



Psychological Distress in parents of physically disabled and intellectually disabled children: A survey study

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Abstract

Title: Psychological Distress in parents of physically disabled and intellectually disabled children: A survey study.

Background: Parents are not at all be expecting or thinking about disabled children, but if they face such condition in their lives, generally encounter many emotional problems. Transitions between infancy to adulthood have a strong impact on a family and if it is with a disabled child then parents frequently suffer with more pressure, stress and demands. It was noted that, the parents who did not come for regular Physiotherapy or were absent for most of a days in month gave reason for absenteeism as suffering from psychological illness or depression.

Objective: To assess psychological distress in parents of physically and intellectually disabled children.

Methodology: A 300 participants of age ranging from 25 years - 35 years were included in the study, out of which 186 participants were parents of physically disabled and 114 were parents of intellectually disabled children. The participants were explained about the study. Psychological distress was assessed using Beck Depression Inventory (BDI) scale. Analysis was done.

Sampling design: Convenient sampling.

Result: Result of this study stated that, there is extremely significant difference in group of parents of physically disabled and intellectually disabled children i.e. they are suffering from psychological distress.

Conclusion: Psychological distress was present in both parents of physically disabled and intellectually disabled children but more present in parents of physically disabled children.

Keywords: psychological distress, parents of physically disabled children, parents of intellectually disabled children, beck depression inventory scale, (BDI)

Introduction

Thousands and thousands of people around the globe share happiness and enthusiasm of being a parent. Actually raising a child is definitely a challenging task. Even though parenthood has a great deal of positive summit for mother and the father, it is probably the most difficult task that they will take on in their lives. All parents are making plan at all times for perfect, healthy and normal babies. Being a good parent requires a great deal of efforts in many different areas throughout the child's life and being able to successfully manage all those areas is what makes parenting so demanding. Parents are the most important individuals in children's life and plays a primary and well-known role in facilitating the growth and development of children ^[1]. All the time parents feel proud when their child gets improvement in life stages one by one progressively and fruitfully. All of them have several dreams and every time a person loses dreams, it brings the most important change in personal character and in the environment ^[2].

The birth of a baby with a disability or finding out that a child suffers from a disability can be disturbing for the parents and has reflective effects on the entire family also is considered to be a permanent and stressful event in the life ^[3]. When a disabled child is born, parents experience remarkable change that impairs their health, feelings, personality, priority, perfection and confidence, this changes their schedule of everyday activity. If one child is disabled in family, parents

habitually experience different emotional and psychological problems ^[2].

In India, disability is still considered in terms of a "tragedy" with a "better dead than disabled" approach, the idea being that, it is not feasible for disabled people to be happy and enjoy life to the fullest ^[4] Psychological distress is widely used as sign of mental health of population in public health and in population surveys. Psychological distress is an emotional condition that involves negative views of the self, others and the environment, furthermore it is characterized by feeling tense and irritable, having fear, worthless, nervous and uneasy ^[5] Living with a disabled child has more effects on the entire family, siblings, child's grandparents and extended family members. It affects allocation of time and financial resources to their healthy and unhealthy children. A short and long-term contribution to the household and the siblings' health development is also altered ^[6]. The quality of life is low in parents of children with disability than other parents. The severity of the disability affects a caregiver's health more than the actual disability of the child ^[3].

In India several depressions screening instruments are available with their psychometric properties in a primary-care Pediatric setting. In clinical and non-clinical settings Beck Depression Inventory (BDI) has admirable psychometric properties in other countries. Beck Depression Inventory (BDI) has also been widely valid among the adolescent population elsewhere ^[7].

Objectives

1. To assess BDI scale in psychological distress in parents of physically disabled children.
2. To assess BDI scale in psychological distress in parents of intellectually disabled children.

