

PATRIARCHY IN FAMILY CARE-GIVING: EXPERIENCES OF FAMILIES OF CHILDREN WITH INTELLECTUAL DISABILITY IN PAKISTAN

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Date Received:

August 09, 2015

Date Revised:

December 29, 2015

Date Accepted:

January 06, 2016

ABSTRACT

Objective: To know the effects of children with intellectual disability (ID) on families in Pakistan with special focus on the experiences of mothers living in nuclear and joint families.

Methodology: This was qualitative study in which qualitative methods were employed for this study. Data was collected from parents and family members of children with intellectually disability. Participants from the diverse socio-economic features were selected from the three rehabilitation centres for children with intellectual and physical disability in Peshawar and Haripur districts of Khyber Pakhtunkhwa province. A total of 58 respondents were interviewed including 30 in-depth individual interviews (IDIs) with parents having children with ID and 4 Focus Group Discussions (FGDs) with a total of 28 parents (7 participants in each FGD). Both mothers and fathers participated in this study for ensuring equal gender ratio.

Results: Women in the families were suffering more as compare to men due to socially assigned role of primary care of the children. Women were facing social exclusion, stress/ fatigue due to role strain, rejection in the form of family breakdown and work-family conflict due to gender imbalance in role performances. Moreover, families were also prone to displacements and social hazards like beggary, child labour and drop out of normal female children from schools due poor institutional role in child support and rehabilitation.

Conclusion: Patriarchy promotes uneven distribution of roles for men and women in the families having children with ID which causes more agonies for mothers and other female members of the house as compared to male members of the family.

Key Words: Intellectual Disability, Social Exclusion, Patriarchy, Joint Family, Nuclear Family

This article may be cited as: Ahmed S, Ali J, Sanauddin N. Patriarchy in family care-giving: Experiences of families of children with intellectual disability in Pakistan. *J Postgrad Med Inst* 2016; 30(1): 73-9.

INTRODUCTION

Intellectual Disability (hereafter referred to as ID)⁴ refers to the substantial restrictions both in intellectual functioning and in adaptive behaviour, as articulated in conceptual, social, and practical adaptive skills¹. It is an evident fact that the occurrence of a child with ID lays a substantial sum of social and economic pressures on families. Such a child needs full time attention throughout his/her life. Moreover, disability may cause shame and humiliation for some families. In societies such as Pakistan, intellectual disability is often kept hidden from people by families owing to fear of stigma². This is mainly because people believe that intellectual disability is a genetic disease for which the parents are held responsible. People culturally associate such circumstanc-

es with a sin that the parents might have committed in the past. Relatives and people in the neighbourhood also refrain from establishing marital relations with such families as they fear that they may get an intellectually disabled child in future. As result, both children and families face multiple economic adversaries,³ emotional disturbance,⁴ and psychological adjustment⁵. Furthermore, the relationship of other sibling with parents get tense as parents might give more time to their intellectually disabled children compared to the normal ones⁶.

The prevalence of ID is increasing globally. According to World Health Organization report, 3% of the world's population (156 million) have some form of intellectual disability⁷. In 2001, it rose to 15% which mean 785 million people globally⁸. Furthermore, it prevails irrespective of developmental status of a country. For

instance, in UK, 1198000 people are suffering from intellectual disability that includes 298000 children of age group 0-17 years⁹. Similarly, in the US, there are about 6 million people which mean that 3% of US population are suffering from intellectual disability¹⁰.

In Pakistan, the exact number of intellectually disabled is not known due to lack of official census on regular basis. According to the 1998 Census, there are 3293155 people suffering from disability as shown in Table 1.

In Khyber Pakhtunkhwa, the most common diseases and disabilities among children are fits, intellectual disability and speech difficulty which constitute a significant part of population, i.e., 4%¹¹.

This article presents the results of a qualitative study conducted in Khyber Pakhtunkhwa with the aim to understand the experiences of parents and other family members of children with ID. More specifically, the article discusses the various problems faced by parents in joint and nuclear families with special focus on how women and mothers as primary care givers suffer more as compared to men.

