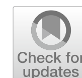
Supportive Care in Cancer (2026) 34:639
https://doi.org/10.1007/s00520-026-10695-x

RESEARCH



Patient-reported and caregiver-reported outcomes after limb salvage or amputation for pediatric bone and soft tissue sarcomas: a scoping review

Lindsay Jibb[1,2,8] · **Juliane Feliciano**[1,3] · **Isabella Zaffino**[1,4] · **Tessa Palmert**[1,5] · **Mikaela Gray**[6] · **Elham Hashemi**[1] · **Erica Deans**[7] · **Leah Deans**[7]

Received: 16 December 2025 / Accepted: 17 April 2026
© The Author(s) 2026

Abstract

Purpose Children diagnosed with bone tumors or soft tissue sarcomas often undergo limb salvage surgery or amputation, procedures that shape long-term functioning and quality of life (QOL). Patient-reported and caregiver-reported outcomes (PROs) provide essential insight into physical, psychosocial, and participation impacts, yet existing evidence is dispersed and methodologically heterogeneous. This scoping review mapped the PRO literature for children, survivors, and caregivers following cancer-related limb surgery and identified gaps limiting clinical care and research advancement.

Methods Six databases were searched. Eligible studies included children with bone or soft-tissue sarcomas and their family caregivers that reported PROs or needs related to limb salvage or amputation. Two reviewers independently screened studies and charted data. Quantitative and qualitative findings were summarized descriptively and synthesized narratively across QOL domains.

Results Twenty-seven studies fulfilled inclusion criteria. Physical functioning was the most assessed domain, with generally moderate-to-good outcomes and limited differences between limb salvage and amputation. Pain remained common months to years post-surgery. Psychosocial findings were mixed, reflecting peer acceptance but also body image, recreation, and school participation challenges. Only four studies included caregivers, who reported anxiety, depression, financial strain, and shifting family roles. Across studies, PRO measurement was highly heterogeneous, with inconsistent domains of assessment, measurement tool use, and timepoints.

Conclusions Children and families experience complex functional and psychosocial impacts after limb surgery, underscoring needs for enhanced rehabilitation, pain care, school reintegration, and caregiver support.

Keywords Pediatric oncology · Sarcoma · Limb salvage · Amputation · Patient-reported outcomes · Quality of life · Caregivers · Scoping review

✉ Lindsay Jibb
lindsay.jibb@sickkids.ca; lindsay.jibb@utoronto.ca

1 Child Health Evaluative Sciences, Hospital for Sick Children, Toronto, Canada

2 Lawrence Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada

3 Faculty of Health, York University, Toronto, Canada

4 Temerty Faculty of Medicine, University of Toronto, Toronto, Canada

5 Faculty of Science, McGill University, Montreal, Canada

6 Gerstein Science Information Centre, University of Toronto, Toronto, Canada

7 Saskatoon, SK, Canada

8 Child Health Evaluative Sciences, SickKids Research Institute, Hospital for Sick Children, 686 Bay Street, Toronto M5G 0A4, Canada

Introduction

Childhood bone tumors and soft tissue sarcomas—most commonly osteosarcoma and Ewing sarcoma—require multimodal therapy that often includes limb-directed surgery. Over the last decades, advances in chemotherapy protocols, prosthetic technology, and surgical techniques have expanded the use of limb salvage procedures, with amputation remaining necessary in certain clinical contexts [1, 2]. These approaches aim to maximize survival but inevitably shape the daily functioning and quality of life (QOL) of patients and survivors—affecting mobility, independence, pain, participation at school and in recreation, body image, social relationships, and long-term wellbeing [3–6]. Understanding impacts across surgery types from the perspectives of children, survivors, and their family caregivers is essential. Patient-reported outcomes (PROs) capture how health status and treatment effects are experienced in everyday life, while reports from caregivers who provide practical, emotional, and advocacy support can illuminate needs that clinician reports and the medical record may miss [7, 8].

Still, despite the critical importance of understanding child function and participation, evidence is dispersed across disciplines and study designs. Outcomes beyond physical function, including psychosocial health, schooling and employment, and caregiver perspectives, are inconsistently assessed and reported. The fields of pediatric surgical oncology care and research lack consensus on which PRO measures (PROMs) are practical to administer and which capture the domains that matter most to children and families. A comprehensive map of what has been studied, how it has been measured, and where the gaps remain is required to inform practice and guide research, including by guiding PRO measure selection and administration, as well as family-centered support. By charting the nature of research in this area and identifying child-reported, survivor-reported, and caregiver-reported post-surgical outcomes, a coherent agenda for interdisciplinary clinicians and researchers working at the intersection of pediatric oncology, surgery, and rehabilitation can be developed.

This review was guided by the following research questions: (1) What health outcomes, reported by children diagnosed with bone tumors or soft tissue sarcomas, survivors of such cancers, and their family caregivers, are associated with having undergone limb-salvage surgery or cancer-related amputation? (2) What gaps exist in the evidence related to measuring PROs and their measurement approaches in these groups that might limit current clinical care efforts or future evidence generation?

Methods

Framework

The scoping review followed the framework developed by Levac et al. (2010), encompassing question formation, study identification and selection, data charting, and synthesis [9]. Reporting adhered to the PRISMA Extension for Scoping Reviews and the PRISMA Extension for Searching guidelines [10, 11] (Electronic Supplementary Material 1). The review protocol was pre-published on Open Science Framework (https://osf.io/f8a94).

Study identification

A health sciences librarian developed and executed *de novo* searches on June 26, 2024, across Ovid MEDLINE, CINAHL, APA PsycInfo, Cochrane CENTRAL, Social Services Abstracts, and ASSIA, using tailored subject headings and keywords without filters or limits. The MEDLINE strategy was peer reviewed using PRESS (Peer Review of Electronic Search Strategies) guidelines [55] before translation to other databases. Search completeness was assessed through retrieval of known studies and dual screening the first 200 records per database. Reference lists of included studies and relevant reviews were also screened. Search strategies are presented in Electronic Supplementary Material 2.

Eligibility criteria

Eligibility was defined using the PCC (population, concept, context) framework. The *population* was children and adolescents (≤ 18 years at surgery) who underwent limb-directed surgery of either the upper or lower extremity for bone or soft tissue cancers, including amputation and limb salvage procedures (e.g., endoprosthetic reconstruction, biological reconstruction, rotationplasty), and their family caregivers (individuals providing primary parental care but not necessarily biological parents). The *concept* was studies of childhood bone tumors and soft tissue sarcomas, as classified in the International Classification of Childhood Cancer (3rd edition) reporting PROs (defined as health information coming directly from patients or caregivers) and needs (subjective states prompting use of medical or other resources). The *context* was all healthcare settings and qualitative or quantitative study designs, excluding single case reports (< 10 participants), commentaries, protocols, discussion papers, book chapters and conference abstracts. No restrictions were applied by

data or language; for non-English studies, translation was planned. Studies without explicit age ranges were included if the mean plus SD was ≤ 18.9 years.

Study screening

Records were managed in Covidence. Duplicates were removed and titles, abstracts, and full texts were independently screened by two reviewers, with disagreements resolved by a third reviewer.

Data abstraction and charting

A standardized Excel abstraction form with an embedded coding manual was piloted on five studies and revised iteratively. Two reviewers independently abstracted data, with disagreements resolved by consensus. Study authors were contacted for clarification where necessary. Extracted data items were publication metadata, study design data, and participant characteristics. Health outcomes were coded with details on measurement tools and reported results.

