

EXPERIENCING AND COPING WITH SOCIAL STIGMA: STORIES OF MOTHERS OF DISABLED CHILDREN IN SOUTH PUNJAB, PAKISTAN

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ABSTRACT

Our society has many social and cultural inequalities, common people face discrimination, inequality and hatred because of one's religion, race, gender and social status. Life for disabled children and their parents is not easy go, they both have to suffer in their respective social environment. Our society is patriarchal, and all evil or bad things are attached to females. So, the first explanation for the birth of a disabled child revolves around between mother. From family members to neighbours, everyone blames the mother. This exploratory study is aimed to find out the social stigmas attached with mothers and how they cope with the social stigma to live a normal life. The study is qualitative by design, researchers used purposive sampling and used the in-depth interview as a tool for data collection. A total of 10 mothers of disabled children were interviewed, and data were analyzed by using thematic analysis. Results show that mother face and experience inhumane/ undesirable behaviour from family members and also from neighbours. They use a lot of different coping strategies such as religious, cultural and different social therapies to avoid the additional socio-psychological pressure due to the social stigma attached with them. Some of them also find social support from their husbands and in-laws but the overall behaviour of their village's people remained negative and discouraging.

Keywords: Social stigma, Disabled Children, Coping Strategies, Social Life

1. Introduction

Children with disability need special attention and care from family members and mothers. It is the core duty of parents to invest their time and financial resources to make their disabled children socially trained. The social life of these children and their parents specifically mothers are very hard and difficult. Children and mothers face the social stigma differently, but the intensity of stigma is the same (Ali & Rafique, 2015). Pakistan shares 15 per cent of disability around the world, with almost 31 million people have some symptoms and characteristics of any disability. The absence of reliable data regarding the number of disabled populations arise many questions for policymakers. Although the 3rd December of every year is observed as Disability Day in Pakistan, awareness about disability causes still lacked in the common population (Rathore & Mansoor, 2019). SAMSON and Shehzadi (2020) rightly questioned the methodology used for

data collection regarding different categories of disabilities. They argued there is a dire need to conduct a fresh survey with appropriate categorization of disability, trained and knowledge equipped enumerator should conduct and report the survey results. Pakistan still unable to fix the problem of a uniform definition of disability. There is no national-level department or registry which has accurate and updated data of disabled persons (Razzaq & Rathore, 2020). It is well-established fact that the family members and disabled person, both went through very tough, undesired and unacceptable social behaviour. The birth of a disabled child brings significant changes in the life of family members, for parents, challenges are even heavier as they are core responsible for the upbringing of the child (Ali & Rafique, 2015). The pressure of neighbourhood and society mount on families which have children with disabilities, in some cases families were forced to conceal the fact that they have a child with a disability. Relatives and other family friends refuse to do engage in marital relation because for them it is a genetic issue and will affect their children also in future. People also tend to explain the birth of disabled children with the sin of parents, this explanation forces the parents to develop a sense of criminality and blame themselves for all the evils that happened to the family (Shakeel Ahmed, 2015).

People stigmatized the family members who are associated with disable or mentally ill children. Stigma can be explained as negative or stereotyping or discrimination and rejection of people who are suffering from any disability (Karnieli-Miller et al., 2013). Courtesy stigma is referred to as the impact on the people who are associated with disabled children; most importantly family members and close relatives of those children (Goffman, 1963). Mitter, Ali, and Scior (2019) explained that there are four types of stigma, first one is public stigma which means the attitude of the public towards a stigmatized group. The second form is self-stigma, which happened when stigmatized people got aware of public stigma and internalized it. The third form is a courtesy stigma or family stigma, in this situation family members develop negative emotions for themselves which may result in avoidance from social interactions and concealment of facts. Internalization of courtesy stigma gives rise to the feeling of affiliation with a disabled person, lead to the fourth type of stigma, affiliative stigma. Green (2003) argued that there is little attention given by social scientist to explore the phenomenon of courtesy stigma, most studies focused on the stigma and problems of people who are facing any type of disability. The issue of distress and emotional well-being of mothers and family members of disabled children has got tiny space in academic debate.

Family members of mentally ill people do support them from financial needs to social and psychological needs. They often face the deviant behaviour of disable person and tolerate it with dignity, even they need to convince other people about the deviant behaviour of a mentally ill member that his act is beyond his mental strength. Mothers spent the bulk of their time with the mentally ill children, and this burden of care turns into a social stigma. The process of socialization and caring for disabled children is time taking and a hectic job. For this purpose, mothers specifically and other family members generally take the responsibility to ensure their socialization. They often shortened or abandoned their social activities to make sure that they are available for disabled children (van der Sanden, Stutterheim, Pryor, Kok, & Bos, 2014). The impact of raring or having a child with a disability could be painful for the mother of a disabled child, especially for those who were not prepared to face this reality. She needs to raise her children in a non-conventional way which sometimes changes the meanings of maternity for her, extra care and burden of social responsibilities change her behaviour dramatically. Her relationship with other family members, often shown negative and the conversation turned into harsh discussions. She showed her helplessness and disbelief because she could not change the situation for herself or family members (Barbosa, Chaud, & Gomes, 2008).

