A National Implementation Approach for Exercise as Usual Care in Pediatric and Adolescent Oncology: Network ActiveOncoKids

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The diagnosis of cancer as well as accompanying acute and late effects of treatment are influencing physical activity behavior of patients with childhood cancer and survivors. Research has shown that a pediatric cancer diagnosis is associated with impairments of physical performance, and function, as well as reduced physical, and psychosocial, health conditions. From an ethical perspective, lack of knowledge of health care providers, lack of physical activity promotion, and environmental, and structural barriers to physical activity restrict children’s right to move and actively engage in physical activities. Network ActiveOncoKids is a German-wide initiative with the main goal of enabling children, adolescents, and young adults with exercise opportunities during and after cancer treatment. Since the network’s foundation in 2012, Network ActiveOncoKids focuses on: (1) physical activity support for patients and families, (2) policy change to establish structures and guidelines, and (3) generating evidence through scientific projects. The purpose of this paper is to present an overview of Network ActiveOncoKids structure, aims, and projects. This topical review will highlight the network’s structural development, research work, and implementation progress of exercise programs for patients with pediatric cancer and survivors, link international collaborations, and discuss future directions.

Keywords: childhood cancer, physical activity, rehabilitation, sarcoma, leukemia

Childhood and adolescent cancer (0–19 y) have a low incidence of 15.3 per 100,000 per year (34). Although treatment has improved within the past decades, cancer still represents one of the leading causes of death in childhood and youth. Survival rates of above 80% for high-income countries are reported (21). Diagnosis and treatment result for short- and long-term reductions in physical activity and fitness (1,6,25). The largest reductions occur during treatment, but significant long-term impairments are prevalent in survivors, as well (1,4). Furthermore, limitations of physical performance, such as reduced cardiorespiratory fitness, muscle strength, and balance often persist throughout treatment and survivorship (3,22,26,32). These limitations are associated with long-term impairments of psychosocial variables like well-being, attainment of social roles, emotional distress, lower physical self-concept, and health-related quality of life (2,19). However, structured physical activity and exercise programs seem to be a promising supportive strategy to minimize several side effects of treatment, general loss of physical performance, and long-term mortality (24,30,37). In addition, regular exercise might also diminish days of hospitalization, and thus economic cost (20). However, findings on the cost-effectiveness of comparable programs vary and need further evaluation (5). Moreover, regular physical activity throughout childhood and adolescence is beneficial for the development of muscular and cardiorespiratory fitness, bone health, cognitive function, cardio metabolic, and mental health (11,36). It is therefore important to implement safe and regular opportunities for exercise therapy and physical activity counseling during treatment and survivorship of patients with childhood cancer. The World Health Organization recommends at least 60 minutes per day on average of moderate- to vigorous-intensity physical activity including strengthening bone and muscle activities on 3 days for healthy children and adolescents aged 5–17 years to achieve health benefits (7). The German physical activity recommendations suggest at least 180 minutes per day of physical activity time (ie, spent moving or physically active in any way, not sedentary) for children aged 4–6 years and at least 90 minutes per day of moderate- to vigorous-intensity physical activity for children and adolescents 6–17 years (29). The same recommendations apply for patients with pediatric cancer, and survivors (8). A group of international experts recently published the “International Pediatric Exercise Oncology Guidelines” (40). Those guidelines provide statements to motivate patients with pediatric cancer, and survivors, to increase their levels of physical activity, and phrase recommendations for exercise professionals regarding the application of exercise programs. Although exercise during and after treatment of pediatric cancer shows promising results in diminishing disease- and treatment-related side, and late effects (4,23,24,27), tailored exercise programs are still not a part of standard care (38). Thus, most patients with pediatric cancer and survivors do not have access to tailored exercise programs and physical activity opportunities that meet their needs.

This review summarizes Network ActiveOncoKids’ (NAOK) approach to promote physical activity for children, and young people, during and after cancer treatment in Germany. Several strategies that facilitate physically active behavior throughout

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treatment and survivorship are presented. Results of this nationwide network might serve as a practical model on how to implement exercise as usual care in pediatric and adolescent oncology on an international level.