Data synthesis and reporting

Quantitative data were summarized descriptively. Qualitative data were synthesized descriptively and organized in a matrix of outcomes and needs by participant type and domain. Given heterogeneity in study design, results were synthesized narratively with subgroup patterns explored where data permitted.

Patient and public involvement

This review was initiated by a patient and public partner (LD) and funded by the Strategy for Patient-Oriented Research–Evidence Alliance (SPOR-EA), which is jointly supported by the Canadian Institutes of Health Research (CIHR) and 41 public and not-for-profit partners across Canada [12]. The SPOR-EA invited public submissions of research questions to guide literature reviews and the topic of PROs in the context of pediatric oncological surgery was proposed by LD based on her experience as the mother of a child with a cancer-related amputation (ED) and the need to improve access to high-quality evidence.

The project was co-led by LD and LJ with contributions from ED. Partners were full team members, providing input across every review phase—such as the creation of the search strategy, study screening, data interpretation, and dissemination of findings. Patient and public partner contributions are reported using the Guidance for Reporting Involvement of Patient and the Public (GRIPP)−2 short form [13] (Electronic Supplementary Material 3).

Results

Study characteristics

The search identified 11,403 records, of which 27 were included (Fig. 1). Studies were published between 1989 and 2023 (Fig. 2) and conducted in North America (USA, Canada), Europe (Netherlands, UK, Italy, France, Spain, Germany), Asia (China, Turkey, Iran), South America (Brazil, Peru), and Australia. Study details are summarized in Table 1, with extracted data presented in Electronic Supplementary Material 4. Designs varied considerably, with cross-sectional ($n = 11$; 41%) [14–24] and retrospective ($n = 8$; 30%) studies most common [25–32]. Three studies (11%) were prospective or longitudinal cohorts [33–35], two (7.4%) were descriptive [38, 40], one was a case-control (4%) [36], and two were randomized controlled trials (7%) [34, 37]. Sample sizes ranged from 11 to 181 participants (median, 37; IQR, 20–72.5).

Patient and survivor characteristics

Characteristics are shown in Table 1. Where reported, sex/gender distribution varied across studies but males and females were generally reflected in equal proportions. Mean age at surgery mostly ranged from 10 to 15 years, although demographic reporting was inconsistent across studies. Osteosarcoma (20 studies; 71%) and Ewing sarcoma (15 studies; 54%) were most frequently represented. Where reported, mean age at surgery ranged from 10 to 15 years [15, 33, 39]. Limb salvage, including rotationplasty, was described in 22 studies (82%), particularly in more recent cohorts [16, 37]. Amputation was described in 16 studies (59%), with older studies focusing exclusively on this approach [23, 31]. Lower extremity resections were reported in 20 studies (74%) [14, 15, 17–23, 25–29, 33, 34, 36–39]. Upper extremity procedures were examined in three studies (11%), within mixed-site populations [30, 35, 36]. Four studies did not report surgical site (15%) [24, 31, 32, 40].

Caregiver characteristics

Caregivers were included in four studies (15%) [23–25, 39]. In all cases, caregivers were mothers or fathers.

Outcome measures

Outcome measures were heterogeneous (Table 1). Multidimensional QOL or functional tools included the Toronto Extremity Salvage Score (TESS) and parent-proxy TESS (pTESS), used in seven studies (26%) [15, 20, 28, 30, 33,

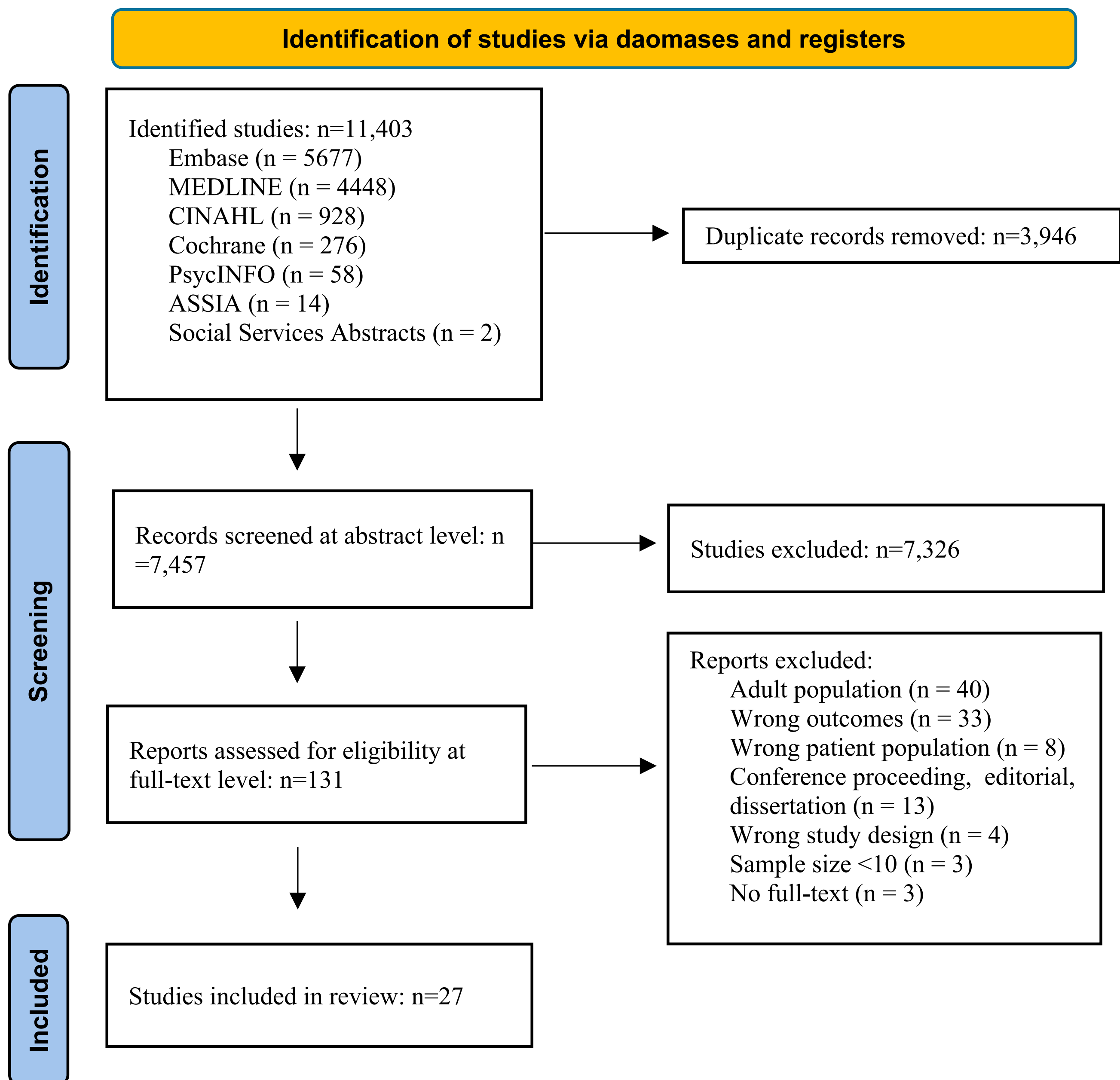


Fig. 1 Study identification process

35, 37]; the Short Form Health Surveys (SF-12 or SF-36), used in seven studies (26%) [17, 19, 21, 22, 28, 33, 38]; the Musculoskeletal Tumor Society (MSTS) tool, used in eight studies (30%) [20, 22, 28, 29, 33, 36, 36, 37]; and the Pediatric Outcomes Data Collection Instrument (PODCI), used in two studies (7%) [26, 29]. Other validated instruments less frequently used included the PROMIS short forms [16], the Child Health Questionnaire (CHQ)[40], and the Pediatric Quality of Life Inventory (PedsQL) [27]. Psychological or symptom-specific measures were also used to measure PROs, such as the Hospital Anxiety and Depression Scale (HADS) [39] and the pain intensity Visual Analog Scale [34]. Eight studies (30%) incorporated qualitative or mixed methods, including interviews, open-ended questionnaires, and telephone surveys [15, 17, 18, 23, 25, 27, 35, 38]. One study used medical records and physician notes to source PRO data [31].

