Implementing Sustainable Physical Activity Opportunities in Pediatric Oncology – Five-Year Experience of a Group-Based Exercise Program

Implementierung eines dauerhaften gruppenbasierten Bewegungsangebotes für krebskranke Kinder und Jugendliche – Erfahrungen aus 5 Jahren

Summary

Problem: Due to physical performance limitations and inactivity after pediatric oncological treatment there is a strong need for childhood cancer-specific exercise opportunities. However, only few sustainable programs have been described in the literature. This article aims to provide an example of implementing an exercise opportunity in pediatric oncology.

Methods: Five-year data (May 2012 to May 2017) have been analyzed on adverse events, attendance rates and barriers to attendance of a group-based exercise program designed for childhood cancer patients after inpatient medical treatment. The exercise sessions included endurance, strength, coordination exercises, as well as relaxation and cooperative games and were offered once a week for 45-60 minutes. In addition, aspects of reintegration into non-cancer-specific PA were explored.

Results: Over 5 years, 32 patients and 14 healthy siblings/friends between 7 and 18 years of age were included. Most patients joined the program for 6-18 months with an average attendance rate of the exercise sessions of 60.28 ± 12.62%. Main reasons for non-attendance of single exercise sessions were medical issues and holidays. No severe adverse events occurred. At program completion, most patients participated in physical education at school, kindergarten and engaged in leisure-time PA.

Discussion: While key aspects for the establishment of sustainable exercise opportunities are highlighted, reintegration into non-cancer-specific PA must be improved and home-based alternatives could be a beneficial complement to the program.

KEY WORDS:
Childhood, Children, Cancer, Sports, Physical Performance

Introduction

Due to improved survival rates in pediatric oncology of approximately 80% in overall five-year survival (8) a growing number of children face post-treatment physical performance limitations and inactivity (14-17, 19) requiring interventions for long term quality of life and health. One beneficial strategy is physical activity (PA) and exercise, as it may reduce mortality (18), mitigate late effects and at the same time improve physical, psychological and social functioning across the cancer trajectory (1,10-11). For the purpose of this manuscript, PA will be defined as "any bodily movement produced by skeletal muscles that require energy expenditure" while exercise is referred to as a subcategory of PA that is "planned,
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Structured, repetitive, and purposefully focused on improvement or maintenance of one or more components of physical fitness” (6).

Childhood cancer specific exercise programs have been found to reduce physical inactivity after childhood cancer and might be a key strategy for PA participation (4). However, only few sustainable exercise opportunities for childhood cancer survivors have been described in the literature (4-5). To bridge this gap, attendance rates, barriers to attendance, adverse events and aspects of reintegration into non-cancer-specific PA from a sustainable group-based exercise program designed for children after inpatient pediatric cancer treatment are described in an effort to provide an example of implementing an exercise opportunity in pediatric oncology.

Material and Methods

The group-based cancer-specific exercise program was initiated in May 2012. For the purpose of this manuscript five-year data from May 2012 to May 2017 was retrospectively analyzed. Ethical approval was obtained through the ethics committee of the German Sports University Cologne (040/2012; 074/2018).

