

EVALUATION OF QUALITY OF LIFE OF PARENTS HAVING CHILDREN WITH SENSORY DISABILITIES

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Abstract

The quality of parent's life is an essential component for the development of healthy atmosphere for the rehabilitation of children with sensory disabilities. The study attempted to evaluate quality of parent's life having children with sensory disabilities. It is a descriptive study in nature. Population of study is parents of children with sensory disabilities living in Faisalabad. Sample of N=200 children with sensory disabilities (n=100 parents of visually impaired children and n=100 of parents of hearing impaired children) is selected through Convenient sampling technique. Parental age is 25-55 years and children age is among 6-15 years. Quality of life BREF is used as instrument of study. Data collected through instrument clearly demonstrated that parents who have children with sensory disabilities have low quality of life as 95% parents responded at neither satisfied nor dissatisfied. It is found out that there is no significant difference in the quality of life of the parents on the basis of gender (mother and father), age groups (26-55) and on the basis of category of disability of child. It is concluded that parents having children with sensory disabilities have low quality of life and their relation with the child, their age or category of the child's disability does not influence parents differently so school administration should arrange workshops and seminars that bring positive wellbeing of the parents having children with sensory disabilities. On the basis of the findings of current study, it is strongly recommended that Parents should visit special schools of their children to keep in touch with the strengths and weaknesses of their child. And Governmental policies makers should bring in further legislation to support family in regard to healthcare for family members with a sensory disability.

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Introduction

Personal success in the modern society is measured by the contribution to the development of the community. That is precisely one of the important factors in making the families with disabilities depend on solidarity and personal vision of justice of other members of the community (Denona, 2000).

The term "quality of life" is a broad concept and subject of various scientific disciplines, including biomedicine and health, based on its multidimensionality. Quality of life is founded on individuals' experience, their aspirations, wishes and values, and is determined by a set of individual psycho-physiological characteristics and the objective conditions in which they live. The range and quality of interaction with the environment, the flexibility of the individual towards the changes in the physical and social environment, as well as the changes within an organism, are determined by individual cognitive and cognitive characteristics (Leutar, 2001). The experience of parenthood is undoubtedly one of the most significant changes in everyone's life. There are factors that affect parenthood experience and they include satisfaction / dissatisfaction with their child, satisfaction / dissatisfaction with themselves as parents, the established relationship between themselves as well as the child's developmental achievements. The relations between parenting practices, environmental relations and the child's developmental outcomes are complex, and, indisputably, are different in various developmental periods and different social environments. Naturally, these relations are influenced by culture and ethnicity affecting the ways of raising children, and also numerous sets of values (Kaliterna, et.al., 2012)

Starting from the assumption that raising a special needs child is more demanding than raising a special needs child, the consequences of that stress were questioned, especially the frequency of physical and mental illness in parents. Studies confirm that, although there are parents who are doing well, there are more of those who experience health problems, a greater degree of depression, anxiety and emotional burden than parents without such problems (Benjak, 2010). Parents of adolescents with developmental disabilities feel isolated and complain about the lack of support during the period of transition from primary to secondary school, As well as the transition period to adulthood. Whether it is a new-born child or an adult member of the family, parents and families are required to know how to properly act to involve the person with special needs in the habilitation and rehabilitation treatments, to be their support and reliance in accepting and adapting to the new situation (Clark, et.al., 2013). There are a few studies dealing with assessing the quality of life in families with disabilities who are involved in associations and centers

for the rehabilitation of people with disabilities within the local community (Azam, 2019; Hamilton, et.al., 2015).

There is a major connection between the evaluation of the quality of parent's life and evaluation of the quality of their children's life. The more satisfied parents are with their quality of life, i.e. the better they estimate their personal welfare, the better are the evaluations for the quality of life of their children. Introduction Personal success in the modern society is measured by the contribution to the development of the community. That is precisely one of the important factors in making the families with intellectual disabilities depend on solidarity and personal vision of justice of other members of the community. The living standard of whole life of the parents of people with disabilities is interesting as the subject of many scientific disciplines (Cummins, et.al., 2003).

