



A STUDY OF PARENTING INTERACTIONS AND CAREGIVING

ENGAGEMENTS

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ABSTRACT

Parenting is assumed to be a shared responsibility. However, it is unlikely that mothers and fathers will engage in similar caregiving roles. Saraff and Srivastava (2008) observe that gendered division of labor in parenting is one of the ubiquitous features of Indian families. This gendered nature of caregiving engagement is likely to render different experiences and outcomes to mothers and fathers. This study looks into how fathers and mothers perceive their caregiving roles and how they engage in their perceived roles.

This study is organized in two parts. The first part will discuss how fathers and mothers perceive their caregiving roles to their child with disability. Here, the analysis and discussion will be on how fathers and mothers differ in terms of their role perception. The second part of the study traces various domains of caregiving and discusses the nature of caregiving engagement in family, community, school, and health care system.

KEYWORDS: Parenting Interactions, Caregiving Engagements, mothers perceive, parenting

INTRODUCTION

While looking at the similarities and differences of fathers and mothers with respect to their caregiving roles in families having children with developmental disabilities, Pelchat, et al (2003)

note that the parental engagements are largely shaped by the gender of the parents. The role perception differs considerably among fathers and mothers. Evidences from their study have contributed to the conclusion that fathers and mothers differ in terms of caregiving experiences and outcomes. In the present study, the researcher examined how parents perceive their caregiving role and how it varies when they respond to the caregiving needs of adolescent boys and girls with disabilities.

The parental accounts from this study reveal that the nature of fathers' and mothers' caregiving engagements is largely shaped by patriarchal norms. The fathers in the study reported that their engagement in caregiving is very limited. They perceive that their prime role is to ensure economic support to their family. The caregiving narratives of the fathers highlight concerns about sustaining financial support to the family and to their child. The hardships stemming from poverty, unemployment, and limited income are some of the prominent themes that surfaced in their narratives. The fathers in the study hold the view that caregiving to their child with disability inside the home is the responsibility of the female members in their family, and it has to be managed by either their wives or other female members.

Whereas mothers in the study perceive that they have to engage in caregiving responsibilities, which stretch beyond their domestic sphere. The present study found that irrespective of socio-economic background of the research participants, female members like mothers, sisters, female cousins, daughters-in-law and grandmothers are largely assigned with the responsibility of caregiving to children with disabilities in family settings.

One of the participants in the study, Mulla, who works in the capacity of caretaker in his village, attests that fathers seldom contribute to the caregiving tasks in the family settings.

I cannot attend to these children throughout the day. If I do not work, my entire family has to suffer, and they will starve. My wife does all caregiving responsibilities throughout the day. I advise parents about the problems of children with disability [as part of Caretaker's work] and how to attend to those problems. But the fact is that my wife handles most of the caregiving tasks at home, and only she knows how to attend them...People think that both mother and father equally share the caregiving responsibilities. In my case, I am an absentee caretaker... It is the practice in almost all families having children with

disabilities.... In every case, mothers take the major responsibility of caregiving to their children. My elder daughter taught Mousin and Mobin how to count up to 20. She used to spare time to teach basic things. After her marriage, my younger daughter teaches ... I don't know what will happen when we marry her off.

Mulla, father of two sons with Multiple Disability.doc 12.7

The interviews with many other parents in the study corroborated the observations of Mulla. Although Mulla is aware of the caregiving hardships that his wife experiences, he expects that his wife and daughters have to occupy a major role in caregiving to his two kids with multiple disabilities. He can hardly envisage the role of men in caregiving even in the absence of female members in his family in the future. The statement that 'only she knows how to handle them' reinforces commonly held perceptions that women are preordained to take up the caregiving role. Such beliefs can be interpreted as a reflection of deep-rooted patriarchal structures that feminize caregiving roles and responsibilities.

The accounts of caregiving from fathers also reveal that the gendered role expectations in caregiving stretch beyond the immediate family members. For instance, Dhaji, father of an adolescent with Multiple Disabilities, revealed that when his wife is not available to attend to his child, he expects that women in his extended family who live in the neighbourhood should take up the caregiving responsibilities.

We take help from his cousin sister to take care of Vital when we have to go to farm or for some other work or function. Her support was a great relief. After her marriage, it is very hard for us...My elder daughter spends time with Vital when she visits home. She feeds him. He is not able to make sense of his toilet needs. He may urinate in bed, and he may defecate in his own clothes. Mostly, his mother does the cleaning work. I help her occasionally.

Dhaji, father of 18 years-old boy with Multiple Disability.doc 12.5 The order in which caregiving responsibilities are passed from one female member to another in the family indicates that male members are less likely to take up this role.