Patient and survivor outcomes

Twenty-five studies (93%) reported patient or survivor outcomes (Table 2). Outcomes were primarily self-reported

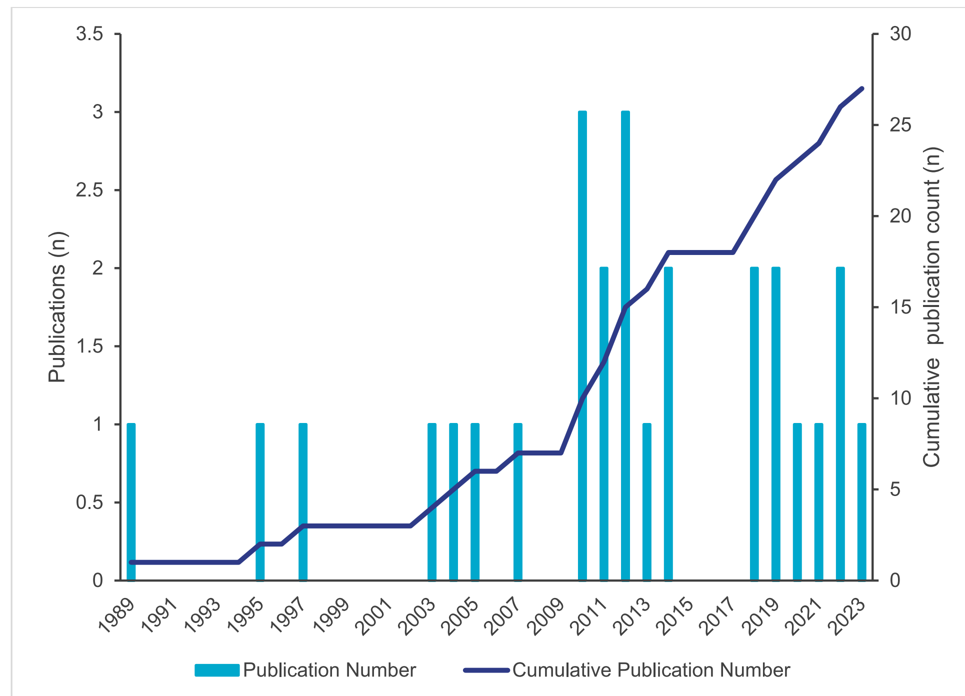


Fig. 2 Study publications over time

($n=18/25$; 72%), with fewer joint patient-caregiver reports ($n=5/25$; 20%) or caregivers-only reports ($n=3/25$; 12%). Thirty-six distinct PROMs were used, most commonly the TESS ($n=8/25$; 32%), SF-36 ($n=7/25$; 28%), PODCI ($n=3/25$; 12%), and semi-structured interviews ($n=3/25$; 12%). Reporting of respondent type (child vs. proxy) was inconsistent and discrepancies between reporters were seldom analyzed. Timing of PRO assessment varied widely across studies, ranging from perioperative measurement through early recovery (≤ 60 days) to long-term survivorship (> 10 years post-treatment), with most studies assessing outcomes at a single survivorship timepoint ≥ 1–5 years following surgery. Longitudinal outcome trajectories were uncommon, limiting insight into critical windows such as pre-operative period, early rehabilitation, return to school, or transition to survivorship.

Physical functioning

Physical functioning was the most evaluated domain, assessed in 23 studies (85%). Within the domain, the most assessed aspects were mobility/function ($n=17/23$; 74%), independence ($n=17/23$; 74%), and pain ($n=13/23$; 56%).

Females reported lower physical QOL and general health than males in two studies [21, 22], while no functional differences were observed between limb salvage and amputation groups [15]. Survivors generally reported lower health-related QOL (HRQOL) than healthy controls [15, 32]. Many patients described being unable to run, having trouble climbing stairs, or struggling to sit on the floor [17, 18]. One study found that the physical functioning and pain significantly improved from surgery to 6 and 12 months post-surgery, with overall HRQOL being lower in bone tumor patients than the general population [21].

Patient and survivor functional independence was evaluated through general indicators (e.g., need for assistive devices) and specific tasks such as housework, childcare, and physically navigating different terrains. Three longitudinal studies documented improvements in independence over time [21, 23, 37], with others noting that independence was closely linked to mobility aid use [15, 23, 27].

Pain was common and persisted months or years post-surgery [23, 32]. Pain was described both as continuous and episodic (e.g., occurring after physical exertion or in cold weather) [17]. Limb-sparing procedures were associated with pain, hypersensitivity, numbness, and stiffness [18]. Three investigations explicitly assessed phantom limb pain [23, 31, 34]. One study found that pediatric cancer amputees were four times more likely to report phantom limb pain than those with trauma-related amputations, especially amongst those exposed to chemotherapy [31]. Another study found that gabapentin was effective in preventing acute post-operative phantom limb pain [34].

Few studies evaluated physical functioning longitudinally. Within repeated-measures studies, improvements in mobility, independence, and pain were observed between early post-operative assessment and 6–12 months following surgery, with functional outcomes generally stabilizing thereafter; however, heterogeneity in timing of assessment

