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Predictors of healthcare seeking delays among children with chronic musculoskeletal disorders in Nepal

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ABSTRACT

Background: Healthcare seeking behaviors among children with musculoskeletal disorders are poorly understood. We sought to analyze healthcare seeking delays among children with chronic musculoskeletal conditions in Nepal and identify predictors of clinically significant delays.
Methods: A cross-sectional study was conducted at a large pediatric musculoskeletal rehabilitation center in Nepal. Baseline sociodemographic data and healthcare seeking behaviors were assessed via interviews with 75 randomly selected caregivers. Delays of at least 3 months between disease recognition and presentation to a health worker were considered clinically significant. Predictors of significant delay were assessed via multivariable logistic regression.
Results: Clubfoot was the most common condition seen in the study sample (N = 33; 37%). Mean and median presentation delays were 33 months and 14 months, respectively. Sixty-seven percent of children were delayed at least 3 months and 40% were delayed at least 2 years. Caregiver occupation in agriculture or unskilled labor was associated with an increased risk of delayed presentation (adjusted OR = 4.05; 95% CI: 1.36–12.09).
Conclusions: Children with chronic musculoskeletal disorders in Nepal face significant delays in accessing healthcare. This poses a major clinical problem as the delayed diagnosis and treatment of childhood musculoskeletal disorders can complicate management options and decrease long-term quality of life.

1. Introduction

Musculoskeletal disorders in children are commonly due to trauma, infection, and congenital deformities [1–4] and can progress to lifelong disability in the absence of timely treatment. Most children with musculoskeletal disorders in low- and middle-income countries (LMICs) have little or no access to basic musculoskeletal and rehabilitation services [5]. Living in resource-limited settings imposes a harsh double burden on these children: they often have limited physical means of mobility in settings with insufficient availability of appropriate healthcare services.

There is a recognized need for further research characterizing the barriers faced by disabled children attempting to access health services [6]. Naturally, caregivers play a critical role in determining the healthcare seeking behaviors of their children. It is therefore essential to view healthcare seeking behavior through the lens of the primary caregiver to design effective interventions aimed at ensuring timely diagnosis and management of pediatric conditions.

Numerous studies have identified key determinants of delays in the diagnosis and treatment among adults with cancer [7], burns [8], ophthalmologic conditions [9,10], and tuberculosis [11] in LMICs. However, the same cannot be said for delays among children, especially those who are disabled [12–14]. Studies involving disabled children have typically focused on single etiologies such as clubfoot and cataract and have been primarily qualitative in nature [15–18].

Abbreviations: LMICs, Low- and middle-income countries; HRDC, Hospital and Rehabilitation Center for Disabled Children.

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To our knowledge, no study has explored predictors of delayed presentation among children with chronic musculoskeletal disorders in LMICs. In Nepal, two recent studies analyzed the national burden of musculoskeletal disease and barriers to surgical care nationwide [19,20]. However, these studies were not designed to assess presentation delays in children or sociodemographic predictors of those delays. Given the 2015 earthquake in Nepal and the resulting rise in post-traumatic musculoskeletal disease, a better understanding of healthcare seeking behaviors among this population is warranted [21]. The purposes of this study were therefore to (1) quantify lengths of delays between disease recognition and presentation to a health facility among children with chronic musculoskeletal disorders in Nepal and (2) identify predictors of clinically significant delays.

1.1. Country and site overview

Nepal is a landlocked country in South Asia. It ranked 145 out of 188 countries on the 2015 Human Development Index [22] and is considered a low-income country according to the World Bank [23]. As in other LMICs, healthcare providers in Nepal are concentrated in large urban areas such as the capital, Kathmandu. The exact number of musculoskeletal providers in Nepal is unknown but thought to be severely insufficient, especially in rural regions like the Himalayas. A recent cross-sectional study estimated the prevalence of musculoskeletal disorders in Nepal at nearly 15% [19]. Multiple studies have identified physical disability affecting locomotion and manipulation as the most common type of disability in Nepal [24–26].

