

Cross, A., Howlett, N., & Sheffield, D. (2020). Social ecological interventions to increase physical activity in children and young people living with and beyond cancer: a systematic review. *Psychology & Health*, 1-20.

### **Abstract**

**Objective:** To identify the behaviour change techniques and intervention components associated with the promotion of physical activity (PA) for children and young people living with and beyond cancer.

**Design and main outcome measures:** A systematic review and narrative synthesis was conducted on the evidence on PA interventions for children and young people (up to 30 years of age) living with and beyond cancer using a social ecological framework.

**Results:** Out of 12 studies, 8 were shown to change PA. Intervention components included: 1) behavioural (Instruction on how to perform the behaviour, credible source, behavioural demonstration and rehearsal), 2) cognitive-emotional (targeting attitude, perceived behavioural control, intentions, resilience and achievement) 3) socio-cultural (family and peer support for PA), 4) environmental (providing access to resources, environmental restructuring, safety), 5) demographic (child, adolescent, young adult or mixed) and 6) medical (tailored exercise depending on age and cancer stage).

**Conclusions:** Interventions designed to increase physical activity participation and adherence during and beyond cancer treatment for young people should integrate psychosocial (behavioural, cognitive-emotional, social), environmental and medical intervention components. Our conceptual model can be used to inform the development of interventions and guides future research objectives and priorities.

*Keywords: cancer, interventions, physical activity, children, young people.*

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Physical activity (PA) during and beyond cancer treatment has been shown in systematic reviews and meta-analyses to have an established range of benefits in terms of biopsychosocial outcomes including physical functioning, role function, social functioning, overall quality of life (Mishra, Scherer, Snyder, Geigle, Gotay, 2014) and cancer-related fatigue (Cramp & Byron-Daniel, 2011). There is growing evidence that young people with cancer who are physically active during treatment benefit from positive psychological effects (Cox, Montgomery, Oeffinger, Leisenring, Zeltzer, et al., 2009; Rosipal, Mingle, Smith & Morris, 2013). A Cochrane systematic review into children and teenagers under 18 years of age concluded that exercise during cancer treatment can improve fitness, flexibility and body composition (Braam, van der Torre, Takken, Veening, Dulmen-den Broeder, et al, 2016). Providing effective, tailored psychosocial support for children and young people during and beyond cancer treatment to increase and sustain PA is a priority to improve physical, psychological, and social health outcomes across the lifespan (Baumann, Bloch & Beulertz, 2013; Sabiston & Brunet, 2012). However, young people report low levels of PA at the time of the cancer diagnosis and for months, years, or decades beyond treatment (Winter, Müller, Brandes, Brinkmann, Hoffmann et al., 2009), which highlights the importance of initiating effective psychosocial interventions for children and young people living with and beyond cancer. Furthermore, these effects may transfer into adulthood as between 20% and 52% of adult survivors of childhood cancer are inactive (Butterfield, Park, Puleo, Mertens, Gritz, Li et al., 2004; Demark-Wahnefried, Werner, Clipp, Guill, Bonner, Jones & Rosoff, 2005; Pinto & Trunzo, 2005). A review confirmed that childhood or adolescent cancer survivors were less likely to be active in adulthood compared with age matched non-cancer controls (Stolley, Restrepo & Sharp, 2010).

As young people's levels of PA are multidimensional behaviour and influenced by a number of factors, such as gender, parental influences, time spent outdoors, intentions to be

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active, perceived barriers and ability (Hinkley, Crawford, Salmon, Okely & Hesketh, 2008; Sallis, Prochaska, & Taylor, 2000; Taylor & Sallis, 1997), interventionists should consider targeting each to elicit behaviour change. Social ecological approaches to intervention design provide one solution in terms of a framework that accounts for the social, environmental, medical and environmental influences on behaviour change, in addition to psychological factors. The social ecological framework (based on ecological systems theory, Bronfenbrenner, 1979; Kazak, 1989) has been used previously in a systematic review of the predictors of PA for child and adolescent survivors of cancer (Gilliam & Schwebel, 2013), although not the intervention features. The review was used to devise a social ecological framework model that integrates the roles of intrapersonal factors (e.g., vulnerability), interpersonal factors (e.g., peer relations) and socio-cultural factors (e.g., minority status). Demographic and medical components interact with social and environmental systems to produce cognitions, emotions and behaviours which allow for greater accuracy in our ability to explain and promote the development and maintenance of PA in young cancer survivors.

We propose to extend this work by mapping the intervention components and behaviour change techniques from interventions designed to increase physical activity in young people and children living with and beyond cancer. Little is known about the behaviour change techniques that might promote long term behaviour change; interventions utilising BCTs are frequently complex, consisting of numerous interacting components that are often poorly described (Michie & Johnston, 2012). This makes synthesising the evidence for effectiveness to inform future interventions challenging. In order to advance behavioural medicine by promoting precise and consistent reporting of complex interventions, the Behaviour Change Technique Taxonomy (version 1) was created (Michie, Richardson, Johnston, Abraham, Francis, Hardeman et al., 2013). Based on expert consensus, this hierarchical classification system has been used in numerous systematic reviews to reliably

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identify behaviour change techniques associated with the most successful interventions (Dombrowski, Knittle, Avenell, Araújo-Soares, & Sniehotta, 2014; French, Olander, Chisholm & McSharry, 2014; Samdal, Eide, Barth, Williams, & Meland, 2017). Coding the behaviour change techniques within interventions may help us to identify which techniques are commonly utilised in interventions designed to improve physical activity for children and young people living with and beyond cancer.

