



RESEARCH ARTICLE

A STUDY ON QUALITY OF LIFE OF PARENTS OF AUTISM CHILDREN WITH REFERENCE TO COIMBATORE

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ABSTRACT

Autism is a multifaceted neurobehavioral state that includes impairment in social interaction and developmental stages combined with repetitive and rigid behaviours. Because of the range of symptoms, this condition is now called autism spectrum disorder. Autism spectrum disorder ranges from normal handicap to severe disability which may require special care. Thus the parents who are taking care of children with autism have to face lots of practical difficulties and challenges. This may put them in stress, depression, anxiety and other issues if they are not properly addressed to manage the problem. If this is the condition then their quality of life is a question to be answer. Thus this study focused on their quality of life and various measures to combat with the problems in taking care of their children were also discussed.

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INTRODUCTION

Autism is refers as a range of conditions characterized by issues in repetitive behaviors, social skills, communication and with distinctive differences and strengths. There are many types of autism which are caused by the combination of genetic and environmental factors. The word "spectrum" means the wide range of variation in strengths and challenges possessed by each autism person. The signs of autism tend to visible between 2 to 3 years of age. In some cases, it may be also diagnosed earlier also. Autism can be identified through the development delays of the child and addressed accordingly. As treatment can help the autism children to improve the conditions, it is important for the parents to seek the early deduction of the issue and take appropriate treatments. Autistic children have problems in communication and understanding, which makes it hard to express themselves with words or gestures, etc. Some children are been affected by the sounds, smells, touch, etc which seems to be normal for other children. Stress is a common factor which prevails everywhere from home to work. The parents with autistic children may experience more stress than other parents due to their present condition. This is evident from literatures, that parents of autistic children suffer from stress, which is found to be more among women when compared to men. There are many reasons why the level of stress among the parents of autistic children is high. The grief coping, feeling about the future,

treatment, financial commitments, societal pressures, etc plays a major role in the stress of the parents with autistic parents. Apart from this the parents of the autism children also suffer from other problems like lack of support from relatives, handling the behaviour changes of the children, dealing with the treatment issues, etc. Though there are numerous studies which are related to the impact of behaviour of children on the stress level of the parents. Such stress may lead to depression in due course of time. If this is the condition there arises lots of questions on the quality of life which these parents lead in their lives?. Thus to address the above question, this study was undertaken to assess the quality of the life of parents of children suffering from autism and the personal factors influencing the quality of life of the parents of autism children.

Review of Literature

Kessler, (2003) their research study found that depressive symptoms are found to be high among the mothers who had autism children when compared to mothers of other children who are affected by other kinds of disabilities. When taking the depressive symptoms of fathers, it was found that fathers also suffer for the same but lesser when compared to mothers. Ranjit and Hemalatha (2013) help and guidance from parents are considered as important in young children as they don't have the ability to lead a independently life. Care and love from parents are more essential and need for young which cannot be substituted by other people. But presently children are adapting to the life of their parents rather than parents to children. Merely parent's functional adjustment may not be

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considered as a factor in cease from their obligations towards their children Kendler *et al.* (2001). Found that compared to women, men are more depressed in reaction to stressors, with problems at work by men and interpersonal relationships by women. Caspi *et al.* (2003); Kendler *et al.* (2005); Jacobs *et al.* (2006) their studies shows that stress and depression are related with particular genes which are naturally occurs. Those individual who are possessed with such genes experiences stressful life more intensively than others who vary in such gene. Such individual tend to suffer more from depressive symptoms. This is confirmation of a gene-by-environment interaction. Life is full of stressful events, but the level of depressions occurs based on the influence of genetic factors. The review of literature also depicts that Ranjit and Maheswaran (2013) their study results found that no significant correlation was found among number of children and life satisfaction of the respondents. Hammen, (2005) when compared to men, women tend to have difference in their depression due to their stressors like carrying of elders, victim of sexual harassment, poverty, single parenthood, etc. W.P., Riley, A.W., & Coiro, Another study by Ranjit (2014) there study found that habit of savings significantly influences the level of quality of life of the respondents. M.J. (2003). Their research study shows that maternal depression is found to be related with psychosocial maladjustment among children with disabilities. Sivaranjane and Ranjit (2014) their study results have shown that majority of the children have stated that their parents are not spending much time with them at home even after their return from work. The children want their parents to plan their schedules in such a manner which helps them to spend more time with them.

