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CANCER REHABILITATION (MD STUBBLEFIELD, SECTION EDITOR)

Rehabilitation and Pediatric Oncology: Supporting Patients and Families During and After Treatment

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Abstract

Purpose of review With increasing survival rates in pediatric oncology, more attention has been paid to improving physical, cognitive, and psychosocial functioning for individuals on and off of treatment. We highlight the need for a multidisciplinary approach in providing care for pediatric oncology patients and their families.

Recent findings There is an emerging field of evidence to support specific interventions within the fields of physical therapy/exercise, speech/language and occupational therapy, individual and family-focused psychotherapy, cognitive remediation, medication, tele-health, and school re-entry. Much of the current research attempts to tailor interventions to oncology patients' complex needs.

Summary Continued efforts are needed to make interventions accessible to all oncology patients and their families, particularly those with limited resources. We discuss an integrated care model for delivering rehabilitative therapies within outpatient oncology clinics, which can help mitigate the challenges this population has of consistently accessing therapeutic support.

Keywords Pediatric rehabilitation · Pediatric oncology · Multidisciplinary intervention · Service delivery · Parents · Caregivers and families · Children · Adolescent and young adult

Introduction

Each year in the USA, approximately 21,000 children and adolescents are diagnosed with cancer [1, 2]. With intensive and aggressive treatment, survival rates have increased to 80% [3], allowing for an increased focus on quality of life during and after treatment. At the same time, the late effects of cancer and treatment are significant and may include organ dysfunction, physical challenges, psychosocial complications, and cognitive deficits [4, 5]. The majority of survivors receiving CNS-directed treatment report sensory, cognitive, neurological, and/or endocrine problems [6, 7]. Integrated multidisciplinary services spanning diagnosis, active treatment, survivorship, and palliative care are needed to improve the physical, psychological, and social impacts of cancer on the patient and family [8, 9]. This includes early risk screening, comprehensive service delivery during treatment, and long-term monitoring after treatment completion. This review will highlight multiple rehabilitation targets, modes of service delivery, and interacting systems that impact the experience of a family facing pediatric cancer.

Service Delivery Challenges

Families require support as their child or adolescent faces oncological diagnosis and treatment. Long-term outcomes are improved when cancer and treatment are integrated into the family experience, rather than making the illness the focus of the family [10]. Rehabilitation must also be incorporated into the fabric of the family experience. This requires acknowledging the notable barriers to oncology patients' participation in inpatient and outpatient therapies. Families are often overwhelmed at initial diagnosis. With service delivery's shift

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from inpatient to outpatient settings [11], there is less opportunity for intensive inpatient rehabilitation. In addition, caregivers may prioritize oncology treatments (e.g., chemotherapy, radiation) over services that ameliorate long-term impacts of treatment. Together with the intensive nature of oncology treatment and side effects that can limit therapeutic engagement (e.g., fatigue, nausea, pain, poor nutrition precluding muscle development), it is understandable that patients and their families may struggle to fully engage in rehabilitation.

Given these challenges, a team of medical providers (e.g., physicians, nurse practitioners, and nurses), rehabilitative therapists (speech-language, occupational, physical therapy), and psychosocial providers (e.g., social work, child life, creative arts, psychologists) is needed to reinforce messages about importance of rehabilitation. This includes support navigating health care systems, monitoring functional abilities, and facilitating progress towards rehabilitation goals, as well as emphasizing the potential long-term risk of deferring prescribed therapies. This comprehensive approach can address family perception that they are not receiving information about ongoing psychological and rehabilitation needs [12].

Patient-Directed Interventions

Exercise/Physical Therapy

During and after treatment, children with cancer have decreased physical activity, muscle strength, balance, and cardiovascular condition compared with peers [13, 14]. This reflects sedentary hospital life, the impact of treatment on physical well-being (including low hemoglobin and platelet levels), and patient's reduced interest in physical activity [15]. After treatment, late effects may complicate patients' abilities to engage in physical activities. Structured exercise interventions are feasible and safe for pediatric oncology patients, with no adverse effects reported when completed according to protocol and under therapeutic supervision [16••]. Furthermore, on and after treatment, these interventions improve physical and physiological functioning (body composition, muscle strength, bone marrow density, motor skills, sleep) [13, 17, 18], mood [19], and overall quality of life [16••, 20] across cancer diagnoses.