Materials and Method

Participants: A 300 participants of age ranging from 25 years - 35 years were included in the study, out of which 186 participants were parents of physically disabled and 114 were parents of intellectually disabled children. Parents were screened according to the selection criteria. Parents of children diagnosed with intellectual, physical, developmental disabilities, genetic and chromosomal disorders, high risk infants or children with any other chronic illness, parents from rural community, parents of both boys and girls from Infants upto 15 year old, parents must have ability to understand, interpret the questions and respond accordingly, parents should be living with disabled children and who were willing to participate were selected for the study the study. Meanwhile parents having history of psychological

disorders, those parents using antidepressant and anxiolytic drugs, parents who have any chronic physical disorder/disease, having one more disabled child or family members, any surgical history, pregnant mother excluded from this study. The study received ethical approval from the Institutional Ethical Committee (IEC) of Dr. A. P. J Abdul Kalam College of Physiotherapy, Pravara Institute of Medical Sciences. All the children’s parents filled and submitted a prior informed consent form.

Procedure: Psychological distress was assessed using Beck Depression Inventory (BDI) scale. The outcome measure ‘Beck Depression Inventory’ is originally in English. The Translated version of BDI was reliable and also best understood by participants so that is used in this study. Marathi version of the inventory was tested for its Psychometric properties and is reliable and valid. The questions in outcome measure were explained to the participants and also given idea how to choose or mark the appropriate answer, they were told to answer about their emotional status in the past week. The fully filled up scale was then received from the participants.

Data Analysis and Results

Table 1.1: Distribution of Beck Depression Inventory (BDI) in parents of physically disabled and intellectually disabled children from (Question 1-Question10)

Questions	Physically Disabled (N=186) Mean±Sd	Intellectually Disabled (N=114) Mean±Sd	Z test of difference between two means	‘p’ value	RESULT
Question 1	1.56± 0.90	0.92±1.02	6.61	<0.0001	Extremely Significant
Question 2	1.51±0.89	0.86±0.69	7.14	<0.0001	Extremely Significant
Question 3	1.63± 1.02	0.80±1.02	2.76	<0.0001	Extremely Significant
Question 4	1.48 ±0.94	0.57±0.83	10.01	<0.0001	Extremely Significant
Question 5	1.55±0.96	0.35±0.60	13.48	<0.0001	Extremely Significant
Question 6	1.78 ± 1.09	0.89± 1.01	8.09	<0.0001	Extremely Significant
Question 7	1.49 ± 0.92	0.52± 0.85	6.04	<0.0001	Extremely Significant
Question 8	1.72 ± 0.94	0.62± 0.66	13.75	<0.0001	Extremely Significant
Question 9	1.03 ± 0.81	0.28± 0.59	5.76	<0.0001	Extremely Significant
Question 10	1.75 ± 0.94	1.05± 1.22	7.01	<0.0001	Extremely Significant

Table 1.2: Distribution of Beck Depression Inventory (BDI) in parents of physically disabled and intellectually disabled children from (Question 1-Question10)

Questions	Physically isabled (N=186) Mean±Sd	Intellectually Disabled (N=114) Mean±Sd	Z test of difference between two means	‘p’ value	Result
Question 11	1.55±0.76	0.66±0.75	11.01	<0.0001	Extremely Significant
Question 12	1.34±0.75	0.53±0.76	10.12	<0.0001	Extremely Significant
Question 13	1.72±0.86	0.58±0.83	14.21	<0.0001	Extremely Significant
Question 14	1.38±1.08	0.35±0.68	10.03	<0.0001	Extremely Significant
Question 15	1.44±0.82	0.45±0.84	11.11	<0.0001	Extremely Significant
Question 16	1.58±0.91	0.78±0.98	8.01	<0.0001	Extremely Significant
Question 17	1.76±0.95	0.78±0.96	9.82	<0.0001	Extremely Significant
Question 18	1.45±0.92	0.61±0.87	8.41	<0.0001	Extremely Significant
Question 19	1.14±0.83	0.58±0.79	7.02	<0.0001	Extremely Significant
Question 20	1.47±0.99	0.58±0.77	8.93	<0.0001	Extremely Significant
Question 21	1.47±0.88	0.66±0.84	8.11	<0.0001	Extremely Significant

Result of this study stated that, there is extremely significant difference in group of parents of physically disabled and intellectually disabled children i.e. they are suffering from psychological distress.

