

Research Paper: Expectations of Mothers of Children With Cerebral Palsy Regarding Physical Therapy



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ABSTRACT

Introduction: This study aimed to find out the expectations of mothers of children with cerebral palsy (CP), who are engaged in rehabilitation programs, especially in physical therapy treatment.

Materials and Methods: Clinical types and gross motor function levels of the children were documented. A questionnaire consisting of 6 open-ended questions was used to define the expectations and views of the mothers of CP children about the physiotherapy and rehabilitation programs for the children. A total of 100 mothers were interviewed through an observational study with six open-ended questions along with demographic data.

Results: There was no significant agreement regarding the applied treatment methods and the appropriateness of the rehabilitation programs.

Conclusion: The expectations of mothers of CP children are not as high as they wanted from rehabilitation according to their children's needs.

1. Introduction

Cerebral Palsy (CP) is a broad term covering a group of non-progressive, but frequently changing, motor impairment syndrome secondary to lesions or anomalies of the brain appearing in the early phase of development [1]. It is defined as a group of developmental disorders of movement and posture, causing limited movement [2]. The brain damage cannot be re-

versed; however, maturational and adaptive procedures may change the clinical profile of the child over time [3]. Globally, it is estimated that 2 to 2.5 out of 1000 birth are affected by this condition every year [4].

The motor disorders of CP are often accompanied by disturbances of sensation, cognition, communication, perception, behavior, and seizure. Insufficient physical fitness is a major problem which distresses the function and health of CP patient [5]. Lack of physical activity

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gives rise to secondary conditions which include chronic pain, fatigue, and osteoporosis [6].

Children with CP do not usually receive physical therapy intervention that can facilitate their motor development and enhance their motor skills independence such as self-care, play, and leisure activities [7].

In the case of CP, there is a paradigm for childhood disabilities and a health-related condition which is also a sociological subject. Thus, multidisciplinary management should be implemented for this condition to prevent it from further complications [8]. Families in which a child with a disability is born will face challenges to make adjustments in their caregiving and their expectations [9]. To begin any rehabilitation program, health suppliers, particularly Physiotherapists (PTs), should talk with the parents of a disabled child before the implementation of any treatment or intervention [7]. The key to a successful treatment is to keep the parents in the center and consider their opinions [10]. This idea not only promotes parent's views about rehabilitation treatment for their children but also encourages them to get more involved and helps PT to implement physical therapy treatment at home [11]. Moreover, this practice helps parents of a disabled child to seek and absorb all information, both positive and negative features, about a physiotherapy and rehabilitation program which are useful for their children [7].

The mothers of CP children are usually neglected by therapists regarding their expectations. Therapists usually guide mothers for exercise and teach them techniques but not listen to their views. Therefore, the objectives of this research were to recognize the views of mothers of CP children concerning the rehabilitation programs and

to report the current knowledge regarding the treatment, highlighting consensus, and the level of expectation.

2. Materials and Methods

This study has a cross-sectional design. The samples were recruited by a non-probability sampling technique. A sample of 100 participants was calculated by an online WHO calculator. The participants included only the mothers of CP children who were actively engaged in physical therapy treatment of their kids for more than a year. All the children were treated at the same center, with the same timeframe of their scheduled appointment, and the plan of treatment was according to the child's needs. All the children had CP of different types with their special individual problems, so they were treated accordingly.

Ethical approval was taken from the Institutional Review Board of Jinnah Postgraduate Medical Center. Before the study, informed consent was taken from mothers of CP children after explaining the purpose of the study, and a then researcher-designed questionnaire was distributed among participants. The confidentiality of their information was assured. The study questionnaire was composed of questions, including demographics, level of education of mother, type of cerebral palsy of their children, level on a Gross Motor Functional Scale (GM-FCS), description of child's health status. Also, there were questions regarding the treatment that the child was receiving, which exercises and therapies were performed by the therapist, what were their views regarding treatment. To assess the level of expectations different questions were asked, including expectations from the treatment and effectiveness of the rehab program (Figure 1).

