

What is the Emotional Acceptance After Limb Salvage with an Expandable Prosthesis?

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Abstract

Background Limb preservation surgery for extremity sarcomas offers the promise of improved function and cosmesis over amputation. Application of limb salvage surgery for pediatric patients with expandable metallic endoprostheses is gaining acceptance. The few studies reporting these devices have focused on functional outcomes; one has addressed quality of life.

Questions/purposes We asked the following questions: (1) how happy are these patients; (2) how do these patients perceive their bodies; (3) do these children have difficulty with social interactions; and (4) how satisfied are patients and their parents with their outcomes?

Each author certifies that he or she has no commercial associations (eg, consultancies, stock ownership, equity interest, patent/licensing arrangements, etc) that might pose a conflict of interest in connection with the submitted article.

Each author certifies that his or her institution approved the human protocol for this investigation, that all investigations were conducted in conformity with ethical principles of research, and that informed consent for participation in the study was obtained.

Investigation performed at Moffitt Cancer Center and All Children's Hospital (St Petersburg, FL).

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Methods We retrospectively identified and contacted 26 living patients who underwent limb salvage with an expandable device. The Pediatric Outcomes Data Collection Instrument was administered to 15 of the 26 families. Attention was paid to the happiness domain of the Pediatric Outcomes Data Collection Instrument and specific answers within this domain were reported.

Results Children who received limb salvage with an expandable endoprosthesis showed high emotional satisfaction with their outcome. Overall patients reported excellent perceptions of body image and physical attractiveness. Most patients reported frequent social interactions with their peers and no difficulty with making new friends.

Conclusions Although this study has a limited number of subjects and no control group, the data correlate with previously scores and indicate a high degree of emotional acceptance after limb salvage with an expandable endoprosthesis in a pediatric population.

Level of Evidence Level IV, therapeutic study. See Guidelines for Authors for a complete description of levels of evidence.

Introduction

Limb salvage surgery is now the preferred treatment for malignant tumors of the extremities at most institutions [3, 12, 16]. Improved function and quality of life have been attributed to limb salvage but have not been universally demonstrated in the adult population [33]. A number of studies document better physical function in patients with limb salvage compared to patients with amputation [1, 10, 15, 22, 24, 32, 38, 39]. Other studies have reported no difference in function with limb salvage [4, 21, 23], but a higher quality of life with limb salvage [37]. Improved

quality of life with limb salvage has been reported due to less social alienation and increased self-esteem compared to amputations [20, 24, 30]. In contrast, some authors report equivalent quality of life in limb salvage and amputation patients [22, 23, 26, 34, 36].

Adolescence is a time of psychological vulnerability for all children [33]. During this period, emphasis on physical appearance is at its highest [9]. The added stressors associated with combating a life-threatening illness are known to have a negative effect on the self-esteem and body image of this population [31, 35]. Adolescents with cancer report negative feelings regarding body image and decreased social interactions compared to their peers [29].

The Pediatric Outcomes Data Collection Instrument (PODCI) was developed to measure global patient functioning after treatment for musculoskeletal disorders specifically in the pediatric population [6]. The PODCI directly addresses patient and parent perceptions of body image, social acceptance, as well as physical function and satisfaction with treatment. The PODCI has been validated by numerous authors and has been applied previously to pediatric populations with bone sarcoma [13, 27, 28].

We administered the PODCI to children who had undergone limb salvage surgery with a metallic expandable endoprosthesis to answer the following questions: (1) How happy are children after limb salvage surgery? (2) How do children who have undergone limb salvage perceive their bodies? (3) Do children who have undergone limb salvage have difficulty with social interactions? (4) How satisfied with their outcomes are children who have undergone limb salvage surgery?