Table 1

| PHASE OF EXERCISE SESSION | CONTENT | PRACTICAL EXAMPLE |
|---------------------------|---------|-------------------|
| Welcoming (5 minutes)     | - assess children's mood  
- introduce the session's content | SMILEYS  
How do you feel today? Choose a smiley. |
| Warm-Up (10 minutes)      | - running/walking games | FIRE, WATER, STORM  
The children are moving (either walking or running) around the gym. When the therapist shouts out a predefined term (fire, water, storm), the children have to react accordingly.  
Fire: lay flat on the ground or a gymnastics mat  
Water: climb on a bench  
Storm: hold on to something (e.g. wall bars)  
Then, the next round starts. |
| Workout (35 minutes, 1-2 main themes) | endurance  
- running/walking games  
- obstacle course  
- relay games  
- walking/jogging | BIATHLON  
Similar to the winter sport biathlon, which combines cross-country skiing and rifle shooting, this game includes running and shooting. Prior to the game a running course (e.g. a 20m loop), a penalty loop (e.g. a 10m loop) and a shooting range (e.g. a gymnastics mat, tennis balls and a box) are arranged.  
When the therapist gives the starting signal, the children run e.g. 3 loops of the running course and then go to their shooting range. There, they have to shoot e.g. 3 tennis balls into a box. For each missed shot the children have to run one penalty loop.  
The game ends when the predefined number of laps (running & shooting) have been completed. |
| | resistance  
- circuit training  
- climbing/obstacle course  
- games including resistance exercises | DICE GAME  
Before the games starts, six resistance exercises (e.g. 10 push-ups) are assigned to the six numbers of spots on a dice. All children throw the dice one after another, perform the assigned exercise and proceed on a game board with numbers from 1-51 accordingly. The first one to reach the predefined goal number (51) wins the game. |
| | coordination  
- coordinative games  
- obstacle courses  
- coordination exercises (coordination ladder, hoops etc.) | JUNGLE ADVENTURE  
Arrange a number of balancing stations and connect them with gymnastic mats. Place an empty treasure chest (e.g. a box) at one end of the course. Place small items along the course (i.e. balls, bean bags, weights etc.). Children have to secure their treasures and carry all items through the jungle course to their treasure chest without touching the floor. |
| | traditional sports  
- ball games  
- racquet sports | TABLE TENNIS  
Play a match of table tennis round-the-table and practice table tennis techniques. |
| Cool-down (5 minutes)     | - relaxation games  
- stretching  
- cooperative games | WEATHER MASSAGE  
One child is lying on a gymnastics mat or sitting on a chair in a relaxed position. The therapist massages the child’s back according to the weather conditions that the child chooses:  
Rainy: drum your fingertips gently on the child’s back  
Sunny: place the palm of your hands on the child’s back having him/her feel the warmth of your hands  
Lightning: paint a lightning flash on the child’s back  
Windy: stroke your fingertips over the child’s back  
Cloudy: stroke the palm of your hand over the child’s back |
| Reflection and Good-bye (5 minutes) | - reflect positive/ negative experiences  
- assess childrens’ mood | SMILEYS  
How do you feel? Choose a smiley. |
Program Participants
Childhood cancer patients (PG) were eligible for program participation if they (i) were 3–18 years of age; (ii) were treated for an oncological disease at the Children’s Hospital Amsterdamer Straße in Cologne (Germany); (iii) completed all their inpatient medical treatments; (iv) received medical clearance from their treating oncologist; and (v) provided written informed consent from the legal guardian. Patients were excluded if they had specific physiological/psychosocial impairments (according to the physician’s advice).

Healthy siblings or friends (HG) were eligible for participation if (i) they were 3–18 years of age; (ii) provided written informed consent from their legal guardian.

Recruitment
All childhood cancer program participants (PG) were recruited through the outpatient clinic for pediatric hematology/oncology, at the Children’s Hospital Amsterdamer Straße in Cologne, Germany immediately after completion of all inpatient medical treatment as described previously (3). However, it should be noted, that the program was open to all patients at any time allowing patients to start participation even months or years after cessation of inpatient medical treatment.

As social relationships are discussed as a key factor determining the success of exercise programs (4) and in order to allow for a sufficient number of same-aged children per group, program participants were invited to bring a healthy peer to the exercise sessions. If a healthy sibling or friend is interested in participating in the program, his/her legal guardian contacts the program coordinators at the German Sports University Cologne in order to clarify any questions, arrange the first exercise session, and provide written informed consent.

