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Cancer Rehabilitation in the Pediatric and Adolescent/Young Adult Population

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ABSTRACT

Objectives: To identify body impairments, activity limitations, and participation restrictions in children, adolescents, and young adults with cancer amenable to rehabilitation, and provide the recommended screening, assessment and rehabilitation referral information for the health care community.
Data Sources: A review of the rehabilitation and pediatric oncology literature regarding functional impairments in combination with clinical expertise from practicing pediatric oncology rehabilitation therapists.
Conclusion: Rehabilitation intervention has great potential to mitigate the impact of cancer and its treatment and may even have a role in reducing morbidity and mortality. All health care providers have a role in optimizing the function and quality of life in the pediatric cancer population.
Implications for Nursing Practice: It is imperative for nurses to utilize subjective and clinical screening to identify persons appropriate for rehabilitation referral, collaborate with the rehabilitation team, and support the patients and families in adhering to rehabilitation recommendations.

Introduction

The relevance of rehabilitation in childhood and adolescent cancer grows exponentially as incidence and survival rates increase. It is estimated that there are over 420,000 survivors of childhood cancer living in the United States, and 15,000 children and adolescents diagnosed each year.[1,2] As survival rates continue to improve, greater focus is needed on the quality of life (QOL) these children will have during and following cancer treatment. Functional limitations in the physical and cognitive domains are reported by children throughout the cancer continuum of care.[3–8] The functional impact spans all ages and diseases, ranging from very young children under the age of 4 with leukemias and lymphomas, to adolescents and young adults with leukemias, sarcomas, or central nervous system (CNS) tumors.[9–12] The multitude of tumor types and locations, surgical approaches, and treatment modalities presents a wide array of side effects influencing function. Survivorship research demonstrates functional impact in adult survivors of childhood cancer citing impaired physical function, reduced physical fitness, impaired neurocognition, weakness, fatigue, and pain impacting employment, life participation, and QOL.[4,6,13,14] Fortunately, children and adolescents with cancer are prime candidates for rehabilitation services that may mitigate the developmental delay or loss of function related to the cancer diagnosis and treatment experience. The National Institutes of Health (NIH) has recently recommended comprehensive rehabilitation services from cancer diagnosis to recovery to address the functional outcomes of care.[15,16] Collaboration among the health care community on screening, assessment, and intervention is important to address the needs of this population.

Comprehensive oncology rehabilitation requires specialists in multiple disciplines to provide services to optimize overall function. The specific roles of the primary rehabilitation team are described in Table 1. Oncology nurses will interface with these professionals through screening and referral. Interventions are designed to restore function, compensate for loss, or adapt the environment when functional recovery is unattainable.[17] Investigations in childhood cancer populations demonstrate full functional restoration by some measures,[18] while others demonstrate significant functional improvements,[19] likely through a combination of restoration, adaptation, and compensation strategies.

Rehabilitation therapists target assessments and interventions at the impairment level through participation, and it is imperative for

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Table 1
Roles of rehabilitation professionals in the childhood cancer population.

Rehabilitation Discipline	Role in Childhood Cancer Rehabilitation
Physical medicine and rehabilitation medical team (MD, CNP, PA, RN)	Maximize function for children and adolescents with cancer through medical management and coordination of rehabilitation plan in complex medical cases Assess and provide interventions related to: • Medical diagnosis and management • Procedures such as electromyography (EMG), nerve conduction study (NCS), botulinum toxin injections • Durable medical equipment • Prosthetics/orthotics
Occupational therapy	Improve a child's ability to perform their "jobs" of living through therapeutic and meaningful activities Assess and provide interventions related to: • Fine motor skills • Sensory motor skills • Visual motor skills • Activities of daily living (ADL) ◦ Dressing ◦ Toileting ◦ Bathing ◦ Eating • Instrumental activities of daily living (IADL) ◦ Meal preparation ◦ Money management ◦ Health maintenance ◦ Home management
Physical therapy	Maximize independent function and participation in home, school, and community environment with focus on movement, motor development, body function, and health and wellness Assess and provide intervention related to: • Strength • Flexibility • Balance • Gait • Running • Agility • Coordination • Physical activity participation
Speech-language pathology	Help children to speak, understand language, communicate wants and needs effectively, and eat and drink safely Assess and provide intervention related to: • Articulation • Voice • Motor speech • Receptive language • Expressive language • Cognition • Feeding/swallowing • Oral motor movements • Facial weakness

the oncology health care team to screen these levels of function to refer appropriately. Nurses can be important figures in recognizing patients' needs with regard to function. A common understanding of function is a key component of the multidisciplinary pediatric cancer care setting, and the *International Classification of Functioning, Disability and Health* (ICF) created by The World Health Organization uses standard language to describe health and health-related states.[20] This model demonstrates the interactions between health conditions, body functions and structures, activities, participation, and contextual factors (environment and personal). The terminology of the ICF is used in this review. Alteration of health condition is a *disorder* or *disease*; problems within body functions and structures are *impairments*; difficulties performing daily tasks are *activity limitations*; and the inabilities to fulfill societal roles are *participation restrictions*. *Environmental factors* include the physical, social, and attitudinal environments within a person's life; *personal factors* include the demographic and psychological components that affect a person's experience. For example, a child with Wilms tumor may have surgery, radiation, and chemotherapy causing trunk asymmetry, peripheral neuropathy, and temporary vocal cord paralysis. These impairments limit the ability to run, write, or eat. As this child ages, these limitations may restrict participation at the playground or academic performance. These restrictions could eventually impact choice of employment or lifestyle choices in physical activity (PA) as an adult survivor. The ICF-Childhood cancer (ICF-CC) model (Fig. 1) is our adaptation of the ICF model to encompass the interplay of childhood cancer and function to assist in defining rehabilitation goals and interventions while considering the individual and environmental factors.[21] While the importance of environmental and personal factors cannot be underestimated, this review focuses on the other components of the ICF-CC.

The purposes of this article are to: (1) identify body impairments, activity limitations, and participation restrictions amenable to rehabilitation in children and adolescents with cancer; and (2) to provide the recommended screening, assessment, and rehabilitation referral information for the health care community. Recommendations are aimed toward a clinical audience including oncology nurses, but researchers and administrators may also use the information to design future studies and develop comprehensive pediatric cancer programs.

Methodology

Rehabilitation clinicians in the fields of physical therapy, occupational therapy, and speech-language pathology with expertise in childhood cancer rehabilitation reviewed the list of complications and late effects of childhood cancer described by the Children's Oncology Group.[22] Those considered to be amenable to rehabilitation were then categorized and used to adapt the ICF to specially address the condition of childhood cancer (ICF-CC, Fig. 1).[21] Once body structure impairments, activity limitations, and participation restrictions in the childhood cancer population were chosen and organized by primary body system, authors conducted a literature review. While many impairments are multi-system (eg, contractures with muscular and nerve restriction) and some side effects (eg, decreased PA) could fit in the ICF-CC model in multiple categories, the authors prioritized the most pertinent system or ICF category related to the childhood cancer population. Research findings combined with clinical expertise were utilized to describe the state of rehabilitation for each area and screening recommendations.

Findings and recommendations

The recommended clinical assessments (both patient-reported outcome measures and standardized clinical assessments) for each impairment, limitation, and restriction in the neurological, musculoskeletal, and multi-system areas are listed in Table 2,[23–106] and quick screen recommendations and appropriate rehabilitation referral are presented in Table 3.

Neurologic System Impairments

Central nervous system

Children with CNS tumors are at risk for neurological sequelae secondary to the disease itself and to the treatment.[107,108] Assessment of function and intervention requires consideration of the complexity of surgical resection, intracranial pressure, radiation, and chemotherapy impact.[109] Comorbidities such as posterior fossa syndrome in the case of a cerebellar tumor cause significant neurological sequelae.[110–113] CNS dysfunction is estimated to occur in 8% to 24% of children who have posterior fossa tumor resection.[114] Dysfunction may present as hemiparesis, ataxia, cognitive impairment, decreased visual-perceptual skills, cranial nerve dysfunction, bowel and bladder

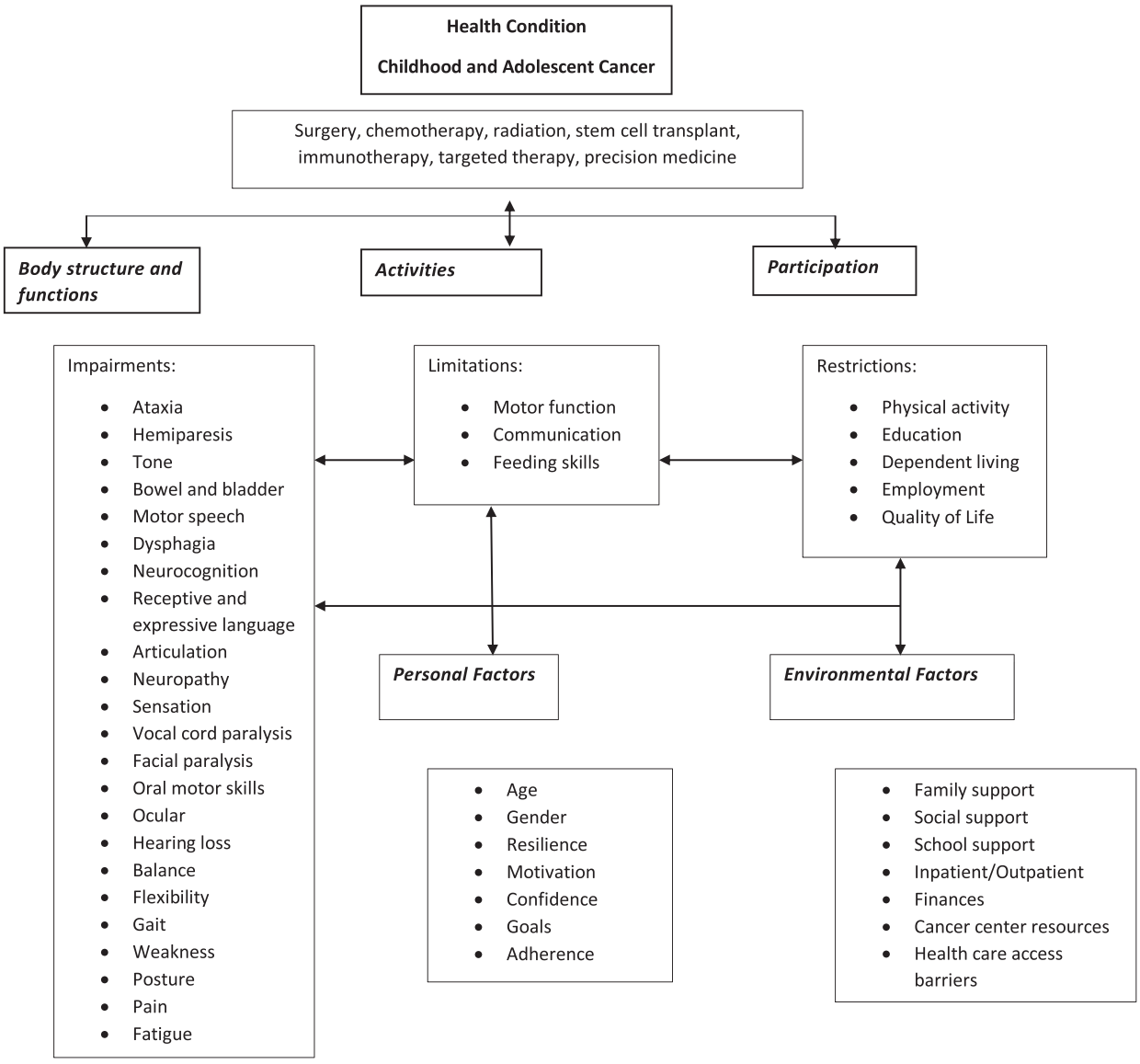

Fig. 1. ICF model for childhood cancer rehabilitation (ICF-CC). Adapted from the ICF model, World Health Organization, 2001.[20,21]