Whilst previous reviews have looked at predictors of PA purely from a behaviour change point of view (Pugh et al., 2016) in young cancer survivors, supporting young people living with and beyond cancer with PA is complicated further with the influences of diagnosis and treatment-related factors, plus cognitive and behavioural reactions by parents, children and their peers to those influences. To date, there are no existing reviews using the social-ecological approach which examine the PA interventions approaches applied in both young people and children at the time of cancer treatment and beyond. Additionally, many of the existing interventions are underpowered due to challenges in recruiting young cancer populations and focus on the outcomes of interventions, rather than the component features which may affect outcomes or delivery in practice. Therefore, the aim of this systematic review is to summarize the psychosocial ecological components of PA interventions for both children and young people living with and beyond cancer. Additionally, we sought to review the commonly used BCTs in interventions.

### **Methods**

#### **Protocol**

The protocol was pre-registered with PROSPERO reference CRD42017064591.

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### **Eligibility Criteria**

We included studies describing a PA intervention for children and young people (up to the age of 30 years) who were undergoing or who had completed treatment for cancer (any form or stage) in order to capture all available interventions in this under-researched population. We excluded studies with participant samples above the age of 30 years in order to capture the range in international definitions of child and young adult oncology populations. Given the emerging evidence base in this under-researched and difficult to recruit population, we included studies describing randomised controlled trials (with or without nested qualitative studies), as well as pilot and feasibility RCTs, observational studies, cohort studies, case control studies, and quasi-experimental studies and excluded qualitative methods studies.

**Interventions.** Studies were only included when they reported outcome measures of objective or self-reported physical activity using standardised subjective or objective tools between baseline, and post-intervention. Studies were included when they reported at least one Behaviour Change Technique (BCT) from the BCT taxonomy v1 (Michie, Richardson, Johnston, Abraham, Francis et al., 2013) but did not have to specify a theoretical basis. We sought to find studies describing interventions delivered in a variety of settings (e.g. community centres, hospital, clinic, private residence) or modes of delivery (e.g., face-to-face, by text message, by phone call).

### **Information Sources**

For our full search strategy, including search terms and databases, see online supplementary materials. This review included comprehensive searches on the following electronic databases: Scopus PsycINFO, CINAHL and Web of Science Core Collection, the Cochrane Central Register of Controlled Trials (CENTRAL), Google Scholar, PubMed and

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SPORTDiscus (from inception up to August 2018). In addition to the electronic database searches, relevant conference proceedings from 1995 to September 2018 were searched by hand in order to identify unpublished studies. Key authors in the field were contacted via email to advise of any unpublished interventions. We also searched the reference lists of relevant articles and books; the Database of Abstracts of Reviews of Effects (DARE); the Cochrane systematic review database; the National Institute of Health Research (NIHR) portfolio for recently completed or ongoing studies; the current controlled trials register; and the System for Information on Grey Literature (SIGLE). A hand search of the bibliographies of all included studies was completed along with a search of key related journals from our scoping search including *Psycho-oncology*, *Journal of Cancer Care*, *British Journal of Health Psychology*, *Journal of Health Psychology* and *Psychology and Health*. Papers were eligible for inclusion in the review when they were available in English as full text, reporting primary quantitative data, and were either published in peer-reviewed sources between 1995 and 2018, or, for registered trials only, are unpublished but had been completed, and the results were obtainable from the authors. Where results from the same trial were reported across multiple sources (e.g. Keats, & Culos-Reed, 2008; Keats, & Culos-Reed, 2009) the information from these sources was pooled and treated as one single intervention for the purpose of analysis.

### **Search terms**

Our search strategy utilised PICO conceptual search terms and well as population MeSH terms including population (e.g. solid tumor, blood or bone cancers ), intervention (e.g. community or hospital based), comparator (e.g., clinical trial, observational cohort study), and outcome themes (e.g., exercise, physical activity) (see online supplementary materials for our full search strategy).

### **Study Selection**

One reviewer (AC) screened all retrieved records identified through initial searches against eligibility criteria in two stages. Initial screening was based on titles, abstracts and keywords and the second reviewer (DS) screened a random 20% of the total titles and abstracts. The findings were discussed to reach a consensus on the studies to take forward to the next stage of the review. Following initial screening, full-text versions of all potentially relevant studies were retrieved and reviewed independently and screened against all inclusion and exclusion criteria by two reviewers (AC and DS).

### **Data Collection Process and Data items**

Data extraction occurred in two stages; 1. general study data was extracted using a data extraction form based on the TIDIER framework for intervention reporting (Hoffmann, Glasziou, Boutron, Milne, Perera et al., 2014), 2. extracting intervention data from each of the social-ecological model domains (see online supplementary materials). Where necessary, we attempted to contact the authors by email on key missing data elements.

