

BRIEF REPORTS

Profile of Childhood Health Conditions referred to Physiotherapy and Attributing Factors to Disablement

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ABSTRACT

Purpose: *This study attempted to profile the prevalence of childhood health conditions and the factors that contribute to the disablement process leading to disability among children who visit a tertiary referral hospital in Mysore, India.*

Method: *A mixed methods approach was adopted. Phase 1 of the study delineated the profile of cases being referred for physiotherapy treatment. Cases of Cerebral Palsy were reported to be the highest (46%). Phase 2 of the study identified 4 major themes based on the mothers' experiences with their children.*

Result: *The findings revealed the need to create awareness among paediatricians about the importance of early intervention in childhood disorders and optimal referral to physiotherapy. The other themes which emerged included various attitudes of family and society, lack of cooperation from school as well as the presence physical barriers in school and community and frustration experienced by caregivers due to lack of help and facilities.*

Conclusion: *There is a need to educate parents and society at large that disability should not be associated with "abnormal". It is rather an interrelated phenomenon where the health issues of an individual and the outlook of society both play an important part.*

Keywords: *Disability among children, prevalence*

INTRODUCTION

Childhood disorders which lead to lifelong disability are a significant cause of disease burden, especially in resource-poor countries like India. Statistics on the

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prevalence and incidence of any health condition, including childhood disorders, help people who work in medical, research and government fields. Prevalence refers to the number of individuals in a specified population who have the condition being studied at a specified time, such as a particular day, regardless of when it began (My Child, 2013). Developed countries like the United States, Australia, Canada and UK, have a lower prevalence rate of childhood disorders compared to developing countries like China, Saudi Arabia, and India (Boyle et al, 2011).

The reason for developing countries showing a significant increase in disabilities compared to developed countries may be attributed to low economic income, low education background and poor nutrition of the mother and child (Gladstone, 2010). Impairment is a problem in body function or structure such as significant deviation or loss; activity limitations are difficulties encountered by an individual in executing a task or action; while participation restrictions are problems experienced by an individual in involvement in life situations (WHO, 2002). Therefore, *disability* is not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives.

The term *disablement*, according to Nagi, refers to the "various impact(s) of chronic and acute conditions on the functioning of specific body systems, on basic human performance, and on people's functioning in necessary, usual, expected, and personally desired roles in society" (Jette, 1994). Therefore, disablement is a process which results in disability. Halfon et al (2012) and Fougeyrollas et al (1999) offer a new and forward-looking definition of childhood disability that reflects emerging and developmentally responsive notions of childhood health and disability. They highlight the relationship between health, functioning, and the environment; the gap in function between a child's abilities and the norm; and how that gap limits the child's ability to engage successfully with his or her world. Their definition also recognises the dynamic nature of disability and how the experience of disability can be modified by the child's environment.

Disability workers and policy in India continue to focus on impairment as the chief cause for disability. However, there is adequate evidence that the health condition is only one factor in the disablement process (Danesco, 1997; Connors & Stalker, 2007; Seligman & Darling, 2007).

We tried to explore factors other than health conditions that contribute to a parent's experience of disablement. It is imperative to understand that in addition

to impairments in functioning; both environment and personal factors, such as attitudes of society, physical barriers, etc. play a key role in disablement and should be brought to the attention of human rights commission.

Objective

This study attempted to profile the prevalence of childhood health conditions and factors that contribute to the disablement process leading to disability among children who visit a tertiary referral hospital in Mysore city of Karnataka state, India.

METHOD

Study Design

A mixed methods approach was adopted.

Phase 1: Prevalence

Phase 2: Qualitative – phenomenological

Permission to conduct the study was taken from the Institutional Review Board.

Sampling and Strategy: Convenience

In Phase 1, all children with special needs who received physiotherapy between the years 2009 and 2013 were included from the intake register.

In Phase 2, children from 2 - 9 years of age who received physiotherapy regularly were included.