impairment, aphasia, dysphagia, and dysarthria.[115] In addition, chemotherapy commonly given to children with cancer adds to the functional impairments because neurologic symptoms include ataxia, myopathy, vestibular impairment, hearing loss, tremors, and neuropathy.[116] A rehabilitation team comprised of a physical therapist (PT), occupational therapist (OT), speech-language pathologist (SLP), and physiatrist is required to offer a comprehensive approach to address CNS dysfunction.

Rehabilitation therapists use a combination of standardized assessments to address the CNS. In the acute stages, general recovery and cognitive status can be rated with a tool such as the Rancho Los Amigos Scale or the Glasgow Coma Score.[117] Muscle tone is typically assessed by scales such as the Modified Ashworth Scale (MAS)[27] for evaluating resistance to movement or the Hypertonia Assessment Tool (HAT) for evaluating abnormal spontaneous or uncontrolled movement such as dystonia or ataxia.[26] Ataxia scales such as the International Cooperative Ataxia Rating Scale (ICARS) or the Scale for the Assessment and Rating of Ataxia (SARA) assess gait and limb ataxia, dysarthria, and ocular nystagmus.[118] Refer to Table 2 for assessment of other specific neurologic impairments.

Children with CNS impairments undergoing comprehensive inpatient rehabilitation demonstrate a significant improvement in mobility, activities of daily living (ADL) and instrumental activities of daily living (IADL).[19,119] In addition, they have demonstrated a similar rate of improvement in self-care, mobility, and cognition in children with non-cancer diagnoses; however, they have shorter stays than children with non-cancer diagnoses likely secondary to cancer treatment requirements.[19] Constraint-induced movement therapy, an evidence-based, intensive intervention involving casting or restraining of the non-involved upper extremity, benefits children with hemiparesis by focusing on ADLs and repetitive motor tasks with the involved upper extremity.[120] Although rehabilitation in this population can be difficult to coordinate with the cancer treatment schedule, early and intensive rehabilitation is recommended[109,115] and the health care team should communicate and advocate for a creative rehabilitation plan to be integrated into the oncology setting to complement the intensive cancer treatment.

Screening for CNS impairments should include muscle tone assessment and observation of movement symmetry in neck and limb motion. Specifically, muscle tone screening includes reflex

Table 2
Recommended clinical assessments for functional impairments, activity limitations, and participation restrictions in children, adolescents, and young adults with cancer.

Impairments	Clinical Assessment
Ataxia	• Box and Block Test (BBT)[23] • International Cooperative Assessment of Ataxia (ICARS)[24] • Scale for the Assessment and Rating of Ataxia (SARA)[25]
Muscle tone	• Hypertonia Assessment Tool (HAT)[26] • Modified Ashworth Scale (MAS)[27]
Dysarthria	• Dysarthria Examination Battery (DEB)[28] • Frenchay Dysarthria Assessment – 2nd ed. (FDA-2)[29] • Speech sample
Apraxia	• Apraxia Profile[30] • Kaufman Speech Praxis Test for Children (KSPT)[31] • Speech sample
Dysphagia	• Clinical bedside swallow evaluation • Flexible endoscopic evaluation of swallowing (FEES) • Marshalla Oral Sensorimotor Test (MOST)[32] • Video Fluoroscopic Swallow Study (VFSS or MBS)
Neurocognition	• Beery-Buktenica Developmental Test of Visual-Motor Integration – 6th ed. (Beery VMI)[33] • Behavior Rating Inventory of Executive Functioning – 2nd ed. (BRIEF-2)[34] • Children's Kitchen Task Assessment (CKTA)[35] • Children's Orientation and Amnesia Test (COAT)[36] • Cognitive-Linguistic Quick Test (CLQT)[37] • Digit Span Test, Verbal Fluency Test, Grooved Pegboard Test, Trail Making Test[38–40] • Miller Function and Participation Scales -VMI Scale[41] • National Institutes of Health Toolbox cognition[42] • The Pediatric Test of Brain Injury (PTBI)[43] • Scales of Cognitive Ability for Traumatic Brain Injury (SCATBI)[44] • Test of Visual Perceptual Skills (TVPS)[45] • The Test of Memory and Learning – 2nd ed. (TOMAL-2)[46] • {Test of Reading Comprehension – 4th ed. (TORC-4)[47] • Weekly Calendar Planning Activity (WCPA)[48]
Receptive and/or expressive language impairment	• Ages and Stages Questionnaires (ASQ-3)[49] • Clinical Evaluation of Language Fundamentals – Preschool – 2nd ed. (CELF-P2)[50] • Clinical Evaluation of Language Fundamentals – 5th ed. (CELF-5)[51] • Comprehensive Assessment of Spoken Language – 2nd ed. (CASL-2)[52] • Expressive One-Word Picture Vocabulary Test – 4th ed. (EOWPVT-4)[53] • Oral and Written Language Scales – 2nd ed. (OWLS-2)[54] • Peabody Picture Vocabulary Test – 5th ed. (PPVT-5)[55] • Preschool Language Scale – 5th ed. (PLS-5)[56] • Receptive-Expressive Emerging Language Test – 3rd ed. (REEL-3)[57] • Receptive One-Word Picture Vocabulary Test – 4th ed. (ROWPVT-4)[58] • The Rossetti Infant-Toddler Language Scale[59] • Test of Adolescent and Adult Word Finding (TAWF)[60] • Test of Integrated Language and Literacy Skills (TILLS)[61] • Test of Language Development – 4th ed. (TOLD-4)[62] • Test of Word Finding – 3rd ed. (TWF-3)[63]
Articulation	• Clinical Assessment of Articulation and Phonology – 2nd ed. (CAAP-2)[64] • Goldman-Fristoe Test of Articulation – 3rd ed. (GFTA-3)[65] • Structured Photographic Articulation Test – 3rd ed. (SPAT-D III)[66]
Peripheral muscle weakness	• Dynamometry • Manual muscle test (MMT) • Pediatric-modified Total Neuropathy Score (Ped-mTNS)[67] • Total Neuropathy Score-Pediatric Vincristine (TNS PV)[68]
Sensation impairment	• Ped-mTNS[67] • TNS-PV[68] • Monofilament testing • Point/dull testing • Vibration testing
Vocal cord paralysis	• Endoscopy/ Laryngoscopy
Facial paralysis	• House-Brackmann Scale[69] • Oral Motor Examination
Oral motor skills for feeding and speech	• Oral Motor Examination
Ocular impairment	• Observation of functional skills (e.g. reading, handwriting, environmental navigation) • Screening of visual acuity (LEA Symbols or age appropriate eye chart)[70] • Screening of visual fields and ocular motility • The Oregon Project for Visually Impaired and Blind Preschool Children[71]
Hearing loss	• Audiometry • Auditory Brainstem Response (ABR) • Otoacoustic Emissions (OAE)
Balance	• Pediatric Balance Scale (PBS)[72] • Bruininks-Oseretsky Test of Motor Performance – 2nd ed. Balance scale (BOT-2)[73] • Modified Clinical Test of Sensory Integration in Balance (mCTSIB)[74]
Contractures	• Active and passive ROM
Fibrosis	• Active and passive ROM
Gait	• Edinburgh Visual Gait Scale (EVGS)[75] • Computerized gait analysis • 30-second Walk Test (30sWT)[76]
Weakness	• Dynamometry[77] • Manual muscle test (MMT)[78] • Functional strength tests[79] • BOT-2 Strength subtest[73]
Posture	• Adam's Forward Bend Test[80] • Foot Posture Index (FPI-6)[81]
Pain	• CRIES scale[82] • Faces Pain Scale-Revised (FPS-R)[83] • Numerical Rating Scale (NRS)[84] • revised Face Legs Activity Cry and Consolability (FLACCr)[85] • Visual Analog Scale (VAS)[86]
Fatigue	• Adolescent Fatigue Scale (FS-A)[87] • Childhood Fatigue Scale (FS-C)[88] • Parent Fatigue Scale (FS-P)[88] • Patient-Reported Outcomes Measurement Information System (PROMIS) fatigue item banks[89]
Activity limitations	
Gross and fine motor skills	• Ages and Stages Questionnaire (ASQ-3)[49] • Battelle Developmental Inventory[90] • Bayley Scales of Infant and Toddler Development – 4th ed. (Bayley-4)[91] • Bruininks-Oseretsky Test of Motor Proficiency – 2nd ed. (BOT-2)[92] • Miller Function and Participation Scales • 9 Hole Peg test[93] • Peabody Developmental Motor Scales – 2nd ed. (PDMS-II)[94] • Print Tool[95] • Purdue Pegboard Test[96] • Test of Handwriting Skills-Revised (THS-R)[97] • Timed up and go (TUG)[98] • Timed up and down stairs (TUDS)[99]
Communication	• See Receptive and/ or expressive language impairment • Language sample • Observation of communication interactions
Feeding	• Oral-motor feeding evaluation
Participation restrictions	
Dependent living	• Unable to recommend
Education	• School Function Assessment[100]
Employment	• Unable to recommend
Physical activity level	• 6-minute Walk Test (6MWT)[101] • FitnessGram PACER test[102]
Quality of life	• Children's Assessment of Participation and Enjoyment (CAPE)[103] • Preferences for Activities of Children (PAC)[103] • The Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales[104], Multidimensional Fatigue Scale[104], Cancer Module[104], or Brain Tumor Module[105] • PROMIS[106]

testing and passive movement of the extremities. The alternating finger to nose test and heel to shin screens limb ataxia, while trunk movement in sitting without upper extremity support reveals truncal ataxia. Most importantly, general observation of a child's mobility for gross and fine motor symmetry, balance, and coordination will reveal CNS dysfunction to support referral to rehabilitation service.

