

**Stress and Depression in the Parents of Intellectually Challenged
Children and the Parents of Intellectually Challenged Children with
Physical Handicap**

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Abstract

Study I

The research was conducted to investigate the amount of difference in stress reported by the mothers of the intellectually challenged children and the mothers of physically handicapped children. It was hypothesized that the mothers of intellectually challenged children will report more stress as compared to the mothers of the physically handicapped children. The sample of physically handicapped children's group consisted of 22 mothers. In this sample 86% were house wives and 13% were working ladies with average age of 27 years. The sample of intellectually challenged group consisted of mothers of intellectually challenged children who suffered moderate to severe mental disability. In this sample 77% were house wives and 22% were working ladies with average age of 28 years. From each group mothers were initially interviewed and later on had to complete the Questionnaire on Resources and Stress (QRS) by Holroyd & Guthrie (1974). The t-test was calculated for the statistical analysis and the results obtained were found to be significant at $P < 0.05$, stating that mental handicap contributed more towards family stress.

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Study II

The second research was a follow up of study-I and was conducted to investigate the amount of difference in stress and depression reported by both the parents of the intellectually challenged children and the parents of intellectually challenged children with physical handicap. It was hypothesized that the parents of intellectually challenged children with physical handicap will report more stress as compared to the parents of the intellectually challenged children. A sample of 25 parents of intellectually challenged children and 24 parents of intellectually challenged children with physical handicap were selected through purposive sampling technique from the various Special Schools in Karachi. The age range of parents was from 22 years to 55 years. The cutoff point for minimum qualification was taken at grade 8. The participants belonged to lower and upper middle socioeconomic backgrounds. Parents of both the groups were initially interviewed and later asked to complete the self-administered Parental Stress Scale (Berry & Jones, 1995) and the Depression Screening Test (Goldberg, 2006). For statistical analysis of data the t-test and correlations were utilized and the results obtained were found to be significant at $P < 0.05$, signifying that mental disability with physical handicap was found to contribute more towards family stress.

A physically and psychologically healthy child is considered to be a symbol of blessing from God in our present society while a physically or a mentally challenged child is considered to be a curse for the family. Hence before the birth of a child, parents pray that their child is born healthy, beautiful, intelligent and physically fit. Obviously the mental and emotional health of a child is of great concern for the parents. One of the most distressing events that can take place in a family is the birth of a special (disabled) child. It can change the lives of parents, and siblings in a dramatic way, upsetting the entire family specially the mother.

Managing a handicapped child is stated to be one of the most stressful experiences for a family. Children with special needs are those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998). The presence of such a child in any family tends to result in disturbed emotional reactions by the parents. The presence of a handicapped child in a family unit has far reaching effects at the periphery of the circle of which he is the center. The effects of his

handicap upon the society at large are immense and the society ultimately has to bear responsibility for his management and treatment. At the core are tremendous impact of his / her condition upon his parents and siblings and these effects indeed may be catastrophic.

The continuing care of children with mental retardation & physical handicap is often stressful for parents as these children's difficulties inevitably touch their lives (Crnic, Friedrich et.al. 2003). The effects on the family unit can be far-reaching, restrictive, and disruptive, and they may be economic, social and emotional in nature. Although management of the daily needs of children with mental handicap has been extensively documented (Hastings & Beck, 2004). Researchers have indicated that parents of children with mental retardation are generally at risk for a variety of family life problems and emotional difficulties (Beckman, 1991).

A mentally or physically challenged child is not only perceived to be stressful and difficult by the parents but the society also finds it intricate to rear such a child. Geddie and Range (1992) investigated how the college students perceive the stress and functioning in the families of children with handicaps. Results revealed that the families of children with autism, and mental retardation were perceived as experiencing more stress but functioning just as well as other families except that they were viewed as more likely to need and seek professional help.

Mentally handicapped children constitute an acceptable parallel to the large contrasting group of Physically handicapped children, the term physically handicapped children include all those children who are beneath par physically through disease, accident of limited native endowment as well as children who manifest specific mental limitation or aberrations. Even in the family without obvious problems, the presence of the handicapped child will present his parent with a situation which is quite outside their ordinary hopes and expectations. The knowledge that the child is permanently handicapped and that he will never fulfill such hopes and expectations may arouse in the mother strong stress. Weingold and Hormouth (1953) clearly point out that the presence of a mentally retarded child accentuates the personality problems of all the family members.

