ORIGINAL ARTICLE

EXPLORING THE HOME AND SCHOOL BASED STRATEGIES FOR CHILDREN WITH CEREBRAL PALSY: A PHENOMENOLOGICAL STUDY

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ABSTRACT

OBJECTIVE

To explore the strategies which can be used by parents and teachers to facilitate a Cerebral Palsy (CP) child at home and school.

STUDY DESIGN

Phenomenology research design was conducted.

PLACE AND DURATION OF THE STUDY

Participants were recruited from special education schools of Lahore over a period of 6 months, from August 2018 to February 2019.

SUBJECTS AND METHODS

The sample comprised six child psychologists working with CP children. For this study, six separate in-depth interviews were conducted with six different psychologists. Saturation was achieved after six interviews. After the in-depth interviews were conducted they were transcribed in Urdu. Interpretive Phenomenological analysis was used to analyse the data.

RESULTS

Two sets of themes emerged from the analysis which included the strategies that can be used by parents and teachers to facilitate their CP child at home and school.

CONCLUSION

The findings of the study highlighted the strategies that can be used by teachers and parents to provide a better environment to the children with Cerebral Palsy. Separate strategies for parents and teachers were suggested. The parental strategies theme further have five sub-ordinate themes namely; attitude of parents, attitude of siblings, attitude of extended family, home environment and home based interventions. The teacher level strategies further has nine sub-ordinate themes namely; attitude of teachers, attitude of class fellows, teaching techniques, curriculum modifications, classroom modifications, use of assistive technology, vocational training, collaborative team work and counseling.

Keywords:

Cerebral Palsy, Parental strategies, Qualitative research, Phenomenology, In-depth interviews

INTRODUCTION

The Global prevalence of developmental disabilities is 16-20 per 1000 people. Developmental disabilities include Cerebral Palsy, Spina Bifida, Mental Retardation, Epilepsy and Autism.[1] Developmental disabilities have become a public health issue in developing countries like Pakistan.[2] Pakistan being a low-resourced country and having an under-developed health care system has a high prevalence of CP.[3] Numerous factors are contributing to the increase in developmental disabilities such as poor maternal nutrition, substance abuse by expecting mother, better perinatal care of premature newborns and lack of healthcare facilities.[4]

Cerebral Palsy is defined as a set of conditions characterized by physical, psychological and sensory impairments that occur due to brain damage in the initial phases of development. Children with CP can have seizures, hearing and vision problems, cognitive impairment, language and speech difficulties and sensory deficits depending on the location and extent of brain damage.[5]

The Disability Acts of Pakistan identifies four main disabilities: physical disabilities, mental retardation, visual and hearing impairments.[6] According to the 2017 census, the total population of Pakistan is 207,684,626 out of this 913,6672.5 are categorised as disabled. The census further identified that 515,815 of the disabled persons resided in Punjab province and 143,529 percent in Sindh province.[7] Almost 132,013,789 Pakistan's population resides in rural areas where people have limited access to health care facilities and often the health units are located at a great distance from the area.[8] Results of the study titled prevalence of early childhood disability in rural areas of Sindh that Cerebral Palsy reported the highest prevalence in childhood disabilities in Sindh that is 1.12/1000 children under age 5 years.[7] A cross sectional study conducted[9] in Karachi concluded that 3.6 percent of the children aged 2-9 years suffered from motor, hearing, visual, seizures or cognitive impairment. Another longitudinal study conducted[10] in Lahore found that 2.8% of the population is disabled.