Bowel and bladder

CNS complications in childhood cancer also include bowel and bladder impairments. For instance, long-term bladder dysfunction is recognized as a complication secondary to pelvic or CNS surgery, or pelvic radiation.[121] In children with intraspinal tumors, neurogenic bowel and bladder dysfunction presents secondary to direct spinal cord injury.[122,123] Peripheral nervous system damage can also impact system function. Limited case studies describe vincristine-induced peripheral neuropathy resulting in urinary bladder paralysis that resolves with adjustment of vincristine dosing.[124,125] Late effects described as a less severe bladder dysfunction include urinary frequency, urgency, or incontinence.[121]

PTs and/or OTs play a role in the management of bowel and bladder dysfunction. Interventions may include pelvic floor awareness and retraining,[126] biofeedback of pelvic-floor muscles,[127] and integrating a bowel and/or bladder program into the context of a child's daily life.[128] Screening questions should include asking a child or caregiver about incontinence or issues with frequency, as well as the independence in management if issues exist.

Referral to a urologist, gastroenterologist, or physiatrist for a comprehensive medical examination may be a necessary first step for any bowel and/or bladder concerns. OTs provide intervention related to task adaptations, adaptive equipment, home and/or community toilet access, and/or clothing management. A PT also may provide intervention related to mobility and toilet access and specialized toileting positioning equipment. A PT or OT trained in the areas of bowel and bladder would be appropriate for treating concerns such as incontinence, urgency, or catheterization management.

Motor speech disorders

Motor speech impairment can be a devastating side effect of cancer treatment for children with CNS cancers. Dysarthria (impaired execution of speech movements caused by muscle weakness), mutism, and apraxia of speech (deficits in speech motor planning) are motor speech disorders common to children with cancer. Dysarthria refers to the strength, control, and execution of speech movements and may affect articulation, resonance, prosody (rhythm, stress and intonation of speech), respiration, and phonation.[129] Dysarthria is characterized by reduced speaking rate, imprecise articulation, distorted vowel production, monopitch, monoloudness, and reduced respiratory support for speech.[130,131] Taylor et al[132] reported that 50% to 100% of patients develop dysarthria after surgery for a CNS tumor, while Mei and Morgan[130] reported that approximately one in three children with posterior fossa tumors will experience dysarthria post-resection.

As mentioned earlier, posterior fossa syndrome, also referred to as *cerebellar mutism*, is characterized by speech, motor, cognitive, and behavioral impairments.[133,134] Mutism or loss of speech is considered the hallmark characteristic of posterior fossa syndrome and typically occurs 1 to 11 days postoperatively. Volitional speech is extremely challenging, though the child may be able to voice while crying or yawning without difficulty. Speech deficits may persist for weeks or months.[114,135] Recovery of speech is often marked by dysarthria and apraxia of speech.[131] Characteristics of apraxia of speech include inconsistent speech sound production, difficulty sequencing sounds for speech, vowel errors, and disturbed prosody, all of which are often accompanied by groping behaviors (effortful oral motor movements performed during speech attempts).[136]

Motor speech disorders in the pediatric oncology population can lead to significantly decreased speech intelligibility, which may impact the child's QOL and their ability to participate in various activities.[129] When a motor speech disorder is evident by the impairments described above, prompt referral to a SLP is necessary. The SLP can make a differential diagnosis and manage the disorder through treatment such as targeting muscle strength and coordination, improving rate and intelligibility, increasing breath support, and providing communication devices to supplement speech.[137,138] Assistive devices may range from low-tech aids to computerized devices based on the severity of the motor speech disorder and needs of the child.

Dysphagia

The diagnosis and treatment of a pediatric CNS tumor can impact various body systems that, in turn, can affect both oral and pharyngeal phases of feeding and swallowing.[139] Dysphagia, or swallowing dysfunction, may be the direct result of a brain tumor itself, especially in the case of a brain stem lesion, or can occur as a side effect of cancer treatment.[140,141] Children may experience impairments of their oral phase skills, such as bolus control and management of specific textures, and/or in their pharyngeal phase of swallowing, including issues with delayed swallow initiation, decreased airway protection (penetration, aspiration), and residue caused by pharyngeal weakness.

If concerns are present for pharyngeal phase dysfunction based on observations or underlying diagnosis, instrumental evaluations may be recommended. Instrumental evaluations can include a video fluoroscopic swallow study and/or a fiberoptic endoscopic evaluation of swallowing.[139] These instrumental assessments can inform additional recommendations regarding diet and compensatory strategies to promote safe oral intake.

Early involvement of a feeding therapist (OT or SLP) is indicated to assess skills and safety and can help prevent progression from temporary feeding difficulties or feeding refusal to more long-term problems including respiratory concerns, aversions, and persistent poor dietary habits.[142] Strategies to help with temporary or long-term management of dysphagia related to CNS disease may include modification of bolus presentation methods, alteration of textures and liquid consistencies, and use of compensatory techniques and exercises. Close collaboration of the feeding therapist with the medical team, including the registered dietitian to determine the most appropriate feeding plan, is key to providing the most appropriate care.

Because concerns for dysphagia can arise at various points in treatment, frequent screening by the medical provider for feeding and swallowing difficulties for patients with CNS tumors is warranted. Screening should include caregiver interview regarding concerns with oral eating/drinking, specifically coughing or choking and decreased secretion management. If concerns are reported or directly observed by the medical team, a referral for a complete evaluation by a feeding therapist is indicated.

Neurocognitive impairments

Neurocognitive late effects in children with cancer and long-term survivors of childhood cancer have been well documented.[143–145] Children treated with cranial irradiation, such as those with high-risk leukemia or brain tumors, are at significant risk for cognitive decline. Cognitive impairments manifest as an inability to acquire new information and skills at a rate comparable to that of healthy, same-aged peers because of progressive deficits in underlying core abilities, such as memory, attention, processing speed, executive function, visual-spatial, and visual motor skills.[146–148] Significant risk factors for cognitive decline in children treated with radiation therapy (RT) include younger age at RT treatment (<5 years), higher dosage of RT, and tumor location (because of potential damage to surrounding tissues).[149] Children treated with chemotherapy alone are also at risk for cancer-associated cognitive impairments, including impaired IQ,

Table 3
Quick screens for functional impairments, activity limitations, and participation restrictions in children, adolescents, and young adults with cancer.

	Subjective Screening Key Elements (as reported by caregivers/patient)*	Brief Clinical Screening†	Rehabilitation Referral‡
Impairments			
Ataxia	Clumsy/coordination, jerky or involuntary movements, falls	Heel to shin test Finger to nose test Trunk sway in sitting/standing	OT/PT
Hemiparesis	Sensation or movement difference between sides	Tone assessment Symmetry in arms/legs	OT/PT
Bowel/bladder	Incontinence, frequency, independent management	N/A	OT/PT
Dysarthria	Imprecise articulation, "slurred," "mumbled," and/or reduced rate of speech, changes in resonance ("nasal" quality)	Listen to speech quality and rate	SLP
Apraxia	Sound distortions/errors, Difficulty coordinating mouth movements Inconsistent speech sound errors, Voicing errors (eg, "bye" for "pie")	Listen to speech production and watch mouth movements	SLP
Dysphagia	Drooling/pooled secretions, Coughing/choking/increased congestion/wet vocal quality with oral feeding Aspiration pneumonia	Observation of eating/drinking	SLP/OT
Neurocognition	Caregiver or patient report of academic issues, difficulty with memory, attention, processing; difficulty following commands	Ask patient to follow 1- and 2-step commands Pose questions that require memory recall Observe attention span, planning/organization when completing tasks	OT/SLP
Receptive and/or expressive language	Difficulty with: asking or responding to questions, following directions, identifying or labeling pictures/objects, participating in conversation, responding to orientation, etc.	Pose orientation questions, yes/no questions, WH-questions (what, where, when, why, how) Ask patient to follow 1- and 2-step commands	SLP
Articulation	Decreased intelligibility/hard to understand, Speech sound errors that do not appear developmental in nature	1–6 months: cooing 6+ months: starting consonants >2 years: speech is understood by familiar listeners >8 years: no speech errors	
Peripheral muscle weakness	Tripping when walking Hand grasp/function change	Manual muscle test of wrist/hand/ankle/toes Heel walking >age 3	OT/PT
Sensation	Numbness (can hardly feel), tingling (itching, tickling), pain	Light touch/vibration/point dull testing	OT/PT
Vocal cord paralysis	Breathy or hoarse vocal quality Noisy breathing Limited pitch and loudness Ineffective cough Coughing with intake	Listen to vocal quality	SLP
Oral motor skills for feeding and speech	Weak suck Persistent drooling Difficulty moving lips and tongue	Observation of eating/drinking	SLP/OT
Ocular impairment	Double vision Blurred vision Difficulty reading (books, computer, board in classroom) Bumping into objects/people Holding objects unusually close to face	Visual acuity Visual fields Ocular motility Visual tracking and scanning Observation of navigation of environment and interaction with toys	OT
Hearing Loss	Frequently asking for clarification Turning up TV/tablet/phone volume Changes in articulation Child's own volume of speech increases	Listen for frequent requests for repetition or increase in volume and speech sound errors Observe non-response to auditory stimuli	SLP
Balance	Falls, near falls, slips, and/or trips Clumbsiness/coordination Afraid of darkness	2 years: walk on a line 3 years: standing on one leg (SLS) 3 sec 5 years: SLS 10 sec 8 years: SLS eyes closed 5 sec	PT
Flexibility	Tightness Difficulty moving body or limbs Skin changes	Passive and active range motion of upper and lower extremity, trunk, jaw, cervical spine Limb length discrepancy Skin Assessment	PT/OT/SLP
Gait	Change in walking/distance Tripping	Asymmetry, foot slap, high knees, bouncy, toe walking, trunk lean, wide base of support, unable to slow down/speed up	PT
Weakness	Dropping things Falling or tripping Losing ability to: climb stairs, get off of floor, and/or jump	Manual muscle testing 2 years: squat to stand I 3 years: $^1/_2$ kneel to stand I 5 years: abdominal crunch 6 years: push-up Older ages: floor to stand, lunge, push up	OT/PT
Posture	Change in posture (slump, hump) Unevenness of trunk or limbs	Ears over shoulders Rib hump with trunk flexion (Adam's Forward Bend Test)	OT/PT

