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Clinical Practice Guideline and Expert Consensus Recommendations for Rehabilitation among Children with Cancer: A Systematic Review

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Abstract

Increased attention to the rehabilitation needs of children with cancer is vital to enhance health, quality of life, and productivity outcomes. Among adults with cancer, rehabilitation recommendations are frequently incorporated into guidelines, but the extent to which recommendations exist for children is unknown. Reports included in this systematic review are guideline or expert consensus reports containing recommendations related to rehabilitation referral, evaluation, and/or intervention for individuals diagnosed with cancer during childhood (<18 years). Eligible reports were published in English January 2000 to August 2022. Through database searches, 42,982 records were identified; 62 records were identified through citation and website searching. Twenty-eight reports were included in the review: 18 guidelines and 10 expert consensuses. Rehabilitation recommendations were identified in disease-specific (e.g., acute lymphoblastic leukemia), impairment-specific (e.g., fatigue, neurocognition, pain), adolescent and young adult, and long-term follow-up reports. Example recommendations included physical activity and energy conservation techniques to address fatigue, referral to physical therapy for chronic pain management, ongoing psychosocial surveillance, and referral to speech language pathology for those with hearing loss. High-level evidence supported rehabilitation recommendations for long-term follow-up care, fatigue, and psychosocial/mental health screening. Few intervention recommendations were included in guideline and consensus reports. In this developing field, it is critical to include pediatric oncology rehabilitation providers in guideline and consensus development initiatives. This review enhances the availability and clarity of rehabilitation-relevant guidelines which can help prevent and mitigate cancer-related disability among children by supporting access to rehabilitation services.

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Keywords

Child; Rehabilitation; Cancer; practice guideline; consensus; survivorship

Introduction

Treatment advances have led to increased survival rates for children with most cancer diagnoses over the past several decades. Approximately 85% of children will survive five years or more following a new cancer diagnosis.[1] Unfortunately, increased cure rates come at a cost; many childhood cancer survivors (CCS) experience secondary treatment-related burden.[2–4] CCS experience challenges in a broad array of domains including physical, cognitive, psychosocial, mental health, and educational difficulties.[5–11] Compared to siblings, CCS have a higher prevalence of frailty, are significantly more likely to use special education services, and are five times more likely to experience functional impairments.[8,12–14] Many of these challenges persist into adulthood.[5,11,15] By young adulthood, many CCS are experiencing similar health challenges to middle age and older adults.[16,17] The combination of impaired health and function contribute to the economic burden of cancer.[18] In adulthood, CCS demonstrate higher annual productivity loss ($8,169 in 2014) compared to people without a cancer history ($3,803 in 2014).[18]

Despite the numerous physical, cognitive, and psychosocial challenges faced by CCS, there remains limited guidance on how to manage treatment toxicity to enhance health, quality of life, and productivity outcomes. Now that cure is frequently achieved, increased attention to the supportive care needs of CCS is vital.[2] Rehabilitation services, such as physical, occupational, and speech therapy and psychosocial support, are key aspects of supportive care and are a required standard for Commission on Cancer accreditation.[19] However, the current state of access to rehabilitation services among CCS is highly variable among published research. Across 330 US hospitals, only 27% of children diagnosed with acute lymphoblastic leukemia (ALL) received inpatient physical therapy (PT) within one year of diagnosis.[20] In contrast, at a single-institution with specific pediatric oncology rehabilitation programing, 96% of children with ALL received inpatient PT within a year of diagnosis.[21] Access to care also differs based on diagnosis and rehabilitation service, with speech therapy typically having lowest utilization rates (4–10%).[21,22] Among CCS five or more years post-treatment, 9% reported using PT services, a similar utilization rate to siblings.[23] These varying utilization rates highlight the lack of consistency in rehabilitation service provision in pediatric oncology.[24] Inconsistency in services may be due in part to the lack of a clear synthesis of evidence-based guideline recommendations.

In 2021, Stout et al. published a systematic review of rehabilitation recommendations in adult oncology guidelines.[25] A rigorous review of pediatric guidelines is also needed to ensure CCS receive optimal care and to enhance outcomes.[26,27] Detailing recommended care standards has the potential to improve the quality of and access to rehabilitation services.[25] The purpose of this systematic review was to summarize guideline and expert consensus recommendations related to rehabilitation referral, evaluation, and interventions for children with cancer.

Methods

This review followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses methodology and was registered in PROSPERO (CRD42021230539).[28] The review team consisted of researchers from: medicine (pediatric hematology/oncology; AK), occupational therapy (AL, SR), and physical therapy (BR). The team collaborated with a health sciences librarian with expertise in systematic reviews (KL) to develop the search strategy.

Clinical practice guidelines were identified based on the Institute of Medicine's criteria for trustworthy guidelines, which include the following characteristics: informed by a systematic review; developed by relevant experts from multiple stakeholder groups; inclusive of patient experiences and preferences when possible, utilizes a transparent, rigorous methodology; clearly presents options and subsequent health outcomes, as well as strength of recommendations and quality of evidence; and mechanisms for revising and updating to account for emerging evidence as needed.[29] Expert consensus statements were also included in the current review due to expected paucity of information regarding rehabilitation recommendations in available clinical practice guidelines. Expert consensus statements were defined as having been developed at a consensus conference or created by a team of relevant experts that used a combination of evidence and experience to formulate recommendations.

Search strategy and information sources

A systematic search of the literature was conducted in March 2021 and updated in August 2022 using the following databases: PubMed/MEDLINE, Cumulative Index of Nursing and allied Health Literature (CINAHL), EMBASE, SCOPUS, Web of Science, The Cochrane Library and Clinicaltrials.gov limited to a range of years from January 2000-August 2022 of each database. The controlled vocabulary of each database and plain language was used in creating a search strategy for the following terms: Search terms included ("neoplasms" OR "cancer" OR "cancers" OR "survivors" OR "cancer survivors") AND ("practice guidelines as topic" OR "guidelines" OR "guideline" OR "consensus") AND ("child" OR "adolescent" OR "children"). The final search results were limited to English language. The full database search strategy is outlined in Supporting Information File 1. Additional methods for identifying articles/guidelines included review of the following: reference lists of included articles and articles identified as relevant to the topic under investigation; National Comprehensive Cancer Network Clinical Practice Guidelines (nccn.org), clinical practice guidelines available on national rehabilitation organization websites, and additional online resources identified in Stout et al.'s 2021 systematic review. See Supporting Information Table 1 for additional sources of evidence.

Eligibility criteria

Eligibility criteria are outlined in Table 1. There were no exclusion criteria related to risk of bias assessment scores. Studies that included recommendations for both pediatric and adult populations were included but only pediatric-relevant information was extracted from those sources. Uncertainty about whether an article met eligibility (e.g., age group or methodology unclear) was resolved by contacting corresponding authors. When a response

was not received following two emails to the corresponding author, the article was ineligible for inclusion in the review due to lack of clarity on whether eligibility criteria were met.

Selection process

Studies returned from the search were uploaded into EndNote (original search) and a web-based systematic review software program for the updated search (Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia). Titles and abstracts were independently screened by a single reviewer (AL, BR). One team member (AL, BR) independently screened full texts to determine study eligibility. When disagreement regarding study eligibility occurred, discrepancies were resolved through team discussion; an external third reviewer (SR, AK) was consulted when needed for a final decision.

Data collection process

Independent data extraction was performed by two authors (AL, SR) using Covidence. Data were extracted using a custom data extraction form which was pilot tested on three included studies (AL, SR, BR). The extraction form was revised to capture additional data elements, enhance clarity of the form, and improve consistency in data extracted. Specific discussion points during pilot testing included level of detail to extract regarding rehabilitation recommendations, differences between clinical practice guidelines and expert consensus statements, and distinguishing between recommendations that were intended for individuals on or off treatment. Following training, two team members (AL, SR) independently completed extraction. Weekly feedback was provided to the secondary extractor (SR) in written reports and discrepancies were resolved via in-person or electronic communication in an ongoing process.

Data items

The data extraction tool (Supporting Information Table 2) consisted of the following sections: *general information* (title, first author, publication date, journal, country of authors/consensus, funding agency/mechanism), *eligibility criteria* (previously outlined), *characteristics of included studies* (number and specialty of experts involved in development, collaboration with survivors during development, professional organization supporting development), *methods* (aim/purpose of the study, process of guideline/consensus development), *characteristics of population to which guideline/consensus applies* (ages included, treatment time period, disease group, disease stage, other relevant characteristics), *recommendations for rehabilitation* (PT, OT, SLP, neuropsychology/psychology/mental health, rehabilitation medicine/physiatry; duration/frequency of treatment, outcome measures, targeted side effects, setting of recommendation). When there were no data available on a specific item (e.g., disease stage, setting of recommendation), it was assumed the guidelines were applicable to a broad group of individuals (e.g., any disease stage, inpatient or outpatient setting).