The Hospital and Rehabilitation Centre for Disabled Children (HRDC) is a non-profit health facility that provides rehabilitative care for physically disabled children and adolescents in Nepal. It is located in Banepa, a town in central Nepal approximately one hour by car from Kathmandu. Services provided at the hospital include surgical treatment for musculoskeletal conditions, physical therapy, and orthotics/prosthetics. All children presenting to HRDC have chronic musculoskeletal conditions. Acute musculoskeletal trauma is not seen at the facility. HRDC also has a community-based rehabilitation network in all 75 districts of Nepal and frequently operates mobile camps for screening and follow up throughout the country.

2. Materials and methods

The study was conducted at HRDC over a 6-week period in July and August of 2014. The target population consisted of caregivers of children presenting to HRDC as inpatients or outpatients during the study period. Children were not interviewed for this study. Because all children seen at HRDC have chronic musculoskeletal disorders, all primary caregivers of children at HRDC were considered eligible for the study. Subject recruitment was conducted on a daily basis to obtain a new daily random sample of children present at HRDC. A complete list of all inpatient and outpatient children present at HRDC was obtained every morning from the hospital registrar prior to conducting interviews. All children on this list were assigned a number via a random number generator to create a randomized list of potential patients currently in the hospital to be screened. Caregivers of children selected from this list were subsequently identified in the randomized order and screened for eligibility. Given that the patient population at HRDC changes on a daily basis due to new admissions, discharges, and outpatient visits, this process was repeated every day for the duration of the study to ensure that all available children were available for sampling. This recruitment strategy was chosen to ensure that all children at HRDC would be represented in the study pool regardless of their status as an inpatient or outpatient. Caregivers were excluded if: (1) they were not present at the time of selection, (2) they or their child was in physical or emotional distress at the time of selection, or (3) they did not identify as one of the child's primary caregivers. Eligible caregivers underwent a comprehensive informed consent process prior to the interview. We conducted a preliminary power analysis to determine the number of patients needed for this study. With a type I error rate (alpha) set at 5% and medium effect size estimated at 0.45, the sample size was calculated for a power of 80%. This analysis resulted in a minimum of 64 patients for an adequately powered cross-sectional study.

Caregivers were interviewed by one author along with an interpreter who was fluent in English, Nepalese, and Hindi. Interviews were conducted face-to-face in the caregiver's native language (Nepalese (n = 68) or Hindi (n = 7)). To ensure reliability of the study questionnaire, a pilot study was conducted. The questions were modified in an iterative manner throughout the pilot study by removing irrelevant questions, consolidating redundancies, and adding additional questions. The questionnaire was finalized by three authors. All interviews were audiotaped and transcribed in full by one of the authors and transcripts were then scrutinized by a second author.

The primary outcome of interest was presentation delay, defined as the number of months between recognition of the disorder and first presentation to any health worker. Recognition of the disorder was defined as the moment a problem was first noticed by the caregiver. A health worker was defined as any individual with medical training working in either a public or private health facility. Local and traditional healers were not considered health workers for the purposes of this study. A series of questions was used to ascertain these two time points – recognition and presentation – based on caregiver recall. In cases of congenital conditions that were noticed at birth, recognition was defined as the moment of birth. In cases of recurrent disease, the immediate reason for seeking evaluation was considered the condition being treated and not the underlying disease. For example, a patient with recurrent clubfoot was considered to have a time of first recognition as the moment the caregiver noticed the clubfoot had recurred following initial treatment.

A presentation delay of at least 3 months was considered clinically significant. This cutoff was determined by expert consensus on what should be considered normal delay for atraumatic musculoskeletal conditions while accounting for increasing risk of long-term clinical complications associated with prolonged delay. Cutoffs from similar studies of different conditions in different settings were considered in determining the 3 month threshold value [7,10,18].

