

PERCEIVED STIGMATIZATION, FAMILY SUPPORT AND MARITAL ADJUSTMENT IN MOTHERS HAVING CHILDREN WITH INTELLECTUAL DISABILITY

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Abstract

Background. Mothers having children with intellectual disabilities (ID) are one of the most ostracized groups and face stigma, prejudice and significant obstacles that restrict their human rights by Mak and Cheung, (2008). Therefore, the aim of the present study was conducted to study the relationship between perceived stigmatization, familial support and marital adjustment in mothers having children with intellectual disability. **Method.** Data was taken from (n=150) mothers who having children with intellectual disability through purposive strategy. Perceived devaluation and discrimination scale, family support scale and marital adjustment test were used as an assessment measure in the present study. **Results.** The result showed that perceived stigmatizations ($r = .33, p < .001$) with marital adjustment and family support ($r = .35, p < .001$) has significant negative relationship ($r = .63, p = .001$) with marital adjustment. Moreover, regression findings revealed both models were significant. In the first step ($\Delta R^2 = .50, F(20, 129) = 8.62, p = .000$) perceived stigmatization was a statistically significant predictor ($\beta = -.13, p = .000$), implying that perceived stigmatization predicts marital adjustment. In the second model ($\Delta R^2 = .60, F(21, 128) = 11.98, p < .001$) familial support ($\beta = -.37, p = .001$) was significant predictor of marital adjustment.

Keywords:

Perceived Stigmatization, Familial Support, Marital Adjustment, Mothers, Intellectual Disability Disorder.

INTRODUCTION

It is well established that early interactions between parents and children form the basis of their relationship by Bowlby (1969, 1973, 1980); Ainsworth et al. (1978). During the course of the first year of life, the child develops an attachment to his or her caregivers especially with the mother. More recent research has investigated the degree to which early mother child relationships influence the child's beliefs about the self and social world, and how these beliefs guide relationships into adulthood. However, mothers having children with intellectual disabilities (ID) are one of the most ostracized groups and face stigma, prejudice and significant obstacles that restrict their human rights (Mak & Cheung, 2008).

The prevalence rate of intellectual disability in our society is between 1% and 3%, with 85% categorized as mild, 10% moderate, 3% to 4% severe, and 1% profound by Pakistan Psychological Association, (2018). Commonness rate for psychological illness in individuals with scholarly inability were observed to be more prominent than the typical individuals at 35.2% to 40.9% dependent on demonstrative criteria. Stereotypes, prejudice and discrimination result from misconceptions about the individual's attributes by the dominant cultural group, and perpetuated by biased social structures by Corrigan, (2000). Stigma has been conceptualized as a mark of social disgrace in which the target individual is discredited based on attributes such as ethnicity, mental health problems, disability or drug-use. It describes the effect of negative attitudes and behaviors on the target individual and often leads to negative psychological health for the individual (Goffman, 1963).

Perceived Stigmatization

Stigma is the negative evaluation of a person as spoiled or shamed on the basis of aspects such as psychological disorder, society, drug misuse or physical disability by Goffman and Link, (1963). Stigmatization is defined as a process in which individuals who are seen as 'unwanted differences' in society are labelled and lose their dignity and status because of stereotyping, discrimination, social exclusion, and negative emotional reactions displayed by the vast majority of people (Kayama et al., 2017).

In addition, Atypical personal characteristics and behaviors are often stigmatizing. For example, people with disabilities have been stigmatized by their disabilities and hence discriminated against by other members of society. In the last 25 years, the stigma of having a disability has become somewhat lessened owing, in part, to the growth of the disability advocacy movement. The mother of a child with intellectual disability feels the stigma of the child's condition. This stigmatization may be, especially pronounced if the child without any intellectual disability. The mother may act out, react to or interact with the child in a manner that reflects the emotional turmoil created by this perception. An ultimate consequence is that the mother may have fewer positive feelings about herself by Whitman and Accardo (1990). Children with Intellectual inability and their families particularly their mothers experience various types of stresses. Mother experienced different difficulties for example, care, financial load, matters of adulthood, and testing activities of their children (Crnic et al.1983).

