Multidisciplinary Network ActiveOncoKids guidelines for providing movement and exercise in pediatric oncology: Consensus-based recommendations

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Abstract

Background: Pediatric cancer leads to reduced participation in exercise and only few patients comply with national physical activity recommendations. Physically inactive behavior hinders motor development and increases physical and psychological adverse effects of therapy and incidence of sequelae. Currently, there is neither nationwide coverage nor uniform level of knowledge regarding exercise promotion. The objective of the guideline is to facilitate qualified exercise interventions through standardized procedures in addition to regular physiotherapy and overall avoid physical inactivity in pediatric cancer patients.

Methods: This guideline addresses the multidisciplinary treatment team and informs physiotherapists and decision-makers in tertiary care hospitals and health insurance companies. The requirements of the Association of the Scientific Medical Societies in Germany were followed. Contents were based on best practice experience of experts, patient advocates, as well as on scientific evidence.
Results: The guideline includes 11 recommendations. Recommendations 1–4 declare the relevance of implementing exercise interventions and address general framework conditions. Recommendations 5–11 focus on the design of exercise programs, prevention and safety issues, relative contraindications for specific training loads, and options to overcome barriers to exercise.

Conclusion: This guideline summarizes existing and established structures and evidence in the context of movement and exercise in pediatric oncology. It takes into consideration the rights, varying needs, and characteristics of children and adolescents as well as national and international experience in this field. In the future, relevant research gaps need to be addressed by high-quality intervention studies to provide the scientific background for a stronger evidence-based guideline.

KEYWORDS
health behavior, health promotion, implementation, physical activity, recommendations

1 INTRODUCTION

Every year, about 2200 children and adolescents under the age of 18 years are diagnosed with cancer in Germany. The worldwide incidence of cancer cases for ages 0–19 years is stated as 15.6 per 100,000.1 Currently, the 5-year survival rate is well above 80%.2 Consequently, the number of long-term survivors is growing and thus the quality of survival gains importance and research interest.3 Certain groups of patients and survivors experience marked disabilities leading to weakness and susceptibility to health complications that can deteriorate unpredictably. During the whole disease trajectory, physical activity with families or friends, participation in physical education and sports programs at school, and in organized or informal sports are greatly reduced leading to high levels of physical inactivity and sedentary behavior.4–7 Physical performance including motor development and activities of daily living are often impaired from cancer diagnosis8,9 until survivorship.10

Exercise-related care services, which are currently included in the Diagnosis Related Groups covered by health insurance, consist of physiotherapy for preselected patients with high needs during inpatient stays and, if necessary, in outpatient settings, as well as exercise and physiotherapy in the context of inpatient rehabilitation programs. Preventive exercise interventions to maintain physical activity levels and motor performance are not yet part of standard care for children and adolescents with cancer.11 Nonetheless, additional supportive exercise interventions have developed over the last years in several countries and hospitals. Based on an environmental scan by Wurz et al.,12 it seems like Germany is one of the countries with a comparatively well spread structure for pediatric oncology exercise promotion. Since absolute national incidences vary widely around the world, this number is not indicating the best national approach to care. However, it illustrates a certain expertise in exercise promotion. In addition, first collaborations with health insurance companies to cover exercise as therapy have been made.13 Most organizations, working groups, and departments are united under the umbrella organization “Network ActiveOncoKids” (NAOK).11 Consequently, high levels of shared experience regarding exercise and movement promotion exist. This experience is supported by research findings about the safety14,15 and positive effects of exercise on health and patient-related outcomes during and after cancer treatment.16–18 Best evidence is available for the endpoints physical performance, fatigue, and quality of life, which is why they were taken into consideration in the guidelines.

The aim of these guidelines was to summarize the available scientific evidence, expert and patient opinions, and best practice examples, with the overall goal to prevent physical inactivity in all phases of pediatric oncology treatment.

2 METHODS

Due to limited evidence in pediatric exercise oncology,19 it was decided to write a consensus guideline that includes expert interviews, patient surveys, best practice experience, and available scientific evidence. A consensus guideline requires a structured consensus-building process involving a representative group of stakeholders. In accordance with the guidelines, we invited all medical and exercise associations whose expertise was important. In addition, as required by the Association of the Scientific Medical Societies in Germany (AWMF), we asked at the first meeting whether any members were missing and then contacted the relevant professional societies asking them to send a representative of their choice. Figure 1 displays the chronological process of the guideline development. All recommendations were discussed and agreed upon in a structured consensus-building process under neutral chairmanship. The guideline was developed between November 2019 and October 2021 with 18 representatives from eleven medical and exercise associations and three patient representatives (Table 1). The patient representatives were a mother of a female child with acute leukemia and two young adult survivors of pediatric cancer.
patient representative were chosen to ensure different views (parents’ view and patients’ view) and histories of cancer. The guideline was supported by an advisory board (n = 10). The content of the guideline was defined in an extensive mixed methods design, taking into account both existing data (literature, experience) and new data collection (qualitative interview with expert, patient survey) with a subsequent consensus-based synthesis. The experts were selected together in the guideline group in order to identify the nationally available experts for specific topics (e.g., tumor orthopedic surgery, neurosurgery). The experts were then recruited either by the central coordination or by the stakeholders involved at the participating centers. During the preparation of the guideline careful attention was paid to meeting the requirements, rules, and regulations of the AWMF for the elaboration of a consensus guideline (stage S2k). Thus, both practical experience and the scientific findings of experts were included.

