

Affiliate Stigma of Mothers of Differently-Abled Children: An Exploration

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ABSTRACT

Affiliate stigma involves the extent of self-stigmatization among associates of targeted minorities or already negatively labelled people. In psychology, the nature of stigmatization has been studied vigorously in the field of mental illness. Comparatively stigma is a less studied but important phenomenon in the field of disability. Caregivers play a major role in the lives of children with developmental disabilities. The quality and efficiency of their caretaking may be affected by the manifestations of stigma. The objective of the current study is to explore the nature of affiliate stigma associated with mothers of children with developmental disabilities such as autism, intellectual disabilities, and ADHD etc. Data were collected using a semi structured interview and 16 mothers were participated in the study. Thematic analysis was carried out to understand the underlying themes and themes identified were belong to type of disability, nature and severity of disability, attitude of family members, coping patterns, attitude of society in general, professional support, time duration after diagnosis. Details are discussed in the paper.

Keywords: *Affiliate stigma, Developmental disabilities, Mothers, Thematic analysis*

Having and caring for a child with a disability may bring multiple challenges to parents, such as additional financial burdens for treating their child's condition, dealing with the child's problematic behavior, and social stigma associated with disabilities (Baker & Heller, 1996; Lecavalier, Leone, & Wiltz, 2006). This in turn results in experiencing more physical health symptoms, negative affect and poorer psychological wellbeing for parents of children with a disability than parents with normal children (Ha, Hong, Seltzer, & Greenberg, 2008; Seltzer, Greenberg, Floyd, & Hong, 2004; Singer, 2006). Apart from the personal challenges, social aspects have a critical role in this regard. Social support and stigma are such kinds.

According to Corrigan (2000) stigma can be explained as a set of prejudicial attitudes, stereotypes, discriminatory behaviours and biased social structures affirmed by a sizeable group about a minority discredited group. Link and Phelan (2001) describes it in terms of

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processes of labelling, stereotyping, separation, emotional reactions, status loss and discrimination in a power situation.

In recent decades, researchers have been vividly focused on various types of stigmas apart from studying public perceptions of stigmatized individuals. Self-stigma refers to the targeted individuals' internalization of public's negative bias and courtesy or associate stigma is pertaining to the internalization of public perceptions by individuals associated with the targeted ones (Goffman, 1963). In 2008, Mak and Cheung made an attempt to distinguish between the stigmatic perceptions of the public about family caregivers (i.e., family stigma) and family members' internalisation of these views, which has been termed affiliate stigma. Affiliate stigma refers to the extent of self-stigmatisation as experienced by associates or caregivers of targeted individuals and the corresponding psychological responses of these associates. They developed the concept of affiliate stigma on the basis of the theoretical understanding that stigma consists of cognitive (stereotypes), emotional (prejudice) and behavioural (discrimination) components.

Disability and related stigma make noticeable consequences that go beyond the stigmatized individual, but it also affects those closely associated with them like parents, family, relatives and neighbours. The type of relation plays a role in this concept. Stigma increases the perceived burden of care giving tasks in parents (Green, 2003) and parents sometimes blame themselves for their child's condition (Mak & Kwok, 2010). Disabled people and their families' reports of stigma put more focus on hurt they experienced from losing social contacts and the ways in which their behaviour shaped how they were perceived by others. Having a disability can become a two-fold challenge for an individual. Firstly, one has to navigate in a primarily able-bodied society and face its accompanying struggles. Additionally, society's misconceptions about disability, stereotypes and prejudice of others, may lead to discrimination.

The stigma can also be varied with respect to disability the individual has. According to Wnoroski (2008), as seemed to be an invisible disability, autism was certainly susceptible to stigmatization against both children and parents. Ng, Lam, Tsang, Yuen and Chien (2020) in their study found increased amount of affiliate stigma among parents of children with autism. Mourya, Singh, and Rai (2016) revealed that the intellectually disabled child's activity limitation was significantly positively related with stigma and restriction in social life of parents.

Mostly stigma associated with disability is culturally sanctioned and such cultural attributions to the cause of disability play a crucial role in shaping attitude towards the person with a disability and their caregivers. In a study by Ghosh and Magana (2009) found certain attributions such as bad maternal blood, karma, or punishment for the actions or sins from a previous birth, as the cause of disability in the child.