Sample Size

Phase 1: Complete enumeration

Phase 2: Five children

Inclusion criteria: Children between 2 and 9 years of age, of both genders, with any diagnosis pertaining to developmental anomalies and neuro-developmental disorders.

Exclusion criteria: Children presenting with traumatic disorders. In Phase 2, the primary care-giving parents of identified children were included till data saturation was reached.

Procedure

Phase 1: The in-patient register for the years 2009 - 2013 was scrutinised, and participants who fulfilled the inclusion and exclusion criteria were identified. The children were referred from JSS Hospital and/or various nearby hospitals to the JSS Physiotherapy Department (by Paediatricians, Neurologists and other departments like Occupational and Speech & Hearing). Information was taken from medical records under the following headings: (a) Diagnosis, (b) Pre-natal, Peri-natal and Post-natal history, (c) Milestones, (d) Primitive Reflexes and Deep Tendon Reflexes, (e) Sensory Evaluation-Visual, Auditory, Tactile, (f) Protective Reflexes and Reactions, (g) Range of motion and Muscle tone evaluation, (h) Balance and Gait evaluation, (i) Gross Motor Functions, (j) Cognitive and Social Functions. In cases where there was a mismatch between the clinical diagnosis and findings, the grouping was done on the basis of the physiotherapy assessment. Although diagnoses are different, the disability is comparable as these children were unable to play with their peers and participate in other life situations as efficiently as typical children of their age.

Phase 2: The purpose of this study was to identify causes of disability, not diagnosis. No attempt was made to recruit clients on the basis of diagnoses noted in Phase 1. After the initial profiling, those children were identified who attended physiotherapy sessions regularly, for more than 5 consecutive times, and who had a significant functional limitation or developmental delay. Primary care-giving parents of the children were approached for informed consent. Those who consented were recruited till data saturation was reached. To study the maternal causative factors that could lead to childhood disability, assessment was done of the mothers' health and emotional and social status before, during and after pregnancy. A questionnaire based on Pregnancy Risk Assessment Monitoring System (PRAMS) was administered, and open-ended in-depth personal interviews were conducted to explore the mother's experiences with their child (CDC, 2013). The items in the PRAMS questionnaire, which was originally designed to be administered in USA, were scored for relevancy in the Indian context by 10 Indian mothers with typically developing children. After the irrelevant items were excluded, the questionnaire was administered and followed by in-depth personal interviews. These interviews took place in a secluded room where the mothers were requested to describe their mothering experiences in the language of their choice. In case mothers were not able to elaborate or would go out of context, probing questions like, "How is your family's attitude towards the

child?" and "Are they sensitive or indifferent?" etc. were asked Data was tape-recorded by the interviewer to get accurate accounts. The average duration of each interview was 20-30 minutes. No incentives were offered to the participants.

Data Analysis

Phase 1: Descriptive analysis - frequency

Phase 2: Observational analysis

To maintain the data quality and credibility of the analysis, the questionnaires as well as the recordings were analysed manually by 2 of the authors. Emergent themes were identified. Descriptions provided by the preconceived themes and the emergent themes were noted down.

RESULTS

Phase1: The results showed that the children referred for physiotherapy treatment between the years 2009 and 2013 were largely children with a diagnosis of Cerebral Palsy (n-43), followed by those with Developmental delay (n-30), Erb's palsy (n-12), Mental retardation (n-11), Hydrocephalus (n-2) and Autism (n-2).

