

Research Article

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Anxiety Level of Caregivers of Children with Common Congenital Lower Limb Deformities

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Abstract

Background: Congenital lower limb deformities prevail at birth either due to aplasia or hypoplasia of bone during fetal development. These deformities can occur either transversely or longitudinally and can be complete or incomplete. One or more bones can be involved. Such deformities may likely to diminish the joy of childbirth with emotional disturbance of their guardians. The present study is therefore meant to measure the anxiety level of caregivers of the children diagnosed with congenital lower limb deformities.

Subjects & Methods: A cross-sectional descriptive study was done among 100 caregivers of the children with established lower limb deformities who were enrolled in the study through purposive sampling. The responses were gathered from caregivers by using Standardized Hamilton Anxiety Rating Scale (HAM-A). Data was entered and analyzed by using SPSS version 25 and MS Excel 2019. Descriptive statistics were applied.

Results: Responses of the 56 male and 44 female caregivers pertaining to their anxiety level due to children with congenital lower limb deformities were collected. Mean age of the respondents were 21.7 ± 9.2 years. Developmental Dysplasia of Hip (DDH) was maximally (21%) reported followed by Leg Length Discrepancy (LLD) (19%) and Pes Planus (17%). About 67 caregivers had mild to moderate anxiety with score in the range of 18-24 while 20 caregivers had mild anxiety with less than 17 score.

Conclusion: Most of the caregivers were anxious due to congenital lower limb deformities of their children.

Keywords: anxiety level; caregivers; congenital lower limb deformities; developmental dysplasia of hip; leg length discrepancy

Introduction

Congenital lower limb deformities impose substantial physical, emotional and financial challenges not only on affected children but also on their families [1]. Congenital Malformations account for approximately 2%-4% of live births across the globe with limb defects representing a notable subset that can result in lasting disability and complications for rehabilitation [2]. Numerous studies emphasize the psychological impact of caring for a child with congenital anomalies, with anxiety prevailing among primary caregivers. A prospective study of parents managing congenital clubfoot treated with the Ponseti method revealed significant depression, stress, and anxiety specifically among highly educated mothers although symptoms were declining with treatment [3].

In the case of congenital pseudarthrosis of the tibia, caregivers also exhibited significantly higher anxiety and depressive symptoms compared to those caring for unaffected children-factors that may influence the

child's behavioral outcomes and long-term rehabilitation [4]. A scoping review on caregivers of children with lower limb amputations highlighted that psychological support was among the most persistent apprehensions as caregivers were more prone to experience depressive symptoms, anxiety and irritability that directed towards the need for psychological counselling, and organized institutional support [5].

A cross-sectional survey from Northwestern Pakistan (2017-2021) among 141 cases with congenitally deformed limbs explored that there was heterogeneity in defect types (transverse, longitudinal, intercalary). Moreover, multifactorial etiology was identified with prime attribution to parental consanguinity [6]. Likewise, a multicenter study carried out among residents of Peshawar revealed that limb abnormalities constituted around 26% of all congenital malformations [7]. Similarly, a survey among cohort of 1185 cases from Baluchistan with congenital malformations illustrated that one percent

of it is sporadic while 51% of deformations were linked with consanguineous marriages [8]. A mixed method study by Saeed S et al at a tertiary care hospital of Karachi emphasized the multi-faceted aspect of burden related to caregivers of hereditary pediatric illnesses [9]. The caregivers of disabled children were subjected to multiple challenges like joblessness, depression and poor quality of life [10].

The psychological burden among caregivers of children with congenital anomalies seems to be a real and unmet need; yet this issue needs methodical study. In the light of this research gap, the present study is intended to investigate the anxiety levels among caregivers of children with congenital lower limb deformities in Pakistan. This study would provide actionable data to inform healthcare providers, policymakers, and rehabilitation services for paying attention to psychosocial needs apart from physical care. This study would facilitate designing responsive, compassionate and holistic care pathways to support the children with physical deformities as well as their families.

Methods

A cross-sectional descriptive study was carried out among 100 caregivers of the children who were diagnosed with lower limb deformities at Benazir Bhutto Hospital Rawalpindi and were enrolled in the study through purposive non-probability sampling. This study was done in the partial fulfillment of BSc (Hons) Orthotics & Prosthetics degree at Informed consent was taken from all the caregivers for data collection. The responses were gathered from caregivers of the children by using Standardized Hamilton Anxiety Rating Scale (HAM-A). This scale

is among the extensively used scales to clinically measure the severity of anxiety. It comprises of 14 items with scoring of each item varying from 0-4 (0=not present, 4=severe). In this way, minimal score = 0 and highest score = 5611.