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There are factors that affect parenthood experience and they include satisfaction / dissatisfaction with their child, satisfaction dissatisfaction with themselves as parents, the established relationship between themselves as well as the child's developmental achievements. The relations between parenting practices, environmental relations and the child's developmental outcomes are complex, and, indisputably, are different in various developmental periods and different social environments. Naturally, these relations are influenced by culture and ethnicity affecting the ways of raising children, and also numerous sets of values (Poljan, 2007). Starting from the assumption that raising a child with intellectual disabilities is more stressful than raising a child without special needs, the consequences of that stress were questioned, especially the frequency of physical and mental illness in parents. Studies confirm that, although there are parents who are doing well, there are more of those who experience health problems, a greater degree of depression, anxiety and emotional burden than parents without such problems. Parents of adolescents with developmental disabilities feel isolated and complain about the lack of support during the period of transition from primary to secondary school, As well as the transition period to adulthood (Vuletić, 2013).

Review of Literature

A study was directed on stress among mothers of children with cerebral palsy going to special schools in Kerala State. Stress level was evaluated utilizing the nearby language form as Survey on Questionnaire on Resources and Stress (QRS) and the information was examined. The examination uncovers that mean stress experienced by mothers of cerebral palsied children matured between 3-6 years was 22.94 and that of 7-11 matured gathering was 22.46. Free "t" test demonstrated that there was no factually huge contrast in the seriousness of stress experienced by mothers (Vijesh, and Sukumaran, 2007).

An examination was directed to evaluate the issues observed by physically and intellectually disabled children. The outcomes show that poverty rate for handicapped individuals was 23.1% contrasted with 17.9% for non-disabled individuals, yet when additional costs related with being incapacitated were measured, the pitiable ratio of the person with disabilities raised up to 47.4% (Tim McQuade, 2011).

A cross sectional examination was led to assess the elements influencing parental emotional well-being. 91 parents of children with physical disabilities took an interest in the investigation. The outcomes uncovered that child related components that adversely influenced parental psychological wellness were poor strolling capacity ($p < 0.05$), reliance on others to perform Workouts of Everyday Life (ADL) ($p < 0.01$), and more youthful age ($p < 0.05$). Parent-related components that adversely influenced parental emotional wellness were low pay ($p < 0.05$), no strict convictions ($p < 0.01$), significant level of parental distress ($p < 0.01$), parent-child broken collaboration ($p < 0.01$) and having troublesome child ($p < 0.05$). The outcomes show that the guardians of the physical handicapped children were very poor emotional level well-being (Hung, Wu and Chiang, 2010).

An investigation was led in Turkey on burnout, depression and stress in mothers of children with brachial plexus injury and the influences of recovery on mother's psychological well-being on 18 mothers. The mothers detailed a insignificant level of anxiety scores. There was no measurably critical contrast between the depression ($p = 0.218$), anxiety ($p = 0.078$), emotional exhaustion ($p = 0.149$), depersonalization ($p = 0.138$), and personal achievement ($p = 0.246$) scores of the mothers in connection to the seriousness of the injury in the child. The outcomes uncovered that Newborn children's inability may cause mental distress in their mothers (Karadavut and Uneri, 2011)

A cross-sectional Examination was directed on the emotional wellness of Australian mothers and fathers of little children with disability. The goal was to measure the commitment of distress among 4,983 parents and by and large parental mental gloominess. The outcomes uncovered that raised mental distress were demonstrative of genuine psychological maladjustment

among mothers (95%) yet not fathers. Around 50% of mothers represented destructive life incidents, more unfortunate maternal wellbeing and diminished personal social life. The relationship between threat of child disability and maternal emotional wellness is vigorously mixed-up by prolonged rates of poverty among children in danger of disability (Vermaes et al., 2008).

A comparative study was directed on hindrances to maternal workforce cooperation and relationship of mother between paid work and wellbeing. 152 moms were incorporated and maternal Wellbeing Related Quality of Life (HRQoL) was evaluated. 82% of mothers needed to work for pay however classifications that predict their work interest are mother-related reasons (28%), child related reasons (29%) and administration confinements (43%). Mothers who worked (n=83) reported significantly better HRQoL over mothers who didn't work (n=69). The outcomes uncovered that, however the mothers had advanced education yet they revealed less fortunate health, lower family income and lower workforce interest because of child's disability (Bourke, Howie and Law, 2011).

