

Perception of Stigma and Coping Resources in the Parents of Intellectually Challenged Children

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Abstract:

The present study endeavors to find out the Perception of stigma and Coping resources among the parents of intellectually challenged children. The 'Stigma Scale' (developed by Ali, et.al, 2008) and 'Coping Resources Inventory' (Form-D; developed by Hammer & Marting, 1988) were administered. Back translation method was used to get Hindi version for both the tool for the convenience of respondents. Sample comprised of 120 parents (60 mothers and 60 fathers) purposively selected from Chetna Institute for the Mentally Handicapped in Lucknow city. They ranged in age from 30-40 years with the mean age of 35 years. The results revealed that there was a strong tendency in mothers to feel more stigmatized than fathers. At the same time mothers have less coping resources as compared to fathers.

Keywords: Intellectually Challenged Children, Parents, Perception of Stigma, Coping Resources.

1. Introduction

Intellectually challenged (or mental retardation) is defined as "a significantly below – average level of intellectual functioning (IQ less than 70) with associated impairments in adaptive functioning (in at least two areas), arising before the age of 18 years" (American Psychiatric Association, DSM – IV, 2000).

Parenting an intellectually challenged child is the most challenging and stressful job on earth, a parent can come across in a life. As intellectually challenged children are yet not accepted by the society. They are still considered to be stigma in our society. Stigma is defined as "the situation of the individual who is disqualified from full social acceptance" (Goffman, 1963).

Stigma is one of most difficult aspects of public encounters experienced by parents with intellectually challenged children. The effect of stigma on the various aspects of parent's live such as, psychological, physical, economical, social and environmental areas, which have an adverse effect on their quality of life and their well-being. Hence, the parents lifelong live with the trauma.

However, perceived stigmatized of parents depends not only how they perceive a stressful event but also on the subjective perception of their capability or available resources in handling or dealing with that event. This is called coping resources. "Coping resources is the characteristics of a person, group, or environment that are helpful in assisting individuals in adapting to stress", (Mosby's Medical Dictionary, 2009).

While reviewing the literature it was witnessed that there is a paucity of work in psychological perspective especially with reference to parents of the intellectually challenged children. As it is obvious that these parents definitely face more difficulties than parents of normal children, which in turn affect their quality of life and well being (**Ravindranadan et.al, 2008**). In this regard some questions led in researcher's mind – Is there any gender difference among the parents of intellectually

challenged children on perceived stigma and on coping resources? What kind of relationship is present between perceived stigma and coping resources? What kinds of coping resources mothers' and fathers' have? What resources can be taken to improve quality of life of parents?

Since it is impossible to answer all the above questions in one study, an attempt has been made to answer some of them in the present study.

2. Objectives

- To find out the perceived stigma among the parents of intellectually challenged children.
- To find out the coping resources among the parents of intellectually challenged children.

3. Hypotheses

- 1. Mothers would be perceived more stigmatized as compared to fathers.
- 2. The coping resources would be higher in fathers than in mothers.
- 3. The fathers would be high on cognitive, social and physical domains of coping resources as compared to mothers.
- 4. The mothers would be high on emotional and spiritual domains of coping resources as compared to fathers.

4.Method

4.1 Sample

Sample consisted of 120 parents of intellectually challenged children (60 mothers and 60 fathers) purposively selected from Chetna Institute for the Mentally Handicapped in Lucknow city. They ranged in age from 30-40 years with the mean age of 35. Further, it was made sure that their children were only mild and moderately intellectually challenged.

4.2 Nature of Study

It was an Ex-post facto research.

4.3 Variables

- 1. Perceived stigma
- 2. Coping resources

5. Tools

5.1 Stigma Scale

This ten item self report instrument for people with mild to moderate intellectual disability has been developed by **Ali et.al, (2008)**. It has an acceptable test–retest reliability and high internal consistency (Cronbach's alpha = 0.78). Back translation method was used to get Hindi version of this tool for the convenience of respondents. After back translation and pilot study, no items were changed in this tool. In this present study this tool was administered on parents because it was very difficult to administer on children. Before administer, it was already checked that all items could be apply same on parents as on children.