Typically, studies in the Intellectual Disability (ID) field have focused on self-stigma as experienced by the individual with ID. Often however, persons associated with the stigmatized person, particularly family members, are also subjected to stigmatization. This type of stigma has been referred to as family stigma by Phelan et al. (1998), courtesy stigma (Goffman, 1963) or associative stigma (Mehta & Farina, 1988). Although, caregiving can often be a rewarding experience, the family caregivers of individuals with ID also face considerable responsibility and accompanying stress by Baxter et al. (2000). They have to cope with both the physical and emotional needs accompanying the affected individual's disability. In addition, the stigma of being undervalued by others and often continuous and/or repeated battles with services adversely affect their quality of life by Chou and Palley, (1998); Chou et al. (2009). Consequently, they may feel dejected and helpless about their association with the stigmatized individual. This may result in lowered self-esteem and impaired family relationships (Wahl & Harman, 1989).

For instance, an individual with ID exhibiting challenging behavior in public can be an extremely distressing experience for family caregivers and may result in increased discrimination from the public and feelings of perceived stigma, social isolation and powerlessness by Cantwell et al. (2015). Mothers of children with ID have been found to be especially susceptible to poor mental health, reporting more depressive symptoms, higher levels of malaise, depression and anxiety than do mothers of typically developing children by by Andersson, (1993); Blacher and Mink, (2004). Affiliate stigma may contribute to the negative impact of being a parent of an individual with ID. As a means of coping with some of the effects of affiliate stigma, caregivers may react by withdrawing socially, or even distancing themselves from their relative with ID to avoid association (Mak & Cheung, 2008).

In most cultures, mothers are regarded as the primary care. They are more likely than fathers to be blamed for the child's disability and hence bear the shame of stigma by Chang, (2009). To avoid such shame, mothers sometimes isolate themselves from friends and families, and at times even their disabled child by Ali et al. (2012). In observations and in-depth interviews with family

members of individuals with ID in Taiwan, Chang (2009) found that stigma was experienced by mothers but not fathers, as it was considered to be the moral duty of mothers to produce healthy children. The relationship to the family member with ID can therefore affect how stigma is perceived and internalized. Since the review, the experience of stigma in family members of individuals with ID is an area that has received growing attention, although research is still somewhat lacking (Werner & Shulman, 2013).

Familial Support

Family Support is a style of work and an extensive range of activities which reinforce positive familiar social networks through societal based programs and services by Hanley, (1998). Family prevails as the primary institution that forms the basis of all other communal institutions. Family could be defined as social and economic group, depends on division of work, with various types such as small, large, narrow or wide where individuals are born into, raised in or spend most of their lives in by Cavkaytar, (2010); Kurumu, (2010).

Initially, a simple form of interaction network based on the foundation of the relationship between the couple is formed. Main purpose of evaluating family needs is to make a contribution to children with intellectual disability and to settle the type, content and quality of the service which will be given to the child and to the family by Akçamete and Kargin, (1996); Bailey and Simeonsson, (1988); Varol, (2006). For that purpose, firstly, problems that families have after they learned they have a child with intellectual disability should be determined, in addition to family needs their strong ways and their supports should be settled (Bennet et al. 1990).

Moreover, Family support is physical, emotional, and social improvement of disabled children, minority disabled children's families, and rising flexibility disabled children's parent participation and resources by Stone et al. (1982). Furthermore, Family could be characterized as social and financial factors, which relies upon division of work, with different styles, for instance, little, extensive, short or wide in which people are naturally introduced themselves and brought up the greater part of their lives Cavkaytar, (2010). Moreover, an investigation of Winton (1986) demonstrated that to decide families' needs it must to be assessed in five informational regions, properties of youngster, knowledge, assistance and support, natural association among kid and caretakers, perspective of the family to childhood the kid or living with an intellectual disability adolescent, family's lifecycle and situations.

Generally, examined the desires of parents having children with intellectual disabilities are, need of knowledge/instruction, need of help, and need of performing family work and these are also stressors for parents by Bernstein and Barta, (1988). Previous researches declared that instructive and educational counseling for the caretakers' needs regarding information/training decreases the worry and stress, and help family's how they direct their emotions and thoughts in positive manners (Pelchat et al. 1999).

Marital Adjustment

Researchers defined marital adjustment as the degree of pleasure or contentment resulting from the union by Locke and Wallace, (1959). Researcher's clarified marital adjustment is a "space of a spouse to each other at specified period" by Locke and Wallace, (1959). Marital adjustment as an ever-altering procedure with a measurable aspect which can be assessed at any point of time on dimension from well-adjusted to disturbed by Spanier, (1976). Another definition is describing that marital adjustment is defined as the state in which there is typically a sense of preference and satisfaction in spouses (Hashmi et al. 2007).