A comparative study was led on relationship of depression in mothers of disabled children with the child's support in integrated education. The goal of the investigation was to measure depression and to see if mothers' depression differed by sex of the child. 59 mothers of children with disabilities who took interest in incorporated training and 67 mothers of children with disabilities who didn't take part in integrated education were remembered for the examination. They utilized Beck Depression Scale and General information forms. The results uncovered that depression in mothers of children with disabilities who didn't take interest in integrated education was higher than in mothers of children with disabilities who partook in integrated education (Ceylan and Aral, 2007)

An investigation was directed to confirm the quality of life (QOL) of mothers of the handicapped kids with Cerebral Palsy (CP) with epilepsy compared and non-epilepsy children. 30 mothers of disabled children and 18 mothers of children without disability (control group) took interest in the investigation. The outcomes revealed that mothers of children with CP have poor QOL than mothers of children with CP without epilepsy (Terra et al., 2011).

A research was conducted regarding quality of life and the emotional intelligence of two hundred special children. In which hundred children were normal and hundred children were having special needs were sampled for the investigation. Emotional intelligence scale and quality of life scale was utilized as the tool for the study. The outcomes revealed that there is a significant mean difference ($P=0.01$) between the investigation and the control group. The investigation likewise reports that the guardians of special children have a lot of experiences regarding tensions and stress responses identified with the child's inability. These stressors would

aggressively pressure the life quality of the parents of special needs children (Ravindranadan and Raju, 2008).

Objectives of the Study

Following are the objectives of study:

1. To evaluate the level of quality of life of parents having children with sensory disabilities.
2. It is desired to evaluate the quality of life of the parents having children with disabilities on the basis of parental age, parental education and relationship with their disable child.

Questions of the Study

Following are the questions of the study:

1. Do the parents of children having sensory disabilities have satisfactory quality of life.
2. Is there no significant difference in the quality of life of the parents on the basis of their relationship with child?
3. Is there no significant difference in the quality of life parents of the children on the basis of category of disability?
4. Is there no difference in the quality of life of the age groups 36-45 & 46-55, 26-35 & 46-55 and 26-35 & 36-45 of the parents of the children with sensory disabilities?

Methodology

This research is a descriptive study that aims to see the description of quality of life among parents having children with sensory disabilities and for the collection of information the survey method is used. Descriptive research is a method of describing the facts accurately and systematically, but does not intend to explain, to test the hypothesis, and make predictions and implications. Descriptive method aims to describe a phenomenon that occurs, without any intention to draw conclusions that apply in general (Hadi and Closs, 2016). This is mixed research method (both quantitative and qualitative) and frequency distribution, t-test and Anova with the help of SPSS are used to assess data.

Population Sample and Sampling Techniques

For the achievement of the objectives of current study 200 parents having children with sensory disabilities are recruited from Faisalabad, Pakistan. Sample of 200 parents having children with sensory disabilities is taken through convenient sampling technique. The researcher selected 100 families of each category of disability (hearing impairment, visual impairment).

Tools of the Study

WHOQOL BREF by Marvin Oliver in 1997 is tool of study. Intra-rater reliability is excellent for the total WHOQOL-BREF and its subscales (ICC range: 0.84-0.93).

Results

Data collected through instrument clearly demonstrated that parents who have children with disabilities have low quality of life as 95% parents responded at neither satisfied nor dissatisfied so it can be concluded from the statistical data analysis that parents who have children with disabilities have low and confusing quality of life.

Overview of Quality of Life of Parents (Mother or Father) who have Children with Disabilities

In this study, there are 78 males (fathers), and 122 females (mothers). It can be concluded that the number of mother respondents are more than the number of father respondents. This can be seen in the following table:

Table: 1. Quality of Life of Parents who have Children with Disabilities on the Basis of their Relationship with Child (Mother or Father)

Sector	<i>N</i>	<i>M</i>	<i>df</i>	<i>T</i>	<i>Sig</i>
Father	78	3.01	56	.176	.98
Mother	122	2.99	121		

**P* < .05 Level of Significance

Table 1 shows that there is no significant difference in the quality of life of the respondents on the basis of their relationship with child (Father or Mother).

Overview of Quality of Life of the Parents on the Basis of Category of Disability of the Child

In this study the parents of children with disabilities are divided into two categories of disabilities in which 100 parents having children with hearing impairment and 100 parents having children with visual impairment which can be seen in the following table.

Table: 2. Quality of Life of the Parents on the Basis of Category of Disability of the Child

Sector	<i>N</i>	<i>M</i>	<i>df</i>	<i>T</i>	<i>Sig</i>
Hearing Impairment	100	85.87	198	.731	.852
Visual Impairment	100	85.73	183		

**P < .05 Level of Significance*

Table 2 shows that there is no significant difference in the quality of life of parents of the children on the basis of category of disability.