It may be stated categorically that all parents of mentally handicapped children and physically handicapped children are likely to show some undesirable personality reactions vary both in degrees from one parent to another and their particular nature depending upon a multiplicity of intricate and closely interwoven factors.

Kanner (1953) states that the parent may react i.e. he might accept, deny or reject the child's mental retardation.

The parents who boldly accept the handicap challenges of their child has no undue anxieties either in regard to his own need and capacities or in regard to the disability of the child. A severe emotional reaction to the stress situation resulting from the mental retardation of the child is shown by the parent who feels the need to deny, both to others and to himself, the reality of the child's disability. Sequeira Eupline (1990) further investigated the coping styles of the mothers of the mentally handicapped children and found that denial, rehearsal of alternate outcomes, finding a purpose and seeking support were the most common Coping Styles used by these mothers.

It is not unusual to find that the parent of a retarded child is unable to perceive the reality of his child's handicap. He often sees the child as being quite different from what he actually is. As a consequence, many family problems arise which are based on faulty perception. Worchel and Worchel (1961) explored some attributes of the way in which the parents perceived the child. They asked the parents from 22 families with at least one retarded child to rate the child on several different variables. It was found many personality traits were attributed when they rated their non retarded child as compared to their retarded child. Zuk (1959) had studied distortions in the information furnished by the parents of the children with motor disability. Children who had slight degree of disability their parents had given an exaggerated version of his/ her disability.

The presence of the mentally and physically handicapped child may cause marital difficulties and according to Schaffer (1964) families with such children do not always break down; there is a strong tendency that they will become "too cohesive".

A study by Beckman (1983), who looked at the influence of Specific Characteristics of physically handicapped children on family stress, has found significant correlations between the amount of stress reported by the mother on the QRS (Questionnaire on Resources and Stress) and the child's deviation in temperament, unresponsiveness, degree of repetitive behavioral patterns, and extent of care giving demands.

The condition or disability of the children can cause serious behavior problems in parents specially in mothers, because mother are usually primary care givers for infants and toddlers and this goes on from childhood to adolescence, in this and most cultures. For handling these children, parents adopt different type of strategies. If these coping strategies are not appropriate and realistic, then this will increase the level of stress. Additional child characteristics such as age and parental characteristics such as employment can also predict stress over time (Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003).

Chetwynd (1985) investigated the factors contributing to stress on mothers caring for a handicapped child. It evaluated the stress among 91 mothers [aged 21-67] actors contributing to that stress. The children mean age [9-6 years] suffered handicaps that included down's syndrome, mental retardation and cerebral Palsy subjects stress level were significantly higher than those reported by mothers of non-handicapped children. Stress levels was higher among subjects whose children had management problems , were abnormally active or under active, were unable to occupy themselves for an hour or less or were unable to play with others. Stress levels were also higher among subjects who reported that their Social life and their time with their other children were severely restricted and that their health had been affected. Factors associated with higher stress also included having to move and having to spend more money on home supplies because of the Children.

The cumulative impact of daily hassles and difficulties in dealing with disabled children represent significant stressors that may subsequently affect parents and family functioning (Crnic et al., 1983). In particular, a great deal of evidence points to associations between the severity or frequency of behavior problems of children with intellectual disabilities and parental stress and psychiatric problems such as depression and anxiety (Baker, et al., 2002). The concept of stress has been used in many different ways.

Despite a general concern about stress in families of handicapped Children (Satterwhite, 1978) most studies focus family members (Sabbeth, 1984). Comparing family response to different types of physical illness requires a measurement approach that reveals the nature and extent of parent stress. The Questionnaire on Resources and Stress QRS (Holroyd, 1974) is perhaps the most widely validated family – evaluation questionnaire specifically developed for assessing the impact of chronic illness and handicapping conditions on family functioning. The QRS has been useful in evaluating the level of Stress in families who are caring for psychiatrically diagnosed, retarded, and autistic children.

This research was designed to identify the problems faced by the parents of mentally and physically challenged children .Handling a challenged child is a very difficult task which requires a lot of patience and devotion. This highly demanding situation in turn can lead to the burnout state of the parents. The stressed out parent can become highly depressed. The focus of the present was to facilitate such parents and provide them with recommendations which would help them in stress management.

Study I

In addition to documenting ways in which different disabilities affect families, the present project is intended to find the differences in the amount of stresses faced by the parents of the mentally challenged and physically handicapped. On this basis the following hypothesis was researched on.