### 2.1 Literature search

The national guideline database was screened to search for existing guidelines or paragraphs in guidelines on this topic using relevant keywords. Three supportive care guidelines were found to refer in only some minor extent to exercise promotion or interventions. In a second step, the evidence on framework conditions and implementation techniques data was extracted from relevant publications. A systematic literature search was performed on the consequences of inactivity for children and adolescents with oncological diseases. This search yielded a total of 156 hits whereof n = 5 were included. To determine the effects of physical activity and exercise interventions, we conducted a systematic literature search in MEDLINE including systematic reviews and meta-analyses (115 hits, whereof 25 were included). This search for systematic reviews was supplemented by an additional search for randomized controlled intervention trials from 2018 to 2020 to include the most recent research developments (45 hits with eight inclusions).

### 2.2 Interviews with experts

Qualitative interviews were conducted including experts for specific topics for which literature was not available, but sufficient practical experience. Topics were mainly on how to overcome movement barriers and indications for load limits. The experts (n = 14) represented the following fields: tumor orthopedic surgery, pedagogy, sports
science, psychology, pediatric and adolescent medicine, palliative care medicine, nursing, pediatric cardiology, neurosurgery, inpatient rehabilitation, and patient advocates. The interviews took place in person, by telephone and virtually, depending on the regional and COVID-19 pandemic opportunities, and were recorded, thematically transcribed, and coded. The duration of the interviews ranged between 15 and 90 min.

2.3 | Patient survey

An online survey was conducted at five pediatric oncology departments with implemented exercise programs in Germany with \( n = 33 \) children and adolescents. Respondents were \( n = 33 \) patients during and after treatment for an oncological disease who were 6–9 years (27%), 10–14 years (34%), 15–17 years (21%), and >18 years old (18%). The children and adolescents were asked anonymously about (a) their preferences and wishes regarding exercise offers, (b) the design and equipment of an exercise room in the tertiary care hospital, and (c) the preferred qualifications and characteristics of clinical exercise physiologists. In addition, the questionnaire included items on self-perceived barriers to exercise and subjectively perceived effects of exercise therapy.

2.4 | Data synthesis

The existing evidence and the new data generated in the interviews and surveys were sorted thematically in small working groups and summarized in a preliminary version of recommendations. Through ongoing discussion by the lead author group (M. G., G. G., and S. V. K.), the three main topics focused on (1) consequences of physical inactivity, (2) effects of exercise interventions, and (3) safety and framework conditions. Based on these, preliminary recommendations were drafted, which then formed the foundation of the consensus meetings with all representatives of the associations and patient representatives.
2.5 Consensus meetings

During two consensus conferences in January and March 2021, the proposed recommendations and key messages were consented using a nominal group process. Both consensus meetings took place via videoconference due to COVID-19 pandemic hygiene measures. The structured consensus-building process was supervised by neutral chairmanship. In the first consensus meeting, the preliminary recommendations from the working groups were presented to the representatives and feedback was gathered. Based on this first meeting, the recommendations were modified, supplemented, and rewritten. In the second meeting, the modified recommendations were commented by all representatives. Deviating suggestions were noted and incorporated immediately, if possible. The methodological steps of acceptance for each recommendation statement included “reconciliation and query of conflicts of interest,” “debating/discussing,” and the “final vote.” Each member of the consensus group had one vote.

3 RECOMMENDATIONS

In total, 11 recommendation statements were confirmed with high consensus (100% agreement). Recommendations 1–4 address children’s right to have access to movement in general, to receive exercise programs and support, and to be actively involved with their individual conditions, preferences, and self-determination. Recommendations 5 and 6 address the importance of communication and training of the exercise physiologists conducting the exercise programs. Recommendations 7 and 8 focus on the contents of the exercise intervention to avoid adverse events and follow general training principles. Recommendations 9 and 10 focus on the evidence-based effects of exercise to positively influence physical performance, fatigue, and quality of life. Recommendation 11 address the multidimensional barriers that might hamper exercise.

In the following, all recommendations are listed with headline and original text translated into English. Furthermore, additional valuable background information regarding each recommendation and associated supply gaps are presented. Some recommendations refer to additional tables with practical examples and suggestions for action that can be found in the supporting information files.

