



FAMILY DYNAMICS OF THE DISABLED CHILDREN- AN ANALYSIS

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ABSTRACT The disability either physical or mental can consume a disproportionate share of a family's resources of time and energy, families with disabled children perceive greater financial stress, frequent disruption of family routine and leisure, poor social interaction, and ill effects on their physical and mental health. The guilt, loss, anger, pain and fears that go along with raising such a child creates psychological and emotional problems aggravating stress and depression. Medications, therapy, counseling, rehabilitation, physiotherapy, occupational therapy and schooling lead to money being swept away causing financial crisis. Families can find themselves isolated from their support circles when dealing with a child that has special needs or disabilities. It is difficult, and it can be disabling in itself to a family who is already struggling to cope with the trauma of rearing a child with disability. Psychosocial problems faced by the parents and other family members were studied in sixty families with a disabled child. Marital problems were reported to be present to a greater degree because of the lack of time for nurturing the marriage plus the frequent problem of parents disagreeing on the disabled child care practices. Divorce, separation and broken families are a common side effect in the families with a disabled child. Parents and professionals alike often lose sight of the need to help siblings understand the problem that is affecting their brother or sister. Then there is the challenge of trying to reduce the jealousy that results when so much attention is focused on one child. Sibling issues are paid the least attention in most of the families. Appropriate management of these problems should be part of rehabilitation programmes in improving family dynamism.

KEYWORDS :

Introduction

The presence of a disabled child in the family poses plenty of problems that may increase stress, affects mental and physical health, make it difficult to find appropriate and affordable child care, and affect decisions about work, education/training, having additional children, and relying on care givers. It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning. The out-of-pocket costs of medical care and other services may be enormous. All of these potential effects could have repercussions for the quality of the relationship between the parents, their living arrangements, and future relationships and family structure. The disability can consume a disproportionate share of a family's resources of time, energy, and money, so that other individual and family needs go unmet.

Surprisingly little is known about the ripple effects of child disability on the family. Population-based research, particularly on demographic or economic outcomes, is scant so the present study was conducted to study the family dynamics that are present in the families with a disabled child and their coping mechanism.

Methodology

Sixty families with a disabled child were selected from Tiruchirapalli district of Tamil Nadu to conduct the study. The samples selected suffered from different types and degrees of mental disability. Both boys and girls who were between 3 to 15 years of age with different types of disabilities were chosen for the study.

A schedule was formulated to collect data on the various aspects of the family dynamics present in the families owing to the disability and their mode of management.

Results and Discussion

Much of the research in the area of disability focuses on the child and explores the different methods of management, but within the family there are a lot of problems, compromises and struggles that are faced by the family members to accommodate a child with disability. The family dynamics is an important criterion for the support, care and motivation that a child requires to overcome its problems. The family needs to be more resilient for a supportive and conducive environment. The findings of the study are presented below

TABLE I
AGE AND GENDER OF THE SUBJECTS

Items	Criteria	Number	Percentage
Gender	Male	43	71.7
	Female	17	28.3
	Total	60	100.0

Disability	Autism	40	66.7
	Down's Syndrome	8	13.3
	ADHD	9	15.0
	Mental Retardation	3	5.0
	Total	60	100.0
Age (Years)	3-6	6	10.0
	6-9	14	23.3
	9-12	18	30.0
	12-15	15	25.0
	>15	7	11.7
	Total	60	100.0

Males outnumbered females 71.7 per cent were males and 28.3 per cent were females. The disability included autism in 66.7 per cent of the samples which had a male predominance, 13.3 per cent were affected by Down's Syndrome, 15 per cent of the children had Attention Deficit Hyperactivity Disorder and 5 per cent were mentally retarded. Ten per cent of the children belonged to the age group of 3-6 years, 23.3 and 30.0 per cent of the children belonged to the age group of 6-9 and 9-12 years respectively while 11.7 per cent were of the age 12-15 years. However 11.7 percent of the samples were above the age of 15 years.

TABLE II
IDENTIFICATION OF THE DISABILITY

Age (Years)	Number	Percentage
At Birth	10	16.7
1-2	22	36.7
2-3	17	28.3
>3	11	18.3
Total	60	100.0

Identification of the disability is very crucial in undertaking appropriate measures to treat and rehabilitate the child. From the above table it is evident that about 16 per cent of the parents identified the disability of their child at birth, 37 per cent were able to identify the disability when the child was about 1 to 2 years of age. Forty seven percent of the parents were able to identify the disability only after the child was above 3 years of age when the child goes to a normal school and the teacher complains about the inability or behaviours of the child branding them to be troublesome.

This shows the lack of awareness among the parents on the issues related to disability. This shows that premarital counseling on the child birth, child rearing and identification of disability are the need of the hour because intervention strategies taken during the golden period

(i.e.,) between 2 to 6 years can go a long way in the rehabilitation of the child and regression of the symptoms.

