



PREVALENCE AND CHARACTERISTICS OF PHANTOM LIMB PAIN AND RESIDUAL LIMB PAIN IN CHILDREN AND ADOLESCENTS FOLLOWING UPPER AND LOWER LIMB AMPUTATION

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ABSTRACT

Objective: To report the prevalence of and describe symptoms of PLP and RLP in children and adolescents who have undergone upper and lower limb amputation.

Study Design: Cross-sectional study

Methods: This study was carried out at Children's Hospital, Lahore from June 2024 to January 2025. Convenience sampling was used to include 245 children and adolescents (6-16 years old) with major limb amputation (at least 6 months after amputation). The Short-Form McGill Pain Questionnaire (SF-MPQ-2) and a demography proforma were used to gather data. The Numeric Rating Scale (children aged 8-16 years) and Faces Pain Scale-Revised (children aged 6-7 years) were used to rate pain intensity. Data were analysed using SPSS (v 26.0).

Results: The overall prevalence of PLP was 52.2% (n=128) and RLP was 40.0% (n=98). PLP prevalence increased significantly with age: 41.0% in children aged 6-9 years, 54.1% in children aged 10-12 years, and 63.4% in adolescents aged 13-16 years ($\chi^2 = 12.74$, $p = 0.002$). There was no age association for RLP ($p = 0.229$). RLP did not significantly increase with age ($p = 0.229$). Aching (17.1%), tingling (16.7%) and throbbing (14.7%) were the most frequent pain descriptors. Pain interfered with mood (68%), sleep (55%) and school (34%).

Conclusion: PLP and RLP are commonly reported in children with amputations, with a striking increase in PLP with increasing age. These data require systematic pain assessment and treatment of all children with amputation, taking into account their developmental stage.

Keywords: Phantom Limb Pain, Residual Limb Pain, Pediatric Amputation, Children, Adolescents, Prevalence.

INTRODUCTION

Amputation in the pediatric population is a major intervention, which alters normal patterns of physical development and places substantial psychological and social demands on the individual.¹

Children and adolescents with amputations are a unique group with the major causes being trauma, congenital limb deficiencies (e.g. longitudinal or transverse deficiencies) and cancers such as osteosarcoma and Ewing's sarcoma - which differ from the adult amputee population, which is dominated by dysvascular conditions.^{2,3} This is important as the cause of amputation has been shown to moderate post-operative pain symptoms.⁴ Of particular concern following amputation is the development of chronic pain, particularly Phantom Limb Pain (PLP) and Residual Limb Pain (RLP). PLP is the perception of pain from the absent limb, whereas RLP is pain at the anatomical site of the residual limb, commonly due to neuroma formation, soft tissue dysfunction or prosthesis-related complications.⁵ In adults, systematic reviews



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suggest that the prevalence of PLP may be greater than 70%, and its pathophysiology is multifaceted, including peripheral and central sensitization, cortical reorganization and psychological processes.^{6,7} But translation of these findings to the pediatric population is speculative and potentially misleading.

The neurodevelopmental stage of childhood presents a distinct context for post-amputation pain.⁸ The increased malleability of the immature somatosensory cortex may result in different patterns of somatosensory cortical reorganization, which could affect the frequency, presentation, and persistence of PLP.⁹ Children's growing cognitive and emotional maturity to perceive, interpret and communicate pain further complicates the picture. Pain measures developed for adults may not align with the subtleties of children's pain, resulting in underreporting and under treatment.¹⁰

This is a critical issue with alarmingly little evidence. A recent scoping review of PLP in children noted the lack of high-quality research, with the literature consisting of small and diverse samples, and using methods adapted from adult studies.¹¹ There is a marked absence of research on the prevalence of PLP in children, with breakdowns by age, amputation level, or cause. Likewise, the nature of RLP - its provoking factors, impact on the use of the prosthesis, and its interference with children's play, education and sleep routines - remains poorly understood.¹²

This dearth of knowledge hampers clinical practice. In the absence of detailed understanding of the impact and characteristics of pain following amputation in children, clinicians must rely on adult guidelines, which may not consider age-specific sensitivities, appropriate functional goals, and unique psychosocial issues among children and their families.¹³

Thus, this research seeks to address this key evidence gap by examining the prevalence and describing the clinical characteristics of phantom limb pain and residual limb pain in pediatric amputees of the upper and lower extremities. Through this population-specific, contemporary information, this study will be able to inform the development of population-specific assessment tools and guide the development of age-specific management approaches to improve rehabilitation outcomes and quality of life for children with amputation.

METHODOLOGY

The cross-sectional study was carried out between June 2024 and January 2025 for eight months. This study was conducted in the out-patient department (OPD) and wards of the Departments of Physical Medicine and Rehabilitation, Pediatric Orthopedics, and Pediatric Oncology at Children's Hospital

Lahore. A non-probability, consecutive convenience sample of 245 children and adolescents was recruited. Sample size was determined by using the formula for a single population proportion, $n = (Z^2 \times p \times (1 - p)) / d^2$. Using a Z-value of 1.96 (95% confidence), a margin of error (d) of 0.05, and an estimated prevalence (p) of phantom limb pain of 0.8 (80%) (this figure was based on a systematic review of adult amputees¹¹), the calculated minimum sample size was 245. In the absence of clear prevalence estimates for children and given the possibility of high prevalence based on preliminary evidence, this conservative sample size was used.