(*continued*)

Table 3 (*Continued*)

	Subjective Screening Key Elements (as reported by caregivers/patient)*	Brief Clinical Screening†	Rehabilitation Referral‡
Pain	Non procedural pain questions surrounding acute and chronic pain and impact on function	FLACCr, FPS-R, VAS, NRS, CRIES, Wong-Baker FACES scales	OT/PT/SLP
Fatigue	Too tired to do usual activities Brain fog	Refer to Table 2	OT/PT/SLP
Activity Limitations			
Gross motor skills	Decline in skills Learning new skills Unable to do skills on the playground, in physical education class, or in sporting/recreational activities	6 months: sitting 12–15 months: walking 2 years: jumping 3 years: alternating stairs up 4 years: hopping, alternating stairs down 5 years: skipping/jumping jacks >6 years: hopping side to side, riding a 2-wheeled bike	PT
Fine motor skills	Decline in skills Delayed development of new fine motor skills	11 months: pincer grasp 3.5 years: holds marker with pads of fingers 3.5 years: uses scissors to cut a line 4 years: buttons Older children – observation of handwriting, in-hand manipulation skills, thumb to finger opposition	OT
Communication	Delayed development of language Loss of previous language skills Peer communication	1–6 months: cooing, laughing, eye gaze 6–9 months: babbling, joint attention 12 months: first words, follows simple commands, identify basic objects/items, 18–24 months: 50+ words and combine 2 words together 2–3 years: 2-3 word phrases, follows 2-step directions, speech is understood by most listeners	SLP
Feeding	Decreased oral intake Limited food and/or texture repertoire Difficulty managing specific textures	1+ months: breast or bottle feeding 9 months: spoon feeding 1.5 years: chewing table foods, finger feeding 2 years: cup drinking	OT/SLP
Participation Restrictions			
Physical activity level	Able to keep up with or participate with others on playground or in sporting/recreational activities Minutes/day	N/A	PT
Dependent living	Unable to plan and execute daily routines Safety concerns Reliance on caregivers	N/A	OT/PT/SLP
Education	Poor academic performance Pain or fatigue that restricts participation in school Difficulty navigating the physical school environment Difficulty viewing academic materials Working on homework all evening Difficulty keeping up with notes or copying from the board Difficulty producing written work Inattentive in class Disorganized – trouble knowing what homework to do and turning it in Motivational problems	N/A	OT/PT/SLP
Employment	Difficulty finding or keeping meaningful employment	N/A	OT/PT/SLP
Quality of life	Able to participate in chosen recreational activities, education, hobbies, jobs, and/or life roles; able to find enjoyment in daily life experiences	Refer to Table 2	OT/PT/SLP

* Subjective screening elements include both elements the health care team can use to pose questions regarding an impairment, or subjects patients and caregivers may report.
† Brief clinical screening includes a quick observation or screening test a provider can perform in a visit to identify a possible impairment.
‡ Rehabilitation referral states the rehabilitation discipline(s) appropriate to assess and intervene for the impairment; however, other appropriate medical referrals are not addressed here.

working memory, attention, executive functioning, and processing speed.[150,151]

Because children with cancer are at risk for experiencing cognitive impairments and deficits may emerge over the course of the cancer care continuum, repeated screening of a child's cognitive abilities and related performance is recommended during treatment and long-term follow-up visits. Comprehensive neurocognitive evaluation and follow-up are recommended for children with cancer who are at risk for cognitive impairments. Given that comprehensive neurocognitive follow-up may not be available in all settings, an effective neurocognitive screening battery has been recommended for children with cancer.[152] Screening includes the Digit Span Test, the Verbal Fluency Test, the Grooved Pegboard Test, and the Trail Making Test.[38–40]

OTs evaluate functional cognitive skills, that is, how the child's cognitive abilities support or hinder performance in relevant everyday life activities such as following directions to complete ADL tasks or organizing school work. OTs use performance-based cognitive assessments designed to assess functional cognitive skills in children with cancer across a variety of contexts and environments. SLPs evaluate and treat cognitive-communication disorders that result from impaired functioning in areas such as memory, attention, orientation, processing, problem solving, reasoning, and executive functioning. Assessments that can identify cognitive-communication disorders in

children and adolescents can be found in Table 2. The results of occupational therapy, speech-language pathology pathology, and neuropsychological assessment can be collaboratively utilized for identification of a child's cognitive strengths and weaknesses and for intervention planning.

While published evidence describing rehabilitation interventions for children with cancer-related cognitive impairment is limited, meta- cognitive strategy training, cognitive behavioral therapy trials, and computerized, home-based cognitive training programs have demonstrated some success in improving academic achievement, attention, memory, and processing speed.[146,153–155] OTs can provide compensatory interventions, such as meta-cognitive strategy training, that help children improve or learn new skills to complete everyday life or school activities. SLPs assist children by teaching techniques and strategies that remediate or compensate for cognitive-communication difficulties. For example, a child with short-term memory deficits may benefit from internal or external memory strategies, such as rehearsal, chunking, visualization, lists, and/or calendars. Collaboratively, an example of an SLP and OT working together may include speech therapy working on memory and organizational strategies while an OT would help implement those strategies for a functional task, such as making a check list for morning dressing and grooming routines.

Members of the oncology health care team may screen a child at risk for neurocognitive deficits by asking questions or identifying concerns involving academic issues, difficulty learning new material, decreased attention, slowed processing, difficulty following directions, or difficulty completing the daily routine independently. In addition to neuropsychology assessment, rehabilitation referrals to OTs and SLPs are appropriate, depending on the type and impact of the cognitive impairment.

Receptive and expressive language impairment

A language disorder can be described as a "deficit in learning to talk, understand or use aspects of language correctly."[156] Impairment can involve spoken and/or written language systems. Receptive language impairment refers to difficulty understanding language, while expressive language impairment refers to difficulty with verbal or written expression. In children undergoing cancer treatment, language concerns may arise at various stages, ranging from the acute phase to long after treatment has been completed. As discussed earlier, children with CNS cancers or those who have been exposed to cranial radiation are known to present with cognitive-linguistic impairments. Goncalves et al concluded that many children treated for CNS disease present with some form of language impairment and could benefit from language screening, even if no specific complaints have been expressed by the child or family.[141] Additionally, children with a variety of other oncology diagnoses have been shown to present with communication disorders and benefit from intervention to target language skills.[132]

Acute and long-term effects on language, including higher-level language skills, may result from underlying disease, surgical intervention, or cancer-directed treatment. Children may experience difficulties across language modalities, including auditory comprehension, expressive communication, reading, and writing. In some cases, language difficulties may be evident early on in treatment. For instance, children who have had a stroke during treatment may develop aphasia, an acquired language disorder that affects their ability to understand or express language. At other times, weaknesses may be more subtle or may not become evident until a child is exposed to academic demands or engages in higher-level communicative interactions. Additionally, children with cancer may present with pre-existing receptive and/or expressive language impairment, including children with developmental disorders such as Down syndrome, or young children who are developing basic language skills.

The Children's Oncology Group recommends that receptive and expressive language skills are monitored regularly during and after treatment, especially in high-risk populations such as children with CNS involvement or those who have received cranial radiation.[157] A timely referral to an SLP for a comprehensive evaluation of language skills is indicated if concerns are observed or reported.

Peripheral nervous system

Chemotherapy-induced peripheral neuropathy

Chemotherapy-induced peripheral neuropathy (CIPN) is a common comorbidity in children and adolescents with cancer secondary to the neurotoxicity of frequently used chemotherapeutic agents, including vinca alkaloids and platinum agents. CIPN is estimated to occur in 20% to 85% of children with non-CNS cancer.[4,67,158,159] The incidence in CNS pediatric cancer has not been reported. Research in survivors of acute lymphoblastic leukemia (ALL) and other non-CNS cancers demonstrates measurable CIPN with associations to function such as walking capacity, balance, handwriting, and manual dexterity skills.[8,67,160] CIPN includes motor, sensory, and autonomic nerve dysfunction leading to the common impairments of peripheral muscle weakness, sensory changes, and autonomic impairments.[161] Peripheral muscle weakness can present as muscle weakness and/or muscle atrophy and can affect a child's ability to use their hands for tasks such as buttoning, tying their shoes, and writing,[162,163] and their lower extremities to walk, jump, or balance.[161,164] Peripheral weakness is typically focused in the wrists, hands, ankles, and feet, with more severe cases causing proximal symptoms and pain.

PTs, OTs, RNs, and other medical professionals can assess CIPN using clinical assessments such as the Pediatric-modified Total Neuropathy Score (Ped-mTNS) or the Total Neuropathy Score-Pediatric Vincristine (TNS-PV).[67,68] In addition, grip strength and ankle strength can be assessed grossly by a manual muscle test or specifically using hand-held dynamometry with available pediatric norm comparisons.[165] Rehabilitation interventions by PTs targeted at strengthening and motor skills in children with ALL have demonstrated improvements in ankle strength.[166] In addition, early evidence on the use of solid ankle-foot orthotics directed by a PT have also improved ankle dorsiflexion strength during the treatment of ALL and Wilms tumor.[167] Improvements in grip strength have not been studied, but articles do suggest that occupational therapy plays a role in the intervention of children with fine motor dysfunction.[162,168] A quick screen for peripheral muscle weakness is manual muscle testing of wrist extension and ankle dorsiflexion. It is important to understand the significant strength that is developmentally appropriate for children to identify mild cases that impact function. Screening for CIPN should also include asking about symptoms of pain, numbness, or tingling in the hands or feet, as well as questions regarding gross and fine motor function (walking change, grasp change). These limitations are described in detail in the Motor Function section.