METHODOLOGY

The study is based on qualitative methods using In-Depth Interviews (IDIs) and Focus Group Discussions (FGDs) with parents and family member of children with intellectual disabilities in two different districts of Khyber Pakhtunkhwa, namely Peshawar and Haripur. The study area was selected due to the high prevalence ratio of children with ID as reflected in the official data obtained from the Directorate of Social Welfare and Special Education, Khyber Pakhtunkhwa¹².

Moreover, participants were selected by keeping in view their age, gender, locality, socio-economic status, family structure, and spousal relationship. This is shown in table 3, 4 and 5 below. The basic demographic factors were taken into account because of their significance association with patriarchy and its effects on the family care giving to children with ID

A total of 58 parents were selected purposively for In-depth Interviews (IDIs) and Focus Group Discussions (FGDs) from the lists of parents whose children were enrolled in three centres for rehabilitation in Peshawar and Haripur. Out of the total, 30 IDIs (15 in each district) and 4 FGDs (2 in each districts) was carried out, its detail is given in the following table 2.

Furthermore, the age group, gender and family structure i.e. nuclear as well joint family structure of the respondents was also taken into account, i.e., parents of children having different age groups and gender were interviewed in this study.

In addition to Individual Interviews, four FGDs (two in each districts) were also conducted with 28 parents and family members. Two of these FGDs were conducted with fathers while two were conducted with mothers of the disabled children. Each FGD consisted of seven members. The purpose of this triangulated method was to ensure cross validity of the data.

The interviews were recorded by using a digital voice recorder. The research was conducted by taking care of all the relevant principles of research ethics such as obtaining informed consent from the participants and maintaining participants' confidentiality and anonymity.

Data analysis in qualitative research consists of different steps, such as transcription, coding, categorizing and labelling of data. Similarly, in this research, first of all, the digital data from the interviews and FGDs was transcribed into the original language used during the discussion, that is, Pashto and Urdu. Later on, the transcripts were translated into English. Each transcript was read again and again by the researchers and different segments were coded in order to find out the most frequently and commonly occurring themes. Codes and themes were discussed thoroughly by the researchers in order to ensure inter-coder reliability and validity of the data interpretation.

RESULTS

The results of the study shows that parents, especially mothers of children with ID face a number of social and economic problems on societal and family levels. Specifically, mothers face social exclusion as they were not able to participate in social and community gatherings. Working mothers frequently go through family-work role conflict. The responsibility to manage both home and paid work along with the extra demand of care of the disabled child cause mental stress and fatigue to such mothers which sometimes results in divorce and separation. The father also has to bear economic pressures as children with intellectual disabilities are considered economic liabilities on families. In such situation, parents who were living in joint families with other supportive members were relatively protected from such negative consequences as compared to those who lived in nuclear families.

Social Exclusion of Mothers

Family members, especially mothers spoke about the social exclusion they faced due to extra care they required to provide to their children with ID. Social exclusion refers to the lack of participation of people in activities such as employment, voting and family relations and customary activities.¹³ It has been found that women constitute a very large section of society's caregiver population¹⁴. At the same time, the role of caregiver harmfully confine and disadvantage women, especially

Table 1: Statistics of Disability in Pakistan – 1998 Census

Forms of disability	Numbers	Percentage
Visually Impaired	263452	8%
Hearing and speech limitation	263452	8%
Physically disabled	625699	19%
Intellectually disabled	461043	14%
Multiple disability	263452	8%
Others (not specified)	1416057	43%
Total	3293155	100

Source: Government of Pakistan (1998). Population Census Organization, Islamabad

Table 2: Detail of interviews and FGDs (area-wise distribution of respondents)

Type of Interviews	Study Locality		Total
	Peshawar	Haripur	
In-depth Interviews	15	15	30
FGDs	2 (7 participants in each FGD i.e. 2 X 7 = 14)	2 (7 participants in each FGD i.e. 2 X 7 = 14)	04 FGDs (28 Participants)
Total Participants/subjects			30 + 28 = 58

Table 3: Relationship of research participants with children having ID

Interview/FGD with care-givers	Frequency	Percentage (%)
Mothers	20 (5 working mothers which constitutes 25%)	34
Fathers	26	44
G. Mothers	5	8
Uncles/Siblings	7	12
Total	58	100