1. The mothers of intellectually challenged children will report more stress as compared to the mothers of the physically handicapped child.

Method

Sample

In order to collect data purposive sampling technique was used. The sample of physically handicapped group consisted of 22 mothers with children having either motor handicap (crippled), visual handicap (blind) or auditory handicap (deaf). The age of these children ranged from 03 to 14 years. In this sample 86% were house wives and 13% were working ladies with average age of 27 years.

The sample of mentally handicapped group consisted of mothers of mentally retarded children who suffered moderate to severe mental retardation, the age of the children ranged from 3-14 years. In this sample 77% were house wives and 22% were working ladies with average age of 28 years. The number of siblings was from 0-6 for both groups. The data was collected from various special schools and hospitals within Karachi.

Measures

Questionnaire on Resources and Stress (QRS)

The QRS is a self-administered questionnaire for parents comprising of 15 subscales. It has 75 items. It is based on statistical factors, which were adapted from Holroyd and Guthrie's Questionnaire on Resources and Stress (QRS) the 285-item Questionnaire with 15 predetermined scales designed to measure the impact of chronic illness and handicapping conditions on the family functioning.

The 15 factors borrowed from this QRS are poor health/mood, Excess time demands, Negative attitude towards index case, over protection/dependency, lack of social support, over commitment/martyrdom, pessimism, lack of family integration, limits of family opportunity, financial problems, physical incapacitation of index case, lack of activities for index case, occupational limitation for index case, social obtrusiveness, difficult personality characteristics. In this questionnaire each factor is measured by 5 statements.

Procedure

Initially consent forms were signed by the parents to meet the ethical considerations for their voluntary participation in the research. A structured interview was taken to establish rapport and get information from parents about family structure and its functioning.

The questionnaire was self-administered and full instructions were given by researcher on how to complete it. These questionnaires were personally handed over to the mothers of children with physical handicap (aged 3-14) and mental handicap. The rate of return was only 40% i.e. out of 120 questionnaires only 55 were returned. The mothers of such children were not at all cooperative. 20% of the families were very hesitant to fill in the questionnaire and 35% directly refused to fill in the questionnaire and bluntly said it was very offensive on the part of the parents to fill in this type of a questionnaire.

Results

The means of the overall stress scores for each group show (table 1) that the mothers of children with mental handicap reported the greatest amount of overall stress as compared to the mothers of the physically handicapped. To test the statistical difference t-test was used and the results show difference between the means significant at $P < 0.05$, refer to table 2.

Table 1

Analysis of variance for overall scores for the physically handicapped and mentally handicapped

	Mentally Handicapped	Physically Handicapped
Mean overall scores	51.46	34.4
SD	18.81	16.60

Further analysis of the data revealed that the difference between the mentally handicapped group and the physically handicapped group is statistically significant at $P < 0.05$.

Tariq, Ismail & Mujeeb

However, the six scales (5, 7, 8, 9, 11 and 14) no significant difference was reported at $P > 0.05$ as shown in table 3, it reflects that the mothers of the mentally handicapped are concerned about the excess time demands, their poor health, over protection, lack of activities and attitude, financial problems, occupational limitations for their child and the difficult personality characteristics of their children as compared to the mothers of the physically handicapped.

Table 2

Differences in the amount of stress between the mothers of mentally handicapped group and mothers of physically handicapped group

Physically	Handicapped		
Mentally	Handicapped	$t = 2.189,$	$df = 28$
$X1 = 34.4$	$X2 = 51.46$	$1.701,$	$P < 0.05$

Table 3

Differences in the amount of stress among the mothers of handicapped group and mothers physically handicapped group on 15 scales

SCALES	M.H. GROUP	P.H GROUP	M.H VS P.H
	M	M	P-value
1. Poor health/mood	67	44	P< 0.05
2. Excess time demand	80	44	P< 0.05
3. Negative attitude	25	10	P< 0.05
4. Overprotection	63	34	P< 0.05
5. Lack of social support	38	36	P< 0.05
6. Over commitment	56	36	P< 0.05
7. Pessimism	16	09	P< 0.05
8. Lack of family Opportunity	26	15	P< 0.05
10 Financial Problems	40	27	P< 0.05
11 Physical incapacitation	44	19	P< 0.05
12 Lack of activities	64	60	P< 0.05
13 Occupational Limitations	61	36	P< 0.05
14 Social Obtrusiveness	75	51	P< 0.05
15 Difficult personality characteristics	69	67	P< 0.05
	48	28	P< 0.05