Program Description
The exercise program is delivered in a group-based setting, but one-on-one training sessions are possible on demand. The exercise sessions are offered once a week for 45–60 minutes within a gym at the Children’s Hospital. Exercise sessions are conducted by a sports therapist/scientist. Training sessions include endurance, strength and coordination exercises, as well as relaxation and cooperative games in order to account for psychosocial aspects while always taking the specific needs and situations of childhood cancer patients into consideration (see Table 1 for an exemplary exercise session and (2) for a detailed description). The training program is paused if children present with thrombocyte levels <20,000/ml; anemia (hemoglobin <8 g); bone metastases; pulmonary disease (50–75% forced expiratory volume in 1 s) or suffer from fever >38°C; nausea/vomiting; pain; dizziness; circulatory complaints or infections.

Outcome Measures
Adverse events: Safety is evaluated by documentation of adverse events that were related to participation in the exercise sessions and resulted in interruption or discontinuation of the program. Muscle soreness and mild fatigue were not defined as adverse events as these can be expected after exercising.

Attendance rate: Attendance is calculated as (number of attended sessions/number of offered sessions)*100. The average duration of program participation and the average number of program participants per month is also evaluated.

Of note: If childhood cancer patients had a second course of medical treatment due to a recurrence of cancer and then re-started the exercise program after cessation of their second course of inpatient medical treatment, only data for the duration of participants’ first program participation is analyzed although they were allowed to participate again. Moreover, if program participants were forced to take a break from program participation for more than 8 weeks (i.e. due to injury, school internships), this time period is also excluded from the analysis.

Barriers to attendance: To determine potential barriers, the percentage of missed training sessions is calculated as (number of missed training sessions/number of offered training sessions)*100 for each participant. Moreover, main reasons for non-attendance are analyzed by calculating percentages (number of missed training sessions due to reason)/(number of missed training sessions)*100 for each patient. All patients who discontinued participation in the exercise program received a brief questionnaire asking why they stopped participating. This questionnaire was administered once to program participants at the end of participation.

PA-reintegration: As the exercise program aims to promote reintegration into regular, non-cancer-specific PA, our brief questionnaire included additional questions asking whether participants (i) took part in physical education at school/kindergarten, (ii) were active in a sports club and/or (iii) engaged in another type of sports after completing the program.

Other data collection: Anthropometric measures and medical data for all program participants are reported.

Table 2
Characteristics of program participants. max=maximum; mdn=median; min=minimum; n=sample size, sd=standard deviation.

|                         | PG (n=32) | HG (n=14) |
|-------------------------|-----------|-----------|
| AGE (YEARS)             |           |           |
| mean ± sd (mdn)         | 9.02±4.88 (7.25) | 8.88±3.84 (8.40) |
| min - max               | 3.12-18.15 | 2.91-13.73 |
| GENDER                  |           |           |
| male (n (%))            | 19 (59.4%) | 8 (57.1%) |
| female (n (%))          | 13 (40.6%) | 6 (42.9%) |
| TIME SINCE CESSATION OF INPATIENT MEDICAL TREATMENT (YEARS)    | mean±sd (mdn) | 0.47±0.67 (0.18) |
|                         | min-max   | 0.04 - 2.70 |
| DIAGNOSIS               |           |           |
| leukemia (n (%))        | 12 (37.5%)|
| lymphoma (n (%))        | 7 (21.9%) |
| CNS tumor (n (%))       | 2 (6.3%)  |
| bone tumor (n (%))      | 2 (6.3%)  |
| rhabdomyosarcoma (n (%))| 2 (6.3%)  |
| germ cell tumor (n (%)) | 3 (9.4%)  |
| neuroblastoma (n (%))   | 2 (6.3%)  |
| MPNST (n (%))           | 1 (3.1%)  |
| dermatofibrosarcoma (n (%)) | 1 (3.1%) |
| MAINTENANCE TREATMENT DURING PROGRAM PARTICIPATION | Yes (n (%)) | 12 (37.5%) |
|                         | No (n (%)) | 20 (62.5%) |
Data Analysis
Descriptive analysis was used to describe the study sample and evaluate parameters of attendance, barriers to attendance and PA-reintegration using IBM SPSS Statistics 26.