According to the systems theory, the family is a complex and interactive social system and each experience within family, affect every member. Components of the system continually change to keep it in balance by Papp, (1983). Within the family, there are three central subsystems: the spousal, parental, and sibling subsystems. In these three subsystems, marital relationship, is seen as a key factor in determining the quality of family life and core of the family unity by Erel and Burman, (1995). Any negative experiences in this subsystem affects all members particularly children. Research on marital adjustment of parents with disabled children mention a negative correlation between marital adjustment and problematic behavior of the children by Amato, (2005); Jouriles et al. (1999). Having a child with disability brings many stresses such as expenses for child care and psychosocial costs to the family, and the presence of a developmental disability in the child prompts questions about the effects it might have on the parents' relationship (Turnbull & Turnbull, 2002; Seligman & Darling, 2007).

The research on the effect on the marital relationship of a child with disabilities have revealed conflicting results with each other. Some studies have indicated that parents that have a child with developmental disabilities have lower marital adjustment than parents of children without disabilities by Crnic et al. (1983); Lee, (2009); Kersh et al. (2006); Risdal and Singer, (2004); while other studies suggest that there is no difference between two groups marital quality by Holmbeck et al. (1997); Tsibidaki, (2013). Perceived stigmatization is the main factor which badly influence the marital adjustment of parents specially mothers having children with intellectual disability. Benson and Gross in 1989, indicated that the influence of perceived stigmatization was negative in some cases such as poor communication, financial problems, shame and guilt and sexual difficulties (Seligman & Darling, 2007).

Similarly, Seligman and Darling (2007) states that although the data regarding marital adjustment and divorce in families of children with disabilities are contradictory, some marriages are challenged by this situation, they are under stress but remain intact, others simply fail, whereas still others survive and are even grow stronger. More research is needed to clarify the relationship between perceived stigmatization, familial support and marital adjustment in mothers having children with intellectual disability.

In addition, the research shown impact on the marital relationship of a child with disabilities have uncovered conflicting outcomes with one another. A few investigations have shown that parents that have a child with developmental disabilities have bring down marital relationship than caretakers of children without disabilities by Lee, (2009), while different studies propose that there is no distinction between marital quality of two groups by Tsibidaki, (2013). An Investigation of Benson and Gross, (1989) showed that the impact of pressure was negative in some cases (poor correspondence, financial issues, and sexual difficulties) and positive in others (increase consistency) and most of the studies are uncertain (Seligman & Darling, 2007).

Moreover, there are few studies examine marital adjustment and family functioning of parents having children with disabilities. The mother takes care of the need of her child with disability. When mother feel abandoned, she might strike or rude to others for comfort or if nothing else she might avoid family by Seligman and Darling, (2007). Likewise, tasks such as managing child care and other important works can increase the stress of parents by Turnbull et al. (1986).

Therefore, the aim of the present study was examining the relationship between perceived stigmatization, familial support and marital adjustment in mothers having children with intellectual disability.

METHODOLOGY

Participants

It is a descriptive correlational study conducted with mother who having children with intellectual disability. Correlational research design was used. We recruited (n=150 mothers) of children with intellectual disability through purposive sampling technique from special schools in the second big city of Pakistan, Lahore. The inclusion criteria were: a biological birth mother, raising a child with intellectual disability aged between 25-50 years and residing in Lahore Pakistan. Three participants were excluded for not meeting the eligibility criteria. The total sample was made of 150 mothers. Age of participants ranged from 25 to 50 years ($M = 37.09$; $SD = 5.82$). Birth order of participants was ($M=2.14$, $SD=.94$), a child with intellectual disability aged between 0-18 years were ($M=8.73$, $SD=.18$). Majority of the participant's (13.3%) education was FA/F.Sc. Majority of the participant's (76%) child with special needs had moderate level of illness.

Assessment Measures

Demographic Questionnaires

A set of questions were developed to capture relevant demographic data about mothers and their children. Mother details included age, educational level and number of children. That of children included age, diagnoses or severity level of disorder.

Perceived Devaluation and Discrimination Scale (PDDS; Link et al. 1989)

The Perceived Devaluation and Discrimination Scale (PDDS) contains 19-items that determines how much stigma an individual perceives from close relations like family, friends and significant others. It is a self-rating scale measured on a 5-point Likert from 1 = "absolutely true" to 5 = "absolutely not true". The total scores can be summed as family, friends, significant others, or total scale. The sum is ascertained when the 19-items are added. Strong psychometric properties have been reported for this scale. For instance, Doku et al., (2015) reported accepted Cronbach coefficient alpha of .79. In this study, the Cronbach's alpha coefficient was ($\alpha=.72$) for the total scale.

