

AFFECTS OF DISABLED CHILDREN ON THEIR FAMILIES (A CASE STUDY OF DISTRICT CHARSAKDA)

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ABSTRACT

In this study, we examined and analyzed the effects of disabled children on their families. Thirty respondents from District Charsakda, Pakistan (half were male and half were females) who had disabled children, were interviewed. Purposive sampling was used as method for the selection of the respondents. Qualitative analysis of their interviews was performed. The findings showed that disabled children greatly affected their families. The major impact of them was that of economic. Overall, the affects were more severe where the respondents were more poor. Male members of the families were more suffered economically than female as economic responsibilities are of the male members. However, health of the female respondents was more affected than male as the caring and rearing of the disabled are the responsibilities of females. The marriages of male were more affected than females. Employment of the females were more affected than males. Government and the charitable trusts should provide medical and financial assistance to the disabled and their families in order to lessen the burden of them.

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INTRODUCTION

Disability means the difficulty faced by a person while performing those tasks which other people take for granted. (Dombeck, 2002) or the inability of performing an activity by a person that is considered as normal for a human being (World Health Organization, 1996). Waqar (214) found that 15 percent of the world's population is disabled, of which 93 million are children. In Pakistan people with disability are 5.035 million with annual growth rate of 2.65percent. The percentage of disabled children in Pakistan are 43.4 of total people with disability; of which 41.6percent are female and 58.4percent are male. Disable children can affect family's finance, employment and health in shape of direct and indirect cost. Direct cost includes medical care like medicines and therapies and indirect cost include means expenses on transportations, education, caregiving etc (Staline & Allin, 2012).

REVIEW OF LITRETURE

Leonard et al., (1992) stated that the parents of disabled children spent extra time in care of these children and also lost their employment. Both medical and non-medical activities require for the care of these disabled children. Due to medical complications, the day care centers may also reject these children or may be expensive. Due to these factors the mothers may lost their jobs or curtail the duty hours.

Doe (1995) found that the disabled parents often have economic impact. These parents have often additional expenses connected with their disability like transportation, medicines or housing modifications. They also require extra expenses for caring of their children. For instance, for adults there are par transit systems or other alternative system available for their movement, but many of these par transit system does not allow the children of these disabled parents with them to go to school, or doctor clinic.

Meyers et al., (1998) concluded from their study in California that caring for a disabled child may impose direct costs on family for medical care, transportation, parental labor-market activity, and other health care needs. Among families who did incur special costs, expenditures averaged \$132 overall, and \$155 to \$163 for those with more than one ill or impaired child. If a child requires exceptional level of care from parent, the parent might reduce hours of work or leave the job to meet the child's need. Families caring for disabled children are likely to experience more material hardship and economic insecurity.

Burchardt & Metts (2000) concluded from their study in Washington that expenditures of disabled person which affected the households are often composed of medical costs, be they one time like wheel chairs and crutches or recurrent monthly dosages or therapies. If the illness persists, there is the addition of one more dependent member in the family who consume the resources of the other earner. In case of the death of working

member in the house may increase the ratio of dependent members to the earner. White's (2001) concluded from their study that in India, for labors associated with agriculture it is very difficult to fulfill the costs of disabled person. They fall in huge debts unlike those families who own lands and have more insurance options for their security to maintain their elite status. For example, 62percent of the households with more than a half-acre had to sell majority of their land within three years if they have disabled person. Also, the findings of Gathwala & Gupta (2004) showed that 60percent of families in India were severely burdened in relation to the physical health of other family member. While another 20percent have postponed their activities due to unavailability of financial resources.

Kandamuthan & Kandamuthan (2004) conducted a study in south India to examine the influence of disability on the economic functioning of the family and income expenditure pattern. About 300 families with normal children and 300 with abnormal children have participated in the study. The results showed that average expenditure of the families with a disabled child was 254 dollars per annum as compared to the 181 dollars per annum of a family with normal children. Further 90percent were deprived from the basic education and medical facilities and 21percent disabled children's mothers were unemployed as compared to 12percent of that of normal children.

Lee et al., (2004) examined in Washington the prevalence of disabilities among mothers and children, and analyzed how these disabilities influence mothers' work participation. It has been found that the disabilities of both mothers and children were more prevalent in low income population as compared high income population. Further the ration was higher in single mother families than married ones. Also both single mothers and married mothers with disability face more economic challenges and hindrances to workforce participation.

Analyzing data from the 1980 Medical Care Utilization and Expenditure Study, Newacheck and McManus (1988) reported that on average disabled children use more health facilities than non-disabled children. They examined that in Europe, families with disabled children are more unstable. Further, these families decline their fertility ratio, have more traditional gender roles, frequently suffer economically, and have unstable health conditions as well as lower well-being as compared to sound families.