Table 1 Characteristics of included studies and population

Study characteristics			Patient characteristics					Caregiver characteristics	Outcome measure
Author and year	Country	Study design	Sample size & sex/gender	Age at surgery in years (mean, SD)	Diagnosis	Surgery type	Surgery location	Sample size & sex/gender	Tools used
Bekkering et al. (2010)	Netherlands	Cross-sectional, multi center	$n = 33$ (17 M, 16 F)	10.5 (SD = 2.5)	Osteosarcoma, $n = 26$; Ewing sarcoma, $n = 7$	Limb salvage, $n = 23$; amputation, $n = 10$	Lower limb, $n = 33$	N/A	TACQOL
Bekkering et al. (2011)	Netherlands	Cross-sectional	$n = 82$ (41 M, 41 F)	14.2 (SD = 4.1)	Osteosarcoma, $n = 67$; Ewing's sarcoma, $n = 15$	Limb salvage, $n = 55$; amputation, $n = 27$	Lower limb, $n = 82$	N/A	TESS and Baecke questionnaire
Cooper et al. [16]	USA	Cross-sectional	$n = 30$ (14 M, 16 F)	12.97 (SD = 2.77)	Osteosarcoma, $n = 17$; Ewing sarcoma, $n = 7$; chondrosarcoma, $n = 1$; soft tissue sarcoma, $n = 5$	Limb salvage, $n = 27$	NR	N/A	PROMIS short form v1.0
Eiser et al. [17]	United Kingdom	Cross-sectional	$n = 41$ (24 M, 17 F)	NR	Malignant primary bone tumor, $n = 41$	Limb salvage, $n = 41$	Lower limb, $n = 41$	NR	SF-36 and interviews
Forni et al. (2012)	Italy	Descriptive qualitative–quantitative study	$n = 20$ (12 M, 8 F)	NR	NR	Limb salvage, $n = 20$	Lower limb, $n = 20$	N/A	SF-36 and interviews
Ginsberg et al. (2007)	USA	Prospective multi-site study	$n = 91$ (48 M, 43 F)	14.52 (SD = 4.06)	Ewing sarcoma, $n = 14$; osteosarcoma, $n = 77$	Limb salvage, $n = 69$; amputation, $n = 22$	Lower limb, $n = 91$	N/A	TESS and SF-36
Han et al. (2012)	China	Cross-sectional	$n = 120$ (79 M, 41 F)	14.1 (SD = 4.6)	Osteosarcoma, $n = 94$; Ewing sarcoma, $n = 26$	Limb salvage, $n = 52$	Lower limb, $n = 120$	N/A	SF-36
Henderson et al. [26]	USA	Retrospective, descriptive	$n = 15$ (8 M, 7 F)	10.6 (range, 4–15)	Primary bone sarcoma, $n = 15$	Limb salvage, $n = 15$	Lower limb, $n = 15$	NR	PODCI
Henderson et al. (2012)	USA	Retrospective review	$n = 38$ (19 M, 19 F)	10.4 (range, 4–15)	Osteosarcoma, $n = 31$; Ewing sarcoma, $n = 7$	Limb salvage $n = 38$	Lower limb, $n = 38$	NR	PODCI and MSTS
Hopyan et al. [28]	Australia	Retrospective cohort study			Lower extremity osteosarcoma and Ewing sarcoma		Lower limb	N/A	SF-36 and TESS
Jamshidi et al. [36]	Iran	Case–control	$n = 43$ (19 M, 24 F)		Ewing sarcoma, $n = 43$	Limb salvage, $n = 43$	Lower limb, $n = 19$; upper limb, $n = 26$	N/A	MSTS

Table 1 (continued)

Study characteristics			Patient characteristics					Caregiver characteristics	Outcome measure
Author and year	Country	Study design	Sample size & sex/gender	Age at surgery in years (mean, SD)	Diagnosis	Surgery type	Surgery location	Sample size & sex/gender	Tools used
Jaraway et al. [25]	Canada	Retrospective exploratory descriptive study	$n=13$ (3 M, 10 F)	Range, 6–16	Bone cancer, $n=23$	Limb salvage, $n=13$	Lower limb, $n=13$	$n=22$ (9 M, 13 F)	5-scale Likert and open-ended interview
Meng et al. (2022)	China	Observation cohort study, longitudinal	$n=56$ (37 M, 19 F)	12.0 (SD = 3.2)	Osteosarcoma, $n=56$	Limb salvage, $n=38$; amputation $n=18$	Lower limb, $n=52$; unspecified $n=4$	$n=104$ (49 M, 55 F)	HADS-A and HADS-D
Piscione et al. [18]	USA	Mixed methods, cross-sectional	$n=21$ (11 M, 10 F)	NR	Osteosarcoma, $n=16$; Ewing sarcoma, $n=5$	Limb salvage, $n=18$; amputation, $n=3$	Lower extremity, $n=21$	N/A	ASKp
Piscione et al. [35]	Canada	Mixed methods, longitudinal	$n=181$ (44 M, 110 F)	NR	Osteosarcoma, $n=57$; Ewing sarcoma, $n=28$; other, $n=8$	Limb salvage, $n=86$; amputation, $n=7$	Lower extremity, $n=154$; upper extremity, $n=27$	N/A	pTESS-leg, pTESS-arm
Sainsbury et al. [27]	Canada	Mixed methods, retrospective	$n=18$	10 (range = 1.5–17)	Osteosarcoma, $n=9$; Ewing sarcoma, $n=8$; adamantinoma, $n=1$	Limb salvage, $n=18$	Lower extremity, $n=18$	N/A	Telephone survey (including components of SF-12 and PedsQL), Gillette functional assessment questionnaire
Smith et al. (1995)	USA	Quantitative, retrospective	$n=67$	NR	NR	Amputation, $n=67$	NR	N/A	Patient medical records and physician notes
Stevenson et al. [30]	United Kingdom	Quantitative, retrospective	$n=11$	NR	Ewing sarcoma, $n=6$; osteosarcoma, $n=5$	Limb salvage, $n=11$	Upper limb, $n=11$	N/A	TESS
Tabone et al. [40]	France	Quantitative, observational	$n=37$ (25 M, 12 F)	NR	Osteosarcoma $n=19$; Ewing sarcoma. $N=18$	Limb salvage, $n=15$; amputation, $n=2$; not specified, $n=17$	NR	NR	CHQ
Tacyildiz et al. [32]	Turkey	Quantitative, retrospective	$n=39$ (24 M, 15 F)		Osteosarcoma $n=39$	Limb salvage, $n=34$; amputation, $n=5$	NR	N/A	Unspecified questionnaire
Tebbi et al. [23]	Brazil	Mixed method, cross-sectional	$n=33$ (16 M, 17 F)	12.9 (SD = 2.7)	NR	Amputation, $n=33$	Lower extremity, $n=33$	N/A	Interview

Table 1 (continued)

Study characteristics			Patient characteristics					Caregiver characteristics	Outcome measure
Author and year	Country	Study design	Sample size & sex/gender	Age at surgery in years (mean, SD)	Diagnosis	Surgery type	Surgery location	Sample size & sex/gender	Tools used
Tran et al. (2023)	Canada	Quantitative, secondary analysis of a multicenter, blinded RCT	$n = 150$ (98 M, 52 F) (total study $n = 597$)	NR	Primary bone sarcoma, $n = 146$; giant cell tumor, $n = 3$; soft tissue, sarcoma $n = 1$	Limb salvage, $n = 150$	Lower extremity, $n = 150$	N/A	TESS
Tunn et al. [20]	Germany	Quantitative, cross-sectional	$n = 78$	NR	Osteosarcoma, $n = 78$	Amputation, $n = 44$; limb salvage, $n = 34$	Lower extremity, $n = 78$	N/A	TESS-LE and unspecified questionnaire
Vasquez et al. [22]	Peru	Quantitative, cross- sectional	$n = 19$ (8 M, 11 F)	NR	Osteosarcoma, $n = 17$; Ewing sarcoma, $n = 2$	Limb salvage, $n = 15$; amputation $n = 4$	Lower extremity, $n = 19$	N/A	SF-36
Tirado et al. (2011)	Spain	Quantitative, cross- sectional	$n = 17$ (8 M, 9 F)	NR	Osteosarcoma, $n = 13$; Ewing sarcoma, $n = 4$	Amputation, $n = 19$; limb salvage, $n = 12$; *some patients had multiple surgeries	Lower extremity, $n = 17$	N/A	SF-36
Wang et al. (2018)	China	Quantitative, prospective RCT	$n = 45$ (23 M, 22 F)	Treatment group mean 14.3 (SD = 2.8), placebo mean 13.9 (SD = 2.7)	Osteosarcoma, $n = 41$; Ewing sarcoma, $n = 4$	Amputation, $n = 45$	Lower extremity, $n = 45$	N/A	Visual analog scale
Weir et al. [24]	USA	Quantitative, cross- sectional	$n = 28$ (16 M, 12 F) (total study: $n = 123$)	NR	NR	Amputation, $n = 28$	NR	NR	Limb loss parent survey