Discussion

The mothers of mentally handicapped children were under more stress; some of the reasons were that most of the mentally handicapped children were severely impaired in their intellectual, behavioral and social development. The findings show that mothers of these children reported great stress in the areas of dependency, excess time demands health and other scales like 3, 6,10,12,13 and 15 (table 3). One of the reasons to be more prone to stress was that these mothers considered their children to be entirely incapable of taking care of themselves and due to this incapacity they had to give them more time and attention and these extra demands were affecting the lives of other family members. Almost 20 % of the mothers reported that due to this kind of extra attention his/her siblings got jealous and fought with these children. This tension on a regular basis was affecting their health; 17 % reported that they had some sort of physical health issues and 17% reported that they had complaints of a physical illness.

The high scores on the difficult personality characteristics scales, which include items like “Is your child very cranky?” and “Due to his maladaptive behavior do you avoid taking him out?” also reflected a typical yet understandable response to dealing with a very difficult child. These mothers did not report many problems on the scale of physical incapacitation which contained items like “Can your child walk like other normal children?” and “Can he dress up and eat with his own hands?” This suggests that such children are not always bedridden and the mothers of such children did not have to worry about carrying them and neither did they have to spoon feed them. Some of the mothers (15 %) reported that although their child does make a lot of mess but eats with his/her own hands. Whereas, 40 % of the mothers reported that their children can walk and run like normal children. However the researchers did observe that these mothers reported more problems on the excessive time demand scale.

The mothers of the mentally handicapped usually had a negative attitude towards their special child and did not love their child as much as their other normal children. One of the major reason is that every parent wants their child to be perfect and flawless and whenever these demands are not fulfilled this creates anxiety within the parent and as a result the parent may develop a hostile attitude towards the child.

The mothers of the mentally handicapped also showed a strong feeling of insecurity and due to this feeling they appeared to overprotect their child i.e. they make their kids sleep with them and would feed them with their own hands. Around 25 % of the mothers reported that they never let their children go out on their own because they think that they might get hurt and get into some sort of trouble.

Most of the mothers of the mentally handicapped children felt guilty and considered themselves responsible for the child's condition. Like one of the mothers reported that her child did not develop normal because during her first trimester she went out when there was a moon eclipse.

Another reason for feeling guilt could be that they find it impossible to make their child function like a normal child and hence these feelings of helplessness are displaced on their own selves in the form of self blame.

Marital difficulties were found in the families of the mentally handicapped. These marital difficulties often arise due to parental anxieties. Each blames the other for the child's condition and behavior (either consciously or unconsciously) and hence some of these feelings towards the child may get displaced on to each other. In addition, the restrictions that the parent may perceive in his/her social relations may result in further hostility and anxiety. These may be displaced upon their marriage partner, producing further marital discord.

The parents of the mentally handicapped and physically handicapped are equally concerned about the uncertainty of their child's future; and questions such as 'will they be able to earn their living' and 'will they lead a respectful life' cause a lot of stress in them from time to time. They are also concerned about the social obtrusiveness, lack of family integration and the negative and taunting attitude of people towards their children.

Most children with physical handicap (especially deaf and blind) are able to retain a relatively normal existence in term of school and peer relationships. Therefore, families of these children may not have to cope with the additional stress linked to the social isolation and stigma that are associated with the mentally handicapped children.

Finally, the results provide empirical support for the suggestion that mentally handicapped children contribute more to family stress than the physically handicapped children.

The families of mentally handicapped children are more entitled to additional help than those of the physically handicapped. Apart from the additional behavioral problems and care giving demands, the greater stress that mothers of mentally retarded children experience could possibly be a reflection of societal attitudes towards mental retardation and the stigma that are so often attached to the families of the afflicted.

The results highlight the need for family-based intervention programs specially tailored to suit the nature of the child's disability. Intervention programs for the family's mentally and physically handicapped children not only help in dealing with despair, shame and isolation that may be experienced, but they also could lobby for an increased understanding by the general public in the form of

educational programs or the distribution of informative pamphlets. Intervention programs for families of such children should also include some sort of psychotherapy for parents as well.

Limitations: While the present study cannot determine the role of societal attitudes in exacerbating family stress further research is encouraged to investigate this phenomena as well given that such knowledge could be useful in the planning intervention programs providing services and public education programs.

