

Impact of Mothers focus group discussions on the Rehabilitation of children with Cerebral Palsy.

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Abstract:

Objective: To determine the effects of generation of mothers focus group discussions in reducing stress on families of children with cerebral palsy (CP).

Study design: Cross sectional focus group survey

Place and duration: Focus group discussions were conducted at the Primary health care center (PHC) situated in a squatter settlement of Clifton Karachi.

The duration of study was six months.

Subjects and Methods: The researchers selected ten mothers of children with CP between ages of one to ten years who sought health services at the PHC for focus group discussions. The total of twenty meetings were arranged during the period of six months. Moderator observed for any change in the group participants regarding their depression.

Children with CP were identified through history and physical examination. Those suffering from any other form of disability or chronic disease were excluded from the study.

Data was entered in SPSS version 11. Chi square test of significance was employed.

Results: In the selected group of mothers the strongest predictor of stress was child behavior problem especially related to the burden of caring. Lack of adequate family support (80%), and poor socioeconomic status (90%) along with lack of both maternal (60%) and paternal education (40%) were the various factors affecting the stress. Delay in the development of mile stones (100%) was the primary concern of mothers to seek health services at PHC. Constant worry of child care with anxiety and tension (100%) regarding future of the child was the primary stress factor.

Conclusion: The researchers feel that if an opportunity is given to parents of children with CP to discuss their problems and share their experiences, this can reduce the impact of stress to a great extent.

The main outcome following the series of focus group discussions generated by the mothers was that "My child need empathy, affection, love and care rather than cure".

Key words: Focus group, cerebral palsy, stress.

Introduction:

Cerebral palsy (CP) is the most common cause of physical disability in children; it is defined as a non progressive neurodevelopmental state affecting child's growth and development. Cerebral palsy develops in early stages of child's development secondary to lesion or anomaly in the brain, but in majority of cases no cause can be identified.¹ It may be associated with other co morbidities like epilepsy, sensory impairment, learning and behavioral problems.^{1,2} Approximately 2-2.5 / 1000 new born children in developed countries are affected by cerebral palsy of varying severity¹. In United States, the rate is varying from 1.5 to 4 per 1000 live births.^{1,3} Cerebral palsy is more common in boys (for every 100 girls there are 135 boys) and its incidence among twins is 12%. About half of the chil-

dren with cerebral palsy are born prematurely, one out of 5-10 children have functional abnormalities in the form of autism, seizures, tremors, ataxia, and three out of ten children have normal/superior intelligence whereas mental retardation is seen in 60% of cases.³ In Saudi Arabia the prevalence of mental retardation is 8.9/1000 children⁴. In Pakistan prevalence was found to be 84.3/1000 by a survey was conducted in 1998 in 6365 children.⁵

Cerebral palsy is usually identified by parents in the first 12-18 months of child's age but milder forms may be detected in later life. Diagnosis depends upon failure to achieve or delayed mile stones, stiffness or floppiness of muscles and delayed motor development.^{6,7} Motor and functional impairment adversely affects child's daily activities, limiting his learning experience, interactive capabilities and independence. Parents falsely perceive the child as more disabled with impaired cognitive and intellectual skills.^{7,8}

Cerebral palsy cannot be cured but symptomatic management involving team work of effected family, health professionals, rehabilitative measures like physiotherapy, speech therapy, and access to special learning schools can play a vital role in maintaining the quality

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of life, improving intellectual and cognitive abilities and motivating their moral and social participation.^{1,9,10}

Team management reduces stress, feeling of isolation and helplessness, increases motivation and empowerment by reducing barriers of communication. Decrease in stress level ultimately benefits the overall management of the child.^{10, 11, 12}

One of the preferable methods of communication, building relationship and developing rapport with health care providers and effected families is focus group discussions. Focus group provide in depth information regarding concepts, perceptions and ideas of a group and the interaction of group members help find out the solution jointly.¹³

In this the moderator plays a very vital role. The main goal behind this study is to use focus group discussion as a cost effective tool in minimizing the effect of stress on families of affected children.

Material and Method:

It was a cross sectional survey based on structured focus group discussion.

Principal investigator and trainee researcher of public health program developed the objectives and protocol of study under the supervision of course director of public health program of College of Physicians & Surgeons Pakistan. Principal investigator also organized focus group discussions with themes recognition. Co-investigators organized focus group discussion and collected data. Faculty of statistics and research survey of CPSP has arranged statistical evaluation included in the manuscript by employing statistical software.

The study was conducted at primary health care centre (PHC) located in Sikandarabad a slum area just adjacent to Ziauddin hospital, from December 2007 to May 2008. The PHC covers catchment population of 6,500 with 40% of children less than five years. Children between 1-10 years of age effected with cerebral palsy were identified by thorough history and physical examination. Children with physical disability and chronic illness other than associated with cerebral palsy were excluded from the study.