Table 4: Demographic profile of child with intellectual disability

Gender of Child	f	%	Age				Birth took place		Relationship of parents	
			3-6	7-10	11-14	15-18	Home	Hospital	Cousin	Outside family
Boys	49	84	11 (22%)	14 (27%)	12 (25%)	12 (24%)	33 (67%)	16 (32%)	29 (60%)	20 (40%)
Girls	09	16	02 (22%)	04 (44%)	2 (22%)	01 (11%)	06 (66%)	03 (33%)	06 (66%)	03 (33%)
Total	58	100	13 (22%)	18 (31%)	14 (24%)	13 (22%)	39 (67%)	19 (33%)	35 (60%)	23 (40%)

Table 5: Family structure and economic status of participants

Gender of Child	f	%	Family structure		Financial Status of Parent			
			Nuclear	Extended	Upper	Middle	Low-er-Middle	Extremely poor
Boys	49	84	21 (42 %)	28 (57 %)	08 (16 %)	13 (26 %)	25 (48 %)	03 (6 %)
Girls	09	16	03 (33 %)	06 (66 %)	02 (22 %)	02 (22 %)	03 (44 %)	02 (22 %)
Total	58	100	24 (42 %)	34 (58 %)	10 (17 %)	15 (25%)	28 (48%)	05 (8 %)

in societies in which their contributions as caregivers are not sufficiently recognized, valued and rewarded ¹⁵.

It was found that almost all mothers (42%) belonging to nuclear family structures (see table 5) were unable to participate in the important ceremonies of their families and neighbourhood like deaths and marriages which usually last for almost a week in Pakistani culture. For instance, a mother in this regard stated her story of social exclusion in an interview in Peshawar:

“Before, I was living a very happy life: participated in family events actively; was a happy person, and used to attend happy occasions like marriage ceremony. But after the birth of my two disabled children, my life has totally changed. Now, I do not participate in ceremonial activities of my family due to full time involvement with my children.”

The same was endorsed by 42 % mothers in four Focus Group Discussions (FGD) in Peshawar:

“We cannot participate in most of the ceremonies due to the care of our child. In case of unavoidable situations, we attended but for a very short time, however, we remain extremely worried about our child at home.”

On the other hand, 57 % mothers who lived in joint family structures were able to participate in social activities of their community due to family support in child care and other household activities. According to them, the support of grandparents and other close relative provided emotional and social strengths to such parents. They also narrated that they provide care to their child (ren) with ID in particular and other children in general without any extra pressure. For instance, a mother who participated in this study, belongs to joint family structure, reported in an interview in Haripur that:

“My sister in law and other relative look after my child during my job timing and when I am away from home. Hence, I am somewhat able to participate in community events.”

The same was almost explained by a father in Haripur:

“My mother and sisters strongly supported my wife in child care of both normal and disabled children.

Furthermore, she (his wife) participates in community events by leaving her child with sisters-in-law in the family.”

These findings show that parents, especially 42 % mothers who resided in nuclear family structure were more prone to social exclusion. Failure to participate in such events results not only in social isolation, but it also negatively affect the social standing of the mothers.

Family-Work Conflict

Besides social exclusion, working mothers (25 %) of children with ID who live in nuclear families find it extremely difficult to manage child care along with their paid jobs outside the home. Owing to the dual demands of child care and paid work, mothers reported that they face family-work role conflict. The extra demand of the care of disabled children and the resultant interference of work into family role and vice-versa put them into mental and physical fatigue. For instance, a working mother shared her feeling during FGD in Peshawar as:

“I remain continuously in stress due to the multiple roles I have to perform both within as well as outside the home. I need two hours for feeding my disabled child... I am a working woman as well and have to give time to my other normal children. Beside this, I give time to household activities. This extra effort has made me sick with high blood pressure.”

Such stressful feelings were expressed by all working mothers (23 %). For example, another working mother narrated her agonies in an Individual Interview in Haripur that:

“Initially, I was doing a private job but after the birth of disabled daughter, it was extremely difficult to make balance in work and household activities. Hence, I had given up that job for the sake of my daughter. But, I have started my job again after admission of Sibgha [name of the child] in the school of disable children.”