**NAOK—Aims and Scopes**

Approximately 2200 children and adolescents aged 0–18 years are diagnosed with cancer in Germany each year. About 60 acute pediatric clinics, collaborating in the German Society for Pediatric Hematology and Oncology, offer anticancer treatment throughout Germany (20). This differs from most other countries, where fewer specialized acute pediatric care centers are available for treatment, resulting in longer travel distances for families. Usual care beyond pharmaceutical therapies and nursing care includes psychosocial services, for example, psychological support, social law counseling, educational activities, and different therapy offers from the fields of art, music, clowning, and movement. In Germany, physiotherapy is medically prescribed and available for patients with high needs (eg, after surgery, high immobility, pain). The percentage of children with prescribed physiotherapy and amount and contents of the interventions vary throughout the clinics. However, although the potential of exercise to prevent deconditioning and medical side effects is well-known, exercise does not happen as part of standard care. In addition, methods to change physical activity behavior are not sufficiently considered yet. Therefore, supportive measures to achieve recommendations of physical activity are not met by the current standard care. Additional supervised physical activity and exercise programs with varying frequency were available at 8% of all acute cancer clinics at NAOK foundation in 2012. After 9 years of networking and collaboration within NAOK, exercise programs are now available at 42% of cancer clinics (Figure 1). The number of exercise physiologists at the individual sites varies and ranges from one person employed for a few hours per week to several full-time positions in a clinic. This limits the services offered to the sick children at many sites, so that some clinics only offer aftercare sports, for example (as shown in Figure 2). Following acute treatment, many patients and families make use of an inpatient 4-week rehabilitation covered by statutory health insurance at one of 4 specialized rehabilitation clinics for pediatric cancer or a specialized neuro-rehabilitation center.

Rehabilitation strategies for children and adolescents after cancer treatment include several therapeutic approaches for the whole family including physiotherapy, sports therapy, psychosocial support, and behavioral and medical support to improve and maintain health and health behavior.

Before 2012, only few initiatives existed in Germany that promoted physical activity in addition to regular physiotherapy for
young patients with cancer and implemented exercise into supportive treatment of pediatric cancer. These initiatives founded NAOK in 2012 with the purpose to strengthen the field of pediatric exercise oncology. The network mostly consists of exercise physiologists but unites experts from multiple disciplines, including medicine, psychology, pedagogy, and physiotherapy, and patient advocates. NAOK’s main goal is to provide opportunities for physical activity promotion and exercise therapy for children, adolescents, and young adults during all phases of cancer treatment. However, during the first years, the network had its focus on professional collaboration and exchange between health care professionals and clinical exercise physiologists working in the field of Pediatric Oncology. In 2019, the network implemented a third party-funded full-time position to coordinate the network, extend structures, contents, and activities, and increase awareness through public relations. Since 2019, NAOK is an official working group in the German Society for Pediatric Hematology and Oncology. In January 2020, at the fourth national NAOK workshop, a general assembly met for the first time and elected the NAOK steering group consisting of 6 elected members and the coordinating person for 2 years in accordance with the statutes. The NAOK’s vision is that tailored physical activity and exercise become a constant part of standard care throughout cancer treatment. All patients with childhood cancer, and survivors should have access to tailored exercise programs and suitable physical activities, so that physical activity and exercise are accessible as a resource to support physical and psychosocial resilience throughout treatment and survivorship. Therefore, NAOK’s actions aim at enhancing physical activity and facilitating participation in exercise programs for children, adolescents, and young people with cancer.

To reach these goals, NAOK acts on different levels, which are in line with current health promotion strategies (9,13,17). Actions target several determinants of physical activity implementation in children and adolescents (summarized in Figure 3), namely physical activity support, policy change, and scientific evidence.

### NAOK Physical Activity Promotion for Children and Adolescents With Cancer in Germany

The attainment of the abovementioned aims requires an analysis of needs and the development of appropriate strategies. The following paragraph summarizes NAOK’s current strategies and activities to realize its predefined aims (summarized in Figure 3). Activities and offers target several groups (such as patients, survivors and their families, health care professionals, institutions, physical education teachers) and areas like research and long-term development of structures and policy.