Objective

1. To study the personal profile of the respondents
2. To assess the quality of life of parents of autistic children.
3. To analyze the influence of personal variables on the quality of life of the parents with autistic children.

Methodology

The present study is descriptive in nature. The universe of the study is the parents of autism children who are undergoing institutionalized training in a special school in Coimbatore. A sample of 50 parents of autism children was selected for the study. Convenient sampling was used to select the sample from the universe. An interview schedule was used to collect the data. The quality of life of parents was assessed using quality of life scale (5 point Likert scale). Higher the score indicates higher level of quality of life and vice versa. The data was analyzed using t-test, ANOVA, Chi-square and Correlation.

Analysis and Interpretation

The table 1 shows that 64 percent of the respondents belong to the age group 31-40 years, 24 percent of them belong to the age above 41 years and 12 percent of them belong to the age below 30 years. More than half of them (56 percent) of them were female and 44 percent of them were male. It also depicts that 74 percent of them were Hindus, 18 percent of them were Christians and 8 percent were Muslims. It is clear that majority (88 percent) of them were residing in nuclear families and 12 percent of them were residing in joint families.

It also shows that 42 percent of the respondents have completed their higher secondary level of education, 22 percent of them have completed their secondary level of education, 20 percent of them have completed their graduation and 16 percent of them have completed their primary education. The Table 1 reveals that 53 percent of them were residing in semi-urban areas, 28 percent of them were residing in urban areas and 20 percent of them were residing in rural areas. It shows that 30 percent of the respondents were working as employees, 22 percent of them were doing business, 8 percent of them were working professionals, 4 percent of them were daily wage earners and 36 percent of them were working in other jobs. The table 1 depicts that 42 percent of the respondents had an family income between Rs.20000-30000, 34 percent of them had an income Rs.10000-20000, 20 percent of them had an income above Rs.30000 and 4 percent of them had an income below Rs.10000. The Table 1 reveals that 68 percent of the respondents were having the problem for the past 2-5 years, 18 percent of them were having the problem below 2 years and 14 percent of them were having the problem above 6 years. It is clear from the Table 1 that majority (42 percent) of the respondents were training their children for the past 2 years, 32 percent of them were training their children for the past 3 and above years and 26 percent of them were training their children below 1 years. The Table 1 depicts that 38 percent of the respondents were referred to the institution by their friends and neighbours, 28 percent of them were referred by their family and relatives and 22 percent of them were referred by other sources and 12 percent of them themselves identified the institution. The table 1 reveals that 34 percent of them were satisfied with training, 24 percent of them were neither satisfied nor dissatisfied with the training, 22 percent of them were highly satisfied with the training, 14 percent of them were dissatisfied with the training and 6 percent of them were highly dissatisfied with the training provided in the institutions.

The table 2 shows that 48 percent of the respondents had a low level of quality of life, 26 percent of them had a very low level of quality of life, 22 percent of them had moderate level of quality of life and 4 percent of them had high level of quality of life.

The table 3 depicts the influence of demographic variables on the quality of life of the parents with autism children. The ANOVA value (16.961) shows that there is a significant difference in the quality of life based on different age groups of the respondents. The t-test value (2.517) shows that there is a significant difference in quality of life among male and female respondents. The chi-square value shows that there is an significant association between the demographic variables namely religion (6.253), type of family (12.393), educational qualification (39.494), place of living (27.846), occupation (121.242) and quality of life of the respondents. The coefficient of correlation value shows that there is a significant relationship between total family income (0.374), years of problem (0.314), years of training (0.67) and quality of life.