### **Risk of Bias in Individual studies**

Risk of bias was assessed by two reviewers (AC, NH) using the Cochrane risk of bias assessment tool (Higgins, Altman, Gøtzsche, Jüni, Moher et al., 2011) for RCTs and the I-Robins tool (Sterne, Hernán, Reeves, Savović, Berkman, et al., 2016) for non-randomised studies. Each study was rated for bias as either: 'low risk for bias', 'unclear risk for bias' and 'high risk for bias' (see online supplementary materials). The quality of evidence for primary outcomes from each of the review studies was assessed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) (Puhan, Schünemann, Murad, Li, Brignardello-Petersen et al., 2014) quality domains for 'blinding

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and allocation', 'follow up and withdrawals', 'sparse data' and 'other methodological concerns' (e.g. incomplete reporting).

Quality of intervention reporting was assessed using the Template for Intervention Description and Replication (TIDieR) checklist and guide (Hoffman et al., 2014). TIDieR is intended as a tool for study authors and systematic reviewers to describe interventions accurately and consistently, with enough detail to allow replication. Two reviewers (AC, NH) coded each intervention description against the checklist as being adequately reported, inadequately reported, not reported, or not applicable to the intervention. A value of 1 was scored where the item was adequately described or not applicable, and a value of 0 where it was inadequately described or not reported (excluding Modifications and Tailoring items as 'not reported' does not indicate a negative value; interventions that were not tailored or modified received a score of 1).

### **Behaviour Change Technique Coding**

Two authors (AC, NH) independently coded BCTs for all included studies who had both completed an online training course in using the BCT taxonomy V1 (<http://www.bct-taxonomy.com/>) and discrepancies were resolved through discussion. Coding BCTs was completed using the BCT taxonomy V1 (Michie et al., 2013) based on information presented in the included papers, as well as any published protocol papers.

## **Results**

A total of 1,835 potential articles were initially identified from the searches following the removal of duplicates (see figure 1 PRISMA flow chart in supplementary materials). After screening the abstracts, 86 full text articles were retrieved and assessed for eligibility against the inclusion criteria. Twelve papers (following the exclusion of one paper as it



reported interim analyses of an intervention included in another review paper) of describing 12 studies met the inclusion criteria and were included in the review

### **Risk of Bias in Individual studies**

This review has been reported in line with AMSTAR (A Measurement Tool to Assess Systematic Reviews) (Shea, Grimshaw, Wells, Boers, Andersson et al., 2007) criteria to reduce the potential for bias in the review and allow other researchers to evaluate the quality of reporting in this review.

**Risk of Bias:** Three studies (Fiuza-Luces et al., 2016; Moyeur-Miller et al., 2009; Tanir et al., 2012) were assessed using the Cochrane Risk of Bias and 9 (Beulertz et al., 2016; Jarvela, et al., 2011; Keats & Culos-Reed, 2009; Muller et al., 2016; San Juan et al., 2007; Sharkey et al., 1993; Takken et al., 2009; Vallet et al., 2015; Yeh et al., 2011) were assessed using I-Robins by two independent raters (high agreement, Cohen's  $k = 0.72$ ;  $p > 0.001$ ), with discrepancies in scoring resolved through discussion (see online supplementary tables). Cochrane Risk of Bias assessment revealed that overall the studies were low risk of bias for selection, performance, detection and attrition and moderate bias for selective reporting. For I-Robins, overall the studies were assessed as 'low risk' for bias of deviation from intended intervention, missing data and measurement of outcomes. There was an overall moderate risk of bias from selection of reported results.

**GRADE:** Two raters independently assessed each paper against these quality domains using a scoring system in which one point denoted a methodological concern against that particular quality domain. Interrater reliability was high (Cohen's  $k = 0.83$ ;  $p > 0.001$ ) and the discrepancies in scoring were resolved through discussion. The overall quality for the corpus of studies was judged as low to moderate quality and we did not exclude any of the review studies on the basis of GRADE guidelines.

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**TIDIER:** In terms of quality of intervention reporting, only 2 (Beulertz et al., 2016; Fiuza-Lucez et al., 2016) of the 12 studies provided sufficient information on all of the domains (see online supplementary materials). A brief description (item 1 reported in  $k = 12$ ), rationale (item 2,  $k = 10$ ), mode of delivery (item 6,  $k = 11$ ), how much and when (item 8,  $k = 11$ ) and procedure (item 4,  $k = 9$ ) were the most well reported. Descriptions of what was delivered in terms of intervention materials (item 4,  $k = 4$ ) and how well the intervention was delivered as planned (item 11,  $k = 3$ ) were the items with the most inadequate reporting. Average inter-rater reliability for the TIDieR items was good (Cohens  $k = 0.73$ ;  $p > 0.001$ ).