This scale encompasses two domains that include psychic (mental) and somatic (physical). Items related to psychic domain are anxious mood, tension, fears, insomnia, memory and depressed mood. Items pertaining to somatic domain are sensory and muscular symptoms, cardiovascular, respiratory, gastrointestinal, genitourinary, autonomic symptoms and behavior at interview. The cut-off levels for interpreting the scores of HAM-A rating scale are illustrated below:

- 0-17: Mild
- 18-24: Mild to Moderate
- 25-30: Moderate to Severe
- 30: Very Severe [12]

This scale has been verified as having good reliability and concurrent validity particularly among anxious and depressed cases [11]. However, its inter-rater reliability and construct validity was determined to be more in acceptable range among adolescents [13]. Data was entered and analyzed by using SPSS version 25 and MS Excel 2019. Descriptive statistics were applied.

Results

Of the 100 caregivers of the patients with congenital lower limb deformities enrolled in the study, 56 were males while 44 were females. Mean age of the respondents was 21.7 ± 9.2 years. Most (21%) of the patients with lower limb deformity had DDH as shown below in Figure 1.

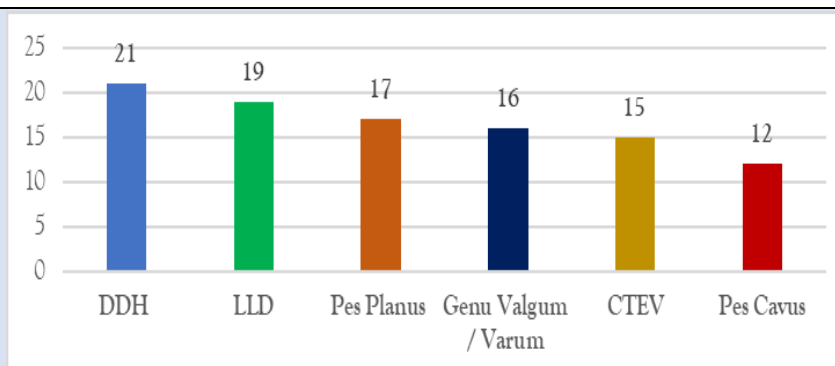


Figure 1: Types of Congenital lower limb deformities among patients.

Majority (67%) of the care givers were determined to have mild to moderate anxiety as depicted below in Figure 2.

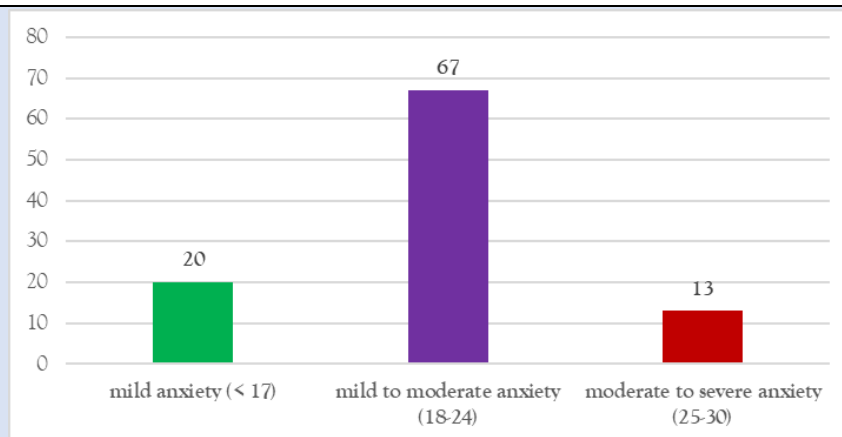


Figure 2: Mild to moderate anxiety, moderate to severe anxiety.

Discussion

Of the 100 children discussed in present study with congenital lower limb deformities, 44% and 56% were females and males respectively. Contrary to our result, data from a book revealed occurrence of one of the lower limb deformities that is DDH more among females in female: male as 6:1. This discrepancy was linked with gender-wise hormonal and anatomical diversities [14]. Contrary to this, a hospital-based descriptive study done among cases of Khyber Pakhtunkhwa presented the congenital occurrence of club foot among 210 males and 104 females [15]. Similarly, an Indian study by Barik S et al reflected the higher prevalence of lower limb deformities particularly Congenital Talipes Equinovarus (CTEV) among males [16]. Apart from gender-based differences, other socio-demographic and environmental aspects should also be studied while developing association of lower limb deformity with an entity. Systematic reviews and meta-analysis can help us to great extent in establishing the relevant causal association.