Salient Findings

- Two-third of them (64 percent) belong to the age group 31-40 years,
- More than half of them (56 percent) of them were female
- Majority (74 percent) of them were Hindus

Table 1. Demographic Profile

Variable	Particulars	No. of Respondents	Percentage
Age	Below 30	6	12.0
	31-40	32	64.0
	41 and above	12	24.0
Gender	Male	22	44.0
	Female	28	56.0
Religion	Hindu	37	74.0
	Muslim	4	8.0
	Christian	9	18.0
Type of Family	Joint	6	12.0
	Nuclear	44	88.0
Educational Qualification	Primary	8	16.0
	Secondary	11	22.0
	Higher secondary	21	42.0
Place of Living	Graduation	10	20.0
	Urban	14	28.0
	Semi urban	26	52.0
Occupation	Rural	10	20.0
	Daily wages	2	4.0
	Business	11	22.0
	Employee	15	30.0
	Professional	4	8.0
Total Family Income	Others	18	36.0
	Below 10000	2	4.0
	10000-20000	17	34.0
	20000-30000	21	42.0
Years of Problem	30000 and above	10	20.0
	Below 2	9	18.0
	2 - 5	34	68.0
Years of training	6 and above	7	14.0
	Below 1	13	26.0
	2	21	42.0
Person referred	3 and above	16	32.0
	Self	6	12.0
	Family and relatives	14	28.0
	Friends and neighbours	19	38.0
Satisfaction towards Institutional Training	Other sources	11	22.0
	Highly Satisfied	11	22.0
	Satisfied	17	34.0
	Neutral	12	24.0
	Dissatisfied	7	14.0
	Highly Dissatisfied	3	6.0

Table 2. Level of Quality of Life

S.No	Level of Quality of Life	Frequency	Percent
2	High	2	4.0
3	Moderate	11	22.0
4	Low	24	48.0
5	Very Low	13	26.0

Table 3. Influence of Demographic Variables on Quality of Life

Variable	Test	value	Result
Age	ANOVA	16.961 p<0.01	S
Gender	t-test	2.517 p<0.05	S
Religion	Chi	6.253 p>0.05	NS
Type of Family	Chi	12.393 p<0.05	S
Educational Qualification	Chi	39.494 p<0.05	S
Place of Living	Chi	27.846 p<0.05	S
Occupation	Chi	121.242 p<0.05	S
Total Family Income	Correlation	0.374 p<0.01	S
Years of Problem	Correlation	-0.314 p<0.01	S
Years of training	Correlation	-0.067 p>0.05	NS

S- Significant NS: Not Significant

- Majority (88 percent) of them were residing in nuclear families
- Less than half 42 percent of the respondents have completed their higher secondary level of education
- More than half 53 percent of them were residing in semi-urban areas
- Less than one-third (30 percent) of the respondents were working as employees
- Less than half (42 percent) of the respondents had a family income between Rs.20000-30000
- More than two third (68 percent) of the respondents were having the problem for the past 2-5 years

- Majority (42 percent) of the respondents were training their children for the past 2 years
- More than one third (38 percent) of the respondents were referred to the institution by their friends and neighbours
- One third (34 percent) of them were satisfied with training
- Less than half (48 percent) of the respondents had a low level of quality of life, 26 percent of them had a very low level of quality of life, 22 percent of them had moderate level of quality of life and 4 percent of them had high level of quality of life
- Demographic variables namely age, gender, type of family (12.393), educational qualification (39.494), place of living (27.846), occupation (121.242) and quality of life of the respondents. The coefficient of correlation value shows that there is a significant relationship between total family income (0.374), years of problem (0.314), years of training (0.67) and quality of life.

Suggestions

- The government has to provide appropriate training institutions for training the autism children with free of cost.
- Stipend can be provided for the parents to manage their economic pressures.
- Counselling centres can be promoted by the government to help the parents of autism children to manage their psychological pressures.
- Proper counselling must be given to the parents in treating the autism children.
- Awareness must be provided in public to support such parents and their children's for better living through formal and informal groups.
- Parents can involve themselves in yoga and meditation to keep them calm and stress free which can help them to take care of their child in a better way.
- The status of special school teachers has to be increased by means of providing them good and adequate salary and recognition which will make the profession to grow which in turn attracts more number of professionals to this field.
- Appropriate measures have to be taken by the government and non-government agencies to form an network group regarding the autism.
- Apart from government, the corporate participation by means of CSR activity must focus on such intellectual disability areas which are more essential in the present scenario.

Conclusion

The present study thus concludes that there was low level of quality of life was found among the parents of autism children. The demographic variables have a significant influence over the quality of life of the parents of autism children. Government support is very much essential in supporting the parents of children with autism and for the children also. If this is unnoticed then it may lead to a social problem in later case.

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