Perceived Stigma and Quality of Life in the Parents of Intellectually Challenged Children

DR. NEHA SINGH
Rehabilitation Psychologist,
Lucknow University, Lucknow- 226007, India.

Abstract:
The aim of the present study was to find out the significant gender difference between the parents on perceived stigma and on quality of life. The 'Stigma Scale' (developed by Ali, et.al, 2008) and 'Whoqol – Bref Scale' (World Health Organization Quality of Life, 1996) were administered. Sample comprised of 20 parents (10 mothers and 10 fathers) purposively selected from Asha Jyoti Institute for the Special Children in Lucknow city. They ranged in age from 30-40 years with the mean age of 35 years. The results showed a significant difference between the parents on perceived stigma and on quality of life. Further, it was found that there was a strong tendency for mothers to feel more stigmatized and at the same time they reveal poor QOL than fathers.

Keywords: *Perceived Stigma, Quality of life, Parents, Intellectually Challenged Children.*

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).

In present scenario people with intellectually challenged continue to remain socially excluded and encounter stigma, prejudice and major barriers that restrict their human rights. That is why intellectually challenged child have a negative psychological impact on the parent's live and they are still considered to be a 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. Quality of life (QOL) has been defined by World Health Organization (1996) as "individual's perception of their position in life in context of culture and value systems in which they live, in relation to their goals, expectations, standards and concerns and a broad concept of person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of environment".

Lot of work has been done on chronically illed patients, but there is a paucity of work with especial reference to the parents and caregivers of the patients because if they were not healthy then how will they take of the patients. This responsibility becomes manifolded when we talk of parents for example – parents of disabled and physically challenged people, cancer patients, old people, and intellectually

challenged people. When we talk about intellectually challenged children this caregiving becomes more crucial because these parents definitely face more difficulties than parents of normal children, which in turn affect their emotional well-being and their quality of life (Ravindranadan et.al, 2008). In Indian scenario, this situation becomes more pathetic because disabled children are not as such accepted by society.

Hence, this intruded the researcher to pick up the present study whatever scanty literature was available by (Blacher,1984 and Schieve, et.al., 2007) reported that parents of children with developmental disabilities experience heightened stress and impaired mental health (Weiss,1991). While reviewing the literatures, some questions came in researcher's mind – Is there any gender difference among the parents of intellectually challenged children on perceived stigma? Is there any gender difference among the parents of intellectually challenged children on quality of life? What domains of quality of life are common in both parents? What measures 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 significant gender difference between the parents on perceived stigma.
- To find out the significant gender difference between the parents on quality of life.

3. Hypotheses

- There will be significant gender difference between the parents on perceived stigma.
- There will be significant gender difference between the parents on quality of life.
- There will be significant gender difference between the parents on physical health, psychological, social relationships and environmental domains of quality of life.

4. Method

4.1 Sample

Sample consisted of 20 parents (10 mothers and 10 fathers) purposively selected from Asha Jyoti Institute for the Special Children in Lucknow city. They ranged in age from 30-40 years with the mean age of 35.

4.2 Nature of Study

It was an Ex – post facto research with exploratory orientation.

4.3 Variables

4.3.1 Independent Variable

1. Perceived stigma
2. Quality of life

4.3.2 Dependent Variable

1. Gender

4.4 Tools

4.1 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 = 0.84). 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.

4.2 The World Health Organization Quality of Life (Whoqol) – Bref Scale

The Whoqol-bref (1996) contains a total of 26 questions, grouped into four domains (physical health, psychological, social relationships and environmental). The Whoqol-bref has good internal consistency ranging from 0.70 to 0.93 (except social relationships domain; 0.66) and excellent test-retest reliability, adequate discriminant validity and concurrent validity.

5. Results and Discussion

The purpose of the present study was to find out the significant gender difference between the parents on quality of life and on perceived stigma.

After collecting the data, the scoring was done for both tools. After that, mean, standard deviation and t–ratio were calculated for perceived stigma and for quality of life and its all domains for seeing whether there is significant gender difference between both parents.

Table 1.0: Mean, SD and 't' value for all mothers and fathers on perceived stigma

Variables	N	Mean	S.D	't' value	Remark
Mothers	10	6	1.26	6.54	< 0.01
Fathers	10	2.4			Significant

Perceived stigma is defined as the personal perceptions of stigma among individuals. As depicted on table 1.2, result was significant which mean that mothers perceived more stigma than fathers. Responses given by parents also support this i.e., mothers reported like "Yes, people make me feel embarrassed" whereas fathers reported like "I don't worry about the way people act towards me". 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 the next variable which is quality of life, it defined as the individual perceptions of their life in context to their goals, their expectations, dreams, happiness etc.