ASKp activities scale for kids—performance version, *CCSS* Childhood Cancer Survivor Study, *CHQ* child health questionnaire, *F* female, *HADS-A* hospital anxiety and depression scale—anxiety, *HADS-D* hospital anxiety and depression scale–depression, *M* male, *MSTS* Musculoskeletal Tumor Society, *NA* not applicable, *NR* not reported, *PedsQL* pediatric quality of life inventory, *PODCI* pediatric outcomes data collection instrument, *PROMIS* patient-reported outcomes measurement information system, *pTESS* parent Toronto extremity salvage score, *SF-12* 12-item short form health survey, *SF-36* 36-item short form health survey, *TACQOL* children's quality of life questionnaire, *TESS* Toronto extremity salvage score, *TESS-LE* Toronto extremity salvage score—lower extremity, *USA* United States of America

Table 2 Outcomes measured across studies

Study	Physical functioning				Emotional functioning					Social and occupational functioning					
	General health	Pain	Mobility and function	Independence	Self-image & esteem	Mental health	Satisfaction with surgery	Cognition	Self-efficacy	Recreational ability	Social & relational	**Financial**	**Educational & occupational**	**Spiritual**	**Acceptance by others**
Patient outcomes															
Bekkering et al. (2010)			X	X	X	X		X		X	X		X		
Bekkering et al. (2011)				X						X					
Cooper et al. (2020)	X	X	X			X			X		X				
Eiser et al. [17]	X	X	X	X	X	X	X			X	X		X		
Forni et al. (2012)	X	X	X	X	X	X	X				X				
Gingsberg et al. (2007)	X		X	X		X									
Han et al. (2012)	X	X	X	X		X					X				
Henderson et al. [26]					X	X	X				X				
Henderson et al., (2012)		X	X	X	X	X	X								
Hopyan et al. [28]			X	X		X									
Jamshidi et al. [36]			X												
Piscione et al. [18]			X	X					X	X			X		
Piscione et al. [35]				X											
Sainsbury et al. [27]	X	X	X	X	X	X	X			X					
Smith et al. (1995)		X													

Table 2 (continued)

Study	Physical functioning				Emotional functioning					Social and occupational functioning					
	General health	Pain	Mobility and function	Independence	Self-image & esteem	Mental health	Satisfaction with surgery	Cognition	Self-efficacy	Recreational ability	Social & relational	**Financial**	**Educational & occupational**	**Spiritual**	**Acceptance by others**
Stevenson et al. [30]				X											
Tabone et al. [40]	X	X	X		X	X					X				
Tacyilidiz et al. (2021)	X	X	X								X		X		
Tebbi et al. [23]	X	X	X	X	X		X				X	X	X		X
Tran et al. (2023)				X											
Tunn et al. [20]				X									X		
Vasquez et al. [22]	X	X	X	X		X					X				
Tirado et al. (2011)	X	X	X	X		X					X				
Wang et al. (2018)		X	X												
Weir et al. [24]													X		
Caregiver outcomes															
Jaraway et al. [25]		––	––	––	––	X	X	––	X	––					––
Meng et al. (2022)		––	––	––	––	X		––		––					––
Tebbi et al. [23]		––	––	––	––	X		––		––					––
Weir et al. [24]		––	––	––	––			––		––		X			––

and limited long-term follow-up restricted conclusions regarding longer-term trajectories [21, 33, 37].

Social and occupational functioning

Sixteen studies (59%) evaluated patient or survivor social and occupational functioning. The outcomes most frequently examined were in the social or relational domains ($n = 11/16$; 69%), which included family involvement, peer relationships, and social activities. Social functioning improved following surgery, particularly among males treated with limb-sparing procedures [21, 22, 29, 32]. Social confidants were primarily identified as mothers, with peers described as being helpful, fearful, avoidant, and pitying after surgery [23]. Survivors also described social discomfort, noting that others appeared uneasy discussing their illness [23].

Educational and occupational outcomes were reported in seven studies ($n = 7/16$, 44%). School challenges included learning difficulties, absenteeism, and repeating grades [15, 17]. Compared to non-amputees and healthy siblings, amputees were less likely to graduate high school or college [32]. School absences among amputees were commonly attributed to fear of injury or difficulties using stairs [17, 24]. Employment outcomes, assessed in three studies ($n = 3/16$, 19%), indicated lower employment rates among survivors relative to siblings [17, 23, 32]. Although one study found no overt hiring discrimination, survivors reported job loss due to their surgery or restricted mobility [23]. While many survivors reported their opportunities as constrained, some described their experiences as influencing career choices, particularly toward health and social sciences [17].

Recreational ability was measured in five studies ($n = 5/16$, 31%), with children often reporting minimal difficulties with activities of daily living such as bathing or dressing [27]. However, significant restrictions were reported for high-demand tasks such as sports and physical recreation, often accompanied by regret and frustration [15, 17, 18, 27].

Financial impacts were described in one study ($n = 1/16$, 6%) with survivors describing prostheses as expensive to purchase and maintain [23]. No studies assessed spiritual outcomes.

Emotional functioning

Emotional functioning was assessed in 15 studies (58%). Mental health outcomes were assessed in 13 studies ($n = 13/15$, 87%). One study reported that survivors sought psychiatric help to address intense fears of disease recurrence [17], with one showing improvement in mental health outcomes with time post-surgery [10].

Self-image and self-esteem were examined in eight studies ($n = 8/15$, 53%). Findings included dissatisfaction with physical appearance, prostheses, or scars, alongside challenges with maturation. While many patients were satisfied with their physical appearance overall, perceptions of body image varied widely [26]. Attitudes toward scars varied and included embarrassment, indifference, and pride [17, 27, 38]. Three studies highlighted clothing restrictions and embarrassment in specific contexts such as swimming [17, 23, 38]. Two studies suggested that self-acceptance was initially difficult but improved with age [26, 38]. Self-esteem was generally comparable across ages and genders, with slightly higher ratings among patients without internally implanted devices (i.e., endoprostheses) [26, 40].

Self-efficacy was examined in two studies ($n = 2/15$, 13%). Findings indicated that pain interference and fear of injury constrained participation in daily and recreational activities, reflecting low self-efficacy for activity engagement [16, 18]. Satisfaction with surgical outcomes was captured in six studies ($n = 6/16$, 40%). Three studies indicated high overall satisfaction with limb salvage surgical results [26, 27, 29]. Two studies reported most patients as satisfied with choosing limb salvage over amputation [17, 38]. Despite this, one study revealed that fewer than two-thirds of amputees felt they had adequately understood the functional consequences prior to surgery, but following surgery most felt their prostheses allowed engagement in desired activities [23]. One study evaluated cognition ($n = 1/16$, 6%) and found it to be lower in patients aged 8–15 years compared to healthy controls, though not statistically significant [15].

Caregiver outcomes

Four studies assessed caregiver outcomes (15%), involving 126 parents (with incomplete reporting in two studies) (Table 1). Outcomes were self-reported by caregivers ($n = 34$; 75%) or reported by patients regarding their caregivers ($n = 1/4$, 25%). Across these studies, six different PROMs were used.