Mothers of ten affected children were selected and registered for focus group discussion. Selection was based on willingness of mothers regarding rehabilitation of children with cerebral palsy. Care was taken in uniformity of composition of group with regard to ethnicity and socio economic status.

A comprehensive questionnaire was designed with closed ended questions regarding socio-demographic details, obstetric and birth history. Open ended questions were used to trigger discussion, provide equal opportunity to all participants and deal cautiously with sensitive issues. The mothers were able to share their experiences. This also provided an opportunity for them to help and discuss with each other the problems faced by them on daily basis. Assistance of tape recorder was used for documentation of discussion.

One hour session of focal group discussions were

conducted at PHC on weekly basis by trained facilitators. After these sessions speech and physiotherapy services were provided for supportive care of the children.

Data was entered in SPSS version 11. Chi square test of significance was employed.

Results:

Demographic analysis of the ten selected families showed that eight were Pushtoo speaking and two belong to Punjabi community. Out of them nine were Muslims.

Regarding education status of mothers more than half were illiterate, and only one was matriculate, whereas 40% fathers were illiterate and 30 % had acquired secondary education or above. Assessment of the average monthly income showed that 60% families had an income of less than Rs 3000, 30% families earned between Rs 3000-5000/ monthly. Only one family earned more than Rs. 5000.

In this study 20% fathers were unemployed, 40% were on daily wages, 30% received monthly salary, and one ran his own business. Addiction status was also studied which revealed that 60% fathers were addicted while no addiction was found in mothers.

Data analysis regarding birth history and family history showed that only

40% went for antenatal checkups, 30% had registered for delivery. Diabetes mellitus and infections were the major complications seen in 30% of mothers during pregnancy. Half of the deliveries were conducted at home. Among them 80% were born full term where as 20% were preterm. Normal birth weight was seen in 60% and 40% were underweight. Post natal complications were seen in 60 % with delayed cry in 50% of cases. Other important postnatal complications were respiratory distress, cyanosis, and aspiration.

A positive family history regarding cerebral palsy was found in 50% and consengious marriages of parents were seen in 60%

The themes identified determining stress in mothers of children in cerebral palsy were lack of family support, large family size, low socioeconomic status and lack of education. In all cases delay in the development of milestones was the primary concern of mother to seek health services at PHC. Lack of awareness of preventive and promotive health services contributed to stress, as mothers were burdened from both ends - caring for the mentally handicapped child and looking after a large family in a socioeconomic deprived circumstances.

Cross tabulation of Chi square test showed positive correlation between father education and socio economic stability along with support of father in the care and rehabilitation of the child.

The results of focus group discussions show that from session one to session 20 various changes took place.

BEHAVIOR MODIFICATION OF MOTHERS OF CEREBRAL PALSY CHILDREN THROUGH FOCUS GROUP DISCUSSION TOOL (N= 10 MOTHERS)

Mothers discussion points	Session 1	Middle session	Last session
Why is my child different from other children	Delayed mile stones	Will physiotherapy help?	Physiotherapy can help to achieve milestones to some extent. Acceptance to delayed milestones
Lack of family support	In most cases the family members were not supportive	Mothers opened in their discussions that they were blamed for their child's condition	Mothers gained confidence by repeated interactions that they are not to be blamed and nature has chosen them for this special task
Life style changes	Burden of looking after the child and extended families makes mothers socially deprived	Special needs schools and support from families and health care providers can help	Cooperation from husband and family can reduce social deprivation and stress of mothers
Expectation from our center	Is there a cure?	Discussion on role of physiotherapy and rehabilitation services	Understand importance of teamwork of health services and parents
Knowledge about schools for children with special needs	How can they go to school when they can hardly take care of themselves?	Special needs school cater for such children and help in obtaining a certain degree of independence	Will send if they know of such special needs school
Future of such children	Who will later look after them	Discussion on benefits of rehabilitation and special schools	Reduced the level of isolation, special arrangements are available for their care

Discussion:

According to WHO definition of health, disease and disability cerebral palsy is a chronic condition which cannot be cured.¹ The strength of current treatment is based on team management of daily issues and long term morbidities. Rehabilitation should be broadly focused to improve quality of life and develop intellectual and cognitive abilities.^{1,9,10}

One of the cost effective quality tool, used to develop interaction and bring out in depth information from participants is focus group discussion.¹³ The key behind

success of focus group discussion is to reduce the structure of the content so that the information is gained from the participant rather than being determined by the questions asked.