Results
Study Sample
Between May 2012 and May 2017, 48 patients received medical clearance to participate in the exercise program. Of these 48 patients, 35 agreed to participate. However, three patients joined only one exercise session and were excluded from the analysis. Thus, 32 childhood cancer patients (patient group, PG) were included resulting in an overall program participation rate of 66.67%. Twelve patients were accompanied by one or more healthy sibling(s)/friend(s) resulting in 14 healthy children (healthy group, HG) participating in the exercise program. Since the program enrolls new participants on an ongoing basis, 23 patients and 7 healthy children had finished their program participation while 9 patients and 7 healthy children were still participating by May 2017. Most childhood cancer patients participated in the group-based program (n=25), while 7 received individual training sessions. Only one healthy child joined his/her sibling in the individual program, while 13 joined the exercise groups. Detailed characteristics of program participants are presented in Table 2.

Adverse Events
No serious adverse events resulting in discontinuation of the exercise program or any permanent negative effect on participants’ health occurred. However, four exercise-related adverse events resulting in interruption of session resp. program participation were documented. One child had to stop exercising during one session due to stomach cramps. Three participants had to interrupt their program participation for 2 (n=2) to 4 (n=1) weeks due to arm, knee and ankle joint injuries which occurred during an exercise session. All patients recovered from their injuries and returned to the program.

Attendance Rate
Childhood cancer patients attended in 60.28± 12.62% of all offered training sessions. Attendance rates varied between 41.59% and 83.33%. Healthy children participated in 48.18± 12.57% of all training sessions. Rates varied between 39.77% and 60.35%.

Patients that had finished their participation by May 2017 took part in the program for 15.40± 13.42 months (1.61 – 51.75 months). While 4 patients (17.4%) participated for less than 6 months, most childhood cancer patients stayed in the program for 6 - 18 months (n=15; 62.5%). Few patients participated for more than 24 months (n=4; 17.4%). Healthy siblings/friends who had finished participation by May 2017 were in the program for 14.01± 8.12 months (4.83 - 28.52 months).

From May 2012 until May 2017, between 7 and 17 childhood cancer patients and 1 to 9 healthy children participated in our exercise program simultaneously each month.

Barriers to Attendance
On average, program participants missed 43.40± 13.70% (PG: 39.72± 12.63%; HG: 51.82± 12.57%) of their exercise sessions while enrolled in the program. In 41.27± 20.69% of those missed training sessions no reasons for non-attendance was provided. The main documented reasons for non-attendance are presented in Table 3. In 21.32± 18.41% of cases healthy participants missed an exercise session because their affected sibling/friend did not participate.

Reasons for discontinuing the program, were time issues (n=7/18) (e.g. world trip, volunteer work, other leisure-time activities, school/study) or because the participant felt able to join a sports club/exercise on his/her own (n=6/18). Few patients discontinued the program because travel to the exercise program became too time consuming (n=3/18) or due to other reasons (n=2/18) (e.g. group structure was not suitable any more, cancer recurrence).

PA-Reintegration
After finishing the program, 15/18 (83.33%) patients were participating in PES at school/kindergarten. Reasons for non-attendance were, that they did not longer attend school (n=1), no PE was offered at their kindergarten (n=1), or cancer recurrence (n=1). 10/18 (55.55%) patients had re-engaged into leisure-time PA (sports club (n=3); exercised on their own (n=3); sports club and exercised on their own (n=4)).

Discussion
Our findings provide insight into key aspects of a sustainable group-based exercise program in pediatric oncology.