6. Coping Resources Inventory

It was developed by **Hammer & Marting** (1988), which consists of 60 items. Each item is responded to on a 4 point rating scale. It measures resources in five domains (cognitive, social, emotional, spiritual and physical). It has 0.72 test- retest reliability and validity fall in 0.60 to 0.80. Originally this tool consists of 60 items but after back translation (58) items were selected for the pilot study. Back translation method was used to get Hindi version of this tool for the convenience of respondents. After a pilot study the numbers of selected items were slightly changed. Finally (55) items were selected for the present study.

7. Results and Discussion

The purpose of the present study was to find out the perceived stigma and coping resources among the parents of intellectually challenged children.

Scoring was done for both tools, the mean, standard deviation and t-ratio were calculated for perceived stigma, and for coping resources, it's all 5 domains.

Coming to the first variable which is perceived stigma, it defined as the personal perceptions of stigma among individuals.

Table 1.1: Mean, SD and 't' value for all mothers and fathers on perceived stigma.

Variables	N	Mean	S.D	't' value	Remark
Mothers	60	56	1.26	7.07	< 0.01
Fathers	60	50.4	4.26	7.27	Significant

As depicted on table 1.1, result was significant which mean that mothers **perceived more stigma** than fathers. Responses given by parents also support this i.e., mothers reported like "हॉ, लोग मुझे पर्मिदा महसूस कराते हैं।" whereas fathers reported like "जिस तरह से लोग मेरे साथ व्यवहार करते हैं, उसकी मैं चिन्ता नहीं करता।". Therefore, the hypothesis made in this regard has been accepted. This was supported by **Gray (1993)** found that mothers feel more stigmatized than fathers. May be that most of the time mothers kept their child whether if she is inside or outside. That is why they perceived more stigmatized between societies than fathers. Now moving on to the next variable which is closely related to perceived stigma i.e., coping resources, it can be understood as those resources which are inherent in individual to cope with their stressful and stigmatized situations.

Table 1.2: Mean, SD and 't' value for all mothers and fathers on coping resources and on all 5 domains

Coping resources & its 5 Domains	Parents	N	Mean	S.D	't' value	Remark
Coping resources	Mothers	60	209.28		3.79	< 0.01
	Fathers	60	216.1	9.91		Significant
Cognitive resources domain	Mothers	60	60	6.94	0.52	> 0.1 NS
Gomani	Fathers	60	60.66	0.74		110
Social resources domain	Mothers	60	65.86	7.87	3.43	< 0.1 Significant
domain	Fathers	60	70.76	7.07	3.43	Significant
Emotional resources domain	Mothers	60	76.6	5.93	3.29	< 0.1 Significant
	Fathers	60	80.16	3.75	3.23	Significant
Spiritual resources domain	Mothers	60	69.76	5.82	3.68	< 0.1 Significant
	Fathers	60	65.86			~-8
Physical resources domain	Mothers	60	48.66	5.19	8.93	< 0.1 Significant
	Fathers	60	57.06			~15

Throwing a glance at table 1.2, obtained results for **overall coping resources** was significant which reveals that mothers have fewer coping resources as compared to fathers. This finding also finds place in **Sullivan's (2002)** study who reported the gender differences among the parents on coping. Responses given by parents also support this i.e., mothers reported like "मेरे पास परिस्थितियों से मुकाबला करने का पर्याप्त संसाधन नहीं हैं।" whereas fathers reported like "मेरे पास अपनी जिंदगी जीने के लिए पर्याप्त संसाधन और समय हैं।". Therefore, the hypothesis made in this regard has been accepted. A probable reason could be that most of the time mothers are extra protective towards their children, leading to this they have paucity of time for themselves in comparison to fathers.