Speech/Language Therapy

Speech and language therapy (SLT) needs can evolve over time for oncology patients. Swallowing and feeding concerns are the most frequent initial referral reasons [21]. In the acute phase, SLT may focus on dysarthria and dysphonia, word-finding strategies, compensatory memory strategies, and organizational supports. Over time, emphasis may shift to remediation of complex expressive language skills, including pragmatic speech and organization of language. Long-term SLT evaluation and therapy are often required for children who have experienced hearing loss secondary to tumor or treatment [22].

Occupational Therapy

Occupational therapies target fine motor abilities, completion of daily living activities (modification, safe task execution), and development and implementation of supportive devices (e.g., braces, adaptive equipment) [23]. Certain populations may have greater needs in specific domains, such as children with brain tumors requiring more support for daily living tasks and children with osteosarcomas requiring adaptive equipment. Some populations will require serial monitoring for emerging needs; for example, infants with retinoblastoma do not always demonstrate need for services at time of diagnosis, although serial screening may identify eventual need for interventions related to impacted visual abilities [24].

Psychological Consultation and Psychotherapy

When examining long-term adjustment after an oncology diagnosis, the majority of youth and their families do not report clinical levels of psychopathology [25]. A certain level of distress is typical during cancer treatment, although most symptoms remit over time [26]. Numerous randomized controlled trials have evaluated psychosocial interventions when they are necessary for pediatric oncology patients [27••]. Multiple studies demonstrate improved pain management and reduced distress with cognitive-behavioral methods [28, 29]. Support and intervention improves adjustment for both patients and their parents [30]. Of note, referral for brief psychological consultation early during stem cell transplant hospitalization predicted lower overall costs for the initial transplant admission [31].

Cognitive Remediation

Childhood cancers and treatment can impact cognitive functioning, particularly with CNS involvement (brain tumor, ALL), with difficulties including impaired attention, working memory, and processing speed [6]. Overall, cognitive training programs targeting neurocognitive effects of pediatric cancer improved attention, working memory, and math skills, without consistent improvement in executive functioning and reading abilities [32••]. Notably, traditional cognitive remediation requires significant time commitments from patients, families, and clinicians [33]. Consequently, efforts have been made to deliver interventions that improve cognitive functioning while reducing family burden.

One option is computerized cognitive training such as Cogmed, which provides tailored mass practice to improve working memory. Children complete each session

(30–45 min, 25 sessions over 5 weeks) with caregiver support and weekly clinician calls. For pediatric ALL and brain tumor patients, Cogmed has demonstrated feasibility, acceptability, and effectiveness in improving working memory, attention, and processing speed, during and after treatment [34–36]. Implementation of an online Cognitive Rehabilitation Curriculum (CRC) after pediatric cancer treatment found improvements in cognitive flexibility, processing speed, and memory [37]. Importantly, pediatric ALL and brain tumor patients have required more time to complete computerized intervention programs than peers [34, 37]. A double-blind randomized placebo-controlled trial revealed no unique positive effects for neurofeedback in a pediatric brain tumor cohort [38].

Sleep

For children, adolescents, and young adults (AYA) undergoing cancer treatment, sleep difficulties are common, including difficulty falling and staying asleep, and shifted sleep times [39], which also impacts sleep duration and sleep quality among caregivers [40]. These problems can continue after treatment ends [41, 42]. Within the adolescents and young adult (AYA) population, insomnia can be amenable to change with cognitive behavioral therapy [43]. It is also important to inquire about children's sleep hygiene and sleep-onset association, as habits related to co-sleeping and electronic device use may develop during treatment and persist after treatment completion. On-going sleep screening is encouraged.