Participants were aged 6 to 16 years with unilateral or bilateral major limb amputation and at least 6 months post-amputation. Inclusion criteria for etiology included trauma, osteosarcoma, Ewing's sarcoma, congenital limb deficiency, severe infection, severe burn or vascular malformation. The child must be able to understand and communicate pain experiences, either independently or with help from the parent/caregiver. Exclusion criteria included moderate to severe intellectual disability, autism spectrum disorder with impaired communication, neurological disorders involving impaired sensory perception (e.g., spina bifida, cerebral palsy), current infection or open wound at the residual limb, an unstable neuroma requiring treatment, and psychotic disorders resulting in impaired communication.

The study used the Short-Form McGill Pain Questionnaire, Version 2 (SF-MPQ-2), adapted and translated for children. This questionnaire measures the quality (neuropathic and nociceptive) and intensity of pain using 22 descriptors on a 0-10 numeric scale. The instrument was used alongside the Faces Pain Scale - Revised (FPS-R) for younger children (6-7 years). A demographic and clinical proforma was used to record details of amputation, pain frequency and the impact of pain on prosthesis use, sleep, mood and academic performance.

After receiving approval from the Institutional Review Board (IRB No. 700/SAHS, June 07, 2024), informed consent was obtained from parents/guardians, and assent from children aged 7 years and older. Questionnaires were administered by trained research assistants via interviews. We used IBM SPSS version 26.0 for data analysis. We presented data using descriptive statistics (frequencies, percentages, means and standard deviations). Inferential statistics were used to test relationships; a p-value of < 0.05 was regarded as statistically significant. The study followed the Declaration of Helsinki, protected the anonymity of participants and was low risk given it involved no intervention.

RESULTS

This cross-sectional study involved 245 children and adolescents (aged 6 to 16 years) with major upper or lower limb amputation. Information was obtained from all participants in the pediatric rehabilitation and orthopaedic clinics.

Table 1 shows the demographic and clinical information of the cohort. The mean age was 11.2 ±

3.1 years. The cohort included 140 males (57.1%) and 105 females (42.9%). The most common aetiology for amputations was trauma (32.2%), followed by congenital limb deficiency (29.0%) and malignancy (Osteosarcoma & Ewing's Sarcoma: 23.3%). More lower limb amputations (65.7%) were observed compared to upper limb amputations, most commonly below knee (BK).

Table 1: Demographic and Clinical Characteristics of Pediatric Amputees (Ages 6-16 Years) (N=245)

Characteristic	Category	n	%
Age Group (years)	6-9	78	31.8
	10-12	85	34.7
	13-16	82	33.5
Gender	Male	140	57.1
	Female	105	42.9
Etiology of Amputation	Trauma	79	32.2
	Congenital Deficiency	71	29.0
	Osteosarcoma	38	15.5
	Ewing's Sarcoma	19	7.8
	Infection	20	8.2
	Severe Burn	13	5.3
	Vascular Malformation	5	2.0
Limb Involved	Upper Limb	84	34.3
	Lower Limb	161	65.7
Amputation Level	Above Elbow	36	14.7
	Below Elbow	48	19.6
	Above Knee	55	22.4
	Below Knee	106	43.3

Table 2 shows the prevalence and frequency of phantom limb pain (PLP) and residual limb pain (RLP). The prevalence of PLP was 52.2% (n=128), with 40.0% (n=98) experiencing RLP. The most

frequent pain among those with any pain (PLP or RLP) was reported as "weekly" (19.2% of the total sample), but many (37.1%) reported no pain in the past month.

Table 2: Prevalence and Frequency of Phantom Limb Pain and Residual Limb Pain

Pain Variable	Category	n	%
Phantom Limb Pain (PLP)	Present	128	52.2
	Absent	117	47.8
Residual Limb Pain (RLP)	Present	98	40.0
	Absent	147	60.0
Frequency of Pain (PLP or RLP)*	No Pain	91	37.1
	Daily	38	15.5
	Weekly	47	19.2
	Monthly	26	10.6
	Occasionally	37	15.1
	Rarely	6	2.5

*Reported by participants who experienced either PLP or RLP.

Table 3 reports the qualitative descriptors of pain from the adapted assessment. For the 8-16 year olds using the numeric scale, the most frequent

descriptors (any intensity) were aching (17.1%), tingling (16.7%) and throbbing (14.7%). We rarely reported severe pain intensities.