However, the mothers who belong to joint family system reported that joint family support considerably reduces the family-work conflict of mother having intellectually disabled children. Appreciating the role of joint family, a mother in Haripur said:

"It is very difficult for a mother to manage her disabled children and job along with other household activities without the help of family members. We are setting here today [in the FGD] due to the support of our family members; if we do not have their support, then, it would have not possible for us to participant in this discussion. Furthermore, in joint family system, workload is divided with the other family members which provide a breathing space to the mother to look after her disable child."

It was found that working mothers belonging to nuclear families who have no support from family members or any institution during their job time face family-work conflict which causes psycho-social problems for them. Jamison (1965) has also found in his study that the health of the mothers who usually bore the brunt of care for these children was often drastically affected. Chronic fatigue and nervous exhaustion was common in homes where there was limited help in management of such child. Occasionally, the mothers were on verge of mental breakdown.

Family Breakdown

It was found during the study that some of the parents (10%) had disturbed relationship due to the birth of a mentally disabled child which ended in family disorganization and divorce.

A teacher and family friend of a child with ID shared the story of family breakdown during informal discussion at the 'Centre of Physical and Mentally Retarded Children' in Haripur as:

"I know the family of the child. Their parents got separated since long. Initially, they lived in nuclear structure and were doing jobs. Owing to extra care of child, the mother was unable to extend care to him; resultantly, it affected the relation of the spouses which ended in divorce. Currently, he (the child) lives with his grandparents; however, grandparents cannot extend care like his own mother."

The family breakdown was often the result of family-work conflict of the parents in general and mothers in particular. A helpless mother of child with ID narrated her experiences in extremely depressive and emotional tone during an interview in Peshawar by saying that:

"My husband is a daily wager; he is also addicted to drugs. The child needs extra care in terms of medication and nutrition but he could not afford it. He blames me for disability of his child and beats me. This situation has really made me depressed and annoyed but nothing could be done."

It was found that wife is normally expected to sacrifice her life and job for the care and look after of child due to their socially assigned role of primary care-giver.

She is not only blamed for the disability of the child but is also abused physically.

Family Displacement

It was found that lack of effective training institutions and special education schools for disabled children in their home districts force the parents (17 %) to migrate to more developed cities, especially Islamabad where quality rehabilitative facilities exist. These were those parents who were financially sound and placed in the upper class. See table 5.

It was found in the study that a family settled in Peshawar from the past five decades, who had two children with ID, unwillingly shifted to Islamabad where they had admitted their two children in a private institute for therapies. Moreover, they shared that they further intended to shift to Australia for the sake of effective treatment and rehabilitation of their children. They further added that they had opted for mobility under extremely compulsion as they were enjoying supportive life in joint family in Peshawar. However, it was a hard decision which was taken for the sake of their children. The same feeling was reflected by a mother who was planning to migrate to Islamabad.

"We have admitted our two children in the Rehabilitation Institute for Intellectually Disabled Children in Islamabad. Now we are also thinking of shifting the whole family to Islamabad. It is a tough decision as this will exert extra financial burden on our family budget."

It was found that parents were facing social and economic pressure due to displacement and migration, the progress they felt in the personality of their children after admitting in a new centre was source of satisfaction for them. They were highly satisfied due to visible improvements in condition of their children after admitting them in the centre for different therapies ranging from speech to physical therapies.

Surprisingly, the staff members of the rehabilitation institutions / special education centres in Peshawar themselves were not satisfied from the performances and services provided by these institutions. For example, an administrative head of a centre for special education for physically and intellectual disabled children who also had a child with ID reported that she intended to shift to Islamabad after retirement next year. The main reason behind this displacement was the poor state of services for children with ID in Khyber Pakhtunkhwa. She said:

"She [her daughter] needs speech therapy and physiotherapy. We do not have such facilities here in the institute, and thus, I intend to shift to Islamabad for the sake of my child. I personally raised voice for these facilities at every forum but the government is not interested to provide such facility. We would shift to Islam-

abad soon after retirement due to availability of very advanced and equipped institutes in Islamabad.”

Likewise, a few other parents were also interested to shift to any such area where their children could get proper training and skill; however, most of them were unable to migrate due to their permanent employment in the local area.