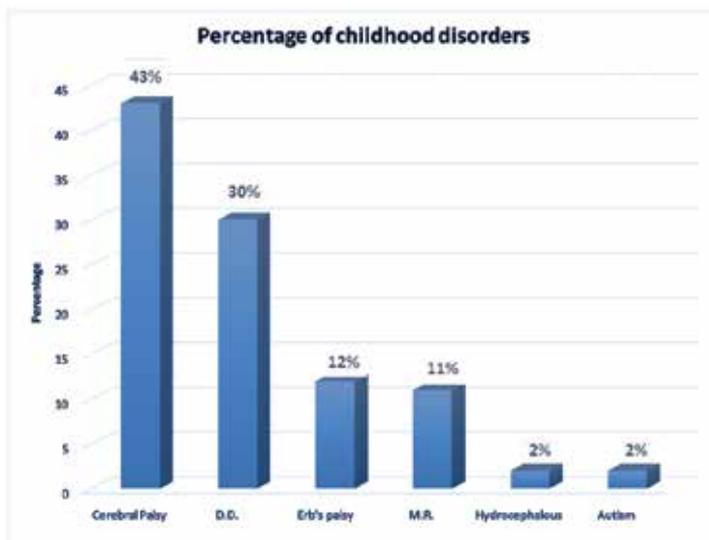


Figure 1: Graph depicting percentage of Childhood Disorders referred for Physiotherapy treatment between the years 2009 and 2013

Phase 2: The PRAMS questionnaire suggested that the social life of the mothers had changed immensely since the birth of their child. Four major themes that were identified while exploring the causative factors of disablement from mothers' experiences with their children.

THEME 1: Inadequate Information from Healthcare Providers

"We went to many doctors in hope of a cure and one doctor gave us false hopes and turned his back after seeing the scan reports which frustrated me a lot."

"My child's file was thrown in the dustbin by the doctor."

"Doctor wrongly diagnosed my child with polio without any investigation and asked us to accept it."

"They couldn't diagnose my child's condition and it took visits to four different doctors to get a correct diagnosis and by then, I think, the recovery period was already lost."

"I was told that my child will never walk by the doctor, but no information as to what should be done."

"We were not involved or told about my son's progress during therapy and were made to sit out."

THEME 2: Attitudes of Family and Society

"People in the locality make fun of my child and call her names because of her bowel incontinence."

"Neighbours pity him since he can't speak."

"Family members pity and pamper my son and I feel that has made him stubborn and lazy."

"My in-laws want her to become alright but do not help in care-giving."

"I was told that someone had done black magic on my son and to get him treated for it."

"My husband and family blame me for the child's deformities."

THEME 3: Lack of Cooperation from Schools

"My son, though having a normal IQ, was denied admission in three schools and we were told that his presence would be a disturbance to other children."

"First two schools did not take my son because they couldn't give extra care to a disabled child."

THEME 4: Physical Barriers in School and Community

“Class is on the third floor and there are no ramps.”

“Toilets are far from classroom.”

“The school is not disability friendly and I find it difficult to carry him around all the time.”

THEME 5: Caregiver’s Frustration due to Lack of Help and Facilities

“Being in a joint family, responsibilities are too much and I’m unable to give proper attention to my daughter and sometimes I tend to take out my frustration on her.”

“I’m unable to spend time with my other children.”

“No one to share the burden of household work and helping with the child.”

