

Socioeconomic Challenges Faced by Mothers of Disabled Children: A Case Study of Karachi, Pakistan

Nigar Zehra¹ , Quratulain Fatima²

¹Applied Economics Research Centre, University of Karachi

²Research Scholar, University of Karachi

Correspondence: nigarzehra17@gmail.com¹

ABSTRACT

This paper aims to highlight the challenges faced by mothers of disabled children especially Cerebral Palsy (CP) children living in Karachi, Pakistan. CP is the most common childhood neurological disorder that is responsible for both physical and mental disabilities. The study addresses both the economic as well as social challenges for instance; health challenges, social challenges, economic and financial challenges, marital life challenges, job challenges, and future worries. The objective is achieved by Qualitative research design using in-depth interviews. Thirty mothers are interviewed in the study most of them are housewives while few are working mothers. It is revealed that all mothers whether they are working or housewives experience health challenges, social isolation challenges, and future worries for their children. However, few mothers experienced marital life and financial challenges. It is observed that apart from the said challenges working mothers also faced job challenges. The study concluded that a wide range of challenges is experienced by the mothers of children with CP. This paper provides valuable information for organizing awareness programs regarding the problems faced by mothers and disabled children.

Keywords: Disabled Children, Mothers, Socio-Economic Challenges.

Introduction

Global Burden of Disease report analyzed that there are more than a hundred million children below fifteen years of age are suffered from moderate to a high level of disability. Most of them are lived in less developed or developing countries. Disabled children are not welcomed in any society as they are not only considered a burden on the socio-economic standards of the household but are also one of the major causes of parental mental distress. In many places, a household hides the disabled child due to the anxiety of being an outsider in society. They start considering them useless to society. These children admit the standard and believe that they are irritating and are punished by God Taye (2011).

There are different forms of disability in children Cerebral Palsy (CP) is one of them. CP is a permanent disability that occurs to the permanent impairment of the brain. It makes the children not only mentally and physically disabled but also makes them socially unfriendly. With this developmental disorder, most of the children also suffer from other disabilities for instance; hearing disability, blindness, epilepsy, and intellectual retardation that create multifaceted limitations in functions of self-care. Cerebral Palsy is the

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most common disorder found in children living in developing countries. Among thousand children at least one or two are unable to achieve the mileposts of motor development from their birth to five years of age for instance; rolling, sitting, crawling, standing, holding and walking, etc. dis achievement of these tasks is the prominent signal of Cerebral palsy (Stacky, 2020; Eyong, 2017).

These children increase the economic burden of their parents as most of the CP children do not complete their routine tasks like going washroom, eating food and changing clothes, etc. For that, the families need to hire some caretakers which are not easy to afford for poor families. In most families, any of the family members start providing these facilities that destroy the physical and mental health of the caretaker. However, looking after a disabled child is not an easy task and it is the responsibility of both parents. Unfortunately, in developing countries mothers are considered more responsible to look after their children as they are the prime caregiver of their children Michael (2019). Mothers who look after their CP children experience a huge variety of challenges. Largely, the challenges consist of psychological ones as they remain worried about the health of their children which further harms their own mental and physical health. Most of the mother's starts remain sick due to the constant assistance of their children in their daily activities. Moreover, mothers face some other social challenges also as it creates problems in their marital life Ahmed (2015) and become the victim of sorrow and grief. Additionally, they have to face the negative behaviors of friends, family, and society as well.

Considering the importance of the issue the objective of this research is to expose the challenges or problems faced by mothers of disabled (CP) children in an urban setup like Karachi. The problems include health challenges, social, financial, and economic challenges, marital life, job challenges, and future worries of the child. Therefore, this paper hypothesizes that mothers who care for their children with disabilities (CP) in an urban area faced health challenges, social challenges, financial and economic challenges, marital life challenges, job challenges, and future worries; either they are working or housewives.

The literature on socio-economic challenges confronted by mothers is very limited, especially in the case of Pakistan. To the best of the author's knowledge, there is no study exists for Karachi, Pakistan. The study is significant as it fills the gap in the literature by exploring the challenges faced by mothers of disabled children in the district of south Karachi, Pakistan. This study will help the government and non-government organizations in creating policies and executing development programs for society to empower and support the mothers of disabled (CP) children. The research will also help to take steps and measures for prevention.

Methodology

Sample Size

Qualitative data is composed via face-to-face individual and telephonic interviews of 30 mothers in the year 2020. The targeted¹ population that is used in this research is encompassed mothers of disabled (CP) children, attending the IBP Institute of behavioral psychology and milestone charitable school, in the District south of Karachi. In this research, most of the mothers were housewives while few of them were working-aged between 30 to 45 years and their qualifications were not more than masters, twenty mothers were interviewed on school premises and ten were on the telephone.