### **Synthesis of Results**

The original objectives of our review were to assess the efficacy of current interventions at improving PA for children and young people living with and beyond cancer and subsequently identify whether differences in efficacy exist depending on behaviour change techniques (BCTs) used within the interventions. With large heterogeneity, underpowered studies and only three RCTs, it is not yet appropriate to combine all of the available effect sizes in an overall calculation of effectiveness. As our planned analysis was not possible, we decided that a narrative synthesis approach would be more appropriate, along with recommendations for future research to ensure that more rigorous quantitative synthesis is possible in years to come when a larger number of homogenous trials have been conducted.

### **Conceptual Model of Intervention Components**

We present a narrative synthesis of the intervention study features which discusses constructs that emerged from the Gilliam and Schwebel (2013) review as unique predictors of PA, along with examples of causal mechanisms that might explain how the constructs predict PA. Our proposed intervention development model (figure 2) uses a social ecological framework to explain child and adolescent survivors' PA from a multi-component view that

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includes intrapersonal, interpersonal and environmental factors. The solid lines reflect empirically-documented pathways and broken lines reflect hypothesised interactions that were found in the Gilliam and Schwebel (2013) review. Our review extends the findings of this review by additionally coding the behaviour change techniques and widening the evidence base to account for both young adults and children, both during and beyond cancer treatment.

Insert figure 2 about here

### **Intervention features: narrative synthesis**

Eight studies reported an overall increase or maintenance in PA following participation in the interventions and nine showed sustained improvements in PA at follow up (range 1-12 months). Our narrative synthesis will explore the intervention features across the domains of the socio-ecological framework: demographic aspects, medical cancer-related factors, behaviour change techniques, cognitive-emotional, environmental, social and cultural intervention features.

### **Demographic Aspects of Interventions**

Participants ranged from 4-19 years ( $k = 10$  studies with study samples aged 18 years and under,  $k = 1$  adolescent young adults and  $k = 1$  both). Given the paucity of intervention work in the area most of the studies were feasibility, exploratory studies with sample sizes ranging from 4 (28) to 150 (29) participants (see online supplementary materials). Interventions were based in France ( $k = 1$ ), Turkey, ( $k = 1$ ), Spain ( $k = 2$ ) Finland ( $k = 1$ ), Canada ( $k = 1$ ), USA ( $k = 2$ ), Netherlands ( $k = 1$ ), Taiwan ( $k = 1$ ) and Germany ( $k = 1$ ). Time since diagnosis ranged in the studies between six months and a year for studies delivering interventions as part of cancer treatment, and between one year and 10 years for interventions for children and

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young people living beyond cancer. Where reported, the study means of survivorship length ranged between 17 months and 10 years. Whilst demographics are not modifiable in a behaviour change sense, it is important to note that modifications that are required to physical activity interventions according to the demographic profile of participants. Several studies tailored the intervention according to the age of the participants.

### **Medical Factors**

A total of 12 studies were included in the review, eight of which evaluated interventions to increase physical activity as part of cancer treatment (Fiuza-Luces et al., 2016; Moyeur-Miller, et al., 2009; Muller, et al., 2016; San Juan, et al., 2007; Takken et al., 2009; Vallet et al., 2015; Yeh et al., 2011) and four were interventions following cancer treatment (Jarvela, Sharkey et al., 1993; Keats & Culos-Reed, 2009, Tanir et al., 2012)

Study populations mainly included individuals who were undergoing or had completed treatment for Acute Lymphoblastic Leukaemia (ALL), lymphoma or sarcoma. Treatment types included chemo, radio, adjuvant or surgical therapies. Where stage of treatment was reported, interventions included participants from all stages of cancer.

However, in one study (Keats & Culos-Reed, 2009) a participant underwent treatment during the 16 weeks of the intervention before moving to maintenance therapy, highlighting the need for intervention design to be sufficiently flexible to meet the needs of both those living with and beyond cancer, particularly given the rates of recurrence in the younger cancer populations.

### **Behaviour Change Techniques**

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The number of BCTs utilised in interventions ranged from three (Sharkey, Carey, Heise, Barber, et al., 1993) to 12 (Keats & Culos-Reed, 2009) with a mean average of 6.4 BCTs per study. The number of BCTs was positively associated with study quality and bias scores (Cochrane, I-Robins). The most prevalent BCTs were *instruction on how to perform the behaviour* ( $k = 12$ ), followed by *demonstration of the behaviour* ( $k = 9$ ), *behavioural practice/rehearsal* ( $k = 9$ ), and *credible source* ( $k = 9$ ); almost all of the interventions included structured exercise classes run or recommended by an exercise professional. Among the BCTs utilised in the 12 studies, the least common were *feedback on behaviour* ( $k = 1$ ), *social support* (unspecified;  $k = 1$ ), *information about emotional consequences* ( $k = 1$ ), *habit formation* ( $k = 1$ ), and *verbal persuasion about capability* ( $k = 1$ ).