Relevant covariates of interest included clinical, sociodemographic, geographic, and travel-related variables. Clinical variables included diagnosis, etiology, distribution of impairment, and comorbid cognitive impairment. Sociodemographic factors related to the child included age, sex, and inpatient status. Sociodemographic factors related to the caregiver included age, relationship to the child, marital status, literacy, and occupation. Geographic factors were home district, topographical region, and developmental region. Travel related variables included travel time to the hospital, cost of travel to the hospital, cost paid out of pocket for travel, source of funding for travel, and primary means of transport to the hospital.

2.1. Statistical analysis

The distributions of clinical, sociodemographic, geographic, and travel-related characteristics were summarized by descriptive statistics. Differences in presentation delay for continuous variables were assessed using the Wilcoxon rank-sum test. Differences in presentation delay for categorical variables were assessed

using the Chi-square and Fisher's exact tests. Odds ratios calculated from univariate logistic regression were used to describe measures of association between covariates and clinically significant presentation delay. A multivariable logistic regression model was constructed based on a univariate screen ($P < .05$) to identify variables that best predicted presentation delay. The use of multivariable logistic regression allowed for adjustment for the most significant predictors based on univariate analysis. Two variables (caregiver age and caregiver occupation) were included in the final model. For all analyses, two-sided tests were used with a level of significance of $\alpha \leq 0.05$. All analyses were performed using STATA 14.1 (StataCorp, College Station, TX, USA).

2.2. Ethical approval

Ethical approval for this study was granted by the Nepal Health Research Council (Kathmandu, Nepal) and the Institutional Review Board of the Hospital and Rehabilitation Centre for Disabled Children (Banepa, Nepal). Prior to the interview, participants were informed about the aims of the study, their right to refuse to participate, and their assurance of confidentiality. There was no incentive for completing the interviews. Written informed consent was obtained from participants. Thumb prints and verbal consent were accepted from illiterate participants.

Table 1
Musculoskeletal disorders of children in study sample.

Class	Condition	n	%
Congenital		**53**	**60%**
	Clubfoot	33	37%
	Primary Clubfoot	*16*	18%
	Secondary Clubfoot	*9*	10%
	Recurrent Clubfoot	*4*	4%
	Neglected Clubfoot	*4*	4%
	Syndactyly	3	3%
	Arthrogryposis multiplex congenita	3	3%
	Constriction band syndrome	2	2%
	Tibial pseudoarthrosis	2	2%
	Other	10	11%
Neuromuscular		**13**	**15%**
	Cerebral palsy	10	11%
	Spina bifida	3	3%
Developmental		**9**	**10%**
	Kyphoscoliosis	3	3%
	Developmental dysplasia of the hip	2	2%
	Rickets	2	2%
	Other	2	2%
Post-infectious		**7**	**8%**
	Septic arthritis sequelae	2	2%
	Joint contracture	2	2%
	Other	3	3%
Post-traumatic		**5**	**6%**
	Joint contracture	4	4%
	Other	1	1%
Unknown		**2**	**2%**

Other conditions (N = 1 for each) include: Osteogenesis imperfecta, macrodactyly, fibular hemimelia, pes planus, osteopetrosis, vertical talus, phocomelia, Apert syndrome, joint contracture, ulnar claw hand, hereditary multiple exostosis, juvenile rheumatoid arthritis, hip ankylosis, equinus deformity, surgical site infection, cubitus varus

3. Results

A total of 88 caregivers were initially selected over the study period. Caregivers were excluded from the study if they were not physically present with their child (n = 9) or if they or their children were in active physical or emotional distress at the time of selection (n = 4). No caregivers refused to participate. A total of 75 interviews were completed. The participants selected for the study represent 9% of all patients visiting HRDC over the study period.

The musculoskeletal disorders of participants' children were diverse (Table 1), with the most common being clubfoot (n = 33) and cerebral palsy (n = 10). This is consistent with prior findings from HRDC [27]. The majority of conditions were congenital and twelve children had more than one unique musculoskeletal disorder.

Two-thirds of respondents reported a delay of ≥3 months between first recognizing their child's disorder and presenting to a health worker. Mean and median delays among all subjects were 33 months and 14 months, respectively (range: 0–187 months). Thirty children (40%) were delayed by at least two years and 16 (21%) were delayed at least five years.