Sample Collection Technique

This study used in-depth interviews following Seaman (1991) approach according to the author an in-depth interview is a thorough conversation regarding the issue where the interviewee does not give any

¹ In 2008 Cox, a targeted population is a group of people to whom the research results apply and can be generalized as they usually share common characteristics.

pre-decided answers to open-ended questions asked by the interviewer. With the help, the researcher judges not only the facial expression but also understands the nonverbal or emotional conditions of the interviewee. Open-ended questions in the in-depth interviews provide a platform for mothers through which they can easily explain their problems. The questionnaire is based on questions regarding the socio-economic, psychological, physical, and marital life challenges faced by the mothers. The interviews are conducted in the language preferred by mothers that lasted between 45 minutes to 1 hour. Simple Proportions and Tables were used to analyses the data. The researcher personally conducted interviews with thirty mothers of children with CP. Demographic data of the parent and child with Cerebral Palsy were obtained through a self-administered questionnaire that contain questions related to their age, gender, educational status, and occupation.

Analysis Technique

This research is assessed through a qualitative approach. According to Denzin and Lincoln (2000), qualitative research is a realistic and descriptive approach that allows the interviewer to better understand the meanings attached to people's decisions, actions values in their social world, and beliefs as well.

Results

This qualitative research is comprised of interviews with 30 mothers of CP children, including both working and housewives. The majority of them are school teachers while few are bankers. The ages of mothers' are between 30 to 45 years while; the ages of children are between 10 to 15 years suffering from different types of CP.

The demographic data of mothers and their children are presented in table 1, showing their age, marital status, education level, and employment status. All mothers are the biological mothers of children with CP among them five are divorced.

Table 1: *Demographic Data of Participants and Their Children with Cerebral Palsy*

Participant code	Participant Age	Marital status	Education Level	Employment Status	Child Age
M1	30	Married	B.Sc	Working	10
M2	30	Married	B.A	House wife	11
M3	42	Married	Masters	House wife	10
M4	40	Married	B.Sc	Working	15
M5	35	Married	B.A	Working	10
M6	32	Married	Inter	House wife	12
M7	40	Married	Inter	Working	12
M8	42	Married	B.A	House wife	10
M9	45	Married	Masters	House wife	15
M10	43	Divorced	Inter	Working	15
M12	35	Married	B.Sc	House wife	10
M13	32	Married	B.A	Working	11
M14	38	Married	Inter	Working	12
M15	40	divorced	B.A	Working	13
M16	42	Married	Masters	House wife	12
M17	40	Married	Inter	House wife	10
M18	45	Divorced	Master	Working	15
M19	30	Married	B.A	House wife	10
M20	32	Married	B.Sc	House wife	10
M21	42	Divorced	B.Sc	Working	13
M22	40	Married	B.A	House wife	11
M23	35	Married	Masters	Working	10

M24	30	Married	Inter	Working	10
M25	42	Married	Matric	House wife	12
M26	35	Married	Inter	House wife	10
M27	38	Married	Masters	House wife	11
M28	40	Married	Inter	House wife	12
M29	43	Divorced	B.A	Working	15
M30	32	Married	B.Sc	House wife	10

Source: Table is illustrated on the basis of interview, M1 till M30 shows mother 1 to mother 30

Table 2: *Challenges Experienced by Mothers of CP Children*

Challenges	Yes	No	Percentage of yes	Percentage of no
Economic and Financial issues	6	24	20%	80%
Social issues	30	0	100%	-----
Health issues	30	0	100%	-----
a) physical				
b) Psychological				
Marital issues	18	12	60%	40%
Future worries	30	0	100%	-----
Job issues	13	17	43.3%	56.6%

Source: Table is illustrated on the basis of interview

The challenges experienced by the mothers are illuminated in table 2. It included economic and financial challenges, social challenges (social isolation), physical challenges, physiological challenges, issues in marital life, future worries for their child, and job challenges. Almost every mother is experiencing some of these problems as they had a child with CP detailed analyses are explained below.

1) Economic and Financial problems experienced by the mothers

The interview revealed that parents of disabled children are suffered from financial crises. The treatment, therapies, and schools for special children are very expensive to afford for a household belonging to the middle class. Furthermore, single mothers faced more financial problems than the rest of the participants. Being single mothers all responsibilities of earning and caring for a child are on their shoulders. It is very difficult for them to manage a full-time or well-paid job that affects the treatment of their child.

2) Health Issues

a) Physical Problems

The entire respondent reported shoulder and back pain resulting from carrying and assisting their children in daily activities. Single and working mothers experienced severe physical problems as all the responsibilities of caring for children are solely on their shoulders as per one mother "The foremost difficult task is taking a child to washroom and physiotherapy" few among them also reported sleep disturbances when the child fell ill.

b) Psychological Problems

The mothers also experience a range of negative emotions from mild anger to fatigue and frustration. This frustration has become more intense on the faces of single mothers. One among the mothers who was working said that "At times she gets so aggressive that she starts beating her child". Another mother said, "At times I feel so overwhelmed and exhausted that I am forced to think that it's better if I had died: that would resolve the issue". Further, she added, "The child is not developing normally, which stresses me, increases my blood pressure, and results in other health issues".

3) Social problems experienced by the mothers

Almost all the mothers complained that it is very difficult for them to attend social gatherings for instance Milad, the family gets together, weddings, and other occasional ceremonies. Their social life has become so reduced. Due to their reduction in social gatherings, the other friends and relatives also minimize visiting their own homes. If people visit their homes, they do not attend to them properly. As per one of the mothers "she avoids attending the gatherings and ceremonies because people ask weird questions about her child that made her feel bad."