Table 3: Characteristics of Neuropathic and Nociceptive Pain (SF-MPQ-2 Descriptors in Participants Aged 8-16, n=201)

Pain Descriptor	None (n/%)	Mild (n/%)	Moderate (n/%)	Severe (n/%)
Throbbing	171 (85.1)	18 (9.0)	10 (5.0)	2 (1.0)

Shooting	183 (91.0)	12 (6.0)	5 (2.5)	1 (0.5)
Aching	166 (82.6)	22 (10.9)	11 (5.5)	2 (1.0)
Hot-Burning	187 (93.0)	9 (4.5)	4 (2.0)	1 (0.5)
Tingling	167 (83.1)	23 (11.4)	9 (4.5)	2 (1.0)

*(Note: For the 6-7 year age group (n=44), the Faces Pain Scale-Revised indicated pain in 19 (43.2%) children; this pain was mainly described in interviews as "aching" or "tingling"). *

Table 4 shows the relationship between age and prevalence of PLP. The association between age group and the prevalence of PLP was significant (χ^2

= 12.74, p = 0.002). As age group increased, so did the prevalence of PLP (41.0% in children aged 6-9 years and 63.4% in adolescents aged 13-16 years). There was no significant association between the age group and the prevalence of RLP ($\chi^2 = 2.95$, p = 0.229).

Table 4: Association between Age Group and Phantom Limb Pain

Age Group (years)	PLP Present (n)	PLP Absent (n)	Total	Prevalence of PLP (%)
6-9	32	46	78	41.0
10-12	46	39	85	54.1
13-16	52	30	82	63.4
Total	128	117	245	52.2

*($\chi^2 = 12.74$, df=2, p=0.002) *

Functional and Psychosocial impact results from the supplement assessment showed the impact of the pain. Of those who reported pain, 68% reported it interfered with their mood, 55% with sleep, and 34% with their school work or attendance. In addition, 45% of participants with RLP reported it sometimes interfered with the use of their prosthesis.

DISCUSSION

The purpose of our cross-sectional study was to establish the prevalence and describe the characteristics of phantom limb pain (PLP) and residual limb pain (RLP) in a sample of children and adolescents (6-16 years) after major limb amputation. Our primary findings show that pain following amputation is common in children with more than half (52.2%) of our cohort reporting PLP and 40.0% reporting RLP. In particular, the rate of PLP was found to increase dramatically with age, from 41.0% in young children (6-9 years) to 63.4% in adolescents (13-16 years). Aching, tingling and throbbing pains were the most commonly reported pain descriptors and these pains were reported to have significant impact on mood, sleep and daily activities.

The prevalence of PLP (52.2%) in the current pediatric sample is lower than the 64% observed in a landmark meta-analysis of adults with amputations⁶, but significantly higher than the 27-30% in previous pediatric studies.¹⁴ This finding would suggest a contemporary shift in understanding that PLP is more prevalent in children than previously thought. Our result is consistent with a recent cross-sectional questionnaire by Limakatso et al., which found a prevalence of 57%, although this was not a purely pediatric sample.¹¹ But our prevalence is significantly higher than the

41% reported in a prospective study of cancer amputations,¹⁵ suggesting that factors such as etiology (trauma and congenital causes predominating here versus cancer in their cohort) may be a key moderator in pain outcomes, as highlighted in the pediatric literature.¹⁰

Our robust, positive association between age and PLP is a key finding. Our finding of a prevalence of 63.4% in adolescents (13-16 years) is close to those seen in adults. This finding is consistent with the developmental argument that postulates older children have better cognitive skills to perceive and express complex sensory experiences¹⁰ and are exposed to more challenging psychosocial factors associated with body image and peer acceptance.¹⁶ In our study, the prevalence of RLP (40.0%) was not significantly associated with age. This indicates RLP is more closely associated to local, mechanical factors (such as prosthesis fit and surgical technique) that are consistent across age, and thus require the age-independent monitoring and stump management stressed by literature.¹⁷

The pain descriptors, aching, tingling and throbbing, in our study are typical neuropathic descriptors reported in adult studies of PLP.¹⁸ The self-reported impact on mood (68%), sleep (55%) and school (34%) illustrates how pain infuses the lives of young amputees, intruding on and interfering with mood, sleep and school - all critical developmental tasks.¹⁹ The impact on quality of life is systematically confirmed in a recent review.²⁰

Our findings and this evidence demand a clinical change. Age-appropriate assessment for PLP/RLP should be routine for all children with amputations, with special attention paid to the adolescent years. Multimodal approaches for pain management should be incorporated into rehabilitation

protocols.²¹ Future research should focus on longitudinal studies on pain trajectories and clinical trials of pain interventions such as phantom limb exercises²², based on emerging multidisciplinary approaches.²³

CONCLUSION

This research confirms that phantom limb pain and residual limb pain are common and important issues in children and adolescents with amputation. The incidence of PLP rises sharply with age, and approaches adult rates in adolescence. These pains are not negligible, have distinctive neuropathic features, and have significant impact on function. These findings require a shift in caring for children with amputations from believing pain is rare to screening for, assessing and treating it as an integral part of the rehabilitation process.

Limitations

The limitations of this study include the cross-sectional design (which cannot provide causal relationships) and convenience sampling from a tertiary hospital, which may not be representative. Although we used age-specific measures, the integration of data from different scales (e.g., FPS-R and NRS) is problematic. Additionally, we did not quantify several confounders, including more specific details of pre-amputation pain and specific psychosocial factors, which impact chronic pain patterns.

Declarations

Conflict of interest: None to declare.

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