In contrast to fathers, the account of caregiving from mothers in the study reveals that they seldom pass on their caregiving responsibilities to other family members. In many instances, it was apparent that mothers were unduly burdened because of the multiple responsibilities related to household work, daily wage work, and caregiving to their child with disabilities and to other family members. However, they seldom pass on their caregiving responsibilities to any other member in their family including their daughters. For instance, Dilshad, mother of an adolescent boy with Cerebral Palsy shared that she is uncomfortable to pass on her caregiving responsibilities to others. Being a single parent, she has to play the dual role of a breadwinner and a caregiver. Her husband died because of alcoholic dependence when her child with disability was less than five years old. She was ousted from her husband's family, and she does not have a house to stay. She has to support her family financially with her daily wage work. Despite the fact that her child needs constant support, she hesitates to seek help from her married daughters.

I work in farms within the village...I get Rs.100 as daily wage. I have to manage all household expenses from the daily wage... I never asked any help from my daughters. It is not a practice to ask help from them. Both of my daughters got married. And they have children. They visit our home occasionally. I do not expect any

Caregiving Engagement: Negotiating Roles

For many participants in the study, farming and daily wage work are the major sources of livelihood. Unemployment and persistent drought in the region offer them very difficult choices in negotiating their responsibilities at home and work place. It is a serious concern for both fathers as well as mothers who participated in this study. When both the parents have to engage in daily wage work, their child remains unattended. The parents in the study shared their helplessness when they have to negotiate their roles at home and work place.

The fathers in the study cited limited flexibility in the work schedule as one of the major constraints in responding to the caregiving needs of their children with disability at home. They expressed that their preoccupation with wage employment outside the home gives them very limited opportunity to be with their child. For instance, Santhosh, father of a child with Autism Spectrum Disorder expressed that his primary role as the breadwinner to his family forced him to be away from his home. He expressed his difficulty in attending to his child in following words.

I have to shoulder many responsibilities at home. I have to take up any work outside the home whether it is fetching water, collecting firewood, to bring grains from PDS shops and so on. I am the only bread winner in the family. My wife cannot take daily wage work as the oldest child has the problem... We are six members. My parents are staying with me. They are old. They are not in a position to contribute economically to the family...I get about Rs. 200 as daily wage from my work. I don't have any regular income. Sometimes I get work and sometimes I don't ...My family members eat when I have some work. We remain hungry when I am unemployed. I don't want to beg for money...I have to feed my family. I have to earn money to support the education of my second child. I also have to keep some money for medical emergencies. Recently, my mother met with an accident. A vehicle ran over her leg...I borrowed money from others to meet the medical expenses.

Santhosh, father of 17-yearsold boy with Autism Spectrum Disorder.doc.18.7

Considering the nature of poverty and unemployment which persists in rural India, it is plausible that these factors impose many hardships on family and caregiving relationships. Santosh shared that he gets only limited daily wage work in his village and during the agricultural off season he moves out of the village in search of jobs. It leaves him little time to spend with his child. Some parents in the study shared that since they do not have land, they have to work in other's fields. They have to work at their land lord's beck and call. It leaves them with little flexibility to stay away from their work placesupport from others including my daughters.

The Domains of Caregiving Engagement

The caregiving engagement of parents in the study can broadly described under following headings a) caregiving engagements of parents domestic sphere/family setting which include caregiving tasks such as attending to activities of daily living, facilitating physical mobility of the child when there are mobility constraints, attending to medical care needs of the child, mentoring, imparting vocational skills, and engaging their child in leisure activities b) caregiving engagements in community setting which includes caregiving tasks associated with socialization of child outside the family settings, monitoring the mobility of the child, inculcating age appropriate behaviours, and providing protective measure from public stigma c) caregiving

engagements in medical care system which includes caregiving tasks associated with the facilitating medical care such as exploring medical care for their child, attending physical care at the home, and ensuring regular medicine d) caregiving engagement in education system which includes facilitating educational needs of child that includes, searching appropriate schooling options, seeking admission for the child, accompanying their child to school, attending classes along with the child, attending school meetings, teaching day to day survival skills such as shopping for grocery, imparting vocational skills, and encouraging their child to be independent.

In order to obtain a better picture of the unequal distribution of caregiving work among fathers and mothers, it is necessary to look at how fathers and mothers contribute to specific caregiving needs of their child with disability at home. It is noticed that parents have to respond to a range of caregiving needs when their child enters into an adolescence stage.