Spastic diplegia form of CP is more common due to the increased survival rate of infants with low birth weight however Dyskinetic form of CP is decreasing worldwide.[3] A study concluded that Spastic form of CP is common in

Pakistani children diagnosed with Cerebral Palsy followed by Ataxic and Mixed types.[3] Likewise, previous studies suggest that males are more likely to suffer from Cerebral Palsy and tend to have more dysmorphic features as compared to females.[11] According to the 1998 population census of Pakistan majority of the disabled population in the country were male both in the urban and rural regions.[7]

CP has a considerable effect on the families' well-being and leads to financial constraints.[12] A study conducted explored the perceptions of caregivers from Sindh and Balochistan about children with disabilities concluded that financial challenges and limited access to health care services leads to frustration in caregiver as a result they give less attention to the disable child.[13] CP individuals encounter numerous challenges in their everyday life such as limitations in mobility, self-care, school and playful activities.[14]

The educational policy of 1972 provided funds for special education facilities in Pakistan. The country made immense progress in providing special education services to disabled children in the period from 1983-1992. This period is referred to as the decade of disable since it raised awareness regarding disabilities in Pakistan.[15] Although there are separate schools for children with disabilities in Pakistan[2] only 2% of disabled children in Pakistan have access to special education schools whereas others are going to normal schools or are not enrolled in any schools and thus remain at homes.[16] The limited number of special education centers and non-governmental organisations cannot facilitate the entire disable population in Pakistan.

The study explored the following research question:
What strategies can be used by teachers and parents of children with Cerebral Palsy to facilitate them?

SUBJECTS AND METHODS

Research Design

The study was Qualitative in nature. Phenomenological research design was adopted for this research to explore the strategies proposed by psychologists to assist CP children at home and school. Phenomenology is a qualitative research design that is used to explore an individual's lived experiences, perceptions and feelings.[17] Phenomenology aims to study psychological and social phenomena from the point of view of people.[18]

Sample and Sampling Strategy

The sample of this study comprised of six child psychologists working with children diagnosed with Cerebral Palsy. Participants were recruited from different special education institutes in Lahore. A sample size of at least six participants is suggested for phenomenological studies.[19]

Purposive sampling was used as a sampling strategy. In this sampling technique participants are recruited who fulfill a predetermined criterion.[20] Practicing child psychologists with an experience of 4-5 years with CP children were included. Since interviews were conducted in Urdu therefore proficiency in Urdu language was also a requirement. For the present study six in-depth interviews were conducted with six separate child psychologists in order to obtain the data.

Procedure

Written informed consents were taken from the participants and interviews were conducted and recorded with their consent. Participants were ensured that their confidentiality would be maintained and their personal information would not be shared with anyone. They were also given the right to withdraw the interview at any time.

Data Analyses

After the in-depth interviews were conducted they were transcribed in Urdu and later translated in English. The audio recordings of interviews should be transcribed entirely and produce a verbatim of the interview.[10] The data from this research was analyzed by interpretative phenomenological analysis (IPA). Interpretivism often leads to a more comprehensive understanding of the situation and it enables to understand the in-depth relationship of human beings to their environment.[21] IPA aims to analyze the importance of events and experiences for the participants.[22] It involves investigating how individuals make sense of their experiences.[23]

Data Verification Method

The four steps for data verification namely; sensitivity to context, commitment and rigor, transparency and coherence and impact and importance. These steps were used to verify the data.[24] Credibility was ensured by peer review. Peer-review was used as a method of verifying the data to remove any researcher bias.[25] The entire coding process was reviewed by two experts in the phenomenon under study. Changes were suggested which were incorporated in the study. These changes included revising the titles of themes and merging some minor themes together to make the findings comprehensive.[24] Activities such as peer review, persistent observation, and triangulation can be used to determine the reliability of analysis.[25]

RESULTS

Two set of themes emerged from the analysis which included the strategies that can be used by parents and teachers to facilitate their CP child at home and school.

The first set of themes has a major theme namely: parental level strategies. This major theme further has five sub-ordinate themes: attitude of parents, attitude of siblings, attitude of extended family, home environment and home based interventions (Table). The second set of theme has a major theme of teacher level strategies which further has nine sub-ordinate themes namely; attitude of teachers, attitude of class fellows, teaching techniques, curriculum modifications, classroom modifications, use of assistive technology, vocational training, collaborative team work and counseling. The themes were derived from the data shown in table below (Table).