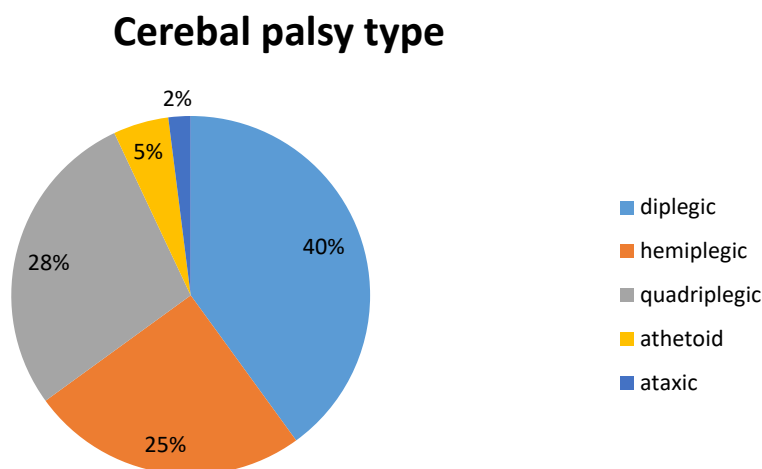


Figure 1. Types of cerebral palsy in studied children

The studied variables were presented in number, percentage, mean and standard deviation. The obtained data were analyzed by using a parametric test (kappa test) in SPSS version 23.

3. Results

The demographic data includes age, education level of a caregiver, and female gender only.

The age category was divided into three major divisions. Group 1 includes participants aged between 21

and 30, group 2 includes 31 to 40 years old mothers, and group 3 includes 41 to 50 years old participants. Also, 38% of subjects were in group 1, 47% of subjects in group 2, and 15% of subjects in group 3.

Level of mothers' education shows that 25% of mothers are matric, 18% are inter, 4% graduates, 13% are middle, 38% of mothers are illiterate and only 2% have masters. The education level in Table 1 shows that the ratio of the subjects at the rate with almost 7 standard deviations was equal in matric and illiterate participants, although almost 6 standard deviations were inter and

Table 1. Levels of Gross Motor Function Classification System (GMFCS)

GMFCS level	No. (%)	Min	Max	Mean±SD	Cumulative Percentage Frequency
Level 2	5 (5)	2.00	2.00	2.0000±0.00000	5.0
Level 3	19 (19)	3.00	3.00	3.0000±0.00000	24.0
Level 4	45 (45)	4.00	4.00	4.0000±0.00000	69.0
Level 5	31 (31)	5.00	5.00	5.0000±0.00000	100.0

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According to the GMFCS scores in Table 2, none of the CP children is at level 1, 5 CP children at level 2, 19 CP children at level 3, 45 CP children at level 4, and 31 CP children at level 5.

Table 2. Description of the health status of CP children

Typs		Description					Total
		Perfect	Very good	Good	Moderate	Bad	
Diplegic (%)	Number	5	7	14	13	1	40
	Within type	12.5	17.5	35.0	32.5	2.5	0.100
	Within description	50.0	41.2	37.8	43.3	16.7	0.40
Hemiplegic (%)	Number	4	6	11	3	1	25
	Within type	16.0	24.0	44.0	12.0	4.0	0.100
	Within description	40.0	35.3	29.7	10.0	16.7	0.25
Quadriplegic (%)	Number	1	3	8	12	4	28
	Within type	3.6	10.7	28.6	42.9	14.3	0.100
	Within description	10.0	17.6	21.6	40.0	66.7	0.28
Athetoid (%)	Number	0	0	3	2	0	5
	Within type	0.0	0.0	60.0	40.0	0.0	0.100
	Within description	0.0	0.0	8.1	6.7	0.0	0.5
Ataxic (%)	Number	0	1	1	0	0	2
	Within type	0.0	50.0	50.0	0.0	0.0	0.100
	Within description	0.0	5.9	2.7	0.0	0.0	0.2
Total (%)	Number	10	17	37	30	6	100
	Within type	10.0	17.0	37.0	30.0	6.0	0.100
	Within description	0.100	0.100	0.100	0.100	0.100	0.100

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Table 3. Level of expectation of mothers of children with cerebral palsy

Variabels	Expectations					Total	
	Walking With/Without Support	Standing With/ Without Support	Sitting With/With-out Support	Indepen-dence in Activities of Daily Living	Increased Bal-ance and Postural Control		
Diplegic	Number	12	10	8	10	0	40
	within type (%)	30.0	25.0	20.0	25.0	0.0	100.0
	within expecta-tion (%)	50.0	45.5	42.1	33.3	0.0	40.0
Hemiplegic	Number	4	7	3	8	3	25
	within type (%)	16.0	28.0	12.0	32.0	12.0	100.0
	within expecta-tion(%)	16.7	31.8	15.8	26.7	60.0	25.0
Quadriplegic	Number	6	3	8	10	1	28
	within type (%)	21.4	10.7	28.6	35.7	3.6	100.0
	within expecta-tion (%)	25.0	13.6	42.1	33.3	20.0	28.0
Athetoid	Number	2	1	0	2	0	5
	within type (%)	40.0	20.0	0.0	40.0	0.0	100.0
	within expecta-tion (%)	8.3	4.5	0.0	6.7	0.0	5.0
Ataxic	Number	0	1	0	0	1	2
	within type (%)	.0	50.0	0.0	0.0	50.0	100.0
	within expecta-tion(%)	.0	4.5	0.0	0.0	20.0	2.0
Total	Number	24	22	19	30	5	100
	within type (%)	24.0	22.0	19.0	30.0	5.0	100.0
	within expecta-tion (%)	100.0	100.0	100.0	100.0	100.0	100.0