Vincristine-induced vocal cord paralysis

Although peripheral weakness secondary to neurotoxicity from vinca alkaloids is widely recognized, cranial nerve involvement resulting in vocal cord paralysis is less frequently reported.[169,170] Children and adolescents receiving vincristine as part of their cancer-directed treatment for lesions such as solid tumors, lymphoma, and leukemia may experience vocal cord paralysis, which results from peripheral damage to the laryngeal nerve and is considered a potentially harmful but reversible condition.[171] Children with an underlying diagnosis of leukemia make up the largest group of patients who acquire vincristine-induced vocal cord dysfunction, most commonly during the induction phase of chemotherapy.[172] Symptoms of vincristine-induced vocal cord paralysis may include respiratory distress, stridor, hoarseness, swallowing difficulty, increased congestion, and facial weakness.[173,174] In severe cases, respiratory failure may

result in tracheostomy or ventilator dependency, and some children require g-tube placement because of significant difficulty swallowing.[172]

Onset of vincristine-induced vocal cord paralysis may occur within a few days or weeks of the first dose.[173] Latiff et al[172] describe a cumulative dose effect in which the symptoms of vocal cord dysfunction are not present until after several doses of vincristine.[172] Children are at higher risk for vincristine-induced vocal cord paralysis if they are hypersensitive to vincristine or have pre-existing liver dysfunction, if a cumulative dose of more than 12 mg is given, or if other drugs (including allopurinol, erythromycin, isoniazid, itraconazole, mitomycin C, and phenytoin) are concurrently used.[170,175] Farruggia et al[176] conducted a literature review of patients reported to have vincristine-induced vocal cord dysfunction and indicated that, of the few reported cases, most were young children and babies, with a median age of 2.7 years. Dependent upon the severity of the reaction, the medical team may adjust the dosage or discontinue use of vincristine altogether.[172,174] Kuruvilla et al[171] described patients with unilateral vocal cord paralysis that persisted for an average of 6.8 weeks, whereas Annino et al[169] reported that paralysis resolves in 4 to 6 weeks.

Vincristine-induced vocal cord paralysis is often first observed by caregivers or health care staff who observe new-onset swallowing difficulty and/or hoarseness. When vocal cord involvement is suspected, referral to an otolaryngologist is essential to visualize the vocal cords, determine presence and severity of paralysis (including if one or both cords are involved), and assess for any treatable causes of stridor or upper respiratory infection.[169,171,177] Additionally, referral to a feeding therapist (SLP or OT) is necessary to assess swallowing function via a comprehensive bedside swallow evaluation. In some cases, instrumental examination such as a video fluoroscopic swallow study or fiberoptic endoscopic evaluation of swallowing may be clinically indicated to determine appropriate diet recommendations and/or compensatory strategies during the period of vocal cord paralysis. Medical staff should provide close observation and serial assessment until symptoms have resolved.

To avoid potentially dangerous outcomes, children receiving vincristine who present with stridor, hoarseness, and/or swallowing difficulty should be promptly evaluated and future dosing of vincristine should be carefully considered.[171]

Facial paralysis

The facial nerve (CN VII) is responsible for facial expression by innervating the muscles of the face, as well as taste of the anterior two thirds of the tongue and the salivary glands. Facial paralysis may be a presenting neurologic symptom, but CN VII dysfunction more commonly arises from surgical insult during tumor resection. When trauma to the facial nerve occurs, children experience limited or absent movement on one side of the face. Rarely, bilateral facial palsy has been reported in children. Most commonly, unilateral facial asymmetry is characterized by labial droop, reduced labial closure, eyebrow droop, incomplete eye closure, and flattening of the nasolabial fold. Children may experience drooling, dysphagia, and slurred speech or articulation difficulties.[178] Additionally, facial paralysis is often accompanied by decreased perceptions of self and psychological concerns.[179]

To rate facial nerve assessment, the House-Brackmann Scale[69] may be used. This scale grades facial movement by assigning a number, with 1 indicating no abnormality and 5 indicating no movement. Referral to a SLP is necessary to further assess facial movement and determine what, if any, treatment is appropriate. Often, speech therapy focuses on exercising facial musculature to increase symmetry and movement. Additionally, the SLP can address swallowing difficulties and articulation or slurred speech.

Children with CN VII palsy who experience lid malposition, decreased tear function, dry eye, or tearing should be referred to an ophthalmologist, who can prescribe treatments such as artificial tears, ophthalmic ointments, or taping.[179,180] In some cases, eyelid weighting, surgical intervention such as facial reanimation, or botulinum toxin injections may be recommended.[180] Consultation by a plastic surgeon may also be indicated if facial movement does not improve with speech therapy and ophthalmologic intervention, and facial reanimation surgery may be recommended.[181]

Oral motor skills for feeding

Oral motor skills refer to the movements of oral structures including the jaw, cheeks, mouth, lips, and tongue. The coordination and strength of these structures and their associated musculature provide the groundwork for feeding tasks.[182] Oral motor skills follow a progression, starting with the suckle reflex followed by sucking, munching, and chewing. Skill acquisition is affected by growth and neurological control and is a result of both maturation and practice.[183]

Of the four stages of swallowing, oral motor skills directly impact the oral preparatory stage and oral stage. In the oral preparatory stage, an infant or child must demonstrate skills such as jaw opening, labial closure and seal, and lingual elevation for bolus acceptance, extraction, and formation. In the oral stage, elevation, lateralization, and posterior lingual movements and elevation of the soft palate are some of the necessary skills for bolus propulsion. The tongue has an essential role in feeding, with lingual movements becoming more and more complex throughout development.[183]

When oral motor difficulties are observed, a feeding therapist (SLP or OT) can conduct a thorough oral mechanism examination to evaluate structure and function. Head control and trunk support will also be assessed. Treatment strategies may include improving muscle tone, providing stimulation to the oral structures, and increasing oral motor control through various therapeutic activities.

Ocular impairments

Children with cancer are at risk for developing diagnosis and treatment-related ocular impairments. Certain CNS tumor diagnoses commonly result in visual impairment. For example, as many as 40% of children with craniopharyngioma experience abnormal visual acuity, and 63% experience abnormal visual fields.[184] Optic pathway gliomas, which arise in or around the optic nerve or chiasm, are among the most frequent tumors affecting children who present with ophthalmologic signs.[185] Damage to cranial nerves, the optic nerve, optic pathway, or areas of the cortex that influence visual abilities may result in ocular motility deficits and subsequent difficulties with tracking, scanning, double vision, impaired visual acuity (mild loss to no functional vision), impaired visual fields, or cortical visual impairment.[186] Additionally, cancer treatments including radiation and glucocorticoids have been identified as established risk factors for eye-related complications (commonly cataracts).[187] Retinoblastoma is a malignancy of the eye that originates in retinal cells of one or both eyes.[188] Treatment includes enucleation (surgical removal of the eye), RT, chemotherapy (periocular injections or systemic), cryotherapy, and/or laser therapy, all of which can lead to vision loss.

OTs assess functional visual abilities and identify related restrictions in participation in age−appropriate and meaningful activities. Because participation can be negatively impacted across multiple settings, assessment of home, community, and school functioning is recommended. Assessment may include observation of functional skills (eg, reading, handwriting, environmental navigation), screening of visual acuity (LEA symbols or age-appropriate eye chart), screening of visual fields, and ocular motility. Additional assessment recommendations are listed in Table 2. Occupational therapy intervention may include compensatory training, training in use of low vision equipment, provision of classroom recommendations, and environmental modification. Evaluation by and collaboration with an ophthalmologist or optometrist is recommended. The child also may

benefit from referral to additional services including physical therapy, speech therapy, a low vision teacher, an orientation and mobility specialist, or a certified low vision therapist. These providers may provide interventions including Braille training, mobility training such as white cane training, or recommendations for magnification devices.

Screening for visual impairments that may restrict a child's participation may include a discussion with the child or caregiver of visual complaints: double vision, blurred vision, difficulty reading (books, computer, board in classroom), bumping into objects/people, or holding objects unusually close to the face. Clinical screening may include an assessment of visual acuity and fields, tracking and scanning, and observation of the child's ability to navigate within their environment and interact with toys, books, or technologies (phone, iPad, etc.).

Hearing loss

It is well-documented that children treated with platinum-based compounds, specifically cisplatin and/or carboplatin, and those receiving cranial radiation, are at increased risk of hearing loss.[189,190] Platinum-based compounds are commonly used during the treatment of various pediatric cancers, including neuroblastoma, hepatoblastoma, and osteosarcoma. Some reports indicate that up to 50% of children who receive these therapeutic agents will develop some form of hearing impairment with cumulative dosage playing a role in degree of loss.[189,191–193] It is important to be aware that this loss may occur early on in treatment or be delayed in onset and arise after treatment has been completed.[189,190,194,195] Additionally, the degree of loss may be progressive in nature.[196] When hearing loss occurs in a young child, it can significantly delay speech and language development.[197] This in turn can have broad-reaching effects and impact a child's learning, social development, and overall educational performance.[189,197,198]

Early identification and treatment of hearing loss in children is vital to optimizing normal speech and language development, educational achievement, and typical social interactions.[189,197] Ototoxicity monitoring at regular intervals is key to early detection and management of hearing loss. Children currently being treated with ototoxic medications or survivors who were exposed to these compounds should be screened regularly for hearing loss.[189,198]

If a hearing loss is identified, hearing aids or other assistive hearing devices may be recommended by the audiologist. Additionally, a referral to a SLP is indicated to evaluate and monitor receptive and expressive language skills as well as articulation, and provide therapy as indicated. It is advised that the SLP regularly screen a child identified with hearing loss for any potential changes over time, given that hearing loss may be progressive in nature.[189,193,196,198] In addition to regularly scheduled hearing evaluations, the health care team can screen a child during medical follow-up visits by asking about changes in hearing or speech and refer for additional testing if any concerns are noted or reported.

Balance

Childhood cancer survivors demonstrate impaired balance in static positions such as sitting and standing, as well as dynamic conditions such as walking, running, and jumping.[160,199–208] Balance is the ability to maintain center of mass within base of support.[209,210] It is necessary for static and dynamic movements and skills including sitting, standing, walking, running, rising from a chair, ascending or descending stairs, and jumping.[209] Balance is developed throughout childhood, adolescence, and adulthood.[211] Multisensory input, including vision and the ability to sense body in space through vestibular and proprioception, is utilized to maintain balance.[210] When balance is compromised, an individual has difficulty performing age-appropriate activities and increases risk for falls and injury.

Balance impairments are most notable in children who have undergone medical treatment for ALL and CNS tumors because of the effects of these diagnoses and treatments on the central and peripheral nervous systems. For example, Gilchrist and Tanner[212] assessed 65 children undergoing treatment for non-CNS childhood cancers and found that 78% presented with below-average balance and 29% presented with well-below–average balance compared with age- and gender-matched norms.[212] When assessed 6 months from the end of medical treatment, balance improved in these children, but 59% continued with mild and moderate balance deficits.[212] At this time, there are no published interventions in the childhood cancer population demonstrating significant balance improvements, signifying a need for greater study.[213]

Monitoring balance in children and adolescents is important both during and after treatment. To screen for balance impairments, the child and/or caregiver can be asked if the child has "fallen, almost fallen, slipped, or tripped recently?" or if there are any concerns with clumsiness/coordination and/or being afraid of darkness. Balance can be assessed through timed performance and postural sway of sitting (with and without reaching), standing (with feet together, tandem, single limb stance, on a balance beam or foam, with eyes open or eyes closed), and the ability to perform dynamic activities such as walking on toes, heels, or on a tandem line or balance beam. Physical and occupational therapy interventions addressing balance should be tailored to patient impairments and desired functional activities.