Table
Summary of major and minor themes of strategies used by parents and teachers of CP children

S.No.	Major Theme	Minor/Sub-Ordinate Theme
1	PARENTAL LEVEL STRATEGIES	1. Attitude of parents 2. Attitude of siblings 3. Attitude of extended family 4. Home environment 5. Home based interventions
2	TEACHERS LEVEL STRATEGIES	1. Attitude of teachers 2. Attitude of class fellows 3. Teaching techniques 4. Curriculum modifications 5. Classroom modifications 6. Use of assistive technology 7. Vocational training 8. Collaborative teamwork 9. Counselling

Major Themes and Minor-Themes
The strategies used by teachers and parents have two major themes namely; parental and teachers level strategies. The major themes further have sub-ordinate themes. These themes have been shown in figure (figure).

Theme 1: Parental Level Strategies
The major theme of parental level strategies consists of subordinate themes such as the attitude of parents, extended family, siblings, home environment and home based interventions.

According to Psychologist 3:
"Do not compare them with others, give them importance. It is seen in some families that they do not introduce their children with others, they hide them. Call it a society barrier or stigma. If we put an end to this it would be beneficial".

Theme 2: Teachers Level Strategies
The major theme of teachers' level strategies consists of subordinate themes of attitude of teachers and class fellows, teaching techniques, curriculum and classroom modifications, use of assistive technology; vocational training, collaborative team work and counseling.

According to Psychologist 2:
"Primary, secondary reinforcement......in which you try to appreciate the child. If the child has interest in something else then that thing can also be used and would be more effective".

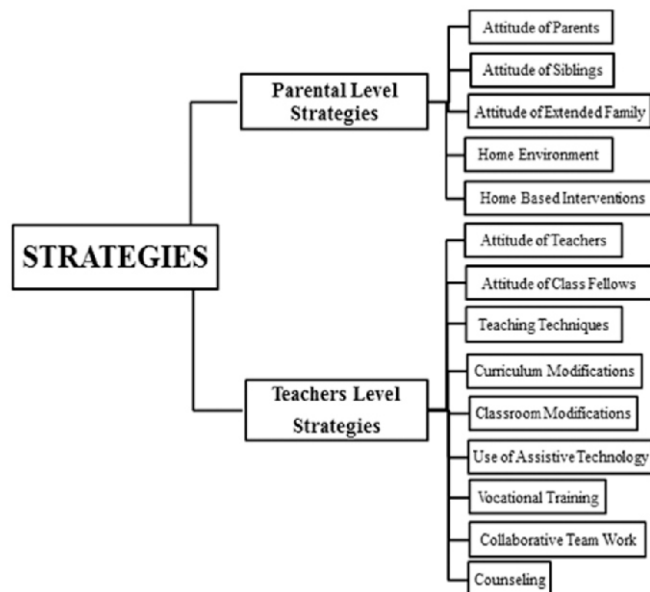

Figure : Thematic Map showing the major and minor themes of strategies used by teachers and parents

DISCUSSION

Two sets of themes emerged which included the daily life challenges of children with Cerebral Palsy and the strategies used by teachers and parents to provide a better environment to the children with Cerebral Palsy. Daily life challenges of children with Cerebral Palsy which have six themes namely: physical, social, financial, psychological, medical and curriculum challenges which further have sub-ordinate themes. The second set of themes were strategies used by teachers and parents to provide a better environment to the children with Cerebral Palsy, which has two major themes namely: parental and teachers level strategies. Major themes further have sub-ordinate themes. Themes that were derived from the data have been shown in table (see table 1).