For interventions delivered alongside cancer treatment, the most common BCTs in home-based interventions were *instruction on how to perform the behaviour* and *self-monitoring of behaviour* (Järvelä et al., 2012; Yeh et al., 2011). In a home-based strength intervention, the *instruction on how to perform the behaviour* BCT consisted of an exercise intervention to be conducted three times a week for 16 weeks, alongside the provision of information on safety, as well as encouragement to perform exercises of their own choice (Järvelä et al., 2012). In other home-based interventions, instruction was provided by text and photos and delivered through instructional videos (Yeh et al., 2011). Vallet et al. (2012) provided instruction on activities outside of the hospital with the assistance of professionals trained in adapted PA for young adapted skiing, snowshoeing and dog sledding. The variety in activities was chosen to create a fun environment away from the hospital setting, which included a diverse range of activities such as dance, cruising sail boarding, trekking and snow activities.

In hospital-based settings, information was given to families on benefits of following a healthy lifestyle comprising of sports, play and walking (>60 min per day), which was

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delivered through a perceived credible source such as a health care professional involved in the medical care (Beulertz et al., 2016; Fiuza-Luces et al., 2017; Müller et al., 2016; San Juan et al., 2007; Sharkey et al., 1993). Self-monitoring was used in several studies through activity monitors such as an accelerometer (Muller et al., 2016; San Juan et al., 2007) or a self-report activity log (Yeh et al., 2011). The BCT *Credible Source* was utilised in 9 studies; the exercise professionals delivering the interventions or advising participants included fitness instructors, exercise psychologists, physiotherapists, and sport therapists.

### **Cognitive-Emotional Intervention Features**

Only one intervention was based on a social cognitive psychological theory; Keats & Culos-Reed's (2009) intervention was informed by the Theory of Planned Behaviour (Ajzen, 1991) and based on findings from the authors' earlier examination of theory in paediatric cancer survivors (Keats, Culos-Reed, Courneya & McBride, 2007). The theory was embedded within psychoeducation sessions targeting the core cognition variables of attitude, perceived behavioural control, subjective norms and intentions. Delivery methods to influence behaviour change included information provision, teaching and rehearsal of skills, modelling, planning and social support. The intervention provided information emphasising the short-term (e.g. anticipated increases in affective attitude towards physical activity i.e. increasing enjoyment and valuing PA) and long-term benefits of regular physical activity (e.g. changes in instrumental attitude towards physical activity). Järvelä, Kemppainen, Niinikoski, Hannukainen and Lähteenmäki et al. (2012) provided motivational phone support on barriers to performing physical activity, health concerns and identifying enablers for increasing their PA, although this was not theory based. The intervention also focused on providing guidance and advice on how to structure more PA into the day through action planning and problem solving.

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**Cognitive-Emotional Outcomes.** Studies often reported cognitive-emotional outcome measures ( $k = 9$ ), such as intention to perform the behaviour, self-efficacy, fatigue and quality of life. Kulos-Reed (2009) reported that baseline measures of behavioural intention ( $r = 0.46$ ), controllability ( $r = 0.75$ ) and self-efficacy ( $r = 0.69$ ) moderately or strongly predicted PA behaviour change at the three month follow up. In addition, 14 measures of affective (e.g. enjoyable-unenjoyable, harmful-beneficial, boring-interesting) and instrumental (e.g. useful-useless, harmful-beneficial) attitude, subjective norms (important others' views on PA) were taken; perceived behavioural control captured the participant's confidence to carry out the exercise (self-efficacy), as well as their belief that they have control over the behaviour (controllability). Although Yeh, Wai, Lin and Chiang (2011) did not report a theory-based intervention, the transtheoretical model was used to assess motivational readiness to change (Prochaska & Velicier, 2007); at one month after the intervention 25% of the sample ( $n = 3$ ) were at the 'action stage', and 17% ( $n = 2$ ) were at the maintenance stage having sustained their PA for >6 months. By the six-month follow up, four (34% of the sample) participants were in the contemplation stage and were not participating in PA at the follow up period. Seven were in the 'preparation' stage (58%) and reporting irregular, infrequent levels of PA with one participant reporting regular levels of PA. In terms of barriers and facilitators to participation in the interventions, participants in T Takken, van der Torre, Zwerink, Hulzebos, Bierings et al. (2009) study cited barriers as boredom and a lack of variation in the exercises which reduced their motivation to finish the intervention or being unable to access the necessary equipment at a local physiotherapy centre (e.g. cycle ergometer, bench) was given as a reason for dropping out of the intervention. To overcome this, more variation in the form of games were added to the intervention

**Fatigue.** Three studies reported a significant reduction in fatigue at follow up (Takken et al., 2009; Yeh et al., 2011; Vallet, André, Gentet, Verschuur, Michel, Sotteau et al., 2015)

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with one study also reporting significant increases in global self-esteem, perceived sport competence and perceived physical strength (Fiuza-Luces, Padilla, Valentín, Santana-Sosa E, Santos-Lozano et al., 2017).

**Quality of Life (QoL).** Müller, Krauth,, Gerß & Rosenbaum, (2016) reported immediate changes in health-related QoL which were sustainable for one year. Two studies reported no significant differences in QoL, although a lack of statistical power may explain such findings (Fiuza-Luces et al., 2017; Tanir & Kuguoglu, 2013).

