

Quality of Life of Parents Having Children with Autism

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ABSTRACT

Background and Purpose: Autism is a complex developmental disorder which is fast growing in nature across the world. Aim of the study was to evaluate the Quality of Life (QOL) of parent with autism. Purpose of this study was to investigate the QOL of parents having children with autism. **Methodology:** Descriptive survey research design was used. The study employed a convenient sampling technique to draw 30 parents having children with autism who were attending special School at Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped, Hyderabad (AP) in year 2013. WHOQOL-BREEF tool was used for data collection and data were analysed by using descriptive statistics namely: frequency distribution, percentages, mean and standard deviations. **Results:** Result revealed that 41% parents expressed that poor quality of life while 30% expressed their life in neither good nor bad. 21% parents perceived their life is good and 5% parents showed very good quality of life. 3% of parents having children with autism expressed very poor quality of life. Parents having children with autism displayed significant impairment in their quality of life especially in the area of psychological and environment domain. **Conclusion:** Findings of this research work will be helpful in building intervention programme and policy making to enhance quality of life of parents having children with autism. The ministry of Human Resource Development should consider the availability of stress management programme for parents, workshops and conferences for teachers and inclusive education for children with various disabilities.

Keywords: *Quality of Life, Parent and Autism*

All parents wish for a healthy baby, but some parents though not by their choice are gifted with a child having disability. The onset of symptoms in autism occurs within the first three years of life and includes three general categories of behavioural impairment common to all persons who have autism: Qualitative impairments in social interaction, Qualitative impairments in communication and Restricted, repetitive and stereotyped patterns of behavior, interest and activities (Diagnostic and Statistical Manual of Mental Disorder, 4th edition -2010). Quality of life as is a multidimensional concept and it is very important for each individual. In day-to-day living, it can be expressed in different contexts. Namely, it is associated with a sense of happiness, life satisfaction, fulfilment of desires and needs, including the need of security. The concept quality of life understood as an individuals'

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perception of their position in life in context of the culture and value systems in relation to their goals, expectations, standards and concerns (WHO, 2012).

Parenting a child with disability is not an easy task (Peshawaria and Ganguli, 1995). Having a child with a disability affects not only the psychological stress levels of the parents, but major life decisions as well. Parents having autistic children and parent having children with mental retardation showed impairment in all the four domains compare to parents of healthy children (Malhotra, Khan and Bhatia, 2012). There were significant differences in the QOL of parents having a child with disability depending on the type of disability variable, favouring parents having a child with learning disability who had the highest QOL scores, followed by parents having a child with physical disability, then parents having a child with mental retardation, and finally, parents having a child with Autism who had the lowest degree of QOL (Haimour and Hawwash, 2012). Parents of children with PDDs seem to display a higher burden, probably for a Combination of environmental and genetic factors. Within this group of parents also those of High function autism or Asperger syndromes people have higher burden (Mugno et al, 2007).

Autism in children in causes not only financial burden but also leads to incomplete state of wellbeing in physical, psychological and social health of the parents. This research study was an attempt to investigate the Quality of Life of parents having children with Autism

RESEARCH METHODOLOGY

Design:

Descriptive Survey method was used in this study.

Sample:

The sample size of 30 parents (Either mother or father) was drawn from the parents having children with autism who were attending special school at Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped, Hyderabad District of Andhra Pradesh state, India in 2013. Inclusion criteria has followed parent whose age range 20 year and above having children with autism and exclusion criteria was parents should have only one child with autism.

Tool:

WHO Quality of Life BREF (WHO QOL BREF, REV., 2012). The WHOQOL-BREF, an abbreviated version of the WHOQOL-100, is a self administered questionnaire. It comprises of 24 items categorized into four broad domains: physical health, psychological well-being, social relationships and environment. The items are rated on a 5-point scale. Internal consistency, Cranach alpha values for each of the six domain scores ranged from .71 (for domain 4) to .86 (for domain 5), Test and retest reliability ranged from 2-8 weeks. Correlations between items at time points one and two were generally high, it ranging from .68 form the Safety facet to .95.

Technique:

Purposive sampling technique was used for sample selection.

Procedure:

Initially school management and principle had informed regarding research work and after got the permission; initially a brief informal interview was held with the parents of Autistic children. After the informal interview, the researchers took a written consent from all the Parents having children with autism. Finally questionnaires were given to parents and instructions had explained. The data was collected over a period of two months.

RESULTS AND DISCUSSION

The sample comprised of parents having children with autism. Table 1 shows the overall perception of quality of life; Table 2 Comparison of all the four domain of Quality of Life of parents having children with autism.

Table 1: Individual Overall Perception of Quality of Life.