2. Review of Literature

Küçük and Alemdar (2018) concluded that being a mother of a disabled child is traumatic even the disability is a smaller one. Mother of disabled children adopted all-new ways to live a social life. Disabled children are dependent on parents with different degree of dependency. Parents often need to sacrifice their social, familial and economic activities which resulted in stress and economic cost for the family. The social and psychological well-being of mothers affected negatively, and it is directly related to life satisfaction. Song, Chun, and Choi (2015) studied the effects of fathers' participation in parenthood and its association with mothers perceived social stress. Their study confirmed that if fathers of disabled children help mothers in the process of socializing of the children, it would have a positive and good effect on the mother's wellbeing. Although this study also revealed that children with extreme disability or out of control might have negative effects on both mother and father and it increased the stress level and anxiety during the process of parenting. Findler (2000) tried to find that how important is the support of grandparents to assist the parents in socializing the disabled children. Parents who are responsible to take care of physically disabled children spent a lot of energy, time and money. Children need special therapies, physical activities and more attention from parents than a child without any disability. In this process support of family members especially grandparents are pivotal to share the burden and stress of parents. Shenaz Ahmed, Bryant, Ahmed, Jafri, and Raashid (2013) interviewed 30 mothers and fathers of Down syndrome children. They found that parents associated the birth of a Down syndrome child with a positive note because of their religious belief. However social and cultural association showed different results, people and family members stigmatized parents for having Down syndrome children. Religious therapy was a core coping strategy for them to minimize the effect of social stigma. Grover et al. (2017) reported that there are no formal caregiver institutions for mentally ill children in a country like India. Most caregivers are the family members of mentally ill children. They found a majority of parents or family members who are involved in the caregiving of mentally ill children reported the stigma. Associative stigma is the dominant form that disturbed mothers at a high level, caused unhappiness, emotional disability and blaming oneself for all evil things. Kimura and Yamazaki (2013) concluded in their study that mothers who have multiply disabled children faced a series of social and psychological problems. Caring for the children all day is a burdensome assignment. Mothers narrated that they are not exempted from other household responsibilities. Most mothers perceived husband and other family members support as a positive thing, it helped them to cope with the social stigma. Greer, Grey, and McClean (2006) concluded that mothers of intellectually disabled children agreed with the statement that their children were a source of happiness, family cohesion and self-fulfillment for the family. They also argued that formal social support plays a positive role in mobilizing family members to take care of children along with mothers. Oti-Boadi (2017) reported that mothers of intellectually disabled children faced stress, psychological problems and social adjustment problem. Although raising disabled children is a very demanding job but at the same time, it gives mothers a sense of pleasure, hope and satisfaction. Spiritual and religious therapies are the best coping strategies to reduce the impact of social stigma. Yousafzai, Farrukh, and Khan (2011) suggested that one positive aspect of being a mother of disabled children is the empowerment of mobility. They can move to rehabilitation centre and study centre for their children education and therapies. The lack of support from family and lack of facilities in rehabilitation centres are affecting them negatively. The role of community-based rehabilitation is pivotal for the care of disabled children.

3. The Objectives of the Study

Followings are the objectives of the current study;

1. To explore the social behaviour of people with mothers of disabled children
2. To explore the lived experiences of mothers of disabled children.
3. To find how the mothers cope with social stigmas attached with them as being a mother of disabled children.

4. Methodology

The present study is a qualitative study and exploratory in terms of research purposes. The researchers used the interview as a tool for data collection. Through the semi-structured interview, the researchers interviewed 10 mothers of disabled children. The researcher used purposive sampling as this sampling technique is suitable for the unique and extraordinary situation and cases. All the 10 participants who are selected for the study belongs to the village of District Dera Ghazi Khan. Before the interview, the researchers briefed participants about the research study and sought their consent to participate as respondents. The researchers assured participants that their identity will not show anywhere, and information will be used only for research purposes. Respondents' names locations and family identity will be kept anonymous and confidential. South Punjab in general, and Dera Ghazi Khan in particular, is considered the most backward and conservative area. The patriarchal family system is a dominant feature of this society. The researchers tried to get appropriate information without breaking their traditional decorum.