Study risk of bias assessment

Two reviewers (AL, SR) independently assessed methodological quality and risk of bias for all publications included in this review. The Appraisal Guidelines for Research &

Evaluation II (AGREE II)[30] was used to assess the quality of clinical practice guidelines. AGREE II is a 23-item tool developed to assess bias in 6 domains of clinical practice guidelines: scope and purpose, stakeholder involvement, rigor of development, clarity of presentation, applicability, and editorial independence.[30] Each item is scored on a 7-point Likert scale, with higher scores indicating better quality reporting.[30] For each domain, a percent coverage or summary score is calculated using the following formula: (total domain score – minimum possible domain score)/(maximum possible domain score – minimum possible domain score).[30]

The Joanna Briggs Institute critical appraisal checklist for narrative, expert opinion, and text[31] was used to evaluate expert consensus papers. The tool assesses seven key criteria (source of opinion, expert(s)' standing in field, patient interests, logic of opinion/consensus, analytical nature of argument, reference to literature, and support of peers) as well as an overall appraisal of include, exclude, or need to seek further information.[31] Two team members trialed risk of bias ratings on two included studies and discussed discrepancies to refine the rating process. Training conversations centered on identifying when sufficient detail was provided to receive high or low ratings on risk of bias instruments. Following pilot testing, two team members (AL, SR) independently completed all ratings. Iterative discussions via electronic or in-person communication were used to reach consensus on ratings that differed by more than two points on AGREE II and any discrepancy on the Joanna Briggs Institute tool.

Synthesis methods

Clinical practice guideline and expert consensus statements are reported separately in this review. Included studies were characterized based on the overarching topic of the guideline/consensus: disease type, impairment, long-term follow-up, age (adolescents and young adults), and additional rehabilitation recommendations, which are synthesized in separate tables. Recommendations with high levels of evidence to support them, as rated by the guideline/consensus developing team, are identified with an asterisk in each recommendations table. Approaches for evidence rating varied across reports but included use of systems such as Grading of Recommendations, Assessment, Development, and Evaluations (GRADE)[32] and the National Comprehensive Cancer Network categories of evidence.[33] Number of guidelines identifying recommendations for a specific discipline are depicted graphically. Summary of additional guideline characteristics (e.g., age range) are reported in supplemental tables.

Results

Twenty-eight reports were included in this review: 18 clinical practice guidelines and 10 expert consensus reports (Figure 1). Full-text reports were primarily excluded because they were not a guideline or expert consensus report (n= 262) or there were no recommendations relevant to rehabilitation (n= 145).

An average of 29 individuals (range: 11–83) were involved in the development of the included guidelines, of the 15 that reported these data (Supporting Information Table 3). Eight guidelines[34–41] included external consultants, typically content experts, in the

guideline review process. The number of individuals involved in developing consensus reports was more variable, ranging from 5 to more than 100 individuals, in the six papers reporting these data. The included reports were developed by groups across the world; half included individuals from multiple countries on the guideline or consensus development team. Guideline and consensus development groups included individuals from eleven countries (Australia, Austria, Belgium, Canada, Germany, Israel, Italy, Netherlands, Switzerland, United Kingdom, and United States) on two or more reports. Individuals from an additional 21 countries were involved in the development of one guideline or consensus report. Survivors or patient representatives/advocates were included in the development of 10 of 18 guidelines and 6 of 10 expert consensus reports (Supporting Information Table 3). Level of involvement ranged from review and appraisal of final recommendations to task force contributors to consensus conference attendees.

A variety of healthcare and research professionals were included in the development of recommendations. Physicians from a broad range of specialty areas (e.g., pediatric oncology, radiation oncology, pathology, etc.) were involved in the development of all but one report, which was an expert consensus on the role of nursing with children with brain tumors.[42] Examples of other disciplines involved in guidelines/consensus development included pharmacists, nutritionists, guideline methodologists, epidemiologists, and rehabilitation providers. Among rehabilitation disciplines, psychologists/neuropsychologists and PTs were most frequently included in guideline/consensus development. Rehabilitation medicine providers (e.g., physiatrists), OTs, and SLPs were rarely included in the development of pediatric oncology guidelines or consensus reports. Psychology and PT were also the disciplines most frequently discussed in the context of referral/evaluation/intervention in guidelines and expert consensus reports. SLP was least frequently discussed (Figure 2).

The included reports identified the need for rehabilitation involvement both on and off cancer treatment. Nine guidelines and two expert consensus reports provided recommendations for on and off treatment[39,42–51]; five guidelines and two expert consensus reports addressed the off-treatment phase only[34–36,40,52–54]; one expert consensus provided recommendations for on treatment only[55]; four guidelines and five expert consensuses provided rehabilitation recommendations for children with cancer but did not clearly specify timing/phase of treatment.[37,38,41,56–61]

Disease-specific recommendations

Four disease-specific clinical practice guidelines were identified, all published by the National Comprehensive Cancer Network (NCCN). Three guidelines were specific to pediatrics (acute lymphoblastic leukemia [ALL],[46] central nervous system [CNS] tumors,[48] and Hodgkin lymphoma[47]); the bone cancer guideline[45] included information for pediatric and adult cancers. The guideline recommendations addressed referral and evaluation needs for impairments across multiple functional domains (Table 2). Disease-specific guidelines did not contain information regarding recommended interventions.

Two papers outlined expert consensus recommendations for specific disease groups. One was specific to the care of children with CNS tumors and included multiple recommendations based on high-quality evidence, as noted in Table 2 and Supporting

Information Table 4.[42] The CNS tumor consensus report included several intervention recommendations such as working with educators to develop academic accommodations and pain management strategies.[42] Rossi et al. focused on rehabilitation recommendations in pediatric oncology and provided specific referral and evaluation recommendations for children with ALL, bone cancer, and CNS tumors.[51] Supplemental files are available in Rossi et al.'s publication with algorithm trees for rehabilitation evaluation pre, during, and post-treatment.[51]

Impairment-specific recommendations

Four impairment-specific guidelines were identified: two addressed fatigue,[49,50] one neurocognitive function,[56] and one chronic pain[41] (Table 3). Fatigue guidelines provided many recommendations for intervention focusing on physical activity, energy conservation and adaptive strategies, sleep hygiene, mindfulness/relaxation, psychological support, and cognitive-behavioral therapy.[49,50] In Jankowski et al. (2022) several recommendations were based on high-quality evidence and two recommendations in Robinson et al. (2018) were rated as strong recommendations based on a moderate level of evidence (Table 3; Supporting Information Table 4).

Physical activity to address fatigue should be tailored to the specific needs of the child/adolescent.[50] Additional caution should be taken when determining activity level among patients undergoing active treatment including bone metastases, thrombocytopenia, anemia, fever, active infection, post-surgery, limitations due to metastatic disease or comorbid illness, and safety issues through assessment of fall risk.[49] For patients who have completed treatment, cautions include identifying late effects of treatment (e.g., cardiomyopathy) and safety issues through assessment of fall risk.[49] Exercise should be recommended with caution in patients with fever, anemia, neutropenia, or thrombocytopenia after treatment.[49]

The neurocognitive function guideline provided numerous recommendations related to neurocognitive evaluation including domains to assess and timing of testing.[56] One intervention was recommended for neurocognition—targeted strategies such as educational accommodations.[56]

The guideline addressing chronic pain management[41] was developed by the World Health Organization and is not specific to individuals with cancer, but this guideline is endorsed by the Children's Oncology Group (COG) and was thus included in this synthesis. Chronic pain management should include PT, psychological, and/or pharmacological intervention and should be tailored to the child's health, underlying conditions, developmental age, physical, language, and cognitive abilities, and social and emotional needs.[41] Both fatigue and chronic pain interventions can be delivered either in person or remotely via telehealth,[41,49] particularly for patients in palliative care or who are not undergoing active treatment.[49]

Four expert consensuses addressed the topics of pain,[58] graft-versus-host disease (GVHD),[57,60] and audiologic monitoring.[55] Pain recommendations included referral to OT and PT, functional and psychosocial evaluation, and inclusion of psychosocial support services into care.[58] Detailed recommendations were provided for rehabilitation involvement with GVHD, particularly from the consensus report that was a National Institutes

of Health-initiated endeavor. Recommendations for neuromusculoskeletal evaluation, neuropsychological testing, adaptive functioning, body image issues, and fatigue were highlighted. Intervention recommendations were provided for joint contractures, strength, pain, musculoskeletal impairments, fatigue, mononeuropathies, and osteoporosis.[57] The second report focused on oral GVHD and was more limited in scope, recommending PT for a mouth opener for those with oral range of motion restrictions.[60] The last consensus report recommended audiology counselling on compensatory communication strategies and the potential need for SLP referral.[55]

Long-term follow-up recommendations

Seven guidelines addressed the long-term follow-up (LTFU) needs of CCS (Table 4). LTFU recommendations addressed the needs of CCS who have completed treatment. The specific timeframe for LTFU recommendations varied but were typically defined as a minimum of two- or five-years post-treatment. COG guidelines provided the most comprehensive recommendations for the population, outlining recommendations based on treatment history and impairments experienced. COG guidelines included numerous recommendations based on high-quality evidence linking the specified late effect with the treatment exposure (e.g., radiation) (Table 4; Supporting Information Table 4).[34] The Scottish Intercollegiate Guideline Network (SIGN) LTFU guideline provided neuropsychological, psychosocial, and physical activity recommendations for those who have completed treatment.[40] Four guideline recommendations were developed through the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) and addressed the topics of fatigue, ototoxicity, education and employment, and mental health.[35–38] IGHG guidelines focused on children and AYA survivors, defined as at least 75% of a study population being diagnosed with cancer before 30 years of age. Last, the Dutch Childhood Oncology Group (DCOG) described the organization of LTFU care and identified rehabilitation providers as key members of the multidisciplinary team but did not provide more detailed recommendations.[52]