A study suggested that environmental factors affect participation since they restrict access to spaces and activities. It is to be noted that social attitudes and physical designs affect the experiences of disabled children and adolescents.[26] Another research explained that physical challenges such as stairs, uneven surfaces and un-appropriate transportation hinder the participation of children and adolescents with disabilities.[27]

Lack of social support was explained by the social stigma theory. According to the social stigma theory, society classifies people as normal or deviants. It defines stigma as a trait that is discrediting, thus considering a person who possesses this characteristic as inferior. As a result, the stigmatised person is socially disapproved.[28] Several studies have highlighted lack of social support as a challenge in the participation of disabled children. A study suggested that attitudes toward disabled children and adolescents restrict their involvement in activities. Particularly, staring, bullying, lack of information, policy segregation, need for adult assistance, and discrimination within schools influence the participation of disabled children.[29]

Financial challenges are another major theme of this study. The findings are supported by a social model of disability. The social model of disability suggests that the environment affects the participation of individuals with learning, sensory and physical impairments. World Health Organization has classified the environmental challenges into three categories namely: the social, attitudinal and physical environment.[30] A study proposed that lack of supportive mechanisms, financial burden and time constraints is a challenge that reduces pleasurable activities of the disabled children and adolescents.[31]

Psychological challenges are a major theme which includes subordinate themes of cognitive and behavioral challenges. The special children have poor cognitions and behavior issues which can be understood by Piaget's cognitive development theory[32] and behaviorist theory. Piaget proposed the stages of cognitive development which enable a child to construct a mental model of the world. He proposed that cognitive development in children occurs in four steps: sensorimotor stage, preoperational stage, concrete operational stage and formal operational stage. The stages specify skills which gradually increase in complexity. Each new skill is built directly on skills from the preceding stage. Each stage shows the kinds of behaviors that an individual can control at that level. The individual performs several actions stimulated by specific environmental circumstances which allow him to combine his actions. Thus, the person combines and differentiates skills from one stage to form skills at the next higher stage. The movement from one level to the next occurs in many micro-developmental steps.

According to the behaviorist operant conditioning theory of Skinner[33] individuals repeat behaviors that have desirable consequences such as reinforcement and behaviors that lead to undesirable consequences are not repeated such as punishment. The extensive work on operant conditioning has led to the development of behavior modification techniques which are used as therapy to alter unfavorable behaviors.[34]

Medical challenges are a major theme which include subordinate themes of sensory, motor and health challenges. This theme was explained by the medical model of disability. The medical model[35] focuses on the impaired individual's functional, physiological and cognitive deficits. It considers disability as the outcome of physical impairment, which may be caused by a disease or damage.[36] This model is also called the 'personal tragedy model' since it views disability as negative. Disability is considered a pitiable and bad condition for the individual and his family. It stresses on prevention of disability and seeking treatment for curing it.[37] It highlights the limitations of individuals with disabilities and neglects the environment's resistance to their mobility.[38]

Curriculum challenges are a major theme which consist of subordinate themes of lengthy syllabus and inappropriate exam pattern. This theme was explained by Piaget's theory of cognitive development.

The second set of themes were strategies used by teachers and parents to provide a better environment to the children with Cerebral Palsy, which has two main themes namely: parental and teachers level strategies. The major theme of parental level strategies comprises subordinate themes of attitude of parents, extended family, siblings, home environment, and home based interventions. This theme is explained by behaviorist and humanistic theory.

According to the humanistic theory proposed by Roger, every individual has an innate tendency called the 'actualizing tendency' which is used to utilize their full potential.[39] This inclination is inherited and manifests itself in infancy. It also implies that, during the development of self-concept, individuals acquire an understanding of their own self in connection to the environment and relationships. Children interpret certain relationships as good, negative or neutral, because of this process. In pleasant circumstances, youngsters perceive their experiences positively, but during unfavourable conditions that threaten their development, they interpret their experiences as negative.

The self-concept is considered in congruence when the actualizing tendency develops. For the proper development of self-concept, the growth process necessitates positive interpersonal relationships. He also introduced the concept of ideal self, which is described as the self-concept with the highest value that a person desires to possess. He suggested that a person's upbringing and interaction with their caregivers influence the development of the ideal-self. The self-structure is influenced by social interactions and parents' judgement, such as good or bad. He explained that unconditional parental love is part of healthy growth, resulting in children's perceptions of themselves as deserving of unconditional parental affection, which gives children the motivation to become their ideal-self. Thus, a person with a congruent self-concept is genuine and whole, as well as goal-oriented. However, denying children unconditional positive regard jeopardises their development of a healthy self-concept, resulting in low self-worth and threatening their need to be loved as an individual. To avoid this, the children use denial or distortion of their experiences, and to prevent being unloved by the parents, youngsters endeavour to meet their parents' 'conditions of worth.' Children suffer from anxiety to uphold these conditions of worth enforced upon them. Thus, the children develop incongruence, which leads to inner tension, and the child becomes rigid, confused and defensive in his behavior, feelings and action.