Patients and Methods

After Institutional Review Board approval was obtained, our operative database was queried for pediatric patients who underwent lower extremity limb salvage with an expandable endoprosthesis. We included only patients who had limb salvage for treatment of tumors of the lower extremities; patients treated for other indications, such as trauma, were excluded from the study. Patients were then contacted and asked to complete the PODCI questionnaire at clinic followup, by telephone, or by mail. Between 1996 and 2008, 39 patients received an expandable endoprosthesis for a primary bone sarcoma. There were 19 boys and 20 girls. The mean patient age at the time of surgery was 10.6 years (range, 4–15 years). Thirty-one children had an osteosarcoma and eight children had histologic confirmation of Ewing's sarcoma. Three patients had proximal femur replacements, three patients total femur replacements, 26 patients distal femur replacements, five patients proximal tibia replacements, and two patients distal tibia

replacements. The surgeries occurred at one of two tertiary centers with pediatric surgical units. Of the primary tumor resections, 12 patients received expandable prostheses manufactured by Biomet (Warsaw, IN), 19 had prostheses manufactured by Stryker (Mahwah, NJ), and eight patients prostheses manufactured by Stanmore (Middlesex, UK). At the time of the study, 26 of the 39 patients were alive, 11 patients had succumbed to their disease, and two patients had moved and updated contact information was not available. All 26 living patients were contacted to complete the PODCI questionnaire. The mean age at time of surgery had been 10.5 years (range 6–15). Minimum followup was 6 months (mean, 63 months; range, 8–155 months). We received a total of 24 questionnaires from the 26 patients. Thirteen parents and 11 patients completed the PODCI questionnaire; PODCI questionnaires were completed by both parent and child in nine families. No patients were recalled specifically for this study.

We performed a review of the medical records for demographic data, tumor type, perioperative variables, and current tumor status. PODCI questionnaires were administered to patients on one occasion at clinic followup visits ($n = 2$), via telephone interview ($n = 10$), and through mailing ($n = 3$) when requested. Separate patient and parent PODCI questionnaires were provided for children older than 10 years. For children younger than 10 years, only parent questionnaires were provided.

The PODCI is a validated scoring system designed to assess functional health outcomes after treatment for orthopaedic conditions. All three PODCI formats include primary questions and secondary questions that may be answered based upon the response to a primary question. PODCI scores are divided into six domains: (1) Upper Extremity and Physical Function; (2) Transfer and Basic Mobility; (3) Sports and Physical Functioning; (4) Pain and Comfort; (5) Happiness; and (6) Global Functioning. The PODCI addresses satisfaction with physical appearance as a separate question from body image. Standardized data scoring sheets developed for the PODCI in a Microsoft® Excel® format (Microsoft Corp, Redmond, WA) were used for score tabulation [5]. Each domain is scored on a 0–100 scale, with 0 representing a poor outcome/worst health and 100 representing the best possible outcome/best health. Each question is assigned to one of the six domains and scores for each question determine the overall score for that domain, based on the algorithm outlined by the American Academy of Orthopaedic Surgeons [5].

We focused this investigation on the emotional functioning after limb salvage. For that reason, the happiness domain of the PODCI is reported in detail. The 95% confidence interval (CI) for this PODCI domain was calculated. Due to the small patient cohort in this study our data reporting is mainly descriptive and no control

population was available for study. The additional data obtained from the instrument is reported for discussion. All analyses were performed with SPSS[®] Version 17.0 (SPSS Inc, Chicago, IL).

Results

Children who received limb salvage with the use of an expandable prosthesis showed high emotional satisfaction. The mean scores for the happiness domain of the PODCI for parent and patient reporting were 87.3 (SD, 16.7; 95% CI, \pm 9.1) and 92.3 (SD, 9.1; 95% CI, \pm 5.4), respectively, indicating a high degree of happiness (Table 1).

We found a wide distribution of responses regarding the body perception after the procedure. Parents reporting perceptions of their children's body image answered "somewhat unhappy" in one case, one parent answered "unsure," three parents answered "somewhat happy," and the remaining eight parents answered "very happy." The child of the parent reporting "somewhat unhappy" was a 15-year-old girl with a primary diagnosis of osteosarcoma; the child of the parent reporting "unsure" was a boy. Of the three parents reporting "somewhat happy," two children were girls and one was a boy. Children reporting their own body perceptions answered "somewhat unhappy" in one case, one patient answered "unsure," two patients answered "somewhat happy," and the remaining six children reported being "very happy." In the case of the parent

who reported her daughter was "somewhat unhappy" with her body, the patient reported she was "very happy." We found agreement between parent and child in two cases, in both of which the answers were "somewhat happy."