DCOG also published recommendations for follow-up in children 5 years after diagnosis.[53] While these are labeled as guidelines by DCOG, they were assessed as an expert consensus as the report did not meet the IOM's key guideline criteria of being based on a systematic review. The DCOG expert consensus report discussed the care needs at identified late effects after pediatric cancer (LATER) expert centers.[53] DCOG provided recommendations for referral and evaluation in domains of education and employment, neurocognition, and mental health but did not provide any intervention recommendations. DCOG also recommended referral for speech therapy based on treatment exposure, PT for delayed motor development and to address oral cavity range of motion restrictions.[53] One additional expert consensus paper identified psychologists and PT as important healthcare providers to involve in care.[54]

Adolescent and young adult (AYA) recommendations

Two guidelines addressed the rehabilitation needs of AYAs, defined as 15 to 39 years at diagnosis, one published by NCCN[44] and the other by Alberta Health Services.[43] Guidelines identified the need for rehabilitation support in the domains of education/

employment, neurocognition, physical activity, and psychosocial/mental health (Table 5). Incorporating physical activity throughout the care continuum was recommended to address physical and psychological health and potentially reduce cancer-related fatigue.[44] The most comprehensive recommendations were provided for psychosocial/mental health evaluation and intervention. AYA guidelines uniquely highlighted the need to evaluate for financial toxicity and refer to mental health support for further assessment of toxicity.[44] Involvement of mental health professionals was recommended in a broad range of areas such as education on peer support opportunities, supporting adherence to medical care, and developing legacy projects at end of life.[43,44]

Additional rehabilitation recommendations

One guideline and three expert consensus reports provided recommendations related to rehabilitation that could not be classified as disease, impairment, LTFU, or age-specific recommendations (Table 6). The guideline was developed by the National Institute for Health and Clinical Excellence (NICE) in the UK.[39] The NICE guideline highlights the need for timely and equitable access to rehabilitation services as well as the importance of having clear routes of referral. The expert consensus reports covered a range of areas. The international pediatric oncology exercise guidelines (iPOEG) highlight that movement and exercise are safe among children and adolescents living with and beyond cancer and may provide benefits such as decreased fatigue and anxiety and improved strength and quality of life.[61] Involvement of PT and physiatry are highlighted in iPOEG related to exercise prescription. Another consensus recommendation report focused on the psychosocial educational and coping needs of patients and families.[59]

The only report identified that aimed specifically to outline rehabilitation recommendations for children with cancer was the result of an Italian consensus conference on the role of rehabilitation among children and adolescents with leukemia, CNS, and bone tumors.[51] Rossi et al. provided a number of recommendations, primarily in the area of rehabilitation assessment—when assessment should/should not occur and domains to evaluate.[51] This rehabilitation consensus report included numerous strong recommendations, but they were based on evidence of low or very low quality.

Risk of Bias Assessment

Supporting Information Table 5 provides a summary of each clinical practice guideline's AGREE II domain scores. Guidelines received higher ratings in domains 4 (clarity of presentation) and 6 (editorial independence). Lowest domain scores were in domain 5 (applicability).

For the Joanna Briggs Institute appraisal of consensus reports, item 3 (interests of patients/clients the central focus of opinion) was rated as "yes" for all 10 included expert consensus statements. Item 1 (source of opinion clearly identified) received the most "no" ratings across all 10 studies. Six of 10 reports received "unclear" ratings for item 2 (source of opinion have standing in the field of expertise) and item 7 (opinion supported by peers).

Discussion

Recommendations for rehabilitation referral, evaluation, and treatment are included in a broad range of pediatric oncology guidelines. Eighteen guidelines and 10 expert consensus reports were identified that include rehabilitation recommendations for children with cancer, a much smaller evidence base than the 69 adult-focused guidelines identified by Stout et al.[25] This report provides a comprehensive synthesis of available recommendations and can be used as a practical guide for clinicians, including both oncology providers and rehabilitation team members, to support comprehensive cancer care. Categorization of recommendations (Tables 2 through 6) allows for easy identification of rehabilitation recommendations based on a child's disease type, clinical presentation, age, stage of treatment, and high-quality evidence. Results of this systematic review can support more consistent and efficient use of available pediatric oncology rehabilitation guideline and consensus recommendations by increasing knowledge among pediatric oncology practitioners.[62] This is an early step toward breaking down silos of information that occur due to separation of medical and disease specialties.

The complexity of oncology guidelines can be a barrier to their implementation.[63] Rehabilitation recommendations are buried within guidelines detailing treatment protocols, risks/benefits of treatment, and disease surveillance recommendations. In a small sample of Canadian rehabilitation clinicians working in pediatric oncology, 61% reported they do not follow any rehabilitation clinical practice guidelines.[64] Of those who reported using guidelines, more than half used guidelines related to adult oncology rather than children.[64] The limited uptake of guidelines among rehabilitation clinicians may be in part due to the perception that there are no available clinical practice guidelines specific to pediatric oncology rehabilitation.[64] The current systematic review highlights that there are extensive recommendations related to rehabilitation involvement with children with cancer and makes these recommendations more accessible to a broad audience.

Guideline-concordant care and further development of pediatric oncology rehabilitation guidelines is critical to enhancing the care and outcomes of children with cancer. Given the challenges with pediatric oncology supportive care guideline adherence,[62] oftentimes low rehabilitation utilization rates among this population,[20,22,23] and lack of available comprehensive pediatric oncology rehabilitation programs,[22] it is suspected adherence is suboptimal. Adhering to guidelines may increase the number of children referred to rehabilitation and can support equity in how rehabilitation services are provided within pediatric oncology. Strategies to support adherence may include use of automatic orders for rehabilitation referrals, clinical champions, and interdisciplinary team collaboration.[21,22,24] Available guidelines do have some limitations, however, including recommendations that are sometimes too vague to inform care (e.g., recommendation for evidence-based rehabilitation training) and are based on low-quality evidence. Recommendations based on high-quality evidence focused on LTFU care, fatigue, and psychosocial/mental health screening (Supporting Information Table 4). There was also a paucity of intervention recommendations. For example, many recommendations were provided for neurocognitive evaluation, but there was an absence of intervention recommendations, a critical gap to intervening when deficits are identified.

In addition to increasing adherence to available recommendations, there is a need for further guideline and consensus development efforts to capture the full scope of rehabilitation practice. There are no pediatric oncology guidelines developed by rehabilitation organizations, but rehabilitation organizations have developed guidelines for adults with cancer.[25] Moving forward, rehabilitation organizations need to champion pediatric oncology guideline/consensus development efforts. Including more rehabilitation professionals in the development of pediatric oncology guidelines is also critical. Very few OTs, SLPs, and physiatrists were included in guideline/consensus development efforts. As a result, the scope of recommendations for OT and SLP are limited because their voices and knowledge are not being captured and communicated with current approaches. Most guidelines are updated frequently (at least annually for NCCN), providing immediate opportunities to incorporate the knowledge and experiences of rehabilitation professionals. Including rehabilitation providers in development efforts can support integration of emerging rehabilitation evidence and broaden the scope of recommendations in this rapidly evolving field.[25]

Limitations

Expert consensus reports were included in this review, which introduces publications with a lower level of rigor in their development than clinical practice guidelines. Inclusion of expert consensus reports is a strength in the context of a developing field such as pediatric oncology rehabilitation to include a broader body of literature outlining clinical recommendations. Results were reported in a way that clearly delineates guideline and consensus recommendations.

Approaches for assessing and reporting the quality/certainty of evidence varied across guideline and consensus reports, making comparisons difficult. Challenges with grading quality of evidence were also reported by Stout et al.[25] In the current review, AGREE II was used to assess rigor in guideline development, accounting for their grading of the quality of evidence. Last, only English-language publications were considered for inclusion in this review. Despite this, numerous international guidelines were identified demonstrating broad guideline applicability beyond English-speaking countries.

Conclusion

Guidelines exist recommending involvement of rehabilitation in the care of children with cancer throughout the care continuum. Interventions recommendations were sparse, potentially due to the developing nature of the field. The extent to which guideline and consensus recommendations are followed in clinical practice is unknown and should be examined in future research. Rehabilitation providers from multiple disciplines (PT, OT, SLP, etc.) should be involved in pediatric oncology guideline development and rehabilitation organizations need to initiate guideline/consensus efforts for the care of children with cancer.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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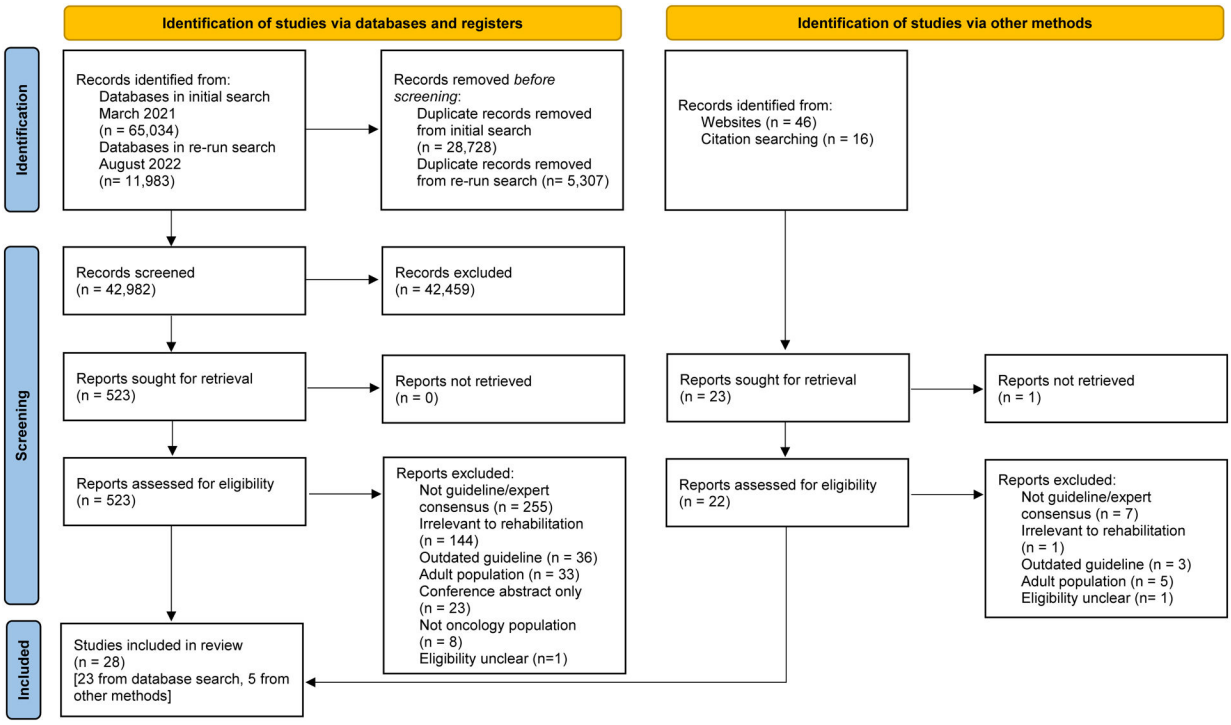