Recommendation 1
Exercise-friendly settings

All children and adolescents during and after a malignant disease should generally have the opportunity to exert the “National Recommendations for Physical Activity” according to Rütten et al. 2016 (60–180 min daily depending on age). This implies that hospital settings (provision of specific areas and physical exercise specialists) should be exercise-friendly and accessible.

Recommendation 2
Active involvement of the children and adolescents

Health status and preferences of children and adolescents should be considered when implementing physical exercise recommendations. This implies that children and adolescents have the right to refuse the offer of physical exercise (and still be asked again), as well as to be involved in choosing the content and physical exercise characteristics such as volume, duration, intensity, and resting periods.

Recommendation 2 addresses the motivation to maintain physical activity from diagnosis to long-term follow-up that can be supported by active involvement of individual wishes and interests. Movement promotion and exercise should be individually tailored according to the patient’s personality, wishes and goals, phase of treatment, diagnosis, and further individual specifics (e.g., sports anamnesis, individual physical capacity). Recommendation 2 also implies that rejection of an exercise offer by patients should be taken seriously and not be interpreted as an argumentation against further exercise offers.

Recommendation 3
Integration of physical exercise interventions

During acute anticancer treatment targeted physical exercise interventions should be integrated into the clinical routine as part of the overall promotion of movement. From the day of diagnosis, this is individualized, goal-oriented and guided by qualified clinical exercise physiologists and takes place up to 5×/week.

Recommendation 3 bridges the gap between general the right to move and targeted training that has a therapeutic effect on patient and health-related outcomes. Physical exercise interventions are indicated for all children and adolescents, for disabled and deconditioned patients to improve their health status, as well as for children in overall good clinical health status to prevent deconditioning and maintain the enjoyment of exercise.
Recommendation 4
Support for survivors and persons in palliative care is based on individual needs

During surveillance after pediatric oncolgical disease and in palliative care situations, movement promotion and physical exercise support should be based on the respective needs of the children and adolescents and adapted to the living conditions, the motivation, and the clinical restrictions of the patient. This comprises (a) exercise interventions and/or (b) counseling on the promotion of movement in everyday life and physical exercise interventions. There is a need for support especially for the following groups, which therefore receive a focused and active support offer:

- Children/adolescents/young adults with physical or mental impairments,
- Children and adolescents with a very inactive lifestyle,
- Adolescents close to transitioning to adult medicine,
- All that look and ask for support.

Recommendation 4 targets the existing care gap after intensive cancer treatment. While some of the children and adolescents return to their school and club sports structures without major problems, there are special phases of life and disabilities that require targeted support. This recommendation lists some of those circumstances and suggests concise exercise offers and/or counselling, based on the individual needs.

Recommendation 5
Ensuring adequate communication of information

The appropriate exchange of information on the patient’s health status should be ensured to the required extent in a timely, comprehensive, and structured fashion. This includes, e.g., regular meetings, transparent documentation of the physical exercise intervention, and consideration of medical aspects and treatment-related adverse effects to ensure responsible exercise interventions.

Recommendation 5 implies that the clinical exercise physiologists that carry out the exercise offer must be appropriately integrated into the clinic structures in order to ensure the flow of information.

Recommendation 6
Appropriate medical training of the employees

Clinical exercise physiologists should be included in the hospital’s internal quality assurance systems for handling medical equipment (e.g., drip stand, pulse oxymetry, ECG monitor, feeding tube) and aids (e.g., crutches, Mecron splint, wheelchair, walker), hygiene guidelines, safety and work safety measures, and other regulations as far as their work area is concerned.

Recommendation 6 emphasizes the required knowledge in the hospital setting with respect to hygiene standards and the ability to choose materials appropriate for the use within this group of vulnerable patients. Infection risks are reduced by disinfecting all materials after use with one patient as well as hand disinfection regularly. To prevent injuries, for example, soft balls can be used instead of hard basketballs. Safety loops of the intravenous line attached to the patients’ cloths reduce the risk of tension at the central venous catheter.

Recommendation 7
Consideration of medical indicators for the prevention of adverse events

In case of medical conditions associated with an increased risk of serious adverse events (e.g., post-surgery, platelet counts < 20,000/µl blood, acute risk of fracture), individualized promotion of movement and physical exercise interventions with the use of low-threshold content should be considered and individually coordinated within the treatment team as well as with the patient as part of a 1:1 care.

Recommendation 7 states that there are no contraindications in general that limit the contact of the children and the clinical exercise physiologist. The principle should always be that the type and intensity of the exercise intervention should be adapted to the state of health, not that the child has to meet certain conditions. This may mean that a child with a fever and wish to have contact could receive a body-focused fantasy journey. A corresponding table with examples is integrated in the long version of the guideline.