Lawal et al., (2014) studied in North West Nigeria the parents of children with neurological deficits. The finding shows financial burden of parenting children with neurological disabilities negatively affects the socio-economic status of families. Poor socio-economic status played an in-avoidable role in the lives of the parents. The parents were supposed to meet the responsibilities of their disabled children and hence cut off from normal social lives.

METHODOLOGY

Purposive sampling was used to select respondents with disabled children from District Charsadda, Pakistan. Respondents aged between 20 and above who belonged to the socio-cultural profile of Pakistan and who had disabled children were the inclusion criteria for this study. Respondents were identified from a school for special children. Potential target respondents were approached and oral consent were obtained from them for the participation in the study because most of the respondents were illiterate.

This study contains the stories of thirty respondents, aged 22 to 62 years, who had disabled children and greatly affected their lives. All respondents were asked one question, to tell what were the affects of those disabled children on their families. Additional questions were asked if the researchers felt that some relevant information were not given or some aspect of the study were not fully addressed. Each interview took approximately one hour. Keeping the cultural and religious context, male respondents were interviewed by male researcher and female respondents by female researcher. During interviews notes were taken by the researchers and all the interviews recorded digitally for cross verification (Audio recording of the females because of the cultural restrictions). Transcribed written stories about each respondent were read and verified and the correctness of transcripts made from audio recordings was checked by the researchers. Content analysis were then performed. All the interviews of the respondents were analyzed using established methods for qualitative content analysis.

Name of the Respondents were Ayesha, Nabela, Fatima, Nazia, Jalwa, Ranigul, Madiha, Yasmeen, Farah, Nazish, Shela, Zainab, Wajeeha, M.Salman and Hamad Ali. Their ages were round about 35 years up to 65 years. Most of the respondents were female and two respondents were male. Majority of the respondents' occupations were household. Nazia was a school servant and her monthly income was Rs.3000/- and Zainab, Wajeeha were house servant and their monthly income were Rs.2000/- and Rs.5000/- respectively. M.Salman was a laborer and his monthly income was Rs.9000/- and Hamad Ali was retired from Govt service and was getting pension from Government and his monthly income was Rs. 40,000/-. Nabila had three disabled children two were mentally retarded and one was hearing impairment and Hamad Ali had three disable children, two were Hearing impairment and one mentally retarded. Jalwa had two mentally retarded disable children, Ranigul had two hearing impairment disable children. Yasmeen had two hearing impairment disable children. Zainab had one disabled child. Majority of the Respondents had only one disabled child, some of them had physical disability, hearing impairment, some were mentally retarded and other had visual disability.

ECONOMIC AFFECTS OF DISABLED CHILDREN

Most of the people in Pakistan are living below the poverty line. Poverty is the main cause of many social problems. The disabled children greatly affect their families. They are considered an economic burden because of the poor status of their families. Majority of the respondents were of the view that disabled children are burden on their economy, especially when the disability is of serious nature. Most of them live from hand to mouth. There are heavy expenses on their treatment which they cannot afford. As the disabled children require regular medical treatment for which huge amount of money is needed. For the treatment, we usually lend money and loans from other people and then it is very difficult to refund those loans as again we have to go for treatment and also other needs of the house have to fulfill. They cannot educate their disabled as well as other normal children because school fees are high. They cannot complete their wishes, they have other children to support them, and they can afford nothing. One respondent who had three disabled children replied while tears in his eyes that

“dwi khu zu char ta kenawalam”

“I am out of money due to them”

It shows the wariness of those parents who have disabled children and are poor. When they were asked about the government support regarding this matter, they said that government is not interested in to solve this problem. There are no hospitals for special children. Government do not provide financial support to us. One respondent said that

“waly Pakistan k hum Government shta su”

“Is there any Government in Pakistan”

This shows the level of dissatisfaction among people regarding government machinery.

One female was of the view that

“hukumat khu bs da maldaru dy nu mung ghareb khalak u, pa mung sok sa kai” *“the government is only for the rich people. We, the poor are just creatures who have no worth.”*

AFFECTS ON FAMILIES HEALTH

Regarding the effects of the disabled children on other family members most of the respondents were of the opinion that due to these disabled children our health is being affected. The disabled children cannot care of their own and their family members have to take care of them. Most of the respondents told that they are always worried due to which they became mentally ill; also, most of them had psychological problems. Those family members were more affected who were involved in the caring and rearing of these children. These affects were becoming intensified as the illness and disability of the children became serious. One respondents replied that *“my daughter cannot move and I have to move her from one place to another. I had operated twice because of this I got a back injury”*

Some of the respondents replied that they have to take care of them all the time irrespective that either we are tired and required rest or not. They further said that as they spend a lot of money on their disabled children so we don't have enough money left to buy medicines and balance diet for us. Majority of them said that we do not eat fruits and meat for months. One of the respondents said

"khpal zan rana heer dy khu bus da dwi gham okhwaru"

"we do not think of ourselves and our needs but all the time we think about their needs, this make us restless and worried"

AFFECTS ON EDUCATION

Education plays a vital role in the development of a nation. In the study area if on one side the disabled children are not able to get education; on the other side the education of other family members is also being affected either due to the financial reasons, due to the care of the disabled children or both of these. Most of the people of the study area are poor who cannot afford both the treatment and care of the disabled children as well as the educational expenses of other family members.

