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].

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 inpa-

tient 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