline self-efficacy and depression, intervention group was likely to quit smoking compared with control group, Odds Ratio 1.99 (95% CI 1.27 to 3.14, p<0.05) 14.5% of all participants quit smoking at follow up. | Quit rate for smoking was higher in the intervention group compared to self-help group: 15% vs 9%, Odds Ratio 1.7 (95%CI 1.05 to 2.63, p<0.05). Controlling for baseline self-efficacy and depression, intervention group was likely to quit smoking compared with control group, Odds Ratio 1.99 (95% CI 1.27 to 3.14, p<0.05) 14.5% of all participants quit smoking at follow up. | Per person cost for intervention estimated at US$300 per person. Nicotine patches provided free by Pharma. Information provided for peer and staff salary and variable costs.
Intervention delivered by peers, supervised by staff. Free nicotine patches may have influenced the outcomes- in the control group participants had to buy their own patches where as they were provided freely in the intervention group. 33% of intervention group used nicotine patches compared with just 8% in control group. Significantly higher quit rates in those who used nicotine patches. Results suggestive rather than conclusive. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Intervention</th>
<th>Outcome</th>
<th>Conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fisher et al, 2015, UK [25]</td>
<td>Before and after study IV</td>
<td>To establish feasibility and potential efficacy of metacognitive therapy for AYA cancer survivors experiencing clinically significant distress</td>
<td>Childhood cancer survivors N=12</td>
<td>Individual treatment with metacognitive therapy (45-60 minutes long) over 12 face-face sessions (6 month FU).</td>
<td>Anxiety (HADS) and Impact of event (scale measuring trauma related symptoms) statistically significant improvements across all symptoms indicating intervention was effective. Most participants showed at least reliable improvement with 50% classified as recovered.</td>
</tr>
<tr>
<td>Hollen et al, 1999, USA [28]</td>
<td>Controlled before and after study III</td>
<td>To test the effects of a decision-making and risk reduction program for cancer-surviving adolescents</td>
<td>Childhood cancer survivors N= 64</td>
<td>Intervention group (n=21) attended workshop on decision making skills, risk behaviour and social support + audio/video recordings. One face-face session and individual components (12 months FU). Control group (n=43) were intervention refusers</td>
<td>Decision making, risk motivation, risk behaviours. Intervention produced short term effects at 1 and 6 months for smoking, and a long-term dampening, but marginal effect for alcohol. Results may be subject to bias. Regression model controlling for age, gender and site: Decision making scores improved by 11% in intervention group and decreased by 1.3% in control group: The intervention accounted for 27% of variance in decision making at 12 months. Mean difference in intervention group -0.34 (p=0.001); Mean difference in control group 1.79 (p=0.01).</td>
</tr>
<tr>
<td>Hollen et al, 2013, USA [35]</td>
<td>Randomised controlled trial II</td>
<td>To definitively confirm the results of an earlier pilot study (Hollen 1999 above) with more diverse sample in more diverse setting</td>
<td>Childhood cancer survivors N= 243, Mean age 16.3 years (11.2)</td>
<td>Decision making, risk motivation, substance use behaviours. Some immediate change in substance use motivation. Feasibility established, but adherence difficult to maintain. Overall effects of intervention were modest, but program was rated highly.</td>
<td></td>
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</tbody>
</table>