### Strengthen Physically Active Behavior

Reductions of physical activity during and following treatment are common in patients with childhood cancer (1,15). Furthermore, uncertainties regarding the type and planning of physical activity (opportunities, intensity, duration, etc.) in combination with physical (eg, pain, nausea), psychosocial (eg, depression, fears), and

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**Figure 3** — Network ActiveOncoKids aims and scopes and 3 main activities each to achieve the aims. SCT indicates stem cell transplantation.
organizational barriers (eg, lack of room and offers) are often increasing physical inactivity (16,22,28). Opportunities for low-threshold physical activity counseling and exercise are scarce. Several measures to enhance physical activity in children and adolescents with cancer that aim directly at patients and families during or after treatment are conducted individually by members at NAOK sites. NAOK offers exercise-related support for patients and families by addressing their questions, discussing uncertainties, and develop strategies to change physical activity behavior. Further activities like patient and survivor workshops, family workshops, and individual physical activity counseling, including reintegration support into sport structures, are organized and conducted directly by the NAOK coordination office. To extend the knowledge of physical activity benefits and to familiarize patients with cancer and survivors with the network, posters, flyers, homepage, and several social media accounts have been created. Moreover, NAOK participates at family and young patient camp activities of the German Pediatric Cancer Foundation and patient conferences.

Besides the general advising and supporting tasks, NAOK implemented several projects at the direct patient level to expand reach and engage families regardless of where they live. As an example, NAOK members have produced educational exercise videos for children, adolescents, young adults, and parents. These aim at different target groups (based on age, general condition, tumor entity, and therapy side effects) and are remotely accessible for free. As a further digital exercise option, a live online exercise lesson was broadcasted monthly between October 2020 and July 2021. All videos, as well as recordings of all online exercise lessons, are accessible on the NAOK homepage. Professional athletes present their sport, demonstrate exercises and movements in different intensities and levels, and discuss possibilities to become active for children with cancer, reduced physical and general condition, or handicaps. At the beginning of each online exercise lesson, participants are invited to join live via twitch.tv and ask specific questions and address individual topics, for example, modifications due to amputation or much reduced general condition to a colleague who is present for this purpose. For the remote videos, NAOK will be named and advertised as the contact person for any questions. For each exercise, a more difficult and easier option is demonstrated. Furthermore, a free accessible training brochure for patients and their families in German language (https://www.activeoncokids.de/betroffene/trainingsbroschuerde-nao/) was developed by experienced NAOK members including international collaborators to inform about physical activity during and after cancer treatment, providing exercise examples and information, and subjective scales of perceived exertion. Since intensive and demanding exercise can also result in overburdening and withdrawal (18,35), especially during active cancer treatment, motivation to be physically active is sought via enjoyment and individual tailoring of exercises and recommendations whenever possible.

Overall, an ongoing challenge is to popularize NAOK among patients, parents, and survivors and connect NAOK’s activities with the arising demand. Therefore, ways must be established to familiarize families with the benefits of exercise and physical activity, as well as NAOK’s activities related to counseling, adapted physical activity programs, and professional workshops.

**Implement Exercise Programs During Acute Care and Aftercare**

Patient-centered care programs usually consist of structured exercise programs during and/or after treatment. This includes 1:1 exercise sessions delivered by a clinical exercise physiologist during inpatient or outpatient hospital visits, on weekdays and/ or weekly group exercise sessions after treatment completion. These activities lie in the purview of the individual cancer clinics or network members.

In regions with several acute cancer clinics, formation of NAOK subcenters, characterized by cooperation between pediatric oncology clinics and institutes of sports science, is intended to strengthening the region through high-quality physical activity programs. These offerings are typically in the areas of outdoor sport activities (including rowing, paddling, surfing, climbing, flying), and accessible regional for participants (not only for individual clinics), to leverage synergies. During action days as well as activity camps, different sports can be experienced and, if interested, further practiced close to home through mediation by the centers or the central NAOK coordination.

Most acute pediatric cancer centers outside of NAOK are not offering exercise programs, as of yet. Furthermore, professionals in common sports structures (eg, community sports club coaches, physical education teachers) often lack experience with children and adolescents following cancer treatment due to the low incidence rate. Therefore, NAOK takes several measures to achieve an exhaustive care during acute treatment and aftercare and reaches out to clinics or professionals outside the network. Strategies for setting adjustment are targeting (1) acute cancer clinics and medical professionals, (2) exercise professionals, and (3) cancer clinic structures and facilities.