Tables 2 and 3 summarize the univariate associations between categorical and continuous variables and presentation delay, respectively. Age of the parent (OR 1.05; 95% CI 1.00–1.10; $P = .036$) and occupation in either agriculture or unskilled labor (OR 4.94; 95% CI 1.70–14.33; $P = .003$) were associated with an increased risk of presentation delay. When these variables were included in a multivariable regression model (Table 4), agriculture or unskilled labor remained significantly associated with presentation delay (OR 4.05; 95% CI 1.46–12.09; $P = .012$).

4. Discussion

In this cross-sectional study of caregivers of children with diverse musculoskeletal disorders, we identified clinically significant presentation delays in the majority of study participants. Furthermore, we identified agricultural or unskilled labor as an independent risk factor for presentation delay among this vulnerable population.

Table 2
Factors influencing healthcare seeking delay (continuous).

Characteristic	No presentation delay (<3 months)	Presentation delay (≥3 months)	OR (95% CI) *P* value
Age of child (years)	6.0 (2.0, 11.0)	8.5 (4.0, 13.0)	1.07 (0.97–1.18) .134
Age of caregiver (years)	30.0 (24.0, 37.0)	35.0 (29.5, 46.5)	1.05 (1.00–1.10) .036
Travel time (hours)	11.0 (5.0, 15.0)	11.0 (8.0, 17.0)	1.00 (0.98–1.03) .823
Cost of travel (NPR)	1000 (600, 1400)	1000 (600, 1200)	1.02 (0.97–1.07)* 1.00
Cost paid for travel (NPR)	825 (160, 1250)	845 (460, 1000)	1.01 (0.97–1.05)* .986

NPR: Nepalese rupees. OR: Odds ratio. CI: Confidence interval. Values are presented as median (first quartile, third quartile). ORs and CIs were obtained from unadjusted logistic regression. *P* values were obtained from the Wilcoxon rank-sum test. *ORs for cost data are reported per 100 NPR.

Table 3
Factors influencing healthcare seeking delay (categorical).

Characteristic	No presentation delay (<3 months)	Presentation delay (≥3 months)	OR (95% CI) *P* value
Sex			0.134
Male	18 (72%)	27 (54%)	ref
Female	7 (28%)	23 (46%)	2.19 (0.78–6.16)
Etiology			0.823
Congenital	14 (56%)	23 (46%)	ref
Neuromuscular	3 (12%)	6 (12%)	1.22 (0.26–5.67)
Developmental	3 (12%)	8 (16%)	1.62 (0.37–7.16)
Infection	1 (4%)	7 (14%)	4.26 (0.47–38.38)
Post-traumatic	2 (8%)	3 (6%)	0.91 (0.14–6.16)
Multiple	2 (8%)	3 (6%)	0.91 (0.14–6.16)
Physical impairment			0.465
Lower limb only	16 (64%)	33 (66%)	ref
Upper limb only	2 (8%)	2 (4%)	0.48 (0.06–3.76)
Spine only	0 (0%)	4 (8%)	–
Multiple	7 (28%)	11 (22%)	0.76 (0.25–2.34)
Cognitive impairment			0.658
No associated cognitive impairment	23 (92%)	46 (92%)	ref
Associated cognitive impairment	2 (8%)	4 (8%)	1.00 (0.17–5.87)
Caregiver relationship			0.534
Parent/step parent	21 (84%)	43 (86%)	ref
Sibling	4 (16%)	7 (14%)	0.85 (0.22–3.24)
Marital status of caregiver			0.658
Married	23 (92%)	46 (92%)	ref
Separated/widowed/single	2 (8%)	4 (8%)	1.00 (0.17–5.87)
Literacy of caregiver			0.123
Literate	25 (100%)	45 (90%)	ref
Illiterate	0 (0%)	5 (10%)	–
Type of work of caregiver			0.003
Agricultural or unskilled labor	12 (48%)	41 (82%)	ref
Professional/student/foreign	13 (52%)	9 (18%)	4.94 (1.70–14.33)
Geographic region			0.845
Hill	10 (40%)	24 (48%)	ref
Terai	12 (48%)	22 (44%)	0.76 (0.28–2.12)
Mountain	1 (4%)	2 (4%)	0.83 (0.07–10.27)
India	2 (8%)	2 (4%)	0.42 (0.05–3.38)
Developmental region			0.437
Central	8 (32%)	18 (36%)	ref
Eastern	6 (24%)	11 (22%)	0.82 (0.22–2.98)
Western	3 (12%)	13 (26%)	1.93 (0.43–8.69)
Mid or Far western	6 (24%)	6 (12%)	0.44 (0.11–1.81)
India	2 (8%)	2 (4%)	0.44 (0.05–3.74)
Source of funding			0.989
Self	16 (67%)	30 (65%)	ref
Family/friend donation	3 (13%)	7 (15%)	1.24 (0.28–5.48)
Organization	3 (13%)	5 (11%)	0.89 (0.19–4.21)
Loan	2 (8%)	4 (9%)	1.07 (0.18–6.47)
Primary mode of transport to hospital			0.370
Bus	24 (96%)	45 (90%)	ref
Walking	0 (0%)	4 (8%)	–
Other	1 (4%)	1 (2%)	0.53 (0.03–8.91)
Caregiver trusts Nepalese doctors			0.070
Yes	14 (70%)	36 (90%)	ref
No	6 (30%)	4 (10%)	0.26 (0.06–1.05)
Patient classification			0.741
Inpatient	15 (60%)	28 (56%)	ref
Outpatient	10 (40%)	22 (44%)	1.18 (0.44–3.12)