The present study deals with one aspect of what remains a very complex area. Nevertheless, it does provide some insight into the potential impact that physical and mental handicap has on the stress levels of the family. Future research might address and try to remove some of the methodological limitations out lined above, regarding the negative and hostile attitude of parents and their lack of cooperativeness to help conduct such a research, as well as determining the role that societal attitudes and social support have contributing to family stress. This research could contribute to the future development of intervention and educational programs that might alleviate at least some of the stressors that the families of physically handicapped and mentally handicapped children experience.

The study only focused on mothers and not the fathers who are also distressed and affected after the birth of a challenged child.

The instrument used was too lengthy and the stressed out parents did not want to answer too many questions.

The variable of depression which came out to be a significant factor was not measured in the present study.

Study II

After reviewing the flaws of the previous study a new study was conducted as a result of follow up. The purpose of this second phase of the current research was to study stress and depression among the parents of both mentally retarded and mentally retarded & physically handicapped children.

The following two hypotheses were framed:

1. The parents of mentally challenged children without physical handicap will have less stress as compared to parents of children with mental & physical handicap.
2. The parents of children with mental & physical handicap will have more depression as compared to parents of children who are mentally challenged without physical handicap.

Method

Sample

The total sample consisted of 50 parents of children with only mental retardation and those with physical handicap along with mental retardation. The data was divided into 25 participants who were parents of children with only mental retardation comprising of 13 fathers and 12 mothers. The rest of the 25 were parents of children with physical handicap along with mental retardation out of whom 13 were fathers 12 were mothers representing the various areas of Karachi. The purposive sampling technique was used as a certain set criterion was decided for sample selection. Their ages ranged from 22 years to 55 years and the children age range were 8 years to 14 years. The education level for mothers and father was middle, to, higher education. Most of the mothers are house wives either as teachers or employs, (16%) were employed mainly the father (98%) were working in different area of occupation. The family monthly income ranged from 8000 to 45,000. The age range of children is 8 year to 14 years. The 60% lived in joint family system and (40%) in nuclear family system. All the children attended a daily center for the handicapped school with special education class.

Material

The Consent Forms to meet the ethical considerations for the voluntary participation of the parents in the research.

A structured interview to establish rapport was conducted initially. The demographic sheet containing the basic information about child and his/her family was also designed.

The Parental Stress Scale containing 18 items, by Berry (1995) included statements that described feelings and perceptions about the parents.

The Depression Screening Test by Goldberg (2006) which included 18 items, referred to how a person have felt and behaved during the past week. \

Procedure

The participants were initially contacted and after setting the interview time with the parents. The parents were requested to fill in the consent forms. After reassuring the confidentiality they were asked to fill in the self administered The Parental Stress Scale containing 18 items, by Berry (1995) and along with it the Depression Screening Test by Goldberg (2006).

educational programs or the distribution of informative pamphlets. Intervention programs for families of such children should also include some sort of psychotherapy for parents as well.

Results

Table 4

Correlation b/w Stress and Depression of both the parental groups

Group	r	df	Pvalue
Parents of mental challenged children	.094	23	P < 0.05
Parents of children with Mentally challenged with Physical handicap	.579	23	P < 0.5

Table 5

Difference between the Stress and Depression level of parents for both groups

Group	t-value	df	Pvalue
Stress Level of Parents	2.34	48	P < 0.05
Depression Level of parents	2.98	48	P < 0.05

Figure A: Graph between stress and depression of parents with mental retarded children