**TABLE III
FINANCIAL BURDEN DUE TO THE DISABILITY**

Expenditure	Number	Percentage
Education	48	80.0
Therapy	21	35.0
Counselling	13	21.67
Medication	10	16.67
Special tools/ Equipments	7	11.67
Special foods	5	8.33

The families with a disabled child have to tackle plenty of problems and one of the crucial aspects is the financial burden which distorts the entire family life. Identification of the disability is followed by consultations from speciality physicians, confirmation at various levels, cross verification and locating a suitable rehabilitation centre or a special school builds stress and reduces the financial resources of the family. Eighty per cent of the parents shelled additional amount for educating their special child, 35 per cent of the parents found it difficult to meet the expenditure on therapies which are numerous and the parents opt for specific therapies based on their financial resources. Around 21 per cent of the parents had to regularly spend on counseling and 16.7 per cent of them had to spend on medication of their special child. Special tools or equipments were required by 11.7 per cent of the children and 8.3 per cent of the parents spent extra amount on procuring special foods for their child. Financial burden is one of the reasons that lead to family discord since many of the parents find it hard to make the ends meet.

Many of the families are not sentient to the various benefits provided by the government in the form of monthly monetary benefits, income tax exemption and the educational, medical and rehabilitative facilities.

**TABLE IV
FAMILY CRISIS**

Crisis	Criteria	Number	Percentage
Quitting the job	Father	2	3.33
	Mother	5	8.33
	Total	7	11.66
Parenthood	Single	Nil	0
	Divorced	1	1.66
	Total	1	1.66

Family discord, broken families, single parenthood and divorce are a common side effect in the families with a special child. Dislocation and quitting the job to take care of the child are the major concerns, 11.7 percent of the parents have quit their job to devote more time for child care. There was only one family with a single parent.

The data obtained from the samples revealed that such crisis were minimum revealing the attitudinal change that had been brought about by constant counseling and rehabilitation measures undertaken by the government and nongovernmental organizations.

**TABLE V
LIVELIHOOD PROBLEMS**

Problems	Criteria	Number	Percentage
Disruption in family routine	Present	10	16.67
	Absent	50	8.33
	Total	60	100.0
Lack of leisure	Present	19	31.67
	Absent	41	68.33
	Total	60	100.0
Social interaction	Restricted	43	71.67
	Not restricted	17	28.33
	Total	60	100.0
Relation with the spouse	Good	42	70.0
	Fair	16	26.67
	Poor	2	3.33
	Total	60	100.0

The day-to-day strain of providing care and assistance leads to exhaustion and fatigue, taxing the physical and emotional energy of family members.

The families with a special child are always messed up until there is complete understanding of the problems of the child by all the family members and the skill the parents possess in handling the special needs and behavior problems of the child. Livelihood problems are of major concern since the family as a whole have to live up to the expectations of the society, which of course is very difficult. Disruption in the family routine always paves way for discord among the family members which was found in 16.7 per cent of the families studied. Parents of the special child especially the mother is always overworked because of the dual burden and they lack leisure which was observed in 31.7 per cent of the families, 71.7 per cent of the parents stated that they had very restricted social interaction due to two reasons one is because they do not find leisure time and the other is because of the social stigma which is prevalent in our society. The parents of the special children are labeled as cursed by the society due to which they restrict their social interaction. Due to stress, depression, overwork, provocation and social discrimination the marital relationship is also affected, 26.7 per cent of the parents opined that they had a fairly good relationship with the spouse while 3.3 per cent reported a poor relationship.

**TABLE VI
HEALTH PROBLEMS OF THE PARENTS**

Health problems	Criteria	Number	Percentage
Physical health problems	Present	57	95.0
	Absent	3	5.0
	Total	60	100.0
Mental health problems	Depressed	59	98.33
	Stressed	58	96.67
	Lonely	27	45.0
Social problems	Isolation	28	46.67
	Avoiding community events	15	25.0
	Fear of future	16	26.67
	Hinder child bearing	53	88.33

Health status of an individual largely depends on their emotional well being and their acceptance of the child's disability. Ninety five per cent of the parents reported that they developed physical health problems after the birth of the special child. In spite of moral and spiritual support offered to the parents through the family members, counselors and parent groups 98.3 per cent of the parents reported that they were depressed, 96.7 per cent of them told that they were stressed and 45 per cent of them expressed that they felt lonely and isolated, all of which necessitates offering reassurance to the parents through motivation, confidence building and orientation in relaxation techniques. There are a whole set of issues that create emotional strain, including worry, guilt, anxiety, anger, and uncertainty about the cause of the disability, about the future, about the needs of other family members, about whether one is providing enough assistance, and so on. Friends, neighbors, and people in the community may react negatively to the disability by avoidance, disparaging remarks or looks, or overt efforts to exclude people with disabilities and their families. Social discrimination is a major issue since the level of awareness in the society is abysmally poor leading to several issues, from the data obtained it is clear that 46.7 per cent of the parents seemed to be isolated from the society, 25 per cent avoided community events for the fear of being bullied by others, 26.7 per cent were worried about the future of the child and 83.3 per cent of the parents reported that having a disabled child hindered further child bearing.