**Support Implementation in Acute Cancer Clinics**

The NAOK offers demand-oriented services to support expansion, facilitate implementation of exercise programs, and overcome common barriers to physical activity and exercise in the clinical setting. Supporting the implementation of exercise programs in acute pediatric cancer clinics is one important aim of NAOK and will therefore be shown exemplary in the following, maybe serving as a role model for institutions in other countries. To increase the number of acute pediatric cancer clinics offering exercise programs, the implementation is guided throughout the whole process (Figure 4). The first step is the intention and interest to offer exercise programs, either as a result of self-initiative by an acute cancer clinic or through attention-led initiative of NAOK. The second step is any kind of contact between NAOK coordination and staff of the acute cancer clinic. Following this, as the third step, on-site visits for transfer of information provide, for example, informative talks for staff members to lower personal barriers or concerns and clarify the purpose of an exercise program. Now staff can gain insight via an intern with an experienced pediatric oncology exercise physiologist in a NAOK clinic nearby. Pediatric oncology wards that are under reconstruction and consider incorporating an exercise room directly at or near the ward can take advice on recommended size and facilities. In addition, further communication and exchange with respect to specific barriers is possible. Fourth, the NAOK coordination performs an analysis with the contact person in the acute cancer clinic to identify possibilities and challenges during the implementation process. Since there is no national solution for covering the costs of exercise, the financing models are discussed individually and solutions are sought through third-party funds, donations, and cooperation with health insurance companies. Continuous support by NAOK and a close cooperation within the network enables development and expansion of the newly implemented exercise
Furthermore, multicentric research projects and exchange of experiences within NAOK gains additional impact for new and existing NAOK members. Since the network’s foundation, 12 acute pediatric cancer centers implemented an exercise program supported by NAOK (Figure 1). The key experience for this successful development probably was the setup of a coordination center and a group of experienced members. Since year 1, NAOK focuses on exchange of experience, sharing expertise and openness. This specialty in Germany might not only be realizable in every country, and is clearly dependent on the number of initiatives and acute cancer clinics, but also transnational networks with a superordinate coordination could be an option to increase the number of exercise programs worldwide.

**Advise Exercise Professionals**

Apart from the clinical setting, NAOK offers consultation service for sports team coaches and physical education teachers. During the return to organized or informal sports after cessation of treatment, patients and parents may contend with uncertainties and, or, anxiety. Physical impairments (eg, amputation, body changes, loss of confidence in own physical capacities) might impede participation and create barriers. Experts’ advice and directing information flow can help to clarify problems, avoid misunderstandings, understand the patient’s perspective and experience, and encourage all concerned parties to meet this challenge. Regular comprehensive biennially and yearly topic-specific workshops for exercise professionals and other therapeutic clinical staff (eg, physicians, psychologists, occupational therapists) are held to promote exchange of expertise and provide a summary of the latest evidence-based knowledge on Pediatric Exercise Oncology. These workshops are accompanied by regular meetings to discuss special cases, best practice physical activity promotion strategies, and offering opportunities to network among the clinics.

**Cancer Clinic Structures and Facilities**

Exercise and physical activity interventions during cancer treatment are often hampered by small patient rooms, lack of space to exercise, lack of equipment, and missing clinical exercise physiologists within the interdisciplinary treatment teams. Those facilities and structures, in addition to the missing knowledge about the benefits of exercise, sustain the severe inactivity of patients and needs to be changed and adapted to enable movement possibilities for children and adolescents with cancer. Although exercise is also possible inside patient rooms, at the ward and with little equipment (like balls, bands, rings, and small strength devices), upcoming cancer clinics should incorporate exercise facilities. Gyms or specifically equipped rooms at the ward for exercise interventions help integrating exercise during acute cancer treatment. If no specific room is available, clinics might develop ideas of a multimodal use of space and rooms, to reduce time lying in bed. Patient’s views on this matter have been assessed in an online survey that are summarized in the consensus-based medical guideline (14).

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**Figure 4** — Exemplary implementation process of an exercise program in an acute cancer clinic guided by the NAOK coordination. NAOK indicates Network ActiveOncoKids.
Policy Change

At present, the German diagnosis-related groups system, as part of German hospital reimbursement, does not cover pediatric exercise oncology programs. Hence, most supervised exercise programs and exercise activities for patients with pediatric cancer, and survivors, operate on mixed financing solutions via third-party funds, research funds, grants, sponsoring, and donations. To reach financial sustainability, collaboration with health insurance companies within the German social security system is sought. To date, few clinics and several health insurance companies have been cooperating to establish individual patient-centered care contracts based on the present social security laws (German Social Welfare Code) (33). This development will preferably expand and continue to establish greater financial sustainability for local initiatives and programs.