Cognitive resource is a first domain of coping resources which has been depicted in table 1.2. The findings suggest that mothers and fathers do not differ with regard to cognitive resources. Thus it can be said that no significant difference was found between them. Hence, the hypothesis made in this regard has been rejected. This was also supported by **Turnbull & Turnbull (1990)** who found that parents may develop low self esteem as a result of having a child with mental retardation.

The next is **social coping resource**. As table 1.2, it can be interpreted that fathers have more social coping resources as compared to mothers. Thus the hypothesis made in this regard has been accepted. Further this finding also goes hand to hand with the finding by **Seth (1979)** who reported that 83% social stress in mothers of disabled children. One can assume that fathers have more chances to expand their social networks than mothers. A cursory glance at the responses brought to the fore that mothers reported like "अपने परिवार के अलावा, मैं किसी भी ऐसे समूह की सदस्य नहीं हूं जो मेरी देखरेख कर सकें।" whereas fathers reported like "मैं हमेषा अजनिबयों से बात करते समय आरामदायक महसूस करता हूं।".

Emotional coping resource is a third domain. The table 1.2 reveals that mothers are more able to accept and express their emotional responses. Responses given by mothers also support the same i.e., "अक्सर, जब मैं दुखी होती हूं रो सकती हूं।" whereas fathers reported like "जब मैं दुखी हूं तो यह किसी दूसरे व्यक्ति को नहीं बता सकता।". Hence the hypothesis made in this regard has been accepted. This was also supported by **Upadhyaya & Havalappanavar (2008)**, who found that mothers use emotion-focused coping more often than the fathers.

Next domain is **spiritual coping resource**, as table 1.2 depicts that obtained results was significant, which can be interpreted that mothers are having more of spiritual form of coping resources than fathers. A cursory glance at the responses brought to the fore fact that mothers reported like "मुझे हमेषा पता है कि मेरी जिदंगी में क्या आवष्यक हैं।" whereas fathers reported like "मैं रोज पूजा नहीं करता। इसमें कुछ नहीं रखा।".

Physical coping resource is last domain, here (table 1.2) obtained results reveals that fathers have more physical resources as compared to mothers. With the help of these resources, they are able to enact to health promoting behaviours which may contribute to their physical well being. Hence the hypothesis made in this regard has been accepted. Incidences of mothers responses viz. "में अन्य की तरह स्वयं को योग्य महसूस नहीं करती।" and fathers viz. "मेरा वजन जितना होना चाहिए उसके आस—पास हैं।". Similarly, Oelofsen and Richardson (2006) found that mothers experienced increased stress, weaker sense of coherence, and poorer health than their husbands.

In totality it can be concluded that mothers have more of spiritual form of coping resources and are more able to express and accept their emotional feelings in front of others in comparison to fathers. Further, it can be also said that mothers have less physical coping resources than fathers. On the other hand, mothers and fathers both are having same amount of cognitive coping resources.

8. Conclusion

The overall results revealed that mothers perceived more stigmatized and tend to have less coping resources in comparison to fathers. To add more to the data it was found that mothers tend to portrays to poor image in terms of social, physical and emotional coping resources than fathers. It seems that

women bear a greater caregiving burden than men. A similar result was found by **Mugno and et.al**, (2007). This may be that fathers play a small role in daily child care compared with that of mothers. In that case, most of the time mothers feel tired and burdened.

Women not only spend more time caring for their children and other family members, but they tend to also experience greater depression, poorer well-being, and worse physical health outcomes than men in caregiving roles (Sullivan, 2002).

Hence, the need of the hour is to acknowledge that mothers need some interventions, so that to enhance their self perception, well-being and mental health. In this way one can lead to move towards more acceptances. This would in turn facilitate them to reflect more unconditional positive regard towards their child. Globally, one can say that this would help them to develop more coping abilities which will make them less stressful. Further, this would motivate them to improve their child's mental health and well-being.

'Learning that the child has a disability or illness is just the beginning of the journey' (Ravindranadan et.al, 2008).

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