The humanistic theory further elaborates that the ideal parenting style is empathetic in nature. This parenting style allows the child to pursue the path that leads to the child's fulfillment and happiness, and has a positive influence on their psychological and emotional well-being. Consequently, the child develops a sense of security and is not afraid of confronting others. Likewise, the child develops acceptance for itself, which leads to high self-esteem. The child feels that it is valued by others. High self-esteem together with a sense of security builds confidence in the child, which brings emotional stability, thus the child does not view the world as threatening.

The major theme of teachers' level strategies consists of subordinate themes of attitude of teachers and class fellows, teaching techniques, curriculum and classroom modifications, use of assistive technology, vocational training, collaborative teamwork and counseling. This theme is explained by behaviorist, humanistic, Vygotsky's universal design for learning theory.

According to Vygotsky theory, a child's thinking is influenced by his relation with individuals, who are expert, knowledgeable, and more capable than the child. He suggested a child can learn a new skill better if he is assisted and helped by someone who is an expert in that area rather than learning themselves. He introduced the concept of 'zone of proximal development,' which is defined as the difference between self-performance and performance accompanied by others. Thus, he argued that learning is a form of assisted performance. The theory proposes that, initially the expert possesses the skill and knowledge, and helps the learner to perform the task. As a result of the expert's help, the student gradually learns the skill which was initially possessed by the expert. This theory also explains that the teacher or expert should not only possess the skill that has to be learned by the student, but should also divide the content into small segments. These segments should be provided to the student in an appropriate sequence to aid learning. The student should try to connect all these segments together to learn the skill.

Universal design for learning (UDL) was introduced by the Centre for Applied Special Technology (CAST). It is based on the principles of universal design (UD) which is a spatial theory that highlights the importance of spaces to be accessible for all individuals. UDL not only focuses on the physical accessibility but it also emphasises on accessible education for all. Thus, an institute that incorporates the concepts proposed by UDL and UD, they in turn facilitate students with diverse modes of learning, physical abilities and knowledge backgrounds.40The principles of UDL are in accordance with the concept of bringing adaptations for disabled students, and therefore stresses on introducing modifications in curriculum for differently-abled students.[41]

UDL focuses that the aim of learning is not only to convey information but to accommodate the changes in skills and knowledge of students. It stresses that having accessibility to knowledge is important for learning but it is not sufficient. This theory proposes that both the information and pedagogy should be accessible. It defines pedagogy as the science of teaching. It includes the teaching methods which are used by teachers to guide the students.

The principles of UDL rest in neuroscience which highlights the different educational needs of learners. This theory classifies pedagogy into three areas namely: the multiple ways of expressing knowledge, engagement styles and various ways of representing information.[42]

CONCLUSION

The findings of the study highlighted the strategies that can be used by teachers and parents to provide a better environment to the children with Cerebral Palsy. Separate strategies for parents and teachers are suggested. The parental strategies theme further have five sub-ordinate themes: attitude of parents, attitude of siblings, attitude of extended family, home environment and home based interventions. The teacher level strategies has nine sub-ordinate themes: attitude of teachers, attitude of class fellows, teaching techniques, curriculum modifications, classroom modifications, use of assistive technology, vocational training, collaborative team work and counseling. Culture specific findings were also reported such that parents of CP children associate the disability of their child to supernatural influences, mothers of CP children and female CP children suffer more as a result of disability since females in Pakistani society are subjected to gender discrimination. Pakistani families strickened with CP have limited access to health care facilities since Pakistan is a developing country with limited resources.

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