Though studies are undergoing in the field of disability and stigma, affiliate stigma is a comparatively newer concept and less explored one, especially in the Kerala culture. As mothers are mostly considered to be the primary caregivers, the current study is an attempt to understand various aspects of affiliate stigma experienced by mothers of disabled children.

Objective

To explore the affiliate stigma experienced by the mothers of differently-abled children.

METHODOLOGY

Participants

Participants consisted of 16 mothers of differently abled children including mental retardation, cerebral palsy, autism, learning disability, ADHD, speech and language problems and the like; selected from Community Disability Management and Rehabilitation Programme (CDMRP) advanced clinic at Calicut University campus. Participants are aged between 23 to 46 years. Out of which 14 mothers were qualified matriculation and the rest two were educated at degree level. Out of 16, eleven mothers had male children and five had female children with certain kind of disability. Children were aged between four to 14 years.

Instrument

A semi structured interview schedule was used to elicit information on affiliate stigma of mothers of disabled children. The interview comprised of questions that focused on different areas such as demographic information, experiences of having a disabled child, and how they adapt with the situation. Some of the questions included were as follows: How did you feel when you first found out the condition of your child? How do people in society react to you and your child? What are the major strategies used in dealing with stress associated with caring for your child? Probing questions were also asked where necessary to obtain information, clarify a point, or expand on ideas.

Procedure

Investigator first consulted the Director and other professionals of community disability management and rehabilitation programme (CDMRP) at the Department of Psychology, University of Calicut to get permission to collect data from different community clinics of the same. After getting consent from the authorities, the mothers who were visiting the clinic were introduced first and requested them to participate in the research work. The queries and doubts were cleared. Face to face semi structured interview was carried out to collect the research data. Each interview took approximately 20 to 40 minutes.

With the permission of the participants, the researcher also used a voice recorder to record the interviews. Thus, use of audio recorder ensured that a detailed account of the interview was captured and allowed the researcher to concentrate on the research proceedings. The data were collected over a period of three weeks.

Data Analysis

Thematic content analysis was employed to analyse data. Thematic content analysis involves identifying, analysing and reporting patterns (themes) within data and minimally organises it and frequently it goes further than this, and interprets various aspects of the research topic (Braun & Clarke, 2006). The researcher made recordings and notes of the interviews conducted. The recorded tapes were encoded and interpreted using the tones and contrast in the voices of the participants. This data was then transcribed. The researcher repeatedly read the transcribed data as well as listening to recording to pin point key words, trends, and themes. The key themes were identified and transformed into codes.

ANALYSIS AND DISCUSSION

The objective of the study was to explore the factors associated with affiliate stigma of mothers of differently abled children. Researchers tried to explore the variable affiliate stigma mainly in a three-dimensional way as the conceptual frameworks demonstrated by Mak and Cheung (2008) on affiliate stigma. Thematic analysis provided themes which can

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be primarily categorised under social, cognitive, affective and behavioural components. Several subthemes have also been identified and discussed as follows.

The stigma experience shared by the participants had more variety and created severe impact. It was just due to the fact that they had a ‘different child’. Most of the experiences which created severe impact were from in-laws, family and relatives, whereas other who experienced stigma was from neighbours, friends and society in general. They usually comment cursing words etc and even nonverbal gestures would be used to express it out. The mothers reported that in-laws, especially mother in laws and sister in laws commented that it was her bad luck and God is cursing them through such a child. Others also said that it’s due to the bad behaviour they had shown to others, earlier and the child is like a punishment from God. A few also reported that ‘it’s enough for you to control your ego. The family usually express control for the disabled child in play, free interaction or touch their personal belongings compared to others.

Some of the mothers reported that they had avoided the social gatherings such as marriage function, long journey with family members and friends, theatres, hotel etc. They reasoned it with the anticipation of fear of confronting the public and relatives. Many of them embarrassed because of their child’s behaviour in crowded settings earlier. Unpredictability of such behaviour made them to avoid such social gatherings.

At the same time, two mothers of mentally retarded children with fifteen years of age reported in a more positive way. They did not feel odd to take their children to outside as they want to explain or show the world that their children were not different from others. But they also reported some negative experiences they faced during social gatherings. Despite such unpredictability of such behaviour of their children they were ready to go outside with them.