Complementary and Alternative Medicine and Creative Arts

Complementary and alternative medicine (CAM; yoga, hypnosis, acupuncture) mitigate some physical and psychosocial effects of pediatric oncology treatment. Yoga has been found to decrease chemotherapy-related fatigue, decrease patient and parent anxiety, increase physical fitness, and improve quality of life [44, 45]. Hypnosis can be used to manage procedure-related pain, anxiety, nausea, and distress [46, 47]. Finally, acupuncture is a safe and feasible option to reduce pain, fatigue, insomnia, and anxiety [48–50].

Creative arts can benefit children and their families during and after cancer treatment. During hospitalization, music therapy improves patient overall well-being and mood [51, 52] and can continue to improve overall mood and quality of life after treatment completion [53]. Art therapy has also been used to help patients and their families increase self-awareness, cope with symptoms, and adapt to traumatic experiences [54–57]. Additionally, art therapy adds meaning and value for patients and their siblings during palliative care and at end-of-life [58].

Social Skills Groups

Survivors of childhood cancer are at risk for long-term social difficulties, including social isolation, low social competence, and social skill difficulties [59–62]. Social skills interventions have focused on pediatric brain tumor survivors, with results indicating positive parental and patient feedback, improvements in social skills, social competence, self-control, and quality of life [63–68].

Medication

Prescribed use of methylphenidate can improve cognitive and psychosocial functioning for childhood cancer survivors. Temporary reduction of attention and social deficits have been reported by parents, patients, and teachers [69, 70].

Caregiver and Family-Directed Interventions

Caregivers play a central role in engaging patients in therapeutic care, both during and after treatment. At the time of a child's cancer diagnosis, parents report being in "survival mode" [71], primarily focusing on the patient's immediate health. In time, parents are expected to weave clinic visits into daily routines, while continuing to cope with their child's diagnosis and prognosis. Given changes in expectations and needs throughout the oncology journey, it is understandable that caregivers may struggle to regulate their own stress and anxiety levels and manage typical disciplinary situations. Evidence suggests that parental distress can predict a child's level of functional impairment [72]. Supporting the family system includes providing services for siblings' of patients due to their increased risk for psychological dysfunction (mood difficulties, anxiety, traumatic stress) [73, 74].

Improvements in parental coping and reduced anxiety symptoms have been demonstrated via implementation of cognitive-behavioral and family therapies with parents/families of newly diagnosed children and of children receiving stem cell transplant [75, 76]. Problem solving interventions can increase parents' feelings of effectiveness and competence when navigating stressors [77], which is important in enabling families to gather information and obtain services. Interventions such as Bright IDEAS Problem-Solving Skills Training (PSST) decreases negative emotions and improve self-reported problem-solving skills, both immediately and 3 months following the intervention [78, 79••]. There is a current federally funded study exploring whether these skills can be developed via remote administration. Emerging evidence exists for the positive effect of parental problem solving on academic outcomes in youth with CNS-directed therapies [80]. Within a quality improvement framework, a single-session, problem-solving consultation targeting executive

function difficulties is being piloted with intent to increase family efficacy, reduce distress, and improve quality of life [81].

Tele-health Interventions

Increased delivery of individual and group tele-health behavioral health services has emerged to improve access to services and build upon AYA's comfort with technology. Targeted outcomes include physical exercise, psychosocial functioning and coping, neurocognitive issues, and mindfulness [82••, 83]. Remote intervention modalities are uniquely suited for post-treatment goals, since patients are often geographically remote from providers and survivor-peers. Intervention success has been attributed to service provided by an experienced pediatric psychologist, with some level of individualized face-to-face interaction recommended (e.g., one session) to increase likelihood of completing participation. Potential challenges include technical barriers (e.g., internet speed) and environmental distractions.