Musculoskeletal System Impairments

Flexibility impairment

Childhood cancer survivors are at risk for flexibility impairments. Flexibility is the range of movement in a joint or series of joints affected by the length of soft tissues such as muscles, tendons, ligaments, and fascia that cross those joints. When flexibility is impaired, full movement of joints are restricted and affect resting trunk and limb positions and functional abilities. Flexibility can be affected by medical and surgical interventions, central and peripheral nervous system dysfunction, and/or immobility.

Children who receive stem cell transplantation are at risk for graft versus host disease (GVHD), a widespread immune response of donor tissue to the host. Chronic GVHD (cGVHD) (onset after day 100+ transplant) may affect the skin and joints with symptoms manifesting as fibrosis of the skin and muscles, muscle cramping, skin breakdown, and severe pain. As a result, the child may experience range of motion (ROM) restrictions, weakness, contractures, inability to grasp objects because of pain or limited fine motor coordination, and mobility and balance deficits.[214,215]

Monitoring for skin and joint cGVHD may occur using an evaluation tool such as the NIH C-GVHD Clinical Scoring System,[216] which is completed by the child's oncology team. Use of the NIH visual scale for assessing ROM has been suggested as a quick and consistent means of monitoring ROM in children with GVHD.[216] Serial assessment should be combined with close collaboration between the medical team and rehabilitation providers, and early intervention and prevention of severe joint contractures should begin at the first signs of cGVHD in the skin or joints.[216,217]

It has been suggested that OT and PT may be effective in the prevention and treatment of GVHD-related skin and joint impairments.[214,217,218] While evidence is limited, interventions including stretching, exercise, orthotics, massage, use of topical ointments, and functional motor training have been reported as successful in maintaining or restoring ROM and function.[214,217,218] Specifically, physical therapy may implement interventions consisting of balance and gait training, prescription of orthotics, stretching, and strengthening. Occupational therapy interventions may include stretching, strengthening, dexterity training, use of orthotics, and education in use of adaptive

equipment or compensatory strategies for participation in play, ADL, and IADL as well as positioning techniques.

Impairments to flexibility can also result from RT. Radiation fibrosis, or radiation-induced pathologic fibrotic tissue sclerosis, can affect skin, muscle, ligaments, tendons, nerves, bones, and organs.[219] The effect of radiation on body tissues and structures occur within and surrounding the zone of radiation acutely (during or immediately after treatment), early delayed (up to 3 months after treatment), or late delayed (more than 3 months after treatment).[219] Radiation fibrosis syndrome describes the range of clinical symptoms of progressive fibrosis.[219] Fibrosis of skin and soft tissues, atrophy of muscles, and damage to nerves lead to functional difficulties.

A specific radiation side effect impacting flexibility is trismus, a tonic contraction of the mastication muscles that limits the ability to open the jaw and may lead to significant consequences, including reduced nutritional intake, compromised oral hygiene, difficulty speaking, and decreased QOL.[220,221] Trismus is reported to affect more than one third of patients during their first year following completion of treatment.[222] Mastication of food can become challenging, requiring modifications to the food or method of intake to maintain nutritional status. When limited jaw opening is observed, referral to a SLP is appropriate to evaluate jaw ROM and provide appropriate treatment strategies. This may include use of passive or active ROM exercises. Often, patients will perform a home exercise program to remediate limited jaw opening. However, if consistent exercise is not performed or patients present with fibrosis, the patient is unlikely to achieve or maintain increased opening.[222,223]

Flexibility can also be compromised when a child experiences surgery, CIPN, weakness, immobility, and/or disuse. For example, childhood cancer survivors of bone tumors around the knee present with decreased ROM of the knee joint.[224] Additionally, children with ALL experience decreased ankle ROM during and after treatment.[8,160,206,225,226] Changes in muscular tone, which can be experienced by individuals with brain tumors, may lead to decreased flexibility and contractures, especially with dystonia.[227] The specific contributions of flexibility impairments in childhood cancer survivors have not been identified, but appear to be multifactorial.

Assessment of body segments during treatment and during survivorship is important to detect and treat flexibility impairments. The question “Do you feel tightness or difficulty moving your body, mouth, or limbs?” can be used. Assessment includes ROM (movement of joints), flexibility (length of muscles-tendons), soft tissue restrictions, and pain.[219,228] Stretching, strengthening, soft tissue mobilization or massage, and/or orthotics (functional or stretching) can be used to address the impairments of flexibility on function.

Posture

Childhood cancer survivors, especially those who have undergone RT or surgery can develop impairments in posture. Postural dysfunction or deformities presenting in children and adolescents with cancer include scoliosis, kyphosis, lordosis, and limb length discrepancies.[229–232] Risk factors of postural dysfunction include craniospinal or abdominal radiation, younger age at time of treatment, and surgery or radiation that occurs on one side of the body or includes the growth plate of a bone.[229–232] Surgical management of postural dysfunctions may be necessary if these deformities affect function, breathing, and/or cause pain. PTs and OTs play an important role in screening for these changes and providing interventions, including postural training, stretching, strengthening, and/or orthotic management such as shoe lifts.[233,234]

Childhood cancer survivors should be assessed for posture impairments. The provider can ask the child and/or caregiver if they have noticed any changes in posture such as a “slump, hump, or unevenness in the trunk or limbs.” Posture can be assessed through observation of symmetry in sitting and standing, assessing the position of the head, pelvis, and shoulders. Specifically, the Adam’s Forward Bend Test can be used to assess the presence of scoliosis.

Gait

Gait impairments occur in children with cancer throughout the continuum of care.[8,164,235] Research demonstrates decreased velocity, step length, abnormal muscle activation, and decreased gait efficiency in children with non-CNS cancer.[164,236] Children with CNS tumors demonstrate asymmetrical gait patterns, ataxic gait, or abnormal gait biomechanics secondary to location of tumor or complications during surgery.[235,237] Additionally, children with CNS tumors may have impairments secondary to treatment because some diagnoses receive neurotoxic chemotherapy. In children with truncal and lower extremity sarcomas, slowed velocity and asymmetries often are present.[238,239] These impairments persist in adult survivors of pediatric cancer in both non-CNS and CNS populations.[8,108]

PTs assess gait and change of gait during treatment using descriptive gait observation, objective gait analysis scales, or computerized gait analysis.[240] Assessments such as the 6-minute walk test and 9-minute walk test also can demonstrate a child’s gait capacity and allow assessment of change in gait with fatigue.[164,240] The use of the 30-second walk test may be useful to determine gait efficiency in the school setting.[241] Emerging evidence on PT, orthotic, and exercise intervention supports an association with improved gait efficiency and gait mechanics.[213,235,242,243] In addition, improvements in other impairments such as joint flexibility, general strength, or balance also may impact a child’s ability to walk.[164,224,244] Screening of gait impairments by the medical team should include subjective questions about change in walking pattern or walking ability over distance. Clinical screening should include observation of gait with expectation of a heel-toe symmetrical gait pattern at the age of 2 years old.[245] Comparisons between pre-diagnosis and diagnosis, as well as between stages of treatment, are important because of the likely combined etiology of disease impact and treatment side effects.

Weakness

Muscular strength is the amount of force a muscle produces with contraction.[209] Muscle strength is developed from infancy, through childhood and adolescence, and peaks between 20 and 30 years of age.[246] Muscle weakness leads to difficulty with or inability to perform functional activities and can lead to compensatory strategies that can have long-term effects on body structures and pain.

Childhood cancer survivors demonstrate muscle weakness that can be a result of chemotherapy, radiation, corticosteroids, surgery, and/or disuse.[4,19,208,229,230,247–256] Muscle weakness is a key finding in individuals with CIPN, functionally observed as foot drop or slap caused by weakness of the ankle dorsiflexors.[257] Weakness is common across childhood cancer diagnoses, but most notable in individuals with ALL, musculoskeletal tumors, or CNS tumors, or those who have undergone a bone marrow transplant.[4,19,208,229,230,247–256] For example, Ness et al[248] found that CNS childhood cancer survivors with a mean age of 22 years demonstrated muscular strength performance comparable to 60 year olds.

Muscle strength is important to assess in children and adolescents during and after treatment for childhood cancer. Muscle strength can be assessed clinically by muscle, muscle groups, or functionally. Measurements of specific muscles or muscle groups can be assessed through manual muscle testing (0–5 scale) or handheld dynamometry (measurement of force). Timed tests for sit ups, planks, superman (trunk extension), wall squats, and ascending/descending flight of stairs can be used to assess muscle strength and endurance. Additionally, functional assessments such as jumping height and upper extremity use during sit to stand or floor to stand can be used. Physical and occupational therapy interventions focus on re-gaining

muscle strength and function.[258–263] Manual muscle tests or age-appropriate functional strength screening (Table 3) should be used to assess along the continuum of care.

Multi-system Impairments

Pain

It is estimated that between 49% and 62% of children and adolescents suffer from pain during cancer treatment.[264] The type and etiology of pain varies widely between mucositis, bone pain, procedural pain, dysesthesias, paresthesias and musculoskeletal pain, among others.[265,266] In a study of 1,776 adult survivors, 58.7% reported pain at a site other than the neck and back.[267] There is limited available literature on nonpharmacologic approaches to cancer-related pain in pediatrics outside of integrative approaches to procedural pain.[213] However, rehabilitation interventions are highly recommended as part of the integrative approach to pain management in children with cancer.[266]

Assessments for pain include the Visual Analog Scale (VAS)[86] and the Numerical Rating Scale (NRS)[84] for older children, and the Faces Pain Scale-Revised (FPS-R)[83] for younger children. Pain can also be rated using the revised Face Legs Activity Cry and Consolability (FLACCr) scale[85] in nonverbal and cognitively impaired children or the CRIES scale in infants.[82] Additionally, based on clinically utility, psychometric properties, and application in children with pediatric cancers, The Academy of Oncologic Physical Therapy EDGE Task Force highly recommends the Wong-Baker FACES Pain Rating Scale.[268] Rehabilitation therapists assess for pain using these scales similar to other health care providers; therefore, the scores can be compared across disciplines. Screening for pain beyond these assessments should include questions regarding pain over a period of time (such as a month) to identify intermittent or chronic pain related to function or daily living, in addition to acute pain symptoms.