CP is identified by parents in the early years due to delayed motor development^{6,7}; the basic concern in majority of mothers who approached PHC for care of their child was developmental delay of gross, fine and social milestones. Primary concern of mothers was "He cannot sit, walk, talk or eat on his own. He attempts to eat but fails and gets frustrated. He has a very stiff body"

"Our concern is delayed milestones, he did not respond even when we shouted, he can't sit or crawl while other cousins of his age can"

Premature births account for half of the children with cerebral palsy.³ In our focus group sample only 20 % were premature births. The reason may be a small sample size or unskilled delivery (50 % home deliveries and 70 % unregistered cases) leading to poor survival in terms of outcome. This is a major concern in especially low socioeconomic community and can be avoided by proper antenatal care. Whereas in developed countries despite improved antenatal and natal services the prevalence of cerebral palsy has not declined in last forty years due to increase survival of pre-term and low birth weight babies¹⁴

As cerebral palsy impairs motor functions to a variable extent, it leads to adverse effects on child's daily activities, development, learning experiences, interactive capabilities and also affects his/ her independence.^{7, 8}

These limitations along with lack of family support, limited accessibility to health care services and economic burden developed a continuum of stress in affected families. Under such circumstances child is falsely perceived by his parents as more disabled and handicapped with impaired cognitive and intellectual skills. According to a Canadian study the strongest predictor of stress is managing the child's health problem with requirements of everyday living.¹⁵ Discussions signified presence of family support in only 30 % while in the majority there was a lack of family support mainly due to large family size, illiteracy and low socioeconomic status. The mothers expressed their worry, frustration, blaming behavior and physical abuse from spouse.

"Father does not look after him, beats him. Only my mother helps and she looks after him more than we do. I worry because of my husband's attitude"

"My husband is not well himself and is not able to work or look after us. I have some support from my family and sister in law who brought me to this center"

Studies show that apart from brain damage mental retardation can occur if the child is not given opportunities to learn as with blindness, deafness, speech difficulties and learning disabilities.³ This can be overcome by educating mothers about the importance of special needs schools. Only two mothers had knowledge about it and they too were reluctant to send because of economic and security reasons. Apposite schooling can

reduce the level and incidence of mental retardation by providing opportunities to overcome learning difficulties. Special education programs are needed to improve the quality of life of mentally handicapped children:

"I know about such schools but do not send him for the fear that he will fall or get lost"

"I don't know about such schools, he can't listen or speak so how can he go to school"

One theme identified through discussions was that majority of the mothers were uncertain about the future of their children. They expressed their helpless feelings, stress and frustrations about the prognosis, complications and future development of their child. The stress was further accentuated by social, economic and cultural issues." I wonder who will look after her when we (parents) are gone."

Reassurance and repeated interactive counseling of families especially the parents can develop empowerment, reduce feeling of isolation and create awareness regarding the care and future challenges of the child.¹⁶

Consensuous marriages and existing strong family history increase the risk of cerebral palsy.¹⁷ In the focus group sample a strong family history and consensuous marriages were also seen in more than half of affected children. The mothers were not ready to accept the importance of birth controlling in reducing the future risk of giving birth to a CP child. Less than half of the mothers were convinced for contraception.

It is vital to educate parents that cerebral palsy cannot be cured. Its prognosis, associated features and rehabilitation vary from child to child. Proper care in the form of team work of health professionals, community and parents can improve the quality of life of children and can significantly reduce the effect of stress on the families.¹⁸

Majority of the families have an expectation that the doctor is primarily responsible to provide cure for their child but with repeated counseling and interactive session's majority developed the concept that "My child need empathy, affection, love and care rather than cure".

Conclusion:

Focus group discussions were found to be primitive cost effective research tool towards the reduction of stress in families of children with cerebral palsy.

The main concern was found that these families need an outlet to share their sorrows and experiences.

Formation and arrangement of focus group will certainly help in reducing the stress of such families Furthermore this could be a guiding place for getting awareness of availability of health facilities of such children.

The main strength behind this study was the sensitive issue of cerebral palsy which was addressed for the first time to mothers of community through cost effective tool of focus group discussion.

Mothers felt empowered and motivated in solving their

own problems through interaction with each other

Through this program physiotherapy and speech therapy services for rehabilitation of children was also started.

The main constraint were the cultural and social norm due to which focus group discussions could not be held at the houses of different volunteer mothers.

The program can made sustainable and generalized in other blocks of the community by active community participation, involvement of some volunteer groups to provide rehabilitation services to the children to improve the quality of life and ultimately reduce the stress of the affected families.

It is important to remember that child's rehabilitation and mothers stress are interlinked with each other. One has to work in team to improve the life of a child as well as of the family

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