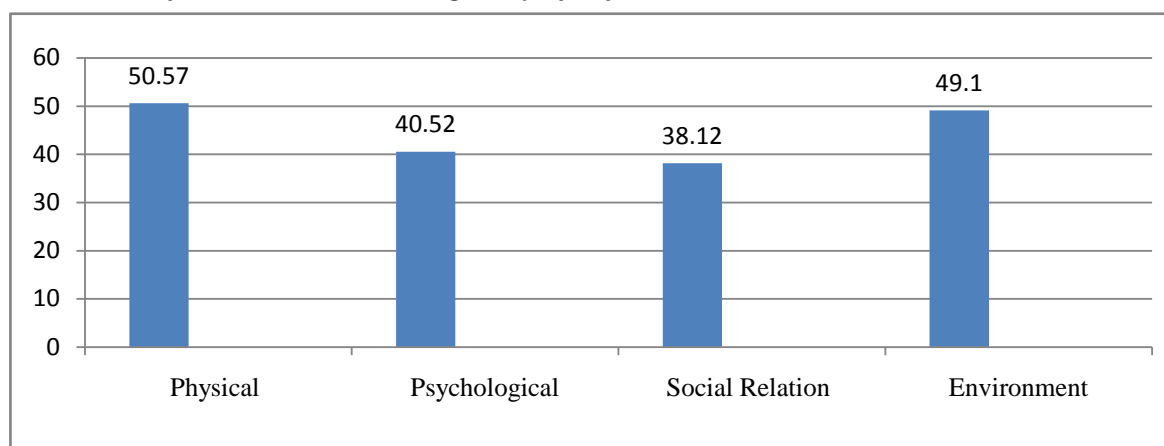
SNo.	Quality of Life	Percentage of Parent’s Responses having Children with Autism
1	Very poor	3%
2	Poor	41 %
3	Neither good nor bad	30%
4	Good	21%
5	Very Good	5%

Table: 1, Scores indicated that 41% parents expressed that poor quality of life while 30% expressed their life in neither good nor bad. 21% parents perceived their life is good and 5% parents showed very good quality of life even though having children with autism. 3% of parents having children with autism expressed very poor quality of life. Similar study has done by Haimour and Hawwash (2012), who found that the QOL of parents having a child with disability depending on the type of disability variable, favouring parents having a child with learning disability who had the highest QOL scores, followed by parents having a child with physical disability, then parents having a child with mental retardation, and finally, parents having a child with Autism who had the lowest degree of Quality of life. This may be due to the fact that the parents is adjusting with change in behavioural and other activities of daily living problem of heir child

Table-2 Mean and SD of quality of life of parents of children with autism on four domain of WHO Quality of Life BREF

S.No	Domain	Parents having children with Autism N=30 (M+SD)
1	Physical	50.57 ± 18.90
2	Psychological	40.52± 12.96
3	Social Relation	38.12 ± 20.06
4	Environment	49.10 ±17.14

Figure: 1 Graph Representation of Mean score parents perception having children with autism on all four domains WHO Quality of Life BREF



Domains of WHOQOL-Bref

Table 2 and figure 1 indicated that parents having children with autism perceived poor quality of life in social relation and psychological domains while they showed average quality of life in physical and environment domains of WHO Quality of Life BREF. The finding of this research is in line with Malhotra (2012) who found that parents having children with autism display higher Burden and poor quality of life in psychological and social relation compared to physical and environment domains. This may be because autism child needed more time to assist for daily living activity and parents have worries about child's health and treatment. Parent's social life also affected and the face rejection from the society which makes feel down.

CONCLUSION

Parents having children with autism displayed significant impairment in their quality of life especially in the area of psychological and environment domain. Findings of these research work will be helpful in building intervention programme and policy making to enhance quality of life of parents of children with autism. The ministry of Human Resource Development should consider the availability of stress management programme for parents, workshops and conferences for teachers and inclusive education for children with various disabilities.

SUGGESTIONS

In the light of the findings that have emerged from the present research, the following suggestions are listed.

1. A similar study can be conducted with a larger sample drawn from all district of the state, so that the finding could be more generalized.
2. A study can be done to identify the need and attitude of parents, sibling and other family member towards inclusion education for autistic children.
3. Parent support group should be initiated to build and strengthen the external support system for families.
4. The relaxation techniques like yoga, walking and mediation will be helpful for parents to cope up with the stress improve their quality of life.
5. As per the PWD, National Trust and, RCI acts the disabled children are having right to education and all the disabled children should be recommended for inclusive education.

IMPLICATIONS

1. Family Members: Involvement of the family in the training and care of the autistic children helps in diminution of the family emotional stress.
2. Community awareness: Community involvement to the rehabilitation programs targeting children, adults and aged would help immensely in shaping and correcting the attitude of the community towards individuals with autism.
3. Special/Inclusion education field: This research work practically helpful to special educator who handles the child in inclusion /special school and some time counsel the parents.
4. Rehabilitation professional: The present study is useful to rehabilitation professional for developing the stress management and wellbeing programme for family of autistic children.
5. State, Central government and NGOs: This research work will provide insight and understanding to the government and non government organization about need of the training programme for parents having children with Autism.
6. For Researchers: present study will serve as basis for conducting further research studies.

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Conflict of Interest

There is no conflict of interest.

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