Emotional functioning was the most frequently studied caregiver domain, reported in three studies ($n = 3/4$, 75%). One longitudinal study documented increasing parental anxiety and depression symptoms 3 years after their child's surgery [39]. Qualitative interviews revealed that parents often expressed denial of the diagnosis, fears about terminal outcomes, and distress about their own inability to cope [23, 25]. Caregiver self-efficacy was reported in one study ($n = 1/4$, 25%), where parents present in the operating room described feeling better prepared to support their child post-surgery [25]. Satisfaction with surgery was measured in one study ($n = 1/4$, 25%), in which parents reported more positivity when their child's amputation appeared less severe than anticipated [25].

Financial health as an outcome was reported in one study ($n = 1/4$, 25%), showing that 57% of parents experienced

limits on insurance coverage for child prostheses, and 38% reported having paid out-of-pocket for prostheses [24]. Family functioning was addressed in one study ($n = 1/4$, 3.7%), where patients described changes in parental behavior post-surgery, including becoming more protective or submissive [23]. No studies assessed caregiver physical health outcomes.

Discussion

This review synthesizes three decades of patient-reported and caregiver-reported outcomes following limb salvage or amputation for pediatric bone and soft tissue sarcomas. Physical functioning was generally moderate to good with small or inconsistent differences between procedures. The predominance of lower-extremity procedures reflects the distribution of pediatric bone and soft tissue sarcomas, which often arise in lower limbs. Pain, including phantom pain, often persisted and affected participation. Psychosocial outcomes varied, with some children and survivors reporting acceptance and others noting body-image concerns and activity limits. Caregiver distress and financial strain were evident but infrequently measured. Evidence gaps remaining include heterogeneous PROM use, limited assessment of priority domains, and minimal attention to caregivers—restricting comparability and impeding family-centered care.

Our review highlights the evolving nature of outcome measurement over time. Early studies focused primarily on physical functioning using orthopedic or general health measures (e.g., MSTS, TESS, SF-36), reflecting emphasis on surgical success and functional recovery. Although these outcomes remain dominant, more recent studies show some expansion to psychosocial domains such as self-image, participation, and emotional wellbeing, as well as the introduction of pediatric PROMs. Despite increasing attention to survivorship, longitudinal and mixed-methods studies remain relatively uncommon and caregiver outcomes remain sparsely assessed across decades.

Our findings highlight the functional and QOL-related impacts of both limb salvage and amputation. Results further suggest that rehabilitation, symptom control, and environmental accommodations at home, school, and in the community may have a substantial influence on lived experience. This aligns with biopsychosocial models of disability in which impairments, activity limitations, and participation restrictions are shaped by contextual facilitators and barriers [52]. It also underscores the importance of anticipatory preoperative guidance that maintains a focus on realistic post-surgical expectations for mobility, stamina, and participation—regardless of procedure [53].

Several areas for improving family-centered care were identified. Pain management requires sustained attention across the surgical continuum. Early identification of phantom limb and neuropathic pain, education about pain triggers, and timely referral to interdisciplinary services may reduce constraints on participation post-surgery. Evidence from long-term survivors indicates that upwards of 41% report chronic pain decades after diagnosis, with one-quarter experiencing severe interference with activities of daily living—and that a history of amputation or limb-sparing surgery increases the odds of daily pain interference [41, 42]. School and recreation reintegration also requires structured planning, including graded return to physical education and close coordination with teachers and coaches [43–45]. Addressing body image and visible differences through strategies including scar normalization and peer education may ease social discomfort [46, 47]. Finally, families could benefit from financial and system navigation support, particularly around prosthesis costs and insurance access barriers.

A wide range of PROMs was used, often without justification for domain selection or consideration of psychometric suitability for pediatric oncology or survivorship. Across studies, TESS/pTESS, MSTS, SF-36, PODCI, PROMIS, and PedsQL were the most frequently used and appear most promising for future research. A combined approach including a limb-specific functional measure (e.g., TESS/pTESS), a multidimensional pediatric QOL measure (e.g., PROMIS or PedsQL), and targeted symptom and psychosocial health measures (e.g., pain, emotional functioning) may best capture the multidimensional outcomes relevant to this population.

Several pediatric cancer-specific PROMs exist (e.g., bone tumor DUX [Bt-DUX] for QOL). However, these were not represented in studies meeting our eligibility criteria, highlighting limited uptake of disease-specific and age-specific instruments in this surgical context. Key domains identified by children, adolescents, survivors, parents, and clinicians as research priorities (e.g., mental health, participation, educational and employment engagement, financial strain, and caregiver outcomes) [54] were only inconsistently assessed, and spiritual well-being was not evaluated at all.

These gaps suggest the need for a measurement agenda in this area. First, efforts should coalesce around a core outcome set anchored to the World Health Organization (WHO)-endorsed International Classification of Functioning, Disability and Health (ICF) [48] and co-designed with patients, survivors and caregivers. Second, the core outcome set should include symptoms, activity, participation, physical, financial and social environments, and factors such as body image and self-efficacy. Longitudinal assessment timepoints should also be mapped to the surgical and overall cancer treatment journey to understand predictors of child and family outcomes, outcome trajectories, and supportive care needs. Third, PRO self-reporting should be encouraged whenever possible, with proxy reports used thoughtfully

given tendencies for caregivers to overestimate children's cancer symptoms and underestimate function [49]. Fourth, transparent reporting of participant disease and demographic characteristics will enable equity-oriented analyses. At present, signals in the current literature (e.g., lower physical QOL among females, insurance barriers) warrant confirmation and targeted response.

The family caregiver literature is notably thin given parents' central roles in decision-making, clinical care, and advocacy. Where measured, anxiety and depressive symptoms were identified and preparedness for child limb surgery appeared to shape care confidence. Additional research is needed to understand caregiver-reported outcomes and support needs over time, and to examine the efficacy of caregiver-centered wellness interventions [50].

Findings have direct clinical implications. In alignment with clinical practice guidelines [51], PRO collection should be embedded into routine practice to enable supportive care provision and to determine the effectiveness of administered interventions. Rehabilitation pathways should include early goal-directed mobility training, progressive return-to-activities, and coordination with schools. Pain care should include anticipatory management, timely treatment, and ongoing assessment. Psychosocial care should continue to focus on peer support, child self-esteem, family mental health, and resource navigation.

Parent and survivor involvement strengthened this review by ensuring the research questions, outcomes of interest, and data interpretation reflected real-world experiences of limb surgery. Parent and survivor contributions directed the assessment of PROs in domains often missed in the literature, such as school participation, family impacts, and long-term psychosocial concerns, which directly shaped our synthesis. A key lesson learned was the value of dedicating time and structure for meaningful engagement, including clear communication about review methods. Future work should prioritize partner representation and supportive processes to enable contribution to emotionally sensitive topics.

Additional review strengths include that we captured both patient and caregiver outcomes, allowing for a family-centered understanding of the surgical experience. Our inclusion of both physical and psychosocial outcomes provides a more holistic understanding of the impact of limb surgery across these groups, which is crucial to direct clinical care. Considering limitations, our synthesis is narrative and dependent on what studies chose to measure and report. Although no language limits were applied, practical constraints including our search strategy may still have favored English-language publications, and grey literature was not systematically searched.