Eleven parents of the 26 children answered the question of satisfaction with physical appearance. One parent answered "somewhat unhappy," two parents answered "somewhat happy," and the remaining eight parents answered "very happy." The child of the parent reporting "somewhat unhappy" was the same parent who reported "somewhat unhappy" for body image. Of the two parents reporting "somewhat happy," one child was a girl and one was a boy. Ten children answered this question. One child who completed the self-reporting adolescent PODCI reported being "somewhat happy" with their appearance; the remaining nine children reported being "very happy." In the case of the parent who reported her daughter was "somewhat unhappy" with her appearance, the patient reported she was "very happy." We found agreement between parent and child in one patient, in which both answers were "somewhat happy."

Twelve out of 13 responders described adequate social interactions with their peers after limb salvage with expandable prosthesis. Eleven parents answered these questions. One parent reported their child rarely associates with other children, one parent reported occasional activities with other children, and the remaining nine parents reported frequent social interactions. Two parents reported making friends as "sometimes easy"; the remaining nine

Table 1. Patients receiving expandable endoprostheses—demographics, expansion data, complications, and PODCI Happiness Domain scores

Prosthesis (expansion type)	Patient	Age at surgery	Gender	Location	Total expansions	Expanded length (cm)	Complications (treatment)	PODCI Happiness Domain score (patient/parent)	
Biomet (surgical)	1	12	F	PTR	2	2.0	1 (1)	100	85
	2	8	F	DFR	4	4.0	3 (2)	85	NA
	3	12	M	DFR	4	4.0	3 (2)	100	NA
Stryker (surgical)	4	11	M	TFR	5	5.2	4 (2); 5(2)	90	100
	5	11	F	DFR	3	3.2	2 (2)	90	90
	6	8	F	PFR	1	1.0		75	50
	7	12	M	PTR	1	0.8		100	100
Stanmore (non-invasive)	8	11	M	DFR	6	0.4		100	100
	9	6	F	PFR	1	2.5		85	85
	10	15	M	PFR	3	1.5	1 (1 & 3)	80	85
	11	15	M	DFR	0	0		100	100
	12	7	M	DFR	11	9.5	6 (2)	NA	100
	13	7	F	DFR	5	8.0		NA	95
	14	10	F	DFR	0	0		NA	55
	15	12	M	DFR	1	1.0		NA	100

Location: PFR = proximal femur replacement; DFR = distal femur replacement; TFR = total femur replacement; PTR = proximal tibia replacement. Complications: 1 = wound dehiscence; 2 = aseptic loosening; 3 = physeal arrest; 4 = deep infection; 5 = prosthesis breakage; 6 = prosthesis expanded to maximum length. Treatments: 1 = wound revision; 2 = prosthesis revision; 3 = irrigation and débridement.

parents answered “usually easy.” Ten patients answered these questions. One child reported rare social interaction with other children, one reported occasional interaction, and the remaining eight children reported frequent social interactions. One child reported making friends as “sometimes easy”; the remaining nine children reported making friends to be “usually easy.” The parent and child reporting of rare social interaction occurred in the same family.

Nine out of ten adolescent patient responders, ten out of eleven adolescent parent responders and two out of two pediatric parent responders reported “very high” satisfaction with the expandable endoprosthesis. Of the eleven adolescent parents answering this question, one parent answered “somewhat satisfied”. Of the ten adolescent children answering this question, one child answered “somewhat satisfied”; the remaining nine children answered “very satisfied.” The parent and child who reported being “somewhat satisfied” with the surgical outcome were within the same family that reported social interaction as occurring rarely or never.