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middle participants, then only 2 standard deviations of the graduated participants and only 3 standard deviations were masters participants.

The description of the health status of children of cerebral palsy is shown in Table 2. Among the 40 diplegic type of CP children, only 5 has perfect health, 7 very good health, 14 good health, 13 moderate health status, and only 1 bad health status. Whereas 25 CP children were hemiplegic in which 4 have perfect health, 6 very good health, 11 good health, 3 moderate health, and 1 bad health status. On the other hand, 28 CP children were quadriplegic in which only 1 had perfect health, 3 very good health, 8 good health and 12 moderate health, and 4 bad health status.

Athetoid was found in 5 participants in which 3 had good health status and 2 had moderate health status. Only 2 CP children had ataxic type in which one had very good health status and the other one had good health status.

The kappa test evaluates the result and shows the asymptotic standard error 0.047 which is less than 0.20 (poor agreement); approx. Tb is about 0.211 (fair agreement), and approx. Sig. value is about 0.833 (very good agreement). The results of the children’s health description show their good status.

Table 3 presents the proportions of the expectations among the mothers of CP children. Most mothers expect to improve their child at sitting and standing indepen-

dently levels. Among 40 diplegic patients 50% MS expectations for walking with/without support. Among 25 hemiplegic patients, the mothers' expectations were 60% for postural correction and balance. Within the quadriplegic patients, mothers' level of expectation was found to be 42% for kids sitting without/with support, whereas the level of mothers' expectation of athetoid and ataxic patients was very low.

The kappa test evaluated the results and yielded the asymptotic standard error of 0.055 which is less than 0.20 (poor agreement); approx. Tb was about 0.2053 (very good agreement), and approx. Sig. value of about 0.040 (less than poor agreement). The results are about MS expectations of mothers of CP children regarding their children's needs, which is different from their children's needs.

4. Discussion

CP is the commonest heterogeneous neurological disorder presented in clinics of pediatric neurology. The mother is the primary caregiver and she is the closest person to their children [11]. This study was conducted to identify the expectations of mothers from the physical therapy treatment of their CP children.

There are many studies conducted on mothers of CP children but they mostly focused on barriers that mothers suffer regarding their children's rehabilitation. Some studies are on mothers' perspectives regarding CP and very little studies are done to assess the level of expectations regarding their children's recovery.

All the studies mainly focus and promote the healthy activities and participation of CP children in different Activities of Daily Living (ADL) but not any study specifically points to the importance of expectations regarding rehabilitation. The results of this research would serve as a foundation to establish the relevant information on the respective discipline.

A study conducted by Erdoğan Kavlak et al. on the level of expectations of mothers of CP children found the definition of the health status of the children to be statistically insignificant ($k=0.0-0.20$). Whereas our study results are found to be fairly significant and all participants presented a good health status.

Moreover, Erdoğan Kavlak et al. concluded that additional therapies and appropriateness of the rehabilitation programs are required for the better outcome and they found a moderate concordance regarding the ap-

propriateness of the therapies ($k=0.21-0.40$). The main idea about different treatments is unknown to mothers which shows they do not have any idea about the benefits of rehabilitation and how much it is important for children. Their expectations are not as high as they really want their children's initial needs. Their expectation was close to their children's condition [10]. Results of another study which was conducted on US and Canadian caregivers of CP children revealed that parents have a high level of expectations from the children with level II GMFCS, whereas the parents of children with GMFCS level v have the least expectations from their child [11].

On the other hand, our research level of expectations of mothers was found to be pretty different from their children's needs. Most of them know which treatment and exercise were applied to their children but they were unaware of the purpose and mechanics of the particular intervention.

Therefore, it is necessary to know parents' perceptions and expectations regarding their children's progress and treatment. Caregivers should be taken into account by the physical therapists when setting goals and preparing a treatment plan for a CP child [12, 13]. This measure helps PT in achieving the desired goal and establishing a trusting relationship with families so that family goals, values, individual circumstances, and their desired level of participation in goal setting can be openly discussed [14, 15].