Family Support Scale (FSS; Hanley, 1998)

The Family Support Scale was developed to estimate an individual's family support who received from families. It is an 18-item scale, rated on a 4-point Likert, where 0 represents "not all helpful" to 4 representing "extremely helpful". We obtained total scores (ranging from 0 to 72) by adding up all responses for all 18 items on the scale. Higher scores are associated with high family support while lower scores on the scale represent low family support. Hanley (1998) reported a good internal consistency coefficient of 0.92 from their research which is higher than what we found ($\alpha = 0.82$).

Marital Adjustment Test (MAT; Locke & Wallace, 1959)

The Marital Adjustment Test was developed to measure the relationship quality of an individual's marital life It was mainly utilized to discriminate between happy spouses and distressed spouses. It is a 15-item scale, rated on a 6-point Likert, where 0 represents "Disagree" to 5 representing "Agree". We obtained total scores (ranging from 0 to 75) by adding up all responses for all 15 items on the scale. Higher scores are associated with higher degree of happiness which most people get from marriage, while lower scores on the scale represent unhappiness which most people get from marriage. In the present study, the Cronbach's alpha coefficient was ($\alpha=.72$) for the total scale.

Analysis

Statistical analyses were conducted using the IBM SPSS Statistics: version 23 with significance set at $p < 0.05$. The demographic variables (see Table 1) were described with mean, standard deviation, frequencies and percentages. For the main study variables, means, standard deviations reliability value (i.e., Cronbach alphas) and normality check (i.e., Skewness and Kurtosis) were computed. It can be seen in Table 2 that all the variables were within normally acceptable ranges of ± 2 (Field,

2013). To ensure easy analysis and interpretation, Pearson product moment correlation analysis and hierarchal regression analysis were used.

RESULTS

The data was analyzed using Statistical Packages for Social Science, version 21(SPSS-21). First of all, the data was screened to find missing values. The Cronbach's Alpha of the scales was obtained using reliability analysis. To explain the internal consistency of measuring instruments used in research.

3.1. Pearson Product Moment Correlation Analysis

The results of the correlation analyses are reported in Table 3. A negative significant relationship was observed between total score of perceived stigmatizations ($r = .33, p < .001$) with marital adjustment and family support ($r = .35, p < .001$) has significant positive relationship ($r = .63, p = .001$) with marital adjustment. See Table 3 for summary.

3.2. Hierarchal Regression Analysis

A hierarchical regression was conducted with perceived stigmatization entered at the first step and familial support entered at the second step. The findings for the regression analysis are in Table 4. We found that both models were significant. In the first step ($\Delta R^2 = .50, F(20, 129) = 8.62, p = .000$) perceived stigmatization was a statistically significant predictor ($\beta = -.13, p = .000$), implying that perceived stigmatization predicts marital adjustment. In the second model ($\Delta R^2 = .60, F(21, 128) = 11.98, p < .001$) familial support ($\beta = -.37, p = .001$) was significant predictor of marital adjustment. In sum, the results showed that perceived stigmatization and familial support were significant predictors of marital adjustment.

Table 3.1

Psychometric Properties of Questionnaires (n=150)

Variables	k	M	SD	Potential		Actual		α
				Min Scores	Max Scores	Min Score	Max score	
PDDS	20	52.51	8.09	19	76	35	69	.72
FSS	19	43.26	18.86	0	76	1	76	.82
MAT	15	38.50	11.90	0	75	21	69	.85

Note. k= Number of Items in the subscales, M = Mean, SD=Standard Deviation, Min Score = Minimum Score, Max Score = Maximum Score, α = Reliability Co-efficient

Table 3.2

Correlational Analysis between Study Variables (n=150)

	12	13	14	M	SD
1. Perceived Stigmatization	-	.29**	-.33**	52.51	8.09
2. Family Support	-	-	.63**	43.26	18.86
3. Marital Adjustment	-	-	-	38.50	11.90

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Note: M=Mean, SD=Standard Deviation Scale.