When asked that why the females are not going to schools, most of the respondents told that for the care and for the work of house the girl should stay in the house because we cannot afford to arrange servants. One respondent told that

"mung khwarak la sa na munu nu, tu la da talim khabarey kay"

"we don't have enough money for food, and you are talk about the education"

This shows that how much these people are poor and are living in miserable condition.

Female were not getting education because of the caring and rearing of the disabled brothers and sisters. On the other hand, when inquired about the status of male education, we came to know that the ratio of male education was also low because they have to earn money for their family. They were bread owners of their homes. The treatment of the disabled required money due to which the young children indulge in the workforce and hence their education was affected by their disabled siblings. When asked from a child who left education because of his two disabled sisters he replied

"che zu school ta zama nu mung la ba pesy sok gati"

"if I go to school then who will earn money for us"

AFFECTS ON EMPLOYMENT

Disabled persons have also great impact on the employment of other family members. It is usually indulging male members earlier into the labor force market for earning money for their families. Some respondents said that they have started second job. One person replied that

“da elaj ao kor kharchy baghair da dwem job na na pura kegi” “expenses of treatment and household are not fulfilled without second job”

Most of the females’ jobs have been negatively affected by these disabled children. They usually left the jobs because they cannot afford to manage both the caring of their children as well as to fulfill the duty’s requirements. One female said

“da mazura mashum pa kor k yawazy na sham prekhudy”

“I cannot leave this disabled child alone at home”

One other female told that

“It is very troublesome situation that on one side you don’t have money in the pocket to fulfill your needs and on the other hand you cannot go out for work because of the disabled children”.

The ratio of leaving jobs is higher among the females as compared to males and especially at that stage when the disabled child is growing up.

AFFECTS ON MARRIAGES

Findings related to this theme, most of the respondents told that marriages of the other family members are affected due to these disabled children. People reported that disability had been responsible for the delayed marriage of one of the other members of their family. It is especially in cases of male children instead of females. The parents were of the view that as they have one or more person with disability at home, and we cannot afford servants for taking care of them so in these situations no one is ready to marry their daughter with their son. One female said

“zu lewanae khu na yam che khpala lor oor ta ghurzum”

I am not mad that I myself throw my daughter into the fire”

It means that marrying daughters to someone in a home in which there are disabled children is considered a hell in this society. That’s why people don’t want marry their daughters.

One other respondent said

“zama lor tol umar da boj na shi wray”

“my daughter cannot bear and care these disabled children for whole life”

This shows the estrangement of people from the disabled children and their families. Even due to one or two disabled children people don’t want to make relationship with the normal people and at the end the normal persons suffer.

CONCLUSIONS

It is concluded from the above discussion that disability is considered as an economic burden by most of the respondents due to the excessive cost associated with their treatment and health care services. However, the study also showed an understanding of the real essence of the problems that majority of the respondents are facing problems just because of having some disable children in their families. We found that most of the respondents are weak economically and therefore the extra healthcare

costs of their disabled family members put an extra burden over their income and that's the only reason behind considering them a burden over their lives. Furthermore, the disabled children have some impact over the lives of the other family members, like they can affect the working schedule of their parents and the educational opportunities of their siblings because the cost that is required for their treatment could also be used for the educational purpose of their other normal siblings. The essence of the study showed an understanding of the real essence of the problems that majority of the respondents are suffering just because of having some disable people in their families. It was found that disabled children greatly affect their families. Majority of the problems aroused because of the poverty of the respondents. Most heinous problem was that of poverty which further creating other problems. The government and the charity trust should come to the front to help these affected families. They should provide medical facilities to the disabled children free of cost and arrange monthly stipend for them in order to give relief to their families.

RECOMMENDATIONS

- These special children should be provided free educational facilities according to their requirements.
- The disabilities of these special children should be treated free of cost.
- Re-habilitation measures should be adopted for these special children, in order to make a useful and effective part of the society.
- Along with special education, these special children should be imparted different skills according to their needs, interest and feasibilities.
- Regular stipend and other support may be provided to these special children, even if they are at their home.

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