Recommendation 8
Application of exercise science and sports pedagogy principles

Promotion of movement and physical exercise interventions should be planned and delivered in a dialogue-oriented manner and according to the following principles: Voluntariness (A), based on pedagogic principles (B) and consideration of patient-specific conditions (C). The objective of the physical exercise intervention is communicated transparently and shall be planned individually (D). It begins with taking medical history (E) and follows general principles of kinesiology and coaching science (F–G).

For the implementation of Recommendation 8, concrete examples are given in tables (see Table S2). These list established suggestions to plan and deliver movement promotion and physical exercise interventions in the clinical setting and can be a guide for the practical implementation of the sports pedagogy principles.

Recommendation 9
Targeted physical exercise interventions for reduced physical functioning and fatigue

Reduced physical function and fatigue are indications for physical exercise interventions throughout all phases of malignant disease. These targeted physical exercise intervention should be offered with supervision over an initial period of 8 weeks, at least 2x/week for 15 to 30 min each, in order to positively influence aerobic capacity, muscular strength and functional mobility, as well as fatigue symptoms.
Recommendation 9 addresses reduction of common side effects during treatment applying specific exercise interventions based on current scientific evidence. An extension of this list is preferable, but an increase of evidence is required. The duration and frequency in this recommendation are minimum disclosures as the lowest level of an intervention. Content and focus of the intervention are adapted individually as required.

Recommendation 10
Consideration of preferences and wishes to improve quality of life

In order to improve quality of life physical exercise interventions should be delivered according to the preferences and wishes of children and adolescents. Major components include addressing the physical self-concept, avoiding unwanted stress, and supporting participation in life with peers.

Recommendation 11
Overcome barriers to movement with the interdisciplinary team and patients

In order to overcome personal, environmental and everyday movement barriers (A-D) as well as movement barriers caused by the hospital setting (E), individual solutions should be sought and defined by an interdisciplinary team together with the patient. These should follow the main principles of communication, orientation on resources, enjoyment of movement as well as awareness of skills and boundaries on behalf of the clinical exercise physiologists.

Recommendation 11 states the need for an active interdisciplinary approach with respect to potential barriers for movement. We included examples for individual physical and individual psychological, environmental, everyday movement, and setting-related barriers presented in combination with suggestions to overcome these barriers for practical purposes (Table S3).

4 | DISCUSSION

Movement promotion and exercise interventions are of increasing importance in pediatric oncology in Germany and worldwide. The recommendations of this guideline do not represent the currently established standard of care in all pediatric hospitals. However, it shows an optimal promotion of physical activity described on the basis of scientific results and expert as well as patients opinions, which can be implemented gradually and resource-oriented during the years ahead. The recommendations are based on the patient’s needs and physical, psychological, and social added value of physical activity. During the implementation of movement and exercise programs in standard care structures, the focus is on the fact that the gradual implementation already represents an added value for those affected and that there are usable support options. The guideline provides support for this implementation of exercise and presents concise recommendations for child-oriented, feasible, safe, and effective interventions. This guideline might serve as an extension of the existing literature and more general recommendations in the field of pediatric exercise oncology like the ipOEg guidelines published in 2021. They are in accordance regarding the recommendation to implement exercise into all phases of pediatric cancer treatment and that exercise and movement differs from day to day. They both highlight the importance of qualified clinical exercise physiologists that closely collaborate and exchange experience with the medical and healthcare team. They add aspects about the children’s right to move and to have same or similar movement promotion and opportunities as healthy children. In addition they incorporate concise approaches to overcome barriers that have also been reported in previous studies.

The strength of this guideline lies in its structured consensus-building process involving a representative group of stakeholders including patients and patient representatives and the use of different valuable methods to generate the recommendations. The limitations are a lack of evidence grading and lack of detailed training content based on the FITT criteria (frequency, intensity, time, type). However, FITT criteria need to be specific for the respective outcomes (e.g., anxiety, bone health, or fatigue) as already been summarized in adult exercise oncology. The eleven recommendations are as specific as it was possible based on the limited experience and research in this field. For the outcomes physical function and fatigue, at least minimum specifications regarding duration and frequency have been presented based on the available evidence.

In conclusion, this guideline includes eleven recommendations that might help to implement movement promotion and exercise interventions for children and adolescents with cancer into usual care. Exercise should not be a privilege for some preselected patients or patients that participate in clinical exercise trials. There is a high need for all cancer patients and survivors: for children in good general health to prevent deconditioning and as well for children with high symptom burden and side effects to ameliorate those symptoms and integrate exercise as an early rehabilitation approach.

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CONFLICT OF INTEREST
The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

DATA AVAILABILITY STATEMENT
The data that support the findings and conclusions of these guidelines are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION
Additional supporting information can be found online in the Supporting Information section at the end of this article.

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