Discussion

Limb salvage surgery for pediatric patients with malignant bone tumors is in its infancy. New technologies allow for implanted endoprostheses to be lengthened without surgery to keep pace with patients’ skeletal growth. Although several small series have reported on functional outcomes of these patients, quality of life has not been thoroughly addressed. Several outcome measurement instruments attempt to quantify global patient performance, including quality of life and satisfaction with limb salvage; these include the Musculoskeletal Tumor Society scoring system and the Toronto Extremity Salvage Score [7, 11]. Neither of these systems is designed for assessing pediatric patients and neither directly addresses body image or social function. By administering the PODCI questionnaire to pediatric patients after limb salvage for lower extremity sarcoma, we sought to gauge happiness, self-image, social functioning, and overall outcome satisfaction in pediatric patients who have undergone limb salvage for sarcoma. We also wished to determine parents’ perceptions of these measures in their children.

We acknowledge limitations to this study. First, we report a small cohort of patients that lacks a control group or comparison group. Second, our data collection on adolescent patients did not include both parent and child reporting for six patients. Third, we lacked serial PODCI reporting, which precluded analysis of temporal trends that could be influenced by time from surgery and situational considerations such as recent lengthening. Despite these limitations, we report a relatively large number of patients

with expandable endoprostheses given the infrequency of the indication for the device.

Scores of the PODCI happiness domain were high overall, indicating a high level of emotional functioning in these patients. The mean happiness domain score for this investigation was 88.8, which compares favorably to PODCI scores in sarcoma patients reported previously [13]. Frances et al. [13] did not find substantial differences in happiness between sarcoma patients and children with a nontumor orthopaedic condition or patients with neither a tumor or orthopaedic diagnosis. Although a comparison group is not included in this investigation, these results reinforce previous reports that happiness may not be affected by limb salvage surgery [13]. Parent-reported happiness scores were generally equal to or lower than those reported by patients. This is consistent with previous reports of patient and parent quality of life after a diagnosis of cancer; disparities in patient and parent cognition of prognosis and caregiver stress are attributed to these differences [25].

Satisfaction with body image and appearance were good in the majority of patients. Patients were more likely to be happy with their appearances than with their bodies, however, which may indicate a level of frustration with functional ability rather than attractiveness. Patients receiving expandable endoprostheses at our institution are cautioned to refrain from sports requiring contact or substantial impact to the lower extremities due to risk to the endoprosthesis. In the case of the patient who reported being ‘somewhat unhappy’ with her body, she stated that she was ‘very happy’ with her outcome, but that she did become tired toward the end of long days and wished that she did not have a limp or a scar. She stated that she would definitely have the surgery again but admitted that she has moments when she is frustrated with her function level and therefore “somewhat unhappy”. This patient did state that acceptance of her body has become easier as she is entering adulthood. Parents’ perceptions of their children’s satisfaction with their bodies and appearances were similar but, on average, lower than those reported by their children. In the case of the parent who reported her daughter was “somewhat unhappy” with her body, the parent was contacted and asked to elaborate on her answer. She stated that her daughter was happy “85–95% of the time” but that her daughter expressed occasional frustration with inquiries about her scar when wearing a bathing suit or shorts. She also stated her daughter had become more sensitive to the comments of others since she entered her teen years. No relationship between satisfaction and postoperative complications or timing of lengthening appeared to exist. The mean happiness domain scores of the patients who did and did not experience a complication were similar to those who did: 92.1 and 87.2, respectively. It appears satisfaction

with appearance may change with age and increase as these patients reach later stages of adolescence and early adulthood as emphasis on appearance is less heightened [9]; however, this requires further study.

Social interactions and overall satisfaction with the patients' outcomes were high for patient and parent reporting alike. All but one patient-parent pairing reported no change in social interactions with peers. Similar findings were reported by Yonemoto and coauthors who reported higher quality of life in long-term survivors of osteosarcoma compared to the national average when function was not considered [37].

Limb salvage with an expandable endoprosthesis is a viable option for function preservation in pediatric patients with a limb sarcoma [2, 8, 14, 16–19]. Only recently have the emotional and social outcomes after this life-altering surgery been explored with the use of an outcome instrument suitable to the pediatric population [13]. Observations presented previously and the current findings suggest patients who have undergone pediatric limb salvage with an expandable endoprosthesis have a level of happiness similar to patients without orthopaedic conditions or tumors and have a good or excellent level of social functioning.

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