5. Results and Discussion

5.1 Experiencing the Social Stigma and Social Support

The pain of knowing that I have given birth to a disabled child is indescribable. We were very happy and expecting a baby. At the time of birth, we were traumatized by confirming our first baby is not a normal child, told one of the participants. Experiencing trauma regarding the birth of a disabled child can bring a lot of negative stress to parents. Gill and Liamputtong (2011) reported the same findings and concluded that to avoid social stigma, the role of coping strategies is critical. *Sara told that she is lucky that she has a very kindhearted husband. He supported her in every matter after the birth of our first child. She further explained that the behaviour of the community is not encouraging, often people use negative words and phrases for my child.* Davis and Manago (2016) concluded that many studies documented the social stigma faced by mothers of disabled children. They also found that social stigma devalued the social position. Dadkhah, Ghaffar Tabrizi, and Hemmati (2009) elaborated that the health quality of mothers of disabled children were low compared to other mothers. Coping strategies have a positive correlation with the health quality of mothers of disabled children. *Amna narrated that her health is not good after the birth of a baby boy. She experienced severe stress and stomach problems. She told that her husband is not cooperative at all. He refused to go to a doctor for her routine checkup.* Taanila, Syrjälä, Kokkonen, and Järvelin (2002) concluded that spouse support has a positive relationship with coping with the social stigma. The families with a high rate of coping scores have a better

understanding of shared responsibilities. Parents both husband and wife accepted the reality and acted accordingly. Sen and Yurtsever (2007) evaluated that the families which have poor knowledge about their disabled children faced the greater challenge of social adjustment. Mothers often reported extreme stress and emotional instability, which affected their relationship with spouses. Mothers faced social exclusion from social events because caring the disabled children is their core responsibility. Most of the participants have experienced same type of social stigma. The situation of every mother with disabled children is identical, same stress, anxiety and social adjustment problems. Li-Tsang, Yau, and Yuen (2001) reported that parents with better understanding and strong spousal relationship performed well in coping with stress and anxiety. These parents are always open to seek social support from family members and the community. Button, Pianta, and Marvin (2001) examined the role of partner support in caring for disabled children. They argued that the husband's role is very complex and under studied regarding caring for disabled children. Mothers of disabled children explained that they need their husband's practical support rather than emotional support. Rasheeda narrated her story of being ignored in the family. *She quoted her husband and mother in law blame her for the birth of disabled children. My family members do not support me in caring for my disabled children. I used to bear the double burden of caring for my disabled children and doing domestic chores.* Karnieli-Miller et al. (2013) reported that family members of disabled children often face rejection, blame and avoidance by the community members. Mothers experienced shame, disappointment and inhuman behaviour from relative, neighbours and community. Aldersey et al. (2018) interviewed 20 parents of intellectually disabled children in the Democratic Republic of Congo. They concluded that almost every family member of intellectually disabled children faced social stigma. The intensity and types of stigma can vary from culture to culture. Tsai and Wang (2009) reported that mother with intellectually disabled children experienced a high level of stress and strain. They also have received minimum social support from family and community. They concluded that social support and social stress has a significant negative relationship. The majority of the participants reported that they are living a life with extreme pain and their value in the family is almost zero. We lacked social support, social empathy and our social position is undermined due to our disabled children.

5.2 Coping Strategies and Social Life

Cankurtaran Öntaş and Tekindal (2016) concluded that mothers of disabled children sacrificed their social and personal life. Their social mobility is restricted to only hospital and schools. They did not have time for family social gatherings. *Naghma narrated that she has abandoned her social activities after the birth of my disabled children. I have devoted myself to his care and I am happy God has chosen me for this.* The religious and spiritual coping strategy is the most effective coping strategy for mothers of disabled children. *Natasha responded that she felt herself a blessed woman that God has given me the responsibility to take care of my mentally ill daughter. I spent all day with her, although my burden of work has doubled, I am still happy.* Sharak, Bonab, and Jahed (2017) reported that religious therapies are the best to cope with mental stress for mothers of mentally ill children. Religious belief gave them immense support and satisfaction. Resultantly, mothers felt much better after practising religious coping strategy. Biesinger and Arikawa (2008) interviewed 27 couples who have children with developmental disability to explore the relationship between religious belief and happiness. Mothers have a positive feeling after performing religious activities or saying prayers. *Ismat told that whenever I feel dejected or gloomy, I used to visit my parents' home. I feel relax there, no one blames me for the all evil things that happened to our family.* Most participants have narrated same type of escape whenever their stress level is out of control. Some of them used to visit their sisters or friends' home to avoid the

extra pain of social stigma. van der Mark, Conradie, Dedding, and Broerse (2019) described that social support from husband and family members is vital in reducing mothers' social stress. The natural obligation or order of God gave mothers a reason to take care of disabled children without complaining. Some of the mothers told that involuntary learning made them use to daily care work. Initially, it was painful to listen to people's negative gossips. *Durdana a mother of developmental disability children, expressed that she is now learnt to live with her baby and his illness. Family members often blame me, but I remained calm and composed.* Social coping strategies like singing, reciting Naat or Holy Quran and visiting the place of their choice were effective in controlling stress.

6. Conclusion

Researchers observed that the life of the mothers of disabled children is pathetic and tough regardless of the type of disability. The role of the community is negative and discouraging, though some community members are very supportive. Mothers faced all types of social stigma. The dual burden made their life difficult to live. Some mother considered themselves lucky because their husband was cooperative and provided full social support. The coping strategies played a vital role in making the life of the mothers comfortable. Religious and spiritual coping strategies are popular among all mothers. The second most successful strategy was to have a gossip with near and dear ones. Singing and reciting Naat/ Holy Quran were successful stress release activities.

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