Figure 1.
Preferred Reporting Items for Systematic Reviews and Meta-Analyses Diagram

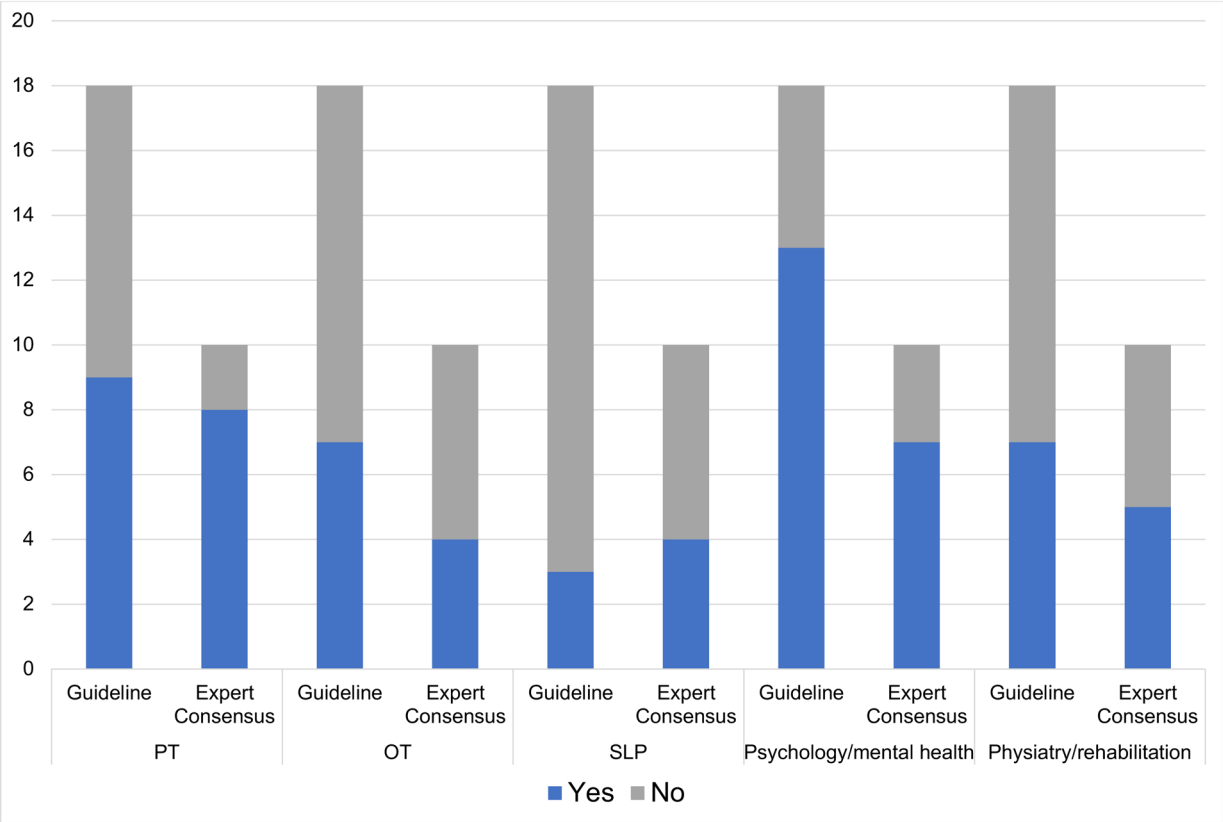

Figure 2.

Number of Guidelines and Expert Consensus Reports in which each Discipline is Mentioned in the Context of Referral, Evaluation, or Intervention

Table 1.

Inclusion and exclusion criteria for guideline and consensus reports

Inclusion	Exclusion
• Guideline formed from a systematic review of the evidence OR expert consensus detailing methodology for consensus development (e.g., Delphi methodology used, described rating process for how consensus was reached, included a review of the literature and findings/recommendations were discussed among consensus group) • Included recommendations for children (birth to 18 years) with a diagnosis of cancer, on or off medical cancer treatment; can also include recommendations for adult survivors of childhood cancer (diagnosed before 18) • Provided recommendations related to referral, evaluation, or interventions within the scope of physical therapy (PT), occupational therapy (OT), speech language pathology (SLP), psychology/neuropsychology, or physiatry • Published in English • Published January 2000 to August 2022	• Lacking a clear and transparent methodology to identify the publication as a guideline or consensus report (e.g., not based on a systematic review for guidelines or literature review for consensus reports; consensus reports were excluded if there was discussion of a consensus conference but no details were provided on how consensus was achieved or a literature review upon which the recommendations were based) • Included recommendations for individuals diagnosed after 18-years-old • Did not provide recommendations for individuals with cancer • Lacks recommendations within the scope of rehabilitation practice • Outdated guidelines (i.e., relevant guideline published in 2010 was updated in 2020; only the most updated guideline version was eligible) • Conference abstract only available

Table 2.

Disease-specific recommendations

Disease Group	Recommendation
	Guideline Recommendations
Pediatric ALL	***Referral***
	• PT for footdrop and other motor neuropathies secondary to vincristine.[46]
	Evaluation
	• Neurocognitive monitoring at baseline, during therapy, and at completion of treatment and/or school entry or re-entry for all patients.[46]
	• Neuropsychological testing as indicated or if there is evidence of new concerns or change.[46]
Bone cancer	***Referral***
	• Surgery: physiatry to evaluate for mobility training and prescription of an appropriate rehabilitation program.[45]
	Access/include in multidisciplinary team
	• Physiatrist in certain cases.[45]
Pediatric CNS tumors	***Referral***
	• Preoperative assessment: refer to PT, OT, and swallow assessment for comorbidity management.[48]
	Access/include in multidisciplinary team
	• Access to a neuro-rehabilitation service, even years after treatment.[39]
Pediatric Hodgkin Lymphoma	***Referral***
	• Counseling as needed to address psychosocial concerns.[47]
	Evaluation
	• Psychosocial assessment during work-up, prior to incisional biopsy and immunohistory chemistry evaluation; during disease surveillance/follow-up post-treatment; and during treatment for relapsed or refractory disease.[47]
	Intervention
	• Encourage patients to undergo counseling on issues regarding survivorship, long-term treatment effects, and psychosocial issues.[47]
	Expert Consensus Recommendations
Pediatric ALL	***Referral***
	• Most children with leukemia require PT and OT.[51]
	Evaluation
	• Rehabilitation assessment is feasible in all treatment phases.[51]
	• Evaluate global and fine functional abilities, balance, range of motion, and muscle.[51]
Bone cancer	***Referral***
	• Most children with bone tumors require PT and OT.[51]
	Evaluation
	• Rehabilitation evaluation before surgery to develop an intervention plan to prepare for surgery.[51]
	• Rehabilitation assessment should be performed at regular intervals after surgery (e.g., 1, 3, 6, 9, 12, and 24 months after surgery).[51]