Caregiving Engagement in Domestic Sphere/Family Setting

The nature of caregiving engagement also varies according to the family types. Some of the observations from the study negate the common perception that joint families in rural areas provide more helping hands in caregiving. The parents who lived under the joint family structure reported that when it comes to caregiving to a child with disability, their extended family members seldom share the responsibility. It was noticed in a few families that grandparents supported the caregiving needs of a child with disability. However, they could not contribute significantly because of their deteriorating health conditions. Mothers in the study shared that they were often ‘sandwiched’ between the tasks of caregiving needs of their child and the aged members in their family. Many of the participants who live in nuclear families shared that both fathers and mothers have to work outside the home to support the family. It imposes a limitation on parents about how to negotiate responsibilities at home and work place. Some of the important caregiving engagements at home are discussed below.

Engaging Activities of Daily Living

The fathers’ engagement in the facilitation of their child’s Activities of Daily Living was found to be very limited. It was more noticeable in the case of their engagement with self-care needs of their child. When fathers listed their caregiving activities, only very few of them listed assisting

self-care as one of the activity in which they regularly support their child. In some cases, there were contradictions in what fathers initially stated and their subsequent disclosure at later stage. For instance, Pankaj, father of a child with Autism initially expressed that

We don't feel uncomfortable about attending to his toilet needs. He is our child and it is our duty to provide care to him. When somebody gets admitted in hospital in a bed ridden condition, the nurses do it for you. This is our child who needs support. We don't feel bad about it.

Pankaj, father of 17 years-old son with Autism.doc.9.1

However, Pankaj's disclosure at a later stage contradicted his earlier statement. It was clearly indicating that he seldom attends to the self-care needs of his child.

He needs support from his mother or step mother to manage his toilet needs. He also needs support for taking bath. We are tired of doing it for him but there is no alternative. We have to do it...One major problem that we still have to deal with the management of his basic toilet needs. .. I get angry and tired of handling it. I get irritated when it happens in front of guests. I feel low and inferior in front of my guests.

Pankaj, father of 17 years-old son with Autism.doc.9.1

For many mothers, there was hardly any choice to abstain from their responsibility to attend the care needs of their child. For instance Paru, mother of 18 years old boy with severe Cerebral Palsy gives an account of her caregiving responsibilities that contribute to a dehumanizing experience.

Santosh does not have any specific schedule with respect to his activities of daily living. There is nobody at home to take care of him when we are away. Nobody in the family except me understands and responds to his needs...We cannot take him to the farm. My daughters have to attend their school and they will return to home only in the afternoon. They do know how to feed Santosh. They are not very much attached to him. Everything I have to manage including his toilet needs. We do not have toilet. Santosh does not have specific toilets routines. Many a times he moves around the village and enters in others

households. When I return from the work and reach home there will be a group of people outside my house shouting at me and complaining about my son that Santosh defecated in their households or near their house. I will then go and clean the spaces wherever my son has defecated. I used to feel bad and embarrassed earlier but now it has become a part of my everyday life. The most difficult challenge is to attend to complaints from village members about Santosh's defecation habit. It is me alone who has to face them. None of the family members helps me. Even my husband never helps me. It is the fate of a mother. I do not have any option. I have to manage the household and I have to attend Santosh.

CONCLUSION

This research shows that the effects of decreased personhood extend beyond disabled children to their families as well. A healthy male infant is regarded as the "perfect baby" in patriarchal families. When parents fall short of the ideal of a "perfect baby," their role as parents is called into question. Being a mother means nothing if she can't give birth to a strong, healthy son. Participants' parents reported feeling unappreciated by their wider social networks. They discussed the many times they were excluded from family and friend events because of their sexual orientation. A child's infirmity, as well as the child's and parents' presence at social or family occasions, is seen as a major stain on the event's auspiciousness and the family's prestige.

According to the parents' accounts, their child's lower personhood status restricts their opportunities in terms of schooling, friendships, and health care. Several parents described experiences where instructors or doctors cast doubt on whether or not their disabled kid would benefit from special schooling or medical treatment. As a result of these kinds of tragedies, some parents may begin to hope that their disabled kid would pass away at a young age.

This research explains how parents use cultural, medical, and legal norms to justify their belief in their child's decreased personality. Many prenatal diagnoses, for instance, might influence parents' expectations and outlooks on their unborn child. Prenatal diagnosis serves to clarify and strengthen the prevailing concept of a human being. Parents who participated in the research and

had access to prenatal diagnostics reported that their doctors had urged them to terminate the pregnancy after discovering abnormalities in the baby. Nonetheless, there were others who choose to give birth.

Life with a handicap is sometimes depicted badly in an effort to induce parents to terminate the pregnancy with probable defects. Medical experts' attitudes and prenatal diagnosis both contribute to the devaluation of persons with disabilities. It can review and reject claims of personhood for disabled individuals. It tells parents what they should value in their children in terms of physical appearance. Prenatal diagnosis has led to an idealization of some forms of human anatomy. Critics within the family and among medical professionals have pointed to the parents' refusal to use reproductive technology to terminate the abnormal baby.

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