Table 1.1: Mean, SD and 't' value for all mothers and fathers on quality of life

Variables	N	Mean	S.D	't' value	Remark
Mothers	10	147.5	41.29	1.66	> 0.01
Fathers	10	177.7			Insignificant

Table 1.0 clearly depicts that the obtained result was insignificant. This shows that both parents scored somewhat equally. This has been supported from the responses given by majority of both parents i.e., "I know that my circumstances are unfavorable but despite all this, I am able to handle everything just because of my partner's support and love". Therefore, in this regard the hypothesis made "there will be significant gender difference between the parents of intellectually challenged children on quality of life" was rejected. Ravindranadan and Raju (2008) found similar findings. May be both parents were faced more or less same challenges which related to their child's disability.

Now, moving on the domains of quality of life where first domain for the same is physical health. It is defined as a state of complete physical well-being and not merely the absence of disease.

Table 1.2: Mean, SD and 't' value for all mothers and fathers on all domains of quality of life

Domains of Quality of Life	Variables	N	Mean	S.D	't' value	Remark
Physical Health	Mothers	10	22.8	10.5	3.10	< 0.01
	Fathers	10	33.3			Significant
Psychological	Mothers	10	26.4	10.31	3.70	< 0.1
	Fathers	10	43.2			Significant
Social Relationships	Mothers	10	86.3	23.14	0.56	> 0.1
	Fathers	10	80.6			NS
Environmental	Mothers	10	12	10.50	1.86	> 0.1
	Fathers	10	20.6			NS

As depicted on table 1.1, obtained result was significant on physical health domain. This reveals that mothers scored low on physical health domain than fathers. The responses given by parents was supported this result i.e., mothers reported like "I am not able to sleep well at night due to my child's health conditions" where as fathers reported like "I have enough energy for everyday life". The hypothesis made in this regard has been accepted. 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.

Second domain for the same is Psychological, which is a state of emotional well-being, in which individuals are more able to cope with / grow with the challenges of daily life. The table 1.1 shows that obtained result was significant which mean mothers showed low psychological health than fathers. This was supported from the responses given by parents i.e., mothers reported like "I have always negative feelings such as blue mood, anxiety" where as fathers reported like "I am satisfied with my health". Hence, the hypothesis made in this regard has been accepted. This was supported by previous research evidence. Mothers perceived more psychological stress than fathers related to the responsibilities associated with parenting a child with handicap (Girolametto and Tannock, 1994). This may be that women tend to spend many more hours than men on family and household chores. Fathers, on the other hand, have more opportunities to avoid problems of their children.

Next is social relationships domain which is a relation between living organisms (especially between people). As table 1.1 depicts that result was insignificant which mean both parents scored somewhat equally. Responses given by parents also support this i.e., majority of both parents reported like "I am satisfied with the support I am getting from the others". Therefore, the hypothesis made in this regard has been rejected. This can be supported by (Orr, Rutter and Quinton, 1993) who found parents are known to get impacted in many ways because of having a special child. Social life of both parents may get affected.

Fourth domain of quality of life is environmental which are those circumstances, objects, or conditions by which one is surrounded. The table 1.1 reveals that result was insignificant. This shows that both parents were scored somewhat equally. This was supported by the responses given by parents i.e., majority of both parents reported like "The information I need for my day-to-day life is available to me". Hence, the hypothesis made in this regard has been rejected. This finding was supported by

(Upadhyaya and Havalappanavar, 2008) who reported that in the area of financial stress both parents report equal level of stress. A probable reason could be that more or less same facilities of security, financial, health care, physical environment and transport were available to all parents, irrespective of gender.

6. Conclusion

The overall results depicts that parents, mothers as well as fathers perceived their quality of life in somewhat equal manner. Although it was found that mothers tend to portrays to poor image in terms of physical, psychological health and perceived stigma in comparison to fathers. It seems fathers play a small role in daily child care and have more opportunities to avoid their child's and family's problem. Hence, the need of the hour is to provide some interventions prepare for parents especially, mothers. So that to enhance their well-being and move toward more acceptance and more of unconditional positive regard towards their child's condition. Parents are required to emphasize on what a child can do instead of what he cannot do. Parents should believe and accept this fact that raising a child with special needs does not take a special family, in fact, it makes a family special. In this way they tend to improve their and their child's mental health and well-being.

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