Discussion

Description of Question 1 gathers information about ones sad mental status. Sen E *et al.* conducted similar study on difficulties experienced by families with disabled children and they concluded that, families of disabled child did not

have adequate knowledge about their children’s condition so mothers felt severe sadness and they indicated that having a disabled children affects parents involvement in society as well as disturbs family relationships [3]. Description of Question 2 collects information about feelings of Pessimism. The result of this study is complimentary to the study conducted by Murphy NA *et al.* who conducted study on health of caregivers for children with disabilities: caregiver perspectives. This study indicated that, stress on caregivers negative impact on caregiver health, distribution of the

burden, worry about the future and caregiver coping strategies.⁸ Question 3 mention about the feeling of failure in the past. As compared to typically developing children, development of disabled children is slow and because most of the times parents don't know the disease process they feel the growth of the child is stagnant or not progressive because they are not able to fulfill the needs or they are not up to the mark as a parent. Question 4 revealed about loss of happiness in parents life. Similar study was conducted by Nimbalkar S *et al.* titled, A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in western India and they concluded that, parents faced common problems such as loss of happiness and troubled social relationships, problems with poor health conditions and financial conditions^[9]. In Question 5, parents of physically and intellectually disabled children showed that most of the time parent felt guilty about many things. The birth of disabled child can affect the parents. Parents may feel ashamed or embarrassed because they don't have word to explain their children's conditions why the child is different from normal developing children. Parents may be embarrassed about the way child acts, sometimes they are not able to control their child and may think that society will blame them that they are not having good parenting skills. Parents having disabled children may have psychological stress, loss of feelings and low self esteem. Due to disappointing behavior of children and their questionable ability to fulfill age appropriate activities increases parents anxiety and awkwardness. In Indian society having disabled member in family is still considered as stigma and people try to avoid social interaction and be isolated with fear of being shamed and embarrassed. Explanation of Question 6 is about parents being punished. When parent know that development of child is abnormal the realization of this may be devastating for parents. In different cultures the interpretation and reactions to birth of disabled child can be various. Parents can be viewed as a punishment from god for some wrongdoing in previous or present life. Parents tend to blame themselves or each other. Question 7 suggests feeling of disappointed. Generally children get happiness in ones home by their playful activities and mischievous behavior. Everybody wants healthy and happy children. But when children are physically disabled they might not be as active as normal child and may just increase parents worry rather than feeling of satisfaction. Question 8 advocated about feeling of blame or fault. This result was supported by the study carried out by Veisson M on Depression symptoms and emotional states in parents of disabled and non-disabled children and they stated that, parents of disabled children have extensively negative emotional feelings and shows more distress symptoms^[10]. Parents may blame themselves or their partners for not being aware about their own physical state before and during pregnancy. Many times parents think because they are residing at rural place they are having very limited source of medical and laboratory facilities, consultation and guidance and other time they think the financial resources for their own survival are also inadequate and such thinking gets them to the feeling where they feel they themselves has to be blamed for having disabled children. Question 9 collects information about suicidal thoughts or wishes. Giulio P *et al.* carried out study on Families with disabled children in different European c and found out similar finding as this study. He saw that parents of disabled children had feelings of

emptiness, loneliness and negative views more characteristically^[3]. Most of the parents when got aware about child's disability, they started to put efforts from their side to improve child in the form of, offering children medical treatment, timely investigations, coming to therapies and following home exercise programs. But when inspite of this they find minimum improvement in children they sometimes feel they are exhausted and feel they are not getting expected results and start to feel failed and frustrated and can have suicidal thoughts. Question 10 mentions about the cry. Parents of disabled children may realize their mistakes which they did in the past. Parents of disabled children dealing with the loss of imagined parenthood to be, which can lead to dissatisfaction, difficulty in accepting reality, they feel they are alone and helpless and think that nothing can be normal as before also think the future is very blur and all these feelings lead to cry.