In terms of other important psychological outcomes, increasing negative affect for physical well-being was found to be significant at 12 months in one study (Muller et al., 2016). Additionally, no significant effects were found for resilience, achievement, satisfaction, comfort and risk avoidance (San Juan, Fleck, Chamorro-Viña, Maté-Muñoz, Mora et al., 2007), nor were there significant effects for cognitive problems between groups. Treatment anxiety was significantly higher in boys, although there were no sex difference at follow. Beulertz, Prokop, Rustler, Bloch, Felsch et al. (2016) found significant differences at baseline in physical and emotional well-being between the intervention and control groups and these effects were observable at the follow up. Vallet et al. (2015) found significant differences in global self-esteem, perceived sport competence and perceived physical strength and additionally measured physical self-worth, perceived physical condition, and own perceived physical attractiveness. Tanir and Kuguoglu (2013) found that control group participants were more likely to score higher on general worry and worry about the diagnosis and methods of treatment compared with the intervention group.

### **Environmental Intervention Features**

The environmental setting for the exercise interventions included hospital-based gyms ( $k = 5$ ), home based ( $k = 4$ ), a university ( $k = 1$ ), physiotherapists ( $k = 1$ ), and a



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combination of hospital, home, and a trip ( $k = 1$ ). Other environmental intervention components included providing resources and space for exercise to be conducted safely.

### **Social and Cultural Intervention Features**

Despite social support being known as a strong determinant of promoting PA, most of the interventions were delivered at the individual level, although one intervention (Vallet et al., 2015) encouraged peer support with other young people living beyond cancer treatment on the intervention through a 15 day trekking and sledding excursion to Canada as a target for the training intervention. One parent from each of the child participants from the Tanir et al. (2013) study was recruited to the intervention as a participant in recognition that they could serve as a ‘motivating force’ and with the intent of fostering long term behaviour change. Parents were advised that their child would have initial difficulties performing the activities but that they would see benefit with regular performance; they were also provided with the researcher’s contact details for queries/problem-solving. San Juan et al. (2007) mobilised social support through initiating group games used to maintain and improve adherence to the training intervention and through making each session different. Sharkey et al. (1993) assessed family-level PA participation at baseline, as well as individual-level PA to assess their competence and motivation to take on home exercise intervention, PA education intervention or sports. Despite the diversity in countries for the intervention settings, none of the studies described cultural issues or activities as part of their interventions.

### **Discussion**

This paper provides a narrative synthesis of the available evidence on the social ecological aspects of interventions designed to support children and young people living with and beyond cancer to be more active, which can be used as a conceptual model for the development of future interventions. Our systematic review of the available evidence showed

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that eight studies reported an overall increase or maintenance in PA following participation in the interventions and nine showed sustained improvements in PA at follow up (range 1-12 months). Study quality overall was low-moderate; with most studies designs being exploratory studies of pilot or feasibility interventions. This is reflective of the current stage of the evidence base, since most of the studies sought to explore the acceptability and feasibility of exercise interventions and no well-powered definitive trials assessing the outcomes and effectiveness of trials are yet in existence.

In recognition that improving PA in this population is a result of the interplay of a wide range of factors, we reviewed the intervention features using the social ecological model as this has been used to determine the predictors of PA in children and young people living beyond cancer (Takken et al., 2016). We present a narrative synthesis of the intervention study features which discusses constructs that emerged from the Gilliam and Schwebel (2013) review as unique predictors of PA, as well as BCT coding. This approach is consistent with ecological systems theory (Bronfenbrenner, 1979; Kazack, 1989) and emphasises the role of multiple biopsychosocial interactive influences on children and adolescents' PA.

In terms of behavioural intervention components, we found that interventions commonly utilised BCTs related to the delivery of PA interventions, which were instruction on how to perform PA/exercise, demonstration of the behaviour, behavioural practice/rehearsal and credible source (usually in the form of an exercise professional). Few studies utilised BCTs on social support, despite this being one of the key predictors of PA in this population. Where social support was part of the intervention, this took the form of parental participation and encouragement and peer support from other young people living with and beyond cancer who were enrolled on the interventions. Environmental factors play a key role in determining the adoption and maintenance of PA behaviour change. Interventions named the environmental setting but did not explicitly discuss how the intervention

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environment was used to improve PA. Further intervention work should consider the influence of environmental factors on short- and long-term behaviour change (i.e. how can the individuals' environment be optimised to increase PA e.g. identifying suitable walking routes, creating space for PA). Whilst cognitive factors (in the form of intentions, self-efficacy, fatigue and QoL) were measured in the majority of interventions, only one intervention assisted individuals in considering the role of their beliefs, perceived behavioural control and intentions to start and maintain PA as part of their on-going care. None of the interventions delivered emotional or affect components despite the high need for psychological support as part of cancer care (Aldiss, Fern, Phillips, Callaghan, Dyker et al., 2019, TYAC, 2015). Developing high quality interventions that support psychological health in terms of self-esteem, confidence and reducing negative affect are key priorities for future intervention development work.

### **Providing tailored, personalised PA plans to create and sustain long term behaviour change**

Our review highlights three main implications for developing PA interventions for children and young people living with and beyond cancer.