Rehabilitation therapists, primarily PT and OT, will utilize different interventions for pain depending on etiology in conjunction with prescribed pharmacology intervention. For example, if a child with ALL has pain from osteonecrosis, a therapist will provide and train the child in mobility with an assistive device if required, and work on strengthening and mobility that are pain-limited. Conversely, if neuropathy is the cause, desensitization techniques or transcutaneous electrical nerve stimulation taught by the OT or PT may be of benefit. An SLP recommends diet modifications in children with mucositis pain or addresses jaw pain associated with radiation-induced trismus by recommending hot compresses, facial massage, and ROM exercises. Therapy with a focus on maintaining function, independence in ADLs/IADLs, and PA is critical during pain episodes and has been successful in the pediatric chronic pain population.[269]

Fatigue

Fatigue is cited as the symptom of greatest distress for children and adolescents with cancer. It is estimated between 50% and 76% of children with cancer experience fatigue.[270] Cancer-related fatigue can be defined as "a distressing, persistent, subjective sense of physical, emotional, or cognitive tiredness or exhaustion related to cancer or cancer treatments that is not proportional to recent activity and interferes with usual functioning."[271]

A recent systematic review on the impact of PA on fatigue demonstrated a significant reduction in fatigue with PA across cancer subgroups with aerobic, neuromotor (yoga, tai chi, etc.), and combination PA impacting fatigue greater than resistance exercise alone; however, this review only included one study with children.[272] PA interventions in small studies improved fatigue in children with brain tumors,[273] ALL,[274,275] and adolescents with cancer[259]; however, other interventions such as yoga, stationary peddling during hospitalization, and a home-based exercise program had no significant impact on fatigue.[276–278] Because of the strong evidence in large adult trials, a multidisciplinary group of health care experts recently published a clinical guideline for the management of fatigue in children and adolescents with cancer, recommending PA, relaxation, and mindfulness as the primary fatigue interventions.[270] In addition, cognitive intervention was recommended to manage fatigue if the former interventions were not efficacious or feasible.[270]

Patient-reported symptom scales can be used to both measure level of fatigue and give the child or adolescent and caregivers words to communicate around fatigue. The Childhood Fatigue Scale (FS-C), Fatigue Scale for Adolescents (FS-A), and Parent Fatigue scale (FS-P) are brief, have low burden, and have been used in multiple studies in children with cancer.[87,88,276,279–282] The patient-reported outcomes measurement information system (PROMIS) pediatric fatigue item banks are also used in assessing this symptom.[106,283]

The clinical guideline on fatigue management recommends PA to be tailored to the specific needs of individual children and adolescents.[270] This is critical secondary to the link between a higher level of symptoms experienced during childhood cancer treatment to a lower level of functioning.[283] Thus, rehabilitation therapists need to assist in both addressing the developmental skills required for PA in children and adolescents as well as providing education and intervention on the frequency, intensity, type, and duration of PA at different stages of the cancer continuum. Screening for rehabilitation referral should include questions on energy level to play with peers (PT), complete ADLs (OT), or complete school tasks (OT/SLP).

Activity Limitations

Motor function

The development of motor function, more specifically gross and fine motor skills, is vital to a child's PA participation, cognitive and social development, and QOL.[213,225,284] Gross motor skills develop from crawling and walking in the first 12 months of life, to skipping and jumping jacks at age 5.[285] Simultaneously, children learn to pick up a small food particle at age 8 months, and progress into tying shoes and buttoning small buttons at 5 years, and handwriting a short story in the first 7 years of life. Treatment and disease-related side effects impact the development of this motor function and may in turn impact participation in play, ADL, school activities, IADL, and leisure pursuits during acute treatment as well as into long-term survivorship.[7,286–288] For example, a child learning to run and jump with ankle weakness from CIPN may compensate in the movement using hip and quadriceps musculature. If the neuropathy resolves, the ankles may have the ability to strengthen; however, the motor skill is developed using a less efficient pattern and is unlikely to change. Similarly, a child who experiences weakness and limited sensation in the hands because of CIPN may be delayed in their acquisition of developmental fine motor activities such as handwriting. Handwriting abilities have been reported to decline during treatment and after treatment for some children treated for leukemia.[289] Rehabilitation services focus on maximizing the skills and minimizing impairment-related compensations to raise a child's ability to participate in physical activities and ADL/IADLS.

Investigations of motor skills in childhood cancer reveal limitations in multiple diagnostic groups and time periods during cancer treatment and beyond. A study of children age $\leq$ 42 months (18.99, SD 11.19) undergoing treatment for non- CNS cancers including leukemia and solid tumor found that children with cancer scored lower than healthy controls on assessment of gross movements and fine manipulation skills.[9] Long-term survivors of childhood cancer may also experience fine and gross motor limitations[22,290] Specifically, survivors of ALL demonstrate impaired gross motor skills with prevalence ranging from 5% to 54%.[213] The range of findings could be a

result of assessment measures because often a screen is completed rather than a full motor skill battery.[291] Diagnoses of a bone tumor or CNS tumor create a higher risk of limitations secondary to surgical and chemotherapy-related effects.[224,288,292–294]

Assessment of fine and gross motor skills in children by an OT and PT may occur through use of a standardized assessment such as the Peabody Developmental Motor Scales II,[94] or the Bruininks-Osertesky Test of Motor Proficiency version 2.[295] Scores can be compared with the general population or can be used to assess change. In addition, specific gross motor skills such as jumping distance or running speed can be assessed and compared with age norms if particular concerns arise. Other gross motor function measures utilized in pediatric cancer include the Timed Up and Go (TUG) and the Timed Up and Down Stairs test (TUDS).[240] These, respectively, evaluate the time it takes to stand from a chair, walk, turn around, and sit in chair; and to walk up and down a flight a stairs, and each can be completed in less than a minute. Assessments of fine motor function include quick measures of dexterity and manipulation, such as the 9-Hole Peg Test[296] or the Purdue Peg Board Test.[297] Other more specific tests of fine motor function, such as assessment of handwriting proficiency, can be found in Table 2. These assessments repeated at set intervals throughout the cancer experience provide reliable information on fine and gross motor function.

Interventions aimed at gross motor skill development or recovery in children and adolescents with cancer include individual or group-based exercise training programs and impairment-based physical therapy interventions.[18,213,298–302] A consensus on the impact of these interventions cannot be reached because results are varied and are typically evaluated in small numbers of participants.[213,298,299] In the acute medical setting, children with cancer demonstrate improvements in function with early initiation of physical therapy services.[300,303,304] Furthermore, intensive inpatient rehabilitation for children with CNS tumors or bone tumors demonstrate significant motor improvements.[19,305] Investigations in the outpatient cancer population do document significant differences in group exercise training,[301,306,307] group yoga intervention,[302] and PT interventions.[18,261,300] Further investigation of rehabilitation and exercise interventions on larger populations through multi-hospital trials is necessary to investigate the ideal time, intervention type, and intensity required to improve motor function. [308,309]

Screening of developmental skills can be completed through standardized scales (reported in Table 2), such as the Ages and Stages Questionnaire (ASQ-3).[310] Quick subjective history and clinical screening tests per age group are presented in Table 3. It is important to assess the quality of the movement, not only the movement itself, to understand if the child is experiencing impact from the diagnosis and treatment of cancer.

Communication

Communication refers to the ability to understand and express language and non-verbal cues allowing for successful interactions with others. Ineffective communication skills can have short- and long-term consequences because a cancer diagnosis and treatment may affect caregiver-child interactions and peer relationships, impact school performance, and contribute to reduced QOL.[312]

The impact of cancer-treating agents on long-term cognitive communication skills is described earlier in the Neurocognitive section. In addition, long-term hospitalization and periods of modified isolation because of compromised immune systems may influence language development in young children and pragmatic language skills in older children, who are unable to engage in typical peer interactions for periods of time. As already discussed, children treated with ototoxic chemotherapy agents and who receive cranial radiation are also at risk for hearing loss, which can impact speech-language development.

A vocabulary-rich environment can assist in language acquisition.[311,312] Environmental factors, such as being in an isolated setting or having periods of feeling unwell because of an underlying disease or treatment, naturally limits typical age-appropriate experiences and may limit a child's exposure to language. Older children who undergo long periods of isolation from peers may experience difficulty with appropriate peer interactions and prefer adults as communication partners.

Speech-language therapy can help provide caregiver education on implementing a language-rich environment, even in a hospital setting, to promote learning and typical interactions and help children meet their speech and language milestones. Screening of a child's communication should include getting caregiver input on a child's language and pragmatic skills or use of a standardized screening tool. If concerns arise, referral to a SLP is recommended to allow for domain-specific testing.

Feeding

Eating and drinking are complex processes that involves the integration of various related systems and muscle groups.[139,313] Dysphagia, vocal cord paralysis, facial nerve paralysis, oral motor impairments, and side effects of chemotherapy and radiation (including nausea, vomiting, mucositis, early satiety, and other gastrointestinal issues) can lead to a significant decrease or even temporary cessation of oral intake. This may lead to longer-term feeding difficulties[314,315] and lack of typical feeding habits and experiences.[316] Malnourishment and caregiver stress are likely consequences when children are unable to efficiently acquire nutrition.[156] Additionally, food refusal, limited food repertoire (food selectivity), inefficient feeding, taste changes, or taste aversions are potential challenges at various stages of treatment. Frequently, adverse behaviors, including gagging, expulsion of food, agitation, and negative sensory responses make mealtimes stressful and can impact QOL.

The feeding therapist can offer direct oral-motor feeding treatment by addressing oral-motor skill development and sensory aspects related to feeding and texture acceptance, and implementing exercise programs that target the pharyngeal phase of swallowing. In addition, the feeding therapist can establish an individualized feeding plan to provide recommendations related to the child's positioning and state, pacing of intake, and recommend compensatory strategies to maximize safety, efficiency, and success with oral eating and drinking.[317] Education to caregivers on expectations related to oral feeding during treatment and ways to encourage positive mealtime experiences at various stages is also an important component of feeding therapy.