**TABLE VI
ATTITUDE OF THE FATHER**

Child care practices	Criteria	Number	Percentage
Taking care during the illness of the child	Present	54	90.0
	Absent	6	10.0
	Total	60	100.0
Playing with the child	Present	51	85.0
	Absent	9	15.0
	Total	60	100.0
Helping in ADL	Present	51	85.0
	Absent	9	15.0
	Total	60	100.0

Punishing the child	Present	9	15.0
	Absent	51	85.0
	Total	60	100.0

Child care especially that of the special child usually rests with the mother and she feels exhausted and burdened. The data from the above table reveals that 90 per cent of the father took care of their special child during illness when they were at home, 85 per cent of the fathers' played with their child and also 85 per cent of them helped their special child in their routine daily activities. This reveals the acceptance of the disability by the father and their concern for their child. A very minimum of 15 per cent of the fathers' punished their child, usually when they disobey or due to abnormal behaviours.

**TABLE VII
ATTITUDE OF THE SIBLINGS**

Parameters	Criteria	Number	Percentage
Acceptance	Good	40	83.33
	Fair	8	16.67
	Total	48	100.0
Kindness	Good	32	66.67
	Fair	16	33.33
	Total	48	100.0
Helping tendency	Good	41	85.42
	Fair	7	14.58
	Total	48	100.0
Supportive	Good	37	77.08
	Fair	11	22.91
	Total	48	100.0
Jealous	Present	9	18.75
	Absent	39	81.25
	Total	48	100.0
Scared	Present	11	22.91
	Absent	37	77.08
	Total	48	100.0
Angry	Present	15	31.25
	Absent	33	68.75
	Total	48	100.0
Embarrassed	Present	18	37.5
	Absent	30	62.5
	Total	48	100.0
Worried	Present	28	58.33
	Absent	20	41.67
	Total	48	100.0

The family integrity and happiness to a great extent depends on the attitude of the siblings towards the special child, 21.7 per cent of the families did not have a sibling because the first child had some disability. The sibling relationship with the special child revealed that 16.7 per cent of the siblings could not accept the special child and 33.3 per cent of them were not kind and sometimes hurt the special child by their words or action. Around 14.6 per cent were not helpful and refused to engage or take care of the special child, 22.9 per cent were not supportive. Eighteen per cent of them were jealous since the special child was given more attention and 22.9 per cent of the siblings were scared of the special child owing to their abnormal behaviours. About 31.3 and 37.5 per cent of the siblings were angry and embarrassed respectively because of the presence of the special child at home, these calls for a sibling's workshop where several issues can be discussed to allay the fears of the siblings. 58.3 per cent of the parents stated that the sibling was worried about the special child especially when they were taken in public or when their friends visit their home.

**TABLE VIII
ATTITUDE OF THE GRAND PARENTS**

Attitude	Number	Percentage
Supportive	46	76.67
Unsupportive	14	23.33
Total	60	100.0

Families with a special child are able to cope up with their burden when they have a support system in the form of an extended family or when the grandparents offer to help the parents in the child care. From the

above table it is clear that 76.7 per cent of the grandparents offered physical, moral and spiritual support to the parents which helped to improve their quality of life

**TABLE IX
RECHARGING MODULES**

Modules	Number	Percentage
Discuss with other parents	23	38.33
Counselling	21	35.0
Spirituality	16	26.67
Engaging in hobbies	25	41.67

The birth of a special child in a family totally distorts the entire family life with plenty of fears, apprehensions, ridicules, embarrassments and the fear of the future of the child. Reassurance, constant counseling and guidance are required for the parents who have a special child. Many parents draw inspiration from other parents who had similar children. Creating parent groups may facilitate sharing of their experiences, child care practices and treatment modules that could build confidence in the parents. 38.3 per cent of the parents recharged themselves through discussion with other parents who have similar children, 35 per cent of them opined that counseling sessions were helpful in clearing their doubts and also offered motivation. Engaging in spiritual activities acted as a stress buster for 26.7 per cent of the parents and 41.7 per cent of the parents relied on their hobbies to divert their mind and recharge themselves for further activities.

Conclusion

Living with a disabled child can have profound effects on the entire family—parents, siblings, and extended family members with respect to their mental and physical health. It is a unique shared experience for families and can affect all aspects of family functioning. On the positive side, it had improved family resilience, broadened horizons, and increase family members' awareness of their inner strength, enhances family cohesion, and encourages connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a disabled child has far-reaching effect. Counseling offered to the siblings and parents could be effective in understanding the grey areas managing the disabled child.

Raising awareness about the reality of their situation, and busting many of the myths could go a long way in reassuring the families with a dignified life. Parent support groups and sibling clubs are some measures that could help in effective conflict management in the families of the disabled children.

References

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