Table 1: The results of Phase 2 are represented below in the ICF Framework

PARTICIPANT	HEALTH CONDITION	BODY STRUCTURE AND FUNCTION (As assessed on the child)		ACTIVITY AND PARTICIPATION (As told by the mother)		CONTEXTUAL FACTORS (As told by the mother)		EMERGENT THEMES (As told by the mother)
		FACILITATORS	BARRIERS	FACILITATORS	BARRIERS	FACILITATORS	BARRIERS	
1.	Spina-Bifida with left foot CTEV (post-surgery)	<ul style="list-style-type: none"> • Good arm strength • Good IQ • Intact sensations 	<ul style="list-style-type: none"> • Poor bowel and bladder control. • Weak dorsiflexion and eversion of left foot • Weak abdominal and trunk muscles • Scoliosis 	<ul style="list-style-type: none"> • Communicates needs • Independent eating • Independent in finishing class notes 	<ul style="list-style-type: none"> • Incapable of boarding a bus • Unable to attend school • Unable to play • Dependent toilet activities • Dependent self-care activities • Unable to move independently in community 	<ul style="list-style-type: none"> • Younger sibling • Motivated to start going to school 	<ul style="list-style-type: none"> • Lazy • Stubborn • Less tolerant to pain 	<ul style="list-style-type: none"> • Frustration with the doctors • Karma or fate • Mother sole caregiver • Outbursts of frustration on child • Worries for the future of being a girl child
2.	Spastic C.P.	<ul style="list-style-type: none"> • Visual and auditory systems intact • Good IQ 	<ul style="list-style-type: none"> • Increased tone in all limbs • No balance • Speech affected • Drooling 	<ul style="list-style-type: none"> • Involves in play • Communicates through gestures • Creeps to reach objects 	<ul style="list-style-type: none"> • Dependent toilet activities • Dependent self care • No peers to play with • Mobility in community-by mother 	<ul style="list-style-type: none"> • Motivated • No tantrums 	<ul style="list-style-type: none"> • Over protective family • Mother unaware of health policies and C.P. support groups 	<ul style="list-style-type: none"> • Mother unable to attend to other children • Told by doctor that child will never walk
3.	G.B.S.	<ul style="list-style-type: none"> • Good upper limb strength • Intact sensory system 	<ul style="list-style-type: none"> • Weakness and increased tone in lower limbs 	<ul style="list-style-type: none"> • Involves in play • Eating independently • Goes to school 	<ul style="list-style-type: none"> • Dependent mobility • Dependent self care • Unable to participate in group play 	<ul style="list-style-type: none"> • Motivated to play like peers • Motivated mother • Supportive school 	<ul style="list-style-type: none"> • Extended family pity and pamper the child 	<ul style="list-style-type: none"> • Wrong diagnoses • Doctor’s insensitivity to parents’ feelings • Black magic • Denied admission in 2 regular schools
4.	Muscular Dystrophy	<ul style="list-style-type: none"> • Good upper limb strength • Sensory, visual and auditory systems intact • Good concentration 	<ul style="list-style-type: none"> • Weakness of pelvic girdle muscles • Delayed speech • Equilibrium reactions absent 	<ul style="list-style-type: none"> • Able to walk • Communicates through gestures • Follows prompts to act 	<ul style="list-style-type: none"> • Assisted self care • Inability to navigate in a crowded place • Speech- mono and bi-syllables • Unable to break the fall 	<ul style="list-style-type: none"> • Motivated to finish tasks by rewards 	<ul style="list-style-type: none"> • Fear • Tantrums or crutches • Dislikes exercises made to do by mother 	<ul style="list-style-type: none"> • Lack of communication between health professionals • Parents not included in therapy • Mother: child will become “normal”
5.	Multiple congenital contractures	<ul style="list-style-type: none"> • Fair upper limb strength • Good IQ • Sensation intact 	<ul style="list-style-type: none"> • Multiple contractures in lower limbs • Osteopenic 	<ul style="list-style-type: none"> • Involves in play to the best of his ability • Goes to school and a rank holder in class • Dressing independent 	<ul style="list-style-type: none"> • Dependent mobility • School architecture is not disability friendly • Toileting and bathing-dependent 	<ul style="list-style-type: none"> • All objects of daily use kept at a reachable level for the child • Highly motivated • Supportive school and peers 	<ul style="list-style-type: none"> • Denying the use of wheelchair or crutches • Difficult for mother to carry the child around 	<ul style="list-style-type: none"> • Negligence from the part of health professionals • Denied admission by 3 private schools • Father blames the mother

Although most clients with GBS recover, some of them have residual impairments. This Table depicts the case of a child with GBS who has not recovered. The denial of admission for this child in a regular school was reported by the mother and audio-recorded during the interview.