Disease Group	Recommendation
	• Evaluate muscle strength, range of motion, skin, functional abilities, possible peripheral deficits, and the need for prostheses.[51]
CNS tumors	***Referral***
	• PT and OT for restorative exercises and compensatory strategies to address muscle weakness and low physical performance.[42]*
	• PT for pain management.[42]
	• Speech-language hearing screen/evaluation as needed.[42]
	• SLP to assess aspiration risk/swallowing impairment before attempting oral feedings following posterior fossa resection.[42]
	• Rehabilitation services to improve function after brain tumor resection.[42]
	• Neuropsychological testing as appropriate to address decrease in social adjustment following brain tumor treatment.[42]*
	• Neurocognitive evaluation, audiology, and neuro-ophthalmology when indicated for children who undergo radiation therapy, particularly those under three years.[42]
	• Nurses should coordinate referrals for assistance with academic needs, psychological assessment, and LTFU.[42]
	Evaluation
	• Complete rehabilitation assessment immediately after surgery, as soon as clinical conditions allow.[51]
	• Rehabilitation evaluation at least at beginning and end of adjuvant treatment.[51]
	• Rehabilitation assessment annually at preschool age and every 6-months at school age following antineoplastic treatments.[51]
	• Rehabilitation assessment should be adapted based on the patient's clinical needs, type of surgery, and tumor location. Assessment should always include global aspects (balance, muscle tone, sensitivity, neuromotor and psychomotor function) and, as needed, site-specific aspects (e.g., ataxia and cranial nerve function for tumors of the posterior cranial fossa and brainstem, spasticity for tumors involving the corticospinal tracts, sphincter function for medullary tumors).[51]
	• Early assessment and intervention for PT and psychosocial services, especially for female survivors.[42]
	• Nurses should work with multidisciplinary team to complete comprehensive neurocognitive assessment and evaluation of academic achievement.[42]*
	• Neuropsychological evaluation for patients with cerebellar mutism syndrome post-operatively.[42]
	Intervention
	• Multidisciplinary team (school teachers, parents, patients, nurses, neuropsychologist) should provide input into Individualized Education Program to promote school achievement and inform parents and teachers about cognitive sequelae.[42]*
	• Promote cognitive-behavioral training within the school system as needed.[42]
	• Work with educators to encourage provision of academic accommodations (e.g., allowing more time to process information, one-on-one i322141MCnstruction, reduced stimulation).[42]
	• Home-based, computerized cognitive training programs.[42]*
	• Interactive intervention and cognitive behavioral strategies that can minimize anxiety and distress, improve physiological responses (heart rate), and decrease risks for complications associated with anesthesia/sedation for radiation therapy. Help parents prepare child for radiation therapy and anticipate potential stressors to reduce overall distress.[42]
	• Nonpharmacological and integrative pain management at end of life can include physical comforts, distraction, cognitive-behavioral methods.[42]
	Access/include in multidisciplinary team
	• Children with CNS tumors require PT, OT, SLP, and neuropsychologists.[51]

*Indicates recommendation is supported by highest level of evidence. In Ledet et al., Level I recommendations are supported by Class 1 evidence (randomized controlled trials or meta-analyses).

Table 3.

Impairment-specific recommendations

Impairment	Recommendation
	Guideline Recommendations
Fatigue	***Referral***
	• Fatigue specialist or supportive care provider (e.g., survivorship, palliative care, integrative oncology, psychology, psychiatry, PT, OT, physical medicine) for fatigue evaluation and management from diagnosis to end of life.[49]
	• Exercise specialists (e.g., PT, physical medicine, rehabilitation specialist) as indicated for assessment and exercise prescription.[49]
	• Patients who have completed treatment:
	– Physiatrist or a supervised rehabilitation program if patient is significantly deconditioned, weak, or has relevant treatment late effects (e.g., cardiopulmonary limitations).[49]
	Evaluation
	• A healthcare provider or exercise expert (e.g., physiatrist, PT) should assess the patient's conditioning level before recommending an exercise program.[49]
	• Patients with moderate to severe fatigue: ask about functional status, changes to exercise/activity patterns, and the impact of deconditioning. The following questions are important when developing a treatment plan that may include exercise:[49]
	– Can patients accomplish normal daily or enjoyable activities?
	– Can they participate in formal/informal exercise programs?
	– How often and for how long do they exercise?
	– Have they modified exercise or activity patterns due to fatigue?
	• Evaluating and addressing cognitive impairments at end of life may reduce fatigue severity.[49]
	Intervention
	• Physical activity
	– Active treatment: maintain optimal level of activity; consider starting and/or encouraging maintenance of physical activity or exercise program, as appropriate, consisting of cardiovascular endurance (walking, jogging, swimming) and resistance (weights) training; yoga.[49] *
	– Patients who have completed treatment: physical activity is recommended.[49] *
	♦ Cardiovascular endurance (e.g. walking, swimming) and resistance training (i.e., weight training) may be encouraged.[49]
	– End of life: optimize level of physical activity with consideration of recommendations for PT and OT.[49]
	– When establishing exercise program, start with discussion and low-level activities which can be gradually increased, especially in individuals who are very deconditioned.[49]
	– Management of fatigue in children and adolescents with cancer or post hematopoietic cell transplant (HCT).[50] [strong recommendation based on moderate level of evidence]
	– Encourage physical activity in infants and young children through play.[50]
	– Children receiving intensive chemotherapy and undergoing HCT as young as 8 years old can participate in yoga.[50]
	– Aerobic, neuromotor, or combination exercises may be more effective for reducing fatigue.[50]
	• Energy conservation and adaptive strategies
	– Energy conservation helps patients set realistic expectations, prioritize and pace activities, and delegate less essential activities.[49]
	– Counsel patients that it is okay to postpone nonessential activities when experiencing moderate-to-severe fatigue.[49]

Impairment	Recommendation
	– Use labor-saving strategies such as wearing a bath robe instead of drying off with a towel; assistive devices such as a walker, grabbing tools, bedside commode. Recommend keeping a daily/weekly log/diary that facilitates self-monitoring of fatigue levels to determine peak energy periods and plan activities accordingly.[49]
	– If experiencing escalating fatigue at end of life, family members/caregivers may have other individuals take over activities the individual with cancer has relinquished.[49]
	• Sleep hygiene
	– Consistent bedtime routine, an environment conducive to sleep, and the presence of security objects (such as blankets and toys) for children.[49]
	– Promote positive sleep hygiene through creating an environment conducive to sleep (e.g., dark, quiet, comfortable). Engage in stress-reducing activities before bed such as reading, journaling, yoga, meditation, or listening to quiet music. Younger patients are prone to engaging in poor sleep hygiene activities (e.g., late-night gaming, computer and cell phone use, social media use) that interfere with sleep.[49]
	– Daytime naps can help replenish energy, but these should be limited so they do not interfere with nighttime sleep quality.[49]
	• Active treatment:
	– Physically based therapies (massage, acupuncture)[49]
	– Cognitive behavioral therapy (CBT)/behavioral therapy[49]*
	– Psycho-educational therapies/educational therapies[49]*
	– Supportive expressive therapies (e.g., in-person or online support groups, counseling, journal writing) may serve as an emotional outlet and as a support network[49]
	• Patients who have completed treatment:
	– CBT for insomnia.[49]*
	– Psycho-educational therapies/educational therapies[49]*
	– Stimulus control/sleep restriction/sleep hygiene.[49]
	– Supportive expressive therapies[49]
	• Patients should be counseled regarding coping with fatigue and educated about anxiety and depression, which are commonly associated with fatigue during cancer treatment.[49]
	• Relaxation and/or mindfulness among children/adolescents who can participate.[50] [strong recommendation based on moderate level of evidence]
	• Muscle relaxation, music therapy, hypnosis, arts therapy, and mindfulness-based stress reduction in combination with CBT may be effective at reducing fatigue in people with cancer.[49]*
	• When other recommended approaches (physical activity, mindfulness, relaxation) are not feasible or successful, cognitive or CBT may be used with children/adolescents who can participate in these interventions; intervene early.[50]
Neurocognitive function	***Referral***
	• Identify patients in greatest need for neurocognitive assessment: treatment history indicating risk for cognitive late effects including those with CNS pathology, CNS radiation therapy or total brain irradiation, history of HCT (with or without GVHD). Special focus on those who experience cytokine release syndrome or immune effector cell-associated neurotoxicity syndrome and children < 6 years at time of treatment.[56]
	Evaluation
	• Testing should focus on cognitive domains potentially at-risk due to HSCT, CAR T-cell therapy, and other immunotherapies.[56]
	– Attention, working memory, executive functioning, processing speed, language, motor coordination, and academic achievement.[56]
	– Brief intellectual estimate recommended unless total brain irradiation/craniospinal irradiation was received.[56]
	• Measures should be appropriate for administration at key time points relevant for HCT, CAR-T cell therapy, and other immunotherapies.[56]

Impairment	Recommendation
	– Pretreatment assessment may be important. May need to rely on parent report if patient cannot participate in cognitive testing before HSCT or CAR-T cell therapy.[56]
	– Parent proxy measures can include Behavior Rating Inventory of Executive Function (BRIEF) or NIH Patient-Reported Outcomes Measurement Information System (PROMIS) Cognition scale.[56]
	• Recommended timing for cognitive assessment include before HCT/cellular therapies, 1 year, 2 year, and 4/5 years after HCT/cellular therapies.[56]
	– Follow-up evaluation of emerging higher-order cognitive skills over time is recommended, but timing and frequency unclear.[56]
	• Due to fatigue experienced by individuals undergoing HCT/cellular therapies, shorter cognitive evaluation may be needed. Need to identify specific relevant cognitive subtests within broader assessment based on the patient's treatment history and presentation.[56]
	• Identify measures that can be administered across the lifespan or have well-established correlations (e.g., Weschler preschool, childhood, adult batteries).[56]
	• Select measures that have alternate forms for repeat assessment over time, when possible.[56]
	• Cellular therapies: brief academic screen may be appropriate in pre-infusion assessment and subsequent follow-up visits.[56]
	• Use patient age to guide selection of measures. Some cognitive domains (e.g., executive function) will not be appropriate to evaluate until later childhood.[56]
	• When assessing risk for cognitive deficits, consider prior treatment and potential impact over time.[56]
	Intervention
	• Targeted strategies (e.g., educational accommodations, job training programs).[56]
	Access/involve in multidisciplinary team
	• Access to neurocognitive evaluations may vary at different centers and may be complicated by insurance or other factors. A triage process to best allocate resources is needed.[56]
Pain (chronic)	***Referral***
	• Manage pain with PT, psychological and/or pharmacological interventions.[41]
	Intervention
	• Psychological management through CBT and related interventions (acceptance and commitment therapy, behavioral therapy, and relaxation therapy) may be used.[41]
	Expert Consensus Recommendations
GVHD (chronic)	***Referral***
	• Recommend PT, home-based exercise program, encouragement and resources for strength training and aerobics.[57]
	• To address neuropathy and myopathy: rehabilitation medicine consultation with PT and OT for all patients with decreased ability to perform activities of daily living or impaired quality of life because of pain or muscle weakness.[57]
	• Refer to physical medicine and rehabilitation when patient cannot walk in 20–30-minute intervals.[57]
	• Perioral cutaneous scleroderma-like involvement and mucosal fibrosis: refer to PT for those with restricted mouth opening.[60]
	• Prevention and treatment of musculoskeletal impairments: PT.[57]
	Evaluation
	• Comprehensive neuromusculoskeletal strength testing, range of motion of affected joints, limb girth, pain, mobility, stamina, activities of daily living, and subjective measures of disability.[57]
	• PT should assess range of motion if joint limitations are present every 3–12 months during systemic immunosuppressive therapy.[57]
	• Monitor for symptoms of carpal tunnel syndrome, ulnar neuropathy at the elbow, and peroneal neuropathy at the fibular head. Electromyography and nerve conduction study can diagnose and grade the severity of mononeuropathies.[57]