First and foremost, the overall program participation rate of 66.67% underlines the high interest of childhood cancer survivors in a group-based cancer-specific exercise program. Attendance rates are comparable to that found in previous exercise intervention studies with childhood cancer survivors (1,3,12,20). Thus, although efficacy may be limited, a frequency...
of one session per week seems ideal in terms of attendance (3–4). Moreover, the group setting may benefit attendance as social support is known to enhance PA participation (9). In order to establish the group setting, it has proven to be advantageous to invite patients to bring along a healthy sibling or friend. In addition, pediatric cancer survivors may feel uncomfortable playing sports or doing PA with their healthy peers (4) while exercising with other childhood cancer survivors is desired (23). Although our research study has found adequate motor performance levels after approximately 6 months of program participation (3), most participants chose to continue participation in our program for a longer period of time (6–18 months). This could indicate that survivors need more time to regain a level of self-confidence necessary to transition into regular PA. The fact that survivors choose the time of program cessation themselves could also be a key to adequate levels of attendance, as reasons for non-attendance were seldom related to a lack of motivation. In addition, our data suggests that a cancer-specific exercise program is likely to support reintegration into PA in school/kindergarten, as more than 80% were found to participate in PES at kindergarten/school at program completion.

Another important outcome assessed in this manuscript is safety. While no serious adverse events occurred, four events resulted in interruption of a single exercise session and program participation, respectively, for a short period of time. While injuries are always possible when exercising, medical issues must be considered when providing childhood cancer exercise programs. Therefore, cancer-specific exercise programs for this patient population are usually supervised and require medical clearance (21).

Moreover, this manuscript aims to highlight some aspects which could be optimized. While cancer-specific exercise programs seem adequate to engage patients in quality PA and develop physical literacy, known as key factors for maintaining lifelong PA (4), participation in regular non-cancer-specific exercise opportunities is important in terms of social reintegration into peer groups (10). Within our program, participants were merely motivated verbally to transition into non-cancer specific PA at a time they were found to have adequate motor performance levels. However, results show that only 7/18 participants reported transitioning into a sports club at program completion. Considering the high number of healthy children participating in organized sports in Germany (e.g., sports clubs) (13), as well as the tremendous psychosocial and social benefits organized sports provide (7), reintegration into these types of exercise needs improvement. Strategies to facilitate reintegration could involve individual counselling (16) or special activities to help educate participants and their families on PA resources and motivate them to try new activities (e.g., rock climbing, gymnastics, skating) (4).

In addition, home-based alternatives should be integrated. Although supervised programs have been shown to result in higher attendance (1) the need for home-based components has been discussed in the context of sustainable exercise programs (3, 4). This is underlined by the fact, that medical issues were the most reported reason for non-attendance in our program. Children still suffer from a higher risk of infections even after cessation of medical treatment and therefore might not be able to attend the program regularly in person (4). An additional time wise flexible home-based component would also address some organizational reasons that were found to contribute to non-attendance. Another reason for non-attendance was participation in a 4-week family-oriented inpatient rehabilitation program, which is offered to children after cancer treatment and their families in Germany as a standard of care. In total, 12 of 32 participants (37.5%) visited a rehabilitation clinic while enrolled in our program. As exercise is usually an important aspect of inpatient rehabilitation programs, communication between sports therapists of the local program and the rehabilitation clinic could be beneficial.

Our results are limited due to the retrospective design resulting in some lack of information (reasons for non-participation in the program of 13 children were not documented; reasons for non-participation in a high number of sessions are not available). Moreover, we may refer to Beulertz et al. (3) for evaluation of efficiency of our program.

The purpose of this manuscript was to provide an example of implementing an exercise opportunity in pediatric oncology. As a next step, research efforts should aim to reduce the distance between research and practice (5, 22). The key strategies for sustainability of our exercise program were the group setting, inclusion of healthy siblings/friends, exercising once weekly, no limit of program duration, addressing cancer-specific needs and the fun nature of the training sessions. These results may help to define more practical studies considering the complexity of the real world, identified as one strategy to translate research into practice (5). Our experiences hope to create adequate exercise opportunities for childhood cancer patients, allowing them to regain physical literacy and initiate lifelong PA.

Conflict of Interest
The authors have no conflict of interest.

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