CP a challenging disorder and for a caregiver, it is burdensome. Day by day, the level of disability of the child increases if he or she does not receive treatment timely or properly [16]. Most of the time, families of disabled children are unable to accept reality and they remain distressed. Mothers who are the main caregiver are affected the most [17]. A study was conducted in Pakistan on mothers of CP children to assess the importance of disability severity and child functional status as predictors of maternal depressive symptoms. The researchers found that 30% of mothers had depressive symptoms according to depression screening instruments and the reasons were either they were a solo or a primary caregiver, marginalized by others, encountering limitations, had no professional support or education [18]. Hence, the high education of a mother for appropriate care and adequate treatment is incumbent [19]. Literature reveals that mothers do not understand the treatment and disease of the children because of their illiteracy and that 83.1% of mothers have an education of 12 years or less. In our research, the illiteracy rate is found to be 38% and 18% of participants have only 12 years of education.

Consequently, the education of mothers is very important to make a treatment effective and condition of a CP child manageable [20]. It is the responsibility of health staff to involve the parents in a health care program and consider their opinions regarding treatment and educate them at every step about their children's health condition and the applied therapeutic intervention. In response, it is the duty of a mother to grasp all the information and follow home exercise plans appropriately to make the treatment effective and to get better outcomes of the therapeutic interventions and rehab sessions [21, 22].

5. Conclusion

This study has some limitations. Because of limited related articles, very few studies are found on the expectations of mothers of CP children from physical therapy. Many research studies are present regarding CP children's treatment and behavior but the studies regarding expectations of mothers are very few. Maybe this point of view is neglected and maybe after my research, more people put their interest in this topic. This study concludes that the expectations of mothers of CP children are not as high as they wanted from rehabilitation according to their children's needs. Therefore, emphasis should be made on educating the mothers and involving them in rehab programs because educating mothers is critical and is beneficial to CP children. This research was conducted as per the degree requirement of the physiotherapy deficiency course.

Ethical Considerations

Compliance with ethical guidelines

The respondents gave their consent and appropriate permission was taken for the use of their information. The confidentiality of the responses will be maintained strictly. The disclosure of respondent identity will be based on their permission.

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Authors contributions

Conceptualization, methodology: Sajida Dilawar; Investigation: Reeta Mahesh; Writing original draft: Amna Yaseen; Writing-review: Amna Yaseen; Supervision: Muhammed Saad Khan.

Conflict of interest

The authors declared no conflict of interest.

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Appendix-I

Informed Consent Form

I Have Been Fully Informed As To The Procedure To Be Followed. In Signing This Consent Form I Agree To Participate In The Study. I Understand That I Am Free To Refuse To Participate Or Withdraw My Consent And Discontinue My Participation In This Study. I Also Understand That If I Have Any Queries, The Researcher Will Answer Them. I Also Understand That Any Information I Provide Will Be Kept Confidential, Used Only For The Purpose To Complete This Assignment.

Participant Name: _____

—

Participant Signature: _____

Date: _____

Contact No.: _____

Name Of Researcher: Sajida Dilawar

Subject's Signature: _____

Appendix-2

Demographic Data

Name: _____

Age: _____

Gender: _____

Education Level: _____

Clinical Type Of Cp: _____

Gmfcs:

Level 1

Level 2

Level 3

Level 4

Level 5

Appendix-3

Questionnaire:

1. Description Of The Health Of The Children With Cp:

- a. Perfect
- b. Very Good
- c. Good
- d. Moderate
- e. Bad

2. Awareness About Received Therapies:

- a. Bobath
- b. Special Education
- c. Reflexology
- d. Botox
- e. I Have No Idea

3. Views About The Appropriateness Of Treatment:

- a. Yes
- b. No
- c. I Have No Idea

4. Expectations From The Treatment:

- a. Walking With/Without Support
- b. Standing With/Without Support
- c. Sitting With/Without Support
- d. Independency In Daily Life Activities
- e. Increased Balanced & Postural Control

5. Additional Therapies:

- a. Not Necessary
- b. Speech Therapy
- c. Water Exercise
- d. Special Education
- e. Psychosocial Support
- f. Reflexology
- g. Surgical
- h. Sensory Perception Motor Education

6. Effectiveness Of Physiotherapy And Rehabilitation Program:

- a. Perfect
- b. Very Good
- c. Good
- d. Moderate
- e. Bad