One individualized intervention with long-term (10 years post-treatment) AYA survivors demonstrated that in vivo and video conference administration of CBT-Insomnia (CBT-I) treatment were comparable in improving sleep quality [43]. In another individualized, largely remote intervention, long-term AYA survivors experienced a reduction in anxiety symptoms after ten writing sessions overseen via web-based responses through Onco-Step [84]. Anxiety and post-traumatic stress symptoms remained improved over many months, with high levels of patient satisfaction [83]. There is demonstrated feasibility of an online cognitive-behavioral group intervention for adolescent cancer survivors' age 12–18 years [85]. This program (OK Onco Online) used a secure chat room/homework site to deliver a small-group manualized intervention, including demonstration videos, online games, and opportunities for patients and their siblings to share their experiences with cancer. There was also psychologist-led instructions related to disease information, relaxation, social competence, and positive thinking. A group videoconference intervention with at-home assignments resulted in improved body image, sense of coping, and mindfulness, and fewer anxiety and depression symptoms among AYA survivors [86].

Smartphone applications (apps) may facilitate ongoing communication between patients and their providers, thereby more quickly identifying when re-screening for rehabilitation services is needed. These apps generally serve to provide information and education to the patient, to track symptoms (physical, mood, pain), and to increase access for peer support [87••]. Use of apps may be particularly appropriate during the transition into survivorship care, with a shift in rehabilitation needs (e.g., increased focus on independence and cognitive needs) and decrease in frequency of medical visits.

School Interventions

Upon school re-entry following diagnosis, children and adolescents may require formalized accommodations and interventions via 504 Accommodation Plans and Individualized Education Plans, which can be informed by multidisciplinary rehabilitation professionals. In addition, school personnel may be unaware of the cognitive late-effects of treatment. When school community members received information regarding treatment, students' feelings of social support at school improved [88]. In addition, school re-entry programs can have a positive impact on teachers, school staff, and peer adjustment and knowledge [89]. One person may serve as an intermediary between pediatric oncology providers, parents and students, and members of the school setting [90], providing direct information about diagnosis, treatment, possible impact on functioning, and potential late effects of the condition and treatment. This position is built into some large pediatric oncology centers. Some states (Pennsylvania, Colorado) providing a consultative school-re-entry team for children with acquired brain injury [91], including brain tumors. When children return to school, rehabilitation goals can be accomplished through coordinated school-based, at-home, and out-patient services.

Conclusions

Despite the understandable distress associated with a pediatric cancer diagnosis, families can be supported and empowered by an interdisciplinary team whose members consistently provide information, problem-solving assistance, and resources. Institutions may assist families by streamlining services through new delivery models, reducing logistic burdens, and connecting remotely with patients and survivors to expand service delivery and participation.

Across the trajectory of treatment, limited resources are a consistent barrier to rehabilitation service delivery. This includes pre-diagnosis family income and the impact of treatment on families' finances, including lost income, co-pays, travel costs, and out-of-network service payments [92, 93]. Families with limited resources may not have the time and parental availability necessary for therapy attendance or to serve as consistent in-home "coach" for cognitive remediation programs. As SES is a moderator of outcome in the long-term cognitive functioning of ALL and brain tumor survivors [94, 95], it is especially important to find ways to support and provide services for low-resource families.

One proposed method to increase participation in outpatient therapies is to embed providers and therapy appointments within an outpatient oncology clinic [96]. This model permits flexible scheduling and adaptations due to treatment and side effects. It also reduces travel costs, and facilitates continuity of

care. This model requires institutional commitment of protected therapist time and designated treatment space, with potential to significantly improve consistent access to rehabilitation care. Institutional support would also be needed to absorb non-reimbursement by health insurance for certain services (including tele-health and computerized interventions) and account for no-shows in provider productivity expectations.

Overall, rehabilitation services are essential at all phases of cancer treatment, with goals including preventing disability, restoring function that has been lost, and reducing burden of acquired disability [97]. The unique challenges within pediatric oncology necessitate flexible and creative therapeutic service delivery for patients and families as services are implemented during acute and prolonged treatment and well after treatment ends.

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