Table 3.3

Hierarchical Regression Analysis Predicting Marital Adjustment by Perceived Stigmatization and Family Support in Mothers having Children with Intellectual Disability(n=150)

Predictors	Marital Adjustment	
	Mothers	
	ΔR^2	β
Step 1	.50***	
Perceived Stigmatization		-.13***
Step 2	.60***	
Family Support		-.37***
Total R ²	.57%	

Note: *p < .05. **p < .01. ***p < .001.

a. Dependent Variable: Marital Adjustment

b. Predictors in the Models: Perceived Stigmatization, Family Support

DISCUSSION

Results revealed perceived stigmatization has highly significant negative association with marital adjustment and familial support has significant positive relationship with marital adjustment in mothers having children with intellectual disability. Moreover, regression findings revealed perceived stigmatization and family support were significant predictors of marital adjustment. According to findings of current study mothers reported they receive rare family support. Previous literature supported these findings.

A study conducted by Corson (2017) to examine the association between perceived psychological illness stigma on caregiver's desires on relinquish care in (n=285) caretakers. Results indicated that caretaker's partnership position, experience to difficult actions, and observations of politeness stigma predicted wish to abandon care. Perceptions of stigma were negatively associated with caretaker wellbeing, logic of mastery, and social support levels, showing stigma's role in the loss of caretaker assets such as marital life. This study give evidence which can update the progress of learning and helpful facilities which can help caretaker's better cope with the stressors and marital issues. Moreover, research was conducted by Basharpour and Sheykholeslami (2015) assess the association between family tasks, marital relationships and quality of life by conducting research on (n=730) women. The results showed all dimensions of family tasks and marital adjustment were negatively correlated with quality of life in women. Results also revealed 33% of total quality of life can be described by family functions and 24% of total quality of life can be clarified by marital adjustment. More study also revealed women's quality of life was affected through family functions and marital adjustment in family.

In addition, another research was conducted to study the perception of the family functioning in parents of children with autism spectrum disorders with normal-range intellect and also examine association between family functioning, parenting stress and quality of life in a group of (n=202 parents) (n=49 mother-father) of autism spectrum disorder and (52 mother-father) parents of normally developing children. Results revealed parents of children with autism spectrum disorders reported lower working of the family as an overall and their own functioning as family members they showed higher levels of parenting stress and lower quality of life. There were also moderate to strong correlations in mother-father marital adjustment between their assessments of family functioning, parenting stress, quality of life in social relations and environmental fields (Pisula & Dorsmann).

Accordingly, research was conducted to investigate the challenges (e.g., Perceived Stigma) and adjustments (e.g. Marital Adjustment) of (n=76) mothers having children with disability. The findings of the present study showed mothers who have children with disability were challenged with multiple stressors (such as, perceived stigmatization). The most observed stressors were physical, psychological, financial, public associated, and management-related stressors followed by social and marital stressors. Adjustment ways were affected through numerous aspects, for instance mother's age, social support, and family income which were associated with occupation of mothers (Omar et al. 2017).

In addition, a study recognizes policies used by these family members to alleviate or cope with stigma and improve marital adjustment of (n=20) families having children with intellectual disability. Results from this study revealed that all participants of the present study discussed experiencing stigma. This stigma was usually felt when people directed negative appearances, used negative language and names, or rejected to touch their family member with intellectual disability. Stigma was also directed at the family members as being the cause of the intellectual disability. Family members noted engaging a range of coping mechanisms or policies to reduce the stigma and make better their marital life (Aldersey et al. 2018).

CONCLUION

The study examined how the sources of perceived stigmatization and familial support influence the marital adjustment of mothers of raising children with intellectual disability in Lahore covarying mother age, number of children and educational level. We found that perceived stigmatization and familial support predicted marital adjustment. The findings extend literature about the role and sources of familial support in enhancing the marital adjustment of mothers raising children with intellectual disability in Lahore. Lastly, it underscores the need to integrate and emphasize not only support from significant others but all other sources in marital adjustment enhancing interventions intended to reduce stigmatization and increase wellbeing.

Key Points and Relevance

- This research suggest perceived stigmatization has significant negative relationship; however, family support has significant positive relationship with marital adjustment in mothers having children with intellectual disability.
- This research was conducted to create awareness in mothers who are still expected assistance or help from the family even when their spouses are not involved. The present research was designed to educate and provide insight to the parents of Pakistani ethnic backgrounds on the benefits of family support.
- This study could help administrators, policy makers and social workers to educate family and spouse about the different level, styles and types of familial support.
- Based on this study, it is not only particular for professionals or parents to be aware from perceived stigmatization and marital adjustment in the Pakistani society but to also be educated about culture itself both in social and clinical fields.

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