Question 11 revealed about irritation as well as annoyance. Parents of children with special needs may feel irritated because they are unable to handle their children's behavior also in order to meet children's needs the burden of work is increased on parents. Because most of the time parents are busy with disabled children they don't find time to attend family gatherings and participation in social activities. This leads to self ignorance, parents not being able to follow their own hobbies, pursue carrier and they feel that their freedom is no more with them and so feel irritated. Question 12 recommends the loss of interest in other people or things. The following article showed result which was similar to this study. Di Giulio P *et al.* carried out study on Families with disabled children in different European countries and they concluded that, parents of disabled children are most commonly unstable and lost interest in others.³ This type of feeling can be seen in parents of disabled children because when they come across things, they realize their child has low ability to use it or play with it and thus they feel let down. When they meet other people they may think that only their lives are stagnant and with so much of problems and struggles and others are having happy and satisfied lives. All such feelings may lead to ignore the people and things. Question 13 justify that parents having ability of making decision. Parents of disabled children may have poor concentration, difficulty in making decisions because of constant stress, over thinking and emotional overload. As parents do not have interaction with other people, avoid to mix socially, parents are not exposed to developing world, opportunities to solve their problems also because they be isolated they have less chance to share their thoughts and they feel alone so parents get more difficult to take decision. Implication of Question 14 gives information about parents looks, as a aged or unattractive. Being parent of disabled child they have to work more as compared to normal child. They do not find time for themselves and also lose interest keeping themselves maintained. Description of Question 15 mention that capability of working. The result of this study is complimentary to study by Sen E *et al.* conducted study on difficulties experienced by families with disabled children and they stated that, families of disabled child suffered in problem with decreased working capacity and financial problems^[11] Some parents lack family support. Where some are nuclear families, so, parents can get more fatigue as they only have to look after their kids. So to maintain health of child mothers may leave their jobs or do it half time and fathers also may decrease the duration of work, they tend to

put leave frequently or may not do overtime work.

Description Question 16 collects information about sleep routine. Disabled children may not be sleep on time, have disturbed sleep patterns or can be early risers. Because of all this parents of children with special needs face interruption of sleep. Question 17 revealed information on feelings of tiredness. A day by day routine of parents with disabled children can be challenging because children are dependent on parents for their needs. The schedule of parents with special needs children can be exhausting and with constant anxiety. Question 18 gather information about capability for appetite. Stress can affect parents in different ways. Parents are more busy with taking care of children thus, proper schedule of having their own meals is not maintained. Some parents are unable to eat on time to time or skip their meals. A parents of child with special needs face increased anxiety thus may affect on appetite of parents. Description of Question 19 gives information about loss of weight. This can be seen as they are irregular at their diet and meals and they are physically working more than others. Psychological aspect of being stressed most of the time can be cause to reduced weight. Question 20 justify that parents are having problems with health. This result was supported by, Riyahi A *et al.* who conducted study on Comparing the parenting role tasks in parents of children with physical disabilities. This study suggested that, parents of disabled children, mostly mothers are at the experiences of numerous health threatening challenges as well as problems and families were more prone to severe health issues ^[1] Di Giulio P *et al.* carried out study on Families with disabled children in different European countries. This study concluded that, parents of disabled children experienced more repeatedly financially viable, constantly facing health issues and have poor quality of life than parents of without disabled children ^[3] Description of Question 21 collects information about interest in sexual category. This result corresponds with other study by Di Giulio P *et al.* carried out study on Families with disabled children in different European countries. This study concluded that, decreased interest in sexual contact in parents of disabled children as well as sacrificed in fertility intentions ^[3].

Conclusion

This study concluded that, prevalence of depression increased in parents of disabled children but is more in parents of physically disabled than parents of intellectually disabled children. The determination of predictors of depression among parents of disabled children may help health professionals in identifying parents at risk. Our study additionally supported the Beck Depression Inventory Scale which was a feasible and reliable measure for identifying probable cases of Depressive disorders among the adolescents.

Limitations of the study

1. There was no equal distribution of sample size in each group.
2. Comparison between two groups was not done.

Future scope of study

Relaxation techniques, coping strategies, counseling and recreational activities can be incorporated as an intervention.

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