Economic Effects

Children with ID need extra care in the form of medication, treatment, education, and transportation. It was also found that beside intellectual limitation, these children are physically weak and more prone to various diseases like chest infection, digestive problems etc., due to which they need continuous medication and treatment. Moreover, these children mostly undergo magnetic resonance imaging (MRI) which is a technique used in radiology to image the anatomy and the physiological processes of the body in both health and disease¹⁶. Such MRI often required for diagnosis of brain's function and diseases. Such process needs ample financial resources.

In addition to that, it was found that mobility of these children is difficult in normal transportation which needs special transport facilities during pick and drop for schools or participation in community affairs with parents.

To exemplify the situation, a mother shared her feelings of financial agonies in the following words:

“My husband has got loan from his department for the treatment and rehabilitation of our children, as it was very difficult for us to afford their treatment in a specialised institution.”

In this regard, a father who was passing through the financial agony due to shortage of resources and the extra medical demands of his disabled child reflected his views as follows:

“The doctor has prescribed regular physiotherapy for three to four months for the physical improvement of the child. However, due to poverty, I cannot continue such treatment. We reside in a rented house (rent of Rs. 2500/- per month), but, my salary is Rs. 6000/- per month. It is difficult for me to bear the expenses of my family.”

Hence, it was found that fulfilling the multiple social, psychological and medical needs of these children exerts extra financial burden on the families of children with Intellectual disabilities. Consequently, the struggle for extra finances compels parents to work extra hours than their normal routine.

Effect on Normal Children

The presence of children with ID not only affects

parents but also the normal or non-disabled children. It was found that normal children, both male and female, suffer in a variety of ways. The care and look-after of disabled children needs ample financial resources which compels not only parents to do extra work but it was found that some parents had forced their normal children into child beggary and/or child labour for catering the needs of their disabled children. Reflecting on this situation, a member in a FGD in Peshawar narrated that:

“We have seen such families of disabled who are extremely poor. They used their children for begging in the streets for affording their family expenses.”

Some children were forced into child labour by the weak economic conditions of their families. The harmful ways of supporting family income such as beggary and child labour badly affect the personality and future of the normal children. It was further found that in such families, the female siblings of the disabled child were affected the most as compared to male siblings. The normal female sibling bears most of the suffering as she is expected to provide the physical and emotional care for her disabled brother/sister. Sometimes she had to remain out of school in order to facilitate her mother in taking care of the disabled children. In other words, patriarchal arrangements in our families not only affect the mothers, but also the female siblings of the disabled children.

DISCUSSION

Providing care to children with special needs and enhancing their potential to become an effective member of society is an undisputed collective concern. In more advance societies, social welfare institutions along with family provide services and support to these children. In traditional societies like Pakistan and most specifically in Khyber Pakhtunkhwa, however, families are wholly and solely responsible for ensuring the care and social welfare of their children. Family support alone is not only insufficient in the recovery/rehabilitation of these children, but it also pushes families into numerous social and economic problems. Moreover, as found in this study, it plays a role in the perpetuation of patriarchal and imbalanced gender relations as the female members of the family have to bore the brunt of the cost associated with care of disabled children.

The presence of intellectually disabled children in family effects parents/family members differently due to family structure and pre-determined gender roles in society. Men in our society are held responsible for bread earning whereas women are held responsible for household activities and provision of care to the family members in general and children in particular. Women as mothers and other female relatives of these children are more likely to go through social, psychological and

physical agonies as compared to male members of the family due to the patriarchal social structure of society and family. In the study, it was found that women/mothers are socially excluded due to primary care of the child and other household activities.

On the other hand, men are usually exempted from such support due to patriarchy and culturally determined roles, both in nuclear and joint families. However, joint family structure was found supportive to care-giving women due to support of other family members as compared to nuclear families.

CONCLUSION

Due to patriarchal arrangement of family care-giving, women as mother and other female members of the household are adversely affected as compared to men. Parents face social exclusion, work-family conflict, family disorganization and family displacement. These issues are more costly for women as compared to men, especially in nuclear families. The non-availability of effective institutional support for care of disabled children in the province further increases the agony of the parents. Hence, wide ranging institutional support is recommended for providing a breathing space to families having children with intellectual disability.

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CONTRIBUTORS

SA conceived the idea, planned the study, and drafted the manuscript. JA helped acquisition of data and did statistical analysis. NS drafted and critically revised the manuscript. All authors contributed significantly to the submitted manuscript.