This review highlights the requirement to better report the experiences and needs of childhood cancer amputees and their family caregivers. Few studies examined whether outcomes differed according to sex, gender, age at treatment, recurrence status, or surgical complexity, and longitudinal analyses were uncommon. These gaps limit understanding of which children may be at greatest risk for poorer functional or psychosocial outcomes and represent important priorities for future prospective research. Future research should prioritize prospective, longitudinal, multi-site studies that adopt common data elements and core PRO sets to enable causal inferences and pooled analyses. Mixed-methods studies integrating child, survivor, and caregiver perspectives and narratives with longitudinal assessments will clarify mechanisms and contextual modifiers of outcomes. Finally, interventional and implementation studies are needed to ensure that improvements in child survival are matched by improvements in QOL and participation. Collaborations led by those with lived experience, researchers, and clinicians will be valuable in fulfilling research gaps and developing interventions that improve outcomes for both childhood cancer patients and their family caregivers.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00520-026-10695-x.

Author contribution L.D. conceptualized this study. L.J. and L.D. drafted the study protocol. All authors participated in data collection, interpretation, manuscript drafting and revision. All authors reviewed the manuscript, approved of its contents, and agreed to be accountable for the work.

Funding This project was supported by the Operating Grant: SPOR—Guidelines and Systematic Reviews: The Evidence Alliance, grant number (154442).

Data availability As this is a scoping review, all data used in this study were sourced from published materials.

Declarations

Competing interests The authors declare no competing interests.

Open Access This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by-nc-nd/4.0/.

References

1. Geiger EJ, Liu W, Srivastava DK, Bernthal NM, Weil BR, Yasui Y et al (2023) What are risk factors for and outcomes of late amputation after treatment for lower extremity sarcoma: a childhood cancer survivor study report. Clin Orthop 481(3):526–538
2. Belayneh R, Fourman MS, Bhogal S, Weiss KR (2021) Update on osteosarcoma. Curr Oncol Rep 23(6):71
3. Geenen MM, Cardous-Ubbink MC, Kremer LCM, van den Bos C, van der Pal HJH, Heinen RC et al (2007) Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. JAMA 297(24):2705–2715
4. Alessa M, Alkhalaf HA, Alwabari SS, Alwabari NJ, Alkhalaf H, Alwayel Z et al (2022) The psychosocial impact of lower limb amputation on patients and caregivers. Cureus 14(11):e31248
5. McQuerry J, Gammon L, Carpiaux A, Talwalkar V, Iwinski H, Walker J et al (2019) Effect of amputation level on quality of life and subjective function in children. J Pediatr Orthop 39(7):e524–e530
6. Robert RS, Ottaviani G, Huh WW, Palla S, Jaffe N (2010) Psychosocial and functional outcomes in long-term survivors of osteosarcoma: a comparison of limb-salvage surgery and amputation. Pediatr Blood Cancer 54(7):990–999
7. Greenzang KA, Montgomery KE, DuVall A, Roth ME, Krailo M, Nuño MM et al (2025) Incorporation of patient-reported outcomes in pediatric cancer clinical trials: design, implementation, and dissemination. J Natl Cancer Inst 117(9):1764–1773
8. Weaver MS, Jacobs SS, Withycombe JS, Wang J, Greenzang KA, Baker JN et al (2022) Profile comparison of patient-reported and proxy-reported symptoms in pediatric patients with cancer receiving chemotherapy. JAMA Netw Open 5(3):e221855
9. Levac D, Colquhoun H, O'Brien KK (2010) Scoping studies: advancing the methodology. Implement Sci 5(1):69
10. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D et al (2018) PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 169(7):467–473
11. Rethlefsen ML, Kirtley S, Waffenschmidt S, Ayala AP, Moher D, Page MJ et al (2021) PRISMA-S: an extension to the PRISMA statement for reporting literature searches in systematic reviews. Syst Rev 10(1):39
12. Tricco AC, Zarin W, Clement F, Abou-Setta AM, Curran JA, LeBlanc A et al (2022) Introducing the Strategy for Patient Oriented Research (SPOR) Evidence alliance: a partnership between researchers, patients and health system decision-makers to support rapid-learning and responsive health systems in Canada and beyond. FACETS 7:639–653
13. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ 2:j3453
14. Bekkering WP, Vliet Vlieland TPM, Koopman HM, Schaap GR, Bart Schreuder HW, Beishuizen A et al (2011) Functional ability and physical activity in children and young adults after limb-salvage or ablative surgery for lower extremity bone tumors. J Surg Oncol 103(3):276–282
15. Bekkering WP, Vliet Vlieland TPM, Koopman HM, Schaap GR, Schreuder HWB, Beishuizen A et al (2010) Quality of life in young patients after bone tumor surgery around the knee joint and comparison with healthy controls. Pediatr Blood Cancer 54(5):738–745
16. Cooper AR, Wilke B, Scarborough M, Gibbs CP, Spiguel A (2020) Pediatric sarcoma patients with worse physical function but better peer relationships and depressive symptoms than U.S. pediatric population as measured by PROMIS®. Cureus 12(2)
17. Eiser C, Cool P, Grimer RJ, Carter SR, Cotter IM, Ellis AJ et al (1997) Quality of life in children following treatment for a malignant primary bone tumour around the knee. Sarcoma 1(1):39–45
18. Piscione PJ, Davis AM, Young NL (2014) An examination of adolescent bone tumor patient responses on the activities scale for kids (ASK). Phys Occup Ther Pediatr 34(2):213–228
19. Expósito Tirado JA, Márquez Vega C, Muro Guerra C, García De Paso Mora M, Rendón Fernández B, Ramírez Villar GL et al (2011) Calidad de vida y funcionalidad en pacientes pediátricos intervenidos de tumores óseos en miembros inferiores: Cirugía reconstructiva versus amputación. Rehabil Madr 45(4):313–319
20. Tunn PU, Schmidt-Peter P, Pomraenke D, Hohenberger P (2004) Osteosarcoma in children: long-term functional analysis. Clin Orthop Relat Res 421:212–217
21. Han G, Wang Y, Bi WZ (2012) Study on the health-related quality of life in patients after surgery for malignant bone tumors. Asian Pac J Cancer Prev 13(1):127–130
22. Vasquez L, Tello M, Maza I, Shah D, Silva J, Sialer L (2022) Quality of life and limb functionality in adolescents and young adults surviving bone tumors in the lower extremity in a developing country: a cross-sectional study. Indian J Med Paediatr Oncol 43(05):404–408
23. Tebbi CK, Petrilli AS, Richards ME (1989) Adjustment to amputation among adolescent oncology patients. Am J Pediatr Hematol Oncol 11(3):276–280
24. Weir S, Ephraim P, Mackenzie E (2010) Effects of paediatric limb loss on healthcare utilisation, schooling and parental labour supply. Disabil Rehabil 32(24):2046–2055
25. Jaraway D, Perry S, Phillips M, Ziegler P, Wolgemuth A, Scott SD (2013) Preparing parents to help support their child post-amputation for bone cancer. ORNAC J 31(4):13–9, 24–5
26. Henderson ER, Pepper AM, Marulanda GA, Millard JD, Letson DG (2010) What is the emotional acceptance after limb salvage with an expandable prosthesis? Clin Orthop 468(11):2933–2938
27. Sainsbury DCG, Liu EH, Alvarez-Veronesi MC, Ho ES, Hopyan S, Zuker RM et al (2014) Long-term outcomes following lower extremity sarcoma resection and reconstruction with vascularized fibula flaps in children. Plast Reconstr Surg 134(4):808–820
28. Hopyan S, Tan JW, Graham HK, Torode IP (2006) Function and upright time following limb salvage, amputation, and rotationplasty for pediatric sarcoma of bone. J Pediatr Orthop 26(3):405–408
29. Henderson ER, Pepper AM, Marulanda G, Binitie OT, Cheong D, Letson GD (2012) Outcome of lower-limb preservation with an expandable endoprosthesis after bone tumor resection in children. J Bone Jt Surg 94(6):537–547
30. Stevenson JD, Doxey R, Abudu A, Parry M, Evans S, Peart F et al (2018) Vascularized fibular epiphyseal transfer for proximal humeral reconstruction in children with a primary sarcoma of bone. Bone Joint J 100-B(4):535–541
31. Smith J, Thompson JM (1995) Phantom limb pain and chemotherapy in pediatric amputees. Mayo Clin Proc 70(4):357–364
32. Tacyildiz N, Cakmak H, Unal E, Dincaslan H, Tanyildiz G, Sonay I et al (2021) Late effects of osteosarcoma and its treatment in pediatric patients: A single-center experience. J BUON Off J Balk Union Oncol 26(3):1102–1110
33. Ginsberg JP, Rai SN, Carlson CA, Meadows AT, Hinds PS, Spearing EM et al (2007) A comparative analysis of functional outcomes in adolescents and young adults with lower-extremity bone sarcoma. Pediatr Blood Cancer 49(7):964–969
34. Wang X, Yi Y, Tang D, Chen Y, Jiang Y, Peng J et al (2018) Gabapentin as an adjuvant therapy for prevention of acute phantom-limb pain in pediatric patients undergoing amputation for malignant bone tumors: a prospective double-blind randomized controlled trial. J Pain Symptom Manage 55(3):721–727