Impairment	Recommendation
	• Brief neuropsychological testing if cognitive deficits interrupt daily activities and safety.[57]
	• Neuropsychological evaluation at one year and annual targeted brief screenings if cognitive or learning deficits are identified.[57]
	• Mood, behavioral, academic, and adaptive functioning difficulties: screen before transplantation, at 6 and 12 months, and then annually with **referral** for cognitive behavioral interventions as indicated.[57]
	• Body image issues and fatigue: query at 6 and 12 months, and then annually with **referral** for cognitive behavioral and supportive interventions as indicated.[57]
	Intervention
	• Focus on early intervention and prevention of severe joint contractures and deconditioning and restoration of range of motion, strength, mobility, and pain relief.[57]
	• Treatment for neurologic organ system[57]:
	– OT and PT to prevent falls and improve function.[57]
	– Orthotics and assistive devices (cane and walkers)[57]
	– Bracing and splinting.[57] *
	• Musculoskeletal impairments[57]:
	– Spinal orthosis for instability and/or intractable pain
	– Walking program, resistance training, core strengthening
	• Management of fatigue and musculoskeletal symptoms: gradually increasing exercise regimen, activity pacing, cognitive behavioral strategies, and sometimes medication.[57]
	• Mononeuropathies: bracing, splinting, off-loading the affected area, or surgical release.[57]
	• Prevention and management of osteoporosis:[57]
	– Spinal orthotic bracing if intractable pain, evidence of neurologic compromise, or unstable spine. Early mobilization with the brace and pain control are the priority. Consult with spine surgery and physical medicine and rehabilitation physician should be strongly considered.[57]
	– Weight-bearing exercise (e.g., walking in 20–30-minute intervals).[57]
	• Exercise should be encouraged based on physician recommendations or through a cancer-trained group program to maintain muscle strength, including strength training, not only aerobic activity.[57]
	• Sclerotic manifestations of oral chronic GVHD:[57]
	– Stretching exercises with or without the use of a PT device to increase range of motion of mouth.[57]
	• Perioral cutaneous scleroderma-like involvement and mucosal fibrosis:[60]
	– Mouth-opener for a few weeks (linked to PT).
	Access/include in multidisciplinary team
	• Multidisciplinary team is key to managing chronic GVHD with consultations from physical medicine and rehabilitation, PT, and OT.[57]
Hearing loss	***Referral and intervention***
	• Audiologist may counsel about implication of a change in hearing and suggest compensatory communication strategies to mitigate the effects of hearing loss. This may ease transition to and advocacy for posttreatment interventions such as SLP and hearing assistance equipment.[55]
Pain	***Referral***
	• OT and PT for pain management.[58]
	Evaluation
	• Level of function (activity of daily living scale, performance status, mood, sleep patterns, mental concentration).[58]
	• Physical, functional, psychological distress, spiritual dimensions, and other factors that affect "the pain experience" should be assessed.[58]

Impairment	Recommendation
	• Social history- psychosocial impact of pain on family, work, and social life.[58]
	Access/involve in multidisciplinary team
	• Use of psychosocial services and other pain relief specialists is imperative. Promote access to and understanding of psychosocial support services.[58]
	• Need for interdisciplinary team: social worker, spiritual care provider, psychologist, and other counselors.[58]

* Indicates recommendation based on the highest quality of evidence. Jankowski et al. followed NCCN evidence rating methods where category 1 recommendations are based on high-level evidence and there is uniform consensus that the intervention is appropriate. Carpenter et al. rated bracing/splinting as high quality evidence from at least one randomized controlled trial, but from an analogous or other relevant disease group.

Table 4.

Long-term follow-up recommendations

Specification	Recommendation
	Guideline Recommendations
Patients who received chemotherapy	***Referral paired with assessment or intervention recommendations***
	• Carboplatin, cisplatin: may experience peripheral sensory neuropathy (paresthesias, dysesthesias) and vinblastine, vincristine: may experience areflexia, weakness, foot drop, paresthesias, dysthesias.[34]
	– PT for patients with symptomatic neuropathy.[34]
	– PT and OT to assess hand function.[34]
	• Carboplatin [myeloablative doses], cisplatin: may experience ototoxicity (sensorineural hearing loss, tinnitus, vertigo).[34]
	– SLP for patients with hearing loss.[34]*
	– Patients with auditory deficits: refer to school liaison in community or cancer center (psychologist, social worker, school counselor) to facilitate acquisition of educational resources.[34]*
	• Corticosteroids, dexamethasone, prednisone: may experience osteonecrosis (avascular necrosis).[34]
	– PT for pain management, range of motion, strengthening, stretching, functional mobility.[34]*
	• Cytarabine, methotrexate: may experience neurocognitive deficits, such as functional deficits in executive function, sustained attention, memory, processing speed, visual-motor integration, fine motor dexterity; learning deficits in math and reading; diminished IQ; behavioral change.[34]
	– Neuropsychological evaluation: baseline at entry into LTFU, then as clinically indicated for patients with evidence of impaired education or vocational progress.[34]
	– School liaison to facilitate acquisition of educational resources and/or social skills trainings.[34]
	– Community services for vocational rehabilitation or for services for individuals with developmental disabilities.[34]*[a]
	– Evidence-based rehabilitation training.[34]
Patients who received radiation	***Referral paired with assessment or intervention recommendations***
	• Head/brain:
	– PT and OT as clinically indicated among those experiencing cerebrovascular complications (stroke, moyamoya, occlusive cerebral vasculopathy, cavernomas).[34]*
	– Consultation with psychologist in patients with adjustment disorders related to facial asymmetry/deformity.[34]*
	– Visual deficits due to ocular toxicity: refer to school liaison to help acquire educational resources.[34]
	– Children who will receive cranial irradiation should undergo a neuropsychological assessment at the start of treatment and annually thereafter.[40]
	• Head/brain, total brain irradiation[34]
	– SLP for patients with hearing loss.[34]*
	– Patients with auditory deficits: refer to school liaison to facilitate acquisition of educational resources. Evaluate for specific needs and/or preferential classroom seating, frequency modulation amplification system, and other educational assistance, as indicated.[34]*
	– Evidence-based rehabilitation training for those who experience neurocognitive deficits.[34]
	– Neuropsychological evaluation: baseline at entry into LTFU, then periodically as clinically indicated for patients with evidence of impaired education or vocational progress.[34]
	• Pelvics:[34]

Specification	Recommendation
	– Psychological consult in patients with emotional difficulties related to vaginal fibrosis/stenosis.[34]
Patients who had surgery	***Referral paired with assessment or intervention recommendations***
	• Amputation or limb sparing procedure[34]
	– PT as needed based on changing physical status (amputation: weight gain, gait training with new prosthesis; limb sparing: post-lengthening, revisions, life changes such as pregnancy) and for pain management.[34]*
	– OT to assist with activities of daily living (listed only for amputation).[34]*
	– Psychology/social work to assist with emotional difficulties related to body image, marriage, pregnancy, parenting, employment, insurance, depression, or sexual health.[34]*
	– Vocational counseling/training to identify vocations that will not produce/exacerbate functional limitations.[34]*
	• Neurosurgery (brain): may experience motor and/or sensory deficits (paralysis, movement disorders, ataxia, eye problems)[34]
	– PT, OT, and SLP for those with persistent deficits.[34]*
	– Evaluation by physiatrist/rehabilitation medicine specialist in patients with motor dysfunction.[34]*
	– Evidence-based rehabilitation training for those who experience neurocognitive deficits.[34]
	• Neurosurgery (brain): may experience neurocognitive deficits
	– Neuropsychological evaluation: baseline at entry into LTFU, then periodically as clinically indicated for patients with evidence of impaired education or vocational progress.[34]
	• Enucleation: may experience impaired cosmesis, poor prosthetic fit, orbital hypoplasia[34]
	– Psychological consultation in patients with emotional difficulties related to cosmetic and visual impairment.[34]*
	– Vocational rehabilitation as clinically indicated.[34]*
	• Orchiectomy: may experience testicular hormonal dysfunction, impaired spermatogenesis[34]
	– Psychological referral because orchiectomy can be associated with psychological distress related to body image.[34]
Patients who had hematopoietic cell transplant	***Referral paired with intervention recommendations***
	• May experience osteonecrosis (avascular necrosis)[34]
	– PT for pain management, range of motion, strengthening, stretching, functional mobility.[34]*
	• Any history of chronic GVHD: may experience joint contractures[34]
	– PT, rehabilitation medicine/physiatrist.[34]*
	• Any history of chronic GVHD: may experience vaginal fibrosis/stenosis[34]
	– Psychological consultation in patients with emotional difficulties.[34]*
Education & employment	***Referral***
	• Surveillance recommendations for employment in survivors of childhood, adolescent, and young adult cancers.[37]
	• Refer to a vocational counselor, psychologist, and/or social worker for assessment and implementation of relevant vocational and/or disability services for those who report vocational problems upon screening.[37]
Fatigue	***Referral***
	• If fatigue is diagnosed with a validated fatigue measure and no underlying medical condition is identified:

Specification	Recommendation
	– Refer to a specialist in fatigue (or more generic specialist such as psychologist, PT, or other relevant specialist).[35]
	• Psychology for behavioral intervention for emotional difficulties contributing to sleep and fatigue.[34]
	Intervention
	• Physical activity.[35]
	• Education about cancer-related fatigue.[35]
	• Relaxation and mindfulness.[35]
	• Cognitive behavioral therapy.[35]
	• Adventure-based training.[35]
Hearing loss	***Referral***
	• Permanent hearing loss: refer to SLP to ensure development of clear speech, comprehensive language use, and acquisition of appropriate social skills.[36]
	Intervention
	• Supportive counseling about hearing loss and its impact on communication, learning, and workplace functioning.[36]
	• Teach compensatory strategies.[36]
	• Recommend accommodations and instructional support at school, college, or work.[36]
Neurocognition, neurological function	***Referral***
	• If a problem is suspected, the patient should be referred to a psychologist for a neuropsychological assessment.[34,40]
	Evaluation
	• Regular review of neurological function should be part of normal follow-up.[40]
Pain	***Referral***
	• Individuals with any type of cancer may experience psychosocial disability due to pain.[34]
	• Refer to pain rehabilitation clinic.[34]
Physical activity	***Intervention***
	• Adult survivors of childhood cancer should be encouraged to do at least 30 minutes of moderate intensity physical activity at least 5 days a week.[40]
	• Advice about increasing physical activity should focus on activities that fit into their everyday life and are tailored to their individual preferences and life situation.[40]
	• Activity patterns will include personal transport, job-related household and recreational activities.[40]
	• Encourage patient to start by doing what they can and gradually looking for ways to do more. Start slowly if they have not been active for a while and after weeks/months, build on activities by doing them for longer and more frequently.[40]
	• Walking can encourage physical activity in daily life.[40]
	– Start out by advising walking 10 minutes a day a few days a week for several weeks.
	– Then add more time (15 minutes walking) and more days per week of walking.
	– Then begin walking at a faster pace.
	• After regular brisk walking for a couple months, add additional activity such as biking or swimming.
Psychosocial/ mental health	***Referral***
	• Psychological consultation in patients with emotional difficulties related to cancer experience, including physical deformities, chronic disabilities, or chronic pain.[34]

Specification	Recommendation
	• Survivors who indicate mental health symptoms but do not indicate severe mental health problems that might substantially interfere with their safety, prompt referral to a mental health professional for diagnostic and risk assessment.[38]
	• Survivors who indicate mental health symptoms that might substantially interfere with their safety: urgent or emergent referral to a psychiatrist, psychologist, or local mental health crisis services.[38]
	• Healthcare professionals should assist patients and their families in identifying support groups or peer support.[40]
	Evaluation
	• Yearly psychosocial assessment with attention to educational/vocational progress, social withdrawal, and risky behaviors.[34] *
	• For all survivors, surveillance is recommended for depression and mood disorders; anxiety; * psychological distress; post-traumatic stress; behavioral problems; suicidal ideation. Positive screening requires follow-up assessment and additional resources.[38]
	• Survivors with an indication for mental health problems from medical history: further testing with a validated parent-report or self-report measure by a mental health professional.[38] *
	• Regular review, at every follow-up visit, for possible educational and psychosocial dysfunction or morbidity. If a problem is suspected, the patient should be referred appropriately.[38,40]
	Intervention
	• Cognitive behavioral therapy (CBT) for the treatment of anxiety, depression, and post-traumatic stress symptoms among survivors.[38]
	• Give patients the opportunity to discuss issues such as stress management, self-esteem, and confidence. Discuss socioeconomic issues associated with late effects with patients and families including access to work and education.[40]
Miscellaneous (care team)	***Access/include in multidisciplinary team***
	• LTFU care should include a multidisciplinary team including PT, occupational worker, rehabilitation physician, neuropsychologist, psychologist[52] to monitor late effects and optimize prevention and treatment.[40]
	Expert Consensus Recommendations
Education & employment	***Referral***
	• In survivors from a risk group (brain tumor or cranial irradiation) actively monitor and document school performance at transition periods. If necessary, expert advice/guidance should be sought (psychologist, rehabilitation physician, neuro-psychologist, school support services).[53]
	– At the age of 17 years plus, an expert employment appraisal is indicated.[53]
	Evaluation
	• Non-risk group: ask about school performance and/or employment and social functioning, preferably at transition periods.[53]
Neurocognition	***Referral***
	• If abnormalities above Kaufman Short Neuropsychological Assessment Procedure (K-SNAP) cutoff score, refer to a neuropsychologist for further diagnostic testing and treatment.[b] 53
	Evaluation
	• Assessment of cognition for all survivors, particularly following treatment for brain tumor, radiation therapy to the brain, neurological complication during treatment where there are obvious signs of mental changes.[53]
	• K-SNAP at first LATER outpatient visit and thereafter every 3 years until 3 consecutive results are normal.[53]
	• Other diagnostic tests: specific medical history, query about school, work, living situation, social functioning (social contacts, hobbies), mobility (driving license).[53]
Psychosocial/ mental health	***Referral***

Specification	Recommendation
	• Referral to a psychologist for further evaluation is indicated by: Score 14 on Strengths and Difficulties Questionnaire (SDQ)-Parent form, score 17 on the SDQ-Child form, score > 5 on the General Health Questionnaire.[53]
	• Refer to outpatient ambulatory psychological care as indicated to meet patient's needs.[53]
	Evaluation
	• All survivors should undergo psychosocial assessment.[53]
	• Socioemotional diagnostic test: SDQ-Parent form (7 to 10 years), SDQ-Child form (11 to 16 years), General Health Questionnaire-28 questionnaire (young adults 17+).[53]
	• Frequency of psychosocial evaluation: children up to 16—5 years after diagnosis and then at key transitions: 10–12 years of age, 14–16 years of age. Children and young adults older than 16 years of age—at 5 and 10 years, then as clinically indicated.[53]
Miscellaneous	***Referral***
	• SLP in patients with speech/language impairment following treatment with cisplatin, carboplatin, and/or cranial irradiation with ≥ 30 Gray in which auditory system was in the radiation field.[53]
	• PT for delayed motor development of children; recommended for those with very mild to severe neurologic problems and those with brain tumors with or without other neurologic abnormalities.[53]
	• PT for range of motion post oral cavity radiation and/or for those who are <13 years at time of chemotherapy.[53]
	• Rehabilitation team specialized in acquired brain injury when neurological abnormalities and functional disabilities exist.[53]
	• Cognitive therapy, rehabilitation, or PT when fatigue is a concern based on standardized measure.[c] 53
	• Every LATER (long term effects after pediatric cancer) expert center needs to have or be affiliated with a multidisciplinary network, including rehabilitation specialists, with specific knowledge in employment and social consequences of cancer.[53]
	• A LATER expert center must be in or be affiliated with a children's oncology unit and should include a team of specialists with knowledge of late effects of childhood cancer including rehabilitation physician and (neuro)psychologist.[53]
	Access/include in multidisciplinary team
	• Psychologist and PT recommended as important healthcare providers to include in the care of young adult cancer survivors.[54]

[*] Indicates recommendation is based on highest quality of evidence. In COG guidelines, this includes category 1 evidence where there was uniform consensus that there is high quality evidence associating the late effect with the therapy received (e.g., radiation) and the screening recommendation is appropriate based on the experience of panel members. For Marchak et al., these recommendations were strong recommendations based on varying level of evidence, including some high-level evidence.

[a] Category 1 rating for methotrexate only, not cytarabine

[b] A K-SNAP cutoff score was not listed.

[c] A specified fatigue measure was discussed in the report (VVV), but no reference was provided for the measure and additional information was not identified through research.

Table 5.