In terms of appearance a family member commented a child as a ‘creature’. The parent reported that the common people either show unnecessary interest in the child or ask too many questions while the parents are not interested to answer. People ask “whether do you have any other child and how is his/her condition?” This question is also humiliating for the parent. Religious people did not find fault with the parent, but the expression was its only God’s fate. Parents who were religious also felt same by thinking that the decision is God’s and they have nothing to do on it. Parents avoided social gathering due to the unempathetic approach of others. People asked about child’s progress and the parents will have nothing to respond. Only because of professional suggestion some of the parents were ready to attend the public functions. All the stigmatizing events were reported as painful and parents find it very difficult to cope. Only when they had some biological difficulties in advance, parents believe that they had a role in it.

Themes and subthemes identified during the analysis of the responses of the participants are summarised and presented in table 1.

Table 1: Themes and subthemes of stigma experienced by mothers of disabled children

Themes	Subthemes
Social	Lack of support from family Lack of adequate support/intimacy from husband Frequent comparison made by family members especially in-laws
Cognitive	Accepting condition as the gift or punishment from god

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Themes	Subthemes
	Feeling of inferiority/feeling of “less” compared to others Helplessness Hopelessness Uncertainty about future of child Thought of lack of competence Feeling of rejection
Affective	Depression Increased anxiety Elevated stress levels Inability to control emotion outbursts
Behavioural	Withdrawing from social gatherings Less contact with isolating family members Less contact with neighbourhood Ventilating emotions through crying

Intense feelings of distress associated with isolation from the part of family members and relatives were reported by some of them. They expressed that family members had avoided them, and passed negative comments on them. As aforementioned they also faced situations of avoiding their children from playing with other children within the family. Mothers of autistic children faced strange gazes from people when children exhibited repetitive behaviour.

Some of them complained about the isolation from social gatherings or avoiding them from attending such functions. One of them reported a painful experience of such an incident where she and her child sat in a closed room for hours in a wedding ceremony, as per the family members “suggested” in order to avoid the unexpected behaviours of children.

Most of them showed symptoms of distress. Sad mood, sleep disturbances, headache, chest pain, loss of interest in daily routines, crying were some of the complaints they reported. They were also concerned about the future of the child. They were thoughtful of their aging. It was their concern of question “who will there for my child after my death?”. Some of them had apprehensions about conceiving again and giving birth to another disabled child.

According to Green (2003), mothers of children with disabilities experience high levels of stigma from society. As per the reports of mothers, most of them were considered as the outcasts in family because of this special condition. It may lead the parents to feel emotionally burdened by the necessity of raising their children (McKeever & Miller, 2004).

In contrast, some of them were getting used with the stigma and adapted by withdrawing from physical or psychological manner. Coping was comparably easier when they receive family support. The parents as well as the child felt worthwhile and useful in this regard. The confidence expressed by the parents is also found to be high, when the social support is high. Social support is not simply having people around but the perceived feel of the parent. Here, the shared responsibilities are being felt when the support is received.

Considerable research resonates the role of support from family, friends and professionals in assuaging stress and promotes positive coping ability among parents of children with

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disabilities (Aldersey, 2012). Furthermore, extensive research has emphasized that mothers of children with disabilities experience enormous burden as a result of the limited support they receive from their family and the community (Aldersey, 2012). Lack of even partner support was reported by many of them. According to Thoits (1995), being able to count on an individual in whom one can rely in difficult situations, especially a spouse or partner, seems to be the most important measure of social support.

While analysing the discussion, lack of support from immediate family members can be considered as the main component of this research work. It indeed acts as a catalyst for internalizing the stigma by the mothers. They also lack effective strategies to manage their emotions.

CONCLUSION

Analysis provides comparatively clearer framework on factors associated with affiliate stigma. At some point of their lives, everyone experienced certain kinds of stigma associated with caring a disabled child. According to them society was comparatively negative in nature and from the family itself as they say, experience of ignorance, embracement, and the like added spices to their feelings of distress. “Who will be there for my child after my death” was a most repeated phrase in everyone’s talk. The tendency of withdrawing from society and feeling of rejection, feeling of “less” compared to others were also to be considered as major contributors of distress. Professional support is a key point where something can do from the side of policy makers, psychologists and social work professionals. As it was a small sample, generalization is not much possible. Furthermore, it can also be observed that as the difficulties relating to child increases the feeling of stigmatization was also increased especially in the case of autism condition. The importance of awareness regarding various stress reduction techniques is also important for many of them to alleviate or reducing their day-to-day life stress. It is only with that they can compete with the condition effectively.

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Conflict of Interest

The author(s) declared no conflict of interest.

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