35. Piscione J, Barden W, Barry J, Malkin A, Roy T, Sueyoshi T et al (2019) The pediatric Toronto Extremity Salvage Score (pTESS): validation of a self-reported functional outcomes tool for children with extremity tumors. Clin Orthop 477(9):2127–2141
36. Jamshidi K, Ramezan Shirazi M, Bagherifard A, Mirzaei A (2019) Curettage, phenolization, and cementation in paediatric Ewing's sarcoma with a complete radiological response to neoadjuvant chemotherapy. Int Orthop 43(2):467–473
37. Tran TH, Hayden JB, Gazendam AM, Ghert M, Gundle KR, Doung YC et al (2023) Pediatric and adult patients have similar functional improvement after endoprosthetic reconstruction of lower-extremity tumors. J Bone Jt Surg 105(Suppl 1):22–28
38. Forni C, Gaudenzi N, Zoli M, Manfrini M, Benedetti MG, Pignotti E et al (2012) Living with rotationplasty—quality of life in rotationplasty patients from childhood to adulthood. J Surg Oncol 105(4):331–336
39. Meng J, Wu J, Zhang X, Guo L, Li H (2022) A longitudinal evaluation on 3-year change of anxiety and depression, and their risk factors among parents of childhood and adolescence patients with resectable osteosarcoma: a cohort study. Medicine (Baltimore) 101(42):e30981
40. Tabone MD, Rodary C, Oberlin O, Gentet JC, Pacquement H, Kalifa C (2005) Quality of life of patients treated during childhood for a bone tumor: Assessment by the child health questionnaire. Pediatr Blood Cancer 45(2):207–211
41. Alberts NM, Leisenring W, Whitton J, Stratton K, Jibb L, Flynn J et al (2024) Characterization of chronic pain, pain interference, and daily pain experiences in adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Pain 165(11):2530–2543
42. Tonning Olsson I, Alberts NM, Li C, Ehrhardt MJ, Mulrooney DA, Liu W et al (2021) Pain and functional outcomes in adult survivors of childhood cancer: a report from the St. Jude Lifetime Cohort study Cancer 127(10):1679–1689
43. Paul V, Inhestern L, Sigmund D, Winzig J, Rutkowski S, Escherich G et al (2025) Addressing gaps and enhancing experiences in support services for families of pediatric cancer survivors. Pediatr Res 98(1):168–173
44. Burns MA, Fardell JE, Wakefield CE, Cohn RJ, Marshall GM, Lum A et al (2021) School and educational support programmes for paediatric oncology patients and survivors: a systematic review of evidence and recommendations for future research and practice. Psycho-Oncology 30(4):431–443
45. Götte M, Gauß G, Dirksen U, Driever PH, Basu O, Baumann FT et al (2022) Multidisciplinary network ActiveOncoKids guidelines for providing movement and exercise in pediatric oncology: consensus-based recommendations. Pediatr Blood Cancer 69(11):e29953
46. Vani MF, Lucibello KM, Trinh L, Santa Mina D, Sabiston CM (2021) Body image among adolescents and young adults diagnosed with cancer: a scoping review. Psychooncology 30(8):1278–1293
47. Hendriks RTJ, van Eenbergen MCHJ, de Boer ML, Sleeman SHE, Boll D, Husson O et al (2025) "There is still a part of me that would love to be the old me again", how do adolescents and young adults (AYA) experience cancer-related bodily changes: a phenomenological interview study. J Cancer Surviv 19(5):1623–1633
48. Karlsson E, Gustafsson J (2022) Validation of the international classification of functioning, disability and health (ICF) core sets from 2001 to 2019 - a scoping review. Disabil Rehabil 44(14):3736–3748
49. Mack JW, McFatrich M, Withycombe JS, Maurer SH, Jacobs SS, Lin L et al (2020) Agreement between child self-report and caregiver-proxy report for symptoms and functioning of children undergoing cancer treatment. JAMA Pediatr 174(11):e202861
50. Rodin G, Malfitano C, Rydall A, Schimmer A, Marmar CM, Mah K et al (2020) Emotion and symptom-focused engagement (EASE): a randomized phase II trial of an integrated psychological and palliative care intervention for patients with acute leukemia. Support Care Cancer 28(1):163–176
51. Heyns A, Jacobs S, Negrini S, Patrini M, Rauch A, Kiekens C (2021) Systematic review of clinical practice guidelines for individuals with amputation: identification of best evidence for rehabilitation to develop the WHO's package of interventions for rehabilitation. Arch Phys Med Rehabil 102(6):1191–1197
52. Ayers DC, Franklin PD, Ring DC (2013) The role of emotional health in functional outcomes after orthopaedic surgery: extending the biopsychosocial model to orthopaedics: AOA critical issues. J Bone Joint Surg Am 95(21):e165
53. Mednick L, Chen C (2026) Do children need to know? Clinical and ethical concerns with caregivers not telling children about surgery. J Pediatr Surg 61(3):162781
54. Aldiss S, Hollis R, Phillips B, Ball-Gamble A, Brownsdon A, Chisholm J, Crowther S, Dommett R, Gower J, Hall NJ, Hartley H, Hatton J, Henry L, Langton L, Maddock K, Malik S, McEvoy K, Morgan JE, Morris H, Parke S et al (2023) Research priorities for children's cancer: a James Lind Alliance priority setting partnership in the UK. BMJ Open 13(12):e077387
55. McGowan J, Sampson M, Salzwedel DM, Cogo E, Foerster V, Lefebvre C (2016) PRESS peer review of electronic search strategies: 2015 guideline statement. J Clin Epidemiol 75:40–46

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.