Most (21%) of the children in present study had DDH followed by LLD (19%). Overall DDH has been diagnosed among 1-1.5 infants / 100 births across the globe but some regional disparities in its prevalence have also been documented [17]. A systematic review and meta-analysis done by Tao Z et al showed occurrence of Developmental Dysplasia of Hip among 1 in 100 female infants. However, recommendation was to promote routine screening among infants for avoiding complex developmental disorders [18]. On the other hand, a retrospective cross-sectional survey spanning over 5 years (2018-2023) demonstrated 0.50% prevalence of DDH [19]. A similar study carried out by Marvi N et al among infants of Karachi revealed higher incidence of DDH among males (16.08%) than those of females (14.78%) although gender-based disparity was statistically insignificant. Moreover, ethnic variation was quite prominent with more Sindhi infants diagnosed with

pathological hips (9.13%) than those of Punjabi (7.39%) and Pathan (6.08%) [20]. Apart from nation-wide discrepancy, ethnic variation is also a noteworthy dimension that should further be scrutinized by community screening primarily at massive scale.

Of the 100 children mentioned in our study with congenital lower limb deformities, 19 were diagnosed cases of Leg Length Discrepancy (LLD). Being a deformity secondary to club foot, a retrospective study by Schaibley C et al, around 14.4% of clubfoot children treated through ponseti casting had LLD [21]. Consistent with these findings, a retrospective cohort study revealed 9% LLD among club foot cases and 23% of them had unilateral clubfoot deformity [22]. The association of LLD with DDH have also been determined by some researchers, therefore a study by Merchant RM et al concluded that meticulous observation of LLD with DDH is markedly needed for appropriate management of the cases [23]. Inclusion of genetics in occurrence of DDH is in dire need of further comprehensive studies [24]. Pes planus is another lower limb deformity that has remarkably been detected among children whose caregivers responded in present study. It has frequently been reported among Pakistani children. Its prevalence among children of Lahore was found to be 40.6% [25]. However, prevalence of pes planus was comparatively less among students of Karachi (15.5%) [26] and those belonging to Rawalpindi and Islamabad (14.8%) [27]. Substantial variations in deformities have been witnessed even among different cities of Pakistan. The underlying etiology demands digging out of real-time evidence. This will definitely prove beneficial for the community as meticulous supervision of the cases would enable the stakeholders to take necessary rehabilitative measures.

About 67% caregivers of the children with congenital lower limb deformities had mild to moderate anxiety in the current study. A comparative cross-sectional study carried out on a large scale by Yu Y et al was illustrative of higher rates of anxiety among parents and relatively

more burden than the parents of healthy children [28]. The parents of children with known DDH were quite apprehensive and depressed at the time of diagnosis but later anxiety level dropped when they learned to manage their children with this deformity [29]. Likewise, according to a prospective study, depression, anxiety and stress among caregivers of children with clubfoot was substantially declined after ponseti casting of their affected children. Although parents of affected children were much disturbed psychologically but initiation of treatment and awareness about managing lower limb deformities considerably relieved their anxiety. Hence, pre- and post-management psychological well-being of the caregivers should be given due consideration for the mitigating their depressiveness [30]. According to a prospective cohort study by Mahan MT et al meeting of the caregivers with pediatric orthopedic surgeon can momentarily relieve their anxiety [31], so this initiative along with prenatal counseling can help a great deal to cope up with existing scenario. One of the limitations of this study was small sample size and short duration of study. Planning a multi-center study particularly gathering responses from caregivers of affected children from both public and private sector can prove quite insightful and enlightening for the stakeholders.

Conclusion & Recommendations

Majority of the patients having children with congenital lower limb deformities were identified with mild to moderate anxiety. Proper counseling of the parents can prove beneficial in mitigating the frequency of anxiety and stress. Moreover, it was suggested to organized awareness campaigns and seminars for such parents that will not only encourage them to improve their quality of life but will also enable them to manage the stress associated with deformity of their children.

List of Abbreviations

CTEV: Congenital Talipes Equinovarus

DDH: Developmental Dysplasia of Hip

LLD: Leg length Discrepancy

HAM-A: Hamilton Anxiety

Declarations

Conflicts of Interest

The authors declared no conflict of interest.

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