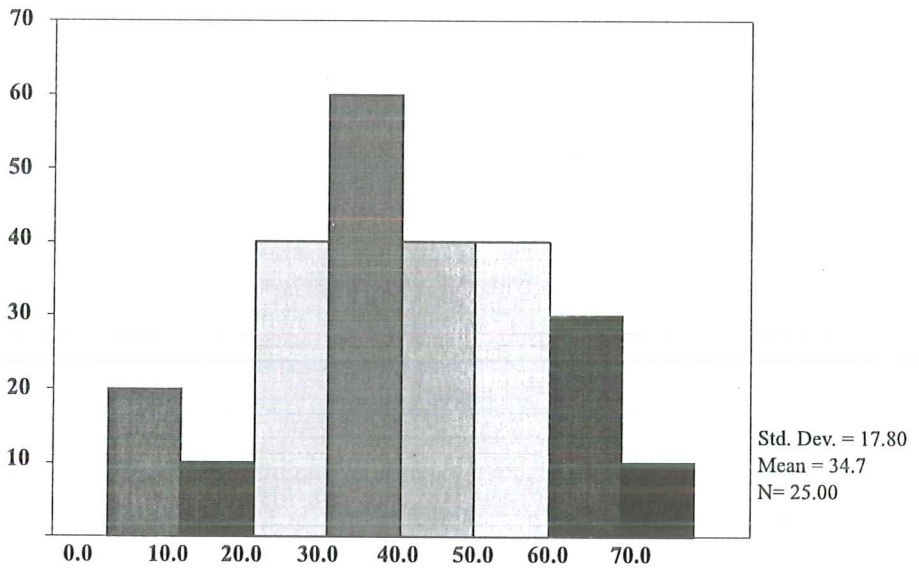


Figure B: Graph between stress and depression of parents with mental retarded and physical handicap children

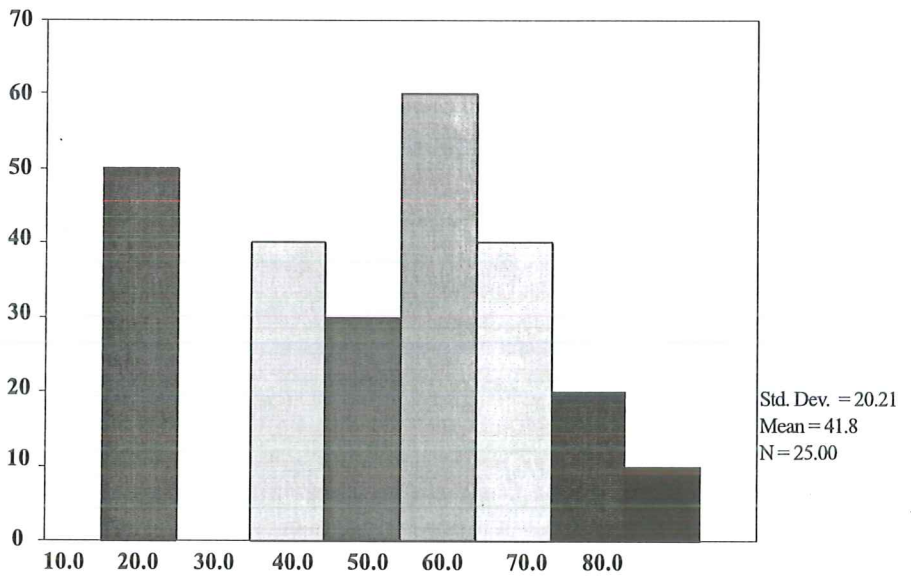


Figure C: Graph between stress and depression of parents with mental retarded children