Description of Quality of Life of the Parents on the Basis of their Age

In this study the parents of children with disabilities have different age groups in which there are 55 parents having age 26-35 117 parents having age 36-45, 28 parents having age group 46-55 which can be seen in the following table.

Table: 3. Quality of Life of the Parents on the Basis of the Age of Parents who have Children with Disabilities

Age	Age	<i>N</i>	<i>M</i>	<i>df</i>	<i>t</i>	<i>Sig</i>
Group I 26-35	36-45	117	93.85	198	.731	.852
	46-55	28	93.60	183		
Group II 36-45	26-35	55	93.78	197	.1.21	.925
	46-55	28	93.60	183		
Group III 46-55	26-35	55	93.78	197	2.32	.804
	36-45	177	93.85	198		

**P < .05 Level of Significance*

Table 3 shows that there is no difference in the quality of life of the age groups 36-45 & 46-55, 26-35 & 46-55 and 26-35 & 36-45 of the parents of the children with special needs

Findings

The study found out that disability of children affects the quality of life of their parents. Most of the parents were neither satisfied nor dissatisfied at different aspects of their life; this shows that they don't have good quality of life. It is found that there is no significant difference in the quality of life of the parents on the basis of their gender. It is also found out that there is no significant difference in the quality of life of parents of the children on the

basis of category of disability. It is found that there is no significant difference in the quality of life of the age groups 36-45 & 46-55, 26-35 & 46-55 and 26-35 & 36-45 of the parents who have children with disabilities.

Conclusion

The present results give an insight into authorities working in the field of education to organize workshops, seminars, lectures and conferences on special education. Such efforts will be helpful in creating awareness among teachers, students, administrators, members of the school management committee, parents, special educators, social workers, and media persons working in the field of special integrated and inclusive education.

Recently, experts have evaluated the mental adjustment of parents who have children experiencing disabilities that those families face a number of difficulties lot more prominent than those looked by parents of normal children, specifically when a handicapped child has more than one inability at the same time (Achilles, McLaughlin and Croninger, 2007).

Unexpectedly, the different type of experience of the guardians of the Intellectually disabled children with the future difficulties depends on ways of dealing with stress that they have and their feelings directly effect those problems and their quality of life. The relationship between child and parent's quality and the guardian's success especially in the mothers of intellectually disabled children is explained by Karande and Kulkarni, (2009). Forty five parents were the sample of the study in which eighteen parents had autistic children and twenty seven parents had normal children. The ages of the children were ranged between 3 to 6 years. The findings of this study showed that stress level was high and quality of life of parents having autistic children were low level but the parents having normal children having low level of stress and their level of quality of life was appreciable. Podjarny (2007) expects to explore the quality of life of those parents who having learning disabled child and also explore the effects of special child on their clinically and socio economic status of quality of life. In this study one hundred and fifty parents who have learning disabled children were the sample of the study. The quality of life of their parents were measured according to quality of life measurement scale which containing 25 aspects of quality of life prepared by World Health Organization (WHO). The measurement scale exists 06 areas such as mental level, physical level, autonomy level, socialization, physically condition and profound. The findings were that only 04 areas of World Health organization Quality of Life such as socialization, physical condition, mental level and otherworldly participated together to the usually speaking of quality of life.

Educational Implications

The present study has its implication for teachers, educational administrators, policy makers and parents. The first responsibility of the parents and teachers should be to know the areas where the children have strengths and weaknesses and try to give better atmosphere to the child to flourish his/her strengths. The schools should provide facilities and encouragement to disable children to become socially, financially and psychologically beneficial member of society. The betterment and improvement in social, cognitive and behavior of disabled children will bring a positive change in the quality of life of parents and they will be able to play their part energetically and effectively in the rehabilitation of their children.

Recommendations

Following recommendations were based on the findings.

1. Administration of Special education schools should arrange certain workshops and seminars for guidance and counseling of the parents.
2. Parents should visit special schools of their children to keep in touch with the strengths and weaknesses of their child.
3. Parents should visit the professionals of the special education schools to learn how they should spend their time with their special child that can be beneficial for them in long run of their life.
4. Governmental policies makers should bring in further legislation to support family in regard to healthcare for family members with a disability.

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