Participation Restrictions

Physical activity

PA restrictions in the pediatric cancer population are concerning in light of the many benefits of PA in relation to long-term health. A recent meta-analysis of PA in childhood cancer survivors reported significantly decreased PA in survivors versus non-athletic controls.[318] Children and adolescents during cancer treatment often struggle to be physically active secondary to hospitalizations, cytopenias, physical impairments, or limitations. One study of 130 patients reported a reduction in PA interest during treatment, 50% of the population being in bed for 23 of 24 hours per day during hospitalizations and a 74% reduction in PA while at home during treatment from pre-diagnosis levels.[319] Cardiorespiratory fitness measured by VO_2 peak are lower than age norms during treatment and into survivorship in pediatric cancer survivors.[248,320,321] The reported relationship of improved lean muscle mass and lower fat mass with higher level of PA in survivorship leads to the assumption that higher PA in survivorship would reduce the cardiovascular late effects many cancer survivors experience.[322] PA also has a cognitive and psychosocial impact in children with cancer, specifically children with brain

tumors.[323] Finally, research is beginning to support the anti-cancer effects of PA with overall lower relapse rates and overall mortality in adult cancers,[324] anti-tumor impact in mouse models,[325] and lower relapse mortality in childhood cancer survivors.[326]

To date, interventions aiming to improve PA and fitness levels during treatment or post-treatment have demonstrated mixed results.[213] Because of the relationship of motor skill proficiency to PA participation in children and adolescents with cancer, interventions should consider targeting both areas for success.[301,327] In small investigations, PTs, exercise specialists, nutritionists, and other health care providers provide a variety of intervention types and frequency from on-site PA sessions three times per week, to coaching over the phone once every 2 weeks.[213,273,328,329] Self-reported PA typically occurs when supervision is provided in both the inpatient and outpatient setting, supporting the need for health care professionals including oncology nurses and rehabilitation professionals to provide PA experiences[319,330]; however, this does not diminish the need for promotion of independent PA throughout treatment and survivorship.

It is imperative that the health care community collaborates on screening and PA promotion during and after cancer treatment. Screening questions in the pediatric population surround the topics of minutes of exercise per day, participation in physical education class, and questions related to activities completed outside of school. Understanding of the intensity of PA should also be explored as a family's perception of what is "normal" may have shifted during intense cancer treatment. For example, a child may say they have no difficulty participating in gym class; however, upon further questioning they report sitting out of the running activities because of fatigue. If a child is not meeting the recommended 60 minutes a day, discussion of barriers to activity should be discussed. Depending on the barriers cited, physical therapy, exercise physiology, cardiology, psychology, or social work may be appropriate referral sources. Whether or not a child requires referral, motivational interviewing concepts could be used by anyone in the health care team to promote PA throughout treatment and beyond.

Educational restrictions

As a result of medical, neurocognitive, physical, or social late effects, children with cancer may experience education challenges. A survey of more than 12,000 survivors of childhood cancer reported that 23% of childhood cancer survivors used special education services. More specifically, upwards of 50% of children with CNS disease and treatment required special education services to support them in school. The survey also reported that survivors of leukemia, CNS tumors, non-Hodgkin lymphoma, and neuroblastoma were significantly less likely to finish high school and college than were sibling controls.[331] Because of the relative rarity of childhood cancer and the unique, fluctuating challenges experienced by a child with cancer, schools may not be equipped to recognize and address the needs of this population.[332,333] Therefore, support from a multidisciplinary cancer care team is necessary to help support the child and family as they transition back to school and beyond.

Rehabilitation providers have an important role in advocating for the educational needs of the child with cancer and educating key stakeholders in the potential impact that impairments may have on educational performance. Children with cancer may qualify for educational supports, including accommodations or modifications through Section 504 of the Rehabilitation Act of 1973.[334] Other children may be eligible for educational services under the Other Health Impaired category of an Individualized Education Plan through the Individuals with Disabilities Education Act.[335] Rehabilitation interventions in the school setting are focused on facilitating access to curricular and extracurricular activities.[336–338]

Dependent living and employment

As a result of physical, cognitive, and psychosocial performance restrictions, adolescents and young adults with cancer may experience difficulties related to employment and achieving independent living. Both survivors of childhood cancer with a recent cancer history and long-term survivors are more likely than individuals without cancer to report difficulty participating in a number of functional tasks, including difficulty completing chores, dressing, going out to events, difficulty walking ¼ mile, and difficulty lifting or carrying 10 lbs.[287,339] These restrictions in functional task performance may contribute to childhood cancer survivors being more than twice as likely to live dependently (odds ratio, 2.07) as compared with siblings.[340]

Additionally, Pang and colleagues[341] found that survivors across varying diagnostic categories and treatment types are 3.7 times more likely to report unemployment than sibling controls. Neurocognitive and communication disorders may result in higher incidence of unemployment among survivors of CNS tumors,[341] while survivors of other childhood cancers indicated fatigue and pain limiting work activities.[342] Survivors with poor emotional health are less likely to be employed, less like to be married, and likely to have household incomes of $20,000 per year or more than survivors who did not report poor emotional health.[343]

Rehabilitation therapists are trained to identify functional performance restrictions that impede independent living and employment and work with survivors to remediate or identify strategies to compensate for difficulties. Vocational rehabilitation programs may also work with survivors and employers to identify feasible changes to job responsibilities or environments that lead to increased employment.[344] Screening by oncology nurses for independent living and employment limitations should include a discussion with survivors and/or caregivers to identify physical or cognitive changes that may impact the ability to obtain or maintain independent living and/or employment.

Quality of life

QOL is obviously impacted for children undergoing treatment for cancer. The treatment itself can lead to lifestyle changes because of need for home schooling, frequent clinic appointments, and hospitalizations.[345] An interview of pediatric oncology patients actively receiving treatment revealed four major themes that affected their current QOL: loneliness, isolation, and the loss of a normal childhood; decreased pleasure from food; physical discomfort and disability; and emotional responses to cancer.[345] One study showed that up to 88% of young adults who were childhood cancer survivors reported at least one late effect that interfered with their ability to participate in major life activities, such as memory, body image, fatigue, cognition, chronic pain, or depression.[342]

Rehabilitation services are crucial during acute treatment for childhood cancer, but can also play a role in cancer survivorship and transitioning into adulthood. Rehabilitation services that treat physical and cognitive performance deficits can lead to improved QOL by improving participation in life roles and activities. A standardized questionnaire, such as the Pediatric Quality of Life Inventory (PedsQL), including the The PedsQL Generic Core Scales, Multidimensional Fatigue Scale, Cancer Module, or Brain Tumor Module, can be helpful to determine patient-identified needs or concerns.[346] See Table 2 for additional scales.

Rehabilitation Service Delivery

The role of rehabilitation in the population of childhood cancer is evident, given the multiple impairments, limitations, and restrictions caused by the disease and treatment. There are proactive and reactive approaches to providing these services that we refer to, respectively,

as a prospective surveillance model (PSM), and the traditional symptom-based referral model. A PSM includes the following components: surveillance for common physical impairments and functional limitations, education to prevent adverse events, early detection of physical impairments, rehabilitation when impairments are identified, and promotion of PA throughout treatment and into survivorship.[18,347] The symptom-based referral model relies on consistent and skilled screening by oncology health care providers to identify impairments and refer to the appropriate rehabilitation professional. The PSM model promotes automatic referral based on risk factors determined by diagnosis and treatment to rehabilitation services where standardized assessments can be performed across the continuum of care. The PSM has shown promise in the ALL population[18] and the breast cancer population[347]; however, further investigation is needed.

Either model of rehabilitation may include episodic rehabilitative care. Episodes of care refers to the provision of rehabilitation services for a defined time period, or having periods of therapy treatment followed by therapy breaks.[348] Therapists will treat immediate impairments and prioritize care to optimize function for the child's developmental age or until a plateau is met. When a therapy break is recommended, therapists will suggest appropriate time frames for reassessment. The health care team should continue to consider the benefit of rehabilitation services beyond the initial episode of care, and repeated referral may be needed.

Transitions of care

As a child with cancer moves through the cancer care continuum, from diagnosis through the long-term survivorship phase, they and their family will likely experience several transitions in care. Major transitions include moving from the diagnosis phase to treatment phase, on treatment to off treatment phase, and moving from acute post-treatment care to long-term follow-up care. For the child with rehabilitation needs, rehabilitation providers and oncology nurses should collaboratively serve as transition navigators for the child and family. For example,when the very young child with a developmental delay completes active cancer treatment at the hospital, they will require assistance from rehabilitation providers and oncology nurses to ensure that adequate supports and services are in place when they transition back to their home community. During the transition to long-term follow-up care the child and family may experience several rehabilitation-related issues, including loss of or exhaustion of rehabilitation insurance benefits, graduation from high school and loss of school-based rehabilitation services and supports, or the appearance of new impairments in function secondary to late effects. The PSM described earlier provides opportunities for the care team to deliver ongoing transitional supports, including advocacy for necessary rehabilitation services, identification of community resources such as vocational rehabilitation, or home exercise programs that will provide opportunities for improved function in the absence of direct rehabilitation services in the home community. Adolescent and young adults who are cancer survivors will also need to make a transition from a pediatric care model to an adult care model, but they differ from other chronic health conditions in that they may not have manifested the late effects of their treatment at the time of this transition.[349]

Multidisciplinary collaboration

Regardless of treatment model or point during the cancer continuum of care, children and adolescents require a collaborative health care team to address their functional needs and QOL. Communication between health care providers, family, and child is necessary on subjects including treatment toxicity, functional concerns, PA, and pain. For example, a PT or OT may assess a significant change in peripheral strength that may indicate an oncology provider to decide to reduce a chemotherapy dose. A non-verbal child may not complain of pain, but a specific gait impairment assessed by PT may indicate a likelihood of pain that causes an oncology provider to prescribe pain medication. An SLP may assess a change in swallowing function that provides insight on recent malnutrition necessitating supplemental feeding. The complicated multidimensional nature of childhood cancer care requires the continuous assessment and perspectives of each health care team member communicating across disciplines to provide comprehensive care for each child and family.

Role of Oncology Nursing

Oncology nurses are vital in screening patients for impairments, limitations, and restrictions that require rehabilitation services. It is imperative nurses understand the multiple functional limitations endured by children with cancer and the impact of cancer rehabilitation. Beyond functional screening, direct actions such as encouraging out of bed activity during an inpatient stay, promoting independence in ADLs such as dressing, or engaging in age-appropriate communication in every stage of the cancer continuum will help a child reach functional goals. In addition, nurses can support rehabilitation goals by asking about rehabilitation attendance and progress, celebrating return or development of functional progress, and directly inquiring about suggested home exercise/activity programs to promote adherence.

Conclusion

In summary, the increasing survival rate of children and adolescents with cancer necessitates a focus on function and QOL. Many multi-system impairments, limitations, and participation restrictions have been explored through research investigation and found to persist into long-term survivorship. Rehabilitation intervention has great potential to mitigate the impact of cancer and its treatment, and may have a role in reducing morbidity and mortality. There is an obvious need for additional research into rehabilitation interventions and models of care for children with cancer. Incorporating rehabilitation into comprehensive pediatric cancer care requires an interdisciplinary effort and depends on greater engagement by all health care providers and nursing staff with the tenets of function, as well as familiarization with the tools and resources that can be used to improve QOL in this population.

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Conflict of Interest

None.

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