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**Notes:**
- Fisher et al., 2015, UK [25] observed significant distress and compared intervention with usual care, with 75% retention at follow-up.
- Hollen et al., 1999, USA [28] developed a CD rom for study, with 60% retention at 12 months.
- Hollen et al., 2013, USA [35] added control group and 6 months follow up.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Aim</th>
<th>Methodology</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Santacroce et al, 2010, USA [33]</td>
<td>Randomised controlled trial</td>
<td>To assess the feasibility of coping skills training in terms of recruitment, retention.</td>
<td>Childhood cancer survivors N= 21 (and 20 parents also recruited) Mean age 21 years (11.2) Response rate 88% Retention 19/21 (90%)</td>
<td>Intervention arm (n=9) received coping skills training aimed to help non-ill youth develop strategies for managing stress. Seven telephone sessions (3 months FU) Control arm received usual care (n=11)</td>
<td>Uncertainty, anxiety, Post traumatic Stress, benefits finding and health promotion behaviours</td>
</tr>
<tr>
<td>Seitz et al, 2014, Germany [27]</td>
<td>Before and after study</td>
<td>To develop and test a therapist guided cognitive behavioural intervention using web based therapy</td>
<td>Childhood cancer survivors N= 20, Mean age 27 years (13.8) Response rate 71% Retention 14/20 70%</td>
<td>Internet based psychological intervention- to reprocess traumatic cancer experiences and build coping strategies. 10 internet sessions over 5 weeks. Treatment delivered by written messages on internet platform. (3 months FU)</td>
<td>Post-traumatic stress diagnostic scale, Hospital Anxiety and depression scale (HADS) and fear or progression/r elapse questionnaire</td>
</tr>
</tbody>
</table>

ALL Acute Lymphoblastic Leukaemia
FU Follow up
HADS Hospital Anxiety and Depression Scale
PTSD Post Traumatic Stress Disorder
Table 2. Intervention focus, outcome measures, attributes and Risk of Bias of included studies

<table>
<thead>
<tr>
<th>Attributes of interventions</th>
<th>Health Promotion</th>
<th>Interventions</th>
<th>Psychological interventions</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Blaauwbroek 2007</td>
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<td></td>
<td>Eiser 2000</td>
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<td></td>
<td>Hudson 2002</td>
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<td>Kunin-Baston</td>
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<td>Mays 2011</td>
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<td>Tyc 2003</td>
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<td>Jarvela 2012</td>
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<td>Keats 2013</td>
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<td>Valle 2013</td>
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<td>Belanger 2014</td>
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<td>Emmons</td>
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<td>Fisher 2015</td>
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<td></td>
<td>Hollen 2013</td>
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<td></td>
<td>Santacroce 2010</td>
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<td>Seitz 2014</td>
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</table>

**Mode(s) of delivery**

- Peer Group face-face sessions
- Individual face-face session(s)
- Telephone
- Online/ Internet based
- Printed guidebook mailed to participants

**Components**

- Information, advice (written paper based)
- Information, advice (Internet based)
- Counselling
- Diary or workbooks
- Pedometer
- Training session/ instruction
- Group activities

**Outcome Measures**

- Quality of life
- Fatigue
- Physical activity /fitness
- Anxiety /Depression/Distress
- Feasibility
- Decision making/ risk taking / motivation
- Body image
- Satisfaction
- Health practices
- Knowledge
### Results (statistically significant)

<table>
<thead>
<tr>
<th>Results</th>
<th>✓</th>
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<tbody>
<tr>
<td>Improved fatigue</td>
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<tr>
<td>Improved quality of life</td>
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<td>Improved decision making</td>
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<tr>
<td>Improved physical activity/fitness/weight loss</td>
<td>✓</td>
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<tr>
<td>Decreased smoking</td>
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<td>✓</td>
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<tr>
<td>Decreased anxiety/distress/depression</td>
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<tr>
<td>Improved body image</td>
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<td>Improved diet</td>
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<tr>
<td>Improved knowledge</td>
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</table>

### Risk of Bias

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<tr>
<th>Risk of Bias</th>
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<tbody>
<tr>
<td>Random sequence generation</td>
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<tr>
<td>Allocation concealment</td>
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<td>Blinding of participants</td>
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<tr>
<td>Incomplete data</td>
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<tr>
<td>Selective outcome reporting</td>
<td>L</td>
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</table>

*Other source of bias include: recruitment (selection bias), measures of exposure, measure of outcome, confounding factors and high lost to follow up.
L=Low, U=Unclear, H=High, N/A= Not applicable as not RCT
Conflict of interest statement

None declared
Highlights

• Survival rate for adolescents and young adults with cancer are high

• The effects of cancer treatment has life-long consequences on health and well being

• Interventions that optimize health and well-being are required for survivors to reach their full life potential