To harmonize conditions and contents of exercise programs and ensure high quality, information about feasible exercise interventions and structured implementation need to be published and disseminated within families, health care professionals, and researchers. Therefore, a multidisciplinary expert group led by NAOK developed a consensus-based medical guideline (14). In addition to the international Pediatric Oncology Exercise Guidelines (iPOEG), primarily for patients and survivors, the NAOK guideline aims at providing recommendations to improve structures and to implement exercise programs, in the course of pediatric anti-cancer treatment. The NAOK guidelines are specifically adapted to national conditions and define concrete recommendations that supplement the iPOEG statements. Furthermore, NAOK’s homepage provides a communication platform for all interested people.

Future challenges include perpetuating and optimizing the developed range of programs and opportunities for patients with pediatric cancer and survivors through promoting cooperation between professionals, and networks and expanding structures.

Scientific Evidence

High-quality research on the benefits and risks of exercise for patients with childhood cancer is still limited (4,24). Although an increasing number of clinical trials focus on the effects of physical activity during, and after cancer treatment with promising results, large research gaps persist (39). In 2016, a NAOK research group was founded, which is funded by Deutsche Forschungsgemeinschaft within a competitive call for network proposals (project number 313088605). The research group is composed of 14 interdisciplinary junior researchers. The group held 8 meetings since 2016 and processed predetermined work packages (ie, grant proposals, training brochures, and systematic reviews). To facilitate selection of evaluation methods in research or clinical contexts, NAOK research group summarized and reviewed existing assessment tools to measure physical activity and physical performance in patients with pediatric cancer and survivors (10,31). Another focus is the design, submission, and conduction of multicenter clinical trials to evaluate the effects of specific exercise and behavioral interventions on physical activity levels, and physical and psychosocial health. Ongoing quantitative and qualitative studies assess motivations and barriers for engagement in outdoor sports, as well as factors influencing physical activity behavior after cancer treatment. A recently launched EU-project, the FORTE study examines a precision exercise program during anti-cancer treatment in 7 European countries (German Clinical Trial Registry DRKS00027978). Methodological limitations, for example, small numbers of patients in each center, and great diversity in pediatric cancer types, often hamper the explanatory power of study results and confuse the generalizability. Therefore, NAOK members are initiating multicenter randomized controlled clinical trials to gain evidence and shorten research gaps.

International Partners and Cooperation

Besides close collaboration and cooperation with the acute pediatric cancer centers in Germany, NAOK strengthens international contacts with initiatives in nearby countries (eg, Switzerland) and worldwide. Further contacts and collaborations exist with iPOEG, FORTEE, and PanCare, among others, to advance research, professional qualification, and exercise opportunities for patients, survivors, and health care professionals in the field of pediatric exercise oncology. For the collection of research initiatives and current evidence, global collaboration and practical exchange, a Pediatric Exercise Oncology Congress was initiated in an international collaboration. This first edition of this congress will be held in April 2022. Participation is open for all professionals and interested parties as well as for patients with pediatric cancer, pediatric cancer survivors, and their families.

Perspectives and Future Work

Since the network’s foundation in 2012, the field of pediatric exercise oncology has developed and gained popularity and importance. However, several challenges still must be met to achieve the overall goal of comprehensive exercise programs for every child and adolescent during, and following, cancer treatment in Germany. Future steps include quality standards and financial sustainability for exercise programs. A current retrospective analysis of adverse events during exercise programs underlines the safety of structured and supervised exercise interventions with only 6 adverse events grades 2–3 according to the CTCAE criteria in 35,110 exercise interventions (12). For a standardized assessment of adverse events in the clinical setting, a registry will be established to prospectively file and evaluate adverse events occurring during exercise programs in acute pediatric cancer centers and aftercare offers nationwide. A systematic assessment of possible risks will strengthen the safety and acceptance of supervised programs in pediatric oncology. In addition, high-impact research is needed to evaluate the overall and the specific effects of exercise interventions on patient-, disease-, and treatment-related outcomes to translate these findings into practice and guidelines. Due to low incidence rates of pediatric cancer, multicentric collaborations are indispensable. Moreover, the increasing number of upcoming exercise programs requires specially trained staff to ensure safety and quality standards. A curriculum for specific qualification courses open for postgraduates is currently under development.

Conclusion

The NAOK is an interdisciplinary network to improve pediatric exercise oncology in Germany and beyond. In the past few years, great progress has been made in the areas of exercise implementation, structural organization, and communication, which might serve as a model for other countries. However, many open tasks remain such as quality assurance of exercise programs, financial coverage, and sustainability.
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