OR: Odds ratio. CI: Confidence interval. Values are presented as N (%). ORs and CIs were obtained from unadjusted logistic regression. *P* values were obtained from Chi-square or Fisher exact tests.

Table 4
Multivariable logistic regression analysis of presentation delay.

Predictors	OR (95% CI)	*P* value
Age of caregiver	1.04 (0.99–1.10)	.135
Type of work by caregiver		
Agricultural or unskilled labor	4.05 (1.46–12.09)	.012
Professional/student/foreign	–	–

Musculoskeletal disorders in children are frequently amenable to treatment in the form of physical therapy and/or orthopaedic surgery [27]. Early diagnosis and treatment of these conditions can be associated with shorter treatment regimens, fewer operations, and better clinical outcomes [28]. It is therefore of the utmost importance that caregivers of children with musculoskeletal disorders recognize their child's condition and promptly seek appropriate care. Our study suggests that delayed presentation among this population is common in Nepal, likely leading to more complicated treatment regimens and worse clinical outcomes.

These findings are complemented by other studies of musculoskeletal disease in Nepal and other LMICs. For example, in a recent survey of the musculoskeletal disease burden in Nepal, Chawla and colleagues found that 69% of individuals with non-traumatic musculoskeletal disorders desired medical evaluation

but were unable to access it [19]. A similar study in Sierra Leone estimated that 64% of individuals were unable to access care for their musculoskeletal conditions [29]. Given the facility-based nature of our study, we were unable to estimate the proportion of caregivers of children with chronic musculoskeletal disorders who desired but were unable to access medical care; however, these findings from Nepal and Sierra Leone suggest that this proportion is likely significant.

A related study by Gupta et al. found that the odds of having an unmet surgical need in Nepal were higher in rural settings compared to urban settings among all age groups and disease types. Our study did not specifically compare individuals from urban vs. rural settings but did collect data on several related geographic variables such as developmental region and topographical region. For example, 13 of the 16 patients (81%) from the largely rural Western region of Nepal experienced significant delays. The mountain region of Nepal, a rural area with difficult terrain, was underrepresented in our study with only 3 patients originating from that region. A larger sample size with more individuals from rural regions would clarify the importance of this finding and its consistency with prior studies. Additionally, caregiver occupation in agriculture or unskilled labor was found to be significantly associated with delays in our study, and this variable may serve as a partial surrogate measure for rural living environment.