Adolescent and young adult recommendations

Domain	Guideline Recommendations
Education/ employment	***Referral***
	• Social worker, OT, and/or vocational specialist to ensure access to educational, vocational, and employment support services and to support return to work/school.[43]
	• Educational and career services.[44]
	• PT and/or OT may help AYA patients transition back to a lifestyle appropriate for their age.[44]
	Evaluation
	• Screen for cognitive impairments and difficulties in school and/or work.[43,44]
	Intervention
	• Educational and career services for training/education, employment, disability disclosure, vocational adjustment, training, and transition services (i.e., social services, vocational counseling, OT, financial counselors).[44]
Neurocognition	***Evaluation***
	• Neuropsychological assessment if concerned about cognitive function and/or prior to educational and career transitions.[44]
	• Neuropsychological evaluation for individuals who receive cranial or craniospinal radiation or intrathecal chemotherapy and high CNS penetrating systemic chemotherapy. Neuropsychological evaluation should be offered regardless of treatment if the patient raises concerns.[44]
	• Screen for cognitive impairments and difficulties in school and/or work.[43,44]
Physical activity	***Referral***
	• Rehabilitation specialist (i.e., physiatrist, PT, OT) to address physical impairments and begin physical activity interventions.[44]
	Evaluation
	• Medical evaluation and clearance by a physician (e.g., oncologist, physiatrist) prior to starting exercise in patients for whom exercise modification or precautions may be indicated.[44]
	Intervention
	• Educate about physical conditioning and related health benefits during and after treatment.[44]
	• Promote healthy lifestyle behaviors and incorporate physical activity into treatment and post-treatment follow-up.[44]
Psychosocial/ mental health	***Referral***
	• Refer early to a psychosocial clinician (social worker, psychologist, or spiritual care provider) and/or psychiatrist for AYAs experiencing coping, transition, mood, or other mental health issues and to alleviate distress.[43,44]
	• Social worker, mental health provider, and community-based resources to screen for symptoms of depression, anxiety, suicidal ideation/behaviors, and self-injurious behavior.[44]
	Evaluation
	• All AYAs should receive psychosocial screening as part of new patient intake.[43,44]
	• When indicated, conduct full psychosocial assessment. Screening should include practical issues (housing, transport, finances), and for educational, family/social, emotional, physical, sexual, spiritual, and informational concerns.[43]
	• Evaluate for potential financial toxicity; **refer** to mental health provider to further assess the impact of toxicity (i.e., loss of employment, withdrawing from school, not being able to socialize with friends due to decreased income).[44]
	• Those with hearing impairments: psychoeducational evaluation and support related to educational, psychological, and social function.[44]

Domain	Guideline Recommendations
	• Assess impact of cancer on support network examining social isolation, lack of discussion of diagnosis due to shame or embarrassment, and loss of family/friends.[44]
	• Routinely reassess psychosocial supports of AYAs.[43]
	Intervention
	• Provide education/information on:
	– Psychosocial supports and services.[43]
	– Peer support to assist in establishment and maintenance of peer relationships (e.g., face-to-face meetings, camp and retreat programs, online support groups, and social networking opportunities)[43,44]
	– Normalize potential psychosocial issues so family members are aware and can continue to support the AYA.[44]
	• Address physical/medical issues that may impact psychosocial wellbeing, including alcohol and drug use during treatment, the impact of treatment on fertility, sexuality and sexual function, physical function, and appearance.[43]
	• Child life or psychosocial support specialists should meet patient soon after diagnosis to address concerns regarding treatment and procedures and assist with coping mechanisms to manage anxiety related to procedures.[44]
	• End of life: involve child life specialists and/or psychosocial team members to discuss legacy projects and memory work with patients and family.[44]
	• For AYA patients at-risk for non-adherence: additional supportive care resources (social work, psychology, palliative care).[44]
	• Introduction to palliative care and psychosocial support should occur before condition is considered palliative.[44]
	• Intervene for consequences of cancer and treatment (e.g., medical problems, emotional distress, financial and social concerns)[43]
	Access/involve in multidisciplinary team
	• Developmentally-appropriate care should be delivered and/or supported by a multi-disciplinary team including age- and disease-specific medical and psychosocial experts to provide evidence-based care.[43]
	• Psychosocial care teams must attend to the cultural diversity (language, religious values, and diverse racial identities) within the AYA population.[43]
Miscellaneous	• Perform surgery at centers where surgeons have expertise in AYA management and where there is access to rehabilitation services to preserve function.[44]

Table 6.

Additional rehabilitation recommendations

Guideline Recommendations
Evaluation
• Structured psychosocial assessment at diagnosis, during treatment, end of treatment, LTFU, relapse, palliative care, bereavement.[39]
Intervention
• OTs can help individuals maximize their physical, emotional, cognitive, social, and functional potential.[39]
• Peer support networks should be encouraged.[39]
Access/involvement in multidisciplinary team
• Timely and equitable access to OT and PT services in the community.[39]
• Clear, agreed routes of referral for rehabilitation (including self-referral) and psychosocial support throughout the care continuum. Referral routes should be agreed upon across cancer and children's networks.[39]
• Rehabilitation should extend into the community setting; involvement of community pediatricians may be beneficial.[39]
• Timely access to OT and psychological or behavioral therapies for patients with anticipatory nausea and vomiting.[39]
• For those who undergo surgery, where possible, involvement of allied health professionals, including PT, OT, and SLP, should be planned before surgery.[39]
• Access to neuropsychological services for cognitive assessment for all patients, particularly those with CNS tumors, and also to guide academic and career decisions.[39]
Expert Consensus Recommendations
Referral
• PT when musculoskeletal and neurological impairments are identified.[51]
• When prescribing exercise, an exercise professional (e.g., exercise physiologist, physical therapist, kinesiologist, physiatrist, or an individual with appropriate knowledge, skills, and training) is recommended.[61]
• An exercise professional may be necessary to support patients with initial movement goals in partnership with the healthcare team and family.[61]
Evaluation
• Clinical evaluation should identify patients who need a rehabilitation assessment and the development of a rehabilitation intervention plan focused on prevention and/or treatment.[51]
– Clinical evaluation [by medical team] of all children with cancer for rehabilitation at the beginning of the cancer journey. The multidisciplinary team would then identify timeline for next evaluation or if they should initiate rehabilitation services.[51]
• Rehabilitation assessment of children and adolescents with cancer:
– Completed by rehabilitation professionals.[51]
– Performed as soon as possible after diagnosis and/or surgery (when applicable).[51]
– Focus on clinical and psychosocial conditions of the patient, family context, and scheduled antineoplastic treatment plan.[51]
– Periodic reassessment based on the needs of the patient, clinical conditions, and stages of antineoplastic treatment, to evaluate the results of the rehabilitation plan and make changes.[51]
– Should not be performed if hemoglobin is less than 8 g/dL and/or temperature is above 38 degrees Celsius and/or platelets are less than 20,000/mms.[51]
– Evaluate sensorimotor function, cognitive and psychosocial skills, and take into account clinical status, comorbidities, and the patient's previous lifestyle.[51]
– PT should complete a functional assessment of pain, fatigue, weakness, range of motion, balance and walking, and psychomotor skills.[51]
– Evaluation by different rehabilitation specialists or intervention of the rehabilitation physician may be needed.[51]

Guideline Recommendations
– Use appropriate tools/scales and quantitative scoring systems when possible[51]
♦ When validated assessment tools do not exist for the pediatric oncology population, use scales validated in other populations at the appropriate developmental age. Qualitative observation should be made if there are no standardized assessment tools and if a patient is unable to participate in standardized assessment.[51]
– Assess pain, skin and mucosal status, fatigue, respiratory function, and the need to adopt aids and orthoses.[51]
– Rehabilitation assessment at end of life should be carried out according to the goals of palliative medicine—seeking the best possible quality of life in relation to the cost-benefit ratio for the patient.[51]
• For children/adolescents who receive treatment that may have adverse neuropathic or myopathic effects, or who have anatomical lesions of the neuromuscular system, evaluate, at a minimum, active and passive range of motion (ankle dorsiflexion, wrist extension) and muscle strength (ankle dorsiflexion, wrist extension, and knee strength).[51]
• When prescribing exercise, consider age, cancer type, setting, treatment-related considerations and contraindications, and individual factors (e.g., previous experience, preferences).[61]
• Intake form for exercise professionals working with children and adolescents with cancer should include: age, diagnosis and date, treatment(s) planned (current and previous), comorbidities, symptoms that could impact movement or exercise, physical restrictions, other therapies (current and previous), physician notes, participant's preferences and barriers, current movement, exercise, and physical condition.[61]
• Assess family readiness to care for the child at home from multiple perspectives (patient/caregiver, nurse, physician, psychosocial services team).[59]
Intervention
• Exercise physiologists: work on restoring motor function to promote reintegration into community-based physical activities.[51]
• Orthopedic technician: promote restoration of motor functioning by providing orthopedic aids.[51]
• Communication between the exercise professional and the healthcare team is important to ensure safety and to promote exercise.[61]
• iPOEG guidelines:[61]
– Choose to move. Do what you can. Do it when you can.
– Movement is possible and important for every child and adolescent with cancer, across all ages, abilities, diagnoses, stages, and phases; and across all settings (e.g., in hospital, community, school, daycare.
– Movement might look (and feel) different day-to-day, and that's okay.
• Psychosocial services team (psychologists, social workers, child life specialists, and/or health educators) should support the family in adaptive coping strategies and managing ongoing life demands after diagnosis.[59]
• Essential educational content:[59]
– Anticipatory guidance and normalization of emotional responses/managing emotions.[59]
– Anticipatory guidance regarding accessing psychosocial support services (e.g., supportive counseling and peer to peer support).[59]
• Surveillance and management of the psychosocial effects of the disease throughout the child's development.[51]
Access/involvement in multidisciplinary team
• The child/adolescent with cancer should be cared for by a multidisciplinary team, including rehabilitation professionals, from diagnosis.[51]
– The multidisciplinary team should include PT, OT, SLP, psychologists, neuropsychologists, physiatrist, orthopedist, neuro- and psychomotor therapists.[51]
• An exercise professional with specific pediatric cancer and exercise knowledge, through training and/or clinical experience, is important to ensure safety and effectiveness of exercise for children and adolescents with cancer.[61]