4) Marital problems experienced by Mothers

It is revealed that several mothers have conflicts with their husbands as they remain distressed due to their CP child and are unable to spend quality time with their husbands. While few mothers got a divorce as a result of giving birth to the CP child.

5) Worries about Child's future

All mothers were fussy and worried about the future of their children. They are more concerned about who will take responsibility for the child once they died. To protect themselves from future worries they leave it to destiny and accepted the fact or truth that whatever goes to happen is bound to occur, and nothing is in their control.

6) Job challenges

All the working mothers unanimously reported that caring for a child with CP harms their jobs. Some mothers reported that they lost their jobs due to lack of concentration on work, while others are struggling to manage well as they have a responsibility to take care of their disabled child that needs more money than the normal child.

Discussion

The study highlighted that mothers of disabled (CP) children belonging to Karachi, Pakistan are facing various socioeconomic problems. For instance, they are undergoing health challenges including both physical and psychological. All participants reported physical problems like excessive fatigue, and back and body pains due to carrying their child. They also reported negative feelings like anger, sadness, and feelings of awkwardness for the child. Similar findings were reported by Chiluba (2017) and Michael (2019). Mothers who look after their disabled children also need some rest and comfort to face these challenges with energy.

One common problem reported by all the participants is that they get limited freedom to interact with their social environment. Comments made by the participants were "I cannot go out and move freely around as initially, I used to do", "I am the sole one that carries him, this hinders me from going out", as per one mother she didn't attend social gatherings due to negative behavior from her family, friends and the social community. Literature also highlighted the less interaction of mothers of disabled children with the social environment. Michelsen and Singongo (2015) illustrated that mothers have low participation in social gatherings like marriages and other ceremonies. Instead of trusting the fact, that the disability of their child is a spiritual cause (Wegner and Rhoda 2015), parents are blamed to be the cause of their children's disability. This behavior of society has enforced the parents of these children to keep themselves and their children away or isolate them from society. The majority of mothers included in this study reported that they are facing marital challenges due to misunderstandings and clash with their husbands. They stated that they have constant arguments with their husbands because they are unable to spend time with their husbands, a few mothers got divorced due to giving birth to a CP child, and similar findings were shown in the studies conducted by Paget (2016). Furthermore, single mothers in this study reported that they are facing financial issues. As per one among them, "She faces financial problems but by the grace of God all these issues resolve automatically".

The study reported that all mothers are anxious about their child's future. The majority are concerned that who will look after their child in their absenteeism. Literature also supports these results as the studies conducted in Zambia, India, and Brazil (Nimbalkar, 2014; Singogo, 2015; Ribeiro, 2016) reported the anxious behavior of mothers for their child's future.

All working mothers reported that they face difficulty in performing their jobs a number of them reported that they lost their jobs due to taking care of CP's child. These findings are similar to the findings of Corman *et al* (2005) that having a disabled child affects the income level badly and also negative effect on employment, especially for mothers.

Conclusion and Policy Recommendation

The purpose of this study is to shed light on challenges faced by mothers of disabled (cerebral palsy) children, the challenges that are studied in this research are health challenges, social challenges, economic and financial challenges, marital life challenges, future worries of children, and job challenges. This research is based on a qualitative approach and the researcher has used in-depth questions. The author personally conducted an interview with the mothers of CP children on the premises of the IBP Institute of Behavioral Psychology and Milestone Charitable School as well as over the telephone, based on the interview the researcher made the following conclusion.

The researcher found that all mothers experienced health challenges including both physical and psychological all mothers reported severe anxiety and depression as well as all reported back pain and neck pain due to carrying their children. All participants reported social isolation they were unable to attend the functions and other gatherings because of their children as they are the only ones who responsible to take care of their children. The findings also elaborated that single mothers have faced financial difficulties, according to one mother "We face financial challenges but these challenges are overcome automatically with the help of Allah"

It is indicated that the majority of mothers faced marital life issues because they are unable to give quality time to their husbands as well a few mothers got divorced because of giving birth to a CP child, while some mothers reported that they have no marital issues. All the participants showed future worries for their children they are worried about their studies, their livelihood as well as who looked after him or them when they died. The study showed that participants are also facing job challenges; many of them lost their jobs because of caring for CP's child.

Based on the research findings, it is recommended that government and non-government institutions should organize such programs that provide awareness about various aspects of disability and its causes, especially in children, and highlights the problems faced by the family. These programs must give the message that children are not the sole responsibility of mothers but they are the responsibility of fathers too. The programs would also explain the way how to treat these types of children rather than dislike them. These programs will help in reducing the problems faced by parents of such children. Furthermore, government should develop more rehabilitation centers that provide therapies at low cost. It is recommended that government should provide the health coverage to these children that will help in reducing the economic burden on their parents.

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Conflict of Interest

Authors have no conflict of interest.

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ORCID iDs

Nigar Zehra¹  <https://orcid.org/0000-0001-6077-3273>

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