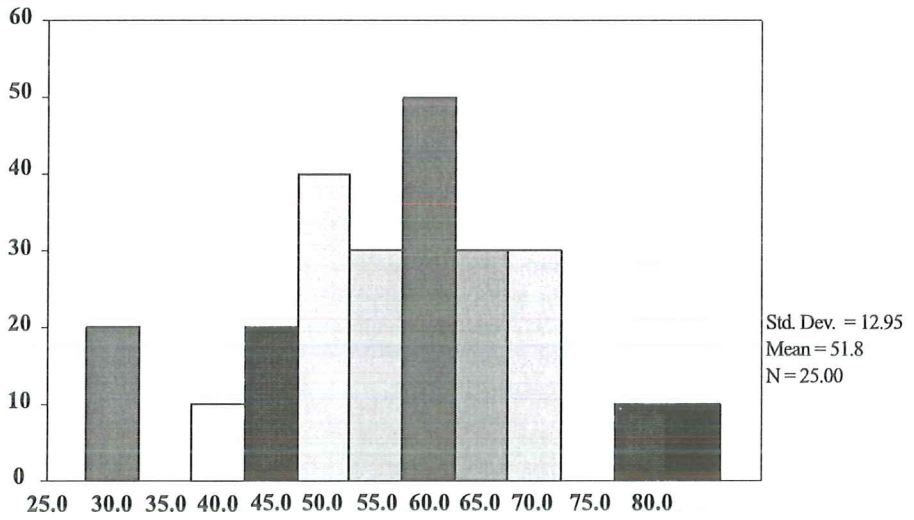
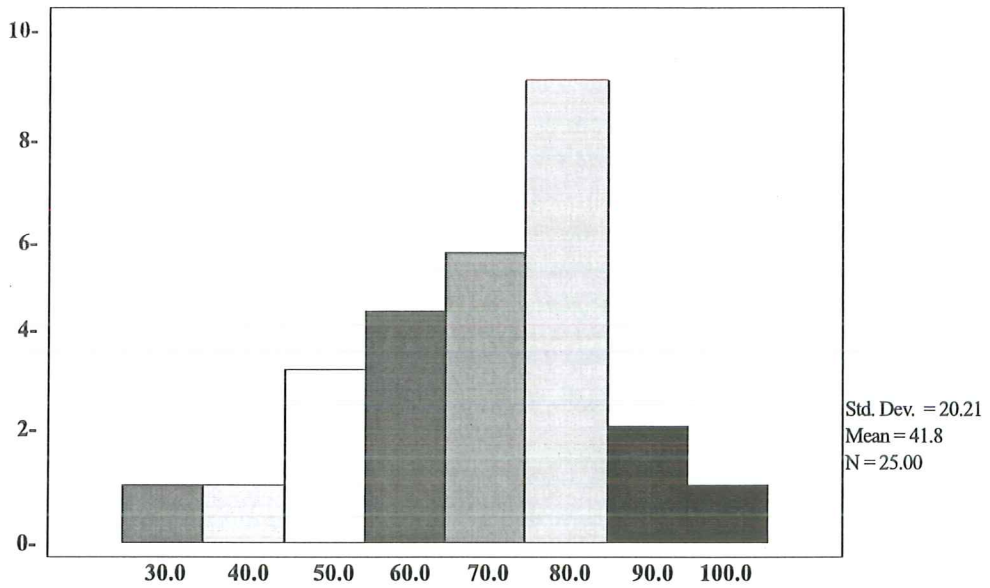


Figure D: graph between stress and depression of parents with mental retarded and physical handicap children



Discussion

The present study discusses the level of stress and depression in the parents with mentally retarded children and the parents of physically handicapped children. Special child needs special and extra care from his/her family and especially from parents. The demanding behavior could have been one of contributing factors in increasing the level of stress and depression in parents. The birth of a disabled child induces complex feelings in both the parents. There is denial, shock, aggression, unhappiness and even lack of acceptance Quine (1987) The mentally retarded child's motor functions are not completely impaired thus he/she can carry out his/her daily routine functions like eating, going to wash room, drinking, changing clothes by him / herself on the other hand the child who is mentally retarded as well as physically handicapped he/she is totally dependent on their parents and family and she / he cannot do work by themselves. So the level of stress and depression would be quite high in the parents of mentally retarded child along with physical handicap. Feelings of guilt, depression, anxiety are all part of the adjustment process and though some of the mothers adjust well, psychopathology remains rampant among the others Kazak (1984).

Stress was found to be high in the parents of mentally retarded & physical handicapped children as compared to the parents with mental retarded children.

The results reveals that there is significant difference on the variable of parents stress in parents with MR children and the parents with MR & PH children One possible factor could be that the therapy cost for children with both the physical and mental handicap is much more then only mentally retarded children . Many disabled children are on medications for long periods and visit specialists from different medical specialties in addition to speech and occupational therapy. The cost of this is often borne by parents only adding to their woes each time. (Silver, 2001). Referring to figure A and B graphs reveal that there is significant difference on the variable of depression among the parents with MR children (SD = 17.80, mean = 34.7, N = 25), the parents of MR & P.H children (SD = 20.21, mean = 41.8, N = 25). Studies have also presented that 33-53% of mothers with disabled children have depressive symptoms (Veisson, 1999) A majority of the mothers in both groups were unemployed. It has been noted in previous studies that employed mothers of disabled children perceive less stress in comparison to unemployed mothers and that employment may also serve as a buffer in their depression (Seltzer, 1989).

In conclusion; results of the present study confirmed that parents with mental retarded & physical handicapped children are at the high level of depression and stress, as compared to the parents with mental retarded children. In general parenting is a stressful and challenging job. Especially when it comes to handling of children with special needs, the stress and depression increases.

Limitations:

The present study is limited to a fixed population of just 50 subjects. Larger studies that encompass various cultures and settings are needed if these findings are to be replicated.

The parents of children with autism may have been included as managing of such a child is very distressing for parents.

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