DISCUSSION

In India, it has been found that the prevalence rate of developmental delay is 19.8% (Ali et al, 2011) and Cerebral palsy is 2-2.8 per 1000 live births (Gladstone, 2010). Every 2-3% of children in India have Mental retardation (Kabra & Gulati, 2003), while Autism is found among 1 in 250 (Barua & Daley, 2008). The results proved that more children with Cerebral Palsy are referred (43%), followed by cases of Developmental delay(30%), Mental retardation (12%), Erb's palsy (11%), Autism (2%) and Hydrocephalus (2%). According to the National Census, more Developmental delay cases should have been referred to the physiotherapy department but referral seems to be delayed until gross signs appear. Referral to the paediatric physiotherapy department for other childhood health conditions such as Spina bifida, Osteogenesis imperfecta, multiple congenital contractures, etc., are also less frequent. This may be due to inadequate knowledge among paediatricians about the role of physiotherapy in treating all these conditions.

The participants in this study were chosen by convenience from the paediatric population that visits this hospital department. Five primary caregiving parents and their children with differing diagnoses, ranging in age from 2-9 years, were included. The primary caregivers in all these cases were the mothers. They came from different backgrounds in terms of religion, family structure, socio-economic status, geographical region, mother tongue and educational levels.

THEME 1: Inadequate Information from Healthcare Providers

The emergent theme that came to light here was that the parents were not given proper counselling by healthcare professionals. Four out of 5 mothers gave an account of the number of doctors and healthcare providers from various fields that they had visited. Their expectations of receiving counselling on how to handle a child with disability, what to do and what not to do, what to expect, etc., were not met. This resulted in visits to various healthcare providers in search of answers, and consequently delayed rehabilitation. In most cases, it was the parents' failure to accept their child's impairment which resulted in disablement. Thus, the focus shifts from what the child "can do" to everything the child "cannot do".

THEME 2: Attitudes of Family and Society

Mysore has a diverse population with varied cultures, languages and beliefs; the authors attempted to explore whether these differences could influence beliefs about causes of disability. A Hindu mother blamed “karma” and “fate” for her child’s state. A Muslim mother had been told that her child was a victim of black magic and the child was given treatment for it. A Christian mother showed more acceptance of her child’s impairments. These varying responses signify that personal beliefs and mind-sets caused by diverse cultural and social backgrounds can hinder parents’ acceptance of the child’s impairments and thus, cloud the abilities that are present and cause disability (Barnes et al, 2000).

THEME 3 & 4: Lack of Cooperation and Physical Barriers in School and Community

Three of the 5 participants who were of school-going age did not attend school due to lack of facilities and because the authorities were not sensitive to their needs. Two of the participants, despite having normal IQs, were denied admission in regular schools due to their inability to walk independently. This throws light on the ignorance of the school authorities whose prejudices are barriers to the social integration of these children.

THEME 5: Caregiver’s Frustration due to Lack of Help and Facilities

Analysis of the questionnaires and personal interviews with the mothers revealed that each one’s social life had changed drastically after her child was born. There were increased levels of stress in providing care and fulfilling the child’s needs, apart from responsibility towards the other children and the family.

Implications

Lack of information from healthcare providers proved to be the major cause of disability as it interfered with parents’ quality of life and the child’s integration into society.

The attitudes of family, society and school authorities was also responsible for jeopardising the opportunities for integration of children with disability into society.

This study reveals the need to create awareness among paediatricians about the importance of early intervention in childhood disorders and optimal reference to

PT for the same. The parents and society at large need to be educated that disability should not be associated with “abnormal” as it is an interrelated phenomenon where the health issues of an individual and the outlook of society both play an important part. Healthcare practitioners may show callous indifference in dealing with a child with disability. Statements such as “Your child will never walk”, can be catastrophic to the parents, and such situations are to be handled with utmost care. The need for a team-based approach in dealing with children with special needs and their families is evident.

Limitations

The PRAMS questionnaire may not be sensitive to measure the maternal causative factors. Further research in this field is needed.

The results of this study have to be interpreted with caution as it is a hospital-based study and is in no way expected to be indicative of the profile of society in general.

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