These studies were distinct from ours in that they assessed all age ranges, relied on self-reported disease incidence, and in the case of the latter study, included all surgical disorders including both musculoskeletal and non-musculoskeletal conditions. While these studies assessed barriers to surgical care, they did not quantify lengths of clinically significant presentation delays. Moreover, our study is unique in that is restricted to a relatively homogenous population of children with chronic musculoskeletal disorders. Presentation delays in this population are of special interest because early intervention in most musculoskeletal conditions can optimize physical function and maximize quality of life.

Our findings are also consistent with other studies that have assessed presentation delays associated with different conditions in other LMICs. In a study from Tanzania, Mwende et al. analyzed 178 children with cataracts and found mean and median delays between recognition and presentation of 34 months and 18 months, respectively [18]. Despite assessing a different clinical entity in a different region, our study found similar lengths of delay with mean and median delays of 33 months and 14 months, respectively. Another study of pediatric cataract in Brazil found that 33 of 70 (47%) of children experienced presentation delays of at least 3 months [10], which is less than the 67% of children in our study who experienced equal presentation delays.

Our study has several limitations. Since there is no existing literature quantifying presentation delays in children with musculoskeletal disorders, we decided on a cutoff of three months for clinically significant delay. This threshold was determined by local provider consensus on what should be reasonable delay for a non-emergent condition; however, a longer delay may also be reasonable. It could also be argued that presentation delay is relative depending on the disorder. A presentation delay of 3 months in a young child with signs of cerebral palsy may be insignificant, while the same delay in a patient with septic arthritis would dramatically alter the child's prognosis. Similar studies in other populations, such as childhood cataract in Tanzania, childhood cataract in Brazil, and breast cancer in Thailand, have used 12 months, 1 month, and 3 months, respectively [7,10,18].

A wide range of musculoskeletal disorders was described in this cohort, which may limit the generalizability of this study to the broader population of children with chronic musculoskeletal disorders in Nepal and other LMICs. However, given that many of the conditions in this report are relatively rare (e.g., osteopetrosis, hereditary multiple exostosis, Apert syndrome, etc.), any study of the barriers associated with these conditions may only be possible via aggregating multiple musculoskeletal conditions into one study. Our study may also be subject to selection bias and recall bias. As this was a hospital-based assessment over a relatively short time period, it is hard to know whether our findings truly represent the overall population of children with musculoskeletal disorders in Nepal. It is possible that the sample of caregivers presenting for care were more health conscious or of higher socioeconomic status than the population of caregivers nationwide. These factors and other unmeasured confounders may bias the sample of caregivers included in this study. There may also be some inaccuracies in reporting presentation delays due to imperfect or biased recall.

Despite these limitations, this study contributes unique and valuable information to the understanding of the degree of presentation delays among children with musculoskeletal disorders in resource-limited settings. Much of the current literature consists of studies assessing barriers to care [19,20], referral uptake [14], and perceptions of disability [30], yet there is minimal data that is specific to children with musculoskeletal disorders or lengths of clinically significant delays. This study adds to that growing knowledge base by quantifying health seeking delays in this vulnerable population and identifying a key predictor of presentation delay. Based on the data presented in the current study and our own experiences working with this population in Nepal, we believe that several interventions could help children access care sooner. These include broadening the community-based rehabilitation network in Nepal with a focus on rural and predominately agricultural regions, expanding health system accessibility at the local level, and solidifying the referral hierarchy from subhealth posts and health posts to secondary and tertiary care facilities.

5. Conclusions

Importantly, in the wake of the 2015 earthquake in Nepal, there is an increasingly important role for healthcare professionals to treat and rehabilitate children suffering from newly acquired musculoskeletal disorders [21]. Our study is an important and timely assessment of the delays Nepali caregivers face in seeking musculoskeletal care for their children. Reducing these delays can improve the prognosis of debilitating musculoskeletal disorders and maximize long-term quality of life among a young population.

Conflict of interest

None declared.

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