#### **Insert figure 3 about here**

Firstly, there is a need to develop theory-based interventions that address each of the domains of the social ecological model. The benefits of theory to develop and test behaviour change interventions (Prestwich, Kenworthy & Conner, 2017) are:

- Theory allows us to identify the key constructs (determinants) to target within an intervention; if there is evidence that constructs (self-efficacy, attitudes etc) are associated with health behaviour change, then changing these constructs should result in behaviour change.

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- Theory can help select appropriate intervention techniques by guiding which BCTs should be used to improve intervention effectiveness
- Theory can be used to refine or tailor intervention techniques and theories e.g. attitudes and perceived behavioural control (PBC) are purported to be determinants of physical activity in this target group (Gilliam & Schwebel, 2013). In this way, theory can be used to tailor interventions. For example, an individual who has a positive attitude towards physical activity scores low on PBC will have different intervention needs to an individual who has a high level of PBC but negative attitude towards physical activity.

Designing and implementing interventions with a theoretical basis means we can continually test the theory and identify the contexts and populations for which it is most effective. Through these processes, we can refine the theory and seek to build a case for the generalisability of the theory. Whilst the evidence that using theory improves the efficacy of health behaviour change interventions is mixed (Prestwich, Sniehotta, Wittington, Drombrowski et al., 2014; Prestwich, Webb & Conner, 2015), by seeking to understand the mechanisms of action of BCTs and designing clear logic models, we can build an incremental science for understanding why an intervention may work.

Our review found that overall the interventions address the medical, demographic and behavioural domains, but need to do more to address the environmental, social and cognitive-emotional domains that influence health behaviour change. To date, much of the intervention work in the area has not considered a psychosocial theoretical basis, with one exception (Keats & Culos-Reed, 2009). It is noteworthy that some interventions that were not theory based instead measured outcomes using social cognition theoretical models, such as the Social Cognitive Theory (SCT), the Transtheoretical Model (TTM) and the Health Belief Model (HBM). It is important to match interventions and outcome measures according to the

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theory and thus measures closely to the target behaviour as possible (Johnston, Dixon, Hart, Glidewell, Schröder et al., 2014). In our review, it was not possible to conduct analysis by behaviour change techniques in relation to a given outcome (e.g. aerobic exercise tolerance) and well-powered intervention trials will allow this in the future. It is noteworthy that the interventions frequently consisted of instruction on how to exercise from a credible source, demonstration, and providing opportunities for rehearsal, with little consideration of the underlying psychological aspects of changing behaviour. Whilst the use of theory is variable amongst PA behaviour change interventions (Howlett, Trivedi, Troop & Chater, 2018; Prestwich, Sniehotta, Whittington, Dombrowski, Rogers, & Michie, 2014), the lack of interventions based on a theoretical model in this review is a concern and remains a priority for future intervention development. Our review and model recommends the development of theory based psychosocial interventions and embedding evidence-based health psychology techniques and therapies into interventions. The model recommends including these alongside a wider range of determinants of PA by including behavioural, cultural, environmental and medical domains.

Many exercise oncology studies have found that post intervention improvements in PA are not sustained beyond the length of the intervention and available support, and interventions often lack psychosocial aspects of behaviour change (Bourke, Homer, Thaha, Steed, Rosario et al., 2014). Teaching psychological strategies for goal setting and overcoming challenges may help to sustain motivation and health behaviour change beyond the effects of the intervention. Mental contrasting has recently been found to be effective for health behaviour change and sustained for as long as two years in a recent meta-analysis (Cross & Sheffield, 2019) with similar effects found for implementation intentions (Gollwitzer & Sheeran, 2006) and self-affirmation (Epton, Harris, Kane, van Koningsbruggen & Sheeran, 2015).

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Secondly, interventions should recognise that physical activity is not necessarily the single and most vital factor determining treatment success, but rather it is emphasised as a way to improve quality of life and wellbeing. On a practical level, interventions should be delivered within the context of a patient's life, in recognition of the often-debilitating effects of chemotherapy, surgery, and radiotherapy that might otherwise prevent patients from participating in exercise, a home and work life that might already be hard pressed to find time for exercise, and the need for an appropriate support network to encourage exercise as a feasible and sustainable treatment option.

Clearer theoretical descriptions and intervention reporting using the TIDIER checklist will help strengthen the evidence base, by allowing easier replication of effective approaches and clearer explanations for secondary analyses (Hoffman et al., 2014; Howlett et al., 2018). Developments in agreeing standard measurements for fatigue and QoL, as well as reliable measurements for assessing PA levels (specificity, etc.) are also needed to draw accurate comparisons across interventions. With the optimal frequency, dose and type of exercise for children and young people living with and beyond cancer under debate, tailoring of intervention is important in terms of both physical and psychological strategies. In our TIDIER analysis, we found that two interventions tailored the PA prescription to the participant but did not provide specific details about the nature of the tailoring; this has important clinical implications as there are large within-person variations for PA (due to low motivation due to fatigue, treatments, negative affect or side effects). We recommend that future studies publish details of the need, rationale and approach used for tailoring in order to develop an incremental science evidence base in this area. To avoid selective reporting bias, studies should pre-register their protocols and outcome measures and publish full results and anonymised datasets.

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Thirdly, adoption of the BCT taxonomy is recommended for future reporting to guide our understanding of which BCTs are important for supporting this population with behaviour change but this should be used in conjunction with addressing the other domains of the model, particularly the cognitive-emotional. Whilst cognitive and emotional factors have received substantial attention as predictors of PA in the childhood cancer literature (Cox, Montgomery, Oeffinger, Leisenring, Zeltzer, et al., 2011; Finnegan, Wilkie, Wilbur, Campbell et al., 2007), only one intervention was based on a psychological theory that addressed some of these factors. Additionally, the publication of intervention manuals and protocols, multidisciplinary collaboration and reflective reports of lessons learned during intervention development, testing and implementation are also recommended to ensure progression in this area.

### **Limitations of the review**

It is recognised that most of the intervention studies were exploratory or feasibility/pilot studies, with small samples and low statistical power and this limits our ability to draw conclusions from the study outcomes. These issues highlight the difficulties in researching young cancer populations, which include difficulties in obtaining consent (Dixon-Woods et al., 2006) and challenges in retaining participants recruited to studies due to changes in health status or functional ability (Fiuza-Luces et al., 2016; Muller et al., 2015). Few interventions were adequately reported, thus limiting our ability to determine the influence of intervention components. Some of the interventions highlighted a bias in selective reporting and thus, pre-registration of study outcomes and intervention design are recommended. It is also acknowledged that although coding of BCTs was based on study reports, it is possible that some BCTs may have been implemented but not reported. Similar to the present review, Howlett et al., (2018) reported a number of studies that were judged as having high risk of bias or were judged as being unclear due to the lack of clear reporting. To

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ensure transparency, replication and robust evaluation, we recommend that future studies use the TIDieR template (Template for Intervention Description and Replication) framework (Hoffman et al., 2014) for accurate reporting of the intervention content. Using the social ecological model in conjunction with TIDIER will help contribute towards the pressing need for transparency in all stages of intervention design, delivery, evaluation and implementation to ensure progression in this area.

Most of the interventions described in the review are pilot and feasibility studies, which is a reflection of many of the challenges in researching young cancer populations, including difficulties in obtaining consent (Dixon-Woods et al., 2006) and barriers in retaining participants recruited to studies due to changes in health status or functional ability (Fiuza-Luces et al., 2016; Muller et al., 2015). In addition, it is acknowledged that designing interventions that target all areas of the socio-ecological model demands intense resources and time. There are further challenges in terms of the implementation of these interventions as definitive RCTs and established evidence of clinical and cost effectiveness do not exist. Furthermore, it is difficult to determine and measure the important clinical differences in terms of biopsychosocial outcomes as a result of PA in this population.

To the review authors' knowledge, this is still the most comprehensive systematic review of psychosocial-ecological aspects of interventions to support PA for children and young people living with and beyond cancer. The psychosocial-ecological approach undertaken in this review goes beyond traditional psychosocial aspects by including environment, medical, demographic factors and the work extends other reviews by coding and classifying BCTs. Recent systematic reviews provide evidence for other BCTs that have not yet been considered with child and young adult living with and beyond cancer populations. A recent systematic review of exercise behaviour interventions in sedentary cancer adult cohorts (Turner, Steed, Quirk, Greasley, Saxton, Taylor et al., 2018) found that a



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number of behaviour change techniques (BCTs) were identified in studies which achieved 75% adherence to the aerobic or resistance guidelines (i.e. at least 150 minutes per week of aerobic exercise ,two resistance strengthening sessions per week) for adults with cancer.

Similar to this review, the most commonly reported BCTs were '*goal setting*,' '*instruction on how to perform the behaviour*' and '*setting graded tasks*'. Finne, Glausch, Exner, Sauzet, Stölzel and Seidel (2018) found that the BCTs '*prompts*', '*reduce prompts*', '*graded tasks*', '*non-specific reward*', and '*social reward*' were significantly related to larger effect sizes in favour of increasing physical activity while '*information about health consequences*' and '*information about emotional consequences*', as well as '*social comparison*' were related to smaller effect sizes. Howlett et al. 's (2018) systematic review and meta-analysis of PA interventions for healthy inactive adults reported that interventions that included BCTs of '*biofeedback*', '*demonstration of the behaviour*', '*behaviour practice/rehearsal*' and '*setting of graded tasks*' demonstrated larger effect sizes for PA outcomes than studies without these BCTs. In summary, this was the first review to examine the psychosocial ecological components of physical activity interventions for children and young people living with and beyond cancer, and explore the BCTs utilised. The findings of this review suggest three priorities for enhancing the effectiveness of PA interventions for young people living with and beyond cancer: 1) theory-based interventions that address each psychosocial-ecological framework domain 2) creation of tailored psychosocial-ecological strategies for the individual 3) pre-registration of study methods, outcomes and intervention protocols.

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Conflict of Interests:

None

